Bangor University

DOCTOR OF PHILOSOPHY

Timeshare beds : a pluralistic evaluation of rota bed systems in continuing care hospitals.

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Award date:
1991

Awarding institution:
Bangor University

Timeshare Beds: a Pluralistic Evaluation of Rota Bed Systems in Continuing Care Hospitals.

Thesis submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy in the University of Wales, 1991.

by

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SUMMARY

This thesis reports the results of a pluralistic evaluation of rota bed systems providing respite care to carers of the dependent elderly. Using a multi-method triangulated design the study examines: the sources and determinants of carers' stresses and rewards; the subjective views of the main stakeholder groups as to the benefits and problems of the rota bed system; the rota bed experience as indicated by the environment and regime of care and the activity levels of rota bed users at two contrasting continuing care hospital wards. Using data from a national sample survey of members of the Association of Carers, convincing empirical support is provided for the transactional approach to the understanding of carer stress. In addition the results extend the conceptualisation of caring to include sources of satisfaction. The benefits and problems of the rota bed system are explicated and, on the basis of these suggestions are made as to how both respite care and related services to carers might be improved. Within the context of recent policy initiatives consideration is given to the nature of professional responses to carers and their dependants with particular reference to the role of the nursing profession.

ACKNOWLEDGEMENTS

This work is dedicated to all those who care.

Inevitably in a research project of this scale it is not possible to acknowledge on an individual basis everyone to whom the author is indebted. Sincere thanks are therefore extended to all those who participated in the study and who gave of their time so freely. Special thanks are due to the **General Nursing Council Trust** who funded the project, to the **Research Committee**, University College of North Wales, Bangor who funded the postal survey and to the **Association of Carers** (now Carers: National Association) for permitting their newsletter to be used as a vehicle for the postal questionnaire.

There are however a number of individuals to whom the author is particularly indebted: **Mr. David Jones** (formerly CANO, Gwynedd Health Authority) who acted as a catalyst for this and earlier research; **Kerry Caldock**, for being the perfect 'sounding board' for emergent ideas and for proof reading the final draft; **Said Shahtahmasebi**, for endless patience in guiding me through the intricacies of the world of the computer; **Dr. Nick Ellis**, for conducting the LISREL analysis of the survey data; **Mr. Keith Talbot, Miss Sue Lees** and **Mrs. Janet Nolan**, for collecting the observational and dependency data with such good humour; **Dr. Gordon Grant** who, as a supervisor and mentor, was a constant source of invaluable advice and guidance; but most of all to my wife, **Jan**, for having braved her third ordeal by thesis and to my **parents** who have always been there whenever it mattered.

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INTRODUCTION

THE STUDY IN CONTEXT: RESPITE CARE AND ROTA BEDS

The politician's syllogism

" Something must be done.
This is something.
Therefore we must do it."

(Yes Prime Minister Diary 1989)

The perception of disorganised action captured very aptly in the above humourous syllogism reflects in many ways the reactive rather than proactive response of policy makers and service providers to the increasing call for community care of dependency groups. Policy initiatives often seem to be plucked out of the air or based on anecdotal or commonsense notions of what might be a 'good thing', rather than being firmly grounded theoretically or empirically. Of course there is a vital place for the bright idea, the eureka experience, that spark of inspiration that is a necessary first step in a creative response to a fluid and rapidly evolving situation. Subsequently however, this first flush of enthusiasm needs to be tempered by a more considered and reflexive evaluation. Such is rarely the case in policy initiatives.

This thesis reports a study which seeks to evaluate a service which falls very firmly into the second category. A service which started life as a bright idea, has grown rapidly and has now achieved the status of what has been termed a 'reborn certainty' (McCoy 1983), demonstrating the tendency for services to gain recognition merely by periodic re-exposition of their worth rather than via any real evidence for their actual utility. The service in question is the provision of hospital based respite care for carers of frail older dependants. In addressing such questions as: What are the aims of the service? Does it work? If so for whom and why?, a pluralistic approach will be adopted utilising a triangulation of methods and data sources.

In this, the introduction, the author hopes to achieve two main aims: firstly to contextualise the study from a national, local and personal perspective, thereby giving an indication of the genesis of the thesis; secondly, to provide the reader with a guide to the thesis structure, a sort of conceptual map signposting the major theoretical and empirical issues to be addressed.

From a national perspective, the growth in the provision of respite facilities for informal carers and the use of hospital accommodation for such a purpose can be viewed in two contexts. At the macro-level there is the continued drive towards the community care of dependency groups which has already been noted and at a more circumscribed level there is the need to consider the influence of the development and future position of geriatric medicine.

A number of authors have documented the major policy objective of successive governments as that of basing the care of dependency groups in the community, a trend apparent since World War Two (EOC 1982a, Charlesworth et al 1984, Henwood and Wicks 1984, Wright 1986, Henderson 1986, Maclean 1989, Qureshi and Walker 1989). In its initial form such a philosophy reflected the shift away from large institutions towards the provision of smaller, more homely residential units, and care in the community. However during the last 20 years, and increasingly during the 1980's, the emphasis has changed to a policy of care by the community, in which responsibility is placed ever more firmly with the family and other informal means of support. Whilst, of course, most of the care given to the frail elderly has always been provided by the community the extent of such care has increased with the changes in demographic structure apparent this century. Certainly the emphasis placed on such informal care has been re-stated quite unequivocally in recent policy documents:

> "If care in the community means anything it means that responsibility is placed as near to the individual and his carer as possible" (Griffiths Report 1988).

However, such changes are occurring at a time when demands for care, particularly from the frail older person, are rising, the numbers of potential carers are falling and public expenditure is being restricted (Wicks 1989). Despite the increased emphasis on community care over the last 40 years, neither concept has been adequately defined (Bulmer 1987, Qureshi and Walker 1989) and yet such a policy has now become part of the accepted wisdom and is seen as being both better and cheaper than other alternatives (Wilkin and Hughes 1986, Maclean 1989). As a consequence the position of the informal carer has emerged as a major focus for policy and research interest (Wicks 1989) and one of the most basic issues has become how to support those with long-term commitments (Phillipson 1988).

The availability of nationally representaive data on the number of informal carers (Green 1988) has helped to put the extent of family care into perspective and has hopefully assisted in rejecting the notion that the family no longer cares for its dependent members. The survey has also illustrated how little support such carers actually receive, with only one in three resident carers receiving even a monthly visit from either the statutory or voluntary sectors. Such a lack of support has been further highlighted by a recent national survey on the services available for informal carers (Webb 1987). The findings reveal how services for carers are fragmentary, disorganised and arbitrary, with availability being more a matter of luck and geographical location than need. In analysing the types of service currently offered, some form of respite care was found to be the most prevalent in both Health Authorities and Social Services Departments, accounting for some 40% of the total, a figure which rose to 54% if sitting services were included. Based on her calculations, Webb estimates that each respite scheme was catering for approximately 6,500 carers and if these figures are adjusted to take account of the more precise national data on the numbers of carers, each scheme would be catering for 28,500 carers. The disparity in the location of respite facilities means that this figure would be far lower in some areas, but conversely far higher in others. Therefore, despite the probable inadequacy of provision in most areas, respite care still represents, at least numerically, the most significant service available to carers at the present moment. This finding alone makes the area worthy of further study.

The present study however is concerned primarily with the provision of respite care in hospital facilities which, within the geographical location studied, effectively means long-stay or continuing care beds.

The single most important contribution of the NHS towards the care of older people has been described as the growth and development of geriatric medicine as a distinct specialty (Wilkin and Hughes 1986). Certainly, there can be no doubting the impact of early pioneers such as Majorie Warren whose efforts resulted in the therapeutic nihilism of the pre-war years being replaced with a newly found optimism and a consequent development of innovative services, such as respite care. However, such a metamorphosis was not accomplished without opposition, most notably from established specialties who often failed to see the need for a separate service for those over 65 (Wilkin and Hughes 1986). Therefore, from its inception geriatric medicine has occupied a somewhat beleaguered position, having constantly to justify itself to its obstensibly more prestigious peers.

One of the cornerstones of modern geriatric medicine is the premise that the conditions of old age are treatable (Millard 1988) and yet many of them are not curable in the best traditions of the 'medical model'. Faced with the threat this posed to the credibility of geriatric medicine the primacy of cure was replaced with rehabilitation and a functional model of health substituted for the medical model (Wilkin and Hughes 1986). The result was progressive patient care and within such a paradigm chronic disease and disability have always occupied an uneasy and ambiguous position, threatening as they do what is still extolled as the ultimate medical goal aspired to by even geriatric medicine, that of the discharge of patients (Hall 1988). This has resulted in a tension between the implicitly curative orientation of acute geriatric care and the more holistic needs of an increasingly large section of the user population, the chronically sick and disabled. Despite the assertion that geriatric medicine comes closest to the WHO ideal of health as being a complete state of physical, emotional and social well-being (Hall 1988), there can be little doubt that the clinical and rehabilitative functions are seen as being more prestigious than the social and preventative (Wilkin and Hughes 1986).

The future development of geriatric medicine seems destined to take the service ever further down this road with the next aim being the reduction and eventual elimination of long-stay beds (Bond and Bond 1987). Such an intention not only accords with the philosophy of community care but also means that geriatric medicine can rightly claim to be a rehabilitative service in that it will have no long-stay patients. Viewed from this perspective the introduction of respite beds is not only understandable but wholly desirable. Firstly, it can be seen as an effort to meet the hitherto rather ignored aspect of geriatric medicine's avowed social role. Secondly, being a service provided mainly for carers with the intention of reducing the demand for residential care, respite beds can be held as a prime example of the efforts of geriatric medicine to meet carers' needs and to hasten the implementation of community care policy. Furthermore in replacing what was often a long-stay bed with a respite bed, the throughput of patients and the notional discharge rate improves dramatically. This is not to suggest that the original introduction of respite beds some 30 years ago did not represent a genuine attempt to alleviate the problems of carers at that time. However it remains that there have been few other attempts to address carers' needs and some service developments which might meet the needs of carers fail to realise this potential, for example day hospital care (Nolan 1986).

Thus, at a national level in the drive towards community care and as an important component of many departments of health care for the elderly, respite care beds are an area of substantive interest as emphasised in the recent White Paper 'Caring for People' (Department of Health 1989a). However, they have perhaps grown without any really holistic consideration of their potential, as will be demonstrated in the next chapter. Before considering these issues in more detail there is a need to place the present study in its local and personal perspectives.

The study forming the basis of this thesis was undertaken in the county of Gwynedd, in North Wales. There is a need therefore to consider the way in which health care is delivered in this locality to highlight important territorial factors, local policy priorities and service delivery models.

The county of Gwynedd covers an area of approximately one million acres and is situated in the north western corner of Wales.

Whilst it is one of the largest counties in Wales in terms of geographical area it has one of the smallest resident populations, the majority of whom live in coastal settlements. In terms of its population structure Gwynedd has a higher proportion of people of retirement age and aged 75+ than the average for Wales and the rest of the U.K..

Population structure of Gwynedd compared to Wales and the U.K.

Percentage of population	Gwynedd	Wales	U.K.
Over retirement age	21.7	18.3	17.1
75+	7.3	5.7	5.7

(Source Gwynedd County Council 1983)

In line with national trends it is anticipated that the most rapid future rise will be in those aged 85+, with the concomitant rise in dependency that accompanies advanced age; at the same time that the numbers of potentially available carers is falling.

The rural nature of the county and its aged population structure present inherent difficulties in providing an adequate health service for this section of the population, not least of which is the distance between the scattered centres of population and the acute in-patient beds.

Administratively the county is divided into five districts which in terms of health care for the elderly are amalgamated into two sectors, east and west. This research was undertaken in the western sector and further descriptions of service provision will be restricted to this area.

However, the philosophy of service provision is relevant to the county as a whole.

Both the Gwynedd Health Authority and Social Services Department, via their Health Care Planning Team (HCPT) and Joint Care Planning Team (JCPT), are committed to a policy of community care for older people and their carers. In order to achieve this the HCPT have identified four principal aims for the Geriatric service in Gwynedd:

1) To provide medical, nursing and social care which will enable the elderly to participate in as many spheres of life as they are able, whether at home, in residential or hospital care.

2) To encourage the active cooperation of families and carers with elderly dependent relatives and to ensure their relief from excessive burdens of care.

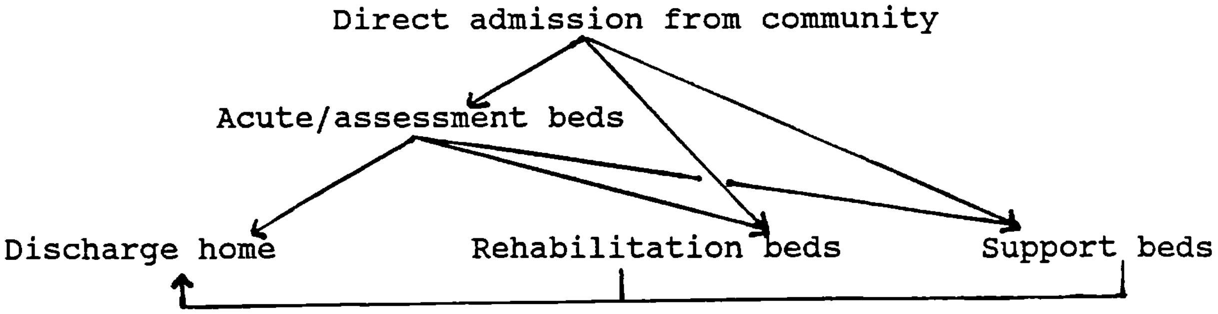
3) To provide therapeutic treatment

4) To care for the dying with sensitivity and competence in a sympathetic environment.

(Gwynedd Health Authority HCPT 1985 p.5)

In operationalising these aims the Department of Medicine for the Elderly has traditionally offered a service based on the progressive patient care model. This is essentially a three tier model comprising acute/assessment beds, rehabilitation beds and long-stay or continuing care beds (the latter being the title of choice in Gwynedd). Following an acute admission, patients requiring continued treatment are transferred to a rehablitation bed and eventually if this is unsuccessful to a continuing care bed. Acute beds and a proportion of the designated rehabilitation beds in Gwynedd are located in the district general hospital, with the remainder of the rehabilitation and all of the continuing care beds being in peripheral hospitals. This type of arrangement is the most common in the UK (Brocklehurst 1978 quoted by Hall 1988). In Gwynedd this system has resulted in a disproportionate number of continuing care beds, a situation which is clearly undesirable in this era of community care. Additionally, over recent years the service has come under increasing strain with, for example, an 81% increase in discharge and death rates betwen 1981 and 1985 (HCPT 1985). This has resulted in an increased throughput in the acute care beds with the consequence that patients are being discharged to the rehabilitaion beds far earlier and in a more dependent state. The inadequacies of the present system have been recognised and, following recent detailed discussions by a special working party of the HCPT, a new model has been suggested. This has been called 'selective patient transfer' and essentially involves a redesignation of function of the continuing care beds and their renaming as support beds. Within this model the crucial decision is made at the time of the acute admission when patients requiring further intensive therapy are transferred to rehabilitation beds and others to support beds. This is a major decision as the ratio of trained to untrained staff and of therapy support is far lower in the latter facility and the physical environment is generally far poorer.

The new model is seen to work in the following way.



This change has meant major readjustments, particularly for the former continuing care beds. Ten years ago a 30 bed continuing care unit had an average length of admission somewhere between 600 and 1600 days and a static population in which the only movement was when a patient died and a new patient was transferred in. Now such a unit accommodates a variety of patients, but in terms of either low or high dependency. The former group consists of patients requiring non-intensive or slow stream rehabilitation, convalescence or so called 'social' cases awaiting placement elsewhere. The high dependency group comprises those patients formerly designated as continuing care and patients attending for custodial care. In addition to the above some direct admissions come from the community, including those not in need of intensive medical care and those whose support network is in danger of breaking down. In recognition of the changing demands that would be made on staff an improved trained/untrained ratio and therapy input was also recommended.

The implementation of this new model has had a profound impact on the former continuing care hospitals with a dramatic fall in the length of stay and a reduction of up to 50% in the number of long-stay patients.

In terms of the present study it is the beds designated as custodial that are of most interest (custodial was the term used by the HCPT in their original discussion document but the author prefers the term respite beds and this will be used in future when referring to these places), but obviously it is not possible to consider them outside the context of other changes occurring in the units in which they are located. Respite beds have been available to a limited extent in Gwynedd over the last 10 or so years but never on the scale or diversity as they are now, where in certain units they account for up to a third of the total available beds.

Three types of respite beds are available as follows:

1) **Rota beds.** These are the most frequently offered and as the name suggests represent a regular service whereby a dependant comes in to hospital on a rota, usually of two weeks in and six weeks out. This however can be varied according to need with up to two weeks in and two weeks out being possible in certain circumstances.

2) **Holiday or relief beds.** Again the name is fairly descriptive and indicates a service available for a fortnight, usually once or twice a year.

3) **Crisis beds.** These are reactive rather than planned. In some units there are no beds officially designated for this function and a crisis admission takes any available bed (crisis in this sense denotes an imminent breakdown of informal support rather than a medical crisis). Other units have designated crisis beds which are often nurse managed, explicitly in one unit and implicitly in others.

With such a variety of provision some restriction on the scope of the present study was required for both logistical and conceptual reasons. A decision was therefore made to focus the study on the **rota bed** service. This was felt justifiable on two main counts. Firstly, rota beds are the most frequent form of respite offered and this made identifying a sufficient sample more likely. Secondly, rota beds offer a qualitatively and quantitatively different service from both the holiday and crisis beds. That the rota beds constitute a regular and repeated contact opens up possibilities for a wider range of therapeutic interventions, taking the debate as to their function beyond the level of merely providing the carer with a break and the dependant with periodic reassessment.

Restricting the study to the west of Gwynedd meant that the logistical demands of the study became manageable whilst at the same time facilitating access to a variety of units operating under the clinical management of different consultant geriatricians and offering users divergent treatment modalities. This ensured that a number of variables of likely import in an evaluation study could be incorporated; for example, access to day hospital facilities within the unit and the availability of physiotherapy and occupational therapy staff.

In practice this resulted in the inclusion of five units operating a rota bed service. Four of these five were formerly designated as continuing care units and one as a mixed rehabilitation /continuing care unit. Three units had 30 beds, one 28 and the other 40, whilst two of the units had access to a day hospital. Full details of the work undertaken at these units will be described later.

The author's personal interest in both services available to carers and the use of respite beds was stimulated whilst he was a charge nurse in a day hospital for the elderly. This involved regular contact with dependent elderly people and their carers and the author always considered the support of carers to be an important part of his role. Despite this, it was not until the author conducted some research into the functioning of day hospitals (Nolan 1986) that he realised how inadequate his clinical practice and wider service provision were in addressing carers' needs. At the same time it was apparent that whilst many of the patients attending the day hospital used respite beds this appeared to be something which, at best, the majority tolerated, many overtly dreaded, and only very few actually seemed to enjoy. Furthermore, many carers seemed to benefit from the break but expressed guilt about having used the system. Therefore, when the opportunity to undertake a research study on a full-time basis presented itself, the use of respite beds seemed to be an obvious choice.

At one level the impetus for this study arose from a clinical situation, an empirically based question which required an answer. At another level the author's previous work raised a number of questions of a wider professional nature, concerning the role of the nursing profession in the care provided to older dependent people and their carers. Such questions as interested the author were particularly concerned with the chronically sick and disabled and their carers in both institutions and their own homes. This will therefore form a particular area of interest within the present work. It is in no way intended to ignore or minimise the contribution of other professional groups but as will be highlighted later the shortage of other professionals in the facilities within which the respite beds are located means that their actual contribution is, in any case, very limited. It therefore seems that the service provided, whether good or bad, is largely as a result of nursing interventions. The author has also had a long-standing interest in the conceptual basis for professional service provision to elderly dependants and their carers, particularly regarding the nature of what constitutes care and who might best provide it. This thesis provides an opportunity to further explore these issues as they relate to actual service provision. It is thereby hoped to add to knowledge that will extend conceptual understandings in this field of study and will help to provide a firmer grounding for currently fashionable ideas about service evaluation and quality.

In Chapter One two of the main substantive themes on which the study is based will be considered. At a theoretical level the chapter will begin by considering the nature of evaluation and the **ontological, epistemological and methodological** questions it raises. Following a review of the literature in this area a case will be presented for the adoption of a **pluralistic approach**, the principles of which will be outlined. A pluralistic model will then be applied to the empirical literature on respite care. Four major stakeholders will be identified as carers using the system, their dependants, the staff providing the service and the other patients within the institutions in which the respite beds are located. It will be argued that there are at present only very limited aims for the service in relation to any of these groups and that in order to inform the study there is a need to consult the wider empirical and theoretical literature. In the subsequent two chapters a number of theoretical models and concepts will be identified which will be used to give direction to the study.

The literature on care is reviewed in Chapter Two and inherent conceptual problems are highlighted, both with reference to what constitutes care and the nature of the burdens carers face. It will be argued that conceptualisations of care have tended to adopt a pathological orientation, with an undue emphasis on instrumental factors as determinants of carer burden. A major theoretical orientation for the study will be the reconceptualisation of carer burden within a **transactional model** of stress. Such a model is predicated on the assumption that burden is based primarily on carers' individual perceptions of events rather than the objective circumstances of care. The implications of adopting such a model for the provision of services to carers will be considered. The potential of respite care for meeting some of carers' wider needs are then presented.

Chapter Three reviews the literature on the other stakeholder groups in order more adequately to address the issue of what respite care might reasonably achieve. In relation to the users of respite care two main conceptual bases will be used. The first of these considers the effects of **relocation** and in exploring this issue the work of Chenitz (1983) will provide the theoretical underpinning of an analytical framework to understand reactions of users to respite care. Secondly specific attention will be given to the potential of respite care to improve the **self-esteem** of the elderly users. In relation to the staff providing the care the concept of **rust out** (Pennington and Pierce 1985) will be used to suggest ways in which respite care might add to staff morale and job satisfaction. In combining the conclusions from Chapters Two and Three with questions posed in Chapter One, this section will conclude with an **evaluation guide** to inform the study. This will not be used in a prescriptive sense but rather as a means to limit the possibility of important questions not being addressed.

The conceptual rationale for the study methodology will be given in Chapter Four. Particular attention will be given to the explication of **triangulation** and to the reasons behind the methods adopted in the study.

Chapter Five will describe how the study was conducted and how key concepts were operationalised. A **reflexive account** is concerned with issues of data quality and the chapter concludes with a consideration of the techniques of data analysis.

The results of a national sample survey of carers undertaken to provide an empirical test for the transactional model of stress applied to carers problems will be presented in Chapter Six. At the outset this exercise was intended to inform the main study and supply some empirical validation for the theoretical stance adopted. In the event, however, the survey provided an extremely rich data source which far exceeded its original intention. It also provides data which extend understanding of the satisfactions carers gain from their role. However in order to keep the thesis within manageable proportions this chapter will concentrate mainly on those aspects of direct relevance to the respite study.

Chapters Seven and Eight report the results of the main study and relate them to the evaluation guide and to the wider theoretical issues that have been raised. A number of key conceptual elements are presented and developed as they emerged during the evaluation study.

The thesis concludes in Chapter Nine with a consideration of how well the study addressed the issues posed at its inception. At a theoretical level the adequacy of the transactional model will be considered and the need to develop non-recursive and dynamic models of carer/dependant relationships that also incorporate carer satisfactions will be highlighted. Moreover the utility of both the transactional model and the pluralistic approach to evaluation will be expanded upon, with particular reference to their application in a nursing context. A synthesis of the key themes and concepts underpinning the study is attempted and this is used to assess the implications for respite care and wider service provision to dependent older people and their carers. The limitations of the study and suggestions for the direction of future research are also be included. In this way it is hoped that the study will help to inform practice and policy, in addition to its contribution to methodological and theoretical debates.

CHAPTER ONE

EVALUATION PARADIGMS AND RESPITE CARE

"When I use a word it means whatever I choose it to mean"
(Humpty Dumpty)

1.1 The nature of evaluation

Whilst the above degree of flexibility in defining terms is advantageous in certain circumstances the lack of an accepted meaning can be positively inhibiting in others. Such is the situation in relation to the word **evaluation**, especially when it is used in the context of research. According to Glass and Ellett (1980) 'Evaluation - more than any other science - is what people say it is'. As such these authors considered that evaluation research is best seen as a set of theoretical and practical activities lacking a widely accepted paradigm rather than a term to which a conceptually rigorous definition can be applied, a situation noted by other commentators (Luker 1981, Bond and Bond 1987). This creates a dilemma for the researcher about to embark upon a foray into the world of evaluation: how to explicate what the intention of the endeavour is. Clearly, if evaluation is indeed whatever anybody chooses it to mean, then the intending researcher has a responsibility to make explicit the paradigm in which the study is to be located. This is the purpose of this, and the following two, chapters. The chapter begins with a review of the literature on evaluation and evaluation research prior to considering the application of an evaluative model to a particular service, namely the use of continuing care hospitals to provide respite care for carers of dependent older people. An outline of a theory-based framework within which to place the evaluative exercise will then be presented.

Whilst evaluation research may lack a globally accepted paradigm a number of authors have proferred definitions from which it is possible to identify some commonalities. An early and widely quoted definition (Goldberg and Connelly 1982, Thomas 1988) is that of Suchman (1967) who sees evaluation as 'A method of determining the degree to which a planned programme achieves the desired objective'. Such a definition requires a number of implicit assumptions to be fulfilled before it can be adequately operationalised. Firstly, it assumes that a programme has a clearly defined 'desired objective'. Secondly, it suggests that such programmes are planned on a rational basis with the intention of meeting the objective. Lastly, in requiring that the degree of success be determined, it assumes measurement on at least an ordinal scale. In the twenty or so years since Suchman offered his definition a number of authors have reiterated the view that, ideally, a programme should have a clear statement of intent if it is to be adequately evaluated (Rossi and Berk 1981, Coulton 1982, Wortman 1983). However as programmes were tested and evaluated empirically it soon became apparent that clearly defined goals were usually lacking and that the intended benefits of the programme were seldom made explicit (Goldberg and Connelly 1982, Hills and Florenden 1987, Gordon 1987, Thomas 1988). Even when objectives were stated they were seldom clear and often contradictory (McGrath and Hadley 1981, Goldberg and Connelly 1982, Cook and Shadish 1986, Gordon 1987). Furthermore it was apparent that interventions might have both anticipated and unanticipated effects, which might in fact be beneficial or detrimental. This led Weiss (1974) to suggest a broader definition of evaluation as an exercise concerned with the study of programme effects in terms of intended and unintended outcomes for a target group or institution. Such an approach acknowledges the likelihood of both expected and unexpected consequences but limits the evaluation of their effects to a defined target group or institution. It is now also clear that any intervention, in addition to affecting a target group, may also have consequences for groups or institutions not originally intended to be beneficiaries (Thomas 1988).

Evaluation research is clearly a diverse undertaking which presents inherent difficulties in its empirical application. It is still possible, however, to isolate certain key conceptual components which should form part of any work. A number of authors agree that evaluation has an underlying connotation of value or worth (Glass and Ellett 1980, Goldberg and Connelly 1982, Wortman 1983, Miller 1984, Cook and Shadish 1986) in addition to determining whether or not a programme works. Therefore it is not in itself sufficient that an intervention might produce the desired effects (if indeed they can be identified) but also that the fundamental purpose of the intervention should in some way be concerned with 'improving human welfare' (Wortman 1983). Crow (1984a) advocates that any evaluation of clinical interventions should have as the main criterion of success a consideration of the extent to which the recipient benefited. A similar stance was adopted by Goldberg and Connelly (1982) who suggested that, in the absence of clearly defined and measurable outcomes, evaluation research should address the question: 'are the recipients of the service any better off for having received it?' Such a requirement, whilst undoubtedly to be applauded, poses additional problems for the researcher in that many of the concepts considered to be of value, for example an improved quality of life, are notoriously difficult to define and operationalise.

Research which seeks to evaluate interventions therefore needs to determine both the extent to which the programme meets its implicit/explicit objectives and the degree of benefit which the service provides. In this way, as Miller (1984) notes, evaluation research compares **'what is'** with **'what should be'**. However, in view of the problems already noted regarding the lack of clear objectives, and the occurrence of both expected and unexpected effects, an increasingly large body of researchers involved in evaluation agree that simple answers to the questions posed by evaluation are seldom possible and that any adequate study must give due consideration to multiple definitions and perceptions of programme purpose, implementation and outcomes (Challis 1981, Bergman 1982, Cook and Shadish 1986, Gordon 1987, Smith and Cantley 1985,1988, Sixsmith 1988).

The need for a broadly based approach to evaluation, together with the difficulties inherent in operationalisation and measurement, have important methodological considerations for the conduct of evaluation research. Early approaches relied heavily on the experimental model and were firmly entrenched within the positivist paradigm. Rossi and Wright (1984), in tracing 25 years of evaluation research, note that the 1960's and 1970's were the halcyon days for what they term the randomised controlled experiment (or efforts to emulate it). However, as Cook and Shadish (1986) point out, 20 years of examining the complexities of the real world have altered many of the naive assumptions of early evaluators regarding the suitability and general applicability of positivist approaches. Clearly they are of little relevance in the absence of specific objectives (Goldberg and Connelly 1982) and even if such objectives are apparent serious limitations remain. For whilst, in certain circumstances, experimental approaches can isolate causal mechanisms, they often fail to address important contextual questions as to **how** and **why** a particular programme worked (Glass and Ellett 1980, Rossi and Wright 1984, Wortman 1983, Cook and Shadish 1986). Experimental models have been termed 'evaluation with one eye closed' (Raynor 1984), and whilst their utility in certain circumstances remains, their hegemony as **the** method of choice is no longer accepted by most evaluators. Thus, a number of authors have called for the wider application of qualitative methods within a triangulation paradigm, especially where objectives are not clear and multiple perspectives on service implementation and criteria for success are likely (Redfern 1981, Goldberg and Connelly 1982, Wortman 1983, Rossi and Wright 1984, Cook and Shadish 1986, Bond and Bond 1987, Lovelock and Powell 1987, Buist 1988, Thomas 1988). In this sense the aim of evaluation becomes **enlightenment** rather than **generalisation** (Sixsmith 1988).

Thus far it seems that evaluation research is primarily conceived of as an activity which attempts to establish the effectiveness and worth of an intervention giving due cognizance to anticipated and unanticipated effects for a plurality of stakeholders. Such an undertaking is best achieved via a triangulation of method and data sources. According to Luker (1981), Suchman distinguishes evaluation from evaluation research, (it has been suggested that the term evaluation research is an oxymoron (Woody 1980) (or a mixture of opposing concepts), but Phaneuf (1980) contends that both evaluation and evaluation research share a common purpose: the advancement of professional practice (in this case nursing practice) in the public interest. In this way the concepts of effectiveness and worth are linked and implicit in evaluation research is the notion that the intervention be of some value. Thus, Luker's (1981) definition of evaluation research as 'any scientific inquiry to appraise the operation and impact of social action programmes' would appear to crystallise current thinking. However the acceptance of such a broad view, whilst freeing the researcher from a rigid adherence to certain methodological approaches, does not absolve responsilibilty for making explicit the model within which key concepts are to be operationalised. It is to this area that attention is now turned.

1.2 Evaluation models: current trends

In recent years evaluators within health care settings have relied heavily upon the model proposed by Donabedian to provide an organising framework for their activities (Luker 1981, Van Maanen 1979, 1981, Redfern 1981, Bergman and Gollander 1982, Crow 1984a, Wright 1984, Dunne 1986, Kitson and Kendall 1986, Barnett and Wainwright 1987) and this remains the most popular approach. This model postulates three perspectives from which an intervention can be evaluated:

A) The structure of care	This addresses relatively objective factors such as staffing levels, buildings and other material resources.

B) The **process** of care	Does care delivery accord with currently accepted definitions as to what constitutes 'good' practice.
C) The **outcome** of care	Measuring the effects of the interventions on those receiving them.

Within such an approach evaluation may be undertaken from any one, or combination of, these areas. However it is suggested that to concentrate on one area alone is insufficient (Bloch 1975). According to Bond and Bond (1987), Donabedian sees the causal order running in the direction:

$$\text{STRUCTURE} \longrightarrow \text{PROCESS} \longrightarrow \text{OUTCOME}$$

and such authors as Bloch contend that to look at the elements in isolation is inadequate. Thus the fact that the structural aspects of care may be adequate does not in itself ensure that the process and outcomes will be satisfactory. Similarly, to concentrate on the process of care as a determinant of outcomes ignores other factors such as patient motivation and carer involvement. Moreover, this model does little to address the crucial issue of what constitutes an appropriate outcome and from whose perspective. Most outcome measures have concentrated on patient outcomes, and have tended to minimise outcomes for other groups, for example staff.

Furthermore, other models exist which, whilst sharing conceptual similarities to that of Donabedian, use terms in differing ways which can lead to confusion.

Coulton (1982), suggesting a model for social work evaluation, takes the Structure-Process-Outcome model using definitions similar to those of Donabedian except that the term structure is replaced with Input. The model is extended by the addition of the categories Output and Access. Output is concerned with the availability of sufficient quantity of a service and Access with the extent to which services reach all those who need them. The addition of Output and Access introduces notions of equity to the equation which are perhaps missing from that of Donabedian.

Turning to the field of social welfare one of the most prevalent models is that termed the 'Production of Welfare' (POW) developed at the University of Kent (Davies and Knapp 1981, Davies 1985, Challis et al 1988). This model is primarily concerned with cost/benefit analysis but shares conceptual similarities to those proposed by Donabedian and Coulton.

The assumption underlying the model is that what are termed final and intermediate outputs are a function of levels and modes of combinations of resource and non-resource inputs:

Resource inputs comprise of staff, physical capital, provisions and other consumable items constituting the monetary costs;

Non-resource inputs (those determinants of final and intermediate outcome which are neither physical or tangible) comprise of the personalities, attitudes and experiences of the principal actors involved (including clients and carers) together with the social environment, dependency and health characteristics of clients. The interaction of these two result in the production of;

A) **Intermediate outputs** which constitute the service itself;

B) **Final outputs** which measure the degree of success in terms of quality of life, individual well-being and so on.

Whilst areas of commonality exist between the POW and those models previously outlined, there are important differences in terminology and approach which might lead to confusion. Thus for

Donabedian and Coulton structure and input are synonymous but within the POW Inputs are operationalised far more broadly and the Non-resource Inputs contain variables that would constitute process factors within the other models. Furthermore both Donabedian and Coulton use the term Outcome to refer to the results of a service, Coulton reserving Output for levels of service provision. Within the POW model Outputs at an intermediate level signify both the level and type of service (a facet of Process evaluation within the Donabedian model and an amalgam of Process and Output in Coulton's) and also, at a final level, the results of the service.

Another variant of such models has been recently suggested (Bond and Bond 1987, Bond et al 1989a) which provides a synthesis of the work of Donabedian and that of Davies and Knapp (from which the POW was developed). The resultant model consists of the following factors:

Structure comprising staff attitudes, organisational policy, staff inputs and knowledge;

Process comprising the physical and social environment and the quality of working life;

Intermediate outcomes including self-rated health, morbidity, dependency, type and level of activity;

Final outcomes including personal survival, well-being and emerging concepts such as quality adjusted life years.

Therefore, whilst returning largely to the terminology of Donabedian Outcomes are divided into intermediate and final, as in the POW. However, although the terminology might be similar the operational definitions of what constitute the various categories differs.

It appears that the notion of programme success (be it termed

Outcome, Final Outcome or Final Output) achieves broad conceptual agreement between the various models. This includes both objective and subjective indicators such as survival, quality of life and well-being. However, concepts such as type and level of activity occupy differing places within the models. This disparity is especially noticeable in relation to the concept of dependency. Within the POW dependency is a pre-existing variable brought into the situation whereas for the Bonds dependency arises out of the care given. The placing of such a crucial variable as dependency as either an antecedent or a consequence of care has important implications for the conduct of evaluation research and further highlights some of the possible confusion that exists within many of the current evaluative models. Moreover all of these models suffer two common deficits. They fail to address the important issue of whose perspective the presumed outcomes of interventions encompass. They also assume a causal ordering which is primarily unidirectional and does not take adequate account of possible feedback effects. Therefore, while such models can act as a useful organising framework they do not ensure the validity of an evaluation study and the inconsistent use of terminology may result in conceptual confusion rather than clarity.

In summarising the argument so far it seems that effective evaluation must concern itself with the interaction of a number of disparate factors, each of which contributes to the understanding of how and why results are what they are. Furthermore, attention must be given to differing definitions of what constitutes success (that is in terms of appropriate outcome(s)) and how such outcomes are to be measured. In meeting these requirements the necessity of adopting a methods triangulation approach has already been highlighted.

The challenges posed by evaluation research have been cogently and concisely presented by Smith and Cantley (1985) who contend that models need to be developed which adopt alternative theoretical and methodological approaches. They suggest that much evaluation has been based on three erroneous presumptions. Firstly, there is the **presumption of rationality** or the premise that services have clearly articulated and measurable aims. As has already been demonstrated this is rarely the case. Secondly, there is the **presumption of the experimental ideal,** the limitations of which have already been alluded to. Lastly, there is the **presumption of consensus** over appropriate outcomes and how to achieve them. Once again consensus is seldom apparent.

In contending with these difficulties Smith and Cantley (1985) suggest the need to locate evaluation within a **subjectivist epistemology** which incorporates a **political and methodological pluralism.** This stance is also adopted by Guba and Lincoln (1989) who criticise current evaluation approaches in similar ways. They also stress the fundamentally social, political and value-orientated character of evaluation research and pose three types of questions for evaluation:

a) **Ontological** questions concerned with issues of existence or being, 'What is the nature of reality?';

b) **Epistemological** questions dealing with the origins, nature and limitations of human knowledge, 'How can we be sure we know what we know?';

c) **Methodological** questions addressing the methods, systems and rules for the conduct of inquiry, 'How can we go about finding things out?'

According to Guba and Lincoln (1989) answers to these questions determine the basic belief system or **paradigm** within which evaluation is located. Their contention is that evaluation research should adopt a **relativist** ontology in which reality is constructed by people as they interact with and make sense of their surroundings, together with, as suggested by Smith and Cantley (1985), a **subjectivist** epistemology. They term this a **constructivist** paradigm, within which evaluations do not produce results which represent the way things 'really' are in some 'true' sense but rather are meaningful constructions of the ways in which people make sense of their situations. In operationalising this paradigm Guba and Lincoln (1989) stress the need to adopt a value pluralistic stance in which the concerns and issues of major stakeholders determine what information is sought. The results of such evaluations are not acontextual and atemporal generalisations but rather **specifications** (Guba and Lincoln 1989) or time-and context-based assertions. Thus we return to the position of Sixsmith (1988) where the main aim of evaluation is **enlightenment** rather than **generalisation.**

In answering the methodological questions raised by adopting a subjectivist approach a **pluralistic** model is advocated (Smith and Cantley 1985, 1988) that is based upon:

a) Pluralistic and subjectivist theoretical models;

b) The need to identify the major stakeholders and to elicit and compare their views;

c) The use of stakeholders' subjective perceptions as the major determinant of 'success';

d) As a consequence of adopting the above stance the notion of success itself becomes pluralistic rather than unitary;

e) The use of multiple methods of data collection which incorprate the principles of triangulation.

This approach has recently been advocated by a number of authors (Carley et al 1987, Sixsmith 1988, McEwan 1989) and is the one adopted in the present study. Questions about how the concepts of relevance to the substantive area of study will be identified, defined and operationalised within a pluralistic framework will be addressed in the following three chapters.

Having argued a case for the adoption of a pluralistic evaluation attention needs to be turned to the substantive area of interest, the use of continuing care beds to provide a respite service for carers of dependent older people.

1.3 Evaluating respite care

From the literature on evaluation research it was apparent that most authors thought it highly desirable to have some clearly stated objectives for the intervention prior to starting the evaluation exercise. Whilst this is often not the case, Bond and Bond (1987) consider that the identification of appropriate outcomes or aims represents the first challenge to evaluation research. This point is further expanded by Goldberg and Connelly (1982) who expound the need to clarify whose values and expectations these aims embody. Consistent with a pluralistic model the values and expectations of all the major stakeholders need to be considered before appropriate aims can be formulated. The recent move towards the primacy of consumer expectations (Wilson-Barnett 1986, Wallace and Rees 1988) is to be applauded, but it is also clear that professionals and institutions have expectations which need to be included.

The review of the literature on respite care will highlight that there is a lack of clearly articulated aims for the service. So stakeholder groups can be identified but the service aims cannot. Such a situation is by no means uncommon and Thomas (1988) contends that prior to evaluation there is a need for conceptual work in order to enrich the exercise by linking the study to broader theories and concepts. Indeed such a call to theory prior to evaluation has been advocated a number of times (Crow 1984a, Cook and Shadish 1986). In the absence of well defined aims for respite care an attempt will be made to construct an evaluation guide to inform the study. This will be used to compare the existing service with what might be considered as possible and desirable for each of the stakeholder groups given the constraints under which the service operates. It is not, however, intended that this guide should form a rigid a priori specification. This would be antithetical to the pluralistic approach. Rather its intention is to signpost possibilities from within the existing literature and thereby, as Wortman (1983) contends, reduce the likelihood of difficult questions being ignored. This differs from Miller's (1984) suggestion as this study will not compare what is with what **should** be for this is too prescriptive in a pluralistic context. Rather the study will compare what is both with what might reasonably be argued **could** be and with what each of the stakeholder groups thinks **should** be.

1.4 The development and current practice of respite care

There can now be no doubting the difficulties inherent in caring for a dependant relative or friend in the community. The extensive literature on the problems faced by informal carers will be reviewed in the next chapter but it is already clear from this literature that one of the most frequently expressed needs of carers is for the provision of a break from the demands of caring (Rossiter and Wicks 1982, EOC 1982b, Bonny 1984, Parker 1985, Jones 1986, Webb 1987). The idea of providing such a break within a hospital setting was, according to Martinus and Severs (1988), first introduced by Sheldon in 1948. Official recognition for such a system has been traced by McCoy (1983) to a Ministry of Health circular dating from 1957, the year in which descriptions of the service appeared in the literature (De Largy 1957). Since that date the literature has contained many anecdotal accounts of respite systems and the service has been mentioned in favourable contexts in a number of influential policy documents (McCoy 1983). As a consequence, there has been a rapid increase in the scale of provision despite the fact there have been few objective evaluations of the effectiveness of the service, a phenomenon termed the 'reborn certainty' (McCoy 1983). Thus, in Local Authority part III homes respite admissions account for 58% of the national total (Allen 1983), the figure being as high as 70% in some areas (Boldy and Kuh 1984). Whilst there are no comparable national statistics for respite care in hospitals such a service is the most frequently available intervention offered to carers (Webb 1987). On the other hand, an increased provision has not resulted in greater clarity of purpose. There has been no clear policy statement on the aims of a respite care service and its development tends to have been practice led (Allen 1983, McCoy 1983, Alderman 1987), a situation noted on both sides of the Atlantic (Spence and Miller 1986). The lack of an accepted model of service delivery (Hildebrandt 1983), coupled with the rather anecdotal descriptions of the service, have resulted in a paucity of hard data on how the service really functions (Allen 1983, Dunn et al 1983, Scharlach and Frenzel 1986).

Despite the increase in provision noted above Thompson (1987) somewhat paradoxically asserts that the inadequacy of the present system is the most serious barrier to care in the community. It appears that the organisation and availability of the service is arbitrary and piecemeal, with full utilisation being inhibited by rigid demarcation lines and eligibility criteria (Thompson 1987, Tyler 1987, 1989). This often results in those most in need of the service being the least able to get it (Parker 1985, Jones and Vetter 1985, Thompson 1987). Frequency and duration of respite admissions can reflect local or individual medical opinion and there is a great deal of variation in the manner in which such beds are used (Tyler 1987). For example they are often reported to be offered too late rather early in the caring history (Lawton et al 1989a). The service is provided in a wide range of settings from long-stay hospitals to Part III homes and purpose built units. There is, further, a growing trend to offer respite in the carer's own home and Tyler (1989) identifies 10 models of respite care covering the range of possibilites outlined above.

From the foregoing it would appear that whilst respite care is a frequently available service it is less than effective in many respects. The following review will focus its attention on institutionally based respite care offered to carers of the dependent elderly, but will draw where appropriate on relevant literature from other fields, for example, mental handicap.

1.5 Respite care: a service for carers

Provision of respite care is underpinned by implicit assumptions as to its worth, the origins of which can be traced back to early descriptions of the service. De Largy (1957) noted that many admissions to acute geriatric care were the result of a breakdown in the carers' ability to maintain his/her role and suggested that the provision of a periodic break via a planned hospital admission would do much to ameliorate this problem. Subsequently the consensus within the literature defines the main purpose of respite admissions in similar terms (Isaacs and Thompson 1960, Robertson et al 1977, Martin 1981 a+b, Oswin 1984, Allen 1983, Thorne and Hursey 1986, Intagliata 1986, Brook and Jestice 1986, Looney 1987, Twigg 1989). Some authors also consider that the admission affords the opportunity to rehabilitate the dependant (De Largy 1957, Robertson et al 1977, Thorne and Hursey 1986, Brook and Jestice 1986, Berman et al 1987), and Tyler (1989) suggests that all hospital based respite schemes make claims to provide some rehabilitation. Within Part III homes a more extensive list of aims has been noted, including a holiday for the dependant and as a trial admission prior to a permanent placement (Allen 1983). However, despite the above there can be no doubt that the primary perceived function of respite is to relieve the carer's burden, as the following recent definitions illustrate:

> "Temporary care of the frail elderly and disabled to permit caregivers to relinquish their duties, stress and responsibility for a time-limited period to maintain their physical and emotional strength".
>
> (Miller et al 1986 p.467)

> "A caregiving service that provides a planned, intermittent break from the on-going responsibility of carers for a chronically disabled individual who is managed at home"
> (Scharlach and Frenzel 1986 p.78)

> "Any form of alternative provision of care for an elderly person which gives the regular carer(s) temporary relief from the sole responsibility and from some or all of the caring"
> (Tyler 1987)

Packwood (1980) considers that the provision of a service such as respite care can be viewed from one of two perspectives. Firstly, there is the moral standpoint which asserts that carers have the right to expect such a facility and that authorities have a responsibility to provide it for no other reason than this. Secondly, there is an economic and instrumental position which views carers as a resource to be utilised and within such a paradigm respite care would be offered as a means of maintaining carers in their role, thereby reducing the demand for institutional places. The major implicit, and occasionally explicit, reason for the present service fits more closely into the second of these two paradigms as the following quote illustrates:

> "Only in this way (by the provision of respite care) can those people caring for elderly patients who would otherwise be a 'burden' on the NHS, as they are all candidates for long-stay beds, be properly provided for"
> (Martinus and Severs 1988 p.29)

Thus, respite care is conceived primarily as a service for carers, intended to maintain them in this role and the assumption is that the provision of a break will be sufficient to achieve this end. Viewed from this perspective how effective is the service?

It certainly appears that the majority of carers have positive perceptions of respite care and it is often described as being of great benefit to them (De Largy 1957, Isaacs and Thompson 1960, Robertson et al 1977, Packwood 1980, Allen 1983, Boldy and Kuh 1984, Scharlach and Frenzel 1986, Tyler 1987, 1989). According to Scharlach and Frenzel (1986) in one of the few studies which has attempted to explicate this benefit to carers, the major gain is in terms of emotional and physical rest provided. This list of benefits has been extended by recent work (Luck et al 1988, Tyler 1989) which has identified other major gains for carers: the chance for a break, to see their wider family, to pursue other activities, to complete work that was otherwise difficult and to maintain their emotional health. On the other hand carers' evaluations are by no means always so positive (Martinus and Severs 1988, Webster 1988) with low levels of satisfaction having been noted by as many as 50% of carers using institutionally based respite care (Bell et al 1987). Furthermore, studies using more objective measures of outcome have indicated that respite care appears to result in few if any concrete improvements in carer well-being (Martinus and Severs 1988, Lawton et al 1989a). Indeed, the only major experimental study that could be located in the literature (Lawton et al 1989a) failed to demonstrate any significant improvememt between an experimental respite group and a control group on a wide range of measures. However, despite the absence of objective improvements the authors of the study described the users' subjective evaluations as a 'resounding endorsement' and concluded that perhaps this should be a sufficient measure of success.

It seems, therefore, that most studies indicate that respite care does make a positive contribution to carers' subjective well-being. However, it is also clear that for many carers such benefits as are apparent do not come without accompanying social costs, usually in the form of guilt at the decision to institutionalise dependants for even a time-limited period (Hildebrandt 1983, Ellis and Wilson 1983, Netting and Kennedy 1986, Devlin 1986, Scharlach and Frenzel 1986, Cunlliffe 1987, Tyler 1987,1989, Fotterell 1988, Murphy et al 1988). A consequence of this guilt is that carers often only use respite care as a last resort (Berman et al 1987) or develop ambivalent attitudes which inhibit their use of the service (Thompson 1987, Cunliffe 1987).

It might therefore be a legitimate cause for concern that staff within institutions offering respite care appear to be largely unaware of the guilt which carers experience and do little to try and relieve it (Tyler 1989, Twigg 1989).

Thus, in the majority of the empirical literature on respite care there has been a general failure to see beyond the provision of a break for carers and to look to how it might also address their wider needs. There was an early recognition that respite care afforded the opportunity to provide carers with knowledge and information (Isaacs and Thompson 1960) but only one subsequent description of the service placed any real emphasis on this teaching role (Berman et al 1987), whilst others suggest that a lack of information during respite care is one of the main complaints carers have (Cunliffe 1987). Before going on to consider the suggestions of the few authors who have advocated a more holistic conceptualisation of respite care, the literature describing the outcomes on other stakeholders affected or potentially affected by respite care systems will be briefly reviewed.

1.6 Respite care: other stakeholder groups

Three other groups of stakeholdes will be considered, these being the elderly people who use the service, the staff who provide it and the other patients or residents of the institutions within which the respite beds are located.

(i) Elderly users

Of these three groups most attention in the literature has been devoted to the dependants. It appears that the impact of respite care admissions on dependants is a matter of some controversy however. Early descriptions considered that the admission resulted in dependants being rested and physically and mentally improved as a result of their stay (De Largy 1957). It is perhaps pertinent to note that the unit described thus was built and staffed for the sole purpose of providing respite. Subsequent to this early optimism other reports have not been so positive. Isaacs and Thompson (1960) noted both positive and negative effects on dependants and considered that there was a very real risk of morbidity and even mortality for some users. More recently such a possibility was reasserted with some conviction by Rai et al (1986), a contention which sparked off a veritable avalanche of opposing viewpoints in the medical press (Oliver 1986, McAlpine et al 1986, Murphy 1986, Lenton et al 1986, Power et al 1986, Bursten 1986). Harper et al (1988) contend that given the small, heavily dependent, sub-group of people who constitute the main users of hospital based respite services that morbidity and mortality is no greater during respite care than would have been the case at home. It is clear from these responses that there is little consensus in the medical literature as to either the positive or negative potential outcomes of respite care for the dependent older person.

However deleterious consequences have been reported by carers themselves, with dependants returning home either physically or mentally deteriorated or both (Wright 1986, Luck et al 1988, Thompson 1987, Tyler 1989), a situation which understandably reduces the benefit to the carers. Such anecdotal accounts have recently been substantiated by empirical studies suggesting that that in some areas such as pain, sleep and mobility, dependants may improve but that in others, for example, emotional state, energy levels and social isolation there is no change (Martinus and Severs 1988). Cunliffe (1987) goes further when she reports that whilst there were no changes in the physical dependency of users in her study, most elderly individuals had a lowered mood state compounded by feelings of anger and depression following respite care. Tyler (1989) describes how basic physiological and safety needs may be adequately catered for but considers that the higher the level of need the poorer the provision. It also seems that staff have little or no awareness of the possible detrimental effects for dependants and therefore do not intervene to ameliorate or correct them (Tyler 1989). Amongst mentally lucid dependants, some can feel rejected and abandoned (Cunliffe 1897, Murphy et al 1988) whilst the increased confusion respite care can cause for the mentally frail has been described a number of times (Martin 1981b, Brook and Jestice 1986). Alternatively, it has been suggested that any detrimental effects for the mentally frail are apparent only in physical abilities, and that even then these are not significant (Seltzer et al 1988).

Such conflicting accounts have been mirrored in those studies examining respite care in social services part III homes, with some individuals reacting positively and others decidedly negatively (McCoy 1983). Those who seem to benefit most are the relatively lucid and articulate who particularly appreciate the hotel aspects of their stay (Boldy and Kuh 1984), a conclusion consistent with the work of Allen (1983). In this study, positive benefits and enjoyment were more frequently reported in units providing only respite care. In other settings many users described themselves as bored, depressed and isolated with Allen (1983) portraying a picture of general inertia in which short-stay residents rapidly became accustomed to institutional life where the majority of tasks were performed for them by staff. There were also problems between the permanent residents and the respite admissions, with friction and jealousy between the two groups. Staff dealt with this by treating the respite admissions in exactly the same way as they did for the often more dependant permanent residents, with the consequent risk of institutionalisation (Allen 1983). Other authors have described the often very different requirements of long-stay and respite users and have questioned the advisability of mixing the two groups (Packwood 1980, Boldy and Kuh 1984).

These descriptions of the impact of respite admissions for the frail older person are very different from those provided by De

Largy (1957) who saw units being purpose built for the sole intention of providing respite care. On the other hand whilst there are undoubtedly disbenefits that can accrue to users of respite care it seems that many of these can be overcome either by the appropriate awareness being demonstrated by staff and remedial action being taken with respite care becoming a carefully planned activity (Allen 1983, Bell et al 1987, Tyler 1987,1989, Spence and Miller 1986) or by the use of facilities whose sole purpose is the provision of a respite service (De Largy 1957, Allen 1983, Twigg 1989). In particular it is increasingly recognised that respite care needs to be able to offer something positive for the elderly users themselves if its acceptability is to be improved (Cunliffe 1987, Dewing 1990). Moreover, more attention needs to be turned to the potential conflict of interest between carer and dependant, with time being allowed for both parties to air doubts and anxieties (Ledingham 1988, Richardson et al 1989, Thornton 1989). Unfortunately, it seems that staff rarely demonstrate such an awareness either in respect of carers or their dependants (Cunliffe 1987, Webster 1988, Twigg 1989, Tyler 1989) and the provision of facilities purely for respite care is often considered as a comparative luxury.

(ii) Other patients/residents

The effects of a steady flow of respite users on others using the facilities providing respite care is also far from clear and is an area to which scant attention has been given. The jealousy and friction reported by Allen (1983) have already been been noted. On the other hand Berman et al (1987) reported that long-stay patients in their study gained emotional and mental stimulation from respite users. There have otherwise been few accounts in the literature, and even the more comprehensive models of respite provision which will be considered shortly (Intagliata 1986, Webster 1988) appear to have ignored the implications of respite care on other patients.

As was noted above one of the key variables determining the impact of respite care for both carers and their dependants was considered to be the attitudes and activity of staff. It is therefore instructive to compare reports of these between studies which have considered respite in hospitals and in Part III homes.

(iii) Staff

A number of authors have descibed how, for hospital staff, the introduction of respite beds has resulted in an improvement in staff morale (De Largy 1957, Martin 1981a, Berman et al 1987) even though it is acknowledged that this can bring additional work (Ellis and Wilson 1983, Miller at al 1986). It also seems that the increased patient throughput accords more closely with the 'medical model' notion of discharge equating with success (Twigg 1989), with such an outcome still being extolled as an appropriate goal for geriatric medicine (Hall 1988).

As was also noted in the introduction, respite care fits nicely into the current medical emphasis on reducing and eventually eliminating long-stay hospital beds (Bond and Bond 1987). However staff within hospitals tend to operate eligibility criteria based on the concept of dependency equating with need (Packwood 1980) and there is disagreement as to the extent to which respite care is offered solely for carers or on a more holistic basis (Berman et al 1987, Tyler 1987). Given the attractiveness of respite users in terms of staff morale there is also a danger that the introduction of such beds may result in less time being available for the care of long-stay patients. Indeed it has been demonstrated that amongst respite users themselves it is the more articulate, less dependant and more socially adept individuals who command more staff attention (Allen 1983, Tyler 1989).

In part III homes the situation is in many ways the reverse of that in hospitals, with staff viewing their prime responsibilities as lying with the permanent residents (Allen 1983). Respite users are acceptable if reasonably self-sufficient but are perceived as problematic once they become dependent or confused (Allen 1983). Generally speaking, staff in part III homes appear to have minimal knowledge of the needs of respite users and there was little or no attempt to individualise care (Allen 1983). Perceptions also differed as to the purpose of the service. Managers seemed to think it was a 'good thing', without being able to specify why, heads of homes saw it mainly in terms of a trial admission and social workers, the main referral agents and gatekeepers, saw it as a service for carers (Allen 1983).

In situations where the service was perceived to be mainly for carers and the break was seen to be largely an end in itself then there was little impetus for change (Boldy and Kuh 1984) and staff had little time for carers who complained about a service that was supposed to be for their benefit (Oswin 1984). That these conditions seem likely to contribute to the inflexibility of respite care services has already been noted.

1.7 Respite care: a more comprehensive evaluation

From the available literature on respite care a number of important factors in a pluralistic evaluation can be isolated. Firstly, whilst there are four main groups of stakeholders in this study, there is little consensus as to what respite care could or does do for them. The overriding rationale for providing a respite service is a largely instrumental one aimed at maintaining carers in their role in the hope of reducing the demand for permanent institutional places. The provision of the break which respite care affords is usually seen as sufficient to achieve this aim and there have been very few descriptions of a service which attempts to look much beyond this. There is a generally described failure on the part of staff to address the guilt which respite care can produce for carers. Furthermore, the existence of eligibilty criteria seems to have resulted in a relatively inflexible system with access available only through official referral mechanisms. There has been even less attention given to the potential of respite care for good or bad in relation to the other stakeholders. There appears to be little doubt that, for many frail elderly, outcomes are negative and seldom as positive as they might be, possibly as a result of respite care being seen as a service primarily for the benefit of carers. Even though staff can do much to ameliorate negative outcomes they often appear, it seems, to be largely unaware of the potentially deleterious effects of respite care.

Despite these conceptual blinkers there are two recent contributions to the literature which have taken a wider perspective.

Webster (1988) contends that if the effectiveness of respite care is to be improved then more attention needs to be focussed on four key factors: the environment in which the service is offered, the needs of the informal carers who are the main beneficiaries, the impact on the frail elderly dependant and the reactions of the staff. This represents a step forward but a more comprehensive model has been postulated by Intagliata (1986) and whilst this approach was developed for use in the field of mental handicap it is considered to have a great deal to offer in the case of respite care for the carers of frail older individuals.

Essentially Intagliata (1986) advocates that any evaluation of respite care should address three main issues. Noting the limitations of current evaluation frameworks he presents a conceptual model comprising of:

A) **Independent variables** under the control of service providers. These include location, availability, accessibilty, provider qualifications and activity provided for the dependant. Confirming the findings of the foregoing review he notes that the tendency to perceive respite care as a service orientated towards the needs of carers has resulted in a neglect of activities provided for dependants.

B) **Intervening variables.** These are largely outside the control of service providers but are important contextualising variables with potentially profound implications for the impact of the service. They include the characteristics of the carer and the dependant, the carer's perceptions of the quality of respite care (which Intagliata sees as being critical, and influenced largely by the nature of staff/carer interactions), the other support the carer is receiving, the manner in which the system was entered or requested by the carer and the way in which the carer uses his/her free time.

C) **Outcome variables.** These are described as being intermediate and ultimate. Intermediate outcomes for Intagliata are confined mainly to a reduction in carer stress and it is in the area of final outcomes that he notes the severe limitations of present conceptualisations. In line with the conclusions of this review Intagliata suggests that ultimate outcomes have been conceived of almost exclusively in terms of decreasing the risk of institutionalisation, whereas the actual potential for respite care is far greater. Other areas which should be addressed include the need for services to be heavily utilised, the contribution they make towards an improved quality of life, a reduction in family dysfunction, the reduction in social isolation for the carer, the development of more positive carer/dependant relationships and improved dependant behaviour.

Intagliata concludes that there is a great deal to be done in terms of providing realistic expectations for respite care and in identifying those contextual factors which facilitate or inhibit its potential. In addition to adopting the broader conceptual framework which he outlines, he also advocates that evaluation should be guided by relevant psychological theories of stress that explicate those desirable, realistically achievable and theoretically and empirically valid outcomes for respite care.

In the context of the present study Intagliata's work is of central importance though his model will not be adopted uncritically. To begin with the model fails to address the impact of respite care on the other patients within the study hospitals. Furthermore, the conceptual similarity between the model proposed by Intagliata and those reviewed earlier by Donabedian, Coulton, the POW and Bond and Bond is apparent and yet once again the terminology is quite different. Within the pluralistic model to be utilised in this study attention will be focussed on the four groups of stakeholders identified.

The literature review has failed to identify a sufficiently broad range of aims for respite care adequately to inform the evaluation as to what is realistically achieveble and desirable from such a service. Therefore in order to construct a more comprehensive evaluation guide the call to theory and the wider empirical work suggested by Intagliata and those other authors previously reviewed will now be undertaken. The next chapter attempts to take account of the literature on informal care and and is followed in the subsequent chapter by a more detailed consideration of the other stakeholders. This represents a considerable undertaking in itself so the review will of necessity be selective. However the selection of literature will be underpinned by the theoretical constructs and empirical evidence which inform the study, which will be drawn together in formulating the final evaluation guide.

CHAPTER TWO

ADDRESSING CARERS' NEEDS: THE POTENTIAL OF RESPITE CARE

> "A child of five would understand this,
> send somebody to fetch a child of five"
>
> (Groucho Marx)

The above quotation is open to interpretation on a number of levels but perhaps the most relevant in terms of its present purpose is the implication that in order to understand something from a child's perspective one has to consult a child. In this chapter a similar philosophy will underpin the conceptualisation of the problems faced by informal carers. The literature on what constitutes caring, the difficulties caring presents and the professional response to such problems will be reviewed. It will be suggested that the failure to apply a consistent and holistic approach to these issues has resulted in a confusing and incomplete picture emerging. A case for conceptualising the problems of informal carers within a stress adaptation framework will be presented and the implications of such a model for the evaluation of respite care will be considered.

2.1 Caring: moving beyond the instrumental

Government committment to the care of dependent elderly people in the community was highlighted in the introduction and it was demonstrated that care in the community has increasingly come to mean care by the community. As a result there has been a rapid increase in research relating to the provision of community care and the position of informal carers, a situation fuelled by the rising numbers of frail older people and the dwindling pool of available informal carers. Related research, according to Twigg (1986), has been concentrated in two main areas:

A) The nature and pattern of community care

B) The burdens and costs of providing such care.

The publication of nationally repesentative data on the numbers of informal carers (Green 1988) has provided fairly definitive answers to questions in the first category, has highlighted the extent of informal care and indicated the relative inadequacy of service responses to this, as was suggested in the introduction.

The nature of what is meant by care is however less clear. There exists a lack of conceptual clarity as to what constitutes caring and accepted definitions appear to have led to an undue emphasis on instrumental activities to the exclusion of more diffuse and often more stressful aspects (Gwyther and George 1986, Bowers 1987, Townsend and Noelker 1987, Cox et al 1988, Sutcliffe and Larner 1988). Such criticisms would certainly seem to have some basis if three recent definitions of a carer are considered:

> "Anyone who looks after or cares for a handicapped person to any extent in their own home or elsewhere"
> (EOC 1982b)
>
> "A person who takes prime responsibility in the home care of a person who, because of handicap or illness needs almost continuous care"
> (Social Work Services Development Group 1984)
>
> "A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household"
> (Green 1988)

The above definitions are instructive from a number of standpoints. The middle definition, for example, came from a DHSS working group looking at the provision of services to carers and assumes that a carer is only someone taking 'prime responsibility' and providing 'almost continuous care'. This is explicitly instrumental in its focus and also provides useful insights as to where services are likely to be directed. The other two definitions arise from major surveys of carers and, whilst having a wider focus, are still implicitly instrumental, both suggesting that caring is mainly about 'looking after' or providing a 'regular service'. In drawing attention to the above it is not the intention to minimise or deny the importance of instrumental activity for carers but, as will be suggested below, there is an emergent view that such activities are often the least stressful. If this proves to be the case, then a concentration of services on instrumental activities is at risk of neglecting psycho-social needs which may be central to the lives of carers.

A number of authors have noted the lack of a comprehensive model for caring and have attempted to extend the way in which the construct is conceptualised. Twigg (1986) identifies caring as a mixed concept revolving around tasks of a supportive character which involve both social and family relationships and complex affective/emotional domains, a position similar to that of Qureshi (1986) who sees caring in two dimensions of practical tending and social/emotional needs. In distinguishing between these two components Pearlin et al (1990) contend that **caring** is best taken as referring to the affective component, whereas the term **caregiving** more accurately describes the behavioural aspects. Bulmer (1987) encompasses both practical and affective dimensions but further considers that a more generalised concern for the welfare of others underpins much of caring. Developing this latter point from a more philosophical perspective Griffin

(1983) contends that caring represents a primary mode of being, a fundamental concept in our understanding of what consitutes human nature. Therefore not to care is somehow to be less than human. Pursuing this line of reasoning Dunlop (1986) argues that whilst caring comprises of both practical and affective components the latter is the dominant concept and one that is primarily a relationship of concern for the person being cared for. There is now a growing body of empirical evidence to substantiate such claims. Thus whilst Qureshi (1986) has demonstrated that people will provide care in the absence of affection, the caring situation is more fragile and prone to collapse and the central importance of the quality of relationships in understanding carer stress is becoming increasingly well documented (Allen et al 1983, Qureshi and Walker 1986, Morris et al 1988, Lewis and Meredith 1988 a,b, Stoller and Pugliesi 1990).

The concept of caring is, then, in Kaplan's (1964) terms, far from closed and is still emergent. Perhaps one of the most comprehensive models proposed is that of Bowers (1987) however. Working from a grounded theory perspective Bowers contends that most of the recent empirical work has adopted a task-based definition of caring and that as a result much of the carer's role has been overlooked. She argues that most of the carer's work is invisible, in that it is only apparent to the carer. In extending this notion, Bowers argues that many of the components of caring are deliberately kept invisible from the dependant in order to preserve their self-esteem. Service providers can remain unaware of these latent needs which has obvious consequences for the tailoring of services to individual needs. In her reconceptualisation of caring Bowers (1987) proposes that caring should be redefined by purpose rather than task and she offers five conceptually distinct but empirically overlapping constructs in these respects.

Firstly there is **anticipatory** care, based on anticipated future need, with the key notion being 'just in case'. Anticipatory care can begin many years before any help is actually required and is deliberately kept from the individual who is the focus of its attention. However, it can have a profound effect on the carer's life as decisions are often influenced by such anticipated future needs. It should be noted at this time that Bowers work was concerned with children caring for parents and that recent research in this field suggests that the concept of anticipatory care has empirical support (Lewis and Meredith 1988 a,b).

The second type of care in Bowers' model is termed **preventive** care, the main component of which is monitoring at a distance. As with anticipatory care it does not usually involve direct help and therefore the 'cared for' may remain largely unaware of its existence. Examples of this type of care are keeping a subtle check that medication regimes are followed, that diets are adequate and so on.

When such a monitoring role requires more direct intervention such as assistance with actually taking medication then Bowers considers that the stage of **supervisory** care has been reached. At this stage the cared for is more likely to be aware of the interventions but the carer may still try to minimise such awareness.

As the need for direct assistance increases and the carer has to 'do for' then the stage of **instrumental** care has been reached. This is the type of care on which much previous research has been focussed. The dependant is now largely aware of their need for help but carers will often try to maintain an element of reciprocity in their relationship. Bowers (1987) argues that carers find this aspect of caring the least stressful.

Underpinning the whole model is the notion of **protective** care, whose purpose is to maintain the self-esteem of the dependant. This involves minimising their awareness of their failing abilities and maximising the extent to which they still perceive themselves as independent. According to Bowers (1987) carers see this aspect as the most difficult, the most important and the most stressful. Furthermore, it is often in conflict with other aspects of caring, especially the instrumental functions. It can, for example, be very difficult both to do something for someone whilst at the same time maintaining their perception of themselves as independent. Consequently carers would often prefer to ignore certain instrumental tasks in order to preserve protective caring.

The potential for conflict between a carer and a professional who usually comes in to provide instrumental care is obvious and the failure of professionals to appreciate this may be a prime reason why, in many cases, professional interventions have actually been considered as a source of stress for carers rather than a method of relieving it.

Bowers' (1987) model is based on a sample of children caring for parents suffering from dementia and was intended as an exploratory rather than as an explanatory study. Nonetheless, it would seem to have wider application and will be explored further when the literature on the problems of informal carers is reviewed.

From the foregoing it would appear that the concept of care, whilst not yet fully developed, extends far beyond the instrumental activities which dominate most definitions of a carer. However it is this latter view of caring which underpins most service interventions. The appropriateness of present services for carers has been increasingly questioned (Allen et al 1983, Qureshi and Walker 1986, Lewis and Meredith 1988 a,b) and it has been suggested that it is not until the needs of carers have been accorded the same status as those of dependants that the situation will improve (Morris et al 1988).

In relation to service provision Twigg (1986) considers that carers occupy an uncertain and ambiguous position which poses difficulties for professionals, a point developed further by Gordon (1987). He contends that carers can be viewed along a continuum from 'resources' at one end to the 'victims of exploitation' at the other. The purpose of services will be instrumental when carers are viewed as resources but when they are seen as victims of exploitation then services should primarily be aimed at reducing the impact of exploitation.

Twigg (1986) thus argues that professional interventions with carers are based on a number of implicit and only partly validated models. If carers are viewed as resources then interventions are minimised for fear of replacing the natural predispositions for care. If carers are to be seen as partners then interventions should be cooperative, enabling and sustaining, with carers' welfare representing a legitimate component of a reciprocal carer/professional relationship. On the other hand, if carers become clients then there is the inherent danger that services will become swamped with ordinary human misery and take over the normal processes of life. Research has to this extent begun to raise the sensitivity of professionals to carers' needs but threatens them with a Pandora's box, the dilemma being heightened by the lack of a consensus as to what constitutes reasonable rights or norms for carers.

The position is not much clearer for carers themselves. Thus Pratt et al (1987a), following a survey of carers, reported that 54% of their sample identified problems of an ethical nature, highlighting the lack of any clear guidelines as to how carers should react. As a consequence many carers saw attention to their own needs as evidence of selfishness and experienced guilt as a result. One significant result of this was that carers were unable to set limits on their care and subsumed their own needs entirely to those of their dependant. Pratt et al (1987a) comment that it is short-sighted to place the responsibility for care on the family without recognising the limits to this demand and providing some acceptable alternative.

It therefore appears that present services fail to address many of the problems which carers face and yet in a world of finite resources some targetting of services is inevitable. Attention is now turned to the research literature on the circumstances and difficulties of informal carers to see if this can help inform the debate as to what services might reasonably provide.

2.2 Care-related stress: conceptual confusion

Having already highlighted the general failure to conceptualise caring in other than instrumental terms, research into the nature of informal care has been hampered by similar problems. Firstly, it has been peculiarly one-sided, concentrating almost exclusively on the problems and difficulites carers face to the virtual exclusion of possible sources of satisfaction (Motenko 1989, Lawton et al 1989b). Secondly, despite the focus on the burdens of care, the failure to adopt a consistent theoretical approach has resulted in conceptual confusion, as will be highlighted below.

From a consideration of the available research it is clear that caring can have detrimental consequences in a number of areas of functioning including physical and emotional health, social and family life, carer-dependant relationships and financial and employment opportunities (Allen et al 1983, Parker 1985, Goodman 1986). However, disparate results have emerged, making it unclear as to who is at the most risk from adverse consequences and which aspects are the most stress-provoking.

Studies have suggested that social life is severely affected (Hooyman et al 1985, Wright 1986) but many investigations have indicated that the most prevalent and pervasive effects relate to emotional components such as feelings of guilt, anger, depression and so on (Hirschfield 1981,1983, EOC 1982a, Horowitz 1985, Cantor 1983, Worcester and Quayhagen 1983, Briggs 1983, Johnson and Catalano 1983, Bowling 1984, Charlesworth et al 1984, Parker 1985, Simmons 1985, George and Gwyther 1986, Bell et al 1987, Thompson 1987, Crookston 1989).

Which aspects of caring produce these adverse reactions is as yet unclear. Studies have implicated a number of dependency and objective factors such as; sleep disturbance,immobility and faecal incontinence (Sandford 1975), mobile dementia sufferers (Hirschfield and Krulick 1985), immobility, incontinence, help with the activities of daily living (ADL), duration of caring (Quine and Charnley 1987). Conversely, whilst factors such as those above are seen as stress-provoking by carers it has been suggested that personality factors, such as a bombastic and demanding dependant, produce more stress (Wade et al 1983). Indeed the bulk of the empirical evidence indicates that there is no clear and consistent relationship between the nature and extent of disability, the duration of caring and the degree of burden which the carer perceives (Zarit et al 1980, Gilhooly 1984, Hawranik 1985, Parker 1985, George and Gwyther 1986, Fitting et al 1986, Winogrond et al 1987, Noelker and Townsend 1987, Whittick 1988, Cox et al 1988, Motenko 1989, Novak and Guest 1989, Kahana and Young 1990).

It is postulated that the subjective perceptions of the carer are more important than objective criteria in determining the degree of burden (Poulshock and Deimling 1984, Parker 1985, Simmons 1985, George and Gwyther 1986, Zarit et al 1986, Noelker and Townsend 1987, Cox et al 1988, Motenko 1989, Kahana and Young 1990) and that burden is differentially experienced by different groups. Once again, there is no consistent pattern of burden with some studies identifying women as suffering the most adverse consequences (Gilleard et al 1984, Fitting et al 1986), others men (Moritz et al 1989) and yet others spouses (Cantor 1983, George and Gwyther 1986) or resident carers (Jones 1986).

Furthermore, factors considered to ameliorate burden also differ and include the frequency of family visits (Zarit et al 1980, Hawranik 1985), carer perceived health and past carer/dependant relationship (Gilleard et al 1984) to the perceived trajectory and course of the caring situation (Hirschfield and Krulick 1985). It has also been suggested that the carer's ability and willingness to care is mediated by the extent of **mutuality** (Hirschfield 1981, 1983), a notion concerned with the carer's ability to find meaning and gratification in his/her role. As mentioned previously there have been no attempts systematically to explore the positive aspects of caring (Noelker and Townsend 1987, Motenko 1989, Lawton et al 1989b) but there is evidence indicating that caring can provide satisfactions, particularly where a good carer/dependant relationship is maintained (Davies 1980a, Allen et al 1983, Qureshi and Walker 1986, Lewis and Meredith 1988a,b, Crookston 1989, Motenko 1989, Lawton et al 1989b). Such findings, whilst being equivocal, do suggest the need to take into account individual perceptions and interpretation of events when considering the burdens and satisfactions that may result from caring.

Until recently the concept of burden has been differentially defined and measured, making comparisons between the results of different studies extremely complex. This has been the result largely of the failure to apply a consistent theoretical approach. The main difficulty seems to have arisen from the causal factors and mechanisms operating to produce burden.

One of the early and seminal studies concerned with identifying and measuring carer burden was that of Zarit et al (1980).

Anticipating that burden would increase as the abilities of the dependant decreased, and working on the assumption that the discomfort caused by certain caregiving situations would translate into burden, they constructed a 29 item scale on the basis of clinical experience and empirical literature. The scale tapped into the domains of carer health, psychological well-being, finance, social life and relationships. Each item was scored on a Likert scale and an overall summary score for the whole scale calculated. This was an important methodological advance but the scale, which has been widely used since, suffers from a number of limitations. Firstly it contains a mixture of items, some of which ask for an emotional response to an event, for example:

'I feel stressed between trying to give to my spouse as well as my other responsibilities'; whereas others only ascertain if an event occurs, for example:
'I feel my social life has suffered because of my involvement with my spouse'.

However, both of these types of questions are scored identically with the implicit suggestion that having a restricted social life **must** be a source of stress, an unwarranted assumption as one person may consider their social life to be very important, whereas another might just as easily not. Furthermore the summative nature of the scale presents an overall burden score and fails to identify the relative contribution of the constituent parts to the overall burden score.

A similar but simplified scale was suggested by Robinson (1983). This consisted of only 13 items with a fixed yes/no response, each 'yes' answer contributing one point to the overall score. A score of seven or more was considered outside the normal range and indicative of carer strain. According to Robinson the conceptual basis underpinning the scale is that of strain, which she defined after Pearlin and Schooler (1978) as 'those enduring problems that have the potential for arousing threat'. Such a definition indicates that a problem may arouse a threat. However, by automatically giving a score of one for each yes answer Robinson assumes not that this **may** arouse a threat but that it **will and does** arouse a threat. Futhermore there are severe weighting problems. For example caring as a cause of inconvenience is weighted in exactly the same way as the carer feeling completely overwhelmed.

Thus, these two scales assume equivalence of stimuli and mask the relative contribution of forms of burden to the overall burden score. Recently the inadequacies of burden scales which only provide an overall global score have been highlighted (Kosberg and Cairl 1986, George and Gwyther 1986, Novak and Guest 1989, Kosberg et al 1989, Pearlin et al 1990, Chiriboga et al 1990). For instance it has been demonstrated that individuals may have an identical total score which masks very different underlying components (Novak and Guest 1989). This clearly limits the effectiveness of interventions which need to address the specific problem (Kosberg et al 1989, Pearlin et al 1990). Moreover a re-analysis of the Zarit scale has suggested that it actually comprises five differing sub-scales (Chiriboga et al 1990).

Cantor (1983) made a significant contribution to the conceptualisation of burden when she highlighted the need to distinguish between the degree of strain and the impact on the carer's life. Therefore, degree of strain and impact were operationalised separately. Strain was concerned with the perceived effects of caring on physical and emotional health and finances, whilst impact measured the limitations caring imposed on such domains of people's lives as time spent with children, available leisure time and so on. Scores on the strain and impact measures were used as dependant variables in a series of multiple regression analyses, with 14 demographic, situational and attitudinal variables acting as the independent variables. Cantor (1983) concluded that degree of strain and impact were separate but related consequences of caring. This represents an important step forward in indicating that strain and impact are not synonomous, but the utility of the analysis was limited by using strain and impact only as dependent variables and by making no attempt to use strain as a predictor of impact or vice versa. Such a possibility was raised by Poulshock and Deimling (1984).

These authors noted the foregoing conceptual and methodological confusion in attempts to measure carer burden and proposed a three part model comprising of:

A) **Elder Impairment**, operationalised in terms of the amount of help required with ADL and three measures of mental functioning (sociability, disruptive behaviour and cognitive incapacity);

B) **Burden**, defined in terms of subjective, individual responses to impairment. In the model the measurement of burden flowed from its connectedness to impairment. Thus it was measured in terms of the difficult, tiring or upsetting nature of help with ADL and perceived problems relating to mental impairment (range: none to great);

C) **Impact**, represented the outcome measure used in the model, the more or less objective changes in the carers' lives. Two scales measured carer/dependant/family relations and social life of the carer.

The model was conceived to run in the causal direction:

IMPAIRMENT → BURDEN → IMPACT

with burden mediating between impairment and impact. Following a series of regression equations the authors concluded that impairment in ADL (mediated via perceived burden) impacts on social life and that impairment in mental functioning impacts on carer/dependant/family relationships. This model is important as it highlights the importance of subjective perceptions as a mediating factor. However it still appears to contain a number of conceptual and methodological limitations.

Firstly, it is predicated on the assumption that burden flows from its 'connectedness' with impairment and yet the empirical literature reviewed (much of which, to be fair, post-dates this model) indicates that this is not a valid assumption. As Zarit and Zarit (1982) suggest researchers in the area of carer burden have a strong tendency to make the inferential leap relating a greater number of problems to a higher degree of burden.

Secondly, there is no real theoretical or empirical evidence to suggest that a restricted social life or change in relationships mark the ultimate outcomes of caring, as the model suggests. Once again the literature indicates that the most likely outcome is poor emotional or physical health, to which a poor social life or family relationship may well contribute. Also, whilst the outcomes are supposed to represent more or less objective features of caring, in operationalising them the authors ask respondents to indicate their subjective feelings of anger and resentment towards their dependant.

Thirdly, there is no theoretical underpinning for the causal ordering they propose, which would seem to work in the following manner:

> The person I care for needs a lot of help with ADL.
> I perceive this to be a burden. Therefore I don't (or
> can't) go out.

The opposite causal ordering would appear to make at least as much, if not more, sense. Hence the model would run:

IMPAIRMENT → IMPACT → BURDEN

and the scenario would be:

> The person I care for needs a lot of help with ADL.
> This means I cannot go out.
> Therefore I see caring as a burden.

Whilst Poulshock and Deimling (1984) have added an important dimension to the conceptualisation of carer burden in postulating a mediating influence for subjective assessments their model is limited in its causal direction, the confounding of burden with impairment and the restriction of its outcome measures.

George and Gwyther (1986) suggested that a better way of conceiving and measuring carer burden would be via discrete measures of well-being that could also be used on non-carers, thus facilitating comparison. In looking at four areas, physical health, emotional health, financial situation and social life these authors contend that carers, in comparison with the general population, are worse off in terms of their emotional health and social life, but that there are no significant differences in physical well-being or financial situation. Whilst such an approach is of use in comparing carers to a sample of non-carers it treats all the outcomes of caring as discrete (distinct) dimensions and as equivalent end-points and thereby fails to explore any possible inter-relationships or to consider the ultimate outcome.

2.3 Care-related stress: a transactional model

Kahana and Young (1990) contend that whilst the concept of burden is a unifying one in carer research previous models have been limited both in their conceptualisation and operationalisation, a point noted by others (Pearlin et al 1990, Chiriboga et al 1990).

What is required to take the conceptualisation of carer burden forward is a model which differentiates impact (in objective terms) from burden (in subjective terms) and accommodates the mediating role of subjective appraisals in determining an outcome for care-giving. The review of the literature on caring indicates quite clearly that negative consequences can accrue in a variety of areas. On the other hand the majority of studies suggest that the most prevalent and pervasive outcome is best seen in terms of a deterioration of physical and emotional well-being, especially the latter. A model to help explicate the relationship between these various factors might well look something like this:

Caring may have Impacts on social life, relationships → Perceived degree of burden → Deterioration in health

Such a model fits in with general theories of stress and is one which has been suggested as the most suitable for advancing our understanding of the nature of carers' problems (Zarit et al 1986, Morris et al 1988, Lawton et al 1989b, Pearlin et al 1990, Chiriboga et al 1990). As the advocates of such an approach point out it allows for the possibility of objective factors being distressing but not burdensome (Morris et al 1988) or differentially burdensome for each individual (Bailey and Clarke 1989), something which necessitates the measurement of the subjective burden of each objective event (Platt 1985). It is the crucial role of subjective appraisal in mediating between the objective circumstances of the caring situation and a deterioration in carer health that is the key concept underpinning this approach (Platt 1985, Zarit et al 1986, Morris et al 1988, Lawton et al 1989b, Bailey and Clarke 1989, Pearlin et al 1990). Such a model is also well suited to the evaluation of respite care as it will be recalled from the previous chapter that one of the recommendations of Intagliata (1986) was that evaluation models that accommodate higher range theories, particularly those considering the nature of stress, need to be constructed.

Attempting to explain carer burden in terms of stress theory may appear to be tantamout to replacing an enigma with a paradox, in that one vague concept is being replaced by another. Certainly stress, as Jacobson (1983) notes, has paid the price of popularity in terms of conceptual confusion. A recent review of the state of development in stress theory and its empirical application (Edwards and Cooper 1988) has highlighted the fact that stress is still the subject of an extensive variety of approaches. On the other hand there is an emerging consensus on a model for applying stress theory to work in problem situations in carer, family and patient/client settings (Goosen and Bush 1979, Scott et al 1980, Clarke 1984 a+b, Spaniol and Jung 1987, Hatfield 1987, Boss 1988, Chilman et al 1988, Bailey and Clarke

1989, Benner and Wrubel 1989). Moreover, the model advocated is the same as that which it is suggested be applied to carer stress (Zarit et al 1986, Morris et al 1988, Lawton et al 1989b, Pearlin et al 1990, Chiriboga et al 1990).

In reviewing the development of stress theory Bailey and Clarke (1989) outline three models. Firstly there is a **stimulus** model in which stress is viewed as being something external to the individual. This environmental stimulus may result in a change within the person, with this change being termed **strain.** The second model sees stress as a **response** made by the individual to some external factor. Both these models are now generally accepted as being inadequate to account for the range and extent of human behaviours. Thus Bailey and Clarke contend that most writers now subscribe to what is generally termed a **transactional** model.

This model has been developed from the work of Lazarus (1966) and is primarily a psychological approach to understanding stress. It consists of a number of components and can be seen as operating in the following way. A demand occurs (an internal or external stimulus that requires a response) and the degree of threat, harm or challenge it poses is appraised (**primary appraisal**). If it is perceived as threatening then the nature of the demand is cognitively matched against the individual's coping resources (**secondary appraisal**). A coping response is evoked and its effect on the original demand is also assessed (**reappraisal**). Stress is only said to occur when there is a perceived mismatch between the nature of the demand and the individual's ability to respond (Scott et al 1980, Clarke 1984 a,b, Panzarine 1985). It will readily be seen that within such a model the crucial determinant is not the nature of the demand but the appraisal of that demand and as Spaniol and Jung (1987) note something therefore only becomes a stressor when the mind identifies it as such.

In summarising this model Bailey and Clarke (1989) utilise the term **Cognitive-phenomenological-transactional model** (CPT) highlighting its three central attributes:

a) **Cognitive** based on the meaning and significance attached to events rather than their objective character;

b) **Phenomenological** as it allows for the unique and possibly idiosyncratic appraisals of each individual. This affords the major strength of accounting for differing reactions to objectively identical events;

c) **Transactional** highlighting the interactive nature of the model and the feedback between demand, appraisal and behaviour.

Edwards and Cooper (1988) state that there is broad agreement as to the way such a model runs:

Stressor →	Appraisal →	Coping →	Health
(Antecedent)	(Mediating)	(Mediating/ Moderating)	(Criterion)

However, they also suggest that other factors require consideration, for example the possibility of coping occurring before appraisal, the fact that coping itself may act as a stressor, or that stress may have positive outcomes; in that successful coping may result in a positive reappraisal of self. This point also made by Pearlin et al (1990) who advocate this model for the explication of carer stress. As they suggest such models should not be seen as end points in themselves but rather as heuristic devices by which to explore the empirical world.

Therefore whilst the dynamic nature of transactional models is still developing, clearly a crucial concept in such a model is coping and as with stress its exact meaning is unclear (Brailey 1984). A number of authors have offered definitions using a potentially bewildering variety of terms (Pearlin and Schooler 1978, Brailey 1984, Clarke 1984a,b, Panzarine 1985, Hatfield 1987, Spaniol and Jung 1987). However from a synthesis of these studies it seems that some sort of broad agreement can be reached and that coping may operate in three main ways, by direct manipulation of the demand, by altering the perception of the demand, or by dealing with the consequences of the demand. Such a synthesis has recently been suggested by Pearlin et al (1990) when they describe coping efforts as being directed to managing the situation, managing the meaning of the situation and managing the stress symptoms. In this way, as Panzarine (1985) suggests, coping is concerned with both problem solving and tension reduction. Within the transactional model the effectiveness of coping is judged by the extent to which the reponse has relieved the original problem or reduced its adverse consequences (Pearlin and Schooler 1978, Bailey and Clarke 1989).

How does caring as a potential stressor fit into this general model? Hatfield (1987) quotes Wrubel et al (1981) in considering a stimulus as a stressor if it is:

A) Unique - beyond the prior experience of the individual.
B) Of extended duration or frequency
C) Pervasive - capable of influencing many different aspects
D) Ambiguous - making varied, unclear or conflicting demands.

Clearly, if these criteria are applied, caring represents a powerful potential stressor.

However as the model of stress outlined above suggests those aspects of caring which are stress-provoking and the degree of stress which actually results will be influenced by the individual appraisal of the circumstances of care and the coping resources available. In the caring situation other antecedent factors will also be important and these include, in addition to the pivotal role already identified for the quality of the past carer/dependant relationship, the beliefs and expectations which the carer has concerning his/her role, the nature and extent of support available and the duration of the caring history. Pearlin et al (1990) term such influences **background or contextual** variables.

In considering the backgrounds variables influencing attitudes to care Qureshi (1986) has identified two main sets variables which she considers operate in determining such attitudes. One she terms internal and these relate to the history of the carer/dependant relationship, already noted above, and also the dependant's response to ageing and dependency. The second she terms external pressures which constitute general societal beliefs about the role of the family in supporting its dependent members, which are reinforced by gender stereotypes, through the media and by peers.

A similar but more comprehensive model has been developed by Phillips and Rempusheski (1986). They consider that both the carer and dependant enter the caring situation with an image of caring which determines their role relationships and the subsequent care given. Factors considered influential are the carer's past image of the dependant and the reconciliation of their present condition with this past image. The carer's general beliefs as to what constitutes healthy living, a good quality of life and the nature of family relationships and responsibilities. Where there is congruence between these factors then carers are said to adopt a style of caring which is more open and protective and in which they have fewer expectations that the dependant will conform. Where image and beliefs are incongruent then carers are more likely to adopt a punitive style and expect the dependant to be more suppliant. Carers constantly evaluate their care against these expectations and feed back their responses into the system. Two other components which influence the situation are termed by Phillips and Rempusheski (1986) the 'currently salient role form' of the carer and the 'role interdependence' between carer and dependant. The former concept relates to the carer's tendency either to nurture/support or monitor/control in their general relationships. The latter concept highlights the fact that, unlike most social relationships, it is very difficult for either party to withdraw from the carer/dependant dyad. Such factors as these are likely to be crucial determinants of carers reaction to their situation and would need to be taken into account when planning service interventions. It is to this area that attention is now turned.

2.4 Reducing care-related stress: service responses

Caring is evidently a complex and diverse role with many determining factors operating in the production of carer stress. It should also be clear that instrumental aspects of care form but one component and a component which both the theoretical and empirical literature suggest is not the dominant one. Yet in terms of services to carers, and this includes respite care, it has already been demonstrated that instrumental activities are the principal focus.

Intagliata (1986), in his model for respite care, suggests that an important criterion for success is the extent to which it reduces carer stress. This would seem to form a reasonable measure for all services provided for carers. How well then do current services 'measure up' in this respect and how may the application of a transactional model of stress provide both pointers to what services could be doing and criteria against which to measure their performance ?

From the literature on informal carers relevant services can perhaps be grouped under four main headings:

A) **Information**-on a variety of topics from a simple who's who to more detailed accounts of their dependant's illness and treatment, services locally available, choice and some degree of control over packaging of services to meet identified individual needs.

B) **Skills Training**-especially in relation to nursing care, dealing with incontinence, lifting techniques and so on.

C) **Emotional Support**-at a number of levels:

- (i) Being recognised and valued for their work
- (ii) Having someone to 'talk over' problems with
- (iii) Help with recognising and dealing with a number of emotions such as guilt, anger, resentment.
- (iv) Setting limits on their care
- (v) Negotiating responsibilities with their dependant

D) **Regular Respite**-in a form which is available when it is needed, is amenable and open to carers' suggestions and is acceptable to both carer and dependant.

The literature reveals a consensus on the needs of carers with numerous authors advocating at least one if not all of the above (Hirschfield 1981,1983, Briggs 1983, Clark and Rakowski 1983, Muir-Gray 1984, Bonny 1984, Jones and Vetter 1985, AOC 1985, Parker 1985, Simmons 1985, Hirschfield and Krulick 1985, Hirst and Metcalf 1986, Hatfield 1987, Edwards 1987, Jowell 1987 et al, Pratt et al 1987a, Bell et al 1987, Tooth 1987, Corbin and Strauss 1988, Robinson 1988a, Robinson 1988b, Crookston 1989).

It is also equally apparent that these are the elements most often missing from carer/professional interactions, with services often being irrational, discriminatory and fragmented (Parker 1985, Tooth 1987, Webb 1987). Services are usually geared to the needs of the dependant (Qureshi 1986, Robinson 1988a) with little attention being given to the carer who is frequently not even seen as a legitimate recipient of services (Challis 1985, Goodman 1986, Bell et al 1987, Thompson 1987, Edwards 1987, Norman 1987). More often than not services are targetted at certain groups such as those living alone or male carers (Henwood and Wicks 1984, Charlesworth et al 1984, Bell et al 1987, Thompson 1987), overlooking the fact that the needs of other carer groups can be left unrecognised. There exists a clear mismatch between the services provided and those desired, with the views of providers and carers often being 'worlds apart' (Bayley 1986, Chenoweth and Spencer 1986, Jowell et al 1987). Furthermore, services are more often than not reactive and provided only in times of crisis, rather than proactive and preventive (Henwood and Wicks 1984, Phillipson and Strang 1984, Tooth 1987, Edwards 1987). It is suggested that professionals are largely unaware of the stresses carers face (Jowell et al 1987) and, due to the sensitivity of carers to professional reactions (Davies 1980a), they may inadvertantly increase carer stress (Clark and Rakowski 1983) and inhibit carers from seeking further professional advice (Bell et al 1987, Corbin and Strauss

1988).

It is suggested here that if professionals were to conceptualise carers problems from within a transactional model of stress that this would provide a useful organising framework which would better sensitise them to carers' needs. A number of authors have advocated just such an approach (Craig and Edwards 1983, Clarke 1884a,b, Rideout 1986, Hatfield 1987, Spaniol and Jung 1987, Zipple and Spaniol 1987, Watkins 1988, Boss 1988, Chilman et al 1988, Bailey and Clarke 1989, Benner and Wruebel 1989). Therefore, if professionally provided services are to seen as part of the carer's coping resources, such interventions may be focussed on any of the following areas (Spaniol and Jung 1987):

A) **Problem orientated**-assisting the carer directly to manipulate the demand. For example if a carer is taught how to lift then the physical demands and risk of back injury might be reduced.

B) **Emotionally orientated**-assisting the carer to deal with some of the emotional consequences of their role

C) **Cognitively orientated**-assisting the carer to alter their perception of the demand. This might be done in a number of ways but the simple provision of information may be enough. For example, there is is reason to believe that in the absence of information about dementia, carers often see behavioural changes as evidence that the dependant is being deliberately difficult and that if they can see this as part of the dependant's illness then they view the situation less negatively (Robinson and Thurner 1979).

D) **Physical techniques**-that assist the carer to relax and reduce their stress.

In achieving the above Zipple and Spaniol (1987) advocate an educative/supportive role for professionals in which they provide a comprehensive service that is information-skills-and supportive-emotionally based at the same time.

It might reasonably be expected that respite care, a service whose prime focus is carers, would not be subject to many of the criticisms above that apply to service provision for carers in general. Yet from the literature review in the preceding chapter it will be appreciated that most of the criticisms do in fact apply. The service is provided from a mainly instrumental view with the provision of the break often seen as being an end in itself.

It was suggested earlier, in the absence of well formulated aims for respite care, that reviewing the wider empirical and theoretical literature on informal care would help to inform a comprehensive evaluation by providing for a consideration of what the service **could** achieve. Following this review the author believes that reasonable theoretical and empirical support has been provided for the adoption of a transactional model of stress in conceptualising carers' problems and service interventions designed to ameliorate these. It is also contended that respite care, in addition to providing a break, could do a great deal to address the other areas of deficit in services for carers. It could, in particular, be used as an opportunity to provide information, skills training and emotional support. These criteria would seem especially relevant where respite is provided on a regular and repeated basis, as is the case with the rota beds which are the focus of this study. Thus one aim for the study will be to test out the relevance of these concepts for respite care. However as Pearlin et al (1990) point out the application of a transactional model to carer stress is still at the theoretical level and there is a need to apply an empirical test. This therefore becomes another main aim for the study.

In order to complete the evaluation guide the following chapter will consider the literature on what respite care could achieve for the other stakeholder groups.

CHAPTER THREE

RESPITE CARE AND OTHER STAKEHOLDER GROUPS

> "If care of the elderly is the Cinderella of services,
> then long-stay care is the ugly sister"
>
> (Anon).

3.1 Present knowlegde: a brief summary

It is the intention of this chapter to complete the evaluation guide by reviewing the wider empirical and theoretical literature relating to the other main stakeholder groups. Prior to this however the results of the literature review on these groups presented in Chapter 1 will be briefly re-rehearsed.

It will be recalled that three other groups were identified, the elderly people who used the service, staff and the more permanent patients or residents of the institutions in which the service was based. The existing literature describing the effects of respite care on the latter group was scant, but it tended to suggested that in Part III homes jealousy and friction could arise between the permanent residents and the respite users, whereas in hospitals at least one study indicated that the long-stay patients were stimulated by the presence of the respite users.

A similar unclear and divided picture emerged relating to staff groups, with institutional differences again apparent. Staff in social services facilities saw their main priorities as lying with the permanent residents and tolerating respite users as long as they were not too dependent. Also, for fear of upsetting the residents they treated both groups alike. Staff were ambivalent in relation to respite users. Alternatively, staff in hospital setings, whilst acknowledging the extra work respite patients cause, seem to perceive this group of patients more positively, suggesting that the addition of respite beds to a unit might be a factor in raising staff morale. From the literature it seems that staff attitudes to both carers and respite users are an important determinant of the quality of the respite experience for both groups. Unfortunately, it appears that staff are largely unaware both of the guilt which carers can experience and of the potentially deleterious effects on the older people using the service.

The literature is also equivocal as to the effects of respite care on the elderly dependants with outcome differences between residential settings emerging. Early descriptions of hospital based respite care portrayed a picture in which patients were physically and mentally rested as a result and also less dependent. However, a number of subsequent reports have been far less positive indicating a very real risk of morbidity and even mortality; the former also having been noted by carers. It is suggested that admission to hospital for respite care affords the opportunity to re-assess the patient and, if neccessary, provide rehabilitation. On the other hand exposure to an institutional regime can increase dependency and lead to the elderly person feeling depressed and abandoned by their carer. For certain groups, particularly the mentally frail, respite care can result in an increase in confusion. In Part III homes respite care is more likely to be seen as a holiday for the dependant or as a trial admission prior to permanent placement. It seems that some users, usually the less dependent or socially isolated, enjoy the hotel aspects of respite care in Part III homes, but generally speaking there is little activity or stimulation for them to enjoy. Within all institutionally based respite care it is suggested that, even if physical needs are attended to, higher level cognitive and affective needs are rarely met.

It seems therefore, that to some extent the effects of respite care on the older person using it varies between institutions and may also be influenced by the personal characteristics of the dependant.

The wider literature will now be consulted to present a case for what respite care could achieve for the other stakeholder groups and also to consider the barriers to this potential. Consideration will initially be given to the elderly users of respite care.

3.2 Respite care: a consumer guide

The more comprehensive evaluation models of Webster (1988) and Intagliata (1986) help to provide a critical focus for this section. Particular attention will be given to the environment of care, the activity provided, the potential for an improved subjective well being, especially self-esteem and a reduction in dependency (or dysfunction as it is termed by Intagliata 1986). Logic would indicate that the most important of these is the effect on subjective well being, although this is likely to be influenced by the other three variables, and all of these will be considered in the following review. In order to keep the review to reasonable proportions consideration of institutional environments will be restricted mainly to continuing care hospitals as this is area of substantive interest in the present work but other literature will be consulted where it is considered relevant.

The quotation with which this chapter began probably gives a fair reflection of the way in which long-stay or continuing care hospitals have been described in the literature. In relation to elderly dependants the problem is further compounded by lack of agreement as to what constitutes a reasonable quality of life, or at least ways in which this might be measured and consequently as to how services might go about achieving this aim.

In order to explore the possibilities of respite care let us take what might be considered as a "typical" case scenario. This of course requires that some assumptions of "typicality" be made and it is stressed that this approach is used for illustrative purposes only. However the eligibility criteria applied in respite care that have already been noted suggest that some of the assumptions now made are not unwarranted.

For the purposes of illustration some characteristics of a "typical" respite user within geriatric hospitals might well be an older, frail individual, probably with physical and/or mental impairment and dependency as a result of a chronic, long-standing condition. Consequently, cure is unlikely and rehabilitative potential is limited, although maintenance of present levels of functioning and small gains in functional ability are possible. However, no matter how limited the potential for functional improvement is, gains can be made in self-esteem and psychological health. Such an imaginary "typical respite user" describes the very sort of individual for whom present services tend to cater least adequately as their needs do not fit into the progressive patient care model which dominates health service provision and yet they are often too dependent for other services. What then is the positive potential of respite care within a hospital environment for such an individual?

Firstly, let us consider the more obvious benefits that might be achieved. According to Evers (1981a) geriatric care is considered to have four mains aims:

A) To make full use of diagnostic services and to discharge patients wherever possible.

B) To promote and encourage physical and psychological independence.

C) To promote self-esteem and quality of life via purposeful activity.

D) To make available the full range of skills offered by the multidisciplinary team.

Therefore, notionally at least, our frail older person admitted for respite care might reasonably expect to be fully assessed both medically and functionally, to be the subject of a range of therapeutic interventions aimed at alleviating any problems discovered and to engage in purposeful activity designed to improve self-esteem and quality of life. That this is unlikely to be the case in a continuing care environment will be highlighted later on, and indeed Evers herself (1981a,b, 1982) makes the telling point that such services as are available are usually focussed on patients perceived as remediable. However these aims do provide a yardstick against which to measure respite care. They also fit in with the wider literature on services for the frail elderly.

Probably the most comprehensive model considering what the outcomes of services for the elderly should be is that provided by Challis (1981). Whilst the main focus of Challis's model was community based services, many of the criteria are equally applicable to respite care. The model contends that any service provided for older people must also take into consideration the effects on the carer/wider family and on the community as a whole. He suggests that services can be evaluated according to seven main criteria, these being the extent to which the service provides for:

A) **Nurturance** which is seen largely in terms of physical maintenance, self-care and personal care.

B) **Compensation for disability** via the provision of aids and instrumental services such as home help.

C) **Maintenance of independence** particularly felt independence. In order to achieve this Challis suggests that services should foster reciprocity and focus on the older person's felt (ie perceived) capacity to manage, their perceptions of themselves as a burden to their carers and the degree of privacy and control they exercise over their lives.

D) **Morale** conceived as relating mainly to continued growth and successful ageing with an absence of overt psychopathology, that is an improvement in subjective well-being and absence of depression.

E) **Social integration** by reducing isolation and providing good quality social contacts and a confidant if one is desired.

F) **Improved** family relationships via a reduction in carer stress

G) **Community development** by fostering the involvement of the wider community in the care of its dependent older members.

From a synthesis of the aims of geriatric care provided by Evers (1981a) and the model of Challis (1981) together with the evaluation models for respite care suggested by Intagliata (1986) and Webster (1988) a reasonably comprehensive conceptualisation of the potential of respite care from the older persons viewpoint is possible. However, how realistic is it to expect these outcomes? The literature would suggest that in terms of respite care provided in continuing care hospitals the positive outcomes outlined above are **theoretically plausible** (and certainly desirable) but, from a consideration of the empirical evidence, are, in reality, **extremely unlikely.**

Attention is first turned to basic needs or, to use Challis's (1981) terminology, **nurturance.** Included within this is physical maintenance, self-care and personal care, and, presumably, absence of overt physical disbenefits. The potential for morbidity and even mortality during hospital based respite care has already been noted. However, basic physiological needs are the ones generally seen to be best provided for (Tyler 1987, 1989) and in relation to continuing care hospitals the most recent reports suggest that technical aspects of care can be high but that a therapeutic approach of a personal, social and psychological nature is often missing (RCN/BGS 1987). Whilst not seeking to minimise the possibility of physical disbenefits accruing as a result of respite care it seems reasonable to say that one would not expect them and, as noted above, the notional exposure to a diagnostic and therapeutic input might well result in an improvement in self-care abilities. On the other hand the tendency to "do for", which is well documented and will be expanded upon below, is more likely to result in deteriorating self-care abilities. However the individual's perception of the quality of their physical care, irrespective of its effects in terms of dependency are now seen as an important component of what constitutes "good care" in institutional settings (Hughes and Wilkin 1987).

In terms of compensation for disability this, if the aims of geriatric care are applied, should form part of the routine assessment procedure and the provision of suitable aids whilst in hospital and upon discharge can be viewed as one of the minimum standards for respite care in hospitals.

It is when attention is turned to the other areas of Challis's model that the potential for respite care becomes less clear. To what extent can a continuing care hospital provide for an increase in perceived independence and a feeling of being less of a burden on carers, to more control over life, an improved subjective well-being and a reduction in social isolation? Whilst empirical literature on respite care indicates that these needs are unlikely to be met (Tyler 1989), there is wider theoretical and empirical literature suggesting that meeting these needs during a respite care admission is at least a possibility if not a very distinct probability, as will now be illustrated.

Two key theoretical reference points are considered in this connection. The first concerns the nature of relocation effects in the elderly and the second examines the concept of self-esteem as a core component of subjective well being in the frail, disabled elderly.

It is axiomatic that institutional based respite care involves a relocation of the older person. There has been a vast amount of research, particularly in the USA, into the effects of relocation which suggests inconclusive results (Schulz and Brenner 1977, Rosswurm 1983, Burnette 1986). However, some issues have emerged which nevertheless appear to go some way towards ameliorating the adverse effects of relocation. In addressing this question Chenitz (1983) has developed a practice theory which she suggests can be used as a framework to better understand and ameliorate the effects of relocation. Whilst this theory was developed with specific reference to entry into permanent care, Chenitz argues that it has wider applicability. This assertion will be tested by applying the central tenets of the theory to the use of respite beds.

The theory was felt to be particularly suited to the present study as underpinning it is the notion that relocation effects are mediated by the individual perception of the event and the personal coping style and resources of the older person. This is clearly consistent with both the pluralistic approach to evaluation and the transactional model of stress. However Chenitz (1983) believes that underlying individual reactions are certain common elements or **basic conditions**, the unique combination of which determines whether people **accept** or **resist** the admission.

The first of these basic conditions are contextualising variables surrounding the event. These include both generally held beliefs about the families responsibilty to care and also the nature of the particular family relationships. The other basic conditions are as follows:

a) **Centrality** or the importance of the event in terms of the individual's struggle to retain **control** over their lives.

b) **Desirability** or the extent to which the move is seen as being desirable and to the personal advantage of the individual in contrast to being associated with being unwanted and dependant.

c) **Legitimation** or whether there is a legitimate reason for the move.

Chenitz (1983) argues that if desirability can be married with legitimation then it is possible for the older person to construct a perception of the admission as being a personal choice, even if in reality it is not.

d) **Temporality**, i.e. the timing of the admission, one of the key concepts here being the extent to which it is seen as being **reversible.**

Chenitz suggests that adverse relocation effects are most pronounced where the admission combines irreversibilty with undesirability, a lack of personal choice and no legitimating circumstances. However she also contends that negative effects can be ameliorated when some of the basic conditions are met.

In describing the possible reactions to admission Chenitz uses two broad categories which are further divided into two sub-categories. Thus people may either **accept** or **resist** the move into care.

Acceptance is achieved either by **strategic submission** or **submission by default.** The former usually occurs when the admission is reversible and therefore accepted for a time-limited period, or alternatively when the individual is able to perceive the event as a considered choice from amongst a very restricted range of options. Submission by default normally follows a catastrophic life event, for example the death of a spouse, when the admission is not seen as the most significant factor.

Resistance is likely to occur when one or more of the basic conditions are not met and may be either **resigned-resisting** or **forceful-resisting.** The former is characterised by withdrawal and apathy, a reaction which results in guilt and anger amongst any family. The latter is, as the name suggests, a more active response involving deliberate failure to participate in the life of the home and possibly culminating in verbal and/or physical abuse.

Therefore, whilst very few people would probably make a deliberate choice to go into respite care, Chenitz's (1983) theory does suggest ways in which the experience can be made more positive and potentially more beneficial. Respite care is not permanent and therefore meets the important basic condition of reversibility, a fact which should reduce anxiety to some extent. However if it is to be of optimum benefit there is still an apparent need to provide a desirable and legitimate reason and to make the environment as positive as possible. The nature of the environment will be dealt with in more detail shortly, but as regards a desirable and legitimate reason for admission, respite care in hospitals can have a distinct advantage over other institutionally based services.

Many elderly people entering respite care in hospital often perceive themselves as being admitted for assessment and/or therapy and this may provide both a desirable and legitmate reason for admission. Therefore whilst true choice may be absent it may still be possible for the person to perceive that the respite care admission is as a result of a personal decision. Such a self-constructed perception of legitimation has been noted in relation to day hospital care (Nolan 1986). Moreover such a perception adds to feelings of personal worth and significance which is a vital component of self-esteem in the chronically disabled (Charmaz 1983). This leads to a consideration of the notion that respite care might improve the subjective well-being in the frail, disabled 'typical' respite user.

Self-esteem is seen as being one of the foundations of psychosocial health in the elderly (Hirst and Metcalf 1984, Taft 1985, Coleman 1990), yet it is recognised that self-esteem is threatened by ageing in general (Taft 1985, Coleman 1990) and that this erosion is further compounded by the addition of chronic ill health and disability (Charmaz 1983, Taft 1985, Coleman 1990). Self-esteem is accepted as being an essentially social construction that is developed and maintained via relationships with significant others (Charmaz 1983, Hirst and Metcalf 1984, Taft 1985, Coleman 1990). Therefore central to continued self-esteem are the reflected appraisal of significant others and feelings of personal competance and control over the environment. Coleman (1990) considers that self-esteem consists of two component parts:

a) **Self evaluation** which involves the measuring of self against some standard;

b) **Self worth** which is more concerned with maintaining a sense of personal worth, of being a person who 'matters'.

Thus it is considered that the promotion of both positive self evaluations and self worth are prime targets for health interventions with the frail elderly, particularly for nursing staff (Hirst and Metcalf 1984, Taft 1985). Central to this is the need to maintain reciprocal relationships, of creating a perception of personal control, of sustaining the notion of being a treatable client, that is that one is not beyond hope and of minimising feelings of being a burden (Charmaz 1983, Taft 1985, Coleman 1990).

Yet as Charmaz (1983) graphically depicts chronic illness results in a crumbling away of former self images without the development of equally valued new ones. Chronic illness further limits opportunities for positive self-validations and existing relationships become increasingly fragile. Indeed as Charmaz (1983) notes it is the paradox of chronic illness to increase reliance on others for self definition at the very time that relationships become strained and problematic.

In such circumstances contacts with health personnel become especially important, but also potentially all the more discrediting (Charmaz 1983). The rota bed system under study offers repeated and regular contact with staff and patients in the hospitals in which it is based and therefore in a very real sense these individuals can become significant others, often the only others to which the dependant might have access outside their immediate family. Furthermore exposure to a therapeutic regime can create and sustain feelings of hope and personal worth, as has been noted in relation to attendance at day hospitals (Nolan 1986). In this context hope (Rideout 1986) is defined as the greater than zero expectation of reaching a goal, with hope being viewed as a vital component of adaptation in chronic illness (Craig and Edwards 1983, Rideout 1986). This adds validity to Chenitz's (1983) notion of the positive effects of providing a desirable and legitimate reason for admission.

Viewed from the above perspective respite care would appear to provide potential gains in self-esteem, especially if attention is paid to creating and sustaining positive perceptions of the admission. Such perceptions are likely to be strongly influenced by the environment of care, the type of activity offered (especially that which fosters reciprocity) and the nature of the social interactions and relationships that occur. Underpinning such ideas are notions of **choice, privacy, dignity, trust and attention to individually perceived needs** which are seen as being essential components, not only of institutional environments but of all services for the elderly (Rosswurm 1983, Wade et al 1983, Willcocks et al 1983, Taft 1985, Burbank 1986, Dixon 1986, Bond and Bond 1987, Hughes and Wilkin 1987, RCN/BGS 1987, Clark and Bowling 1989, Redfern 1989).

Therefore, in the 'best possible' case scenario, where all the above criteria are met and where care is planned on an individual basis, there is no inherent reason why respite care should not achieve those aims suggested by Evers (1981a) for the geriatric service and by Challis (1981) for service provision to the elderly in general. This represents a largely theoretical scenario but one that is still essentially achievable. However, even a brief consideration of the empirical literature about care in continuing care hospitals presents a starkly different reality.

It is fair to say that virtually every hospital study of continuing care for the elderly since the early days of gerontological nursing research (Norton et al 1962) to more recent work (Horrocks 1988, Clark and Bowling 1989) has described environments, activities and patterns of care which are the antithesis of those deemed desirable. These criticisms relate less to standards of basic physical care, which are often satisfactory (RCN/BGS 1987), but are concerned with care that is routinised with minimal attention to individual needs or to notions of choice, privacy and dignity. Furthermore activity is extremely limited with staff/patient interaction confined largely to instrumental needs during the direct provision of physical care.

Horrocks (1988) reviews the last 12 Health Advisory Service reports and reaches the conclusion that the picture painted 'must sadly reflect the general situation of long-term hospital care of elderly people in the 1980's. He describes ward environments in which privacy is threatened or absent, nursing care is batch provided with little evidence of individual care, quality of life is extremely poor with patients' minds numbed by routines and no evidence that independence is encouraged. Hence, although individualised nursing care forms the statutory basis for the profession with proven benefits for long-stay elderly patients (Miller 1984, 1985a,b), Kitson (1986), as with Horrocks (1988), is forced to the conclusion "without exception studies have demonstrated how.... nursing care was depersonalised, routine orientated and lacking in goal direction". Activity tends to be centred on the provision of personal care, the meeting of minimal universal needs (Wells 1980) with staff being over-protective, doing tasks for the patient and getting as much work as they can done in the first three to four hours of each shift (Robb 1984). In describing the type of routine which results, Evers (1981a) utililises the concept of "warehousing" first suggested by Miller and Gwynne (1972) and proposes that most care is based on "minimal warehousing" where there is no attempt to individualise care. Such a regime tends to produce depression, humiliation and boredom. Furthermore, as noted above, activity, except for the provision of physical care, is extremely limited with studies describing how the majority of patients are totally inactive for much of the time (Godlove et al 1981, Mc Donald et al 1985, Armstrong-Esther and Browne 1986, Clark and Bowling 1989). The nurse/patient verbal interaction that does occur is often of a controlling nature and does not encourage independence (Lanceley 1985), and is of very limited duration and quality focussing largely on physical care needs (Smith 1986, Seers 1986, Fielding 1986, Armstrong-Esther and Browne 1986, Clark and Bowling 1989). Limited though this interaction is there is also evidence to indicate that certain types of patients obtain a disproportionate share. It has been known for some time that some patients are more 'popular' than others and therefore receive more nurse attention (Stockwell 1972). Nurses caring for older patients appear to be no exception. What is perhaps more worrying is that patients seen to be more popular in continuing care environments are those demonstrating behaviours which are the opposite of those the staff are supposed to be encouraging. Nurses appear to value compliant, cooperative and less demanding patients (Gilliard and Brunston 1984, Robb 1984, Lanceley 1985, Fielding 1986). Furthermore, the socially adept and appreciative patient gets more attention (Robb 1984, Gilliard and Brunston 1984, Fielding 1986) whilst those who complain, are unappreciative, 'know it all' or lack communication skills are the least popular (Gilliard and Brunston 1984, Fielding 1986). It would therefore seem that, implicitly at least, staff often either reinforce, via social contact, dependent behaviours or give their time and attention to the socially skilled who are probably interacting more with other patients anyway. On the other hand the seminal work of Menzies (1960) suggested that nurses limit their interaction with patients, not because they do not value them, but to protect their own psyche, and there is more recent evidence to indicate that this might be the case with elderly patients (Lanceley 1985, Smith 1986).

These studies suggest that whilst respite care in continuing care wards might have undoubted potentialities the empirical reality indicates something quite different. At this point it is perhaps apposite to state that the problems noted above in terms of poor care and little stimulation/interaction have been described just as bleakly in other institutional setings for the elderly (Willocks et al 1983, Dixon 1986, Hughes and Wilkin 1987) which might lead to the conclusion that there is something inherent within such environments that makes poor standards inevitable. The nature of the organisational features which might contribute to poor quality care will be considered shortly. Particular attention will be given to staff attitudes and how these are influenced by the value and prestige accorded to working with the frail elderly.

So far, the review of care in continuing care environments for the elderly indicates that whilst geriatric medicine may have "turned around" the standards in acute settings, the same can hardly be said to be true of care for the chronically sick or disabled older person who is too dependent to be supported in the community. Indeed, as Gallagher (1986) notes, there would appear to have been little or no improvement over the last 40 years. The burning question of course is why? It is suggested here that to see poor care as an inevitable and unavoidable result of institutionalisation is not a satisfactory answer and it adds nothing to the debate if institutions are constantly blamed without reference to other factors. It is perhaps better to accept, as has been recently suggested (Clark and Bowling 1989), that institutional care of the heavily dependent will always involve some form of routine, like a good deal of so called 'ordinary living'. The question then becomes "What is the minimal routine in these circumstances and how can we ensure that it is used to maximise opportunities for choice, privacy and autonomy?".

3.3 Quality respite care and staff satisfaction: a symbiotic relationship?

In trying to answer the above question attention will be focussed on staff attitudes and practices rather than other factors. This is not to minimise the impact of such variables as the physical environment and staffing levels, the importance of which have been well documented (Norton et al 1962, RCN/BGS 1975, Lipman and Slater 1977, Wells 1980, Willcocks et al 1983, Bond and Bond 1987). It is rather an attempt to recognise that attention to these factors is neither a necessary and certainly not a sufficient condition for "good" care. Indeed, as recent reviews of the literature demonstrate (Bond and Bond 1987, Clark and Bowling 1989), even if staff numbers are raised to apparently ideal levels care does not necessarily change. It often results in more of the same. It is argued later that the main reason why institutional care does not improve is that the type of care required is accorded no real value and prestige. The result is low staff morale and little impetus for change. In addressing these issues particular attention will be given to care in continuing care hospitals, which means nursing care and its interface with medicine.

It must be stressed at this point that this in no way seeks to underestimate the potential contribution of other members of the multi-disciplinary team (MDT), which is recognised as being essential (RCN/BGS 1987). However, the input from therapy staff in the environments under consideration is severely restricted by low staffing levels and therefore the crucial determinant of care is likely to be nursing related.

In the introduction to the first major piece of multi-disciplinary research into care of the older patient in geriatric hospitals almost 30 years ago (Norton et al 1962), it was noted that "Geriatric nursing has long been recognised as being largely routine work of a particularly heavy nature". The intervening period of time would seem to have done little to alter this perception with Heiskanen (1988) describing the work as " discouraging, burdensome and unchallenging". Working with the elderly is rarely seen as a positive career choice, mainly due to the percieved lack of skill required (Ingham and Fielding 1985, Fielding 1986). Even within the field of geriatric care itself, the lowest status is usually accorded work with long-stay patients. Indeed the low prestige accorded by nurses to the care of elderly patients with continuing depenedency needs has been noted on numerous occasions, as has the consequent low morale of staff working with such patients (Baker 1978, Ingham and Fielding 1985, Armstrong-Esther and Browne 1986, Clark and Bowling 1989).

The concept of **burn out** has been applied to nursing work in all care settings and describes a reaction to an environemnt which places constant demands on the individual. However, the alternative formulation of **"rust out"**, proposed by Pennington and Pierce (1985), would seem far more apposite to work in continuing care environments. Rust out is said to occur where the work environment is characterised by boredom, tedium and a lack of stimulation, resulting in an emotional isolation and a failure to empathise with the needs of patients. That low morale and a general unwillingness to work with the heavily dependent elderly remains the case is probably true. It will be argued that, as Evers (1981a) contends, the main reason for this is that no professional group has as yet actively claimed the prime responsibility for the care of such individuals.

As was outlined in the introduction the positive contributions of geriatric medicine to the medical care of older people cannot be over-estimated. On the other hand it was also argued that in its struggle for both recognition and, more importantly, its continued survival, geriatric medicine had to be seen to be meeting the expectations of the medical model approach to care. This is essentially based on the notions of diagnosis, intervention and discharge and seems to work admirably in cases of acute need. The fact that most of the patients of geriatric medicine also had chronic needs resulted in progressive patient care and a functional model of health. Even within this modified approach the heavily dependent individual who could not be discharged has always tended to represent a "clear embarrassment" to medicine (Evers 1981a). Indeed the present trend for geriatric medicine to discharge and eventually eliminate all its long-stay beds (Bond and Bond 1987) gives the clearest indication yet that such individuals are not seen as legitimate users of hospital services unless a more defined medical need becomes apparent.

The consequence of this for continuing care has been that nurses have been left with work which nobody else wants but without the legitimate authority to determine care, which has remained with the medical profession (Evers 1981 a,b, 1982). However, it would represent a totally unbalanced view to lay all the blame with the medical model. It has been suggested, admittedly by geriatricians (Brocklehurst 1978 and Hodkinson 1981, both in Bond and Bond 1987), that routines in continuing care wards are more for the convenience of nurses than anything else and there is also evidence to indicate that nurses are quite happy not to take the ultimate responsibility as blame can then be apportioned elsewhere if things go wrong (Smith 1986). Certainly, within nursing's own value system and subculture some tasks are more highly valued than others. For example, physical tasks and treatments are not only easier to comprehend and give readily observable results (Lipman et al 1979) but they are often seen as being more important and enjoyable than psycho-social aspects of care (Armstrong-Esther and Browne 1986). The result of this is that nurses tend to perceive themselves as "only practising nursing when they are engaged in physical care" (Janforum 1985).

Furthermore, such care is divided into basic and technical components and early within their socialisation nurses equate "being professional" with technical aspects (Melia 1983); a value system which remains with most of them throughout their careers (Kitson 1985). Therefore technological and curative aspects of nursing are still viewed as the more prestigious, skilful and desirable (Kitson 1987). As a consequence nursing has never really fully developed its caring function (McFarlane 1976), a fact particularly relevant to the care of the dependent older patient where it is considered that nurses have generally failed to define what they do (Wells 1980), have few explicit aims (Evers 1981a) and usually lack a well grounded theoretical approach to underpin their care (Kitson 1984).

These issues of responsibility for, and direction of, care are particularly important in relation to care delivered in continuing care environments as it has been demonstrated that where care, as opposed to cure, is valued and the sister can control the work on this basis, regimes, whilst still routine based, are more likely to be personalised (Evers 1981 a+b, 1982). Indeed, the ability of the sister to determine care has been seen as a crucial variable in the delivery of good quality care (Baker 1978, Syred 1981,), especially when this is underpinned by a relevant and explicit model of care (Kitson 1984). Delegation of responsibilty, which should extend to all members of the caring team, is also likely to result in an improved level of morale and job satisfaction in addition to more patient centred care (Raynes et al 1979, Simpson and Sears 1985).

From the foregoing it seems that staff attitudes to care and delegated responsibility are crucial determinants of quality. However, in continuing care of elderly patients barriers to an improved standard of care are still apparent in the low prestige accorded to this work, the failure to clarify lines of responsibility and the failure to define satisfactory outcomes. This has left something of a void in terms of identifying who is going to take the lead role.

The reader may be forgiven for thinking that the last few pages have been something of a digression from the main focus of the study. However, the issues raised are important components of any evaluation of respite care in continuing care hospitals, and are of relevance not only to standards of care for the patients but also for staff. It will be recalled from the first chapter that whilst limited attention has been given to the effects of respite care on staff in the units providing the service, there was the suggestion that the introduction of such beds, despite creating more work, raised staff morale. Indeed within a continuing care ward it is not hard to see why this might be so. The potential for "rust out" in a unchallenging and unchanging environment has already been described and therefore the introduction of respite beds, especially those based on a rota system whereby four patients (on average) occupy the same bed, affords a potentially most welcome change. In addition to being different faces, these individuals represent different personalities and care challenges. It has already been demonstrated that staff/patient interactions in continuing care environments are very limited and that those social interactions that occur are focused on the socially skilled patient. Whilst this is not to be condoned it is again understandable. In a relatively unchanging environment where many of the patients are likely to be confused, human nature would draw staff to those individuals with whom the culturally accepted reciprocities can occur. The predominant system of rota bed respite operating in the study area ensures that patients return to the same environment for two weeks in every eight, providing both a degree of continuity and change. Rota bed patients therefore represent a continuing and relatively large pool of new faces and personalities. The importance of this should not be underestimated with recent evidence indicating that, for staff working with the elderly, the most satisfying aspect of their work relates to having good interpersonal relations with patients (Cohen-Mansfield 1989). This perhaps suggests that social interaction within institutional care is as much the result of limited opportunity and access to a variety of individuals, for both patients and staff, as it is of other factors. The introduction of respite beds, in addition to raising staff morale, might in this manner act as a stimulus for change resulting in a more active and varied ward environment. Alternatively, the possibility always exists of certain respite users being perceived as demanding and difficult, especially if they do not fit in with existing regimes or are too independent. If this proves to be the case the potential exists for staff to view them negatively, react punitively and restrict their contact with them to the provision of physical care tasks.

For reasons already outlined, this review has concentrated on the possible effects of nursing staff attitudes on the respite experience for the elderly users of the service and on the possible effects of respite users on the staff. The potential benefits of respite beds for the medical profession were discussed in the introduction, and it is considered that the arguments developed above for nurses might equally apply to other members of the MDT.

If these changes in staff morale and activity are in evidence they could have a profound impact on the fourth stakeholder group, typically long-stay patients in the hospitals providing the respite care. This group might also reap the twin benefits of renewed staff enthusiasm and exposure to the more stimulating social environment provided by the respite users. Alternatively, the reverse might occur with staff devoting more time to the respite users to the detriment of the long-stay patients.

3.4 The completed evaluation guide

In summary this chapter has, with reference to the wider theoretical and empirical literature, focused attention on the potential that respite care **could** have, for good or bad, in relation to the other stakeholder groups. In conducting the actual study it is not the intention to use this, now complete, evaluation guide in a prescriptive sense, to indicate what **should** or **ought** to be, although in certain instances it might have been legitimate for it to be used in such a way for what **should not** be. For instance, few would argue that respite care should not result in, for example, increased stress in the carer, or morbidity or mortality in the dependant. However, using a guide in such a way does nothing but reduce things to the level of the lowest common denominator. Nor is the guide intended to represent an ideal form of "super respite" in which every service must meet every criteria. This would be of little more use than the lowest common denominator approach. Rather, the guide is intended to provide a set of sensitising concepts which are firmly grounded in the theoretical and empirical literature and thereby hopefully reduce, as Wortman (1983) suggested, the possibility of important questions remaining unasked. However given that one of the main bases of a pluralistic evaluation is that the subjective impressions of major stakeholders are used as a measure of success it would be inappropriate to have too rigid a set of a priori sensitising concepts, no matter how well grounded they might be. Therefore it cannot be over-emphasised that the evaluation guide is to be used as just that, a guide, and that the opinions of the stakeholders will be incorporated once the project begins and the guide developed accordingly as the project progresses.

At this point it is appreciated that a large number of concepts have been introduced. Before examining how the concepts were operationalised, a brief summary of the questions they raise for the evaluation of respite care is provided in note form to conclude this chapter.

Evaluation guide and sensitising concepts.

Evaluation approach: **pluralistic**, characterised by a concern with:
A) Institutional functioning
B) Project implementaion/client characteristics
C) Subjective views of major stakeholders as a guide to success
D) Methodological triangulation
E) Quality of service

Substantive area of interest: **respite care** in continuing care hospitals. Within study area three main types:

A) Rota beds
B) Holiday beds
C) Crisis beds

Main focus on rota beds but other beds considered as they potentially impinge upon other variables of interest for example institutional functioning, implementation, quality of service. Within study area need to consider implications of selective patient transfer model.

Four main groups of **stakeholders**

A) Carers
B) Elderly dependants
C) Staff providing the service (anticipated main focus on

medical/nursing interface)
D) Other patients within the hospital environment

From review of existing literature on institutional respite care and consideration of wider theoretical and empirical literature on the stakeholder groups, sensitising concepts guiding preliminary stages of the project are:

A) Location of service, availability, access, eligibility criteria, flexibility in terms of referral and use. Place of service within wider selective patient transfer model. Extent to which service is fully utilised.

B) **Carers:** main theoretical basis **transactional** model to understanding carers problems based on subjective appraisals.

- i) Characteristics, for example, age , gender relationship to dependant,length of time caring and so on.
- ii) Other support received, formal and informal, perceived adequacy.
- iii) Subjective impressions of caring situation. Main problems, rewards, nature of relationship with dependant.
- iv) Entry to respite system, feelings re access, flexibility and so on. Expectations of the service and perceptions of how well these are met, possible improvements.
- v) Perceived effects of respite care on dependant and carer dependant relationships. Own reactions to the system, for example, guilt.

C) **Dependant** to consider influences of **relocation effects** and possible effects on **self-esteem**

- i) Characteristics; for example, age, gender, physical and mental dependency.
- ii) Impressions of respite system; element of choice, reasons for referral, any evidence of legitimation/desirability.
- iii) Expectations of the system and extent to which these are met. Perceptions of nature of environment and routine and positive/negative effects of respite care on felt independence, perception of selves as a burden to carers, morale, self-esteem and so on.

D) **Staff** influence on **Morale.** with particular reference to **rust out** Awareness of wider possibilities of respite care for carers, dependants and other patients. Nature of medical/ nursing interface.

- i) Perceptions of how system works; for example, eligibility criteria, access, referral and so on.
- ii) Main functions of the system. Any awareness and effort made to see wider contexts, for example, to provide carers with information, training and emotional support and dependants with an individually tailored programme. Any evidence of basic model/philosophy underpinning the system.
- iii) Perceived advantages and disadvantages of the system for carers, dependants and other patients. Any evidence of awareness of possible deleterious effects and steps taken to reduce these.

iv) Perceptions of characteristics of respite users and other patient groups.
v) Perceived effects of introduction of respite care and selective patient transfer model on institutional functioning, staff morale and workload, environment of care and regime offered.

E) Other patients

i) Characteristics; for example, age, gender, dependency need length of admission and so on.
ii) Perceptions of respite users and influence on environment.

F) Institutional environment and activity

i) Extent to which environment provides for key concepts such as, privacy, choice and autonomy.
ii) Access of respite users to full assessment and diagnostic facilities. Attempts made to compensate for disability.
iii) Adequacy of care in meeting basic needs.
iv) Evidence of planned, individual approach based on full assessment.
v) Evidence of therapeutic interventions aimed at improving functional abilities.
vi) Purposeful activity designed to improve self-esteem and quality of life.
vii) Nature of social environment and patient/patient and staff/patient interactions.

CHAPTER FOUR

RESEARCH DESIGN: A RATIONALE

> "Our quarrels about the value of hard v's soft data are irrelevant to the world and its problems and uneccessary and distracting for us. Differing research methods need not compete we need only to understand that they tell us different sorts of things".
>
> (Rubin in Swanson and Chenitz 1982)

In operationalising a pluralistic evaluation it will be recalled that a triangulated research design was advocated. This requires the use of multiple and complementary methods within the same study. This chapter aims to provide an analysis of the concept of triangulation and of the rationale behind the research design adopted in the present study. It therefore addresses the conceptual underpinnings of the study's methodology. The subsequent chapter provides an account of the research process itself and of issues about operationalisation.

4.1 Triangulation: a multi-method approach

The review of the literature on evaluation and evaluation research in Chapter 1 indicated quite conclusively that current thinking on the conduct of evaluation research favours a combination of methods. Indeed this approach, commonly termed **triangulation,** is one of the central tenets underpinning the pluralistic approach to evaluation which is the basis of this study. Attention is therefore turned to the meaning of the term triangulation and its operationalisation within the present study.

Most authors (Denzin 1970, Smith 1975, Jick 1979) attribute the term "triangulation" when used in a research context to Webb et al (1966), although as Smith (1975) points out the origin of the word itself lies in its navigational and military usage when it relates to the use of multiple reference points to locate the position of a given object. Within its research context the term is commonly held to refer to the use of different methods within the same study (Jick 1979) but to limit its application to methods alone is not only essentially inaccurate but also inhibits the full potential of the approach. Thus Denzin (1970) identifies four types of triangulation:

A) **Methods**, as mentioned above. This approach will be discussed in more detail shortly.

B) **Data**, when data are collected on the subject of interest from the same individual but using differing temporal and spatial referents and/or from differing individuals.

C) **Investigator**, when different reseachers are used within the project. Denzin makes a plea for the most skilled researchers to remain closest to the data.

D) **Theoretical**, when subjects are studied using a broad range of relevant theoretical and conceptual bases.

The main type of triangulation used in the present study was undoubtedly methodological. However, to a greater or lesser extent, all four approaches were incorporated and therefore the study can be said to be multiply triangulated (Denzin 1970, Mitchell 1986).

4.2 Methodological triangulation

Whilst, as noted above, the research usage of the term triangulation is attributed to Webb et al (1966), Jick (1979) contends that the conceptual basis of the approach can be traced to the notion of multiple operationism first suggested by Campbell and Fiske (1959). Essentially this approach advocated the use of differing methods to study the same phenomena, in order that the degree to which the results converged might be determined. The convergence of results from differing methods was seen to increase the validity of the conclusions. Since that time the relevance of positivistic approaches to the study of social phenomena have been increasingly questioned and qualitative and triangulated approaches have been propounded, in order that, as Denzin (1970) quoting Trow (1957) advocates, we can move away from the X v's Y philosophy and "get on with the business of attacking our problems with the widest array of conceptual and methodological tools we possess". The basic tenet of triangulation is that differing methods of scientific observation tend to open up one avenue of investigation whilst closing another (Denzin 1970) and that by combining methods triangulation aims to exploit the assets of differing approaches, whilst at the same time neutralizing and not compounding their liabilities (Jick 1979). There are generally held to be three types of methodological triangulation (Denzin 1970, Jick 1979, Mitchell 1986):

A) **Within method.** This combines variants of the same general approach within one study. Thus a questionnaire might contain differing scales and types of question. Such an approach is of most benefit in cross checking for internal consistency or reliability (Jick 1979).

B) **Between method.** In which differing but complementary methods are used. This combination of complementary methods is seen to add to the validity of results.

C) **Holistic methods.** This is the term coined by Jick (1979) to indicate that both within and between method triangulation are utilised.

According to Jick holistic approaches are preferred as they not only add to reliability and validity but also enrich the study by bringing into the open data which might otherwise have remained hidden.

The present study is considered to have used an holistic approach. However, as has been pointed out even by its advocates (Jick 1979, Mitchell 1986), triangulation is not without its drawbacks and is unsuited to certain types of study.

In the first instance, whilst the approach is based upon the use of different methods, there is little if any guidance as to whether data should be equally weighted and as to how qualitative and quantitative data can be brought together. Jick (1979), whilst not denying the central importance of quantitative methods, suggests that "qualitative data and analysis function as the glue that cements the interpretation of multi-method results".

This tenet has been adopted in the present study, not only because of Jick's recommendation but because there are sound theoretical, conceptual and empirical reasons why qualitative data should take centre stage. Firstly, within the pluralistic approach guiding the study, the main determinant of a service success is held to be the subjective views of the major stakeholders. Secondly, most of the important sensitising concepts identified from the literature are based upon essentially qualitative phenomena, for example; transactional approaches to stress which are based on subjective appraisals of events; the notions of hope, being a person who matters, felt independence and perceived control which underpin self-esteem in the dependent elderly; morale, rust out, delegation of authority and the medical/nursing interface important for staff in continuing care environments; activity which is purposeful, meaningful and raises self-esteem. Thirdly, although quantitative evaluations of respite care have been limited in number, the large and well-controlled experimental evaluation carried out by Lawton and colleagues (1989a) failed to find any differences between the experimental and control group on a wide range of objective measures and yet the subjective evaluations of the carers using the respite system were a "resounding endorsement". On the basis of these results the authors are forced to the conclusion that perhaps such measures should be taken as sufficient evidence of success to merit the continued provision of the service. A similar conclusion has recently been reached regarding the relative insensitivity of quantiative data in determining the quality of care in residential settings for older people (Clark and Bowling 1989).

For these reasons, whilst the study adopts a holistic, multiple triangulation approach, the qualitative data, as Jick (1979) suggests, hold the interpretation of the results together. Quantitative data are of course not ignored and both of the methods suggested by Mitchell (1986) for the bringing together of qualitative and quantitative data have been utilised. Therefore statistical synthesis is used where appropriate but the main approach is conceptual validation in which the differing data are brought together and logical patterns and meanings sought. This integration of data at the conceptual level is considered to result in a more in-depth understanding of the phenomena under study (Mitchell 1986).

Other considerations are also relevant when applying a triangulated paradigm (Jick 1979, Mitchell 1986). Therefore it is essential that the appropriate methods are combined, that is methods which do not share the same inherent weaknesses. Furthermore the appropriate questions need to be asked, questions which have a clear theoretical and conceptual basis and it is hoped that the preceding chapters will have met this requirement.

Triangulation is also demanding in terms of time and financial resources. Time was at a premium in the present study as the author was only contracted for two years. Fortunately the procurement of additional small grant monies from the institution within which the author was based allowed the funding of the postal survey which formed the first stage of the study and permitted three research assistants to be employed for a time-limited period to assist in the observational phase of the study. Lastly, triangulation makes demands on the researcher. Mitchell (1986) argues that there is a need for flexibilty of thought based on a sound and broad knowledge of research methods, including both qualitative and quantitative approaches and the author hopes that his previous work (Nolan 1986, 1988) has provided adequate preparation. Jick (1979) goes further in suggesting that the real challenge of triangulation is its requirement for creativity from its user, ingenuity in collecting data and insightful interpretation in its analysis. These are requirements to which we can but aspire and the extent to which they may be apparent in the present study is for the critical reader to decide.

4.3 Data collection:Triangulation in action

In applying the above concepts to the substantive area of study an holistic multiple triangulation approach was adopted. Thus the study consisted of three main stages providing a progressive focus:

A) A national sample survey of members of the Association of Carers (now Carers:National Association).

B) A series of in-depth semi-structured interviews with the main stakeholder groups involved in the provision of respite care in a defined geographical location.

C) A comparative study of respite provision in two contrasting units within the above geographical location.

This method generated large quantities of both qualitative and quantitative data which were subjected to a variety of analytical techniques. In providing a more detailed account of the strategy used consideration will first be given to the rationale behind the differing methods adopted at each stage. This will be followed in the next chapter by a description of the manner in which the study was conducted and the key elements operationalised. A reflexive account addressing the quality of the data produced will then be presented prior to details of the techniques used in the analysis of the qualitative and quantitative data. Copies of all of the questionnaires, letters and other documents which are referred to can be found in the appendices.

4.4 Methodological rationale

(i) Stage one: The postal survey

The postal survey did not form part of the original research proposal. However, following the literature reviews on carer stress and the decision to adopt a transactional approach, it seemed that a number of purposes might usefully be served if a postal survey were to be conducted.

Firstly, despite the burgeoning of research in the field of informal care it is still considered that important questions regarding the nature of carer stress and how it might be ameliorated remain unanswered (Parker 1985, Gwyther and George 1986). In addition most of previous studies have either been small scale or focussed on carers of particular dependency groups or both of these. It was hoped that by carrying out a survey of a more diverse group of carers which was underpinned by a sound conceptual approach that a more balanced picture of the nature of carer stress might be provided.

Secondly, whilst the transactional model of stress has been advocated as the one of choice in much recent carer research, there has, as yet, been no really systematic attempt to provide an empirical test for the wider applicability of such models to carers. The survey afforded the opportunity to do this.

Thirdly, both of the above would add to and inform the respite study. Thus, if certain problems could be identified as being particularly stressful to carers then the extent to which respite care might alleviate these could be considered. This would provide a check for the validity of the criteria outlined in the evaluation guide. Also, empirical support for the transactional model of stress would greatly strengthen the arguments previously rehearsed concerning the extent to which subjective measures of outcome for the respite service are the most appropriate.

As with most methods, postal surveys have their advantages and disadvantages. They are generally considered to be relatively cheap, quick, provide a ready means of geographic access and, if well designed, can generate sensitive data without the problem of interviewer bias. Difficulties can arise due to lack of flexibility, response rates and the inability to tap into and probe complex data (Bailey 1978). However as Cohen and Manion (1985) point out many of the potential difficulities can be overcome by careful preparation and attention to detail. As will be highlighted when the postal survey is discussed, consideration was given to these points when planning the present survey.

(ii) Stage two: The interview survey.

Following the postal survey, the main phase of data collection began with the in-depth interviews of members of the four major stakeholder groups. The intention was to elicit the subjective impressions of the respite service from these stakeholder groups as these were to form one of the main measures of "success". It was therefore necessary to decide which form of the interview was most suitable to obtain this type of data.

a) Interviewing as a research technique

According to Denzin (1970) the interview is the favourite "digging tool" of the sociologist but it is a difficult technique as it must be guided by the polite rules of etiquette whilst at the same time eliciting intimate and private perspectives. The central and vital position of the interview as a data gathering technique but also its varied and difficult nature has been described by many other commentators (Bailey 1978, Davies 1980b, Burgess 1982, Whyte 1982,1984, Cohen and Manion 1985) and yet it is considered that in the hands of a skilled interviewer that the interview can "hardly be surpassed"

(Denzin 1970). What then are the characteristics of a good research interview and what steps can be taken to ensure that they are met?

Firstly it is a matter of selecting the correct interview technique for the job in hand. The authors cited above maintain that interviews can be distinguished by the degree of structure and form that they possess. Unfortunately the terminology used is not always consistent and possible confusion can emerge. However, the technique is generally described as ranging from the highly structured with a fixed order and form of questioning from which no deviation is allowed and where even prompts (if permitted) are standardised, to the completely unstructured interview having the appearance of a conversation. Unstructured interviews are sometimes termed non-directive interviews, but Whyte (1982, 1984) considers that this is a "grave misnomer" and argues that **all** research interviews have a minimal degree of direction imposed by the research question and that in any case a totally undirected interview is likely to be a poor data collection tool as it is inhibiting and confusing for the informant. It is generally considered that the less structured techniques are most appropriate when the purpose of the interview is to ascertain meanings and definitions from a subjective standpoint (Denzin 1970, Davies 1980b) and such approaches are seen as being particularly suitable for use with the elderly (Hughes et al 1980, Hughes and Wilkin 1987, MacPherson et al 1988). However interviews, as with all techniques, suffer limitations and it is recommended that they should be combined with other methods (Denzin 1970, MacPherson et al 1988). In the present study the main round of interviews took place in the two units which were to be the focus of the observation study which meant that much of the interview data could be supplemented with observations (both structured and unstructured) as well as data from questionnaires.

In terms of general abilities it is considered that the interviewer using less structured techniques should have good verbal and non-verbal communication skills and be a sympathetic and attentive listener (Denzin 1970, Burgess 1982, Whyte 1982, 1984). Whyte (1982) provides one of the seminal descriptions of this approach and contends that the interviewer should:

A) Listen more than (s)he talks with a lively and sympathetic interest.
B) Occasionally rephrase and reflect back what the informant has said.
C) Avoid giving advice or being judgmental.
D) Accept, without indicating disapproval, statements that disagree with his/her own beliefs.
E) Never interrupt unless this is intentional and then do so gracefully.

Ideally this technique is best practised when there is repeated contact with the informant.

Certainly the interviews conducted in the present study were at the less structured end of the spectrum and might be usefully considered as being of three broad types. As indicated above there is some confusion in the terminology applied to these various interviews, so the ones below are not presented as "correct" in any sense but are those used by the author in operationalising interviews in the present study.

(b) Formal, semi-structured interviews.

These were the interviews with the highest degree of structure and those for which the author had the most overt agenda. However the term formal does not indicate that they were rigid or inflexible, but rather that both participants in the encounter were aware that a research interview was taking place and that it had usually been formally arranged via a covering letter from the author. A small number of these interviews were not by prior arrangement but occurred as the opportunity presented itself, for example when the author had been visiting a unit to interview patients he might also ask staff if they had time for a chat. Whilst these encounters were not formally arranged both participants were conscious that they constituted an interview. The interviews themselves were usually relaxed and open, with the best data emerging when the author was required to use the minimum of probing and questioning. An agenda for the interview was available in the form of an interview guide which outlined the main topics that the author wished to cover based upon the areas raised in the evaluation guide (see appendix one for examples) but there was no order or form of questioning and the interview followed a differing path in each case. Furthermore as the initial interviews were analysed the interview guide evolved according to emerging categories in order that the principles of constant comparison could be applied.

Such techniques are predicated on the assumption that each encounter is best conducted in a language and format to suit the individual informant (Denzin 1970, Davies 1980b).

With regard to the community nursing staff, interviews of this nature took place but in a group situation. Thus nursing staff working in the same area or out of the same base usually met with the researcher together. Numbers varied from two to seven.

Group interviews of this sort have both advantages and disadvantages. In reviewing these Burgess (1982) contends that the group interview allows for insights into competing views and permits inferences to be made about how the shared world of the participants is negotiated. However less vocal members might be inhibited from speaking, their contribution can be lost and individual critical attitudes can be swayed and remain hidden due to group pressure to conform. The extent to which these problems were thought to surface in the group interviews with the community nurses will be addressed in the reflexive account which follows in the next chapter.

(c) Informal, semi-structured interviews.

This group represents a range of situations. In contrast to the formal semi-structured interviews they were not pre-arranged and there was a less overt agenda, overt that is in terms of its physical presence. Therefore there was no written interview guide although the author had a mental checklist in most cases. The extent to which participants were conscious that an "interview" was taking place varied. Broadly speaking two forms of this type of interview occurred.

The first was with the respite users themselves. It was decided to interview this group in hospital, for reasons which are explained later. Interviews were not prearranged as the formality of an arranged interview might have heightened anticipatory anxiety and adversely affected the quality of the data. Rather, the researcher would arrange with the ward staff to visit at a certain time (usually that which would interfere as little as possible with planned therapeutic programmes) and ask if rota bed patients present could be told of the purpose of the visit and afforded the opportunity to refuse to participate if they so wished. Upon arrival the researcher checked with the staff on duty which of the rota bed users were suitable for interview. This was necessary as a number were frail and might not have been well enough to be interviewed on any given day. The reseacher was then introduced to patients by a member of the ward staff and an explanation of the project was offered. The researcher explained that he was interested in the way in which hospitals for the elderly were changing in function and in how people who came in and out on a regular basis found the experience. He then asked if the individual would mind having a chat with him about how they found it. As already stated no written agenda was produced as it was hoped to make the encounter as natural as was possible in the circumstances. By adopting this method it is hoped that the tenets of informed consent were met but that the actual interview itself was as least contrived as possible.

The other main form of interview in this category took place when the reseacher engaged staff in informal conversation, for example, over coffee, or by just dropping in to the office. For the units included in the observation phase the researcher made many repeat visits to each unit (over 10 in each case) and consequently became a familiar figure to the nursing staff and to domestic and therapy staff. This provided the opportunity for a degree of non-participant observation. During informal conversations the opportunity often arose to "check out" various perspectives that had arisen in the more formal interviews and to enrich the data by enlarging on categories of meaning that the reseacher was developing. In this sense there was no formal agenda and the extent to which there was an awareness of an interview is open to debate. On the other hand this was by no means a one way process and staff likewise used these informal chats to see in which direction the researcher findings were going. For example, such questions as "Are you getting the information you wanted?" or "What sort of light are we appearing in" gave a clear indication that some feedback was required. The researcher usually responded in what was thought to be a neutral but encouraging fashion, for example, "Yes thank you every one has been most helpful". Quite often data of an unsolicited nature would be volunteered which staff thought would be "useful" to the researcher. This, as Cormack (1981) contends, provided valuable insights into the way staff were reacting to the project, particularly in the observation phase. Also if the researcher was thought to have missed something of interest then staff would often "fill him in". In this way these two latter forms of "interviewing", one by the researcher and one by the staff might be thought of as types of "impression management", a method, as Davies (1981) points out, of establishing the vital balance between personal acceptability and scientific enquiry that it essential for successful field research. Furthermore for the researcher they provided valuable data checks on the emerging categories of meaning that were being developed.

(d) Serendipitous, semi-structured interviews.

These were totally unplanned and had no agenda as they were responses to chance and random events that occurred during certain phases of the study. As such they allowed insights into the unpredictable world, particularly of the informal carer, which could not be accounted for beforehand. For example the researcher called to interview one carer, by prior arrangement, on the very morning that she finally decided that she could no longer go on and had made the decision to have her mother admitted to permanent care. The researcher immediately suggested that the interview be cancelled but the carer did not wish this and seemed to want to be able to talk things through with a neutral party. The resulting interview gave little time to the rota bed system and focussed more on how and why the decision to relinquish care had been reached, as this was the direction that the carer repeatedly led the encounter. In this way data emerged with almost no guidance and were somewhat chaotic, but did provide information of a traumatic experience in the caring history which in many ways contextualised the issues that respite care seeks to address.

Having outlined the three main types of interviews which were used, attention is now turned to factors important to the use of the interview as a research technique. These are the manner in which data are recorded, the degree of self-disclosure that the interviewer employs and the timing and location of the interview.

(e) The recording of the data.

Whyte (1982, 1984) decribes three main ways of recording interview data: the tape recorded account, taking notes during the interview or writing out the interview as soon as possible afterwards. He contends that each of these methods has advantages and disadvantages. He suggests that the first produces the fullest details but is formal and expensive. The second can be distracting and lead to missing non-verbal cues during the interview. The third, on the other hand, leads to an accurate but more condensed and organised version. The tape recorder and notes method are only available in what has been termed in this study the formal interview, that is where both parties are aware of the interview situation.

For the most part a combination of methods two and three was used in the present study. The use of a tape recorder was not considered for a number of reasons. Firstly, previous research with carers and staff and particularly with elderly dependants (Nolan 1986) had convinced the researcher that the reactive effects of the machine were very difficult to overcome and responses were less than frank. This has been found by other authors using recording devices with the elderly (Clegg 1978, MacPherson et al 1988). Secondly, pilot work on the present study indicated that the same was likely still to be true and that critical attitudes would be suppressed when a tape recorder was used. True most people would not overtly object, although a couple did refuse outright, but many were clearly uneasy and volunteered further information when they thought that the machine had been turned off. Thirdly, attempts to elicit perceptions of recording during the project evoked negative responses and the researcher remains convinced that the reactive effects of recordings are often written off a little too hastily.

As suggested above the method used to record data was a combination of brief notes made during the interview and a dictated account immediately afterwards. Thus in those interviews for which a guide was produced space was left for notes under the topic headings. This proved to be less than satisfactory as the interviews did not follow the same pattern as the guide in most cases. Therefore during the interview key phrases and anecdotes were written down verbatim and used as pegs for the memory. Following each interview the researcher would dictate as near verbatim an account as possible into a hand-held tape recorder. This is a technique used before by the researcher to good effect (Nolan 1986) but as Whyte (1982, 1984) points out it does tend to produce data which are accurate but condensed and organised. However, the immediate return to the data in this way can help to avoid post-hoc rationalisations when recorded interview data are returned to, often a considerable time after they have been collected. Moreover, as the interviews occurred within a fairly circumscribed period the data recording method used facilitated speedier analysis so that a form of constant comparative method could be applied. Additionally, the mental discipline involved in recording interview data in this way paid dividends in the informal situations when both a tape recorder and notes would be inappropriate and the mind was better honed to recall valuable data which the "lazy" method of recording does not prepare it to do.

(f) Self-disclosure.

The quality of all interview data is of course greatly influenced by the personal characteristics of the researcher. Certain characteristics such as gender and race are unavoidable perhaps because they are culture bound, whilst others such as communication skills and self-disclosure strategies can be learned. One of the most important elements of self-disclosure in the present study was the author's previous background as a nurse. All of the staff in the study were aware of this and many knew, or knew of, the reseacher quite well. This is considered to have been a distinct advantage. Firstly the researcher shared a common culture with the majority of the staff and this meant that he was more likely to get "backstage" data (Carter 1981) and was less likely to be mislead. Also certain types of questions were more legitimate as they could be posed as common or shared problems and perspectives, giving increased credibility. The more difficult decision was whether to divulge to other informants that the researcher had been a nurse. To do so might be to inhibit critical comment about nurses but not to do so might have restricted access to other types of data, particularly that of a personal nature. Thus the fact that the researcher was male might have inhibited the many women in caring roles from discussing openly aspects of care considered as intimate or highly personal. The decision was therefore made to bring out the reseacher's nursing background as casually as possible during an early stage of the interview. This turned out to pay rewards as had been anticipated when personal aspects of care were discussed.

g) The timing and location of the interviews.

Timing and location are particularly relevant to the data collected from the carers and the rota bed users. To have interviewed both together would have been very limiting as both parties would have been reluctant to discuss certain difficulties that they faced. Therefore carers were interviewed at home whilst their dependants were in hospital for a period of rota bed care and dependants were interviewed in hospital during the same rota bed admission. The possible consequences of this strategy on the quality of the data produced will be discussed in the reflexive account.

(iii) Stage three: the observation study

The main intention of the interview stage was to elicit the subjective impressions of the staff and users about the value of rota beds. However anecdotal data and subjective impressions were also to be collected, thus giving some insight into the nature of the regime and the type and level of activity offered in the units. This permitted some inferences to be made about the institutional environment. The aim of the observation phase was to "flesh-out" these perceptions and provide quantitative data on the type and level of activity, the nature of the institutional environment and regime and the dependency levels of the patients. Furthermore the perspectives elicited from staff during interview were to be expanded upon by the use of a structured questionnaire containing both closed and open questions on important areas of the rota bed service and its wider implications. This provided an additional form of triangulation. At this stage the main methodological consideration was the type of observation technique to be used. The rationale informing the decision reached is outlined below.

(a) Methodological notes on observation

There is an extensive literature on the use of observation as a research activity and the technique has been applied in a variety of forms and settings over the last 30 years when the nature of institutional regimes and activity patterns have been investigated. It is beyond the scope of the present section to provide an in-depth review of this literature; rather its purpose is to describe and justify the methods used in the present study.

The main form of observation used to collect the activity profiles is best conceived of as **"naturalistic field observation"** (McCall 1984). McCall (1984) quotes Weick (1968) who determines that such observation is distinguished from merely watching by the use of careful plans to select and record the activity of interest. The activity is **systematic** in proportion to the extent that these plans are explicit and preset rather than emergent or implicit and qualifies as **field observation** dependent upon the extent to which observation occurs in the field. The less each behaviour of interest is provoked, the more valid is the claim to **naturalism** (McCall 1984). Excluded from such observations are classical participant observation and experimental, laboratory based studies (McCall 1984).

When deciding to use such approaches three main types of questions need to be considered (Sackett et al 1978). These are whether observation is the correct method to answer the questions posed, and should this be the case then major decisions relate to the coding and sampling strategies to be adopted.

In terms of the suitability of the technique, McCall (1984) contends that under favourable conditions virtually all social phenomena are amenable to observation. Whilst such a degree of flexibility is useful and suggests **where** the technique may be used, it does little to indicate **when** it is suitable. Fortunately guidance is available. Thus McCall (1984) contends that observation explores the fit between words and deeds and, in terms of triangulated designs, interviews and observations are thought to be complementary in balancing respective strengths and weaknesses (Denzin 1970, Davies 1980b, Carter 1981, MacPherson et al 1988, Clark and Bowling 1989). Furthermore Crow (1984b) points out that if the research question asks **what** happens then observation is an appropriate method. Judged by these criteria observation was deemed to be not only an appropriate but an essential element of the present study.

This required decisions as to the coding and sampling of behaviours. Most methodological texts (Hutt and Hutt 1978, Sackett et al 1978, Polit and Hungler 1983, Crow 1984b, McCall 1984) distinguish between two broad categories of both coding and sampling frameworks. In relation to coding the usual convention is to classify systems as either **"Molecular"** or **"Molar"**. Molecular systems classify behaviours as closely as possible to those which actually occur and are generally applied to small sections of larger actions, for example individual muscle movements, tics and so on. Molar codes involve a higher level of abstraction and greater judgement on the part of the observer and class responses together because they are considered to share a "common function, target or goal" (Crow 1984b). Therefore complex human behaviours where some degree of judgement is required prior to coding are only amenable to molar frameworks. In this sense the observational paradigm is considered as ecological rather than ethological or experimental/psychological (Hutt and Hutt 1978). Within such a paradigm the main intention of the observation is to describe aspects of the life situation of individuals by reference to particular critical incidents (Hutt and Hutt 1978).

A similar broad dichotomy can be applied to sampling of behaviours, which can be observed either in "real time" or via some form of "time sample". Real time observations are considered to be the "state of the art" (Powell et al 1975) and give measures of duration and frequency which are precise and absolute (Hutt and Hutt 1978). However, such techniques are expensive and time-consuming. Time sample techniques are slightly less accurate as they give estimates of duration and frequency which are approximate and relative (Hutt and Hutt 1978) but they are easier to operationalise and, according to Polit and Hungler (1983), are accurate enough providing that:

A) Behaviours are carefully and explicitly defined so that an observer can recognise an example of that behaviour each time it occurs.

B) Categories are mutually exclusive.

C) The system is exhaustive of all behaviours likely to be demonstrated.

These authors also consider that the less complex the coding system, the more reliable the observations are likely to be, hence they suggest that a system of 15 major categories is at the upper end of desirability.

Having in this chapter considered the concept of triangulation and the rationale behind the methods to be used in the study, the next chapter describes how the study was actually conducted and the main concepts operationalised.

CHAPTER FIVE

OPERATIONALISING A MULTI-METHOD APPROACH

This chapter provides an account of the research process and describes how the principles of triangulation were operationalised. This is followed by an account reflecting upon the quality of the data collected. The chapter concludes with an overview of the techniques of data analysis.

As described in the preceding chapter the study design consisted of three stages and these are now considered in turn.

5.1 Operationalising stage one: The postal survey

Once having decided to carry out the postal survey the first main issue to be addressed related to the selection of a suitable sample. Obviously a random sample would be the one of choice. However the difficulties in identifying a random sample of carers have been well documented and attempts which have been made have often been disappointing (Bonny 1984, Parker 1985, Bell et al 1987, Thompson 1987). Consequently, most research on informal care has involved a non-random sample of some sort (Clark and Rakowski 1983, Gwyther and George 1986). A method was therefore sought which would allow access to as large a sample as possible over a dispersed geographical area. Faced with similar problems previous researchers have sought established carer groups from which to identify a sample for postal survey (Chenoweth and Spencer 1986, George and Gwyther 1986) and a similar strategy was adopted in the present study.

Therefore, in order to identify a sample a national carers' group, The Association of Carers, of which the author is an associate member, was approached. At the time of the study there were about 2000 members, approximately 1750 of whom were carers (the remainder being associate members, usually from various caring professions). Permission was sought and granted to enclose a questionnaire with one of their regular Newsletters.

At this stage careful consideration was given to the design and content of the questionnaire in order to maximize the response rate. As an inclusion in the Newsletter, possibly along with a number of others, much thought was given to designing a cover for the questionnaire which was thought to be eye-catching without being trivial. Many designs were tried and subjected to the critical appraisal of a variety of colleagues and carers in the local area. Finally, university headed paper was used within which was inset a parchment scroll effect. The covering letter was short but felt to be sufficiently explicit to encourage participation. In addition a further letter was printed within the body of the newsletter to try and maximise the response rate and a freepost envelope was provided. The outside of the questionnaire, whilst of importance, serves mainly to encourage the respondent to participate and it is the content which is of greater import. Having negotiated access to such a large sample of carers the temptation existed to maximise the value of the exercise by trying to cover as wide a range of topics as possible. This was rejected on the grounds of wishing to avoid superficiality. Therefore, the decision was made to focus the questionnaire on the stresses faced by carers and to omit questions about other issues.

It was then necessary to consider some difficult issues to do with the operationalisation of the concepts involved and the manner in which individuals were asked to respond. Clearly the question of stress is potentially sensitive to individuals and it was important to anticipate and try to ameliorate the effects of receiving a questionnaire which might confront them with issues of which they were previously unaware or had perhaps consciously chosen to ignore. The author was concerned that receipt of such a questionnaire might actually add to carer stress. In the event this was to prove a groundless fear (at least from the responses of those people who returned the questionnaire) as many respondents indicated that completing the questionnaire had actually been therapeutic, as the following quote indicates:

> "Completing this questionnaire has been really therapeutic, a sort of way of helping one realise that you are not, as you once thought, the only person who faces these sorts of problems. THANK YOU." (Original emphasis).

The number of respondents voicing similar sentiments and actually thanking the reseacher for taking an interest in their problems ran into the 100's, as did those who provided additional written comment which often covered several pages. Whilst reassuring the reseacher that the questionnaire did not appear to have caused overt harm, this was nonetheless salutory as it served to highlight a more general lack of concern about the anxieties of many carers, a point which will be developed later. Furthermore, piloting of the questionnaire produced encouraging responses from a number of professionals involved with carers and from a small number of local carers and this persuaded the reseacher to continue.

When consideration was given to the content of the questionnaire a number of components were seen as being essential. Firstly, some form of stress outcome measure was required which was easy to complete and relatively non-threatening in content but which nonetheless provided valid and reliable results. A number of scales were considered and eventually the Malaise Inventory (MI) was selected. This is a 24 item symptom checklist adapted from the Cornell Medical Index (Rutter et al 1970 a,b) with the intention being to produce a scale that used simple language to tap into emotional disturbance in adults. The 24 items comprise of psychological symptoms, or physical symptoms thought to have important psychological components and is completed by a simple Yes/No format. It was originally validated against independent psychiatric assessment and demonstrated a test-retest reliability of .91 (Rutter et al 1970 a,b). Since then it has been used a number of times in studies examining carer stress in the field of mental handicap (Quine and Pahl 1985) and in those caring for elderly dependants (Wright 1986, Quine and Charnley 1987, Charnley 1989). Whilst there has been some suggestion that it might not represent a unidimensional measure (Hirst 1983) the most recent evidence available at the time of the survey indicated that the MI could be considered as a reliable, valid and unidimensional scale (Quine and Charnley 1987, Bebbington and Quine 1987). This well established measure represented the outcome in terms of carer stress and the dependent variable in a number of multi-variate analyses.

A number of other variables were included in the questionnaire as possible independent factors which might contribute to carer stress. Once again the potential range was enormous and a degree of selectivity was needed to keep the questionnaire to a reasonable length. Variables were selected for their empirical and theoretical relevance. Thus questions addressed the biography of the caring relationship, the dependency characteristics of the cared-for, the quality of past and present relationships, the carer's perceived physical and emotional health and the perceived trajectory of the caring situation. In operationalising dependency the author constructed scales to measure the amount of assistance required with the main activities of daily living (ADL), the degree of incontinence present and the extent of mental frailty and problematic behaviour. These scales were devised specifically for the study with the intention of measuring the amount of help (including supervision) that the dependant required. In this way they were not intended to measure actual functional ability but rather the carer's perception of the help required, a quality not apparent in previous scales the author had considered. The content validity was ensured by reference to a number of other scales of a similar but not identical nature (Cantor 1983, Worcester and Quayhagen 1983, Poulshock and Deimling 1984, Quine and Charnley 1987). Upon analysis the scales demonstrated very high internal consistency (ADL scale Alpha =.86, Continence scale Alpha =.85, Mental frailty scale Alpha =.83).

The need for further development work became apparent in connection with appraising carers' subjective impresions. The limitations of existing scales were highlighted in the literature review so it was decided to construct a new scale which attempted to overcome some of the identified deficits.

The new instrument, devised by the author, was originally called the Carers Perceived Problem Checklist (CPPC) but was later renamed as the Carers Assessment of Difficulties Index (CADI). The content validity of the scale was ensured by extensive reference to existing scales and the empirical and theoretical literature. CADI consists of 30 common difficulties which carers might face covering a number of domains, for example, social life, carer/dependant relationships, family relationships, financial situation and so on. Carers were asked to consider each of these 30 problems from two standpoints. Firstly to indicate the extent to which they thought they experienced each problem (on a three point scale: always, sometimes, never) and then for each problem experienced they indicated if it was actually considered to be stressful (Very stressful, moderately stressful, not stressful). In this way CADI, in contrast to previous scales, could be used to determine both the prevalence of individual problems faced by carers as well as those which are subjectively rated as the most stressful. Furthermore by using multivariate techniques the nature of the relationship between objective factors (this event exists) and subjective appraisals (I find it stressful) in the production of carer stress (on the MI) could be investigated, and an empirical test for the transactional model of stress applied which, if demonstrated, would provide construct validity for the measure. Additionally CADI could provide an overall summary score as well as indicating the prevalence and perceived stressfulness of individual difficulties. This latter characteristic has been suggested as an essential requirement of burden scales (Platt 1985).

An open question on other difficulties which may have been omitted from CADI was included in order to further test its content validity and inclusiveness.

As highlighted earlier previous carer research has tended to adopt a pathological orientation and has largely ignored possible rewards and satisfactions. This represents a significant gap in our knowledge of the dynamics of the caring relationship. In an effort to increase the empirical data base in this area and potentially add to the development of a more holistic theoretical model of the carer/dependant relationship the opportunity was taken to include a brief section on the satisfactions of caring. Due to the exploratory nature of this data an open format was used. Moreover by making this the last section of the questionnaire it was also hoped that it might assist respondents to finish the questionnaire on a more positive reflexive note.

Piloting of the questionnaire was undertaken involving 15 professionals involved with carers and 10 actual carers. This resulted in a number of changes being made, most notably to the instructions for the completion of CADI which were felt to be too long and complex. The final questionnaire thus contained a number of differing scales, some straightforward factual questions and a number of open questions and was thought to demonstrate the within-method triangulation described earlier. A copy of the final questionnaire is located in appendix two. Two thousand copies of the questionnaire were sent out with the April 1988 issue 31 of the Association of Carers Newsletter.

To the 2000 questionnaires originally distributed a further 50 were added in response to requests from carer groups. Of these a total of 726 were returned, a response rate of 35%. If one excludes the 250 Associate members of the AOC who were non-carers then the response rate is 40%. This is lower than other surveys of a similar nature (Chenoweth and Spencer 1986, George and Gwyther 1986) but in the circumstances represents a most satisfying return. According to OPCS estimations (quoted in Cohen and Manion 1985) a well planned postal survey can expect a return of 40% in response to the first mailing, a figure which can be increased to an average 75% by the use of three follow up requests. Unfortunately, in the present case reorganisation of the AOC precluded the use of any follow up letters and therefore by OPCS standards the response rate achieved is about as good as might reasonably be expected. Of the 726 questionnaires returned a number were from ex-carers and were therefore excluded from the present analysis, whilst others arrived too late or were insufficiently complete to be included in the quantitative analysis. As a result 671 responses were included in the qualitative analysis and 554 in the full quantitative stage. It must however be borne in mind that details of non-respondents are not known and the sample generated cannot be considered as randomly drawn. Hence the findings cannot be generalised to carer populations.

Before describing the next two stages of the study the subject of negotiating access for the field work is addressed, together with some of the sampling decisons which were made.

5.2 Negotiating access

As Atkinson (1979) contends problems of access arise in most research contexts and are to do not only with getting into formal organisational structures but also of having reasonable freedom of action once access has been obtained. Generally speaking the more formalised and bureaucratic an organisation the more tortuous is the process of obtaining access. The difficulties in hierarchial organisations such as the Health Service have been well described with multi-level/multi-stage negotiating strategies being suggested as the most effective (Cormack 1980). Webb (1986) contends that it is often wise to conduct a less structured "reconnaissance" before more formal channels are adopted. The author had experienced problems of access before and was aware of the delicate balance that needs to be struck between obtaining formal consent from ethical committees and the requirement of negotiating freedom of action once in the field. The latter is based mainly on establishing trust, which no amount of formal approval can guarantee.

Fortunately the author started with some advantages as he had been involved in previous studies in the field of health care for the elderly in the study location (Nolan 1986, 1988) and these had been well received. Furthermore he had worked as a Charge Nurse in a day hospital for the elderly and as a nurse tutor and was therefore known to the consultant medical staff and many of the other personnel who were likely to be involved and whose cooperation was essential to the smooth running of the project. There was therefore a degree of established credibility and trust stemming from earlier research and from practitioner roles. This made "reconnaissance" a relatively easy matter and once the initial idea for the project began to take shape early contact with key individuals could be pursued. At this stage agreement in principal only was required and was duly obtained from the Chief Administrative Nursing Officer (CANO) and the Directors of

Nursing Services (DNS) involved as well as the consultant geriatricians who had clinical responsibility for the areas in which the study was to be conducted. Not only was consent in principal given but a degree of enthusiasm for the work was in evidence which seemed to augur well if ethical consent was granted.

Following these initial informal contacts a formal proposal was submitted to the Gwynedd Health Authority Ethical Commitee. Ethical approval was duly given without modification to the original proposal. Following this the author made a more formal approach to the CANO, DNS's and consultants involved. When meeting the consultants at this stage an interview was also held to ascertain how respite services operated and to consider the logistics of how many units could be studied in the time available. Subsquently nursing officers and sisters in charge of wards were approached.

This stage of formal entry proceeded very smoothly. Once a sample of carers had been identified from the clinical records of patients using the rota beds an individual approach was made by letter (see appendix three) explaining the project briefly and seeking cooperation. Individual patients were approached on the units and their permission sought after the project had been explained to them. As will be highlighted later the levels of cooperation and participation achieved in this manner were exceptionally high.

5.3 Sampling decisions: selecting the study sites and informants

(i) Selecting study sites

The study area was selected in order to facilitate access to as wide a variety of settings as possible within a reasonably circumscribed location. Thus the western sector of the county was selected covering three administrative areas. These areas contained five units operating a rota/respite service under the clinical management of three consultant geriatricians. One of the units had been recently used to conduct some pilot work for an earlier study that the author had undertaken (Nolan 1988) and it was thought best not to use it again so soon. This left four units to be used in the interview and observation stages of the study.

Between these four units a total of 22 rota beds were available. The usual rota was two weeks in and six weeks out, with the result that four patients would use each bed in any given two month rota. Although the rota did vary occasionally, a simple calculation suggested that the four units would provide access to approximatley 80 or more carers and dependants, about 60 long-stay patients and a variety of staff, a sufficiently large population from which to draw a meaningful sample. Initially it was intended to focus the staff interviews on personnel working within the hospitals themselves. However as the carer interviews progressed it was apparent that virtually all the carers received support from the community nursing services and it was therefore felt that their views would provide a valuable additional source of data. This meant that the potential population for interview was now over three hundred, too large a group for a single researcher to manage in the time available. It was therefore decided to concentrate the majority of the interviews on the two units that were to be used for the observation stage of the study.

The units selected for observation were purposively sampled as they offered the most comprehensive respite service as well as interesting areas of similarity and contrast. Thus, both had 30 beds and a similar proportion of long-stay/short-stay patients (approximately 50/50) and each was under the management of a single consultant geriatrician. On the other hand one unit had a day hospital attached and regular input from therapy staff, whilst the second unit had very limited input from any staff group other than nurses. These were considered as potentially important contextual variables influencing the respite service offered. By contrast the other two hospitals which might have been used for observtaion had a much more limited respite service.

This sort of purposive sampling limits generalisation but then this did not constitute a major aim of the pluralistic approach informing the study. Therefore the sample generated was based more on a theoretical sampling paradigm and was intended to optimise access to data most likely to provide answers to the types of questions posed in the evaluation guide.

(ii) Selecting informants

The rationale behind the interview survey and the types of data collected have already been considered in some detail, therefore the focus of this section is on the sample interviewed.

Based on the purposive selection of the units just described the majority of the interviews were conducted at the two units which were to be the subject of the observation study. Whilst some interviews were undertaken in the other units these were confined to key staff members (for example the consultant involved, unit nursing officers and ward sisters) and a small number of carers, dependants and community nurses. In the other two units an attempt was made to interview as many of the individuals involved as was possible in the time available.

In terms of the unit staff all of the key personnel were interviewed (as defined above but including therapy staff) together with a convenience sample of other personnel, mainly staff nurses, enrolled nurses and auxiliaries. In total over three quarters of the staff involved in the two units were included. In addition to the interviews numerous other data were collected from these individuals during informal conversations.

A random sample of carers and dependants was taken. The carers interviewed represented the majority of those avaliable at the time of the study (over 70%). The number of dependants included was lower due to the mental frailty of the individuals concerned but a similar proportion of those able to respond to interview was achieved.

Interviews with the community nurses were similarly concentrated in the locality served by the main respite units and all the major practices were covered.

In the above manner a total of 50 carers, 30 dependants, 35 hospital staff and 27 community nurses were included in the interview survey.

5.4 Completing the triangle: the observation study

It was during this phase of the study that the author made use of the additional funding that he had managed to procure and employed three research assistants for a two week period. Each of these assistants was from a nursing background, as it was felt important that they were able to fit into the environment as quickly as possible. Financial considerations also meant that they were only available for a brief period. Each also had prior research experience. One was in the process of completing a full-time Ph.D., one was a nurse tutor completing an M.Ed. and the other was a nursing officer who had recently undertaken the Welsh National Board course 'An Introduction to the Understanding and Application of Research'. Two assistants concentrated their efforts on the observation study by collecting data of a largely quantitative nature. Each research assistant spent a two week period at one of the units undertaking both structured observation and activity sampling, and some participant observation.

It will be recalled from the literature review and subsequent evaluation guide that important components of the institutional regime likely to be vital determinants of the quality of the respite experience included the extent to which the environment facilitated choice, privacy, autonomy, purposeful activity and social interaction for individuals. Whilst these were identified as being highly desirable they were also seen to be absent from most institutional environments for the elderly. It was therefore considered important to use the observational study to guage whether these conditions were present at the study sites. It was anticipated that the author would have already obtained some data of an anecdotal nature about this and that the interviews would provide valuable subjective assessments of the institutional regime. The assessment of the unit regime and organisation of care was to be further augmented by a structured questionnaire completed by the ward nursing staff. However the principal source of data on patient activity levels was to come form the observation study, supplemented by periods of participant observation.

Therefore two types of observational data were collected concurrently by the two observers, one being based at each unit. During their two weeks at the unit observers undertook a total of nine observation periods of approximately six hours each. The observation periods were planned so as to sample adequately the time between 8am to 8 pm on weekdays and at the weekend. Whilst the bulk of these observations were concentrated on the rota bed users, other short-stay patients and long-stay patients were also observed for varying periods. In this way typical data on a rota bed stay were obtained and also data on other patient groups which were used to contextualise the rota bed experience.

In order to measure activity in the present study a molar coding system based on a time sampling paradigm was adopted. This was a modified version of two previous tools. The molar category system was an extended version of one developed by the author for an earlier study (Nolan 1986) and this was incorporated into the time sampling method suggested by MacFadyen (1984). The final instrument had been developed and tested by the author (Nolan 1988) and was found to be a reliable and valid tool which was easy to use yet provided a comprehensive picture of activity levels in the type of environment under consideration. Observers were trained in the use of the technique according to the criteria laid down by MacFadyen (1984) and developed by the author (Nolan 1988). The reliability of the observation tool was satisfactory with inter-observer agreement of 90% following the training period. Whilst the use of percentage agreement has been criticised as a method of establishing reliability it is considered to be an acceptable approach for use with nominal data obtained from observation schedules comprising of a small number of discrete categories (Goodwin and Prescott 1981).

In collecting the data observers concentrated on six individuals for each observation period (usually six hours, with a break half way through) and recorded the activity of each individual every 10 minutes. The activity recorded was that occurring at the moment the observation began, although a period of up to 30 seconds was allowed in order to place each activity into context. This usually presented little difficulty as very often the observer had been present for the previous 10 minute period or else the nature of the activity was self evident. A number of other contextualising features were also noted such as location (for example Day room), posture (sitting, lying and so on), a brief description of the activity, classification of that activity into one of a number of molar codes and the contact that the patient had (whether physical or verbal contact or both with another patient, member of staff or visitor). Full details of the molar code and the recording sheet can be found in the appendix four. During the period of observation a total of 24 patients were observed in unit one (1963 observations, 60% of observations focussed on rota bed users) and 25 patients in the other (1995 observations, 63% of observations focussed on rota bed users).

Whilst the observations were being undertaken the third research assistant completed "patient profile" data for each patient at both of the units. These recorded levels of physical and mental dependency and other patient characteristics, such as sociability and cooperation which were thought to be potentially important in determining staff interactions during the structured observations. The data gathered from these profiles are largely self-explanatory and a copy of the questionnaire is located in the appendix five.

The third main data source from the observation study was the structured questionnaires completed by both the qualified and unqualified nursing staff. These requested important biographical details such as age, qualifications and training and original reasons for working with the elderly as well as seeking further clarification as to those aspects of work with the elderly that were considered to be interesting, difficult and important. These were included to obtain an overview of the way in which staff in such units perceive their work. In addition more details were sought on the respite service and how staff perceived this in relation to each of the stakeholder groups. This was included not only to check on perspectives given some time previously at interview, but also to cover ground that may not have been raised then or to get the opinions of staff whom it had not been possible to interview.

It was also felt important to try and obtain some measure of staff appraisal of the institutional regime. This presented some problems as it was difficult to phrase questions in such a way that staff did not respond purely on the basis of social desirability of answers. An attempt was therefore made to operationalise a well known typology of different care models (Wade 1983, Wade et al 1983). This typology examines institutional regimes from two standpoints. Wade and colleagues contend that regimes can be either open/closed or person centred/task-centred making for a four cell typology. Using these criteria it is suggested that the best institutional environments are "Supportive" (open and person-centred). Such environments are characterised by consultation and choice possibly resulting from the deliberations of a staff/resident committee, the provision of salient and therapeutic activities which are suggested, where appropriate, by the elderly themselves, together with unrestricted access and full involvement of visitors and volunteers. Whilst this model was originally suggested as being applicable to NHS nursing homes it is also felt to provide a useful analytic tool with which to consider any residential environment for the frail elderly.

In trying to operationalise these concepts an instrument was produced which asked trained staff to apply the criteria characterising a supportive environment to their own ward and to consider the extent to which each criteria was already in force (all/most of the time, some of the time, rarely if ever) and also how desirable and possible each element was (desirable and possible, desirable but not possible, not desirable). It must be emphasised that the resulting measure was exploratory at best, as there was no time for development work. Therefore the validity of the results as they stand are open to question. Nonetheless, as will shown later, the questionnaires provided useful insights into the extent to which staff shared common perceptions about the way their units functioned and about which aspects of the ward regime were adjudged to be viable and desirable in a practice context. Questionnaires were left at the units for indivuals to complete and return. As a consequence response rates varied. Fourteen out of a possible 19 were returned by unqualified staff and 10 out of a possible 15 from qualified staff. It is possible that the lower response rate from qualified staff might be attributable to the fact that those who did not return their questionnaires had all been interviewed and therefore perhaps did not see the need. It is fortunate however that between the interviews and the questionnaires the views of virtually all the staff (with the exception of one enrolled nurse and one auxiliary) were obtained. A copy of the staff questionnnaire is located in appendix six.

An overview and summary of the data collection phase of the study is found below in Table one.

A reflexive account adressing issues to do with the quality of the data collected now follows. This focusses mainly on the interview and the observational data and is concerned with the reliability of the former and the reactivity of the latter.

5.5 Factors affecting data quality

Interview data

A number of questions can be asked when one is considering the quality of data collected. With respect to the interview one of the most salient was aptly stated by Dean and Whyte (1969) when they posed the question 'How do you know if the informant is telling the truth?'. They rightly point out that there is ultimately no way of knowing, but they and others (Mc Call 1969, Becker 1969) have provided a number of clear pointers to the

Table 1 - Overview and summary of data collection and analysis

Stage of Study	Main data collection techniques	Sample procedures & size	Analysis used
Postal survey to provide data for an empirical test of the transactional model of stress and to consider difficulties and satisfactions of carers	Postal questionnaire incorporating: Demographic details/background Continence scale (Alpha .85) ADL scale (Alpha .86) Mental frailty scale (Alpha .83) C.A.D.I M.I (test-retest .91) Open questions on difficulies and satisfactions of caring	Non-random convenience sample using National Association of Carers Sample size approx. 1,800 (excluding non-carers) Total response: 726 (40%) Entered into qualitative ananlysis - 671 Entered into quantitative analysis - 554	Quantitative analysis Multi-variate approaches Factor analysis (SPSS X) Causal Modelling (LISREL VI) Content analysis applied to qualitative data
Interview survey to gain views of main stakeholder groups on the respite service	Main data collection technique semi-structured interviews with staff (hospital and community nurses) carers respite users	Purposive sampling of staff to include all key personnel and convenience sample of remaining staff in units used for observation Random sample of carers/users. Interviews completed: hospital staff: 35, Carers: 50, Users: 30, Community Nurses: 27	Detailed content analysis (mainly latent)
Observations survey to provide details of activity levels and regimes of care in respite units	Non-participant observation using 10 minute time sample and molar code (% agreement 90%) Compilation of methodological diary, structured self-completion questionnaires for nursing staff	Units sampled purposively to provide areas of contrast. Observations to cover periods 8am-8pm in 6 hour shifts. Total observations: Unit 1 - 1995, Unit 2 - 1963 Completed questionnaires Qualified staff - 10 from 15, Unqualified staff - 14 from 19	Observations: Frequency distribution & Chi square Questionnaires simple frequency counts and content analysis

quality of interview data. These may be summarised under a number of broad headings. The first is concerned with the **credibility** of the informant and addresses such issues as: is the informant in a position to have valid **knowledge** of the topic under consideration?; does (s)he have the **reportorial** abilities (memory, language and so on) to provide a good account?; is there any reason why (s)he should provide a **biased** account, for example a desire to please or a hope of personal gain. The second group of factors centres around the **circumstances** of the interview: are there any **bars to spontaneity**, such as the presence of another person inhibiting a frank response?; are there any **idiosyncratic factors** (transient events in the immediately prior life history of the informant) which might produce an atypical mood or attitude?; what are the **reactive effects** of the interview, does the informant, for example, appear hesitant or combative? The final area to be addressed revolves around the **manner in which the response was produced.** The suggestion here is that responses which are volunteered by the respondent are to be preferred to those which have been directed by the interviewer. With these criteria in mind, what was the quality of the data from the present study? This question will now be considered for each of the main groups interviewed.

a) The carers.

Interviews with the carers produced rich and varied data. It seems that the majority of carers are only too willing to recount their position to an interested and neutral listener, as often no one is available for them to confide in. The interview is perhaps therapeutic in itself as has been suggested by other researchers in this field (Bell et al 1987) and in this sense the description provided by Caplow (1956 quoted by French 1981) seems particularly appropriate:

> "The formal interview is gratifying- both participants enter the conversation with explicit expectations- the one to talk the other to listen- which are satisfied to an extent unusual in everyday life. Moreover, the expression of opinion, the narration of fact, the playing of roles by the respondents are systematically encouraged. Resistances normally encountered in spontaneous conversation are suppressed" (p.18).

Certainly the carers represented credible informants with expert knowledge and with very few exceptions excellent reportorial abilities. The researcher stressed the confidentiality of the interview and his own non-involvement with the respite beds in order that carers might feel free to talk frankly. Interviewing carers whilst their dependant was in hospital was a deliberate decision taken to try and eliminate this potential bar to spontaniety. Interviews with the carers were open and frank, with most of their responses being volunteered rather than directed. Indeed such was the depth of emotion expressed in many of the interviews that when they had finished individuals were embarrassed as to how frank they had been and required considerable reassurance that they had not "overstepped" the mark. Whilst carers may have been tempted to provide a 'glowing' account of the service for fear that it might be witheld from them if they offered criticism, this did not appear to be the case. Many carers were just as scathing in their criticisms of the service as they were fulsome in their praise of it. In sum the carer interviews were judged to have provided data of a high quality.

The main disadvantage of the interview approach used was the fact that only one contact with each carer was possible. This meant it was impossible to return to each carer to expand upon emerging analytic themes. However, as suggested earlier the type of recording of interview data used meant that preliminary analysis could take place almost at once, techniques of constant comparison could be employed, and significant themes checked out and developed in subsequent interviews, albeit with different carers.

b) The elderly users.

The advantages gained by interviewing carers alone had to be balanced by the difficulties of interviewing the dependants whilst they were in hospital. Interviewing the elderly about service provision, especially whilst in an institution, is notoriously difficult and the problems of obtaining valid responses are well documented (French 1981, Bond 1989, Webb 1989, MacPherson et al 1988, Clark and Bowling 1989). It has been suggested that a better indication of true feelings might be obtained by attending to what is not said rather than what is said, and that essentially neutral comments might best be seen as being more negative than positive (Bond 1989). Following the present study the author is inclined to take this view. The comments of the rota beds users fit into three analytic categories. A number were overtly positive and a similar number overtly negative and their interpretation presented few problems. The largest number were however essentially, and almost studiously, neutral but with undeniable "I'd rather not be here" undertones. These will be illustrated later in the results section. This may well have been due to the inhibiting effect of being interviewed in hospital which represents both a possible bar to spontaneity in addition to increasing the pressure to provide a favourable, or at least a neutral account, for fear of creating potential ill will should negative views become known to staff. Moreover the reportorial ability of many of the users was limited due to mental frailty, with a number of such individuals having to be excluded from the interviews. This inevitably introduces bias in that the views of the cognitively impaired are not known. This problem is not unique to the present study and it represents a dilemma to which there is no easy solution.

However these problems did not apply to all the users interviewed and many provided full and frank accounts of both the problems and benefits of the system.

The quality of the data from some of the rota bed users is therefore considered to be relatively poor in comparison to that from the carers, but it nonetheless gave useful insights into the respite experience which could fortunately be validated by observation and interviews with the other stakeholders.

c) Staff.

Hospital staff interview data were greatly supplemented by that obtained during informal "chats" and the observation phase, together with responses to the structured questionnaires used in the observation phase. In this way multiple triangulation on staff opinion was obtained. Moreover the actual observation of staff/patients interactions allowed for further data checks to be undertaken. Staff of course were aware that a copy of the completed research was to be made available to the library in the district general hospital and was therefore to an extent 'public property'. This may have increased the possibility of favourable accounts being presented. On the other hand whilst staff quite naturally wished to point out the positive aspects, they were also keen to highlight the extra work the system caused and some of the administrative challenges this posed. As already signalled the author's nursing background was also an advantage during these interviews, facilitating easy access to 'backstage data' (Carter 1981). Given this and the multiple checks on the data that occurred it is felt that the staff interviews produced data of good quality.

The researcher's nursing background also proved useful in the group interviews with the community nurses. These interviews were of a group nature and the potential strengths and weaknesses of this approach have already been alluded to. However the interviews with the district nurses were considered to have capitalised on the strengths, whilst minimising the problems. This occurred for a number of reasons. Firstly, the author only approached already existing groups. The nurses were interviewed with their professional peers and immediate work colleagues. Such groups met regularly to consider the day to day issues of practice. Thus group interactions were well established and each nurse was used to sharing their views within the group in an open manner. Secondly district nurses from an almost uniquely collegiate group in that the vast majority are at the same grade, that is sister. Only two of the nurses interviewed were enrolled nurses and both possessed personalities which ensured that they were not inhibited about voicing their views. Moreover the author knew many of the nurses from his time as a charge nurse when he worked closely with them in a collegiate relationship. These factors combined to produce interview situations in which data of a good quality emerged.

d) Long-stay patients.

It was in relation to this last stakeholder group that the interview proved to be of little use in obtaining data. Such were the levels of physical and mental frailty amongst long-stay patients in the two main study sites that there were only four who were thought capable of providing information which could be relied upon. To base any sort of inference on so few individuals seemed to be of little use so it was decided to rely on staff accounts, supplemented by observations in determining the impact of the system on these patients.

Having considered the quality of the interview data attention is now turned to the observations.

(ii) Observation and reactivity

The use of observation as a method of data collection poses a vexing question, 'To what extent does the presence of a relative stranger engaged in observing behaviour influence and perhaps determine the behaviour that is being observed?' Clearly if the behaviour is an artifact of the observation then the credibility of the results is severely compromised. In the present study the observers were instructed not to interfere in any overt way with the functioning of the unit. However it is naive to assume that their presence in a relatively unchanging environment (at least in terms of staff) would have no impact. Such impacts are usually considered under the general heading of reactive effects. The efforts taken to establish and limit such reactivity in the present study are now considered.

Any research is considered as reactive depending upon the effects which the research activity itself has on the data produced. In this sense it is an important potential source of bias which needs to be controlled or accounted for. Generally the classical experimental approaches to research attempt to rule out reactive effects by standardising all procedures and ensuring that any interaction that occurs is therefore the same for all participants. Critics of such an approach argue that this procedure in itself is reactive as it is not natural and is likely to result in people behaving in an unnatural way. Naturalistic investigators attempt to interfere as little as possible in events but acknowledge that their presence is likely to have some effect. In documenting these they provide reflexive accounts in which they attempt to make explicit the likely reactive effects they have produced.

The type of data gathered during the observation phase, whilst termed naturalistic field observation, is in fact far from natural, in the sense that it is part of the normal order of daily events. Where observation of activity is overt, and there are both ethical and practical problems in collecting covert observations, then individuals are usually aware that they are being observed and the possibility always exists that they will alter their behaviour as a consequence. This type of problem has long been recognised and as Blau and Scott (1963 quoted in Lelean 1975) note the problem becomes how is observation to be carried out without altering the phenomena under study ?

As already highlighted observational techniques have a long history in the study of institutional environments both for the elderly and other patient groups and a number of accounts of this problem have been offered. Many authors simply report that reactive effects are minimal and soon dissipated (Norton et al 1962, Altschul 1972, Hawthorn 1974, Cormack 1976, Wells 1980, Wilkin and Hughes 1987) and consider that the accounts they provide represent a fair reflection of the normal routine. Others take a slightly more rigorous approach and suggest that as they saw evidence of such bad practice even though individuals were aware that they were being observed, then impression management was not being used (Godlove et al 1981, Clark and Bowling 1989). Bond (1987) advocates a variant of the second approach and suggests that insights into reactive effects can be gained by the extent of "unofficial activity", for example coffee breaks, that occur in the researcher's presence, or whether attempts are made to hide such activity. Only one study was found in which a systematic attempt was made to quantify reactive effects of observations in a hospital setting (Rutherford and Spitzer 1968) and this reached the conclusion that if interference is kept to a minimum and a non-judgemental approach is taken then reactive effects are of marginal significance. On the other hand, McCall (1984) in a major review contends that reactive effects must be seen as an idiosyncratic factor which should be addressed in every study as there are likely to be widely divergent effects between studies.

In the present study a number of steps were taken to try and reduce possible reactive effects. To a large extent these can be considered as a function of the role of the observer, including the degree to which they establish "personal acceptability" (Davies 1981) and to the purpose attributed to the observations by the individuals under study. In the present investigation the purpose of the study was explained to staff both by letter and personal visits from the author (appendix seven). It was stressed that the actual intention was to be able to describe a typical rota bed stay within the hospital under study. Staff were therefore reassured that their activity was not the prime focus of the observations but that when they were interacting with a patient being observed then that activity would be recorded. Anonymity was assured and the help of staff was enlisted to explain the purpose of the observations to patients and to ask patients to ignore the observers. Staff were also told that if at any time they or the patients wished to see what was being written then they had only to ask. In the event no one asked to see anything at either site. Staff were also asked to act as second observers during the project and to report to the assistants any events that made them think that behaviour had altered as a result of the observers' presence.

In terms of observer roles, overt observation permits access to only two of the four master roles suggested by Gold (1958), those of observer as participant and participant as observer. Most of the studies previously cited have advocated the former role and participation has been minimal, with observers adopting the "fly on the wall" technique (Lelean 1975). However a number of authors consider that roles are rarely static and become determined by reactions occurring in the field (Pearsal 1965, Bryley 1969, Jackson 1975,) and that, particularly in hospital settings, to ignore staff and patients is likely to increase rather than reduce reactivity (Webb 1989). Hawthorn (1984) suggests that this might be overcome by acting like a "polite visitor" but the author's previous experience with observation in institutional settings involving the elderly (Nolan 1986, 1988) had demonstrated that if the aim is to minimise reactive effects **during** periods of observation then it is important to establish relationships and rapport **between** periods of observation. Observers were therefore instructed to establish a good rapport with staff and patients during periods when they were not actively engaged in observation, for example coffee breaks and meal times.

In order to provide some indication of the effects of observer presence each observer compiled a field diary in the form of methodological and observational notes and anecdotes, as suggested by Webb (1989). Observers were requested to record these each day and the author met with them during the observation period to check developing perspectives and offer any advice. The observers were also requested to make mental notes (later to be added to their daily accounts) of activities and aspects of the ward environment which they thought exemplified the ward in relation to the criteria contained in Wade's typology (Wade et al 1983, Wade 1983). A form was provided to help the observers crystallise their thoughts at the end of each day (see appendix eight). They were asked to record quantitative and qualitative data. The former included the number and types of patients observed, the total patient population each day, staffing levels and visits made by other staff. Qualitative data were mainly to do with staff perceptions of any unusual or atypical event occurring during the day and staff assessments of any reactive effects they felt the observers presence had had. This was supplemented by the observers own account of the day including any impression management that they engaged in or were the subject of and their impressions regarding the ward routine and environment. These data were found to be very useful in supplementing the quantitative activity data.

The observer in unit one was a nursing officer who worked in the county's district general hospital 20 miles distant from the unit under study. Staff in the unit were aware of his position. He reported that initially he felt there was a degree of suspicion which was as much to do with who he was as what he was doing. Therefore during a break from observation he deliberately joined staff whilst they were having an impromtu coffee break. Following this staff very soon began to use first name terms with the observer and then he was invited to join the staff group at regular intervals. Almost immediately the atmosphere was felt to have relaxed and very soon it was noted that conversation moved from the level of polite chit-chat to that which a group of nursing colleagues would normally engage in during coffee. These are the type of criteria suggested by Bond (1987) as evidence for a reduction in reactivity. Similarly, between periods of observation patients were engaged in conversation and in this way valuable additional data were gained. It was also possible to obtain data which added to that on the environmental regime and the interaction between rota bed users and staff. This will be considered in more detail in the results section. However it was also apparent that the observer's presence was not without some reactive effects. For example, during conversation with patients one day it transpired that some had noticed that the regime seemed to have altered and that they had been assisted out of bed a little later than usual, something that the patients attributed to the staff wishing the observer to see this process.

Similar valuable additional data were obtained from the second observer. She noted the friendliness of all the staff and their personal knowledge of particular patients. Her only prior experience of geriatric care had been during her own nurse training and she had not found this pleasant. She was therefore suprised by the contrast with the present environment. At first she thought that staff were talking to patients for her benefit. However, it soon became apparent that this was not the case. She noted that when a rota bed patient came in that staff knew a considerable amount about them and that patients knew a similar amount of personal detail about staff. From this she concluded that such a level of knowledge could only be obtained by an established reciprocal relationship which could not have been for her benefit as it quite obviously predated her presence. Again during observations staff ignored her presence but she joined them for coffee and quickly established a friendly relationship. Staff in both units frequently offered unsolicited information to both observers which further enriched the data.

Whilst one can never rule out the presence of reactive effects nor guarantee the reliability of interview data, it is hoped that the foregoing account will permit the reader to reach an informed judgement on these aspects in the present study.

This chapter concludes with a consideration of the techniques of data analysis used.

5.6 Techniques of data analysis.

The use of multiple methods of data collection requires multiple methods of data analysis. Different methods were used in the analysis of the quantiatitive and qualitative data so these need to be discussed. Consideration is first given to the quantitative analysis, with the major emphasis being placed on the multi-variate approaches of factor analysis and causal modelling. This will be followed by an account of how the content analysis was applied to the qualitative data.

(i) Quantitative data analysis

Two main sets of data required the application of quantitative techniques of data analysis. These were the data from the postal survey and those from the observational studies. The latter were analysed by the author by means of simple descriptive statistics, with Chi square analysis being used to compare the observations at the two sites.

Whilst descriptive approaches were also applied to the data from the postal survey, in order to test the transactional model of stress more sophisticated multi-variate techniques were required. The multi-variate analyses were conducted in two distinct stages. The purpose of the first stage was to explore the CADI and see if it consisted of meaningful underlying dimensions which might be used as determinants of carer malaise. This initial stage was carried out by the author using the techniques of factor analysis available on the Statistical Package for Social Sciences (SPSSX). If analysis of the CADI suggested underlying factors it was the intention to test the transactional model of stress using causal path analysis. As will be discussed shortly this second stage exceeded the author's statistical ablilities and therefore expert advice was sought. A brief description of these two stages now follows.

a) Initial Factor Analysis of the CADI

Chapter Two provided a critique of the literature on carer burden scales, especially those which rely upon a single global score and thereby fail to identify the components comprising carer burden. In an attempt to rectify this deficit a number of multi-dimensional scales have been developed. Such scales have identified conceptually distinct domains of burden from an underlying set of variables. In order to achieve this such studies have, almost without exception, employed the techniques of factor analysis (Poulshock and Diemling 1984, Kosberg and Cairl 1986, Kosberg et al 1989, Lawton et al 1989b, Novak and Guest 1989, Pearlin et al 1990). This approach is well suited to this purpose as the central aim of factor analysis is the 'orderly simplification' of data (Child 1970, Cohen and Manion 1985), with the basic assumption being that there are a smaller number of dimensions or factors underlying a larger set of variables (Norusis 1985). Therefore by the use of factor analysis many variables are condensed into a few underlying constructs (Hedderson 1987).

A number of sequential stages are involved in such an analysis beginning with the computation of a correlation matrix from which an initial set of factors is extracted. This is usually termed the direct solution (Child 1970). However the interpretion of this initial solution can often be difficult and it is therefore usual to adjust this in order to aid interpretation (Child 1970, Norusis 1985, Hedderson 1987, Alt 1990). This is achieved through a process termed rotation during which the reference axes for the factors are manipulated. The resulting factors are said to constitute a **derived** solution (Child 1970).

However there is no mathematically unique solution in factor analysis. Indeed there are an infinite number of such solutions (Child 1970, Neale and Liebert 1986, Alt 1990). Furthermore, there is no single 'best' way of determining the answers to a number of important questions (Child 1970, Norusis 1985, Alt 1990) such as:

Which technique should be used to extract the initial factors;
What number of initial factors should be extracted;
What method of rotation should be adopted;
Which variables are significantly related to, or **load on** each factor?

Moreover, whilst guidelines exist on the above issues, these too are opinions and therefore subjective (Neale and Liebert 1986). The following section describes the approach used by the author in analysing the CADI.

Underlying the variety of approaches to the extraction of the initial factors are two basic techniques, component analysis and factor analysis. These are generally described as being related but not synonymous (Child 1970, Ehrenberg 1975, Alt 1990). According to Child (1970) the main difference is that in factor analysis some account is taken of unique variance, but in component analysis unique variance is ignored. However Child (1970) maintains that the use of either technique does not result in any significant differences amongst the important factors and that therefore either approach might be used without any real alteration to the overall picture. Principal components analysis is now the approach most widely used (Child 1970, Ehrenberg 1975, Norusis 1985, Hedderson 1987, Alt 1990) and was adopted by those studies previously cited which applied factor analytic techniques to the exploration of domains of carer burden. In being consistent with previous work this was the model used by the author to explore the CADI.

In determining the number of factors to extract no single approach is seen as being obviously superior. However a widely used technique is to retain only those factors with an eigenvalue of greater than one. Such an approach is considered as especially appropriate when the number of variables is between 20 and 50 (as in the present study) and is recommended particularly for use with principal components analysis (Child 1970, Alt 1990). It was therefore adopted in the present study.

As with the intial extraction of factors there are numerous different models available for the rotation phase, but these again fall into two main groups (Child 1970, Norusis 1985, Alt 1990). Factors may be rotated in an **orthogonal** manner so that they remain at right angles to each other, that is factors remain independent. Alternatively an **oblique** rotation can be conducted in which factors are permitted to be correlated. Of those methods currently available the varimax model is the most widely used (Norusis 1985, Hedderson 1987, Alt 1990). This is an orthogonal rotation and being the method of choice in previous studies examining carer burden it was employed in the present analysis. Principal components, eigenvalue determination of the number of factors and varimax rotation are the default criteria in the SPSSX package.

Whilst these procedures are used in determining the factor structure, such factors as are extracted still require interpretation. Initially this requires a decision as to which variables constitute each factor. Once again no single method exists but as a good rule of thumb it is suggested that only those variables with a factor loading of greater than .3 be retained. For samples of over 50 this is generally considered as being a rigorous test (Child 1970, Alt 1990) and was adopted in the present study.

All these considerations relate to the mathematical properties of factor analysis but it is widely accepted that a mathematically robust solution is not of itself sufficient and that a good factor analysis also needs to be conceptually meaningful (Child 1970, Norusis 1985, Neale and Liebert 1987, Alt 1990). Therefore there is nothing in the technique of factor analysis to ensure validity and one prime consideration is whether the factors 'make sense' (Norusis 1985, Alt 1990). In addition any factor analysis should be accompanied by data external to the analysis against which to validate the factors (Child 1970, Alt 1990). With regard to the present study it will be seen in the following chapter that the analysis resulted in empirically meaningful factors emerging. Moreover strong validation for the factors is provided from the analysis of independent qualitative data, with such analysis having preceded the factor analysis by three months. This adds considerable confidence to validity of the results .

(b) Causal path analysis

The emergence of distinct and meaningful factors from the CADI gave promise that these factors could be used to explore the determinants of carer malaise. However it was also apparent at this stage that the author had reached his limit of statistical expertise and therefore expert opinion was sought from Dr. N.C. Ellis of the Psychology Department, UCNW. The causal path analyses were conducted by Dr. Ellis using the LISREL VI model. The description below of the model that was used is based on that provided by Dr. Ellis in a published paper relating to this phase of the analysis (Grant, Nolan and Ellis 1990).

Causal paths in the data were explored using the LISREL system. The LISREL model (Joreskog and Sorbom 1984, 1985, Saris and Stronkhorst 1984) allows estimation and testing of recursive and non-recursive causal models, with and without latent variables, measurement models and factor analytic models using maximum likelihood estimation of covariance structure within the same programme. The variables which the model should explain are termed **endogenous** variables and the predetermined variables which are not explained by other variables in the theory are called **exogenous**. Effects on endogenous variables from prior endogenous variables are denoted by **beta** paths, whilst effects of exogenous variables on endogenous variables are denoted by **gamma** paths. The model specification entails that the beta and gamma weights on the causal paths reflect specific direct causal weights between the variables controlling for all indirect effects, spurious relationships and joint effects. Once a model has been formulated the causal paths within the theory are specified, information about covariances is obtained from the data, and LISREL estimates the causal effects and other parameters and tests the model against the data.

The type of model specified in the present analysis rested on few prior assumptions. It had few restrictions in that any prior abilities were allowed to affect any later ones. Aspects of the caring environment were taken as the exogenous variables and these environment factors were allowed to affect all of the endogenous variables (both caring specific stressors from the CADI and general malaise factors from the MI). Beta paths were allowed within the endogenous variables from the caring specific factors to the general malaise factors. Thus all possible causal paths were allowed, as was covariance between the complete set of variables within each column.

In determining which variables to enter into the model it had been the intention to estimate a measurement where the factor-analytic procedures were performed by LISREL as part of the causal path analysis but this proved to be far too large a computation. The variables used in the model were therefore factors derived from a combined analysis of the environment factors and CADI using SPSSX.

The type of fully saturated model originally fitted is shown in figure one. On completion of this saturated model it was 'tuned' in progressive stages so as to:

a) Delete all paths with t values < 1.0;
b) Drop all paths with t values < 1.65;
c) Drop all paths with t values < 1.96;
d) Include any paths with a high modification index*

* LISREL computes modification indices for all paths not specified in the original model and paths with high indices are those which would improve the fit of the model if they had indeed been included.

The final model had a goodness of fit index of 0.981 and did not

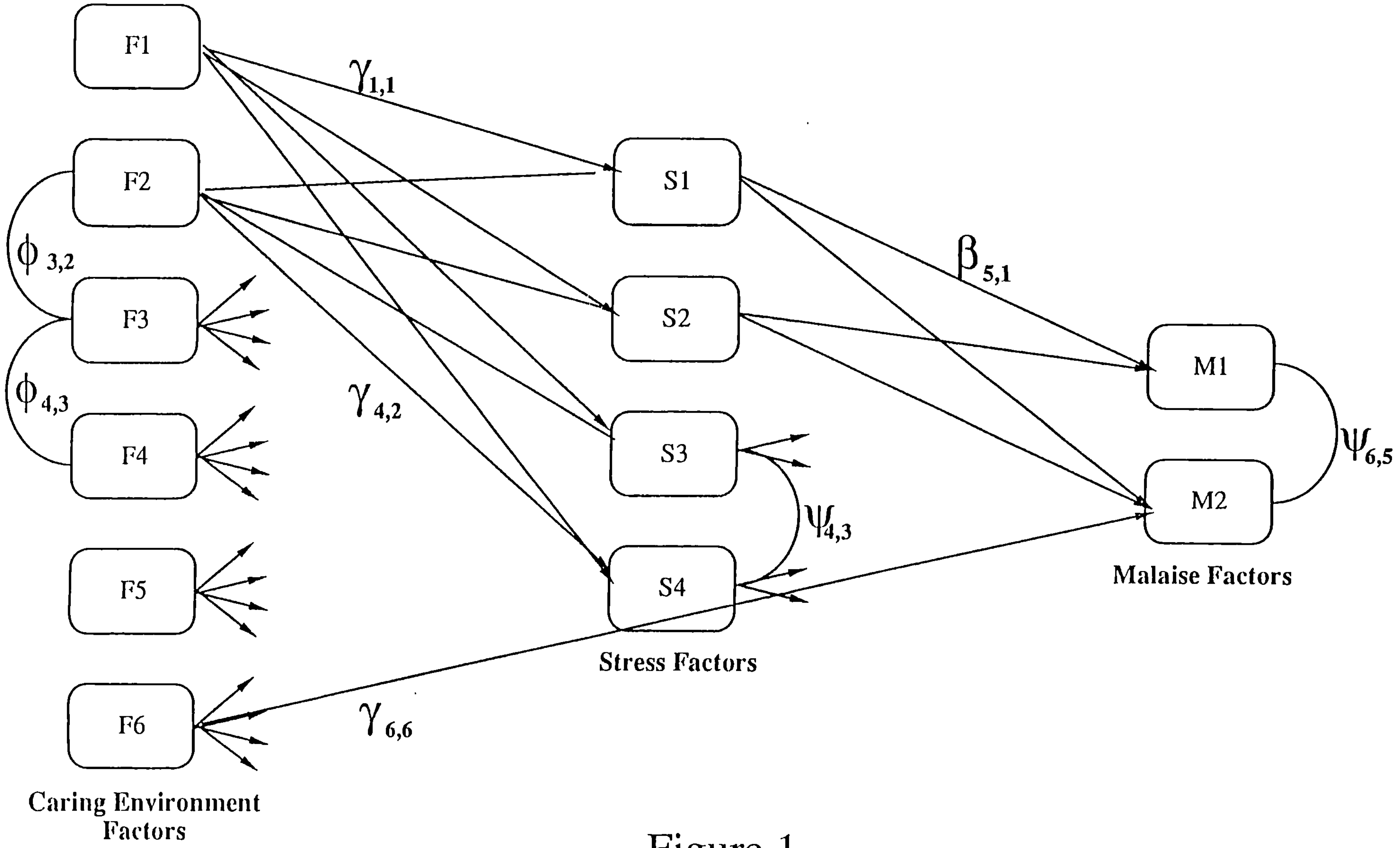

F1
F2
F3
F4
F5
F6
Caring Environment Factors
$\gamma_{1,1}$
$\gamma_{4,2}$
$\gamma_{6,6}$
$\phi_{3,2}$
$\phi_{4,3}$
S1
S2
S3
S4
Stress Factors
$\psi_{4,3}$
$\beta_{5,1}$
M1
M2
Malaise Factors
$\psi_{6,5}$

Figure 1

deviate significantly from the data on the Chi square goodness of fit test. It should be emphasised that LISREL was used in an explanatory fashion to do the causal path analysis in order to identify patterns in the data, rather than testing a precisely specified a priori model. However as will be seen in the following chapter, the results are conceptually meaningful and consistent with a transactional model of stress.

(ii) Qualitative data analysis

The qualitative techniques produced a large volume of data on which it was necessary to impose some conceptual order. For example, responses to the open questions on the postal questionnaire provided some 1200 statements of either problems or satisfactions of caring, varying in length from a few lines to several pages. Further comments of a diverse nature were made by many respondents which gave valuable insight into their circumstances. Added to this were the open questions from the staff questionnaire, the 142 interviews conducted with staff, carers and respite users and, the field diaries of the author and the research assistants, and some indication is gained of the scale of the analysis required.

The main form of analytic technique applied to the qualitative data might best be termed **content analysis.** Caution is required when using this term however because content analysis as a method is loosely applied to a variety of approaches rather than a single conceptually distinct technique (Crano and Brewer 1973, Smith 1975, Krippendorf 1980, Polit and Hungler 1983, Weber 1985). Beneath this heterogeneity however these techniques share a common purpose in that their aim is to to make valid and reliable inferences from textual data concerning human communications (Weber 1985).

The original intention of content analysis was to quantify communications (Crano and Brewer 1973, Bailey 1978). However the term now encompasses both quantitative and qualitative approaches (Field and Morse 1985, Weber 1985) and is considered to be a methodological tool that is still in the developmental stages (Krippendorf 1980).

As such there is no "right" way to conduct a content analysis (Weber 1985) and due to the variety of its forms and the emergence of other techniques to analyse communications (for example Discourse Analysis (Potter and Weatherall 1987)) it is a term which might cause confusion. Thus, Krippendorf (1980) considers that when using content analysis it is the responsibility of the researcher to describe how the data were collected and to justify the steps taken in the analysis. This is the purpose of this section.

In order to illustrate salient points data from the postal questionnaire will be used as an example. The same techniques were also applied to the interview data and to the field diaries.

Quantitative and qualitative approaches to content analysis are sometimes referred to as manifest and latent analyses respectively (Smith 1975, Field and Morse 1985). Manifest content analysis results in a statistical account of the frequency of categories within text and is a method which is considered to be more reliable but potentially less valid. It is the type of analysis most usually associated with traditional definitions of content analysis (Field and Morse 1985). Latent analysis on the other hand is a technique by which:

> "Passages and paragraphs are reviewed within the context of the entire interview (or other textual form) in order to identify and code the major thrust or content of the section and the significant meanings within the passage. This permits the overt intention of the informant to be coded in addition to the analysis of the underlying meanings in the communication. Thus the method has high validity, but may be less reliable due to the possible subjective nature of the coding system"
> (Field and Morse 1985 p103).

In applying content analysis in the present study the main approach was latent but some descriptive frequencies are also supplied as these give valuable insights about the presence of certain perspectives in accounts of the population of interest. The type of latent analysis used seems far removed from the original intent of content analysis which was the quantification of textual data. Indeed, it has been suggested that such methods of analysis, whilst having affinity with conventional content analysis, differ in important ways, most notably in that they eschew the a priori formation of categories and the adherence to quantification (Lincoln and Guba 1985). Thus, the approach used in this study is best considered to have been guided, but not constrained, by conventional content analysis. As such it is akin to the constant comparative method of data analysis described by Glaser and Strauss (1967) and by Lincoln and Guba (1985). The following description is an attempt to give a sense of its application in the present study. The method used is outlined in three sections. The first will provide a brief description of how the formation of categories was handled and this will be followed by an account of issues relating to the reliability and validity of the analysis.

a) Category formation

The raw data were in the form of open responses either to questions in the questionnaires or from interview. As highlighted above the data from the carer survey will be used for illustrative purposes. The open data from this survey were generated from two questions about problems and satisfactions of caring.

The first stage of the analysis involved a detailed reading of responses in order to become familiar with the data. At this stage a mental working of the data occurred in which emerging areas of conceptual commonality and difference were identified. This represents a thematic approach to the data, a theme being considered as a major idea or thought which distinguishes data on conceptual grounds (Banks 1976, Krippendorf 1980). Following this preliminary reading, individual responses were reconsidered and compared to the rest of the questionnaire in order to place responses to the open questions in the context of all the data for that individual. This was an important step for a number of reasons. Firstly, contextualising data for content is a vital stage in the process of content analysis (Krippendorf 1980, Weber 1985). Secondly, many respondents had provided other relevant data in the form of notes in margins at various points which helped to clarify their perspectives. Thirdly, as will be seen, this was a preliminary step in ascertaining the validity of the emerging categories.

Individual responses were then re-read to try and encapsulate the emergent themes. It is important to state that themes were not related to length of response and that a short piece of text might contain two or more themes whilst a long passage might be a detailed description of a single important theme. Emerging themes were written onto sheets of paper which were then used to sort and resort the data until the boundaries of individual categories became clear. At this stage sub-categories were added to some of the major categories so that all the data could be incorporated. The categories thus developed were grounded in the data rather than having been developed a priori. A similar approach was used by Sixsmith (1986) to analyse data gathered from older people during semi-structured interviews. He describes the process in the following way:

> "A great deal of qualitative data was generated from the discussions. Initially this was reduced to a set of manageable conceptual categories using content analysis, where the salient points from each interview were assigned to a set of meaning categories. These categories were not predefined, but were developed from the responses themselves by a continuous process of sorting and grouping" (Sixsmith 1986 p340).

At the end of this stage in the present study a number of "meaning" categories had been developed for each of the main dimensions, that is the problems and satisfactions of caring. Once these categories had been identified and their boundaries defined, rules for inclusion within each category were applied in order to establish a measure of the system's reliability.

b) Reliability considerations

Reliability is an essential element in any content analysis (Bailey 1978, Krippendorf 1980, Weber 1985) but is particularly important in latent or interpretative approaches (Crano and Brewer 1973, Smith 1975, Polit and Hungler 1983). Reliability considers the extent to which data are consistent across different applications and do not represent artifacts of the measurement process or idiosyncratic factors amongst coders. It is also a necessary, but not a sufficient, condition for the validity of the analysis.

Krippendorf (1980) considers there to be three main approaches to reliability testing in content analysis:

A) **Stability:** The extent to which the same coder would produce the same results on differing occasions. This is concerned with intra-observer factors.

B) **Reproducibility:** The agreement between results from two independent coders, measuring inter-observer variation.

C) **Accuracy:** Comparing results to some agreed standard or norm.

Accuracy is rarely attempted in content analysis but reproducibility should form the minimum acceptable standard (Krippendorf 1980). The present system was subjected to both stability and reproducibility testing. The author re-analysed the raw data on three occasions with a gap of at least one month between each. The percentage agreement between codings was over 90% in each case. Stability is considered to be the weakest form of reliability. As the author had devised the coding system a test showing that he agreed with his own codings is not really adequate. Therefore, the reproducibility of the codings was also tested. In order to make this test as rigorous as possible, within the limits of time and financial resources available, the categories requiring the greatest amount of interpretaion on the part of the coder were included. A stratified random sample of 50 statements from the four categories with the highest levels of abstraction was compiled and written onto numbered index cards as were the rules for the placing of responses into each category.

Independent coders were selected and given instructions about the coding exercises required. After having read the coding rules they were asked to place each of the 50 statements into one of the four categories. Following this procedure the author reviewed the codings with each coder and the nature of any difficulties were explored. This discussion did not occur until after the codings to ensure the independence of coders as insisted upon by Krippendorf (1980) and Weber (1985). When difficulties arose the rules for defining the coding system were reframed and the procedure repeated with a different coder. Following the first round of changes, agreement between three independent coders was over 90% and the coding system was considered to have an acceptable degree of reliability.

c) Validity considerations

Whilst reliability is concerned with the consistency of results, validity relates to issues of whether or not they actually represent examples of what they purport to be. Validity has therefore to do with meanings and is not so easily tested. To begin with validity is a diverse concept with various meanings depending upon the paradigm within which a study is located. Therefore the account below is restricted to the attempts made to establish the validity of the analyses in the present study using terms which appear to have achieved at least broad consensus.

Validity, following Sapsford and Evans (1979), is considered as comprising:

A) **Face Validity:** "Well it certainly looks as though it measures that". This constitutes the weakest argument.

B) **Content validity:** Are the known boundaries of content adequately represented?

C) **Predictive validity:** To what extent can future behaviour be predicted from the results?

D) **Concurrent Validity** How do results compare to others obtained from a well established measure of the same concept?

C and D are sometimes referred to as **criterion validity.**

E) **Construct Validity:** Concerned with the extent to which results accord with a range of theoretical predictions or hypotheses about the concept under consideration.

Content analysis can often pose real problems in terms of validity as the data are often collected for purposes other than research, are beyond the control of the researcher or are collected at a single point in time. These problems are exacerbated for latent analyses. In order to test the validity of latent analyses it is generally considered essential to have data of a different sort from the same individuals in order that a form of triangualtion be can performed (Crano and Brewer 1973, Smith 1975, Polit and Hungler 1983). Fortunately for the present analyses such data were available from other parts of the questionnaire. This enabled predictive, concurrent and construct validity to be established.

It would be surprising if the categories developed did not have face validity and this does little more than reconfirm existing notions that have already been imposed on the data during the analysis. However many of the themes emerging from the open questions were conceptually related to questions in the structured section of the questionnaire and this facilitated a more rigorous consideration of their validity.

A form of predictive validity could be established in a number of ways. It was possible, for example, to cross check on responses to the nature of past carer/dependant relationships as self-rated on a five point scale with those described in the open questions. Also, tentative hypotheses could be postulated, for example, the relationship between finding caring satisfying and having a better relationship with their dependant could be tested against the data. Thus, of the 546 statements of satisfaction only 28 came from respondents who rated their relationship as fair and only one from an individual who rated their relationship as poor.

Yet again, because respondents gave open questions to both satisfactions and problems of caring a form of convergent and divergent validation could take place. For example many respondents indicated that a major source of satisfaction was feeling appreciated for their caring efforts, whilst others said that a lack of appreciation was one of the major causes of difficulties in their caring relationships.

Furthermore, the categories could be checked out against those created from the factor analysis of CADI and in this way a form of conceptual synthesis as recommended by Mitchell (1986) occurred as an important way of bringing the qualitative and quantitative data together. The extent to which the results produced from differing approachs were congruent both with each other and with the theoretical literature provides a stringent test for the construct validity of the analyses and will be demonstrated in the next chapter.

Having described the rationale behind the study and the manner in which it was conducted attention is now turned to the results obtained from each of the main stages of data collection.

CHAPTER SIX

CARERS' STRESSES AND REWARDS: IMPLICATIONS FOR RESPITE CARE

> "Everything I do for him I do willingly. We have a lot of laughs, he still has a wonderful sense of humour.He tries to help when I tend to him and we manage the best we can"
>
> "No matter what I do there is no response of pleasure or appreciation. I know I'm not useless or worthless but often wonder why I bother. I keep on trying to get some response"
>
> (Two faces of caring: quotes from carers in the postal survey.)

Reporting the results of the postal survey represents a most difficult task. The original intention of the survey was to have been as a sensitising exercise to inform the evaluation of the respite care service. It was to have highlighted important areas of carer stress that respite care might help to ameliorate and to provide an empirical test for the transactional model of stress that forms one of the key theoretical underpinnings of the study. In the event the survey achieved this and much more. The data proved to be capable of interrogation on such a range of fronts that analysis is not yet complete and further work is in progress to develop aspects of the results considered to be particularly important.

This chapter is limited to reporting those aspects of most relevance to the respite study. It will therefore focus primarily on the causal model applied to the data and on the results of the qualitative analysis detailing carers' sources of problems and satisfactions. However, for interested readers reports giving detailed descriptions of the results of the analysis to date are available (Nolan and Grant 1989 a,b, Nolan, Grant and Ellis 1990, Grant, Nolan and Ellis 1990).

The chapter is divided into four main sections. The first will provide brief details of the sample characteristics and outline the extent of the care they provided. The second will report on the causal model applied as a test for the transactional model of stress, whilst the following section will outline the results of the qualitative analysis. Finally, these results will be brought together and their implications for the respite study considered .

6.1 Sample characteristics.

Details of the response rate to the postal survey were provided in the preceding chapter and its non-random nature was stressed. This said, it has already been pointed out that due to the difficulties in identifying a random sample of carers, most carer research has been based on non-random samples. Furthermore the sample in the present study is far larger (often by a factor of 10 or more) than many previous studies. The availability of nationally representative data on carer numbers and characteristics (Green 1988) also allows comparison of the sample to a nationally representative one. When the present sample were considered it was clear that the vast majority (94%) were resident carers. This group therefore is compared to the national data (Table 2).

In so doing a number of differences are apparent. Firstly the present sample is biased towards female carers, 75:25 as opposed to 50:50 in the GHS data. Additionally the AOC sample contains greater numbers in the 45-64 age range and spouses and children as carers are over-represented, with there being proportionately lower numbers of parents and other relatives.

Duration of caring is broadly comparable and the nature of disability/handicap not dissimilar. The AOC sample is however far more functionally impaired than would appear to be the case in a national sample, although differences in the measurement of functional ability makes direct comparison on all but a limited number of parameters somewhat problematic. These differences aside it can be seen that the AOC sample does not appear to be unduly atypical of carers looking after heavily dependent family members at home.

A closer examination of the charactistics of dependants in the sample (Table 3) indicates how much assistance carers were required to give. The pervasive nature of caring is apparent when it is considered that 66% of the sample perceived themselves to be providing constant day and night care and only 2% gave less than daily attention.

The frequency with which various difficulites associated with caring occur also provides an indication of the scale of demands on carers' lives. Of the 30 problems listed in CADI four were experienced by over 90% of carers either all or some of the time, eight were experienced by over 80% of carers, six by over 70% of carers, eight by over 60% of carers, three by over 50% of carers, and only one by less than 50% of carers and that was experienced by 49% of the sample.

Table 2: Comparison of AOC sample with GHS sample.
(resident carers only)

Characteristics	AOC sample (n = 522) %	GHS sample (n =727) %
Handicap/disability		
None/other	3.0	2.0
Physical	58.0	67.0
Mental	11.0	9.0
Physical and mental	28.0	22.0
Gender of Carer		
Male	25.0	50.0
Female	75.0	50.0
Age of carer		
16-29	3.0	12.0
30-44	13.0	20.0
45-64	60.0	43.0
65+	24.0	25.0
Relationship dependant to carer		
Spouse	49.0	40.0
Child	10.0	19.0
Parent/parent-in-law	37.0	29.0
Other relative/friend	4.0	12.0
Duration of caring		
Under 1 year	5.0	9.0
1-2 years	18.0	19.0
3-4 years	19.0	18.0
5-9 years	31.0	27.0
10-14 years	10.0	13.0
15+ years	17.0	15.0
Dependants requiring help with		
Aspects of personal care	94.0	53.0
Mobility	82.0	46.0
Household tasks	98.0	81.0

Table 3: Dependency profiles AOC sample
(n=522)

% needing some help with		% exhibiting a degree of	
Washing	74%	Urinary incontinence	52%
Feeding	43%	Faecal incontinence	40%
Dressing	81%	Wandering	34%
Toilet needs	64%	Disorientation	56%
Mobilising	82%	Difficult behaviour	52%
Bathing	94%	Agitation/uncooperative	65%
Household tasks	98%	Difficulty conversing	65%

The impacts of caring were apparent on both the health of the carer and the nature of the carer/dependant relationship, although in the latter case this was by no means always negative. Thus, when health was self-rated on a five point scale (excellent to poor) 49% of carers rated their physical health as fair or poor and 63% rated their emotional health likewise. Caring was felt to have contributed to poor physical health by 63% of carers and to poor emotional health by 88% of the sample. It therefore appears that whilst both physical and emotional health are negatively influenced by caring it is emotional health that is the most affected, as will be demonstrated when the scores on the MI are considered below. Caring was also thought to have resulted in a change in relationship between carer and dependant in 46% of cases, with the relationship having deteriorated in 35% of cases and improved in 11%. That caring can no longer be considered in terms of only negative outcomes for carers will be discussed when the qualitative results are considered later in this chapter.

Perceptions that emotional health suffered as a consequence of caring was borne out by the scores on the MI. The mean MI score was 8.97, with 81% having a score of 5+ and 60% a score of 7+. A score of five is normally considered outside the normal range and a sample mean of almost 9 has rarely been reported before. Quine and Pahl (1985), for example, reported a mean of 5.83 in 200 carers of severely mentally handicapped children. Quine and Charnley (1987) obtained a score of 3.86 in 226 carers of elderly dependants and Charnley's (1989) study of carers of elderly dependants reported a mean of 3.8 in her sample of resident and non-resident carers, with the mean score for resident carers being 4.0.

It is clear, therefore, that the present sample represents a group of carers providing care of high intensity to a heavily dependent population over a prolonged time period and suffering high stress levels as a consequence. Having delineated the sample characteristics, attention is now turned to factors influencing stress and to the conceptual acceptability of a transactional model in explaining the findings.

6.2) The results of the quantitative analysis.

The results of the quantitative analysis reported here are restricted to those concerning the empirical test applied to the transactional model of stress. In order to test this model a series of multi-variate analyses were undertaken using the computer packages SPSSX and LISREL VI (Joreskog and Sorbom 1984,1985) as discussed previously.

In determining which variables to enter into the causal model factor analytic techniques were used. The first of these considered factors within the caring environment and consisted of the dependency characteristics of the cared-for (assistance required with ADL, degree of incontinence and behavioural problems) as measured on the questionnaire together with column A of CADI (indicating that the carer considered that they faced certain problems in their caring environment). From these analyses 11 factors emerged which, as can be seen from Table 4, form highly interpretable clusters of variables resulting in empirically meaningful factors.

The second set of analyses considered those problems to which carers were exposed which they actually perceived as stressful, as indicated in column B of CADI. As can be seen from Table 5 seven factors emerged that fittingly divide the construct system of perceived stress into similar partitions to those derived from the totally independent analysis of the caring environment. Frequency distributions and correlation matrices of the variables included in these analyses can be found in appendix nine.

The Malaise Inventory (MI) was used as the outcome measure of carer stress. Whilst recent analysis of this measure suggested a unidimensional instrument (Bebbington and Quine 1987), earlier work had indicated that this might not be the case (Hirst 1983). In order to clarify the structure of the MI further analysis was carried out by Dr. Ellis. This indicated that the MI is best considered of as comprising two sub-scales, one measuring psychological malaise and the other physical. Full details of this analysis are available in a published paper (Grant, Nolan and Ellis 1990). Therefore two sets of causal path analyses were conducted, one for psychological malaise and the other for physical.

Table 4: Factor structures for caring environment

FACTOR 1: DEGREE OF PHYSICAL HELP
(% VARIANCE EXPLAINED 19.0)

VARIABLE	FACTOR LOADING
Help required to dress	.84
Help required to wash	.78
Help required to toilet	.76
Help required to mobilise	.72
Help required to bathe	.71
Help required with personal care	.65*
Help required to feed	.63
Dependant is immobile	.51*
Help required with housework	.38
Carer feels physically tired	.31*

FACTOR 2: CARER/DEPENDANT RELATIONSHIP
(% VARIANCE EXPLAINED 11.6)

Dependant is unappreciative	.75*
Dependant doesn't help carer	.72*
No meaningful relationship	.61*
Dependant is manipulative	.60*
Dependant is too demanding	.59*
No satisfaction from caring	.56*
Dependant's behaviour a problem	.54*
Dependant becomes agitated	.45
Carer feels angry	.44*
Dependant's behaviour upsetting	.41

FACTOR 3: INCONTINENCE
(% VARIANCE EXPLAINED 7.3)

Urinary incontinence at night	.83
Urinary incontinence during day	.83
Dependant is incontinent	.78*
Faecal incontinence at night	.75
Faecal incontinence during day	.74
Help required to toilet	.33

FACTOR 4: DEPENDANT'S CONFUSED BEHAVIOUR
(% VARIANCE EXPLAINED 4.7)

Difficulty with normal conversation	.78
Dependant is disorientated	.77
Dependant's behaviour upsetting	.68
Dependant wanders	.67
Dependant becomes agitated	.59
Dependant's behaviour a problem	.44*
Dependant is immobile	-.31

N.B. Minus sign indicates the more mobile the greater the problem.

FACTOR 5: CARER'S REACTION TO CARING
(% VARIANCE EXPLAINED 3.6)

Carer can't relax as worried re caring	.71*
Carer feels out of control	.69*
Carer experiences guilt	.63*
Caring threatens emotional health	.57*
Caring threatens physical health	.51*
Caring affects sleep	.45*
Carer feels angry	.40*
Carer feels tired	.40*
Caring strains family relationships	.38*

FACTOR 6: RESTRICTIONS ON SOCIAL LIFE
(% VARIANCE EXPLAINED 3.6)

Caring affects social life	.69*
Carer has no time for friends	.67*
Carer has no private time	.64*
Carer has few holidays	.62*
Carer feels tired	.43*
Caring threatens emotional health	.32*

FACTOR 7: FINANCIAL CONSEQUENCES
(% VARIANCE EXPLAINED 3.1)

Carer experiences financial problems	.73*
Caring lowers standard of living	.70*
Caring threatens physical health	.42*
Caring affects sleep	.37*

FACTOR 8: LACK OF FAMILY SUPPORT
(% VARIANCE EXPLAINED 2.8)

Family don't help much	.83*
Family don;t visit often	.81*
Carer feels angry	.34*

FACTOR 9: LACK OF PROFESSIONAL SUPPORT
(% VARIANCE EXPLAINED 2.6)

Professionals don't help much	.79*
Professionals don't understand carers problems	.78*

FACTOR 10: FAMILY RELATIONSHIPS
(% VARIANCE EXPLAINED 2.4)

Carer has no time for family	.77*
Caring threatens family relationships	.53*
Dependant is manipulative	.33*

FACTOR 11: OTHER PROBLEMS
(% VARIANCE EXPLAINED 2.1)

Carer experiences other problems	.87**
Help needed with housework	.39

* These variables are taken from column A of CADI

** A dichotomous variable indicating that the carer identified further problems to caring in the open questions.

__Table 5: Factor structures for stress factors__

All variables are taken from column B of CADI

FACTOR 1: CARER/DEPENDANT RELATIONSHIP
(% VARIANCE EXPLAINED 10.4)

VARIABLE	FACTOR LOADING
Dependant is unappreciative	.68
Dependant's behaviour a problem	.64
Dependant doesn't help carer	.60
Dependant is too demanding	.58
Dependant is manipulative	.57
No meaningful relationship	.56
No satisfaction from caring	.47
Carer feels angry	.37
Caring threatens family relations	.35
Caring threatens emotional health	.34
Carer feels guilty	.32
Carer has no time for friends	.32

FACTOR 2: CARER'S REACTION TO CARING
(% VARIANCE EXPLAINED 22.3)

Carer feels out of control	.61
Carer can't relax	.56
Carer feels guilty	.49
Caring threatens emotional health	.46
Carer has no private time	.45
Carer feels angry	.39
Caring threatens family relationships	.37
Caring threatens physical health	.36
Caring affects sleep	.33

FACTOR 3: PHYSICAL DEMANDS OF CARING
(% VARIANCE EXPLAINED 3.6)

Help required with personal care	.62
Carers feels tired	.49
Dependant is immobile	.46
Dependant is incontinent	.46
Caring threatens physical health	.45
Caring affects sleep	.41
Carer can't relax	.35

FACTOR 4: RESTRICTIONS ON SOCIAL LIFE
(% VARIANCE EXPLAINED 3.5)

Carer has no time for friends	.63
Caring affects social life	.62
Carer has few holidays	.45
Carer has no private time	.36
Caring threatens emotional health	.35

FACTOR 5: LACK OF FAMILY SUPPORT
(% VARIANCE EXPLAINED 3.0)

Family don't help much	.80
Relatives don't visit often	.66

FACTOR 6: LACK OF PROFESSIONAL SUPPORT
(% VARIANCE EXPLAINED 2.0)

Professionals don't understand problems	.95
Professionals don't help much	.54

FACTOR 7: FINANCIAL CONSEQUENCES
(% VARIANCE EXPLAINED 2.1%)

Carer experiences financial problems	.73
Caring lowers standard of living	.61

It will be recalled from the literature review on models of stress that transactional approaches are underpinned by assumptions as to the central mediating role of subjective appraisals. Therefore, an event does not become an actual stressor until it is appraised as such by the individual concerned. Simply put the type of model predicated on such assumptions runs:

CIRCUMSTANCE ——————→ APPRAISAL ——————→ STRESS
(Potential stressor) (Actual stressor)

It is normally considered that two types of appraisal occur, a primary appraisal in which the potential stressor is seen as an actual stressor, and a secondary appraisal when coping resources are cognitively matched against the nature of the demand. Stress is only said to occur when there is an imbalance between the demand and the individual's perceived coping resources.

In operationalising these concepts in the present study, coping mechanisms were not measured and therefore the test applied is best considered as a partial one. However, the other three components of the model were included. The existence of a potential stressor was operationalised via the dependency scales together with column A of CADI and the factor analysis conducted resulting in 11 empirically meaningful factors (Table 4). These were termed **environment factors** in the LISREL model. The appraisal of these events was measured by column B of CADI and once again an independent factor analysis isolated seven empirically meaningful factors (Table 5), termed **stress factors**. The outcome measure, that is malaise, was operationalised via the MI and the factor analysis revealed that this scale is best considered as comprising of two sub-scales, one measuring psychological malaise and the other physical malaise. These were termed **malaise factors**.

If the transactional model of stress is adequate in explaining the outcome measure (malaise factors) then the model should run in the following causal order:

ENVIRONMENT FACTORS → STRESS FACTORS → MALAISE
(Carer exposed to potential stressor) → (Potential stressor perceived as stressful) → (Malaise results)

This was the model that was tested using LISREL VI. Whilst the basis of the modelling procedure used has already been described this will be briefly outlined again.

Within the LISREL model used the environment factors were taken as predetermined and are termed **exogenous variables**, with the variables which the model should account for (that is the stress and malaise factors) being termed **endogenous variables**. Causal paths emanating from the exogenous (environment) factors are termed gamma paths and those from within the endogenous variables are beta paths. Using a fully saturated model all of the possible gamma paths were allowed to run to all of the endogenous factors (both the caring specific stress factors and the general malaise factors) and furthermore, beta paths were allowed from the caring-specific stress factors to the general malaise factors, which were the outcome measures used. Covariation between the complete set of variables within each column was also permitted. The fully saturated model was then 'tuned' in progressive stages guided by the t values of the paths in the model and the modification indices of those omitted.

If the transactional model of stress is adequate in explaining the causal ordering then one would expect that the gamma paths from the environment factors would not run directly to the malaise factors (for example the path gamma 6,6 running from F6 to M2 in Figure 1, page 149) but that the gamma paths would run to the stress factors and then beta paths would run from these to the malaise factors (for example this is illustrated in Figure 1 by gamma path 1,1 from F1 to S1 and then beta path 5,1 from S1 to M1).

For clarity and ease of understanding the two models which were tested are presented in diagrammatic form in which arrows, the widths of which are linearly related to the size of their effects, are used to indicate the significant causal paths in each model. Figure 2 presents the model for psychological malaise and Figure 3 that for physical malaise. It should be noted that in each model an additional environment factor has been added. This variable (INT) is a measure of the intensity of care that the carer had to provide and was measured on a seven point scale running from constant day and night care to less than daily care. For interested readers the full numerical model is located in appendix ten.

The model for psychological malaise (Figure 2) is powerful, accounting for 47% of the variance, and an examination of Figure 2 reveals a number of striking and significant variables contributing to psychological malaise. Firstly psychological malaise is the result of a complex interaction of factors. However there is only one direct gamma path, that from F5 to M1, all of the other gamma paths being mediated via stress factors and subsequent beta paths to M1. In other words, with the exception of F5, environment factors do not result in psychological malaise unless they are also perceived as stressful. This is exactly as the transactional model of stress would predict. Furthermore, if the variables comprising F5 are examined (Table 4) it can be seen that the most important (those with the highest factor loadings) are themselves mainly to do

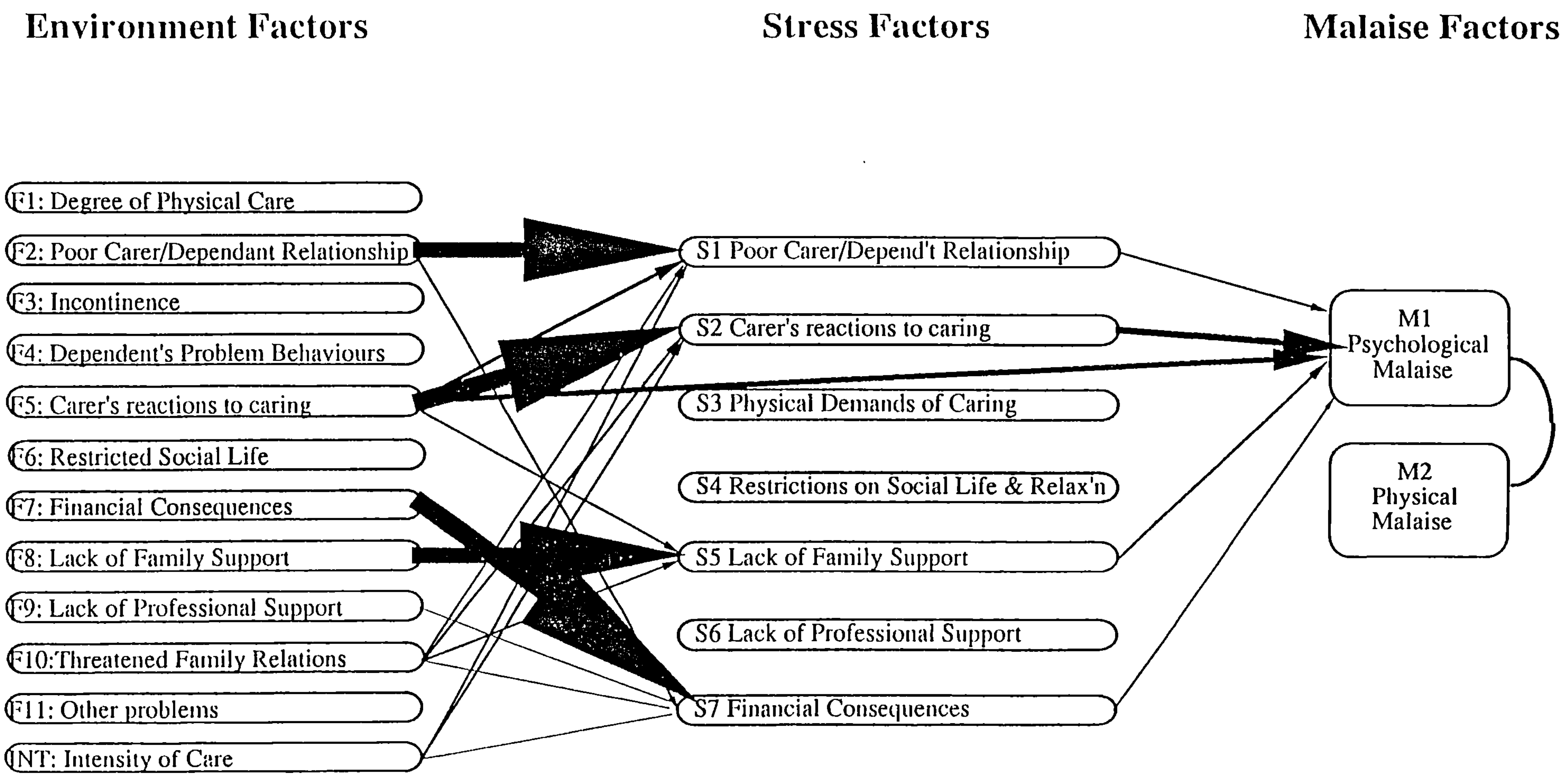
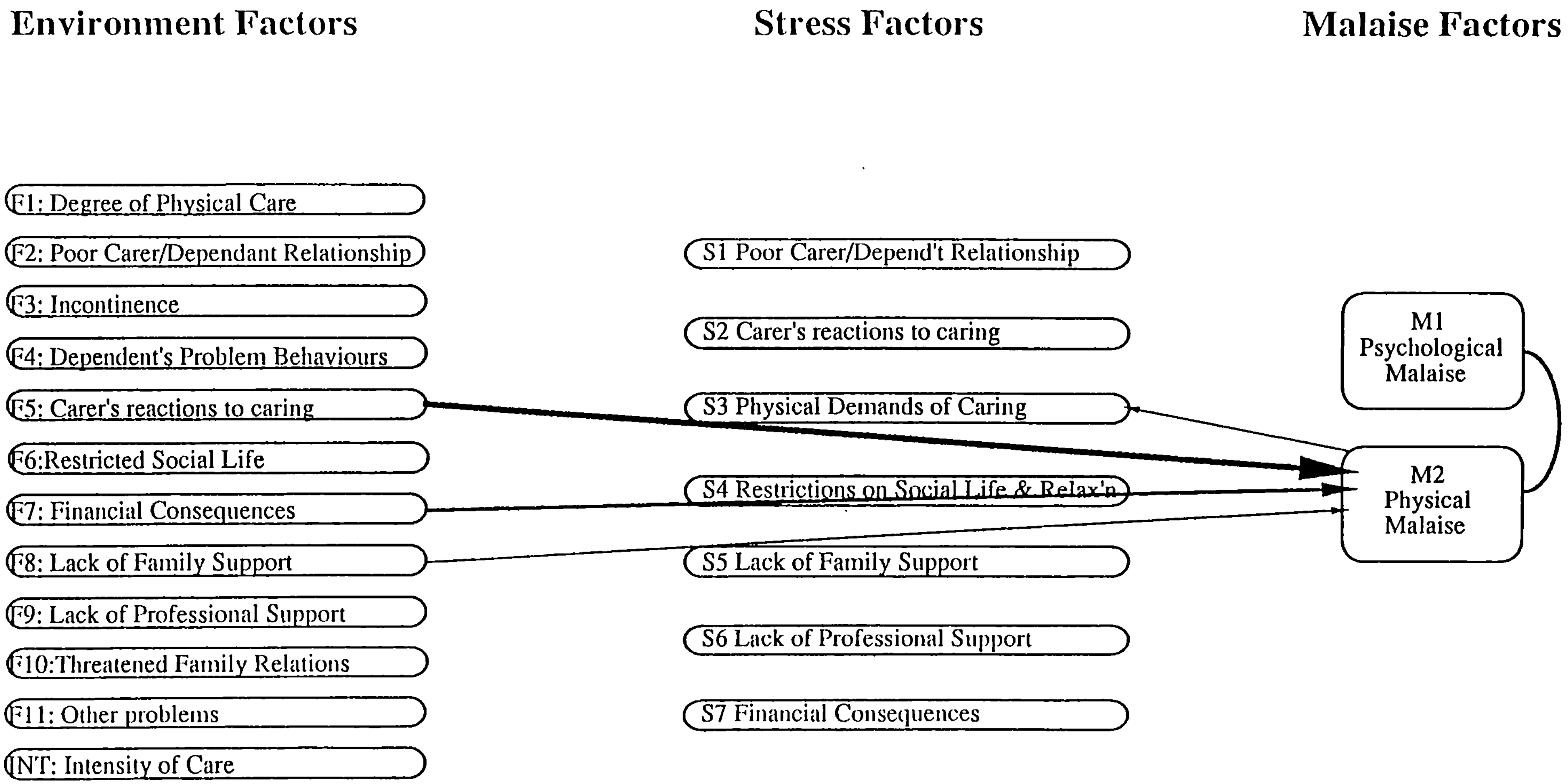

Environment Factors
Stress Factors
Malaise Factors
F1: Degree of Physical Care
F2: Poor Carer/Dependant Relationship
F3: Incontinence
F4: Dependent's Problem Behaviours
F5: Carer's reactions to caring
F6: Restricted Social Life
F7: Financial Consequences
F8: Lack of Family Support
F9: Lack of Professional Support
F10:Threatened Family Relations
F11: Other problems
INT: Intensity of Care
S1 Poor Carer/Depend't Relationship
S2 Carer's reactions to caring
S3 Physical Demands of Caring
S4 Restrictions on Social Life & Relax'n
S5 Lack of Family Support
S6 Lack of Professional Support
S7 Financial Consequences
M1 Psychological Malaise
M2 Physical Malaise

Figure 2


Environment Factors
Stress Factors
Malaise Factors
F1: Degree of Physical Care
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S1 Poor Carer/Depend't Relationship
S2 Carer's reactions to caring
S3 Physical Demands of Caring
S4 Restrictions on Social Life & Relax'n
S5 Lack of Family Support
S6 Lack of Professional Support
S7 Financial Consequences
M1 Psychological Malaise
M2 Physical Malaise

Figure 3

with emotional responses to the caring situation and therefore it is conceptually quite reasonable that they should have a direct effect on psychological malaise without firstly being appraised as stressful. This model therefore provides convincing empirical validation for the transactional approaches to stress. This however is not the only interesting and significant finding. Equally important is the nature of the variables operating to produce stress. It will be seen that some variables have no significant effect at all (those with no arrows running from them) and these are F1, F3, F4, F6, F11, S3, S4 and S6. Thus it would seem that the degree of physical care required, the levels of incontinence, the dependant's confused and difficult behaviour and a restricted social life, even when these are seen as stressful, have no part to play in the production of psychological malaise. Such malaise has far more to do with the carers reactions to caring (especially constant worry, feeling out of control and experiencing guilt), the perceived nature of the carer/dependant relationship, the perceived adequacy of family support and the financial situation. These findings are of particular significance in relation to interventions aimed at alleviating carer stress and their implications for respite care are considered briefly at the end of this chapter and in more detail in the concluding chapter. The extent to which the results of these quantitative analyses are consistent with those from the qualitative data are also addressed later in this chapter.

Prior to this however, an examination of the model for physical malaise (Figure 3) is required. It will be seen that this also reveals a number of interesting findings.

Firstly, it is a less powerful model explaining only 20% of the variance. This in itself is not surprising as the predictor variables used were caring specific and physical malaise is likely to be influenced by many extra-caring factors. Futhermore, this is wholly consistent with carers' subjective ratings of their own health when it will be recalled that emotional health was rated as being both worse and more influenced by caring than was physical health. Secondly, the model is far less complex and more direct. Thus there are only three significant paths and all of these are gamma paths running directly from the environment factors to malaise. It therefore seems that physical malaise resulting from caring is influenced directly by events themselves, without these having to be seen as stressful. These widely differing causal paths operating in the production of psychological and physical malaise add further validation for the two factor structure of the MI; that is, it seems that psychological and physical malaise are indeed separate effects with differing causal mechanisms.

On the other hand, there are also some surprises in the model. One would perhaps expect that physical factors, such as the amount of physical care required, would be influential in the production of physical malaise, but as with psychological malaise this is not the case. Indeed the same main variables, especially the carer's reaction to their situation, are influential in producing both sorts of malaise, albeit in one model their effects are mediated via perceived stress whereas in the second these effects are direct.

It will also be seen that in Figure 3 there is an arrow running back from physical malaise to the perceived stressfulness of the physical demands of caring. This is a modification factor produced by the LISREL model. LISREL computes modification indices for all paths not specified in the original model and paths with high indices are those which would improve the model if indeed they had been included. The inclusion of this significant modification factor is of interest as it indicates that the physical demands of caring are not seen as stressful until physical malaise is actually present. That is, physical factors are not significant in the production of physical malaise and indeed only become stressful after physical malaise is already apparent.

To summarise, convincing empirical validation for the transactional model of stress (at least in the production of psychological malaise) was provided and the relative insignificance of physical and mental fraility and dependence was highlighted. This finding is consistent with much of the recent literature reviewed in Chapter Two. From the analysis it seems that both psychological and physical malaise result from similar variables operating in differing ways. Central among these is the carer's reaction to caring (particularly guilt, constant worry and feeling out of control), the nature of the carer/dependant relationship (particularly strained when the dependant is unappreciative and exhibits difficult behaviour by not helping, being overly demanding and manipulative: see factor loadings for Factor 1 Table 4), the perceived adequacy of family support and the carer's financial situation. The extent to which such factors were apparent from analysis of the qualitative data will now be considered.

6.3 The results of the qualitative analysis

In triangulated research designs it is considered to be the qualitative data that hold the interpretation of the results together (Jick 1979), and Mitchell (1986) contends that quantitative and qualitative results are best brought together by a process of conceptual synthesis. This section details the results of qualitative data analysis and attempts a conceptual synthesis of both types of data.

Fortunately, the qualitative analysis was completed three months prior to begining the Lisrel analysis thus removing any suspicion in the author's mind that the qualitative categories formed had been in anyway subconsciously influenced by the factor analysis. Thus the congruence between the results of the two analyses described below adds significantly to the validity of both.

The qualitative data came from three main sources and addressed two main issues concerning the additional problems, and also the satisfactions, of caring. The three main sources were responses to open questions on both the additional problems and the satisfactions of caring, together with further unsolicited comments written onto the questionnaire itself or in letters accompanying the questionnaire. In describing the results of this analysis the additional problems of caring will be dealt with first. This separation of the problems and satisfactions of caring is for ease of presentation only as it will readily be seen that there are strong conceptual similarities between the two domains which suggest that they are often inextricably linked.

That, in addition to the 30 problems listed in CADI, 64% of the sample gave a total of 657 problem statements in response to the open question or in their letters provides further evidence of the diverse and pervasive effects of long-term care on carers' lives. Whilst these additional problem statements were often not conceptually distinct from those in CADI they allowed for a degree of individual interpretation and indicated how apparently similar situations could create very different problems for individual carers. This highlighted the need for individual assessment in each case, an assessment which often seems to be conspiquous by its absence:

> "Case study after case study illustrates that professional consultation with them (carers) is very often non-existent. They are neither trained nor counselled and if support is offered at all it is very often on a take-it or leave-it basis with no attempt to provide a package which fits the expressed needs of the individual supporter" (Norman 1987, p.12).

This assertion found support in the present analyses, with only 25% of carers feeling that professionals understood their problems. Indeed of the 657 additional statements 22% (145 statements) were directly concerned with the nature of carer/professional interactions, the largest single category to emerge.

The area of greatest concern was that of professional attitudes which were described as ranging from 'indifferent' through 'uncaring' to 'downright aggressive'. It was clear that in many cases carers felt that their welfare was not viewed as a legitimate focus for professional attention, with professionals tending to see their role in terms of the dependant's needs. Furthermore, in conducting assessments of need, professionals often failed to take account of the carer's own knowledge and caring strategies, imposing instead their own professionalised paradigms which focussed on mainly instrumental activities. When this occurred carers felt doubly slighted in that not only were their needs ignored but also their opinions. In such cases the services and advice given were usually seen as irrelevant, and therefore either refused or forgotten.

Members of the medical profession came in for particular criticism because of their attitudes to the long-term sick and disabled. The words of carers themselves best illustrate some of the problems caused:

> "There is a total failure to see the carer's side of things, professionals are all for the rights of the patient/client, but what about us? There is no appreciation for the contribution of carers. The dependant gets all the sympathy and the carer all the work".

> "My criticism is with the local social services because it has no sincere philosophy in caring for either disabled nor the elderly. It is manned by 'assistants' and a clique. My dealings are with the Head Office and either I get what I want for my sister or she ends up on their doorstep. Logic and argument have long been accepted as a cul-de-sac in long-term arrangements and planning"

> " I've only seen a G.P. once in 10 years of caring. He was a locum who came one night after my desperate plea for help after my husband had been wandering for most of the night. His parting shot as he left was 'You look bloody awful, why don't you get some rest? ' ".

> "Doctors say there is nothing they can do for my wife, and take very little notice of what I say. I regret to say that I've found the suggestions made by social workers totally useless and a waste of time following up"

> "They're (professionals) not interested, its just a paid job to them. When you ask for help they say 'nobody asked you to do it'. When I came to help her 14 years ago, in her badly paralysed state, she had no G.P., no nurse, no home help, no social worker. This in a so called civilised country. It has opened my eyes to what society is all about and its total selfishness and it has left me disgusted"

Perhaps the most telling illustration was also one of the most concise:

> " A lot of people today just don't give a damn."

Additional criticisms about professional interventions included at a specific level the **failure to supply promised aids and services**, the **lack of information and advice** and a **paucity of regular respite**. At a more general level many carers felt exploited by a system which failed to provide any real **recognition or recompense** for their efforts:

> "My criticism is with the general failure to recognise the contribution of carers. I had to attend the local out-patient department recently concerning my own health and when asked my occupation I said 'carer'. The person who was filling in the form said 'What's one of those', so I explained my position. At the end she said 'I don't think that counts as an occupation, I'll put you down as unemployed".

> "I feel totally and cynically abused by the government that I am saving a lot of money. If my mother were to go into care this would cost the state over 200 a week. Yet all I get is 27.75p, this for constant care, 168 hours a week, a rate of pay of about 15p an hour per 24 hour day"

In the face of such criticisms a considerable reorientation of professional practice would seem to be required if carers are to receive the relevant support they require.

Three other categories together with that discussed above accounted for over 60% of the total additional problem statements. The next largest concerned the difficulties carers had in **addressing their own needs.** It was clear that for many carers their own needs had been almost entirely subordinated to those of the dependant. Carers in this situation expressed feelings of being trapped both physically and emotionally to such an extent that they had no life outside caring and experienced guilt if they even thought about themselves. These feelings were exacerbated when carers had no one other than the dependant to discuss their situation with and lacked a confidant with whom to share these emotions. Many carers expressed frustration at missing out on life and being unable to visualize any sort of future outside of caring:

> "The lack of freedom that the situation entails causes me to feel completely trapped and, at the age of 67, I despair of ever being able to live life again as an ordinary human being".
>
> " Resentment at being so trapped and then guilt at the resentment. I try to think positive to reduce the angst, but it's difficult when there is no one else to share things with"
>
> "I find it impossible to have a chat nowadays to iron out problems. If I try the older person just seems to close off and gets very defensive. As I've no one else to talk to the anger builds up. I find this **very** stressful" (Original emphasis)

The emotional responses of carers were further heightened when they perceived that the dependant was **manipulative, unappreciative or did not try to help.** Many dependants would refuse to accept help from anyone other than the carer and, whilst being manipulative and occasionally aggressive, were often very adept at giving an entirely different picture to outsiders:

> "He's bright when someone else calls but saves all his most difficult, worrying and aggressive behaviour for me. As a consequence there's a tendency for outsiders to say there's nothing wrong with him"

> "I feel trapped and resentful and insecure. He is so arrogant and thinks only of himself. I am the first one he gets on to constantly about small things"

> " My wife is capable of doing certain small things for herself, but instead of concentrating on these and trying to improve them she spends hours each day moaning about what she can't do. I find this attitude of mind very <u>frustrating</u> and I feel that other members of the family have stopped trying to help for this reason" (Original emphasis)

In these sorts of circumstances carers found few satisfying aspects to their role, and yet when carers felt appreciated and dependants reacted less negatively then caring was far less onerous:

> "I find no satisfaction in caring as the cared for has forgotten what 'please' and 'thank you' mean. They are no longer in her vocabulary. This may sound trivial to some people but I would appreciate the odd 'thank you'"

> "Humour is an ingredient that can lighten the burden of caring to an amazing degree"

The last major category to emerge from the analysis of the additional problem statements concerned the fear of the future, which caused anxiety and a feeling of pessimism:

> "After such a long period of caring (20 years) the frustrations which arise when one realises that, in addition to getting older, the situation can only get worse"

> " Each year it gets a little bit harder, a little bit worse, a lot more soul destroying"

> "When will it end?
> How will it end?
> What traumas lie ahead before it ends?
> HOW WILL <u>I</u> END? (Original emphasis)

Also, many carers not only took responsibility for the dependant but had other family commitments, which they often felt they were neglecting. Even when the family was clearly supportive carers still felt guilty at neglecting their needs:

> "When all my time is given to caring for someone as old as my mother (in her 99th year), I have little time and energy for other things. My husband is a great support; I couldn't manage on my own, but at the same time the situation is unfair to him. He is 78 and during the whole of his retirement we have had very little social life and few holidays. FOR THIS I FEEL VERY GUILTY." (Original emphasis)

The major categories outlined above crossed boundaries of relationships and dependency needs and were apposite to all groups of carers. At a conceptual level there is a high degree consensus between these categories of additional problems seen as stressful and the factors isolated as being stressful in the causal model. Particularly relevant are the carer's reactions to caring and the guilt, anger and frustration that can arise, together with the problems caused by a dependant who is unappreciative, does not help and is manipulative, these variables reinforcing one another in both the qualitative and quantitative analyses. Similarly, the stressful nature of the financial burdens of caring were apparent in both analyses. The nature of professional interactions with carers was isolated in the causal model but did not emerge as a significant contributor to stress. This was not the case with the qualitative data where difficulties with professionals emerged as the largest single category. This suggests that perhaps such considerations were not adequately operationalised by the questions in CADI. Nonetheless the congruence between the stressors isolated from two very different types of analysis begins to achieve the sort of conceptual synthesis suggested by Mitchell (1986).

As highlighted in Chapter Two the literature on caring, until quite recently, has had very little to say about possible sources of **satisfaction**. After having conducted the analysis of the difficulties of caring it was tempting to conceptualise caring in purely negative terms. However, despite the high levels of stress and obvious problems experienced by the present sample, 60% identified sources of satisfaction, providing 546 supporting statements. The content analysis of these statements resulted in 14 conceptually distinct categories but, as with the problem statements, four major categories accounted for about 60% of all statements. These will now be discussed in more detail.

The largest single category provided a clear indication that a for many carers satisfaction was gained primarily by the **act of giving to the dependant**. This occurred at two levels. At its most basic, satisfaction was related to the **giving of simple pleasures** that provided some joy to the cared-for:

> "Seeing her smile, her pleasure when things go well, my pleasure when she is contented. It's a joy to help her, to always be near her bringing her a cup of tea in the mornings"
>
> "On seeing my wife pleased at being able to arrange some rare treat, such as going shopping, taking a picnic to the park or going to the seaside. If we're lucky we might manage this once a year"

At a more abstract level satisfaction was achieved by **maintaining the dignity and self-esteem of the dependant**:

> "I get great satisfaction from helping to keep my husband's remaining faculties intact so that visitors and children regard him as intelligent and treat him as an ordinary human being"

The second main source of satisfaction indicated that for many carers there was no real alternative. This category can be considerd from two standpoints. The first and dominant reason highlighted the totally unacceptable nature of any sort of institutional alternative:

> "A few of my mothers contemporaries are in nursing homes that we visit. I'm determined that she is **NOT** to go into a nursing home or hospital as I **KNOW** the neglect that occurs when staff are overstretched" (Original emphasis).
>
> "Great satisfaction because I know that care in hospital would be much worse than care at home and this would apply to the nursing homes I've investigated" (Retired consultant).

When the carer was forced to institutionalise the dependant this often caused extreme guilt, even if standards of care were considered high:

> "Mum is now in a residential home. However the feelings I experience at her being there are ones of great guilt and terrible sadness. I vowed never to let this happen but things were just too difficult. I feel as though a part of me is missing and I will never forgive myself even though she is well cared-for and in beautiful surroundings"

The second sub-category in this group of statements did not indicate such obvious reluctance to consider institutional care but still effectively left the carer with no choice as it was considered that no one but the carer possessd the type of intimate knowledge of the dependant that was required to provide adequate care:

> "The knowledge that in a one to one situation he is getting the sort of care that only I can give him"
>
> "The satisfaction is great knowing that she is in the care of someone who understands her 'funny little ways'"

This category in many ways reflects aspects of the problem statements where it was considered that the carer often had knowledge to which professionals failed to pay due cognizance, a fact which was seen to detract considerably from the services and interventions offered.

The third main source of satisfaction was a direct mirror image of one of the categories from the analysis of the problem statements and was concerned with the carer **feeling appreciated and valued for their efforts**. Such appreciation was most valued when it came from the dependant, when even the perception of appreciation appeared to be sufficient. However in circumstances where the dependant was unwilling or unable to express appreciation then such sentiments were valued from significant others with whom the carer had contact:

> "The fact that he has a lovely disposition and is appreciative of the help I give him more than compensates for any extra care he might need"
>
> "When I put mum to bed she always smiles and says 'you're so kind'. After all the stresses and strains this can always bring a tear to my eye"
>
> "The impression that she appreciates my caring even after 10 years with Alzheimers disease"
>
> "Compliments from friends and relatives - I never get any from the patient"
>
> "Someone saying 'well done' (very rare)"

The last main source of satisfaction indicated a more **direct gain** for the carer and can be divided into three sub-categories.

At the most fundamental level caring met **basic psychic needs for protection from negative self perceptions** such as guilt or the desire to feel wanted and needed. At a much higher psychic level caring undoubtedly achieved what has been termed **existential** significance (Davies 1980a), a way of providing life with a purpose and a mechanism for a better understanding of the human condition:

> "A development of sensitivity and awareness of people. A depth of experience and the development of personality, resilience and stamina in the face of adversity; it's like the maturing of a fresh wine; it takes time and there are no short-cuts"
>
> "An enhanced awareness, new perspectives on life, feeling that I am a very capable and caring person, developing neglected sides of myself"

Somewhere in between these extremes caring enabled some carers to develop outside interests or new skills that added to their lives:

> "Since becoming a carer I've met a lot of interesting people. I have become involved in a number of charities through our daughter. My life is better as a carer than it was before"

It was therefore clear from the analysis of the sources of satisfaction that caring can no longer be viewed in purely negative terms. Furthermore, it was apparent that satisfaction was unrelated to the dependency characteristics of the cared-for and that in some respects experiencing satisfaction could reduce stress levels amongst carers (Nolan and Grant 1989b). This provides additional corroborating evidence for the limited importance of dependency needs in determining both the stresses and the rewards of caring. Indeed very few of the statements on either the problems or satisfactions of caring even mentioned physical dependency. Where it was mentioned it was usually in two main contexts, either the tiring nature of care or else when the carer had injured themselves (usually a back injury caused by repeated lifting). Mental frailty was mentioned more often and for a small number of carers was a major problem. However problems to do with mental state usually surfaced in relation to manipulation and a failure to try on the dependant's behalf.

Thus, from a consideration of the causal modelling and the qualitative analysis of both the problems and satisfactions of caring a conceptual synthesis of the type recommended by Mitchell (1986) when bringing together disparate results from a triangulated research design is possible. It seems that the major concepts underpinning both the stresses and rewards of caring relate in particular to the carers' reactions to their situation (especially guilt, feeling out of control and the constant demands of caring making it difficult to relax or pay attention to individual needs), the nature of the carer dependant/relationship (particularly in terms of appreciation, help and manipulation) and the extent to which both family and professional interventions are seen as appropriate and adequate. It is clear that carers feel that they have **'expert knowledge'** which is often ignored and that in the absence of such knowledge it is difficult for anyone to provide an adequate level of care. These findings have significance for the provision of respite care to carers and this is discussed next.

6.4 The implications of the survey results

As was suggested in the introduction to this chapter it is felt that the survey results have relevance far beyond the respite study which they were meant to inform. They add, for example, to the growing consensus concerning the relative unimportance of dependency factors in our understanding of the stresses of caring (Zarit et al 1986, Noelker and Townsend 1987, Cox et al

1988, Morris et al 1988, Motenko 1989) which in turn has policy implications for the targeting and delivery of services. The results also contribute to the emergent literature on the satisfactions of caring (Lawton et al 1989b, Motenko 1989) and at a theoretical level extend many of the embryonic concepts in this area (Nolan and Grant 1989b). From a methodological and service delivery perspective further work is being undertaken to develop CADI and a complimentary instrument CASI (The Carers' Assessment of Satisfaction Index) as a research and assessment tool and the debate as to the unidimensionality of the MI has been reopened (Grant et al 1990).

Some of these issues are addressed further in the concluding chapter and others have yet to be fully considered. It is the intention of this section briefly to outline the main implications of the postal survey for the respite care evaluation.

The original purpose of the survey was two-fold, to identify the common stresses and rewards of caring and their relevance for the provision of respite care, and to provide an empirical test for transactional theories of stress.

In considering the latter area the survey allowed for a partial test for transactional models (partial as secondary appraisal of coping resources were not included) which nonetheless supplied convincing evidence for the centrality of subjective appraisal of events in the production of care-related stress and malaise. This in turn validates the pluralistic approach to evaluation which uses subjective interpretations as the major determinant of the success of a service.

In isolating, from both the quantitative and qualitative data, those factors best predictive of care-related stresses and satisfactions a number of pointers, important for the effective delivery of respite care, emerged.

Firstly, carers identified the tiring and tying nature of care and the lack of respite as a problem. Therefore respite care in itself has the potential to meet a keenly felt and widely expressed need. On the other hand many carers voiced deep dissatisfaction with the thought of institutional care, a fear apparent from previous work (Davies 1980a, Worcester and Quayhagen 1983, Ungerson 1987) and considered that they possessed knowledge, the lack of which meant that the cared-for would receive poor care. Furthermore, guilt was a pervasive emotion in caring and often both the stresses and rewards of caring hinged upon the nature of the carer/dependant relationship. The implications of the results of the postal survey for the provision of respite care are discussed briefly below. More detailed discussion is provided when the results of the interview and observation stages have been presented.

Attention will initially be turned to some of the potentially negative implications of the findings for respite care. The above would suggest that there may be some resistance to institutionally-based services unless the carer is happy with the institution in question. Even then guilt might be anticipated, and as the literature on respite care revealed this is an area which is often not adequately appreciated by staff. Furthermore, if admission for respite care causes resentment in the dependant and this adversely affects the carer/dependant relationship, then once again respite care is likely to cause problems.

As regards assessment of need, the literature on respite care indicated that eligibility criteria were often in operation, usually based on the dependency characteristics of the cared-for. The marginal importance of physical dependency in predicting stress suggests that if such a system is in operation then many carers may not be assessed as needing the service when in fact they do. This concerns the issues of access outlined in the evaluation guide.

It is also apparent that service interventions which ignore the carer's needs and opinions can add to rather than reduce stress and this would suggest that if respite care is to be effective then due attention must be paid to these factors when respite care is offered. The wider literature would suggest that this is often not the case however and that service interventions often 'ride roughshod' over the complex carer/dependant relationship and fail to take notice of the carer's 'expert' knowledge (Lewis and Meredith 1988a,b), focussing instead on the instrumental and often least stressful aspects of care (Gwyther and George 1986, Bowers 1987). This lack of awareness from professionals (Jowell et al 1987) and the sensitivity of carers (Davies 1980a) can lead to an increase in carer stress (Clark and Rakowski 1983) and perhaps risk inhibiting them from seeking further help (Bell et al 1987, Corbin and Strauss 1988), all of these points being well demonstrated by carers in the present survey.

Considered from this standpoint respite care which is not sensitive to these important issues is just as likely to increase as to relieve carer stress.

From a more positive perspective carers in the present survey identified a number of needs which a well planned respite service could meet.

More information on a variety of topics was clearly required, as was skills training, for example in lifting techniques. Furthermore, there was a clear need to provide emotional support at all the levels previously identified, from acting as a confidant or just a sympathetic ear to dealing with a range of complex emotional reactions. Regular respite, particularly on a rota basis which involves repeated contact, has the potential to provide just such support. Obviously if the service is to meet these needs then they must be recognised as a legitimate and important component of the care provided. To operate such a system successfully would also require a sensitive assessment of need based on a truly holistic approach which overtly sought out and valued both the carer's and the dependant's wider needs and opinions.

In relation to the respite evaluation the survey is considered to have achieved its stated aims. More confidence is placed in both the pluralistic evaluation adopted and in the adequacy and empirical relevance of the sensitising concepts unperpinning the evaluation guide.

The next chapter will report the results of the interviews with the four main stakeholder groups.

CHAPTER SEVEN

ROTA BEDS: THE VIEWS OF THE MAJOR STAKEHOLDER GROUPS

> "I really don't know how I'd manage without these breaks, I live for the two weeks when he's (father) in and after he's been out for about four weeks I find myself counting the days until he goes in again "

> "The main problem is the guilt I feel every time that my husband goes in for a fortnight. I don't want to upset the staff by telling them their job but they don't know him like I do and haven't bothered to find out by asking me"

> (Differing responses to rota beds taken from carer interviews)

This chapter reports the results of the 142 interviews undertaken with those carers, dependants and staff associated with the rota bed system. These data form the bedrock of the study, providing the subjective impressions and experiences of the principal actors (with the exception of the long-stay patients who were too frail for interview). The key issues from the evaluation guide, together with those highlighted in the postal survey, are addressed within the context of the rota bed experience. Implications of the results are signposted and will be more fully discussed in the concluding chapter.

The present chapter is therefore divided into a number of sections. The first briefly describes the sample interviewed and the following three sections provide an analysis of the perceptions of the carers, their dependants and the staff groups concerning the organisation and impact of the rota bed system. Due to the relatively small numbers in each of the samples actual numbers rather than percentages are used to describe sample characteristics.

7.1 Sample characteristics and caring history

(i) Carers

A total of 50 carers were interviewed in 42 separate interviews. Two carers were present at eight of the interviews. The vast majority were women (43), mostly daughters or daughters-in-law (21) or female spouses (16), with a small proportion of other female relatives (sister 1, niece 2, cousin 1) or non-kin (unmarried partner 1, neighbour 1). Of the men, most were husbands (5) with one son and one nephew. Of the dependants 24 were women and 18 men. The mean age of the carers was 67 years (range 46-87 years) and most had been caring for a substantial period of time (mean 8.6 years, range 8 months to 60 years) providing care to an elderly (mean age 82years, range 68-101 years) and frail group of dependants. The main disabilities of the elderly people were the result of cerebro-vascular accidents, musculo-skeletal disorders (mainly arthritis, fractures and falls), Parkinsonism and mental frailty. Most carers (31) became involved in the overt caring role following a sudden catastrophe and subsequent period of hospitalisation for their relative, whereas for others caring was the result of their relative's increasing dependency and frailty over a number of years. In all but one case the dependant was resident with the main carer.

There were high levels of physical and mental dependency and incontinence amongst the sample (see Table 6 below). This was reflected in the other services that the carers received, 40/42 having a visit from the district nursing services (from as infrequently as once a month to as regularly as twice daily, seven days a week), 18/42 receiving help from the social services (mostly home help or day care) and 4/42 employing private help, usually on an occasional basis to provide domestic assistance. In a small number of cases the statutory carer was clearly a second main carer and in a significant number of cases provided invaluable help and assistance. On the other hand for many carers there were obvious gaps in the statutory provision but, as will be highlighted later, many carers were reluctant to criticise the services they received and they found it very difficult to imagine what other forms of support would have been possible. Approximately a third of carers considered that they had good support from other family members who were either resident or lived in the locality; about half either had no family or their family lived a considerable distance away, whilst the remainder had poor and deteriorating relationships with their family. Very few of the carers considered that neighbours and friends provided direct practical assistance. Many of the carers were new to the rota bed system whereas others had been using it for five years or longer. In the table below both actual numbers and percentages are presented, the percentages being in parentheses. This convention is adopted in all subsequent tables in which the actual numbers are below 100.

Table 6: Dependency profiles: carers' assessments

(n = 42)

Activity	Completes alone n %	Help with part n %	Help with all n %
Washing	5 (12)	11 (26)	26 (62)
Dressing	7 (17)	5 (12)	30 (71)
Feeding	22 (52)	7 (17)	13 (31)
Toilet	5 (12)	4 (10)	33 (79)
Mobility	5 (12)	7 (17)	30 (71)
Bathing	2 (5)	0	40 (95)

<u>Incontinence</u>	Never	Occasional	Frequent
	n %	n %	n %
Urinary day	10 (24)	17 (40)	15 (36)
Urinary night	11 (26)	14 (33)	17 (40)
Faecal day	26 (62)	11 (26)	5 (12)
Faecal night	26 (62)	11 (26)	5 (12)

<u>Behaviour</u>	Never	Occasional	Frequent
	n %	n %	n %
Wanders	28 (67)	7 (17)	7 (17)
Disorientated	17 (40)	14 (33)	11 (26)
Embarrassing	26 (62)	7 (17)	9 (21)
Uncooperative	14 (33)	11 (26)	17 (40)
Poor conversation	18 (43)	7 (17)	17 (40)
Depressed	13 (31)	18 (43)	7 (17*)

* Four respondents could not make a judgement on this.

(ii) <u>Dependants and staff</u>

A total of 30 dependants, 35 hospital staff and 27 community nurses were interviewed. Of the dependants, 18 were women and 12 were men. As with carers their experience of the rota bed system varied with a number being on their first visit and others being 'old hands', having used the rota beds for many years.

The hospital staff comprised three consultant physicians in geriatric medicine, three nursing officers, five sisters, eight staff nurses, five enrolled nurses, seven nursing auxiliaries, two physiotherapists, an occupational therapy helper and a domestic. Interviews were of both the formal variety (that is by prior arrangement) and the informal and opportunistic. With those respondents at the two main study sites there was repeated contact. Some of the data from the staff questionnaires will be considered in this chapter and some in the subsequent one.

As already indicated the interviews with the community nursing staff were of a group format and in this manner data were collected from 27 community nurses covering seven main 'patches' within the study area. The vast majority were of sister grade, two were enrolled nurses, all had frequent contact with carers and were familiar with the rota bed service.

Having briefly described the respondent samples attention is now turned to their perceptions of the rota bed service.

7.2 Carers' views

As already indicated in Chapter Five the interviews with carers were, almost without exception, of uniformly high quality. The interviews generated data about caring in general as well as about issues specifically to do with the rota bed system. The majority of the interviews lasted about an hour and a half, the shortest being half an hour and the longest over three hours. Prompting was rarely needed, with carers responding frankly and spontaneously once the initial introductions were over. This has been the author's previous experience when interviewing carers (Nolan 1986). A number of important themes were raised during these interviews. Attention is turned first to general issues about caring. When reporting the prevalence of major analytic themes in these interviews the numbers quoted relate to their occurence in each interview situation (n=42).

(i) Carers' perceptions of their problems and satisfactions

To obtain an understanding of the potential benefits of the rota beds it was important to elict from carers the types of problems and satisfactions they experienced. Data from the postal survey had suggested that such problems and satisfactions were often related more to the nature of the carer/dependant relationship and the cared-for's reaction to dependency than to the actual physical demands of caring. This was borne out during the carer interviews. Many carers provided unprompted insights into the nature of their relationship with their dependant and those who were initially somewhat reluctant often opened up whilst completing CADI. For these individuals it seemed that when the problems were presented in a checklist format and the carer realised they were not alone in experiencing such emotions this provided a legitimizing stimulus to which they responded. The nature of the difficulties reported by the interview sample matched almost exactly those from the postal survey.

One of the most frequently voiced stressors, (19/42) and certainly the most problematic, concerned the extent to which the carer felt **manipulated** by a dependant. The nature and degree of manipulation varied, as did the degree of stress it was perceived to provoke. In certain circumstances perceived manipulation was very destructive to the caring relationship, particularly where such behaviour was seen as being deliberate and willful. Indeed, a number of carers went to quite elaborate lengths to verify that difficult behaviour was deliberate. One carer recounted how her father-in-law was incontinent a number of times during the day whilst at home but always returned from the day hospital dry. She was unsure if this was because the day hospital changed his 'paper knickers' or because he was continent whilst at the day hospital. However, she did not feel she could ring the day hospital to ask. In order to check out her suspicions she used to mark his underwear each time he went to the day hospital so that she could see if they had been changed. When she found that he always returned in the same underwear her suspicions seemed to be confirmed. The relationship subsequently deteriorated as a result. It did not occur to her that there may have been other reasons for her father-in-law's apparent continence when he was at the day hospital, perhaps due to more frequent toileting or more accessible toilet facilities.

This type of situation was further exacerbated when the dependant varied their behaviour according to the circumstances. One of the most negative situations was described by a daughter sharing the care of her mother with her sister. When the interviewee was providing care the mother would be totally uncooperative, not to say deliberately obstructive, refusing to wash, dress or even feed herself. She was described as being deliberately incontinent, and prone to swearing and bouts of physical aggression. Moreover, she would acuse her daughter of stealing her money. However when the interviewee's sister was providing the care the mother's behaviour would be entirely different and fully cooperative. Consequently the sister could not see the interviewee's problems, and often hinted that these were overstated.

A lack of appreciation and 'not trying' often co-existed with manipulative behaviour. When this occurred it further heightened feelings of anger in a number of carers. This sometimes seemed close to spilling over into more physical manifestations of frustration:

> "I can understand how people become aggressive and actually hit the person they look after. Sometimes mother just sits there demanding attention and wanting it there and then. I wouldn't mind so much but some of the things she could do herself if only she'd try. In any case no matter what I do it never seems good enough and she never says thank you. Things would be so much better if just once in a while at the end of a meal, she said 'Thank you that was very nice'."

On the other hand it was possible for carers to perceive the behaviour of possibly difficult and manipulative dependants in more positive and constructive ways. This was especially apparent when carers acknowledged the situation, confronted their dependant directly and made light of the situation, turning potential anger into humour:

> "Of course he becomes a bit 'demanding' now and again and I think if I let him he'd have me doing every thing for him. I can understand how he feels, it must very difficult having to rely on someone else all the time. But I don't let him get away with it and when I think he's going too far I say 'Anymore of that and you'll be on the street'. Then we have a good laugh and things are OK again."

> "He's always been like that, you know wanting his own way, and I don't suppose he's going to change now. So I deal with it the way I always do, by pretending not to hear him. This is something of a joke between us, and after a while he'll shout 'Have you gone deaf again?"

In terms of the coping strategies reviewed in Chapter Two such carers coped by dealing directly with the problem itself.

Alternatively other carers were able to reframe their perception of the event and thereby reduce its potential as a stressor. Thus if the carer was able to see difficult behaviour as part of the dependant's illness, and therefore not deliberate, then negative perceptions seemed far less likely. The following quote from a wife caring for her dementing husband illustrates this well:

> "Sometimes I could cry when I look at him now and think of the man he used to be. But you have to see the humour in things or else you'd go mad. The other day he was hitting out at me and I said 'What are you doing that for?' He said 'Because you keep kicking me, what's the use in having a good woman if she kicks you all the time'. Well what else could I do, I just laughed. I mean it's not his fault that he's the way he is, is it?"

This ability to reframe similar events either in the context of past behaviours or to perceive them as non-deliberate was important in determining their stressful nature and is wholly consistent with the transactional approach to the understanding of stress.

The nature of the carer/dependant relationship was another influential factor in determining the degree of perceived stress. Where there was a long history of a **good relationship** then carers perceived far fewer problems, even in the face of manifestly heavy caring demands. Conversely a **poor or fragile relationship** was soon exposed even by comparatively minor demands and in such circumstances behaviour was far more likely to be construed as demanding and deliberate, with the result that caring was all the more stressful:

> "I think the main difficulty is that he's my second husband and we married more for companionship than love. We'd only been married a couple of years when he had his stroke and suddenly not only was he not a companion, he was a burden. I looked after my disabled mother for 15 years, whilst raising a family and working at the same time. Now there's no doubt that was far more demanding, but I didn't see it that way because I loved my mother and all that entails."

These data serve to reinforce the conceptual framework of Phillips and Rempusheski (1986) outlined in Chapter Two, suggesting that carers often have an implicit set of expectations concerning their interactions with their dependant. This is based on the past history and their idealised beliefs about the nature of family interactions and expected behaviour. Where carers have a **normalised** view of their past relationship (one in which the strenghths and weaknesses are acknowledged but which remains positive overall) and when present interactions are consistent with this, then carers are more likely to be accepting of certain behaviours and less likely to adopt caring styles that revolve around the dependant conforming. Alternatively, if carers have a **stigmatised** (only negative perceptions) or **deified** (only see very positive perceptions) past relationship and if the stigmatised view remains or the deified relationship has been spoilt, then carers are less tolerant and have a greater expectation of conformity from the dependant.

The most pervasive of the difficulties expressed by carers (26/42) concerned their feelings of being **constantly on edge** and of being **unable to relax**, a finding again consistent with the postal survey. This was succintly described by a husband caring for his elderly wife:

> "I would say that the main problem is the feeling that I can't turn my back for a minute in case she falls and hurts herself. Even during the night I only get a catnap. She takes her stick to bed and when she wants something she knocks on the floor and I think 'Hello, there goes the deathwatch beetle again."

Allied to this feeling of being 'on call' were the restrictions placed on the carer's personal time and time available for their wider family. This was especially apparent when other family crises occurred to which the carer felt they should but could not respond. Thus one carer described how her daughter-in-law had had trouble with a recent pregnancy and how her son had asked her for help. However she had been unable to leave her mother and had been forced to refuse him. This had left her feeling both upset and impotent. The perceived neglect of other family members was a particular stressor in three generation households when carers often felt pulled between their parent and their own children:

> "It's my son I feel most sorry for. He's a teenager and is facing all the usual problems that teenagers have, but these are made worse by his grandfather. He feels he can't bring his friends home because of dad's behaviour and this restricts his social life. Worse than that is my own snappy temper. I get so on edge sometimes that I feel I take it out on John (son). He's a good boy really and deserves a mother who supports him more."

Also when carers had either just retired (or were about to) or their own children had recently left home, and they suddenly had to take on the caring role, things were more likely to be seen as stressful and difficult. One carer's husband was about to retire and this was causing increased tension in the household. Long-term plans for retirement had been made and whilst the husband had not made specific reference to how caring would disrupt these, his wife (caring for her 94 year old mother) was giving it considerable thought. This, in her own words, increased the guilt and resentment that caring caused.

That caring had no obvious end point and that increased frailty from the dependant was anticipated at a time when the carer was also ageing could assume major significance in many carers' minds. For one carer this was causing particular difficulties. She had married a man some years older than herself who was now in his early 70's and suffering from arthritis. It was becoming increasingly apparent to her that she might shortly be forced to choose between caring for her father and caring for her husband.

Perceived stress was further heightened if the wider family was seen to be **unsupportive** and if the carer felt that they were left to carry all the burden alone. This type of situation was exacerbated when relatives lived some distance away and failed to appreciate or acknowledge the efforts that the carer was making:

> "It's when my sister calls that things seem to get worse. She lives about 50 miles away and visits about once a month. Of course when she arrives he (father) perks up and is grand for the couple of hours she is here. Because he doesn't see her very often he's all over her, but he is never that nice to me. Then when I tell my sister of the strain I'm under she doesn't believe me. It makes me so cross, she never does anything but gets all my fathers affection."

All of the above difficulties are consistent with the findings of the postal survey and serve to reinforce the importance of the subjective rather than the objective determinants of carer stress. Indeed, physical dependency was rarely seen to be an immediate problem for most carers and a number indicated that initial problems of this kind were something to which they soon became accustomed.

One further major difficulty faced by a number of carers (11/42) related to a **lack of information**. That carers lack information is by now not a surprising finding, having been identified in much of the carer research reviewed in Chapter Two and further highlighted in the postal survey. More surprising, however, is the perceived lack of information amongst the present sample given that they were all service users with very high levels of support from community nurses and, to a lesser extent, social services.

When asked about their satisfaction with these services many carers stated that they were quite happy but upon closer questioning a number of areas in need of improvement were identified. Paramount amongst these was the need for service providers to give greater recognition to the carer's 'expert knowledge' of their dependant's condition and needs, a point which will be addressed in more detail later in this chapter.

Shortfalls were also apparent at the week-ends and during evenings when services were rarely available. Generally speaking however the satisfaction of the carer and the type of input they received were dependent upon the individual service provider's view of the reason for their visit. Thus where explicit recognition was given to carer's needs as well as to those of the dependant then the provider (most often a community nurse) frequently became a valuable source of support. On the other hand where the focus was on instrumental tasks then the carer usually saw the visit as of less use. Help from social workers and home helps appeared to be of marginal use, the interventions of the former group being treated with some suspicion:

> " The person I most value is the district nurse. She seems to understand my problems, perhaps because she has to deal with her (mother) much as I do. Not only does she provide practical help but she'll sit and listen. Not like social workers, they came prying and poking into my business, wanting to know everything and then all they did was suggest some aids that were a waste of time anyway".
>
> "I don't really know why she (district nurse) bothers to call. She comes once a week to wash my wife and then she doesn't arrive until 11 o'clock. She's only here about 15 minutes, whoosh, whoosh, in and out like a jet plane. I wouldn't miss her if she stopped coming".

When asked what other services they would like to receive many carers found it very difficult to conceptualise a range of services outside those that they were already receiving, a finding consistent with previous work (MacCarthy et al 1989, Caldock 1990). This has important implications for services such as the rota beds which, as will be highlighted below, seem to rely on carers in receipt of the service approaching them if they have a problem.

Despite the problems faced by most of the carers in the interview sample many of them, as in the postal survey, found elements of satisfaction which were conceptually similar to those in the AOC sample. Thus in 29 of the 42 carer interviews some element of satisfaction was expressed. These related to the continuity of a loving relationship, the reaffirmation of marriage vows, a feeling of providing the best care possible, of feeling appreciated for their efforts and of repaying past kindnesses. What was also clear was that for many carers, both their problems and satisfactions were strongly influenced by the nature and degree of the perceived choice they had been able to exercise when entering into the caring role. As already signposted about 30 carers had entered the overt caring role at a time of crisis, following the hospitalisation of the dependant and their experiences at this time appeared to influence their future perceptions. It was apparent that professional (mostly medical) perceptions of their ability and willingness to manage were often at variance to those of the carer. Medical perceptions seemed to revolve largely around notions of physical dependency and functional ability in the dependant, whilst those of the carer focussed on relationship issues. As a consequence carers who wished to take a very frail dependant home were often advised not to, whilst others (particularly children) were expected to take a parent home despite the fact that they might not wish to. These types of situation evoked a variety of responses from carers.

Some appreciated being told that they could not manage as this reaffirmed that it was their choice when they decided to anyway:

> "Of course I didn't have to take her (mother) home. In fact the doctors advised me against it. But I knew I wanted to and having reached that decision everyone was very good and I got all the help I needed".

Conversely others considered that the doctor had overstepped the mark and was interfering in decisions which were not his to make:

> " This consultant chap told me that I couldn't take her (wife) home and that I'd have to put her in a nursing home. I said 'who the bloody hell do you think you are? I've been married to her for 44 years and you're not going to tell me where's the best place for her'".

For children who had voiced doubts about their ability and willingness to take a parent home there often appeared to be little choice in the matter. One carer described how she had been asked to come and see the consultant and then been 'given a good telling off', after which she felt obligated. Despite the relatively good functional ability of the mother in this case and the fact that she did not live with the daughter, the situation was one of the most fraught that was encountered during the carer interviews:

> "I knew as soon as I started that things could only go from bad to worse. We'd never been very close anyway but I was surprised how, in just a couple of days, I could grow to almost hate my mother".

These considerations have importance for respite care because, as will be illustrated shortly, rota beds were sometimes used as a 'carrot' to encourage reluctant prospective carers to take on the role. Furthermore they provide pointers as to the implicit, and sometimes explicit, eligibility criteria operating when services are offered. Moreover the reduced length of stay and faster throughput rates in acute care wards are likely to result in increased pressure being placed on family members to adopt a caring role. The implications of this will be discussed more fully in the concluding chapter.

Having outlined the problems and satisfactions of the carers interviewed, attention is now turned to their thoughts and experiences of the rota bed system and the extent to which it helped ameliorate the difficulties they experienced.

(ii) Carers' perceptions of the rota bed service

Carers had a range of different experiences of the rota beds. Some were 'first time users'; others had been using the system for a number of years. Some had been offered the service immediately upon taking on the caring role; others had been gradually introduced via the holiday bed system and others had been unaware of the existence of the service until their situation was near to collapse. This variety provided for a range of differing insights into the rota bed system.

However, despite this variation the benefits of the system seemed almost universal and, with a few notable exceptions, the rota beds provided an invaluable service to many of the carers using them.

Over half of the sample interviewed (27/42) considered that caring would have been intolerable without the rota beds, that they would probably have had to relinquish their caring role and so institutionalise their dependant. Such individuals variously described the system as a 'godsend', a 'lifeline', 'absolutely vital'. For the majority of the others the system was also greatly appreciated and they considered that its withdrawal would have resulted in a rise in perceived stress and a reduction in their own quality of life. However for many carers the benefits were accompanied by feelings of **guilt** and for some this proved more stressful than having the dependant at home. Indeed guilt proved to be one of the major problems caused by the rota beds.

For the majority of carers for whom the rota beds were a positive asset the most frequently cited benefit was the **break** provided. More often than not this period was used to **recharge the physical and emotional reserves** so that they were better able to continue in their role. This was reflected in a variety of ways: relief from the constant demands of caring, not feeling constantly on edge, an opportunity to get a good night's sleep, and so on. This for some was sufficient. Many others used the break as an opportunity to **complete domestic tasks** which had to be left partly done whilst the dependant was at home. For others it represented a chance to have some **life outside their caring role**, sometimes to take a holiday or have some sort of social activity. Many carers in three generation households described the qualitatively different atmosphere which resurfaced during respite periods. These perceived benefits are consistent with those described by Tyler (1987, 1989) and also reflect many of the problems identified by carers during the interviews. However they are also salutory as they describe what for most of us are taken-for-granted events, which had become luxuries for the carers interviewed.

Some carers (6/42) felt that their **relationship** with their dependant improved as a result of the break, whilst others (5/42) considered that their dependant's **physical and mental** condition was better when they returned home. Indeed many carers (14/42) saw the benefits of the rota beds as much for their dependant as for themselves. This was an important factor in reducing the guilt which many of the carers experienced. Therefore if carers considered that respite care was to the advantage of the dependant then they were less likely to feel selfish. The fact that respite care was in a hospital meant that there was access to nursing and medical care. In rationalising the admission some carers saw it as an opportunity for an **assessment of their dependant's condition** and this provided a **legitimate** reason for care, other than their own need for a break. Other carers felt that the service provided dependants with the opportunity to **mix with peers**, a perceived benefit of respite care also previously described (Luck et al 1988). Indeed numerous dependants were felt to have developed good relationships with staff and other respite patients so that the admission actually became a positive event in their lives. This was seen to provide a **desirable** reason for the admission. As will be discussed in detail shortly factors such as these were also crucial to the dependant's perception of the rota beds.

The perceived **reaction of the dependant** was a crucial variable in the carer's acceptance of respite care as it did much to reduce or heighten the guilt which many carers experienced. Not all the dependants were seen to enjoy the experience. Many carers (10/42) describing the boredom, lack of privacy and change in normal routines that admission to an institution caused. This sometimes resulted in increased confusion amongst the mentally frail or a deterioration in mobility and continence in others. Furthermore, contact with heavily dependent long-stay patients proved depressing for some dependants. Notwithstanding these drawbacks the advantages of the break provided were still seen to outweigh the disadvantages for most carers.

Only a small number of carers (5/42) saw the rota beds as providing an opportunity for receiving information, counselling or training. This was for a number of reasons. Firstly, despite the fact that over half the carers made frequent visits to the hospital most had relatively little contact with staff. For those who did not visit the only contact they often had was when they took or collected their dependant. This was not necesarily seen as a bad thing. Staff were often described as helpful and approachable and carers considered that if problems arose they could approach the staff or telephone them, even between admissions, a finding again consistent with those of Luck et al (1988). Others felt that there was little need for contact with the staff other than that which they already had. Some carers had, over the years, established a very good relationship with the sister at the unit and saw her as someone to whom they could turn for advice and information. Thus, where contact was established this seemed to be beneficial. However, this contact was either initiated by the carers or else by the staff, when they perceived that a problem existed. This left a hiatus for carers who did not like to make the contact and for whom staff perceived no problem. Such individuals were often deferential or long-suffering and, as a result, frequently overlooked.

It was clear that these carers would have valued more information and contact. Some had not seen anyone since their dependant had started to use the rota beds. Many of these individuals felt it was important at an early stage to see how their dependant was settling in and to pass on to staff the expertise they clearly felt they possessed. Futhermore, the consultant medical staff rarely saw carers once they started to use the system, unless the nursing staff felt it was necessary. At least six carers voiced a strong desire to see the consultant as they saw this as one of the main benefits of the rota beds and wished to discuss their dependant's condition and future prognosis. It seemed that there was a place for a detailed assessment involving all carers at the onset of the rota bed use, with reviews at regular intervals. Whilst this frequently occurred on an informal basis, and there was an undoubted exchange of information between staff and certain carers, it was by no means universal.

There were a number of expressed drawbacks to the rota beds which reduced the undoubted benefits for the vast majority of carers. These can be considered under two broad headings, one concerned with the manner in which the system was organised and the other to do with factors influencing the acceptability of the rota beds.

A number of these difficulites were to do with the administration of the system and would be difficult to overcome. Carers usually received their dates for the entire year in advance. Whilst this allowed for forward planning any alteration to the rota could then occasion problems. Moreover, the dates given did not always fit into a pattern the carer would have wished for. This was particularly true when the carer had young children or a spouse who worked and would have liked their holiday at the same time as the rest of their family. For others there were key events during the year when a break would have been most valued. A number indicated that they would have been prepared to have fewer respite admissions if these dates could have been given. Furthermore, because the respite admission constituted 13 days rather than 14, this made it impossible for certain carers to take a fortnight package holiday.

Emergencies were also a cause for concern and carers felt particularly vulnerable at such times, considering that the respite system was **not flexible enough** to respond to a call for a break 'on demand'. One carer described how her daughter had broken her arm in a fall at school and this had required hospital admission. She would have dearly loved a break at this time but did not think this was possible. Yet, most of the units operated a crisis bed system, of which many carers were unaware, despite the fact that such knowledge would have filled this perceived gap in service provision.

In terms of the administration the main expressed concern was the need for **more frequent admissions**. Carers described how, after about four weeks, they were reaching the limits of their tolerance and that the last two weeks prior to the respite admission were very difficult. As a result by the time the admission came around many were physically and emotionally drained. Consequently, it took most of the first week for them to get back on a even keel before they could really start to gain a benefit from the break. It seemed that a rota of two weeks in and four weeks out would have been the ideal for many carers, an impression that was confirmed during the interviews with the community nursing staff.

However, carers were often reluctant to raise these matters for fear of appearing over-demanding. This was something that was also raised by staff during interviews and it was clear that a number of carers were indeed seen as 'greedy' if they repeatedly requested more admissions. As Oswin (1984) suggests there is little room for criticism in a system which is seen to be for the carer's benefit. This issue of flexiblity is one that will be returned to in the concluding chapter.

Others factors limiting the value of respite care concerned the rural nature of the study area and the problems this created for visiting. Given the geography of the locality and the dispersed nature of the population these problems were to some extent inevitable.

It must not be thought that these matters seriously detracted from the value of the respite break as for most carers they represented the 'icing on the cake'. Far more concern was voiced over the **guilt** carers experienced, a problem apparent for over half the sample interviewed (24/42). Guilt, as a reaction to respite care, has been described in much of the previous research reviewed in Chapter 1 and it was certainly the most prevalent and pervasive reaction for many carers. It was not, however, universal. Carers who perceived their dependant as benefitting from the admission and/or who realised that their own health was a vital factor in continuing in the caring role tended to have a well balanced perspective in which guilt did not figure.

The extent to which carers experienced guilt seemed to be critically determined by the interaction of three sets of factors.

Firstly, there was the **reaction of the dependant** to the respite admission. This caused most problems when the dependant clearly did not wish to be admitted and the carer had to resort to what they considered as subterfuge in order to persuade them. This occurred most often when there was a poor and deteriorating carer/dependant relationship, but it was also described by carers who still had a good relationship. For those in the latter category the perceived subterfuge was gentle with carers resorting to what were described as 'little white lies'. These were aimed at creating a perception in the dependant that the respite admission was for their own good and something which the doctor had ordered as part of their rehabilitation process. In this way they often provided a **legitimate** reason for admission that was 'acceptable' to the dependant. This importance of providing a legitimate reason for admission in order to reduce the potentially negative effects of relocation has already been highlighted (Chenitz 1983) and will be further elaborated shortly. Moreover, for some dependants the chance to see the consultant was a very important part of their perceived self-esteem and provided both a legitimate and **desirable** reason for admission.

For those carers with a poorer relationship such subtlety was often not in evidence and respite care was either presented as a straightforward case of 'Doctors' orders' or else as an ultimatum, refusal of which was likely to result in permanent institutionalisation. Paradoxically, one carer described how she used the possibility of witholding respite care as a threat to control difficult behaviour between admissions.

The second major source of guilt was the **perceived (in)adequacy** of **institutional care**. This was apparent in the postal survey and has been well described in the literature. In the study area it related both to the local perceptions of the study hospital(s) and the quality of the care given. Thus some hospitals had a 'bad' historical reputation which was difficult to shed despite service improvements. Sometimes these perceptions were purely local and another hospital a few miles down the road, which itself may have had a bad local reputation, was quite acceptable for people outside the immediate area. For many other carers and dependants a close family member had died in certain hospitals and they had vowed never to go in or let a family member go in if they could help it. Conversely where a hospital had a good reputation or the dependant had previous or current experience which had been positive, for example day hospital attendance, then respite admission was far more likely to be seen in a positive light. This notion that reputation is an important component of acceptability is consistent with previous work (Bell et al 1987).

All carers, irrespective of the hospital's reputation, wished to be convinced of the **quality of the care** that their dependant would receive and often engaged in various strategies to obtain the evidence that they required. The most obvious of these was to visit frequently and to observe care for themselves. Some were quite adept at this and, realising that their dependant might not get much care whilst they were present, took pains to observe the care other patients received. These and similar strategies have been described in the literature (Fotrell 1988, Bowers 1988). Whilst convincing some carers of the quality of care, frequent visiting was often a cause of tension for staff who could not see why the carer visited so often when the purpose of the admission was seen as a break for them. In fact carers tended to visit regularly for three main reasons.

Firstly, as described above, it acted as a form of quality assurance. Secondly, many carers genuinely missed their dependant and wished to visit. Such individuals still received benefits from the respite admission as they had a good night's sleep and could also relax from the constant demands of care. Thirdly, there were those who visited regularly out of a sense of obligation, as if it was expected of them by the wider family and the community in which they lived. These carers seemed to think that others would accuse them of abandoning their relative if they did not visit. Staff, on the other hand, seeing regular visiting as reducing the benefits of the service, in all good faith discouraged carers from calling too often. This was beneficial for some carers who now had an acceptable reason for not visiting. Such legitimation was often reinforced by community nursing staff. Conversely, discouraging carers who genuinely wished to visit was stress-provoking and was an indication of staff failure to acknowledge the guilt some carers experienced.

The third and major theme running through many carers' dissatisfactions and guilt was the idea that they possessed 'expert knowledge' of the dependant which they felt staff failed to recognise. The concept of carers' expert knowledge has been described a number of times (Robinson and Thorne 1984, Hasselkus 1988, Webster 1988, Twigg 1989) and for carers in the present study it was something that they felt they possessed at a number of levels. Yet it was also something to which staff were seen to pay little attention. This undoubtedly detracted from the perceived quality of the respite care.

At one level carers felt that they had **knowledge of the dependant's condition and disability** and where this was not recognised or elicited then medical care was seen as lacking and often ignored. One carer described how her husband was known to be anaemic and was undergoing a series of investigations. She knew from her knowledge of the family history that his mother, father and brother had all died of bowel cancer and clearly thought this was a distinct possibility in her husband's case. Yet no one had asked her for the family history. It may well have been that the history had been obtained from the husband and that this potential cause had been excluded. If so she had not been informed. The result of the failure to consult her was not only guilt but also preventable worry and anger.

Another example of a similar failure to acknowledge a carer's expertise was recounted by a woman whose mother had a long history of mental illness. Yet, when the daughter insisted upon informing the staff of the behaviour patterns which heralded an onset of her mother's condition, she was labelled as neurotic. Indeed she recounted a conversation with one member of staff who suggested that her mother might be influenced by the phases of the moon, to which the carer replied 'What do you think she is, a bloody werewolf'. The above examples were by no means isolated.

At another level carers considered that they had knowledge of their **dependant's normal behaviour patterns** of which staff should be aware. This type of knowledge sometimes related to personality factors. Therefore they described how their dependant would behave like the 'perfect granny' whilst in hospital but at home was a 'real tyrant'. This tendency to 'put on a different face' has been termed the 'brief visitor syndrome' (Wright 1990 Personal Communication). Failure to elicit this kind of knowledge indicated to carers that staff were not fully aware of the problems they faced. There appeared to be a good deal of truth in this. In certain instances staff were well aware that dependants might behave differently during respite care, but in many others they were not. In such cases, especially where there was relatively good functional ability in the dependant then the 'legitimacy' of respite care was questioned by staff. Furthermore, if staff offered advice to carers that was considered unrealistic then such advice was not only likely to be ignored but also to generate anger in the carer. For example, staff told one carer that her mother was more dependent than she needed to have been and it was suggested that this was as a result of the carer doing too much for her. The carer was advised to let the mother do more for herself:

> "It's all very well them (hospital staff) telling me to let my mother do more for herself. They can do that in hospital and it doesn't matter if it takes all morning. I can't do that when she's at home, she'd scream the place down and its just not worth the hassle. I sometimes wonder if they really know the sorts of problems I face".

Other carers felt there was a need to 'teach staff' how to care for their dependant, a feeling also described by Hasselkus (1988). In situations were staff failed to respond to these attempts at instruction negative results often ensued. This was graphically detailed by one carer. Her husband suffered from dementia and had a tendency to wander. However whilst at home she never sedated her husband and had devised strategies to limit his difficult behaviour. The carer was concerned lest her husband's wandering proved problematic for staff and tried to explain what she perceived to be the cause of her husband's wandering and how she normally controlled it. However she considered that her advice had not been heeded by the staff. She then recounted how, upon visiting her husband, she had found him, in her own words, "heavily sedated and semi-conscious with his mouth full of half chewed food". She had immediately insisted on taking her husband home and resisted all further offers of a respite bed.

Perhaps the most prevalent form of expert knowledge concerned the nature of the dependant's likes and dislikes. Many carers could not conceive of good quality care until the staff to whom they were relinquishing responsibility knew something about their spouse or parent as a person. The importance to carers of such biographical details and intimate knowledge are similar to the conclusions of Bowers (1988) and for the present sample they were highly significant in illustrating to carers that staff were genuinely concerned with making the respite admission as positive as possible for the dependant. For example, one carer described how her husband loved bananas so on every respite admission she gave him a bunch to take in with him. However because he was hemiplegic he could not eat the fruit unless someone helped him peel it. The carer noted that when she visited the fruit had either gone rotten or was returned with her husband at the end of his stay:

> "I'm sure the physical care he gets is good and everyone seems nice and friendly. But its not until they bother to find out that he likes bananas that I'll be really happy to let him go in."

It was abundantly clear that, to the carers concerned, eliciting their expert knowledge would have done much to improve their perception of the quality of the care given and, in all probability, would have have resulted in improvements to care the dependant received. Many staff had this knowledge, particularly for respite users who had been coming over the years, but once again there did not appear to be any systematic effort to obtain it from the outset.

One final issue with regard to the carers perceptions of the respite experience remains to be addressed. This relates to the location of the rota beds in a hospital. As already described, for some this was important and provided a legitimate and convincing reason for the dependant to accept admission. For others, respite care would have been better placed in an institution where this was the only service offered and where more attention could be given to creating a holiday for the elderly user. For some carers the break was all that mattered and the location was unimportant. However, a number of carers and dependants had, over the years, come to trust the hospital in question and felt that if permanent institutional care was required in the future that this was the only place they would be happy to consider. The fact that the hospitals in question were now not offering long-stay places caused much anticipatory anxiety in many carers.

In summary therefore it should be re-iterated that for the vast majority of carers interviewed the rota beds were invaluable. It was also apparent that attention to some of the difficulites which were also highlighted could do much to improve the service at little or no extra cost.

7.3 The views of the elderly users

It was suggested in Chapter Three that two main concepts might be used as a framework for considering the impact of respite admissions on the elderly users. These were the nature of the relocation effects and the influence of the admissions on the self-esteem of the dependants. In addressing the former concept the practice theory of Chenitz (1983) was advocated in which relocation was mediated by the interaction of a number of **basic conditions** which determined whether the admission was **accepted** or **resisted**. These basic conditions were **contextual variables**, particularly the nature of carer/dependant relationships, **centrality** or the importance attributed to the admission in terms of the dependant's wish to remain independent, the **desirability** and/or **legitimacy** of the admission and its **temporality**, particularly the extent to which it was **reversible**.

Self-esteem was seen as being one of the foundations of psycho-social health in the elderly, with particular significance for the frail and disabled. It was described as being socially defined and constructed with the key elements being the extent to which: people could maintain **reciprocal relationships** with significant others through which to sustain their perception of being a person who mattered; the degree of **hope** which could be engendered; the notion of remaining a **treatable client** and the degree to which perceived **control** could be maintained. The interaction of these factors was influential in sustaining a sense of **meaning** for the older person.

The perceptions of the elderly users of the respite beds can be neatly divided into three groups. The extent to which the above factors can be used as an analytical framework to better understand these reactions will now be considered.

The first group of users constituted about a quarter of those interviewed (7/30). They will be termed the **beneficiaries**, a particularly apt descriptor as for these individuals the respite admission was a most positive experience. The overall impression was that coming in had some **meaning and perceived benefit** for themselves. Such individuals also considered that they exercised an element of **choice** in the decision to enter hospital. Whilst they saw the importance of the break for their carer, this was a secondary consideration as the main reason for the admission was described in terms of personal benefit. As such the two weeks in every eight they spent in hospital became an important and enjoyable part of their lives. Typically the admission afforded a perceived opportunity for treatment or at least re-assessment and moreover most people in this group had been coming in for respite care for a number of years and had developed good relationships with the staff and other respite users, who had become significant in their lives. Just as importantly, they still had good relationships with their carer(s). Thus in terms of Chenitz's (1983) theory all the basic conditions had been met and one would predict an acceptance of the admission. However one of the basic conditions,**temporality**, requires some modification when the theory is applied to respite care . In Chenitz's (1983) original conceptualisation temporality referred mainly to the degree to which the admission was reversible. In relation to respite care this is clearly the case. However when applied to rota beds another consideration arises in that reversibility is combined with both **predictability** and **regularity**, in that both the duration of the admission and the timing of subsequent readmissions are known. This adds another dimension, which the author terms **anticipation**. This was influential in determining reactions to the respite care. Therefore for the beneficiaries the rota bed stay was anticipated with pleasure and a positive reinforcement cycle was created.

These factors meant that acceptance by the beneficiaries went beyond that suggested by Chenitz as this was not merely acceptance by **strategic submission** or **submission by default**, both of which imply a rather passive reaction. This is not to criticise Chenitz's (1983) conceptualisation, which was derived from a consideration of admission to care on a more or less permanent basis, rather it is an extension of it. Therefore just as applying the theory to another situation involving a qualitatively different form of relocation required some modification to the **basic conditions**, it is also apparent that the nature of the acceptance requires expansion. Therefore, for the beneficiaries, acceptance was not by a process of mere submission but a much more positive reaction. To describe this the author offers the term **embracing** as better conveying the positive acceptance of the respite care.

Furthermore for the above group the respite care also added to the self-esteem of these users. They had developed reciprocal relationships with staff and other users, had maintained the notion of being a treatable client and considered that they exercised the choice of whether to accept the admission or not. All of this served to reinforce their perception of themselves as being a person who mattered.

It was also apparent from observations of staff contact with such individuals that they might be considered as 'favourites' whom staff would go out of their way to engage in conversation. It was not difficult to see why, as the researcher also enjoyed the interviews with these respondents who were socially adept and had interesting tales to tell. The extent to which staff interactions were influenced by the social skill of the patients will be considered in the next chapter.

In contrast to the above group the largest number of users (17/30) are best described as **tolerating** the admission on the basis that it was for a time-limited period. The basic condition of **temporality** had been satisfied. However, as will be described below, the manner in which this group **anticipated** the admission differed considerably from the beneficiaries. Moreover they also varied in other basic conditions. Therefore, whilst they had maintained good relationships with their carers, they saw no benefit to themselves in accepting the respite care. Rather they perceived that the respite admission was for the benefit of their carers. This apart they were not a homogeneous group however and can be further divided into three sub-groups for which the author has coined the terms, **the endurers, the disillusioned** and **the martyrs.**

The largest sub-group (10/17) were the **endurers.** Such individuals put up with the respite admission for the benefit of their carers. They appreciated that the person looking after them both needed and deserved a break, and this provided a legitimate reason for them to accept the admission. Therefore whilst not embracing the admission, acceptance and anticipation of the respite care was by and large good humoured, with no real resentment. It was appreciated that two weeks in hospital in every eight was a prime factor in maintaining them at home for the other six. An element of **centrality** was in evidence. However, there was little evidence of a positive effect on the self-esteem of this group.

Some found comfort in that sharing an environment with the long-stay patients made them realise that their own circumstances could be a lot worse. For others however this had the opposite effect and they found the prospect that they themselves might end up in such an institution on a permanent basis depressing.

A number of others made fairly mundane comments about the food being 'good' and the staff very 'nice', but most described long periods of boredom and inertia with time hanging heavy on their hands. However, none felt that they could be critical as they were conscious that they would be returning again in six weeks.

Moreover, whilst being sociable with both staff and patients no really significant relationships had been forged with either group.

Therefore whilst sufficient **basic conditions** were met for this sub-group to accept the admission, both **choice** and **desirability** were absent. However they **endured** the admission and generally made the most of a bad job.

A smaller sub-group (3/17) were the **disillusioned.** For these three people the respite care had been sold to them on the basis that it would afford an opportunity for further treatment. Whilst they still appreciated that the admission would provide a break for their carer, thus providing an element of **legitimation,** the prospect of benefit to themselves added **desirability** and also increased their sense of self worth and hope. Thus initially there was an element of positive **anticipation.** However the hoped for treatment did not materialise for these individuals and therefore the desirability was removed and there tended to be a reduction in self-esteem. This led to **disillusionment.** However the good relationship with carers sustained an element of **legitimation** and the **centrality** of the admission in terms of keeping the carer going was quite apparent.

For both the above groups the admission did not appear to have affected the quality of their relationship with their carer and there was a realisation that their carer both **needed** and **deserved** a break. The time-limited nature of the admission made it tolerable, even though anticipation was on the whole negative:

> "Well let's say I put up with it. I know my wife needs the break and it's only for a fortnight. Mind you if I thought I was here on a permanent basis I'd say 'Give me the gun'."

In terms of acceptance these groups therefore adopted what Chenitz (1983) termed a'**strategic submitting**' stance .

There was also a third group (4/17) who might be described as tolerating the admission. The over-riding rationale for accepting respite care for such individuals was the realisation that their carer **needed** a break. However in contrast to the previous two groups there was apparent an element of resentment amongst these individuals and they did not describe the break as being **deserved.** Therefore whilst they tolerated respite care because they felt refusal might lead to a collapse of the caring situation, they also felt as if their acceptance was a sacrifice made by them for the carer. They felt like **martyrs.** For the martyrs respite care seemed to threaten the more fragile relationship with their carer and anticipation tended to be in terms of a negative reinforcement cycle. The martyrs therefore were in danger of joining the third main group.

For this third group of users (6/30) the respite care was a totally negative experience with none of the **basic conditions** really being met and it often resulted in a reduction in their perceived self-esteem. Such individuals saw **no legitimate reason** for the admission at all. They were aware that they were attending in order for their carer to have a break but did not consider that such a break was either **needed or deserved.** They therefore felt that they had been **abandoned** by their carers. These were most often the individuals who were described as manipulative, domineering and unappreciative by their carers. They clearly saw that they had no **choice** in the decision to come in for care and deeply resented the fact that they perceived themselves as having been forced to accept it:

> "I'm coming because they (doctor and staff) tell me that my daughter needs a break and if she can't get one then I'll have to go into a home. I've got no choice in the matter. It's like everything else, I always have to jump when she says so."

For this group the respite admission served only to reinforce their poor relationship with their carer and anticipation of each admission created a negative reinforcement cycle resulting in a downward spiral. The abandoned were much more likely to resist the admission, either by resigned resistance, that is largely passive withdrawl or more forceful means, typically refusal to cooperate and participate in the ward. This understandably had the added effect on making these individuals less popular with both other patients and staff, further compounding their already negative perceptions.

From a consideration of the reactions of the users to respite care both Chenitz's (1983) theory and the concept of self-esteem are considered to have proved most useful as analytical frameworks to better explain and possibly predict and identify individuals who experience a positive, a neutral or a negative respite stay. The potential application of these theoretical positions will be discussed in more detail in the concluding chapter.

Before describing staff perceptions of the respite care one other point requires expansion. It was noted earlier that one of the key variables in the carers' acceptance of the respite care was the reaction of the dependant. From the above discussion of users' responses it is now possible to expand on this. Therefore amongst the carers of the beneficiaries no guilt was in evidence and, as Cunliffe (1987) suggested, the provision of a positive respite experience for the dependant does much to reduce the anxiety of carers. Conversely amongst the carers of the abandoned guilt, despite the now poor relationship between carer and dependant, was pervasive. This further serves to reinforce the reciprocal relationship between the quality of the carer/dependant relationship and the reaction of both parties to respite care. This is also an area to which further attention will be turned in the concluding chapter.

7.4 The views of the staff

Views of the staff about the functioning of the respite system in general and the rota beds in particular can be considered from three main perspectives: those of the consultant geriatricians with clinical responsibility for the units, those of the staff serving the units, and those of the community nurses providing care to carers and dependants whilst at home.

The role of the consultants is pivotal as referral is via formal channels in which the consultant staff act as gatekeepers to the service. The respite systems were under the clinical management of three consultants, with essentially similar operating practices, but each having differing views on certain aspects of the rota bed service.

Each consultant saw the main purpose of the respite system as to **sustain the carer in their role**, and each also offered a certain number of places to social services part III homes. This was an attempt to recognise that such institutions were also catering for a number of heavily dependent elderly people from whom the staff needed periodic respite.

However, despite these similarities the manner in which rota beds were allocated varied. New patients could enter the system in one of two main ways; either upon discharge from hospital or via the community following a referral from their GP.

Every new patient referred from the community was assessed at out-patient clinic to review their condition and to determine their suitability for the rota beds. Implicit eligibility criteria seemed to be in operation such that preference was given to carers who were perceived to be carrying the greatest burden. Burden in this case was equated with physical and mental dependency. The consultants reasoned that this was necessary in order to limit the demands made on a finite resource. Thus some patients were seen as being 'too fit' for hospital care. As will be highlighted below similar criteria for determining burden were also in evidence when the frequency of respite care was considered. The operation of such a system not only increased the time between referral for respite care and eventual admission, but also meant that it was more difficult for certain carers to stake a claim as being deserving of respite care. This limited both the flexibility and adaptability of the service. This is consistent with the literature reviewed in Chapter One and given the findings of the postal survey suggests that many genuinely stressed carers may have been effectively excluded from the service. This is an issue which will be adressed more fully in the concluding chapter. Moreover, in most cases of referral from the community, the rota beds themselves were usually kept in reserve with a holiday bed often being offered in the first instance.

The extent to which places were allocated on discharge from hospital also varied. One consultant used them as a incentive for carers to take a dependant home. Thus if a carer expressed reservations about entering or remaining in the caring role they were more likely to be offered a respite place. Another consultant expressed doubts as to the advisability of such a practice, and the third consultant reserved judgement about using beds in this fashion. The most frequent rota offered by all the consultants was two weeks in and six weeks out, although each consultant would operate a two week in and two week out rota in exceptional cases. Exceptional cases were usually described as those carrying the heaviest burden and although there was awareness that burden did not always equate with disability, as noted above disability was nonetheless the implicit criterion operating in the definition of 'exceptional'. Thus some less dependent patients were described as 'not really hospital cases' and, according to the consultants, carers who managed to get such dependants in 'knew how to play the system'.

Once an individual was in the system however there was far more latitude and the nursing sisters in the individual units could then accept 'known patients' at their own discretion. Furthermore, they could make representations to the consultants on behalf of community nurses who knew of deserving cases in the locality. There were also crisis beds available in each unit to which an individual could be admitted immediately if there was the prospect of an imminent breakdown in their support network. In one unit these were officially nurse managed, and at the others sisters could again accept 'known patients' on this basis.

The consultants were conscious that access was in some respects piecemeal, arbitary and tended to favour individuals already familiar to the service.

Once elderly patients were in the system the consultants relied heavily on nursing staff for information, especially about carers, whom they did not see routinely unless arranged via the sister. In this sense the gatekeeeper role became transferred to the nurses. A similar pattern was evident to a lesser extent with respect to patients. This is consistent with previous work in which medical staff in continuing care hospitals have been noted to rely on nursing staff for information relating to a patient's condition (Evers 1981a). This afforded nurses a pivotal role in the flow of information during the respite process. However the fact that carers identified a perceived difficulty in obtaining access to consultants suggests that nurses did not always exercise this role to its full extent.

In the opinion of all the consultants, the fairly rapid phasing in of the respite beds over the last five years and the practice of accepting referrals for continuing care units directly from the community was a response to the speedier throughput and discharge of patients from the acute facilities. This had a profound effect on the way in which the continuing care units now functioned. For example in 1978 one of the units in the study had a total of 15 discharges or deaths and an average length of admission of 726 days. The same unit in 1986 had 140 discharges or deaths and an average length of admission of 67 days. Initially each consultant described how this change had been met with great suspicion and resistance from the nursing staff; indeed some nurses had left rather than working in the new environment. However, it was now felt that the job satisfaction and prestige of nurses had risen and that the local profile and reputation of the units had been substantially improved.

Despite this, the very success of the units gave rise to some operating problems. Notwithstansing the ten-fold increase in activity, some of the units were still designated as continuing care and staffed accordingly. The most obvious effect of this was felt in terms of therapy staff. In acute or rehabilitation units recommended therapy staffing levels were 1 therapist to 15 patients. In a continuing care unit the recommended level was 1 to 120. A less quantifiable but equally worrying consequence was that, in the words of one consultant, 'truely holistic care', one of the central tenets of geriatric medicine, was now rarely possible. Additional problems caused by the extra throughput also included the non-availibilty of patient case notes and the need to supply medication. The latter need often caused considerable administrative difficulties as the peripheral hospitals were not well served by a pharmacist. Thus it was apparent that staffing levels, in terms of both numbers and diversity, had not kept apace of service developments. This fact undoubtedly contributed to the disillusionment of some respite users.

In terms of the benefits of the system to the users the consultants considered that, notionally, both carers and dependants could benefit. For the carers the main benefit was seen as the break respite care provided. However as was suggested by Packwood (1980) the ultimate aim of the service was instrumental, sustaining the carer in their role, rather than for any altruistic notion. Thus as Twigg (1986) contends the primary manner in which carers are conceptualised by service providers is as resources. Whilst this remains the case the needs of carers will continue to be inadequately met. The balancing of carers needs with those of the dependant and dominant service ideologies will be addressed more fully in the concluding chapter. However, as noted above, the potential benefits to both carers and dependants were seen to be limited by the lack of staff and the consequent failure to provide an environment that was as actively therapeutic as it might be. Thus there was a recognition that admission to respite care could result in a **deterioration in the physical and mental health** of the dependant, creating potentially more work for the carer.

Overall the consultants seemed to have a balanced view of the respite system, much as it had been described in the literature. It was at the same time perhaps fairly restricted in the sense that it was confined to well versed notions of function which concerned giving a break to the carer in order that they could continue to care. This implies no criticism of the individual consultants as in many respects they were responding to the increased demands for care within the constraints of limited staffing and resources. It was equally apparent that, whilst the consultants occupied a gatekeeper role, much of the day to day functioning of the system and the majority of the care was the responsibility of the nursing staff and it is to their perceptions that attention is now directed.

Interviews were held with staff in four units operating the rota bed system. In two of these interviews were largely confined to the key decision makers, that is the nursing officers and the sisters. At the two units which were to be the focus of the observation study a much wider range of staff were included and due to the return visits made to these units there was the opportunity to have repeated contact with the staff and therefore to check out developing themes and categories. Furthermore, comments obtained at interview were also cross referenced against those from the staff questionnaire which was completed by 10 qualified nurses and 14 unqualified nursing staff.

The clear consensus of opinion amongst all the staff was that the rota beds were one of the best things to have happened to the units. Whilst it was acknowledged that they caused much additional extra work, especially of a clerical nature with particular problems noted in relation to obtaining casenotes and medications, the benefits were seen to far outweigh the disadvantages. Although there were perceived benefits for all the stakeholder groups the prime purpose was seen as being for the carers.

Staff described the rota beds as being a service for carers with additional benefits for the dependant in that there was access to treatment and assessment facilities. Rota beds were seen to give carers a break from the demands of caring, an opportunity to relax or take a holiday and to have more time with their family. Regular visiting by carers was considered by many staff to reduce these benefits and staff often stated that they would discourage frequent visiting. On the other hand some staff considered that if carers did not visit or phone at all then they were guilty of abandoning their relative. Thus, it seemed that for some staff not to visit was alright but not to phone was unacceptable.

There were few clear indications that staff saw the rota beds as affording the opportunity to meet the wider needs of carers for information, advice, skills training or emotional support. There was no doubt that for some carers the hospital represented a source of advice and support and in a number of cases an important one. However this situation usually arose more by chance than as the result of a planned intervention. Moreover, there seemed to be no systematic attempt to determine the extent to which carers wished to be involved from the outset. There was also very limited recognition of the guilt carers could face with only two staff members making explicit reference to this. Some problems for carers were recognised particularly for those caring for the mentally frail, who often took time to settle upon returning home, but over half the staff saw the rota beds as causing no problems for carers at all.

This should not be construed as criticism of the staff as most of them genuinely believed that the service they were offering was vitally important in sustaining carers. However delimiting the benefits to the break seemed to imply that the wider potential for providing support, information and training was seldom explicitly realised. Yet it was apparent from the carer interviews that this is something a number of carers would clearly have valued. These findings are consistent with the literature which suggested that staff are often unaware of the difficulties which respite care can cause for carers and also fail to perceive of benefits which extend beyond the break provided.

The more senior nursing staff were aware of their important gatekeeping role, both in mediating access to the consultants and in accepting 'known' patients. As with the consultant staff, implicit rather than explicit eligibility criteria were in operation and value judgements were made about 'deserving cases'. Again, consistent with the views of the consultants, these more often than not related to notions of dependency equating with need. Carers seen to be asking for more than their share were described as 'greedy'. Such perceptions are understandable in that the potential demand for rota beds far outstripped their availability and therefore some form of rationing was needed. However, this resulted in those with mainly 'social needs' being seen as 'less legitimate' than those with dependency needs, making access for the former group more difficult. The prioritisation of instrumental above other needs has been well described in the literature (Bowers 1987) and has implications for service delivery which will be addressed in the concluding chapter.

For the elderly service users rota beds were seen to offer a number of benefits as well as some problems. Routine monitoring of medical and nursing needs was seen as important, confirming the findings of Tyler (1989). Conversely there were widely held views that there were too few therapy and nursing staff which meant that dependants often did not obtain as much rehabilitation or activity as they would have liked, a perception consistent with that of many of the users themselves. However, the perceived lack of sufficient activity varied between the units, particularly those with access to a day hospital and a full-time physiotherapist as opposed to those without them.

Both qualified and unqualified staff saw the rota beds as offering a change of environment and a chance to make new contacts. This was acknowledged in that there was usually an attempt to ensure that the same people came in on the same dates and shared accommodation with familiar faces and friends. It was also apparent that staff themselves had developed good relationships with many of the rota bed users and knew them on an individual and personal basis. Whilst this undoubtedly resulted in a degree of individualised care it developed over time and in a rather random fashion, rather than being overtly planned and systematic.

Staff were also aware that the physical environment in some of the units left a lot to be desired but in practice there was little that could be done about this. However, despite these problems, the overall impression amongst staff was that most dependants, if not actually enjoying the experience, didn't actively dislike it. In this sense staff perceptions, whilst being somewhat more positive were largely congruent with those of the service users.

Staff considered that for long-stay patients the rota beds users **brought variety** to the ward which was beneficial for the few lucid patients able to enjoy their company. It was felt that new relationships had formed and some of the permanent patients were described as 'missing' the rota bed users when they went home. The introduction of the rota beds were not seen to have resulted in any disbenefits for long-stay patients.

The full value of the rota beds and other short-stay patients appeared to be seen in terms of the functioning of the units and **staff morale**.

With regard to morale, staff considered that the changes had **raised the status** of the unit in the locality and amongst the local population. Hence the units were seen in terms of serving the wider needs of the community rather than just 30 or so long-stay patients. Equally important was the fact that the status of the units in particular and of work with the dependent elderly in general was seen to be raised relative to that of the district general hospital (DGH). Historically, within the study area, staff at the peripheral hospitals considered that they were usually seen as playing second fiddle to the centralised DGH, and that this was a reflection of the value accorded to the work done at the various hospitals. Rota beds and wider changes of which they were part were seen to redress this balance. This was succinctly summed up by one staff member:

> " We've always been considered as the backwater, perhaps now people will start to realise that we're actually the backbone."

However, perhaps the most dramatic impact to emerge on staff was in the nature of their own day to day work and overall satisfaction. For both qualified and unqualified staff the respite beds and the introduction of direct admissions from the community had brought a variety and purpose to their work which had previously been lacking. The rota beds in particular ensured both continuity and variety. There was continuity in as much as each patient returned on a regular basis, but also variety because each bed had up to four different patients in an eight week period. This stood in stark contrast to the work environment existing prior to the rota beds, where staff saw the same thirty patients week after week. Under the old regime there was typically little or no change other than gradual deterioration and, due to high levels of mental frailty, few opportunities for meaningful interaction.

In addition to these benefits, which were appreciated by all staff, the respite patients presented the trained staff with new care challenges. For many this meant that they now had the chance to practice the nursing skills for which they had been trained and which they felt had not been fully utililised over the years:

> "What is geriatric nursing? Beds, backs, baths and bowels, beds, backs, baths and bowels. No real change and no real challenge. Well all that's changed recently and I think it's the best thing thats ever happened."

It was easy to see and to appreciate the impact of the new system on staff satisfaction and morale. It was also clear that the concept of 'rust out', suggested by Pennington and Pierce (1985), had empirical meaning for many of the staff and, furthermore, that the variety, stimulation and challenge provided by the respite beds had done much to counteract it.

However, whilst the overall impact on staff was positive, this was by no means universal. As discussed by the consultants introducing the new regime had been difficult and some staff had left as a result. Whilst the respite beds were seen as beneficial there was still some resistance from the nursing staff to the total removal of long-stay patients from the units in question. There was widespread concern as to where such individuals would be placed in the future. There was a related feeling that the medicalisation of care of the elderly was going too far. This generated tensions between medical and nursing viewpoints as to the ultimate function of the peripheral hospitals. Issues such as these are likely to become more important as the trend towards the elimination of long-stay hospital beds gains momentum and this raises the questions posed by Evers (1981a,b, 1982) as to responsibilities and authority in this field which still remain unanswered.

The last main group of staff to be interviewed was the community nursing staff. Interviews with this group of service providers had not been part of the original proposal but, it became apparent during the carer interviews that virtually all of the carers received some support from the community nurses so it was thought important to take account of their views. Furthermore, carers obviously had different perceptions of the value of the nurses' visits which seemed contingent upon the meeting of carers' wider needs.

The literature on community nurses suggests that historically they have had little interest in the needs of the chronically sick and their carers (Kratz 1978), spending relatively little time in providing advice to carers (Dunnell and Dobbs 1982) or in wider health promotion and counselling (Ross 1985) concentrating their efforts on medical components of care (Poulton 1981) and crisis orientated interventions (Phillipson and Strang 1984, Edwards 1987). This was certainly not the case with the present sample, all but a few of whom seemed very well aware of the problems carers faced. Indeed they felt that they had a vital role in supporting carers, which unfortunately it was not always possible to fulfil.

Interviews with the community nurses concentrated not only on their perceptions of the rota beds but also attempted to address wider issues about community support in general and their role in particular. In reporting these views the rota beds will be considered first.

The community nurses considered that they were pivotal in facilitating access to the rota beds for the carers. It was they who most frequently approached the GP suggesting referral to the consultants. Where they worked in close geographic proximity to the rota bed unit they made direct representations to the sisters. By the time carers actually had contact with the rota beds the community nurses had often been involved for some time. Many carers, it seemed, would not accept the suggestion of a rota bed when the idea was first put to them by the community nurses and they would often leave it until their coping resources were virtually depleted before asking directly themselves. This the community nurses attributed to the guilt carers felt and also to the perceived reaction of the wider community whom carers considered might think they had in some way abandoned their dependant. Community nurses often had to work hard at overcoming these perceptions. In this connection they felt that the first impressions of the unit by carers were of paramount importance. It was suggested that some form of preliminary visit to the unit or a home visit by the hospital staff could do much to create a favourable impression. In addition dependants were sometimes reluctant to be admitted and once again the community staff often had to intervene, reassuring dependants that admission was only temporary.

Community nursing staff saw themselves as advocates for carers in terms of negotiating access to services. Their success at this with respect to the rota beds was largely determined by the GPs. A number of GPs were willing to accept the nurses' assessments and would refer on accordingly. However, even in these cases district nurses felt that the system was cumbersome and slow. They were mindful that carers often waited until the last moment before considering a respite bed. Many suggested that direct access to respite care would have been preferable. Yet strangely, even nurses working in the area operating the nurse managed crisis beds were unaware of their existence unless they worked in immediate vicinity of the hospital. Other nurses felt that GPs rarely listened to their suggestions and this was something which engendered anger and frustration. The nurses considered that they had real knowledge of the home situation and failed to see why they could not access services themselves. Similar problems were described regarding access to services and relations with the social services. In parts of the study area this had come to a head following the introduction of a new hybrid worker.

The hybrid worker provided direct personal care as well as domestic assistance and was organised via the social services. In order to gain access nurses had to go through official channels. This meant that someone reassessed each case prior to the service being allocated. Because the service was new the person doing the assessment was usually new to the job and often had no formal qualification or training. Nurses then became understandably angry that services were allocated on the strength of a short visit, from what they perceived as an unqualified person. This was compounded by the fact that such an assessment was given more credibility than their own which was often based on years of experience with a particular family. The issue of assessment and access to services will become increasing important in the future following the recent White

Paper 'Caring for People' (Department of Health 1989a) and will be discussed more fully in the final chapter .

In addition to access, the community nurses, as with the carers, felt strongly that a four week out, two week in rota would have been far better. They were also concerned about the flexibility of the system and its capacity to cope with 'on demand' crises. However, despite these problems nurses, like carers, saw some form of respite as essential.

As regards their own role with carers the vast majority interviewed described a **broad and holistic view** which indicated that they often appreciated the wider needs of carers. This stands in sharp contrast to those references previously cited which suggested that community nursing staff have little interest in the needs of carers. Indeed many staff saw themselves as part of the extended family with a befriending role in offering teaching, advice, counselling and emotional support to carers. Furthermore, because they were going in to perform often intimate personal tasks they saw this as enhancing their credibility, a point which had been made by carers themselves. Conversely, some of the nurses saw their role primarily in terms of the more overt nursing duties, and once again from the carer interviews these interventions were not so highly regarded.

Many nurses felt that they were too few in number to adequately fulfil all the role expectations and they readily identified obvious gaps in services for carers. These included services at night, tailored services for the confused elderly, a lack of day care and respite care and difficulties in obtaining aids. Many felt that their own training needs were largely ignored and that they worked in professional isolation from their hospital colleagues. In this sense they too, like GPs, were considered to pay too little attention to the **'expert knowledge'** that their community colleagues possessed. This was most apparent on admission to and discharge from hospital when the community nurses often felt that carers' needs could be neglected.

From the interviews conducted the community nurses seemed to have a better appreciation of the wider needs of the carers and offered interesting insights into the functioning of rota beds in relation to carers needs.

Having in this chapter presented the views of the main stakeholder groups and signposted some of the key issues they raise, the following chapter focusses on the respite experience itself.

CHAPTER EIGHT

THE ROTA BED EXPERIENCE: TWO WARDS COMPARED

> " It is, however, impossible to spend long periods of time observing old people at the receiving end of various services without experiencing any emotions about what is seen.....Many events took place in front of us which we felt moved to set down in detail as they occurred....hospital wards were the settings for most of the incidents which lead us fervently to hope that we will never be treated in this way."
>
> (Godlove et al 1981 p.50)

This chapter provides a description of the respite experience and the environment in which it was located. It also considers the extent to which the evaluation criteria were met, namely the achievement of autonomy and choice, access to a full range of assessment and therapeutic facilities and individualised programmes designed to promote self-esteem and social interaction.

8.1 Selecting two wards

This part of the study was restricted to two wards purposively selected on the grounds of similarity and contrast. Both had thirty beds and were under the clinical direction of separate consultant geriatricians. Both had a similar proportion of long-stay patients (approximately 15) with the remainder of the patients being either respite care (rota beds, holiday beds and crisis beds) or short-stay. There, however, the similarities ended.

Integral to one ward, **Tudwal**, was a ten place day hospital and as a consequence there was a full-time physiotherapist, two therapy aides as well as an additional nursing sister responsible for the day unit. Ward patients of all types were actively encouraged to integrate with the day patients. Indeed, some of the rota bed patients also attended the day hospital between admissions. In contrast, Castell ward had no such facilities, with therapy staff input limited to a brief visit from a physiotherapist two mornings a week.

In comparing the respite experience in these two wards data from a variety of sources were collected by the author and the three research assistants involved in the observation study.

Dependency data were collected from the senior nurse on duty for those patients who were observed during this stage of the study. These data provided information about assistance required with key Activities of Daily Living (ADL), continence, mental state and perceived sociability and cooperativeness. Two of the research assistants conducted a two week period of structured observation using a molar coding frame.

During this period the assistants also completed methodological and observational notes, recording each day their emerging perceptions of the ward environment and 'regime'. They noted in particular any evidence of the reactive effects of observation and the extent to which they, as experienced nurses, felt the wards met the criteria in the evaluation guide. These qualitative data complemented similar data collected by the author during his frequent visits to both Tudwal and Castell.

In addition to the above nursing staff of all grades completed structured questionnaires asking them to describe the most important, interesting and difficult components of their work.

Qualified nursing staff also completed the checklist operationalising the typology of Wade and colleagues (Wade et al 1983, Wade 1983). Data from these varied sources provide an overview of the respite care as experienced by the elderly users at Tudwal and Castell.

8.2 Dependency profiles

Dependency profiles were completed for all patients observed at each unit, a total of 25 patients at Tudwal and 24 at Castell. These are summarised in the Tables 7,8 and 9 below. Table 7 compares the two units in terms of the overall dependency, whilst Tables 8 and 9 compare the long-stay, respite and short-stay patients on each ward.

At both units approximately three quarters of the patients were women (75% at Castell and 72% at Tudwal). The mean age of patients at Castell 81.5 years (range 65-93) and at Tudwal 77.9 years (range 69-91). It will be noted that patients at Tudwal, despite being younger, were generally more dependent, mentally frail and were considered to be less sociable, less able to help with their care and to have greater difficulty in holding a normal conversation. In addition, there were higher levels of incontinence, particularly double incontinence, at Tudwal. However, when the tables for long-stay and respite/short-stay patients are examined it will be seen that the differences in help required for ADL between the wards are largely attributable to variations amongst the short-stay and rota bed patients.

Comparing the long-stay patients on the two wards, those at Castell appeared to be marginally more dependent in ADL whilst those at Tudwal were more incontinent and mentally frail.

However, differences amongst the respite and short-stay patients during the observation study may well have been due to the cross-sectional nature of the data. The staff at Castell indicated that during the observation study the respite patients were not as 'heavy' as some of the other respite users on differing rotas. In as much as these data relate to the period of observation they provide an indication of levels of staff support required by the patient populations.

Table 7: Dependency profiles Castell and Tudwal

Castell n=24 Tudwal n=25
% requiring help with ADL

	Independent		Some help		Total help	
	C	T	C	T	C	T
	n %	n %	n %	n %	n %	n %
Mobility	3(13)	3(12)	7(29)	4(16)	14(58)	18(72)
Transfer	5(21)	5(20)	5(21)	3(12)	14(58)	17(68)
Washing	6(25)	4(16)	4(17)	3(12)	14(58)	18(72)
Hair Care	5(21)	0	4(17)	3(12)	15(63)	22(88)
Mouth Care*	8(33)	5(20)	1 (4)	2 (8)	15(63)	18(72)
Foot Care	2 (8)	0	1 (4)	3(12)	21(88)	22(88)
Bathing	2 (8)	0	4(17)	2 (8)	18(75)	23(92)
Eating	12(50)	13(52)	2 (8)	5(20)	10(42)	7(28)
Dressing	3(13)	3(12)	5(21)	7(28)	16(66)	15(60)
Toilet	6(25)	4(16)	4(17)	3(12)	14(58)	18(72)

* Indicates ordinary oral hygiene not oral toilet

Patient usually nursed

	C	T
	n %	n %
In bed	8(33)	7(28)
Up in chair	6(25)	15(60)
Up and about	10(42)	3(12)

Continence

	C	T
	n %	n %
Fully continent	7(29)	4(16)
Catheter	4(17)	2 (8)
Incontinent urine	7(29)	4(16)
Incontinent faeces	3(13)	1 (4)
Doubly incontinent	6(25)	15(60)

Table 7 continued

Pressure sores

	C	T
	n %	n %
Skin intact	17(71)	16(64)
Grade 1 sore*	0 (0)	5(20)
Grade 2 sore	3(13)	2 (8)
Grade 3/4 sore	4(17)	2 (8)

* Grading system after David (1983)

Mental frailty

	C	T
	n %	n %
Wanders	4(17)	1 (4)
Danger to self	3(13)	2 (8)
Disorientated to		
Time	10(42)	16(64)
Place	6(25)	14(56)
Person	2 (8)	10(40)
Behaves in		
Embarrassing way	1 (4)	4(16)
Agitated way	5(21)	9(36)
Conversation poor	11(46)	19(76)
Becomes depressed*	6(25)	13(52)

* Staff had difficulty in classifying some patients

Sociable

	C	T
	n %	n %
Sociable	11(46)	6(24)
Not sociable	3(13)	9(36)
Can't*	10(42)	10(40)

* Due to speech difficulties or severe confusion

Cooperative

	C	T
	n %	n %
Tries to help	15(63)	11(44)
Doesn't help fully	5(21)	5(20)
Unable to help	4(17)	9(36)

Table 8: Dependency profiles (Long-stay patients)

Castell n=11 Tudwal n=13
% requiring help with ADL

	Independent				Some Help				Total Help			
	C		T		C		T		C		T	
	n	%	n	%	n	%	n	%	n	%	n	%
Mobility	0		0		1	(9)	2	(15)	10	(91)	11	(85)
Transfer	0		1	(8)	1	(9)	1	(8)	10	(91)	11	(85)
Washing	0		0		0		0		11	(100)	13	(100)
Hair care	0		0		0		0		11	(100)	13	(100)
Mouth care	0		0		0		0		11	(100)	13	(100)
Foot care	0		0		0		0		11	(100)	13	(100)
Bathing	0		0		0		0		11	(100)	13	(100)
Eating	1	(9)	5	(38)	1	(9)	2	(15)	9	(82)	6	(46)
Dressing	0		0		0		2	(15)	11	(100)	11	(85)
Toilet	0		0		1	(9)	1	(8)	10	(91)	12	(92)

	Patient usually nursed	
	C	T
	n %	n %
In bed	7(64)	6(46)
Up in chair	4(36)	7(54)
Up and about	0	0

	Continence	
	C	T
	n %	n %
Fully continent	0	0
Catheter	4(36)	1 (8)
Incontinent urine	3(27)	1 (8)
Incontinent faeces	3(27)	1 (8)
Doubly incontinent	4(36)	11(85)

	Pressure Sores	
	C	T
	n %	n %
Skin intact	6(55)	6(46)
Grade 1 sore	0	3(23)
Grade 2 sore	2(18)	2(15)
Grade 3/4 sore	3(27)	2(15)

	Mental frailty	
	C	T
	n %	n %
Wanders	1 (9)	1 (8)
Danger to self	0	2(16)
Disorientated to		
Time	7(64)	11(85)
Place	3(27)	10(77)
Person	2(18)	8(62)
Behaves		
Embarrassing way	1 (9)	2(15)
Agitated way	4(36)	7(54)
Conversation poor	8(73)	12(92)
Becomes depressed	3(27)	6(46)

Table 8 continued

	Sociable	
	C	T
	n %	n %
Sociable	3(27)	1 (8)
Not sociable	1 (9)	2(15)
Can't	7(64)	10(77)

	Cooperative	
	C	T
	n %	n %
Tries to help	7(64)	1 (8)
Doesn't help fully	0	5(38)
Unable to help	4(36)	7(54)

Table 9: Dependency profiles (Respite/short stay patients)

Castell n=13 Tudwal n=12
% requiring help with ADL

	Independent		Some help		Total help	
	C	T	C	T	C	T
	n %	n %	n %	n %	n %	n %
Mobility	3(23)	3(25)	6(46)	2(17)	4(31)	7(58)
Transfer	5(38)	4(33)	4(31)	2(17)	4(31)	6(50)
Washing	6(46)	4(33)	4(31)	3(25)	3(23)	5(42)
Hair care	5(38)	0	4(31)	3(25)	4(31)	9(75)
Mouth care	8(62)	5(42)	1 (8)	2(17)	4(31)	5(42)
Foot care	2(15)	0	1 (8)	3(25)	10(77)	9(75)
Bathing	2(15)	0	4(31)	2(17)	7(54)	10(83)
Eating	11(85)	8(67)	1 (8)	3(25)	1 (8)	1 (8)
Dressing	3(23)	3(25)	5(38)	5(42)	5(38)	4(33)
Toilet	6(46)	4(33)	3(23)	2(17)	4(31)	6(50)

	Patient usually nursed	
	C	T
	n %	n %
In bed	1 (8)	1 (8)
Up in chair	2(15)	8(67)
Up and about	10(77)	3(25)

	Continence	
	C	T
	n %	n %
Fully continent	7(54)	4(33)
Catheter	0	1 (8)
Incontinent urine	4(31)	3(23)
Incontinent faeces	0	0
Doubly incontinent	2(15)	4(33)

	Pressure sores	
	C	T
	n %	n %
Skin intact	11(85)	10(83)
Grade 1 sore	0	2(16)
Grade 2 sore	1 (8)	0
Grade 3/4 sore	1 (8)	0

	Mental frailty	
	C	T
	n %	n %
Wanders	3(23)	0
Danger to self	3(23)	0
Disorientated to		
Time	3(23)	5(42)
Place	3(23)	3(25)
Person	0	2(17)
Behaves in		
Embarrassing way	0	2(17)
Agitated way	1 (8)	2(17)
Conversation poor	3(23)	7(58)
Becomes depressed	3(23)	7(58)

	Sociable	
	C	T
	n %	n %
Sociable	8(62)	5(42)
Not sociable	2(15)	3(25)
Can't	3(23)	4(33)

	Cooperative	
	C	T
	n %	n %
Tries to help	8(62)	10(83)
Doesn't help fully	5(38)	0
Unable to help	0	2(17)

Given the high levels of dependency, mental frailty and general inability to communicate amongst the long-stay patients it is easy to appreciate how the respite users were seen to enrich the work environment and satisfaction levels of the staff.

8.3 The respite care experience

In describing the experience of the rota bed users the qualitative data considered in the last chapter suggested that dependants could be divided into three groups; one group finding it a positive experience, a second group tolerating their stay with a final group positively disliking the experience. The majority of those tolerating the experience described periods of inactivity and boredom, with little therapeutic input. The observational data give a indication of how respite users actually spent their time, providing a comparative frame of reference for the users' subjective impressions of the relative lack of activity.

The data summarised in this section are taken from the structured observations undertaken by the two research assistants based at Tudwal and Castell. Each assistant spent a fortnight at one unit and during nine observation periods sampled activity patterns which represented the period 8 am. to 8 pm. during weekdays and over the week-end. Six patients were observed each day on a 10 minute time sample, and in this way 1995 observations were recorded at Tudwal and 1963 at Castell. Whilst observations were focussed on rota bed users, they were also recorded on both long-stay and other short-stay patients in order to provide some comparative data. Thus, approximately 60% of the observations at each unit were on rota bed users and the remainder on other patients. In total 24 different patients were observed at Castell and 25 at Tudwal.

During the observation period bed occupancy and staffing levels were also recorded. At Tudwal the mean number of patients was 24 (range 22-28) whilst at Castell it was 20 (range 18-22). The lower bed occupancy at Castell reflected the consultant's absence for part of the period, with a consequent fall in referrals. Both wards seemed to have broadly similar staffing levels, with about 50-60% of staff on duty at any one time being unqualified nursing auxiliaries. Tudwal had a higher proportion of first level nurses (seven compared to two) although not all of these were full-time. On an early shift both wards usually had six staff on duty, with four staff covering the late shift. It will be recalled that Tudwal also had access to the day hospital with its own staff.

In presenting the results of the observation study the 13 category molar code has been collapsed into four major categories with social interaction being considered separately. Individuals were considered as being **'passive'** when not obviously engaged in any activity (codes in this category were doing nothing, doing nothing/watching, watching and asleep (see appendix 4 for operational definitions of codes). Activity was classed as **'Instrumental'** when it related to basic care needs (codes in this category were personal care, mobilising and eating/drinking. **Constructive'** activity includes the categories of informal activity, organised activity and treatment, indicating that the individual under observation was engaged in purposeful activity other than that relating to basic care needs. The last major category **'other'** includes times when an individual was unobserved or engaged in deviant behaviour.

If a patient was engaged in **interpersonal contact** at the time of observation this was recorded separately. For patient/patient or patient/visitor contact this indicated that the patient observed was engaged or being engaged in conversation at the time of observation. Staff/patient contact was recorded each time a member of staff was noted to be attending to a patient, whether or not conversation was occurring. Futhermore, when staff/patient verbal interaction occurred observers made a judgement as to whether the interaction was **instrumental** (giving instruction or seeking cooperation/information) or **social**. Thus staff/patient contact is divided into three types: contact but **no conversation**, contact with **instrumental conversation** and contact with **social conversation**.

In the first set of tables below the activity and interaction patterns of three groups of patients (rota bed users/long-stay/short-stay) are presented for each of the two units. It will be noted that significant differences emerge, especially with regard to the long-stay patients as compared to the other two groups.

Table 10: Patient activity Castell Ward

Total observations n=1963

Engagement	Patient category Rota (n=1172) %	 Long-stay (n=414) %	 Short-stay (n=377) %
Passive	31	76	40
Constructive	46	7	41
Instrumental	21	15	17
Other	2	3	2
	χ^2 =283.59	6df	Sig < .001

Table 11: Patient interaction Castell Ward

Total observations n=1963

Interacting with	Patient category Rota (n=1172) %	 Long-stay (n=414) %	 Short-stay (n=377) %
No interaction	81	88	73
Patient/patient	4	0	8
Patient/visitor	3	1	12
Patient/staff with			
No conversation	2	4	1
Instrumental	7	6	4
Social	3	1	2
	χ^2 =116.35	10 df	sig < .001

Table 12: Patient activity Tudwal Ward

Total observations n=1995

Engagement	Patient category Rota (n=1257) %	 Long-stay (n=517) %	 Short-stay (n=221) %
Passive	46	74	44
Constructive	36	10	39
Instrumental	16	15	18
Other	2	1	0

χ^2 = 156.52 6 df sig <.001

Table 13: Patient interaction Tudwal Ward

Total observations n=1995

Interacting with	Patient category Rota (n=1257) %	 Long-stay (n=517) %	 Short-stay (n=221) %
No interaction	70	80	71
Patient/patient	10	3	12
Patient/visitor	4	1	4
Patient/staff with			
No conversation	8	11	5
Instrumental	1	1	0
Social	7	5	7

χ^2 = 52.88 10 df sig <.001

For both wards there are significantly higher levels of activity and interaction amongst the rota bed users and other short-stay patients than amongst the long-stay patients. Given the dependency and mental frailty of the latter group this is perhaps not unexpected. It is apparent that the long-stay patients on both wards spend the majority of their time disengaged and isolated from human contact. Such constructive activity and social interaction as there was amongst long-stay patients was almost exclusively confined to one or two slightly less dependant individuals who were able to spend their time in the day room. When these patients were excluded from the analysis those long-stay patients at both units who were nursed in bed or in a chair within their own bay area were passive for 87% of the time. The remainder of their time was taken up with instrumental activity. Hence, other than attention to nutritional and personal care needs, these long-stay patients did nothing at all.

It also seems that rota bed users and other short-stay patients within the same ward spend similar periods engaged in constructive activity. The proportions being virtually identical in Tudwal ward (36% rota/39% short-stay), whilst in Castell ward rota bed users spend slightly more of the day engaged in some form of constructive activity (46% rota/41% short-stay). When comparing the two wards the short-stay patients were engaged for comparative periods of time (39% Tudwal/41% Castell) but in Castell the rota bed patients were more active (36% constructive activity Tudwal/46% constructive activity Castell). This is perhaps surprising given the presence of the day hospital at Tudwal. This apparent anomaly is examined later in this chapter.

The above pattern seems to be reversed with respect to interaction, especially amongst rota bed users (Rota beds users 30% interaction Tudwal/19% Castell). Once again it seems that the short-stay patients have similar levels of social interaction on both wards (29% Tudwal/27% Castell) although a greater proportion of this is accounted for by visitors at Castell.

Whilst there is a relatively small proportion of staff-patient contact at either unit (from a low of 7% for short-stay patients on Castell to a high of 17% for long-stay patients on Tudwal) there are more staff-patient interactions at Tudwal across patient groups and the nature of these interactions is qualitatively different, with more instrumental verbal interaction at Castell and more social verbal interaction at Tudwal.

In the tables which follow, closer attention is given to these inter-unit differences comparing particularly levels of constructive activity amongst rota bed users and interaction patterns for all groups of patients.

Table 14: Constructive activity: rota bed users

Total number observations engaged in constructive activity
Castell n=539 Tudwal n=453

Type of activity	C %	T %
Informal	96	83
Organised	0	11
Treatment	4	6

$\chi^2 = 64.31$ 2 df sig <.001

It is first of all apparent that practically all the constructive activity at both units was informal, initiated of the patients own volition. Secondly, there was very little active treatment at either unit. Thirdly there was no organised activity at Castell (although a trip which had been organised had to be cancelled due to staff shortages). The differences in facilities and numbers of therapy staff between the two units might help explain these variations. Indeed, with the presence of the day hospital at Tudwal one would perhaps expect them to be greater than they are. On the other hand, some of the rota bed users at Tudwal chose not to attend the day hospital, preferring to sit by their bed and read or chat. This indicated that rota bed users exercised a degree of choice about how they spent their time. There was no pressure placed on patients to attend the day hospital. This is a positive feature which will be elaborated on later in the chapter.

There were also qualitative variations in the type of activity between the two units. Informal activity at Castell consisted in the main of watching television, with patients spending most of the day in the dayroom with the television switched on. For some individuals this activity was interspersed with conversation or with spells of reading the newspaper. At Tudwal, on the other hand, few rota bed patients spent their day in the dayroom. Patients enjoying organised activity spent their time at the day hospital, whilst those who wished to read, or just sit and chat, remained by their beds.

These differences seemed to contribute to the higher levels of patient-patient and staff-patient interaction at Tudwal. The presence of a television, whilst undoubtedly providing a stimulus for a number of patients, did not encourage verbal interaction. Whereas patients in Tudwal ward could chat in the day hospital or by their beds. Most of the staff-patient social interaction was seen to occur at the day hospital and patients at Tudwal had contact with a greater range and variation of differing staff members. At Castell 95% of all staff-patient contact was with nursing staff, 58% with unqualified staff. However at Tudwal only 55% of staff-patient contact was with nursing staff, most of the remainder being with day hospital staff, notably one particularly active therapy aide who on her own accounted for 24% of the total staff-patient contact as well as for the greatest proportion of the organised activity. This suggests how just one person who is free to concentrate on activities alone can significantly improve levels of both social interaction and activity. Self-evidently this need not be a professionally qualified individual.

It was also noticeable to the observers that much of the staff-patient contact was centred on the more sociable patients, a subjective impression borne out when patient interaction was analysed by patient sociability (as rated by staff). This is demonstrated in Tables 15 and 16 below. Here patients have been divided into three groups, those classed as **sociable** easy and interesting to talk to, those as **not very** or **not at all sociable** and those who, because of speech difficulties or confusion were considered to be **unable to socialise**. These differences are highly significant at both units. Despite the overall low levels of activity at Castell the significant trend towards the more sociable patients as being the more engaged in interaction is apparent. Also, whilst staff-patient interaction was very similar across groups and at Castell occurred predominantly during care related tasks, this was more likely to be of a social nature with sociable patients, and of an instrumental nature with patients perceived as unsociable.

At Tudwal, where there were much higher levels of interaction, there were also highly significant differences between groups. Patients classed as sociable clearly got the lions share of the interaction, from both patients and staff, although those patients who were less sociable or could not socialise had more staff interaction at Tudwal than even the most sociable at Castell. Somewhat paradoxically, there were more instances of staff-patient contact without conversation at Tudwal. For sociable patients these were more often seen to occur in a social context, for example whilst playing cards or bingo. For less sociable patients contact without conversation mostly took place during instrumental tasks such as handing out meals or assisting with personal care, whilst for patients unable to socialise most contact either with or without conversation took place in a care-related context.

From these data it appears, as the research previously reviewed would suggest, that socially skilled and adept patients attract more interaction both from other patients and staff. This was common to both units. This is not be interpreted to mean that basic physical needs of patients went unmet as there were almost identical levels of staff-patient care-related contact across units, with relatively more time being spent on direct physical care with the long-stay patients. However, during care-related contact staff were more likely to engage in social conversation with the socially adept. When the staff had some spare time, it was noticeable that they engaged in social interaction for its own sake with these same patients.

Such an observation is perhaps not surprising, being consistent with previous literature and is in no way intended as a criticism of staff. It is easy to appreciate how, given a little free time, staff would unconsciously gravitate towards the more socially able patients who could reciprocate. It was apparent that staff at both units had developed good relationships with a number of rota bed users and that such relationships were mutually reinforcing. Furthermore, as will be demonstrated shortly, many staff identified the most interesting aspect of their work as that relating to interpersonal relationships.

The extent to which these higher levels of interaction with rota bed users and the socially able detracted from the attention given to long-stay patients remains problematic. However, for those few long-stay patients capable of social interaction the rota bed users were a benefit, as indeed they were for the short-stay patients.

Table 15: Interaction by sociability at Castell

Total observations n=1963

Interacting with	Patient category		
	Sociable	Not Sociable	Unable
	(n=1361)	(n=301)	(n=301)
	%	%	%
No interaction	81	86	85
Patient/patient	5	2	1
Patient/visitor	4	1	5
Staff/patient with			
No conversation	2	2	4
Instrumental	5	8	6
Social	3	1	0

χ^2 =44.12 10 df sig <.001

Table 16: Interaction by sociability at Tudwal

Toatl observations n=1995

Interacting with	Patient category		
	Sociable	Not sociable	Unable
	(n=699)	(n=964)	(n=332)
	%	%	%
No interaction	59	78	84
Patient/patient	17	5	1
Patient/visitor	3	5	1
Staff/patient with			
No conversation	9	6	10
Instrumental	1	1	0
Social	11	5	5

χ^2 =168.22 10 df sig <.001

The group comparisons shown in tables 15 and 16, whilst illustrative of the points raised above, can also be misleading. In comparing individual differences, sociability on its own was insufficient to explain variations in interaction levels for these also had to do with opportunity, familiarity, gender and culture. Thus individuals amongst the rota bed users who had been coming longer, were female and Welsh speaking were more likely to be socially active, even though other individuals were classed as being sociable. Also, choosing to go to the dayroom or day hospital was more likely to result in staff-patient contact. At the same time some patients preferred their own company so that low levels of social contact for them did not necessarily affect their quality of life. Indeed enforced contact, as with activity, is no better than its opposite. A few more detailed descriptions of individual rota bed experiences will serve to illustrate these points. All of the individuals below were described as sociable by staff. All names are pseudonyms.

Mrs Llewelyn was a 79 year old woman who had been using the rota beds for a number of years. She was a fluent Welsh speaker and had an out-going and friendly personality. She chose to attend the day hospital during the week but was equally happy and active sitting by her bed at the week-end. During six days of observation she was passive, on average, for only 24% of observations. She spent the day reading, engaged in group activities but mostly talking to anyone who would listen. Indeed she was interacting for 48% of observations over a six day period, this time being almost equally divided between patients and staff. The research assistant noted that following her discharge the whole ward seemed decidedly quiet and subdued. When interviewed Mrs Llewelyn was most positive about the rota beds, describing how she looked forward to each two week stay.

Mrs Braithwaite had also been using the respite system for many years. In contrast to Mrs Llewelyn she chose to stay in bed and despite the fact that staff considered her capable of sitting in the chair they respected her usual pattern, as Mrs. Braithwaite also insisted on staying in bed whilst at home. As a result, she had relatively little patient-patient interaction as the other patients from her bay went to the dayroom. Over a four day period she was not interacting for 81% of all observations. However, this was her choice and staff were left to 'pop-in' to see her. The mean staff-patient social contact for her of 7% over the four day period was over twice the average for sociable patients at Castell. Although she was on her own for long periods this did not mean that she was inactive. Indeed only 18% of observations suggested that she was passive. Rather Mrs. Braithwaite spent long periods reading and listening to the radio, her normal pattern whilst at home.

Mrs. Williams, another 'old hand,' also chose to stay by her bed despite the availability of the day hospital. She was noted to have a good relationship with another rota bed user who also preferred to sit out by her bed and these two spent long periods chatting. Therefore, Mrs. Williams was interacting on 42% of all observations and was passive for only 36% of observed time, interspersing her conversations with reading.

These three women all had positive respite experiences and were in the group which made this clear at interview. Futhermore their carers also described the benefits of the rota bed stay in regard to the maintenance of peer group contact. In addition, a high degree of choice was apparent, in that staff respected these patients' wishes to spend their time as they decided.

In contrast the two men described below did not have so positive a respite experience.

Mr. Smith , by comparison to most of the other patients, was a young man in his late sixties. He had only recently (within the last 12 months) had a stroke and had been told that functional recovery was possible up to two years after the initial crisis. He was an English migrant who had retired to the area only shortly before his stroke. His comparative youth and inability to speak Welsh meant that he had little in common with most of his fellow patients, the majority of whom were older, female and spoke Welsh as a first language. Whilst he was classed as a sociable man, Mr. Smith spent most of his time in the day room either watching the T.V. or doing crossword puzzles. Over a seven day period he was seen to engage in interaction on only 10% of observations, but was passive for only three percent of observed time. When interviewed it was clear that this was Mr. Smith's usual pattern at home. He was apparently an avid crossword fan. Furthermore, he considered that the staff were friendly and made an effort, within the constraints of the institution, to accomodate his usual habit of going to bed very late (well past midnight) and of rising late in the mornings. However, on the whole he was dissatisfied with the respite care and tolerated it at best. One of the main causes of this dissatisfaction was attributable to the lack of therapy he received. Mr. Smith, not unreasonably, considered that as he was in hospital he should have been receiving regular physiotherapy. Because there was extremely limited therapeutic programming input at Castell he received minimal physiotherapy over the two week period. His expectations for treatment were not met and he could see no positive personal benefits to the respite admission.

Mr. Peters, like Mr. Smith, was a fairly recent user of the rota beds and also an English migrant. He was, however, considerably older, blind and confined to a wheelchair. Staff encouraged Mr. Peters to go to the day hospital, but because of a problem with urinary frequency he resisted this and as a result spent most of his time in the dayroom. Staff sat him by a table and ensured that he had a drink to hand and a call bell with which he could summon help if needed. However he was usually the only man in the dayroom and consequently spent most of his time passive (77% of observations over a three day period) and in isolation (only 14% in contact with anyone, of which the vast majority was staff contact without conversation). Indeed over a three day period only 4% of observations included verbal interaction. When interviewed Mr. Peters, although initially stoic and uncomplaining, expressed his dissatisfaction with the respite experience. It was only his second period of attendance and he clearly did not relish the prospect of many more even though he appreciated that his wife needed the break. When asked what he did at home he indicated that his great joy was listening to talking books. Asked if he had informed staff of this he said 'no' as he did not wish to disturb the other patients. When the author suggested that earphones should have been possible he admitted that he had not thought of that possibility. Neither, as was clear, had the staff. In this case whilst staff had encouraged Mr.Peters to attend the day hospital they had not really been creative in seeking ways in which Mr. Peters could have more constructively passed his time.

These vignettes provide some insights into the nature of individual differences in rota bed admissions.

On the basis of these observational data, can the respite admissions be seen to have provided for purposeful activity that encouraged social interaction, raised self-esteem and provided access to a full range of therapeutic services giving evidence of a planned individual approach?

Obviously, this varied not only between units but also between individuals. The presence of the day hospital, with its access to a wider range of staff and to day patients, seemed to result in higher levels of social interaction at Tudwal and the chance to engage in organised activities. Whilst there were higher levels of constructive activity at Castell this was largely watching T.V.. This may have reflected the personal preference and normal activity pattern of some individuals, but conversely resulted in others having fewer opportunities for social interaction.

It was also clear that much of the higher levels of interaction and activity at Tudwal were the result of the activities of one particular therapy aide who acted as a facilitator and catalyst. It was noted by the observers at both units that whilst nurses had developed relationships with a number of patients, they rarely took what opportunities were available to initiate group activity. It seems that nurses are still reluctant to see this as a legitimate part of their work, valuing the obvious nursing duties more highly. This was described in the literature reviewed in Chapter Three and was also apparent from the staff interviews. It perhaps explains, as Tyler (1989) noted why care needs are generally well attended to during respite care, but why higher levels needs for cognitive stimulation are generally poorly met. This reluctance of nurses to become engaged in providing activities for patients has been described by other researchers who have spent periods of time observing care in hospitals for the elderly (Godlove et al 1981, Clark and Bowling 1989) and is an area to which attention will need to be given if the situation is to be improved.

In the present study staff were aware of limited chances for activities but saw this being a result of too few therapy staff, rather than something they themselves might address. Certainly the lack of therapy staff delimited opportunities for physiotherapy at Castell and this was seen as detrimental by both staff and patients. Whilst each rota bed patient had a medical and nursing assessment during each stay there was little in the way of physical therapy.

It is also necessary to put these observations into some form of context. During the time spent at Tudwal and Castell there were many examples of good care witnessed. Patients had choice as to how to spend their day and activities often reflected individual preferences. This was clearly important in distinguishing those rota bed users who valued their stay from those who did not.

The levels of activity and interaction in the present study were far higher than has been noted in some observational research in similar environments. For example, Godlove et al (1981), in observing the activity levels of moderately impaired elderly individuals in a number of slow stream rehabilitation wards, noted that only 14.5% of time was spent in constructive activity, 68% of time totally passive and only 16% of time in contact (both verbal and non-verbal) with another person. These observations were made between 10am to 4 pm, rather than the 8 am to 8 pm period used in the present study, when one might reasonably expect there to be higher levels of constructive activity. This makes the levels of constructive activity in the present study seem more impressive by comparison.

Having described how the rota bed and other patients spent their time attention is now turned to the environment and organisation of care. Here, consideration is given to evidence of the key elements within the typology of Wade and colleagues (Wade et al 1983, Wade 1983), these being autonomy, choice, privacy, salience, patient and visitor consultation and participation, and a planned individual approach to care.

8.4 The environment and organisation of care

The data on which this section is based came from two main sources. Firstly, there were the subjective impressions and observational notes of the author and the two research assistants. These were collected by the author over his repeated visits to Castell and Tudwal and by the assistants during the structured observations. Secondly, there were the responses of the staff to the questionnaire which gave their impressions of work with elderly patients and of those aspects of work that they found most interesting, important and difficult, together with the completion by qualified staff of the environment of care checklist. Attention is first given to the impressions of the reseachers.

(i) Subjective impressions of the ward environment

In terms of the physical environment both units are perhaps best considered as adequate rather than very good. This had nothing to do with staff but is in recognition of the fact that there were limitations to the degree to which compensation could be made for the structure of the buildings. The wards were generally light and airy with attractive bedding and curtains, which were nonetheless obviously institutional. Both wards were considered to be exceptionally clean and yet not sterile, with evidence of personal possessions. There was limited day and dining space, especially at Tudwal and most of the accommodation was in six bedded bays with very few individual rooms. Therefore, whilst each patient had some personal space and a locker, privacy was lacking, as was a quiet area. Both wards had attractive views out on to open spaces.

Aspects of the social environment have already been described in the previous section but both observers thought that the staff were friendly creating a general atmosphere which was happy and, as far as was possible, homely. Such considerations applied equally to domestic and other staff, giving what the observers described as a 'family feel' to the wards.

The standard of physical care on both wards was considered as high and there was certainly no evidence of the poor, often verging on the abusive, care that has been described by some observers within similar environemnts (Godlove et al 1981, Clark and Bowling 1989). Patients who were nursed out of bed were dressed, wherever possible in their own clothes.

Whilst there were indications that individual preferences and choices were catered for, most of the care, especially that provided to the long-stay patients, was routine rather than individualised. Also, as already highlighted, whilst staff had personal knowledge of some respite users preferences, this information was collected serendipitously and over a period of time rather than being systematically sought for each patient. Furthermore such information was rarely recorded within the patient's records. Therefore it cannot be said that truly individualised care was planned on a rational basis and delivered to all patients; rather the regime would seem closest to that described by Evers (1981a) as 'personalised warehousing.'

(ii) Staff data and biographical details

The staff interviews revealed the very positive light in which the rota beds were seen and provided clear indications of the improved staff morale and job satisfaction that eventually resulted from their introduction. The data below are from the structured questionnaires completed by both qualified and unqualified staff at Castell and Tudwal.

At Tudwal there was a higher response rate, with a good return from both qualified (7/8) and unqualified staff (7/9). At Castell the response rate was lower, with proportinately fewer questionnaires being returned form qualified staff (3/7 qualified, 7/10 unqualified). Therefore the views of unqualified staff from both wards are well represented, but the views of qualified staff from Castell are not as representative as those at Tudwal. The total number of completed questionnaires was 10 from members of qualified staff and 14 from unqualified staff.

These questionnaires provided basic biographical details of age, qualifications, time spent working with the elderly, and so on, together with reasons for working with the elderly. Data were also sought as to the purpose and benefits of the rota beds and these were presented in the previous chapter. Data considered here relate to responses to open questions asking staff to describe in their own words what they felt about nursing older people and also to indicate the most important, the most interesting and the most difficult part of their work. Trained staff also completed the environment of care checklist which operationalised a well known typology of care models (Wade et al 1983, Wade 1983). Attention is first given to the biographical details.

It was obvious that most staff had worked with the elderly for a number of years, usually at the same unit.

At Castell, the mean age for qualified staff completing the questionnaire was 50 years (range 45-57). Staff had been working with the elderly for an average of 13 years, with 7.6 of these being at Castell. The mean age for unqualified staff was 37.5 years (range 20-56). They had been working with the elderly for 8.8 years, nearly all of this time (7.7 years) being at Castell. Three quarters of staff (13/17) had spent all their time at Castell. Of these staff seven considered they had no real choice in the original decision to work at Castell and took the job because it was the only one they could get: three took the most convenient job and seven made a conscious and deliberate choice to work with the elderly.

A similar picture emerged at Tudwal. The average age for qualified staff was somewhat younger at 41.5 years (range 23-55), with staff having worked with the elderly on average for 8.0 years with nearly seven and a half of these at Tudwal. For unqualified personnel the mean age was 42 years (range 28-56) with a mean time working with the elderly of 7.8 years, 6.8 of these at Tudwal. Twelve of the staff had spent all their time at Tudwal, eight considering themselves as having no choice in the original decision as to where to work, with the same number making a positive decision to work with the elderly.

Therefore, in terms of staff both wards had a fairly stable workforce comprising in the main of more mature individuals. Roughly half of the staff had originally taken the job because it was a job and the others took it because it was the one they wanted. All of the workforce were women. What then were their perceptions of their work?

(iii) Staff perceptions of working with the elderly

It was felt important to elicit staff perceptions of work with the elderly for two main reasons. Firstly they provided a check on those perceptions given at interview and secondly they gave some indication of staff attitudes to their work. This last point is of particular importance as much of the literature on the quality of care given to older hospitalised individuals reviewed in Chapter three suggested that staff attitudes are more important determinants of care than staffing levels.

Staff perceptions were elicited by means of a series of open questions asking them to provide a general description of work with older people, followed by a more specific consideration of the most important, interesting and difficult aspects of such work. In applying a content analysis to the responses to the open questions a number of analytically and conceptually distinct themes emerged for each question.

In terms of their general descriptions of working with older people responses could be distinguished by the extent of the **positive or negative content** of the answers provided. Thus a continuum was created with responses containing only negative statements (coded **totally negative**) at one end and those containing only positive statements (coded **totally positive**) at the other. Categories in between were **essentially negative** (where there was some positive elements but the overall impression remained negative), **neutral** and **essentially positive** (where difficult aspects of the work were acknowledged but the overall impression was positive).

For both trained and untrained staff at both units the majority of responses were either **essentially positive** or **totally positive**. The trained staff (7/10) were more likely to see work in essentially positive terms, recognising the demanding nature of the work, but stressing the positive aspects:

> "Nursing with the elderly involves a lot of hard work and can be frustrating at times because they are still treated as the cinderellas of the service. However it's always rewarding and always fun"

For most of the unqualified staff (11/14) the work was seen as being totally positive. These perceptions reinforce those given at interview. Despite both the long periods of time staff had spent at each unit and the lack of vocational interest expressed initially in working with the elderly, most derived considerable satisfaction from their work. From the interviews this was attributed almost solely to the respite beds and the changes they had brought about.

Reponses to the most important part of their work could be divided into three categories. The first of these was described as **'essentially caring'** and indicated that the most important aspect related to fostering a kindly and protective environment for patients. The second category was termed **'essentially tending'** and indicated the importance of meeting basic nutritional and hygiene needs. The last category **'essentially autonomous'** suggested that the most important aspects of working with the elderly was the maintenance of personal choice and independence.

Responses of both qualified and unqualified staff at both units fitted mainly into the first two categories. Thus only one unqualified staff member and two qualified staff described the most important aspect of caring for the elderly as maintaining choice and independence. The response given by the majority of respondents (6/10 qualified, 10/14 unqualified) clearly indicated that the most important aspect of their work was about being caring. For most this meant creating a homely environment and exhibiting such personal characteristics as kindness and patience. Whilst this was undoubtedly positive in tone, the fact that only three respondents stressed the importance of maintaining independence suggests why this goal is perhaps so rarely reached. However, this should perhaps still be seen as a positive indication as a number of writers whose work was reviewed in Chapter Three have criticised nurses for failing to value the caring aspects of their role.

In terms of the interesting aspects of their work reponses were clearly divisible into four groups. **'Essentially interpersonal'** responses stressed, as the name suggests, the positive aspects of staff-patient interactions. Responses were coded as **'essentially physical'** where emphasis was placed on the improvements in a patient's condition and health status, whereas the conceptually similar but nonetheless distinct **'essentially rehabilitative'** responses emphasised functional ability. The last category **'essentially psychological'** related to maintaining a patients mood and happiness.

For half of the staff (4/10 qualified, 8/14 unqualified) the most interesting aspect of their work was **interpersonal**, clearly indicating the importance of getting to know patients and listening to them talk about themselves. This again should be seen as positive as nurses have also been criticised for failing to value interpersonal relationships with patients. However, it also helps explain why the more sociable patients commanded staff attention. The majority of the remainder of the responses (4/10 qualified, 4/14 unqualified) were **essentially physical** and this gives an indication, as Evers (1981a) points out, that many staff still get a major part of their satisfaction from the 'magic of cure'. The fact that staff identified the two most interesting aspects of their work as resulting from interpersonal relationships with patients and an improved health status for patients gives a further indication as to why respite care and other short-stay patients were seen to have improved the quality of staffs' working environment.

Staff perceptions of work difficulties could be coded into three groups. One group described difficult aspects specifically in relation to certain **categories of patients**, most notably the confused and the aggressive patient. Those patients with communication difficulties, incontinence and pressure sores were also described as making work with the elderly difficult.

Another significant cause of difficulties for some staff was as a result of a patient's **failure to respond to treatment.** The death of a familiar patient often caused staff considerable personal distress, again reinforcing the importance of interpersonal relationships and also problems encountered when cure did not result. The third group of difficulties mentioned by a small number of staff were **administrative** and concerned a lack of facilities, time and resources.

Interestingly, qualified and unqualified staff could be split into two almost equal groups. Other than those qualified staff who mentioned administrative problems (2/10), all the difficulties **trained staff** revolved around **problem patients**, especially **confused or aggressive** individuals. Therefore it was easy to see how a respite user who fell into this category was perceived as particularly problematic. On the other hand virtually all of the **auxiliary staff** (12/14) saw the most difficult part of their job as relating to the **helplessness** they felt when a patients condition deteriorated and especially when a patient died.

Although based on a small sample of staff, the responses to the open questions were instructive in fleshing out the interview data and in providing insights into how staff perceptions affected the care provided.

Thus, the value and impact of the introduction of respite care was reinforced as it provided staff with interesting and important aspects of their work.

It was suggested above that the ward regime at both Castell and Tudwal might best be described as 'personalised warehousing' (Evers 1981a) in which individual choice was given but with care still being delivered in a routine fashion. From the staff responses it is possible to suggest some of the factors operating to produce this result. That staff saw the important aspects of their work as essentially caring or essentially tending indicates how things might be done paternalistically in the best interests of the patient. Therefore Evers' (1981a) notion of tender loving care, whilst intending to facilitate greater patient involvement might in fact do the opposite. It is not until staff perceive the important and interesting aspects of their work as relating to the promotion of independence that real choice and participation is likely to result for patients. In this sense it is perhaps not to the benefit of patients, even those requiring extensive assistance, for nursing to be described in terms of care. Rather the concept of facilitation or enablement would be more appropriate. This is an issue which will be more fully considered in the next chapter.

Having considered staff responses to the open questions, attention is now turned to those qualified staff who completed the typology checklist.

(iv) The typology of care checklist

It should be emphasised at this point that the checklist is best considered as an exploratory instrument in its developmental stages. The analysis of the results is therefore confined to the consideration of broad patterns within the data. The distribution of responses from staff can be found in appendix 11. Notwithstanding these limitations the checklist provided some interesting and instructive results.

The checklist was completed by 10 qualified members of staff, 3 at Castell and 7 at Tudwal, and was intended to provide an indication of the extent to which the environments of care equated with the supportive environment recommended by Wade et al (1983). Such an environment should ideally facilitate consultation, choice and salience of activities and incorporate a staff-resident committee. There should be a therapeutic input and a range of activites organised by the elderly themselves. Visitors and volunteers should have full access to the unit with unrestricted visiting and involvement in the regime of care.

Staff completed the checklist considering the extent to which these criteria were met within their present care regime (all/most of the time, some of the time, rarely, if ever) and also how desirable and possible each option was (desirable and possible, desirable but not possible, not desirable). Given that there was room for some improvement to the regime of care on both wards the results were instructive from two viewpoints.

Firstly, there was little consensus amongst staff as to the extent to which their ward met the criteria on the checklist. Some staff clearly considered that their ward met many of the criteria whereas others felt it met few. Even with the low numbers of staff completing the checklist there was only complete agreement on a very limited range of criteria. This would suggest both the lack of an **agreed definition** as to what constitutes the elements on the checklist and the absence of any **explicit conceptual basis** underpinning the delivery of care. The failure of nurses to explicate their therapeutic nursing function by reference to a relevant theoretical model has been identified by Kitson (1984, 1988) as one of the major obstacles to improving the nursing care received by elderly patients. Clearly until there is agreement on such crucial issues as to whether patients already have sufficient choice or involvement in their own care, then change designed to bring about improvements in the regime of care is likely to be unsuccessful.

Secondly, with few exceptions, there was **no agreement** as to which of the criteria were **desirable**. For example some staff felt that patients should attend case conferences, whereas others considered that this was inappropriate.

Thus motivation for change is likely to be poor where some staff feel that they are already achieving many of the criteria of good care and others feel that some of the changes are not desirable. Furthermore, even items seen as desirable were often deemed not to be possible and if change were to be introduced the conditions for making desirable items possible would need to be sought.

Despite this lack of consensus most staff descriptions of the model of care discernible from the checklist indicated one in which patients experienced limited choice and involvement, but enjoyed open visiting and a varied, but modest, therapeutic input. In terms of the ideal types in the original typology the model was an amalgam of the protective and controlled models (Wade et al 1983, Wade 1983). Therefore despite the exploratory nature of the checklist the instrument was thought to have produced data which were given concurrent validity when compared to the author's and observers' impressions.

The checklist is also thought to warrant further development especially as a component of a planned change initiative or action research project. Here it could be used to determine existing perspectives, to establish the degree to which they were shared by all the key actors and to identify sources of resistance to change that may need to be tackled. Moreover the checklist would prove very useful as a precursor to a standard setting exercise, which relies on the identification of agreed aims and outcomes of care. Further attention will be turned to this point in the concluding chapter.

This detailed consideration of the respite care experience and the environment of care concludes the presentation of the empirical results. In the following, and final chapter, a brief summary and synthesis of the project is presented prior to a consideration of the theoretical, methodological, policy and practice implications.

CHAPTER NINE

SUMMARY AND CONCLUSIONS

"Life is like 10 speed bicycle, we all have gears we don't use"
(Charles Schulz)

The research described represented an attempt to develop and implement an evaluation of a specific service within a defined geographical location. The service in question was the provision of respite care for carers of the dependent elderly in the form of regular periodic admission of elderly persons to continuing care hospitals, so called **rota beds**. The location was the county of Gwynedd in North Wales.

In the event it is felt that the results have wider policy and practice implications ranging from the provision of respite care and services for carers in general to the nature of long-term care for the dependent elderly. There are also professional and inter-professional issues concerning the assessment for, and provision of, the above services in addition to broader theoretical and methodological concerns. Before discussing these, a brief summary of the conceptual underpinnings of the study is presented together with the rationale for the evaluation guide which gave direction and focus to the empirical work. This is followed by a synopsis and discussion of the main results.

9.1 Constructing and operationalising the evaluation guide

(i) Current literature on evaluation and respite care

The literature review on the nature of evaluation and evaluation research with which the thesis began illustrated the tension between early methodological approaches located within the positivist paradigm and their empirical application to services which often lacked any clearly articulated aims. Furthermore, as the science of evaluation developed, it soon became apparent that even where explicit aims could be identified, services often had unintended consequences. These consequences, which could be desirable or undesirable, were seen to apply not only to the original recipient of the service but also to other groups.

The complexities of the empirical world lead evaluators to seek methods that would accommodate multiple perspectives in efforts to determine not only if a service worked but also address important contextual questions such as **how** and **why** it worked.

Following this review of the literature the **ontological, epistemological and methodological** bases of evaluation were challenged and a case was presented for the adoption of a **pluralistic approach** to evaluation. This essentially seeks to identify the perspectives of each major stakeholder group involved in the provision, delivery and receipt of a service. These subjective impressions are elicited within a multi-method triangulated design and form the basis for inferences about service success and quality.

Attention was then turned to the empirical literature on the provision of respite care, tracing the history and development of the service from its origins in the 1950's to the present day.

It was apparent that respite care is seen as being a 'good thing' so that, quantitatively, it now represents the most significant service provided for carers. However, the nature of its benefits are often implicit and most descriptions of these are anecdotal. It was also apparent that current provision is piecemeal and fragmented. Moreover, access to most respite services is restricted by eligibility criteria which, in the case of hospital services, equate dependency with need. This restricted access is often accentuated by formal referral mechanisms.

Applying a pluralistic rationale to respite care it was argued that four main stakeholder groups could be identified; carers, their elderly dependants, care staff and the more permanent patients living within the institutions in which the respite care was located.

From the literature it was evident that carers were seen as the main beneficiaries of respite care. However, respite care schemes appeared to have operational aims conceived largely in instrumental terms. It was suggested that many carers benefitted from the respite break which allows them to replenish their physical and emotional reserves and maintain contact with a wider circle of family and friends. It also permitted some personal time free from the constant demands of care which was utilised in a variety of ways ranging from the completion of neglected domestic tasks to taking a holiday. Conversely, such benefits were not without their costs and many carers experienced guilt at allowing dependants to enter institutional care. There was little in the literature to indicate that respite care might also afford the opportunity to attend to the wider needs of carers for information, skills training and emotional support.

Hospital based respite care was seen to facilitate regular assessment of the dependant and notionally to improve health and functional ability as a result of therapeutic treatment during the respite admission. The literature was equivocal on this point and there were indications that dependants returned home less mobile, less continent and more confused, a situation which understandably detracted from any benefits the carer might receive. Even where physical care was adequate it seems that respite care rarely makes provision for the cognitive and esteem needs of the older person.

The scant literature on the implications of respite services for staff suggested that their attitudes were vital determinants of the quality of the respite experience for both carers and dependants. It was apparent that where staff recognised the sense of guilt which carers could experience and helped them to address it, and that when specific attention was given to the needs of the dependant, that respite care was more likely to be optimally effective. Such conditions rarely exist however and it seems that staff usually fail to appreciate and compensate for the deleterious effects of respite care for either carer or dependant. On a more positive note, a small number of references did suggest that respite care improved the morale and satisfaction of hospital staff.

By comparison, the literature concerning the patients resident in the facilities in which the service was located was even more sparse. It was suggested, for respite care located within social services facilities, that respite users detract from the life of the residents and that jealousy between the two groups can often occur. Conversely, respite care in hospitals has been described as providing new contacts for isolated long-stay patients.

More recently a number of objective, experimentally based evaluations of respite services have failed to identify significant gains for either carer or dependant. Nonetheless, subjectively, carers still seem to value the service highly, further highlighting the tension between relatively objective measures of outcome and the percieved benefits of a service to those in receipt of it.

Despite the paucity of clear operational aims for respite care there was noted in the literature a trend towards identifying the potentially wider benefits for carers and their dependants. This led to a search of the empirical literature about the stakeholder groups so as to construct an evaluation guide cabable of suggesting what respite care could achieve.

(ii) The wider empirical literature on the stakeholder groups

(a) Carers

It was reasoned that if respite care is to fulfil its potential then it might, in addition to providing a break for carers, also take the opportunity to address their wider needs. This presupposes that these wider needs and the nature of the difficulties which carers face are fully appreciated.

Despite the extensive literature, the review revealed a failure to apply a consistent theoretical approach to the conceptualisation and measurement of the burdens of care. It was argued that carers' problems are best conceived of within a **transactional model** which focusses on the subjective appraisal of events rather than their objective characteristics. This allows for the possibility of the same event being differentially stress-provoking for each individual and for the same individual on different occasions.

It was also clear that current interventions with carers often failed to address their need for information, skills training and emotional support. It seemed reasonable to suggest that a rota bed respite care model, based as it is on a regular and repeated contact, might meet these needs.

(b) Elderly dependants

Respite care within the study area is based exclusively within continuing care hospitals. Therefore, in consulting the wider literature attention was focussed on these and similar environments.

It emerged that institutional regimes of the type predominant in continuing care environments have little positive to offer the respite user, the care provided being typically described as routine, depersonalised and with limited therapeutic input and stimulation. Nonetheless, this bleak picture appears to be the result of staff attitudes and the organisation of care more than an inevitable consequence of admission to an institution.

It was therefore argued that respite admissions do not **have** to have deleterious consequences so the literature was consulted in order to identify circumstances when more positive outcomes might accrue.

It was shown that initial admission to an institution is less traumatic when the older person perceives a degree of choice and desirability in the move, can identify a legitimate reason for admission and can see the admission as time-limited and reversible. The practice theory of Chenitz (1983) was suggested as a basis for identifying the effects of relocation on the older user.

Self-esteem was offered as a key concept via which to look to the potential of respite care. Following admission positive institutional environments are typically described as those which recognise the needs of the older person for autonomy and privacy and which maximize opportunities to exercise choice and a degree of control. Furthermore, the environment is seen as providing for social interaction and individually tailored activities. All of the above were considered to promote the self-esteem of the individual. A hospital based respite scheme has the added potential advantage of facilitating access to the full diagnostic and therapeutic interventions of the multi-disciplinary team. It was argued that there was no inherent reason why good respite care should not provide all of the above.

(c) Staff

From the foregoing it is apparent that the attitudes of staff are vital determinants of the respite experience and that if respite care is to achieve its full potential then staff have to be conscious of the full range of potential problems and benefits of the service for both carer and dependant. It was indicated that they also need to take deliberate actions to ensure that problems are minimised and benefits maximized.

It was further postulated that respite admissions could result in benefits for staff. The concept of **'rust out'** (Pennington and Pierce 1985) was presented as more useful than burn-out for understanding the position of staff in static and unchanging environments and it seemed that respite beds might introduce a variety to work with consequent improvement in staff morale and job satisfaction, especially amongst nurses.

(d) The long-stay patients

The limited attention given to the impact of respite beds on long-stay patients was identified from the literature review. However, it seemed that the throughput of new faces and personalities following the introduction of respite beds might result in a more stimulating environment for the long-stay patients. Conversely, if staff found the respite users interesting and stimulating, it was considered that less staff time might be spent interacting with the long-stay patients.

8.2 Conducting the study

Following this review of the wider literature an evaluation guide was constructed which suggested how the potential of respite care might be realised. This was used to shape the direction of the empirical study which was based on a three phase **multiple triangulated design.**

Phase one consisted of a national sample survey of the members of the Association of Carers (now Carers:National Association) via a postal questionnaire. It was the intention of the survey to provide an empirical test for the transactional model of stress which was adopted as the conceptual basis underpinning an understanding of carers problems. In order to operationalise this stage a new instrument (CADI:The Carers Assessment of Difficulties Index) was devised and incorporated into a multivariate causal path analysis using the computer packages SPSSX and LISREL VI. A content analysis was also applied to responses to open questions which asked carers to describe in their own words the difficulties and satisfactions that resulted from caring.

The second stage of the study consisted of a series of semi-structured interviews with carers, dependants and staff intimately involved with the provision of respite care in the western sector of the county of Gwynedd, North Wales. One hundred and forty two interviews were conducted with 50 carers, 30 dependants, 35 staff in four hospitals and 27 community nurses. These data provided detailed accounts of the perceived benefits and problems of the rota bed service. Although it had also been the intention to interview long-stay patients within the institutions providing the respite care this population proved too mentally frail to identify a meaningful sample. The interview data were subjected to a detailed content analysis.

The final stage of the data collection was an in-depth case study of two hospitals purposively selected to provide interesting areas of similarity and contrast. These studies were based on a two week period of structured observation undertaken by a research assistant at each unit. During this period a ten minute time sample incorporating a molar observation code was used to construct a detailed description of how patients spent their time at the two units. Dependency data were also collected for all the patients included in the observation study. In addition, qualified and unqualified nursing staff completed a structured questionnaire about the perceived benefits and problems of the rota bed service. It also asked them to describe in their own words the most important, interesting and difficult part of caring for older patients. In an attempt to elicit staff perceptions of the organisation of care a checklist was constructed which operationalised a well known typology of care models (Wade et al 1983).

8.3 The study results: a brief synopsis

The empirical results can usefully be summarised in three sections corresponding to the stages of the study.

(i) The results of the postal survey

The non-random method of identifying the postal sample suggests caution in generalising from the results. Nevertheless the survey respondents represented a large group of highly stressed carers providing care over a prolonged period to a highly dependent and mentally frail population of dependants. As such they would be considered a suitable target group for service interventions and the mechanisms operating to produce their stress are highly relevant if such interventions are to be effective in meeting their needs and expectations.

Both the quantitative and qualitative analyses demonstrated that subjective factors were far more important than dependency in the production of carer malaise and the results provided empirical validation for the transactional approach to understanding care-related stress.

Thus levels of physical dependency, incontinence and mental frailty did not appear in the causal path analysis. Factors operating to produce stress had far more to do with the nature of the carer/dependant relationship and the carer's perception of their caring role.

Specifically, stress resulted in situations where the carer felt that the person they were looking after was unappreciative, manipulative and overly demanding and refused to help and cooperate in their care. In such circumstances, carers found it difficult to maintain a meaningful relationship and experienced little satisfaction or reward. Many carers also felt out of control of events and were constantly on edge and unable to relax. The stress this caused was further heightened where the carer felt guilty and had little time to see to their own needs. Adequate financial resources and the importance of feeling that sufficient help was being received from the wider family were also important considerations. These variables were identified in both the qualitative and quantitative analyses which were conducted independently of each other, adding to the concurrent and construct validity of the findings.

Furthermore, from the qualitative data gathered from carers' responses to the open questions about their difficulties and satisfactions, it emerged that professional attitudes and service delivery patterns often increased carer stress. This was especially likely to occur when professionals concentrated efforts on the dependant and did not acknowledge the needs and expertise of the carers.

Despite the high stress levels experienced amongst the sample 60% found that some elements of caring provided satisfaction and these, like the difficulties they experienced, were linked very much to the nature of the carer/dependant relationship. There was also evidence that experiencing satisfaction could protect carers from some of the stresses. It emerged also that carers felt they were in possession of 'expert knowledge' which meant they perceived themselves as providing the best care available for their particular dependant. A widespread distrust of institutional care was in evidence .

Thus, if service interventions are to address care-related stresses it is clear that a central part of any assessment process must consider the carers' subjective appraisal of events and circumstances.

(ii) The results of the interview survey

Interviews with carers using the rota bed system focussed firstly on the caring role, its problems and satisfactions, and secondly on services received.

Data on the first of these topics, adding confirmation to the conclusions of the postal survey, described the most potent stresses as resulting from dependants who were manipulative, demanding and unappreciative. Those who had maintained a good relationship described few problems, even in the face of heavy caring demands, whereas for carers with a poor past or present relationship numerous difficulties emerged, even though dependency needs were minimal.

A crucial variable in the equation seemed to be the degree of choice carers felt they exercised when taking on the role. Thus, many carers had assumed an overt caring role at a time of crisis, some reluctantly as a result of what they perceived to be implicit or explicit pressure from medical personnel.

Over 90% of the carers were receiving support from the community nursing services and about 40% from the social services. It was apparent that the services of the former group were highly regarded, especially in circumstances where explicit recognition was accorded to the carer's own needs as well as to those of the dependant. It was interesting to note however that many carers still felt they lacked information and that when asked to describe what other services they would have liked they found it difficult to articulate or conceive of alternatives.

The carers interviewed had varied experiences of the rota beds ranging from first time users to 'old hands'. Most of them saw the service as invaluable and felt that they would have been unable to continue in their caring role without the break that respite care provided. This permitted some time free from the constant demands that caring imposed and allowed carers to 'recharge their batteries'. Some carers used this time to visit family and friends, others to take a holiday, but many just to relax. A number felt that their relationship with their dependant improved and that the dependant returned home physically improved. Conversely, the reverse was just as likely to happen.

In relation to the wider needs of carers some individuals had evolved a good relationship with the unit providing the rota beds and received advice and support, although there was no systematic method of utilising the repeated contact with carers to assess and meet their wider needs.

The operation of the rota system (usually two weeks in and six out) also caused some difficulties. Whilst carers had their dates for a year in advance the periods involved often did not coincide with family holidays or special events in the family calendar. A number of interviewees suggested that they would be happy with fewer breaks if the timing could have been of their choice. Whilst notionally providing a two week break this in practice meant 13 days which, infuriatingly, was almost impossible for some carers to dovetail with much anticipated package holidays. Most of the units might have been able to accomodate carers' requests an extra two days, but carers did not like to ask and staff did not think to offer. These were minor complaints however which carers did not really like to raise in case they were seen as being 'greedy.'

Of greater concern was the need to have immediate access to a break in emergency situations. In addition, most carers felt that a two in/four out rota would have been preferable. Many carers described how the last two weeks of the six out so depleted their reserves that all they could do during the fortnight's admission was return to an even keel.

However, the main concern was the guilt carers experienced, the extent of which was crucially determined by three factors: the reaction of the dependant to the admission, the local reputation of the hospital and the extent to which staff drew upon the carers' 'expert knowledge'. Unfortunately, as was evidenced from the staff interviews, expert knowledge was very rarely sought from carers; rather it was collected seredipitously over time.

The interviews with the dependants revealed three broad clusters of service users. The practice theory of Chenitz (1983) proved most useful in differentiating these groups and with modification was applicable to respite admissions. About a quarter positively enjoyed the admission and looked forward to their 'holiday'. These were individuals who saw the main purpose of the admission as being for their benefit. They could identify a legitimate and desirable reason for going into hospital, saw themselves as exercising a degree of control and had developed meaningful relationships with staff and other respite users.

The largest group, approximately half, tolerated the experience. They realised that their carer needed a break and whilst not really happy to go into hospital they 'put up and shut up', not wishing to complain as they had to return on a regular basis. They usually found sharing an environment with the long-stay patients unstimulating and depressing. Few had developed meaningful relationships. Most would have preferred admission to an environment that provided them a holiday too. A few felt that they should have had 'therapy' but when this failed to materialise it merely reinforced the perceived futility of the respite experience for them. Most users in this group were 'making the best of a bad job' because they realised that their carer needed a rest.

In contrast, the remaining quarter felt they had been dumped by their carer who was now 'having a good time'. They could see no reason why their carer should need a break and accepted the rota bed under obvious duress, perceiving that they had no choice in the matter. This perception was congruent with views expressed by some carers in interview who had 'put it on the line' to their dependant to accept the rota bed place or go into care. These were situations where there existed a poor carer/dependant relationship.

The three consultants with clinical responsibility for the rota beds placed their recent development and growth in the context of faster throughput and discharge rates from the acute geriatric beds. The introduction of the rota beds to the continuing care wards had resulted in a dramatic increase in activity and yet the staff number remained at the same levels as those for a traditional continuing care ward. Consequently, there were operational problems, especially in relation to adequate numbers of therapy staff. Furthermore, there had been some initial resistance to the introduction of the rota beds on the part of nursing staff. More recently, the consultants described how, in their estimation, the rota beds and other short-stay patients had helped to bolster morale and satisfaction amongst nursing staff. Further consequences were that senior nurses had added service responsibility with the result that the consultants relied heavily on them for information both about the rota bed users and their carers.

Access for new patients was formal, either via a referral from their GP or upon discharge from hospital. Respite care was occasionally used as an incentive encouraging a potentially reluctant carer to take a dependant home. Implicit eligibility criteria favoured the more heavily dependent individual or those whose carers were the most vocal. Greater flexibility was apparent once patients were in the system with nursing staff being able to extend the admission of a known rota bed patient.

To some extent the gatekeeper role, particularly regarding access for carers to the consultant, now lay with the nurses.

The aims of the system were described in terms of giving carers a break and reassessing the dependant, that is in mainly instrumental terms. There was recognition of the fact that dependants might deteriorate whilst in hospital.

As was suggested by the consultants, the respite system was seen very positively by the nursing staff who decribed how its introduction had brought variety and new challenges to their work. Furthermore, the status of the units operating the beds was seen to be raised. Therefore, despite the extra administrative work occasioned, the rota beds were perceived very favourably.

The main function was still seen as to provide a break for the carer with few nurses describing interventions aimed at meeting carers' wider needs. Nurses considered that the admission afforded elderly people an opportunity to have a medical and nursing assessment in addition to helping them to make new relationships with other respite patients. Other than disruption to the elderly person's routine and a possible increase in their confusion, rota beds were seen to pose few problems. There was however little overt recognition of the guilt carers experienced.

Many of the nursing staff came to know both carer and dependant well. However, this knowledge was usually the result of a developing relationship over time rather than a planned intervention. For some carers this was wholly satisfactory whereas others would have welcomed more contact with the staff but were unsure as to how to initiate it.

Staff were aware that there was little planned activity available for many of the respite users, a fact attributed to the chronic shortage of all grades of staff, but especially therapists. Nurses did not generally see it as part of their role to provide activity for patients.

Community nurses interviewed placed a high value on the rota beds but considered that a rigid referral system limited their accessibility. The nurses seemed more aware of the carers' wider needs and felt that they often knew the home circumstances best. It was a source of great frustration to them that they could not access services directly but needed to go through the GP or social services personnel. This caused particular problems when their own assessment of need was replaced by a brief visit from a relative stranger like a domiciliary care organiser.

Unlike the hospital based staff, community staff recognised the guilt carers felt, as they often had to help carers come to terms with it. This guilt often inhibited carers from using the respite beds until their own resources were almost depleted. As with the carers, community nurses felt that a two week in four week out system would have served most carers better.

From these interviews it was clear that rota beds provided a vital service, but that they rarely addressed the wider needs of carers as outlined in the evaluation guide. The perceived benefits were restricted to those mainly instrumental functions ascribed in the literature.

(iii) The results of the observation studies

Two wards had been purposely selected for this stage of the study as they each had 30 beds and similar proportions of long-stay, respite and short-stay patients. However one ward, Tudwal, had a day hospital attached and consequent access to a full time physiotherapist. The second ward, Castell, had no such facility and the only therapy input was a brief visit from a physiotherapist two mornings a week.

The long-stay patients on both wards had similar, high levels, of dependency, incontinence and mental frailty, but during the study period the respite users on Tudwal were observed more dependent, incontinent and mentally frail than those at Castell.

At both units the care given was considered by the observers to be of a good standard but rather routinised. The physical environment was pleasant with some evidence of non-institutional furnishings, however, it afforded little real privacy. The staff were felt to be friendly and to create a family like atmosphere. Those patients nursed out of bed were dressed wherever possible in their own clothes. There was evidence of choice in certain aspects of the ward routine such as rising and retiring to bed and what to do during the day. Both units had an open visiting policy.

From the open questions it was clear that all grades of nursing staff had positive attitudes to work with older people. Aspects of their work felt to be important centred around the need to create a caring ward environment which ensured that basic needs were met. Few staff provided evidence of the need for autonomy amongst patients. Staff saw the most interesting part of their work as concerning interpersonal relationships with patients and in seeing an improvement in their condition. For qualified staff most work-related difficulties were described in terms of problem patients, especially the confused and the aggressive. For unqualified staff death and dying were seen as the most difficult areas of their work. Given these responses and those from the interviews it is easy to appreciate how the rota bed users helped to raise staff morale, job satisfaction and prestige.

From qualified staff who completed the models of care checklist it emerged that there was little consensus even amongst staff on the same unit as to which aspects of the care regime were either desirable or possible within their own ward . Some staff felt that most criteria were met, whereas others felt few were. This indicated a lack of an agreed and explicitly defined philosophy of care on either ward, a fact which helps to explain the routinised nature of the care provided.

With a few exceptions long-stay patients at both units spent approximately 85% of the observed time disengaged, with most of the rest of the time being devoted to their basic care needs, which were attended to by staff.

Respite users and other short stay patients were far more engaged in activities. Short-stay patients at both units were engaged and interacting for similar periods of time but there were differences in the activity of respite users between Castell and Tudwal. There was little formal treatment for respite users at either unit (about 1% or 2% of total time) but this did not mean they were inactive.

At Castell, there was little organised activity and respite patients spent most of their time reading or watching the TV. Although day trips out were organised none occured during the observation period. There were generally low levels of social interaction between patients and little verbal interaction between staff and patients. Ninety five percent of staff contact was with nursing staff.

At Tudwal, organised activity was more in evidence but confined largely to the day hospital. Most of this activity was initiated and sustained by one particular therapy aide. There were far higher levels of social interaction at Tudwal, both between patients and between staff and patients. However, much of this was again attributable to the same therapy aide. Nevertheless there was more diversity of staff contacts, only 58% of which was with nurses.

At both units there were significantly higher levels of interaction with patients classed by staff as sociable, easy and interesting to talk to. However, even between sociable patients individual differences were discernible with some women and long-term rota bed users appearing, in particular, to have developed meaningful relationships with both staff and patients. From these observational studies further evidence of the impact of the rota beds on staff morale emerged and it was easy to appreciate how socially adept patients readily commanded staff time. Differences in activities between the units where largely attributable to the presence of the day hospital at Tudwal. However, these differences were not large and were mainly as a result of one active and motivated therapy aide. It was also easy to identify those rota beds users for whom the admission was a positive and meaningful experience.

Before going on to discuss what might be considered as the strenghths of the study by assessing its contribution to theoretical, methodological and policy/practice debates it seems appropriate at this point to briefly restate some of its limitations.

8.4 Limitations of the study

In a study of this nature operating as it was under financial and temporal constraints there are obvious caveats that should be considered. These are both conceptual and methodological.

From a conceptual standpoint a certain degree of selectivity was required to keep the study within reasonable bounds. The dilemma faced was that of attempting to include all potentially relevent aspects with the risk of superficiality or of adopting a narrower focus but providing a more comprehensive consideration. In the present study this dilemma was most apparent in relation to the transactional model of stress. New development work was required in operationalising carer burden, and it is hoped that the CADI represents an advance in this area. However because of the above limitations and constraints it did not prove possible to undertake similar work on coping mechanisms. These were therefore not addressed adequately in the study. Therefore, as stated previously the test applied to the transactional model can best be considered as a partial one. Thus whilst strong empirical validation for the model was provided by both the quantitative and qualitative data the mediating role of coping was not included and this must be bourne in mind.

Methodologically the major limitation relates to the sampling methods adpoted. These were by and large non-random. This means that the results cannot be generalised to other populations. Thus the carer survey, despite being one of the largest conducted needs interpreting with caution and ideally its conclusions require further testing using a random community sample. Similar caveats apply to the respite results which were based on smaller samples in defined geographical locations. This having been said the main aim of the evaluation approach adopted is enlightenment rather than generalisation and the extent to which the study might be considered as valid against this parameter is now addressed in the discussion.

8.4 DISCUSSION

This discussion outlines the contributions that the study is considered to have made to the areas of substantive interest which the research addressed. In so doing it focusses on a number of areas. It therefore begins with theoretical contributions to the literature on caregiving, before addressing such additions to nursing knowledge. Within this section a number of methodological advances are also highlighted. Subsequent sections will outline some of the implications of the study for policy and practice in the context of commmunity care initiatives, before concluding with a consideration of respite care.

(i) Theoretical contributions

(a) Developing a model of caring

At a conceptual level the study was underpinned by a number of explicit theoretical approaches. In terms of explicating the caring situation a transactional model of stress was adopted. Whilst this model has been advocated in much of the recent literature it lacks empirical validation when applied to caring. This is in part due to a lack of adequate operationalisations of such an approach. The development of the CADI offered a way of testing the validity of the transactional model. The application of the CADI demonstrated such validity with the transactional model accounting for nearly half of the variance in carer malaise. This is especially significant when it is considered that recent work from America (Chiriboga et al 1990) suggests that at least half of the malaise carers experience is as a result of extra-caring factors. The credibility of the results from the study are further enhanced by the congruence between the qualitative and quantitative data. The study reinforces the relative unimportance of dependency factors in the genesis of carer stress, highlighting instead the central mediating role of subjective appraisals. In this connection the nature of the carer/dependant relationship appears to be a crucial variable. Thus the study draws attention to the complex dynamics of the caring situation, dynamics which are also strongly influenced by the satisfactions which the carer experiences.

The lack of attention accorded to the potential satisfactions of caring was highlighted in Chapter Two and this represents a gap in the conceptualisation of the caring paradigm. This deficit has been cogently described by Kahana and Young (1990). They contend that present conceptualisations are largely unidirectional and unidimensional, focussing primarily on the burdens of carers and the health problems that these may occasion. They argue that more comprehensive models need to be developed which address the relational, dynamic and symmetrical aspects of caring for both carer and dependant. They advocate the use of transactional approaches in suggesting a congruence model which is largely concerned with the match and mismatch between the needs of carer and dependant and the efforts taken to meet these needs. Within such a model negative outcomes are more likely when there is a mismatch or disequilibrium. Such a model is required to accommodate both the burdens and uplifts of caring, accounting for the interdependence that often exists between carer and dependant. However before advances can be made the nature of the satisfactions of caring must be more fully explored and the present study might be considered as having made a contribution here, both conceptually and methodologically.

As far as it is possible to tell, data collected in the study represent the largest pool of empirical information thus far available on the satisfactions of carers.

Understanding the nature of potential rewards from caring is important not only from a theoretical perspective but also a pragmatic one. Thus there is empirical evidence to indicate that carer satisfaction is positively associated with improved emotional health (Gilhooly 1984, Cox et al 1988, Motenko 1989), an increased personal commitment to the caring relationship (Pruchno et al 1990) and a reduced likelihood of institutionalsation of the dependant (Hirschfield 1981, 1983, Pruchno et al 1990).

Whilst, as already suggested, there have been few systematic attempts fully to explore the rewards of caring some empirical evidence for their existence is available which can be compared to that from the present study. A key concept is that of **mutuality** (Hirschfield 1981, 1983) in which the carer attempts to find meaning and gratification in their situation. It is apparent that the foundations for any gratification are laid in the nature of the carer/dependant relationship. Thus there needs to have been a good premorbid relationship which is maintained in the present circumstances (Gilleard et al 1984, Phillips and Rempusheski 1986, Qureshi 1986, Qureshi and Walker 1986, Lewis and Meredith 1988 a,b, Motenko 1989). A positive relationship is more likely to be maintained when the dependant (a) is still valued as a person rather than being seen as a problem (Fengler and Goodrich 1979, Davies 1980a), (b) can maintain an element of reciprocity (Simmons 1985) and (c) generates a relatively normalised as opposed to a stigmatised or spoiled image in the eyes of the carer (Phillips and Rempusheski 1986). The central importance attached to the maintenence of positive relationships has been reinforced by the present study, as has the contribution of the above factors to such a relationship. Carers viewed as particularly problematic relationships in which dependants did not contribute but were rather manipulative, over-demanding, refused to help where they were able and failed to appreciate the carers efforts. A similar situation has been described in previous studies (Lewis and Meredith 1988 a,b, Qureshi and Walker 1989, Knipscheer 1989 in Wenger 1990). There is thus, as Phillips and Rempusheski (1986) suggest, an expectation that dependants should make the above contributions. However, in the presence of a good relationship a number of satisfactions were identifed by carers. The extent to which these are consistent with previous work will now be considered.

In achieving an element of conceptual order amongst the varied responses made by carers an analytic framework was applied which differentiated replies on the basis of what appeared to be the main factor operating to produce staisfaction. Thus carers could be seen as gaining satisfaction as a result of acting from an essentially **altruistic** perspective. Alternatively satisfactions were also apparent where both parties were perceived as benefitting, that is, from a more **reciprocal** perspective. However, many carers also described satisfactions as arising from situations where the main benefit was clearly for themselves. There were also a number of sub-categories which, whilst being empirically distinct, were conceptually related to the broad categorisations outlined above. The extent to which the previous literature might be accommodated within such a framework is now considered.

The possibility of altruism being the main gain for carers was raised by Abrams (1985) who suggested that the psychic gain carers achieved from helping their dependant constituted a form of return. In explaining this phenomenon Abrams (1985) used the concept **altruism as reciprocity**. Such a notion has been criticised as representing an over-idealised view of caring (Bulmer 1987), yet recent work suggests such criticism is unfounded. Thus Stoller and Pugliesi (1989) consider that a major gain for the carer is the contribution (s)he makes to the dependant's quality of life. Similarly Lawton et al (1989b) contend that one uplift carers get is their own pleasure at bringing pleasure to the cared-for. Such sentiments are implicitly altruistic. Kahana and Young (1990) are more explicit when they contend that caring offers some individuals the opportunity to express altrusitic behaviour where their reward is through giving to the other person. This stance is substantiated by the present study. The major source of satisfaction for carers was through the act of giving to their dependant. Viewed from such a perspective it is possible to maintain satisfactions even in the most exacting of circumstances where there is no obvious form of return for the carer.

Indeed this complements Bowers' (1987, 1988) contention that much of caring is invisible, in that it has little to do with the instrumental act of caring, but is concerned with preserving and protecting the integrity and dignity of the person being cared for. The invisible aspects of caring as conceptualised by Bowers (1987), that is, anticipatory, preventive and protective care, were described in some detail in Chapter Two and are reinforced by a more recent but limited conceptualisation provided by Lewis and Meredith (1988b). According to these authors what they term 'full care' is often preceded by a period of 'semi-care', which is not characterised by direct instrumental tasks but is nonetheless accompanied by a sense of responsibility which can be every bit as tying as full care. However this type of care is not recognised as such by service providers, something noted by Bowers (1987) as relating to anticipatory, preventive and protective care. This perception as to what constitutes caring would extend the definition of a carer far beyond those presented in Chapter Two. This has special relevance to carers' convictions that they were providing the best care possible, a source of considerable satisfaction to many of them. This was due to the expert knowledge of their dependant that they had accumulated over the course of their relationship. Possession of such knowledge was seen as being essential to the delivery of adequate care and many carers obviously doubted the ability of professional carers who failed actively to draw upon their expertise.

The second broad category suggested by the author to explain carer satisfaction relates to situations in which caring is for the mutual benefit of both carer and dependant or at least where the carer perceives some direct reciprocity on the dependant's behalf. This is in contrast to the diffuse return in altruism as reciprocity. Once again it is possible to fit previous work into such a framework. Therefore one of the main sources of satisfaction in the present work related to situations in which the carer felt appreciated by the dependant. This is entirely consistent with the findings of Lewis and Meredith (1988a,b) who conclude that appreciation was the chief reward reported by carers in their study. This is not an isolated empirical finding as appreciation has been described by other authors (Wright 1986, Lawton et al 1989b). The fact that carers perceive appreciation as a form of reciprocity again suggests that exchanges need not be concrete to be meaningful. In situations such as those described above carers often considered that caring had strengthened their relationship with their dependant, again consistent with previous work (Lawton et al 1989b, Stoller and Pugliesi 1989, Kahana and Young 1990). This serves to reinforce the subjective nature of carer/dependant perceptions already highlighted within the transactional model.

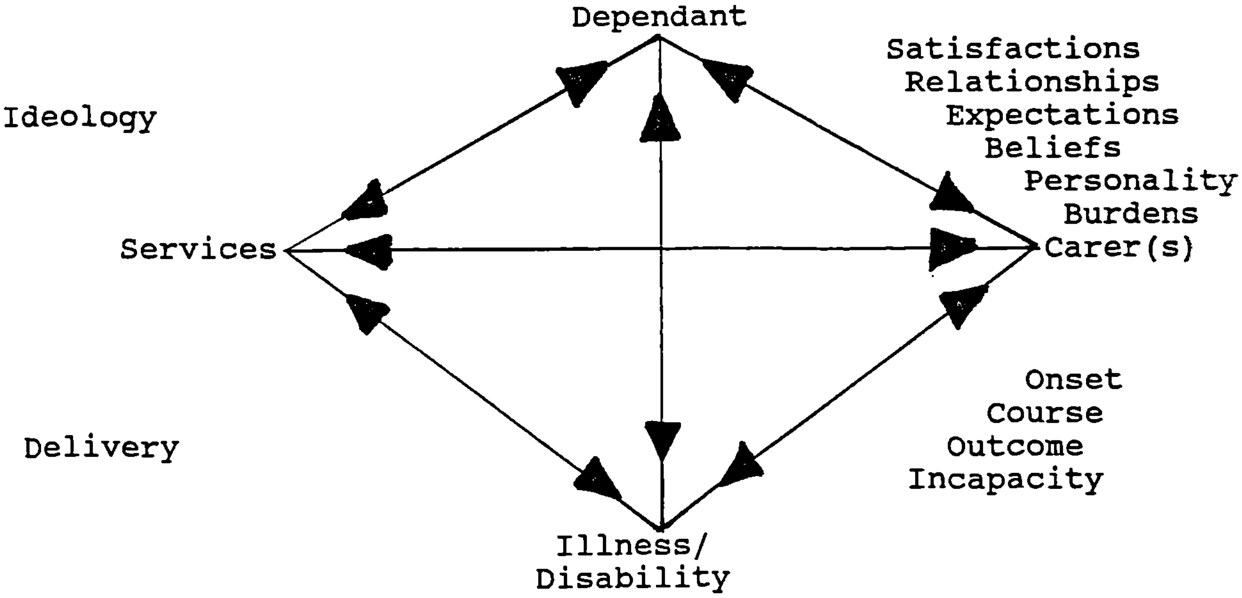
The last broad categorisation used by the author suggested that carer satisfactions could constitute a more direct gain for the carer. However sub-categories are involved here. Thus at its most basic level, caring protected the carer from negative self-perceptions such as guilt, as suggested by Stoller and Pugliesi (1989). At a much more abstract level caring clearly achieved the existential significance suggested by Davies (1980a) and became a vehicle for making sense of one's life. Carers described having grown as a person, or being more confident and fulfilled, exactly as contended by Pearlin et al (1990). For yet others caring represented a challenge, an opportunity to enhance their sense of competence and usefulness, feelings recently described in other studies (Stoller and Pugliesi 1989, Kahana and Young 1990).

From these results it would seem that in order fully to understand and respond to the needs of informal carers, attention must be given to both their difficulties and satisfactions, as suggested by Motenko (1989). This will require further conceptual and empirical work. However, the present study has a modest contribution to make in this respect.

It will be recalled that Kahana and Young (1990) suggest that it is vital to develop new models of the caring situation if more comprehensive theoretical frameworks are to emerge. Further advances can be made if the above findings are incorporated into the model suggested by Rolland (1988). In a model termed the **therapeutic quadrangle** he incorporates service provider, carer and dependant perspectives within a typology of chronic disease and disability. Such an approach has the added advantage of considering the diverse nature of chronic illness and the differing demands this imposes on both carer and dependant over time. It also accommodates the complexities of professional ideologies. As such it is entirely consistent with the pluralistic stance in the present work. If we add to this model the work of Phillips and Rempusheski (1986) considered in some detail in Chapter 2 then this may help to explicate the nature and importance of expectations and beliefs. This model provides a flexible framework incoporating the tenets of the transactional and pluralistic approaches. It delineates those areas that need to be explored if real advances are to be achieved. It also represents a most useful heuristic device. A schematic representation of the constituent components of this model is presented in figure 4.

__Figure 4: The Therapeutic Quadrangle__

(Adapted from Rolland 1988)



The present study has begun to explicate certain elements in the above model and through the further development of both the CADI and the CASI offers instruments with which to operationalise other components.

Having outlined the contributions that the study is considered to have made to enhancing the conceptualisation of the caring paradigm, attention is now turned to the implications of the results for the advancement of nursing knowledge and practice.

(ii) Contributions to nursing knowledge and practice

In terms of a contribution to nursing theory and practice the study is best considered from a number of perspectives which develop a progressive focus in terms of scope and abstraction. At the most general level there are issues to do with what constitutes nursing and what approach is best suited to the development of its knowledge base. The transactional model has a contribution to make to this debate. Narrowing the focus somewhat but still of relevance to the discipline as a whole are questions to do with the definition and measurement of quality of care for which the adoption of a pluralistic approach has considerable implications. More specifically one can consider what the study has to offer in terms of the care of the older, dependent individual. At their most focussed the results have clear implications for the future provision of respite care. The first three of these areas will be addressed in this section, with respite care being considered subsequently in the section on specific policy and practice implications.

Nursing, with its historical roots in practice, has always tended to have an uneasy relationship with theory. In attempting to develop an epistemological basis for praxis an eclectic approach has often been adopted. Therefore theory from a number of more overtly academic disciplines has been used in an attempt to synthesise something obstensibly unique to nursing. This has resulted in a bewildering array of models which have tended to confuse rather than clarify. Certainly the nursing literature abounds with references to the theory-practice gap such that practitioners are berated for their lack of concern with the conceptual basis for their actions, whilst practitioners bemoan theoretical approaches which are seen as having little or no relevance for their daily work.

One potentially unifying construct which straddles both camps is that of care. Care appeals at an intuitive level to practitioners and both theoreticians (McFarlane 1976, Kitson 1984, 1985, 1986, Benner 1984, Benner and Wrubel 1989 to name but a few) and policy making bodies (RCN 1987, DoH 1989b) have variously described care as a 'central', 'primary' or 'core' concept. Indeed in a recent strategic statement (DoH 1989b) care is accorded definitional status with the comment that "Nursing is professional caring" (emphasis added).

However in a recent comprehensive review of the nature and meaning of care in nursing (Morse et al 1990) it was concluded that the definition of this fundamental concept still remains elusive. It was suggested that true progress will not be made until a definition of caring is achieved which is applicable to nursing in all its diverse forms. Here lies the nub of the problem. Nursing on the one hand seeks an overarching paradigm to provide a sound theoretical basis whilst at the same time it is essentially concerned with individualising the care it delivers. This would seem to require a model which is at once both universal and particularistic. It is here that the transactional model may have a contribution to make.

Recently influential writers on both sides of the Atlantic (Bailey and Clarke 1989, Benner and Wrubel 1989) have advocated that the concepts of stress and coping, when viewed from a transactional perspective, offer a solution to the above conundrum. It is argued that such an approach can be used to explain a variety of disparate phenomena whilst also providing a mechanism for the assessment, delivery and evaluation of individualised care, constituting what Bailey and Clarke (1989) term an 'elegant practice model'. In developing a transactional model they advocate the use what they term 'significance theory'. The central assumption of this theory is that events can only be really understood in terms of the significance they hold for a given individual in a given context, taking account of the nature of the situation and any antecedent beliefs that the individual holds. In other words the theory is driven by a search for meanings. Benner and Wrubel (1989) develop essentially the same argument. Starting from an explicitly caring perspective they contend that in reality care must always be specific and relational and therefore cannot be defined outside of a particular context. Thus they consider that nursing is essentially concerned with understanding the 'lived' experience of illness, access to which is best achieved via the concepts of stress and coping which frame 'meanings' in a given situation. Central to this approach is the belief that personal concerns ultimately determine what is important for any individual. The challenge for nursing is to access and interpret such personal concerns.

Both of the above therefore offer a transactional model as the basis for both understanding and action. Indeed Bailey and Clarke

(1989) consider that stress and coping are 'metaconcepts'. The transactional approach allows individual meanings to be ascertained for apparently identical situations (the particularistic) whilst coping provides a broad framework within which to locate action (the universal). In this way caring can be operationalised in a manner which accounts for the diversity and commonality of human needs in a nursing related context.

Certainly the present study has demonstrated the utility of the transactional model for explicating the nature of informal care and the central importance of 'meanings' is quite apparent. Similarly the concept of self-esteem was used to better understand how the psychosocial health of the elderly frail individual is intimately bound up with a search for new meanings and roles, as indeed was the practice theory of Chenitz (1983) in explaining the impact of relocation.

Therefore the transactional approach demonstrated its empirical validity in a number of differing situations. It thus represents a broad framework providing direction for nursing action. However if meanings are specific to the context, and this is axiomatic in the above model, then theories are still needed which help to explicate the nature of specific situations. This is the purpose of the mid-range theory, that which postulates relationships which are testable but deals with only a limited, particular behaviour (Rogers and Shoemaker 1971). Such was the practice thoery of Chenitz (1983). She suggests that a good practice theory must be specific enough to guide action in particular settings yet also be potentially generalisable to other related but not identical contexts. Therefore whilst the theory was developed specifically to explicate the nature of admission to care, Chenitz (1983) considered that it should be refined and elaborated by testing it in similar situations. The present study achieved this aim. Therefore the theory was found to be applicable to a qualitatively different form of admission and whilst the basic conditions of the theory held these did require modification to account for the variation in responses to rota beds. This would suggest that nursing, rather than continuing its search for one unifying definition of care, might be better served by using mid-range theories to frame action in a given situation. Such an approach would seem to offer real promise for advances in nursing knowledge which might truly bridge the theory-practice gap.

Adopting the above stance also suggests certain methodological approaches to theory generation. Thus theory should be developed inductively rather than deductively (Chenitz 1983, Benner 1984, Benner and Wrubel 1989, Morse et al 1990, Draper 1990) with theory emerging out of the experiences of nurses and patients. This need not mean abandoning quantitative methods altogether. Indeed the present study demonstrated their usefulness in the development of the CADI. Therefore nursing should not eschew any suitable method but the ontological and epistemological underpinnings should relate to what Guba and Lincoln (1989) termed the constructivist paradigm. This leads to a consideration of the value of the pluralistic approach to the evaluation of nursing care.

There can be no doubt that one of the major challenges facing health care in general and nursing care in particular is the need to determine the quality of the service offered. Whilst 'quality of care' has been on the agenda for a number of years renewed impetus has been provided by recent official statements as to the need to develop sytematic approaches to its measurement (Welsh Office 1990a, DoH 1990). Underpinning such pronouncements is the adoption of a cyclical, action oriented model, central to which is the formulation of 'agreed, precise performance standards and arrangements to met them' (Welsh Office 1990a).

Mirroring the increased importance accorded this aspect of care is the growth of systems and approaches to the measurement of quality. In a recent comprehensive review of this area (Redfern and Norman 1990) the appeal of quantitative measures was highlighted but caution was urged against the wholesale adoption of superficially sophisticated measures which actually say very little about quality. The inherent dangers of a measurement philosophy in evaluation has been cogently summarised by Guba and Lincoln (1989) who state:

> "After a time these measuring instruments take on a life of their own, whilst initially intended as "operationalisations" of scientific variables, they become, in the end, the variables themselves" (p37)

This is the danger for nursing. If quality is equated with a percentage score and such a score is used to determine standards which are then linked to staffing levels, as in the widely used 'Criteria for Care' package (Ball et al 1984) then ultimately there will only be sufficient staff to achieve the standards defined by the instrument and Guba and Lincoln's (1989) prediction will have become reality.

In cautioning against the use of 'off the shelf' measures Redfern and Norman (1990) advocate a 'bottoms up' model in which standards are agreed and monitored at a local level. Such is the thinking behind the RCN Standards of Care Project (RCN 1989). Ulitising this approach standards are defined as:

> "..Professionally agreed levels of performance, appropriate to the population addressed, which reflect what is acceptable, observable, achievable and measurable" (Sale 1990)

This is a clear application of the 'professional as expert model' (Wallace and Rees 1988). However there is an emerging movement towards adopting an approach in which the user is viewed as the arbiter of standards (Wilson-Barnett 1986, Wallace and Rees 1988, Morse et al 1990, Taylor et al 1991), a 'client as expert model'.

Within the present study considerable emphasis was placed by carers in both the postal survey and the interviews on the need for professionals to take account of their expert knowledge. Closer attention to this area has the potential to create a much more meaningful partnership between carer and professional. Neither is such a suggestion a new one. The possession of such expert knowledge has been described in the literature (Robinson and Thorne 1984, Lewis and Meredith 1988a,b, Bowers 1988, Pitkeathley 1990) and it is suggested that carers have a sense of ownership every bit as strong as that felt by professional carers and feel the need to teach professionals how to care for their dependant (Hasselkus 1988). Professional and informal carers, therefore, have differing but complementary skills (Hasselkus 1988, Twigg 1989, Pitkeathley 1990). It is considered that if professional carers make a conscious effort to elicit and make use of carers' skills and knowledge, this has the potential to give informal carers a sense of control (Hirst and Metcalf 1986) as well as reduce their feelings of guilt about using services (Bloomfield 1986, Tooth 1987, Buckwater and Hall 1987). However it is apparent that such knowledge is rarely obtained, or worse still dismissed (Wright 1990 personal communication). This has the effect of undermining the trust of carers in service providers, a trust which can be difficult to re-establish (Robinson and Thorne 1984). It is also likely to lead to the rejection of professional interventions which run counter to the carers' perceptions, a reaction which further compromises the carer-professional relationship (Bowers 1987, Webster 1988). Furthermore where roles are not clarified then carer stress can be increased (Pratt et al 1987b). This failure to acknowledge the skills of informal carers represents a wasted resource (Buckwater and Hall 1987). All this has clear implications for the provision of services which must be accounted for in any equation which addresses quality. One obvious consequence of the failure to account for carer expertise in the present study was the perceived inadequacy of any form of institutional care, a feeling well described in the literature (Davies 1980a, Worcester and Quayhagen 1983, Gilhooly 1986, Ungerson 1987).

However, it is also necessary to consider the views of the patient (Morse et al 1990, Taylor et al 1991). Indeed in their lucid consideration of the nature of expertise Benner and Wrubel (1989) contend that, especially in cases of chronic illness where there is long experience of a condition, patients actually represent a source of clinical knowledge which nursing must explore if it is to offer a true quality service to these individuals. It emerged from the interviews with dependants in the present study that services were more acceptable to them when they perceived a degree of choice and, ipso facto, control and where interventions were seen as relevant and appropriate. This is a key point because, as Keith (1990) argues, the recent, and deserved, attention to the needs of carers should not result in an already disadvantaged group of disabled people being pushed 'even further into the shadows'. It was suggested in Chapter Three that 'loss of self' is the most fundamental form of suffering in the chronically ill (Charmaz 1983) and that interactions with professionals can do much to increase the self-esteem of disabled individuals. However in order to do so there is a need to establish a relationship of trust in which the dependant's knowledge of their condition is recognised and which affirms and validates their worth as a person (Thorne and Robinson 1988).

Such thinking is also permeating other diciplines and contexts. Therefore Kellaher and Peace (1990) argue that whilst the term quality assurance is used with increasing frequency there is not necessarily confidence as to its meaning. In considering ten years' work assessing quality in residential care environments for the elderly they describe the move away from measures of satisfaction towards approaches which assess the complex experience of the elderly residents themselves. They contend that outcomes are best described in terms of the day to day experiences of the residents. Here a comment from only one individual is accorded significance, especially when it has obvious communal implications.

Such consumer opinions should take a central stage. However they are not without problems, as consumers may have too low an expectation (Redfern and Norman 1990) and will not possess sufficient knowledge to judge certain aspects of care. Therefore staff opinions must also be accorded weight. It is here that the pluralistic model comes into its own. Its utility was apparent in the present study and as noted in Chapter One, it is an approach which is increasingly recommended. Thus when standards and quality are addressed a pluralistic approach should be given serious consideration. Whilst not producing easy solutions it nevertheless offers comprehensive ones. Indeed within the aforementioned official statements on quality (Welsh Office 1990) a person oriented consumer approach is seen as essential. If this is to become anything other than rhetoric then consumers must be involved in setting the 'agreed, precise performance standards'.

Having considered the contributions of the study to broad domains of nursing the focus will now narrow somewhat to look at the care of older individuals, particularly those with long-term dependency needs.

There are clear pointers from the study as to how the care of such individuals might be improved. The literature reviewed in Chapter Three painted a fairly bleak picture of institutional care for the elderly with little or no stimulation, minimal attention to individualised care and few opportunities to exercise choice. Work in such institutions has traditionally had a very low status with little satisfaction for staff. The concept of 'rust out' (Pennington and Pierce 1985) has been used to describe the effects on staff of an unchanging environment. However it seems that low staffing levels and poor facilities, whilst contributing to the problem, are not the main cause and that staff attitudes to work are a very important determining factor in the quality of care delivered. In terms of hospital care the crucial relationship is often that between the nursing sister and the consultant, especially in relation to the value placed upon care and the level of responsibility vested in nurses. It has also been argued that care will not improve until nurses value their caring function and have an explicit conceptual framework in which to locate care for older people (Kitson 1984, 1985, 1986).

From the present study the impact of the respite care users on the work environment of staff was abundantly clear. Staff described how the variety and new challenges which followed the introduction of the rota beds had transformed their perception of their work and raised the perceived status of nursing care for the frail elderly. In addition more autonomy and delegated authority had been given to the sister with nurse controlled beds in one unit and with nurses being able to accept 'known' patients in the other. From the staff responses to the questionnaire it emerged that perceptions of their work were positive and that they perceived the interesting and important aspects as relating to providing a caring environment and to the interpersonal relationships with their patients. On the other hand staff were also aware of the move towards further reduction of the long-stay beds. They did not feel this was appropriate considering that the levels of dependency amongst long-stay patients demanded skilled nursing care. Despite the generally good standards of care given there was still evidence of perhaps unnecessarily rigid routines with little consensus on important aspects of care such as the extent of patient and visitor involvement.

These findings have a number of further practice implications. Firstly, it seems that an environment which consists only of very dependent and mentally frail individuals with whom staff cannot have a reciprocal relationship results in the type of unchallenging work situation in which staff 'rust out' is inevitable. Indeed in a recent and challenging paper Marck (1990) contends that good quality care is largely determined by the extent to which what she calls 'therapeutic reciprocity' can be established. Therapeutic reciprocity is said to exist where there is a mutual exchange of meaningful thoughts, feelings and behaviour between nurse and patient. This suggests that in every care environment staff need some reciprocal interaction with patients if they are to gain satisfaction from their work. Thus the introduction of respite places might prove to be a key element in this solution. On the other hand, this may not be desirable from the respite user's perspective, as many find it depressing to share an environment with very dependent people. There is also the vexed question of what is the best environment for the very frail elderly. There has been a good case presented for the concept of NHS nursing homes (Wade et al 1983) and recent evaluations of experimental facilities (Bond et al 1989b, Bond and Bond 1990) suggest that they represent a preferred option for many consumers. On the other hand it seems that new initiatives such as these and nursing units are struggling to maintain their impetus in times of financial stringency. What seems to lie ahead therefore is a rebalancing of the imperative for sustainable care-effective solutions within the prevailing economic and political constraints.

If nursing is to make its contribution in these respects then as

Kitson (1988) suggests it will need to break free of the medical model, assume greater responsibility in restructuring the environment of care and develop an explicit conceptual framework to give direction and purpose to the service delivered. The new kind of nurse envisaged would not value cure as the only important outcome, concentrating instead on promoting the autonomy of the older person (Redfern 1989). The present study suggests that there is still some way to go if this is to be achieved. Some of the barriers to the development of geriatric nursing identified nearly 30 years ago (Norton et al 1962) still remain, in that care is not fully recorded and assessed. Whilst there was evidence of personal and individualised care for the respite users in the present study it was based on personal knowledge which was rarely explicitly recorded. Thus despite progress there is still room for improvement, particularly as to what nurses perceive as legitimate components of their professional role.

Therefore, some of the changes needed to bring about improvements in the environment of care need not be extensive nor necessarily expensive, requiring instead little more than a reorientation of nursing care. Nurses in the present study were aware of the paucity of stimulation for many of the patients, but saw this as resulting from a lack of therapy staff rather than something they might address themselves. However, as demonstrated at Tudwal the increased levels of organised activity and social interaction were largely attributable to one individual. There is recent evidence that the introduction of a 'club' activity programme for as little as an hour a day can result in significant improvements to activity, social interaction and choice (Clark and Bowling 1989). Although the units in the present study considered themselves short of staff the observers felt that there were times when activities could have been introduced. At Castell there was space available to do this but no one who seemed to take the initiative. As suggested elsewhere (Godlove et al 1981, Clark and Bowling 1989) nurses need to see the provision of such activity as an integral and important part of their role if gains are to be made.

Kitson (1985) suggests that nurses need to address more fully the real implications of their caring function, extending the concept to give explicit recognition to affective components. She suggests (Kitson 1986) that there are at least two key concepts underpinning good nursing care for the elderly, a recognition of the profession's primary caring function and a positive approach to the health and welfare of elderly people. The author would contend that the utilisation of a transactional model accompanied by the development of appropriate mid-range theories provides a conceptual basis for the way forward. Certainly a construct worth considering further in this context is that of self-care.

Recent conceptualisations of self-care have been far more encompassing than narrow functional definitions which have often underpinned interventions in the health and personal social services. It can be argued that self-care relates not only to the steps taken to preserve and maintain personal health (Hickey 1986) but also to a reaffirmation of individual dignity and worth (Illsley 1986). In this sense there is a requirement to construct a role for the frail elderly person that is based not only on obligations but also on their own ability to cope and contribute (Holstein 1986). This approach to the conceptualisation of self-care results in a broad synthesis which subsumes functional, social and health related issues in a manner which is lacking in current bio-medical or socio-funtional models of service intervention, whilst also accommodating important concepts such as self-esteem. Within a self-care paradigm the legitimate focus for health-related interventions is expanded considerably beyond that which is used as the basis for professional practice. Health is seen as a goal for all individuals irrespective of current levels of frailty or dependency. Therefore health is not only a crisis related intervention (Kane and Kane 1986) and health professionals should pay greater attention to self-care needs (Liddiard and Ritvo 1986). The acceptance of such a broad definition means that even those with extremely limiting conditions amongst the frail institutionalised elderly can be seen to benefit from health and self-care interventions. It also raises a number of questions about the appropriateness of recent community care policy initiatives which ascribe the lead role in service provision to social services departments. This is an area to which further attention is given shortly.

By adopting the above it should prove possible to achieve a synthesis between a positive regard for the health and welfare of the elderly and the need to provide a practice model which explicates the nurse's role. In this manner nursing the elderly might be taught and perceived as an important specialty rather than being seen as an area requiring only minimal skill (Fielding 1986, Redfern 1989). Certainly the present education preparation of nurses fails adequately to provide a sound understanding of the processes of normal ageing and the skills of health education and self-care enabling techniques that are required (Phillipson and Strang 1984, 1986, Phillipson and Walker 1986, Liddiard and Ritvo 1986, Dean et al 1986, Wenger 1988, Maclean 1989), instead adopting a decremental, medical model approach to the care of older people (Fielding 1986, Redfern 1989). The present changes in nurse education at both a basic and post-basic level will have to address these issues if progress is to be made.

Having considered the more specific contributions of the study to the advancement of nursing, attention is now turned to some of its implications for community care policy. Whilst a case will be presented for nurses playing a key role in this area also, some of the conclusions are just as relevant to other disciplines.

Given the recent heightened emphasis on the needs of informal carers and the tailoring of services to individuals rather than vice versa (Department of Health 1989a), the study results have a number of implications for community care policy and related services. Whilst the policy rhetoric is laudable there is a need to make something meaningful out of 'the trite term partnership' (Allen et al 1983) as well as central ideas about choice, the availability of acceptable alternatives, the assessment of individual needs and effective targetting of services and resources . This is considered next.

(ii) Implications for community care policy and related services

a) The decision to care

The first and perhaps most significant issue to be considered here concerns the degree of choice operating in the provision of community care itself. It was noted in the introduction that the philosophy of community care has been repeatedly endorsed in policy terms and, despite the fact that neither 'community' nor 'care' have been adequately defined, the philosophy of community care has been accepted as better than alternatives. It is now obvious that community care for the frail elderly usually translates to family care, with most of the responsibilities shouldered by female kin. It is also clear that most of the frail elderly would prefer to remain in the community and that most carers actually wish to continue in their caring role. However this should not be taken as universal. The recent White Paper 'Caring for People' states that the "decision to take on the caring role is never an easy one" (Department of Health 1989a para. 1.9). Implicit within this statement is that there exists an element of choice on the carer's part.

However the literature suggests that choice is rarely obtained and that carers often take on their role at a time of crisis without realising the full extent of the commitment (Allen et al 1983, Lewis and Meredith 1988b, Pitkeathley 1990). These authors also note that one of the major variables inhibiting any real choice is the availibility of acceptable alternatives. It is also questionable if all individuals should be expected to care. Whilst it has been demonstrated that affection and a good prior relationship are not a necessary precondition for care, in such circumstances the situation is more fragile and prone to collapse (Qureshi 1986, Qureshi and Walker 1989). Furthermore in situations were the caring relationship has deteriorated then carers appear to need help to set limits to their care and if necessary given encouragement to relinquish their role (Bell et al 1987, Fottrell 1988). This again assumes the existence of acceptable alternatives (Pratt et al 1987a).

The literature, reinforced by the results of this study, suggests that it is possible to predict which caring situations are most likely to be stressful and where there is likely to be a poor carer-dependant relationship. These involve situations in which the dependant is demanding, manipulative, unhelpful and unappreciative and where the carer perceives this as stressful. Expecting someone to take on or continue the caring role in such circumstances may therefore be questionable, especially where such an individual has already expressed reservations.

Yet there was evidence from the present study that services, in this case respite care, can be used as an incentive to encourage reluctant carers either to take on or to continue in their role. Individuals already feel strong normative pressures to care (Qureshi and Walker 1989, Pitkeathly 1990) and where this is reinforced by implicit or explicit professional pressure then real choice is all but absent.

Therefore community care should not be seen as right for all, especially when it burdens the carer beyond endurance (Maclean 1989). Nor should reluctant carers be forced into their role, especially when there is a poor caring relationship because, as Qureshi and Walker (1989) note, when difficult or strained family relationships are added to powerful normative pressures then it can "quite inappropriately force daughters and elderly people into potentially disastrous close physical and emotional relationships". At a time when abuse of the elderly has been the subject of much professional debate (Tomlin 1989), and bearing in mind the role of relationships in possible abuse (Phillips and Repusheski 1986), there is a need for a proactive approach that recognises discharge procedures themselves might be a link in the causal chain.

If this is to be avoided it will be necessary to assess caring relationships prior to and during the caring history and to have acceptable available alternatives. Therefore when planning the hospital discharge of a frail older person the availability of a family member should not be taken to mean that the family member should automatically take on the role of carer. Their willingness and ability to care needs to be assessed and such assessment should include the nature of their relationship with the person awaiting discharge. Where there is a history of a poor relationship or where the family member expresses doubts about caring, then questions should be asked about the advisability of that family member assuming the caring role. Thus pressures should not be brought to bear on such individuals; nor should they be made to feel guilty for voicing doubts about caring. This may well require acceptable institutional alternatives. Further research in this area would appear to be indicated. Unfortunately such research is unlikely to be commissioned until there is government acceptance that community care based solely on the family is not right for everyone.

For those majority of family members (or friends) who wish to care then discharge procedures need to be better planned and coordinated. This requirement has recently been stressed by official statements (Welsh Office 1990b) with the nurse being suggested as the most appropriate individual to coordinate the discharge process. The need for change and improvement is apparent. The increased throughput and faster discharge of older people from hospital means that discharge planning rarely takes a priority and individuals are returned to the community with little consultation or prior notice, often without important information (Waters 1987 a,b, Victor and Vetter 1988, Jackson 1989). A key requirement for individuals who assume the caring role is that services offered are available, accessible and acceptable, in addition to being sufficient and effective. This assumes coordination, choice and involvement.

The proposals within the White Paper (Caring for People, Department of Health 1989a), if adequately funded and put into practice, offer hope for improvements to the services carers receive. The proposals highlight the fact that services should be targetted on those most in need and individually tailored to the requirements of each carer. The two key concepts here are targetting and assessment. The discussion now turns to the implications of the study in these areas.

(b) Identifying and assessing those in need of services

It was demonstrated in Chapter Two that present services are often geared to meeting instrumental needs which are all too often equated with the notion of functional dependency. Those invisible aspects of caring already alluded to are usually ignored. Therefore if present services for carers are truly to be improved a number of fundamental changes are required.

Firstly, the conceptualisation of what constitutes caring will need to be broadened. Secondly, assessment must move beyond narrow objective measures of dependency to incorporate carers' subjective impressions and the nature and dynamics of the carer-dependant relationship. Services will need to extend beyond a concern for the instrumental and address carers' wider needs for information, skills training and emotional support. In addition the appropriate balance between the needs of carers and dependants must somehow be achieved. How may some of these necessary changes be achieved?

The adoption of a transactional approach to an understanding of caring relationships appears to provide a useful conceptual framework which has empirical validition from the present study. Not only does it locate the assessment procedures but it also suggests broad dimensions of appropriate interventions. Thus carers may be assisted to alter the nature of the demand itself, for example the fitting of a male incontinence sheath might alleviate the problem of incontinence. Alternatively where the demand cannot be directly manipulated assistance may be given in altering the perception of the demand; for example if carers are given information which helps them to improve their understanding of their dependant's condition then behaviour once viewed as deliberate might be reframed within the disease process. Helping carers to identify rewarding aspects of their role might also result in them having a more balanced perspective. Finally carers can be assisted to deal with the consequences of a demand, for example by means of stress reduction techniques. On the other hand all that may be required is a confidant with whom the carer can share their fears and worries. Utilising such an approach, Zipple and Spaniol (1987) suggest incorporating a stress-

adaptation model within a **supportive-educative** framework. Interventions may then be **information based, skills based, emotionally focussed** or incorporate all of these approaches achieving a **comprehensive** service.

The model still nevertheless assumes the existence of the requiste tools and technology of assessment. Also, as stressed earlier, specific attention would need to be turned to the carer's expert knowledge. Work by the author is already in progress to develop further the assessment scales resulting from the present study. Thus CADI is being refined and the complementary instrument, CASI, is in the pilot stage. These tools, combined with open discussion, provide for a potentially useful assessment of the perceived problems and satisfactions of the carer's role.

Professionals will also need to be flexible and creative in developing a full range of services. They will need to be free to operate beyond traditional professional roles as it was demonstrated in the present study that carers often find it difficult to articulate services outside those available, a finding consistent with other work (McCarthy et al 1989, Caldock 1990). Thus, assessment will need to be accompanied by creativity in devising appropriate and sensitive services which reflect where possible both carer and dependant perspectives, and which move beyond the conventional, incorporating the natural resources of the community and the buying in of complementary care.

This properly leads to the question of who should conduct the assessment.

(c) Conducting the assessment: whose function?

The type of in-depth assessment suggested above cannot be derived from a single visit for it requires a substantial degree of trust and detailed knowledge built up over a period of time from within an established relationship. The White Paper (Caring for People, Department of Health, 1989a) is not prescriptive about who should be the key worker but suggests that social workers, home care organisers or community nurses may be particularly suitable. There is evidence from the present study that the last group may well, in a number of circumstances, prove to be both the most appropriate and the most acceptable to many carers. Thus the interventions of district nurses, where these gave explicit recognition to the needs of carers, were well accepted. Social workers on the other hand were often viewed with suspicion and even hostility. Such findings are not restricted to the present study. The services of district nurses are highly valued (Wade et al 1983, Wenger 1988, Lewis and Meredith 1988b, Caldock 1990). Indeed they have been described as the linchpin in community care, co-ordinating services often by default (Wade et al 1983). It certainly seems that at present many social workers have neither the skills, the necessary degree of contact, nor the credibility to undertake this type of detailed assessment (Maclean 1989), with social work visits to the elderly often being 'one off' and regular involvement rare (Wenger 1988). This of course need not be the case as social workers can undertake detailed assessments effectively as demonstrated in the Kent Community Care Project (Challis and Davies 1986), a fulcrum of Sir Roy Griffiths' report on community care and the subsequent White Paper (Caring for People, Department of Health 1989a).

However the adoption of this role by social workers would seem to require a radical shift in public perceptions. These points are summarised in a recent publication addressing the issues raised by community care policy:

> " Community nurses and in particular district nurses are already more acceptable and familiar visitors in the homes of old people than are social workers, whose attentions have become associated in the public mind with a certain stigma". (Maclean 1989 p.105)

The contribution of community nurses has been recognised as a 'crucial resource' well acquainted with a network of help (Department of Health, 1989a). In the present study district nurses certainly had the kind of relationship and knowledge needed to achieve a comprehensive assessment. Yet this knowledge was often ignored or not sought by other professional groups, for example GPs. This was extremely frustrating for many of these staff who usually had no direct access to services and whose assessment could be overturned following half an hour's visit by someone unfamiliar to the family.

The White Paper also advocates the need to promote positive and healthy lifestyles, and health care in its 'broadest sense' is seen as an essential component of the range of services. If health care is incorporated within the self-care model previously suggested then nursing could be seen to be a key professional group in this connection. In relation to carers they are considered to occupy a 'pivotal' position (Bowers 1987) and numerous authors have advocated a much more active role for nurses in supporting this group (Fry 1984, Batchelor 1984, Ross 1985, Bell et al 1987, Edwards 1987, Corbin and Strauss 1988).

Given the substantial increase in the numbers of elderly people aged 85 and over in the population (Caring for People, Department of Health, 1989a) and the well established relationship between advanced age and dependency it is hard to foresee how nursing can fail to have a major role.

In moving to this position at least two current obstacles need to be tackled. The first relates to the education and training of nurses and the changes suggested a few pages previously highlighting the need to provide a more comprehensive consideration of normal ageing processes together with the further development of skills in health education and counselling are just as relevant in the present context.

The second main obstacle is more difficult to overcome and relates to the protectionism of professional groups in relation to traditional roles and functions (Maclean 1989, Redfern 1989). It has already been noted in Chapter Three that no professional group has claimed ownership of the disabled elderly and that work with such individuals is accorded a low status. However, as Maclean (1989) notes, this does not mean that responsibility, real or imagined, will be easily relinquished:

> "Even a territory of field work and professional practice which is generally despised and neglected can become a cause for boundary disputes once it is a matter of deciding upon the appropriate division of power and public resources."
>
> (Maclean 1989, p.79).

However the most important concern must not be which group takes the lead role but that the frail elderly and their carers do not suffer as a result of being, as Maclean (1989) puts it, within 'disputed territory'. Therefore whilst a reasoned case has been presented for nursing taking a lead role, perhaps the best way forward lies in true multi-disciplinary training, as advocated for example by Runciman (1989). Whichever group or individual takes the lead role will need both credibility in the eyes of both dependants and their carers, coupled with the competences and sensitivity to conduct holistic assessments of need.

The requirement to provide acceptable institutional alternatives to community care has already been alluded to so the implications of the study for such provision is now considered.

(d) Providing acceptable institutional alternatives

Despite its emphasis on community care the White Paper recognises a role for continuing hospital care for the very frail elderly. Indeed it has already been argued that some form of alternative to care in the community is essential if informal carers are to have any element of choice in a decision to care. The key issue then becomes what is an acceptable alternative for carers. It was apparent from the responses to the postal survey that, for many carers, none of the currently available institutional alternatives were perceived as acceptable. However, it emerged from the interviews with carers using the rota beds that many of them, over a period of time, had come to trust the hospitals to which their dependants were admitted for respite care. They indicated that, if the time came when they could no longer cope, they would be quite happy to see their dependant enter that particular hospital on a permanent basis. It was therefore a source of great frustration to them that the continuing care hospitals in the study area were no longer accepting long-stay patients. This was one obvious disadvantage of the system for a number of carers. It seems that if there is to be an acceptable alternative for carers they will need to be convinced of the quality of the care that is offered. In the present study this was partly a function of the local reputation of the hospital in question and as well as a result of the carer feeling that the staff 'knew' their dependants likes and dislikes. For the elderly person admission was more acceptable if there was perceived to be a legitimate reason and an element of choice. The notion of an NHS nursing home has already been suggested as one possible solution.

In terms of relevance to permanent care the findings from the respite study can only provide pointers. However wherever institutional care is located there are some general areas to which the study contributes. The notion of expert knowledge again emerges as very important and there would seem to be support for the continued involvement of the carer following any permanent admission. This has been well described in the literature and such involvement would include the carer's assessment of the elderly person's needs and their continuing involvement in meeting some of these needs (Buckwater and Hall 1987, Pratt et al 1987b, Bowers 1988). Indeed such involvement was one of the core areas within the supportive institutional environment advocated as the one of choice (Wade et al 1983). Staff working within institutions need to be aware of the research in this area which ought to be a core topic in the education of those staff involved in institutional care.

Similarly the research on relocation effects described in Chapter Three and the practice theory derived from it (Chenitz 1983) provides a useful conceptual basis explicating how the admission process for the elderly individual can be eased. It seems that the first eight weeks following admission to care are the most crucial and that it is often the process of admission which is as important as the event itself. Attention to the basic conditions suggested in Chenitz's work (1983) and to the older person's normal coping styles is clearly crucial. In addition, the provision of adequate support from carers and staff is considered essential. Again it would seem that the use of a transactional model might well be appropriate and that support could be provided along dimensions similar to those suggested for carers themselves, that is information and emotional support.

The final section of the discussion seeks to address the implications of the results for the provision of respite care.

(iii) The future provision of respite care

It has already been demonstrated that in numerical terms respite care represents the most significant service presently available for carers. Following the White Paper (Caring for People, Department of Health, 1989a) the importance accorded respite care is likely to increase as one of the key services for carers. The research reviewed in Chapter One indicated that, despite the increased availability of respite care, eligibility criteria and inflexible operating practices constrain its effectiveness for carers. It is axiomatic that if the flexible services insisted upon in the White Paper are to develop then respite care will need to address these issues. This section considers the contribution that the present study has made to this debate.

The placing of the study within an explicitly pluralistc framework allowed a broad conceptualisation of the potential of respite care to emerge. This breadth was enhanced by the transactional model which permitted a range of subjective perceptions to be considered. The debt which the present work owes to the thinking of Intagliata (1986) has already been acknowledged and it is to be hoped that some of the findings from the study will have provided at least tentative answers to what he considered to be one of the challenges facing respite care:

> " A great deal remains to be learned about the kinds of benefits that respite care can realistically be expected to provide as well as which contextual factors facilitate or inhibit these benefits from being realised"
>
> (Intagliata 1986, p. 283)

The author would suggest that a major reconceptualisation of the bases of respite care needs to occur on at least two fronts; the range and extent of provision and the perceived functions of the service.

The present study was confined to the consideration of respite care in continuing care hospitals. This of course represents only one of a wide range of potential options. Studies have stressed the need to extend current provision (Thompson 1987, Tyler 1989, Thornton 1989, Twigg 1989, Richardson et al 1989, Dewing 1990) and to be creative and innovative in respite schemes. Tyler (1989) suggests that respite care can be conceived of as falling into one of ten models, including the use of fostering schemes. Models are differentiated in terms of whether they are insitutionally or community based and whether they offer day, night or more lengthy periods of care. A similar conceptualisation is suggested by Richardson et al (1989) who postulate a typology based on location, duration and planning. Thus respite care can be either long or short in duration, in-home or out-home in location, and planned or unplanned in administration.

There is no doubt that greater flexibility in provision would be to the advantage of carers, offering true choice amongst a range of options. However the relative paucity of both choice, and in some areas of any respite care at all, has been demonstrated in recent surveys (Thompson 1987, Webb 1987). Nevertheless there are now emerging some encouraging signs that a more holistic respite service is developing. Thornton (1989) provides a detailed evaluation of an in-home scheme with care being provided by selected and trained lay individuals. She highlights the advantages that such a scheme offers in terms of flexiblity and adaptability. Thus whilst regular day relief formed the central plank of the service, more intensive living-in care could also be arranged. Despite the success of the scheme it was found, as in the present study, that carers' reactions to the service were crucially mediated by two main considerations, the acceptability of the helper providing the care and the carer's perception of service quality. Whilst schemes such as these will undoubtedly mushroom it should not be considered that all such innovations will be automatically successful. Therefore as Wenger (1990) points out for older spouse carers in particular respite care might not be appropriate and some form of befriending scheme might be more valued. Moreover, Gaze (1990), for example, reports the difficulties she encountered in recruiting carers to a night hospital scheme, despite the obvious intuititve appeal of a good nights sleep. However further innovation in providing a much wider range of in-home and day/night care schemes is to be encouraged, provided that they are accompanied by clarity of thinking as to their purpose and some systematic evaluation of their effectiveness.

Despite these developments, institutionally based schemes are likely to remain the most numerous for the forseeable future. Here also it is apparent that greater flexilbilty would be highly desirable. Firstly, it would be preferrable for many carers and dependants if the respite service were to be the sole purpose of the unit. This was the original thinking behind the idea, with a unit staffed and equipped purely for the provision of respite care (De Largy 1957). Staff could then provide a regime that catered more for the individual preferences of the users. However in the present financial climate within the health service such a facility is unlikely to develop.

However, whilst innovation is to be encouraged the potential of respite care is unlikely to be reached unless innovation is accompanied by a greater breadth of vision in conceptualising the purpose of respite care. It was suggested in Chapter One that there have been few explicit statements as to the purpose of respite care but that implicit assumptions have a definite instrumental bias. That such remains the perceived basis for respite care is quite clear from a recent official pronouncement about its purpose :

> "An arrangement whereby elderly or disabled people, normally cared for at home by relatives, are placed temporarily in alternative accommodation to give their usual carers a break."
> (Caring for People, Department of Health 1989a para. 9.5)

As Intagliata (1986) points out such limited perceptions have inhibited the development and true potential of respite care. From the present study it is apparent that respite care affords an opportunity to attend to other needs of carers, such as information, skills training and emotional support. Moroever, consistent with the literature reviewed in Chapter One, staff often failed to identify the guilt carers could feel and demonstrated relatively little awareness of the problems respite care could cause. Futhermore there is a need to provide a respite experience which is meaningful for the elderly user. This, as earlier work suggests (Cunliffe 1987, Dewing 1990), is likely not only to reduce the guilt carers experience but to add to the self-esteem of the dependant. The practice theory of Chenitz (1983) affords valuable insights into how such benefits for dependants can be optimised.

It is also clear that more attention needs to be given to the process of respite care. As Twigg (1989) contends respite care is a social process and needs to viewed in such a context with due regard to the meanings it has for both carers and their dependants. The present study reaffirms Twigg's (1989) suggestion that carers have a strong desire to pass on their knowledge as well as their responsibilities. However as other authors advocate (Richardson et al 1989, Thornton 1989, Dewing 1990) it it also essential that careful pre-admission assessments should consider the dynamics of the caring relationship and provide carers and dependants with the opportunity to explore their respective fears and worries.

If all this is to be achieved additional factors relating to the referral process need some consideration. A system that is more open and less restrictive and which does not rely on strict adherence to dependency based eligibility criteria is highly desirable. Key community groups should be afforded direct access. Notable amongst these in the present study were the community nursing staff. This is consistent with the work of Thornton (1989) who considered that the most appropriate referrals for her scheme were received from health professionals, particularly community nurses and community psychiatric nurses who often had the most complete knowledge of the care needs of their clients. Such knowledge also emerged in the present study with community staff making valuable suggestions as to how the service might be improved. Thus, as one community nurse suggested, a home visit by one of the hospital staff, or a prior visit to the hospital by the carer, might do much to reduce anxiety. Furthermore each carer should be seen on the first admission if possible. A conscious and deliberate effort could also be made to elicit any worries carers may have and to obtain their expert knowledge. In this way a relationship of trust could be developed from the outset and carers who feel it is appropriate could be encouraged to look to the hospital as a source of advice and support. On the other hand, this should not be forced on carers, and staff would also need to recognise that the break itself might be all that some carers require. If this kind of approach was to be adopted then, as Twigg (1989) contends, the respite experience would provide care as close as possible to that given at home and the carer would have transferred knowledge as well as responsibility.

Additionally there is a need to consider carers' subjective appraisals of their difficulties when assessing the need for respite care. Greater flexibility in the organisation of rotas would also be advantageous. A case could be argued for respite care on demand, or certainly of a system which accommodates key dates in the carer's calendar, particularly those coinciding with family holidays. It is appreciated that this would cause more administrative work but on the other hand some of this might be left to carers themselves. Thus, one of the carers interviewed suggested that if the four carers on each rota were put in touch with each other they could negotiate a rota between themselves. This would obviously involve close liaison with the hospital but the increased sense of control afforded to carers seems likely to produce benefits over and above the break as well as greater flexibility. It is also vital to look closely at the frequency of admission as many carers felt that the period between respite admissions was too long. Here it might be possible to balance the more frequent admissions required with the reduction achieved by those carers happier with less frequent breaks if they could negotiate their own dates.

These changes cannot be instituted without significant adaptations to prevailing professional practice. Careful preparation and staff education would be a needed if such a system were to be successful and it would be essential to delegate more authority to nursing staff.

If these suggestions for improvements in the operation of respite care are held to have validity, they represent potentially low cost developments for they have few capital or revenue costs.

In what follows, a brief resume is offered as the basis for a "good practice guide" for institutionally based respite services in which some practical "do's" and "don'ts" are highlighted.

A good practice guide for respite care: some do's and don'ts"

DO'S

1) **Assessment.** Adequate assessment of the need for respite care is vital. This should include not only organisational factors such as timing, location and duration, but also the nature of the caring relationship. A range of respite options should be available, including facilities which can respond to 'on demand' requests. Every effort needs to be made to accomodate key dates that the carer may request. Assessment must also comprise regular review of the respite care and its effectiveness. Explicit recognition is required when the carer's limits of care have been reached.

2) **Involvement.** Both carers and dependants should be fully involved in the process of respite care. Attention should be given to their perceptions, worries and fears, particularly carers' guilt and expertise.

3) **Referral.** Open mechanisms need to be established which are flexible, creative and responsive.

4) **Purpose.** In addition to the break afforded consideration is required of:
a) Carers' needs for information;
b) Carers' needs for skills training;
c) Carers' needs for emotional support;
d) The provision of a meaningful stay for the elderly user;
e) The impact of respite care on the other residents/patients.

DON'TS

1) Use respite care as a 'carrot' persuading carers either to enter into or remain in the caring role.

2) Leave the offer of respite care too late.

3) Have eligibilty criteria which equate dependency with need.

4) See the break as a means to an end.

Before concluding brief attention is turned to areas for further research which are suggested by the study.

8.6 Extending the study: areas for further research

There is obviously scope for more detailed work into the caring paradigm and the usefulness of the model suggested as a heuristic device needs to be explored. One major aspect not addressed in the present study concerned the coping styles of carers and how these mediate in the appraisal process. This warrants more attention than has been received so far. A significant contribution of the present study related to the increased empirical evidence for the importance of satisfactions in caring. The experience of satisfaction may act as a coping resources. In attempting to unravel the often complex balance between difficulties and satisfactions the two instruments developed specifically for the present study, CASI and CADI, offer potential not only as research tools but also as assessment instruments in service delivery situations. Field testing of these and similar instruments with practitioners is now required if progress is to be made in helping agencies to turn research tolls into useful practice instruments.

Turning attention to nursing research the application of the transactional model to other caring situations requires empirical testing. Its advocates (Bailey and Clarke 1989, Benner and Wrubel 1989) suggest that it can guide practice across a diverse range of care settings from hospital admission to intensive care, from health education to death and bereavement. Should this prove to be the case then the model might indeed represent a unifying element linking theory and practice.

Moreover nursing needs to continue its search for practice relevant mid-range theories in an inductive and grounded manner and the value of a pluralistic approach in the context of quality of care warrants development. In relation to the care of older people with dependency needs the typology of care checklist merits further development work as it has potential to assist staff in exploring the value base and philosophy underpinning their care. Furthermore it could itself form the basis of an audit tool, helping to highlight the extent to which care environments meet the key requirements of Wade et als' (1983) typology. These might then be used to develop appropriate standard statements.

From a more focussed perspective the study considered a specific service and what it might achieve. Further research testing of some of the results in similar respite environments seems in order, as indeed does more plurlaistic evaluation of respite schemes. It is hoped that the study will stimulate thinking and empirical studies in all of these areas.

8.7 Conclusion

It was suggested in the introduction to the study that the research might make a modest contribution to the advancement of theory whilst also having methodological, policy and practice issues. It is to be hoped that at least some of these aims have been achieved. However it is perhaps fitting that the final word should be provided by a carer. The following is taken from a letter which accompanied one of the questionnaires in the carers survey. It describes her passage through the system of care with accounts of professional reactions and their consequences:

DAY CARE

By the consultant geriatrician- "Yes it is available but I don't think that your mother would like it".

Result-It was never provided or mentioned again.

HOME CARE

By the social worker- "We can provide a home help, but it wouldn't be for sufficient hours to meet your needs. Let me know if you need anything".

No assessment was made nor my mother ever seen by a social worker-they knew that I am unmarried, work full-time and have no family support.

By the district nurse- "We will get your mother up for you on the days you go to work."

She did so at approximately 11 am which gave the option of lifting, washing and changing my mother before breakfast and then going to work.

Result- I employed private daily help and after two years of district nursing assistance, I stopped the service as the extra 10 minutes it took me to dress my mother didn't seem worth the time which the nurse commandeered to assist her as she couldn't manage my mother on her own!

RESIDENTIAL RESPITE CARE

From the consultant- "Yes it can be arranged, but although it will help you it will be detrimental to your mother."

I accepted the respite care on three occasions. During the last of these I was told by the ward sister that it was only intended for carers actually going away and not if I was staying at home. No further offer was made although I was told that I could apply for it again when I felt I needed it.

Result- I never applied for respite care again even though the break was good and allowed me to catch up with the 'odd' job at home.

All this happened during the first few years and since help did not seem to be forthcoming without a fight, I pulled myself together and got on with what was necessary one day at a time. The most helpful advice which I was given was from a health visitor friend. She told me to remember that I was human and that I shouldn't punish myself so much after I have been tired, exasperated and irritable. With that advice I have been able to come to terms with my restricted lifestyle and find pleasure in different ways.

Good luck with your survey.

If, as a result of the present study, one less carer has a similar experience then it will have been considered worthwhile.

REFRENCES

Abrams, P. (Edited by Bulmer, M.) (1985) Policies to promote informal care: some reflections on voluntary action, neighbourhood involvement and neighbourhood care, Ageing and Society, 5, 1-18.

Alderman, C. (1987) Formal back-up for informal carers, Nursing Times, 83(24), 51-53.

Allen, I. (1983) Short-stay Residential Care for the Elderly. London, Policy Studies Institute, Report no. 616.

Allen, I., Levin, E., Siddell, M. and Vetter, N. (1983) The Elderly and their Informal Carers. In Elderly People in the Community: Their Service Needs. London, H.M.S.O.

Alt, M. (1990) Exploring Hyperspace: A non-mathematical of multivariate analysis, Berkshire, Mc Graw Hill (UK).

Altschul, A. (1972) Patient-Nurse Interaction: A Study of Interaction Patterns in Acute Psychiatric Wards. Edinburgh, Churchill Livingstone.

Armstrong-Esther, C.A. and Browne, K.D. (1986) The influence of elderly patients mental impairment on nurse-patient interaction, Journal of Advanced Nursing',11, 379-387.

Association of Carers (1985) Response to the Review of Community Nursing. Rochester, Association of Carers.

Atkinson, P. (1979) Research Design in Ethnography, Part 5 Block 3, Research Methods in Education and the Social Sciences. Milton Keynes, Open University Press.

Banks, J.A. (1976) A Content Analysis of the Black American in Textbooks. In Golden, P.M. (ed) The Research Experience. Illinois, Peacock Publishers.

Bailey, K.D. (1978) Methods of Social Research. New York, The Free Press.

Bailey, R. and Clarke, M. (1989) Stress and Coping in Nursing. London, Chapman Hall.

Baker, D.E. (1978) Attitudes of Nurses to the Care of Elderly People. Unpublished Ph.D. Thesis, University of Manchester.

Ball, J.A., Goldstone, L.A. and Collier, M.M. (1984) Criteria for Care: The Manual of the North West Nurse Staffing Project. Newcastle, Newcastle upon Tyne Products Limited.

Barnett, D. and Wainwright, P. (1987) A measure of quality, Senior Nurse, 6(3), 8-9.

Batchelor, I. (1984) Policies for a Crisis: Some Aspects of DHSS Policies for the Elderly. Occasional Paper 1. London, Nuffield Provincial Hospitals Trust.

Bayley, M. (1986) Paper presented at Seminar on Supporting Informal Carers, Llandrindod Wells, 23/24 March 1986.

Bebbington, A. and Quine, L. (1987) A comment on Hirst's 'Evaluating the Malaise Inventory', Social Psychiatry,22, 5-7.

Becker, H.S. (1969) Problems of Inference and Proof in Participant Observation. In Mc Call, G.J. and Simmons, J.L.(Eds) Issues in Participant Observation. New York, Random House.

Bell, R., Gibbons, R. and Pinchen, I. (1987) Action Research with Informal Carers:Patterns and Processes in Carers Lives, Report on phase two. Cambridge, Health Promotion service.

Benner, P. (1984) From Novice to Expert: Excellence and Power in Clinical Nursing Practice. California, Addison-Wesley.

Benner, P. and Wrubel, J. (1989) The Primacy of Caring: Stress and Coping in Health and Illness. California, Addison-Wesley.

Bergman, R. (1982) Evaluation of nursing care:could it make a difference? International Journal of Nursing Studies, 19(2), 53-60.

Bergman, R. and Golander, H. (1982) Evaluation of care of the Aged: a multi-purpose guide, Journal of Advanced Nursing, 7, 203-210.

Berman, S., Delaney, N., Gallagher, D., Atkins, P. and Graeber, M.P. (1987) Respite care: a partnership between a veterans administration nursing home and families to care for frail elders at home, Gerontologist, 27(5), 581-584.

Blau, P.M. and Scott, W.R. (1963) Formal Organisations. London, Routledge.

Bloch, D. (1975) Evaluation of nursing care in terms of process and outcome, Nursing Research, 24, 256-263.

Bloomfield, K. (1986) Ask the family, Nursing Times, 12/3/86, 28-30.

Boldy, D. and Kuh, D. (1984) Short-term care for the elderly in residential homes: a research note, British Journal of Social Work, 14, 173-175.

Bond, S. (1987) A comparison of two methods of describing activity levels among frail elderly people in institutions. Paper presented at International Nursing Research Congress, University of Edinburgh, July 1987.

Bond, S. (1989) Evaluation of Innovation in a Rural Community Hospital. Paper presented at Royal College of Nursing Research Society Annual Conference, University College Swansea, 14-16 April.

Bond, J. and Bond, S. (1987) Developments in the Provision and Evaluation of Long-term Care for Dependent Old People. In Fielding, P. (ed) Research in the Nursing Care of Elderly People. London, John Wiley.

Bond, S. and Bond, J. (1990) Outcomes of care within a multiple case study in the evaluation of experimental NHS nursing homes, Age and Ageing, 19, 11-18.

Bond, B., Bond, S., Donaldson, C., Greyson, G. and Atkinson, A. (1989a) Evaluation of an innovation in the continuing care of the very frail elderly, Ageing and Society, 9(4), 347-382.

Bond, J., Gregson, B.A. and Atkinson, A. (1989b) Measurement of outcomes within a multi-centred randomised controlled trial in the evaluation of experimental NHS nursing homes, Age and Ageing, 18, 292-302.

Bonny, S. (1984) Who Cares in Southwark? Rochester, Kent. Association of Carers.

Boss, P. (1988) Family Stress Management. California, Sage.

Bowers, B.J. (1987) Intergenerational caregiving: adult caregivers and their aging parents, Advances in Nursing Science, 9(2), 20-31.

Bowers, B.J. (1988) Family perceptions of care in a nursing home, Gerontologist, 28(3), 361-367.

Bowling, A. (1984) Caring for the widowed elderly: the burden on their supporters, British Journal of Social Work, 14, 435-455.

Brailey, L.J. (1984) Issues in coping research, Nursing Papers, 16(11), 5-13.

Briggs, A. (1983) Who cares? Chatham, Kent, Association of Carers.

Brock, A.M. and O'Sullivan, P. (1985) A study to determine what variables predict institutionalisation of elderly people, Journal of Advanced Nursing, 10, 533-537.

Brocklehurst, J.C. (1978) Geriatric Services and the Day Hospital. In Brocklehurst, J.C. (ed) Textbook of Geriatric Medecine and Gerontology, Second Edition, Edinburgh, Churchill Livingstone.

Brocklehurst, J.C. and Andrews, K. (1985) Geriatric Medicine: the style of practice, Age and Ageing, 14, 1.

Brook, P. and Jestice, S. (1986) Relief for the demented and their carers Geriatric Medicine, June 1986, 31-36.

Bryley, E.L. (1969) The nurse researcher as a participant observer in a nursing setting, Nursing Research, 18(3), 230-236.

Buckwater, K.C. and Hall, G.R. (1987) Families of the Institutionalised Older Adult: a Neglected Resource. In Brubaker, T.H. (ed) Aging, Health and Family. Beverley Hills, Sage.

Buist, M. (1988) Illuminative Evaluation. In Lishman, J. (ed). Evaluation: Research Highlights in Social Work(8), Second Edition. London. Jessica Kingsley.

Bulmer, M. (1987) The Social Basis of Community Care. London. Allen and Unwin.

Burbank, P.M. (1986) Psychological theories of aging: a critical review, Advances in Nursing Science, 9(1), 73-86.

Burgess, R.G. (1982) The Unstructured Interview as a Conversation. In Burgess, R.G. (ed) Field Research: a Sourcebook and Field Manual. London, George, Allen and Unwin.

Burnette, K. (1986) Relocation and the elderly: changing perspectives, Journal of Geriatric Nursing, 12(10), 6-11.

Bursten, G.R. (1986) Correspondence, British Medical Journal, 292, 481-483.

Caldock, K. (1990) Consumer Perspectives on Community Care: Appropriateness, Co-ordination, Packaging and Case Management. CSPRD Working Paper. Bangor, University College of North Wales.

Campbell, D.T. and Fiske, D.W. (1959) Convergent and discriminant validation by multitrait:multidimensional matrix, Psychological Bulletin, 56, 81-105.

Cantor, M.H. (1983) Strain amongst caregivers: a study of experience in the United States, Gerontologist, 23(6), 597-604.

Caplow, T. (1956) The dynamics of information interviewing, American Journal of Sociology, 62, 165-171.

Carley, M., Dant, T., Gearing, B. and Johnson, M. (1987) Care of Elderly People in the Community: a Review of the Issues and the Research. Project Paper 1, Care of Elderly People at Home Project. Milton Keynes. Open University/Policy Studies Institute.

Carter, J. (1981) Day Services for Adults: Somewhere to go. London, George, Allen and Unwin.

Casenta, M.S., Lund, D.A., Wright, S.D. and Redburn, D.E. (1987) Caregivers to dementia patients: the utilisation of community services, Gerontologist, 27(2), 209-214.

Challis, D. (1981) The measurement of outcome in social care of the elderly, Journal of Social Policy, 10(2), 179-208.

Challis, D. (1985) Case Management and Consumer Choice. Personal Social Services Research Unit, Discussion paper 396, University of Kent.

Challis, D. and Davies, B. (1986) *Case Management in Community Care.* Aldershot, Gower.

Challis, D., Knapp, M. and Davies, B. (1988) Cost Effectiveness Evaluation in Social Care. In Lishman, J. (ed) *Evaluation.* Research Highlights in Social Work 8, Second Edition. London. Jessica Kingsley.

Charlesworth, A., Wilkin, D. and Durie, A. (1984) *Carers and services: a Comparison of Men and Women Caring for Dependent Elderly People.* Manchester, Equal Opportunities Commission.

Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill, *Sociology of Health and Illness,* 5(2), 168-195.

Charnley, H. (1989) *Carer Outcomes and the Social Production of Welfare,* Discussion Paper 595/2, PSSRU, University of Kent.

Chenitz, W.C. (1983) Entry to a nursing home as status passage: a theory to guide nursing practice, *Geriatric Nursing,* March/April 1983, 92-97.

Chenoweth, B. and Spencer, B. (1986) Dementia: the experience of caregivers, *Gerontologist,* 26(3), 267-272.

Child, D. (1970) *The Essentials of Factor Analysis*. London, Holt, Rinehart and Winston.

Chilman, C.S., Nunnally, E.W. and Cox, F.M.(Eds) (1988) *Chronic Illness and Disability.* Families in Trouble Series, Vol.2. London, Sage.

Chiriboga, D.A., Weiler, P.G. and Neilsen (1990) The Stress of Caregivers. In Biegel, D.E. and Blum, A. (Eds) *Aging and Caregiving: Research, Theory and Policy*. California, Sage.

Chommie, P.W. and Hudson, J. (1984) Evaluation of outcome and process, *Social Work,* 19(6), 682-687.

Clarke, M. (1984a) Stress and coping: constructs for nursing, *Journal of Advanced Nursing,* 9, 3-13.

Clarke, M. (1984b) The constructs of stress and coping as a rationale for nursing activities, *Journal of Advanced Nursing,* 9, 267-275.

Clark, P. and Bowling, A. (1989) An observational study of quality of life in N.H.S. nursing homes and a long-stay hospital ward for the and elderly, *Ageing and Society,* 9, 123-148.

Clark, N.M. and Rakowski, W. (1983), Family caregivers of older adults: improving helping skills, *Geronotologist,* 23(6), 637-642.

Clegg, P.E. (1978) *Day Care for the Elderly in the Metropolitan Borough of Kirlees.* Monograph, University of Bradford, Social Work Unit.

Cohen-Mansfield, J. (1989) Sources of satisfaction in nursing home caregivers: preliminary results, Journal of Advanced Nursing, 14, 383-388.

Cohen, L. and Manion, L. (1985) Research Methods in Education. Second Edition, London, Routledge.

Coleman, P. (1990) Adjustment in Later Life. In Bond, J. and Coleman, P. (eds) Ageing in Society: An Introduction to Social Gerontology. London, Sage.

Cook, T.D. and Shadish, W.R. (1986) Program evaluation: the worldly science, Annual Review of Psychology, 37, 193-232.

Corbin, J. and Strauss, A. (1988) Carers-working together, Nursing Times, 84(15), 48-49.

Cormack, D. F. (1976) Psychiatric Nursing Observed: A Descriptive Study of the Work of the Charge Nurse in Acute Admission Wards of Psychiatric Hospitals. London, Royal College of Nursing.

Cormack, D.F. (1980) Obtaining access to data sources: an exploration of methods, problems and possible solutions, Journal of Advanced Nursing, 5, 357-370.

Cormack, D. F. (1981) Making use of unsolicited research data, Journal of Advanced Nursing,6, 41-49.

Coulton, C.J. (1982) Quality assurance for social service programs: lessons from health care, Social Work, 27(5), 397-402.

Cox, E.O., Parsons, R.J. and Kimboko, P.J. (1988) Social services and intergenerational caregiving: issues for social work, Social Work, 33(5), 430-434.

Craig, H.M. and Edwards, J.E. (1983) Adaptation in chronic illness: an eclectic model for nurses, Journal of Advanced Nursing, 8, 397-404.

Crano, W.D. and Brewer, M.B. (1973) Principles of Research in Social Psychology. New York, McGraw Hill.

Crookston, E.M. (1989) Informal Caring: The Carers View. Middlesborough, Cleveland County Council Research and Intelligence.

Crow, R. (1984a) Criteria for evaluation research. Paper presented at Nursing Research: does it make a difference? Workshop of European Nurse Researchers, London 10-13/4/1984

Crow, R. (1984b) Observation. In Cormack, D.F. (ed) The Research Process in Nursing. Oxford, Blackwell Scientific Publications.

Cunliffe, L. (1987) Respite Care of the Elderly : an Investigatio of the Needs of Patients and their Informal Carers, Unpublished M.Sc. Thesis (Clinical Psychology), University of Birmingham.

Darbyshire, P. (1987) Sour grapes, Nursing Times, 83(37), 23-25.

Davies, A.D.M. (1981) Research with elderly people in long-term care: some social and organisational factors affecting psychological interventions, Ageing and Society, 2, 285-298.

Davies, A.J. (1980a) Disability, homecare and the care-taking role in family life, Journal of Advanced Nursing, 5, 475-484.

Davies, A.J. (1980b) Research as an inactional situation: objectivity in the interview, International Journal of Nursing Studies, 17(4), 357-370.

Davies, B. (1985) The Production of Welfare. Personal Social Services Research Unit, Discussion Paper 400, University of Kent.

Davies, B. (1986) American lessons for British policy and research on long-term care of the elderly, Quarterly Journal of Social Affairs, 2(3), 321-355.

Davies, B. and Knapp, M. (1981) Old People's Homes and the Production of Welfare. London, Routledge and Kegan Paul.

Dean, J.P and Whyte, W.F. (1969) How do you know if the informant is telling the truth? In Mc Call G. J. and Simmons, J.L. (Eds) Issues in Participant Observation. New York, Random House.

Dean, K., Hickey, T. and Holstein, B.E. (1986) The Behavioural Component of Health Education: Key problems and Recommendations. In Dean, K., Hickey, T. and Holstein, B.E. (eds) Self Care and Health Care in Old Age. Beckenham, Croom Helm.

De Largy, J. (1957) Six weeks in-six weeks out: a geriatric hospital service for rehabilitating the aged and relieving their carers, The Lancet, 23/2/1957, 418-419.

Denzin, N.K. (1970) The Research Act in Sociology: a Theoretical Introduction to Sociological Methods. London, Butterworths.

Department of Health (1989a) Caring for People: Community Care in the Next Decade and Beyond. London, HMSO.

Department of Health (Nursing Division) (1989b) A Strategy for Nursing: A Report of the Steering Committee, London, HMSO.

Department of Health (Nursing Division) (1990) Measuring the Quality:Nursing Care Audit, London, NHS Management Executive

Devlin, R. (1986) Holiday home, Community Outlook (Nursing Times), April 1986,5,6,11.

Dewing, J. (1990) What a Relief, Nursing Times, 86(8), 43-45.

Dixon, S. (1986) Away from Institutional Dependence: Toward a More Resident Orientated Institutional Environment. In Phillipson, C., Bernard, M. and Strang, P. (eds) Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives. London, Croom Helm.

Donabedian, A. (1966) Evaluating the quality of medical care, Millbank Memorial Fund Quarterly, 44, 166-206.

Donabedian, A. (1980) The Definition of Quality and Approaches to its Assessment. Michigan, Health Administration Press, Ann Arbor.

Draper, P. (1990) The development of theory in British nursing: current position and future prospects, Journal of Advanced Nursing, 15, 12-15.

Dunlop, M.J. (1986) Is a science of caring possible? Journal of Advanced Nursing, 11, 661-670.

Dunn, R.B., MacBeath, L. and Robertson, D. (1983) Respite admissions and the disabled elderly, Journal of the American Geriatric Society, 31(10), 613-616.

Dunne, L.M. (1986) Defining Quality Assurance, Professional Nurse, 2(2), 47-49.

Dunnel, K. and Dobbs, J. (1982) Nurses Working in the Community. London, OPCS Survey Division.

Eagles, J. M., Craig, A., Rawlinson, F., Restall, D.B., Beattie, J.A.G. and Besson, J.A.O. (1987) The psychological well-being of supporters of the demented elderly, British Journal of Psychiatry, 150, 293-298.

Edwards, N. (1987) Nursing in the Community: A Team Approach for Wales, Report of the review of Community Nursing In Wales. Cardiff Welsh Office.

Edwards, J.R. and Cooper, C.L. (1988) Research in stress, coping and health: theoretical and methodological issues, Psychological Medicine, 18, 15-20.

Ehrenberg, A.S.C. (1975) Data Reduction: Analysing and Interpreting Statistical Data., London, John Wiley.

Ellis, V. and Wilson, D. (1983) Respite care in the nursing home unit of a veterans hospital, American Journal of Nursing, October 1983, 1428-1431.

Equal Opportunities Commission (1982a) Caring for the Elderly and Handicapped: Community Care Policy and Womens Lives. Manchester, Equal Opportunities Commission.

Equal Opportunities Commission (1982b). Who Cares for the Carers: Opportunities for those Caring for the Elderly and Handicapped. Manchester, Equal Opportunities Commission.

Evers, H.K. (1981a) Tender Loving Care: Patients and Nurses in Geriatric Wards. In Copp, L.A. (ed) Care of the Ageing. Edinburgh, Churchill Livingstone.

Evers, H.K. (1981b) Multi-disciplinary teams in geriatric wards: myth or reality?, Journal of Advanced Nursing, 6, 205-214.

Evers, H.K. (1982) Professional practice and patient care: multi-disciplinary teams in geriatric wards, Ageing and Society,15a, 581-588.

Fairhurst, E. (1983) Organisational rules and the accomplishment of nursing work on geriatric wards, Journal of Management Studies, 20(3), 315-332.

Fengler, A.P. and Goodrich, N. (1979) Wives of disabled men: the hidden patients, Gerontologist, 26(3), 248-252.

Field, P.A. and Morse, J.M. (1985) Nursing Research: the Application of Qualitative Approaches. London, Croom Helm.

Fielding, P. (1986) Attitudes Revisited. London, Royal College of Nursing.

Fitting, M., Robins, P., Lucas, M.J. and Eastham, J. (1986) Caregivers for dementia patients: a comparison of husbands and wives, Gerontologist, 26(3), 248-252.

Fotrell, E. (1988) Why good respite care is so difficult to provide, Geriatric Medicine,18(10), 71.

French, L. (1981) Methodological considerations in hospital patient opinion surveys, International Journal of Nursing Studies, 18(1), 7-32.

Fry, J. (1984) Relative Support, Nursing Mirror, 158 (21), 25-26.

Gallagher, A.P. (1986) A model for change in long-term care, Journal of Gerontological Nursing, 12(5), 19-23.

Garland, J. (1985) Adaptation skills in the elderly, their supporters and carers, British Journal of Medical Psychology, 58, 267-274.

Gaze, H. (1990) A good night's crest, Nursing Times, 86(5), 16-17.

George, L.K. and Gwyther, L.P. (1986) Caregiver well-being: a multidimensional examination of family caregivers to demented adults, Gerontologist, 26(3), 253-259.

Gilhooly, M.L.M. (1984) The impact of care-giving on care-givers: factors associated with the psychological well-being of people supporting a dementing relative in the community, British Journal of Medical Psychology 57, 35-44.

Gilhooly, M.L.M. (1986) Senile dementia: factors associated with caregivers' preference for institutional care, British Journal of Medical Psychology, 59, 165-171.

Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E. and Gledhill, K. (1984) Emotional distress amongst caregivers of the elderly mentally infirm, British Journal of Psychiatry, 145, 172-177.

Gilliard, N. and Brunston, A. (1984) Nurses' typification of nursing home patients, Ageing and Society, 4, 45-67.

Glaser, B.G. and Strauss, A.L. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago, Aldine.

Glass, G.V. and Ellett, F.S. (1980) Evaluation Research, Annual Review of Psychology, 211-228.

Glasser, G. and Wexler, D. (1985) Participants evaluation of educational /support groups for families of patients with Alzheimers Disease and other dementias, Gerontologist, 25, 232-236.

Godlove, C., Richard, L. and Rodwell, G. (1981) Time for Action: An Observation Study of Elderly People in Four Different Care Environments. JUSSR, University of Sheffield.

Gold, R.L. (1958) Roles in sociological field observation, Social Forces, 36(3), 217-233.

Goldberg, E.M. and Connelly, N. (1982) The Effectiveness of Social Care for the Elderly: an Overview of Recent and Current Evaluative Research. London, Heinnemann Educational Books.

Goodman, C. (1986) Research on the informal carer-a selected literature review, Journal of Advanced Nursing 11, 705-711.

Goodwin, L.D. and Prescott, P.A. (1981) Issues and approaches to estimating interrater reliability in nursing research, Research in Nursing and Health, 4, 323-337.

Goosen, G.M. and Bush, H.A. (1979) Adaptation: a feedback process, Advances in Nursing Science, 1(4), 91-100.

Gordon, D.S. (1987) Interweaving informal care: a conceptual framework. In Twigg, J (ed) Evaluating Informal Care Conference papers, University of York.

Grant, G., Nolan, M.R. and Ellis, N.C. (1990) A reappraisal of the Malaise Inventory, Social Psychiatry and Psychiatric Epidemiology, 25, 170-178.

Green, H. (1988) Informal Carers. General Household Survey 1985 series, GH5 No.15, Supplement 16, London, OPCS, Social Survey Division.

Griffin, A.P. (1983) A philosophical analysis of caring in nursing, Journal of Advanced Nursing, 8, 289-295.

Griffiths, R. (1988) *Community Care: Agenda for Action*, A Report to the Secretary of State for Social Services, London, HMSO.

Guba, E.G. and Lincoln, Y.G. (1989) *Fourth Generation Evaluation*. Beverley Hills, Sage.

Gwynedd County Council (1983) *A Report on Services Provided for the Elderly in Gwynedd.* Gwynedd County Council, Social Services Department.

Gwynedd Health Authority (1985) *Caring for the Elderly in Gwynedd: Towards a More Effective Pattern.* Gwynedd Health Authority, Health Care Planning Team (Elderly).

Gwynedd Health Authority Health Care Planning Team (1987) *Discussion Documant on the Future of Long Stay Beds* Gwynedd Health Authority.

Gwyther, L.P and George, L.K. (1986) Caregivers for dementia patients, complex determinants of well-being and burden, *Gerontologist,* 26(3), 245-247.

Hall, M. (1988) Geriatric Medicine Today. In Wells, N. and Freer, C. (eds) *The Ageing Population: Burden or Challenge?.* Hampshire, MacMillan Press.

Harper, N., Mc Dowell, D.K., Turner, J.J.,and Sharma, A.K. (1988) Planned short-stay admission to a geriatric unit: one aspect of respite care, *Age and Ageing*, 17, 199-204.

Hasselkus, B.R. (1988) Meaning in family caregiving: perspectives on caregiver/professional relationships, *Gerontologist,* 28(5), 686-691.

Hatfield, A.B. (1987) Coping and Adaptation: a Conceptual Framework for Understanding Families. In Hatfield, A.B. and Lefley, H.P. (eds) *Families of the Mentally Ill: Coping and Adaptation.* London, Cassell Education.

Hawranik, P. (1985) Caring for aged parents: divided allegiances, *Journal of Geriatric Nursing,*11(10), 19-22.

Hawthorn, R. (1974) *Nurse I Want My Mummy.* London, Royal College of Nursing.

Hawthorn, P.J. (1984) Measuring change in nursing practice, *Journal of Advanced Nursing*, 9, 239-247.

Hedderson, J. (1987) *SPSSX Made Simple.* California, Wadsworth Publishing.

Heiskanen, T.A. (1988) Nursing staffs' perceptions of work in acute and long-term care hospitals, *Journal of Advanced Nursing,* 13, 712-725.

Henderson, J. (1986) By the Community: an Ideological Response to the Crisis in the Welfare State. In Phillipson,C., Bernard, M. and Strang, R. (eds) Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives. London, Croom Helm.

Henwood, M. and Wicks, M. (1984) The Forgotten Army: Family Care and Elderly People. London, Family Policy Studies Centre.

Hickey, T. (1986) Health Behaviour and Self Care in Later Life: an Introduction. In Dean, K., Hickey, T. and Holstein, B.E. (eds) Self Care and Health Care in Old Age. Beckingham, Croom Helm.

Hildebrandt, E.D. (1983) Respite care in the home, American Journal of Nursing, October 1983, 1428-1431.

Hills, N. and Horflorenden, S. (1987) Evaluation as a Developmental Activity. In Twigg, J. (ed) Evaluating Support for Informal Carers. Conference papers, University of York.

Hirschfield, M.J. (1981) Families Living and Coping with the Cognitively Impaired. In Copp, L.A. (ed) Care of the Ageing. Edinburgh, Churchill Livingstone.

Hirschfield, M.J. (1983) Homecare versus institutionalisation :family caregiving and senile brain disease, International Journal of Nursing Studies, 20(1), 23-32

Hirschfield, M.J. and Krulick, T. (1985) Family caregiving to Severely Chronically Ill Children and the Aged. In King, K. (ed) Long-term Care of the Elderly, Recent Advances in Nursing 15. Edinburgh, Churchill Livingstone.

Hirst, M.A. (1983) Evaluating the Malaise Inventory: an item analysis, Social Psychiatry, 18, 181-184.

Hirst, S.P. and Metcalf, B.J. (1984) Promoting self-esteem, Journal of Gerontological Nursing, 10 (2), 72-77.

Hirst, S.P. and Metcalf, B.J. (1986) The learning needs of caregivers, Journal of Gerontological Nursing, 12(4), 24-28.

Hodkinson, H.M. (1981) An Outline of Geriatrics. London, Academic Press.

Holstein, B.E. (1986) Health Related Behaviour and Aging: Conceptual Issues. In Dean, K., Hickey, T. and Holstein, B.E. (eds) Self Care and Health Care in Old Age. Beckingham, Croom Helm.

Hooyman, N., Gonyea, J. and Montgomery, R. (1985) The impact of in-home services termination on family caregivers, Gerontologist, 24(2), 141-145.

Horowitz, A. (1985) Sons and daughters as caregivers to older parents: differences in role performance and consequences, Gerontologist, 26(6), 612-617.

Horrocks, P. (1988) Caring in Hospital. In Tomlin, S. (ed) Abuse of the Elderly: an Unneccessary and Preventable Problem. London, British Geriatric Society.

Hughes, B. and Wilkin, D. (1987) Physical care and quality of life in residential homes, Ageing and Society,' 7, 399-425.

Hughes, B., Wilkin, D. and Evans, S. (1980) The definition and measurement of quality of life: some methodological issues. Paper presented at BSA (Medical Sociology) Conference University of Warwick, 19-21 September.

Hutt, S.J. and Hutt, C. (1978) Direct Observation and the Measurement of Behaviour. Illinois, Charles Thomas.

Illsley, R. (1986) Preface. In Dean, K., Hickey, T. and Holstein, B.E. (eds) Self Care and Health Care in Old Age. Beckingham, Croom Helm.

Ingham, R. and Fielding, P. (1985) A review of the nursing literature on attitudes towards old people, International Journal of Nursing Studies, 22(3), 171-181.

Intagliata, J. (1986) Assessing the Impact of Respite Care Services: a Review of Outcome Evaluation Studies. In Salisbury, C.L. and Intagliata, J. (eds) Respite Care: Support for Persons with Developmental Disabilities in the Family. Baltimore, Brookes.

Isaacs, B. and Thompson, J. (1960) Holiday admissions to a geriatric unit, Lancet, 30/4/1960, 969-971.

Jackson, M. (1975) An experience in participant observation,Nursing Outlook, 23(8) 552-555.

Jackson, M.F. (1989) geriatric versus general medical wards: comparison of patients ' behaviours following discharge from an acute care hospital, Journal of Advanced Nursing, 14, 906-914.

Jacobson, S. F. (1983) An Overview of Coping. In Jacobson,S.F. and McGrath, H.M. (eds) Nurses Under Stress. New York, Wiley.

Janforum (1985) Present and future care of the elderly, Journal of Advanced Nursing,10, 491-496.

Jick, T.D. (1979) Mixing qualitative and quantitative methods: triangulation in action, Administrative Science Quarterly, 24, 602-611.

Johnson, C.L. and Catalano, D.J. (1983) A longitudinal study of family support to the impaired elderly, Gerontologist, 23(6), 612-618.

Jones, D.A. (1986) A Survey of Carers of Elderly Dependants Living in the Community. Research Team for the Care of the Elderly, University of Wales College of Medicine.

Jones, D.A. and Vetter, N.J. (1985) Formal and informal support received by carers of elderly dependants, British Medical Journal, 291, 643-645.

Jones, D.A., Victor, C.R. and Vetter, N.J. (1983) Carers of the elderly in the community, Journal of the Royal College of General Practitioners, 33, 707-710.

Joreskog, K.G. and Sorbom, D.(1984) LISREL VI Users Guide. Sweden, University of Uppsala.

Joreskog, K.G. and Sorbom, D. (1985) LISREL VI: Analysis of Linear Structural Relationships by Maximum Likelihood and Least Squares Method. Sweden, University of Uppsala.

Jowell, T. (1990) Partners in policy, Community Care (Inside), 22/2/1990, ix-x.

Jowell, T., Quine, L. and Elson, B. (1987) Caring about Carers: an Initiative of Birmingham's Community Care Special Action Project. In Twigg, J. (ed) Evaluating Support to Informal Carers. Conference papers, University of York.

Kahana, E. and Young,R. (1990) Clarifying the Caregiving Paradigm: Challenges for the Future. In Biegel, D.E. and Blum,A. (Eds) Aging and Caregiving: Theory, Research and Policy. California, Sage.

Kane, R. A. and Kane, R.L. (1986) Self Care and Health: Inseperable but Equal for the Well-being of the Old. In Dean, K., Hickey, T. and Holstein, B.E. (eds) Self Care and Health Care in Old Age. Beckingham, Croom Helm.

Kaplan, A (1964) The Conduct of Inquiry: Methodology for Behavioural Sciences. San Francisco, Chandler Publishing.

Keith, L. (1990) Caring partnership, Community Care (Inside), 22/2/1990, x-xi.

Kellaher, L. and Peace, S. (1990) From respondent to consumer to resident: shifts in approaches to quality assurance-the last decade, Paper given at BSG Annual Conference, University of Durham, September 1990.

Kitson, A. (1984) Steps Towards the Identification and Development of Nursing's Therapeutic Function in the Care of the Hospitalised Elderly. Unpublished D.Phil Thesis, University of Ulster.

Kitson A. (1985) Educating for Quality, Senior Nurse, 3(4), 11-16.

Kitson, A. (1986) Indicators of quality in nursing care: an alternative approach, Journal of Advanced Nursing, 11, 133-144.

Kitson, A. (1987) A comparative analysis of lay caring and professional (nursing) caring relationships International Journal of Nursing Studies, 24(2), 155-165.

Kitson, A. (1988) Something special, Geriatric Nursing and Home Care, 8(6), 20-22.

Kitson, A. and Kendall, H. (1986) Rest assured, Nursing Times, 27/8/86, 29-31.

Knipscheer, K. (1989) The relationship between formal and informal care: family cultures of caregiving, Paper presented at XIV International Congress on Gerontology, Acapulco, Mexico, 18-23 June.

Kosberg, J.I. and Cairl, R.E. (1986) The cost of care index: A case management tool for screening informal care providers, Gerontologist, 26(3), 273-278.

Kosberg, J. I., Cairl, R.E. and Keller, D.M. (1989) Components of burden: interventive implications, Gerontologist, 30(2), 236-242.

Kratz, C.R. (1978) Care of the Long-term sick in the Community, Edinburgh, Churchill Livingstone.

Krippendorf, K. (1980) Content Analysis: an Introduction to its Methodology. Beverly Hills, Sage.

Lanceley, A. (1985) The use of controlling language in the rehabilitation of the elderly, Journal of Advanced Nursing, 10, 125-135.

Lawton, M.P., Brody, E.M. and Sapstein, A.R. (1989a) A controlled study of respite services for caregivers of Alzheimers patients, Gerontologist, 29(1), 8-16.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M. and Glicksman, A. (1989b) Measuring caregiving appraisal, Journal of Gerontology, 44(3), 61-71.

Lazarus, R.S. (1966) Psychological Stress and the Coping Process. New York, Mc Graw Hill.

Ledingham, K. (1988) Respite Care: What Choice. In Gordon, D.S. (Ed) Independence in Old Age: Issues for Planning and Practice, Conference Papers, British Society of Gerontology, Aberdeen Group.

Lelean, S.R. (1975) Ready for Report Nurse. The study of Nursing Care Research Project, Series 2, No.2, London, Royal College of Nursing.

Lenton, R.J., Murdock, P.S. and Simpson, A. (1986) Correspondence, British Medical Journal, 292, 481-483.

Lewis, J. and Meredith, B. (1988a) Daughters caring for mothers, Ageing and Society, 8(1), 1-21.

Lewis, J. and Meredith, B. (1988b) Daughters Who Care. London, Routledge.

Liddiard, R. and Ritvo, R.A. (1986) Self-care and Health Policy: a Conflict in Interests. In Dean, K., Hickey, T. and Holstein, B.E. (eds) *Self-care and Health Care in Old Age.* Beckingham, Croom Helm.

Lincoln, Y.G. and Guba, E.G. (1985) *Naturalistic Enquiry.* Beverley Hills, Sage.

Lipman, A. and Slater, R. (1977) Homes for old people: towards a more positive environment, *Gerontologist,* 17, 146-156.

Lipman, A., Slater, R. and Howard, H. (1979) The quality of verbal interaction in homes for old people, *Gerontologist*, 19, 275-284.

Looney, K.M. (1987) The respite care alternative, *Journal of Gerontological Nursing,*13(5), 18-21.

Lovelock, R.J. and Powell, J. (1987) Carers Views Within a Pluralistic Evaluation of Services: the Development of a Methodology. In Twigg, J. (ed) *Evaluating Support to Informal Carers.* Conference papers, University of York.

Luck, M., Lawrence, B., Pocock, B. and Reilly, K. (1988) *Consumers Market Research in Health Care*. London, Chapman Hall.

Luker, K. (1981) An overview of evaluation research in nursing, *Journal of Advanced Nursing,* 6, 87-93.

MacCarthy, B., Lesage, A., Brewin, C.R., Brugha, T.S., Margen, S. and Wing, J.K. (1989) Needs for care among the relatives of long-term users of day care, *Psychological Medicine,* 19, 725-736.

MacFadyen, M. (1984) The Measurement of Engagement in the Institutionalised Elderly. In Hanley, I. and Hodge, J. (eds) *Psychological Approaches in the Care of the Elderly.* London, Croom Helm.

Maclean, U. (1989) *Dependent Territories*. London, Nuffield Provincial Hospitals Trust.

MacPherson, I., Hunter, D.J. and McKeganey, N.P. (1988) Interviewing elderly people: some problems and challenges, *Research Policy and Planning (Journal of the Social Services Research Group),* 5(2), 13-28.

Marck, P. (1990) Therapeutic reciprocity: a caring phenomenon, *Advances in Nursing Science*, 13(1), 49-59.

Martin, I. (1981a) Floating beds, *Journal of Community Nursing,* June 1981, 12-13.

Martin, I. (1981b) Further adventures with floating beds, *Journal of Community Nursing,* October 1981, 15-16.

Martinus, P. and Severs, M. (1988) Quantifying the effects of respite care, *Geriatric Medecine,* 18(10), 73-79.

McAlpine, C.H., Lennox, M. and Roberts, M. (1986) Correspondence, British Medical Journal, 292, 481-483.

McCall, G.J. (1969) Data Quality Control in Participant Observation. In Mc Call, G.J. and Simmons, J.L. Issues in Participant Observation., New York, Random House.

McCall, G. J. (1984) Systematic field observation, Annual Review of Socilogy, 10, 263-282.

McCoy, P. (1983) Short-term Residential Care for Elderly People: an answer to Growing Older. In Jerrome. D. (ed) Ageing in Modern Society. London, Croom Helm.

McDonald, A.J.D., Craig, T.R.J. and Warner, L.A.R.(1985) The development of a short observation method for the study of activity and contact of old people in residential settings, Psychological Medecine, 15, 167-172.

McEwan, R.T. (1989) Issues in evaluation: evaluating assessments of elderly people using a variety of methods, Journal of Advanced Nursing,14, 103-110.

McFarlane, J.K. (1976) A charter for nursing, Journal of Advanced Nursing, 1, 187-196.

McGrath, M. and Hadley, R. (1981) Evaluating Patch-based Social Services Teams-a Pilot Study. In Goldberg, E.M. and Connelly, N. Evaluative Research in Social Care. London, Heinnemann Educational Books.

Meila, K. (1983) Doing nursing and being professional: students' views of nursing', Nursing Times, 1/6/83, 28-30.

Menzies, I. (1960) A case study of the functioning of social systems as a defence against anxiety Human Relations, 13(2), 95-123.

Millard, P. (1988) New Horizons in Hospital Based Care. In Wells, N. and Freer, C. (eds) The Ageing Population: Burden or Challenge. Hampshire, Macillan Press.

Miller, A. (1984) The nursing process and patient care, Nursing Times, Occasional Papers, 179(25),56-58.

Miller, A. (1985a) A study of the dependency of elderly patients in wards using different methods of nursing care, Age and Ageing,14, 132-138.

Miller, A. (1985b) Nurse/patient dependency:is it iatrogenic?, Journal of Advanced Nursing,10, 63-69.

Miller, E.J. and Gwynne, G.V. (1972) A Life Apart: a Pilot Study of Residential Institutions for the Physically Handicapped and the Young, London, Tavistock.

Miller, D.B., Gulle, N. and Mc Cue, F. (1986) The realities of respite care for families, clients and sponsors, Gerontologist,26(5), 467-470.

Mitchell, E.S. (1986) Multiple triangulation: a methodology for nursing science, *Advances in Nursing Science,* 8(3), 18-37.

Moritz, D.J., Kasl, S.V. and Berkman,L.F. (1989) The health impact of living with a cognitively impaired elderly spouse: depressive symptoms and social functioning, *Journal of Gerontology,* 44(1), 17-27.

Morris, R.G., Morris, L.W. and Britton, P.G. (1988) Factors affecting the emotional well-being of the caregivers of dementia sufferers , *British Journal of Psychiatry,* 153, 147-156.

Morse, J.M., Solberg, S.M., Neander, W.L., Bottorff, J.L. and Johnson, J.L. (1990) Concepts of caring and caring as a concept, *Advances in Nursing Science,* 13(1), 1-14.

Motenko, A.K. (1989) The frustrations, gratifications and well-being of dementia caregivers, *Gerontologist,* 29(2), 166-172.

Muir-Gray, J.A. (1984) The prevention of family breakdown, *Nursing Mirror,* 158(23), 16-17.

Murphy, E. (1986) Correspondence, *British Medical Journal,*481-483.

Murphy, D., Gearing, B. and Webber, A. (1988) Caring in the Community. In *Mental Health Problems in Old Age (workbooks).* Milton Keynes, Open University Press.

Neale, J.H. and Liebert, R.M. (1986) *Science and Behaviour: An Introduction to Methods of Research.* Third Edition, New Jersey, Prentice Hall International.

Netting, F.E. and Kennedy, L.N. (1986) Project RENEW: the development of a volunteer respite care program, *Gerontologist,* 25(6), 573-576.

Nissel, M. and Bonnerjea, L. (1982) *Family Care for the Handicapped Elderly: Who Pays?* London, Policy Studies Institute.

Noelker, L.S. and Townsend, A.L.(1987) Perceived Caregiving Effectiveness: The Impact of Parental Impairment, Community Resources and Caregiver Characteristics. In Brubaker, T.H. (ed) *Aging Health and Family :Longterm Care.* Beverley Hills, Sage.

Nolan, M.R. (1986) *Day Care in Perspective: a Comparative Study of two Day Hospitals for the Elderly.* Unpublished M.A. thesis, University of Wales.

Nolan, M.R. (1988) *Facilitating Change in an Institutional Environment for the Elderly: an Action Research Proposal.* Unpublished M.Sc. thesis, Open University.

Nolan, M.R. and Grant, G. (1989a) Addressing the needs of informal carers: a neglected area of nursing practice, *Journal of Advanced Nursing,* 14, 950-961.

Nolan, M.R. and Grant, G. (1989b) Informal carers: sources and determinants of satisfaction, CSPRD working paper, University College North Wales, Bangor.

Nolan, M. R., Grant, G. and Ellis, N.C. (1990) Stress is in the eye of the beholder: reconceptualising the measurement of carer burden, Journal of Advanced Nursing, 15, 544-555.

Norman, A. (1987) Aspects of Ageism: a Discussion Paper. London, Centre for Polciy on Ageing.

Norusis, M.J. (1985) SPSSX Advanced Statistics Guide, New York, McGraw Hill.

Norton, D., Mc Claren, R. and Exton-Smith, A.N. (1962) An Investigation of Geriatric Nursing Problems in Hospital, Research Report NCCOP, Reprinted 1979, Edinburgh, Churchill Livingstone.

Novak, M. and Guest, C. (1989) Application of a multi-dimensional caregiver burden inventory, Gerontologist, 29(6), 798-803.

Oliver, J. (1986) Correspondence, British Medical Journal, 292, 481.

Oswin, M. (1984) They Keep Going Away: a Critical Study of Short-term Residential Care Services for Children who are Mentally Handicapped. London, King Edward's Hospital Fund for London.

Packwood, T. (1980) Supporting the family: a study of the organisation and implications of hospital provision of holiday relief for families caring for dependants at home, Social Science and Medicine, 14A, 613-620.

Panzarine, S. (1985) Coping: conceptual and methodological issues, Advances in Nursing Science, 7(4), 49-57.

Parker, G. (1985) With Due Care and Attention: a Review of Research on Informal Care. London, Family Policy Studies Centre.

Pearlin, L. and Schooler, C. (1978) The structure of coping, Journal of Health and Social Behaviour,19, 2-21.

Pearlin, L., Mullan, J.T., Semple, S.J. and Skaff, M.M. (1990) Caregiving nad the stress process: an overview of concepts and their measures, Gerontologist, 30(5), 583-594.

Pearsall, M. (1965) Participant observation as a role and method in behavioural research, Nursing Research, 14, 37-42.

Pennington, R.E. and Pierce, W.L. (1985) Observations of empathy of nursing-home staff: a predictive study, International Journal of Aging and Human Development, 21(4), 281-290.

Phaneuf, M.C. (1980) Future direction for evaluation and evaluation research in health care: the nursing perspective, Nursing Research, 29(2), 123-126.

Phillips, L.R. and Rempusheski, V.F. (1986) Caring for the frail elderly at home: towards a theoretical explanation of the dynamics of poor quality family care, Advances in Nursing Science, 8(4), 62-84.

Phillipson, C. (1988) Planning for Community Care: Facts and Fallacies in the Griffiths Report, Working Paper 1, Centre for Social Gerontology, Keele University.

Phillipson, C. and Strang, P. (1984) The Role of Paid Carers. London, Health Education Council.

Phillipson, C. and Strang, P. (1986) Training for health education with older people: a survey of district nursing and health visitor courses, Nurse Education Today, 5, 247-251.

Phillipson, C. and Walker, A. (1986) Alternative forms of policy and practice. In Phillipson, C. and Walker, A. (eds) Ageing and Social Policy: a Critical Assessment. London, Gower.

Pitkeathley, J. (1990) Painful conflicts, Community Care (Inside) , 22/2/1990, i-ii.

Platt, S. (1985) Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales, Psychological Medicine, 15, 383-393.

Polit, D. and Hungler, B. (1983) Nursing Research: Principles and Methods. Philadephia, Lippincott.

Poulshock, S.W. and Deimling, G.T. (1984) Caring for elders in residence: issues in the measurement of burden, Journal of Gerontology, 39(2), 230-239.

Potter, J. and Wetherall, M. (1987) Discourse and Social Psychology: Beyond Attitudes and Behaviour. London, Sage.

Poulton, K. (1981) Perceptions of Wants and Needs by Nurses and Their Patients. Unpublished Ph.D. Thesis, University of Surrey.

Powell, J., Martindale, A. and Kulp, S. (1975) An evaluation of time-sampling measures of behaviour, Journal of Behaviour Analysis, 4, 463-469.

Power, M.J.P., Mc Connell, G. and Taylor, I.(1986) Correspondence, British Medical Journal, 481-482.

Pratt, C., Schmall, V. and Wright, S. (1987a) Ethical concerns of family caregivers to dementia patients, Gerontologist, 25(5), 632-638.

Pratt, C., Schmall, V., Wright, S. and Hare, H. (1987b) The Forgotten Client: Family Caregivers to Institutionalised Dementia Patients. In Brubaker, T.H. (ed) Aging, Health and Family. Beverley Hills, Sage.

Pruchno, R.A., Michaels, J.E. and Potashnik, S.L. (1990) Predictors of institutionalisation among Alzheimers disease victims with caregiving spouses, Journal of Gerontology (Social Sciences), 45(6), S259-266

Quine, L. and Charnley, H. (1987) The Malaise Inventory as a Measure of Stress in Carers. In Twigg, J. (ed) Evaluating Support to Informal Carers. Conference papers, University of York.

Quine, L. and Pahl, J. (1985) Examining sources of stress in families with severely handicapped children, British Journal of Social Work, 15, 501-517.

Qureshi, H. (1986) Responses to Dependency: Reciprocity, Affect and Power in Family Relationships. In Phillipson, C., Bernard, M. and Strang, R. (eds) Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives. London, Croom Helm.

Qureshi, H. and Walker, A. (1986) Caring for Elderly People: The Family and State. In Phillipson, C. and Walker, A (eds) Ageing and Social Policy: a Critical Assessment. Aldershot, Gower.

Qureshi, H. and Walker, A. (1989) The Caring Relationship. London, MacMillan.

Rai, G.S., Bielawska, C., Murphy, P.J. and Wright, G. (1986) Hazards for elderly people admitted for respite (holiday) admissions and social care, British Medical Journal,292, 240.

Rakowski, W. and Clark, N.M. (1985) Future outlook, caregiving and care-receiving in the family context, Gerontologist, 25(6), 618-623.

Raynes, N.V., Pratt, M.W. and Roneo, S. (1979) Organisational Structure and the Care of the Mentally Retarded. London, Croom Helm.

Raynor, P. (1984) Evaluation with one eye closed: the empiricist agenda in social work research, British Journal of Social Work, 14, 1-10.

Redfern, S.J. (1981) Evaluating the Care of the Elderly: a British Perspective. In Copp, L.A. (ed) Care of the Ageing. Edinburgh, Churchill Livingstone.

Redfern, S.J. (1989) Key Issues in Nursing Elderly People. In Warnes, A.M. (ed) Human Ageing and Later Life: Multidisciplinary Perspectives. London, Edward Arnold.

Redfern, S.J. and Norman, I.J. (1990) Measuring the quality of nursing care: a consideration of different approaches, Journal of Advanced Nursing, 15, 1260-1271.

Richardson, A., Unell, J. and Aston, B. (1989) A New Deal for carers. London, Kings Fund.

Rideout, E. (1986) Hope, morale and adaptation in patients with chronic heart failure, Journal of Advanced Nursing, 11, 429-438.

Robb, S.S. (1984) Behaviour in the Environment of the Elderly. In Yurick, A.G., Spier, B.E., Robb, S.S. and Ebert, N.J. (eds) The Aged Person and the Nursing Process. Connecticut, Appleton-Century-Crofts.

Robertson, D., Griffiths, R.A. and Cosin, L.Z. (1977) 'A community based continuing care program for elderly disabled: an evaluation of planned intermittent hospital re-admission, Journal of Gerontology, 32, 334-339.

Robinson, B.C. (1983) Validation of a care-giver strain index, Journal of Gerontology, 38(3), 344-348.

Robinson, K.M. (1988a) A social skills training program for adult caregivers, Advances in Nursing Science, 10(2), 59-72.

Robinson, J. (1988b) Support systems, Nursing Times, 84(14), 30-31.

Robinson, B. and Thurnher, M. (1979) Taking good care of elderly parents: a family transition cycle, Gerontologist, 19(6), 586-693.

Robinson, C.A. and Thorne, S. (1984) Strengthening family interference, Journal of Advanced Nursing, 9, 597-602.

Rogers, E.M. and Shoemaker, F.F. (1971) Communication of Innovations: A Cross-cultural Approach. Second Edition, New York, Free Press.

Rolland, J.S. (1988) A conceptual model of chronic and life threatening illness and its impact on families. In Chilman, C.S., Nunnally, E.W. and Cox, F.M. (eds) Chronic illness and Disability. Families in Trouble series, Vol. 2. Beverley Hills, Sage.

Ross, F. (1985) A challenging district, Nursing Mirror, 160(8), 35-37.

Rossi, P.H. and Berk, R.A. (1981) An overview of evaluation strategies and procedures, Human Organisation, 40(4), 287-299.

Rossi, P.H. and Wright, J.D. (1984) Evaluation research: an assessment, Annual review of Sociology, 10, 331-352.

Rossiter, C. and Wicks, M. (1982) Crisis or Challenge: Family Care, Elderly People and Social Policy. Occasional Paper No.8 London, Study Commision on the Family.

Rosswurm, M.A. (1983) Relocation and the elderly, Journal of Geriatric Nursing, 9(12), 632-637.

Royal College of Nursing (1987) In Pursuit of Excellence: A Position Statement on Nursing, London, Royal College of Nursing.

Royal College of Nursing (1989) A Framework for Quality, London, Royal College of Nursing.

Royal College of Nursing/British Geriatric Society (1975) Improving Geriatric Care in Hospital. London, Royal College of Nursing.

Royal College of Nursing, British Geriatric Society and Royal College of Psychiatrists (1987) Improving Care of Elderly People in Hospital. London, Royal College of Nursing.

Rubin, L.B. (1981) Sociological research: the subjective dimension, Symbolic Interaction 4, 99, Spring 1981.

Runciman, P. (1989) Health assessment of the elderly at home: the case for shared learning, Journal of Advanced Nursing, 14, 111-119.

Rutherford, M. and Spitzer, (1968) Observer effects and hospital interaction, Nursing Research, 17(1), 65-68.

Rutter, M., Graham, P. and Yule, W. (1970a) A Neuropsychiatric Study in Childhood. London, Heinnemann.

Rutter, M., Tizard, J. and Whitmore, K. (1970b) Education, Health and Behaviour. London, Longmans.

Sackett, G.P., Ruppenthal, G.C. and Gluck, J. (1978) An Overview of Methodological and Statistical Problems. In Observational Research in Sackett, G.P (ed) Observing Behaviour, Vol II Data Collection and Analysis Methods. Baltimore, University Park Press.

Sale, D. (1990) Quality Assurance. Essentials of Nursing Management Series, London, MacMillan Education Ltd.

Sandford, J. (1975) Tolerance of debility in elderly dependants by supporters at home, British Medical Journal, 3, 471-473.

Sapsford, R.J. and Evans, J. (1979) Evaluation of Research. Block 8, Research Methods in Educational and the Social Sciences. Milton Keynes, Open University Press.

Saris, W.E. and Stronkhorst, H.L. (1984) Causal Modelling in Nonexperimental Research. Amsterdam, Sociometric Research Foundation.

Scharlach, A. and Frenzel, C. (1986) An evaluation of institutional-based respite care, Gerontologist, 26(1), 77-82.

Scott, D.W., Oberst, M.T. and Dropkin, M.J. (1980) A stress-coping model, Advances in Nursing Science, 3(1), 9-23.

Schulz, R. and Brenner, G. (1977) Relocation of the aged: a review and theoretical analysis, Journal of Gerontology, 32(3), 323-333.

Seers, C. (1986) Talking to the elderly and its relevance to care, Nursing Times Occasional Papers, 82(1), 51-54.

Seltzer,B., Rheaume, Y., Volicer, L., Fabiszewski, K.J., Lyon, P.C., Brown, J.E. and Volicer, B. (1988) The short-term effects of in-hospital respite on the patient with Alzheimers disease, Gerontologist, 28(1), 121-124.

Sheldon, J.H. (1948) The Social Medicine of Old Age. London, Oxford University Press.

Silverstein, N.M. (1984) Informing the elderly about public services: the relationship between source of support and service utilisation, Gerontologist, 24(1), 37-40.

Simmons, S. (1985) Family Burden: a Qualitative Study. Paper presented at Royal College of Nursing Research Society Annual Conference, University of Nottingham.

Simpson, K. and Sears, R. (1985) Authority and responsibility delegation predicts quality of care, Journal of Advanced Nursing, 10, 345-348.

Sixsmith, A. J. (1986) Independence and Home in Later Life . In Phillipson, C., Bernard, M. and Strang, P. (eds) Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives. London, Croom Helm.

Sixsmith A.J. (1988) The Role of Evaluation in Care Provision. Paper presented at British Society of Gerontology Annual Conference, University of Swansea, 23-25 Sept. 1988.

Smith, D. (1983) Non-reciprocating recipients, Nursing Mirror, 7/9/83, 8-10.

Smith, G. (1986) Resistance to change in geriatric care, International Journal of Nursing Studies, 23(1), 61-70.

Smith, H.W. (1975) Strategies of Social Research: The Methodolgical Imagination. London, Prentice Hall.

Smith, G. and Cantley, C. (1985) Assessing Health Care: A Study in Organisational Evaluation. Milton Keynes, Open University Press.

Smith, G. and Cantley, C. (1988) Pluralistic Evaluation in Lishman, J. (ed) Evaluation. Research Highlights in Social Work (8) Second Edition. London, Jessica Kingsley.

Social Work Services Development Group (1984) Supporting the Informal Carers: Fifty Styles of Caring-Models of Practice for Planners and Practitioners. London, DHSS.

Spaniol, L. and Jung, H. (1987) Effective Coping: a Conceptual Model in Hatfield, A.B. and Lefley, H.P. (eds)Families of the Mentally Ill:Coping and Adaptation. London, Cassell.

Spence, D.L. and Miller, D.B. (1986) Family respite for the elderly Alzheimers patient, Journal of Geriatric Social Work,9(2), 101-112.

Stockwell, F. (1972) The Unpopular Patient. The Study of Nursing Care Project Reports Series 1(2). London, Royal College of Nursing.

Stoller, E.P. and Pugliesi, K.L. (1989) Other roles of caregivers: competing resposibilities or supportive resources? Journal of Gerontology (Social Scinces), 44(6)S, 231-238.

Strong, C. (1984) Stress and caring for elderly relatives: interpretations and coping strategies in an American Indian and white sample, Gerontologist, 24(3), 251-256.

Suchman, E.A. (1967) Evaluative Research. New York, Russel Sage Foundation.

Sutcliffe, C. and Larner, S. (1988) Counselling carers of the elderly at home: a preliminary study, British Journal of Clinical Psychology, 27, 177-178.

Swanson, S.M. and Chenitz, W.C. (1982) Why qualitative research in Nursing? Nursing Outlook, April 1982, 241-245.

Syred, M.E.J. (1981) Changing the face of geriatric care, Nursing Times Occasional Papers, 79 (2), 5-8.

Taft, L.B. (1985) Self-esteem in later life: a nursing perspective, Advances in Nursing Science, 8(1), 77-84.

Taylor, A.G., Hudson, K. and Keeling, A. (1991) Quality nursing care: the consumers perspective revisited, Journal of Nursing Quality Assurance, 5(2), 23-31.

Thomas, N. (1988) Evaluative Research and the Personal Social Services. In Lishman, J. (ed) Evaluation. Research Highlights in Social Work (8), Second Edition. London, Jessica Kingsley.

Thompson, D.M. (1987) Calling all Carers. Manchester, Association of Carers, South Manchester Branch.

Thorne, T. and Hursey, K. (1986) Short hospital breaks Nursing Times, 25/5/86, 28-31.

Thorne, S.E. and Robinson, L.A. (1988) Reciprocal trust in health care relationships, Journal of Advanced Nursing, 13, 782-789.

Thornton, P. (1989) Creating a Break: A home Care Relief Scheme for Elderly People and their Supporters, Research Paper 3, London, Age Concern Institute of Gerontology.

Tomlin, S. (1989) Abuse of the Elderly: an Unnecessary and Preventable Problem. London, British Geriatric Society.

Tooth, J. (1987) Partnerships in Care: a Strategy for the Support of Carers of Frail Elderly People. London, Age Cocern Greater London.

Townsend, A.C. and Noelker, L.S. (1987) The Impact of Family Relationships on Perceived Caregiving Effectiveness. In Brubaker, T.H. (ed) Aging,Health and Family. Beverley Hills, Sage.

Trow, M. (1957) Comment on participant observation and interviewing, Human Organisation, 16, 33-35.

Twigg, J. (1986) Carers: Why do they Pose Problems for Social Services Departments? University of Kent, Personal Social Services Research Unit, Paper No. 433.

Twigg, J. (1987) Introduction: Evaluating Support for Informal Carers. Conference Papers, University of York.
Twigg, J. (1989) Not taking the strain, Community Care,77 3, 16-19.

Tyler, J. (1987) Give us a break, Nursing Times,83 (50), 32-35.

Tyler, J. (1989) Respite Care for the Elderly. Unpublished M.Phil. Thesis, Cranfield Institute of Technology.

Ungerson, C. (1987) Policy is Personal: Sex, Gender and Informal Care. London, Tavistock.

Van Maanen, H.M.Th. (1979) Perspectives and problems on quality of nursing care: an overview on contributions from North America and recent developments in Europe, Journal of Advanced Nursing, 4, 337-389.

Van Maanen, H.M.Th. (1981) Improvement of quality of nursing care: a goal to challenge in the eighties, Journal of Advanced Nursing, 6, 3-9.

Victor, C. and Vetter, N. (1988) Preparing the elderly for discharge from hospital: a neglected aspect of patient care, Age and Ageing, 17, 155-163.

Wade, B. (1983) Different models of care for the elderly Nursing Times, Occasional papers, 79(12), 33-36.

Wade, B., Sawyer, L. and Bell, J. (1983) Dependency with Dignity. Occasional Papers on Social Administration 68. London, Bedford Square Press.

Wallace, A. and Ress, S. (1988) The Priority of Client Evaluation. In Lishman, J. (ed) Evaluation, Research Highlights in Social Work (8), Second Edition. London, Jessica Kingsley.

Waters, K.R. (1987a) Discharge planning: an exploratory study of the process of discharge planning on geriatric wards, Journal of Advanced Nursing, 12, 71-83.

Waters, K.R. (1987b) Outcomes of discharge from hospital for elderly people, Journal of Advanced Nursing, 12, 347-355.

Watkins, M. (1988) Lifting the burden, Geriatric Nursing and Home Care, 8(9), 18-20.

Webb, C. (1989) *A Ward Development Action Research Project: Philospohy, Methods and Experience.* Paper presented at Royal College of Nursing Research Society Annual Conference, University College Swansea, 14-16 April.

Webb, I. (1987) *People who Care: a Report on Carer Provision in England and Wales.* London, Cooperative Womens Guild.

Webb, P. (1986) *Gaining Access, Proposals and Ethical Committee Approval,* Paper presented at RCN Research Society Meeting, 8/1/86.

Webb, E.J., Campbell, D.T., Schwartz, R.D. and Sechrest, L (1966) *Unobtrusive Measures: Non-reactive Research in the Social Sciences*. Chicago, Rand McNally.

Weber, R.P. (1985) *Basic Content Analysis.* Beverly Hills, Sage.

Webster, S. (1988) Boosting the effectiveness of respite care, *Geriatric Medicine,* 18(10),81-83.

Weick, K.E. (1968) Systematic Observational Methods. In Lindzey, G. and Aronson, E. (eds) *Handbook of Social Psychology*, Second Edition, Mass., Addison-Wesley.

Weiss, C.H. (1974) Alternative models of program evaluation, *Social Work,* 19(6), 675-681.

Wells, T.J. (1980) *Problems in Geriatric Nursing.* Edinburgh, Churchill Livingstone.

Welsh Office:NHS Directorate (1990a) *A Quality Health Service for Wales (Summary)* Cardiff, Welsh Office.

Welsh Office (1990b) *Discharge of Patients from Hospital*, Circular WHC (90)1, Cardiff, Welsh Office.

Wenger, G. Clare (1988) *Old Peoples' Health and Experience of the Caring Services: Accounts from Rural Communities in North Wales*, Occasional Paper 4, Institute of Human Ageing, Liverpool University Press.

Wenger, G. Clare (1990) Elderly Carers: The Need for Appropriate Intervention, *Ageing and Society,* 10, 197-219.

Whittick, J.E. (1988) Dementia and mental handicap: emotional distress in caregivers, *British Journal of Clinical Psychology,*27, 167-172.

Whyte, W.F. (1982) Interviewing in Field Research. In Burgess, R.G. (ed) *Field Research: a Source Book and Field Manual.*

Whyte, W.F. (1984) *Learning from the Field: a Guide from Experience.* Beverly Hills, Sage.

Wicks, M. (1989) Community care: the challenge for social policy, *Generations, Bulletin of the British Society of Gerontology,* 9.

Wilkin, D. and Hughes, B. (1986) The Elderly and the Health Service. In Phillipson, C. and Walker, A. (eds) Ageing and Social Policy: a Critical Assessment. Aldershot, Gower.

Wilkin, D. and Hughes, B. (1987) Residential care: the consumers' views, Ageing and Society, 7, 175-201.

Willcocks, D., Peace, S. and Kellaher, L. (1983) A Profile of Residential Life: a discussion of Key Issues Arising out of Consumer Research in 100 Old Age Homes. In Jerrome, D (ed) Ageing in Modern Society. London, Croom Helm.

Wilson-Barnett, J. (1986) A measure of care, Nursing Times, 13/8/86, 57-58.

Winogrond, I.R., Fisk, A.A., Kirsling, R.A. and Keynes, B. (1987) The relationship between caregiver burden and morale to Alzheimers disease patient functioning in a therapeutic setting, Gerontologist, 27(3), 336-339.

Woody, M.F. (1980) An evaluators perspective, Nursing Research, 29(2), 74-77.

Worcester, M.I. and Quayhagen, M.P. (1983) Correlates of caregiving satisfaction: prerequistes to elder home care, Research in Nursing and Health, 6, 61-67.

Wortman, P.M. (1983) Evaluation research: a methodological perspective, Annual Review of Psychology, 34,223-260.

Wright, D. (1984) An introduction to the evaluation of nursing care: a review of the literature, Journal of Advanced Nursing, 9, 457-467.

Wright, F.D. (1986) Left to Care Alone. Aldershot, Gower.

Wright, M. (1990) Personal Communication.

Wrubel, J., Benner, P. and Lazarus, R. (1981) Social Competence from the Perspective of Stress and Coping. In Wine, J.D. and Smye, M.D. (Eds) Social Competence. New York, Guilford.

Zarit, S.H., Reever, K.E., and Bach-peterson, J. (1980) Relatives of the impaired elderly: correlates of feelings of burden, Gerontologist, 20(6), 649-655.

Zarit, S.H and Zarit, J.M. (1982) Measuring Burden and Support in Families with Alzheimers Disease Elders. Paper presented at 35th Annual Scientific Conference Of the Gerontological Society of America, Boston.

Zarit, S.H., Todd, P.A. and Zarit, J.M. (1986) Subjective burden of husbands and wives as caregivers: a longitudinal study, Gerontologist, 26(3), 260-266.

Zipple, A. and Spaniol, L. (1987) Current Educative and Supportive Models of Family Intervention. In Hatfield, A.B. and Lefley, H.P. (eds) Families of the Mentally Ill: Coping and Adaptation. London, Cassell.

APPENDICES

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APPENDIX ONE

EXAMPLES OF INTERVIEW GUIDES

Interview guide for staff and carer interviews

Topics: Staff

1) Introduction/statement of purpose

2) Organisation of system:
a) perceived purpose;
b) Referral procedure;
c) Assessment procedure;
d) Attendance details;
e) Review procedure.

2) Benefits to:
a) Carers;
b) Dependants;
c) Staff;
d) Other patients.

3) Reactions of:
a) Carers;
b) Dependants;
c) Staff;
d) Other patients.

4) Problems for:
a) Carers;
b) Dependants;
c) Staff;
d) Other patients.

5) Any other issues

Topics: Carers

1) Introduction

2) Background information:
a) Entry to caring;
b) Length caring;
c) Relationship with dependant;
d) Nature of caring (Problems and satisfactions);

3) Help received and its perceived adequacy:
a) Health services;
b) Social services;
c) Voluntary;
d) Private;
e) Family.
f) Other help desired.

4) Rota bed system:
a) Entry to system;
b) Length using it;
c) Benefits;
d) Difficulties;
e) Contact with unit;

f) Reactions of dependant;
g) Effects on dependant;
h) Improvements to system.

5) Complete dependency scales/CADI

6) Any other issues.

APPENDIX TWO

QUESTIONNAIRE:CARERS POSTAL SURVEY

Coleg Prifysgol
Gogledd Cymru

CANOLFAN YMCHWIL A DATBLYGIAD
POLISI CYMDEITHASOL

Adran Gwyddor Cymdeithas a'i Sefydliadau
Bangor, Gwynedd LL57 2DG
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GORAU DAWN DEALL

University College
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CENTRE FOR SOCIAL POLICY RESEARCH
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A CALL TO CARERS

Dear Carer,

As a person who provides care to a dependent relative or friend you have unique and invaluable first-hand knowledge of the stresses, strains and pleasures of caregiving. Could you spare about 15 minutes of your time to increase our knowledge about the effects of caregiving by completing the following questionnaire? The questionnaire forms part of a survey of carers being conducted by the Centre for Social Policy Research and Development, University College of North Wales, Bangor. All your answers will be both confidential and anonymous.

A freepost envelope is provided for your reply. Please spare a little time to make your contribution to increasing our knowledge by giving us your views.

Yours sincerely,

Mike Nolan

Mike Nolan,
(Research Officer).

Directors:
Professor Roy King, Dr.Gordon Grant

Below are some questions about the person you care for and about the caregiving situation. Please answer the questions by ringing the appropriate number or by writing you answer in the space provided.

How old is the person you care for?	.... years
Is the person you care for?	1. Male or 2. Female
How long have you been caring for him/her?	.....years .....months
What is your relationship to the person you care for?	1. Father 2. Mother 3. Husband 4. Wife 5. Son 6. Daughter 7. Son-in-law 8. Daughter-in-law 9. Brother 10. Sister 11. Other male relative 12. Other female relative 13. Male friend/neighbour. 14. Female friend/ neighbour.
Do you live in the same household?	1. Yes 2. No
If no, how far away do you live?	1. Under half a mile 2. Under a mile 3. Between 1 and 5 miles 4. Over 5 miles
How often do you provide care and/or supervision?	1. Constantly night & day 2. Constantly by day 3. Constantly by night 4. Frequently during the day 5. Daily 6. Less than daily,more than weekly 7. Weekly or less often.

How much help does the person you care for need to complete the following? (Help includes supervision and/or direct assistance.)

	Able to complete on his/her own	Help needed with part of activity	Help needed with all of activity
Washing	1	2	3
Dressing	1	2	3
Feeding	1	2	3
Toiletting	1	2	3
Walking	1	2	3
Bathing	1	2	3
Household tasks e.g. cooking, cleaning	1	2	3

Does the person you care for have problems with their continence? i.e.does he/she ever wet (bladder problem) or soil (bowel problem) themselves?

	Never	Occasionally (once or twice a week or less often)	Frequently (more than twice a week
Bladder by day	1	2	3
Bladder by night	1	2	3
Bowel by day	1	2	3
Bowel by night	1	2	3

Does the person you care for

	Never	Occasionally (once or twice a week or less often)	Frequently (more than twice weekly)
Have a tendency to wander or be a danger to themselves	1	2	3
Have difficulty remembering the time of day or where he/she is.	1	2	3
Behave in an embarrasing or upsetting way.	1	2	3
Become agitated or unco-operative	1	2	3
Have difficulty holding a normal conversation	1	2	3

How would you describe your PAST relationship with the person you care for?	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor
Compared with your past relationship would you say that your present relationship has	1. Generally improved 2. Stayed about the same 3. Generally got worse
How would you describe your present physical health?	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor
How would you describe your present emotional well-being?	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor.
How do you see the caregiving situation developing in the future?	1. Improving 2. Staying about the same 3. Getting worse
Does the person you care for suffer from any disability, illness or handicap (ring more than one number if required)	1. No disability, handicap or illness. 2. Physical disability/ chronic illness 3. Mental handicap 4. Mental illness.
How old are you?	.... years.

Below are some statements which carers have made about the difficulties they face. Please read each statement and show if it applies to you by ringing the appropriate number in Column A.

For each statement which sometimes or always applies to you, please show how stressful you find it by ringing the appropriate number in Column B.

CARING CAN BE DIFFICULT BECAUSE	Column A This statement Always applies to me	Column A Sometimes applies to me	Column A Never applies to me	Column B I find this aspect of caring Very stressful	Column B moderately stressful	Column B Not stressful
1) I don't have enough private time for myself	1	2	3	1	2	3
2) I sometimes feel helpless/not in control of the situation	1	2	3	1	2	3
3) I can't devote enough time to other family members	1	2	3	1	2	3
4) It causes financial difficulties	1	2	3	1	2	3
5) The person I care for sometimes manipulates me	1	2	3	1	2	3
6) The person I care for is immobile/has problems in getting about.	1	2	3	1	2	3
7) Professional workers don't seem to appreciate the problems carers face	1	2	3	1	2	3
8) It restricts your social life/ outside interests	1	2	3	1	2	3
9) It can put a strain on family relationships	1	2	3	1	2	3
10) It is physically tiring	1	2	3	1	2	3

	Column A			Column B		
	This statement			I find this aspect of caring		
CARING CAN BE DIFFICULT BECAUSE	Always applies to me	Sometimes applies to me	Never applies to me	Very stressful	moderately stressful	Not stressful
11) The person I care for can demand too much of me	1	2	3	1	2	3
12) I no longer have a meaningful relationship with the person I care for	1	2	3	1	2	3
13) The person I care for needs a lot of help with personal care	1	2	3	1	2	3
14) The person I care for doesn't always help as much as they could	1	2	3	1	2	3
15) My sleep is affected	1	2	3	1	2	3
16) Relatives don't keep in touch as often as I'd like	1	2	3	1	2	3
17) I feel angry about the situation	1	2	3	1	2	3
18) I can't see friends as often as I'd like	1	2	3	1	2	3
19) My emotional well-being suffers	1	2	3	1	2	3
20) I can't have a break or take a holiday	1	2	3	1	2	3
21) my standard of living has fallen	1	2	3	1	2	3
22) the person i care for doesn't always appreciate what i do	1	2	3	1	2	3
23) my physical health has suffered	1	2	3	1	2	3

	Column A			Column B		
	This statement			I find this aspect of caring		
CARING CAN BE DIFFICULT BECAUSE	Always applies to me	Sometimes applies to me	Never applies to me	Very stressful	moderately stressful	Not stressful
24) The person I care for is incontinent	1	2	3	1	2	3
25) The behaviour of the person I care for is a problem	1	2	3	1	2	3
26) There is no satisfaction to be gained from caring	1	2	3	1	2	3
27) I don't get enough help from the health and social services	1	2	3	1	2	3
28) Some family members don't help as much as they could	1	2	3	1	2	3
29) I can't relax because of worry about caring	1	2	3	1	2	3
30) I feel guilty about the situation	1	2	3	1	2	3
Please write below any other things which make caring difficult for you and show how stressful they are.	1	2		1	2	3

Below are some questions about your health. Please answer them either YES or NO by ringing the appropriate number.

	YES	NO
Do you often have backache	1	2
Do you feel tired most of the time?	1	2
Do you often feel miserable or depressed?	1	2
Do you often have bad headaches?	1	2
Do you often get worried about things?	1	2
Do you usually have great difficulty in falling asleep or staying asleep?	1	2
Do you usually wake up unnecessarily early in the morning?	1	2
Do you wear yourself out worrying about your health?	1	2
Do you often get into a violent rage?	1	2
Do people often annoy and irritate you?	1	2
Have you at times had a twitching of the face, head or shoulders?	1	2
Do you often suddenly become scared for no good reason?	1	2
Are you scared to be alone when there are no friends near you?	1	2
Are you easily upset or irritated?	1	2
Are you frightened of going out alone or of meeting people?	1	2
Are you constantly keyed up and jittery?	1	2
Do you suffer from indigestion?	1	2
Do you often suffer from an upset stomach?	1	2
Is your appetite poor?	1	2
Does every little thing get on your nerves and wear you out?	1	2
Does your heart often race like mad?	1	2
Do you often have bad pains in your eyes?	1	2
Are you troubled with rheumatism or fibrositis?	1	2
Have you ever had a nervous breakdown?	1	2

Whilst caregiving can be a difficult and stressful situation, many people find aspects of caring to be satisfying. Please list below any aspects of caregiving that you find give you satisfaction.

Thank you very much for your help.

APPENDIX THREE

LETTER CARERS INTERVIEW SURVEY

Coleg Prifysgol
Gogledd Cymru

**CANOLFAN YMCHWIL A DATBLYGIAD
POLISI CYMDEITHASOL**

Adran Gwyddor Cymdeithas a'i Sefydliadau
Bangor, Gwynedd LL57 2DG
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**CENTRE FOR SOCIAL POLICY RESEARCH
AND DEVELOPMENT**

Department of Social Theory and Institutions
Bangor, Gwynedd LL57 2DG
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Mike Nolan, Research Officer.
Ext. 2598.

Dear

My name is Michael Nolan and I am a researcher working at the Centre for Social Policy Research & Development, UCNW, Bangor. For a number of years now, research carried out at the Centre has been looking at the support available to people caring for dependent relatives or friends in the North Wales area.

At present I am interested in people such as yourself whose relative or friend goes into hospital on a regular basis in order that you may have the occasional break. This type of service is very important but as yet we know little about the way it works and the benefits it provides. I understand from Dr. that your goes into hospital and I was wondering if I might come and talk to you about your views on this service. The interview would be in complete confidence and would not take up too much of your time. If it is convenient I would like to come and see you on at . If you will not be at home at that time, perhaps you would be kind enough to let me know.

Thanking you, in anticipation of your valuable help.

Yours sincerely,

Mike Nolan.
Research Officer.

Directors:
Professor Roy King, Dr.Gordon Grant

APPENDIX FOUR

MOLAR CODING FRAME AND DATA OBSERVATION SHEET

Molar coding scheme for observation schedule
Patient identification/location at observers discretion

POSTURE

Sitting in chair	S/C (include wheelchair S/WC)
Sitting or laying in bed	S/B or L/B
Standing	ST
Transfering	T

ENGAGEMENT At the moment of observation the patient was

Doing nothing	(D/N)	Not actively engaged in any activity nor, as far as it is possible to tell not attending to any stimuli in the environment.
Watching	(W)	Showing a passive interest in some identifiable event in the physical or social environment.
Doing nothing/ Watching	(DN/W)	Observer unable to differentiate between the above categories
Asleep	(A)	Self-explanatory

Actively engaged

Informal activity	(I/A)	One of a range of activities the main purpose of which is the constructive use of time and the distinguishing characteristic of which is that it is patient initiated. Would include for example, reading, watching T.V., knitting and so on. Include social verbal interaction in this category.
Organised activity	(O/A)	As above but distinguishing characteristic is that it is staff initiated
Eat/drink	(E/D)	Any activity concerned with eating and drinking including cutting up of food being fed etc.
Personal care	(P/C)	Includes any hygiene and tiolet needs washing dressing, grooming bathing performed by patient or staff
Mobilising	(M	Engaged in the process of getting from A to B include use of wheelchair,rising or returning to the seated postion etc.
Treatment	(T)	Activity intended to maintain or improve patients condition To include in addition to overt medical or nursing interventions, organised excercise, functional assessment, consultation and instruction. For example if a patient is being mobilised and at the same time is ajudged to be receiving instruction in the use of a walking aid then this would constitute treatment rather than mobilising .
Deviant behaviour	(D/B)	Behaviour judged to be delusional, hallucinatory or of an unproductive and repetitive nature. For example, talking to self, repeated shouting and screaming, aimless wandering or other purposeless activity
Unobserved	(UN)	At time of observation patients whereabouts unknown or known but observer is unable to code nature of activity occuring
Verbal interaction		0= none X= unknown eg. when patient unobserved. Other verbal activity or presence of staff member to be noted by means of code and the direction of the interaction recorded via arrows

Thus for example

P P Two way conversation between patients

P Sis One way conversation between Sister and patient, Sister addressing patient

P Sis Sister present but no conversation occuring

P Sis Sister and staff nurse present conversation between staff members patient excluded
S/N

When possible the nature and content of the conversation is to be noted longhand in the brief description of activity column. For example purely social, giving instruction or advice seeking cooperation and so on. Also to be recorded in this column is the extent to which the observer feels that the patient is being actively encouraged to participate in their own care or if staff are 'doing for' the patient.

NO.	LOC.	POST.	BEHAVIOUR	CAT.	CONTACT

APPENDIX FIVE

PATIENT DEPENDENCY PROFILE

Patient Dependency Profile

Age Gender Date/length of admission

Reason for admission

Dependency characteristics

	Independent	Part help	Total help
Mobility			
Transfer			
Washing			
Care of hair			
Mouth care			
Foot care			
Bathing			
Feeding			
Dressing			
Toilet			

Usually nursed	In bed	Up in chair	Up and about

Continence

	Never	Occasionally	Frequently
Urine			
Faeces			
Doubly			

Cooperation

a) Fully cooperative, helps as much as he/she is able

b) Difficult at times, doesn't help as much as able

c) Often difficult, rarely helps as much as able

d) Unable to help.

Mental state/behaviour

	Never	Occasionally	Frequently
Wanders			
Danger to self			
Disorientated to			
a) Time			
b) Place			
c) Person			
Embarrassing behaviour			
Agitated/ uncooperative			
Difficulty with conversation			
Depressed			

Pressure areas

a) All areas in tact, no redness or blistering
b) Area intact but red/blistered or healed sore
c) Superficial break
d) Full thickness break
e) Deep sore

Sociability

a) Sociable, easy and interesting to talk to
b) Not very sociable, difficult to talk to
c) Rarely sociable, very difficult to talk to
d) Completely unsociable
e) Confused/disorientated/cannot communicate.

APPENDIX SIX

STAFF STRUCTURED QUESTIONNAIRE

This questionnaire is divided into three sections. The first is concerned with some details about yourself and your feelings about working with older people. The second asks you to consider the way in which care is delivered on the unit in which you work and the third looks at the role of post-basic education. As already stressed there is no single right answer to most of the questions as this is not a test of knowledge. Most questions involve either writing out the answer or placing a tick in the appropriate place.

AGE .....years GENDER(M/F)......... GRADE(Sister, Staff Nurse etc.)................
How long at this grade.........years/months
(delete as required)

QUALIFICATIONS

A) Upon leaving school (CSE, 'O' Levels, 'A' Levels etc., numbers only eg. 5 'O'Levels)
....

B) Registerable Nursing Qualifications (Eg. E.N.,R.G.N., etc. with date obtained)
....

C) Any other qualifications (Certificates, Diplomas etc, please give date and awarding body)
....

D) Post-Basic courses attended (With dates)
....

How long have you been working with the elderly.....................years/months
(Delete as required)

How long at this unit.............years/months
(delete as required)

Why did you choose to come and work with the elderly (tick the appropriate box)

TICK

← No real choice, it was where the vacancies where at the time

Yes, it was convenient at the time

Yes, I always wanted to work with the elderly

Other reason, please specify...

Do you think that your basic training prepared you adequately for working with the elderly
YES

NO (If no please state why not).. ....
....

Do you think there is a need for specialist post-basic training for those working with the elderly
YES

NO

In your own words how would you describe nursing the elderly
....
....
....

What do you think is the most important aspect of nursing elderly people
....
....
....
What do you think is the most interesting aspect of nursing elderly people
....
....
....
What do you think is the most difficult aspect of nursing elderly people
....
....
....
Below are a few questions about the rota beds

What do you see as the main purpose of the rota beds
....
....
....
What are the benefits of the rota beds for
A) Carers
....
....
....
B) Patients who use them
....
....
....
C) Other patients on the unit
....
....
....
D) Staff on the units
....
....
....
What are the disadvantages of the rota beds for
A) Carers
....
....
....
B) Patients who use them
....
....
....
C) Other patients on the unit
....
....
....
D) Staff
....
....
....

Below is a series of statements which have been made about the ways in which care might be organised in hospitals for the elderly. Please read each statement and then indicate in Column A the extent to which you feel that statement applies to the unit you work in. In Column B indicate how desirable and possible you feel each statement is. Give your response by placing a tick in the appropriate box.

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
The best way to ensure all the work gets done is to establish a regular routine						
Work is best organised when people know which jobs they are responsible for						
Patients have a totally free choice						
a) When to have a bath						
b) When and what to eat						
c) When to get up or go to bed						
d) What to wear						
e) Of a single room or which dormitory to sleep in						
f) What to do during the day						
Patients can bring in and keep personal items						
Each patient should have an identified nurse of their own						
Patients are fully involved in planning their own care						
Patients are always consulted about any change that might affect them						
Patients attend all case conferences in which they are discussed						
There is a patient/staff committee to discuss the way things are run						

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
Relatives are fully involved in planning patient care and attend case conferences						
Visitors can come at any time, without prior notice						
Relatives/visitors organise activities						
There is a regular programme of activities/ outings organised by patients themselves						
Staff organise a programme of activities/ outings for patients						
There is a full range of therapeutic inputs by or, if required, access to						
a) Physiotherapy staff						
b) Occupational therapy staff						
c) Speech Therapists						
d) A Chiropodist						
e) A Social Worker						
f) A Hairdresser						
Patients have sufficient privacy						

If there is anything that you think that is missing from the above list or you would like to add further comment please do so below

This questionnaire begins with a few questions about yourself and then asks you for your thoughts about the type of work you do. As already stressed there are no 'right' answers to these questions as this is not a test of knowledge. Please give your response by writing your answer or placing a tick in the appropriate place.

AGE .....years GENDER(M/F).........

How long have you been working with the elderly....................years/months
(Delete as required)

How long at this unit.............years/months
(delete as required)

Why did you choose to come and work with the elderly (tick the appropriate box)

TICK

No real choice it was where the vacancies where at the time

It was convenient at the time

I always wanted to work with the elderly

Other reason, please specify...

Were you given any training when you started to work with the elderly. If yes please give a brief description of this training. If no, would you have liked some training and what would you have liked.

Yes (give brief description of content, length and who gave the training)............................
....
....
....
No (please state if you would have liked some training and what you would have liked included).......
....
....
....
Have you had any recent training or instruction

Yes (give a brief description of content, length and who gave the training)........................
....
....
....
No (please state if you would have liked some training and what you would have liked included).......
....
....
....
Do you have any formal qualifications (eg. CSE, GCE. and so on if so please list these below)........
....
....
In your own words how would you describe caring for the elderly
....
....
....

What do you think is the most important part of caring for elderly people
....
....
....
What do you think is the most interesting part of caring for elderly people
....
....
....
What do you think is the most difficult part of caring for elderly people
....
....
....
Below are a few questions about the rota beds

What do you see as the main purpose of the rota beds
....
....
....
What are the benefits of the rota beds for
A) Carers
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C) Other patients on the unit
....
....
....
D) Staff on the units
....
....
....
What are the disadvantages of the rota beds for
A) Carers
....
....
....
B) Patients who use them
....
....
....
C) Other patients on the unit
....
....
....
D) Staff
....
....
....

APPENDIX SEVEN

LETTER REGARDING OBSERVATIONAL STUDY

Coleg Prifysgol
Gogledd Cymru

**CANOLFAN YMCHWIL A DATBLYGIAD
POLISI CYMDEITHASOL**

Adran Gwyddor Cymdeithas a'i Sefydliadau
Bangor, Gwynedd LL57 2DG
Ffôn: Bangor (0248) 351151

University College
of North Wales

**CENTRE FOR SOCIAL POLICY RESEARCH
AND DEVELOPMENT**

Department of Social Theory and Institutions
Bangor, Gwynedd LL57 2DG
Tel: Bangor (0248) 351151

Mike Nolan,
Research Officer.
3/5/89

Dear Sister

I write to you following our meeting of last week to confirm the arrangements for the next stage of my project on the rota beds. Firstly may I thank everyone at   for their friendliness and cooperation during the interview phase of the research. Secondly, as we already discussed ,I would now like to be able to describe a typical rota bed stay. This will involve spending some time each day on your ward for a period of two weeks between the 14 and 28 of May.
In order to be able to achieve this I have managed to get the help of three research assistants, all of whom are nurses and are helping out during their annual leave.
I would be very grateful if you could inform the staff on the unit of the purpose of this part of the work, which is to describe the two weeks stay from the viewpoint of the patient. Therefore the focus of the work will be on patients and not staff, although when a member of staff attends one of the patients being observed then that activity will be noted. Strict confidentiality of all patients and staff will be maintained.
I would hope that in carrying out this part of the study that the important contribution of the rota beds will be further highlighted. Should any member of staff wish to discuss this further then I would be only too happy to see them.

Thank you very much for your continued help,

Yours sincerely,

Michael Nolan.

Directors:
Professor Roy King, Dr.Gordon Grant

APPENDIX EIGHT

RECORDING SHEET FOR METHODOLOGICAL AND OBSERVATIONAL NOTES

Date Observations from to Break from to

Number and category of patients observed

Number and categories of patients on ward
Total number
Number in each category

Staff on duty (with grades)

Visits made by other staff (eg. Medical, Therapy etc) with times

Any other unusual or atypical event

Staff opinions on reactivity

Observers impressions of day (record for example own thoughts on observer role, degree of intervention (if any), reactive effects, attempts at impression management, observer fatigue, any events that typify or exempify emergent patterns within ward routine, atmosphere and so on)

APPENDIX NINE

FREQUENCY DISTRIBUTIONS AND CORRELATIONAL MATRICES FOR FACTOR ANALYSES

FREQUENCY DISTRIBUTIONS OF VARIALBES IN FACTOR ANALYSIS

n=522 for both sets of factors

ENVIRONMENT FACTORS

Variable	% Respondents coding		
Help with ADL	None	Part	All
V1 Washing	25	38	37
V2 Dressing	19	39	42
V3 Feeding	57	28	15
V4 Walking	19	37	45
V5 Bathing	7	25	68
V6 Housework	2	8	90
Continence	Never	Occasional	Frequent
V7 Bladder day	48	28	24
V8 Bladder night	50	26	25
V9 Bowel day	60	27	13
V10 Bowel night	69	21	10
Behaviour			
V11 Wander	66	22	13
V12 Disorientated	44	22	34
V13 Difficult	48	34	18
V14 Agitated	35	42	24
V15 Poor conversation	35	25	39
Environmental stressors	Always	Sometimes	Never
V16 No private time	50	44	5
V17 Out of control	14	65	21
V18 No family time	18	43	40
V19 Affects finances	18	31	51
V20 Dependant manipulative	16	47	37
V21 Poor mobility	73	16	11
V22 Professional attitudes	35	39	26
V23 Social life	70	26	4
V25 Family relationships	35	44	21
V26 Tiring	61	36	4
V27 Demanding	27	57	16
V28 Poor relationship	24	33	44
V29 Personal care	60	33	7
V30 Won't help	21	44	36
V31 Poor sleep	38	47	14
V32 Family don't visit	35	29	37
V33 Feels angry	26	51	24
V34 Friends don't visit	45	44	11
V35 Emotional health suffers	37	51	11
V36 No holidays	46	36	18
V37 Poor standard of living	29	25	46
V38 No appreciation	26	40	35
V39 Affects physical health	35	43	22
V40 Incontinence	27	37	36
V41 Problem behaviour	19	49	32
V42 No satisfaction	13	43	44
V43 Poor professional help	28	39	33
V44 Poor family help	31	32	37
V45 Can't relax	34	48	19
V46 Feels Guilty	24	35	41
V47 Experiences other problems		Yes	No
		64	36

STRESS FACTORS

Stressful nature		Very	Moderately	Not
V1	No private time	35	52	13
V2	Out of control	34	43	23
V3	No family time	16	39	45
V4	Affects finances	16	27	57
V5	Dependant manipulative	23	35	42
V6	Poor mobility	37	41	22
V7	Professional attitudes	34	34	33
V8	Social life	40	47	13
V9	Family relationships	34	42	24
V10	Tiring	46	44	10
V11	Demanding	37	45	19
V12	Poor relationship	24	27	49
V13	Personal care	26	49	26
V14	Won't help	18	40	43
V15	Poor sleep	38	42	21
V16	Family don't visit	23	29	48
V17	Feels angry	33	40	27
V18	Friends don't visit	26	51	23
V19	Emotional health suffers	38	48	14
V20	No holidays	38	40	23
V21	Poor standard of living	17	30	53
V22	No appreciation	20	35	46
V23	Physical health suffers	33	41	26
V24	Incontinence	20	30	51
V25	Problem behaviour	24	39	37
V26	No satisfaction	14	35	51
V27	Poor professional help	26	35	39
V28	Poor family help	24	31	45
V29	Can't relax	33	46	20
V30	Feels guilty	24	36	41
			Stressful	Not Stressful
V31	Experiences other problems		64	36

CORRELATION MATRIX: ENVIRONMENT FACTORS

	V1	V2	V3	V4	V5	V6	V7
V1	1.00000						
V2	.70476	1.00000					
V3	.47659	.51877	1.00000				
V4	.62797	.67039	.53532	1.00000			
V5	.40659	.54388	.38079	.53869	1.00000		
V6	.55986	.55809	.31632	.46088	.48251	1.00000	
V7	.26723	.31457	.15997	.18284	.16770	.36242	1.00000
V8	.22026	.23568	.26978	.35897	.13205	.17112	.04941
V9	.23066	.23883	.26257	.37354	.15745	.18660	.09628
V10	.26647	.26434	.26233	.36083	.16062	.19966	.07182
V11	.27168	.26873	.26255	.35700	.16521	.19856	.09085
V12	.03280	.02380	.04344	-.01752	-.13984	.01486	.08193
V13	.14356	.08493	.16837	.10127	-.03194	.15301	.12994
V14	.11799	-.01172	.09245	.02531	-.08622	.10875	.13695
V15	.07584	-.01783	.09822	-.02786	-.10128	.05722	.12174
V16	.16941	.11760	.20924	.11545	-.02148	.10338	.16680
V17	.17117	.14743	.06280	.08358	.05456	.13559	.11309
V18	.02595	-.00380	.06499	.06436	-.05685	-.02593	.00610
V19	.11156	.07522	.04178	.06697	.09551	.13915	.01099
V20	.07676	-.01427	.04774	.06154	.01144	.00035	-.01064
V21	-.07013	-.14299	-.05744	-.09442	-.09627	-.04295	.00895
V22	.22585	.32425	.24893	.27990	.49179	.30451	.14230
V23	.08760	.03822	.07112	.13004	.05810	.06206	.09208
V24	.16267	.15826	.10828	.12647	.12284	.15204	.13762
V25	.01621	-.08070	.02188	-.00882	-.04109	-.00876	-.02282
V26	.25675	.23229	.14047	.24969	.20133	.20763	.15853
V27	.12605	.00414	.00057	.04631	-.02856	.08159	.06348
V28	.05349	.00471	.06704	.02047	-.04039	.03506	.02834
V29	.54584	.54538	.32498	.49380	.37719	.45515	.25071
V30	-.00589	-.04913	.01077	-.02646	-.05450	-.02766	.02047
V31	.22474	.22724	.15447	.22828	.09002	.13395	.11479
V32	.04405	-.01141	-.01318	.00469	-.05871	.01014	.00942
V33	.02321	-.05265	-.01073	-.01785	-.07399	.00190	-.01773
V34	.16081	.08611	.04842	.07614	.10285	.19156	.09968
V35	.03616	-.04982	-.02033	-.02727	-.05632	-.00562	.04499

	V1	V2	V3	V4	V5	V6	V7
V36	.05841	.00641	-.12383	-.00574	.04075	.07420	.09838
V37	.10497	.02957	.05885	.10857	.02534	.03635	-.02131
V38	-.01670	-.08544	-.00843	-.07457	-.04915	-.02611	.04203
V39	.18897	.10828	.12886	.18232	.10458	.15530	.05791
V40	.28043	.31734	.33224	.46616	.25183	.25990	.12474
V41	.00027	-.07878	.02324	-.06743	-.13292	.00062	-.00830
V42	.01134	-.01147	-.02951	-.05395	-.05074	.02450	.03488
V43	.18364	.09359	.09602	.14592	.01793	.08757	.08282
V44	.01103	-.03040	.00001	-.01418	-.08886	.00757	.03305
V45	.05014	.04006	.03560	.06418	.00145	.04694	.05838
V46	-.05193	-.02722	-.05699	-.00872	-.04650	-.01122	-.02857
V47	-.03819	-.00989	.01697	-.05171	-.04241	-.02279	.06063

	V8	V9	V10	V11	V12	V13	V14
V8	1.00000						
V9	.78217	1.00000					
V10	.49881	.48723	1.00000				
V11	.46571	.55501	.73015	1.00000			
V12	.14747	.13541	.13892	.13109	1.00000		
V13	.21891	.23948	.16252	.19113	.45317	1.00000	
V14	.18035	.19573	.14102	.16893	.39563	.47154	1.00000
V15	.13716	.14280	.13660	.14409	.38505	.48772	.67379
V16	.25089	.23915	.24321	.20615	.39622	.60339	.51167
V17	.12428	.14372	.14411	.11484	.13516	.08765	.16309
V18	.08482	.05673	.03254	.03674	.09238	.09773	.22493
V19	.10720	.11610	.07434	.05598	.07371	.05127	.21120
V20	.12844	.14445	.12183	.11975	.13875	.00295	.12618
V21	.01499	.02233	.03323	-.06780	.06264	-.00401	.25332
V22	.07299	.04976	.04284	.06440	-.21385	-.10513	-.09273
V23	.06209	.09829	.07610	.06788	.07072	-.01633	.04879
V24	.06012	.09966	.09543	.09645	.03908	.10284	.10786
V25	.04712	.00841	.05387	-.01240	.10192	.06008	.22221
V26	.08266	.10911	.15124	.10883	-.00192	.04908	.09599
V27	.04440	.06482	.11256	.09986	.18794	.13068	.33337
V28	.09730	.05602	.09249	.07703	.16751	.20927	.35553
V29	.17330	.22354	.27815	.26925	.09577	.15141	.14041
V30	.05960	.02502	.04526	.02053	.13278	.11536	.36737
V31	.13501	.19198	.15105	.17276	.09522	.11114	.12302
V32	.08373	.08216	.01759	.00424	.13957	.09653	.12480
V33	.05524	.05133	.08933	.03556	.09638	.08630	.20854
V34	.10818	.10858	.11026	.08853	.05039	.16249	.19233
V35	.03560	.04010	.07040	.06005	.08855	.09606	.23144
V36	.01880	.01723	.01528	-.01137	.02380	-.02495	.07204
V37	.12638	.12330	.15430	.15995	.11060	.02853	.17388
V38	.04156	.04599	.07210	.08726	.13541	.16449	.40223
V39	.11021	.14137	.15530	.17484	.01492	.09481	.17630

	V8	V9	V10	V11	V12	V13	V14
V40	.69803	.67715	.51872	.53649	.12043	.22769	.19254
V41	.14499	.14787	.13765	.10902	.30463	.31142	.56804
V42	.04116	.01937	.08866	.04595	.12839	.10582	.19356
V43	.10756	.15882	.10086	.07394	.07234	.02596	.08575
V44	.05361	.05768	-.04851	-.05075	.12551	.08121	.15390
V45	.05515	.05821	.04472	.05342	.10987	.12761	.19406
V46	.05202	.04464	.05120	.04408	.07839	.03839	.14823
V47	.07831	-.08027	-.06296	-.00130	-.03682	-.07911	.00188

	V15	V16	V17	V18	V19	V20	V21
V15	1.00000						
V16	.50691	1.00000					
V17	.18707	.09868	1.00000				
V18	.20209	.06616	.28648	1.00000			
V19	.17619	.06899	.29170	.24052	1.00000		
V20	.07898	.02877	.14671	.14165	.18412	1.00000	
V21	.27808	-.03426	.23919	.33159	.25324	.22571	1.00000
V22	-.09051	-.10155	.11260	.00557	.07342	.07130	.03487
V23	.14236	.00761	.23627	.26626	.16185	.26049	.23669
V24	.08480	.11121	.45820	.20870	.21669	.14962	.15065
V25	.23382	.09655	.28341	.36370	.42057	.20685	.33841
V26	.06437	.08626	.38496	.28381	.16522	.14440	.08153
V27	.35347	.10887	.37864	.30930	.22985	.18772	.49882
V28	.32768	.25891	.20182	.23998	.10019	.07046	.26157
V29	.10467	.18674	.21292	.08885	.15428	.07674	-.00009
V30	.35293	.14279	.21687	.24375	.13905	.13060	.41940

	V15	V16	V17	V18	V19	V20	V21
V31	.11402	.09375	.29093	.27529	.14963	.21737	.14630
V32	.10613	.09538	.21454	.18277	.14546	.15418	.19159
V33	.22599	.05486	.28743	.31549	.24915	.19911	.33226
V34	.17783	.14329	.47748	.21594	.28687	.14917	.26258
V35	.23226	.09469	.38344	.40958	.26440	.21453	.34077
V36	.07917	-.01766	.32741	.19452	.12042	.15520	.12611
V37	.11594	.04878	.23879	.17501	.16733	.52651	.18625
V38	.45343	.19557	.23134	.20170	.17452	.14173	.41260
V39	.15615	.05713	.29571	.33086	.14120	.28217	.18262
V40	.12775	.26653	.19257	.03687	.13247	.12373	.01158
V41	.56759	.33386	.25970	.25838	.28415	.13608	.37608
V42	.27568	.05763	.27015	.23608	.15799	.02402	.26202
V43	.11868	.04625	.21988	.20176	.18137	.29714	.11604
V44	.13139	.06684	.17944	.19720	.19658	.14151	.21489
V45	.21035	.08492	.35922	.46142	.23792	.14508	.26232
V46	.16398	-.03495	.20865	.42172	.26556	.10221	.33187
V47	.01187	-.02596	.06557	.09458	.01306	.13276	.06854

```
           V22        V23        V24        V25        V26        V27        V28

V22      1.00000
V23       .04459    1.00000
V24       .21747     .17590    1.00000
V25     -.01119      .26149     .29749    1.00000
V26       .22204     .18671     .35761     .21022    1.00000
V27       .05124     .21666     .25275     .36365     .28367    1.00000
V28       .01278     .10653     .15488     .25771     .09483     .34679    1.00000
V29       .27007     .13815     .24977     .06287     .39207     .18088     .06205
V30     -.03680      .09876     .12759     .26002     .10403     .40666     .39519
V31       .10976     .24122     .26197     .15502     .33299     .22844     .13951
V32       .04794     .26342     .14072     .29129     .15074     .21473     .15411
V33       .00117     .26099     .19796     .38188     .17764     .38935     .34186
V34       .15158     .14454     .48332     .29273     .30395     .36873     .20313
V35     -.00744      .27327     .32163     .43599     .29613     .42320     .34507
V36       .03690     .25359     .35029     .15264     .20776     .23175     .12365
V37       .11893     .26529     .25680     .21660     .22706     .28492     .17438
V38     -.07440      .15174     .14994     .28554     .09494     .48143     .38175
V39       .18715     .27408     .28148     .24299     .44729     .29941     .17106
V40       .16628     .08828     .12252     .07502     .17109     .09500     .08799
V41     -.06149      .10436     .22550     .32867     .11533     .41517     .41694
V42       .01041     .16422     .21273     .24702     .10771     .31159     .41595
V43       .00217     .65468     .18707     .21323     .19650     .18615     .08712
V44       .01139     .22482     .19628     .27743     .08298     .17012     .16882
V45       .05876     .28652     .28278     .36648     .33034     .35957     .23792
V46       .04408     .24018     .17840     .35652     .13973     .32314     .28814
V47       .05260     .03904     .05890     .08085     .07862     .09537     .02562
```

	V29	V30	V31	V32	V33	V34	V35
V29	1.00000						
V30	.09844	1.00000					
V31	.30847	.11641	1.00000				
V32	.07935	.18044	.20611	1.00000			
V33	.12260	.31793	.20098	.33875	1.00000		
V34	.22008	.23061	.24828	.23397	.34570	1.00000	
V35	.11543	.25460	.32910	.26219	.46183	.41969	1.00000
V36	.16424	.14622	.25753	.19383	.22334	.35433	.29467
V37	.17978	.16989	.35302	.27391	.24631	.30838	.29489
V38	.06920	.51138	.09625	.17169	.32459	.31353	.30853
V39	.26592	.16867	.40679	.24356	.29142	.33217	.39591
V40	.31223	.09479	.17585	.10214	.06896	.17283	.04545
V41	.10220	.42376	.15260	.15947	.30369	.28190	.29884
V42	.06583	.28592	.05628	.10234	.39767	.26692	.29283
V43	.22179	.10914	.22749	.23754	.29342	.22566	.26472
V44	.04127	.15839	.11473	.61659	.35534	.21319	.22207
V45	.18861	.20239	.36963	.26619	.39223	.34854	.51934
V46	.02125	.22001	.19176	.17779	.42985	.21613	.43192
V47	.06021	.01581	.05540	.01004	.09127	.08855	.09931

	V36	V37	V38	V39	V40	V41	V42
V36	1.00000						
V37	.30029	1.00000					
V38	.17144	.14406	1.00000				
V39	.22271	.38864	.13025	1.00000			
V40	.04072	.14586	.07519	.12316	1.00000		
V41	.18349	.17344	.46902	.20487	.19942	1.00000	
V42	.15542	.11035	.35101	.15019	.06037	.32085	1.00000
V43	.25374	.28132	.14559	.31181	.14461	.09943	.16403
V44	.13937	.21003	.16518	.19509	.06100	.15837	.16462
V45	.29432	.27497	.20125	.44992	.07578	.29922	.25356
V46	.18401	.19225	.17859	.22320	.05885	.24844	.27882
V47	.07013	.12366	-.01752	.13023	-.05318	.06966	-.01532

	V43	V44	V45	V46	V47
V43	1.00000				
V44	.26040	1.00000			
V45	.24886	.37928	1.00000		
V46	.17579	.23667	.48516	1.00000	
V47	.11152	.16366	.12878	.10126	1.00000

CORRELATION MATRIX: STRESS FACTORS

	V1	V2	V3	V4	V5	V6	V7	V8	V9
V1	1.00000								
V2	.44912	1.00000							
V3	.35807	.24508	1.00000						
V4	.17348	.19338	.16387	1.00000					
V5	.35962	.30426	.27651	.19756	1.00000				
V6	.19434	.21079	.15768	.13350	.11229	1.00000			
V7	.26424	.30672	.16842	.28898	.16680	.18374	1.00000		
V8	.47204	.27181	.30001	.15853	.31129	.29969	.23810	1.00000	
V9	.37452	.38130	.42803	.21965	.35489	.12445	.30111	.41326	1.00000
V10	.36679	.32854	.21616	.23455	.18161	.33858	.29092	.34383	.23416
V11	.47887	.36613	.30452	.19998	.51993	.16889	.24913	.39538	.40766
V12	.26288	.28722	.12106	.09307	.29107	.14861	.15489	.21770	.30290
V13	.31792	.25005	.20176	.21440	.17865	.35927	.23785	.34061	.25110
V14	.30519	.26399	.19425	.20646	.41459	.12942	.15358	.30435	.29498
V15	.35115	.34428	.21282	.26692	.19030	.25355	.30426	.35004	.29787
V16	.22195	.18353	.19235	.21926	.20151	.20462	.27082	.30024	.33471
V17	.43060	.40620	.30024	.24587	.35590	.20729	.33703	.39315	.42790
V18	.43629	.26077	.34281	.14560	.35326	.23973	.17459	.58647	.34465
V19	.50386	.45896	.31706	.20630	.35981	.24459	.34227	.48446	.42921
V20	.40287	.22611	.19767	.18002	.26435	.13628	.25399	.46063	.30080
V21	.27622	.18353	.21042	.55012	.22251	.22509	.33679	.28132	.30139
V22	.28223	.21249	.19248	.18194	.46079	.13440	.17116	.34218	.32079
V23	.34694	.33675	.20950	.31820	.19060	.29907	.29638	.35370	.25960
V24	.15728	.14622	.15156	.15039	.09208	.23959	.11179	.19344	.14203
V25	.30040	.28143	.24503	.15798	.40096	.03912	.10227	.26590	.34916
V26	.34795	.30864	.17398	.08880	.32401	.15491	.23510	.29354	.27181
V27	.27605	.26494	.18285	.34280	.17531	.20846	.65305	.28031	.28851
V28	.24957	.26493	.26019	.14750	.24647	.14254	.24176	.29999	.37062
V29	.41119	.48300	.25057	.14956	.21838	.23173	.28070	.36730	.38719
V30	.38000	.40219	.26955	.12128	.30559	.17819	.23099	.32934	.38270
V31	.07415	.15116	.02082	.11776	.10212	.09371	.08034	.08474	.10959

	V10	V11	V12	V13	V14	V15	V16	V17	V18
V10	1.00000								
V11	.36653	1.00000							
V12	.16662	.36667	1.00000						
V13	.40625	.33620	.26295	1.00000					
V14	.20663	.44718	.37654	.32597	1.00000				
V15	.33403	.29972	.20551	.33619	.25756	1.00000			
V16	.20628	.21670	.23140	.27695	.18485	.25391	1.00000		
V17	.30721	.43765	.38429	.35518	.29174	.32558	.31803	1.00000	
V18	.28966	.40173	.25883	.28232	.30757	.29291	.34408	.45876	1.00000
V19	.33342	.44309	.33221	.29880	.34528	.45274	.30077	.49927	.49196
V20	.28298	.35178	.20125	.27882	.27830	.31549	.24270	.35403	.44048
V21	.28087	.27766	.18231	.29815	.27703	.39341	.29628	.31921	.31793
V22	.17326	.52001	.41426	.23452	.49023	.19188	.19832	.35256	.44612
V23	.43466	.32987	.22662	.36125	.24047	.45702	.25969	.41204	.31364
V24	.24493	.20210	.16516	.37888	.23644	.28684	.15446	.16874	.23778
V25	.15219	.44538	.41341	.26358	.42599	.19655	.11965	.33590	.28393
V26	.25066	.37753	.39635	.25776	.31288	.19842	.19556	.40874	.33693
V27	.31144	.24465	.18509	.30372	.21093	.32355	.28534	.32969	.23024
V28	.19444	.23303	.19063	.19813	.14518	.23427	.60855	.37296	.31772
V29	.38593	.38804	.21374	.34654	.25481	.43614	.27943	.42120	.36566
V30	.21591	.31043	.29432	.21936	.26337	.23352	.15722	.46741	.33351
V31	.08860	.12505	.05285	.03611	.01368	.05493	.01001	.12178	.08726

	V19	V20	V21	V22	V23	V24	V25	V26	V27
V19	1.00000								
V20	.42364	1.00000							
V21	.28270	.35972	1.00000						
V22	.41530	.30249	.27949	1.00000					
V23	.43665	.29774	.38476	.22691	1.00000				
V24	.18749	.11453	.19623	.14401	.19821	1.00000			
V25	.36744	.25834	.20563	.46499	.25034	.25606	1.00000		
V26	.32343	.25659	.22042	.38068	.26447	.18084	.36578	1.00000	
V27	.32172	.32962	.35075	.19077	.38611	.16197	.14761	.26648	1.00000
V28	.33289	.23970	.25062	.20809	.25380	.15618	.14932	.25935	.32225
V29	.50387	.32593	.29561	.27807	.46642	.22024	.27496	.29629	.31533
V30	.40391	.26379	.18534	.29313	.27959	.14923	.31083	.33123	.20677
V31	.10904	.10774	.08796	.00606	.13429	.04861	.04882	-.01355	.12920

	V28	V29	V30	V31
V28	1.00000			
V29	.36457	1.00000		
V30	.23527	.49939	1.00000	
V31	.03716	.10522	.09307	1.00000

APPENDIX TEN

LISREL MATHEMATICAL MODEL

Table 4: Results of the LISREL Causal Path Analysis

```
       SQUARED MULTIPLE CORRELATIONS FOR STRUCTURAL EQUATIONS
           S1         S2         S3         S4         S5         S6         S7         M1         M2
           --------   --------   --------   --------   --------   --------   --------   --------   --------
              0.794      0.822      0.640      0.574      0.687      0.596      0.751      0.465      0.200
        TOTAL COEFFICIENT OF DETERMINATION FOR STRUCTURAL EQUATIONS  IS  0.999

STANDARDIZED SOLUTION
        BETA
           S1         S2         S3         S4         S5         S6         S7         M1         M2
           --------   --------   --------   --------   --------   --------   --------   --------   --------
S1             -          -          -          -          -          -          -          -          -
S2             -          -          -          -          -          -          -          -          -
S3             -          -          -          -          -          -          -          -         0.066
S4             -          -          -          -          -          -          -          -          -
S5             -          -          -          -          -          -          -          -          -
S6             -          -          -          -          -          -          -          -          -
S7             -          -          -          -          -          -          -          -          -
M1            0.084      0.313       -          -         0.099       -         0.055       -          -
M2             -          -          -          -          -          -          -          -          -
        GAMMA
           F1         F2         F3         F4         F5         F6         F7         F8         F9         F10
           --------   --------   --------   --------   --------   --------   --------   --------   --------   --------
S1             -         0.768       -          -         0.146       -          -          -          -         0.067
S2             -          -          -          -         0.866       -          -          -          -         0.091
S3            0.291       -         0.120       -         0.486      0.087      0.097      0.052       -          -
S4             -         0.091       -          -         0.198      0.494       -         0.064       -         0.115
S5             -        -0.105       -          -         0.079       -          -         0.790       -         0.096
S6             -          -          -          -         0.111       -          -          -         0.720       -
S7             -         0.069       -          -        -0.195       -         0.921       -         0.051      0.059
M1             -          -          -          -         0.255       -          -          -          -          -
M2             -          -          -          -         0.284       -         0.174      0.080       -          -
        GAMMA
           F11        INT
           --------   --------
S1             -         0.072
S2             -         0.084
S3             -          -
S4             -         0.116
S5             -          -
S6             -          -
S7             -         0.088
M1             -          -
M2             -          -
```

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        PSI
           S1         S2         S3         S4         S5         S6         S7         M1         M2
        --------   --------   --------   --------   --------   --------   --------   --------   --------
 S1        0.206
 S2        0.069      0.178
 S3        0.073      0.049      0.360
 S4        0.086      0.099      0.089      0.426
 S5        0.030      0.029      0.031      0.068      0.313
 S6          -        0.035        -          -        0.043      0.404
 S7        0.031      0.031      0.042      0.041        -        0.042      0.249
 M1          -          -          -          -          -          -          -        0.535
 M2          -          -          -          -          -          -          -        0.161      0.800

              MEASURES OF GOODNESS OF FIT FOR THE WHOLE MODEL :
   CHI-SQUARE WITH  86 DEGREES OF FREEDOM IS    105.81 (PROB. LEVEL = 0.072)
                        GOODNESS OF FIT INDEX IS 0.981
               ADJUSTED GOODNESS OF FIT INDEX IS 0.950
                ROOT MEAN SQUARE RESIDUAL IS     0.019
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APPENDIX ELEVEN

STAFF RESONSES TO TYPOLOGY OF CARE CHECKLIST

Staff responses: Tudwal Ward

Key: S = Sister, E = Enrolled Nurse. Each number relates to 1 staff nurse who made that response. In order to discern patterns of responses for each staff nurse the same number denotes the same staff member throughout the responses.

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
The best way to ensure all the work gets done is to establish a regular routine	235	S14E		235	E	S14
Work is best organised when people know which jobs they are responsible for	All			All		
Patients have a totally free choice						
a) When to have a bath		S124	35E	S124	35E	
b) When and what to eat	15	S2	34E	S12	E345	
c) When to get up or go to bed	S14	25E	3	S124	35E	
d) What to wear	S14	2E5	3	S12 4E	35	
e) Of a single room or which dormitory to sleep in		245	S1 3E	24	S13 5	E
f) What to do during the day	5	S124 E	3	24E 5	S13	
Patients can bring in and keep personal items	S124	35E		S12 4	35E	
Each patient should have an identified nurse of their own		35E	S12 4	5	S12 3E	4
Patients are fully involved in planning their own care		S134	25 E	S34	125 E	
Patients are always consulted about any change that might affect them	S13 4	2E5		S23 4E	15	
Patients attend all case conferences in which they are discussed	3	5	S12 4E	3	S12 5	4E
There is a patient/staff committee to discuss the way things are run			All		All	

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
Relatives are fully involved in planning patient care and attend case conferences	45	S12 E	3	S12 45	3E	
Visitors can come at any time, without prior notice	S123 4	5E		S123 45	E	
Relatives/visitors organise activities		S5	123 4E	S23 5		41 E
There is a regular programme of activities/ outings organised by patients themselves		45 1	S2 3E	45	S12 3	E
Staff organise a programme of activities/ outings for patients	4	S125 E	3	E5	S12 3	4
There is a full range of therapeutic inputs by or, if required, access to						
a) Physiotherapy staff	S1235	4E		All		
b) Occupational therapy staff	124	S35E		1234 E	5S	
c) Speech Therapists			All	23	S145 E	
d) A Chiropodist		All		All		
e) A Social Worker	345	S12E		12345 E	S	
f) A Hairdresser	S134	25E		All		
Patients have sufficient privacy	S134	25	E	S12 34	E5	

If there is anything that you think that is missing from the above list or you would like to add further comment please do so below

No further comments were added

Staff responses: Castell Ward

Key: Sn = Staff Nurse, 1 = Enrolled Nurse, 2 = Enrolled Nurse

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
The best way to ensure all the work gets done is to establish a regular routine	2	1Sn		2Sn	1	
Work is best organised when people know which jobs they are responsible for	2Sn	1		2Sn	1	
Patients have a totally free choice						
a) When to have a bath	Sn	1	2		1Sn	2
b) When and what to eat	Sn	12			1Sn	2
c) When to get up or go to bed	1Sn		2	Sn	1	2
d) What to wear	All			All		
e) Of a single room or which dormitory to sleep in			All		1Sn	2
f) What to do during the day	2Sn	1		2Sn	1	
Patients can bring in and keep personal items	All			All		
Each patient should have an identified nurse of their own	1		2Sn		12	Sn
Patients are fully involved in planning their own care		1Sn	2	Sn	12	
Patients are always consulted about any change that might affect them	2Sn	1		2Sn	1	
Patients attend all case conferences in which they are discussed		All		2Sn	1	
There is a patient/staff committee to discuss the way things are run		Sn	12	Sn	12	

	COLUMN A This applies to this unit			COLUMN B I feel this is		
	All/most of the time	Some of the time	Rarely, if ever	Desirable and possible	Desirable but not possible	Not desirable
Relatives are fully involved in planning patient care and attend case conferences	All			2Sn	1	
Visitors can come at any time, without prior notice	All			All		
Relatives/visitors organise activities		Sn2	1	Sn	12	
There is a regular programme of activities/ outings organised by patients themselves			All	Sn	12	
Staff organise a programme of activities/ outings for patients		All		Sn	12	
There is a full range of therapeutic inputs by or, if required, access to						
a) Physiotherapy staff	2	1Sn		12	Sn	
b) Occupational therapy staff		Sn	12	12	Sn	
c) Speech Therapists	2	Sn	1	12	Sn	
d) A Chiropodist	2	1Sn		2Sn	1	
e) A Social Worker	2	1Sn		All		
f) A Hairdresser	2	1Sn		All		
Patients have sufficient privacy	2Sn	1		2Sn	1	

If there is anything that you think that is missing from the above list or you would like to add further comment please do so below

No further comments were added