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Health service users' help-seeking decisions in primary healthcare: A health psychology approach

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Health service users' help-seeking decisions in primary healthcare:

A health psychology approach

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Dedication

First and foremost, I would like to thank my wife Clare who initially inspired and then encouraged me throughout this endeavour. My children, Caitlin and Ossian, have been great and constant sources of company to me. My parents, John and Kay, have also been sources of encouragement and guidance, and for much longer than anyone else. Cathy, my mother-in-law's ability to fill the breach at a moment's notice and travel from afar to look after our children is very much appreciated. My extended family have also been a fantastic source of support and encouragement as have my friends. Getting to this point without their support would have been very difficult indeed. Finally, I would like to mention my Grandfather, Rob; thank you for the wisdom, encouragement and kindness that you showed to me through the years.

To all these people, without whom, I would not have been able to complete this project, I dedicate this thesis.

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Health service users' help-seeking decisions in primary healthcare

The effectiveness with which healthcare users make decisions about self-referred consultations has anecdotally been a cause of concern. Exploration of the detrimental effects of poor quality self-referral help-seeking decisions on patients' health and NHS resources has been disjointed but is believed to be substantial.

The project explored its main aims through four studies. The first study established definitional parameters of patients' effective and ineffective help seeking behaviour in self referral help seeking situations from the perspective of health care professionals. These definitional parameters enabled the objective measurement of patient mistargeted consultations in the second study where the scale of the issue of patients' ineffectively made help seeking decisions (mistargeted consultations) was assessed with general practitioners. It was found that 28.59% of all consultations made were mistargeted in some way.

The third study considered this issue from a patient's perspective. While it is acknowledged that the factors that underpin the decision to seek help are complex, this study identified several important themes. Respondents reported that they mostly want to consult a GP despite the increasing number of choices available and this array of choice led to confusion. Perceived knowledge and gaps in knowledge centred on the availability of services and of basic health issues were important antecedents to the decision to seek help. Other factors identified as important antecedents included those related to anxiety and to social support. Theoretical explanations of these findings were sought which enabled more effective interpretation and thus prediction of help-seeking behaviour aiding the design of the fourth study.

The fourth study investigated whether factors thought to underpin help-seeking decisions were manipulable. The intervention with first time mothers was designed to directly increase social support and address any significant knowledge gaps and indirectly manipulate factors such as health locus of control, coping strategies and anxiety. Analysis indicated that health locus of control and some coping strategies were significantly affected by the intervention.

Policy makers in Wales have recognised that this is an important issue with the Delivering Emergency Care (DECS) strategy. However, more research is needed to establish whether cost-effective interventions aimed at improving the quality of patients' help seeking decisions can be established.

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Chapter 1

Introduction

and

Background Literature

1.1

Introduction

"My little boy got hit on the head with a golf club- he had a gaping hole in his head. It was blatantly obvious that he needed to go and see someone. Other situations, you wake up and you've got a runny nose. The journey doesn't need to begin."

[A 35 year old male health service user talking about the journey to the consultation]

Effective decision making about when to seek help and with whom by patients who experience health-related symptoms is an issue for the health service. This thesis examines some of the factors associated with this issue from a number of perspectives.

Largely neglected in the research, the effectiveness of everyday health help-seeking decisions may have important consequences for patients making those decisions. With 291 million consultations (OHE, 2005) made with general practitioners (GPs) each year, even a small minority of ineffective help-seeking decisions may have a substantial impact on the use of limited resources.

The day-to-day health help-seeking behaviour of normally healthy health service users (HSUs) has been largely ignored by researchers while an extensive body of literature exists examining the behaviour of specific patient cohorts, patients with specific morbidities and the behaviour of patients seeking help from specific service providers. Literature searches did not reveal any definitional parameters that might describe effective and indeed, ineffective day-to-day help-seeking behaviour which is somewhat surprising given the potentially vast scale of ineffectively made help-seeking decisions. Not surprisingly, given the lack of definitional parameters, tools for measuring the scale of this issue do not exist.

Examination of the effectiveness of help-seeking decisions in this thesis is an inclusive, rather than exclusive exercise. Issues about the effectiveness of help-seeking decisions transcend patient populations and boundaries between different sectors of self referral health services. The vast majority of research in help-seeking behaviour to date has however focused on either specific patient cohorts or specific health services, excluding the majority of help seekers who do not fall into those discrete categories. Research, in this thesis, aims to be inclusive rather than exclusive in its consideration of the day-to-day help-seeking and consultation-seeking decisions. Acknowledging the work done in these specialised help-seeking domains, the

research presented here aims to take a more holistic approach to help and consultation-seeking decisions.

Hannay (1979) described the 'symptom iceberg' where the vast majority of symptoms that we experience form the bulk of the iceberg and are below the 'waterline'. These symptoms are never brought to the attention of a healthcare professional (HCP). Rather, they are dealt with by the individual either through self-treatment, social support from others or they are simply ignored. It is worth noting that in this thesis self-treatment is taken to be any attempt by the individual to address symptoms or issues without formal medical help. This is different from self management or self care undertaken with the supervision or direction of an HCP as this implies that the decision by the patient to seek formal medical help has been taken. At some point, the interaction of this multitude of factors leads the individual to seek professional or formal help. As the symptoms are brought to the attention of the HCP, they form that part of the iceberg that is above the waterline. GPs' anecdotes about bizarre or unusual consultations led to the question; what motivates individuals to make the journey (or indeed, decide not take the first step) from the submerged part of Hannay's iceberg to the world of formal help above the surface? The quality of the decision about taking that journey is the subject of this thesis.

To fully explore the dimensions of this issue, a mixed methods research approach (discussed in detail later) was adopted. The thesis begins with a broad review of literature that provides a chronological account of investigations into relevant areas of research, indicating how thinking about the issue has changed over time. This is followed by reports of three empirical research studies, an examination of relevant psycho-social theoretical perspectives and finally a report of an intervention study.

Review of Literature

An overview of the main areas of research pertaining to the psychological and social behaviour of patients when seeking health-related help is presented here first. After a review of work that describes the most recent data available on consultation rates with a GP, elements of the Wanless Report (2004) relevant to this thesis are considered. This review of literature considers research evidence that informs the studies in the thesis and is ordered chronologically to indicate how perspectives on health and illness developed. It leads to the biomedical and biopsychosocial model of health, an examination of Parson's (1951) 'sick role' and the subsequent identification of factors that motivate individuals to seek consultations with doctors. More recent research investigating aspects of patients' help-seeking behaviour is then reviewed.

This chronological approach enabled the studies presented here to be viewed in the wider context of health and help-seeking behaviour over time. Given the lack of research directly relevant to the issue of day-to-day help seeking, a systematic review of literature was less appropriate at the beginning of the thesis than was placing the research in an historical context. Considering the development of ideas over time allowed discussion of some seminal work which, tangentially, provides a wider framework for the current investigations.

Literature considered relevant to this thesis centres on two distinct areas; help-seeking behaviour and health behaviour. When seen simply as an action, help-seeking is the journey taken by the patient to the source of help. However, help-seeking behaviour must consider the socio-cultural and physiological circumstances that affect the patient's decision to take that journey. The complex interaction of these factors influences the timing and destination of the help-seeking journey, and, indeed whether the patient embarks upon the journey at all. Help-seeking research typically examines help-seeking for specific conditions such as mental health and specific types of cancer (see for example, Smith, Pope and Botha, 2005; Oliver, Pearson, Coe and Gunnell, 2005). Examination of the nature of delay in seeking help for specific cancers has led to the development of models of patient delay (Anderson, Cacioppo and Roberts, 1995). In primary care situations, research has considered the frequency with which patients make consultations (Neal, Heywood and Morley; 2000, for example). While examination of this type of help-seeking behaviour illuminates aspects of the help-seeking process, it is focused on help-seeking for specific

conditions or focused on help-seeking targeted at specific services such as primary care, accident and emergency departments or pharmacists. However, help-seeking for mental health problems may differ markedly from help-seeking for cancers or contraception, for example. The generalisability of results from these studies to other sectors of the help-seeking population may therefore be limited. Research has also considered the effect of specific factors on health behaviour and help-seeking. For example, Farmer, Iversen, Campbell, Guest, Cheeson, Deans and MacDonald, (2006) examined the effect of rurality on health and help-seeking behaviour. Knowing more about the effects of these factors may help the understanding of help-seeking behaviour of specific populations but are not necessarily generalisable to the majority 'healthy' population.

Health behaviour research has examined the behaviour engaged in by people in order to maintain or aspire to a state of health. Health behaviour models have been developed in an attempt to explain such behaviour and are concerned primarily with wellness, not illness. Whilst it seems logical to consider models of health behaviour and their supporting research, their application for this investigation into help-seeking is limited because they are concerned with behaviours an individual engages in *to avoid* the onset of illness. The exception to this has been the Common Sense Model of Illness Representation (Diefenbach and Leventhal, 1996) which has been applied, amongst other things, to delayed help-seeking (Quinn, 2005). Health behaviour models have also, to a lesser extent, been used to explain behaviour after the onset of illness: investigations into patients' concordance with treatment regimes and prescriptions have been undertaken (see for example, Mullen, 1997; Bissell, 2003) with models of health behaviour at their core.

The Health Belief Model (HBM) is the most commonly used model of health behaviour and was first described by Rosenstock, (1966) then revised and developed by Becker (1974), Janz and Becker, (1984), Becker and Rosenstock, (1984). It is most often used to explain why people engage in health promotion and disease prevention behaviours. The HBM has been developed to include self-efficacy components (Protection Motivation Theory; Rogers, 1975; 1983) and social environment components (the Theory of Reasoned Action; Ajzen and Fishbein, (1980). It was originally developed from notions of expectancy value theories (Fishbein and Ajzen, 1975).

Expectancy value theories sought to predict an individual's behaviour on the basis of the value they placed on the expected outcome of that behaviour. For example, one might attempt to lose weight if one considered the value of losing weight to be greater than the effort needed to achieve that goal (self-efficacy). Additionally, individuals needed to perceive that they possessed the resources necessary to achieve such a goal.

Typically, health behaviour has investigated issues such as smoking behaviour (See for example, Flay, Hu, Siddiqui, Day and Hedeker, 1994) and a wide variety of other issues that might affect health ranging from taking exercise to engaging in activities designed to minimise accidents (e.g. wearing seatbelts or the removal of tripping hazards). Theories of health behaviour are discussed in more detail in Chapter 5. Whilst recognising the inherent relationship between health behaviour and help-seeking behaviours, this thesis focuses primarily on an investigation into health-related help and consultation-seeking decisions.

Data from the Morbidity Statistics from General Practice (MSGP), illustrate that patient consultation rates increased from 2 visits per person, per year in 1955-56 to 2.9 visits in 1991-92 (Rowlands and Moser, 2002). When viewed by age and sex, the data show that all children under 4 years consult between 6 and 7 times per year; males between 5 and 50 years consult between 2 and 3 times per year, and females, from the age of 16, begin to consult more frequently (around 5 times per year). Males begin to catch up with the female consultation rate at about 50 years of age when the consultation rate for males is only slightly less than the female rate of between 5 and 6 consultations per year. The consultation rate steadily increases with age for both sexes to approximately 7 consultations per year at the age of 75. Data from the Royal College of General Practitioners Weekly Returns Service was compared with MSGP data by Rowlands and Moser (2002). They found an overall increase in consultation rates from 15% to 29% since 1992. Rowlands and Moser also note that rural practices have a higher consultation rate than urban practices which reflects Farmer et al.'s (2006) findings that rural patients have different patterns of consultation in primary care situations than do their urban counterparts. Differences between male and female consultation rates are greatest in the age range 25-59 with the male consultation rate being 1.8 (mean visits per year) and the female rates being 5.2. The mean age of first time mothers, who are likely to be high users of primary care

services is 26.6 years (ONS, 2004). This partially explains the difference in male and female consultations rates for this age range.

The data described and analysed by Rowlands and Moser (2002) details consultations made with a general practitioner only and does not include consultations with a practice nurse, midwife or other HCP. However, the majority of a patient's symptoms are self-treated and the use of the primary health care services is in addition to these self care practices (Rogers and Nicolaas, 1998). They also found that past experience of illness and of the primary care service was central to decision making regarding primary care consultation. It follows then, that a variety of factors, psychological, psychosocial, social and experiential, influence the movement between self-treatment and consultations at a primary care level. The influence and mix of these factors will vary between patient groups, over time and in relation to patient circumstances. It should be noted, however, that, despite the importance of this type of data for understanding historical health care use and meeting future service demands, its availability and scope are limited. The cost and complexity of gathering national statistics on consultation data (such as the data analysed by Rowlands and Moser, 2002) is considerable, but potential improvement in patient outcomes and increased efficiency in the use of resources may off-set a significant proportion of this cost.

The final version of the Wanless Report was published in 2004 (Wanless, 2004) with the aim of determining what resources would be needed for a high quality health service in the UK. The comprehensive report states that a high quality health service is needed but that health service can only by funded by existing means and its resources are therefore going to be limited. Wanless observed in 2002 that the existing resources need to be used more effectively both by the health services and by the users of those services: "Government, those who work in the health service and those who use it all have a role to play in helping to ensure that health resources have the maximum impact on health outcomes" (Wanless, 2002; p.97). Wanless also observed that if the general level of education and levels of income increased, demand for health services may also increase, even if underlying health needs do not change. Interestingly, this is highlighting the distinction between patients' desires and expectations and their needs.

Wanless goes on to suggest that HSU need more say in health service issues but remarks that health seeking behaviour needs to change: "A public fully engaged

on health issues will impact on the health service in many ways. Some have been picked up in the Review's analysis, in particular of increased health promotion and disease prevention, self-care and health seeking behaviour" (Wanless, 2002; p.115). While he calls for a change in health seeking behaviour, Wanless does not specify the nature of that change. It can be assumed that this change must involve a more effective and efficient use of health services by HSUs. The point at which HSUs can affect change is the point at which they initially decide to seek help. This is the point at which they cross the 'water line' on Hannay's Iceberg of Illness and subject of this thesis. Wanless recommends an expansion of patients' choices but states that it should be part of a contract between the health services and patients that sets out not only patients' rights but also their responsibilities.

Health and illness

The notion of being healthy and being ill means different things to different people. The concept of health and illness has also changed over time and varies across cultures. As such, producing a succinct definition which is applicable to and accepted by all, has proved difficult. The World Health Organisation defines health as:

> *"a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."*
>
> *(World Health Organisation, 1948 p.100)*

This definition has remained unchanged since 1948. The WHO definition speaks of health and illness and the 'highest attainable standard of health'. The position one has on the continuum between health and illness is dependent upon many external factors. These factors include: age; socio demographic profile; diet; and employment to mention but a few. Even within the same context, the perception of health and illness is highly subjective. Two individuals with identical symptoms may have very different perceptions as to how 'ill' they are and different perceptions of the threat from the illness (Leventhal, Diefenbach and Leventhal, 1992). This subjective perception of illness may be dependent upon a wide variety of factors such as

personal experience of illness and one's preparedness to accept symptoms as part of every day life.

There have been many other attempts to define health. Blaxter (1990) for example, noted that; "Health can be defined negatively, as the absence of illness, functionally, as the ability to cope with everyday activities, or positively, as fitness and well being" (Blaxter, 1990, p.14). This was one of several potential definitions of health discussed by Blaxter. Here, like the WHO definition, health and illness are seen as opposite ends of a continuum and this suggests that individuals aspire to move along that continuum. The notion of a continuum invites speculation as to the state of an individual's health at any point along that spectrum: the comedian Spike Milligan's epitaph read; "I told you I was ill". An individual may consider if, according to the WHO definition, they have ever had a day of 'complete physical, mental, and social well-being'. The strength of the definition is that it acknowledges that the notion of health is complex, subjective and difficult to measure or quantify. Marks, Murray, Evans, Willig, Woodall and Sykes, (2005) proposed an amendment to the WHO definition of health to address some of its criticisms:

> *"Health is a state of well-being with physical, cultural, psychological, and economic and spiritual attributes, not simply the absence of illness".*
>
> *Marks, Murray, Evans, Willig, Woodall and Sykes, (2005, p.4)*

Marks et al.'s (2005) definition acknowledges the parts played by culture, economics and spirituality in one's state of health. Mechanic (1978) observes that "the doctor, if he is to meet his responsibilities as a physician, must attune himself to the social situation of the patient" (Mechanic, 1978, p.114). Marks et al. acknowledge that it is nearly impossible to have a universal definition of a state of being that is, by its very nature, subjective and unique to each individual.

The biomedical model

Historically, doctors have been the biomechanics who have maintained and mended the bodies of their patients. This approach has been characterised by the biomedical model which has been the traditional cornerstone of western medicine since the eighteenth centaury (Crossley, 2000). While not strictly a model (it is best described as a framework rather than a model as it is a 'loose' term intended to describe a generally applicable idea), the biomedical model centres on the notion that diseases

are biological malfunctions of the body and any repair should be focused on the biological nature of the body. This is intuitively logical because we are biological entities and when something malfunctions with the biological nature of our functioning it makes sense to employ a biomedical method of repair. This seems to be borne out by the highly effective nature of some of the medical and chemical fixes offered by the medical profession. While the biomedical model provided a framework for the development of medical science, it was fundamentally flawed in that it saw disease and illness as something that existed within the patient's body and thus the approach to disease was treatment focused rather than prevention focused (Marks, Murray, Evans, Willig, Woodall and Sykes, 2005). This informed the relationship between the doctor and the patient: the doctor's role was to fix the broken biological machine while the patient's role was to allow the facilitation of that process without taking an active role in the process.

The biopsychosocial model

In 1977, Engel proposed a new model of health and illness. The Biopsychosocial model (Engel, 1977) was conceived as a response to what he saw as a failure to recognise the patient as a person. Engel's model was proposed as a response to the limitations of the traditional biomedical model. Where the biomedical model considered the disease process to be something that happened *inside* the patient, the biopsychosocial model looked at all the factors that might lead to disease or ill health. These included: psychological and behavioural factors; environmental factors; and physical (genetic) factors. The combination of these factors lead, Engel argued, to an individual's state of health. The inclusion of psychological and social factors in the biopsychosocial model meant that it has been closely associated with the development of health psychology (Crossley, 2000).

This influential model initiated several developments, one of the most notable being Dahlgren and Whitehead's (1991) framework which illustrates the wide range of factors that influence an individual's state of health. Reflecting Bronfenbrenner's (1979) Ecological Systems Theory, the individual is seen as lying at the centre of this multilayered framework, the product of their genetic make-up. This determines all their predispositions to health and illness at various times of life and will affect their response to influences affecting health. The first of four layers in this framework illustrates the next most influential set of variables. These include the individual's

lifestyle and habits such as the amount of exercise, diet and smoking undertaken. Each subsequent layer has a less direct influence on that individual's health and is less controllable by the patient. The next layer corresponds to the individual's social and community influences. For example, community and social activities may inspire a more or less healthy lifestyle and this may change over time as these influences change. The third layer depicts living and working environments. Housing and working environments may have a profound influence on an individual's health but may also be subject to change. Finally, the general economic, cultural and environmental conditions refers to influences on health such as climate, culture and national (and, to an extent, international) economics. Dahlgren and Whitehead's framework illustrates the wide range of factors that more or less directly influence an individual's state of health.

Parsons' (1951) the 'sick role'

Anyone who has suffered illness will observe that, to some degree, participation in the normal activities of society are curtailed. In sociological terms, they deviate from normality. In other words, illness can be seen as deviant behaviour (Blaxter, 1990). This notion was first described by Parsons (1951) who described the rights and responsibilities of those who are sick to wider society. Parsons' Sick Role was rooted in the biomedical model and was much criticised but it does however highlight an important aspect of the behaviour of the sick, namely that they should seek help (from the medical profession, as Parsons saw it) in a timely fashion. While, from Parsons' perspective, this was for the good of society, it is still important for the optimum outcome for the patient. Parsons only considered the medical profession as an appropriate source of help and did not acknowledge the important part played by the sick person's social support network which more recent studies have shown to important (see, for example, Brugha, Sharp, Cooper, Weisender, Britto, Shinkwin, Sherrif and Kirwan 1998; Campbell and Roland, 1996; Dirkzwager and Verhaak, 2007; Ellaway, Wood and MacIntyre, 1999). The notion of the rights and responsibilities of the sick has been revisited by Wanless (Wanless, 2002) with his call for a contract between the patient and the health services. The contract echoes Parsons' notion of the Sick Role in that the patient has to undertake certain responsibilities to use health services in order to enjoy the rights to that service. Wanless' 'contract' differs from that of Parsons' Sick Role in that it does not imply a

paternalistic role for the doctor or health services. The notion of the Sick Role implicitly acknowledges that there are factors other than the biological that can affect the state health of the individual. By not seeking timely medical help, Parsons considered that the sick would be responsible for their continuing state of ill health. This is an acknowledgement that an individual's behaviour can have a direct affect on that person's health, albeit in Parsons' view, after the initial onset of illness (Parsons, 1951).

Identification of factors and attempts and failures to model them

Since Parsons' definition of the Sick Role, research has focused on the identification of the factors that lead to symptoms being reported to a doctor. Not surprisingly, a wide range of factors have been identified as being associated with the decision to seek medical help.

Having symptoms and pain is obviously associated with seeking a consultation with a doctor, but, as Tuckett points out; "Having symptoms and the extent of their seriousness, therefore, although a common reason, is by no means a sufficient one to explain why and how somebody becomes a patient and where he will receive treatment" Tuckett (1976 p.164). Tuckett goes on to describe how the recognition of a symptom may be dependent upon previous experience of illness, either directly or through the observation of the experience of others (Tuckett, 1976). Clearly, individual differences play a significant role in determining when and whether medical help will be sought and from whom.

Kasl and Cobb (1966) and Rosenstock (1960) both proposed models of help-seeking behaviour which attempted to show how the factors thought to be associated with medical help-seeking behaviour interacted, leading to a consultation with a doctor. However, the plethora of factors that these models attempted to integrate made them cumbersome and overly complex resulting in them being little more than "lists of possible variables rather than a model of how they interact" (Tuckett, 1976 p.171).

Studies continue to investigate these factors and new factors continue to be identified. Some of these are associated with environmental factors (for example, Farmer, Iverson, Campbell et al., 2006) whilst others investigated HCP or patient-related factors. Recently, Farmer, Iverson, Campbell et al., (2006) investigated the effect of rurality on health and help-seeking behaviour. Duberstein, Meldrum,

Fiscella, Shields, and Epstein, (2007) examined the effect of the personality of primary care physicians on the patients' satisfaction. Duberstein et al.'s study illustrates that patient satisfaction with a doctor can be influenced by the personality of the doctor. It can be reasonably assumed that patient satisfaction with a doctor may influence subsequent decisions to consult but this was not investigated or discussed despite this being a potentially important factor in the help-seeking process. Ellaway, Wood and MacIntyre (1999) identified loneliness as an important factor in the decision to seek a consultation with a GP. While loneliness may be an important factor, it affects a limited proportion of help seekers. Additionally, Ellaway et al. only considered the effect of loneliness on consultations with GPs. They did not attempt to consider the effect of this factor on other health services such as accident and emergency departments. The sample for this study was drawn exclusively from an urban setting (Glasgow). How loneliness affects rural populations was not considered in this study or by Farmer et al. (2006).

Studies such as these rightly consider factors that influence help-seeking behaviour, but they are limited in that they either consider the affect of only one factor in isolation from a raft of other factors, or they consider the help-seeking behaviour of a limited cohort of HSUs.

Recent research into help-seeking behaviour and health service usage

Research into help-seeking behaviour has focused on specific patient groups such as men (Galdas, Cheater and Marshall, 2005) or the elderly (Ellaway, Wood, and MacIntyre, 1999), specific services such as primary care (Rogers and Nicolaas, 1998) or accident and emergency departments (Rajpar, Smith and Cooke, 2000) and help-seeking for specific conditions (Smith, Pope and Botha, 2005; Oliver, Pearson, Coe and Gunnell, 2005 for example). Research into help-seeking behaviour in primary care has tended to focus on patients who attend frequently (for example, Neal et al., 2004) while other research has considered delayed attendance (for example, Corner, Hopkinson and Roffe, 2006). While this body of research focuses on the behaviour of a minority of patients, it does illuminate some interesting aspects of help-seeking behaviour. The consultation rates of various patient groups are continuously monitored and this type of information is used for the effective planning of resource allocation. The effect of community pharmacists (Hassell, Noyce, Rogers, Harris and Wilkinson, 1997) or innovations such as NHS Direct (Chapman, Smith, Warburton,

Mayon-White and Fleming, 2002) on types and patterns of consultation and consultation rates has also been investigated.

Patterns and Types of Patient Consultation Behaviour

In primary health care settings, frequent attendance has been the subject of much research. The generally accepted definition of frequent attendance is any patient who attends more than 20 times per year. Howe, Parry, Pickvance and Hockley (2002) proposed a change in the definition of frequent attendance arguing that this somewhat simplistic definition may result in some patients being negatively labelled as frequent attenders when in fact they have a clinical need to attend frequently. Howe and colleagues suggest that if researchers apply a simple correction for age and sex then high attenders within patient sub groups can be identified. They go on to acknowledge that previous studies have identified significant minorities of patients (for example the unemployed, the elderly and female patients) who consult most frequently. By selecting the top 3% of adult male attenders, divided into two age ranges (above and below 45) and the top 3% of female attenders it is possible to identify patients who attend frequently without necessarily having a clinical need (Howe, Parry, Pickvance and Hockley, 2002).

Little and colleagues (Little, Somerville, Williamson, Moore, Wiles, George, Smith and Peveler, 2001) examined why certain groups of patients attend frequently. The psychosocial variables associated with frequent attendance among adults were investigated and their study identified MUPS (Medically Unexplained Physical Symptoms) as the most significant predictor of high attendance. Other factors were associated with frequent attendance in general practice including health anxiety and a patient's perception of their own health. Little et al. considered MUPS to be important in predicting frequency of attendance, but its relationship with other variables makes its impact difficult to assess. MUPS, as a cause of frequent attendance is difficult to untangle from MUPS as a consequence of frequent attendance. It is, however, clear that MUPS is linked with health anxiety. Little et al. go on to suggest that the exact nature of the relationship between MUPS and other variables requires further research but they do point out that MUPS, health anxiety and perception of health are associated independently with attendance. Somatic symptomatology is another significant variable in frequency of attendance. Little et al. suggest that self management information may have an impact on consultation

behaviour and that leaflets have an effect here but are not as effective as specific information provided to the patient during a consultation. Anxiety and depression were also identified as significant variables associated with frequent consultations. They suggest (after a review of literature) that improvement in social conditions and perhaps the treatment of anxiety and depression may affect the patient's decision to consult. Attitudes have also been identified as important, both in terms of the patient's attitude towards their own health (willingness to tolerate symptoms, exercise and lifestyle for example) and in terms of the patient's attitude towards the HCPs, use of the surgery and, interestingly, the use of the pharmacy (Little et al. 2001).

The different patterns of frequent attendance were examined by Neal, Heywood and Morley (2000) using semi-structured interviews. They identified five distinct patterns:

- longer (chronic health problems)
- shorter (episodes of illness) bursts of consulting
- not consulting (gaps due to seasonal variation, symptom resolution and consulting elsewhere)
- multiplicity (this occurs when a patient frequently consults and gets used to the process and procedures for consulting and becomes familiar with a particular doctor)
- Passivity associated with perceptions of external control (the patient feels that control over consultations does not lie with them- the condition forces the pattern of consultation).

According to Neal et al. these patterns of consultation behaviour formed the basis of a model of consultation behaviour. However, this model does not identify *who* the frequent attenders are. Neal et al. note that their respondents acknowledged that the doctor can have a powerful influence on consultation patterns. They suggest that there is considerable scope for the development of intervention strategies designed to influence consultation behaviour through the GP actively addressing help-seeking behaviour. This study examined consultation behaviour with general practitioners only and did not consider the consultation patterns with other HCPs. In an attempt to reduce frequent attendance with GPs, Jiwa (2000) provided a detailed summary of data from the notes of patient's identified as frequent attenders. Patients were defined as frequent attenders if they attended more than 11 times per year. No attempt was

made in this study to differentiate between valid and invalid frequent attenders. Jiwa's study was based in a small primary care practice in a semi rural locality (a Nottinghamshire market town). The summary of data was placed in the patient's notes which were then highlighted as those of patients who attended frequently. Jiwa hypothesised that doctors could cope better with this type of patient if important information was easily available to them. It was anticipated that GPs' approaches to patients highlighted as frequent attenders would change their patients' behaviours. To this end the patient's summarised notes were made readily accessible to the doctor at each consultation but no significant difference was found between the frequency of attendance of patients in the intervention group (notes summarised) and controls (notes not summarised). It is reasonable to assume that patients who attend frequently would be well known to the partners in a small practice such as the one under investigation in this study and the effectiveness of Jiwa's intervention may well have been limited by this. The intervention, which was highly focused on the general practitioner, made no attempt to intervene directly with patients and their consultation behaviour.

Neal, Wickenden, Cottrell, Mason, Rugiano, Clarkson and Bearpark, (2001) studied the way frequent consulters of general practitioners used other health care services in the community. Health diaries were completed over an 8 week period by thirty-five individuals in seven families. Health care records were examined from both community care and primary care and satisfaction scores were collected from both the families and HCPs. The study's findings indicated that those who were frequent attenders at general practices were also frequent attenders of other community based health care providers. Neal et al., (2001) suggest that the use of other community based health care services should be used as an outcome measure for trials of interventions designed to affect frequent attendance in general practice settings. Other than presenting the GP with information, no attempt was made to alter the GPs' behaviour.

Studies reviewed so far have looked at who the frequent attenders are and the shape the frequent attendance takes; the 'who' and the 'how'. Other factors that influence consultation behaviour have also been considered. Ellaway, Wood and MacIntyre (1999) examined data collected in a 1992 survey of patients in the west of Scotland. Focusing on frequent attenders, they investigated loneliness as a factor and found it to be significantly associated with the number of consultations made by

patients. Donaldson and Watson (1996) highlighted the elderly as a group likely to experience loneliness but surprisingly, Ellaway et al. found that it was not just the elderly who consulted more frequently because of loneliness but also younger frequent attenders (aged between 40 and 60 at the time of interview). The researchers went on to conclude that GPs may be 'fulfilling a role for those who need someone to talk to and he or she is viewed as an appropriate confidante for problems formerly seen as being the province of the clergy' (Ellaway et al. 1999 p.365).

Anxiety and depressive disorders were shown by Ronalds, Kapur, Stone, Webb, Tomenson and Creed (2002) to be factors associated with frequent attendance, although not all anxious and depressed patients are frequent attenders. An inequality in morbidity and consulting behaviour for socially vulnerable groups was investigated by Baker, Mead and Campbell (2002): lone mothers; the unemployed; the elderly; and members of ethnic minorities. They found that problems with mental health are common amongst these patients but physical health problems are more likely to be condition specific. Baker et al. point out that lone mothers are more likely to have mental health issues than other groups of women and the unemployed are more likely to suffer a wide range of health issues including cardiovascular problems. Their findings suggested that although lone mothers are likely to have poorer health, they are no more likely to consult than other patient groups. Their results also confirmed the association between lone motherhood and the likelihood of poorer mental health which is conventionally attributed to lack of social support and high levels of stress. They also found that members of ethnic minorities are more likely to suffer poorer health but little is known about the causes of this situation. Unlike the other identified socially vulnerable groups in the study, ethnic minorities are more likely to have higher consultation rates for illnesses such as backache, indigestion, migraine or minor respiratory symptoms but Baker et al., were unable to explain this difference (Baker et al., 2002). Baker et al. identified why certain patient groups attended frequently, but did not examine their patterns of attendance. The study focused only on the patient's consulting behaviour with GPs and no other HCPs. Focusing exclusively on general practitioners can only provide a limited picture of the patient's consultation behaviour.

Of interest here is the complexity caused by the potential interaction of multiple factors. Ronalds et al. (2002) point to stress and anxiety as a factor in frequent attendance and Baker et al. (2002) point to the socially vulnerable. Baker et

al. did find that some socially vulnerable groups (lone mothers) had higher levels of anxiety. However, they did not specify whether the frequency of consultation was due to social vulnerability or to anxiety. Clearly, the two factors are closely associated. This close association illustrates the complex relationships that exist between factors associated with help-seeking and the challenges faced by researchers with limited resources for complex interventions.

Whilst frequent attendance has been highlighted as a major problem by practitioners and researchers, the opposite end of the consultation spectrum is non-attendance. George and Rubin (2003) concluded that, while the epidemiology of non-attendance has been well documented, there is little work on the reasons for non-attendance. They point out that Department of Health targets mean that patients will be able to have access to a GP within 48 hours and that moves towards improving the efficiency of the service are vital for meeting these targets. They suggest that further research is needed to reduce non-attendance as one means of improving service efficiency.

The studies of frequent attendance all consider that the frequently attending patient is somehow a 'problem' and interventions such as Jiwa's (Jiwa, 2000) have attempted to address this using interventions aimed at reducing the frequency with which patients attend. However, attention should be paid to the revised definition of a frequent attender developed by Howe et al. (2002) that, after considering patients by sex and age, enables the identification of those patients who are extreme frequent attenders. Examination of their consultation patterns may enable the differentiation between those who need to attend frequently and those who attend frequently for other, non-medical reasons. It is also important to recognise that patients with certain chronic medical conditions will naturally need to consult HCPs more frequently. Simply attempting to reduce frequency of attendance may be detrimental to those patients who may legitimately need to consult frequently. Few studies on frequency of attendance do differentiate between valid and invalid frequent attendance or consider the issue in the context of other health services, the exception to this being Neal et al. (2001).

Changing Patient's Consultation Behaviour and Health Service Usage

Intervention studies aimed at altering consultation rates and patterns of patients' consultations in primary care have been conducted, some specifically with general

practitioners and some involving other primary HCPs. These included exercise (Peters, Stanley, Rose, Kaney and Salmon, 2002) the summarising of patient's notes (Jiwa, 2000), and patient education (Little, Somerville, Williamson, Warner, Moore, Wiles, George, Smith and Peveler, 2001). Studies have also assessed the impact of a variety of innovations in primary health care. These include Hassell, Noyce, Rogers, Harris and Wilkinson (1997) assessment of the introduction of community pharmacists on patterns and rates of consultations with GPs and Munro, Sampson and Nicholl's (2005) study of the effect of the introduction of NHS Direct on demand for out-of-hours GP care and A&E usage.

Exercise was used by Peters, Stanley, Rose, Kaney and Salmon (2002) as an intervention to reduce frequent attendance amongst patients with MUPS. When these patients undertook regular exercise, the number of consultations they made over a six month period was significantly reduced. Peters et al. found that the nature of the exercise (aerobic verses non-aerobic) was not significant but the extent of reduction in the use of primary care services was related to the attendance at the exercise sessions rather than the nature of the sessions themselves. Participants stayed within their exercise groups for the duration of the study but the function of social support was not examined. It would appear that social support was a critical factor. Again, this study was limited to considering consultation behaviour with the general practitioner only.

The use of information leaflets about the treatment of minor illnesses was shown by Little, Somerville, Williamson, Warner, Moore, Wiles, George, Smith and Peveler (2001) to have a modest effect on the rate of consultations for these conditions but they were seen to be helpful by the patients. Little et al's intervention was, like Peters et al.'s intervention, directed at patients with a specific condition or symptoms.

Hassell et al. (1997) examined the role of the community pharmacist as a source of advice for minor ailments and whether or not to consult a GP. Considering the relationship between GPs and community pharmacists (CPs), Hassell et al. found that CPs often give patients 'legitimacy' when seeking advice about whether or not to consult a GP. Pharmacists would support patients' attempts to self-treat and would also advise patients about consulting a GP when there was uncertainty. Their study focused on patients who utilised the services of the CP and did not attempt to assess the attitudes of patients who were not regular users of the service. Hassell et al.'s study illustrates the potentially important role of the CP in helping patients to make

effective decisions about consultations with HCPs. Whether CPs affected frequency of attendance with GPs was not investigated.

The effects of the use of outpatient pharmacies (community pharmacies) on primary care service utilisation were examined by reviewing literature by Beney, Bero and Bond et al. (2000). They found that, in general, when pharmacists targeted their services at patients, patient use of non-scheduled health services and visits to the GP decreased. They also found that patient outcomes improved but patient quality of life did not seem to be affected. Both Hassell et al. and Beney et al. implicitly acknowledge the interrelationship between patients' consultation behaviour, their general practitioners and other HCPs, in this case, community pharmacists.

Research into another innovation by Myers, Lenci, and Sheldon (1997) investigated the suitability of nurse practitioners as the first point of call for urgent medical conditions. They found that patients who were offered the opportunity to consult with a nurse practitioner as an alternative to a GP were less likely to return for a repeat consultation within 14 days than were patients who chose to consult with a GP. They also found that the morbidity of the patients choosing to see the nurse practitioner mostly related to upper respiratory tract infections (one of the commonest reasons for infants under 4 to consult a GP). Patients in the study were free to choose whether they saw a nurse practitioner or a doctor. This element of patient choice may have been influenced by factors such as waiting times or patients' perceptions of who was the most appropriate professional to consult (Myers et al., 1997). While the introduction of a nurse practitioner had an effect on consultation behaviour, it was effective only in that it provided an additional layer of choice. It would appear that choosing a nurse practitioner over a GP influenced a patient's consultation behaviour by reducing the number of subsequent consultations made over the following 14 days. Whether this means that a nurse practitioner is more effective than a GP or whether patients are less inclined to make subsequent consultations when faced with the prospect of consulting a nurse practitioner again is unclear.

These studies show that there are effective methods for reducing primary care consultations and that these methods vary widely. It is likely that interventions aimed at making patients' day-to-day help and consultation-seeking decisions more effective can be developed. Directing these interventions to the patient rather than on specific health services may improve help and consultation-seeking behaviour with the full spectrum of self referral services.

In summary, the literature shows that consultation rates in general have increased over recent years (Rowlands and Moser, 2002) whilst Department of Health targets require primary health care services to become increasingly more efficient (George and Rubin, 2003). While primary HCPs can go some way to improving the efficiency of the service they provide, the literature makes it clear that patient consultation behaviour in the form of frequent attendance (Little et al., 2001; Howe et al., 2001 for example) and non-attendance (George and Rubin, 2003) puts strain on finite resources. Work has been done in an attempt to identify high service users (Little et al., 2001; Bruijnzeels, Foets, van der Wouden, van den Heuvel and Prins, 1998), frequent attenders and patterns of attendance (Howe et al. 2002, Baker et al., 2002; Ellaway et al., 1999). Studies investigating a variety of means to reduce frequency of attendance in certain groups have also been carried out with varying degrees of success (Jiwa, 2000; Peters et al., 2002; Beney et al., 2000; Hassell et al., 1997; Myers et al., 1997). Psychological factors affecting consultation behaviour have been identified.

Conclusion

The way in which help-seeking behaviour has been studied has been influenced by changes in the predominance of different conceptual frameworks from the biomedical model to the biopsychosocial model. This has been reflected in changes in the perception of the doctor-patient relationship. Different models of health behaviour have been formulated as psychological theories have been developed. These health behaviour models have been shown to be useful in predicting the behaviour of an individual aimed at maintaining or aspiring to a state of health. The models have, to a lesser extent, been useful in describing and predicting patients' behaviour once they have been diagnosed with a chronic health problem. A vast array of factors affecting the way we make our decisions about seeking medical help have been identified and work in this area continues. However, investigating the interaction of these factors, especially modelling them, in an attempt to predict help-seeking behaviour has proved to be difficult.

Research to date has considered the behaviour of individuals who wish to avoid illness and their behaviour once they have been diagnosed with a health problem. However, the actions of individuals upon first experiencing symptoms and their subsequent decision making behaviour has not been studied. Described in terms

that Hannay (1979) might recognise, behaviour in the iceberg below and above the iceberg has been studied but decisions associated with movement between the two have not. Frequent attender research suggests that a cohort of patients attends more frequently than others. Other research has shown that socially vulnerable groups use health services less frequently than the general population. What is not known, however, is whether patients who do not attend frequently make potentially unnecessary consultations when they do consult. Conversely, we do not know the extent to which people who do not fall into the socially vulnerable categories under-use health services. While Neal et al. (2001) examined whether frequent attenders at GP surgeries were also frequent attenders with other health services, we do not know whether the help-seeking behaviour for non frequent attenders is reflected across all service spectrums. In an editorial, Neal (1996) suggests that, 'In time, useful, non-pharmacological interventions may be developed to modify the behaviour of both patients and doctors' (Neal, 1996, p131). This may include the manipulation of some of the underlying psychological variables that influence patient consultation behaviour.

The demand for and delivery of health care is subject to constant monitoring by health policy makers and results in innovations in service delivery such as the introduction of NHS Direct. Changes in the way health services are delivered means that patients' help-seeking behaviour needs to adapt to changing situations. That is not to say that patient behaviour changes as a consequence of service delivery changes. Indeed, service providers and policy makers adapt delivery mechanisms and systems in response to changing patient demands as a consequence of, for example, changing population demographics. Service providers and policy makers will also need to consider the nature and supply of health care resources. For example, the number of doctors and nurses available may change causing health service managers to change doctors and nurses working patterns. The new GP contract may be an example of such a response.

While the advantages of health care system that adapts and changes in response to demand for health care are obvious, patients will, as a consequence, have to adapt their help-seeking behaviour. Modelling and constructing patterns in the patients' responses to such constant change is difficult for the researcher. No sooner has a pattern emerged than changes in health care systems make the model or identified pattern obsolete. The Wanless Report (Wanless, 2004) sought to examine

future demand for health care in the UK and recommended changes in the structure of the health service. Wanless acknowledged that funding for a quality health service is finite and providing a quality health service necessitates careful use of resources by health care providers and users alike but he went on to call for greater patient choice. Increasing patient choice (which will necessitate adaptations in patients' help-seeking behaviour) may not be conducive to careful use of health services by patients unless they are better prepared to make effective choices within the limited resources.

Conclusion

This review of literature has highlighted a lack of understanding about how patients cross from the submerged part of Hannay's iceberg to that part which is above the water-line. Objective investigations of ineffective help-seeking decisions require useful definitional parameters if the scale of the issue is to be determined. The experience of individuals who make day-to-day help seeking decisions is also poorly understood as is the extent to which health service users can be empowered to make more effective help-seeking decisions. The breadth of the consequences, to the health service and patients alike, of an improved understanding of these issues needs to be highlighted.

The multidimensional and diverse nature of the components of decisions about help-seeking requires the use of both qualitative and quantitative methods of inquiry. In the existing literature there is a lack of clarity about how ineffective help-seeking decisions can be defined and no obvious agreement (other than anecdotally) that there is an issue to be investigated.

The first task, therefore, in this research was to seek pertinent definitional parameters of effective help-seeking behaviour from the perspective of healthcare professionals. Given the absence of a theoretical or research framework for this investigation, a qualitative methodology was chosen to gather richer data than would be possible with a quantitative approach. Following the identification of definitional parameters the size of the issue was measurable using quantitative surveys of effective and ineffective help-seeking decisions. Research methods in this thesis were chosen to meet the different needs within each separate study and are inevitably a mixture of qualitative and quantitative.

Mixed methods approaches are designed for just such situations. Creswell describes the foundation of mixed methods research on the pragmatic school of philosophy (Creswell, 2009). This philosophical stance takes the 'problem' (in this case, the issue of the effectiveness of day-to-day help-seeking decisions) as the central part of the research process itself. Unlike the postpositivist philosophical stance where quantitative research tests a null hypothesis in an attempt to identify probable causes of outcomes or effects, the pragmatic stance considers the nature of a problem to determine the most appropriate method of inquiry.

In this thesis, the factors underlying help-seeking decisions in a health context were identified using qualitative methods. There were well-established ways of measuring these which are supported by theory, allowing a quantitative approach to be taken. The pragmatic approach allows the researcher to consider the nature of a problem or issue and apply different research methods appropriately to the different aspects of the investigations, as is the case here. Mixed methods research uses a variety of different research methods, both qualitative and quantitative to investigate an issue or problem with a view to finding or testing solutions to that problem (Creswell, 2009).

Applied to the issues under investigation in this thesis, a sequential mixed methods approach featuring a qualitative, semi-structured interview study enabled the parameters of the problem of ineffective help-seeking decisions to be identified. An exploration of the opinions of individuals (in this case, HCPs) could have been made using questionnaires but the generally closed nature of the questionnaires would have necessarily limited the respondents to a pre-determined set of answers. Given the lack of existing research relating to the issues being investigated here, it was appropriate that the initial research methods allowed the diverse and unknown views of a variety of respondents to be gathered. Semi structured interviews facilitated this endeavour and avoided the constraint of questionnaires. As such, useful and objective definitional parameters of effective and ineffective help-seeking behaviour were developed.

Although respondents in the first study indicated their perceptions of the scale of the issue of ineffectively made help-seeking decisions, an objective assessment of the issue's scale was necessary. A quantitative survey of GPs was conducted based upon the objective definitional parameters established in the first qualitative study. The quantitative methods employed in the second study enabled a larger sample of HCPs to be surveyed than would be possible using a qualitative approach. The quantitative survey based on findings from the previous study was more objective than any qualitative approach which would inevitably be limited by subjectivity

Having established definitional parameters and the scale of the issue of ineffectively made help-seeking decisions, it was necessary to identify the factors that underpin HSUs' help-seeking decisions. Gathering the views of HSUs and understanding their help-seeking experiences did not lend itself to quantitative methods. Given the lack of previous research evidence that might have provided

insights into HSUs decision-making processes and the absence of valid measurement tools a qualitative semi-structured interview approach was adopted because it actively sought the richness of the subjective experiences of individual HSUs. This would have difficult to using quantitative techniques such as questionnaire surveys.

Findings from these three studies, in conjunction with information gleaned from an examination of relevant theoretical perspectives, enabled the design of a qualitative study that tested the manipulability of an array of variables. Hypotheses were proposed and tested using quantitative methods in the context of a controlled trial.

This sequential mixed methods approach enabled the findings from one study, be it qualitative or quantitative, to inform the nature of subsequent studies. Ultimately, the mixing of methods through these four studies revealed findings that can be used to suggest solutions to the real and potentially large scale issue of ineffectively made help-seeking decisions following in the pragmatic philosophical tradition. Consequently, a much richer data set was obtained than would have been the case if a purely qualitative or purely quantitative approach was taken. Limited resources mean these studies necessarily focus on specific health services (mainly GPs) and specific HSUs. Despite this, these studies have been designed with generalisability across HSUs and services in mind.

Chapter 2

Study 1:

Consultation-seeking behaviour amongst self-referring patients: views of healthcare professionals

2.1

The previous chapter explored the literature that is concerned with the way in which patients make decisions about seeking health-related help. This literature search established that little is known about day-to-day help seeking decisions and what constitutes an effective or an ineffective decision. Given this lack of previous research and, indeed, a lack of clarity about how professionals perceived or might differentiate effective and ineffective decisions, a qualitative approach to data collection was chosen to explore ways in which help-seeking behaviour was described by healthcare professionals (HCPs). Definitional parameters of patients' effective and ineffective help-seeking behaviour were developed using a semi-structured interview method. This enabled respondents to explore the parameters of the effectiveness of help-seeking decisions without the constraints that would have been imposed by the use of quantitative approaches.

Introduction

Previous research indicates that multiple factors influence patients' decisions to seek a consultation with an HCP. These factors often interact in complex ways that make modelling the process of seeking a consultation very difficult. Diefenbach and Leventhal (1996, p.12) point out that; "it is easy for the researcher to become overwhelmed by the number of potential factors that might influence health-related evaluations and decisions". The very complexity associated with patient consultation decision making processes has limited research in this area. In a review of literature, Hallam (1994) found no criteria for judging the 'appropriateness' or 'inappropriateness' of patients' decisions to seek consultations in accident and emergency departments. To date, no such criteria have been identified. This paper seeks to address this problem through the examination of the quality of patients' consultation-seeking decisions while acknowledging the complexity of multiple antecedent factors. The quality of those decisions are explored by examining the views of a range of HCPs who regularly encounter this issue. A subsequent study explores the views of health service users (HSUs). From this study, HCP's definitions of effective and ineffective help-seeking decisions are developed.

Interest in health and health behaviour gained momentum during the middle of the last century with Parsons' (1951) paternalistic definition of the 'sick role'. In this the rights and responsibilities of the patient and the physician are set out. Since Parsons' definition of the sick-role, interest in issues associated with health and health

behaviour has grown steadily resulting in the development of disciplines such as medical sociology and health psychology.

Blaxter (1990) discusses several definitions of health. One of her definitions; "Health can be defined negatively, as the absence of illness, functionally, as the ability to cope with everyday activities, or positively, as fitness and well being" (Blaxter, 1990, p.14) sees health as a continuum. A continuum between health and illness implies that an individual's position on that continuum is dynamic and is affected by a variety of factors. This definition describes the *effect* of health or its absence on the individual. It does not attempt to describe the interaction of this complex range of factors that affect health and influence consultation-seeking decisions. Blaxter (1990. p.21) illustrates the bio-medical model which evolved during the nineteenth century by describing a state of health as being "not ill". Describing health as the absence of disease is simplistic and sees the individual as a biological machine maintained and repaired by medical 'mechanics'. In this context, responsibility for health rests paternalistically with the physician. The shortcomings of the bio-medical model of health led to the development of the bio-psycho-social model (Engel, 1977) which saw health in a social context, with social and cultural factors mediating chronic modern diseases and, by extension, consultation-seeking behaviour. The bio-psycho-social model gave rise to the notion of illness behaviour and this led to the identification of numerous factors that influence a patient's decision about seeking a consultation. These factors include amongst others: Sociological, cultural and economic circumstances; perception of and attitude towards symptoms; access to healthcare services; and previous experience of the use of those services. A patient's perception of a symptom refers to a patient's understanding of the symptom. For example, symptoms of heart disease may be interpreted as such by the patient, but equally, those symptoms may be interpreted as indigestion by other patients. Another example is that of a cough. Some patients may interpret a cough as a symptom of a cold whereas others may perceive a cough to be a symptom of lung cancer. A situational response towards a symptom refers to the way in which a patient responds to their perception of a symptom. For example, a patient's response towards a cough maybe to seek relief for the symptoms of a common cold but the same symptom may be perceived as something more serious by another patient (or indeed at a different time for the same patient) after witnessing a friend or relative suffer from lung cancer and engender a formal help-seeking response. Modelling has

been used to illustrate the relationship between some of these factors and an individual's help-seeking behaviour (for example, Kasl and Cobb, 1966) but as Tuckett (1976) points out, these 'models' are of limited utility because of the complexity and wide array of factors that the models attempt to incorporate. Diefenbach and Leventhal (1996, p.12) suggest that they should be seen as lists of factors that will have a differential effect on individuals' illness behaviour. Whilst factors associated with individual differences include fear and anxiety of medical situations and diseases and the experience of disease and subsequent treatment, there are also factors associated with the social context of the patient.

A major factor affecting patients' consultation-seeking behaviour appears to be the increasing complexity of the self-referral healthcare services. For example, the expanding use of community pharmacists (Hassell, Noyce, Rogers, Harris and Wilkinson, 1997; Beney, Bero and Bond, 2000), the introduction of NHS Direct (Chapman, Smith, Warburton, Mayon-White and Fleming, 2002) the new general practitioners' (GP) Out-of-hours services and the introduction of nurse practitioners (Myers, Lenci and Sheldon, 1997; Kinnersley, Anderson, Parry, Clement, Archard, Turton, et al., 2000) are recently introduced options from which patients may choose. Patient confusion, as a consequence of the rapid expansion of available choices, must now be seen as another decision-influencing factor, as must gaps in patients' knowledge, (Scott, Grunfeld, Main and McGurk, 2006), social and economic marginalisation (Baker, Mead and Campbell, 2002) and psychological factors such as fear (De Nooijer, Lechner, and de Vries, 2001), patient anxiety and depression (Ronalds, Kapur, Stone, Webb, Tomenson and Creed, 2002). Corner, Hopkinson and Roffe (2006) found that gaps in patients' knowledge leading to uncertainty about the normality of symptoms led to delays in seeking help for symptoms of lung cancer and Galdas, Cheater and Marshall (2004) found that men are more likely to delay help-seeking than women. This wide array of factors and the interactions between them, create a multidimensional influence on the effectiveness with which patients target their self-referral consultations.

Several studies have considered the phenomenon of frequent attendance by patients (Ellaway, Wood, and MacIntyre, 1999; Howe, Parry, Pickvance and Hockley, 2002; Little, Somerville, Williamson, Moore, Wiles, George, Smith and Peveler, 2001; Neal, Heywood and Morley, 2000; Neal, Wickenden, Cottrell, Clarkson and Bearpark, 2001) and some studies have investigated ways in which patient

consultation behaviour with a GP can be affected (Beney, Bero and Bond, 2000; Hassell, Noyce, Rogers, Harris, and Wilkinson, 1997; Jiwa, 2000; Peters, Stanley, Rose, Kaney, and Salmon, 2002). These studies have identified patient groups that are most likely to attend frequently and have described the nature of that attendance including the frequency of the visits. Research into the phenomenon of frequent attendance necessarily focuses on small cohorts of patients, i.e. those who are frequent service users. In contrast, the nature of this research does not differentiate between groups in self-referral situations and therefore provides a broader picture of the issue.

If it is possible to assess the quality (i.e. the effectiveness) of patients' decisions after they have been made, the antecedent factors that most affected the quality of that decision can be identified. Despite its potential significance with regard to poor patient outcome and the drain on healthcare resources, an agreed definition of what constitutes effective self-referral behaviour by patients has not emerged from the literature. The research into frequent attendance has investigated one consequence of patients' ineffective help-seeking decisions. This body of research illustrates the significance of the *quality* of patients' decision making behaviour.

In this study the views of HCPs who deal with the consequences of the quality of patients' consultation-seeking decisions were gathered and agreed parameters of effective patient consultation targeting behaviour defined. HCPs have been chosen as the participant population for this study because they are best placed to judge where their skills can be most effectively employed. They can also offer an opinion, from the professional's perspective, about the extent to which a patient's consultation decision is likely to achieve the optimum outcome. By considering the quality of help-seeking decisions made by patients from the HCPs' perspectives, and developing definitional parameters for the quality of those decisions, it is felt that identification of causal factors for different aspects of poor quality decisions may be identified in future research. Given the present strain on the healthcare services in the UK, being able to address causal factors of poor quality consultation decisions might lead to a better use of limited resources in the future.

Method

Design

A semi-structured interview approach was used to obtain HCPs' views and opinions about the nature of decisions patients make when seeking consultations with HCPs in self-referral situations. Semi-structured interviews were used as the 'open' nature of this method of inquiry would yield richer data than alternative methods such as questionnaires which were felt to be more restrictive and 'closed'. It was also important for participants to have the opportunity to explore and discuss ideas as they emerged during the data gathering process. Semi-structured interviews made this possible. Interview guides were developed during informal discussion with a number of GPs who were not participants. These discussions led to a basic interview guide that evolved during the process of data collection as participants raised interesting ideas or notions. This enabled those ideas to be explored with subsequent participants. During these informal discussions, simple hypothetical consultation scenarios were also developed which were broadly based upon GPs' actual experiences and these were used during interviews. Interviews were transcribed and returned to participants who were asked to check there accuracy and add other ideas if they wished. Participants were later invited to attend group meetings where themes that had been extracted from transcripts by the researcher were presented. Participants then discussed and expanded upon these themes.

Participants and setting

The lead researcher invited a variety of HCPs to participate in the study. None of those approached declined the invitation to participate. As such, a purposive sample of 13 participants was drawn from a North Wales primary care general practice (n=4, 2 male and 2 female GPs), a North Wales Accident and Emergency department (n=3, 1 male and 2 female doctors), NHS Direct (n=3, 2 male and 1 female nurses) and out-of-hours general practitioners (n=3 all female). Range of time in service was as follows: GPs 1-16 years (mean=10.5 SD=0.57), Out-of-hours GPs 6-7 years (mean=6.3 SD=0.57), Accident and Emergency doctors 1-20 years (mean=11.6 SD=9.71), NHS Direct nurses 1.5-5 (mean=2.83 SD=1.89). Ethical approval for the study was obtained from the North West Wales Local Research Ethics Committee. All participants gave informed consent.

Interviews

A series of semi-structured interviews with individual HCPs was conducted in order to obtain their views concerning the perceived reasons for, and the consequences of, patients' consultation-seeking decisions. Firstly, the language and terms used to describe this behaviour was explored. As themes emerged within each interview, the concept of consultation targeting was introduced. Hypothetical consultation scenarios were described and used to derive definitional parameters of an effectively 'targeted' consultation and different manifestations of 'mistargeted' consultations (see Appendix 1 for interview discussion points).

Analysis

Each semi-structured interview was recorded and transcribed and a copy returned to the interviewee for comment or amendment. Eight transcripts were returned; seven were unchanged. One participant corrected minor transcription errors and clarified one point. Based upon Ritchie & Spencer (1994) Framework Analysis, the content of each was then analysed and emergent themes and categories were identified. These were verified through independent analysis by a second researcher.

Ritchie & Spencer (1994) describe Framework Analysis as a "systematic process of sifting, charting and sorting material according to key issues and themes" (Ritchie and Spencer, 1994 p. 177). The five stages of the process of analysis of qualitative data are: familiarisation; identification of a thematic framework; indexing; charting; and mapping and interpretation. The first stage of familiarisation is achieved through actively gathering data (conducting interviews, for example) and reading and re-reading transcripts and developing a familiarity with the material. The second stage involves the identification of key issues or thematic threads usually from notes made during the process of familiarisation. Indexing material is the third stage and involves placing index references on the actual transcript or text so that the indexed material can be 'lifted' from the original source and arranged and sorted (stage five) according to the thematic threads identified in the second stage of the process. The sorted and charted data are then ready for the final stage of interpretation whereby themes and threads are organised to build an overall picture of the data sets.

The themes and categories were summarised by the researcher and a copy of the overall summary was given to each participant. Group meetings of participants,

using the summary as a stimulus for discussion, were used to validate and expand interpretations of the findings from the individual interviews. While the groups were assembled to discuss the themes extracted from interview transcripts, the groups were not typical 'focus groups' in that their purpose was not the primary generation of data. Rather their purpose was to expand data which had previously been generated by individuals. The role of the lead researcher was to present the themes extracted from transcripts for discussion. Whilst debate was encouraged, the researcher's role was primarily to clarify and expand the data rather than to draw out individual differences or to challenge participants which is the typical role of focus group facilitators (Gibbs, 1997).

Results

Aspects of the definition of well targeted and mistargeted consultations

When questioned, 10 participants agreed that the terms 'appropriate' and 'inappropriate' when used by HCPs to describe patient consultations were subjective in nature. Five participants thought that 'patient consultation targeting' was a better concept than that of the 'appropriate' or 'inappropriate' consultation and one participant noted that the term should be acceptable to both patients and HCPs. Four respondents questioned from whose perspective the term was being used. In group discussions the subjectivity and changeable nature (between individuals and over time) of the term 'inappropriate' was discussed.

> *"I think targeting would be better because appropriateness will mean different things to different people" (A&E doctor; I).*

> *"I suppose 'appropriate' is just how I feel when I am there, and targeting is more what they [the patients] have actually done to get there" (Out-of-hours GP; G).*

> *"Appropriate and inappropriate implies some sort of judgement by the healthcare worker and in all these scenarios, indeed it's not that the patient is seeking help, necessarily inappropriately but they are seeking help perhaps at the wrong time, to the wrong place to the wrong person.... I think it's a better term. It doesn't imply a sort of judgement on the patient's decision making" (A&E doctor; J)*

"You need a word for it because if you told someone he'd come to an inappropriate place- its not rude but you don't want to send somebody off so maybe they don't access anybody" (NHS Direct nurse; M).

Six elements of an effectively targeted consultation were offered. These elements were: the HCP best suited to the patient's needs should be consulted; the consultation should make the most efficient use of the HCP's skills; the consultation should be made at the optimum time; the consultation should be made in the optimum place; the patient should have a genuine need; and the patient should be treated or advised.

Five participants considered that the choice of a HCP most appropriate for the patient's needs was important and four thought that the most efficient use of the HCP's skills was important. For example, both a practice nurse and a GP may be able to dress a minor wound, but the GP's skills may be more efficiently applied to diagnostic activities. Three respondents considered the timing of the consultation to be important. Group discussions revealed that HCPs think 'time' should be thought of in terms of a flexible bracket rather than a rigid point. Two respondents considered that a patient should have an unmet need that is best addressed in a healthcare environment for the consultation to be effectively targeted.

Two HCPs thought that the patient should be treated rather than simply being advised. One respondent considered cost effectiveness important. Group discussion revealed that the place of consultation was important, for example home consultations are not made in a sterile environment. In discussions, A&E doctors also revealed that they rarely refer patients back to their GP for initial treatment but treat them directly in A&E despite guidelines from the British Association for Emergency Medicine to refer these patients back.

Types of mistargeted consultations

11 of the 13 HCPs interviewed considered that consultations made by patients with the wrong HCP were a significant issue. 10 considered that a consultation made at the wrong time, either too early or too late, was also important. Some consultations were considered potentially avoidable by seven respondents and five cited patients making consultations in an emergency time slot rather than in a normal appointment slot as a problem.

"Young mums come in and ask me what they should be doing about feeding their child- I mean I have no clue. Go and talk to the health visitor, they'd know exactly what to tell you, that's what they do" (General practitioner; C).

"If you have got an asthma problem, and somebody has left things really late like they have got a chest infection which has been brewing for days then its more effective in the short term if they come along" (Out-of-hours GP; E).

"I think not seeking any attention from anybody is always a bit dodgy, but I suppose some people prefer to wait and see" (A&E doctor; H).

"A lot of what see you could reasonably argue would be self-limiting, non-threatening presentations which if they left it for a while wouldn't need to be seen at all" (General practitioner; A).

"It's a reasonable consultation; it's just defining it as an emergency is completely- that's not appropriate" (General practitioner; D).

Healthcare professionals' perceptions of the scale of mistargeted consultations

All participants were asked to estimate the difference that the removal of mistargeted consultations would make to their daily workload. All but one offered a response (see Table 1).

Low	*Medium*	*High*	
-	1	3	Daytime general practitioners
-	-	3	Out-of-hours general practitioners
2	-	1	Accident and Emergency doctors
-	-	2	NHS Direct nurses

Table 1: Healthcare professionals' perception of the scale of mistargeted consultations

Causes of mistargeted consultations

HCPs offered numerous explanations for mistargeted consultation-seeking decisions. This is an area that has been extensively explored in the literature and continues to be so. However, some of the perceived causes of mistargeted consultations-seeking decisions by patients offered by the respondents were noteworthy. They considered the healthcare system itself and their own professional behaviour to be causal factors. The healthcare system as a cause of mistargeting was highlighted by 10 of the 13 participants. The target-driven nature of the primary care system, the lack of access to antibiotics over the pharmacy counter and the structure of the healthcare system itself were all considered by HCPs to be healthcare system related causal factors in patients' mistargeted consultation-seeking decisions. The changing nature of access to the healthcare system, namely the change in GPs' contracts and out-of-hours provision mistargeting is now rarely experienced by out-of-hours GPs but there is a perception that some of this mistargeting has now moved to daytime work.

> *An out-of-hours GP (one of the three respondents who did not mention the healthcare system as a cause of patient mistargeted consultations) who worked in a highly triaged system noted: "...there's a much better tailoring-up of patients' needs and doctors' availability..."*

But,

> *"... there are several places of healthcare advice which are all appropriate from minor injuries to minor complaints to urgent minor complaints, things like acutely painful conditions; gout. You can seek help appropriately in several places. So there is an enormous overlap..." (A&E doctor; J).*

HCPs acknowledged that they have a causal role in ineffective consultation-seeking behaviour. Reinforcement of ineffective consultation behaviour by HCPs was mentioned by four respondents. Patients and HCPs reinforcing each other's behaviour was also mentioned.

> *"... we're at fault here as well, and that's because we've tended to prescribe, and therefore people think, 'Oh I've got a problem, therefore I must go and see the doctor in order to get something'." (General practitioner; A).*

"...that's partly our fault because we over prescribe so that encourages people, or we expect that people want a prescription but often they may not want a prescription, they just want justification for their day off work..." (Out-of-hours GP; E).

Healthcare professionals' affective responses

Some HCPs communicated their affective responses to mistargeted consultations. Five HCPs mentioned that they felt under pressure from various sources and four mentioned the negative emotional response that patient demands engendered in them.

"...it's actually much harder to try to convince people that they don't need things than it is to just- you know –fine have it and take it away. And often when it's very busy or when you're pressured, the sort of patient you know you don't want to spend too much time with and you're turfing them out really" (A&E doctor; H).

"You know, that's something that drives me mad here because of the people who come for your opinion, and then they'll say, 'but I've been looking it up on the-, or I've been reading about it on the internet', and they'll come up with a whole lot of different ideas. It can be quite intimidating really, sometimes" (A&E doctor; I).

"I'm completely powerless, and can't actually sort out their problems, or because I feel that I'm, you know, being thought of as – I suppose a little bit it's because you feel a little bit – it kind of engenders a kind of emotion in a GP when a patient says I can't get to see a dentist. 'Yes, but you've got a dental problem', and – 'you can give me antibiotics' and – and it kind of makes you feel a bit worthless that's what it is" (General practitioner; C).

Outcomes and potential solutions to mistargeted consultations

Two consequences of mistargeted consultations emerged. Two respondents cited poorer patient outcome and one cited poor use of resources. This was reiterated in discussions involving GPs. In further discussions, NHS Direct nurses expressed a general feeling of wasted resources within the NHS. Respondents mentioned four

benefits of mistargeted consultations as providing an opportunity for HCPs' development. A doctor's skills at identifying patients with significant needs has to be practiced; providing a safeguard for patients via an opportunity for a second opinion; identifying problems that might otherwise be missed. Group discussions highlighted that GPs are currently trained to be opportunistic in their diagnostic work.

> *"In general practice you become skilled at spotting the sick ones, so if you get rid of one level- you know the sort of 'knockers on the door', you're actually going to become deskilled at spotting things" (General practitioner; B).*

> *"The second opinion stuff, you know you get a lot of it and I guess to some extent it's nice to have a- almost a safety net" (A&E doctor; H).*

> *"Certainly, we are bringing more people into the practice who probably wouldn't be necessarily be seen by the doctor. And in a lot of circumstances that's great because we pick up on new things..." (General practitioner; C).*

Two solutions to mistargeted consultations were proposed. Five respondents suggested patient education and three suggested an additional layer of triage. One HCP considered that resolving the issue of mistargeted consultations would lead to harder consultations as the simpler, mistargeted consultations are redirected.

Discussion

Summary of Findings

There was general agreement that the terms 'appropriate' and 'inappropriate' were subjective in nature whilst the terms 'effectively targeted' or 'mistargeted' were more objective and therefore more useful in enabling investigation of the phenomenon. Three basic categories of mistargeted consultations emerged: Patients do not choose the best HCP for their needs; patients consult either too early, too late or in the wrong appointment slot; patients make potentially avoidable consultations. The main causes of mistargeted consultations identified by HCPs were the structure and nature of the healthcare system, patients' symptoms and unmet needs, patients' abuse of the

healthcare system, patients' social circumstances, patients' response to illness, gaps in patients' knowledge, and the behaviour of HCPs themselves.

In group discussions HSUs commented that the healthcare system caused some mistargeting. In particular the procedure for patients acquiring a sick note for an employer was mentioned. For self-limiting conditions and conditions that can be self-treated, both the patient and the GP may recognise that a consultation is not medically necessary for treatment of the condition but the employer's demand for a sick note requires that a potentially avoidable consultation is made. The healthcare system's array of available services to patients was highlighted by HCPs as another potential cause of confusion and mistargeting.

HCPs discussed the consequences to themselves of mistargeted consultations. Additional pressure of work and feelings of helplessness caused by mistargeted consultations were highlighted as issues. While acknowledging these feelings, one GP described how mistargeted consultations can prevent 'de-skilling' because mistargeted consultations ensure that the HCP is continually watching for potentially serious conditions that are far less frequent than day-to-day conditions.

Better patient education was suggested as a potential solution to mistargeted consultations. This seems to contradict the sentiments of A&E doctor 'I' who found seemingly well informed patients intimidating. This suggests that the nature of patient education is important. While a patient who is well informed about a specific symptom or disease process may be described as 'educated', it does not necessarily follow that being well informed necessarily helps patients make more effective help-seeking decisions.

The problem of the subjective nature of the terms 'appropriate' and 'inappropriate' was identified by the participants. The subjective nature of these terms necessarily limits their usefulness when investigating and describing the quality of patients' consultation-seeking decisions. The definitional parameters developed here are more objective than the terms used traditionally by HCPs. As such, they can provide a framework for future research in this area. Whilst they are intended to be objective, the use of these terms to judge patients' help-seeking decisions is likely involve an element of subjectivity.

Strengths and limitations of the study

This study explored a variety of HCPs' views about the behaviour of all patients who self-refer rather than the behaviour of a specific cohort of patients. The study also derived definitional parameters for that behaviour which will form the framework for future research. Participants were HCPs drawn from the same geographical area (Bangor and the surrounding district) and were therefore familiar with the same patient population and from a range of services from which the patient can self-refer. Data from semi-structured interviews was validated individually by participants and again through group discussions. Both steps in the process allowed richer data to be gathered. However, no attempt to quantitatively measure the scale of the phenomenon has been made and the issue was considered from the HCPs' perspective only. This could be criticised as taking a paternalistic approach. HCPs make difficult judgments about patients daily. They are therefore considered to be best placed to judge the outcomes and consequences of patients' help-seeking decisions and therefore the quality of those decisions. A small number of HCPs were interviewed in depth and data collection was intensive and involved two layers of participant validation of findings. The HCPs interviewed here were from a variety of settings and represented some of the services to which patients are most likely to self refer.

To date, research into consultation-seeking behaviour has focused on areas such as the frequency with which patients consult, particularly with GPs (Howe et al., 2002; Little et al., 2001; Neal et al., 2000; Neal et al., 2001; Ellaway et al., 1999; Ronalds et al., 2002). It has considered who frequent attenders are and why they behave in the way they do. These studies provide a valuable insight into one aspect of patients' behaviour but they are limited in scope in that they only consider the quality of decisions made by a small cohort of patients. This study offers a way of describing and investigating the relationship between patient consultation behaviour in different but necessarily related self-referral situations and is not limited to those patients who only attend frequently in general practice.

Changing terminology in a medical setting is not new. Compliance with 'doctors orders' was seen as paternalistic and HCPs were encouraged to use the term 'concordance' in its place because it was seen as denoting a partnership between the doctor and patient (Bissell, 2003; Horne and Weinman, 1999). This study has explored the acceptability among HCPs of the term 'targeting' to describe the effectiveness of patients' decisions to seek consultations. The use of this term which

is considered by HCPs to be practical, acceptable and objective should replace terms such as 'appropriate' or 'inappropriate' enabling the evaluation of patients' decisions to seek consultations.

Conclusions and future research

It is suggested that the effectiveness with which patients targeted their consultations as described here can facilitate a focused, objective and scientific discussion, and exploration of consultation-seeking behaviour, its forms and its consequences. It will allow specific aspects of patient behaviour to be studied in depth (for example the way in which patient consultation behaviour is influenced by the supply of and demand for antibiotics) and interventions to be designed. The concept of consultation targeting effectiveness allows the researcher to ask why a consultation was made in such a way without attributing blame or error to the patient.

The scale of mistargeted consultations and how patients' behaviour varies in different healthcare settings is yet to be investigated but, from the perspective of HCPs interviewed for this study, the perception that there is a high incidence of mistargeted consultations is a significant issue which cannot be ignored. It is clear that mistargeted consultations adversely affect both patient outcomes and the efficient use of scarce healthcare resources and, as such, are worthy of further investigation.

Patients' consultation targeting effectiveness needs to be understood from the patient's perspective. The acceptability of the term to patients needs to be assessed and compared with the acceptability of terms traditionally used to describe patients' consultation behaviour. Research centred on patients is needed to investigate why they consult in the way they do and how different and changing circumstances affect patients' behaviour. Beyond this, it is necessary to understand if it is possible to intervene to improve the effectiveness with which patients' target their consultations.

Chapter 3

Study 2:

The measurement of patients' ineffective consultation-seeking decisions with general practitioners

3.1

Chapter 2 reported a qualitative study that developed definitional parameters of patients' effective and ineffective help-seeking behaviour. The following chapter reports a quantitative study that used these definitional parameters as the basis for measuring the scale of ineffectively made self-referral help-seeking decisions by patients in the primary care sector. An objective measurement of the scale of this issue involved the use of a quantitative approach that enabled a larger sample of HCPs to be surveyed than would have been the case with a qualitative approach. The quantitative study reported here is firmly grounded in the findings of the previous qualitative study.

Introduction

Healthcare professionals (HCPs) have identified the features that characterise consultations which are mistargeted by patients when making self referral help-seeking decisions. These are consultations made with the wrong HCP, consultations made at the wrong time (i.e. too early, too late or the wrong type of appointment, e.g. an emergency consultation rather than a routine consultation), and consultations made that are potentially avoidable.

Consultations made with the wrong HCP can take the form of patients consulting A&E rather than their GP or pharmacist, for example. Recent years have seen an increasing range of services available to self-referring patients. Confusion as a consequence of innovations such as the introduction of NHS Direct, GP services located within A&E departments, nurse practitioners and changes to the GP Out-of-Hours system can lead to patients seeking consultations with the wrong type of HCP. Munro, Sampson and Nicholl (2005) found that NHS Direct reduced demand for GP Out-of-Hours services but the effect was small. The effect of NHS Direct on day time demand for GP services was difficult to detect and Munro et al. acknowledge that calls handled by NHS Direct might have been handled by GP cooperatives giving telephone advice. In many areas, calls to Out-of-Hours GP services are automatically directed through NHS Direct making the impact of this service difficult to determine. NHS Direct may have reduced the number of calls taken by GP cooperatives but, Munro et al. acknowledge, not necessarily the number of patients seen face-to-face (Munro et al. 2005). When exploring the effect of NHS Direct on the use of GP services during the winter of 1999-2000, Chapman, Smith, Warburton, Mayon-White and Fleming (2002) found that demand for GP services was not affected.

Chalder, Sharp, Moore and Salisbury (2003) examined how NHS Walk-in centres affected demand for other services including day time and Out-of-Hours general practitioner (GP) services and A&E departments. They concluded that the effect of this innovation could not be detected and suggested that further longitudinal investigations were necessary to accurately determine the effect of walk-in centres.

The introduction of nurse practitioners was investigated by Kinnersley, Anderson, Parry, Clement, Archard, Turton, Stainthorpe, Fraser, Butler and Rogers (2000). They compared patient satisfaction from nurse practitioner appointments with GP appointments and found that patients were generally satisfied with the service and the longer appointment times than offered with GPs. These finding were broadly in line with those of Myers, Lenci and Sheldon (1997).

Despite the acceptability amongst patients of some of these innovations such as nurse practitioners, the proliferation of choice may only serve to confuse patients who may not fully understand how and when to access them and it is likely patients will use these alternative services ineffectively. Campbell, Iversen, Farmer, Guest and MacDonald (2005) concluded that the changes in service provision may cause some urban patients to seek help from A&E departments rather than from GP or Out-of-Hours services and rural patients to delay help-seeking.

Consultations made at the wrong time can have potentially profound effects on outcomes from disease. Work exploring delayed help-seeking has focused on specific diseases such as cancers or specific patient cohorts such as men. Anderson, Cacioppo and Roberts (1995) examined this issue with cancer patients and developed the General Model of Total Patient Delay (Anderson, Cacioppo and Roberts; 1995). The model depicts the different stages of delay through which the patient may pass before seeking help. The model's applicability to day-to-day help-seeking situations is unknown but it is likely that many of the features that contribute to delayed help-seeking for cancer are applicable across different situations and diseases. Fear and anxiety as a consequence of potentially cancerous symptoms experienced by patients was found by De Nooijer, Lechner and de Vries (2001) to delay help-seeking in some patients while prompting a rapid response in others.

When considering prescribing strategies for sore throats (a common presentation of upper respiratory tract infections) Little, Williamson, Warner, Gould, Gantley and Kinmouth (1997) showed that patients receiving antibiotics also received 'legitimation' of their illness and thus found their behaviour easier to explain and

justify to family, friends and work colleagues. Receiving antibiotics may well encourage consultation for similar symptoms in the future, despite there being no medical necessity for them in most cases. HSUs interviewed for Study 1 (see Chapter 2) commented that the tendency to over prescribe may contribute to patients making potentially avoidable consultations.

Duberstein, Meldrum, Fiscella, Shields, and Epstein, (2007) considered how the demographics and personality of physicians influence the doctor-patient relationship. They found that these factors strongly influenced the way patients rated doctors and they concluded that patients' trust in doctors and adherence to prescribed medications were affected by personality and demographics. Patients' help-seeking decisions may also be affected by these same factors. Campbell and Roland (1996) highlighted the importance of the individual's ability to self-manage a condition and seek and access social support. They went on to note the high levels of demand for consultations from socially disadvantaged groups and questioned the cause of this comparatively high level of demand. They suggest that while this may be due to higher levels of morbidity amongst those groups it may also be a function of their need for social support usually provided through informal networks or Social Services. These studies illustrate the wide range of factors that affect patients at an individual and emotional level.

Traditional approaches to the study of health help-seeking behaviour have focused on the multitude of antecedent factors that affect patients' decisions to seek consultations (Kasl and Cobb, 1966, for example). This process has been the subject of numerous theoretical models, (see for example, the Health Belief model, Rosenstock, 1966; the Health Action Process Approach, Shwarzer, 1992; and the Self Regulatory Model, Leventhal, Diefenbach and Leventhal, 1992; Diefenbach and Leventhal, 1996). All of these acknowledge the multidimensionality of factors affecting patient decisions but most focus on behaviours for the maintenance of health.

Campbell and Roland (1996) in a review of literature considered those factors that influence patients' decisions to seek help from a General Practitioner (GP). They concluded that the decision to consult a GP is influenced initially by the experience of symptoms. Once an individual experiences symptoms a range of factors that are individual to the patient interact with environmental factors to affect that individual's help-seeking decision. Whether or not an individual seeks a consultation with a GP is

influenced by that individual's perception and beliefs about the nature and consequences of their illness and an assessment of the likely consequences symptoms being alleviated by a visit to the GP.

The very complexity of the interaction of these factors has resulted in overly complex, descriptive models of health help-seeking behaviour, leading Tuckett (1976) to suggest that the factors should simply be listed. More recently, Diefenbach and Leventhal (1996, p.12) point out that; "it is easy for the researcher to become overwhelmed by the number of potential factors that might influence health-related evaluations and decisions".

The environmental factors that affect patients' decisions about seeking health related help is an ongoing subject of research. For example, Carr-Hill, Rice and Roland (1996) examined data from the Fourth National Morbidity Survey of General Practices and noted that individuals, particularly girls and elderly men living near to a GP were more likely to seek consultation with a GP. Farmer, Iverson, Campbell, Guest, Chesson, Deans and MacDonald (2006) investigated rurality as a factor influencing patients' decisions about seeking healthcare. They concluded that location (rural or urban) affected patients' perception of the availability of services. They found that patients living in urban areas base their decisions about seeking out of hours care on relative distances to healthcare services. In contrast, rural patients engage in more complex decision making processes involving the assessment of a number of factors. These include the perceived and actual availability of services and the self-assessment of symptoms and the consequences of delays in seeking care as a result of perceived lack of service options. The level of complexity of decision making is likely to have an influence on the quality of that decision. Studies by Campbell and Roland, (1996), Farmer, Iverson, Campbell et al., (2006), Little, Williamson, Warner, Gould, Gantley and Kinmouth, (1997), and De Nooijer, Lechner and de Vries, (2001) illustrate some of the wide range of factors, beyond the immediate necessity of the alleviation of symptoms, which affect the timing and quality of health help-seeking decisions.

Much of the research in this area has been limited to specific patient cohorts who exhibit a specific type of behaviour such as frequent attenders. Research is often focused on the use of one specific service by patients such as accident and emergency departments or general practitioners. Frequent users of self-referral healthcare services have been the focus of many studies. Howe, Parry, Pickvance and Hockley

(2002) developed a definition of frequent attendance whilst the personality factors and use of services (Neal, Haywood and Morley, 2000) and family patterns (Neal, Wickenden, Cottrell, et al. 2001) have also been investigated. Other research has identified loneliness (Ellaway, Wood and MacIntyre, 1999), social support (Campbell and Roland, 1996), and lifestyle and health status (Little, Somerville, Williamson et al., 2001) as impacting on frequency of attendance whilst George and Rubin (2003) were more concerned with factors affecting non-attendance. Neither frequent attendance nor non-attendance is necessarily mistargeted consultation behaviour which requires more careful definition.

Whilst few attempts have been made to alter consultation behaviour, Jiwa (2000) reports an intervention study. Jiwa sought to alter consultation behaviour and reduce the frequency of consultations of patients identified as frequent attenders by asking GPs to mark their patients' notes. This did not have a significant effect on the GPs approach to them or to their behaviour. Other studies have examined the effect of various innovations on demand for other services including the introduction of a nurse practitioner (Laurant, Hermens, Braspenning, Sibbald, and Grol, 2004), the introduction of NHS Direct (Chapman, Smith Warburton, Mayon-White and Fleming, 2002; Munro, Sampson and Nicholl, 2005) and. the effect of NHS walk-in centres (Chalder, Sharp, Moore and Salisbury, 2003). None of these studies found a statistically significant effect of the intervention on GP consultation rates. Similarly, Beney, Bero and Bond's (2000) review of literature found no conclusive evidence that community pharmacists significantly reduced the workload of GPs. However, they noted that more work was needed in this area. Understanding the scale of poorly made consultation decisions is essential for effective resource allocation and policy decisions.

The quality of patients' consultation-seeking behaviour has been identified as a significant issue for patients and HCPs alike, (Chapter 2) but the scale of poor quality decisions has not been established. Hannay (1979) described the 'symptom iceberg' where only a very few symptoms experienced, the tip of the iceberg, result in consultations with HCPs. The point at which the iceberg breaks the surface is the point where a range of underlying factors come together resulting in the patient's decision to consult. Making an ineffective consultation-seeking decision (or mistargeted consultation) can have profound consequences, not just for the health outcome for the patient, but for the use of limited healthcare resources. Evidence

from the study reported in Chapter 2 indicated that HCPs perceived mistargeted consultation as having one or a combination of characteristics. These were making a consultation with the wrong HCP (e.g. consulting A&E rather than NHS Direct); at the wrong time (either too early or too late); or making that is potentially avoidable.

Figure 1 illustrates the process from the point where a patient first experiences a symptom to its eventual resolution. There are two critical points where an ineffective decision can have potentially negative effects: The first is deciding whether or not to seek help for a particular symptom. Not seeking help may have adverse consequences for treatment of the symptoms or condition experienced. The second is deciding what sort of help to seek and from whom. 'Help' may take any form, including informal advice from social support networks. In the majority of cases, as described by Hannay (1979), the decision is not to seek formal help (from a HCP), either because self treatment will resolve the symptoms or the symptoms are perceived to be self limiting. In some cases, it may be prudent to seek formal help, but if this is not done at the optimum time, the condition may worsen resulting in a potentially poorer outcome for the patient. If formal help is sought too soon, limited health resources may be ineffectively used. Equally, if help is sought too late, the consequences for the patient may be profound (Anderson, Cacioppo and Roberts, 1995). Anderson proposed a general model of total patient delay in which five stages of patient delay were identified amongst cancer patients. Additionally, if help is sought from the wrong type of HCP or the wrong type of service provider (for example, A&E departments rather than the GP) patient outcome and the consumption of resources may be adversely affected. The list of potential sources of help is as diverse as it is long but can be divided into roughly two categories; informal help and social support from friends, family or non-medical sources such as social services; formal healthcare from self-referral HCPs; Primary care; A&E departments; NHS Direct; and complementary and alternative therapists are examples of self referral health services. This list is by no means exhaustive.

A range of HCPs' perceptions of the consultation decision making behaviour of patients in a range of self referral situations were investigated and reported in Chapter 2. Findings revealed that HCPs considered that the mistargeting of consultations by patients is potentially detrimental to patient outcomes, an inefficient use of scarce healthcare resources and is a significant problem. These findings concurred with those of Hallam (1994) who, in a review of literature, found that

doctors considered many out-of-hours calls to be medically unnecessary. The investigation reported in Chapter 2 found that a range of HCPs categorised the features of a mistargeted consultations as: the wrong choice of HCP for patient needs; a mis-timed consultation (too early, too late or consulting in the wrong appointment slot e.g. making an emergency appointment when a routine appointment would be sufficient); a potentially avoidable consultation. In the same study five elements of a well-targeted consultation were identified as consulting: the HCP best suited to meeting the patient's needs and which most efficiently uses the HCP's skills; at the optimum time; in the most appropriate place; when there is a genuine need; when the outcome is treatment or advice given.

Some of the potential causes of mistargeted consultations identified by the HCPs in the study reported in Chapter 2 included the structure of the healthcare system, patients' social circumstances and social support network, and the behaviour of HCPs. Whilst the study did not consider the phenomenon from the patient's perspective, it concluded that future investigations into patient consultation targeting effectiveness should seek to identify, describe and understand the factors that influence patients' decisions about who to consult, when to consult and how to consult in an increasingly complex range of healthcare options. While the study reported in Chapter 2 revealed that HCPs considered mistargeted consultations to be a significant issue, the study did not attempt to quantify this. In order to gain some understanding of the size of the problem this second study was undertaken. Using the parameters identified in Chapter 2, the proportion of routine consultations made with GPs that are perceived by the GPs to be mistargeted in some way were measured.

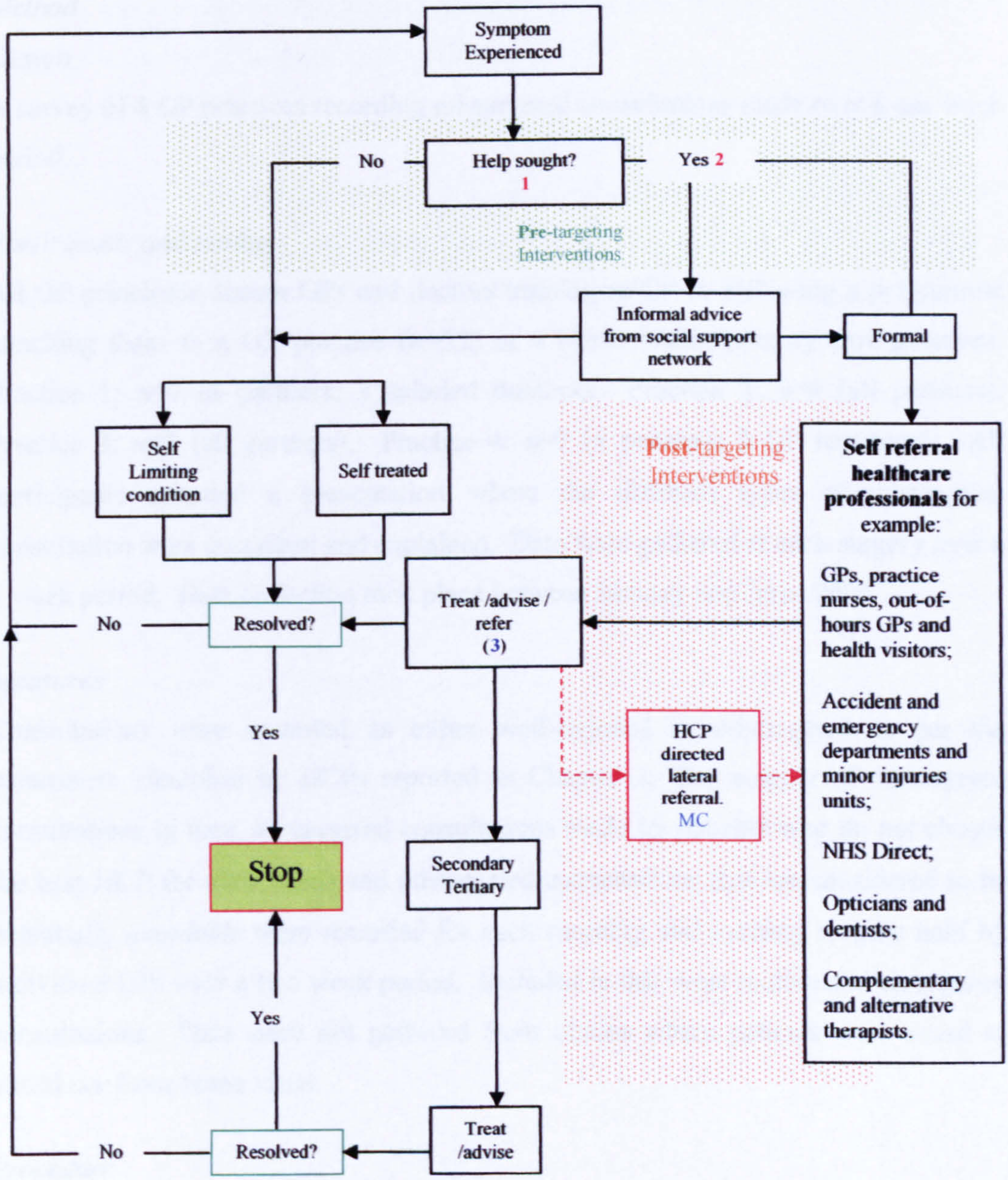

Figure 1: The process of patient consultation decision making

Notes to figure 1:

- Points at which patients make decisions potentially leading to mistargeted consultations are marked with 1 and 2.
- Post-targeting Interventions is the point at which interventions have been made to date.
- Pre-targeting Interventions is the point at which proposed interventions will be made.
- MC is a 'mistargeted consultation'

Method

Design

A survey of 4 GP practices recording mistargeted consultations made over a one week period.

Participants and setting

All GP principals, locum GPs and doctors training as GP or following a programme attaching them to a GP practice (n=22) at 4 North Wales primary care practices. Practice 1: n=7 (4 partners; 3 salaried doctors). Practice 2: n=4 (all partners). Practice 3: n=5 (all partners). Practice 4: n=7 (4 partners; 3 GP registrars). All participants attended a presentation where the different types of mistargeted consultation were described and explained. Data were gathered at each surgery over a 1 week period. Data collection took place between January and June, 2006.

Measures

Consultations were recorded as either well-targeted or mistargeted as per the parameters identified by HCPs reported in Chapter 2; The number of mistargeted consultations in *time*, mistargeted consultations made by patients who do not choose the best *HCP* for their needs and mistargeted consultations that are considered to be potentially *avoidable* were recorded for each morning and evening surgery held by individual GPs over a two week period. Included in this were routine and emergency consultations. Data were not gathered from clinics where patients were asked to attend nor from home visits.

Procedure

A presentation was given to GPs participating in the study during which a standardised explanation of the definitional parameters of an effectively targeted consultation and the three categories of mistargeted consultation were given. The use of the standardised record sheet was explained (See Appendix 2).

All consultations for 1 week were assessed as to whether they were effectively targeted or mistargeted. Out of hours consultations, home visits and clinic consultations (e.g. asthma clinics, blood pressure clinics etc) were not included. GPs recorded whether a consultation was effectively targeted or mistargeted using three categories: in time (made too early, too late or in the wrong appointment slot); made with the wrong HCP; or was potentially avoidable. A separate record sheet was used

for each surgery session and this was divided into male and female patients and GPs recorded mistargeted consultations by category.

Analysis

The proportion of consultations that were effectively targeted or mistargeted for each category were calculated as percentages of total consultations and comparisons between surgeries were made using Fisher's exact statistic. The level of independence of individual GPs' data was examined using chi-square measure of independence. All analysis was carried out using SPSS computer software.

Results

Overall, across all surgeries, 28.59% of all consultations were recorded as mistargeted in some way. Of all consultations made, 8.46% were made with the wrong HCP, 5.01% were made at the wrong time and 15.12% were potentially avoidable.

The percentage of consultations that were mistargeted varied across surgeries (see Table 1 for a breakdown of these figures by practice). However, a cross-tabulation of the rates of mistargeted consultations between surgeries using Fisher's exact test revealed that the overall variation between surgeries 1, 2 and 3 ($p > 0.7$) was not significant. Practice 4's rate of mistargeted consultations, overall was significantly greater than all other surgeries ($p<0.002$). See Table 2.

	Number of mistargeted consultations			
	wrong HCP	time	potentially avoidable	Total
Practice 1 **452 consultations**				
No. of MCs	43	10	56	109
%age MCs	*9.51*	*2.21*	*12.39*	*24.11*
Practice 2 **149 consultations**				
No. of MCs	16	1	21	38
%age MCs	*10.74*	*0.67*	*14.09*	*25.50*
Practice 3 **196 consultations**				
No. of MCs	11	8	27	46
%age MCs	*5.61*	*4.08*	*13.78*	*23.47*
Practice 4 **420 consultations**				
No. of MCs	33	42	80	155
%age MCs	*7.86*	*10.00*	*19.05*	*36.91*
All surgeries **1217 consultations**				
Total number of MCs	**103**	**61**	**184**	**348**
%age of* total *consultations mistargeted	***8.463***	***5.012***	***15.119***	***28.594***

Table 1: Summary of results for *all* consultations by practice.

MC= mistargeted consultation

Practice 4 had significantly more avoidable consultations than practice 1 ($p<0.01$) but was not significantly different from surgeries 2 and 3 ($p>0.1$). Practice 4 had significantly more consultations made at the wrong time than the other surgeries ($p<0.01$) but there was no significant difference between any of the surgeries for consultations made with the wrong HCP ($p>0.1$).

Practice comparisons	Avoidable v unavoidable *P*=	Wrong v right time *P*=	Wrong v right HCP *P*=	Well-targeted v mistargeted *P*=
1 v 2	.574	.308	.637	.742
1 v 3	.611	.198	.121	.920
1 v 4	**.009**	**.000**	.403	**.000**
2 v 3	1.000	.084	.105	.705
2 v 4	.212	**.000**	.308	**.002**
3 v 4	.112	**.011**	.401	**.001**

Table 2: Summary of results of *Fisher's Exact Test* comparing different practice's rates of mistargeted consultations overall and by type. Where there is a significant difference, Practice 4 scores higher.

In practice 4, one partner recorded 65% mistargeted consultations and another recorded 51%. While these two partners from this practice recorded more mistargeted consultations than the mean per GP across all practices (*mean=28.84% SD=15.60*), (partner 1: 65%; partner 2: 51%), mistargeted consultations at this level were not unique to this practice (see Fig. 2) and were not considered to be outliers.

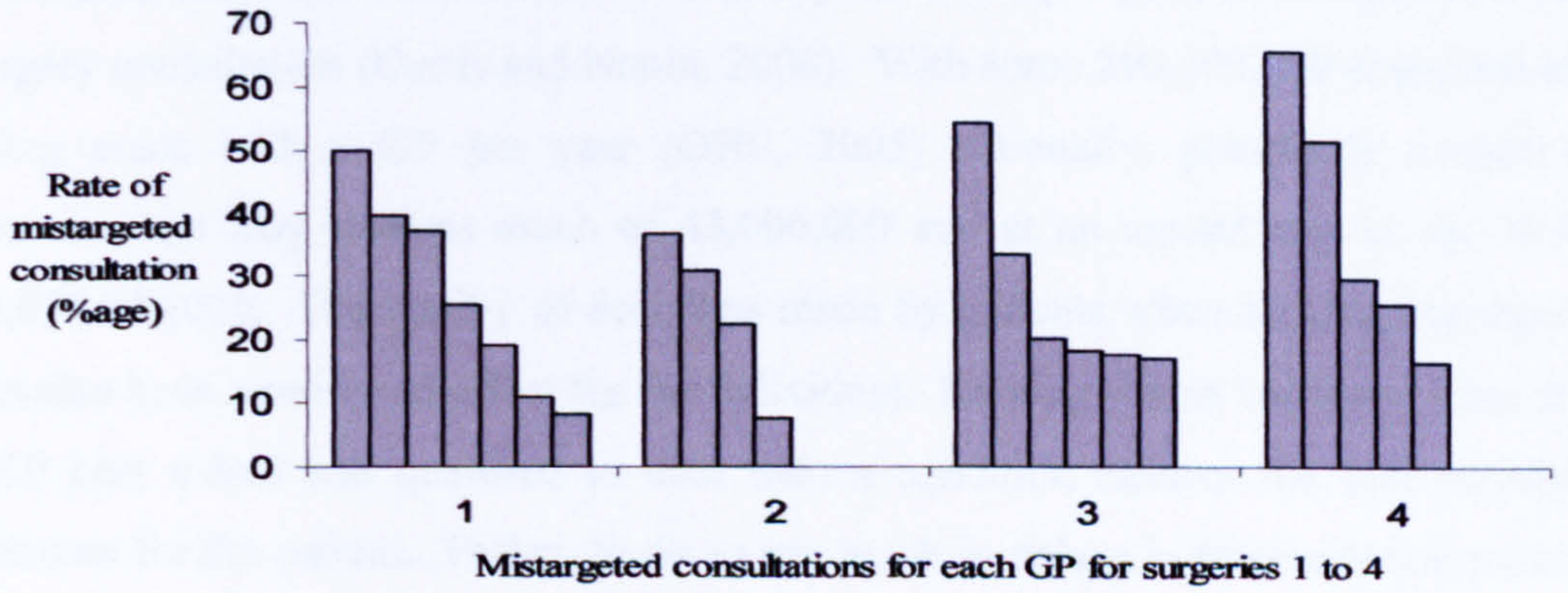

Figure 2: percentage mistargeted consultations per GP by practice.

Discussion

The purpose of this study was to examine the scale of the issue of mistargeted consultations with GPs. Four GP practices were surveyed. The rate of mistargeted consultations over a one week period were assessed and found to be significant (28.59%). The study, reported in Chapter 2, found that HCPs considered the issue to be significant and this study has shown that to be the case.

When all GPs were considered together (regardless of practice) the mean mistargeted consultation rate was 28.84% (SD=15.6). The high standard deviation reflected the wide difference in the number of mistargeted consultations recorded by individual GPs. This may be due to a combination of factors; the individual personality of GPs (Duberstein, Meldrum, Fiscella, Shields, and Epstein, 2007) and the potentially subjective nature of parts of the measurement tool (i.e. 'potentially avoidable' consultations). Despite outward agreement that the term 'potentially avoidable' was more objective than the traditional language used to describe help-seeking decisions, individual GPs had different opinions about what the nature of a potentially avoidable consultation. This was seen in follow up discussions where HCPs opinions varied on the extent to which some consultations could be classified as mistargeted.

The results from this study suggest that the issue of mistargeted consultation is significant. How far these results can be generalised is uncertain but there is no evidence to suggest that this rate of mistargeting is uncommon. There were 184 potentially avoidable consultations made during one week at the four practices surveyed in this study. Assuming that this is a typical weekly rate at these practices, potentially avoidable consultations cost nearly £240,000 per year, based upon £25 per surgery consultation (Curtis and Nettin, 2006). With some 290,000,000 consultations being made with a GP per year (OHE, 2005) nationally, potentially avoidable consultations may total as much as 43,000,000 and at an annual cost to the NHS £1,075,000,000. The quality of decisions made by patients when seeking healthcare can also have a profound effect for the individual. Seeking timely treatment from the HCP best suited and qualified to deal with a condition ensures the best possible outcome for the patient. Failure to do so can result in delays in treatment and poorer outcome for the patient.

Consultations made with the wrong HCP accounted for 8.46% of consultations made across the four practices and the difference between practices was not significant. This similarity between the four practices suggests that HCPs had a reasonably consistent, objective understanding of consultations made with the wrong HCP. However, consultations judged to be made at the wrong time (5.01% of all consultations made) were not significantly different between practices one, two and three, but practice four recorded a significantly higher number of consultations made at the wrong time.

15.119% of all consultations made were considered to be potentially avoidable making this the largest of the three categories of mistargeted consultation (wrong HCP; wrong time; and potentially avoidable consultations). This may reflect an issue with the term 'potentially avoidable' consultation. Despite a standardised explanation of the definition, this term still has the potential for subjective interpretation by GPs. Because of this, the category may have been used as a general category where GPs considered the consultation to be mistargeted in some way but were unsure which category the consultation fell into. The term or the definition of the term may need to be reconsidered in order to make it more objective and less open to interpretation. Again, practice four was significantly different from the remaining practices.

The difference between practice four and the three other practices may be partly explained by the timing of data gathering in practice four. This was during the January while the other practices gathered data during the spring months (April, May and June). Practice four differed from the other practices in that it was a 'split site' practice with two surgeries based in two separate communities. Interestingly, the results from practices 1, 2 and 3 were not significantly different suggesting that the measurement tool was reasonably robust.

Consultations made by frequent attenders (Neal et al., 2000; Neal et al. 2001; Ellaway et al., 1999; Campbell and Roland, 1996; Little et al., 2001) and high users of GP services do not necessarily meet the criteria to be categorised as mistargeted in some way. Howe et al., (2002) considered frequent attenders to be the highest attending 3% of male patients and highest attending 3% of female patients. This includes patients who attend frequently due to morbidity as well as those making medically unnecessary consultations (Hallam, 1994) and described by Neal as "deviant individuals who create an unnecessary and unwelcome workload, with whom 'something must be done'." (Neal, 1996, p.131). Clearly many of those who attend frequently are making effective consultation decisions but a proportion of frequent attenders are likely to be making 'potentially avoidable' consultations. The concept of the effectiveness of consultation decision making transcends all patient groups and includes those who may attend infrequently and those who do not attend at all (George and Rubin, 2003) when seeking medical advice may be the prudent course of action.

More research is needed to develop the measurement tool used here. The term 'potentially avoidable' needs to be developed to reduce the opportunity for subjective

interpretation by GPs. In addition, the concept of a consultation being mistargeted in time needs to be made clearer; an opportunity for the researcher to differentiate between consultations made too early or too late should be provided as should the opportunity to record a consultation as being made in the wrong type of appointment slot (i.e. routine versus emergency consultation).

The present study has focused on the scale of the issue of ineffectively made consultation decision from the perspective of GPs. While this offers us some insights into the scale of the issue, it does not help us understand why patients behave in the way they do. The terms traditionally used by HCPs to describe the quality of patients' help-seeking decisions were perceived as subjective and pejorative (see Chapter 2). The terms used as the basis for this study's investigation are both more objective and acceptable to the HCPs interviewed but their acceptance by patients is still unknown. Further research is required that focuses on the factors that underpin patients' decision making including research into the acceptability by patients of the term 'mistargeted'. An attempt has been made to illustrate the financial impact of poor quality help-seeking decisions but it is clear that some more work examining the impact on healthcare resource use is urgently needed.

This study has clearly shown that an ineffectively made help-seeking decisions by patients is a significant issue in primary care both for the patient and for the use of healthcare resources. However, primary care is not the only sector that might be affected by poorly made help-seeking decisions. Patients' decisions may lead them to seek consultations with other healthcare services such as A&E, GPs and Out-of-Hours services, practice nurses, nurse practitioners and NHS Direct. When ineffectively made consultation decisions in these sectors are considered in addition to those made in primary care, the cost to both patients and the NHS may be considerable.

Chapter 4

Study 3:

Help-seeking behaviour amongst self-referring patients: views of health service users

4.1

The previously reported qualitative and quantitative studies developed definitional parameters of patients' ineffective and effective help-seeking decisions and measured the scale of patients' ineffectively made help-seeking decisions. These studies have focused on the perspective of a variety of healthcare professionals (HCPs) leaving patients' perspectives unexplored. The qualitative study reported in this chapter explored help-seeking behaviour from the patient's perspective. Qualitative techniques were employed for this study because they enabled the exploration of health service users' subjective experiences. An understanding of the rich variety of experience enabled factors that underpin help-seeking decisions to be identified. This was achieved through the use of qualitative techniques that gave participants the opportunity and freedom to explore their experiences of day-to-day help seeking.

Introduction

The effectiveness with which patients make consultations with self referral primary HCPs has been identified as a significant issue (see Chapter 1). Investigations into patient consultation behaviour have, until now, largely focused on ineffective consultation behaviour. More specifically, research has looked at the frequency with which patients attend consultations, usually with general practitioners (GPs). This work includes Neal, Haywood and Morley's (2000) study that examined the different patterns of frequent attendance at GPs' surgeries. Howe, Parry, Pickvance and Hockley (2002) considered who frequent attenders were and proposed a redefinition of frequent attenders making identification of those whose are most likely to attend frequently for non-medical reasons. Neal, Wickenden, Cottrell, Mason, Rugiano, Clarkson, and Bearpark (2001) studied the use made of other health services by patients who frequently attend GP surgeries. Research into patterns and types of delay in attendance usually focuses on a range of cancers (see, for example, Scott, Grunfeld, Main and McGurk, 2006; Corner, Hopkinson and Roffe, 2006; Rozniatowski, Reich, Mallet, Penel, Fournier and Lefebvre, 2005) and Anderson, Cacioppo and Roberts (1995) developed the General Model of Patient Delay which described several different types of delay in help-seeking and models the consequences of that delay. Some researchers have also considered the impact on consultation behaviour of various initiatives, such as the introduction of NHS Direct, drop-in centres, nurse practitioners in GP surgeries, and the development of GP Out-of-hours schemes (Chapman, Smith, Warburton, Mayon-White and Fleming, 2002;

Chalder, Sharp, Moore and Salisbury, 2003; and Munro, Sampson and Nicholl, 2005). A small number of studies has attempted to alter some aspects of this behaviour but with limited success (for example, Jiwa, 2000). Overall, research has been somewhat disjointed, with studies focusing on specific aspects of patient behaviour and specific types of health service provision.

Earlier research from the 1950's, 60's and 70's sought to model the complex interaction of antecedent factors thought to affect help-seeking behaviour. The factors were found to be too numerous to model effectively and this approach was largely abandoned with researchers acknowledging that the list of antecedent factors was very large (Tuckett, 1976). The list continues to grow with new factors being identified (e.g. Farmer, Iversen, Campbell, Guest, Cheeson, Deans and MacDonald, 2006). Models of health behaviour such as the Health Belief Model (Rosenstock, 1966) have been developed but these tend to focus on a wide range of behaviours that protect or maintain health, from wearing seatbelts and taking action to prevent accidents to behaviour change related to smoking, drinking, taking exercise and eating healthily. Having undergone several developments, these models have also been applied to patients' responses to and conceptualisations of chronic health problems such as asthma, diabetes and cardiovascular problems. Diefenbach and Leventhal's (1996) Common Sense Model of Illness Representation has also been used to explain patients' behaviour when faced with chronic conditions such as diabetes and asthma.

The research in this chapter deals with health behaviours either side of the decision to seek help, i.e. behaviour before the onset of illness and attempts to maintain or improve a state of health and behaviour after the diagnosis of illness. Definitional parameters of patients' effective and ineffective health help-seeking behaviour were developed through interviews with a range of HCPs (see Chapter 2). It was found that HCPs considered that ineffective health help-seeking behaviour or the mistargeting of consultations by patients is potentially detrimental to patient outcomes and an inefficient use of scarce healthcare resources. HCPs considered that patients mistarget their consultations in three different ways;

- consulting the wrong HCP
- consulting at the wrong time; either consulting too soon or too late or consulting in the wrong appointment slot (for example making an emergency appointment when a routine appointment would be sufficient)

- making a potentially avoidable consultation

Some of the potential causes of patient mistargeted consultations (PMCs) were identified in the study reported in Chapter 2 but the study did not consider this issue from the patient's perspective, something that this study seeks to address. The study reported in Chapter 3 investigated the scale of PMCs. They surveyed all routine GP consultations including 'extra' or emergency consultations made at 4 primary care practices in North Wales. Of the 1217 consultations made, 28.59% were considered by GPs to be mistargeted in some way. 8.46% were made with the wrong HCP, 5.01% were made at the wrong time and 15.12% were potentially avoidable. Ineffective consultation-seeking behaviour such as this can have potentially detrimental effects on patients, ranging from wasted patient time, to substantially reduced positive outcomes of illness. In addition, if this rate of potentially avoidable consultations was found to be similar across all primary care practices, at £25 per surgery consultation (Curtis and Nettin, 2006) and 289.8 million GP consultations in England per year (Hippisley-Cox, Fenty and Heaps, 2007), potentially avoidable consultations may cost the NHS more than £1,090,000,000 per year. Recent initiatives within the Welsh Assembly Government have recognised the need to address the issue of ineffectively made consultation-seeking decisions, particularly those associated with A&E visits. The "Delivering Emergency Care Services: An Integrated Approach for Delivering Unscheduled Care in Wales" initiative acknowledges that patients need to make more effective use of services but service providers should recognise the demands of patients but the effective support of self care is also promoted (Welsh Assembly Government, 2008).

However, in order to begin to close this gap in our understanding of effective and ineffective health help-seeking behaviour, we need to know what healthy patients consider normal help-seeking behaviour to be. This largely ignored area of health behaviour is the bridge between the behaviour of people before they become ill and the behaviour of people after illness has been identified. Crossing that bridge is the decision to seek help. How and when people choose to cross that bridge can have profound consequences for the outcome of their particular condition and the resources available to the health services. Whilst many factors affect the help-seeking decision and attempts have been made to model them (Kasl and Cobb, 1966; Rosenstock, 1960), the large number of these factors means that modelling this process is all but futile (Tuckett, 1976; Diefenbach and Leventhal, 1996). This study seeks to explore

the help-seeking process and its antecedents holistically rather than identify new factors or make another attempt to model their interaction.

Behaviour associated with the decision to seek help has largely been ignored or dealt with in a disjointed manner resulting in a gap in our understanding of the normal, day-to-day health help-seeking process. This poses the question; what are the features of normal, day-to-day help-seeking behaviour from the perspective of health service users (HSUs)? Of interest are the factors involved in the decision to seek help that have the potential to adversely affect the quality of that help-seeking decision. Also of interest are the HSUs perceptions of the sources of their help-seeking behaviour.

Method

Sample

The sample consisted of HSUs selected from the general population of a small north Wales town (Llanfairfechan) and students from a local further education college. All participants were local to North Wales but one now lives in Cornwall. Participants were approached by the lead researcher and invited to participate. The purposefully selected sample consisted of 20 individuals (n=20), comprising n=10 males and n=10 females whose ages represented a spectrum from 18 to 74+ years. Participants were also asked about their educational background to ensure that both high and low educational achievers were represented.

2 males and 2 females in each of the following age ranges were selected: 18-24 years, 25-44 years, 45-60 years 60-74 and 75 plus years. Educational level was a factor in the choice of participant. Of the 2 males in each age band, one had experienced higher education while the other had not. Female participants were selected on the same basis. Participants with long-term or acute patterns of illness were not specifically selected as the aim of the study was to gather the views of a representative sample of the wider spectrum of help seekers. Participants were not chosen on the basis of their use of a particular general practice and no attempt was made to assess their history of or current health service usage.

Procedure

Participants were invited to take part in a recorded, semi structured interview after the lead researcher ascertained their age and educational background in order to ensure a

sample as described above. Participants were informed of the aims of the study and the purpose of the interview, assured that their anonymity would be respected and that no medical information or details would be needed or sought. Participants were assured of their right to withdraw at any time. A consent form was then signed. The semi structured interview was based upon interview discussion points (see Appendix 3). This schedule formed the basis of the interview but as participants described themes or incidents, these were explored further. The interview schedule was continually revised as participants highlighted points of interest to allow those points to be explored with subsequent participants for a richer data collection. The interview was transcribed in full and a transcript of the interview was returned to the participant as a first level of validation. Participants amended or added to it as they felt necessary and returned it to the lead researcher. After all participants had validated their transcripts they were invited to attend focus group meetings where anonymised major findings and themes identified from returned transcripts were presented. As a second level of validation, participants at the focus group meetings were invited to comment upon or add to these general, summarised findings. Two researchers were present at the focus group meeting, one of whom facilitated the meeting while the second made detailed notes on the points discussed by the participants. Throughout the interview and subsequent focus group process, participants were encouraged to consider consultations with a range of HCPs.

Data analysis

Analysis of the transcripts returned by participants was based upon Ritchie and Spencer's (1994) framework analysis. Framework analysis was developed to meet a range of objectives among which were diagnostic objectives. Diagnostic questions seek to explore the causes and reasons for the existence of an identified phenomenon. In the context of this study, normal, day-to-day help-seeking behaviour and attitudes amongst the general population of HSUs was the identified phenomenon.

Following the process of Framework analysis, transcripts were read to enable the researchers to familiarise themselves with the data. Recurrent themes and sub-themes were identified which enabled individual transcripts to be annotated. This facilitated the production of a comprehensive index: data were lifted from individual transcripts and used to produce charts illustrating themes and sub-themes. This enabled the researchers to take an overview of the data and interpret the findings.

Results

The results from this study take the form of eight themes identified from the analysis of the transcripts of interviews conducted with HSUs.

1. What patients seek in a consultation
2. Factors perceived to initiate help-seeking
3. Factors perceived to affect the help-seeking decision
4. Perceived barriers to seeking help
5. Factors perceived to facilitating help-seeking
6. Lay influences on the decision to seek help
7. Perception of the source of skills necessary to make help-seeking decisions
8. HSUs' perception of HCPs' control of treatment decisions

These categories were further subdivided as indicated in the theme sections below.

1. What patients seek in a consultation

Participants spoke about the different things that they wanted from a consultation. These fell into two broad sub divisions; symptom and non symptom associated 'wants'. Patients' 'wants' from a consultation was considered to be qualitatively distinct from the second category (factors that initiate help-seeking) because 'wants' from a consultation are constant and are more likely to remain stable over time whereas the factors that initiate help-seeking are situation specific and likely to change as situations change.

Symptom associated 'wants':

The majority of respondents said that, more than anything else, they sought advice about the symptoms or issues they are experiencing in a consultation. Some respondents went into more detail expressing a desire for reassurance, while others wanted an explanation of the problems or symptoms they were experiencing. Generally, information about their condition was a respondent's first desire from a consultation.

> *[Interviewer]: "What do you expect to get from those sorts of meetings. What would you want from them?"*
> *[Respondent]: "Professional advice, professional opinion, and if in their opinion it was necessary – professional treatment – or drugs or whatever*

– I wouldn't expect anything else from them other than what they would consider in their professional opinion what was right for me" (BN 65-74 male).

"I would expect to get from consultation guidance on whatever was wrong and obviously medication if needed and an explanation of why it happened, would it happen again, is it anything to do with my lifestyle, - anything like that, anything to do that would help me to make sure whatever it was never happened again. If there was a chance it could happen again. But definitely explanation on what it was and why it happened" (SY 45-64 female).

"I'd suspected what it might be but by then I thought perhaps I'd better – you know have an expert point of view. So it was OK, it was what I thought it was but I was glad to have that reassurance really" (DX 45-64 female).

The HCP's approach to dealing with symptoms was important to patients. Respondents highlighted a number of points that were important to them. Examination and treatment where necessary was important or referral to another HCP if specialist care was necessary. The restoration of health and the resolution of symptoms were also considered important as was a speedy recovery and a prompt and timely service.

"Depending on where the ailment is, I would think there would be some – at least brief examination, even if it's blood pressure, pulse and temperature. I would expect that and I would – you know say if you've got a pain in the leg I would expect them to look at the leg, you know. Not saying 'oh really, and there we are, I'll give you this' – sort of thing. So I'd expect them to examine the place as it were, and then come out with some sort of advice" (DX 46-64 female).

[Interviewer]: "Other than finding advice, what's your goal? What's your aim if you like?"
[Respondent]: "Well to get better, to get cured" (TP 74+ female).

"The main thing I'd want is to see if they could make me a bit more comfortable so if I was in pain, some painkillers and some antibiotics to clear up the illness, so I'll try and get better sooner" (MK 18-24 female).

Non-symptom associated wants:

Participants also spoke of other qualities and services that they wanted from an HCP. These included: expertise; the ability to maintain existing levels of health; professionalism; a trusting relationship; and good communication skills.

"One would have had an awareness something is wrong, and in case it's something other than advancing years, which deprives one of as much energy as one used to have, one is concerned to get it treated in case it needs – in case it might otherwise get worse, and have a bigger effect. It's to do with preserving – maintaining, whatever level of health you have" (SH 75+ male).

"You don't know what's wrong with you but that you expect to be treated professionally by somebody who understands what they're doing by somebody who has been trained properly and educated properly" (EF 25-44 male).

2. Factors perceived to initiate help-seeking

The second category is concerned with the factors that participants mentioned as being important in initiating help-seeking. Generally, these factors were symptom related. Symptom related factors are likely to be situation or symptom specific and may change as the situation or symptom changes. These factors were: the perception of the severity of the symptom; the persistence of the symptoms; the perceived urgency of getting treatment; discomfort and pain; the perception of an abnormality or an unfamiliar symptom; and fear and anxiety caused by the symptom. Other factors mentioned that prompted help-seeking were the response of others to symptoms and, the antithesis to this, the failure of social support. Help-seeking was also instigated when self-treatment failed (self-treatment will be examined later). On a more practical level, the prevention of work or leisure activities was also mentioned as something that caused help to be sought.

"At our age you get aches and pains ..... And then if you think - well this is serious enough to go the doctors then you go to the doctors" (CP 74+ male).

"Well he'd [respondent's son] *already been previously, and we thought he should perk up in a couple of days, which most kids do, and then he just didn't perk up so we decided to go quickly and they decided to take him straight to the hospital and have blood tests and all the rest of it" (EK 18-24 male).*

"Being in absolute pain or feeling completely ill that you think that you think - I do need something else here" (MH 25-44 female).

"I'd be anxious, I'd be worried about it and I wouldn't feel myself, I would feel ill, but I wouldn't be cross about it, I would be worried about it and I'd be anxious to get it sorted as soon as possible" (SY 45-64 female).

3. *Factors perceived to affect the help-seeking decision*

The third category was concerned with factors identified by respondents as important when making the help-seeking decision. These factors might tip the decision to seek help either way or they might affect the way that help is sought. These factors are: the selection of the best HCP for the perceived need; the time of day in which the help is needed, the perceived availability of services and psychological and attitudinal factors.

[Interviewer]: "So when you're ill, or a friend is ill – what's your main priority, your main concern? What do you want to happen?"
[Respondent]: "To get the appropriate help – I mean particularly of an optician that I had to go and see, for obvious reasons,, but I ended up having to have a consultation. But it really is working out whether it's a GP or whether it's somebody – I mean a GP can't help you if you've got toothache, so you would choose the appropriate person" (BX 65-74 female).

Respondents also mentioned the need to comply with the system:

"Yes, I mean OK the health centre here lays down its rules and you know its rules, that's fair enough. You may not agree with them necessarily, but you know it's fine, you abide by them" (SK 65-74 male).

Also within this category were factors considered to be psychological in nature. Making a conscious decision to consult and its antithesis, making the decision to consult automatically were mentioned. The GP was often mentioned as the first choice, either as a conscious decision or as an automatic choice.

[Interviewer]: "When you make your consultations are they usually conscious decisions about who to go and see, or .."
[Respondent]: "Yes. You know if I just feel I need an opinion for something I'll make for the chemist. You know you can speak to the pharmacist or .... with the children I've got the health visitor. With little things that I feel I need you know I can.... Yes consciously I have" (MH 25-44 female).

"I think basically it's automatic. You would, or I would anyway, I would think, I would immediately think of my GP. Health Service Direct on a telephone that would be something I would have to think about as an alternative, my automatic reaction would be to contact my GP – or as I say – if I've chopped two fingers off, then probably then Casualty straight away" (IN 45-64 male).

Respondents stated that they would 'wait and see' before making taking any action to seek help. This is perhaps, closely related to the notion of not wanting to bother the GP. However, the notion of waiting and seeing implies a willingness to consult should it become necessary whereas not wanting to bother the GP implies a general reluctance to make a consultation. This notion of not wanting to bother the GP is considered further as a barrier to seeking help (see below).

Several respondents considered that they made the choice to consult a GP (and in one case, a herbalist) as an automatic choice. They would only consider another HCP for emergency situations, for example, an Accident and Emergency department doctor:

[Interviewer]: "The doctor would be your first port of call would it?"
[Respondent]: "It's more automatic, go and see a doctor, it's an automatic response really" (MK 18-24 female).

[Respondent]: "Well if you are ill you naturally go to the doctor. Anything else – I don't think anything else would occur that I would have to go and see someone else. ... mental problem, I can cope with anything myself" (CP 74+ male).

By contrast, only one participant stated that he would make the decision to consult a GP as a conscious choice:

> *[Interviewer]: "Do you actually sit down here for instance and think 'em I need to go and get that done' or are these decisions more sort of automatic or subconscious if you like, or do you actually sit down and contemplate for a while?"*
> *[Respondent]: "Well I think I sit down and contemplate for a while" (SK 65-74 male).*

4. Perceived barriers to seeking help

Participants identified several perceived barriers or factors that might cause a delay in help-seeking. Patients perceived that they should wait and see how their symptoms progressed before seeking help. Several participants mentioned that they tried to avoid 'bothering' the HCP and some said that they would avoid seeking help.

> *"I'd never go to the doctor the first day I was ill. I always take about a week or so to make sure that it wasn't something minor. Be no point in something like missing work, college etc, with something that was going to go away anyway" (EI 18-24 male).*

Other participants mentioned anxiety as a factor that would make them less likely to seek help: Some mentioned that medical situations caused anxiety and others mentioned that they felt anxiety about how the HCP may perceive their actions.

> *"They are wonderful places and all the rest of it. God help us if I go in. I mean even when my husband was in hospital I used to have to go because*

he was in hospital but I didn't like it at all. I thought right you've got to do this- you've got to do this. Ridiculous but I that's how I feel and even going to do the ordinary surgery. I don't like going. I don't think a lot of people do but I really don't. I've really got to brace myself to do it" (ED 65-74 female).

Confusion caused by the advice from others (i.e. social support) and by the health care system was mentioned as was the perception of the complexity of the health care system.

"If it was for the children, I'd check their temperature. See if they've got a temperature and they've been like that for a while, then I'd take them down [to consult the GP]. *But I don't understand this new system because you phone and you get an appointment on the day but that's not an emergency is it?" (MX 25-44 female).*

Participants indicated that there was a perception of limits to the skills of HCPs while others considered that perceived financial costs and perceived limited choice of service might affect their help-seeking.

"If I'm dealing with a sickness and there's a problem that's come on with a child that's more illness related then okay then you think where have I got to go.? I don't have many choices. We have got one hospital in Cornwall with casualty so anything else will basically be to the doctors the surgery. It is a big undertaking to get into casualty because you know you are going to be stuck there for 6, 7, 8 hours. You also know that you are going to have to pay the car parking whilst you are in there. It is never easy" (QX 25-44 male).

A lack of guidance on making help-seeking decisions and a generally poor knowledge of service availability were also mentioned as factors that might impede help-seeking.

5. *Factors perceived to facilitate help-seeking*

In contrast, respondents also highlighted factors that facilitated the decision to seek help. One of the most widely mentioned was the failure of self treatment. This may be closely linked with the notion of waiting and seeing how symptoms progress before seeking help. The failure of social support in helping to resolve symptoms was also mentioned as was the response of others to symptoms. Some respondents were influenced to seek help if their symptoms prevented them from working or pursuing leisure activities.

> *"If it's just a case of I've got a headache, well I know what to do for a headache – if I can't sleep I know what to do if I can't sleep, but if that got beyond my ability to deal with it, if what I was doing wasn't curing it, then I would go and seek help. I don't believe in rushing off ..." (BX 65-74 female).*

> *" It was because they didn't know what I had wrong with me, so I said to myself I'll look on the internet and see what the symptoms are and stuff – and – because my Mum said it could be cancer that I had, so I went into it and looked – and it was similar to what I had"(NQ 18-24 female).*

> *"If I didn't get it cleared up it might prevent me going to work or it might prevent me from enjoying myself, so in which case it would be my main priority – would be to get shut of it, whatever it was" (IN 45-64 male).*

The perception of the HCP as a safety net and the notion that the GP knows best was also mentioned.

> *"You've gone to him so he would decide or she would decide what's best for you. If it isn't, then you go back if it doesn't work" (JH 75+ female).*

One participant saw treatment as a right and several participants considered that the ease of access to the GP made help-seeking easy.

> *"A lot of the time if I think I can treat myself than I would rather treat myself. Although I should be able to go and have a proper... and I think I*

deserve that, because, like I've said, my mother and my father have all paid in, to this thing, which is a great thing, the NHS" (EF 25-44 male).

6. *Lay influences on the decision to seek help*

The decision to seek help was reported to be influenced by informal or lay people. Often this was the influence of social support networks but participants' own response to symptoms was also an important factor. Respondents frequently mentioned that they would attempt to self treat before they sought help. This is reflected in interviewees reporting that they would seek help only when self treatment had failed. Respondents' perceptions of their own ability to self treat was an important factor in that those who saw themselves as able to self treat said they attempted to self treat before seeking help. Closely related to this was the individual's perception of the level of knowledge they had about their own body.

"I think I'd wait a little while to see if it got better maybe. If the pain didn't get better, I'd probably get some paracetamols and try them, and if they didn't work then I'd go to the doctors" (MK 18-24 female).

"If I can deal with something myself and I know I can deal with it, then I will. I've too much respect for the GP" (BX 65-74 female).

Advice from others and social support was often mentioned by respondents as an important influence on their decision to seek help, but for some respondents, social support was not trusted or sought. Others valued social support and saw it as a type of insurance while others were keen to offer social support and help to others.

[Interviewer]: "What would make you decide to take that [help-seeking] *journey?"*

[Respondent]: "Being bullied by people around me to actually go ahead and do it, because you don't feel you want to" (MH 25-44 female).

[Interviewer]: "Would you ever for instance phone up a friend or something of that nature, or ask your husband – something of that nature?"

[Respondent]: "Maybe. Before my older sister died she was the one I would phone if there was anything bothering me. So it was my sister that I used to go to."
[Interviewer]: "Right and I presume obviously if you did phone her up then you valued the advice?"
[Respondent]: "Oh yes. Yes she was very wise, she had 8 children but she knew what she was talking about. Because you get all sorts of problems with 8 children (laughter)" (TP 65+ female).

7. Perception of the source of skills necessary to make help-seeking decisions

Participants were questioned about where they acquired the skills to make help-seeking decisions. The most frequent response was that these skills were acquired from their parents. This response transcended all age ranges.

[Interviewer]: "How did you know how to make those decisions? Where did that come from?"
[Respondent]: "I suppose it would be something that I've always done, - when I was ill as a child I was taken to the GP before hospital, and it's just something that's remained with me" (EI 18-24 male).

"Its your mother's knee I should think. Most things are taught at your mother's knee I reckon. Yes, basic skills of life aren't they?" (CP 74+ male).

Another important influence here was experience. The experience of using different health care services seemed to have a strong influence on subsequent service use. One respondent mentioned that their experience and subsequent distrust of pharmacology influenced their help-seeking and as such that individual sought help from an herbalist rather than a GP.

"He's dealt with me since he's been here, knows me more than anybody else in the medical profession, and I think there's a certain amount – you get a rapport with people anyway, I mean you can go to a surgery and see one doctor and you think, well I won't be bothering seeing you again – and you go to another and you think – yes, this guy or this lady seems to

know what they are on about.... So that was why I would choose to go there..... So no reservations about going to our General Practice, that's the first place I would go for" (IN 45-64 male).

"Well there again, I'm into the homeopathic, because you don't get side effects with homeopathic medicines, and I've had so many experiences of side-effects – I mean once I told my husband I was going to die. I said I shall die if nothing is done. And so of course I just take homeopathic medicine now" (TP 74+ female).

Participants' perceptions of the roles of different HCPs were also an important factor in seeking help. Several participants spoke of their experience of the communication skills and attitudes of HCPs and how this had an influence on subsequent help-seeking behaviour.

"Just the hassle of going there and they don't actually treat you with much respect because they just sit there and say well what do you think's wrong with you – and well, that's why I'm here – I don't know what's wrong with me. Yes, they treat you as though – I mean I'm not asking to be treated personally but like they treat you just the same, 'ah we've just had another case like you come in' whatever. So I tend not to" (NQ 18-24 female).

8. HSUs' perceptions of HCPs' control of treatment decisions

Several participants spoke of their desires to deal with symptoms and issues themselves before seeking help but once that help was sought, they would let the HCP make treatment decisions.

"If you think you can't cope with it yourself, see the doctor." (IN 45-64 male).

"I suppose it all depends on what you think you are poorly with, they don't normally take your blood pressure or temperature or that sort of thing. They ask for your symptoms first and try and narrow it down, and then you leave it to their good judgement" (CP 74+ male).

Another participant commented:

"If it was me you just need someone to come in takeover really sort you out- do what you must do on what you can't do and get real help if you need it. Because when you're like me there is an awful lot of help out there that you don't know about that you need someone to sort you out, tell you what to do and where to go and contact who....."

And later:

"But I will always try and find a cure first. The doctor would be the last resort" (ED 65-74 female).

This theme was echoed by another respondent:

"If I've had something wrong and I've treated it myself, and treated it for over a week and it isn't getting better, it's getting worse, and I know then I need to see a professional. That's when I would go."

Later, she said:

"Well no, it's up to your doctor then isn't it? You've gone to him so he would decide or she would decide what's best for you. If it isn't, then you go back if it doesn't work" (JH 74+ female).

Discussion

This study set out to describe the central features of normal, day-to-day help-seeking behaviour from the perspective of HSUs and investigate the antecedents of these behaviours. The factors involved in the decision to seek help were also of interest as were HSUs' perceptions of where they thought they learned their help-seeking behaviour. The main themes identified from the interviews and group meetings in this study were:

1. What patients seek in a consultation
2. Factors perceived to initiate help-seeking
3. Factors perceived to affect the help-seeking decision
4. Perceived barriers to seeking help
5. Factors perceived to facilitating help-seeking
6. Lay influences on the decision to seek help

7. Perception of the source of skills necessary to make help-seeking decisions
8. HSUs' perception of HCPs' control of treatment decisions

Not unexpectedly, the respondents in this study described multiple factors that they perceived as affecting their decision to seek help from an HCP. The operation and interaction of these factors is complex and has defied effective modelling (Tuckett, 1976; Diefenbach and Leventhal, 1996). Factors related to anxiety and to social support featured strongly in participants' responses as did perceptions of knowledge about health matters and use of and access to health care services.

Factors that are related to anxiety

Fear and anxiety can have a significant effect on the individual's decision to seek help. Smith, Pope and Botha (2005) found that symptom related fear and anxiety was a factor in delayed help-seeking for a variety of cancers. Both Smith et al and Galdas, Cheater and Marshall (2005) noted that men delayed help-seeking for symptoms of cancer because of stereotypical views confirming masculine behaviour. Both these studies focused on specific patient groups. HSUs across all ages and sexes commented that anxiety influenced the decision to seek help. This might lead to delayed help-seeking or cause patients to seek help too soon (for self limiting conditions, for example). Either of these would be categorised as help-seeking mistargeted in time While the findings here reflect those reported by Smith et al. and Galdas et al., it was also observed that the anxiety observed experienced by individuals in this study had several different antecedents, not just the experience of symptoms.

As well has having a variety of triggers, anxiety can affect the individual in a variety of ways and can operate as a factor in both delayed and premature help-seeking behaviour for a wide variety of conditions. Little, Somerville, Williamson, Moore, Wiles, George, Smith and Peveler, (2001) found that anxiety tended to operate through other variables such as the patient's perceived health status and as an independent predictor was not significant. In other words, manipulating the causes of anxiety will have a greater effect on attendance rates than intervening directly with anxiety itself. Causes of anxiety can be many and varied. For instance, anxiety may be the consequence of a gap in knowledge which might lead to low perceptions of health self-efficacy. While patients cannot be expected to have the range and depth of

knowledge of an HCP, a basic understanding of day-to-day health care may go some way to reducing anxiety. Anxiety and fear, however caused, can have a significant effect on the decision to seek help either too soon or too late. Identifying how fear and anxiety operate for the individual or group of individuals may be central to improving the quality of help-seeking decisions.

Factors related to social support

Social support was important to many respondents which reflected findings in the literature (see for instance, Armstrong and Edwards, 2004; Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson, Heyden, Tibblin and Gehlbach, 1983). They described how it could be a valuable source of advice but at the same time it can cause confusion, making the help-seeking decision more difficult and perhaps increasing anxiety. One participant reported that advice offered by family members was sometimes contradictory while others did not trust or seek social support. Some saw it as a valuable form of insurance but most considered it to be a significant influence on their help-seeking decisions. Ellaway, Wood and MacIntyre (1999) note that reduced social support can increase attendance and that those with access to greater levels of social support tended to consult less. It was found that social support was described in different forms and was seen to act as both a barrier and a facilitator to seeking help. Social support will also interact with other variables described here. For example, social support may act to increase anxiety. The mother of a young, female respondent was reported to have commented that the respondent's symptoms may be indicative of cancer. This type of advice may act to raise anxiety levels and trigger an unnecessary consultation. However, it should be noted that increased anxiety may speed the decision to seek help which, in certain circumstances may be prudent. Social support does not just take the form of advice about symptom related action. It may take the form of help in getting to a consultation or support with simple daily tasks, for example. Information about the availability of this type of social support may also influence the decision to seek help. HCPs in the first study reported that some frequent attenders consult because they lack social support networks. Galdas et al. (2005) and George and Fleming's (2004) findings that gender issues and socio economic factors affected help-seeking, indicate the importance of social support networks.

Knowledge

It was found that the perceived level of knowledge that a patient has about health matters will have a direct effect on their help-seeking behaviour. Participants' perception of their own skill and knowledge level when dealing with symptoms was an important factor. Again this variable may act as a facilitator or barrier to effective help-seeking. The role of knowledge about symptoms of specific conditions such as cancers has been well documented in the literature (Scott et al., 2006; DeNooijer, Lechner and DeVries, 2001; Corner et al., 2006). These studies have demonstrated a link between delayed consultation through lack of knowledge about specific symptoms and resultant anxiety once symptoms are perceived to be cancerous. This study has revealed that knowledge about general health matters and day-to-day symptoms is important and can be a strong influence on the decision to seek help.

Data indicate that knowledge about the health care system is important. For instance, one participant in this study reported that changes in the way appointments with GPs are made caused confusion. This is likely to be reflected throughout the self referral system where changes and new innovations are made. Participants frequently commented that they did not use, understand or trust NHS Direct. However, a minority of participants said they did use and were satisfied with the service. Some respondents declared that they always preferred to consult a GP which may be a habitual response to a health need. This habit may have been acquired over a long time or as a result of a strong significant other influence. Such habitual factors are likely to be stable over time and resistant to change. Therefore HSUs' acceptance of new services such as NHS Direct or new ways of accessing services may take some considerable time before they become the choice for the majority as a source of advice. Making the right choice of service or HCP is also likely to be dependent upon an individual's knowledge of the availability of services and an understanding of how to access that service. Any changes to the provision of services are likely to cause confusion amongst HSUs unless comprehensive education programmes are initiated that provide HSUs with the knowledge necessary to make effective use of the service. While participants were reminded that a consultation with an HCP does not necessarily mean seeing the GP, most respondents spoke about just that. The GP was the default source of help for all but one participant. Indeed, some participants acknowledged that they would seek help from their GP surgery for minor wounds before considering casualty. Whilst this might simply be a reflection of the distance

to travel to the hospital, many respondents expressed that feelings of comfort and familiarity with the GP practice was a strong influence on choice of service.

It is important to acknowledge that the factors discussed will affect each individual differently. In addition, it is likely that the interaction of these factors will vary between individuals. Despite this, the assumption that these factors can affect the quality of a decision to seek help is reasonable, based upon the data from HSUs.

Most striking about the responses was that when participants were asked what they expected from a consultation with an HCP they expressed a desire for advice before anything else. This was consistent across all ages, sexes and education levels. It was also observed that, despite continual reminders that HCPs included a wide spectrum of professionals including pharmacists, A&E departments and NHS Direct, for example, HSUs continually spoke and referred to their GP as the first choice for help unless an extreme situation requiring an ambulance was encountered. Even then, some participants said that they would contact their local surgery first. This may be indicative of a gap in knowledge about alternatives. While HSUs cannot be expected to have the breadth and depth of knowledge of an HCP, a basic understanding of common ailments and diseases may help them make better decisions about when to seek help and where to seek that help from. The desire for advice and information took several different forms but among these was the desire for reassurance about the nature and consequences of symptoms. This is likely to be related to fear and anxiety caused by the experience of symptoms, either first hand or through observing the experience of others. However, the desire for advice and information as a result of a gap in knowledge seems to be a primary reason for seeking help.

The source of this behaviour was examined in interviews and found to be strongly rooted in childhood but tempered with experience. The assumption that a consultation with an HCP means an appointment with a GP may reflect the way in which respondents learned their help-seeking behaviour and again this was found to transcend age, sex and educational experience. If, as many respondents reported, help-seeking behaviour is learned from significant others, usually their parents and their parents' parents etc. then it is likely that the local doctor was the first choice of help (if it could be afforded) as the limited alternatives (social support and self medication) may have been far less effective. It also reflects the fact that the GP remains the first choice of help for the majority of help seekers today even when the GP is not necessarily the most effective source of help. Interestingly, the most elderly

of participants (70+ years) said that they learned their help-seeking behaviour from their parents meaning that the help-seeking skills they learned evolved before the inception of the NHS. If this behaviour has been passed down through the generations (and the data suggests that it has) it is not surprising that the habitual, automatic response of help seekers is to consult the GP. This finding transcended all ages, sex and level of educational attainment.

Attempting to deflect demand away from GPs to nurse practitioners or NHS Direct, for example, necessitates the manipulation of entrenched behaviours that have been passed down through generations. One respondent (aged 70+) observed that he learned his help-seeking behaviour at his mother's knee. Observing the help-seeking behaviour of those around you can be explained by Bandura's (1977) Social Learning Theory. Seeing parents and family having unpleasant symptoms relieved after a consultation with a GP is a powerful reinforcement of behaviour which may be difficult to alter, and may explain the reluctance of the majority of respondents in this study to use NHS Direct. One participant did however have a firm belief that homeopathy was the best source of advice and treatment for matters concerning her health. She reached this conclusion after negative experiences of conventional medicine coupled with advice and recommendations from sources of social support.

Control of personal health

Several respondents mentioned that they felt that they were largely responsible and in control of the factors that affected their health but once they sought help from an HCP they were happy to hand over that control of their health to an HCP albeit on a temporary basis. Other participants mentioned their confidence in their own ability to self treat. It is important to recognise that, if individuals have a strong sense that they can successfully self-treat, they may not seek timely help for a condition that requires prompt medical intervention. This may result in help-seeking that is defined as mistargeted in time (i.e. too late). Clearly for the majority of the participants in our study, the perceived ability to control health matters either directly or through a trusted HCP is an important factor when seeking medical help. It was found that respondents thought of the HCP as a safety net but more often they considered that the HCP (usually the GP) knows best. At the opposite end of this spectrum, some participants considered that they would always attempt to self treat before they sought help. This and other dimensions such as an individual's perception of the influence of

'powerful others' can have a significant influence on health behaviour Norman, Bennett, Smith and Murphy (1998) and help-seeking. The majority of participants in this study appeared to have a strong sense of personal control over their health as they seemed to recognise a close link between their behaviour and the outcome of illnesses.

Strengths and Limitations

The subject of this investigation, day-to-day help-seeking, is one that affects virtually everyone. Unlike studies that investigate help-seeking for specific conditions or for specific patient groups or specific circumstances, the subject of this study transcends all of these boundaries. Consequently, the sample size is proportionately very small. HSUs were drawn largely from one small town in North Wales were interviewed. The help-seeking behaviour of people in other settings may well be different and our results therefore have limited generalisability. That said, day-to-day help-seeking amongst a sample of HSUs of males and females from all age ranges and educational backgrounds was investigated. Lack of attendance at focus groups by predominantly younger participants is likely to have skewed views expressed at these meetings toward those of older participants. This investigation has focused entirely on users of primary care health services in day-to-day help-seeking situations. The recording and analysis of their perspectives on why they seek help in the way that they do was attempted. This patient-centred approach was chosen because it reveals HSUs' perceptions of their decision-making and their perceptions about the sources of their consultation behaviour.

This approach to the investigation of factors that affect the help-seeking process is very much top-down in that we do not attempt to investigate the function of all the factors implicated in the decision to seek help. Rather, this study considers the help-seeking process from the point at which the quality of that decision can be judged and then those factors that are likely to affect the quality of that decision are considered. Taking this approach has allowed us to focus on the factors that are most likely to affect the quality of the help-seeking decision. The qualitative methods used here have enabled access to a rich source of data.

Implications

This study has demonstrated that fear and anxiety can be engendered not just by the experience of symptoms but by other factors such as HSUs' expectations of the response of HCPs to the behaviour of HSUs. This study has also shown that an HSU's perceived knowledge not just about particular symptoms, but about their own ability to treat and deal with them and knowledge about the existence, function and appropriate use of the range of health services available is important when making decisions about help-seeking. However, the majority of respondents declared that the deep-rooted initial response is to consult with a GP as the person most familiar with the patient. Social support has been recognised in the literature as an important factor in help-seeking behaviour, but evidence from this study suggests that in some circumstances social support may adversely affect the quality of help-seeking decisions. Research is needed to determine how these factors might function to adversely affect the quality of help-seeking decisions. Further, the degree to which these factors are susceptible to manipulation needs to be understood if interventions to improve the quality of help-seeking decisions are to be implemented effectively.

Chapter 5

Theory

A number of factors that relate to decision making in self referrals to the health services have emerged in the findings from the first three qualitative and quantitative studies in this thesis. In order to aid investigation of these findings and more effectively plan the final intervention study, a number of theoretical perspectives that are considered to be relevant to the themes that have emerged are discussed in this chapter. The consideration of theoretical perspectives in mixed methods research is, as Creswell describes, "an orientating lens that shapes the questions asked" (Creswell, 2009, p.208).

Five relevant theoretical perspectives are identified from the three studies and well-established findings from the literature. These perspectives are the Common Sense Model of Illness Representation, Social Cognitive Theories and Social Learning Theory, Locus of Control, delay and social support.

The Common Sense Model of Illness Representation

A commonly occurring theme in patients' decisions to seek consultations was the desire to receive advice, reassurance and information.

> *"Its generally information I want. If I know what's wrong with me, and generally I do my own treatment as far as I can, but if I don't know then I want information" (Male retired, 65 years).*

> *"It would have to be finding out what's causing it- finding appropriate treatment or getting it repaired or whatever the injury was. I'd like to know what exactly is wrong" (Male student, 20 years).*

An HCP interviewed for study 3 noted that there were many mistargeted consultations:

> *"A lot of what see you could reasonably argue would be self-limiting, non-threatening presentations which if they left it for a while wouldn't need to be seen at all" (General practitioner; A).*

The type of potentially avoidable consultation described above is a common occurrence for general practitioners (GPs) and other HCPs to whom patients can self refer. It falls within the definitional parameter of a 'potentially avoidable'

consultation. Potentially avoidable consultations were found to account for 15.12% of all consultations made with a GP (Chapter 3). Data from study 3 with health service users (HSUs) indicated that patients often saw the GP as the default source of healthcare advice and, as such, they often made potentially avoidable consultations for a self limiting condition, when they could have visited a pharmacist or practice nurse for a condition that might reasonably be self treated. Leventhal, Mayer and Nerenz's (1980) Common Sense Model of Illness Representation (CSM) attempts to model the way in which individuals cognitively and affectively represent illnesses and enables the response to those illness threats to be predicted.

The CSM (Leventhal et al., 1980) integrates the affective, emotional aspect of the representation of illness when there is a perceived objective reality of a threat to health. It was developed from Leventhal's (1970) *parallel processing model* and was adapted to explain how patients represented and dealt with illness threats. It addresses some of the criticisms of the most commonly used approaches to health behaviour (e.g. the medical model, the Health Belief model (Rosenstock, 1966) and the Theory of Reasoned Action (Fishbein and Ajzen, 1975) which, Diefenbach and Leventhal (1996) argue, do not consider the patients' common-sense representations and beliefs about their illness (Diefenbach and Leventhal, 1996).

The parallel-processing model considers two basic and largely independent, parallel processing systems; one *emotional* or affective, the other more psychologically objective or *cognitive.* These two parallel processes are involved when a symptom is experienced. The emotional processing system generates an emotional response to an illness threat while the other generates a cognitive representation of the stimulus (symptom). The cognitive representation will be affected by the emotional response to a symptom but equally, the cognitive representation will elicit an emotional response. Leventhal et al. (1980) proposed that these two systems (the emotional and the cognitive) work in parallel and inform each other (see Figure 1) which gives rise to a set of coping procedures. These are appraised and evaluated by the individual for their effectiveness in dealing with a perceived threat to health which can arise from external or internal sources.

The cognitive processing system is based upon schematic representations of illness which are derived from prior experience of illness or experiences of another's illness. For instance, the schematic representation can be prompted by a number of

potential schemas. The matching process appears to be dependent upon five distinct attributes:

The identity; disease label and symptoms associated with that label

The timeline; whether the disease will be chronic, acute or cyclical

The (imagined) cause; eating too much, too much exercise, binge drinking, genetic predisposition etc

Controllability; the perceived effectiveness of self treatment, medication etc in treating or controlling the disease or its symptoms

The (imagined) consequences; disability, impact on social functioning etc

According to the model, these criteria for matching a stimulus to a schema will determine the way in which the illness threat is represented by the individual. The representation of that illness threat will subsequently determine the coping strategy employed to deal with that threat (including the *decision* to seek or not to seek help). The individual will then appraise the effectiveness of the coping strategy, a process which is continual until the symptom is alleviated.

Leventhal, Meyer and Nerenz (1980) point out that there are three important underlying tenets to the model:

- The individual sets out to solve a problem by gathering information and testing hypotheses about the illness threat experienced.
- The representation of the illness guides the coping strategies adopted as a result of interpretation of information gathered. Outcomes of coping strategies are appraised and the expectation of outcomes of coping strategies adjusted.

Representations about the illness threat constructed by the individual are highly individualised and may not necessarily reflect current medical understanding of a condition or symptom. As far as the individual is concerned, the response to an illness threat (the coping strategy) is correct even if it is medically irrelevant to the resolution of the threat.

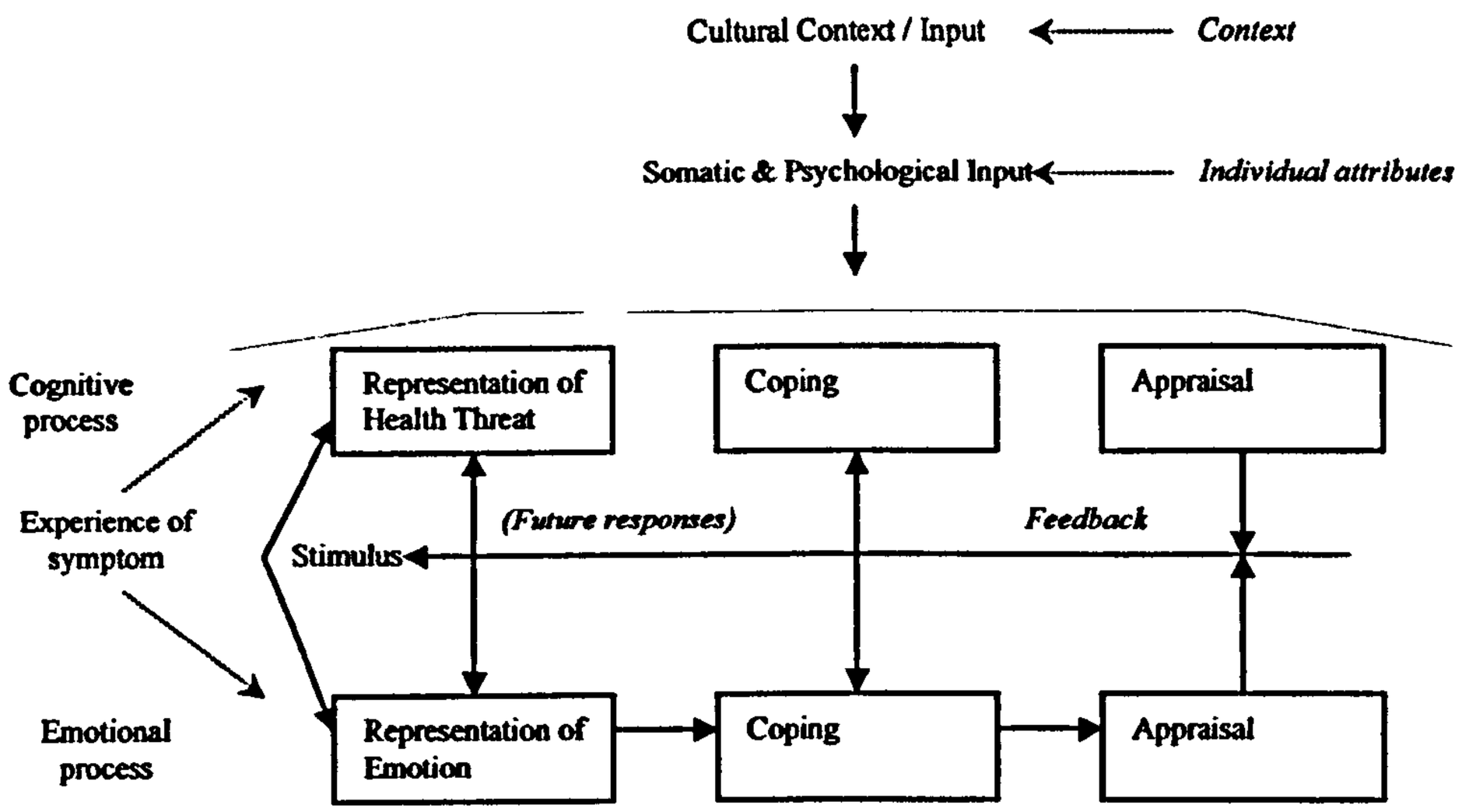

Figure 1: The Common Sense Model of Illness Representation Adapted from Diefenbach and Leventhal (1996)

For instance, head lice are a common problem amongst school-age children (Ibarra, 2001). However, reactions from parents can differ profoundly. An Out-of-Hours GP commented that *"The patient's perception of nits may be* [that an infestation is] *disastrous."* Different patients may have very different representations of the same symptom. A nit infestation can be seen as an inevitable consequence of children mixing in close proximity or an embarrassing anti-social problem. As such the response to the condition varies greatly between parents.

The CSM provides a framework for understanding such a wide variation in response. The start of the CSM is the experience of a stimulus or illness threat which in this hypothetical case is a child's infestation of head lice. The parent is the patient inasmuch as the parent is the individual who responds to the condition. The CSM proposes that the somatic stimulus is dealt with on two levels; the cognitive and the emotional. Beginning with the cognitive, the stimulus may be represented in the following way: *identified* as an infestation of head lice which is an irritation to the child who scratches her head. Additionally, she may suffer from secondary symptoms associated with scratching, such as a sore scalp. The child may also be upset and experience an adverse reaction from other children in the school, all of which the parent may consider to be severe and wish to alleviate. The *timeline* of the condition may be chronic or on-going unless remedial steps are taken. The cause of the condition is the source of the infestation, i.e. other children in the school. The

condition can be controlled by a number of methods, for example, chemical treatment or careful combing. The *consequences* of the condition may be physically unpleasant for the child, socially isolating and have an economic cost associated with the purchase of medication. The emotional representation of the condition may be one of embarrassment, annoyance or acceptance as part of normal school life also depending on the perceived health threat. The coping mechanisms employed by the parent to deal with the condition are informed by both the emotional response to and the cognitive representation of the condition. If the parent's cognitive representation of the condition is based upon prior experience of the condition and the emotional representation is one of acceptance of head lice as a normal part of school life, the coping response may be to visit the pharmacist, take advice and purchase a suitable remedy for head lice. If, on the other hand, the cognitive representation is not based upon prior experience and the emotional representation is based upon embarrassment and annoyance, the parent may seek an emergency consultation with a doctor. If the economic consequences of purchasing appropriate medication are important to the parent, a free prescription may be an additional reason for choosing a consultation with a doctor as a coping mechanism. When the parent appraises the adopted coping procedure, the response of the doctor, the effectiveness of the pharmacist's advice, the medication purchased and the speed of the condition's resolution will all inform the parent's future emotional response to and cognitive representations of the condition should it occur again. Whatever the eventual, future representation of the condition, it will be highly individualistic and may not have much basis in medical 'fact'.

According to Diefenbach and Leventhal (1996), the CSM integrates an individual's emotional responses and cognitive, schema-based response to an illness, or threat of illness to form an integrated representation of that illness threat to which the individual responds. The CSM enables hypotheses to be developed and tested about why individuals behave in the way they do to an illness threat. Diefenbach and Leventhal describe the model as 'open'. By this they mean that the model can accommodate numerous variables which may be unique to specific domains. For instance, specific diseases or social conditions, or variables that are specific to individuals or groups.

The model addresses the major criticism levelled against most social and cognitive models; namely that they assume decisions about engagement in health behaviour are rational and based upon a balance between benefit and the cost of

engaging in such behaviours. The Social and Cognitive theories and models (such as the Health Belief Model and the Theory of Reasoned Action, for example) tend to focus on the behaviour an individual may engage in to aspire to or maintain a state of health. The Health Belief Model (Rosenstock, 1966; Becker and Rosenstock, 1984), for example, considers psycho-social variables, but does not consider the emotional context within which the individual operates. The CSM however, acknowledges the more subjective, emotional dimension (emotions that were frequently acknowledged by participants in study 3) involved in deciding whether or not to adopt a particular health behaviour.

The CSM has been applied to areas other than health maintenance or avoidance of the threat of illness, such as compliance (or concordance) with medical advice (Leventhal, Diefenbach and Leventhal, 1992; Cameron, Leventhal and Leventhal, 1993) or treatment regimes and care seeking behaviour. Diefenbach and Leventhal (1996) note that the model can consider 'external' factors individually despite their diverse nature, whereas other models simply group them under an 'external' heading.

However, the model describes the behaviour of individuals in a largely isolated context. Acting in a social environment, the individual will be strongly influenced by others and the model does not explicitly address this effect. For example, an individual's first realisation of the potential severity of a condition may be via a comment or advice from another individual which was not sought by the person with that condition.

> *"My mum said it could be cancer that I had, so I went into it and looked* [on a web site] *and it was similar to what I had" (18 year old female student).*

Such a might be the first indication an individual has that they have a condition that warrants intervention. The model assumes that the information seeking stage is entered into pro-actively by the individual, but this may not necessarily be so in many cases.

The CSM describes the process of making a decision about healthcare that an individual follows. This process is traced from its origin (the experience of illness or the threat of an illness) to the action an individual engages in to either alleviate or

manage that illness or mitigate the perceived threat of that illness. One of the central tenets of the CSM is that the decision made is psychologically correct, i.e. it is subjectively correct. Leventhal, Diefenbach and Leventhal (1992, p.148) recognise that; "the specific procedures selected to cope with it [illness or the threat of illness] are perceived as appropriate and necessary: that is, they are correct psychologically even though they may be irrelevant to the control and cure of the condition". The decision is judged by the *individual* therefore the assessment of the quality of the decision is highly subjective and may not bear any relationship to the *actual* quality of the decision.

The CSM has been successfully applied to a wide variety of situations, both medical and non-medical. Some examples of its application are the reduction of stress in symptom management (Fowler, Kirschner, Van Kuiken and Baas, 2007), the examining of perceptions of risk of common diseases in family histories (Walter and Emery, 2007), perceptions of risk of cancer (Kelly, Leventhal, Andrykowski, Toppmeyer, Much, Dermody, Marvin, Baran and Schwalb, 2005) and understanding the perceived risk of the presence of arsenic in well water (Severtson, Baumann and Brown, 2006). Quinn (2005) applied the CSM to patient delay in seeking help for acute myocardial infarction (AMI) and found the CSM to be significant predictor of delay time in seeking emergency healthcare. Delay was caused by a complex interaction of factors which, conceptualised within the framework of the CSM, included the identity of the health threat and a causal attribution of the health threat (an AMI). Those patients who correctly identified and attributed the cause of the health threat sought help more rapidly than those patients who did not. In the context of Study 1 this was the difference between an effectively targeted consultation and a consultation mistargeted in time.

In Study 3 it was found that patients' perception of their own skills and abilities was a significant factor in deciding when to seek medical help or advice. Patients who perceived their skill level to be reasonably high reported that they would attempt to self-treat before seeking medical help and only seek help if that self treatment failed. The CSM considers this in the form of the patients' perception of the controllability of a condition. It is important to note that 'controllability' not only refers to the patients' perceived ability to deal with an *actual* symptom, but also the patients' perceived ability to control the perceived or actual *threat* of symptoms by taking preventative exercise or diet, for example.

The CSM models the emotional aspect of illness representation in conjunction with cognitive representations allowing predictions of coping strategies to be made. More than this, the model goes on to illustrate how individuals' assessments of the coping mechanisms they employ go on to affect future representations of illness and subsequent coping strategies. One of the central tenets of the model is that the coping mechanisms employed by the individual are:

- psychologically correct and
- subjectively assessed in terms of the quality of the decision to employ a given mechanism.

The CSM does not therefore, lend itself to predicting the actual, objective quality of an individual's decision of when and how to seek healthcare and from whom.

As Diefenbach and Leventhal (1996), point out, the model is 'open' and has been developed to accommodate adaptations. The model can thus be applied to a range of cultural and social situations as well as to different individuals. However, the qualitative and objective assessment of an individual's coping strategies by, for example, a HCP cannot easily be integrated into the model because the model centres on the *individual* and the individual's subjective, emotional representation and cognitive representation of an illness threat resulting in a coping response unique to that individual.

Any intervention designed to manipulate variables that underpin the quality of a patient's help-seeking decisions will need to take into account the factors that, according to Leventhal et al. (1980) can result in a potentially avoidable consultation. To that end, emotional or affective factors such as the fear and anxiety experienced by an individual as a result of the perception of an illness threat must be considered. Similarly, cognitive factors such as a patient's basic knowledge of healthcare systems and their own health and physical needs and conditions, health locus of control and self-efficacy are implicated. How patients apply coping mechanisms is also important. If these variables are susceptible to manipulation, it follows that interventions can be devised where the quality of help-seeking decisions can be improved according to the CSM.

Social Cognitive Theories and Social Learning Theory

> *"I'd have to say my parents, because you know when you're growing up and you're ill they take you to the doctor. And you see them go to the doctor if they are ill, so I think it's just a learned response off the parent, you know, I go to the doctors and see if they can help" (Female homemaker, 18-24 years).*

> *"Its your mother's knee I should think. Most things are taught at your mother's knee I reckon. Yes, basic skills of life aren't they?" (Male retired, 74+ years).*

The above quotations illustrate the central role played by parents and family in an individual's consultation-seeking decisions. This notion was repeated by several HSUs and transcended age and sex. Indeed, some of the oldest participants considered their parents to be one of the strongest influences on their consultation-seeking behaviour. General life experience and the more focused experience of being ill were also considered to be important factors but these were usually reported as secondary to the influence of parents and family. Bandura's (1977) Social Learning Theory (SLT), which is the best known and arguably the most influential Social-Cognitive theory suggests that individuals learn much of their behaviours from significant others around them, modelling their own behaviour on the behaviour of others. Children especially learn much from vicarious observation of the reinforcement of actions.

SLT was born out of Bandura's work examining learning in a social context. Evolving his ideas from the behavioural approach, Bandura described learning in the classical behavioural context but considered the effect of cognitive factors mediating the responses to stimuli. Bandura considered the role of others in the learning process, being unconvinced by the behaviourists' somewhat laborious process of stimulus-response learning. He considered that learning is far quicker and more effective when the learner observes a 'model' in the social environment. Learning, he considered, would take place immediately upon observation of the model but reinforcement would be necessary for that learned behaviour to be displayed. Furthermore, he argued that the display of the learned behaviour may not take place

immediately. The notion that an individual could learn through the experiences of others resulting in outcome expectancies for their own behaviour led to a paradigm shift in psychology.

In a health setting, for example, if a parent's visit to the HCP results in the resolution of an unpleasant symptom, the child will learn by observation that visiting the HCP is the best course of action, should a similar circumstance be encountered by them. This perception may be facilitated through the observation of the actions and responses of others or through direct personal experience. Of course, some visits to the HCP may result in uncomfortable or painful treatments but if the observed attitudes and actions of others, together with personal experience, lead to satisfactory outcomes, the benefits of consulting the GP will be seen to outweigh the discomfort of treatments.

Interestingly, the data from the third study indicates that this social learning process has informed the consultation-seeking behaviour of the oldest through to the youngest participants. They stated that they learned their behaviour from preceding generations, i.e. the oldest participants. The oldest participants would themselves have learned their consultation behaviour before the creation of the NHS and might have been expected to express different attitudes to those of a younger generation.

Bandura's (1977) Social Learning Theory is central to the Social Cognitive group of theories. This group of theories includes some of the most commonly used theoretical models in health psychology such as the Health Belief Model, the Theory of Reasoned Action and the Theory of Planned Behaviour which also owe much to the expectancy value group of theories (Lewin 1936, 1952; Tolman 1932; von Neuman and Morgenstern 1944; and Rotter 1954, for example).

The Health Belief Model (HBM; Rosenstock, 1966; Becker, 1974; Janz and Becker, 1984; Becker and Rosenstock, 1984) is the most commonly used model of health behaviour. It has undergone extensive revision since it was first proposed by Rosenstock in 1966. A development of Field Theory (Lewin, 1936; 1952), the HBM is based on the underlying principle that positive and negative influences affect people's behaviour. The HBM is therefore aimed primarily at explaining and predicting behaviour that will influence a person's state of health such as taking exercise and avoiding behaviours that increase the risk of disease or injury.

Central to the model are five key variables:

1. *Perceived susceptibility*

2. *Perceived severity*
3. *Perceived benefits*
4. *Perceived barriers*
5. *Cues to action*

The collective effect of these variables will result in a health 'action'. The model has been criticised as being little more than a collection of variables (Oliver and Berger, 1979) offering little to explain the way help-seeking decisions are made by individuals when they experience illness.

The Theory of Reasoned Action (TRA: Fishbein and Ajzen, 1975) evolved shortly after the HBM and attempts to address the major criticism of the HBM, namely that it is little more than a collection of variables. It differs from the HBM in that it is based on an individual's perception of what is normal (subjective norms- the individual's internal representation of the social world). The intention to behave is therefore a function of the individual's attitude (subjective expectations / probability of a particular outcome occurring) towards the salience of behaving in a particular way and what the individual sees as normal for a situation. The intention to act in the future is a reasoned thought followed by behaviour and includes the social context in relation to the individual's view of social normality. This theory is an application of an expectancy-value theory (EVT). An adaptation of the TRA, the Theory of Planned Behaviour (TBP), incorporates an individual's perception of control over the performance of a behaviour in terms of their perception of the locus of control of that behaviour (Conner and Sparks, 2005). Behavioural intentions (i.e. intentions to respond to a *potential* threat) are the result of three sets of beliefs; *attitudes towards behaviour*; *subjective norm*; *perceived control*. Again, this model is not specifically a 'health' model but is an EVT applied to the health setting.

Protection Motivation Theory (PMT: Rogers, 1975; 1983) and the Trans Theoretical Stages of Change (TTSC: DiClemente, 1993) are two further theories that have been applied to the health setting. While not developments of the HBM or subsequent theories or models, they are social cognitive theories. The PMT has been used in two basic ways, firstly as a method of evaluating the effectiveness of the communication of health messages to HSUs (smoking cessation, for example) and secondly as a social cognition model of behaviour that predicts health behaviour (Norman, Boer and Seydel; 2005). Again, this theory of health behaviour has been developed to explain behaviours that people engage in to protect, maintain or aspire to

a state of health. It therefore considers the actions of an individual when considering perceived future threat to health. As such it offers little which helps to explain or predict help-seeking decisions.

Trans Theoretical Stages of Change is the dominant member of a sub-group of social cognitive theories known as 'stage theories' that evolved from an extensive range of psychotherapeutical theories of behaviour change (Sutton, 2005). As the name suggests, its principal role is to describe and predict health behaviour changes. It has been used most widely to explain the process of smoking cessation and inform interventions designed to facilitate smoking cessation. As such its relevance to the help-seeking decision making is at best limited.

The theories described above consider and predict an individual's *intended* actions as a response to a perception of a *future potential* health threat. Variables central in these theories include; the perception of the likelihood of the occurrence of a threat (TBP); the perception of susceptibility to a threat to health (HBM); threat perception (TRA); and perception of vulnerability to a threat (PMT). All these variables are concerned with a *potential future* threat to health that may or may not occur. Predictions of the outcome of action based upon the mediation of other variables such as perceived *severity* of the threat and the perceived ability to take action are then made. These models do not lend themselves well to predicting an individual's response to an occurring health threat (i.e. the immediate presentation of health threats or symptoms) and as such have little theoretical relevance to the prediction of behaviour at the onset of symptom experience. They do however, facilitate the understanding of how individuals conceptualise and respond to perceived vulnerabilities to health threats. They are also reasonably reliable in predicting behaviours which are aimed at protecting, maintaining or helping the individual aspire to a state of health but they are of limited use in explaining how an individual makes an immediate decision or response to a symptom.

Individuals' belief in their ability to effect change and have control over events and demands in their lives is central to Bandura's concept of self-efficacy within a social learning theory paradigm. Self-efficacy is now a central theme of social cognitive theories. Having a low self-efficacy means an individual has a poor perception of his/her ability to accomplish tasks which makes undesirable behaviours such as avoidance of decision making more likely (Marks, Murray, Evans, Willig, Woodall and Sykes, 2005). Increasing self-efficacy will improve an individual's

ability to display positive behaviours such as effective consultation actions and increase his/her perception of his/her own ability to effect change and achieve goals.

Based on Bandura (1977) and Egan (1994), Rollnick, Mason and Butler (1999) suggest five ways in which self-efficacy can be improved:

- Perceived self-efficacy varies across situations. Where it is high, an individual needs praise and encouragement and where it is low, the individual should be helped to seek different approaches for improving self-efficacy.
- Practical exposure and practice in situations where self-efficacy is low is the best way to enhance self-efficacy.
- Individuals need to have the necessary skills to succeed and enhance performance and thus self-efficacy.
- Egan (1994) suggests that any deficiencies within an individual's performance should be highlighted but not presented as deficiencies in the individual.
- Modelling is important- individuals with low self-efficacy should be encouraged to interact with people who have achieved desired goals, for example peer groups and self help groups.

(Adapted from Rollnick et al., 2005)

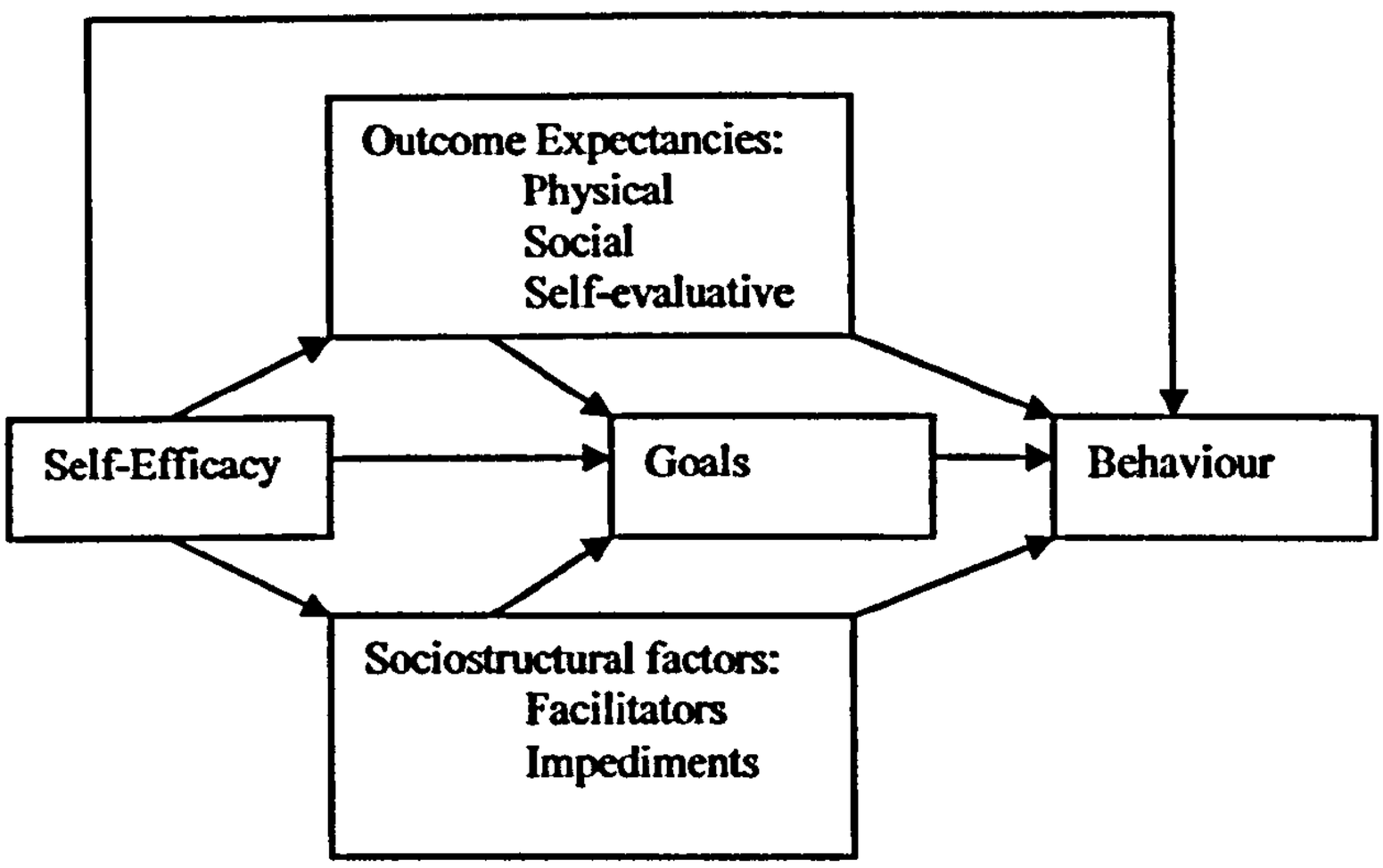

Figure 2: An illustration of the role of self-efficacy in social cognitive theory (adapted from Bandura 2000)

Self-efficacy has a direct effect on outcome expectancies. High self-efficacy leads to higher outcome expectancies. For instance, high self-efficacy in an exercise context

might lead an individual to have high expectations of success and set higher performance goals. This may be further enhanced by the individual actively and effectively seeking circumstances that facilitate the pursuit of personal goals that they perceive they can achieve and confidently addressing any barriers to success. The successful achievement of personal goals will promote individuals' self-efficacy which will lead to higher expectations of future success and more positive achievement behaviours (see Figure 2).

One of the central tenets of SLT is that learning is facilitated by the role of models and subsequent learned behaviour is positively reinforced. There are multiple factors that mediate this process such as the degree to which a learner identifies with a model and the relevance of the modelled behaviour. In the context of health behaviour, specifically help-seeking behaviour, the actions of a parent in seeking a consultation with an HCP may act as a model for a child. If the visit to the HCP or multiple visits consistently result in the alleviation of the child's symptoms, the child may learn that the process of visiting the HCP leads to an improvement in health. The visit is positively reinforced by the alleviation of unpleasant symptoms.

Learning is not restricted to children, of course. SLT predicts that individuals are likely to model their behaviour on that of successful others in order to achieve a desired outcome. However, an individual's level of perceived self-efficacy directly influences the effectiveness with which he/she is able to model the behaviour of others and thus become more effective. Individuals with low self-efficacy are less likely to adapt their behaviour successfully to changing situations. When health systems change through the introduction of new methods of accessing health care or the need to access different types of health care (for example, health visitor services when a first child is born) high self-efficacy individuals are more likely to adapt more quickly and effectively than are those with low self-efficacy.

SLT offers a theoretical explanation for the way individuals learn to make help-seeking decisions and also offers an explanation of how they adapt their behaviour to new circumstances. Bandura's approach can be applied to immediate circumstances such as the experience of symptoms. This is unlike other social-cognitive models mentioned here that predict health behaviours such as taking exercise or eating healthily, based upon the avoidance of perceived or actual health threats. Self-efficacy has been shown to be an important predictor of health behaviour change. For instance, Wulfert and Wan (1993) examined condom use amongst

university students. They found that changing self-efficacy had a significant impact on increasing condom use but increasing knowledge about health risks alone did not.

Social cognitive models of health behaviour have been criticised by several authors (see for example, Conner and Norman, 2005; Sutton 1998; Smedlund, 2000; Ogden 2003). Ogden directs her criticisms at four models; the HBM, the TRA, PMT and the TBP. She discusses four main criticisms of the social cognitive approach. Firstly she highlights the limited ability of the approach to explain the variance in behaviour observed in a number of studies. Secondly, she argues that the data collected during these studies is presented as supporting the models but data that challenges or refutes these theories cannot be found, therefore making the theories untestable. Thirdly, from a philosophy of science standpoint, the theories are criticised as being analytically true rather than being scientifically testable through observation (synthetically true). Ogden points out that the four theories singled out above are inherently analytically true by virtue of the operationalisation of variables through participant self report. Finally, Ogden questions whether cognitions under examination are pre existing or being created by inviting participants to imagine their response to a hypothetical situation. If the participant has to imagine a novel situation then cognitions associated with that event will inevitably have to be created by the participant. Therefore, the cognitions being measured are not pre-existing and the action of measurement creates that which is being measured.

Ajzen and Fishbein (2004) responded specifically to Ogden's (2003) criticisms pointing out, amongst other rebuffs, that Prochaska and DiClemente's (1992) Transtheoretical Stages of Change Model and Bandura's (1977) Social and Cognitive model are "conspicuous by their absence" (Ajzen and Fishbein, 2004; p431) suggesting that these models do not succumb to Ogden's criticisms. Marks et al., (2005) criticise the social cognitive approach as being "too mechanistic" (p.202) and considers the cognitive process in isolation from the social context of health promotion.

Despite criticisms of the majority of the social cognitive theories, Bandura's (1977) Social Cognitive Theory which encompasses self-efficacy can inform interventions designed to manipulate some of the psycho-social variables that underpin help-seeking decisions. Social learning theory predicts that effective (or ineffective) learning is facilitated by exposure to behaviours modelled by significant others. In the context of help-seeking decision making, learning of effective

behaviour would occur through the exposure to others who have made effective help-seeking decisions in the past and who can provide support and encouragement to those who will engage in that decision making process. An intervention designed to increase the effectiveness of help-seeking decisions would benefit from providing participants with effective models of help-seeking decision makers. Simply providing information, as Wulfert and Wan (1993) have shown is not sufficient. As Rollnick et al. (1999) suggest, equipping individuals with the tools necessary for achieving their goal (improving decision making effectiveness) is important. To this end, an educative approach is necessary where individuals are given the knowledge and skills necessary to make effective decisions. This must be coupled with exposure to models of successful or effective behaviour, facilitated by others who have achieved desired goals. It is hypothesised that this will have the effect of increasing their perceived self-efficacy for making effective decisions. Hypothesised effects such as improved self-efficacy and enhanced knowledge levels and exposure and support from others can be measured using health self-efficacy report scales, measures of social support and measures of health and health systems knowledge.

Self-efficacy, along with perceptions of control, was considered by Ajzen (2002) as important within the Theory of Planned Behaviour. Although the Theory of Planned Behaviour was an adaptation (Ajzen and Fishbein, (1980) of the Theory of Reasoned Action, unlike the premise of the Theory of Reasoned Action, it is not assumed that all human behaviour is under volitional control (Ajzen, 2002). Behavioural intention is seen as the antecedent of behaviour. This, along with the actual degree of control an individual has over the behaviour predicts the behavioural action, but, actual control must be considered as a covariate with perceived control. It is important to acknowledge that the ultimate behavioural goal is often achieved by the attainment of a series of lesser behavioural goals. Actual and perceived control issues interact to affect the individual's ability to perform behavioural actions resulting in the goal behaviour. Self-efficacy impacts on individuals' perceptions of control and, as discussed previously, affects expectations and behaviour. For instance, two patients experiencing a skin infection may demonstrate very different consultation-seeking behaviours based on their levels of self-efficacy in a health context.

When considering the concept of self-efficacy and its role in TPB, Ajzen (2002) addresses the importance of differentiating between perceived controllability

and self-efficacy. According to Ajzen, perceived controllability is the subjective belief in one's ability to control / perform a specific behaviour or set of behaviours, whereas, self-efficacy refers to an individual's belief in their general / global ability to perform behaviours and achieve goals. While it is difficult to differentiate these two variables, studies have shown that, when considered as two separate variables, they better explain data from studies examining control in a TPB context. Ajzen highlights two studies amongst several that have challenged the concept of perceived controllability and self-efficacy acting as a unitary variable. Terry and O'Leary (1995) found the differentiation of self-efficacy and perceived controllability better predictors of actual behaviour than taking perceived controllability and self-efficacy as a unitary variable. Manstead and van Eekelen (1998) found that self-efficacy predicted school children's test scores better than perceived controllability that was found to be a poor predictor.

Ajzen (2002) goes on to consider the concept of locus of control and its relevance to TPB (see below for an examination of the concept of locus of control). He argues that the locus of control has little effect as a predictor of behaviour as an individual's general locus of control within a context does not affect the perceived control an individual has within that context. For example, when considering an individual who has been advised to lose weight, the individual may have adequate knowledge of the calorific values of various foods which he/she is eating. This is an internal factor, i.e. internal locus of control. The individual happens to live in close proximity to a low calorie food store. This factor is beyond the immediate control of the individual and is as such, is an external factor. Conversely, the individual may have little willpower to succeed or may prefer to eat high calorie food. This is the individual's choice and is an internal factor. Similarly, the individual may have no access to healthy or low calorie food despite having the willpower to lose weight. This is an external factor and is beyond the control of individual. The ease or difficulty in eating a low calorie diet reflects the beliefs about factors that are within and beyond the control of the individual.

Locus of Control

> *"If you asked* [my partner] *she would say 'myself of course', she would be very confident but when it comes to practical things she does defer to other people" (Male craftsman, 25-44 years speaking about his partner's perception of control of her health and their children's health).*

The degree to which people feel in control of their own health is an important factor in their decisions about seeking healthcare. Locus of control was first described by Rotter (1966) as an element of his earlier Social Learning Theory (Rotter, 1954). As first described, locus of control operates on the two dimensions of internal locus of control and external locus of control. Individuals who perceive themselves to be in control of the outcome of their behaviours are described as having an internal locus of control whereas those who consider the outcomes of events that affect them to be controlled by powerful others or by chance are said to have an external locus of control. As a general concept, locus of control can be applied to any behavioural situation. Locus of control is distinguished from Perceived Locus of Causality (PLOC) in that PLOC is concerned with the extent to which the individual perceives they have a choice of their behaviour (either internal or external to the individual) whereas locus of control is concerned with the perception of control over the *outcome* of their behaviour (Ryan and Connell, 1989).

Individuals understand that they have varying degrees of control over the outcome of their behaviour in different situations. For example, they may perceive strong internal locus of control in a situation in which they are skilled (high self-efficacy) and have previously experienced a strong behaviour-outcome contingency. Equally, individuals may find themselves in a situation where their behaviour has not led to the desired outcome and may, as a consequence, perceive a more external (powerful others or chance) locus of control. Pre-dispositional locus of control is said to be relatively stable (Rotter, 1990) although Skinner (1995) considers 'pre-dispositional' locus of control to be more 'state' than 'trait' suggesting that locus of control is susceptible to manipulation. However, as with many other psychological characteristics (e.g. self-efficacy, Bandura, 1977) measurement at the global level is less likely to be predictive of behaviour than is measurement of locus of control at the situational or action level. Social Learning Theory (Rotter, 1954) suggests that, as an

individual's experience of specific situations increases, so that individual will develop specific expectations about that situation. As such, when researchers are interested in behaviours in specific situations, a general measure, such as locus of control, will be inherently limited at predicting that behaviour (Bandura, 1997).

Ajzen (2002) criticised the distinction between internality and externality in that an individual may consider it internally easy to perform a behaviour such as losing weight, but there are external factors that act as barriers to that behaviour being carried out such as difficulty in accessing low fat food (Ajzen, 2002). In this sense, he argues that "perceived control over an outcome or event is independent of the internal or external locus of the factors responsible for it." (Ajzen, 2002; p. 676). Ajzen goes on to note that the locus of the resources necessary to perform a behaviour is irrelevant: it is whether the necessary resources for that behaviour to be performed are available to the individual.

An individual who believes that they can perform a behaviour effectively is more likely to attempt that behaviour and is said to have a greater perceived self-efficacy (Bandura, 1977). Considered together, an individual with a high perceived self-efficacy (capacity) and an internal locus of control (control) is likely to attempt a behaviour and expect a high degree of success in achieving the desired outcome of that behaviour. Low perceived self-efficacy and an external locus of control may eventually result in learned helplessness (Seligman and Maier, 1967). When an individual learns over time that there is no behaviour-outcome contingency and that the outcome of any action is entirely externally controlled and thus beyond the individual's sphere of influence, the long term effects can be very debilitating.

Locus of control has been applied to the field of health behaviour where it has been used to predict the adoption of positive health behaviours (Marks, Murray, Evans, Willig, Woodall and Sykes, 2005). The general locus of control scale was further developed specifically for application to health behaviours resulting in the Health Locus of Control scale (Wallston, Wallston, Kaplan and Maides, 1976). The HLC scale still retained the two dimensional quality of the original locus of control scale. To address this limitation, the HLC scale was further developed to include a third dimension; chance or luck. The result was the Multidimensional Health Locus of Control (MHLC) scale (Wallston, Wallston and DeVellis, 1978).

The HLC scale and the concept of health locus of control have not been without limitations. Norman, Bennett and Smith (1998) asked participants to

complete a questionnaire that assessed Health Locus of Control, health behaviours and health values which were combined to form one variable; a health behaviour index. They found, as expected, a positive correlation between the health behaviour index and internal locus of control and a negative correlation between the index and chance and powerful others subscales. While this was an expected outcome, overall, Norman et al. noted that health behaviour was only weakly predicted by HLC scales.

Writing in 2005, Wallston notes that locus of control should not be considered in isolation when trying to predict health behaviour. Indeed, he states:

> *"Not only does the value of health theoretically moderate the relationship between health locus of control beliefs and health behavior, but so does self-efficacy, a behavioral expectancy that the individual can do the behavior, as well as perceived instrumentality, an outcome expectancy [locus of control] that doing the behavior will lead to good health."*
>
> *Wallston (2005, p.629)*

Essentially, Wallston is acknowledging that, on its own, even the multidimensional HLC scales need to be considered in conjunction with other measures because they are, by themselves, weak predictors of health behaviours.

Despite these identified limitations to the concept of locus of control when applied to health, HLC measures continue to feature in research. The locus of control scales used are focused specifically to certain behaviours and conditions, for example, the Weight Locus of Control (WLOC) scale (Saltzer, 1982) and The Parental Locus of Control Scale (Campis, Lyman and Prentice-Dunn, 1986). Health locus of control will be measured in the intervention study as this, despite measurement difficulties, is viewed as a key factor in determining the direction of decision-making.

Delay

> *"I've tried all my things- you know? What I would do to try and cure it, and probably I'm my own worst enemy because I leave it too late sometimes, as I have recently" (Female, retired, 74+ years).*

Many of the participants interviewed for study 3 expressed their reticence about visiting the doctor. Attitudes such as these can lead to delays in seeking consultations. Cacioppo (1983) described different types of patient delay in his General Model of Total Patient Delay. Delay in seeking treatment for a potentially serious condition may have profound consequences for the patient's eventual recovery. Cacioppo described some of different types of patient delay and Anderson et al. (1995) used Diefenbach and Leventhal's (1996) CSM to explain why people delayed seeking consultations for potentially cancerous symptoms.

Cacioppo's (1983) The General Model of Total Patient Delay based upon Psychophysiological Comparison Theory (PCT) illustrates the process of patient delay in seeking help for unexplained symptoms. This simple model, founded on PCT, posits a "general attributional framework [that] has been proposed for the psychological processes governing the detection of symptoms and their translation into illness inferences and appraisal delay" (Anderson, Cacioppo, and Roberts, 1995. See Figure 3). PCT brings together a range of theoretical explanations for illness behaviour and responses from social psychology; motivational explanations (Festinger, 1954; Schachter, 1959); symptom evaluation and the need for explanation (Schachter and Singer, 1962); coping responses (Lazarus and Folkman, 1984); and, from health psychology, symptom interpretation (e.g. Meyer, Leventhal and Gutman, 1985).

The PCT (Cacioppo, 1983) has at its core, 8 guiding principles:

Assumptions

1. People are motivated to maintain an explicable physiological condition.
2. Symptom perception need not be accurate in terms of physiological aetiology.

Antecedents

3. The strength of the motivation to understand and evaluate one's symptoms is a function of their unexpectedness, salience, personal relevance and perceived consequences.

Psychophysiological comparisons:

4. Symptom interpretation involves the comparison of the symptoms with known consequences of salient situational stimuli (e.g. exposure to pathogens, recent medications) and physiological conditions (e.g. allergies, diseases, that is, illness prototypes).
5. Symptom interpretation is governed in parts by logical consistency. For example, the probability of a specific illness inference is a direct function of its accessibility (familiarity) and an inverse function of the discrepancy between the symptoms and the illness prototype.
6. Symptom interpretation is governed in part by an optimistic bias. For example, innocuous explanations (e.g. prototypes which suggest symptoms are transient or self-correcting) diminish an individual's motivation to obtain additional information or explanations for the condition to a greater degree, *ceteris paribus*, than do threatening explanations.
7. The more diffuse the symptoms, the greater the number of potential comparisons. Consequently there is a greater likelihood of erroneous interpretations of the symptoms and interpretations are more susceptible to change.

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From: Anderson, Cacioppo, and Roberts, (1995)

A number of different authors choose different variables for calculating patient delay. For example, delay can be calculated as the time from initial experience of symptoms or signs to; the moment a patient actively seeks help; the moment a patient sees a doctor; the moment of diagnosis; or the moment treatment begins (Anderson, Cacioppo and Roberts, 1995). Education and exposure to others in a similar situation through social support may help individuals accurately recognise symptoms that require timely help-seeking. To this end, the measurement of social support and health and heath systems knowledge will be measured in the intervention study.

Social Support

"I do research to see what I think- if its something serious I'd research what I think and see what point I think I'm at, so I go on the internet" (Female student, 18-24 years).

"Obviously mum and dad. Their opinion is important you know? Your mum knows you better than anybody" (Male builder, 25-44 years).

Social support was seen by many participants in the study 3 as an important when making help-seeking decisions. Hupcey (1998) examined the relationship of the theory of social support to its use in research. She considered the wide range of definitions of social support from a variety of authors and concluded that they fell into 5 categories. These were: types of support provided; recipients' perceptions of support; intentions or behaviours of the provider; reciprocal support; and social networks. The five categories identified by Hupcey indicate the complex nature of this concept. Some of the wide range factors that lead to this multifaceted structure include the motivations of providers of social support, the perceptions of the support received and the characteristics of the recipients.

The dimension that is of primary interest in the context of health help-seeking is the individual's perception of the level of social support received. HSUs interviewed for Study 3 reported that social support was an important factor affecting their help-seeking in a variety of ways but generally, they perceived social support as a positive factor, helping them make the right help-seeking decision. It was also clear that some participants saw social support as something they would not use or trust, choosing rather to approach HCPs. For HSUs, social support took many forms including advice from family and friends and advice from other sources such as the internet, leaflets and other health professionals. HCPs reported that patients sometimes consulted them simply because of a lack of social support from elsewhere. It can be concluded that a lack of social support can lead to ineffective help-seeking (Galdas, Cheater and Marshall, 2005; George and Fleming, 2004). Therefore, the measurement of this variable in the intervention study is important.

The theoretical constructs described above all have a greater or lesser degree of relevance to the concept of the quality of consultation-seeking decisions made by patients. Strongly featured in health behaviour literature, but not directly relevant to my studies, are a group of models and theories which includes the Health Belief Model and the Theory of Reasoned Action. These are primarily used to describe how people attain, maintain or aspire to a state of good health. As such, these models and theories are limited in their ability to explain decision making behaviour at the point where a patient first experiences symptoms which might lead to a consultation with an HCP. The exception to this is Social Learning Theory which offers an interesting explanation of how individuals develop what amount to health decision making schemas. The Common Sense Model offers an explanation of how the individual represents an illness or threat of illness and this may have a consequential effect on the way individuals make decisions about seeking help.

Chapter 6

Study 4:

Intervention with first time mothers to manipulate factors underpinning help-seeking decisions (rationale, design and procedure)

6.1

The following chapter sets out the rationale for a quantitative study which investigates the degree to which central factors that underpin the decision to seek help are susceptible to manipulation. Findings from studies, both qualitative and quantitative undertaken for this thesis, and from studies described in the literature are reviewed together with theoretical explanations of behaviour. These sources contribute to the identification of factors that underpin day-to-day health help-seeking behaviour. The degree to which these factors are susceptible to manipulation is unknown although if, as intended, this research is to inform future strategy in primary health care, an essential part of the overall investigation. The choice of variables for investigation in a quantitative study are described and justified in this chapter as are the study design and study population and sample.

Part 1: Rationale, variables, study design and sample-

Rationale

Definitional parameters of well targeted and mistargeted day-to-day consultation decisions have been established enabling the measurement of mistargeted consultations (Chapter 2). A consistent rate of mistargeting across the four primary care surgeries surveyed suggests that the issue is highly significant (Chapter 3). Poor quality help-seeking decisions may be detrimental for optimising patient outcomes and ensuring effective use of limited health care resources (Welsh Assembly Government, 2008). Semi structured interviews with health service users (HSUs) identified several important features of help-seeking behaviour that are likely to inform the decision to seek help. Responses to different factors that influence help-seeking decision (from a both HSUs and healthcare professional's [HCP's] perspectives) vary across individuals leaving some individuals making better decisions than others. Whether these factors are susceptible to manipulation is the focus of this study.

The effectiveness of help-seeking decisions in day-to-day situations has largely been ignored in the literature as have the causes and consequences of ineffective help-seeking decisions. Rather research has focused on ineffective help-seeking for specific groups (men for example; Galdas, Cheater and Marshall (2005), for specific symptoms and illnesses (for example, cancers; George and Fleming, 2004; Smith, Pope and Botha, 2005; or mental health problems; Oliver, Pearson, Coe

and Gunnell, 2005) and for specific patterns of ineffective help-seeking such as delayed and frequent attendance. Focusing on men as a specific group of help seekers, Galdas et al. (2005) sought to understand why men sought help less frequently than women. After a review of literature, they concluded that masculine belief systems and socio-economic circumstances were important factors contributing to delayed help-seeking. However, the impact of socio-economic circumstances is a factor affecting both men and women, alike. George and Fleming's (2004) study again looked at men as a specific group of help seekers. They focused on men's help-seeking behaviour with regard to prostate cancer and, like Galdas et al., concluded that masculinity was a central factor. The focus on men as a specific cohort of help seekers seems to imply that women do not delay seeking help. Clearly this is not the case. Burgess, Hunter and Ramirez (2001) investigated why women delay seeking help from their general practitioner (GP) for symptoms of breast cancer and concluded that a gap in knowledge amongst women was the primary cause of delay. In this sense, delayed help-seeking amongst different patient groups may be caused by the same factors (knowledge gaps; socio-economic circumstances etc.) but the relative strength of the effects of these factors may differ across groups.

Smith et al. (2005) reviewed literature relating to help-seeking for symptoms of cancer amongst both men and women. Rather than focusing on a distinct patient cohort, they examined a specific aspect of help-seeking for a specific condition i.e. delayed help-seeking for symptoms of cancer. They found that, despite having symptoms of different cancers, patients displayed similar delayed help-seeking behaviour, essentially through fear and anxiety. The study of HSUs in this thesis indicated that anxiety was often a stimulus for help-seeking behaviour rather than avoidance although some participants mentioned their reluctance to seek help

De Nooijer, Lechner and de Vries (2001) also considered help-seeking specifically for symptoms of cancer and conducted semi structured interviews in an attempt to understand why some patient consult too early, at the right time or too late. They identified three important factors that impacted on the effectiveness of patients' decisions to consult for symptoms of cancer in terms of time. These were: knowledge of symptoms; fear; and trust in medical consultations. DeNooijer et al. went on to emphasise that delayed consultation for potentially cancerous symptoms (mistargeted in time) is significant. The focus on these three contributing factors risks overlooking other factors that may play a key role in the patient's decision to seek

help. DeNooijer et al. did not consider, for example, the socio-economic element acknowledged by Galdas et al. or the role played by gender, identified by Galdas et al. and George and Fleming. It is likely that a multiplicity of factors affects the decision to seek help, not just for cancers but for day-to-day symptoms. Oliver et al., (2005) found that people suffering from mental health problems preferred to seek help from social support networks and women were more likely to seek help from these than men. They also found that socio demographic factors affected help-seeking, with those living in deprived areas more likely to seek help from a GP rather than from social support networks. The findings of Galdas et al. and George and Fleming that socio economic factors and gender issues affected help-seeking, indicate the importance of social support networks. Oliver et al.'s research was condition specific for mental illness but it did illustrate the importance of social support to the help seeker. However, their findings may be very difficult to generalise beyond patients seeking help for mental illness because of the nature of the condition. Individuals will have a wide variety of different responses to the same situation (for example, a diagnosis of cancer) and also will react differently to the cognitive and emotional dimensions of their response (for example, anxiety).

Inevitably some factors that affect the decision to seek help will be more manipulable than others. For example, as mentioned above, sex can affect delay in seeking help for potentially cancerous symptoms and this is clearly not open to manipulation. Other factors such as levels of knowledge about health and health care services can be addressed through education. The differentiation between the manipulation of factors underlying help-seeking decisions and the manipulation of individuals' effective responses to those factors is important. An individual with poor knowledge of basic health issues may, as a consequence, experience anxiety about seeking help. Rather than attempting to manipulate the consequent anxiety related seeking help, increasing basic health knowledge through education may help make help-seeking decisions more effective. Little, Somerville, Williamson, Moore, Wiles, George, et al. (2001) noted that (trait) anxiety tended to operate through other variables such as somatic symptoms and health anxiety. Anxiety caused by gaps in knowledge may lead to frequency of attendance. HSUs in Study 3 often mentioned the desire for advice and information to fill knowledge gaps. Closing such knowledge gaps may indirectly reduce anxiety. The extent to which these factors are susceptible to manipulation in day-to-day help-seeking circumstances is largely unknown.

Should they be open to manipulation, interventions can be developed with the goal of improving the quality of help-seeking decisions.

Variables

While an extensive array of factors that affect the quality of the decision to seek help have been identified (see Chapter 1), it is reasonable to conclude that these factors do not affect all individuals in the same way. It is also reasonable to assume that some factors are likely to have a more profound impact on the quality of the help-seeking decision for some individuals than for others. It is important not only to identify those factors that appear to be most influential in decision making but also to identify those that might be manipulable (or sensitive to manipulation).

Coping

When interviewed for this thesis, HSUs fell into two broad categories: those who self treated before seeking any kind of help and those who sought social support. While this distinction cannot be seen as indicative of different ways of coping, it does suggest that coping may play a role in the decision to seek help. Of course, in the study presented here, the choice of seeking social support or self treating may be a function of the complex interaction of a number of distinct factors. Nevertheless, the preferred strategy for coping with stressful health situations is likely to have an effect on the decision to seek help. As such, the coping strategies adopted by HSUs may change when, for example, knowledge gaps are addressed, social support networks are expanded or anxiety levels are reduced. The assessment of coping strategies employed when in stressful health-related situations is of interest: will emotion-focused coping strategies give way to problem-focused strategies when an individual's basic knowledge of health and health care systems increases?

When Hannay (1979) described the symptom iceberg he observed that we do not seek help for the majority of symptoms that we experience and HSUs in Study 3 confirmed this. When a symptom is experienced that may warrant some sort of help it is reasonable to conclude that that symptom is causing the individual stress and that demands a certain degree of coping. As symptoms increase in severity, so the stresses caused by that symptom also increase. The experience of stress and the way that the individual copes with it may well have an impact on the help-seeking decision. Lazarus (1966) described ways of coping with stress which fell into two distinct

categories: problem focused coping and emotion focused coping assessed using the Ways of Coping scale (Folkman and Lazarus, 1980). While research has established that the boundaries between these two categories have, in some respects, blurred and led to the identification of other categories, it is worth considering the distinction between them. Problem centred coping involves actively engaging to mitigate the source of stress. In terms of a health related problem, that might involve seeking help in order to resolve the stress inducing symptom. Emotion centred coping typically involves dealing with the emotional consequences of the stressor. Again, in a health related situation, this may involve a psychological reappraisal of the stressor or symptom from being something perceived as causing concern to something that conceptualised as insignificant. In this sense, an emotion-focused approach to dealing with a health related stressor may result in not seeking help regardless of whether seeking help is the most prudent course of action. Holahan and Moos (1987) highlight the often-drawn distinction in the literature between active and passive coping strategies. Active coping strategies are those aimed at directly reducing the effect of the stressor which can be either be behavioural action or emotional responses designed to change the way an individual perceives the effect of the stressor. Passive strategies are those that are adopted which reduce the individual's exposure to the stressor. This type of coping strategy can take the form of activities such as substance abuse or psychological reactions such as withdrawal from the situation. Passive strategies are often seen as less effective than active coping strategies at dealing with stressful situations (Holahan and Moos, 1987). Gil, Carson, Sedway Porter, Schaeffer and Orringer (2000) found that coping skills training improved pain coping skills in sickle cell disease patients thus demonstrating that coping skills are susceptible to manipulation. However, they found that these effects were not over the time following training.

Locus of Control

Evidence from study 3 suggests that HSUs are prepared to relinquish control of their health to HCPs but they generally value being able to self treat when appropriate. The majority of participants made statements indicating that they were aware of the link between their behaviour and their health. They also appeared to value a strong element of control over their health. This varied between individuals, with some respondents seeing their own ability to self treat as important whereas others saw the

HCP as a valued safety net. Perceived personal control was high amongst the respondents in this study as was the notion that seeking help from an HCP should not be done before other avenues of self care had been explored. Obviously, this was situation specific and most acknowledged that they would seek help in an emergency.

Norman, Bennett, Smith and Murphy (1998) found those individuals who had high internal locus of control (LoC) scores were more likely to engage in health behaviours such as eating healthily, not smoking and moderating alcohol consumption. Holt, Clark, Kreuter and Scharff (2000) considered targeted health education materials and found those with a predominantly normatively high an external LoC were resistant to targeted health education materials. Those who had normatively high internal locus of control scores were more likely to respond positively to health information.

Wallston (1994, 2005) suggests that individuals who have high scores for internality tend to consider themselves in control of their health. Conversely, those who score highly on measures of externality tend to consider that external forces, usually beyond their control, are responsible for their health. This includes perceptions that luck is important in the achievement of goals. The perception that powerful others have an influence over one's health is reflected in high scores on the "powerful others" scale. This leads to the hypothesis that those with a high internal locus of control will attempt self-treatment before seeking help rather than those with a high external locus of control who may perceive that an HCP should be consulted as they are perceived to have control over the individual's health. It is therefore important to understand whether locus of control is sensitive to manipulation (Wallston, 1994; 2005).

Self-efficacy

The strong link between Self-Efficacy (SE), coping and locus of control is summarised by Bandura (1977) who stated that "The strength of people's convictions in their own effectiveness is likely to affect whether they will even try to cope with a given situation." (Bandura, 1977; p193). He went on to point out that threatening and fear-inducing situations are generally avoided when individuals perceive that their skills to deal with the situation will be exceeded. Conversely, people will enthusiastically engage in a situation that they feel confident of handling. Dealing with stressful health situations and making decisions about seeking help in those

circumstances are likely to be affected by the coping mechanisms employed by the individual help seeker and the extent to which they believe they can influence the outcome. However, perceptions of SE are dynamic in that an individual who perceives that a situation is beyond their control is less likely to engage in behaviours to deal with that situation. If the individual does act to deal with the situation and finds that their actions do have an effect, their SE will increase. They would subsequently be more likely to readily engage in a similar situation in the future, having learned that their abilities are adequate. Behavioural disengagement in medical situations as a consequence of low SE can result in a failure to attempt to seek help when it may be the prudent thing to do. The effect of SE on the help-seeking decision is therefore central but the extent to which it is manipulable by intervention is unknown in the context of help-seeking and it is therefore a variable of interest in the current study.

Anxiety

HSUs in Study 3 referred to anxiety, in several different forms, as influential in their decision to seek help. Some responders reported that anxiety was strongly felt in most medical situations including visiting patients in hospitals or as a patient themselves. Others reported feelings of anxiety engendered by the experience of symptoms. The effect of anxiety can vary across individuals with some commenting that anxiety caused them to consult as soon as symptoms (or certain kinds of symptoms) were experienced while others commented that anxiety would probably cause them to delay seeking help. In the literature, anxiety has been shown to lead to delay in seeking help. George and Fleming (2004) found that men reported high levels of anxiety when experiencing symptoms of cancer but nevertheless delayed seeking help. De Nooijer, Lechner and De Vries (2001) observed that patients who had delayed seeking were often 'paralysed' by fear and unable to make effective decisions. They suggested that this type of fear was closely related to trait anxiety. Little et al. (2001) found that anxiety was independently associated with attendance. However, Little et al. did go on to note that anxiety operated through other variables and when those variables are mitigated, rates of anxiety tended to decrease. They went on to state that doctors should be mindful of these secondary causes of anxiety as they, rather than anxiety per se, are the likely causes of the decision to seek help. This is not at odds with the finding from the study of HSUs presented in chapter 4,

this thesis. Understanding the role and impact of anxiety on the help-seeking decision is important. There are numerous examples of the manipulation of anxiety in clinical settings. Cognitive behavioural therapy is used routinely to treat anxiety disorders with great success (see for instance, Ladouceur, Dugas, Freeston, Léger, Gagnon and Thibodeau; 2000). While this intervention is not designed to manipulate clinical symptoms of anxiety or use cognitive behavioural therapy, evidence from the literature shows that anxiety is susceptible to manipulation through other variables such as knowledge. The extent to which anxiety as a variable in the context of the help-seeking decision is susceptible to manipulation will be investigated in this study.

Social support

The significance of social support to HSUs was shown in the third study presented in this thesis. There were different opinions about whether social support was positive or negative. For most, social support was a valuable resource either for assistance in making the help-seeking decision or as something to be relied upon if the experience of symptoms impeded day-to-day functioning. Knowing that support was available, if necessary, might facilitate the help-seeking journey for most people.

In the literature, the level of social support has been shown to be associated with frequency of attendance. Baker, Mead and Campbell (2002) found that poor levels of social support were significantly associated with poor mental health in lone mothers who then consulted frequently. Studies of post natal depression have shown that social support has a mediating positive effect. Brugha, Sharp, Cooper, Weisender, Britto, Shinkwin, Sherrif and Kirwan (1998) suggested that interventions to reduce depressive symptoms in specific patient cohorts should include steps to improve social support. Harrison, Neufeld and Kushner (1995) who studied women in normal life transition (child birth, return to work after extended absence etc), concluded that social support played a crucial role in decision making. The significance of the influence of social support on the help seekers' decision making cannot be underestimated. Provision of an effective social support group within an intervention should, it is hypothesised, improve effective help-seeking behaviour.

Knowledge gaps

HSUs in the third study presented here often showed little appreciation of the range of help available from HCPs other than GPs. When invited to consider occasions where

they sought help for health related issues, respondents were reminded that the source of help could come from anywhere. Despite this, respondents rarely considered any source of help other than the GP and expressed a general reluctance to try alternative sources of help. This may well be related to the manner in which help-seeking behaviour is learned. When asked where they learned their help-seeking behaviour from, respondents consistently stated that, as young children, they copied the help-seeking behaviour of their mothers (or similar significant other). This theme was repeated by young and old respondents alike and is consistent with Bandura's (1977) Social Learning theory. It is not hard to visualise the oldest of participants learning from their parents that the doctor should be consulted for virtually all health related issues. The belief that the GP should be the first port-of-call for nearly all formalised medical help has probably been passed down through the generations. HSUs are likely to alter and adapt their help-seeking behaviour as a consequence of experience to some extent, but the evidence from Study 3 suggests that this behavioural adaptation is limited and the choice of GP for health related help is the default decision.

Health related help-seeking behaviour is an important, if not fundamental, behaviour that has implications for the individual's well being and indeed survival. As a behaviour that has been imprinted at a very young age, it is likely to be entrenched and not easily changed. This may explain why most respondents were not willing to try innovations such as NHS Direct or nurse practitioners. In addition, respondents referred to the confusion caused by changes in the appointment booking system for consultations with GPs. Knowledge about the range of help available and the manner in which that help is accessed is important if patients are to make informed, effective help-seeking decisions. Interventions to close knowledge gaps about the availability and access to help can be made *prior* to the decision to seek help.

General knowledge of basic health and health related issues were found to be important for respondents in Study 3 when deciding when to seek help. For example, respondents who considered themselves to be competent in dealing with minor health issues expressed a willingness to attempt to self treat before seeking help. This suggests that the closure of gaps in basic health knowledge could enable individuals to self treat before seeking help where appropriate. When closing knowledge gaps, it is important to acknowledge the strong link between self-efficacy and an individual's ability to respond to increased knowledge.

The point at which these knowledge variables are manipulated has important theoretical implications. Innovations such as NHS Direct, triage nurses and nurse practitioners impact upon the HSU after they have made the decision to seek help. NHS Direct can direct the patient to the best source of help as can a triage nurse but these innovations are resource intensive and simply shift the burden of work from one sector to another. Interventions aimed at impacting on HSUs before they make the decision to consult have the potential to be more effective and less resource intense (see Figure 1. chapter 3).

Design

A between groups (intervention v control), repeated measures design was chosen. This design was considered best for determining the effect of targeted education and social support interventions on the factors associated with the effectiveness of help-seeking decisions. Intervention group participants attended a six week programme of sessions that featured targeted educational activities whilst a control group received no structured education. Data were collected from intervention and control participants via a series of questionnaires at: baseline; week 6 (the end of the intervention period); and 4 weeks later at follow-up.

Sample

The population selected for this study was new (first time) mothers. A specific patient group was chosen to test the feasibility of the intervention in order to reduce the number of extraneous variables associated with a general population of healthcare users. This particular study population has been chosen for the following reasons:

- They are a broadly homogenous group (all female, all of a similar age, the same experience of first time motherhood).
- They are high users of primary care services both for themselves and for their infants which generates a relatively high volume of data.
- They will have broadly similar needs and issues arising from first time motherhood such as anxiety. Anecdotally, new parents often express the sentiment that children do not come with instruction manuals.

The population from which the sample was drawn comprised all first time post-partum mothers over an 11 month period from the practice populations of three GPs surgeries in Llanfairfechan and Bangor, North Wales. Two GP practices identified

control participants and one practice identified intervention group participants. The GP practices were matched, having similar patient population profiles. Criteria for inclusion in the study were:

- Mothers must have delivered a healthy baby.
- Mothers must be registered patients of Plas Menai Surgery, Llanfairfechan for inclusion in the intervention group.
- Mothers must be registered patients of Bronderw Surgery or Bodnant Surgery, Bangor for inclusion in the control group.

Exclusion Criteria:

- Previous neo-natal death or still-birth.
- Baby born with significant abnormalities.
- Mother experienced significant trauma during delivery that has ongoing debilitating consequences.

18 participants were recruited to the intervention condition and 9 participants were recruited to the control arm of the study. 2 intervention participants failed to start the study and 2 partially completed the study. All control participants completed the study and submitted full sets of data. Recruitment to the control group was more difficult because the intervention programme itself acted as an incentive to participate and for this reason two GP practices were asked to identify potential control participants.

Ethics

The study was given ethical approval from the North West Wales NHS Trust Ethics Committee on DATE (ref no. 06/WNo01/25). In discussion with partners at participating GP practices, it was felt that randomising participants from the same practice into intervention and control conditions presented an ethical dilemma. Partners at the practices felt that it was unethical to offer the benefits of the intervention arm of the study to some patients but not others within the practice. As such intervention and control participants were recruited from GP surgeries in separate towns and this alleviated the ethical issue identified above and also reduced contamination effects that might have resulted from participants from the different conditions interacting.

Part 2: Instruments-

Two measures were developed specifically for the study: The Health Knowledge Questionnaire and the Health Systems Knowledge Questionnaire. The remainder were validated and well recognised instruments, some of which underwent minor modifications for use with the specific sample under examination (see Appendix 4 for examples of all of these measures).

COPING was measured using the Brief COPE (Carver, 1997). The Brief COPE is short version of the full COPE (Carver, Scheier and Weintraub, 1989). With 28 items, the Brief COPE is self administered in less than 10 minutes. The 28 individual items are paired to give an indication which of 14 coping mechanisms the respondent has been utilising. Participants were presented with 28 statements and asked to score each one from 0 ("*I haven't been doing this at all*" to 3 ("*I've been doing this a lot*"). Two statements pertain to one of 14 ways of coping. The score for that pair of statements is added to give a score for that particular coping method. For example, the score for Active Coping is calculated by adding the scores participants have given for the following two statements:

I've been concentrating my efforts on doing something about the situation I'm in

And

I've been taking action to try to make the situation better

The reliability of the Brief COPE was confirmed by David, Melman, Mendoza, Kulick-Bell, Ironson and Schneiderman (1996), Ironson, Wynings, Schneiderman, Baum, Rodriguez, Greenwood et al., (1997) and Carver (1997). Carver reported alpha values greater than .50 with all but three items (venting, denial and acceptance) having alpha values greater than .60.

MOTHER'S HEALTH LOCUS OF CONTROL was assessed using the Multidimensional Health Locus of Control scale (MHLC) (Wallston, Wallston and DeVellis, 1978). Form C of the MHLC scale (Wallston, Stein, and Smith, 1994) was designed to be adapted for specific situations, in this case, the recent birth of a baby. The scale is used here to measure locus of control on three dimensions: internal; chance; and powerful others. Scores on each subscale can range from 6 to 36. Scores at the higher end of this range indicate that the respondent believes strongly that their

health is influenced by internality, chance or powerful others. The three subscales are each made up of six statements that rate internality of control, the extent of the influence of powerful others and the role of chance in the participant's perception of control over their health. Participants rate a series of 18 statements with a score from 1 to 6. A score of 1 equates to a strong disagreement with the statement while a score of 6 equates to a strong agreement with the statement. The even number of available responses means that the respondent must either agree or disagree with the statement.

The mother's perception of the locus of control of her infant's health was also assessed using an adaptation of Form C and was scored in the same way as Mother's Health Locus of Control. Wallston (2005) reviewed evidence for the validity and reliability of the MHLC scales and concluded that they were both reliable and valid. However, Wallston does strike a note of caution commenting that validity of the theoretical context in which the scale is being applied should be considered. He goes on to note that

> "*Taken as a whole, the evidence for the validity of the MHLC subscales has been modest, but this varies as a function of the particular subscale being used, the appropriateness of the statistical analyses being conducted, and, most particularly, the theoretical contexts in which validity is being examined.*"
>
> *(Wallston, 2005; p.630)*

In the context of this study, the use of Form C of the MHLC is appropriate for measuring the mother's health locus of control. However, while the scales have broad validity, the application of this method for the measurement of the mother's locus of control of her infant's health is uncertain and, as such, data from this measure have to interpreted with caution.

PERCEIVED SELF-EFFICACY for HEALTH was measured using an adaptation of Jerusalem and Schwarzer's (1992) General Self-efficacy scale (GSE). The GSE scale is self administered and takes about 4 minutes. It is made up of 10 items (statements) that are scored on a scale of 1 to 4. Participants read each statement and consider whether it is; *Not at all true, Hardly true, Moderately true* or *Exactly true*. The total score for the 10 items yield a score between 10 and 40. Scores at the higher end of this range indicate higher self-efficacy. The GSE scale

was adapted by tailoring statements to reflect health seeking situations but the scoring system remains the same. Rimm and Jerusalem (1999) and Luszczynska, Scholz and Schwarzer (2005) measured the reliability of the scale across a number of different languages and found Cronbach's alphas ranging from .75 to .94 indicating a high level of reliability. Luszczynska et al. also confirmed high levels of validity.

PERCEPTIONS OF SOCIAL SUPPORT were measured using the Duke-UNC Functional Social Support Questionnaire (Broadhead, Gehlbach, DeGruy, and Kaplan, 1988). The validated instrument comprises of a 10 item scale and respondents score between 10 and 50. Higher scores indicate a higher perceived level of social support. The instrument was used without adaptation. Broadhead, et al. report studies where significant correlation coefficients show construct validity to be high. A correlation coefficient of .66 was found when, over a 2-week period, test-retest reliability was evaluated (Broadhead, Gehlbach, DeGruy, and Kaplan, 1988).

TRAIT ANXIETY was assessed using the trait element of the validated and widely used State-Trait Anxiety Inventor (Spielberger, 1983). Only trait anxiety was of interest in this study and a 20 item scale measures trait anxiety and reveals a score between 20 and 80. Some reversing of scores is necessary with a higher overall score indicating higher levels of trait anxiety. The original scale was tested for construct validity and produced correlations of between 0.52 and .080 and the reliability of trait anxiety elements reliability was reported to be high (r=0.90) which would suggest internal consistency (Bowling, 2005).

MOTHER'S HEALTH DISTRESS as a consequence of her own health was measured using the Health Distress Measure (Lorig, Stewart, Ritter, González, Laurent and Lynch, 1996). The four item scale produces a mean of the four scores. In this study, the measure was renamed the "Health Perception Questionnaire" because it was felt that the term "distress" in the title might affect participants attitudes towards the measure. The final score ranges from 0 to 5 with higher scores indicating higher levels of health related stress.

MOTHER'S PERCEPTION OF INFANT HEALTH DISTRESS was adapted to measure mothers' distress as a consequence of her infant's health. The scale was adapted by adding the "infant" to the original questions in the scale. For example, "Were you discouraged by your health problems?" was altered to read: "Were you discouraged by your infant's health problems?" Again, the measure was re-titled: "Infant Health Perception Questionnaire" as the use of the term "distress" might affect

participant's attitudes towards the measure, especially as it might associate distress with having an infant. Internal consistency reliability of 0.87 and test re-test reliability of 0.87 were reported in Lorig et al. (1996) for the original Health Distress Measure. The validity of the original scale was also reported in Lorig et al. where correlations with other Health Status measures were found to be good (Correlation coefficients were all significant $p<.001$).

BASIC HEALTH KNOWLEDGE was measured using a specially designed instrument; the "Health Knowledge Questionnaire". This instrument has face validity in that it is a measure of the level of knowledge that an individual has about issues of general health. It is a 27 item instrument where scores are totalled. Higher scores indicate a better level of knowledge about general health issues. Items were generated after consultation with a GP.

HEALTH SYSTEMS KNOWLEDGE was assessed using another specifically designed instrument: the Health Systems Knowledge Questionnaire. This 25 item instrument was designed to test participants' knowledge about basic healthcare systems such as access to GP services. Again, scores nearer 27 indicate a greater level of knowledge of healthcare systems. Again, items were generated after consultation with a GP.

HEALTH VISITOR SUPPORT was measured using the Health Visitor Support Questionnaire. This 6 item instrument was designed to assess the level of support participants perceived they received from their health visitors. This instrument was adapted from the Duke-UNC Functional Social Support Questionnaire (Broadhead, Gehlbach, DeGruy and Kaplan, 1998). Broadhead et al. cite three studies that report high reliability and validity of the Duke-UNC Functional Social Support Questionnaire.

SOCIO DEMOGRAPHIC profiles were also constructed to test whether there were any differences between the groups that might have a confounding effect. The following variables were measured:

- Age
- Education level
- Employment status
- Household income
- Marital status

- Computer owner / access
- Car owner / access

Age was recorded in years. Education level was recorded as either "high" or "low" based upon the highest educational qualification achieved. Participants who had successfully completed a higher qualification such as a Higher National Diploma or equivalent were recorded as having a "high" level of education. Employment status was recorded as being either "employed", "unemployed" or "student / in education". Participants were asked to indicate whether their household income was "less than £10,000p.a.", "£10,000-£19,000p.a.", "£20,000-£29,000p.a.", "£30,000-£39,000p.a." or "more than £40,000p.a.". Marital status was either "single" or "living with partner / married". Owning or having access to a computer was recorded as either "yes" or "no" as was ownership / access to a car. Age (Rowlands and Moser, 2002) and education levels (Little, Somerville, Williamson, Warner, Moore, Wiles, George, Smith and Peveler, 2001) have been shown to affect consultation-seeking behaviour and were therefore analysed as covariates along with baseline measures of variables found to differ significantly between groups. The remainder of the socio economic variables were recorded and analysed to detect any underlying differences between the groups.

HEALTH DIARIES were kept by participants in which they recorded the occurrence of symptoms both for themselves and their babies and the action they took (if any) to deal with them. Participants were advised that the level of detail reported in the diaries was entirely within their control and they were not obliged to report anything of a personal or private nature. The diaries were completed on a daily basis where possible. The lead researcher collected the diaries on a weekly basis and issued a new, blank diary upon collection of the completed diary. It is recognised that a diary record suffers from all the problems of validity associated with self report measures and so there was no intention to analyse their contents but to use the diary contents to enable interpretation of other findings.

Part 3: Procedure

Health visitors (HVs), community midwives and GPs identified potential participants and gave them information packs which contained detailed information about the study. Interested potential participants contacted the lead researcher who, after answering any questions they might have about the study and ensuring the potential participant met inclusion criteria, took informed consent and recruited them to the study.

For both intervention and control groups, baseline measures were taken at 4 weeks post-partum and post intervention 6 weeks later. Follow up data were gathered at 28 weeks post partum. Measurement questionnaires were self administered and were given to participants to complete in their own homes and the completed forms were collected 1 week later (see Table 1 for variables and outcome measures). Total participation in the study was 19 weeks.

Variable	*When Measured*		
Age	*BL*	-	-
Education level	*BL*	-	-
Employment status	*BL*	-	-
Income	*BL*	-	-
Marital status	*BL*	-	-
Computer	*BL*	-	-
Car	*BL*	-	-
Trait Anxiety Inventory	*BL*	-	-
the Brief COPE	*BL*	*PT*	*FU*
Health Locus of Control measure	*BL*	*PT*	*FU*
Health Locus of Control measure for Child	*BL*	*PT*	*FU*
Health Self-efficacy Scale	*BL*	*PT*	*FU*
Duke Functional Social Support Questionnaire	*BL*	*PT*	*FU*
Infant health distress	*BL*	*PT*	*FU*
Maternal health distress	*BL*	*PT*	*FU*
Health Knowledge Questionnaire;	*BL*	*PT*	*FU*
Health Systems Knowledge Questionnaire	*BL*	*PT*	*FU*
Health Visitor Support Questionnaire	-	-	*FU*

BL – Baseline
PT – Post intervention
FU – Follow up

Table 1: Variables and administration of measures

All measures were administered again at week 6 (post intervention) with the exception of the socio demographic profile and the trait anxiety measure. At follow up during week 10, all measures were again administered with the same exceptions as for week 6. In addition, the Health Visitor Support Questionnaire was also administered at follow up.

Intervention sessions took the form of a rolling programme of mother and baby sessions. The rolling programme of sessions was designed so that participants could join the sessions at any point for six weeks. Only data from those mothers who participated in at least four of the six intervention sessions were included in the final analysis.

Mother and Baby sessions: Sessions lasted for up to two hours depending on the nature of the session. Sessions took place in the comfortable environment of a local community centre. Upon arrival, participants were offered refreshments and invited to chat with other participants. The lead researcher facilitated the sessions and introduced the HCP delivering that week's session. The sessions were as follows:

- Session 1: The role of the Health Visitor. This session, delivered by a Health Visitor centred on the variety of services offered by the Health Visitor team. Information about how to contact the team and advice on identifying and accessing the support that is available to new mothers was provided to help them feel better able to cope with new motherhood. The Health Visitors also gave out a variety of information leaflets.
- Session 2: Infant 1st Aid. This session was delivered by an appropriately qualified member of the Welsh Ambulance Service NHS Trust. Participants received training in infant resuscitation and were given the opportunity to practice this skill on a specially designed resuscitation doll. Participants were reassured about the likelihood of needing such skills. They were also advised about when to seek help and the type of help necessary in different circumstances. The session was designed to increase mothers' confidence in coping with unexpected health situations.
- Session 3: Baby Massage. This session was delivered by an assistant health visitor who was qualified to teach baby massage. The session was designed to give mothers an insight into the benefits, for both mother and baby, of baby

massage. Participants were also told about a free baby massage course run locally and were invited to attend.

- Session 4: Focusing on common infant ailments and diseases, this session was run by a local GP. Participants were advised about recognition of symptoms that could be indicative of various common infant ailments. They were also told how to recognise the symptoms of potentially more serious conditions. New mothers were reassured that potentially more serious conditions are unlikely. The purpose of this session was to help mothers understand the incidence of various ailments and to help them identify and cope with the most common symptoms likely to result in help-seeking from an HCP.
- Session 5: Access to and use of various health care services. This session was delivered by a Nurse Practitioner who advised participants about the roles of various HCPs including GPs, Out-of-Hours GPs, practice nurses, nurse practitioners, A&E departments and NHS Direct. Participants were told how to contact the various HCPs and under what circumstances they should be consulted.
- Session 6: the aim of this session was to focus attention on the new mother. To this end, participants were offered a Pilates session focused on new mothers which was run by a practicing midwife. Participants were told about the benefits of this gentle exercise and about regular local sessions that they could access.

The intervention sessions described here were designed after close consultation with HVs and GPs. HVs described the unmet needs of first time mothers and GPs helped identify some of the key knowledge gaps patients may have about basic health matters and access to and function of health services.

Intervention group participants were invited to attend a focus group session at the end of the trial where they were asked for their opinions about the intervention sessions. They were asked for feedback about the content of the sessions and also asked what they might change about the sessions, should the sessions be repeated.

Data Analysis

The effectiveness of the intervention on the outcome variables was assessed using ANCOVA tests. ANCOVA was chosen because of the small sample size. It is a

more robust test than the alternative ANOVA when dealing with small samples. ANCOVA tests the hypothesis that scores from two (or more) groups differ on measures taken at time 2 versus time 1 after adjusting for pre-intervention differences between the groups. The dependent variable was the post intervention score with the covariate being the baseline score. The effect of other variables could be measured by including them as covariates. If a significant effect was found for a variable another ANCOVA was conducted, this time using the follow up measure as the dependent variable. Data was assessed for equality of variance and homogeneity of regression slopes to ensure that the assumptions of ANCOVA were not violated. Data analysis was conducted using SPSS for Windows Release 14.0 (Pallant, 2007; Tabachnick and Fidell, 2007). Demographic data were assessed for differences between groups using an independent samples T-test or chi square test for independence. Differences in health visitor support between groups was assessed by compared intervention versus control scores on the Health Visitor Support Questionnaire using an independent samples T-test.

Where differences between groups were detected using ANCOVA, participants' age and education levels, recorded at baseline, were analysed as covariates with baseline data for the variable found to be significantly different between the groups. Additionally, an ANCOVA using trait anxiety in addition to other baseline data, was performed.

Within groups repeated measures ANOVA were used to examine the data for changes in scores from baseline to post test to follow up. When significant changes between groups are detected using ANCOVA, ANOVA were used to determine whether the differences between scores at each measure were different within groups.

The data were scrutinised for outliers before being tested using ANCOVA. Outlying scores were changed so that they were (at the upper end of the distribution) the value of the next highest score +1 or (if at the lower end of the distribution) the next lowest score -1. This ensured that the scores, while still being deviant, could be included in the analysis. This is particularly important when dealing with small sample sizes (Tabachnick and Fidell, 2007).

Chapter 7

Study 4:

Intervention with first time mothers to manipulate factors underpinning help-seeking decisions (results and discussion)

7.1

Chapter 6 set out the rationale for the manipulation of certain variables that are thought to underpin self-referral help-seeking behaviour amongst health service users (HSUs). The first part of this chapter reports the results of the intervention study designed to manipulate these variables. Part two critically discusses these results and makes recommendations based upon them.

Part 1: Results

Treatment of Outliers

Data from each variable and measure (baseline, post test and follow up) were considered separately and examined for outliers. Intervention and control groups were examined separately but the total number of outliers for each variable was added together (see Table 1 for summary). The groups were examined independently and treated as independent populations. Variables were then considered individually to determine whether any were particularly susceptible to outliers.

	Variable	Baseline Measure	Post Test	Follow up	Total
1	Brief COPE: Active Coping	1	2	-	3
2	Brief COPE: Planning	1	-	-	1
3	Brief COPE: Positive Reframing	-	2	-	2
4	Brief COPE: Acceptance	-	-	2	2
5	Brief COPE: Religion	3	3	2	8
6	Brief COPE: Emotional Support	-	2	-	2
7	Brief COPE: Instrumental Support	2	2	-	4
8	Brief COPE: Denial	-	2	4	6
9	Brief COPE: Substance Abuse	3	1	3	7
10	Brief COPE: Behavioural Disengagement	3	4	3	10
11	Health Locus of Control: Internal	-	-	1	1
12	Health Locus of Control: Powerful Others	-	1	1	2
13	Infant Health Locus of Control: Internal	-	1	1	2
14	Infant Health Locus of Control: Powerful Others	1	1	1	3
15	Infant Health Perception Measure	-	-	2	2
16	Health Knowledge Questionnaire	1	-	2	2
17	Health Systems Knowledge Questionnaire	-	1	1	2

Table 1: Number of outliers for each measure by variable

Box plots indicated that very few individuals scored other than 0 on Brief COPE: Religion and Brief COPE: Substance Abuse. Outliers on these 2 variables were not altered because they had a model value of 0 and manipulation of outlying scores would result in all scores in the variable being given a value of 0 (see Appendix 6 for table illustrating outliers). While Brief COPE: Behavioural Disengagement had 10 outliers, the scores produced a more normal distribution than Brief COPE: Religion, and Brief COPE: Substance Abuse. Religion was recorded as a coping mechanism by 5 participants overall and substance abuse was recorded by 3 participants overall as a coping mechanism. 2 of the 3 participants who recorded substance abuse as a coping mechanism also recorded religion as a coping mechanism. Manipulation of the data for outliers occurred before any other statistical analyses were conducted.

Significance

The level of statistical significance in this study was set at 10% or $p<0.1$ Statistical significance is usually accepted as being <0.05 (or 5%). However, for pilot studies, studies that employ a small number of participants or those where a more conservative significance level is not required for safety of interpretation, a significance level of <0.1 is acceptable (Cramer and Howitt, 2004).

Differences between intervention and control groups on baseline measures

Analyses were conducted to determine if differences existed between intervention and control groups on baseline socio demographic variables. T-tests were conducted on the continuous variables of age and trait anxiety (see Table 2) and indicated that the two groups were not significantly different on either variable.

Baseline variable	*Control Mean*	*Control SD*	*Intervention Mean*	*Intervention SD*	*t*	*p*
Age (years)	27.75	6.735	28.93	7.830	.356	.725
Trait anxiety	44.75	14.018	41.86	13.682	.473	.641

Table 2: T-test analysis of difference between intervention and control groups on baseline socio demographic variables

Chi Square tests of independence were conducted to determine if differences between intervention and control groups existed at baseline in categorical data. No significant differences were found between intervention and control groups ($p. > .10$) on any baseline socio demographic variables (see Table 3).

Baseline variable	*df*	*N*	X^2	*p*	*phi*
Education level*	1	22	0.00	1.0	-.11
Employment status	2	22	3.87	.145	.419
Household income	5	22	5.36	.37	.50
Marital status*	1	22	.003	.96	.13
Computer ownership/access*	1	22	.003	.96	.13
Car ownership /access*	1	22	.003	.96	.13

**With Yates Continuity Correction*

Table 3: Chi Square test of independence between intervention and control groups on baseline socio demographic variables

Support received by participants from health visitors was identified as a potential extraneous variable and the Health Visitor Support Questionnaire was administered at follow up to determine whether perceived support received from health visitors differed between intervention and control groups. Data were analysed using an independent groups T-test. No significant difference in the scores for control (mean = 24.13, *SD* = 7.594) and intervention groups (mean = 20.86, *SD* = 7.882) was found: t (20) = 0.949, p = 0.10). As such, no adjustment of scores on outcome variables to account for this difference was necessary.

Differences between groups on outcome measures

Analyses of Covariance were conducted to test for differences between intervention and control groups at post test on all outcome measures. In each initial analysis baseline data were used as the covariate, post test (or follow up) data were entered as the dependent variable and group (intervention v control) was the fixed factor. The main effect of the intervention (difference between baseline and post test or follow up) was tested. Where differences between the groups at baseline and post test were found to be significant, subsequent ANCOVAs were conducted to test for differences between the groups. Checks were conducted to test for violations of the assumptions of normality, linearity, equality of variances and homogeneity of regression slopes.

Health Locus of Control: Internal Subscale

Internal Health Locus of Control scores differed significantly between the groups at post test after non-significant baseline differences between the groups had been

controlled by entering baseline scores as covariates [$F(1, 19) = 8.0$, $p = 0.011$, partial eta squared = 0.29]. The intervention group scored higher at post-test. A significant difference between the groups on this measure was also found at follow up [$F(1, 17) = 6.26$, $p = 0.022$, partial eta squared = 0.25] with the intervention group still scoring higher than the control group.

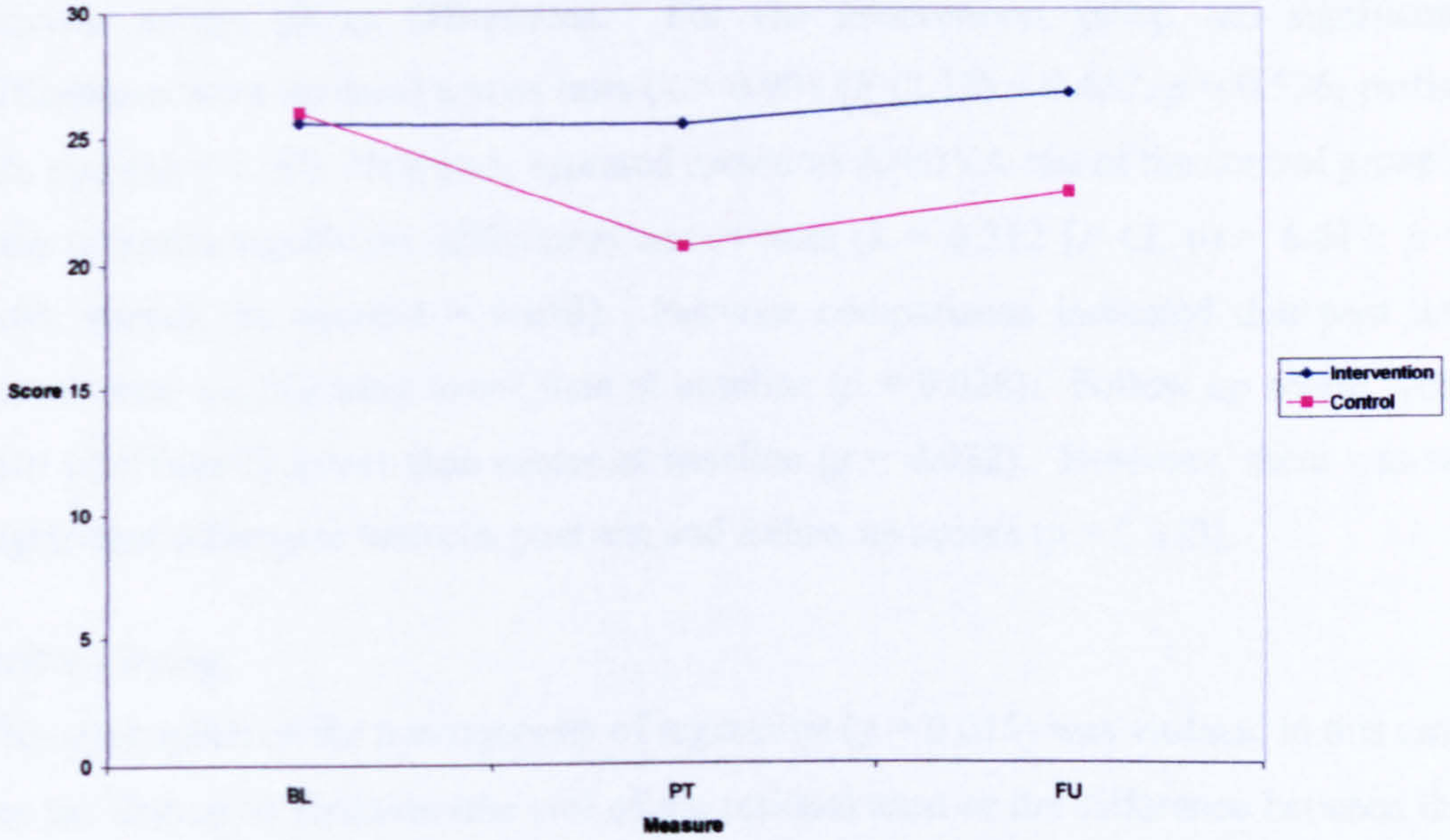

Figure 1: Intervention and control group mean scores on Internal Health Locus of Control at baseline (BL), post test (PT) and follow up (FU).

The analysis was repeated with participants' age and education levels, measured at baseline, entered together as additional covariates. With the potential interaction effect of these variables controlled, the intervention group still had a significantly higher perception of internal health locus of control at post test than did the control group [$F(1, 17) = 6.74$, $p = 0.019$, partial eta squared = 0.28]. The difference in perception of internal health locus of control between the groups with the interaction effect of participants' age and education levels controlled was still significant at follow up [$F(1, 17) = 5.12$, $p = 0.037$, partial eta squared = 0.23] with the intervention group scoring significantly higher on perceived levels of internal health locus of control than the control group.

The potential interaction effect of trait anxiety was removed by entering trait anxiety, measured at baseline, as a covariate with baseline measures of internal health locus of control scores. Analysis revealed significant differences between the groups on post test measures [$F(1, 18) = 8.84$, $p = 0.008$, partial eta squared = 0.33]. The

level of significance indicates that the difference between the groups at post test is greater after the effect of trait anxiety is removed. Again the intervention group had a higher perception of internal health locus of control than did the control group and this difference was maintained at follow up [$F(1, 18) = 6.31$, $p = 0.022$, partial eta squared = 0.26].

Repeated measures ANOVA with repeated measures on tests were used to explore within group differences. For the intervention group, no significant differences were revealed across tests ($\lambda = 0.901$ [$F(2,12) = 0.657$; $p = 0.536$; partial Eta squared = 0.99). However, repeated measures ANOVA test of the control group's data revealed significant differences across tests ($\lambda = 0.312$ [$F(2, 6) = 6.619$; $p = 0.03$; partial Eta squared = 0.688]. Pairwise comparisons indicated that post test scores were significantly lower than at baseline ($p = 0.028$). Follow up scores were also significantly lower than scores at baseline ($p = 0.032$). However, there was no significant difference between post test and follow up scores ($p = 0.373$).

Active Coping

The assumption of the homogeneity of regression ($p = 0.015$) was violated in this case but the degree of violation (the size of the residual term or the difference between the actual value of the dependent variable and its predicted size) was not considered problematic as it is unlikely that there is an interaction between the independent variable (group) and covariate (baseline measure) (see Tabachnick and Fidel, 2007). As ANCOVA tests the hypothesis that the intervention will be the primary cause of any difference detected between the groups (as opposed to the hypothesis that the passage of time between measurements is the likely cause) ANCOVA is therefore the most appropriate statistical method to use.

At post test the intervention group's scores on the Active Coping subscale of the Brief COPE were significantly higher than the control group's scores after ANCOVA had adjusted for baseline differences between the groups [$F(1, 19) = 5.97$, $p = 0.024$, partial eta squared = 0.24]. The significant differences between intervention and control group scores on Active Coping found at post test were not found at follow up [$F(1, 19) = 0.513$, $p = 0.482$, partial eta squared = 0.026].

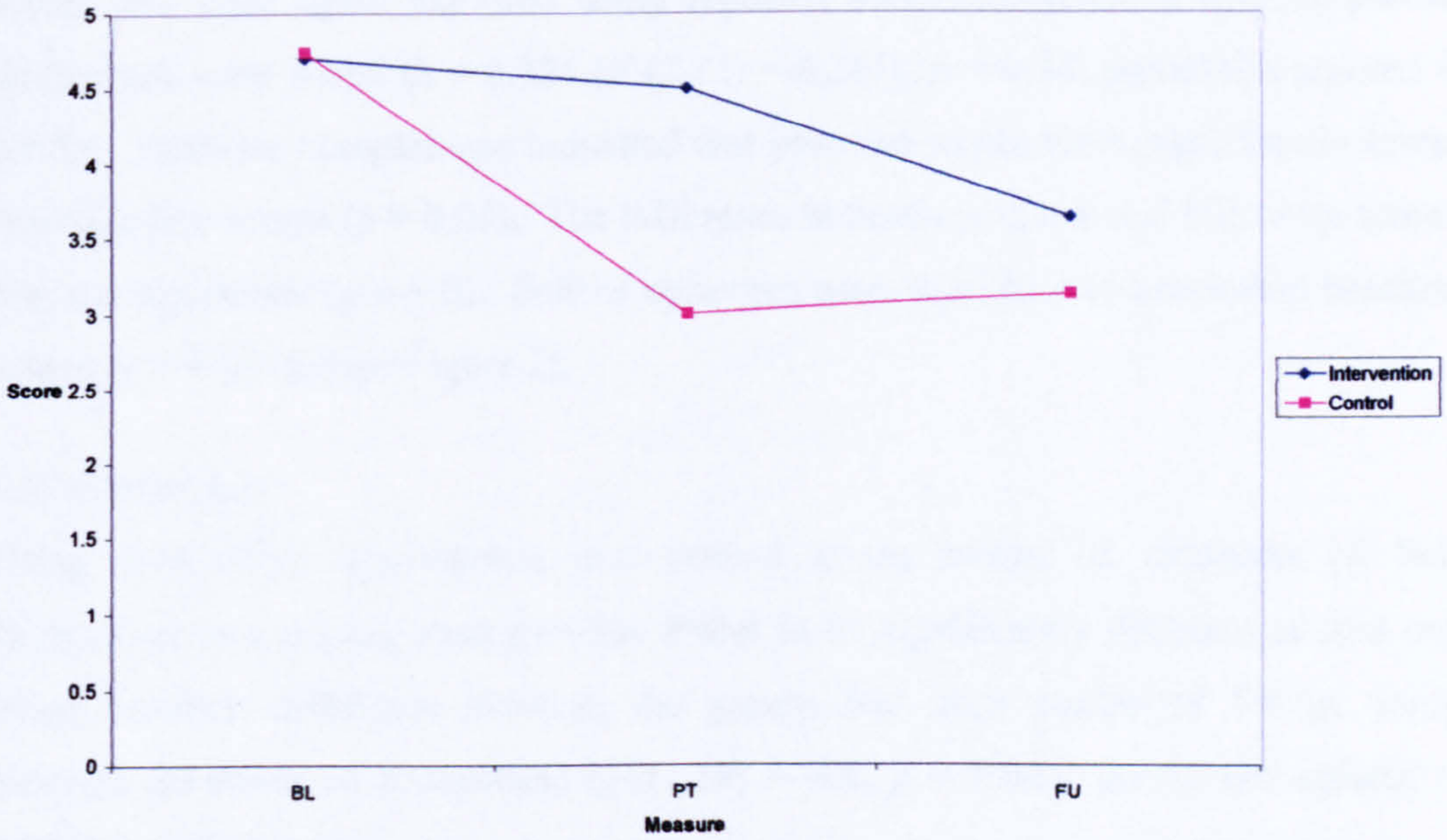

Figure 2: Intervention and control group's mean scores on Brief COPE: Active Coping at baseline (BL), post test (PT) and follow up (FU).

ANCOVA was repeated with the effect of participants' age and education levels controlled for by entering them into the analysis as additional covariates. Once the interaction effect of these variables was removed and any baseline differences in the use of Active Coping controlled, it was found that at post test the intervention group's use of Active Coping techniques was again significantly greater than the control group's use of this technique [$F(1, 17) = 9.37$, $p = 0.007$, partial eta squared = 0.36]. The level of significance of the difference between the groups at post test was greater when the effect of age and education levels was controlled.

The influence of trait anxiety was controlled for by entering this baseline measure into the analysis as an additional covariate. Again, the scores at post test for intervention and control groups were significantly different [$F(1, 18) = 7.0$, $p = 0.016$, partial eta squared = 0.28].

Within group differences were explored using repeated measures ANOVA with repeated measures on tests. For the intervention group, significant differences were revealed across tests ($\lambda = 0.656$ [$F(2,12) = 3.141$]; $p = 0.08$; partial Eta squared = 0.344). Pairwise comparisons indicated that baseline scores were not significantly different from post test scores ($p = 1.0$) but follow up scores were significantly lower than scores at post test ($p = 0.083$). No significant difference between baseline and follow scores was found ($p = 0.151$). For the control group, within group differences

across test were again explored using repeated measures ANOVA and significant differences were found ($\lambda = 0.324$ [F (2,12) = 6.261]; $p = 0.34$; partial Eta squared = 0.676). Pairwise comparisons indicated that post test scores were significantly lower than baseline scores ($p = 0.05$). The difference between post test and follow up scores was not significant ($p = 1.0$). Follow up scores were significantly lower than baseline scores ($p = 0.0410$, (see Figure 2).

Self Distraction

Using ANCOVA, intervention and control group scores on measures of Self Distraction as a coping strategy were found to be significantly different at post test when baseline difference between the groups had been controlled for by using baseline measures as a covariate [$F(1, 19) = 4.8$, $p = 0.041$, partial eta squared = 0.202] (see Figure 3).

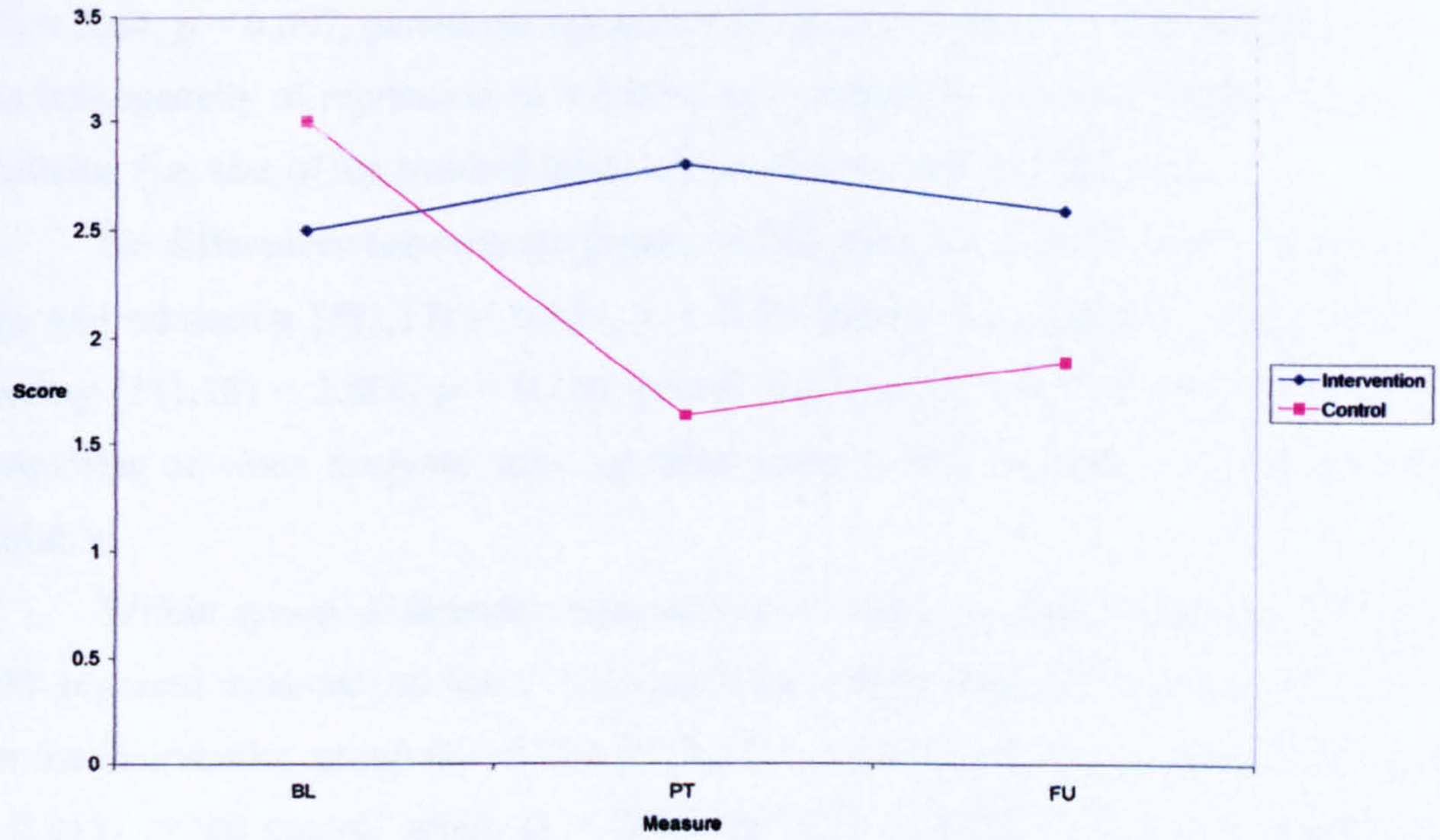

Figure 3: Intervention and control groups' mean scores on Brief COPE: Self Distraction at baseline (BL), post test (PT) and follow up (FU).

The difference between the groups disappeared when age and education were entered as additional covariates [$F(1, 18) = 0.148$, $p = 0.705$]. Trait anxiety was added to baseline scores as a covariate in another ANCOVA. When the influence of this variable was controlled for, a significant difference between the intervention and control group was found on measures taken at post test [$F(1, 18) = 6.12$, $p = 0.024$,

partial eta squared = 0.25]. This difference between the groups was greater when the influence of trait anxiety was controlled than when only baseline scores were used as a covariate [$F(1, 19) = 4.8$, $p = 0.041$, partial eta squared = 0.202]. As with the first analysis, differences found between intervention and control groups at post test were not detected at follow up [$F(2, 18) = 2.387$, $p = 0.140$, partial Eta squared = .117].

Within group differences were explored using repeated measures ANOVA with repeated measures on tests. No significant within group differences were found for the intervention group ($\lambda = 0.968$ [$F(2,12) = 0.201$; $p = 0.82$; partial Eta squared = 0.32) or the control group ($\lambda = 0.722$ [$F(2,6) = 1.155$; $p = 0.376$; partial Eta squared = 0.278).

Venting

Measures of the use of venting as a coping strategy by intervention and control groups differed significantly at post test after baseline differences had been removed; [$F(1, 19) = 3.04$, $p = 0.097$, partial eta squared = 0.138 (see Figure 4)]. The assumption of the homogeneity of regression ($p = 0.026$) was violated in this case but the degree of violation (i.e. size of the residual term) was not considered problematic.

No differences between the groups on this outcome measure were found when age and education [$F(1,17) = 0.924$, $p = 0.35$, partial Eta squared = 0.52] or trait anxiety [$F(1,18) = 2.896$, $p = 0.106$, partial Eta squared = 0.139] were included as covariates or when analyses were repeated using follow up data as the dependent variable.

Within group differences were explored using repeated measures ANOVA with repeated measures on tests. No significant within group differences were found for the intervention group ($\lambda = 0.787$ [$F(2,12) = 1.625$; $p = 0.237$; partial Eta squared = 0.213) or the control group ($\lambda = 0.556$ [$F(2,6) = 2.397$; $p = 0.172$; partial Eta squared = 0.444).

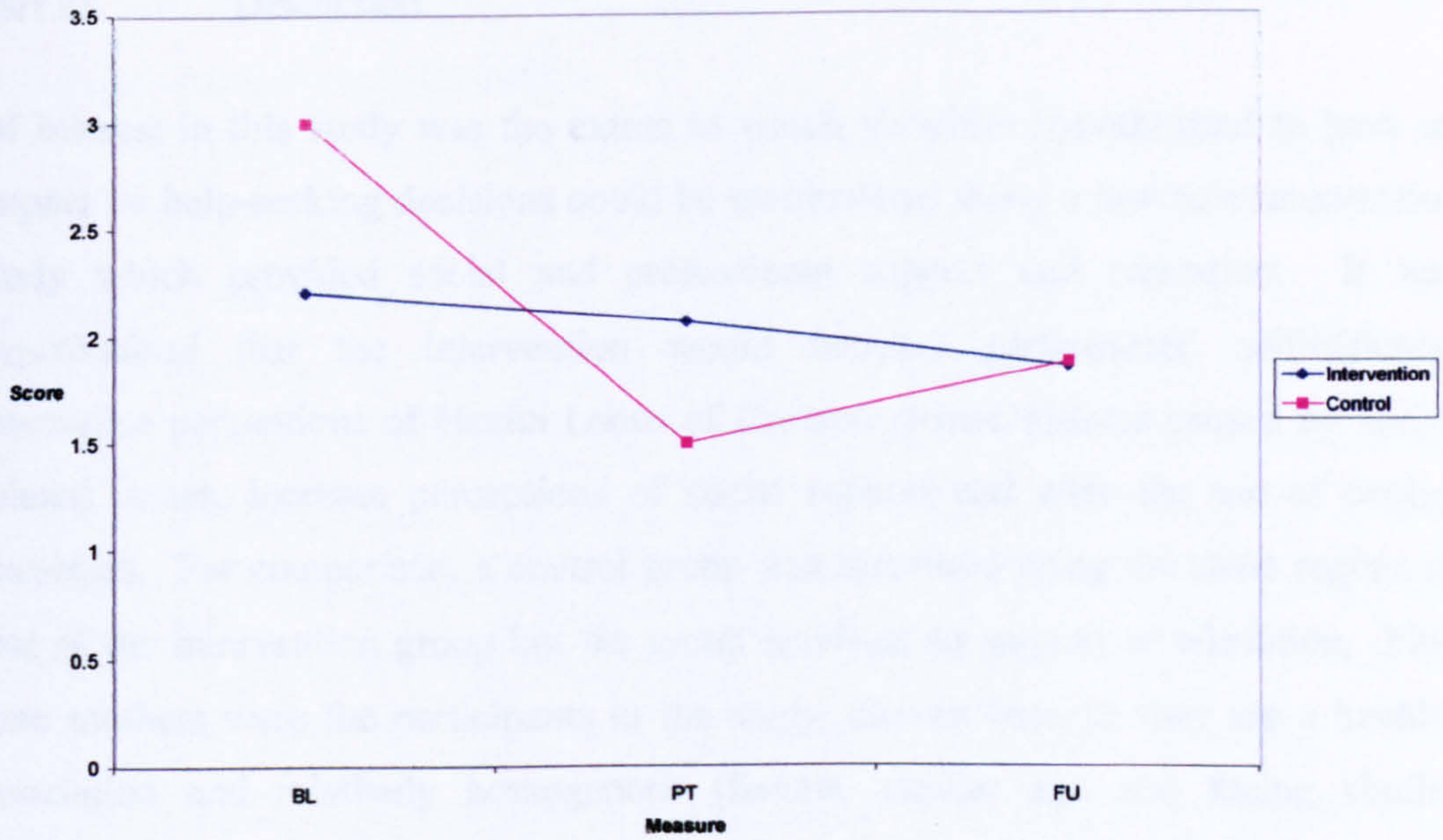

Figure 4: Intervention and control group mean scores on Brief COPE: Venting at baseline (BL), post test (PT) and follow up (FU).

ANCOVA tests on other variables revealed no significant differences between groups.

Part 2: Discussion

Of interest in this study was the extent to which variables hypothesised to have an impact on help-seeking decisions could be manipulated using a low cost intervention study which provided social and professional support and education. It was hypothesised that the intervention would increase participants' self-efficacy, internalise perceptions of Health Locus of Control, reduce distress caused by health related issues, increase perceptions of social support and alter the use of coping strategies. For comparison, a control group was measured using the same regime as that of the intervention group but the group received no support or education. First time mothers were the participants in the study, chosen because they are a healthy population and relatively homogenous (female, similar age and facing similar challenges).

The intervention was designed to operate directly to manipulate health and health systems knowledge and perceptions of social support amongst participants. Through the direct manipulation of these variables, the use of coping strategies, health locus of control, health self-efficacy and state anxiety were expected to be manipulated. These variables are, theoretically, closely related. Bandura (1997) considered that efficacy beliefs regulated stress and anxiety through their impact on a sense of agency and coping behaviour. In an editorial, Ledoux and Gorman (2001) suggested that anxiety and the avoidant coping strategies that they engender can be mitigated by the use of more effective, active coping techniques. Bandura (1997) considered that an individual with high perceived self-efficacy would be more likely to attempt a behaviour and, coupled with a high perceived internal locus of control would expect a high degree of success. Rollnick, Mason and Butler (1999) suggest five ways in which self-efficacy can be improved. Social support and the encouragement that it brings are at the heart of Rollnick et al.'s recommendations along with ensuring that the individual has the skills necessary to succeed in their endeavour.

It was expected that the control group's scores on measures of state anxiety would be higher than those of the intervention group. The intervention group were expected to have higher self-efficacy and internal health locus of control scores. Scores on the powerful others and chance subscales of the Health Locus of Control measure were expected to be lower for the intervention group than the control group

and the intervention group were expected to show a propensity toward using more active than passive coping strategies.

Scores on the Health Locus of Control (internal subscale) and three Brief COPE subscales (Active Coping, Self Distraction and Venting) were found to differ significantly between intervention and control groups when measured at post test indicating that some of these variables are open to manipulation in a health setting. Each of these variables in which group differences were found will now be considered individually (see Appendix 7 for table comparing intervention and control group's mean scores at baseline, post test and follow up and Appendix 8 for graphs comparing intervention and control group's mean scores at baseline, post test and follow up).

Health Locus of Control (internal subscale) was found to have remained virtually constant from baseline to follow up for the intervention group whereas it fell significantly for the control group from baseline to post test, remaining constant from post test to follow up. This suggests that the intervention helped participants to maintain a perception that they were in control of their own health while those not in the intervention perceived a loss of control. At baseline, the group scores were not significantly different with the control group, scoring significantly lower than the intervention group at both test points. At post test and at follow up, there was a significant difference between the groups. The control group's score had fallen significantly but the intervention group's score had not changed significantly. When age, education and trait anxiety were used as covariates, the difference between the groups was still evident at post test and also at follow up.

The difference detected between the groups at post test and follow up were expected. It was hypothesised that the intervention would operate to internalise the health locus of control of intervention participants. However, the intervention group's scores did not vary significantly across time but the control group's scores decreased significantly across time. The reduction in the control group's scores that resulted in the significant difference between the groups was unexpected. Rather than operating to increase the intervention group's internal health locus of control scores, the intervention appears to have enabled mothers to maintain scores while the mothers in the control group reported a significantly lower perception of being in control at post test than at the beginning. This suggests that the experience of becoming a mother for the first time reduces internal health locus of control and participation in the

intervention protected against this decline. Such a finding was not predicted by searches of the literature.

Wallston, Stein and Smith (1994) and Wallston (2005) suggests that those who have higher internal health locus of control scores are more likely to feel that they are in control of their own health. While both groups in this study may have had scores that might be considered high (or indeed, low), the fact that intervention group's scores were significantly higher at post test than those in the control group would suggest that the intervention put them at an advantage. This should be considered in relation to Norman, Bennett, Smith and Murphy's (1998) findings that individuals who have higher internal health locus of control scores are more likely to engage in positive health behaviours (reducing smoking, healthy eating etc). Participants in Study 3 (Chapter 4) who made statements indicating that they value being in control of their own health also reported attempting to self treat before seeking help. However, Holt, Clark, Kreuter and Scharff (2000) used the Weight Locus of Control Measure and assessed participants' responses to targeted and non-targeted health education material. Participants' self-efficacy was measured and the thoughts participants had relating to health education material presented to them was recorded as either positive or negative. Participants with high internal weight locus of control scores responded positively to targeted health education materials whilst participants who recorded low internal weight locus of control scores were more resistant to the material. Holt et al. also concluded that those with a high external locus of control are adept at developing counter arguments against health education materials as a consequence of acting negatively towards such material. Holt et al. also found that, where there was the combination of high external locus of control and low self-efficacy beliefs in their capacity to change, individuals were reluctant to engage in messages from targeted health education materials. Those participants with higher internal locus of control scores were found to have higher levels of self-efficacy. Whether the same is true of the present study is unknown as no differences between the groups on measures of health self-efficacy were recorded. Interestingly, Holt et al. noted, as a limitation to their study, that participants were recruited through a newspaper advert and as such were likely to be highly motivated. Participants in this study were also a self-selecting sample and may also have been well motivated with pre-existing high levels of self-efficacy which would explain why no differences in self-efficacy were observed over time.

In this study, those who score higher on measures of internal health locus of control may be more likely to be receptive and responsive to the educational element of the intervention reflecting the findings of Holt et al. (2000). However, while the intervention in this study operated to maintain mothers' levels of internal locus of control, no significant difference between the groups was detected on measures of health knowledge or health systems knowledge (see later for full discussion).

The differences between the intervention and control groups on measures of health locus of control reported here are consequences of the intervention. The intervention's administration of enhanced levels of social support and targeted health and health systems education were the main mechanisms through which the intervention operated to produce the measured differences. The exact manner in which the intervention operated to produce these differences is unclear but an interaction of a variety of factors (such as health self-efficacy, educational input, social support and anxiety for example) may have facilitated the group differences between groups. Unexpectedly, there were no observable changes in scores either within or between groups on powerful others or chance subscales of the health locus of control measure. No normative data is available that would help determine whether participants' scores on these two subscales was high or low but it was anticipated that any change as a result of the intervention would have resulted in a decrease in these two external factors.

Health locus of control was considered to be an important factor underpinning the decision to seek help as HSUs interviewed for Study 3 overwhelmingly stated that they would prefer to self treat rather than consult an HCP. This and examples from literature suggest that an internal health locus of control is an important factor in decisions associated with health behaviour (Norman, Bennett, Smith and Murphy, 1998).

Coping strategies employed by participants to deal with the demands of becoming a parent for the first time and any differences between intervention and control conditions were assessed using the 14 subscales of the Brief COPE (Carver, 1997). Classically, Folkman and Lazarus (1980) and Lazarus (1966) categorised coping strategies as either problem focused or emotion focused. More recently however, Folkman and Moskowitz (2003 p. 751) comment that, "There is no gold standard for the measurement of coping." This reflects the wide variety of classifications of different strategies, the number of different strategies that have

evolved or even which might be described as positive and which negative in behavioural terms. Some authors have suggested as many as 400 different coping strategies exist which should no longer be classified as either problem or emotion focused strategies (Skinner, Edge, Altman and Sherwood, 2003). There is no received opinion about the classification of different coping strategies and as such, the 14 subscales of the Brief COPE used here have been classified using the somewhat simplistic approach of Holahan and Moos' (1987) dichotomy of active or passive coping strategies. Active coping strategies are characterised as coping strategies that are intended to directly affect the source of stress whereas avoidant coping leads the individual into strategies (such as alcohol or substance abuse) that are intended to avoid dealing with the stressor directly.

Significant differences were found at post test between the intervention and control group's use of Active Coping, Self Distraction, and Venting all three of which might be considered to be active coping strategies. Self distraction, from a source of stress that cannot necessarily be changed, can be seen as an active way for the individual to protect themselves from psychological distress. Venting too can be seen as a valuable release of emotion which offers the individual protection from psychological distress. Once venting has occurred the individual may feel better able to cope with the stressor directly.

It had been anticipated that the intervention would increase mothers' use of active coping techniques and reduce the use of passive techniques. According to Holahan and Moos (1987), the use of active rather than passive coping techniques is more effective. Analysis indicated that three Brief COPE subscales (active coping, self distraction and venting) demonstrated that there were significant group differences at post test with the intervention group scoring higher than the control group. Rather than increasing mothers' use of active coping techniques however, the intervention enabled mothers to maintain initial levels whilst mothers in the control group reported decreases in the use of the three coping strategies. This led to the significant post test differences between the groups. The difference between groups had disappeared by follow up as non-significant increases were made by the control group and non-significant decreases by the intervention group with the exception of a significant decrease in intervention group scores on Active Coping from post test to follow up. The intervention, rather than increasing active coping, actually protected against a decline. When the intervention was finished that protection against a decline

was lost. Using anxiety, education and age as covariates in the analysis did not alter this pattern (except on venting where the necessary assumption of homogeneity of regression was violated). The interesting phenomenon of a decline in control mothers' use of coping mechanisms was an unexpected finding. This decline may be a response to the naturally difficult circumstances of having a first child.

Gil, Carson, Sedway Porter, Schaeffer and Orringer (2000) trained adult sickle cell patients in the use of coping strategies to manage pain, focusing on the use of relaxation and self distraction strategies. Gil et al. also found differences between intervention and control groups (who did not receive coping skills training) at post test but again these differences had disappeared at follow up, three months later. They concluded that continual reinforcement of coping skills training was necessary to prevent natural decay in the use and effectiveness of this strategy. Although the time between post test and follow up was less in this study than in Gil et al.'s study the significant decline in active coping scores and non-significant decline on Self Distraction and Venting scores for the intervention group was still evident.

The intervention did not attempt to *directly* manipulate the use of coping strategies but it did operate to produce the observed post test, between groups differences. The features of the intervention (targeted educational input and enhanced social support) functioned to prevent the decline in the use of active coping seen in the control group. The educational input may have helped participants understand the nature of the stress created by new parenthood and suggested positive ways to cope with situation. In follow up focus groups, participants reported that intervention sessions facilitated the passing of effective ideas between participants for coping with the demands associated with caring for a new baby. This type of social support may have expanded the tools available for active coping. However, the complex interaction of different factors facilitated by the intervention (for example, individual differences or changes in perceptions of self-efficacy) may have operated in conjunction with the overt manipulations of the intervention (targeted education and social support) to affect the observed results.

Self distraction was reported as being used significantly more by the intervention group than the control group when measured at post test. The difference occurred through a non-significant increase in the intervention group's scores (base line mean = 2.5, post test mean = 2.79) and a non-significant decrease in the control group's scores (base line mean = 3.0, post test mean = 1.63). The significant between

groups difference observed at post test had disappeared at follow up where the intervention group's scores decreased (though not significantly) and the control group's scores increased (again, not significantly). While there are no significant within group changes in scores for either group, the pattern of non significant changes are interesting. They suggest that the control group's use of self distraction decreased whereas the intervention group's use of this strategy increased resulting in the significant between group differences observed at post test (see Figure 3). Again, the intervention appears to have operated to protect intervention participants from a decline in the use of a coping strategy.

The group differences at post test may indicate that the first ten weeks of living with a small baby are particularly traumatic for mothers, leading to a perception that fewer active coping strategies are being employed. The intervention protected the women against the negative effects of the pressures of a new baby by, perhaps, helping them adjust more quickly. However, when this support was removed, scores on the coping subscales tended to decrease at a time when those of the control group were increasing.

The difference between intervention and control groups at post test on the *venting* subscale was significant with the control group showing a greater reduction (though not significant) in the use of venting as a coping strategy. While no significant within group differences were detected between baseline, post test and follow up scores, the control group reported mean scores falling from baseline to post test (control group baseline mean = 3.0, post test mean = 1.5) and then increasing at follow up (follow up mean = 1.88) whereas the intervention groups' scores showed a gradual non significant reduction (intervention group baseline mean = 2.21, post test mean = 2.07 and follow up mean = 1.86). However, when age and education levels and anxiety were entered as additional covariates, significant between groups differences disappeared.

The between group differences found here should be treated with caution. The assumption of the homogeneity of regression slopes required for analysis using ANCOVA was violated. While this was not considered serious, it may have increased the risk of a Type I error in the first instance or a Type II error when analysis included additional covariates.

It is unclear why anxiety and age and education should mitigate this effect in the case of venting. While venting may be inappropriate if it involves an emotionally

charged outburst, it could also be interpreted as a positive affective response if the outlet is focused and controlled, perhaps in the circumstances of the intervention sessions, for example. The results observed from measurement of this subscale should be treated cautiously as no data exists (including from participants' health diaries) to indicate the nature of the venting that the intervention group used.

The coping strategies employed by the intervention participants, especially active coping, are important for making effective help-seeking decisions. An active coping strategy suggests that participants are likely to take steps to address issues as they arise. Somewhat paradoxically, intervention participants also used self distraction as a coping strategy but, when considered in the context of caring for a new-born infant, it may be a positive strategy for coping with a highly demanding situation. This may be especially relevant in the first few weeks post partum when the mother is learning how to deal with a new and demanding situation. Active coping is clearly a strategy for dealing with the problem at hand and is an active coping approach. Self distraction can also be seen as an active coping approach and can be described as a strategy used to mitigate potentially negative emotions engendered by the situation. Participants in this study may have adopted this strategy to deal with an emotional situation in the short term which may explain the short-lived, albeit non-significant increase in the use of this strategy. Venting too is an emotional response and may play a vital role in reducing affective responses allowing a more rational problem-focused approach to be adopted. Thus, venting can be considered an active coping strategy. The balance of coping strategies employed by participants in this study may enable them to make more effective help-seeking decisions.

General interpretation of findings

Through the intervention process it was anticipated that the social support and education offered in the intervention would operate directly to close gaps in health and health systems knowledge, increase perceptions of social support and indirectly alter coping strategies, health distress, and health self-efficacy, health locus of control. Changes across time leading to between group differences were expected. This was observed in measures of health locus of control (mother's internal subscale) and three of the 14 Brief COPE items (active coping, self distraction and venting). Between group differences were expected to take the form of changes on the intervention group's scores. Significant between groups differences at post test were the result of

the control group's scores decreasing from baseline while the intervention group's scores remained similar to baseline or changed far less than the control group's scores. Between group differences disappeared at follow up on the three coping measures but were still evident for internal health locus of control. The pattern of results that has emerged is that of the intervention serving to protect intervention participants from declines in scores experienced by the control group.

Between groups differences at post test were only observed on three of the 14 Brief COPE subscales. Two other subscales, Substance Abuse and Use of Religion were discounted from the analysis because all scores other than zero appeared as outliers. No significant within group changes or between group differences were observed on the remaining nine subscales. The remaining nine subscales were a mix of active and passive coping strategies. It is unclear why the intervention did not yield a significant between groups difference on these subscales.

Surprisingly, no differences between the groups occurred in health and health care systems knowledge, health distress, self-efficacy, or social support. As the intervention was directly designed to close any significant knowledge gaps, it is somewhat surprising that no significant differences between the groups on either health knowledge or health systems knowledge were observed. The instruments used to measure health and health systems knowledge may have lacked reliability or validity while the education sessions themselves may not have focused sufficiently on the needs of the participants. However, at the follow up focus group sessions, participants reported that the information regarding use of and access to different health professionals and systems was useful. Despite the strong message from participants in Study 3 that there was little guidance on making choices between service providers when seeking health-related help attempts to address this knowledge gap were unsuccessful or undetectable. Respondents also noted that their perceived level of knowledge of health issues was important in determining the extent to which they would self treat.

The strength of the effect on mothers' internal locus of control was not found on infant internal health locus of control which was unexpected. Infant health locus of control was assumed to be perceived by mothers in the same way mothers perceive their own health locus of control. Health locus of control for infants did not differ between groups on any of the health locus of control subscales. Literature searches did not reveal whether measuring an individual's perception of locus of control of

another, albeit an infant was tested or possible. Whether this is an anomalous result or whether it is because of the measure used is unknown and warrants further investigation.

Intervention participants were expected to have higher perceived self-efficacy scores than control participants as an indirect consequence of the social support and targeted education provided by the intervention sessions but this was not found. Increasing participants' specific health and health systems knowledge and thus providing them with one of the key tools necessary for improving self-efficacy (Rollnick, Mason and Butler, 1999) was expected to raise perceptions of self-efficacy. The social support element of the intervention was expected to provide significant, informative models of motherhood thus increasing self-efficacy. The provision of effective models of behaviour is another of the key tools expected to increase self-efficacy (Rollnick et al., 1999). As self-efficacy concerns individuals' perceptions of their own capacity in a situation (in this case, health), it is closely linked to locus of control perceptions. When individuals perceive they can do something, (self-efficacy) they are more likely to adopt a belief that what they do will achieve desired outcomes (internal locus of control). In this study the expected intervention effect of significantly increased self-efficacy scores compared to control scores was not evident despite the intervention group increasing its self-efficacy scores across time. The control group also increased its self-efficacy scores from baseline to follow up but the difference between groups was not significant despite the control group's internal locus of control scores decreasing significantly from baseline to post test. It had been expected that changes in internal locus of control scores would be mirrored by changes in self-efficacy scores, given the strong link between perceived capacity and perceived control over outcomes of behaviour and achievement. The lack of measurable change in knowledge (systems and health) perhaps explains the lack of any change in self-efficacy.

Self-efficacy was measured in this study using the Health Self-efficacy scale which was an adaptation of Jerusalem and Schwarzer's (1995) Generalised Self-efficacy scale. While the original scale has been shown to be both reliable and valid, the adapted version has not been tested and may not have been a valid measure of this specific manifestation of self-efficacy. Additionally, the participants in this study were a self selecting sample and it is reasonable to assume that such a sample may have a higher perceived self-efficacy than mothers who chose not to participate in the

study (in either the intervention and control arms). As such the effect of an intervention designed to help increase perceived self-efficacy amongst participants whose perceived self-efficacy might be already high is likely to have limited potential for change.

No difference was found between intervention and control groups on measures of trait anxiety which was measured only at baseline. State anxiety was measured using the Health Perception Questionnaire (HPQ) which was an adaptation of the Health Distress Measure (Lorig, Stewart, Ritter, Gonzalez, Laurent and Lynch, 1996). This instrument measured mothers' state anxiety as a consequence of their own health problems. Mothers' state anxiety as a consequence of their infant's health was also measured using another adaptation of the HPQ. These measures did not reveal any differences between the groups at any test point which implies that the intervention sessions did not operate to reduce anxiety as consequence of either the mother's or infant's health problems. However, it should be noted that the Health Distress Measure was designed as a measure of state anxiety caused by illness but participants (and infants) in this study, despite being in a medical setting, were not necessarily ill. As such, the validity of the measure may have been compromised. Extensive searching for a suitable instrument to measure state anxiety in a health-related context did not reveal a more suitable instrument. Future research might address this gap given the major role played by anxiety in help-seeking decisions (Baker, Mead and Campbell, 2002). Little et al., (2001) noted that anxiety operated through other variables to influence the frequency of attendance and mention perceptions of health, somatic symptoms and health anxiety as variables through which anxiety can operate. Perceptions of health and misperceptions of health can result from knowledge gaps, for example. Little suggests that the mitigation of the effects of anxiety should be addressed through interventions directed towards those variables. The role of anxiety amongst new mothers and its effect on help-seeking remains unknown but anxiety has been shown to increase attendance at GP surgeries (Little et al., 2001) and has also been found to cause delay in help-seeking associated with specific diseases or particular patient groups (De Nooijer, Lechner and De Vries, 2001; George and Fleming, 2004). The intervention sessions were designed to address issues arising from knowledge gaps and thus indirectly affect state anxiety. No significant changes in either knowledge or state anxiety were found.

The intervention was also designed to engender a sense of mutual social support amongst participants. Findings from Study 3 indicate that social support has an important role in help-seeking decisions and other studies have highlighted the importance of social support amongst mothers for effective decision making (Harrison, Neufeld and Kushner, 1995), positive mental health (Baker Mead and Campbell, 2002) and mitigation of symptoms of post natal depression (Brugha, Sharp, Cooper, Weisender, Britto, Shinkwin, Sherrif and Kirwan, 1998). Results from this study did not indicate that the intervention sessions increased perceptions of social support at post test or follow up although observation by the researcher suggested that outside the formal sessions, various liaisons had been formed. While intervention participants in the focus group meetings commented on the social support derived from the intervention sessions, this may not have been enough to produce significant differences between the groups. For each participant, the intervention sessions lasted for six weeks. Once the sessions came to an end, the social support formally engendered by the intervention sessions came to an end although there was evidence that informal relationships continued. This may have fostered a perception of a temporary social support network but it did not have a detectable impact on reported social support scores. Analysis of health diaries did not reveal the presence of any formal social support networks amongst the control group although the researcher is aware that mothers have access to an increasing number of social opportunities.

The intervention programme was considered useful by participants who expressed satisfaction with its content and enjoyed participating in the study. The programme, which was designed with input from health visitors and other healthcare professionals (HCPs), has been adopted by health visitors who saw it as a positive activity. At the time of writing the support sessions continue to run, albeit in a slightly different format. Throughout the intervention, numbers of mothers participating in the study and attending intervention sessions was low. A larger sample may have engendered a greater perception of social support. 14 intervention participants completed the programme which lasted nearly 12 months. Each session was attended by between 2 and 6 participants. Participants were encouraged to bring spouses or others who might regularly care for their infants and mothers with second or third children were also invited to attend sessions. These individuals often acted as experienced mentors, increased available social support and increased the overall

numbers of individuals attending sessions. Only first time mothers were included in the data collection.

It is possible that control group participants had access to other sources of support that were not available to the intervention group. Although the GP surgeries were 'matched' in terms of the socio demographic profile of the populations from which their patients were drawn, the two groups were from different areas that had different levels of provision for new mothers. In the area from which intervention participants were drawn there were no mother/infant support groups. However, in the area from which the control group was drawn, there were mother and toddler sessions that the participants may have attended. Attendance (if any) at these sessions was not recorded and control participants did not mention any such sessions in health diaries. Future studies should ensure that any such activities are recorded.

Drawing the intervention and control group participants from the same geographical area, would help ensure that participants in both intervention and control arms had access to the same facilities. This would address the confounding issue of potential differences in the use of organised social support.

Flaws / issues

This study has shown that some of the variables underpinning help-seeking decisions in a health setting are manipulable. Issues of small sample sizes and numbers of participants attending intervention sessions may have muted potential changes in other variables making them undetectable in the current study. Sampling a larger urban population rather than the semi rural population sampled here could increase the potential sample size therefore increasing the likelihood of detecting the effects of the intervention. Individuals in an urban setting are likely to have access to a range of GP practices and organised social support from which to choose Campbell, Iversen, Farmer, Guest MacDonald (2006). Recruiting intervention and control participants from separate practices in urban settings, more densely populated than rural areas, increases the potential for larger samples while addressing the ethical issue of offering support (the intervention) to some patients from within a GP practice and not others. While this study has focused on a specific group of help-seekers, it is nevertheless possible that interventions with other patient groups may yield similar results.

This study measured six outcome variables that were comprised of 26 subscales. Locus of control and self-efficacy (Ajzen, 2002; Manstead, 1998, for

example) are known to be related but the interaction between them in a help-seeking setting is unclear. The decision to seek help is underpinned by a complex interaction of a range of variables. This complexity has the potential to mask measurable effects caused by an intervention such as the one reported here. Attempting to manipulate multiple variables within the same intervention may compound an already complex situation. Reducing the number of variables under investigation when exploring help-seeking may mitigate some of the consequences of complexity thought to dilute potentially significant result but does not provide the advantages of holistic investigation.

The effectiveness of the intervention sessions could be enhanced by increasing the number of intervention sessions from six to as many as resources allow. This would allow continued reinforcement of the use of active coping strategies. Gil et al. (2000) noted that the effects of coping skills training were subject to decay over time unless reinforced and the extension of the intervention sessions from six to eight or more weeks may facilitate that reinforcement. No measurable increase in social support was detected either at post test or follow up and again, extending the intervention sessions may facilitate the perception of increased social support.

The intervention sessions were partly intended to facilitate first time mothers' understanding of their infants' health and health related issues leading to enhanced self-efficacy, an internalisation of health locus of control and more effective coping strategies. The intervention sessions were also designed to help mothers make better general help-seeking decisions. Through this, the outcome variables measured were expected to change. However, the division of focus between the needs of first time mothers and more general health needs could have reduced the effectiveness of the intervention. Focusing the intervention either on the needs of first time mothers or on general health needs, but not both, may have made the intervention more effective, increasing the likelihood of manipulating the variables in question.

The recruitment process was designed to be facilitated by a variety of HCPs. This approach was chosen because the HCPs involved were in a position to judge the suitability of potential participants from a clinical perspective. However, the HCPs involved in the recruitment of control participants were not significant stake holders in the study. Some of the HCPs in the intervention arm were involved in the delivery of intervention sessions as well as the identification of potential participants and stood to gain patients who were theoretically better able to make effective help-seeking

decisions. Whilst HCPs involved in the delivery of intervention sessions valued the opportunity to build relationships with participants, the practice involved in recruiting control participants did not have these incentives. In addition, the control participants did not have the incentive to participate and receive free mother-and-baby sessions so recruitment to this arm of the study was slower. Repeating the study in an urban setting where there is likely to be a bigger pool of potential participants (or designing a study where both groups were eventually involved in activities) may go some way to addressing this issue.

The involvement of HCPs in recruitment of potential participants was necessary from an ethical perspective but additional demands on their limited time compromised their ability to fully engage with recruitment. It may be possible to develop a recruitment process that still involves HCPs, albeit to a lesser extent, but which has more support from the researcher.

Implications for practice

This study has shown that some of the variables that underpin health help-seeking decisions are susceptible to manipulation. Other variables may also be manipulable but more work is necessary to determine this. For those professionals working in the field of health, the potential to enhance the effectiveness of help-seeking decisions is important not just for the effective use of resources, but for maximising positive outcome from disease and other health-related issues.

The intervention here was specifically designed to manipulate a range of variables with first time mothers. Health visitors who helped deliver some of the intervention sessions spoke of the value they felt the sessions had given to both them and the participants. As this study has demonstrated, mothers tend to lose a sense of personal control over what happens in their lives after their first child is born. A sense of irritability, mood swings and anxiety are common amongst this group (Armstrong and Edwards, 2004). The implications of this for a wide range of behaviours, including potentially consultation behaviour could be critical to a successful adaptation of lifestyle and mother and infant well being. Whilst all mothers in this study were screened by HCPs and defined as healthy, the possible impact of a similar intervention on mothers with post natal depression can only be speculative. It was demonstrated here that there was a protective effect by the intervention against loss of personal control and this might help mitigate some

symptoms of depression. However, the effect did not last beyond the intervention, suggesting that longer term support is needed. Given the low cost nature of the intervention applied here, it is recommended that HCPs and those with a support role for new mothers consider a longer intervention period than the six weeks of this study. As well as having positive effects on perceptions of control, the intervention proved valuable for the mothers' use of active coping techniques. As it is unclear which aspects of the intervention created the positive effects on internal health locus of control and coping, it is recommended that a similar format, appreciated by the mothers in the intervention group (and considered worthwhile by the HCPs involved in its delivery), is used although clearly further research is warranted. Raja, Williams and McGee (1994) reported finding a strong association between mothers' high, pure internal health locus of control and a sense of good health. In addition, they found that those mothers who reported high scores on all the three dimensions of health locus of control (internal, chance and powerful others) were more likely to come from a poorer socio economic background, reported poorer health and experienced more symptoms of depression than other groups in the study.

The low cost and relatively simple intervention reported here significantly manipulated a range of variables in a way that is beneficial to first time mothers. Rolling out this intervention for first time mothers would spread the benefits seen here to other first time mothers and associated health professionals. Additionally, adapting the intervention for other patient groups such as frequent attenders may directly improve the effectiveness of their help-seeking behaviour by manipulating internal health locus of control. An adaptation of this low cost intervention may reduce frequent attendance amongst those who make potentially avoidable consultations.

The intervention reported here has been deliberately designed to operate *before* the decision to seek help has been made. GP's are in a position to identify frequently attending patients who have already made their decision to seek help and invite them to attend an intervention. Despite the post facto nature of intervening in this way, the frequently attending patient (or the patient making potentially avoidable consultations) is still the next potential help seeker and the attendant health professional is in a position to direct the patient to the intervention or deliver support or advice that might make that decision more effective.

Future research

Development of an intervention that can be adapted for use in a variety of situations must be based on an understanding of the effective manipulation of variables that underpin help-seeking decisions. To that end, variables that did not appear to be manipulable in this study but which should theoretically have been responsive to manipulation need to be explored further to determine whether and to what extent they can be manipulated. The factors affecting the longevity of any changes to these outcome measures also need to be understood.

After the extent to which the variables that underpin help-seeking decisions can be manipulated is understood, it is important to understand how this translates to changing the effectiveness with which individuals make help-seeking decisions. This study investigated the susceptibility of variables to manipulation, but it did not attempt to investigate whether this translates into more effective help-seeking behaviour. To do this, the measurement of the effectiveness of help-seeking decisions needs to be refined. The instrument developed and used in Study 2 (Chapter 3) can be further developed so that it is easier for HCPs concerned to objectively assess each consultation and accurately record it.

General Conclusion

This study aimed to test whether variables hypothesised to underpin effective help-seeking decision making were susceptible to manipulation. Of the six variables (made up of 26 subscales), Health Locus of Control (internal subscale) and three subscales from the Brief COPE were affected by the intervention. Whilst, the intervention group's scores remained stable, the control group's scores declined from baseline to post test. The intervention, it would appear, provides first time mothers with a degree of protection from the decline in the use of coping strategies that the control group reported and helps maintain a perception of internal health locus of control, considered to be important for effective help-seeking decision-making. The intervention employed here does seem to have had a limited ability to affect some of the variables associated with the health and well being of first time mothers.

Chapter 8

Conclusion

This final chapter discusses the findings from the four studies reported here and considers the implication for practice, for policy and for future research.

> *"I had a patient recently who made an emergency appointment for his child because his child had nits. Another patient made an emergency appointment because her new shoes had rubbed a blister on her heel and she wanted to know if this would affect her fake tanning session the following day" (Female GP).*

General practitioners (GPs) have anecdotally reported patient behaviour that can seem somewhat incredulous. They speak of help-seeking decisions that are sometimes erroneous or sometimes instigated by fear and anxiety. The patients' decision to seek help is underpinned by a complex array of factors that can operate to affect the quality of that decision. These factors may or may not be under the control of the patient. This thesis has considered the quality of decisions made by patients and the factors most likely to impact upon them. The scale of the issue of ineffectively made help-seeking decisions, and the potential consequences of such decisions from the perspective of health care professionals, has been explored. Literature that explores some of the manifestations of ineffective help-seeking behaviour includes, delayed help-seeking (Scott, Grunfeld, Main and McGurk, 2006; Corner, Hopkinson and Roffe, 2006; Quinn, 2005; Rozniatowski, Reich, Mallet, Penel, Fournier and Lefebvre, 2005; Bish, Ramirez, Burgess and Hunter, 2005; Anderson, Cacioppo and Roberts, 1995) and frequent attendance (Neal, Pascoe and Allgar, 2004; Neal, Heywood and Morley, 2000; Baker, Mead and Campbell, 2002; Howe, Parry, Pickvance and Hockley, 2002; Ellaway, Wood and MacIntyre, 1999). Work has also been done that explores behaviours intended to defend against threats to health (Norman, Boer and Seydel, 2005), behaviours intended to maintain or aspire to a state of health (Ajzen, 1991; Janz and Becker, 1984; Becker, 1974) and ways in which patients conceptualise and respond to illnesses and threats associated with that conceptualisation (Diefenbach and Leventhal, 1996). However, little work has been done to explore the antecedents of day-to-day effective help-seeking decision-making or the consequences of making that decision ineffectively, both in terms of patient outcome and finite health resources.

The four studies reported in this thesis were designed to explore sequentially facets of patient consultation decisions in primary care settings from both the patients' and healthcare professional's (HCPs') perspectives, in order to understand and potentially intervene to improve effectiveness. From these studies definitional parameters, including elements of well targeted and mistargeted consultations, were established. From the HCPs' perspective, the potential consequences of making an ineffective help-seeking decision and the scale of the issue of ineffectively made decisions were investigated. Healthcare users' opinions about their consultation behaviours and the behavioural antecedents were also investigated. Together these three studies informed the design of an intervention to test the manipulability of some of the psychological and sociological factors that were hypothesised to inform health-related help-seeking decisions. While the use of a mixed methods approach was largely successful in the exploration of the issues within this thesis, the qualitative methods used in study 1 did not wholly remove the element of subjectivity from the definitional parameters of effective and ineffective help-seeking. Given that no evidence directly associated with effective consultation behaviour existed at the start of the investigation, a qualitative approach was required to access some of the less obvious opinions of HCPs. Further research, testing the findings from this study with a larger and wider group of HCPs would provide more confidence in the conclusions. As the second study's validity relies on the use of data from the first study, the measurement of the scale of mistargeted consultations would also benefit from use with a larger sample. Use of a quantitative methodology for this second stuy is entirely appropriate, as long as the measurement instrument is valid and reliable. Further research is required to establish this.

Study 1 reported three types of mistargeted consultation. Included was help-seeking mistargeted in time which could take the form of help sought too early, too late or in the wrong appointment slot. The qualitative methodology employed in this thesis enabled the identification of the phenomenon of patients not seeking help soon enough, or indeed, at all. However, the identification of individuals who have not come to the attention of an HCP is difficult and beyond the scope of the limited resources of this project. Nevertheless, the issue of individuals who have not yet sought help but perhaps should is a cause of concern. Accessing this patient cohort presents the researcher with significant challenges that are best met using a mixed methods approach. A quantitative survey of patients identified by HCPs (through

questionnaires for example) as seeking help too late might be able to inform the extent to which this is an issue concerning effectiveness and help identify cohorts of patients likely to avoid seeking help. Such methodology, used with HCPs, would be unlikely to identify those who persistently avoid contact with formal medical help. The use of qualitative methods with reluctant consulters would help reveal factors underpinning their decisions and behaviour.

The topic of the thesis was developed following anecdotal evidence that emerged in conversations with GPs. These suggested that patients made consultations that GPs termed as 'unnecessary' or 'inappropriate'. However, a consultation that is considered by one GP to be unnecessary may be considered entirely 'appropriate' by another, which makes the development of instruments to measure the scale of ineffective consultation behaviour difficult. Hannay (1979) described symptoms for which medical help was sought as being that part of the 'iceberg' of symptoms that is visible above the water line. The majority of the symptom iceberg is below the waterline which represents symptoms that are experienced by patients but not brought to the attention of the medical profession. The waterline is the point at which individuals make the decision to seek help or not. Clearly for GPs, some aspects of patient behaviour involved in crossing the 'waterline' are considered to be problematic. However, the subjective nature of the language used by HCPs to describe patients' help-seeking decisions did not lend itself to objective exploration. The behaviours of interest in this thesis were the patients' decisions to seek health-related help and the quality of those decisions. Definitional parameters of effective (good quality) and ineffective (poor quality) help-seeking decisions from the HCP's point of view were developed here to enable further exploration of the issue of patient help-seeking decision-making. Such objective definitional parameters enabled the exploration of the size of the issue of ineffective help-seeking decisions. However, an exploration of the issue from a patient perspective was also necessary in order to identify factors that patients considered to be important to them in the help-seeking process. In this regard it was recognised that it is the complex interactions between the patient, the HCP and the system that need to be explored.

When interviewed, HCPs agreed that patients' help-seeking decisions could be either effective (or 'well targeted') or ineffective ('mistargeted') and health service users (HSUs) acknowledged their role in this by, for example, avoiding making consultations wherever possible. According to the HCPs involved in the study, a well

targeted consultation is one where the patient seeks help from the HCP best suited to their needs, at the optimum time and in the right place. HCPs also agreed that the patient's issue or need brought to the attention of the HCP should warrant some sort of treatment or advice. A mistargeted consultation, on the other hand is one where the patient makes a consultation that is: mistargeted in time (too early or too late or made in the wrong appointment slot); potentially avoidable (for example, a consultation made for a self limiting condition or a condition that might reasonably be self-treated), or a consultation made with the 'wrong' HCP. While these definitional parameters were developed to be objective, there is a degree to which HCPs' interpretation is still partially subjective. Potentially avoidable consultations are those which the HCP considers to be avoidable if the illness is a self-limiting condition or where self treatment would resolve the symptom or issue that led to the consultation. Here, the element of subjective interpretation of definitional parameters can potentially lead one HCP categorising a consultation as potentially avoidable (the patient could have self-treated, for example) while another may consider the same consultation to be necessary because the patient did not have the knowledge necessary to self treat. However the degree of subjectivity is much reduced through the agreement about these definitional parameters reached between HCPs, as reported in Chapter 2. Whilst these definitional parameters do not eliminate subjectivity entirely, they have facilitated a shift along the continuum between subjectivity and objectivity enabling the measurement of the issue, reported in Chapter 3, and the identification of variables of interest investigated in Chapters 6 and 7. Clearly more work is needed to investigate the validity and reliability of the definitions used here and the applicability of them to a wider group of HCPs.

HSUs commented that their perceptions of knowledge about health and health systems usage determined the extent to which they would self treat. It is clear that both HSUs and HCPs consider that the line between a consultation made too early and one made too late can be fine and may be difficult to draw. However, under most circumstances, it should be possible for both HSUs and HCPs to distinguish between consultations made too early and made too late. Development of these definitional parameters, providing HCPs with more stringent guidelines on what constitutes a mistargeted consultation, would help reduce the element of subjectivity. The factors that have underpinned the patient's decision to seek help are important here. These are acknowledged by HCPs as being important. They may, for instance, legitimise

the decision to consult when the 'hidden' reason for consulting emerges during the consultation. One HSU spoke of waiting until she had several issues before making a consultation with a GP rather than making one consultation for one issue. In focus group meetings, GPs expressed concern about HSUs making one consultation for several 'saved up' issues as this often resulted in surgeries running late. While making consultations in this way is not effective from the HCPs' perspective, it may be effective in the context of HSUs' time constraints. It is difficult to categorise this type of consultation pattern as mistargeted within the definitional parameters of mistargeted consultation established here. However, the sheer complexity of the interaction of the many factors identified (including the conflict of the HCP /HSU agenda described above) to date make the task of the predictive modelling of these factors very difficult (Diefenbach and Leventhal, 1996; Tuckett, 1976) and attempts to do so have usually ended in failure (Kasl and Cobb, 1966; Rosenstock, 1960).

One aspect of patient help-seeking behaviour that has been the subject of much research and has been identified as problematic is that of frequent attendance (Neal, Pascoe and Allgar, 2004; Neal, Heywood and Morley, 2000; Baker, Mead and Campbell, 2002; Howe, Parry, Pickvance and Hockley, 2002; Ellaway, Wood and MacIntyre, 1999). Generally, a frequently attending patient is one who makes more than 20 consultations per year but that includes those who have genuine health issues that require frequent consultations. Frequent attenders may, however, be patients who mistarget their consultations. Howe, Parry, Pickvance and Hockley's (2002) definition considered frequent attenders to be those who have the highest attendance within patient sub groups after a simple arithmetic adjustment for age and sex. This may help identify frequent attenders who may be mistargeting their consultations through making potentially avoidable consultations. HSUs in Study 3 did not make statements indicating that they made frequent consultations with HCPs nor that this was an issue that affected them. Only one respondent mentioned the behaviour of other HSUs as having an affect on him. This type of information was not sought from participants in Study 3 and may therefore be a limitation to this study.

Delayed help-seeking has been the subject of several studies (Scott et al., 2006; Corner et al., 2006; Quinn, 2005; Rozniatowski et al., 2005; Bish et al., 2005; Anderson, et al., 1995) but these studies have tended to focus on specific diseases such as various cancers or specific patient groups such as males. Delayed help-seeking can have undesirable consequences for patient outcome as these studies have

indicated. However, little work has been done on the phenomenon of delayed help-seeking in day-today circumstances. Delay, whether it is in specific or day-to-day situations can be described as help-seeking mistargeted in time. The study of patients' views sought to gain an understanding of how patients approached the problem of when to seek help and what influenced that decision. Most reported attempting to self treat before seeking help and others made statements indicating that they would avoid seeking help if possible. Anxiety amongst HSUs about seeking help and notions of not wanting to bother the GP were regularly cited as reasons for this behaviour.

Researchers have observed the increasing level of confusion amongst patients as a consequence of the expanding array of choices available to them (Hassell, Noyce, Rogers, Harris and Wilkinson, 1997; Beney, Bero and Bond, 2000; Myers, Lenci and Sheldon, 1997; Kinnersley, Anderson, Parry, Clement, Turton, Stainthorpe, Fraser, Butler and Rogers, 2000; Scott, Grunfeld, Main and McGurk, 2006). This can result in patients deciding to consult an HCP who is not best suited to their needs. This type of mistargeted consultation is characterised by patients seeking help from the wrong service or HCP. Both HCP and patient groups mentioned the complexity of 'the system' as an important factor in patient consultation behaviour and this was addressed in the intervention study.

The definitional parameters developed here can enable these different aspects of patient help-seeking behaviour identified by HCPs (frequent attendance, delay and use of service not best suited to need) to be considered holistically in that they encompass different areas of research, such as explorations of delayed help-seeking, help-seeking for specific services (for example, frequent attendance in primary care), or the effect of different diseases or conditions on help-seeking. The variables that were the subjects of manipulation in this thesis underpin these different areas of research. The concept of the quality of help-seeking decisions can provide a common platform for these different areas of research. The effectiveness of patient consultation targeting goes beyond the three categories discussed above and encompasses phenomena such as using 'extra' appointment slots at GP practices for routine consultations. The concept is not necessarily restrained by patient groups or patient action when faced by specific diseases or conditions unlike much of the work to date on, for example, delayed help-seeking. It is also applicable across service provisions. Some of the frequent attender work had considered services other than

general practice (Neal, Wickenden, Cottrell, Mason, Rugiano, Clarkson and Bearpark, 2001) but much of the work has focused on primary care settings.

Using the definitional parameters of effective / ineffective help-seeking behaviour, GPs were asked to categorise all routine consultations made in a one week period. These included 'extra' consultations- those made by patients for conditions that they considered to merit urgent attention. Results indicated that for the surgeries surveyed, 28.59% of all consultations were considered to be mistargeted in some way. Factored nationally, this represents a significant issue for the NHS. Taking consultations judged to be potentially avoidable only, the cost of these consultations is some £1,075,000,000 annually. Clearly this issue is of a significant scale and in finite health resource terms, serious. When patient outcome is considered, it is difficult to underestimate the human cost.

Several factors underpinning the quality (i.e. the effectiveness or ineffectiveness) of patients' help-seeking decisions have been identified as particularly important from the perspective of the HSU. These are: the relationship between HCP and patient; patients' knowledge of the health care system and patients' perceived knowledge of basic health issues; anxiety and its effect on the timing of help-seeking; patients' expectations from an encounter with an HCP; patients' perceptions of social support; and the patients' individual characteristics. Notably, there are many similarities here between HCPs' views and those of their patients. HCPs and HSUs recognised that a GP was the preferred choice when seeking help but, where patients primarily sought advice, HCPs perceived that a desire for treatment (i.e. prescriptions) was the primary reason for consultation.

Often, HSUs mentioned that the GP was their preferred choice of help. The relationship between the doctor and the patient is one of the central elements that determine the effectiveness of patients' consultation-seeking decisions. Parsons (1951) saw the relationship between the doctor and the patient as paternalistic where the patient follows the advice or 'doctor's orders' in order to get well. The focus was very much doctor-centred where the physician considered the patient's needs before their wants. It was accepted that the doctor knew what was best for the patient. This attitude has changed dramatically over recent decades and is now characterised by patient 'concordance' with doctor's advice (Mullen, 1997; Bissell, 2003) and was reflected in conversations with HCPs. HSUs interviewed here considered the relationship they had with their GP as being of primary importance and central to their

decision to seek advice. Findings in this thesis indicate that this relationship is characterised, from the patient's perspective by trust and familiarity with the doctor. Despite respondents being continually reminded of the spectrum of potential self referral services, findings here are focused on HSUs' perspective of primary care. However, it is reasonable to assume that the factors underpinning this relationship affect patients' approaches to other health service providers. HCPs (across all health services) now need to consider patients' wants as well as their needs, reflected in comments from HCPs acknowledging that they sometimes over prescribe to satisfy what they perceive to be patients' wants. This may in part have led to the many changes to the provision of health services and the manner in which they are accessed. Patients have learned to expect that their wants will be satisfied by a health service provider. One HSU considered that access to the NHS was a right and that he should receive the treatment that he had paid for through taxation. This inevitably leads to a blurring of the boundary between patients wants and patients needs- the satisfaction of one does not necessarily lead to the other and it is this that might lead to consultations such as the one illustrated in the quote at the beginning of this chapter.

Patients have certain expectations of the outcome of a consultation. When interviewed, the most frequently cited desired outcome from an encounter with an HCP was advice. Participants reported the desire for advice over and above the desire for symptom relief or treatment. This is likely to be related the notion of trust in the HCP-patient relationship and, perhaps, patients' perceived lack of it in contexts such as NHS Direct. The desire for advice suggests that HSUs are making consultations in part to fill knowledge gaps. HCPs recognised this desire of patients for advice but did not perceive that often all they wanted was advice or information.

Patients' knowledge of basic health issues and knowledge of the health care system and access to it have been shown to be significant factors in the quality of the decision to seek help (Scott, Grunfeld, Main and McGurk, 2006; Corner, Hopkinson and Roffe (2006). Scott et al. (2006) found that gaps in patients' knowledge about health were a significant factor in delayed help-seeking for symptoms of oral cancer. Corner et al. (2006) also concluded that health knowledge gaps were a significant factor in delayed consultation for lung cancer. When interviewed here, HSUs reported that gaps in knowledge about common (or not so common) symptoms engendered other factors such as fear and anxiety. Gaps in knowledge about service provision were also found to be high amongst the same HSUs interviewed here.

Respondents were particularly wary of NHS Direct which they saw as highly impersonal. There was a lack of trust in the service which had systems which respondents felt dissuaded from using it. The lack of trust is likely to be closely linked to the issue of a relationship with a GP which is based on trust. This relationship with the GP is perhaps the one by which others are measured. Several studies have considered the impact of NHS Direct on the demands for other services and have found only a minor impact (Munro, Sampson and Nicholl, 2005; Chapman, Smith, Warburton, Mayon-White and Fleming, 2002). Chapman et al. (2002, p. 1398) note that, "NHS Direct was not introduced to decrease or increase the number of general practice consultations but to make consultations more appropriate." They go on to point out that they did not set out to explore this issue. Interestingly, they use what has been shown here to be a subjective and difficult term: "appropriate". Again, limited effects of other initiatives such as community pharmacists and nurse practitioners and NHS walk-in centres have been found (Hassell, Noyce, Rogers, Harris and Wilkinson, 1997; Beney, Bero and Bond, 2000; Myers, Lenci, and Sheldon, 1997; Chalder, Sharp, Moore and Salisbury, 2003). HCPs commented on the perceived frequency of consultations for minor, self-limiting conditions. Many of these consultations could be a consequence of patients' knowledge gaps leading to potentially avoidable consultations. The reluctance to use nurse practitioners, NHS Direct and other recent service delivery initiatives may be due to a simple lack of knowledge about what that service can provide and how and when to access it. This reluctance to use alternative services in preference to the preferred and trusted GP may in part be the cause of frequency of attendance amongst some HSUs.

The issue of trust has been explored extensively in the literature (see for example, Brownlie, Greene and Howson, 2009) and findings presented in this thesis reiterate the importance of this notion. Guthrie (2009) discussed the trust that a doctor needs to have in the patient, such as the accurate and honest reporting of symptoms by the patient. The abuse of that trust when, for example a patient exaggerates symptoms in order to attain state benefits can result in a negative affective response in the doctor (Guthrie, 2009). Findings in this thesis suggest that the trust a patient has for their GP is closely related to the relationship between the parties which can be an important factor in the decision to seek help from the GP. In Chapter 2 GPs reported feeling undervalued when patients consulted them for dental problems which may affect trust between the parties in the future. The complex issue

of trust between doctors and their patients and the perceived lack of trust for services such as NHS Direct, where longer term relationships cannot be built, is important in understanding how and why consultation decisions are made. The HSU's perception of the availability of trusted GPs will have an effect on decisions to seek help and warrants further exploration. Of course, other factors will impact on the use of services such as availability and perceptions of cost as commented on by an HSU for this thesis

The extent of patients' knowledge about their own health and health issues will vary across individuals with some having smaller knowledge gaps than others. It is unreasonable to expect patients to become health experts but having a basic understanding of common health issues, knowing when and how to self treat, knowing when and how to seek help from an increasing range of sources is clearly a important step. Individual differences will dictate the extent to which health education of this type of will be effective but understanding the influence of better education on variables such as locus of control (Holt, Clark, Kreuter and Scharff, 2000) self-efficacy (Luszczynska and Schwarzer, 2005) and social support (Ellaway, Wood and MacIntyre, 1999) in this process would appear to be important. Although the intervention study, which sought to address lack of knowledge, did not yield measurable results, this may be the consequence of the tool used to measure health and health systems knowledge.

As mentioned above, patient anxiety engendered by unexplained symptoms has been associated with delayed attendance for a variety of cancers and other conditions. In a general practice setting, Ronalds, Kapur, Stone, Webb, Tomenson and Creed, (2002) found that anxiety and depression were factors associated with frequent attendance. It seems then, that anxiety is closely associated with the effectiveness of help-seeking decisions made by patients. HSU interviewed for this thesis described how anxiety operated to impede the journey to the consultation and how it operated to induce them to take that journey. The intervention study reported here attempted to reduce anxiety in a health context but no effect was detected. Whether this was because of the interaction of other variables or because of the choice of measurement tool is uncertain.

The element of trust that was reported here as being important in the relationship between the GP and patient can also be found in aspects of patients' use of social support. Patients interviewed about their help-seeking behaviour often

commented that they would attempt to self treat in the first instance and then seek help from an HCP. However, the use of social support was seen as important to many respondents. Social support was not seen as a simple alternative source of advice but of course, in many cases it served that function; it was also seen as a potential source of confusion or was simply not trusted at all. In these two latter scenarios, social support may serve either directly or indirectly as an instigator to seeking a consultation with an HCP. In discussions, HCPs commented on their perception of providing a social support role for the lonely or elderly, for example. It was because of this phenomenon observed during interviews with HSUs that manipulation of levels of social support was attempted in the intervention study. While this did not produce a measurable effect, participants did report liaisons with other members of the group outside formal sessions. Ellaway et al., (1999) observed that those with strong social support networks consulted a GP less frequently than those whose social support networks were not as strong. Social support then, is an important factor in determining the targeting and quality of help-seeking decisions.

When asked about the source of their knowledge of how to seek health-related help, patients interviewed here spoke of their significant others (particularly their mothers) as being important with most learning taking place at a young age. This was true for participants of all ages suggesting that a strong social learning (Bandura, 1977) process was the source of this knowledge. Of course, this social learning process is not the exclusive source of knowledge about seeking help; life experience and exposure to health education imparting information about changes in choice also play a role.

The complexity of the interaction between factors associated with help-seeking has eluded effective modelling (Diefenbach and Leventhal, 1996; Tuckett, 1979). The issue of complexity goes beyond the factors that made effective modelling of the help-seeking process untenable for Kasl and Cobb (1966) and Rosenstock (1960). The number of factors that are now thought to have an impact on an individual's help-seeking effectiveness rises almost continually. For example, Farmer, Iversen, Campbell, Guest, Cheeson, Deans and MacDonald (2006) found that rurality affected help-seeking. The individual differences between help-seekers can affect the manner and timing in which help is sought and contributes to the complexity associated with help-seeking. The variety of responses from HSUs interviewed here, illustrate this. Some stated that they would wait and see how their

symptoms or issue progressed before seeking help (with a GP); others said that they would avoid going to seek help because they did not want to bother the GP; some said that they would 'automatically' consult a GP whereas others said that they would make a conscious effort to consult elsewhere. When interviewed, some HCPs considered that their own behaviour affected HSUs' decisions to seek help. Lam and Lam (2003) found that GPs often over prescribed antibiotics to satisfy the patient and to avoid medicolegal issues if the patient did not improve. Over-prescription of, for example, antibiotics or providing justification for time away from work can encourage potentially avoidable consultations and contributes to an already complex array of factors. Different medical conditions can affect the way in which individuals seek help and individuals can respond differently to very similar medical situations. Causing fear and anxiety, the perception of the symptoms associated with different medical conditions have been shown to affect help-seeking with opposite effects on consultation-seeking behaviour (Baker et al., 2002, for example). Fear and anxiety have been associated with delayed help-seeking (Scott et al., 2006, for example) or can lead to potentially avoidable consultations. The fear and anxiety associated with the perception of certain symptoms may be the consequence of gaps in individuals' knowledge about the condition or symptoms that may or may not be associated with them or individual differences in response to symptoms.

The implications that can be drawn from this thesis fall into three distinct but related areas: implications for future research; implications for policy makers; and implications for practitioners. Research findings and subsequent recommendations can be the driving force for policy change which can lead to changes in practice. However, changes in practice do not necessarily need to be policy driven- practitioners can implement change if they consider it to be beneficial for patient care and outcome.

For the researcher, the complexity of the interrelation of numerous factors affecting the day-to-day help-seeking behaviour of patients cannot be underestimated. The researcher who chooses to take a bottom-up approach to exploring help-seeking behaviour is faced with this complex array of factors where the relative influences of all the factors affecting help-seeking decisions are considered. As acknowledged by Diefenbach and Leventhal (1996), researchers taking this approach can easily become overwhelmed. However, whilst a top-down approach may reduce this complexity by only considering the factors thought by HSUs and HCPs alike to have the most direct

effect upon help-seeking decisions, much potentially valuable data may be missed. For instance, exploring with individuals the antecedents of consultations made with a GP that are potentially avoidable may reveal the factors associated with that type of mistargeted consultation. If the same approach were to be adopted with other types of mistargeted consultation, a picture of the factors that are most associated with mistargeted consultations could be produced and appropriate interventions developed to address the underlying causes of mistargeting. The development of the definitional parameters of the effectiveness of help-seeking decisions reduced the number of degrees of freedom to be considered and thus the complexity, by facilitating a top-down approach to the exploration of ineffective help-seeking decisions. The studies reported here in Chapters 2 and 4 have begun this task and have informed subsequent research exploring the parameters of effective and ineffective help-seeking decisions as well as identifying those factors that are most likely to empower help-seekers to make better decisions. Future research exploring help-seeking behaviour, not just in day-to-day circumstances but in specific disease, patient cohort and service situations, could incorporate this top-down approach.

The distribution of finite health resources is continually being managed by policy makers. The effective use of those resources is a politically expedient endeavour. The final version of the Wanless Report (Wanless, 2002) and the Welsh Assembly Government's delivery of emergency care initiative (Welsh Assembly Government, 2008) make recommendations that seek to make better use of scarce resources available for healthcare while maintaining an acceptable level of service for HSUs. Both reports acknowledge that HSUs need to use the available services more effectively and have asked for guidance on how to do this. However, neither report offers any mechanisms for achieving this other than encouraging better health service-patient partnerships. An attempt to address this issue was made in the intervention study reported here, partly through educational sessions focused on information about how and when to access different health services. Although no improvement in knowledge about health systems was observed, probably due to issues with the measurement tool, in follow up focus group meetings participants reported that they appreciated the information regarding access and use of alternative sources of help that they might otherwise not have considered. The Wanless Report (2002) suggests that there should be greater public engagement with the health services in order to foster awareness and public-health service partnerships. While this may relate

indirectly to more efficient use of health resources by patients, it does not offer a concrete approach to dealing with the issue.

The two reports referred to here reflect the way in which health care has responded not only to patients' needs but also to their perceived wants. This may, in part, have led to patients having expectations that are sometimes unrealistic. The satisfaction of the wants of some patients may be at the expense of the needs of others. Facilitating the effective use of scarce health resources by patients in self referral situations, through interventions such as the one reported here, can potentially lead to better use of scarce resources while helping patients towards more satisfactory outcomes from disease.

Aside from the obvious benefits to individuals from potentially better outcomes from disease, the reduction in the cost of days lost to sickness for the economy as a whole is both important and difficult to calculate. For health policy makers, the potential reduction in the cost of providing healthcare can be substantial. Findings presented here suggest ineffectively made help-seeking decisions could cost in excess of £1,075,000,000 in the primary care sector alone. More effective self referral help-seeking may make expensive post help-seeking decision initiatives such as NHS Direct less relevant or more efficient again releasing resources.

For the practitioner, the findings presented here form a platform from which to implement changes that can affect the future help-seeking decisions of their patients. Firstly, an awareness of the issue of ineffectively made help-seeking decisions as an objectively quantified phenomenon can help practitioners target effective patient education aimed at improving patient help-seeking. HCPs are best placed to identify patients who have made mistargeted help-seeking decisions and as such can offer advice about more effectively targeted future help-seeking. This, it is acknowledged, is not going to address some of the potentially complex psychological issues that can underpin help-seeking, but, despite being a post help-seeking intervention, it has its place especially before pre-help-seeking interventions are developed which can be widely implemented (refer to *fig 1 p.3.9*). As stakeholders, HCPs will need to be aware of any pre-help-seeking interventions operating to affect their patient populations. Their partnership and understanding of these interventions is likely to play a central part in their success.

HCPs too would benefit from more effective help-seeking. Their skills can be directed towards patients who have conditions or issues that warrant more intensive

treatment while those who have self-treatable or some self-limiting conditions can find resolution without having to involve the primary care sector. Data presented here relates to consultations with GPs only but conversations with HCPs from other sectors suggest that the issue is significant in other sectors of the healthcare system.

Helping HSUs make more effective help-seeking decisions will involve understanding more about the phenomenon through the development of more objective definitional parameters of ineffectively made help-seeking decisions to exploring ways of reducing the effects of complexity when attempting to manipulate variables that underpin those help-seeking decisions. The important conclusion from the intervention study is that, despite its low-cost, limited nature, changes in some key psychological characteristics of healthy patients, that are likely to have an impact on help-seeking behaviour, can be changed. Research, utilising the skills of health economists, exploring the cost implications of the phenomenon across other sectors is necessary to gain a perspective of the true scale of the issue and have an impact on policy.

Ultimately, as users of health services, we all have an interest in seeing this issue fully explored: A more effectively used health service will benefit us all both as patients and as contributors to the health economy.

References

Ajzen I (1991). The theory of planned behavior. Organizational Behavior and Human Decision Processes, 50(2), 179-211.

Ajzen I. (2002). Perceived Behavioral Control, Self-Efficacy, Locus of Control, and the Theory of Planned Behavior. Journal of Applied Social Psychology 32(4): 665-683.

Ajzen I. and Fishbein M. (1980). Understanding attitudes and predicting social behavior. Englewoodcliffs, NJ, Prentice-Hall.

Ajzen I. and Fishbein M. (2004). Questions Raised by a Reasoned Action Approach: Comment on Ogden (2003). Health Psychology 23(4): 431-434.

Anderson B.L., Cacioppo J.T., and Roberts D.C (1995). Delay in seeking a cancer diagnosis: Delay stages and psychophysiological comparison processes. British Journal of Social Psychology, 34, 33-52.

Armstrong K. and Edwards H. (2004). The effectiveness of a pram-walking exercise programme in reducing depressive symptomatology for postnatal women. International Journal of Nursing Practice 10: 177-194.

Baker D., Mead N., and Campbell S. (2002). Inequalities in morbidity and consulting behaviour for socially vulnerable groups. British Journal of General Practice, 52, 124-130.

Bandura A. (1977). Towards a unifying theory of behaviour change. Psychological Review, 84, 191-215.

Bandura A. (1997). Self Efficacy: The exercise of control. New York, Freeman.

Bandura A. (2000). Health Promotion from the Perspective of Social Cognitive Theory. In P. Norman, C. Abraham and M. Conner (Eds). Understanding and changing health behaviour: from health beliefs to self-regulation. London, Psychology Press.

Becker M.H. (1974). The Health Belief Model and personal health behavior. Health Education Monographs 2: 324-508.

Becker M.H. and Rosenstock I.M. (1984). Compliance with medical care. In A. Steptoe and A. Matthews (Eds.), Health Care and Human Behaviour. London: Academic Press.

Beney J., Bero L.A. and Bond C., (2000). Expanding The Roles of Outpatient Pharmacists: Effects on Health Services Utilisation , Costs And Patient Outcomes. Database of Systematic Reviews. Art No.: CD000336. DOI: 10.1002/14561858. CD000336.

Bish A., Ramirez A., Burgess C. and Hunter M. (2005). Understanding why women delay in seeking help for breast cancer symptoms. Journal of Psychosomatic Research 58(4): 321-326.

Bissell P. (2003). Compliance, concordance and respect for the patient's agenda. The Pharmaceutical Journal 271: 498-500.

Blaxter M. (1990). Health and Lifestyles. London: Tavistock / Routledge.

Bowling A. (2005). Measuring Health. Maidenhead, Open University Press.

Broadhead W.E., Gehlbach S.H., DeGruy F.V. and Kaplan B. H. (1988). The Duke-UNC Functional Social Support Questionnaire: Measurement of Social Support in Family Medicine Patients. Medical Care 26(7): 709-723.

BroadheadW.E., Kaplan B.H., James S.A., Wagner E.H., Schoenbach V.J., Grimson R., Heyden S., Tibblin G. and Gehlbach S. H., (1983). The Epidemiological Evidence For A Relationship Between Social Support and Health. American Journal of Epidemiology 117(5): 521-537

Bronfenbrenner U. (1979). The Ecology of Human Development: Experiments by Nature and Design. Cambridge MA, Harvard University Press.

Brownlie J., Greene A. and Howson A. (2008). Researching Trust and Health. Oxon, Routledge.

Brugha T.S., Sharp H.M., Cooper S. A., Weisender C., Britto D., Shrinkwin R., Sherrif T. and Kirwan P.H. (1998). The Leicester 500 Project. Social support and the development of postnatal depressive symptoms, a prospective cohort survey. Psychological Medicine 28(1): 63-79.

Bruijnzeels M.A., Foets M., van der Wouden J.C., van den Heuvel W.J. and Prins A. (1998). Everyday symptoms in childhood: occurrence and general practitioner consultation rates. British Journal of General Practice 48(426): 880-884.

Burgess C., Hunter M.S. and Ramirez A.J. (2001). A qualitative study of delay among women reporting symptoms of breast cancer. British Journal of General Practice 51(473): 967-971.

Cacioppo J.T. (1983). Psychophysiological comparison theory: The physical, psychological and social meanings of symptoms. Midwestern Psychological Association. Chicago, Il.

Cameron L., Leventhal E.A. and Leventhal H. (1993). Symptom Representation and Affect as Determinants of Care Seeking in a Community-Dwelling, Adult Sample Population. Health Psychology 12(3): 171-179.

Campbell S.M. and Roland M.O. (1996). Why do people consult the doctor? Family Practice, 13(1), 75-83.

Campis L.K., Lyman R.D. and Prentice-Dunn S. (1986). The Parental Locus of Control Scale: Development and Validation. Journal of Clinical Child Psychology 15(3): 260-267.

Carr-Hill R.A., Rice N. and Roland M., (1996) Socioeconomic determinants of rates of consultation in general practice based on the fourth national morbidity survey of general practices. British Medical Journal, 312, 1008-1012

Carver C.S. (1997). You want to measure coping but your protocol's too long: consider the brief COPE. International Journal of Behavioral Medicine 4(1): 92-100.

Carver C.S., Scheier M.F. and Weintraub J.K. (1989). Assessing Coping Strategies: A Theoretically Based Approach. Journal of Personality and Social Psychology 56(2): 267-283.

Chalder M., Sharp D., Moore L., and Salisbury C. (2003). Impact of NHS walk-in centres on the workload of other local healthcare providers: time series analysis. British Medical Journal, 326(8), 352.

Chapman R.S., Smith G.E., Warburton F., Mayon-White R.T., and Fleming D.M. (2002). Impact of NHS Direct on general practice consultations during the winter of 1999-2000: analysis of routinely collected data. British Medical Journal, 325, 1397-1398

Conner M., and Sparks P. (2005). Theory of Planned Behaviour and Health Behaviour. In M Conner and P Norman (Eds.), Predicting Health Behaviour: Research and practice with social cognition models. Maidenhead: Open University Press.

Corner J., Hopkinson J., and Roffe L. (2006). Experience of health changes and reasons for delay in seeking care: A UK study of the months prior to the diagnosis of lung cancer. Social Science and Medicine, 62(6), 1381-1391.

Cramer D. and Howitt D. (2004). The SAGE Dictionary of Statistics. London, Sage.

Creswell J.W. (2009). Research Design: Qualitative, quantitative and mixed methods approaches. Sage, London.

Crossley M.L. (2000). Rethinking Health Psychology. Buckingham, Open University Press.

Curtis L. and Netten A., (2006). Unit Costs of Health and Social Care 2006. University of Kent, Canterbury.

Dahlgren G. and Whitehead M. (1991). Policies and Strategies to Promote Equity and Health. Stockholm, Institute for Future Studies.

David D., Melman T., Mendoza L., Kulick-Bell R., Ironson G. and Schneiderman N. (1996). Psychiatric Morbidity after Hurricane Andrew. Journal of Traumatic Stress 9: 607-612.

De Nooijer J., Lechner L., and De Vries H, (2001). Help-seeking behaviour for cancer symptoms: perceptions of patients and general practitioners. Psycho-oncology 10(6): 469-478.

DiClemente C.C. (1993). Changing Addictive Behaviors: A Process Perspective. Current Directions in Psychological Science, 2(4), 101-135.

Diefenbach M.A. and Leventhal H. (1996). The Common-Sense Model of Illness Representation: Theoretical and Practical Considerations. Journal of Social Distress and the Homeless 5(1): 11-38.

Dirkzwager A.J.E. and Verhaak P.F.M. (2007). Patients with persistent medically unexplained symptoms in general practice: characteristics and quality of care. BMC Family Practice 8(33). Retrieved 25.08, 2007, from http://www.biomedcentral.com/content/pdf/1471-2296-8-33.pdf.

Donaldson J. M. and Watson R. (1996). Loneliness in elderly people: an important area for nursing research. Journal of Advanced Nursing 24(5): 952-959.

Duberstein P., Meldrum S., Fiscella K., Shields C.G., and Epstein R.M., (2007). Influences on patients' ratings of physicians: Physicians demographics and personality. Patient education and counselling 65(2): 270-274.

Egan G. (1994). The skilled helper: a problem management approach to helping. Pacific Grove CA, Brooks/Cole.

Ellaway A., Wood S. and MacIntyre S. (1999). Someone to talk to? The role of loneliness as a factor in the frequency of GP consultations. British Journal of General Practice, 49(442), 363-367.

Engel G.L. (1977). The need for a new medical model: a challenge for biomedicine. Science, 196, 129-136.

Farmer J., Iverson L., Campbell N.C., Guest C., Chesson R., Deans G. and MacDonald J. (2006) Rural / urban differences in accounts of patients' initial decisions to consult primary care. Health and Place 12, 210-221.

Festinger L. (1954). A Theory of Social Comparison Processes. Human Relations 7(2): 117-140.

Fishbein M. and Ajzen I. (1975). Belief, attitude, intention, and behavior. New York: Wiley.

Flay B.R., Hu F.B., Siddiqui O., Day L. E. and Hedeker D. (1994). Differential Influence of Parental Smoking and Friends' Smoking on Adolescent Initiation and Escalation of Smoking. Journal of Health and Social Behavior 35(3): 248-265.

Folkman S. and Lazarus R.S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior 21: 219-239.

Folkman S. and Moskowitz J.T. (2003). Coping: Pitfalls and Promise. Annual Review of Psychology 55: 745-774.

Fowler C., Kirschner M., Van Kuiken D. and Baas L. (2007). Promoting self-care through symptom management: a theory-based approach for nurse practitioners. Journal of the American Academy of Nurse Practitioners. 19(5): 221-7.

Galdas P.M., Cheater F. and Marshall P. (2005). Men and health help-seeking behaviour: literature review. Journal of Advanced Nursing, 49(6), 616-623.

George A. and Fleming P. (2004). Factors affecting men's help-seeking in the early detection of prostate cancer: implications for health promotion. The Journal of Men's Health and Gender 1(4): 345-342.

George A. and Rubin G. (2003) Non-attendance in general practice: a systematic review and its implications for access to primary health care. Family Practice 20(2), 178-184.

Gibbs, A. (1997). *Focus Groups.* Available: http://www.afmrd.org/cms/files/Social%20Research%20Update.pdf. Last accessed 07 January 2009.

Gil K.M., Carson J.W., Sedway J.A., Porter L.S., Wilson Schaeffer J.J. and Orringer E. (2000). Follow-Up of Coping Skills Training in Adults With Sickle Cell Disease: Analysis of Daily Pain and Coping Practice Diaries. Health Psychology 1: 85-90.

Guthrie B. (2008). Trust and Asymmetry in General Practitioner-Patient Relationships in the United Kingdom. In Brownlie J., Green A. and Howson A. (Eds.), Researching Trust and Health. Oxon, Routledge.

Hallam L. (1994). Primary medical care outside normal working hours: a review of published work. British Medical Journal, 308, 249-253.

Hannay D.R., (1979). The symptom Iceberg. London, Routledge and Kegan.

Harrison M. J., Neufield A. and Kushner K. (1995). Women In Transition: access and barriers to social support. Journal of Advanced Nursing. 21: 858-864.

Hassell K., Noyce P.R., Rogers A., Harris J. and Wilkinson J. (1997). A pathway to the GP: the pharmaceutical 'consultation' as a first port of call in primary health care. Family Practice, 14(6), 498-502.

Heywood P.L., Cameron B.G., Cameron I.H. and Dowell I.C., (1998). An assessment of the attributes of frequent attenders to general practice. Family Practice, 15(3), 198-204.

Hippisley-Cox J., Fenty J., and Heaps M. (2007). Trends in Consultation Rates in General Practice 1995 to 2006: Analysis of the QRESEARCH database. Information Centre and Department of Health.

Holahan C.J. and Moos R.H. (1987). Risk, Resistance, and Psychological Distress: A Longitudinal Analysis With Adults and Children. Journal of Abnormal Psychology 96(1): 3-13.

Holt C.L., Clark E.M., Kreuter M.W. and Scharff D.P. (2000). Does locus of control moderate the effects of tailored health education materials? Health Education Research 15(4): 393-403.

Horne R. and Weinman J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. Journal of Psychosomatic Research, 47(6), 555-567.

Howe A., Parry G., Pickvance D. and Hockley B. (2002). Defining frequent attendance: evidence for routine age and sex correction in studies from primary care settings. British Journal of General Practice, 52(480), 561-562.

Hupcey J.E. (1998). Clarifying the social support theory-research linkage. Journal of Advanced Nursing 27(6): 1231-1241.

Ibarra J. (2001). Head lice: changing the expensive chemotherapy culture. British journal of community nursing 6(3): 146-151.

Ironson G., Wynings C., Schneiderman N., Baum A., Rodriguez M., Greenwood D., Benight C., Antoni M.H., LaPerriere A., Huang H., Kilmas N. and Fletcher M.A. (1997). Poet-traumatic stress symptoms, intrusive thoughts and immune function after Hurricane Andrew. Psychosomatic Medicine 59: 128-141.

Janz N.K. and Becker M.H. (1984). The Health Beleif Model: A Decade Later. Health Education and Behavior, 11(1), 1-47.

Jerusalem M. and Schwarzer R. (1992). Self efficacy: Thought control of action Self-efficacy as a resource factor in stress appraisal processes. Schwarzer R. Washington D.C., Hemisphere.

Jiwa M. (2000). Frequent attenders in general practice: an attempt to reduce attendance. Family Practice, 17(3), 248-251.

Kasl S. and Cobb S (1966). Health Behaviour, Illness Behaviour and Sick-Role Behaviour (in two parts). Archives of Environmental Health, 12, 246-266 and 531-241.

Kelly K., Leventhal H., Andrykowski M., Toppmeyer D., Much J., Dermody J., Marvin M., Baran J. and Schwalb M. (2005). Using the common sense model to understand perceived cancer risk in individuals testing for BRCA1/2 mutations. Psycho-oncology 14(1): 34-48.

Kinnersley P., Anderson E., Parry K., Clement J., Archard L., Turton P., Stainthorpe A., Fraser A., Butler C.C. and Rogers C., (2000). Randomised controlled trial of nurse practitioner verses general practitioner care for patients requesting "same day" consultations in primary care. British Medical Journal, 320, 1043-1048.

Ladouceur R., Dugas M.J., Freeston M.H., Léger E., Gagnon F. and Thibodeau N. (2000). Efficacy of a Cognitive-Behavioral Treatment for Generalized Anxiety Disorder Evaluation in a Controlled Clinical Trial. Journal of Consulting and Clinical Psychology 68(6): 957-964.

Lam T.P. and Lam K.F. (2003). What are the non-biomedical reasons which make family doctors over-prescribe antibiotics for upper respiratory tract infection in a mixed private/public Asian setting. Journal of Clinical Pharmacy and Therapeutics 28(3): 197-201.

Laurant M.G.H., Hermens R.P.M.G., Braspenning J.C.C., Sibbald B. and Grol R.P.T.M., (2004). Impact of nurse practitioners on workload of general practitioners: randomised controlled trial. BMJ, doi:10.1136/bmj.38041.493519.EE

Lazarus R.S. (1966). Psychological stress and the coping process. New York, McGraw-Hill.

Lazarus R.S. and Folkman S. (1984). Stress, Appraisal and Coping. New York, Springer.

Ledoux J.E. and Gorman J.M. (2001). A Call to Action: Overcoming Anxiety through Active Coping. The American Journal of Psychiatry 158(12): 1953-1955.

Leventhal H. (1970). Findings and theory in the study of fear communications. Advances in Experimental Social Psychology, 5, 119-186.

Leventhal H., Diefenbach M., and Leventhal E.A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. Cognitive Therapy and Research 16(2): 143-163.

Leventhal H., Meyer D. and Nerenz D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), Medical Psychology pp. 7-30. New York: Pergamon.

Lewin K. (1936). Principles of topological psychology. New York: McGraw-Hill.

Lewin K. (1952). Field Theory in Social Sciences. London: Tavistock.

Little P., Somerville J., Williamson I., Warner G., Moore M., Wiles R., George S., Smith A. and Peveler R. (2001). Psychosocial, lifestyle, and health status variables in predicting high attendance among adults. British Journal of General Practice, 51, 987-94.

Little P., Williamson I., Warner G., Gould C., Gantley M. and Kinmouth A.L., (1997). Open randomised trial of prescribing strategies in managing sore throat. British Medical Journal 314, 722

Lorig K., Stewart A., Ritter P., Gonzalez V., Laurent D. and Lynch J. (1996). Outcome measures for health education and other health interventions. London, Sage.

Luszczynska A., Scholz U and Schwarzer R. (2005). The general self-efficacy scale: Multicultural validation studies. Journal of Psychology: Interdisciplinary and Applied 139(5): 439-457.

Manstead A.S.R. and van Eekelen S.A.M. (1998). Distinguishing Between Perceived Behavioral Control and Self-Efficacy in the Domain of Academic Achievement Intentions and Behaviors. Journal of Applied Social Psychology 28: 1375-1392.

Marks D.F., Murray M., Evans B., Willig C., Woodall C. and Sykes C.M., (2005). Health Psychology: Theory, Research and Practice. London, Sage.

Mechanic D. (1978). Medical Sociology: 2nd Edition. New York, Free Press.

Meyer D., Leventhal H. and Gutmann M. (1985). Common-sense models of illness: The example of hypertension. Health Psychology 4: 115-135.

Mullen P.D. (1997). Compliance becomes concordance. British Medical Journal, 314, 691.

Munro J., Sampson F. and Nicholl J., (2005). The impact of NHS Direct on the demand for out-of-hours primary and emergency care. British Journal of General Practice, 55(519), 790-792.

Myers P.C., Lenci M. and Sheldon M.G. (1997). A nurse practitioner as the first point of contact for urgent medical problems in a general practice setting. Family Practice, 14(6), 492-497.

Neal R.D., Dowell A.C., Heywood P.L. and Morley S. (1996). Frequent Attenders: Who needs treatment? British Journal of General Practice 46: 131-132.

Neal R.D., Heywood P.L. and Morley S. (2000). 'I always seem to be there'- a qualitative study of frequent attenders. British Journal of General Practice, 50(458), 716-723.

Neal R.D., Pascoe S.W. and Allgar V.L. (2004). Alternative forms of consulting: survey of patients and GPs about their consultations. Family Practice 21(2): 104-142.

Neal R.D., Wickenden G., Cottrell D., Mason J., Rugiano J., Clarkson P. and Bearpark A. (2001). The use of primary, secondary and community care by families who frequently consult their general practitioner. Health and Social Care in the Community, 9(6), 375-382.

Norman P., Bennett P., Smith C. and Murphy S. (1998). Health Locus of Control and Health Behaviour. Journal of Health Psychology 3(2): 171-180.

Norman P., Boer H. and Seydel E.R. (2005). Protection Motivation Theory. In M. Conner and P. Norman (Eds.), Predicting Health Behaviour: Research and practice with social cognition models. Maidenhead: Open University Press.

Ogden J. (2003). Some Problems with Social Cognition Models: A Pragmatic and Conceptual Analysis. Health Psychology 22(4): 424-428.

OHE (2005). Compendium of Health Statistics, 2004-05,16th Edition., Office of Health Economics.

Oliver M.I., Pearson N., Coe N. and Gunnell D. (2005). Help-seeking behaviour in men and women with common mental health problems: cross-sectional study. British Journal of Psychiatry 186: 297-301.

Oliver R.L. and Berger P.K. (1979). A path analysis of preventive care decision models. Journal of Consumer Research, 6, 113-122.

ONS (2004). Socail Trends. London, Palgrave Macmillan.

Parsons T. (1951). The Social System. New York: Free Press.

Peters S., Stanley I., Rose M., Kaney S. and Salmon P. (2002). A randomised controlled trial of group aerobic exercise in primary care patients with persistent unexplained physical symtoms. Family Practice, 19(6), 556-674.

Prochaska J.O. and DiClemente C.C. (1992). The Transtheoretical Approach: Crossing the Traditional Boundaries of Therapy. Homewood, IL, Dow Jones/Irwin.

Quinn J.R. (2005). Delay in seeking care for symptoms of acute myocardial infarction: applying a theoretical model. Research in Nursing and Health 28(4): 283-94.

Raja S.N., Williams S. and McGee R. (1994). Multidimensional health locus of control beliefs and psychological health for a sample of mothers. Social Science and Medicine 39(2): 213-220.

Rajpar S.F., Smith M.A. and Cooke M.W. (2000). "Study of choice between accident and emergency departments and general practice centres for out of hours primary care problems." Journal of Accident and Emergency Medicine 17: 18-21.

Rimm H. and Jerusalem M. (1999). Adaptation and validation of an Estonian version of the General Self-Efficacy Scale (ESES). Anxiety, Stress and Coping: An International Journal 12(3): 329-345.

Ritchie J. and Spencer L. (1994). Qualitative Data Analysis for Applied Policy Research. In A. Bryman and G. Burges (Eds.), Analyzing Qualitative Data pp. 173-194). London: Routledge.

Rogers A. and Nicolaas G. (1998). Understanding The Patterns And Processes of Primary Care Use: A Combined Quantitative and Qualitative Approach. Sociological Research Online 3(4): <http://socresonline.org.uk/socresonline/3/4/5.html>.

Rogers R.W. (1975). A protection motivation theory of fear appeals and attitude change. Journal of Psychology, 91, 93-114.

Rogers R.W. (1983). Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation. In J. Cacioppo and R. Petty (Eds.), Social Psychophysiology. New York: Guilford Press.

Rollnick S., Mason P. and Butler C. (1999). Health Behaviour Change. Edinburgh, Churchill Livingstone.

Ronalds C., Kapur N., Stone K., Webb S., Tomenson B. and Creed F. (2002). Determinants of consultation rate in patients with anxiety and depressive disorders in primary care. Family Practice, 19(1), 23-28.

Rosenstock I.M. (1960). What Research on Motivation Suggests for Public Health. American Journal of Public Hygiene, 50, 295-302.

Rosenstock I.M. (1966). Why people use health services. Millbank Memorial Quarterly, 44, 94-124.

Rotter J.B. (1954). Social Learning and Clinical Psychology. Englewood Cliffs N.J., Prentice-Hall.

Rotter J.B. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs 80(1): Whole No. 609.

Rotter J.B. (1990). Internal Versus External Control of Reinforcement: A Case History of a Variable. American Psychologist 45(4): 489-493.

Rowlands S. and Moser K. (2002). Consultation rates from the General Practice Research Database. British Journal of General Practice 52: 658-660.

Rozniatowski O., Reich M., Mallet Y., Penel N., Fournier C. and Lefebvre J. L. (2005). Psychosocial factors involved in delayed consultation by patients with head and neck cancer. Head and Neck, 27(4), 274-280

Ryan R.M. and Connell J.P. (1989). Perceived Locus of Causality and Internalization: Examining Reasons for Acting in Two Domains. Journal of Personality and Social Psychology 57(5): 749-761.

Saltzer E.B. (1982). The Weight Locus of Control (WLOC) Scale: A Specific Measure for Obesity Research. Journal of Personality Assessment 46(6): 620-628.

Schachter S. (1959). The Psychology of Affiliation. Stanford, Stanford University Press.

Schachter S. and Singer J.E. (1962). Cognitive, social and physiological determinants of emotional state. Psychological Review 69: 379-399.

Scott S.E., Grunfeld E.A., Main J. and McGurk M. (2006). Patient delay in oral cancer: a qualitative study of patients' experiences. Psycho-oncology, 15(6), 474-485.

Schwarzer R. (1992). Self efficacy in the adaptation and maintenance of health behaviours: theoretical approaches and a new model. Self Efficacy: Thought Control of Action. R. Schwarzer. DC, Hemisphere: 217-243.

Scott S.E., Grunfeld E.A., Main J. and McGurk M. (2006). Patient delay in oral cancer: a qualitative study of patients' experiences. Psycho-oncology 15(6): 474-485.

Seligman, M.E.P. and Maier S.F. (1967). Failure to escape traumatic shock. Journal of Experimental Psychology 74: 1-9.

Sutton S. (1998). Predicting and Explaining Intentions and Behavior: How Well Are We Doing? Journal of Applied Social Psychology 25(15): 1317-1338.

Severtson D.J., Baumann L.C. and Brown R.L. (2006). Applying a health behavior theory to explore the influence of information and experience on arsenic risk representations, policy beliefs, and protective behavior. Risk Analysis 26(2): 353-68.

Skinner E.A. (1995). Perceived Control, Motivation and Coping. London, Sage.

Skinner E.A., Edge K., Altman J. and Sherwood H. (2003). Searching for the Structure of Coping: A Review and Critique of Category Systems for Classifying Ways of Coping. Psychological Bulletin 129(2): 216-269.

Smedlund G. (2000). A Pragmatic Basis for Judging Models and Theories in Health Psychology: The Axiomatic Method. Journal of Health Psychology 5(2): 133-149.

Smith L.K, Pope C. and Botha J.L. (2005). Review: delays in help seeking for cancer symptoms related to recognition and interpretation of symptoms and fear of consultation and were affected by gender and sanctioning of help seeking. The Lancet, 366, 825-831.

Spielberger C.D. (1983). Manual for the State-Trait Anxiety Inventory (Form Y). Palo Alto, CA, Consulting Psychologists Press.

Sutton S. (2005). Stage theories of health behaviour. In M Conner and P. Norman (Eds.), Predicting Health Behaviour: Research and practice with social cognition models. Maidenhead: Open University Press.

Tabachnick B.G. and Fidel L.S. (2007). Using Multivariate Statistics. Boston, Pearson.

Terry D.J. and O'Leary J.E. (1995). The theory of planned behaviour: The effects of perceived behavioural control and self-efficacy. British Journal of Social Psychology 34: 199-220.

Tolman E.C (1932). Purposive Behavior in Animals and Men. New York.

Tuckett D. (1976). Medical Sociology. London: Tavistock

von Neuman J. and Morgenstern O. (1944). Theory of games and economic behavior. New Jersey, Princeton University Press.

Wallston K.A. (2005). The Validity of the Multidimensional Health Locus of Control Scales. Journal of Health Psychology 10(4): 623-631.

Wallston K.A., Stein M.J. and Smith C.A. (1994). Form C of the MHLC scales: a condition-specific measure of locus of control. Journal of Personality Assessment 63(3): 534-553.

Wallston K.A., Wallston B.S. and DeVellis (1978). Development of the Multidimensional Health Locus of Control (MHLC) scales. Health Education Monographs 6: 160-170.

Wallston B.S., Wallston K.A., Kaplan G.D. and Maides S.A. (1976). Development and Validation of the Health Locus of Control (HLC) Scale. Journal of Consulting and Clinical Psychology, 44(4), 580-585.

Walter FM. and Emery J. (2007). Perceptions of family history across common diseases: a qualitative study in primary care. Family practice 23(4): 472-80.

Wanless D. (2002). Securing our Future Health: Taking a Long-Term View, HM Treasury.

Wanless D. (2004). Securing Good Health for the Whole Population, HM Treasury.

Welsh Assembly Government (2008). Delivering Emergency Care Services An Integrated Approach for Delivering Unscheduled Care in Wales. H. a. S. Services, Welsh Assembly Government.

WHO (1948). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States. Official Records of the World Health Organization, no. 2, p. 100.

Wulfert E. and Wan C.K. (1993). Condom Use: A Self-Efficacy Model. Health Psychology 12(5): 346-353.

Appendices

Appendix 1: Discussion Points: Study 1

Discussion points for Study 1 Interviews

Explain the scope of the study.
Begin:
In the following scenarios the patients have sought advice or help from NHS Direct before any other sources.

- Some examples of a miss-targeted consultation are:

~ Where a patient makes a casualty consultation at night with symptoms of an upper respiratory tract infection (Different HCP).

- ❖ Can you think of any other examples like this?
- ❖ Is this an inappropriate appointment?
- ❖ Can you describe the problem here, without referring to the example?

~ Where a patient consults with a minor self limiting condition such as a cough (Self treatment / social support);

- ❖ Could the needs of this consultation be met somewhere other than a healthcare setting?
- ❖ Again, can you describe the problem here, without referring to the example?

~ Where a patient consults with an advanced change in a skin mole, first noticed by the patient a month or more ago or where the patient does not consult at all with these symptoms OR a laceration that occurred several days ago which has now become septic OR . It is obvious that the laceration should have been treated immediately (consults too late- mistargeted in terms of time).

- ❖ Has the patient made any mistakes here?
- ❖ Can this be described as an appropriate consultation?
- ❖ Again, can you describe the problem here, without referring to the example?

~ Where an elderly patient consults without any clinically significant symptoms but during the consultation it becomes clear that the patient is suffering from loneliness (Consulting with a non-clinical need).

- ❖ Again, can you describe the problem here, without referring to the example? OR How would you characterise this consultation? OR
- ❖

- We have looked at mistargeted consultations so far. How would you describe an accurately targeted consultation?
- What do you consider to be the difference between an inappropriate and a mistargeted appointment?

- In your experience, how big is the problem of mistargeting? Wave the magic wand.....
- Could you identify patient groups who mistarget frequently?
- What symptom most frequently results in miss-targeting?
- Can you think of any other causes of mistargeting as we have just described it?

Appendix 2: Standardised Record Sheet: Study 2

Day_____ AM / PM GP initials_____ Surgery_____

Patient No.	1		2		3		4		5		6		7		8		9		10		11		12		13	
Male Female	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m
Wrong HCP																										
Wrong Time																										
Potentially avoidable																										
Patient No.	14		15		16		17		18		19		20		21		22		23		24		25		26	
Male Female	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m
Wrong HCP																										
Wrong Time																										
Potentially avoidable																										

Appendix 3: Discussion Points: Study 3

The health service user's perspective on PCTE

Explanation of requirements: No personal information required. No medical information required.
General, open questions, scenarios with follow-up questions followed by specific questions.

1. General, open questions:

Think about your last non-routine consultation.

- When you are ill, what is your main priority or concern?

Your consultation starts with a journey from your house to the HCP

- What made you decide to take that journey / Why go to seek help?
- Would you seek social support?
- Why don't you go?
- What made you decide to consult when you did?
- What made you decide to consult the person you did?
- What did you want or expect from the consultation? And why?
- Do you consciously THINK about making a consultation / WHO to consult?
- Where did you learn your consultation behaviour from?

2. Scenarios and follow-up questions.

The following are examples of consultations made by a friend or family member:

- Imagine you have cut your hand badly one morning while preparing a meal at home and it is bleeding heavily. It looks like it needs some attention. What would you do? And WHY there?

(HCP)

- What would you do if you had a simple common cold?

(Avoidable)

- You experience a painful knee. You have not injured it and it doesn't appear swollen. What would you do?

(Time)

3. General Questions:

- If you were told, after you had been treated, that the consultation you have just made was inappropriate, how would you feel?
- If you were told, after you had been treated, that the consultation you have just made was appropriate but mistargeted, how would you feel?
- Who is available to seek advice from or make consultations with?
- What is your highest academic qualification?

Appendix 4: All Instruments: Study 4

Socio-Demographic Profile

Participant ID number: _____ Date: ____/____/____

Your date of birth:	
Your address:	
Highest educational level achieved:	
Your work experience: (a brief answer is enough, e.g. simple job titles	
Marital status:	
Your siblings – if any (age & sex):	
Other children in household:	
Household income:	<£10K £10K-£19K £20K-£29K £30K-£39K £40+K
1st / preferred language:	
Computer user (owner or access):	
Car driver (owner or access):	

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Appendix 6: Tables Illustrating Outliers: Study 4

Variable 1: Brief COPE: Religion;

Control - Brief COPE: Religion - Baseline

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	5	62.5	62.5	62.5
	1	1	12.5	12.5	75.0
	2	2	25.0	25.0	100.0
	Total	8	100.0	100.0	

Control - Brief COPE: Religion – Post intervention

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	8	100.0	100.0	100.0

Control - Brief COPE: Religion – Follow up

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	7	87.5	87.5	87.5
	3	1	12.5	12.5	100.0
	Total	8	100.0	100.0	

Intervention - Brief COPE: Religion – Baseline

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	11	78.6	78.6	78.6
	2	1	7.1	7.1	85.7
	4	2	14.3	14.3	100.0
	Total	14	100.0	100.0	

Intervention - Brief COPE: Religion – Post intervention

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	11	78.6	78.6	78.6
	1	1	7.1	7.1	85.7
	2	1	7.1	7.1	92.9
	4	1	7.1	7.1	100.0
	Total	14	100.0	100.0	

Intervention - Brief COPE: Religion – Follow up

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	13	92.9	92.9	92.9
	3	1	7.1	7.1	100.0
	Total	14	100.0	100.0	

Variable 2: Brief COPE: Substance Abuse;

Control - Brief COPE: Substance Abuse - Baseline

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	6	75.0	75.0	75.0
	3	1	12.5	12.5	87.5
	4	1	12.5	12.5	100.0
	Total	8	100.0	100.0	

Control - Brief COPE: Substance Abuse – Post intervention

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	8	100.0	100.0	100.0

Control - Brief COPE: Substance Abuse – Follow up

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	8	100.0	100.0	100.0

Intervention - Brief COPE: Substance Abuse – Baseline

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	12	85.7	85.7	85.7
	2	1	7.1	7.1	92.9
	6	1	7.1	7.1	100.0
	Total	14	100.0	100.0	

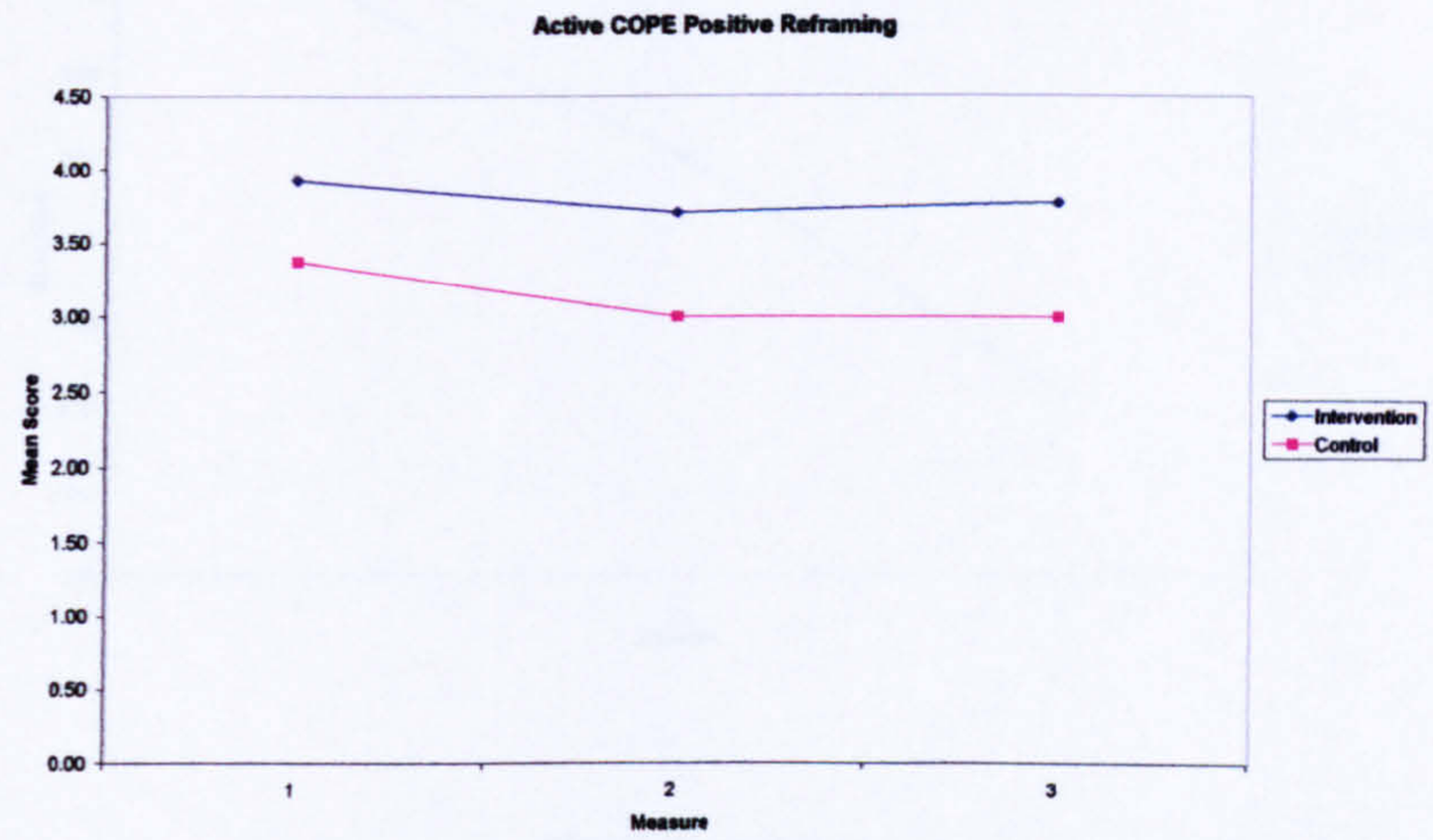
Intervention - Brief COPE: Substance Abuse – Measure 3

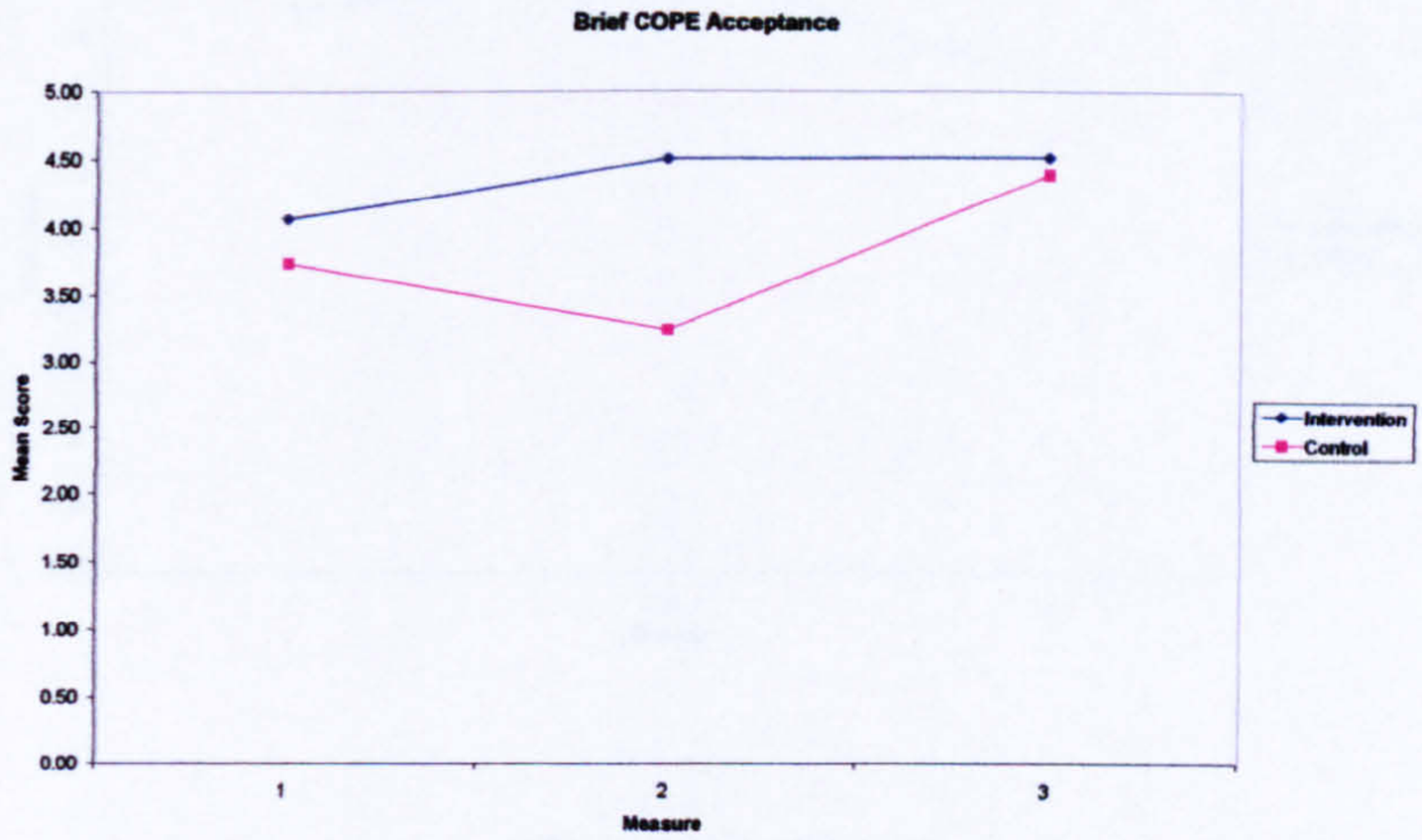
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	9	64.3	64.3	64.3
	1	3	21.4	21.4	85.7
	2	1	7.1	7.1	92.9
	6	1	7.1	7.1	100.0
	Total	14	100.0	100.0	

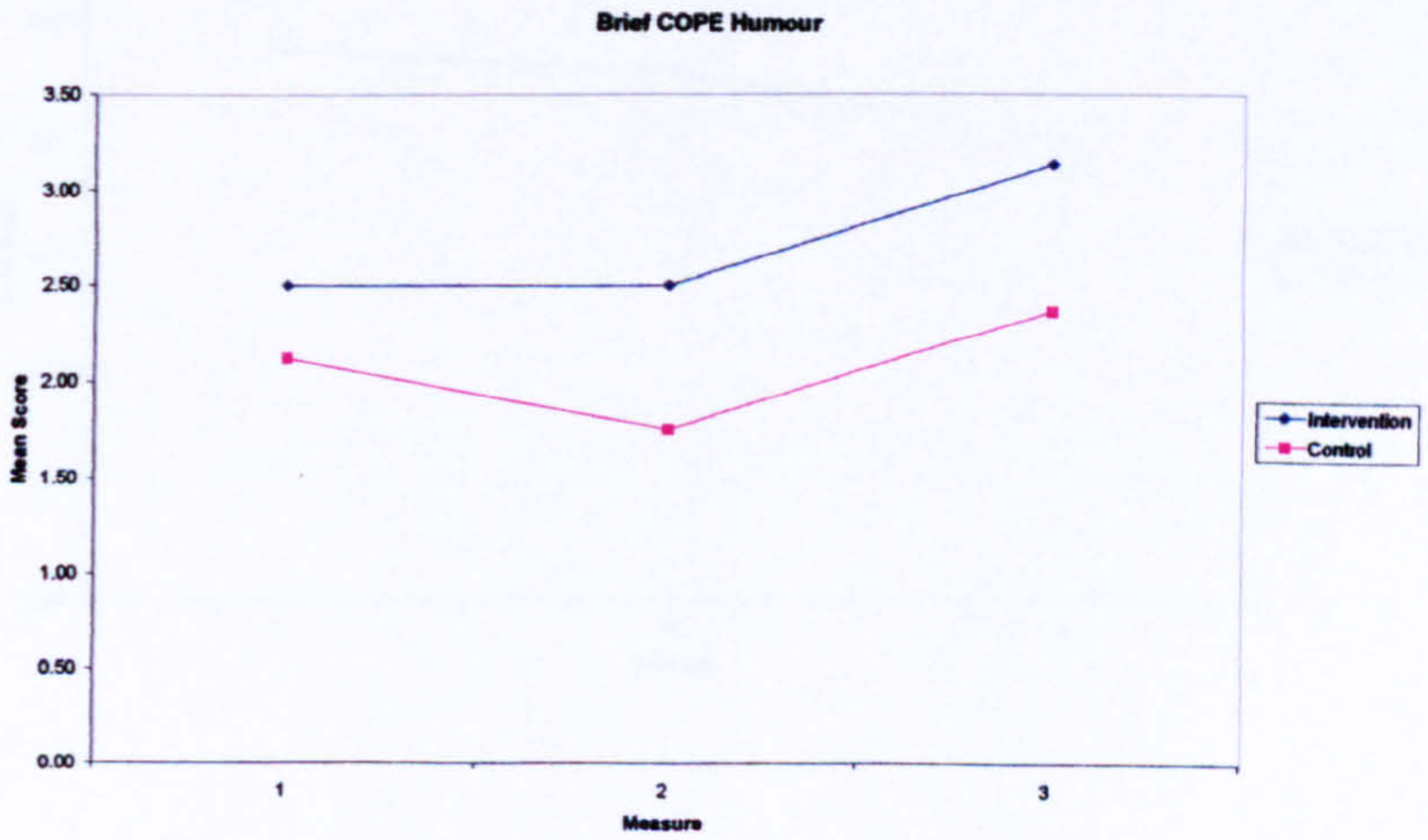
Intervention - Brief COPE: Substance Abuse – Follow up

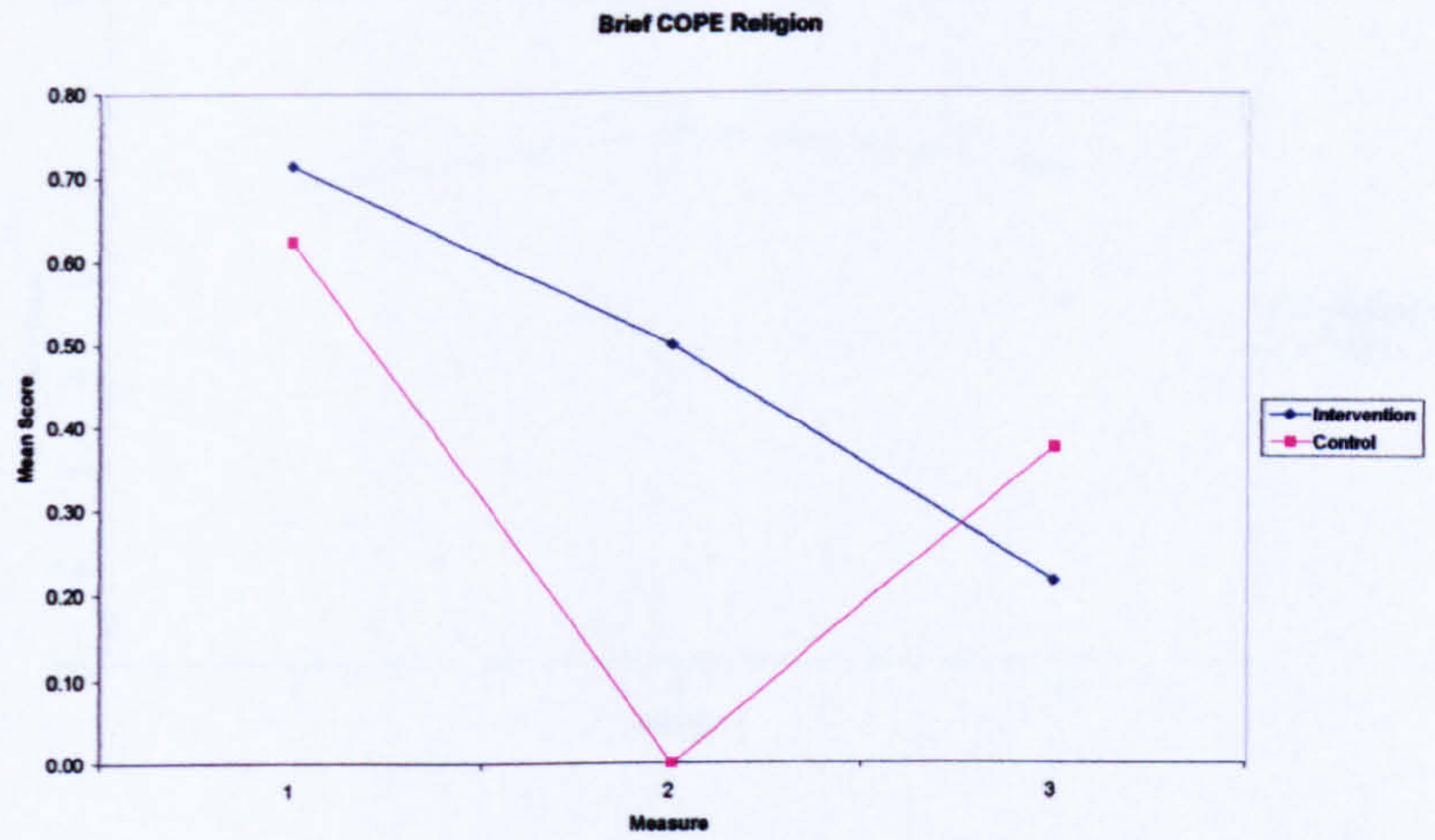
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	11	78.6	78.6	78.6
	2	1	7.1	7.1	85.7
	4	1	7.1	7.1	92.9
	5	1	7.1	7.1	100.0
	Total	14	100.0	100.0	

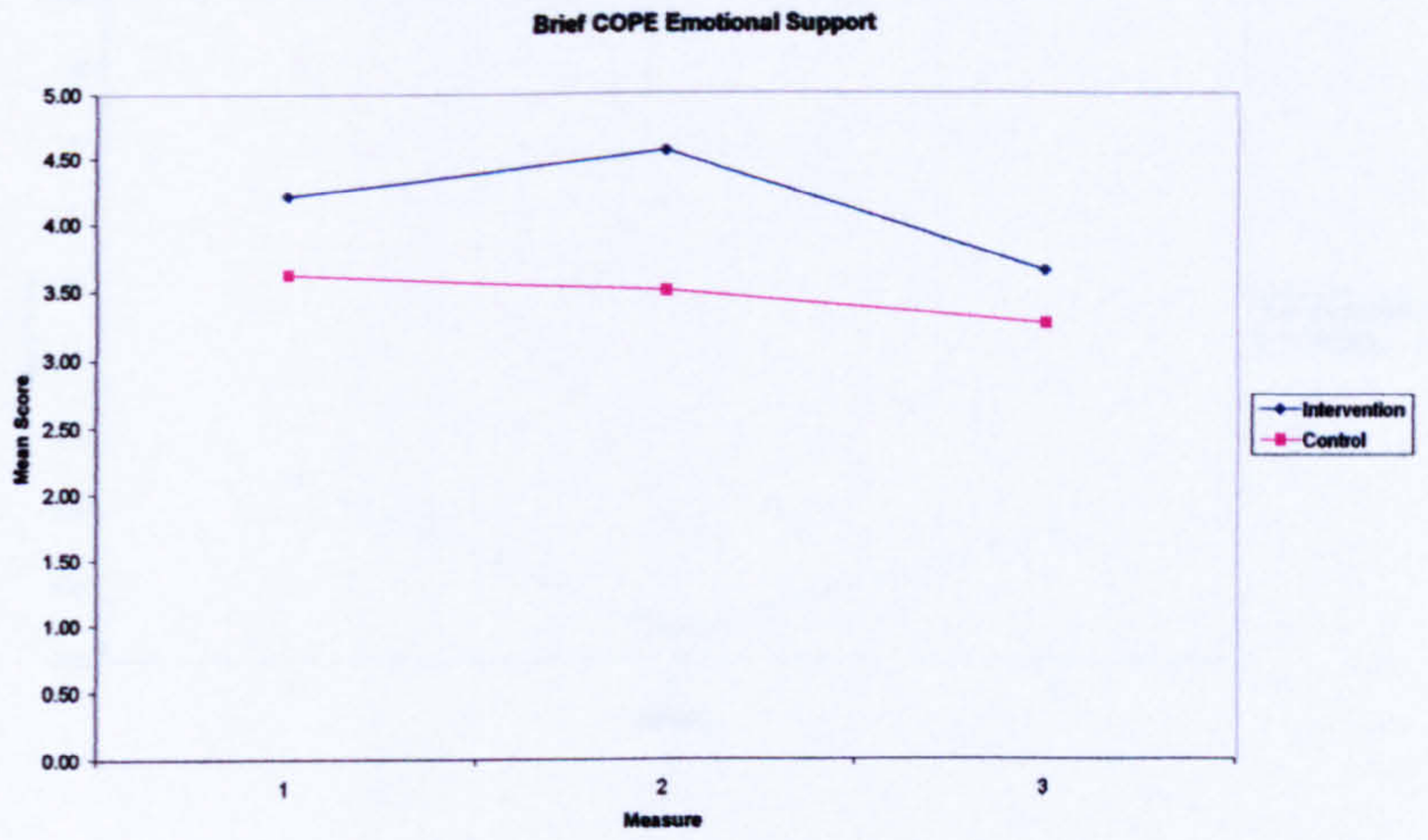
Appendix 7: Graphs comparing mean, non-significant-between group scores at baseline (1), post test (2) and follow up (3) measures: Study 4

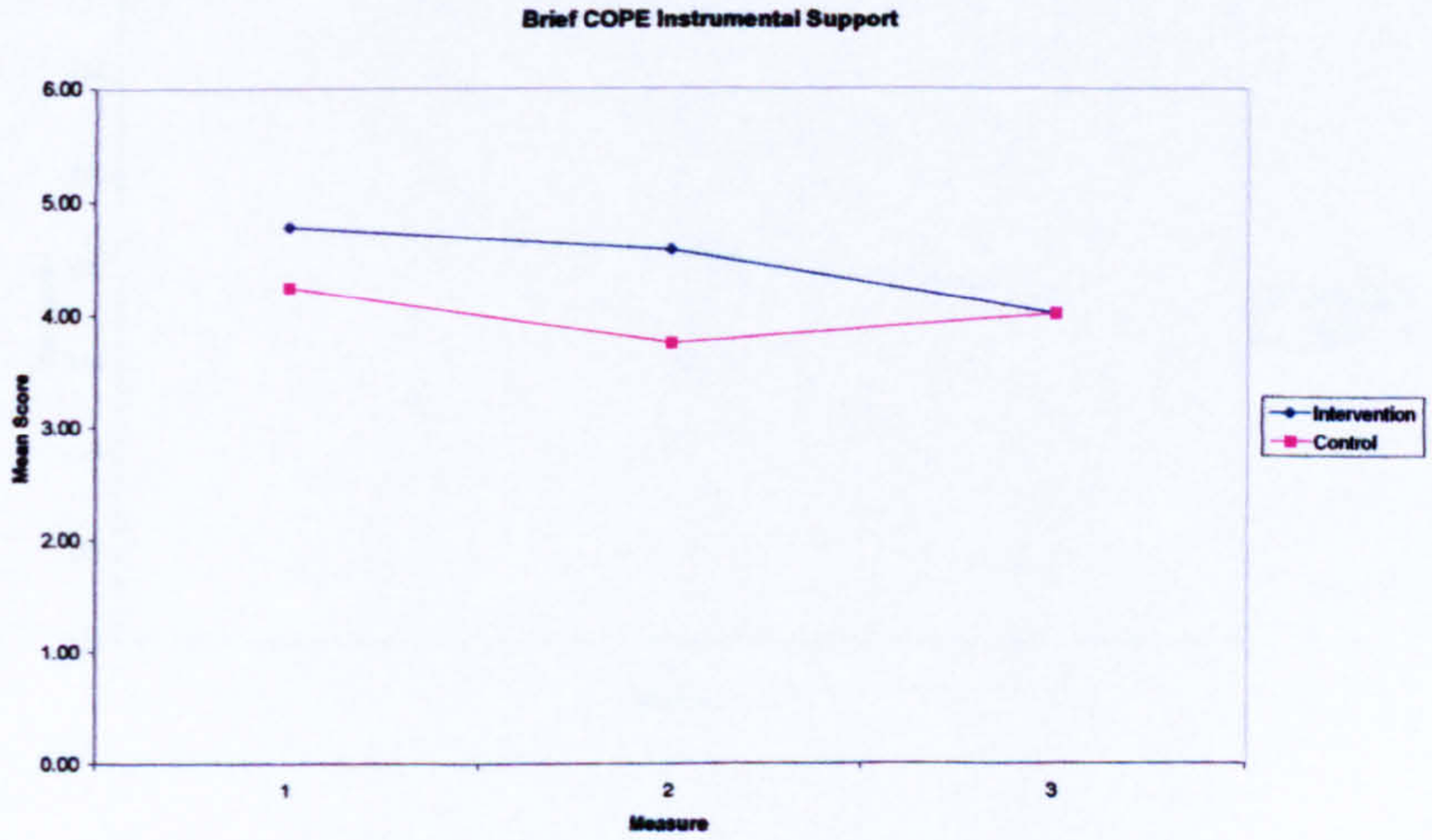


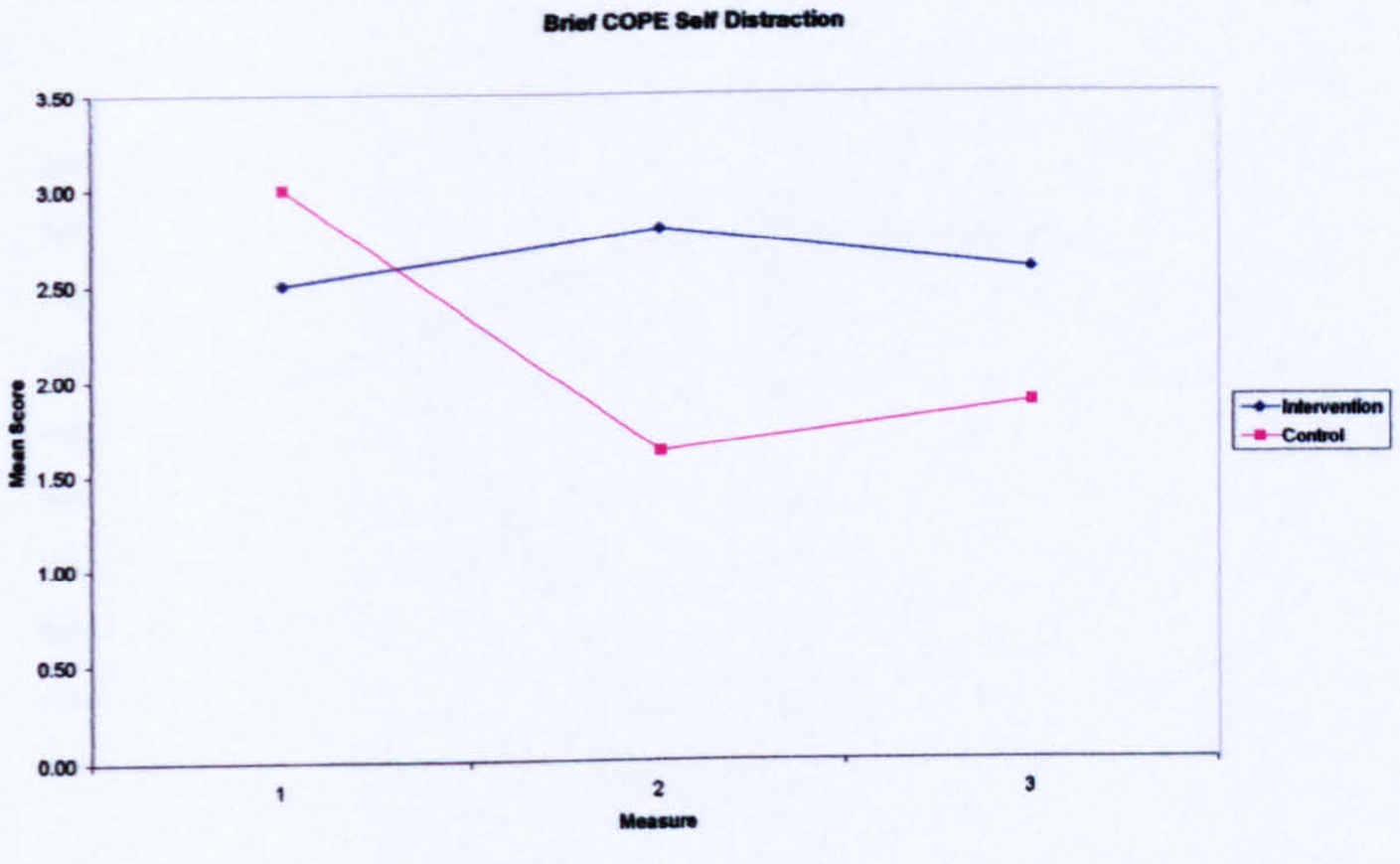


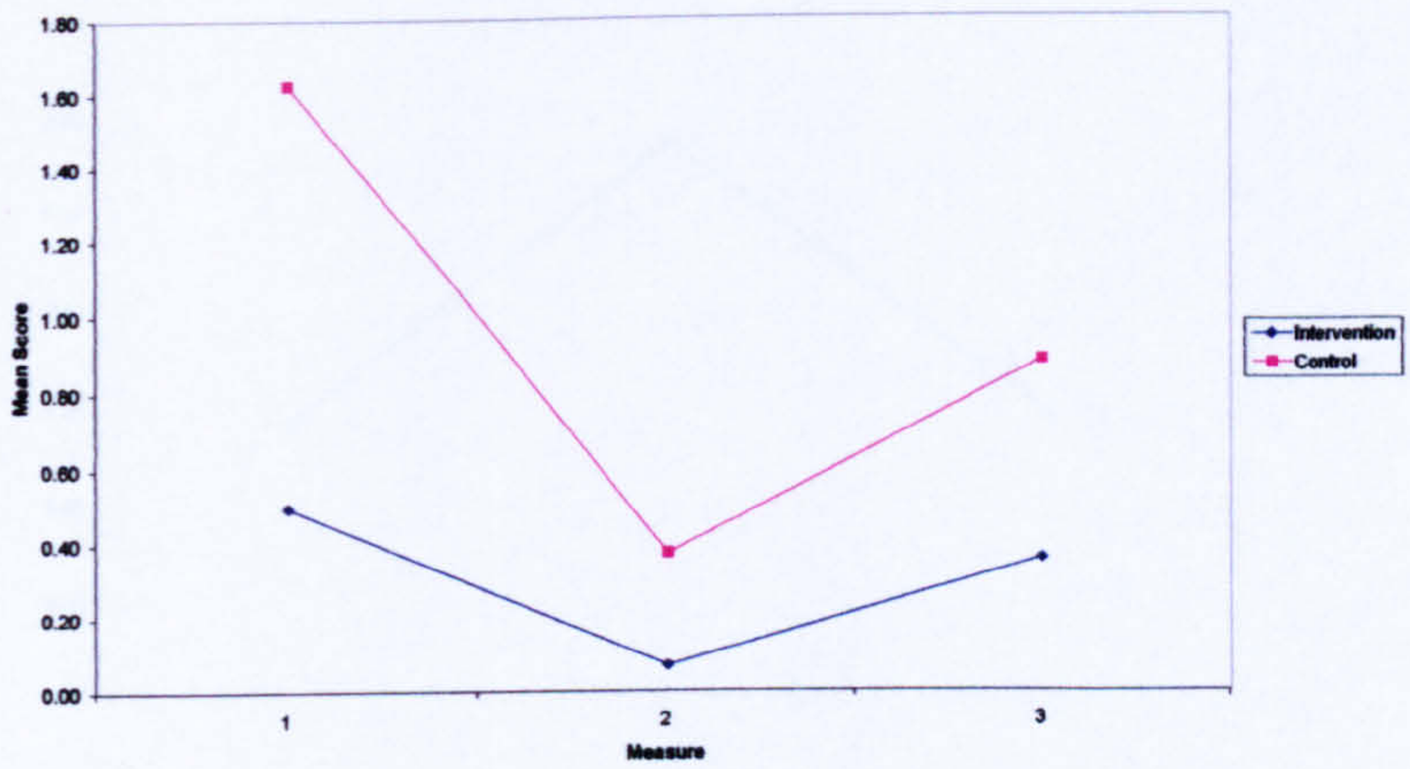


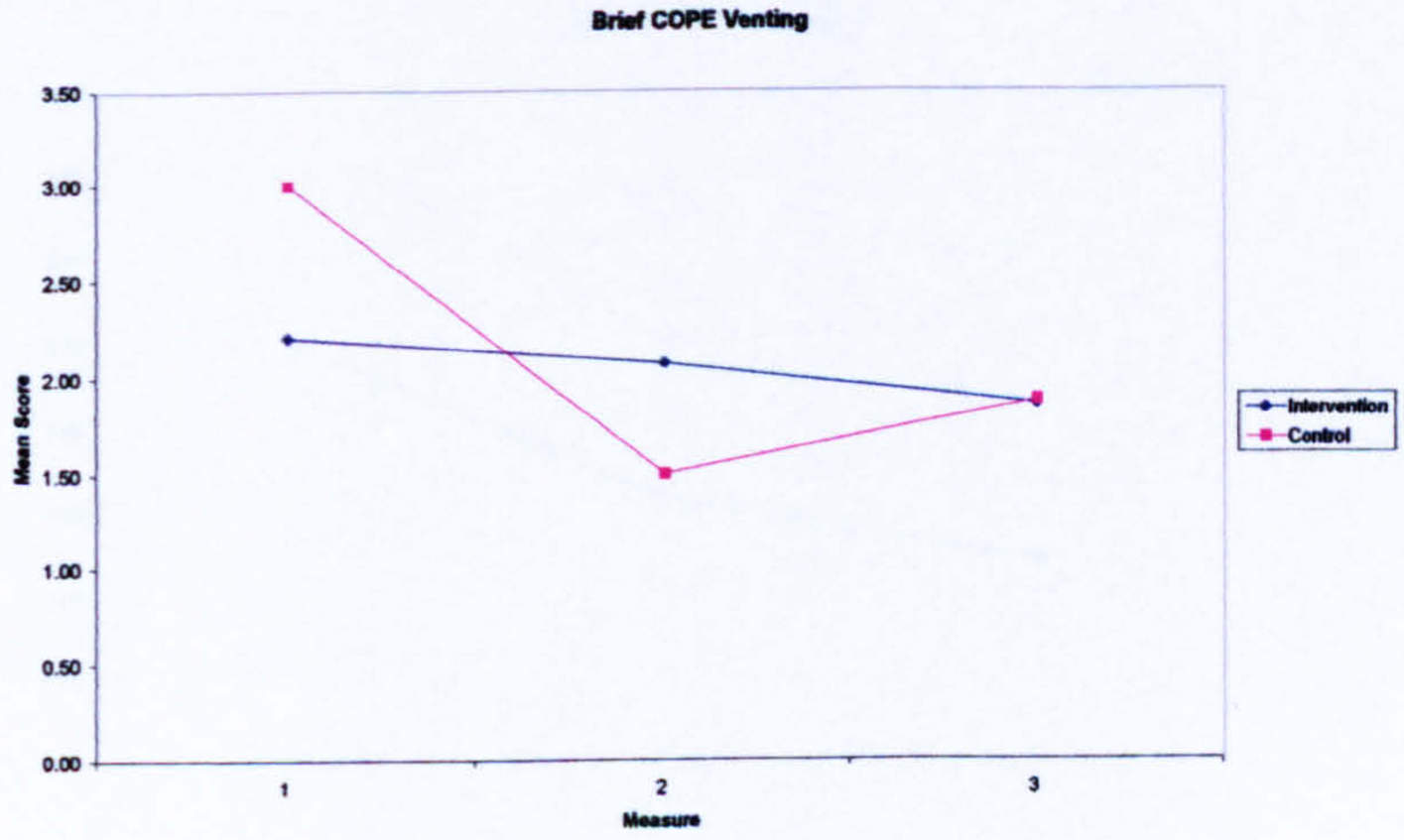

Brief COPE Religion
Mean Score
0.80
0.70
0.60
0.50
0.40
0.30
0.20
0.10
0.00
1
2
3
Measure
Intervention
Control


Brief COPE Emotional Support
Mean Score
5.00
4.50
4.00
3.50
3.00
2.50
2.00
1.50
1.00
0.50
0.00
1
2
3
Measure
Intervention
Control

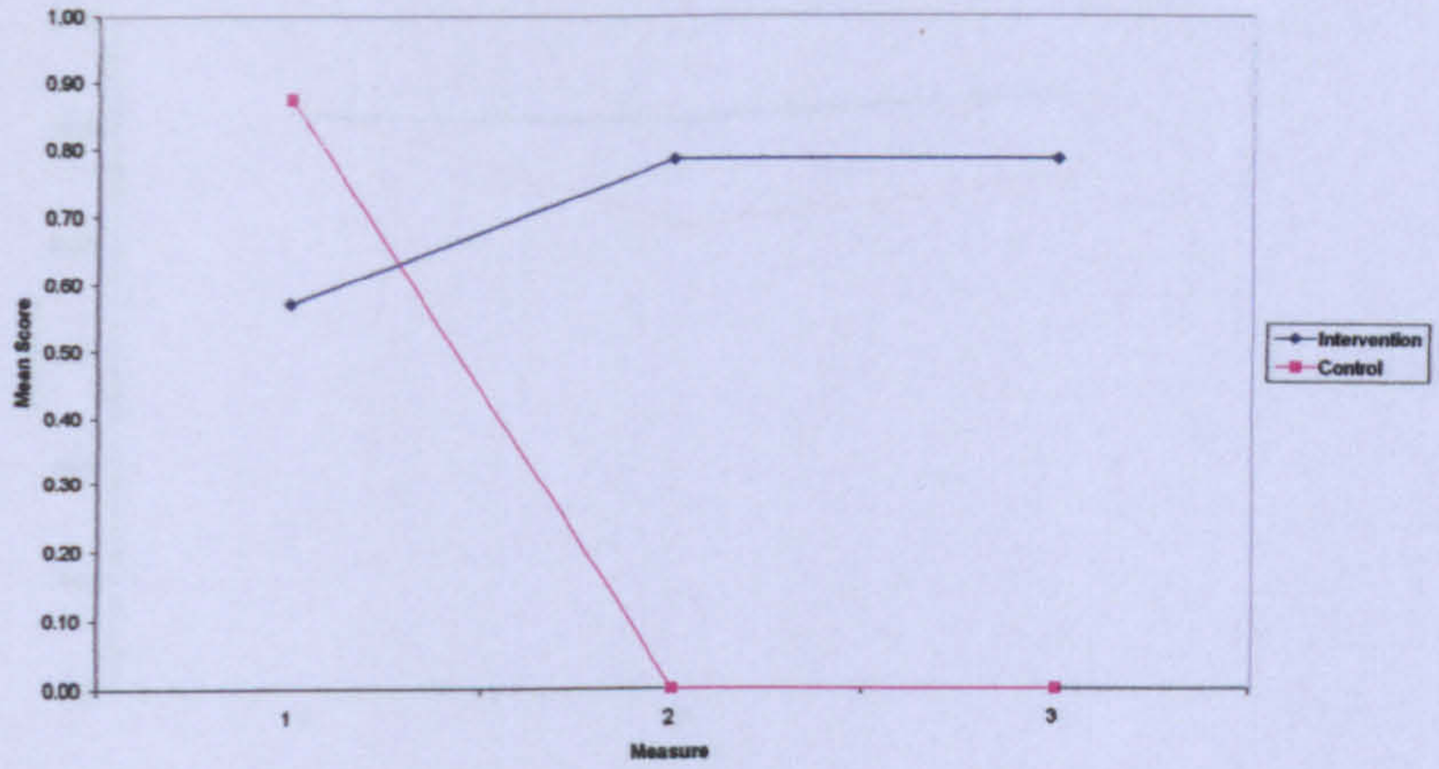

Brief COPE Instrumental Support
Mean Score
6.00
5.00
4.00
3.00
2.00
1.00
0.00
1
2
3
Measure
Intervention
Control


Brief COPE Self Distraction
Mean Score
3.50
3.00
2.50
2.00
1.50
1.00
0.50
0.00
1
2
3
Measure
Intervention
Control

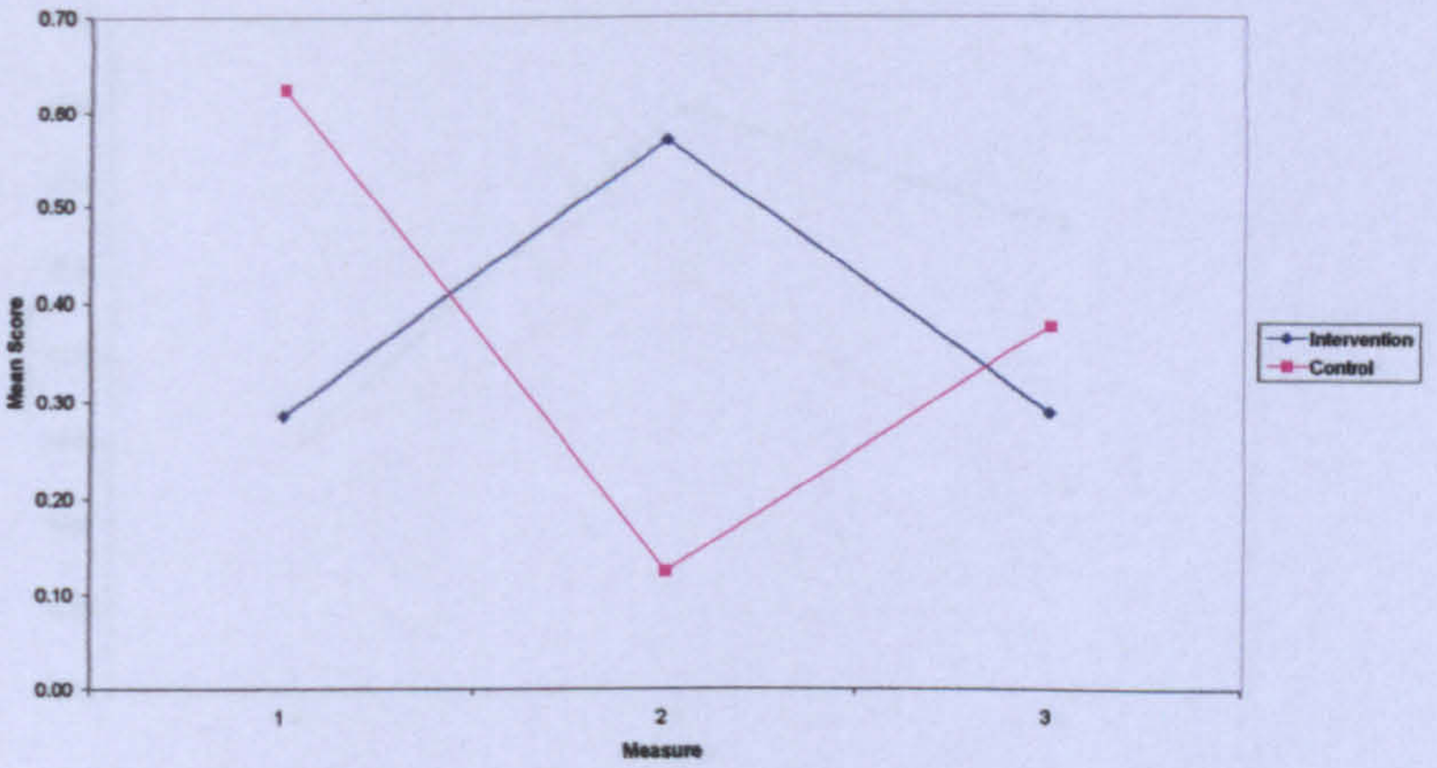

Brief COPE Denial
Mean Score
1.80
1.60
1.40
1.20
1.00
0.80
0.60
0.40
0.20
0.00
1
2
3
Measure
Intervention
Control


Brief COPE Venting
Mean Score
3.50
3.00
2.50
2.00
1.50
1.00
0.50
0.00
1
2
3
Measure
Intervention
Control

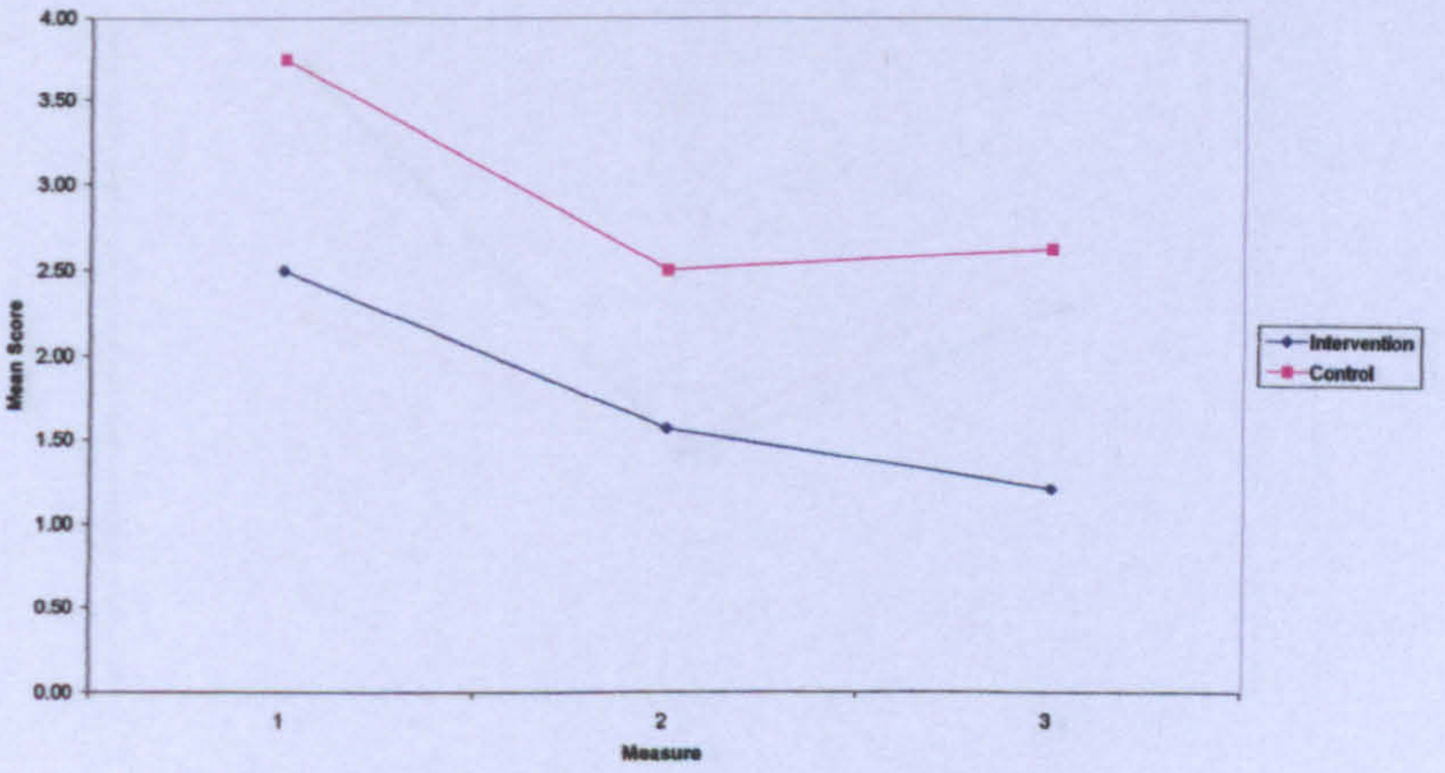
Brief COPE Substance Abuse

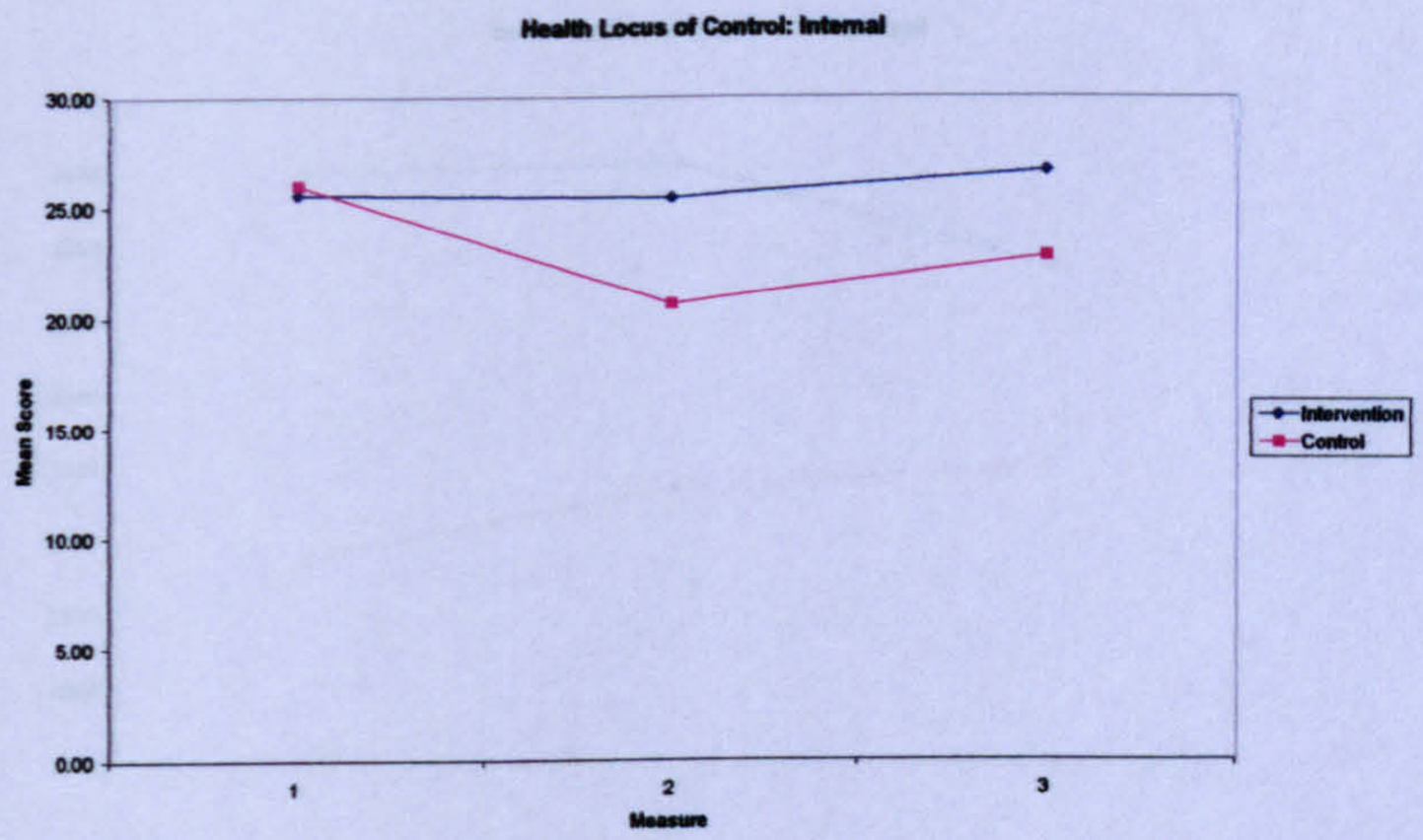


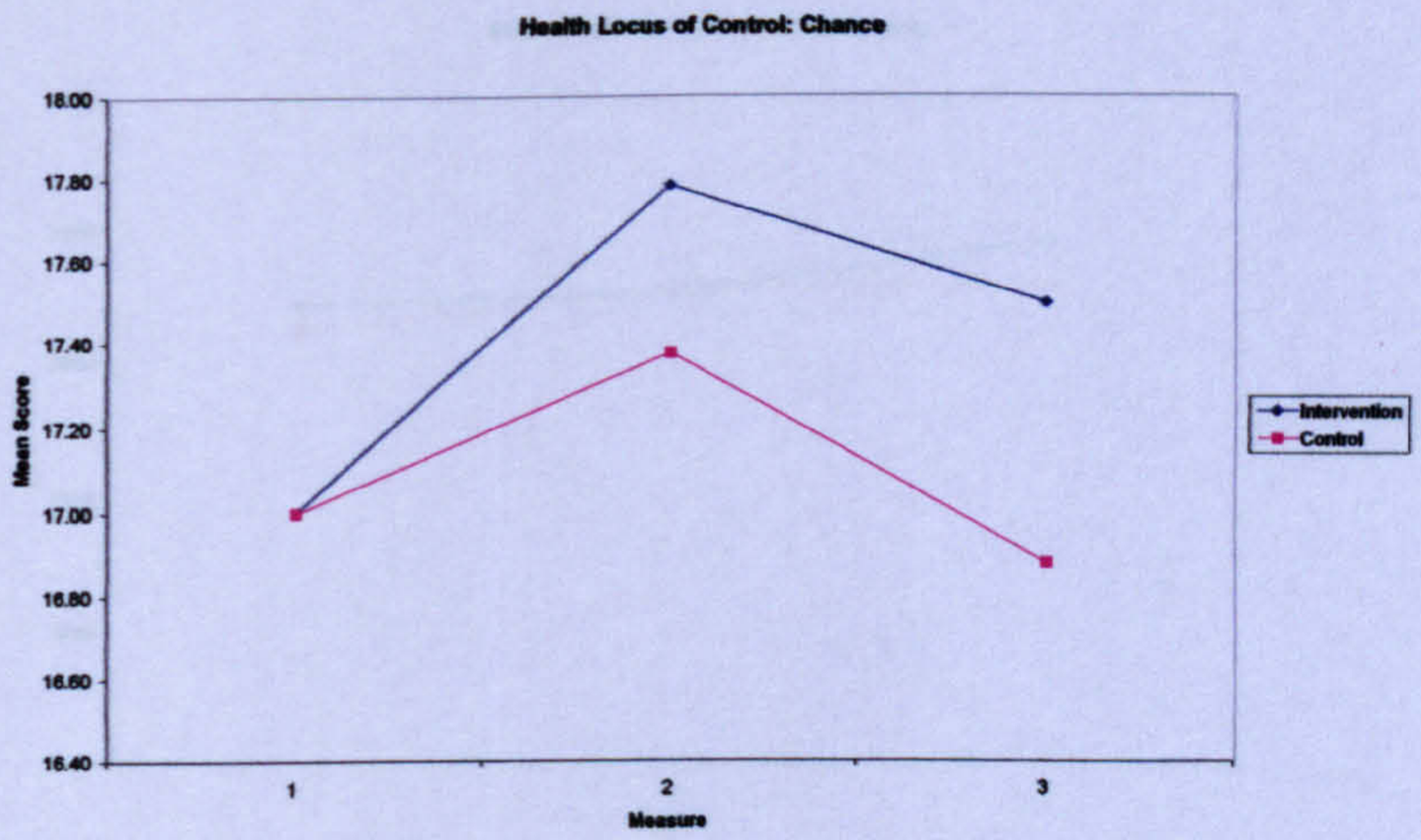
Brief COPE Behavioural Disengagement

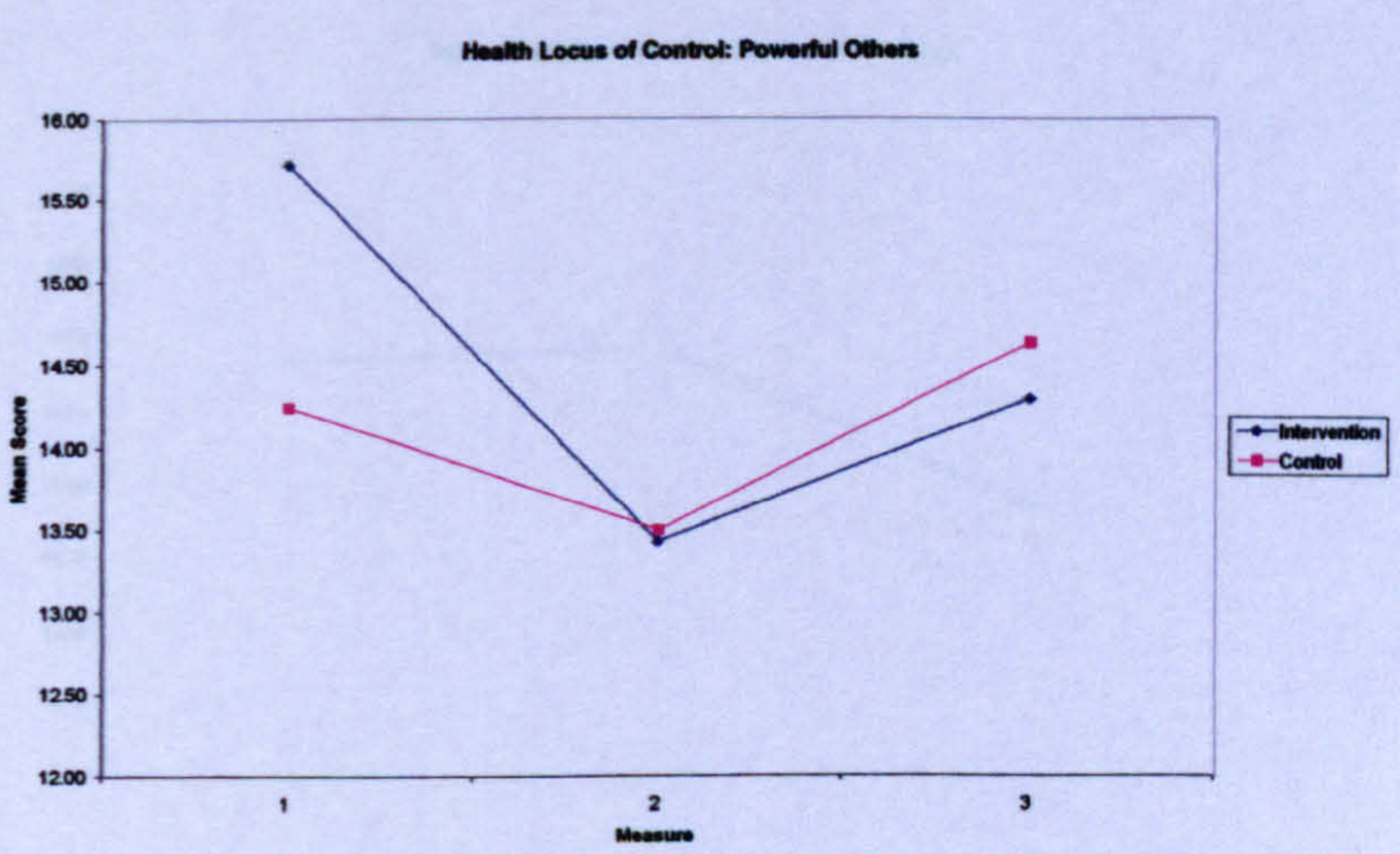


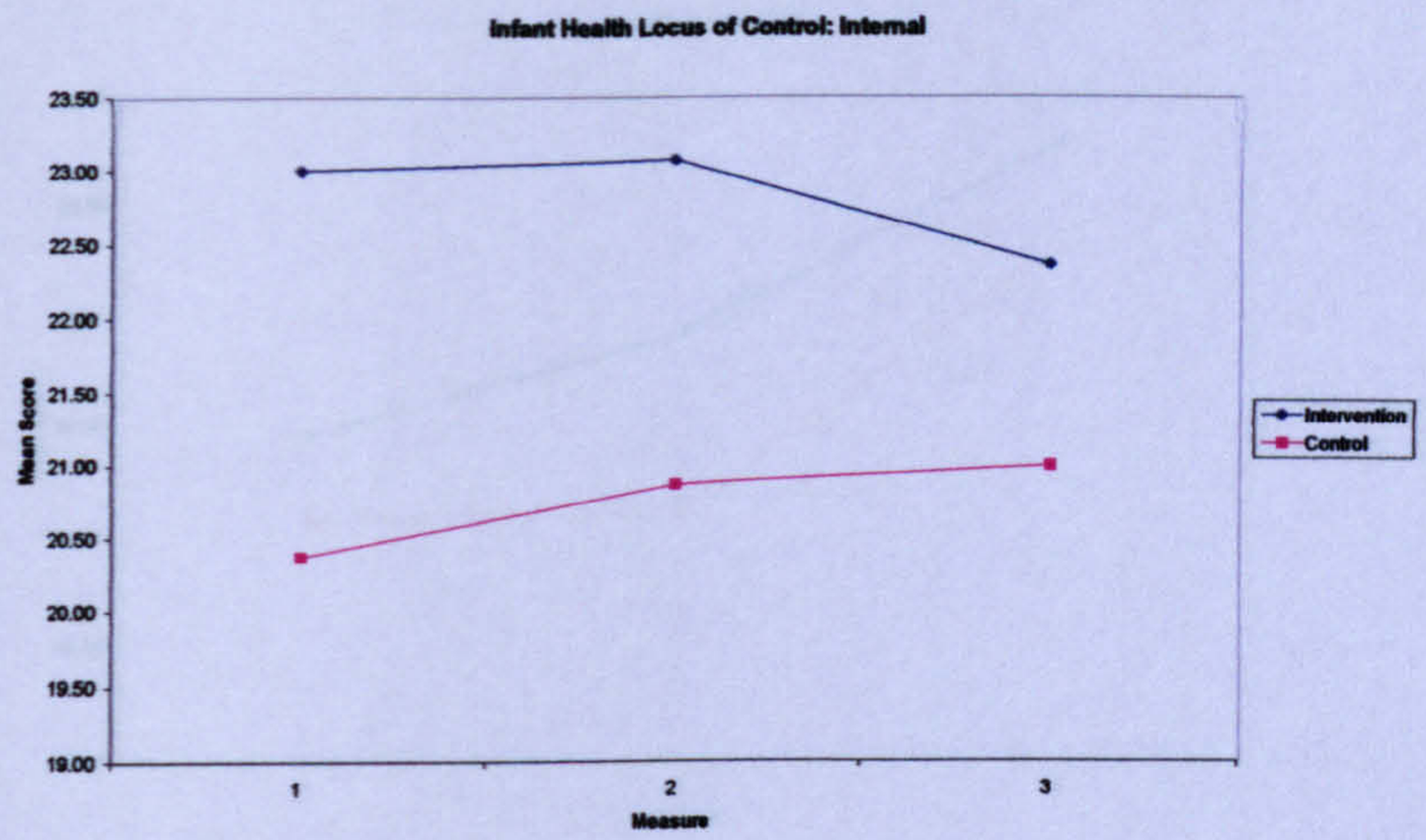
Brief COPE Self Blame

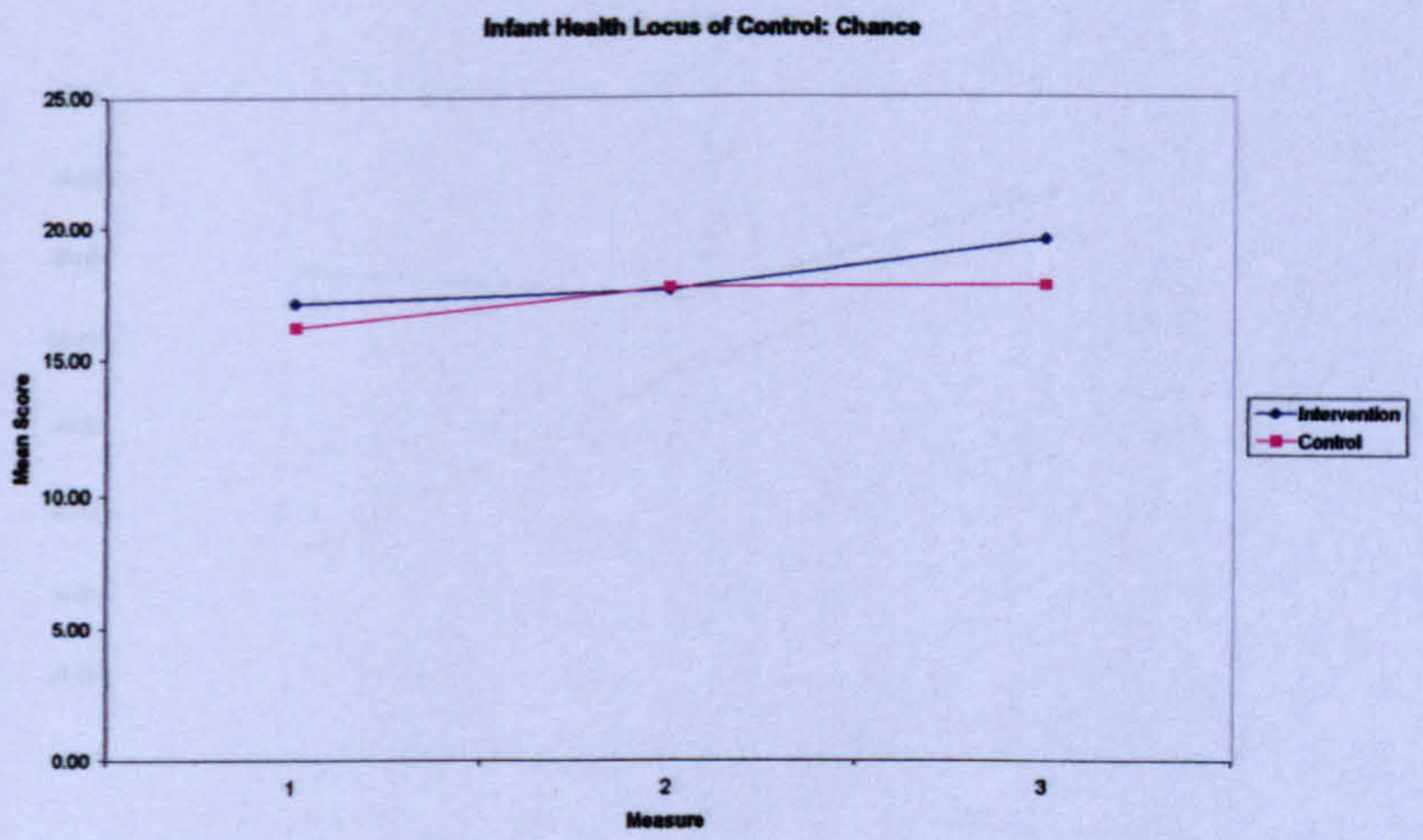


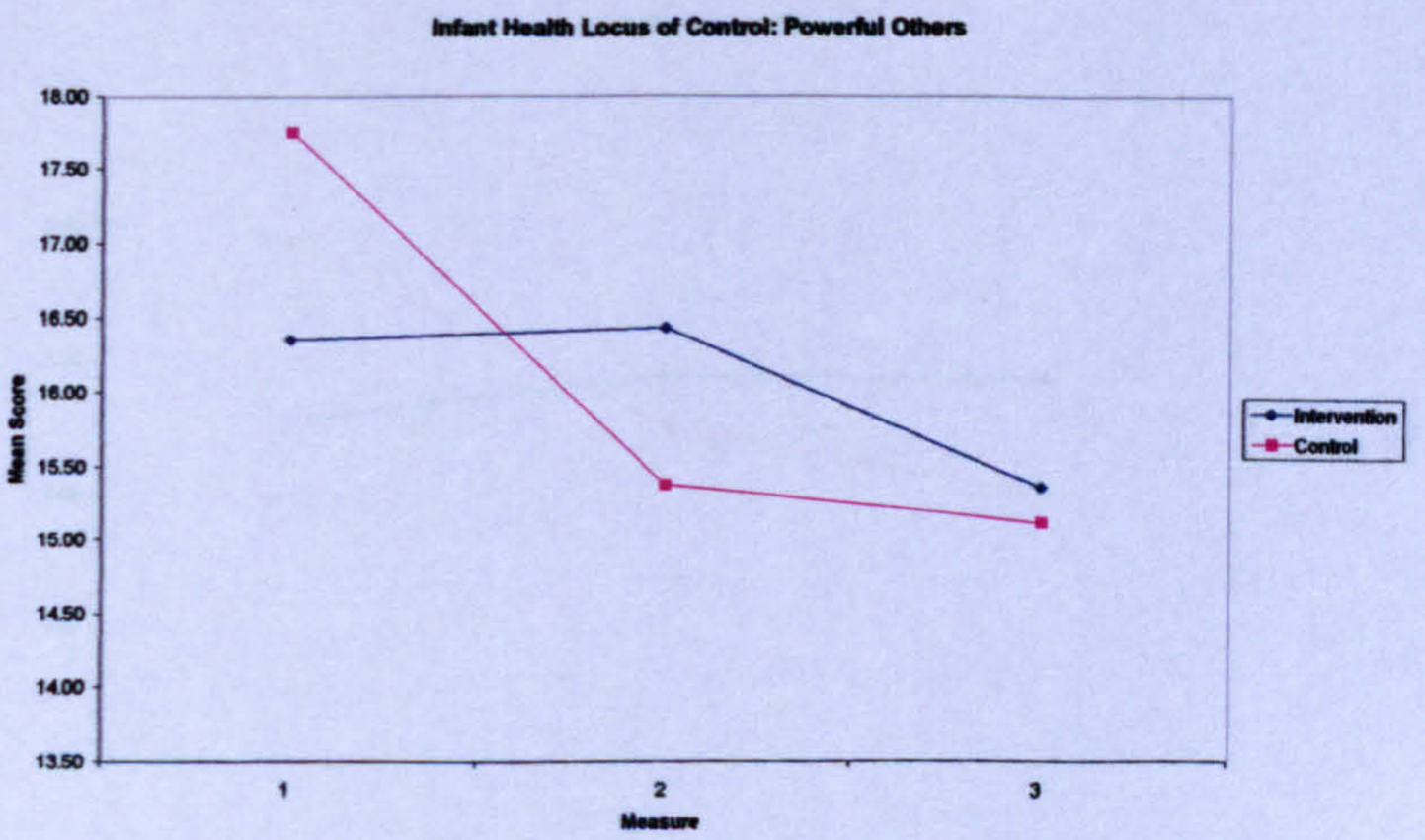

Health Locus of Control: Internal
30.00
25.00
20.00
15.00
10.00
5.00
0.00
Mean Score
1
2
3
Measure
Intervention
Control

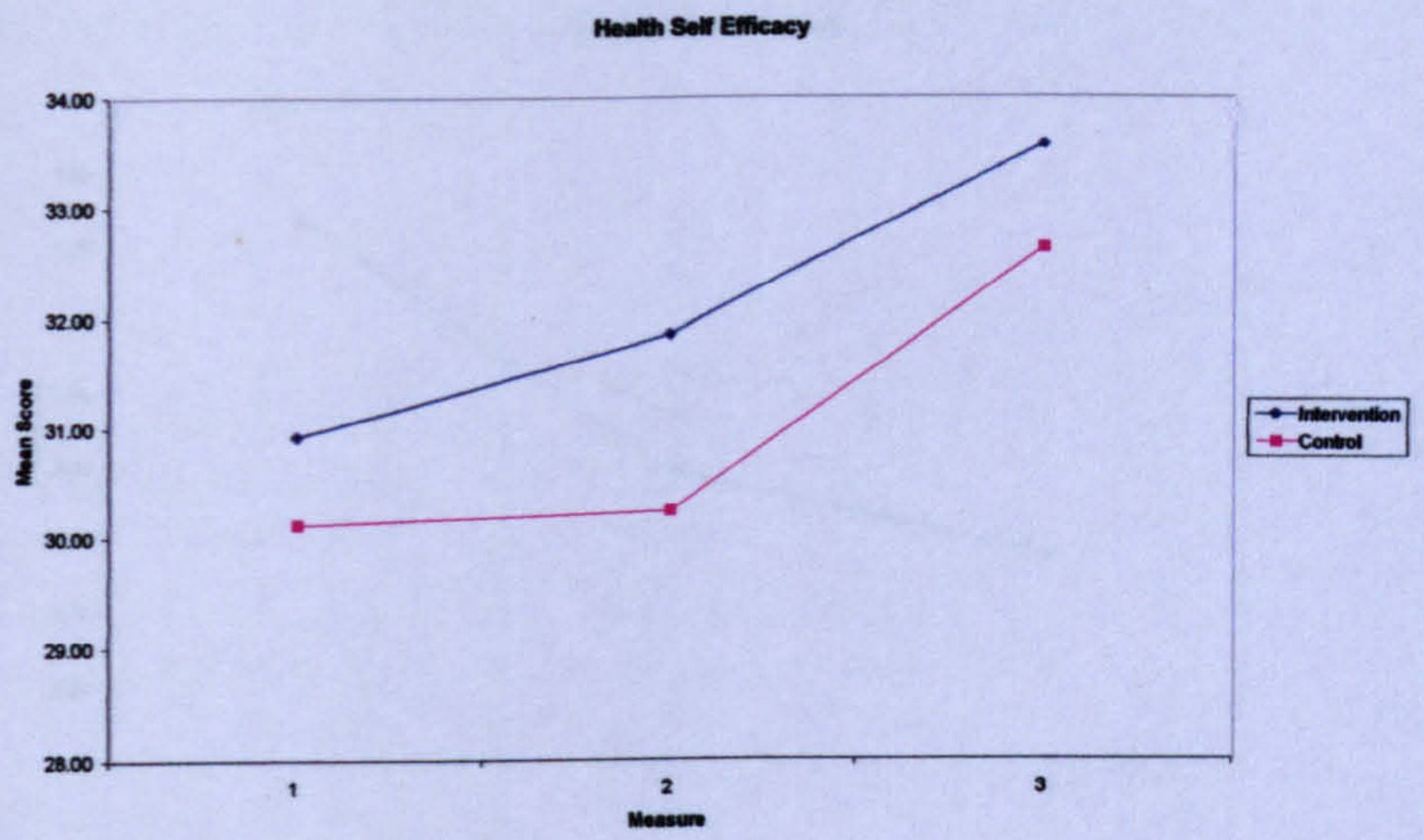

Health Locus of Control: Chance
18.00
17.80
17.60
17.40
17.20
17.00
16.80
16.60
16.40
Mean Score
1
2
3
Measure
Intervention
Control

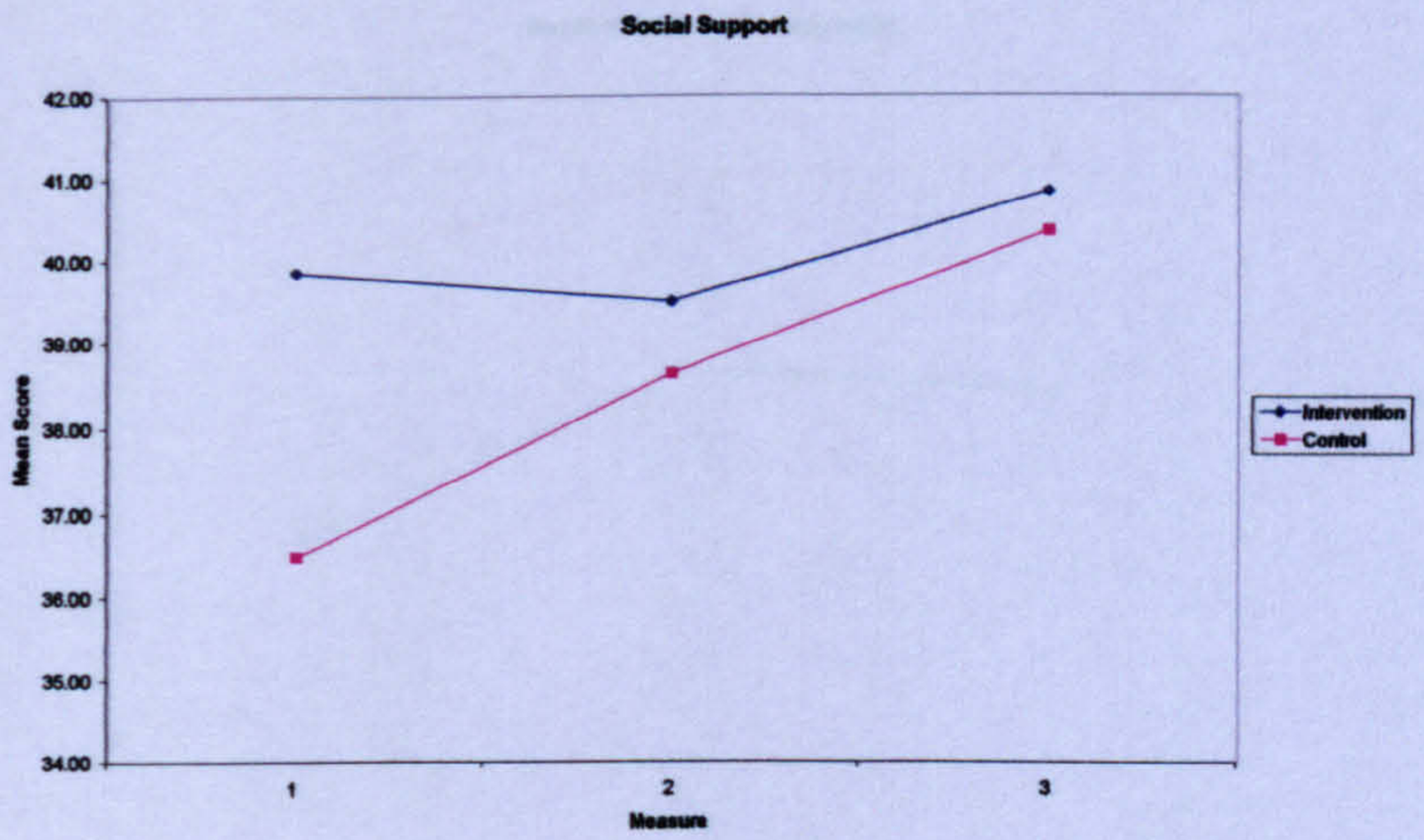

Health Locus of Control: Powerful Others
16.00
15.50
15.00
14.50
14.00
13.50
13.00
12.50
12.00
Mean Score
1
2
3
Measure
Intervention
Control

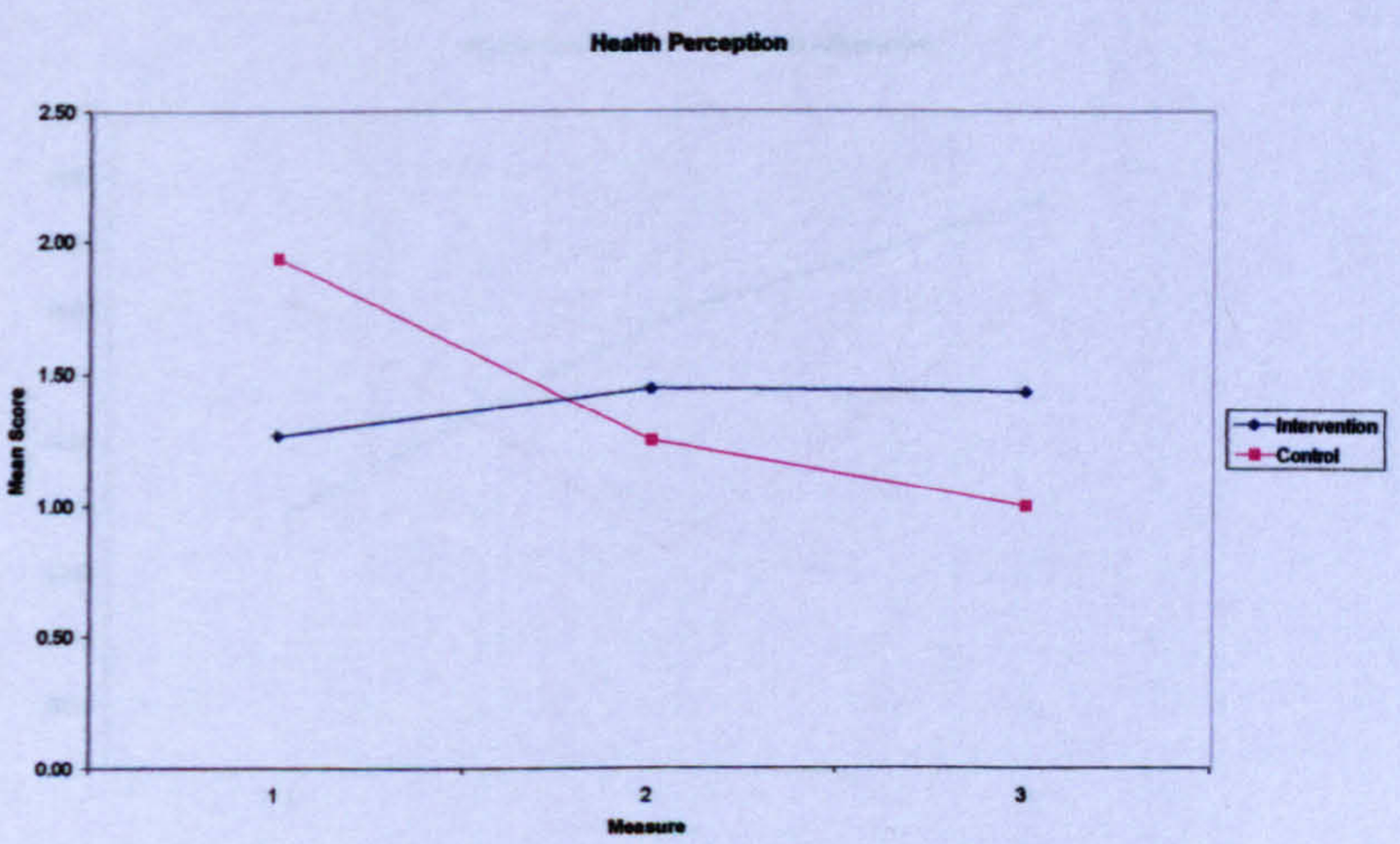

Infant Health Locus of Control: Internal
23.50
23.00
22.50
22.00
21.50
21.00
20.50
20.00
19.50
19.00
Mean Score
1
2
3
Measure
Intervention
Control

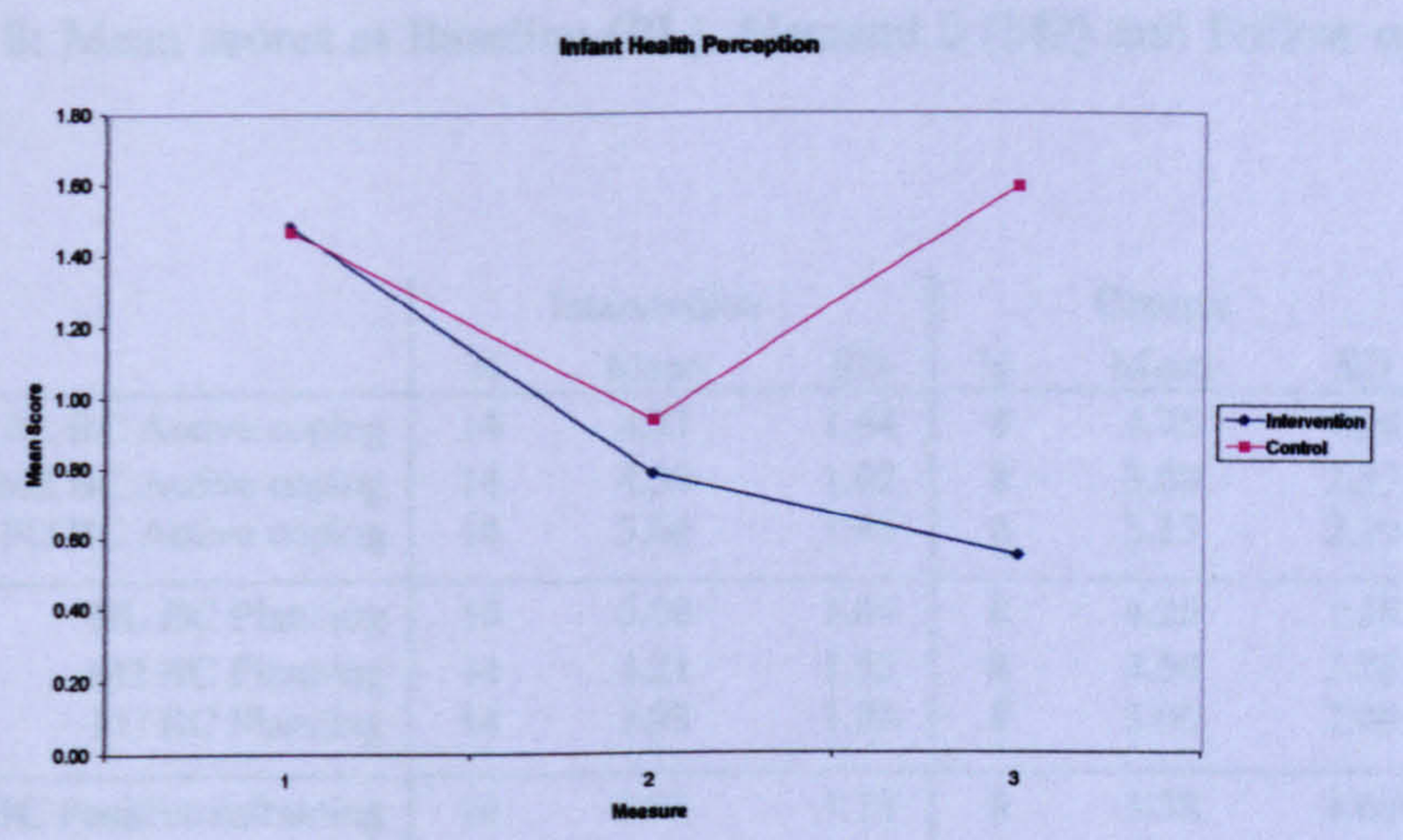

Infant Health Locus of Control: Chance
25.00
20.00
15.00
10.00
5.00
0.00
Mean Score
1
2
3
Measure
Intervention
Control

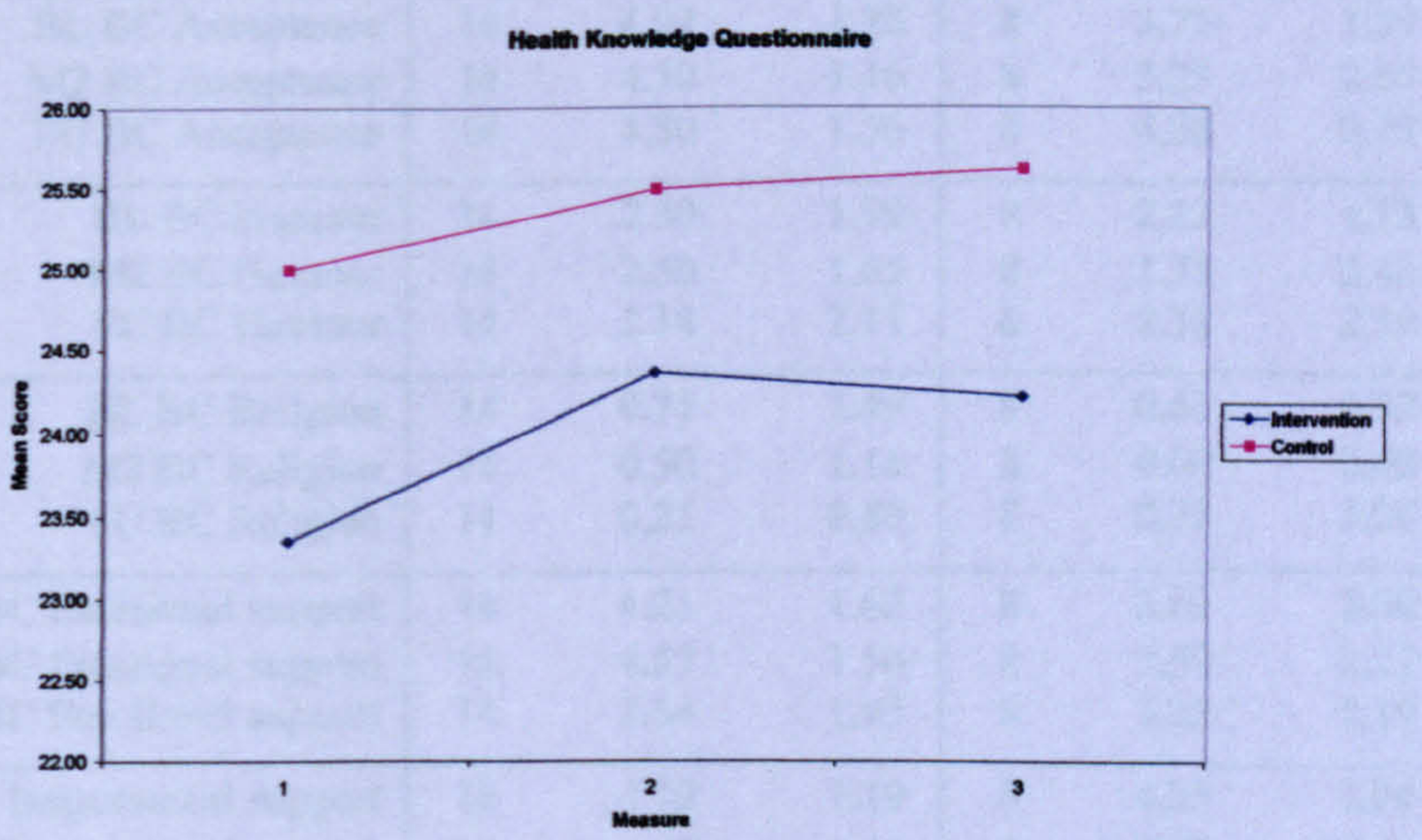

Infant Health Locus of Control: Powerful Others
18.00
17.50
17.00
16.50
16.00
15.50
15.00
14.50
14.00
13.50
Mean Score
1
2
3
Measure
Intervention
Control

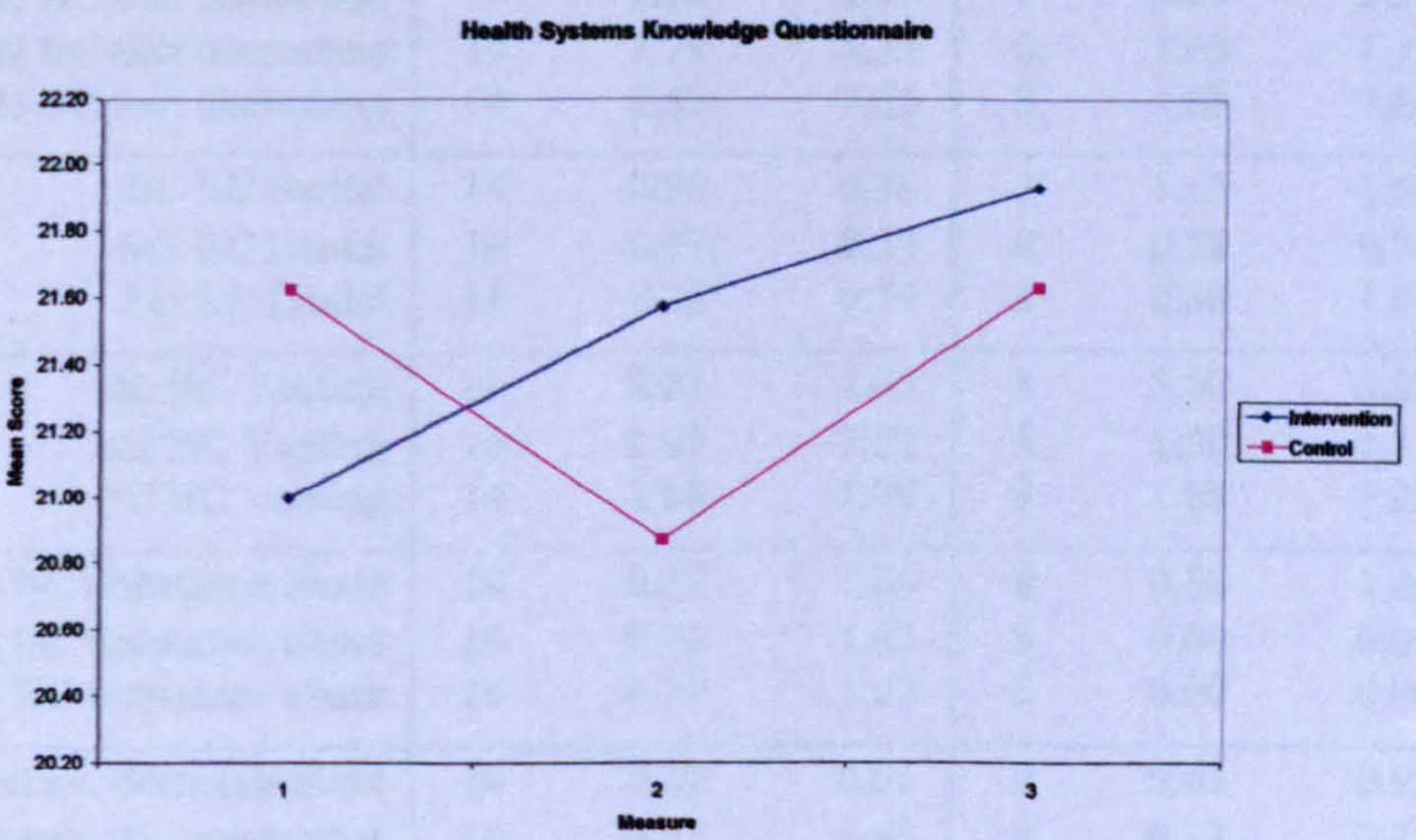

Health Self Efficacy
34.00
33.00
32.00
31.00
30.00
29.00
28.00
Mean Score
1
2
3
Measure
Intervention
Control


Social Support
42.00
41.00
40.00
39.00
38.00
37.00
36.00
35.00
34.00
Mean Score
1
2
3
Measure
Intervention
Control


Health Perception
2.50
2.00
1.50
1.00
0.50
0.00
Mean Score
1
2
3
Measure
Intervention
Control


Infant Health Perception
Mean Score
1.80
1.60
1.40
1.20
1.00
0.80
0.60
0.40
0.20
0.00
1
2
3
Measure
Intervention
Control


Health Knowledge Questionnaire
Mean Score
26.00
25.50
25.00
24.50
24.00
23.50
23.00
22.50
22.00
1
2
3
Measure
Intervention
Control


Health Systems Knowledge Questionnaire
Mean Score
22.20
22.00
21.80
21.60
21.40
21.20
21.00
20.80
20.60
20.40
20.20
1
2
3
Measure
Intervention
Control

Appendix 8: Mean scores at Baseline (BL), Measure 2 (M2) and Follow up (FU) by variable

	Intervention			Control		
	N	Mean	SD	N	Mean	SD
BL BC Active coping	14	4.71	1.64	8	4.75	1.16
M2 BC Active coping	14	4.50	1.02	8	3.00	2.33
FU BC Active coping	14	3.64	1.95	8	3.13	2.10
BL BC Planning	14	5.00	1.04	8	4.25	1.58
M2 BC Planning	14	4.21	1.53	8	3.50	2.78
FU BC Planning	14	3.93	1.94	8	3.00	2.00
BL BC Positive reframing	14	3.93	1.73	8	3.38	1.69
M2 BC Positive reframing	14	3.71	1.07	8	3.00	1.93
FU BC Positive reframing	14	3.79	1.85	8	3.00	2.00
BL BC Acceptance	14	4.07	1.98	8	3.75	1.39
M2 BC Acceptance	14	4.50	1.16	8	3.25	2.55
FU BC Acceptance	14	4.50	1.56	8	4.38	0.92
BL BC Humour	14	2.50	1.99	8	2.13	1.73
M2 BC Humour	14	2.50	1.65	8	1.75	2.43
FU BC Humour	14	3.14	2.11	8	2.38	2.39
BL BC Religion	14	0.71	1.49	8	0.63	0.92
M2 BC Religion	14	0.50	1.16	8	0.00	0.00
FU BC Religion	14	0.21	0.80	8	0.38	1.06
BL BC Emotional support	14	4.21	1.63	8	3.63	2.00
M2 BC Emotional support	14	4.57	1.50	8	3.50	2.27
FU BC Emotional support	14	3.64	1.95	8	3.25	2.19
BL BC Instrumental support	14	4.79	1.19	8	4.25	1.04
M2 BC Instrumental support	14	4.57	1.45	8	3.75	0.89
FU BC Instrumental support	14	4.00	1.80	8	4.00	2.07
BL BC Self distraction	14	2.50	1.95	8	3.00	2.39
M2 BC Self distraction	14	2.79	1.37	8	1.63	1.19
FU BC Self distraction	14	2.57	1.65	8	1.88	1.64
BL BC Denial	14	0.50	0.76	8	1.63	1.60
M2 BC Denial	14	0.07	0.27	8	0.38	0.74
FU BC Denial	14	0.36	0.74	8	0.88	1.64
BL BC Venting	14	2.21	1.85	8	3.00	2.27
M2 BC Venting	14	2.07	2.02	8	1.50	1.51
FU BC Venting	14	1.86	1.99	8	1.88	1.25
BL BC Substance abuse	14	0.57	1.65	8	0.88	1.64
M2 BC Substance abuse	14	0.79	1.63	8	0.00	0.00
FU BC Substance abuse	14	0.79	1.67	8	0.00	0.00
BL BC Behav. disengagement	14	0.29	0.61	8	0.63	0.92
M2 BC Behav. disengagement	14	0.57	1.40	8	0.13	0.35
FU BC Behav. disengagement	14	0.29	0.83	8	0.38	0.74
BL BC Self Blame	14	2.50	2.10	8	3.75	2.05
M2 BC Self Blame	14	1.57	1.95	8	2.50	2.39
FU BC Self Blame	14	1.21	1.58	8	2.63	2.39

Mean scores at Baseline (BL), Measure 2 (M2) and Follow up (FU) by variable, continued.

BL HLC Internal	14	25.57	4.27	8	26.00	2.62
M2 HLC Internal	14	25.43	5.08	8	20.63	5.55
FU HLC Internal	14	26.64	5.29	8	22.75	3.06
BL HLC Chance	14	17.00	7.15	8	17.00	6.50
M2 HLC Chance	14	17.79	7.23	8	17.38	4.87
FU HLC Chance	14	17.50	6.41	8	16.88	4.97
BL HLC Powerful Others	14	15.71	5.76	8	14.25	5.63
M2 HLC Powerful Others	14	13.43	3.61	8	13.50	1.51
FU HLS Powerful Others	14	14.29	3.60	8	14.63	3.70
BL Infant HLC Chance	14	17.14	6.56	8	20.38	3.74
M2 Infant HLC Chance	14	17.64	5.60	8	20.88	4.82
FU Infant HLC Chance	14	19.64	7.03	8	21.00	3.25
BL Infant HLC Powerful Others	14	16.36	3.10	8	16.25	7.46
M2 Infant HLC Powerful Others	14	16.43	4.09	8	17.75	5.92
FU Infant HLC Powerful Others	14	15.36	4.38	8	17.88	6.69
BL Infant HLC Internal	14	23.00	3.44	8	17.75	8.71
M2 Infant HLC Internal	14	23.07	4.53	8	15.38	1.60
FU Infant HLC Internal	14	22.36	3.73	8	15.13	3.44
BL Health Self Efficacy	14	30.93	4.73	8	30.13	4.55
M2 Health Self Efficacy	14	31.86	3.84	8	30.25	6.65
FU Health Self Efficacy	14	33.57	3.63	8	32.63	5.15
BL Social Support	14	39.86	9.03	8	36.50	12.02
M2 Social Support	14	39.50	9.75	8	38.63	10.95
FU Social Support	14	40.86	9.94	8	40.38	9.81
BL Health Perception	14	1.27	1.28	8	1.94	1.96
M2 Health Perception	14	1.45	1.57	8	1.25	0.86
FU Health Perception	14	1.43	1.43	8	1.00	0.96
BL Infant Health Perception	14	1.48	1.15	8	1.47	1.17
M2 Infant Health Perception	14	0.79	0.90	8	0.94	0.89
FU Infant Health Perception	14	0.55	0.45	8	1.59	1.56
BL Health Knowledge	14	23.36	3.25	8	25.00	1.77
M2 Health Knowledge	14	24.36	3.13	8	25.50	1.20
FU Health Knowledge	14	24.21	2.83	8	25.63	0.74
BL Health Systems	14	21.00	2.42	8	21.63	2.33
M2 Health Systems	14	21.57	2.50	8	20.88	2.36
FU Health Systems	14	21.93	2.23	8	21.63	0.74