Psycho-social factors associated with terminal illness : comparison of patient and nurse perceptions over time.

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Psycho-social factors associated with terminal illness: Comparison of patient and nurse perceptions over time.

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Abstract

Psycho-social factors of terminal illness were explored with 36 terminally ill hospice patients. These findings were compared with staff accounts to assess whether staff held different perceptions of terminal illness from patients. The dynamic nature terminal illness was explored by re-interviewing thirteen of the original patient-staff dyads 4-6 weeks later.

Psychological responses to cancer have been shown to be affected by a variety of psycho-social factors, including age, length of illness and social support. The experience of terminal illness may be different from previous stages of cancer, possibly due to the patient's realisation of the nearness of death (Yalom, 1980). Models of dying highlight the patient's perspective and social environment in the determination of the dying process. Possible communication difficulties between patient and staff and the use of 'proxy data' in clinical and research settings highlights the need to explore patient and staff perspectives more fully.

A measure which described positive and negative experiences of terminal illness was developed (POTIS) and administered with the Hospital Anxiety and Depression Scale to terminally ill patients within a hospice. Staff were identified with a patient and their ratings of the patient's experience gathered. Thirteen patients/staff pairs were re-interviewed using the above procedure.

Results indicated that staff rated patients as being more anxious than patient's own ratings. There was no difference between staff and patient ratings of depression. Cluster analysis was used to describe natural groups occurring within patient responses to the POTIS and patient demographic data used to describe these groups. Small sample numbers limited conclusions regarding change of perceptions over time. Issues regarding staff and patient perceptions were discussed in terms of the clinical and research use of proxy data. Possible problems with the internal reliability of measures and sample bias which occur with this population were discussed.

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Psycho-social factors associated with terminal illness: Comparison of patient and nurse perceptions over time.

1.0 Introduction

"The dying are living, just like us. They are still on stage, still playing their part, their words not yet finished. If we hog the limelight we will miss their last lines and in doing so, wreck the whole drama."

(Dr Sheila Cassidy, 1992, In: Final Gifts, M. Callahan and P. Kelley, p7.)

1.1 The psycho-social aspects of cancer

Cancer is characterised by a prolonged period of progressive physical deterioration, with corresponding loss of function and pain. It is therefore not surprising that the diagnosis of cancer is likely to represent a major and catastrophic life event to individuals (McIntosh, 1974), with associated disruption to all aspects of their life. Numerous studies have indicated the enormous variability of individuals' responses to cancer (Hughes, 1987). Although there are many conflicting results, psycho-social factors such as pain or social support have been shown to affect adjustment in cancer patients. For example, increased pain has been related to mood disturbance (Spiegal & Bloom, 1983) and the quality of social support has been related to well-being and good prognosis (Hinton, 1975; Dobratz, 1993; Goodkin, Antoni, & Blaney, 1986). Younger patients with advanced cancer appear to experience higher levels of depression (Plumb & Holland, 1977) and psychiatric symptomatology (Craig & Abelaff, 1974), whereas older patients demonstrate higher levels of well-being (Reed, 1987).

1.1.2 Psychological disturbance and cancer

Experiences of loss, hopelessness, poor control over life, and perceptions of threat or harm may accompany cancer, resulting in significant levels of anxiety and depression. However, there seems to be little consensus regarding the degree of distress experienced. There is a large disparity in figures, with 5 to 40 per cent of patients experiencing depression and 4 to

52 per cent experiencing anxiety (Hinton, 1984; Rees, 1972). There are a number of reasons which may account for this variation. Various measures have been utilised for the assessment of distress, some poorly validated or based on observational data (Hinton, 1984). Measures of distress with items regarding somatic symptoms of distress may over-estimate distress levels where these items confound with illness symptoms. Evidence suggests that levels of distress change through the disease process although the direction of this change is disputed. Silberfaub, Maurer and Crowthamel (1980) found high levels of anxiety and depression during the initial stages of illness which decreased during the terminal stage. However, Hinton (1984) suggested that the degree of emotional distress increased as the illness progresses. This may be supported by two recent studies. Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss (1991) found that 8.7 per cent of early stage cancer patients were depressed, whereas Williams (1993) found that 31 per cent of terminally ill patients were depressed.

Psychological distress in cancer patients may be largely undetected by professional staff (Levin, Silberfarb & Lipowski, 1978). Patients may be reluctant to reveal their fears to preserve self esteem, social relationships or to maintain hope. Verbal or non-verbal signals of distress may be difficult for staff to detect. However, certain levels of psychological distress may be part of a normal psychological reaction to cancer.

1.1.3 Well-being & cancer

Levels of well-being or good psychological adjustment have also been reported with cancer patients (Plumb & Holland, 1977, Dobratz, 1993). Some studies have found similar levels of anxiety and depression in cancer patients to other patient groups or healthy populations (Breetvelt & Van Dam, 1991). It has been suggested that psychological distress may be reduced by the use of cognitive process which include a search for meaning (Dirkson, 1995), hope, and a positive attitude towards illness (Viney & Westbrook, 1988-89). A wide variability has been noted in the adjustment of patients to cancer. Dirkson (1995) found that not all individuals constructed a positive meaning to cancer, but for those who did, better adjustment was predicted.

Conflicting results encountered within cancer research may be due to the range of illnesses which are collectively called cancer, with resulting range of prognosis, treatment regimes and symptoms experienced by patients. This may compromise general comparison across studies. Doka (1995-96) suggested that cancer could be divided into pre-diagnosis, acute, chronic and terminal stages. Particular issues may be salient at each stage for each individual, with different coping responses evoked as the illness progresses.

1.1.4 Terminal illness

Terminal illness is not curable, with death expected within six months or less. Based on theoretical and research grounds, the terminal stage may be distinct in nature from preceding stages of cancer. Ageing, illness, major life events or life threatening experiences may be accompanied by an assessment of life and meaning. Thus, terminal illness may raise a host of existential issues for patients, which may act as a 'spur' (Heideggar, 1962) to shift the individual from one state of existence or awareness to another (Yalom, 1980). Some studies suggest that, for a number of patients, terminal illness resulted in a positive reappraisal of their situation (Dobratz, 1993). This reappraisal may be linked to the individual's 'stage of life'. Erikson (1963,1968,1988) described eight stages of psychosocial development characterised by tasks to be achieved at certain points during an individual's life span. The last task, during old age, was to integrate life-time experiences to achieve ego integration. Individuals with a terminal illness may face the task of ego integration irrespective of age or life stage (Kaufman, 1986). It is possible that younger individuals find this evaluation difficult as they have not achieved certain tasks congruent with becoming older. Younger terminally ill patients may be more likely to search for meaning than older patients (Dirkson, 1995).

1.2. Models of terminal illness

A number of models have been developed to provide a framework from which to understand psychological responses to terminal illness.

1.2.1 Stage Theory of Dying: Kubler-Ross

Kubler-Ross (1970) proposed a stage theory of dying based on feelings commonly experienced by the dying over time. Following diagnosis, shock and numbness would occur, then anger, depression and bargaining for goals to be achieved in the time left. Eventually a state of acceptance would be achieved, and hope would be maintained. Kubler-Ross suggested that these stages were not mutually exclusive and may not occur in the above order.

There have been a number of criticisms directed towards the model. Dying individuals may experience a wide range of emotions simultaneously (Schneidman, 1978) and in addition to those outlined above. The stage of acceptance has been described as being 'value laden' and it has been suggested that it may in fact be a state of resignation. Doka (1995-96) argued that the model does not account for the range of individual responses to terminal illness. Interpersonal or environmental factors are not taken into account (Kastenbaum, 1991) and the emphasis on emotions may cause difficulties if patients are unable to focus or articulate their feelings. Therefore the emotional state of a patient may be misconstrued by staff or relatives. This could lead to an incorrect assessment of the patient's 'stage' in the dying process.

On methodological grounds, Kastenbaum (1975) argued that the subjects used in the study were from a small and limited population and the study did not take into account a wide range of variables such as a range of diseases, sex, age and different cultural background of individuals. He suggested that it is questionable whether the results can be generalised to the whole dying population. As the study is based on observations of terminally ill individuals, Schultz and Aderman (1978) suggest that investigator bias and the confounding of physical symptoms with psychological response may limit the usefulness of the model.

However, the model may provide a basic framework for understanding the process of dying if it is not interpreted too rigidly. The recognition that negative emotions such as depression or anger may be healthy or normal responses may mean that these emotions are more easily accepted or expressed.

1.2.2 Model of grief

Models of grief or bereavement use a task based perspective to understand how individuals who are terminally ill experience a range of losses which may initiate a grieving process (Worden, 1990). These may include the loss of employment and income, role and status in society, and a reduction in social activities or hobbies. Individuals may experience a deterioration in physical health as well as decreased independence, altered self image, reduced self esteem, and reduced energy. They may no longer be able to attain goals or plan for the future and may become aware of the termination of their close relationships through their pending death, which may precipitate anticipatory grief.

Worden (1990) proposed four tasks of grieving, which he later revised, which the individual may need to address for a healthy process of coping with loss to be achieved.

Task 1. Accept the reality of loss - for the dying individual, this may be preceded by numbness and denial, with occasional outbreaks of distress. It is possible that this process needs to be re-experienced as new losses become apparent as the disease progresses.

Task 2. Experience the pain of grief - here the pain encompasses physical, emotional and spiritual aspects. As Twycross & Lack (1990) outlined, a variety of factors affect the individual's perception of pain including anger, anxiety, depression and physical factors.

Task 3. Adjust to a new environment - including social, physical, interpersonal and psychological changes.

Task 4. Emotionally relocate the deceased and move on - or, for the dying individual, to relocate their loss of life as they knew it and move on with life as it is. Accepting that there is no going back to the pre-bereavement stage.

The use of tasks rather than stages allows for greater individual variability and active coping activities (Doka, 1995-96). The model also emphasises the role of interpersonal relationships and their impact on the dying person.

1.2.3 The Death Trajectory (Glaser & Strauss, 1968)

This model takes into account the social context of the dying individual, in particular interpersonal relationships, time and the impact of different perceptions on the dying process. According to Glaser and Strauss, (1968), the dying process is a unique process which takes place over time (duration), and may vary from being instantaneous to occurring over a number of months. It also has shape, for example, steady deterioration or a series of remissions. Duration and shape are perceived properties and the dying trajectory may depend on the expectations of how dying will proceed. Death expectations surrounding the patient also determine to some extent the behaviour of the patient, family and carers (Strauss, 1993). There are 'critical junctures' or turning points which are important aspects of the trajectory. The expectations of all involved is crucial to how these junctures are handled as problems arise for staff, family and the dying individual when these junctures are not anticipated or occur at the wrong time. A clear understanding of the individual's current state of functioning is therefore important for healthy resolution of crisis points along the death trajectory.

The above models contribute to our understanding of psycho-social process related to terminal illness. Individually, the models may neglect important aspects of the dying process. Although models provide a useful framework from which to describe this complex area, it is possible that reliance on such intellectual structures may become a burden to nurses, and as a result may put up a barrier between staff and patients (McNamara *et al*, 1994).

1.3 The hospice movement

Up until recently, the treatment of dying people in hospital was dominated by institutional practices including impersonal care and distancing between staff and patients (Seale, 1989). The hospice movement was initiated by Dame Cicily Saunders in 1967 to address these perceived deficiencies. Instead of depersonalised care, dying patients were treated as individuals, with the family being seen as the unit of care (Seale, 1989) The emphasis was on palliative rather than curative care, with the aim of maintaining a good quality of life for the patient by providing relief form pain and other distressing symptoms. The psychosocial needs of the patient and their family were recognised, including social, spiritual, cultural and emotional concerns. A central tenet of hospice philosophy was the emphasis on open communication between patients and staff, in particular, clear information regarding prognosis and issues of death and dying.

At present, hospice care is rapidly expanding across the UK (Seale, 1989) with many hospices being independently funded. A variety of services are generally offered, including in-patient, day care, home care teams, bereavement services, education, and voluntary support. Estimation of the percentage of deaths occurring in the UK in hospices range from 2.5 to 7 percent (Seale, 1989). However, a greater number receive hospice care, as not all patients die in hospices. Terminal cancer is the focus of care, although some hospices also provide care for a small number of patients with chronic illness. It is likely that cancer patients attending hospices are a distinct sub-population from chronic or elderly dying populations. They are likely to be younger, and therefore probably married, with cancer being their only significant illness. Cancer attracts significant social sympathy, and according to Seale (1989), cancer patients "have a clearly delineated right of entry into the sick role".

1.4 Communication and attribution theory

Clear communication between professional staff and patients with terminal illness is an important aspect of hospice care. However, differences between nurses and patients in terms of their respective expectations, assumptions and subjective experience of terminal illness, may mean that communication is not always easy. McNamara *et al*, (1994) found that nurses found it difficult to discuss impending death with patients. One nurse commented that it "seemed cruel". Attribution theories suggest that perceptions of two individuals regarding complex social situations are likely to differ. This may be due to a number of attribution errors which can occur between individuals, or, when considering terminally ill, between the patient and staff. The fundamental attribution error (Jones & Nesbitt, 1971) suggests that staff perceptions may be based on information relating to the patient rather than their illness or situation. Staff are likely to explain the patient's problems in terms of their personal characteristics. Conversely, patient's attributions are more likely to be based on their situation, rather than themselves. In addition, individuals are likely to look for confirmatory information to confirm their hypothesis and ignore evidence to the contrary. Therefore judgements, once made by staff or patients are likely to remain static rather than change over time (Eiser, 1986).

It is difficult to assess whether hospice staff practice a distinctive approach from other professionals when communicating with patients about dying, and whether this approach reduces distress or symptomatology in hospice patients. This difficulty is partly due to the lack of well controlled outcome studies regarding hospice care in the UK (Seale, 1989). However, client satisfaction studies in terminal care indicate that poor communication between staff and patients is the most common source of distress for patients (Field 1994). Non-verbal, indirect, or metaphorical communication from patients may be mis-interpreted or ignored by staff (Callanan & Kelley, 1992). Yates (1993), in a study of the maintenance of hope with terminally ill patients, suggested that patients assess their situation based on a subjective appraisal of their situation, whereas staff base their views on clinical, epidemiological or theoretical knowledge. This could lead to differences in the assessment of prognosis between staff and patients. Nurses may present facts on illness which the patient may need to disregard in order to maintain hope and their own perspective (Ersect, 1992). Individual patient's evaluation may be based on internal and subjective sources as illustrated by Rijkin, Kompoe, Ros, Winnabst & Van Heesct (1995) who found that patient's evaluation of subjective well-being is increasingly based on physical health as the physical state deteriorates. Staff would possibly utilise different experiences from the patient for their assessment of the patient's situation.

1.4.1 Surrogate accounts

Differences between patient and staff perceptions have also been illustrated indirectly by the increasing use of surrogate accounts. Physical illness and levels of emotional distress have led to problems recruiting and interviewing terminally ill patients (McDonnell, 1989). To address this, some researchers or clinicians have supplemented missing data with 'proxy' data gathered from relatives or professionals known to the patient. Some studies have relied on bereaved carers as proxies to collect retrospective data after the patient has died. When this data has been compared to the patient data, some disparity has been indicated. For example, nurses recorded pain as less severe than the patient, and professionals rated anxiety as more severe than patients own ratings (Higginson & McCarthy, 1993). Lay carers were more likely to over-estimate pain, disability and dependence (Field, 1994). Magaziner (1992) suggested that 'proxys' are better at predicting external factors such as pain rather than internal factors, such as psychological states. However, Dona (1995-1996) found a good correlation between patient and proxy's assessment of patient's pain, spiritual and patient values, and poor correlations with estimates of social support. The above studies suggest that the use of proxy data is problematic within clinical and research settings (Field 1994). It is therefore surprising that there are few examples of studies looking directly at the different perceptions of patients, professional staff and families regarding the dying process.

1.5.1 Research methodology and ethical issues

Research into terminal illness is fraught with difficulties based around the awareness that the terminally ill are a vulnerable population. Issues of informed voluntary consent, preservation of dignity, privacy and confidentiality are obviously salient. Some researchers have even questioned whether 'voluntary' participation is possible where a power relationship exists between a vulnerable subject and researcher (Holloway & Wheeler, 1995). Access to patients may also be difficult due to the aim of health providers to minimise distress with vulnerable patients. This, together with a high refusal rate, has led to many studies experiencing small sample sizes and sample bias where only robust subjects participate (Bass, 1982-1983). Emotionally sensitive, time consuming research, or repeated assessments may also be avoided with this population. This has resulted in many studies being cross-sectional rather than longitudinal in nature. Some researchers have advocated the use of predominately qualitative research methods to explore the complex and sensitive issues of terminal illness. Comparison across these studies is limited by this approach. To limit the effect of uncontrolled variables, quantitative approaches have been used to study one aspect of dying, for example, hope or locus of control. Although useful this has meant that complex interaction between factors relevant to psychological adaptation and terminal illness has been neglected. Albert (1992) recommended the combination of qualitative and quantitative data to assist in the study of complex areas. Insights gained from open-ended interviews could be used for the development and implementation of an appropriate instrument for use with a larger sample, whilst accounting for 'rich' information gained from the qualitative design.

1.5.1 Areas for further research: present study

Perusal of the above literature indicated a number of areas which merited a closer and more systematic investigation. The perceptions of terminally patients and professionals may be important in determining the experience of terminal illness within a hospice (Kastenbaum & Thuell, 1996). The exploration of staff's views of psychological aspects of terminal illness would give an indication of attribution errors which may contribute to communication difficulties between staff and patients. Psychosocial factors which have been shown to be relevant to cancer in general may be more or less salient to terminal illness. Research which acknowledges the positive outcomes related to terminal illness may highlight protective factors and beneficial coping strategies for patients. Longitudinal approaches which take into account the dynamic nature of the dying process as described by Glaser and Strauss (1968) are also important. Calls have also been made for research to be based within a clinical setting with recommendations for practical applications (National Council for Hospices and Specialist Palliative Care Services, 1995).

There are few measures which have been designed and validated with the terminally ill population (Mor, 1986) and there appeared to be no measures which quantify the perceptions of terminally ill patients. It was decided to develop a scale for use with this population in this study. This would described the patient's experiences and perception of their situation. This scale could also be used to measure staff's perceptions of terminal illness, and comparisons made between both groups. In addition, patient's experiences would be described further by analysis of the patient's responses to individual items from this scale. This would highlight whether patients could be distinguished from each other in terms of their responses to the scale and therefore indicating whether patients with differing perceptions of terminal illness could be distinguished, This would be achieved by the use of cluster analysis by looking for natural groupings within the patient responses.

2.0 Research Aims

1. To describe terminally ill patient's psychological and psycho-social status by the development and administration of an appropriate measure with hospice patients.

2. To describe both difficult and positive aspects of terminal illness, as experienced by hospice patients.

3. To compare hospice staff's assessment of patients psychological and psycho-social situation with patient's accounts.

4. To assess whether patient's accounts of their psychological and psycho-social situation changes in nature after 4-6 weeks.

5. To assess whether staff's measurement of patient's psychological and psycho-social state changes over time, in accordance with patient's accounts.

2.1 Hypotheses

1. Nurses perceptions of patients' psychological adjustment would differ from patients' reports.

2. Patient's psychological adjustment to terminal illness would change over time.

3.0 Method

3.1 Ethical Approval

Ethical approval from the local ethics committee was applied for, and received November 1995. The exact wording of the scale used in the main study depended on the results of the pilot study. Therefore it was agreed that the completed scale would be submitted at a later date for chair's consent.

3.2 Design

The study was divided into three sections, qualitative data collection (pilot study), archive data collection and quantitative data collection (main study). The results of the open-ended interview with terminally ill patients in a pilot study were used to develop a questionnaire for use in the main part of the study. The main study was a repeated measures design, using terminally ill patients and nursing staff from a hospice setting.

3.3 Pilot study: Qualitative Data

3.3.1 Participants

Eight adult hospice patients were interviewed. Five were currently receiving in-patient care and 3 were receiving day care. Four male and 4 female patients participated. The mean age was 62.62 years, (range, 46-82 years, SD =13.16). All patients were diagnosed with cancer, the mean length of illness being 13.19 weeks (range, 1-104 weeks, SD=10.62). Mean attendance at the hospice was 27.44 weeks (SD=35.77) Day patients had attended the hospice from 2 days to 2 years, and in-patients from a week to 4 weeks.

3.3.2 Interview

Questions for the semi-structured interview were developed from the literature and discussion with colleagues and hospice staff. The questions were open-ended to gather information regarding problems and positive outcomes relevant to terminally ill patients. There were no specific references to the dying process, although issues were discussed if raised by the patient (see appendix 1).

3.3.3 Procedure

Terminally ill patients were identified by hospice staff. Patients who were physically frail, showed evidence of cognitive impairment or high levels of emotional distress were excluded. Patients were approached by nursing staff and introduced to the interviewer. The study was briefly outlined, confidentiality and freedom to withdraw from the study outlined, and written consent obtained (see appendix 2). If necessary, the interview was moved to a private room. Interviews lasted from 20 minutes to 45 minutes. Subject's comments were recorded by hand at the time by the author and later written up in full.

3.3.4 Analysis

Scripts were analysed using content analysis. A number of themes regarding positive and negative aspects of terminal illness were developed (see appendix 3 for an outline of these themes). Reliability of 78% was obtained by comparison of themes with an independent assessor. Social changes, medical and physical difficulties, interpersonal concerns and emotional/psychological changes represented difficult aspects of illness. Positive aspects included interpersonal support, a change in perspectives, increased appreciation of life and professional support. On the basis of these themes, a number of questions were generated using respondent's words whenever possible. Additional items were included from relevant literature and discussion with colleagues and hospice staff. Questions covered psychological, social, emotional and physical and existential aspects of terminal illness. After discussion with hospice staff, items which could be construed as distressing were re-worded or excluded. Items were divided into sections regarding difficult and positive aspects of terminal illness. Thirty items were included, and a rating scale of 1-5 for each question provided. A score of 1 signified definitely agree, 2, mostly agree, 3, not sure or does not apply, 4, mostly disagree, and 5 definitely disagree. This measure, the Perception of Terminal Illness Scale, (POTIS) was used in the main study (See appendix 4).

3.4 Archival data

3.4.1 Method

Previous research with terminally ill patients has noted that a high proportion of non-participating patients had resulted in a sample bias (Bass, 1982-83). Archival data was collected to demonstrate whether this had occurred in this study. Limited data regarding in-patient care was available. Information regarding through-put, age and gender of patients had been collected by the hospice for patients from 1st January to 31 December, 1995. Day-care information was not routinely collected by the hospice at that time and was not available to the author.

3.4.2 Results

A total of 362 adult patients had been admitted to in-patient care between 1/1/95 and 31/21/95. Of these, 170 (47.0 per cent) were female, and 192 were male (53.0 per cent). Two hundred and two had died and 160 had been discharged, some of whom had been re-admitted. Five patients (1.38 per cent) were 16-35 years of age, 74 (20.4 per cent) 36-55 years, 205 (56.6 per cent) between 56-75 years, and 78 (21.5 per cent) were over 75 years.

3.5. Main Study: Quantitative Data.

3.5.1 Participants

Time 1

Group 1 - Patients. Thirty seven patients from day and in-patient care were interviewed. One interview was terminated due to ill-health, and one patient did not have time to complete the HAD. Thirty six patient responses were used for the POTIS analysis and thirty five responses were used for HAD analysis. Twenty five patients (69.4 per cent) from day care, 11 patients (30.6 per cent) from in-patient care participated. The mean age was 68.1 years (SD = 11.19, range, 47-86 years).

Group 2 - Staff. Staff were approached and asked if they could comment on the identified patients. Eight nursing staff participated, giving responses for a number of separate patients. Three nurses were from day care, five from in-patient care. All were female, with five qualified, and three unqualified nursing staff participating.

Time 2

From the above sample, thirteen patient/nurse dyads were re-tested 4-6 weeks later. Eleven day-patients, and 2 in-patients participated. Of these, 11 were female and 2 were male. In all, 53.8 per cent of patients attended between 1-25 weeks, 15.4 per cent between 26-52 weeks, 23.1 per cent for 53-79 weeks, and 7.7 per cent for 80-104 months. The length of time which patients had been diagnosed ranged from 30.8 percent for 1-12 months, 38.5 per cent for 13-24 months, 7.7 per cent for 23-36 months, and 30.8 per cent for over 53 months.

Three staff from day care and two staff from inpatient care participated in the second time period. Four were qualified staff.

3.5.2 Measures & Data Collection

a. Patient demographic information

Limited patient information was routinely collected by nursing staff in case notes. However, this data was not collated, was fragmented and difficult to access. It was decided instead to collect demographic information from patients, and subsequently ask nursing staff to check the information for accuracy (see appendix 5).

b. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

The HAD self rating scale (Appendix 6) is comprised of 14 items and is divided into two sub-sections measuring depression which produce separate scores. It has been recommended for use with cancer patients in preference to alternative measures as items regarding somatic symptoms of depression or anxiety, which may result in an inaccurate or inflated score, are eliminated. Psychometric properties have been established using early stage cancer patients (Moorey, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). Using the replies of 568 people, Cronbach's alpha of 0.93 for the anxiety scale and 0.90 for the depression scale was established. However, the HAD has not been validated specifically with terminally ill patients or for verbal administration as used with patients in this study.

Zigmond & Snaith (1983) recommended that scores of 8 or above to indicate significant levels of symptomatology. However, Lloyd (1990) suggested that higher cut-off levels may be necessary with medically ill patients. Studies using the HAD for other patient groups have used scores of ten and above to demonstrate severe levels of distress (Bass, Chambers, Kiff, Cooper & Gardener, 1988; Wood, Magnello & Sharpe, 1992).

The HAD was utilised to gain information regarding levels of distress in the patient sample and to explore patient and nurse's perceptions of terminal illness.

c. The Perception of Terminal Illness Scale (POTIS)

The POTIS was administered to patients verbally and visually, and was completed manually by nursing staff in their own time.

d. Open-ended questions

Two additional open-ended questions were presented to patients:

i. What has been the most difficult aspect of your illness for you so far?

ii. What has been the most positive aspect of your illness for you so far (if any)?

The questions would highlight aspects of terminal illness which had not been included in the POTIS. To reduce staff work load and reduce risk of a decreased return rate, staff were not asked to answer this section.

3.5.3 Procedure

As for the pilot study, patients were identified and approached by nursing staff. Two refused to participate at this point. Patients were given a verbal explanation of the study, and written consent was obtained (see appendix 7).

Information regarding age, marital status, day or in-patient status, employment status, a description of their illness, duration of illness, length of attendance at the hospice and religious beliefs were obtained from patients.

Patients were asked to complete the POTIS by rating each statement as it applied to them. Questions were shown to the patient on an A4 size card and simultaneously read out. Patients were asked to complete the open-ended questions. The HAD items and responses were given verbally. All patient's responses were recorded during the interview. Patients were asked if they would mind taking part in the second data collection in 4-6 weeks time.

The POTIS and HAD measures were given to a nurse who had known the patient for over a week. They were asked to respond as they felt the identified patient would answer the questions. They completed the scales in their own time and completed questionnaires were picked up 2-3 days later.

The above procedure was repeated 4-6 weeks later with the same nurse/patient dyads from the original sample. Patients were approached in the same order as in the main study. Five patients did not consent, five had already died, eight were not available or were too ill, and time limitations precluded further interviews.

3.5.4 Analysis

Data was analysed using SPSS for Windows. Information regarding patient's demographic information was collated and presented using means and frequencies. The internal reliability of the HAD and POTIS measures were established using Cronbach's alpha. Staff responses to the HAD were compared with patient's responses. In addition, discrepancies between staff and patient reaponses were examined descriptively by computing difference scores, and average discrepancy scores for each staff member were compared. In order to assess statistically whether there were significant differences between staff and patient HAD ratings, and whether discrepancies were greater for some individual staff members, a 2 x 8 mixed ANOVA was conducted; Factor A (2 levels) was the repeated measures factor comparing staff and patient scores; Factor B (8 levels) compared scores according to which of the 8 members of staff gave the rating. In this analysis, significantly larger discrepancies between staff and patient ratings for (an) individual member(s) of staff would manifest as an interaction. This analysis was preferred to the alternative of using a t-test to compare staff and patient scores and a one-way ANOVA comparing discrepancy scores, as it combined the two analyses in one, and avoided problems in the distribution of discrepancy scores. Furthermore, this analysis also checks whether (a) member(s) of staff was asked to rate extreme scoring patients.

A bar graph was used to illustrate differences in patient HAD responses between time one and time two, and t-tests used to assess these differences statistically. Hierarchical agglomerative cluster analysis using squared Euclidean distance for between-groups linkage was performed on patient responses to the POTIS for the two time periods. The number of clusters to be extracted were decided on the basis of a dendogram (Everitt, 1993). Descriptions of the cluster membership for the two time periods were obtained using POTIS responses and patient demographic data. Qualitative data from the open-ended questions was collated using content analysis, and presented as themes.

3.5.5 Results

3.5.6 Demographic information: Hospice Patients

A total of 36 adult hospice patients were interviewed. Of these, twenty five patients (69.4 per cent) were attending day care, 11 (30.6 per cent) were in-patients.

Age

According to table 1, the mean age for patients was 68.1 years (range 47-86 years). Over a third of the total patients were above 75 years of age. There were no patients below 45 years of age. Day patients were more likely to be older, many over 75 years of age, whereas in-patients were younger in age.

Table 1. Age-groups of patients by day and in-patient status.

Age (years)	Day-patients	In-patients	Day & in patients
45-54	2 (8.0%)	3 (27.3%)	5 (13.9%)
55-64	5 (20.0%)	3 (27.3%)	8 (22.0%)
65-74	4 (16.0%)	4 (36.4%)	8 (22.0%)
75-84	13 (52.0%)	1 (9.1%)	14 (38.9%)
85+	1 (4.0%)	0	1 (2.80%)
Total	25	11	36

Gender

Seventy five per cent of patients interviewed were women (n=27). Twenty five per cent were men (n=9).

Marital Status

As can be seen from table 2, over half the patients interviewed were widowed and over a third were in a married relationship.

Table 2. Marital status of patients

Marital Status	**Number**	**Percent**
Married	13	36.1
Divorced	2	5.6
Widowed	19	52.8
Single	2	5.6
Total	36	

Retirement

None of the patients interviewed were working (table 3). The majority had retired due to age, and a third had retired due to illness. Patients who had not worked before retirement age were classified as retired if they were above 60 for women, or 65 for men.

Table 3. Patient retirement status

Retirement status	**Number**	**Percent**
Retired	24	66.7
Long term sickness leave	1	2.8
Early retirement due to illness	11	30.6
Total	36	

Social class

Patients were asked to describe their most recent job. Their socio-economic status was then determined on the basis of this information (based on Registrar General's Classification of Occupations, HMSO, 1991).

Nearly half the patients interviewed were described as being in socio-economic class III (See appendix 8, table 1 for breakdown of socio-economic status).

Religion/spiritual beliefs

Patients were asked how they would describe their religious beliefs. If they described themselves as being part of an organised religion, they were asked if they attended the church regularly. The majority of patients described themselves as being religious. Over a quarter described themselves as being religious but not ascribing to any particular church (see appendix 8, table 2).

Of patients who described themselves as religious, half said they were regular attenders at church. Under half the patients were not regular attenders. For those who did attend church, a proportion were visited by their vicar/priest at home on a regular basis.

Length of time of attendance at hospice

The mean attendance was 27.9 weeks (SD=37.26, range, one week to 2.5 years). Due to the different types of service provision, it was expected that in-patients would have attended for shorter periods than day patients. This pattern is shown in table 4. Some in-patients had previously attended as day patients, and vice versa. Only their current status was collected.

Table 4. Length of time that patients had attended the hospice

Attendance (weeks)	**Day-patients**	**In-patients**	**Total**
1-25	12 (48%)	11 (100%)	23 (63.9%)
26-52	5 (20%)	0	5 (13.9%)
53-79	5 (20%)	0	5 (13.9%)
80-104	2 (8%)	0	2 (5.6%)
105+	1 (4%)	0	1 (2.8%)
Total	25	11	36

Diagnosis

All patients had a diagnosis of cancer. There was a range of types of cancer. According to nursing staff, all patients had a non-curable cancer. Patients were able to describe their diagnosis. However, two patients later explained that they were not actually ill. Information given by patients regarding their diagnosis was checked with nurses. The majority had described their diagnosis correctly and concisely. The remainder had described their illness vaguely, rather than incorrectly (see appendix 8, table 3). Nine patients also had additional chronic illness. These included arthritis, stroke, Parkinson's disease and diabetes. One patient was receiving treatment for severe depression.

Length of illness

Patients were asked how long it had been since they had first been diagnosed as having cancer.

Table 5. Time in months since patient's initial diagnosis.

Time (months)	Day-patients	In-patients	Total
1-12	7 (28.0%)	5 (45.5%)	12 (33.3%)
13-24	10 (40.0%)	2 (18.2%)	12 (33.3%)
23-36	2 (8.0%)	0	2 (5.6%)
37-48	2 (8.0%)	2 (18.2%)	4 (11.1%)
49-52	0	0	0
53+	4 (16.0%)	2 (18.2%)	6 (16.7%)
Total	25	11	36

The mean length of time since diagnosis was 27.2 months (SD=21.34, range, 2 months to 4 years). According to table 5, day patients were more likely to have been diagnosed from between 13-24 months, and in-patients for less than a year.

Anxiety and Depression

One patient did not complete the HAD scale. Therefore 35 data sets were used for HAD analysis. Patient's mean anxiety score was 7.31 (SD=3.49, range, 0-16), and mean depression score was 7.14 (SD=3.53, range 1-16).

Two cut-off points of 8 and above and 10 and above are described to indicate significant levels of symptomatology (See appendix 8, table 4 for breakdown of time one and time two patient HAD scores).

Using a cut-off point of 8 and above, 17 (48.6 per cent) patients were anxious, and 13 (37.1 per cent) patients were depressed. Using a cut-off point of 10 and above, 8 (22.9 per cent) patients were anxious and 7 (20 per cent) patients were depressed.

Time two: 4-6 weeks later

For this sample, the mean anxiety score was 7.08, (SD=3.59, range, 1-17), and the mean depression score was 7.92, (SD=4.23, range, 2-16). Using a cut-off point of 8 and above, 4 patients (30.8 per cent) were anxious and 5 (38.5 per cent) were depressed.

Table 6. Proportion of respondents scoring above clinical cut-off points for HAD data compared with data from other medical populations.

Authors	Sample	Cut-off point	Number in sample	Subjects who were anxious (%)	Subjects who were depressed (%)
Bass *et al.* (1988) *(a)*	Typical chest pain	>10	32	22	9
	Atypical chest pain	>10	81	25	11
Wood *et al.* (1992) *(b)*	Chronic fatigue syndrome - recovered	>10	9	11	11
	Un-well	>10	19	15.8	5.3
Williams (1993)	Terminal illness	> 9	19	N/A	31
Moorey *et al.* (1991)	Early stage cancer	>8	575	27	8.7
This study	Terminal illness	>8	35	48.6	37.1
	Terminal illness	>10	35	22.9	20

a. Bass, Chambers, Kiff, Cooper and Gardener, (1988).
b. Wood, Magnello and Sharpe, (1992).

Examination of data from table 6 indicates that the proportion of patients from this study who were categorised as anxious or depressed (using cut-off points for patients who scored 8 and above, and 10 and above) was higher than figures found in medical populations and other cancer populations. The studies above used differing cut-off points and a range of sample numbers.

3.5.7 Hospital Anxiety and Depression Scale: internal reliability

The HAD has not been previously used as a way of measuring terminally ill patient's perceptions of their mental health status or nursing staff's perceptions of patient's level of distress. Therefore the internal reliability was established for patient and nurses HAD responses.

Patients

Cronbach's alpha of 0.72 was established for the anxiety scale. Closer inspection of the data indicated that question 11 (I feel restless as if I have to be on the move) was less strongly correlated with the other items, having an alpha value of 0.774 if the item was deleted. Cronbach's alpha of 0.71 was established for the depression scale. There were no questions which seemed less consistent with the other questions here.

Staff

An internal reliability of 0.81 was calculated for the anxiety scale. Question 11 seemed to be slightly less consistent with the other questions (alpha=0.80). An internal reliability of 0.82 was calculated for the depression sub-scale.

3.5.8 POTIS: Internal reliability

Before assessing the internal reliability of the POTIS, patient and staff responses were examined to assess whether the answers tended to be polarised or skewed towards a particular response. The frequency of responses to all questions was examined. Items were excluded from analysis where 60 per cent of subjects had agreed on the response. On this basis, questions 7, 9, 16, 19, 20, 21, 22, 23, 25, 28, were excluded (See appendix 9 for breakdown of frequency values). Administration of the POTIS had highlighted poorly worded questions which produced limited information and therefore questions 6 and 8 were also excluded from analysis. The remaining 18 questions were analysed using Cronbach's alpha to assess internal reliability. Cronbach's alpha levels were established for the difficulties and positive aspects sections.

Difficulties

Questions included in the analysis included questions 1,2,3,4,5,10,11,12,13,14,15,17 and 18. Cronbach's alpha was 0.68 was established. Scrutiny of the individual question scores indicated three questions which appeared inconsistent. These were question 5: ' I feel very upset if I see others around me who are very ill', Question 13: 'I find that I become upset much more easily than I used to', and Question 14: ' I have been less able to get a good nights sleep since my illness'. These items were excluded, giving a total alpha score of 0.727.

Positive Aspects

Only a small number of positive questions remained after elimination of skewed response questions. Analysis was performed on questions 24,26,27,29 and 30, giving Cronbach's alpha of only 0.46. If question 27 was deleted, the alpha score increased to 0.54. However this score was unsatisfactory, indicating low internal reliability of the positive POTIS questions.

As themes regarding psychological, social, physical and interpersonal aspects of terminal illness had appeared to be important during construction of the POTIS, these sections were analysed for internal reliability. Questions 4,13,18,24,26,27,29,30 (psychological aspects) were analysed, giving an alpha score of 0.51. Questions 1,2,3,4,5,10, (social aspects) produced an alpha level of 0.55. Questions: 1,11,12, (aspects of illness) gave an alpha level of 0.71. However, these levels were still unsatisfactory for further analysis of the POTIS responses.

Staff

Staff responses from the POTIS were analysed regarding internal reliability. Questions from the difficulty section gave an alpha level of 0.83. Cronbach's alpha for the positive questions was 0.76. However, further analysis of perceptions between staff and patients and across time was not carried out with these groupings due to the poor alpha levels for the patient's answers.

3.5.9 *HAD scores - discrepancies between staff and patient ratings.*

Table 7. Differences between staff and patient anxiety ratings

Staff member	**Staff ratings of patient anxiety**		**Patient ratings**		**Staff minus patient ratings**		**Cases**
	Mean	SD	Mean	SD	Mean	SD	
1	8.9	3.3	6.3	3.7	2.5	2.8	11
2	6.5	2.1	7.0	2.8	-0.5	4.9	2
3	9.9	3.3	8.3	2.8	2.0	2.6	10
4	9.0	2.8	12.0	5.7	-3.0	2.8	2
5	10.3	3.0	6.0	3.0	4.3	4.9	3
6	11.6	4.7	6.3	5.7	5.3	5.0	3
7	13.0	-	6.0	-	7.0	-	1
8	10.7	3.7	7.3	2.3	3.3	5.1	3
Overall	**9.7**	**3.3**	**7.3**	**3.5**	**2.5**	**3.7**	**35**

As can be seen from table 7, the mean staff rating of patient's anxiety was higher than the patient's own self-rating. The majority of patients were rated by just two members of staff. Mean discrepancies varied between staff.

Table 8. Differences between staff and patient depression ratings

Staff member	**Staff ratings of patient depression**		**Patient ratings of depression**		**Staff minus patient ratings**		**Cases**
	Mean	SD	Mean	SD	Mean	SD	
1	5.7	3.0	7.1	3.7	-1.4	4.1	11
2	8.5	9.2	11.0	5.7	-2.5	3.5	2
3	6.5	2.8	6.6	2.9	0.2	2.9	10
4	10.0	1.4	12.0	5.7	-2.0	4.2	2
5	10.0	0.0	7.0	2.0	3.0	2.0	3
6	9.7	2.5	5.7	4.2	4.0	4.6	3
7	2.0	-	4.0	-	-2.0	-	1
8	7.0	2.0	6.0	1.7	1.0	1.0	3
Overall	**7.1**	**3.3**	**7.1**	**3.5**	**0.0**	**3.6**	**35**

As can be seen from table 8, the staff mean overall was the same as the patient mean overall. As with anxiety scores, mean discrepancies varied between staff.

A 2 by 8 mixed ANOVA was then conducted; Factor A (2 levels) was the repeated measures factor comparing staff and patient scores; Factor B (8 levels) compared scores according to which of the 8 members of staff gave the rating.

Patient and staff anxiety responses

There was a highly significant main effect for staff vs patient anxiety score F (1,27) = 11.52, $p < .01$, confirming that staff rated patients as being significantly more anxious than the patient's own ratings.

There was no effect on anxiety scores according to which staff member was making the ratings, F (7,27) = .50, ns. No such effect was predicted - a significant main effect of this factor would have indicated very high or low anxiety amongst the particular sub-group of patient's rated by (an) individual staff member(s).

There was no significant interaction between the factors F (7,27) = 1.63, ns, indicating that discrepancies between staff and patient anxiety ratings were not significantly different between individual staff members.

Patient and staff depression responses

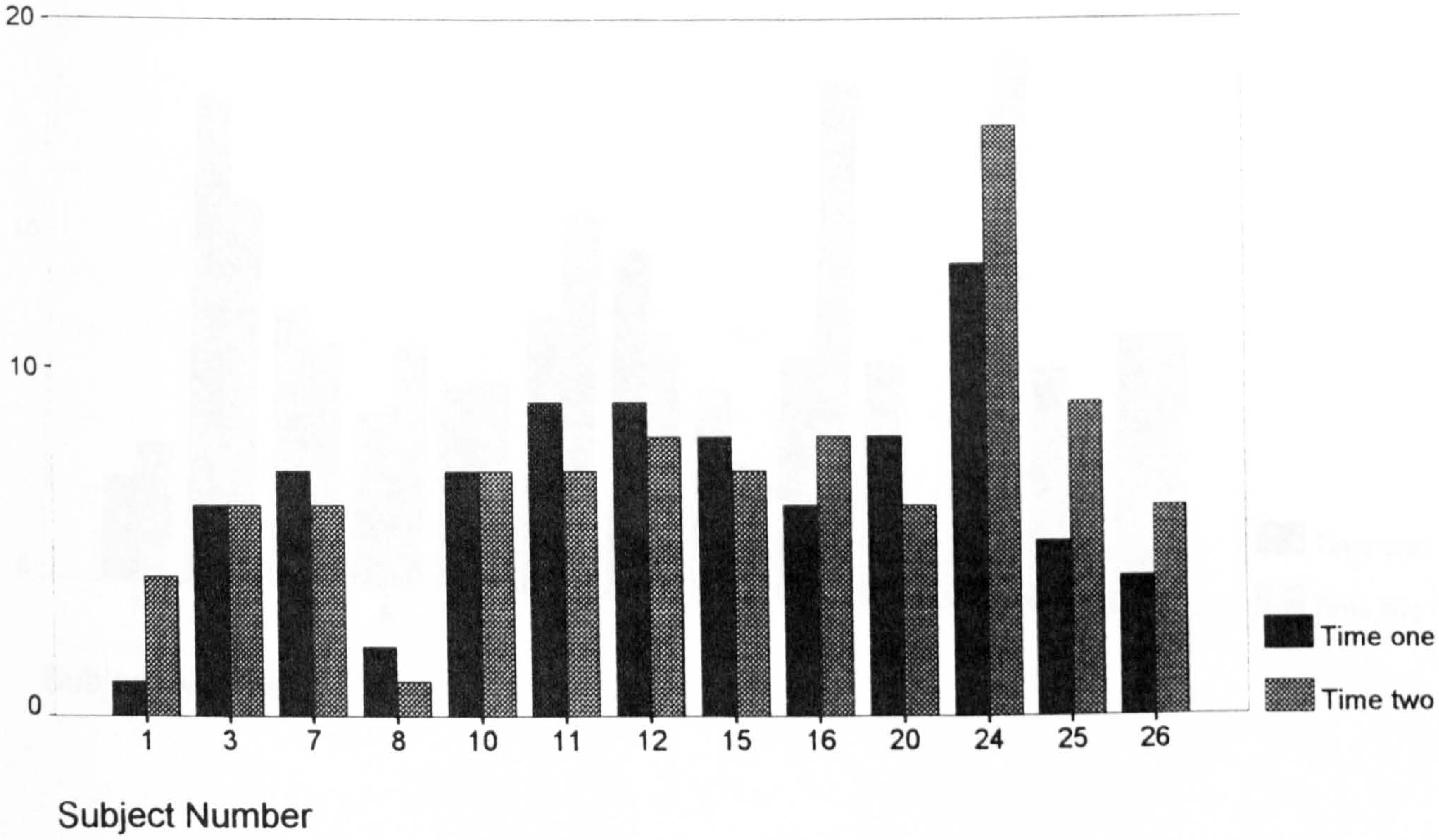
There was no main effect for staff vs patient depression score F (1,27) = .00, ns, indicating that staff and patient ratings of patient's depression were the same.

There was no effect on depression scores according to which staff member was making the ratings, F (7,27) = 1.35, ns.

There was no significant interaction between the factors F (1,27) = 1.48, ns indicating that discrepancies between staff and patient depression ratings were not significantly different between individual staff members.

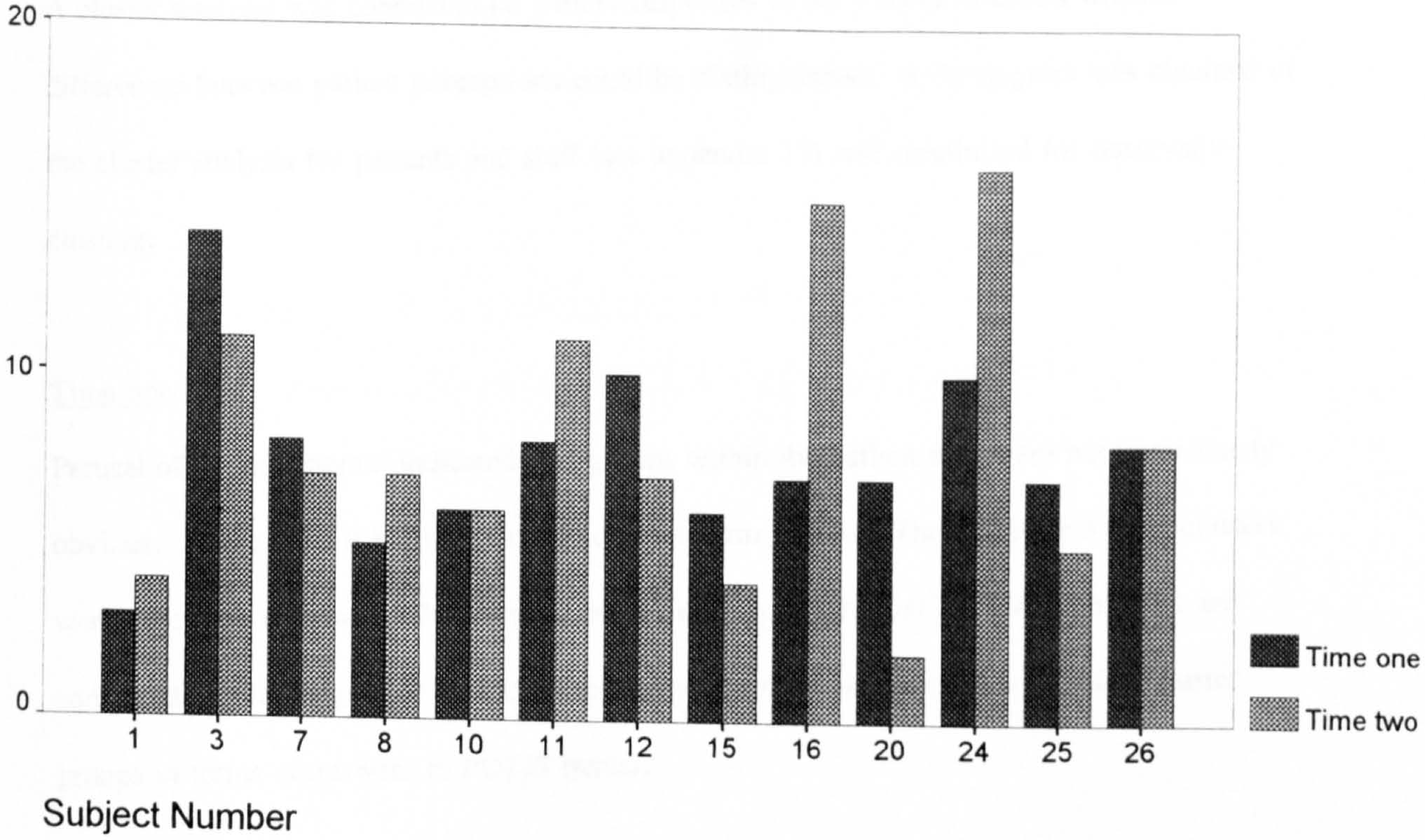
Change in patient responses to HAD after 2-4 weeks

Figure 1. Difference between time one and time two patient anxiety levels.



Examination of the data as illustrated in figure 1 indicates that anxiety levels for a small number of patients increased greatly after 4-6 weeks. Although no pattern was discernable for the remaining patients there were no patients whose anxiety levels decreased greatly over time. A t-test was performed to compare patient's time one and time two anxiety scores. There was no significant difference between patient time one and time two scores (t (11) = -.89, ns), although examination of the means indicates that patients were slightly more anxious during the second data collection point (see appendix 10).

Figure 2. Difference between time one and time two patient depression levels.



Examination of the data as illustrated in figure 2 indicates that there were two patients whose depression scores increased greatly between 4-6 weeks. However, no pattern was discernable with the remaining patients. A t-test confirmed that there was no overall difference between patient's depression levels between time one and time two (t (11) = -.30, ns).

Difference between staff and patient responses to HAD between time- one and time-two. Differences between staff and patient responses to the HAD for the time two data was examined using t-tests. Results indicated no significant difference between staff and patient's ratings of anxiety (t (11) = -1.71, ns), or between staff and patient's ratings of depression (t (11) = 1.38, ns).

3.5.10 Evidence of groups within patient POTIS responses - Cluster analysis

A cluster analysis was conducted on patient responses to the POTIS to assess whether differences between patient perceptions could be distinguished. A dendogram was obtained of the cluster analysis for patients and staff (see appendix 11) and scrutinised for observable clusters.

Time one

Perusal of the dendogram indicated that groups within the patient data were not immediately obvious. There were 8 individuals who did not form groups. Therefore the 3 main clusters were described in detail. Cluster membership was then identified for each individual and compared with demographic data (See appendix 12 for breakdown of main patient cluster groups in terms of answers to POTIS items).

Table 9. Time one: main patient clusters described in terms of their demographic information.

	Age (years)	**Time since diagnosis (months)**	**Attendance at hospice (weeks)**	**Number in cluster**
Total population	68.14 (11.18)	27.29 (21.34)	27.94 (37.26)	36
Cluster 1	72.00 (8.49)	28.80 (18.20)	53.80 (38.19)	5
Cluster 2	69.86 (11.81)	8.17 (5.78)	8.29 (9.53)	7
Cluster 3	67.50 (10.72)	35.71 (22.13)	23.93 (34.61)	14

Description of patient clusters in terms of POTIS and demographic characteristics.

Patient Cluster 1 (n=5): Older patients with few problems

This group appeared to have no difficulties related to terminal illness. For example, they had no difficulties with family which need to be sorted out, said they did not miss their social life, and could tolerate pain levels and side effects of their medication. They did not wonder why they had become ill. Patients in this cluster tended to be older and had attended the hospice for a long period of time. They were likely to be married. All were female. Social class V were over-represented in this group.

Patient Cluster 2 (n=7); Newly diagnosed, some problems, but coping.

This group felt that their illness had affected their social and interpersonal life. They missed work and social based activities, and felt upset by others who were ill. They appreciated the support of friends. They used positive coping strategies, as they didn't let little thing bother them and they tried not to dwell on their difficulties. Patients had attended the hospice for a very short time and were also newly diagnosed. They tended to have a religious faith, but did not attend a particular church. Social class V was over represented.

Patient Cluster 3 (n=14); Worried patients, ill for long period of time

Although this group didn't like to be on their own, relationships were also a source of distress. They experienced illness and social difficulties. They were worried about their family, were sad that they wouldn't see their children or grand-children grow up and found symptoms of illness and side-effects of medication a problem. They were unlikely to see the positive aspects of their situation, or use positive coping strategies to help themselves. They felt that they were to blame for their illness, and felt they had little control of their lives. However, they found information about their illness helpful. These patients had been diagnosed for a long period of time, but had only recently attended the hospice. They were likely to have retired early due to sickness. They were likely to be churchgoers, in particular, Church of England.

It was possible that day or in-patient status might have had an impact on cluster formation, due to variation in demographic distribution between the two groups. However, no effect was found. Patients from day and in-patient groups were distributed among all three major clusters.

Time Two

Cluster analysis was also carried out with patient POTIS data gathered after 4-6 weeks. Three clusters were discernable from patient responses. (See appendix 12, table 2, for breakdown of main patient cluster groups in terms of answers to POTIS items during second data collection point)

Table 10. Time two: Patient clusters described in terms of their demographic information

	Age (years)	Time since diagnosis (months)	Attendance at hospice (weeks)	Number in cluster
Total population	71.08 (10.35)	32.92 (26.82)	35.00 (37.41)	13
2: Cluster 1	77.33 (2.08)	34.00 (22.72)	54.67 (16.17)	3
2: Cluster 2	67.67 (12.89)	45.17 (30.99)	32.50 (46.12)	6
2: Cluster 3	71.50 (9.26)	13.75 (11.90)	24.00 (36.29)	4

The cluster groups from time-two were compared with demographic and POTIS answers to assess whether the cluster were distinguished from each other using similar groupings across time, and whether patient and staff perceptions had changed over time.

Patient Cluster 2.1 (n=3) Coping well

These patients were not worried by the impact of their illness on themselves or others. They were not worried about the effect of their illness on their family, and didn't find medication side-effects a problem. They didn't feel upset when others were ill. They remained hopeful and didn't require more information about their illness. These patients appeared to be older in age, likely to be married, all day patients and likely to be Church of England attenders.

Patient Cluster 2.2 (n=6) Moderate copers

This group found it hard to cope with pain and had difficulties sleeping. They were likely to miss being active. They didn't wonder why they had become ill, and felt that some good had occurred as a result of being ill. They felt their friends had been particularly helpful to them. These patients were younger, although had been diagnosed a long time, and had attended the hospice for a long length of time. They were less likely to be married or retired. There were more in-patients than expected.

Patient Cluster 2.3 (n=4) Distressed patients

This group was worried about the social, interpersonal and emotional impact of their illness on themselves and their family. Income and side effects of medication were a problem. They wondered why they had become ill, felt they were to blame, and that nothing good had happened as a result of being ill. Their family had been supportive, and they required more information about their illness. They had been diagnosed for a short time and only recently attended the hospice. All were day patients and all female.

3.6 Qualitative data: Open-ended questions

Difficult aspects

There seemed to be a general agreement amongst patients regarding the most difficult aspect of being ill (see appendix 13). Answers reflected difficulty with loss of physical functioning. For example, one patient said, "I'm not able to do what I usually do". Alternatively, patients found the increasing loss of independence difficult, reflected by one patient who answered that "Being dependent on others" was difficult. However, these two areas appear to be inter-linked, as loss of function will inevitably lead to increasing dependence. Some patients gave answers which reflected this. One patient said, "I'm not able to write and so my son has to do every thing for me". The remaining difficulties included being worried that the illness would become worse in the future, having to tell others about the illness, and being alone. These constituted only a minority of answers.

Positive aspects

The answers to the question about positive aspects were, in contrast to those above, more varied. The most common theme was the appreciation or development of personal relationships. Relationships with family and health professionals (mainly hospice staff) were mentioned most often, with support from friend mentioned slightly less.

Other answers reflected an awareness of personal growth, such as increased empathy with others, appreciating life more, looking at life differently, increased spirituality, or having little pain. Only three patients replied that there had been nothing positive for them as a result of their illness.

4.0 Discussion

4.1 Summary of Results

The breakdown of demographic information indicated that the samples were not representative of the local and national hospice population. Although patients experienced a number of difficulties associated with their illness, and a proportion were distressed, a number of positive outcomes were described. Staff perceived patients as being more anxious than patients, and patients became more anxious over time. There seemed to be no effect of individual staff member responses on patient or staff responses to the HAD. Cluster analysis was used to describe groups of responses within patient data for the two periods of sampling. These indicated that similar groups were found within the patient data for both of the time periods. Responses to open-ended questions indicated that patients report very similar difficulties associated with terminal illness whereas a wide range of positive outcomes of terminal illness were reported.

4.2 Patient Characteristics - Main Study

Demographic information indicates that patients used in the main study were not representative of the national and local terminally ill hospice population (see introduction and method section). The sample was distinctive in a number of ways as illustrated below.

Age

Patients interviewed were older than expected and no patients were under 45 years of age. This is in contrast to the overall hospice population. Results from previous studies indicate that younger patients are more likely to be in pain and are more depressed than older patients (Plumb & Holland, 1977; Dobratz, 1993). It is likely that younger, more distressed patients were not selected by nursing staff for involvement in the study. Due to the high representation of older age groups, a high proportion of patients were widowed. The experience of a significant bereavement and lower levels of marital support were possibly more common in this group than the hospice population. It is possible that lower levels of distress would be experienced by this older sample, due to losses experienced at the appropriate life stage (Erikson, 1988). However, the common experience of loss and low social support may increase levels of depression in comparison to national and local populations.

Employment

The majority of patients in the main study had retired due to old age. As the loss of work had occurred at the appropriate stage of life (Erikson, 1988), it is possible that the impact of loss of employment was not significant for them. The question from the POTIS regarding loss of work was largely redundant for this group.

Religion

This sample appeared to be highly religious, with a small minority describing themselves as agnostic. This could be related to the older age of patients. It is also possible that the experience of terminal illness had initiated a search for spirituality or meaning for many patients (Yalom, 1980).

Gender

Gender has rarely been considered in terminal illness research. It is not clear whether gender was an important variable regarding cluster membership, as cluster one (time one), and cluster three (time two) were all female. Overall, females were over-represented in the main sample in contrast to the hospice in-patient figures. Staff may have introduced this bias by mainly selecting females for the study. Females may have appeared more able to articulate their thoughts or feelings regarding their illness than men. They may have been, or perceived by staff, as being less distressed than men. However, it was possible that more women attended the day hospital, giving an overall bias to the figures. Relevant figures were not available from the day hospital to verify this.

In/day care

The majority of patients were receiving day-care and therefore likely to be mobile, relatively healthy and less disabled than patients receiving in-patient care. A break-down of age, length of time of attendance at the hospice and time since diagnosis indicated that patients from day and in-patient care formed separate sub-populations. Day patients tended to be older and had spent longer periods of time attending the hospice. In-patients were likely to be either newly diagnosed or diagnosed a long time compared with day patients. Nurses in-day care would be more likely to have become acquainted with patients that in-patient staff due to longer attendance times in day-care. In turn, day patients would have had more opportunity to benefit from professional support than in-patients. However, some patients had attended both in and day-patient care, producing overlap between the two sub-populations. This limits the conclusions which can be drawn from the whole group, or from break-down of day/in-patient care.

4.3 Patient and Hospice Characteristics.

Terminal vs Chronic Illness

A significant proportion of patients from the main study sample had attended the hospice for over 6 months. Some patients were therefore not terminally ill when admitted to the hospice (that is, their life expectancy had been longer than six months, although it is not known whether this had been expected by staff). It is likely that some patients were chronically rather than terminally ill at the time of sampling. This illustrates difficulties in the definition, selection and inclusion of patients in terminal illness research. Even if patients were not terminally ill when interviewed, some may have been confronted with existential issues which may have produced an existential crisis and search for meaning (Yalom, 1980).

Awareness of diagnosis

All the patients were aware of their diagnosis, and to varying degrees were able to discuss the subject openly. This suggests that the hospice philosophy of communicating about diagnosis was effective. The two patients who denied that they were ill may have been operating a strong denial mechanism or may not have experienced any symptoms consistent with the conventional view of illness (i.e. feeling 'under the weather'). The word 'illness' was used in the POTIS, as opposed to 'terminal illness', to reduce distress to patients. However, in retrospect, 'cancer' may have reflected patient's experience better.

Time diagnosed

The length of time since diagnosis ranged considerably between patients, resulting in a range of issues experienced. This may have led to a range of levels of adjustment and distress experienced by patients. This was reflected by the different characteristics of the patient cluster groups.

4.4 Levels of distress

The proportion of patients from the first time sample who scored above a cut-off point was compared with data from other medical populations. This indicated that, using the cut-off point of above 8, the proportion of patients who were categorised as depressed or anxious was higher in this study compared with other medical populations (Bass *et al*, 1988; Wood *et al*, 1992). Using the cut-off point of 10 and above, the proportion of patients showing clinical levels of anxiety in this study was similar to patients with typical and atypical chest pain although the proportion of patients who were depressed was more than double compared to chest pain patients (Bass *et al,* 1988). A higher proportion of patients in this study were anxious or depressed compared with early stage cancer patient when using a cut off point of 8 and above (Moorey *et al,* 1992). This suggests the proportion of cancer patients who are significantly distressed increases as the illness progresses. It is also possible that early and terminal cancer patients are distinct populations and not readily comparable. The use of different cut off points and range in subject numbers (as shown in table 6) illustrates the difficulties involved when comparing findings between studies.

It is unfortunate that no reliable figures of anxiety and depression have been established using the HAD with the terminally ill. The poor available information raises issues for professionals working within a hospice setting. Levin *et al,* 1978 suggested that depression is under-diagnosed in general by health professionals. However, over zealous diagnosis of clinical levels of distress in the terminally ill could mean that the process of dying is pathologised and physically frail individuals unnecessarily medicated, whereas under-diagnosis would lead to unnecessary suffering. This dilemma could be partly resolved if clearer prevalence figures were established for terminally ill populations.

Differences found between this study and previous research may be related to some extent to the verbal delivery of the HAD to patients. A positive response bias may have occurred, or poor concentration and poor memory may have may have affected responses. To reduce this problem, questions and responses could have been presented on flash cards in large type in addition to the verbal delivery in line with the POTIS presentation.

4.5 Internal Consistency

Internal consistency was poorer for the patient HAD results compared with previous studies using early stage cancer patients (Moorey *et al*, 1991), although this could be related to the small sample size utilised. The breakdown of alpha values indicated that the item "I feel restless as if I have to be on the move" was less consistent with the other items. This may be due to increased levels of disability in the terminally ill, and may mean that the HAD is less reliable when used with this group.

Staff use of the HAD indicated a more a acceptable internal consistency score. Nurses may have been more homogenous in their answers than patients. It is not clear whether these differences in internal consistency are related to different perceptions of patient's distress. Further research to establish the reasons for these differences may be warranted.

Poor internal consistency was also obtained for patient's responses to the POTIS scale. This could be related to the individualistic nature of psychological responses to terminal illness. Poor internal consistency has been highlighted in other studies of psychological aspects of terminal illness. Dobratz (1993) found that measures which had a high internal reliability with other populations showed lower scores with the terminally ill. Researchers may need to be aware of the poor internal consistency of some measures when used with the terminally ill.

4.6 Differences between patient and staff ratings.

Poor internal reliability scores meant that comparison of patient and staff responses to the POTIS was not possible. However, comparison of patient and staff responses to the HAD during time one showed that staff rated patients as being more anxious than the patients' own ratings. This effect was also found in a study by Higginson & McCarthy (1993). It is possible that staff in this study over-estimated patient's levels of anxiety. There may be a number of explanations for this, one being that staff members may have 'projected' their own fears regarding terminal illness onto patients, increasing their perception of patient's anxiety levels. In contrast, staff and patient ratings of depression were very similar. This may be because staff were good at estimating patient's levels of depression. These patterns were also present during the second time of data gathering although the differences were not significant.

The small staff group and use of one member of staff to provide data on more than one patient may also have produced bias in the sample and thus limit interpretation of the data. This effect was explored by comparison of staff and patient responses to the HAD and discrepancies between their responses examined by computing difference scores. This indicated that, although mean discrepancies varied between individual staff members, there was no statistically significant difference between staff discrepancy scores, as shown by the ANOVA analysis. Thus there was no significant effect of staff member on staff and patient HAD ratings. There was also no evidence that individual staff members had been asked to rate sub-groups of patients who had particularly high or low anxiety/depression scores, as shown by the findings from the ANOVA. It is acknowledged that the uneven numbers of ratings given by a small number of staff meant that interpretation of the data was limited. In future, to allow for a fuller exploration of staff's perceptions, few and more even numbers of ratings from each staff should be considered.

4.6. Perception of terminal illness: Cluster analysis

The large number of clusters which were formed from the patient POTIS answers in the main study suggested that patients responses did not fall into easily distinguished responses due to a variety of response patterns in the patient data.

The first main cluster, older patients with few problems indicated a patients who perceived few difficulties related to their illness. It seems likely that these patients had experienced less physical symptoms than younger patients, and undergone less social changes related to their illness. They may have been well adjusted due to their age, and had time to come to terms with their illness. They were likely to have benefitted from the long period of time that they had attended the hospice. They were also more likely to have had support from a marital partner. Alternatively, they may have been denying the full extent of their difficulties.

The second cluster appeared to be comprised of patients who were newly diagnosed and who described a range of social and interpersonal difficulties associated with the recent diagnosis of their illness. They appeared to be actively addressing these difficulties by using positive coping strategies which is surprising for the early stage of illness. They had only recently started to attend the hospice.

The third cluster were new attenders who experienced a range of difficulties in their lives including interpersonal, emotional, and illness-related difficulties. It seemed that they were unable to utilise positive coping strategies, although they found information about their illness helpful. They had only recently attended the hospice. Thus it is possible that they had recently become more ill, and were re-adjusting to this situation.

Therefore, these patient clusters appeared to show distinct patterns of responses which reflected the dynamic process of adaptation to terminal illness. Length of time diagnosed, attendance at the hospice, number of difficulties and positive coping statements appeared to be important distinguishing variables. The large number of individuals who did not form any cluster suggests a range of reactions to terminal illness.

4.7 Change of patient and staff perceptions after 4-6 weeks

The patients and staff which were drawn from the original sample 4-6 weeks later appeared to be older and had attended the hospice for longer periods of time compared to first sample. It seems that the response bias encountered in the first part of the study was amplified during the second period of measuring. Small sample numbers mean that only limited conclusions can be drawn from time two data.

There appeared to be a trend whereby patients were slightly more anxious at the second time of data collection. It was possible that this increase could have been due to an increase of anxiety in a minority of patients, producing a biased result. Examination of the data when displayed graphically indicated that a small number of patients had become much more anxious over time, compared with their peers. This may have produced a bias in the results, or may have been an artefact of the small sample numbers utilised. Patient depression levels were very similar depression between time periods. Perusal of the data as displayed in the bar graph suggested that there were two patients who showed a dramatic increase in levels of depression over time. However, there was little discernable pattern in the remaining patients, with a small number of patients becoming less depressed over time. In future, a larger sample group would be preferable to reduce the risk of bias from a small number of respondents.

4.8 Description of Terminal Illness

Patients in the pilot study and open-ended questions described a wide range of social, interpersonal and psychological changes which they had encountered over the course of terminal illness. Themes of disability and dependence had not been highlighted from the results of the pilot study, perhaps due to the slightly younger age of pilot subjects. Regaining independence was also raised as an issue by terminally ill patients in a qualitative study by

Bliss and Johnson, (1995). Problems regarding dependence and disability may need be taken into consideration by hospice staff.

The pilot study indicated that a large number of difficulties are experienced by terminally ill. It is important to recognise that patients also outlined a number of positive outcomes, as Hinton, (1975) and Viney & Westbrook, (1986-87) found that psychological distress was diminished in patients who utilised an actively positive approach to their illness. However, it is likely that distressed patients were not interviewed in this study, so the proportion of patients experiencing positive outcomes to their illness may have been unrealistically high in this study.

Patients cited interpersonal relationships as being the most common positive aspect of terminal illness, although relationships were also a common source of difficulty. This finding supports the hospice philosophy of good communication and the inclusion of family and friends in hospice care.

Perception Of Terminal Illness Scale

It is not clear whether the POTIS scale actually measured patient's perceptions of terminal illness. At face value it seemed to give an indication of the impact of terminal illness on patients, although further work on internal consistency is needed.

The 'Difficulties' section of the POTIS showed higher internal consistency than the 'Positives' section. This supported observations made during the pilot study and the use of open-ended questions, whereby patients appeared fairly universal in their suggestion of difficulties, but showed greater variation for positives. The positive aspects of cancer may not be an intrinsic part of the terminally ill experience, in contrast to the difficulties, but may be developed by the patients as part of the adjustment process. Thus the experience of terminal illness may have acted as a 'spur' from which some patients positively reassessed their lives (Yalom, 1980).

To improve internal consistency of the POTIS scale, only items regarding difficult aspects of terminal illness could be utilised. However, this may be a depressing read for respondents, and would present a very negative image of terminal illness. Alternatively, sections on the psychological, emotional, illness and social aspect of terminal illness could be developed and questions on disability and independence included, as they appear to be highly relevant for this group. Questions which were dropped from analysis due to skewed response bias could be re-worded. It is possible that these skewed responses could have been avoided by piloting the POTIS with a small group of patients and staff. However, this would have reduced the sample available for the main study and time was also limited.

Changes to POTIS questions

Administration of the POTIS indicated a number of questions which were unclear or produced limited information. These included question 8, *I miss not going to work any more*. Question 7, *Since my illness the reduction in my income has been a particular problems for me,* Question 14, *I have been less able to get a good nights sleep since my illness* and Question 6, *I find it hard to tolerate the pain that I am in*. The latter two questions were both confounded by patients intake of medication. Some patients experienced sleep difficulties before their illness and a small proportion of patients were sleeping better since their illness.

4.9 Methodological and Practical Difficulties

A number of methodological difficulties related were encountered in the study. As described by Bass (1982-83), the sample was likely to have been physically stronger and less distressed that the overall hospice population. Time-two data was difficult to collect and therefore the sample was small. This limited the conclusions which can be drawn between the two time periods. It is difficult to suggest how these problems may have been avoided.

It was realised that interviewing ill, distressed and easily tired patients would require sensitivity. Likert scales were used as they are relatively straight forward and quick to administer. They did not require the patient to write or talk extensively. However, patients were reluctant to give numerical answers, preferring to give a 'Yes' or 'No' answer. Some patients were keen to qualify their answers with long explanations. It is possible that a positive response bias occurred with many patients preferring to appear to be 'coping well'.

As it was important not to overload patients, only two short scales were administered. There is a risk that a floor effect occurred, with material being too simplistic to account for the wide range of experiences encountered by patients. Practical restraints meant that measures were presented differently to staff. That is, measures were presented verbally and visually to patients, and as printed material to staff. This may have contributed to differences between staff and patient responses. A time difference may have occurred between staff and patient response to measures, although staff were remarkably prompt and efficient, with all staff returning questionnaires. This seemed to reflect the positive attitude and interest in the research study from all levels of the hospice staff.

In this study, day and in-patients appeared to be from different sub-populations. Detailed information regarding staff age, status and time since qualification would have been useful, along with broader information from hospice sources. Demographic information gathered from patients may have been imprecise due to problems with recall, understanding. Information regarding medication may have been useful as it may have affected patient responses. However, the number of uncontrolled variables encountered in this study were difficult to avoid. The varying lengths of illness, attendance times at the hospice and variety of cancers meant that the data collected was inevitably messy.

Ethical Issues.

Ethical issues regarding vulnerability and privacy of patients were apparent to the author at all stages of the research. Pressure to complete data collection could have resulted in a lack of sensitivity to patients' needs during the interview, although no patients appeared distressed during the interview. The author was careful not to assume a counsellor role if distressing information was divulged. Instead, nursing staff were informed on two occasions that patients had appeared distressed or low in mood. Supervision had been arranged for the author to address distressing emotions raised during the study, although this was not taken up. In fact, interviews were often a source of inspiration. There was little evidence that patients were withdrawing from the world (De Raeve, 1994) and all patients were willing to talk about their experience. It was interesting that it was nursing staff, not patients, who were keen to avoid raising sensitive or emotional topics.

4.10 Implications of study

The individual nature of patient's psychological response to terminal illness may need to be recognised. Short but structured questionnaires such as the POTIS may be helpful to clarify important areas for nurses to explore with patients. The use of task-based models which acknowledge the importance of individuality may need further consideration.

Staff may be over-estimating anxiety. The use of standard measures such as HAD, or raised awareness of the range of symptoms related to anxiety may be necessary.

The hospice has already recognised the importance of communication and the development of interpersonal relationships with patients. It is not clear however how issues of disability and dependence are addressed with patients. The hospice appears to be providing a positive service as some patients who have been at the hospice a long time demonstrate positive attitudes and complain of fewer difficulties.

Further research

Poor internal reliability of scales measuring psychological aspects of terminal illness may be an unrecognised problem. Scales need to be carefully constructed and validated with this population rather than the general cancer population. More research is needed to validate the HAD for use with the terminally ill, as the internal consistency scores were poor in this study.

The use of proxy data in research is very questionable. Staff and patients may use different models on which to base their perceptions of patient adjustment. Further research is needed to compare staff and patient perceptions on a number of variables, using well-validated measures and larger patient samples.

Suggestions for possible improvement of the POTIS have been noted. It may be of use as a measure to gather information for nursing staff. An improved scale could be used to compare responses with healthy populations and other patient groups, such as hospital and home-based patients and the chronically ill.

Lastly, it has been suggested that the fundamental question of terminal illness and the process of dying should remain unanswered as motivation to research this area may be related to our morbid curiosity of the unknown (De Raeve, 1994). There have now been enough studies to discount the view that terminally ill patients should not be interviewed at all (Field, Douglas, Jagger & Dand, 1995). This study has raised a number of issues which may be of interest to the terminally ill, researchers, clinicians and families involved in this area. By raising awareness of terminal illness, fear and distress may be reduced for all concerned.

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Appendix 1. Format of Semi-Structured Interview

1. Introduction to study and consent form.

2. Collection of subject details.

Name
Age
Gender
Day or in-patient
Occupation
Length of time at hospice
Frequency of visits to hospice (if relevent)

3. Information regarding subject's illness and reaction to diagnosis.

Could you describe your illness to me.
How did you find out that you were ill?
When were you diagnosed?
How did you react to the news of your illness?
How did family/friends react to your news?

How do you feel in yourself now?
Are you in much pain?
Are you receiving treatment?
Are you taking medication?

4. Information regarding subject's perspective regarding illness.

This has obviously been an incredibly difficult time for you. How have you coped, what has helped?
What have been the most difficult things for you to come to terms with, in the past, at present?
How have you dealt with these?
Do you feel that there have been any positive things which have occurred as a result of this illness?
What things, if any, are you most worried about regarding the future?

Thank you for your participation.

Appendix 2 Patient Information Sheet and consent form, pilot study

I am a trainee clinical psychologist in the last year of my training, undertaking some research as part of my course.

I am very interested in the view points of patients and nurses in a hospice environment, and I am carrying out a research study to look at these in depth across time. It is hoped that the results will be of interest and use to other patients and staff in hospices in the future.

To do this, I am carrying out a small number of interviews with patients here. I am asking them some questions about their situation. I am especially interested in the patient's views on the positive and difficult aspects of their situation at present. I will be using these responses to develop a short questionnaire

The interviews last approximately half an hour, although this depends entirely on the participant. I will be writing down their responses at the time. The interview will be held in a private room.

If patients wish, I will be very happy to give them a summary of my findings when the study is completed.

Participation in the study is entirely voluntary and patients are able to withdraw from the study at any stage. The answers to the interview will, of course, be entirely confidential, and no identifying material will be kept after the study.

If for any reason, patients feel they wish to discuss any aspect of the study in more depth, then they are encouraged to arrange to speak to myself or Matron. We will be happy to spend some time dicussing any concerns.

If you would like to participate in the study, please read and sign the section below. Thank you very much for your time and consideration.

....

I, ______________________ (BLOCK LETTERS) give my consent to participation in this study. I understand that I may be interviewed by in the near future, at a convenient time for me. I am free to withdrew from the study at any stage. I understand that my answers will be completely confidential.

Signed .... Date ....

Appendix 3. Themes from pilot questions: Difficult and positive aspects of terminal illness

Difficulties	No. of responses	Positive aspects	No. of responses
Little money	5	Support of family	6
Low in mood	5	Support of friends	5
Easily tired	4	Live from day to day	5
Delays with medical procedures	4	Changed outlook on life	5
Medication	4	Coped better than thought	4
Worry regarding family well-being	4	Being at the hospice	4
Not being able to work	4	Appreciate life more	3
Seeing others ill/dying	4	More able to talk of feelings	3
Negative effect on family	4	Relatively little pain	2
First visit to hospice	4	Alternative therapies	2
Being alone	3	Meeting others	1
Pain	3		
No hope of cure	3		
Not able to go out	3		
Physical symptoms	3		
Hospital visits	3		
Poor sex life	2		
Not in control	2		
Disability	2		
Increased lability	2		
Dependence on others	2		
Poor sleep	1		
Why me	1		
Can't concentrate	1		
TOTAL	75		42

Appendix 5. Demographic information sheet, Main study

1. Subject number ....

2. Name ....

3. Date of Birth ..../........./........

4. Gender M / F

5. Marital status ....

6. Occupation

....

....

7. Status: Day / In-patient

8. Diagnosis

....

9. Length of time since diagnosis

....

10. Length of time at hospice

....

11. Religion/spiritual beliefs / attends church?

....

....

Appendix 7. Patient information and consent form

I am a trainee clinical psychologist in the last year of my training, undertaking some research as part of my course.

I am very interested in the view-points of patients and nurses in a hospice environment, and I am carrying out a research study to look at these in depth across time. It is hoped that the results will be of use to other patients and staff in hospices in the future

To do this, I will be asking patients to complete a short questionnaire which I have developed regarding their views on the positive and difficult aspects of their situation in the hospice. This is made up of number of statements and patients will be asked to say whether they agree or disagree with these statements. Patients will also be asked to fill in a short questionnaire regarding their mood.

The interviews last from fifteen minutes to half an hour. The interviews will be held in a private room.

I will also be asking nursing staff to fill in the same questionnaires from the patient's viewpoint, to give an idea of their views of the patient's situation.

I will be contacting some patients in approximately a months time to repeat the two questionnaires, if this is convenient. If patients wish, I will be happy to give them a summary of my findings when the study is completed.

Participation in the study is entirely voluntary and patients are able to withdraw from the study at any stage. The answers to the interview will, of course, be entirely confidential, and no identifying material will be kept after the study.

If for any reason, patients feel they wish to discuss any aspect of the study in more depth, then they are encouraged to arrange to speak to myself or Matron. We will be happy to spend some time discussing any concerns.

If you would like to participate in the study, please read and sign the section below. Thank you very much for your time and consideration.

....

I, ______________________ (BLOCK LETTERS) give my consent to participation in this study. I understand that I may be interviewed by in the near future, at a convenient time for me. I may be approached by her in a months time to repeat the questionnaire. I understand that I am free to withdrew from the study at any stage, and that my answers will be completely confidential.

Signed .... Date ....

Appendix 8. Breakdown of Demographic information

Table 1. Distribution of patients according to Social Class Classification

Social class	**Number**	**Percent**
I	0	
II	2	5.6
IIIN - Non manual	7	19.4
IIIM - Manual	15	41.7
IV	1	2.8
V	4	11.1
House-wife	3	8.3
Missing Data	4	11.1
Total	36	100

Table 2. Patients' religious allegiance

Religious allegiance	**Number**	**Percent**
Agnostic	2	5.6
Independent church	6	16.7
Non-specific religious	10	27.8
Church of England	11	30.6
Catholic	5	13.9
Hindu	1	2.8
Missing data	1	2.8
Total	36	

Table 3. Patient's description of their diagnosis

Diagnosis	**Number of sites described by patients**
Breast	10
Lung	7
Gynaecological	7
Bowel	2
Brain	1
Bone	6
Liver	2
Bladder	2
Stomach	2
Other	7
Total	46

NB. Numbers do not add up to 36 as some described more than one site for cancer.

Table 4. Breakdown of patient and staff responses to HAD over two time periods.

		Patients		**Staff**	
	Score	Time 1	Time 2	Time 1	Time 2
Anxiety	0-7	18 (51.4%)	9 (69.2%)	10 (28.6%)	4 (30.8%)
	8-10	13 (37.1%)	3 (23.1%)	12 (34.3%)	7 (53.8%)
	11-14	3 (8.6%)	0	9 (25.7%)	2 (15.4%)
	15-21	1 (2.9%)	1 (7.7%)	4 (11.4%)	0
Depression	0-7	22 (62.9%)	8 (61.5%)	20 (57.1%)	11 (84.6%)
	8-10	8 (22.9%)	1 (7.7%)	11 (31.4%)	1 (7.7%)
	11-14	2 (5.7%)	2 (15.4%)	3 (8.6%)	0
	15-21	1 (2.9%)	2 (15.4%)	1 (7.7%)	1 (7.7%)
	n	**35**	**13**	**35**	**13**

Appendix 9. Frequencies: Staff and patient responses to POTIS

	Value & percent	STAFF	RESPONSES		
Qu	1. Agree	2. Mostly agree	3. Not sure	4.Mostly Disagree	5. Disagree
1	14 (38.9)	11 (30.6)	5 (13.9)	2 (5.6)	4 (11.1)
2	5 (13.9)	4 (11.1)	8 (22.2)	8 (22.2)	11 (30.6)
3	13 (36.1)	10 (27.8)	5 (13.9)	3 (8.3)	5 (13.9)
4	9 (25.0)	12 (33.3)	5 (13.9)	3 (8.3)	6 (16.7)
5	14 (38.9)	12 (33.3)	3 (8.3)	4 (11.1)	3 (8.3)
6	4 (11.1)	10 (27.8)	7 (19.4)	9 (25.0)	6 (16.7)
7	2 (5.6)	3 (8.3)	7 (19.4)	10 (27.8)	14 (38.9)
8	9 (25.0)	2 (5.6)	5 (13.9)	4 (11.1)	16 (44.4)
9	15 (41.7)	11 (30.6)	6 (16.7)	2 (5.6)	2 (5.6)
10	6 (16.7)	9 (25.0)	11 (30.6)	6 (16.7)	4 (11.1)
11	5 (13.9)	15 (41.7)	8 (22.2)	4 (11.1)	4 (11.1)
12	8 (22.2)	14 (38.9)	7 (19.4)	2 (5.6)	5 (13.9)
13	13 (36.1)	9 (25.0)	7 (19.4)	4 (11.1)	3 (8.3)
14	7 (19.4)	8 (22.2)	7 (19.4)	3 (8.3)	11 (30.6)
15	11 (30.6)	9 (25.0)	10 (27.8)	3 (8.3)	3 (8.3)
16	3 (8.3)	2 (5.6)	4 (11.1)	12 (33.3)	15 (41.7)
17	5 (13.9)	7 (19.4)	8 (22.2)	8 (22.2)	8 (22.2)
18	10 (27.8)	12 (33.3)	3 (8.3)	6 (16.7)	5 (13.9)
19	14 (38.9)	6 (16.7)	5 (13.9)	1 (2.8)	9 (25.0)
20	18 (50.0)	11 (30.6)	2 (5.6)	1 (2.8)	4 (11.1)
21	21 (58.3)	7 (19.4)	3 (8.3)	2 (5.6)	3 (8.3)
22	21 (58.3)	8 (22.2)	1 (2.8)	4 (11.1)	2 (5.6)
23	17 (47.2)	9 (25.0)	5 (13.9)	2 (5.6)	3 (8.3)
24	20 (55.6)	10 (27.8)	3 (8.3)	2 (5.6)	1 (2.8)
25	22 (61.1)*	10 (27.8)	0 (0.00)	1 (2.8)	3 (8.3)
26	16 (44.4)	6 (16.7)	4 (11.1)	6 (16.7)	4 (11.1)
27	14 (38.9)	11 (30.6)	5 (13.9)	5 (13.9)	1 (2.8)
28	15 (41.7)	11 (30.6)	6 (16.7)	2 (5.6)	2 (5.6)
29	14 (38.9)	11 (30.6)	5 (13.9)	5 (13.9)	1 (2.8)
30	7 (19.4)	7 (19.4)	8 (22.2)	10 (27.8)	4 (11.1)

Answers starred are over 60% are were therefore omitted from the analysis.

	Value and percent	PATIENT RESPONSES			
Qu.	1. Agree	2. Mostly agree	3. Not sure	4. Mostly Disagree	5. Disagree
1	16 (44.4)	9 (25.0)	2 (5.6)	4 (11.1)	5 (13.9)
2	4 (11.1)	0 (0.00)	2 (5.6)	9 (25.0)	21 (58.3)
3	16 (44.4)	5 (13.9)	5 (13.9)	0 (0.00)	10 (27.8)
4	13 (36.1)	5 (13.9)	5 (13.9)	2 (5.6)	11 (30.6)
5	18 (50.0)	6 (16.7)	4 (11.1)	1 (2.8)	7 (19.4)
6	4 (11.1)	5 (13.9)	7 (19.4)	4 (11.1)	16 (44.4)
7	5 (13.9)	3 (8.3)	0 (0.00)	2 (5.6)	26 (72.2)*
8	9 (25.0)	5 (13.9)	9 (25.0)	0 (0.00)	13 (36.1)
9	26 (72.2)	4 (11.1)	1 (2.8)	1 (2.8)	4 (11.1)
10	17 (47.2)	3 (8.3)	2 (5.6)	3 (8.3)	11 (30.6)
11	13 (36.1)	4 (11.1)	4 (11.1)	2 (5.6)	13 (36.1)
12	13 (36.1)	9 (25.0)	3 (8.3)	1 (2.8)	10 (27.8)
13	18 (50.0)	6 (16.7)	0 (0.00)	1 (2.8)	11 (30.6)
14	17 (47.2)	5 (13.9)	3 (8.3)	2 (5.6)	9 (25.0)
15	17 (47.2)	6 (16.7)	0 (0.00)	0 (0.00)	13 (36.1)
16	1 (2.8)	4 (11.1)	1 (2.8)	3 (5.6)	28 (77.8)*
17	12 (33.3)	2 (5.6)	0 (0.00)	6 (16.7)	16 (44.4)
18	11 (30.6)	5 (13.9)	1 (2.8)	4 (11.1)	15 (41.7)
19	25 (69.4)*	4 (11.1)	5 (13.9)	1 (2.8)	1 (2.8)
20	29 (80.6)*	3 (8.3)	1 (2.8)	2 (5.6)	1 (2.8)
21	30 (83.3)*	5 (13.9)	1 (2.8)	0 (0.00)	0 (0.00)
22	26 (72.2)*	4 (11.1)	2 (5.6)	2 (5.6)	2 (5.6)
23	29 (80.6)*	4 (11.1)	1 (2.8)	2 (5.6)	0 (0.00)
24	22 (61.1)	10 (27.8)	1 (2.8)	1 (2.8)	2 (5.6)
25	33 (91.7)*	3 (8.3)	0 (0.00)	0 (0.00)	0 (0.00)
26	17 (47.2)	2 (5.6)	3 (8.3)	7 (19.4)	7 (19.4)
27	17 (47.2)	7 (19.4)	1 (2.8)	2 (5.6)	9 (25.0)
28	25 (69.4)*	7 (19.4)	0 (0.00)	2 (5.6)	2 (5.6)
29	21 (58.3)	2 (5.6)	7 (19.4)	2 (5.6)	4 (11.1)
30	17 (47.2)	6 (16.7)	0 (0.00)	5 (13.9)	7 (19.4)

Appendix 10. Results of t-tests on time-one and time-two HAD data

Table 1. Time-two: Comparison of staff and patient HAD ratings.

Anxiety	Mean	SD	*t*
Patients	7.08	3.59	-1.71
Staff	8.69	2.49	
Depression			
Patients	7.92	4.23	1.38
Staff	6.31	3.82	

Table 2. Time-one & Time-two: Comparison of patient HAD ratings.

Patients	Mean	SD	*t*
Anxiety - time 1	6.58	3.15	-.89
Anxiety - time 2	7.08	3.59	
Depression - time 1	7.61	2.69	-.30
Depression - time 2	7.92	4.23	

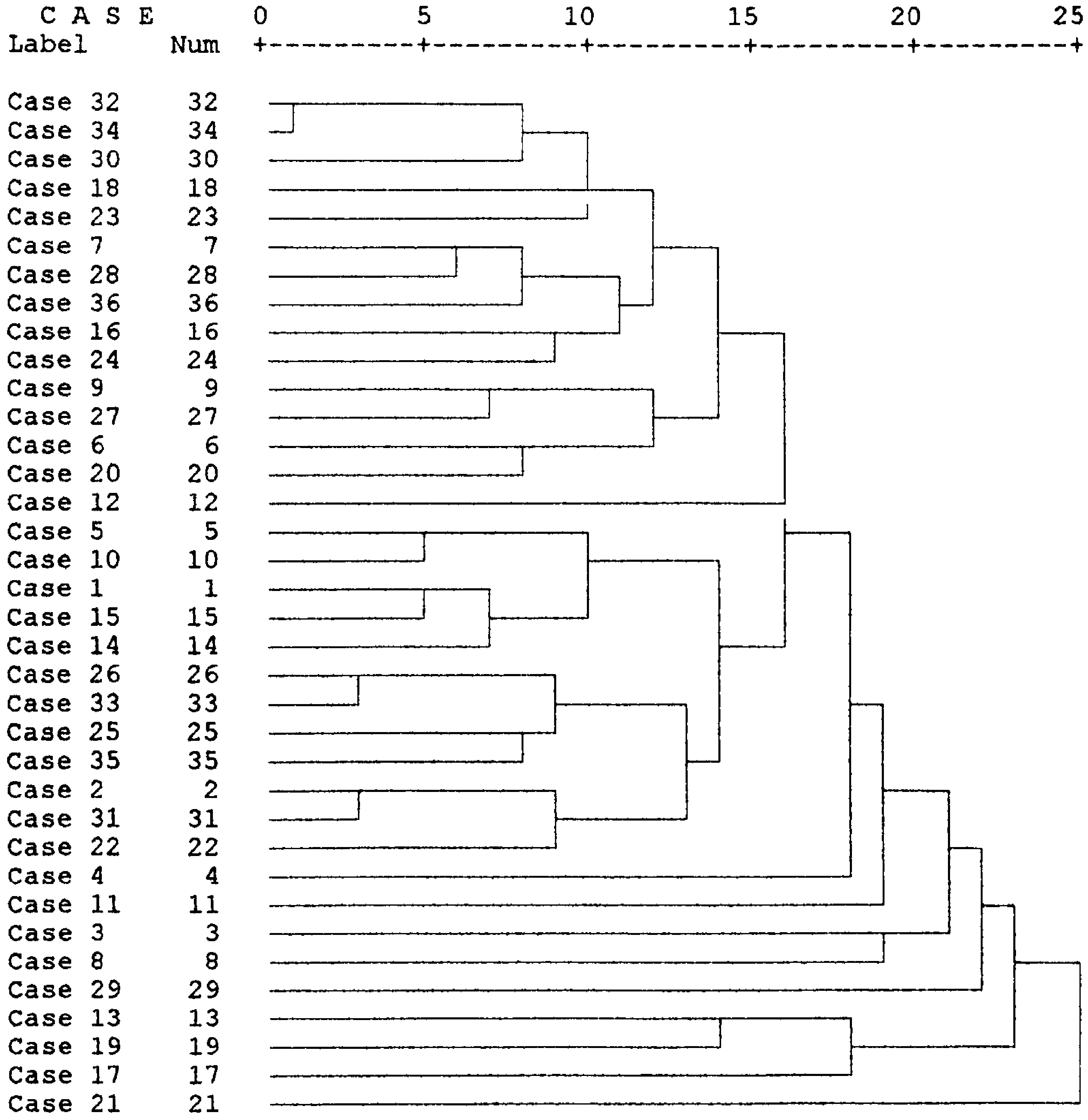
Appendix 11. Dendograms from POTIS data

Main study: Patient POTIS responses

****** HIERARCHICAL CLUSTER ANALYSIS ******

Dendrogram using Average Linkage (Between Groups)

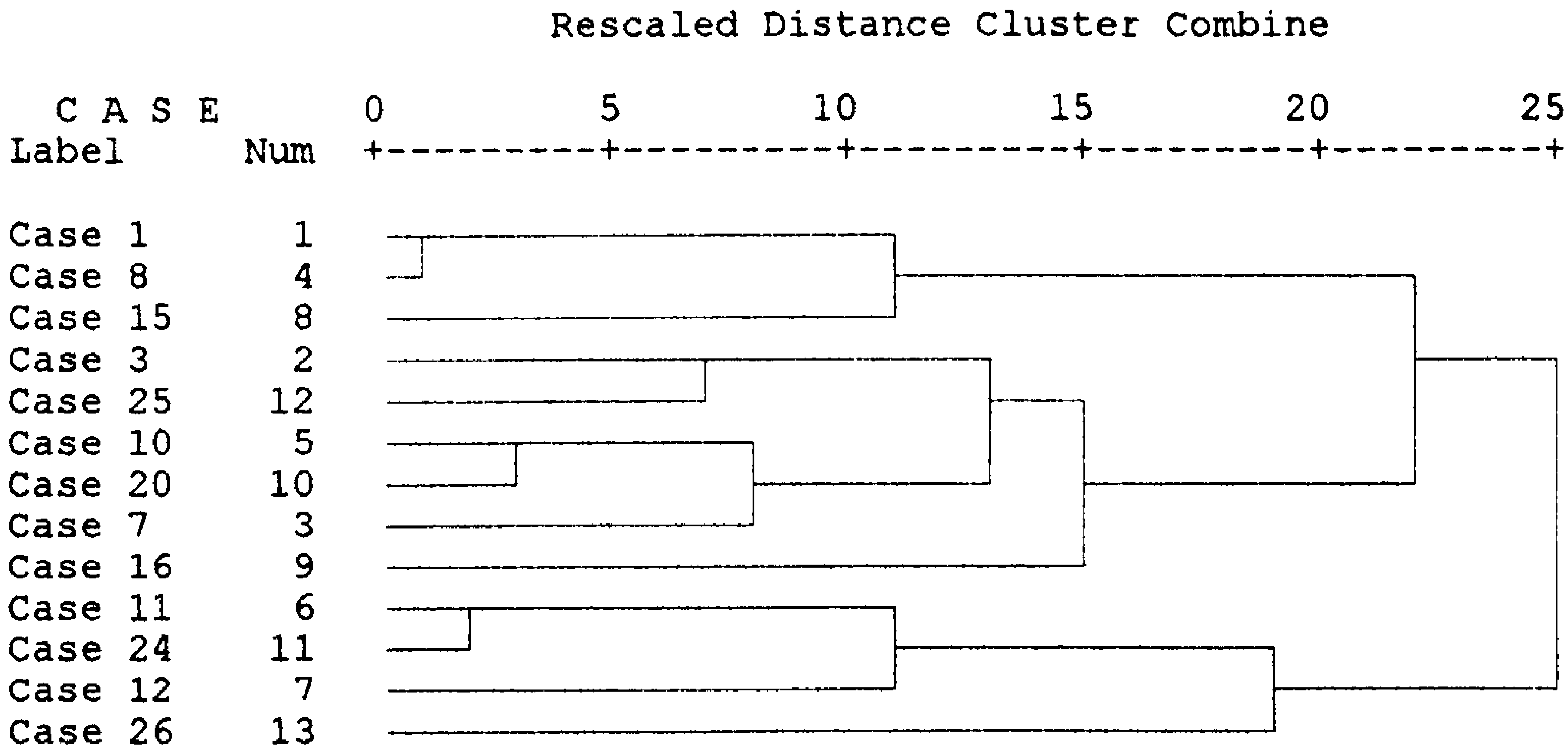
Rescaled Distance Cluster Combine



Time two: Patient POTIS responses

* * * * * * HIERARCHICAL CLUSTER ANALYSIS * * * * * *

Dendrogram using Average Linkage (Between Groups)



Appendix 12. Patient cluster membership and responses to POTIS items

Table 1: Main patient clusters and mean responses to individual POTIS items (1= definitely agree, 2 =mostly agree, 3=not sure, 4=mostly disagree, 5=definitely disagree).

Question Number	Cluster 1 - mean score (n=5)	Cluster 2 - mean score (n=7)	Cluster 3 - mean score (n=14)	Mean for entire sample
1	4.60 (0.55)	2.42 (1.27)	1.42 (0.51)	2.25 (1.48)
2	5.00 (0.00)	4.43 (0.79)	3.00 (2.83)	4.19 (1.28)
3	3.00 (1.22)	3.14 (1.86)	1.93 (1.49)	2.52 (1.69)
4	3.42 (1.67)	3.85 (1.68)	2.07 (1.27)	2.81 (1.70)
5	2.80 (1.79)	1.42 (0.79)	2.43 (1.55)	2.25 (1.57)
6	4.60 (0.89)	3.71 (1.25)	3.29 (1.20)	3.69 (1.43)
7	4.60 (0.89)	5.00 (0.00)	4.36 (1.45)	4.22 (1.44)
8	3.40 (0.89)	2.28 (1.49)	3.43 (1.74)	3.08 (1.63)
9	2.00 (1.73)	1.14 (0.38)	2.07 (1.54)	1.69 (1.35)
10	4.20 (1.79)	2.71 (1.79)	2.43 (1.74)	2.67 (1.80)
11	5.00 (0.00)	3.28 (1.70)	2.14 (1.46)	2.94 (1.78)
12	3.60 (1.52)	3.29 (1.70)	2.00 (1.47)	2.61 (1.67)
13	2.20 (1.63)	4.57 (1.13)	1.78 (1.42)	2.47 (1.79)
14	1.80 (1.09)	3.85 (1.67)	2.29 (1.81)	2.47 (1.69)
15	5.00 (0.00)	1.57 (1.51)	2.00 (1.36)	2.61 (1.86)
16	5.00 (0.00)	5.00 (0.00)	3.93 (1.38)	4.44 (1.15)
17	4.60 (0.55)	4.43 (1.51)	3.21 (1.76)	3.33 (1.82)
18	4.00 (1.22)	5.00 (0.00)	2.07 (1.49)	3.19 (1.79)
19	1.80 (0.84)	1.71 (0.95)	1.29 (0.83)	1.58 (1.02)
20	1.60 (1.34)	1.00 (0.00)	1.36 (0.84)	1.42 (0.99)
21	1.00 (0.00)	1.29 (0.49)	1.14 (0.36)	1.19 (0.47)
22	1.20 (0.44)	1.71 (0.95)	1.14 (0.36)	1.61 (1.18)
23	1.00 (0.00)	1.43 (1.13)	1.29 (0.47)	1.33 (0.79)
24	1.20 (0.45)	1.57 (0.79)	1.36 (0.49)	1.64 (1.07)
25	1.20 (0.45)	1.00 (0.00)	1.14 (0.36)	1.08 (0.28)

26	2.60 (1.14)	3.00 (1.91)	2.35 (1.69)	2.59 (1.69)
27	2.00 (1.41)	1.43 (0.53)	2.29 (1.68)	2.41 (1.69)
28	1.20 (0.44)	1.00 (0.00)	1.57 (0.85)	1.58 (1.13)
29	1.80 (1.09)	2.00 (1.29)	1.64 (1.01)	2.06 (1.43)
30	2.80 (2.04)	2.42 (1.81)	1.57 (0.85)	2.42 (1.65)

Table 2: Time-two, main patient cluster groups and mean responses to individual POTIS items (1 = definitely agree, 2 = mostly agree, 3 = not sure, 4 = mostly disagree, 5 = definitely disagree).

Question Number	Cluster 1 - mean score (n=3)	Cluster 2 - mean score (n=6)	Cluster 3 - mean score (n=4)	Mean for entire sample
1	4.67 (0.58)	2.00 (0.89)	1.00 (0.00)	2.31 (1.55)
2	5.00 (0.00)	4.67 (0.82)	5.00 (0.00)	4.85 (0.55)
3	2.27 (0.57)	3.00 (1.41)	1.25 (0.50)	2.38 (1.26)
4	4.00 (1.00)	3.17 (1.83)	2.00 (1.41)	3.00 (1.63)
5	4.00 (0.00)	2.50 (1.22)	1.25 (0.50)	2.46 (1.33)
6	5.00 (0.00)	2.67 (1.21)	4.50 (1.00)	3.77 (1.42)
7	5.00 (0.00)	5.00 (0.00)	3.00 (2.31)	4.39 (1.50)
8	5.00 (0.00)	3.67 (2.06)	3.25 (2.06)	3.85 (1.82)
9	2.33 (2.31)	1.50 (1.22)	1.00 (0.00)	1.54 (1.33)
10	2.33 (2.31)	2.33 (1.36)	2.00 (2.00)	2.23 (1.64)
11	5.00 (0.00)	2.67 (1.86)	1.00 (0.00)	2.69 (1.93)
12	2.67 (1.15)	2.83 (1.72)	3.00 (2.31)	2.85 (1.67)
13	5.00 (0.00)	2.17 (1.17)	2.00 (2.00)	2.76 (1.79)
14	2.67 (2.08)	1.83 (1.60)	2.00 (2.00)	2.07 (1.71)
15	3.33 (1.52)	4.16 (1.60)	1.50 (0.58)	3.15 (1.72)
16	5.00 (0.00)	4.83 (0.41)	3.25 (2.06)	4.38 (1.32)
17	2.00 (0.00)	4.83 (0.41)	1.00 (0.00)	3.00 (1.83)
18	3.33 (2.08)	1.33 (0.52)	1.50 (1.00)	1.85 (1.34)
19	1.33 (0.57)	2.33 (1.21)	1.00 (0.00)	1.69 (1.03)

20	2.00 (1.73)	1.00 (0.00)	1,25 (0.50)	1.31 (0.85)
21	1.00 (0.00)	1.17 (0.41)	1.00 (0.00)	1.08 (0.27)
22	2.00 (1.73)	1.67 (0.82)	1.25 (0.50)	1.61 (0.97)
23	1.33 (0.58)	1.00 (0.00)	1.00 (0.00)	1.07 (0.27)
24	1.67 (0.57)	2.00 (1.26)	1.50 (1.00)	1.77 (1.01)
25	1.00 (0.00)	1.00 (0.00)	1.00 (0.00)	1.00 (0.00)
26	4.00 (1.73)	3.83 (1.47)	2.50 (1.73)	3.46 (1.61)
27	3.33 (1.15)	1.67 (0.52)	3.25 (2.06)	2.53 (1.45)
28	1.00 (0.00)	1.50 (0.56)	1.50 (5.77)	1.38 (0.50)
29	1.67 (0.57)	3.16 (1.72)	2.50 (1.00)	2.61 (1.38)
30	5.00 (0.00)	2.50 (1.97)	1.00 (0.00)	2.61 (1.98)

Appendix 13. Responses to open-ended questions

Table x. Number of responses regarding difficult and positive aspects of terminal illness.

Difficulties	**Number of responses**	**Positives**	
Physical deterioration	17 (39.5%)	Relationships with friends	4 (11.1%)
Dependence on others	18 (41.8%)	Relationships with family	7 (19.4%)
Uncertain future	3 (6.9%)	Relationships with health professionals	7 (19.4%)
Having to stay inside	2 (4.6%)	Personal growth	6 (16.7%)
Telling others	1 (2.3)	Spiritual growth	3 (8.8%)
Being alone	2 (4.6%)	Hope of getting better	2 (5.5%)
		Appreciation of life	2 (5.5%)
		Meeting new friends	2 (5.5%)
		Nothing	3 (8.8%)
Total responses	43		36

N.B. There were some answers which reflected more than one category, therefore responses add up to more than 34.

The following material has been excluded from the digitised copy due to 3rd Party Copyright restrictions:

Appendix 4: Perception of terminal illness scale (POTIS), 2 pages
Appendix 6: Hospital Anxiety and Depression Scale (HADS), 1 page

Readers may consult the original thesis if they wish to see this material.