THE UNIVERSITY OF HULL

Specialist Palliative Day Care: Patients’ Perspectives

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by

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Overview

This portfolio has three parts.

Part one is a systematic literature review entitled ‘Patients’ Psychosocial Experiences of Attending Specialist Palliative Day Care: A Systematic Literature Review’. Recent reviews conclude that the benefits of attending Specialist Palliative Day Care are likely to be in the social, psychological and spiritual domains. However these areas are not easily identified, leaving researchers and practitioners unclear as to what aspects of these domains patients most need and desire. The objective of this review was to systematically evaluate literature on patient perceived psychosocial experiences of attendance at SPDC. Twelve studies were included. Evidence showed that patients value a person-centred approach which reduces isolation, increases social support, encourages communication and provides activities. Future research could focus on investigating why patients value the psychosocial experiences reported in this review and how these experiences can be defined in a way that would be meaningful to clinical service commissioners. Once this has been done, clinicians can start to measure clinical effectiveness and devise justifiable interventions for this patient group.

Part two is a qualitative study, using Interpretative Phenomenological Analysis (IPA) to explore patients’ perspective of attending SPDC. The importance of services helping patients cope with terminal illness has been emphasised throughout Department of Health (2000) and NICE (2004) cancer guidance. However, whether or not services are achieving this aim has been sparsely researched to date; particularly in relation to Specialist Palliative Day Care (SPDC). Eleven semi-structured interviews were carried out and analysed utilising qualitative methodology (Interpretative Phenomenological Analysis – IPA) to allow for an in depth investigation of patients’ views of attending
Emerging themes suggest that SPDC provides an environment in which patients are helped to cope by facilitation of acceptance of the reality of death, thereby freeing them to focus on ‘life’. The study does not claim to provide the definitive answer to what processes may underpin attendance at SPDC, however in such an under researched area it provides a much needed exploration which can be built upon or challenged by future research.

Part three comprises of appendices relating to the research. This includes a reflective statement on the process of conducting the research, the challenges faced and the lessons learnt.
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Please see appendix 1 for the Guideline for Authors.

Patients’ Psychosocial Experiences of Attending Specialist Palliative Day Care (SPDC):

A Systematic Review

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Abstract

Recent reviews conclude that the benefits of attending Specialist Palliative Day Care are likely to be in social, psychological and spiritual domains. However these areas are not easily identified, leaving researchers and practitioners unclear as to what aspects of these domains patients most need and desire. The objective of this review was to systematically evaluate literature on patient perceived psychosocial experiences of attendance at SPDC. Twelve studies were included. Evidence showed that patients value a person-centred approach which reduces isolation, increases social support, encourages communication and provides activities. Future research could focus on investigating why patients value the psychosocial experiences reported and how these experiences can be defined in a way that would be meaningful to clinical service commissioners. Once this has been done, clinicians can start to measure more effectively clinical effectiveness and devise justifiable interventions to help this patient group.

Key words: Psychosocial, Psychological, Social, Specialist Palliative Day Care, Patients’ Perceptions
Introduction

There are currently 280 Specialist Palliative Day Care (SPDC) facilities for adults in the UK (1). SPDC services aim to support people with progressive illness who wish to be cared for in their own homes. Referrals come from a variety of sources including general practitioners, community nurses and consultants. There are no nationally agreed criteria for admission to SPDC (2), however a review of forty centres in the London area found 90% of patients had cancer with the other 10% most commonly suffering from HIV/AIDS, motor neurone disease or stroke (3). This distribution mirrors overall access to UK Specialist Palliative Care (SPC) services although over the past 10 years there has been increasing recognition that services should increase access for patients with non-malignant disease to address inequity. The National Institute for Clinical Excellence (NICE) guidance for Supportive and Palliative Care for Adults with Cancer (2004) acknowledges that SPDC services have a scanty evidence base compared with other SPC services and that there is great variety with regard to service configuration and referral or discharge criteria (4).

While organisational structure varies greatly, SPDC generally provides a multi-disciplinary approach to holistic care. Staff include doctors, nurses, chaplains, allied health care professionals, complementary therapists, social workers and hairdressers. Some services are able to provide art and music therapy and have access to psychological and psychiatric services. The most common activities occurring within SPDC have been shown to be: monitoring and review of patients’ symptoms or needs, bathing, wound care, physiotherapy, hairdressing and aromatherapy (3). SPDC services were shown to describe themselves in terms of whether they adhered to a more medical or social model of care. Social models of care are geared towards social activities and are more likely to pay for creative artists; medical models of care offer treatments and
medical assessment’ (p. 279, 3). Douglas, Higginson, Myers and Normand (5) reported that despite different origins in terms of model of care SPDC showed similarities in that all services ‘combined therapeutic and social support, and aimed to ensure that the package of care included assessment and creative and therapeutic interventions’ (p342).

In reviewing patient perceived experiences of SPDC, we need to be clear on what is exactly meant by the term ‘Palliative Care’. The term was originally coined by the Canadian surgeon Balfour Mount in 1974. Based upon the notion of non-curative care, the concept satisfies a need to care for the dying as declared by religious leaders in the nineteenth century. Since this notion was first proposed, hospices such as St Christopher’s Hospice in London have demonstrated the feasibility of applying these principles in a variety of settings. An essential principle of modern palliative care came from Dame Cicely Saunders. Saunders proposed the holistic concept of ‘total pain’ as a way of describing the holistic experience of patients including physical, emotional, social and spiritual realms of distress (6). More recently this concept of ‘total pain’ has been defined by the term ‘bio-psychosocial’, first coined by George Engel; it extends the biomedical model by acknowledging the influence of patients’ thoughts, feelings, behaviour, social context and their interaction with the health care system (7). It moves away from a traditional reductionist biomedical model and states that the workings of the body can affect the mind, and the workings of the mind can affect the body (8).

The psychosocial aspect of bio-psychosocial care is hard to define. However in relation to palliative care services psychosocial care is said to be concerned with ‘the psychological and emotional well being of the patient, including issues of self-esteem, insight into and adaptation to the illness and its consequences, communication, social functioning and relationships’ (pg 6, 9). Psychosocial care is said to incorporate the psychological experiences, culture, values, spiritual beliefs and social factors of the
patient, including practical aspects such as finance and housing (10). For the purposes of this review, the term ‘psychosocial experiences’ will be defined in accordance with literature incorporating psychological, social and spiritual experiences of attending SPDC.

SPDC is one area where the bio-psychosocial model has been widely incorporated into patient care. SPDC is defined as “... a service, which enhances the independence and quality of life of patients through rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms and provision of psychosocial support” (pg 1, 11). However despite recognition of the need to provide holistic care the provision of psychosocial support is desperately under researched. Commissioned by NICE, Gysels and Higginson (12), carried out a systematic review of the literature to outline evidence on interventions undertaken within SPC with the aim of improving service organization; a specific section of this review was concerned with SPDC services. Further to this, Davies and Higginson (13) published an updated and extended version of Gysels et al. (12) systematic review focusing only on SPDC. Both reviews presented a number of interesting findings, including highlighting high levels of patient satisfaction with care and the value of psychological and social support, particularly in relation to the social contact SPDC provides and the opportunity to take part in a range of activities. Gysels et al. (12) conclude that although findings suggest the benefits of SPDC are likely to be in the social, psychological and spiritual domains, these areas are not easily identified, leaving researchers and practitioners unclear as to what aspects of these domains patients most need and desire. To date there is no review that examines the literature regards patients’ perceptions of psychosocial factors. Therefore, this review aims to systematically evaluate literature on patient perceived psychosocial experiences of attendance at SPDC. This information could provide additional insight
into how to structure SPDC services and determine the most appropriate outcomes to measure.

**Method**

*Data sources and search strategies*

Data sources were selected with the aim of being sensitive enough to incorporate the wide range of areas implicated by the term ‘psychosocial’ whilst being specific enough to access journals examining SPDC (specificity refers to the ability to dismiss irrelevant articles and sensitivity is being able to find relevant documents). An electronic search was conducted including the databases: Web of Science, Pubmed, Medline, Allied and Complimentary Medicine, CINAHL, PsychINFO and Cochrane Review Library. References from selected reviews and articles were searched by hand to ensure additional relevant studies were also included.

Search terms were: specialist palliative day care, palliative day care, specialist hospice day care, hospice day care, terminal day care, psychosocial, psycholog*, social and spiritual. Search terms relating to psychosocial aspects were chosen with reference to definitions from the National Council for Hospice and Specialist Palliative Care Services (12) and Lloyd-Williams (10). All terms were applied to ‘topic’, ‘title’ and ‘abstract’.

Searches were carried out in January of 2009.

*Selection criteria*

Five inclusion criteria were applied:

1. Reported in the English language, due to potential loss of meaning through translation process.
2. Published empirical articles subject to peer review (dissertations, conference and review papers excluded); to ensure articles had undergone scrutiny and were considered valid, significant and original.

3. Adults aged 19 and above, diagnosed with a terminal and/or life threatening illness.


5. Utilised quantitative, qualitative or mixed design methodology.¹

Quality assessment

Due to the qualitative characteristics of all included studies a specific qualitative checklist was utilised (14). This checklist was developed through in-depth interviews with commissioners and managers of research within Government Departments; Government-based policy-makers who use qualitative research; funders of research from research councils and foundations; and a group of expert involved in conducting qualitative research. The development also involved review of 29 pre-existing frameworks for reviewing quality in qualitative research.

The framework consists of 18 appraisal questions designed to focus on four methods: in-depth interviews, focus groups, observation and documentary analysis. There is an absence of scores accompanying the framework, therefore a scoring system was devised by the author (Omitted= 0, Poor=1, Good= 2, Excellent= 3) with a maximum total score.

¹ Articles with qualitative, quantitative and mixed methodology were included to allow for the widest scope of evidence concerning psychosocial experiences.
of 54. (For a Summary of Quality Assessment of Qualitative Research see Appendix 2. For a copy of the Revised Version of the Quality Assessment Framework see Appendix 3.)

Data Extraction

Systematic data extraction was performed utilising a data extraction form specifically designed to address the research question (For an example of the Data Extraction Form see Appendix 4).

Data synthesis

Data synthesis by means of a descriptive account was utilised due to the qualitative nature of reviewed studies.

Details of included and excluded studies

Figure 1 illustrates the article selection process. From electronic and hand searching study references, 369 articles were identified. Initial screening of titles and abstracts eliminated 335 articles that were not eligible for review. Reprints of the remaining 34 articles were ordered for further scrutiny. Twenty two articles were rejected on the basis of inclusion criteria 4 and 5 (15-19, 5, 20-22, 3, 23-34). Twelve articles became the focus of the review (35-46).
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Figure 1. Represents the article selection process for this review.

369 articles identified from database search (including repetitions) → 335 excluded based on title and abstract failing to match inclusion criteria

34 Full text obtained → 22 articles excluded in accordance with inclusion criteria 4 and 5.

12 articles eligible for inclusion

Results

Quality Assessment

Quality was assessed using Spencer et al. (14) framework. The maximum score achievable was 54. Scores were drawn from four criteria: omitted (0), Poor (1), Good (2), Excellent (3). Overall the quality of articles ranged from 11 (study 45) to 49 (study 40). Specifically articles scored highest (score of 25) on criteria asking ‘How well does the evaluation address its original aims and purpose’ reflecting the clarity of purpose within each study. Articles scored lowest (score of 11) on criteria 5 ‘How clear is the basis of evaluative appraisal?’ which concerned discussion of how evaluative judgements of the paper had been reached and whether any formalised appraisal criteria were used. All studies were assessed to meet ten of the criteria (1, 2, 4, 6, 9, 11,12,13,14 and 15) with scores ranging from 0.5-3. Criteria 15 (‘How clear and coherent is the reporting?) was the highest scoring criteria (24.5) without any omission scores. Five studies (34, 36-37, 41, 45) received omission scores on criteria 18 (‘How adequately has
the research process been documented?’) making this criteria the most frequently omitted.

(For a Table of Itemised Quality Assessment Scores see Appendix 5)

Findings of the review

The review included 12 articles (For a Table of Descriptive Data see Appendix 6). Research was reviewed according to study purpose and content: Eight main themes emerged from reviewing psychosocial aspects of SPDC.

Purpose of studies

Specific aims of empirical studies varied greatly however six of the articles (35, 37, 39, 42, 43, 45) broadly aimed to investigate patients experiences of attending SPDC. Specific aims were:

- To describe palliative day care from the patient’s perspective (35).
- To explore palliative day care patients' experiences in a Western Australian context; in particular, to explore their needs from, and understandings of, palliative day care (36).
- To explore the experiences of patients, informal carers, day unit managers and volunteer staff involved in UK palliative care day services (PCDS) and identify the important outcomes of the service (39).
- To find out what was important to people about their day care experience (42).
- To build on previous research particularly patients use of everyday phrases such as ‘getting out’ ‘like day care’; understand significance of day care and perceptions of what is offered (43).
• To enhance understanding of day care through an in-depth qualitative case study (45).

The remaining 6 studies varied more broadly in their aims. Study 36 aimed to ‘report the findings of a survey of day care patients, which was undertaken for quality enhancement purposes’. Study 44 aimed to ‘assess the cultural specific palliative care needs of ethnic minority patients’ and study 38 was concerned with examining ‘processes surrounding talk about cancer, illness and death amongst patients in a palliative day care unit’.

Three studies were concerned with specific activities/complimentary therapies and the experiences of patients. Study 40 aimed to ‘gain insight into the creative experience of people with advanced terminal illnesses’ (p. 420) whilst Study 41 aimed to ‘evaluate the effects of shiatsu therapy on clients attending hospice day services’ (p. 234). Lastly study 46 stated their aim as being to explore ‘art as a vital activity, as opposed to a pastime’ (p. 86).

Day care service characteristics

Studies were carried out in a variety of SPDC settings; ‘conventional’ hospice in Northern Ireland (36); palliative day care centre in Perth (37); day unit in large purpose built wing of hospice (38); ‘Creative Living Centre’ at St Christopher’s Hospice in London (43); day care unit in a hospice of a university hospital (44); specialist day care unit attached to an inpatient unit in Nottinghamshire (45), and Liverpool Marie Curie Centre Day Unit (46). Four studies outlined the facilities offered, specifying medical and nursing assessment of all patients, social, recreational and therapeutic activities, specialist art therapists and aromatherapists (35); bathing, general clinical procedures like dressing changes and drug administration, art and craft activities, social outings,
aromatherapy, massage, reflexology and beauty treatments (38); visiting professional artists, an art therapist and a writer who facilitated pottery, painting, craft, textiles, art therapy and creative writing groups, (40); creative and social opportunities, individual and group emotional support, complementary therapies and hairdressing (this paper also specifically stated that nursing and medical input was kept to a minimum with patients seen at home for ongoing symptom control (43))

*Participant demographics*

All studies specified age of participants with the exception of studies 44 and 46. Participants’ ages ranged from 23 to 89 years with one study reporting two participants aged between 90-95 years (40). Participants were both male and female. Seven studies (35-38, 40-42) reported participants diagnosis including a range of terminal and life-threatening diseases; Cancer (Lung, Gastrointestinal, Stomach, Bladder/Bowel, Ovarian, Renal, Breast, Oesophageal, Brain, Pancreatic, Colon, Prostate, Head and Neck) HIV, AIDS, Severe Cardiac Insufficiency, Heart Disease, Lymphoma, Multiple Sclerosis and Motor Neurone Disease. Six out of the twelve studies (35, 37, 39-40, 43-44) explicitly stated the ethnic background of participants, which included Anglo-Celtic, White British, Indian, Black African, African Caribbean, Asian, Jamaican and Ukraine.

*Methodology*

Despite the scope of this review specifying inclusion of quantitative methodology all included studies utilised qualitative or mixed methodology. Seven utilised patient interviews; three of these were semi-structured interviews (length between fifteen minutes and two hours (37, 40, 44) carried out with eight, ten and four participants respectively). One study reported using open ended questions in twelve participant
interviews lasting 30 to 90 minutes (42). Two studies that utilised interview methodology were longitudinal in nature. Study 35 used three semi-structured interviews with 102 participants at baseline (within 2 or 3 visits to day care); 59 participants after 6–8 weeks of attendance at day care, and 40 participants after 12–15 weeks (35). Study 41 used unstructured interviews over a 26 week period of shiatsu treatment. Eleven participants were interviewed five times: 2 weeks before their sessions began, on three occasions during the therapy and 1 month after treatment had ceased (41). The last study to utilise interview methodology did so in conjunction with observation and document analysis (45). Seven interviews with patients were carried out ranging in duration from 10 – 25 minutes. Observations were participatory (five full days observing day care, taking part in day care activities and attending meetings) and non participatory (observing 20 patients for 1 hour and recording at 4 minute intervals patient activity or involvement with staff). Documents analysed included information leaflets, the patient resource file, minutes of all staff meetings and seven patient case notes.

One study solely utilised participant observation methodology over a seven week period detailing events and conversations. Observation episodes ranged from 2 and a 1/4 hours to 5 and a 1/2 hours per day observing fourteen participants (38).

Two studies employed group methodology (39, 43). Study 39 carried out focus groups within four SPDC settings. The day care centres were purposively recruited to represent a wide range of services and varying in the amount of input provided by medical, nursing, social work and allied health professionals and the structure of service delivery i.e. traditional model or a more appointment-based system (these structures were not further explained). Eighteen patients participated in the study with focus group numbers ranging from 3 to 6 (39). Study 43 used a technique of group observation termed ‘gold
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“fish bowl observation”. The aim of these groups was to provide future medical students with an understanding of patients’ experiences. The structure of the groups involved patients and one facilitating staff member sitting in a circle facing each other, and then another outer circle facing inwards which included medical students and their tutors. Thirty four patients participated in six ‘gold fish bowl’ groups which involved an initial discussion (30 minutes) followed by students being invited to ask questions (43).

The final two studies utilised questionnaire methodology (36, 46). Study 36 created a questionnaire based on previous satisfaction questionnaires and input from staff. The questionnaire was designed to examine patients’ perceptions of referral, benefits from attending SPDC, satisfaction with the services offered, awareness of the multi-professional team and suggested areas for improvement. The questionnaire consisted of 26 items including ‘several’ open-ended questions to encourage conversations about patients experiences and was administered by a trained lay volunteer with no experience of working in an adult day hospice; 26 patients completed the questionnaire. Study 46 used semi-structured questionnaires to evaluate how much time patients were prepared to spend making sculptures and their opinions of sculpting. The study reported that 63% (of 42 patients) participated in the sculpture group however it was unclear how many patients participated in the research study.

**Insight into illness**

Two studies provided insight into patients’ experiences of their illness (37, 43). Both studies included descriptions of loss of abilities, including the ability to carry out everyday routines which patients found frustrating and detrimental to their sense of self (37, 43). Patients in both studies described fatigue, which was sometimes overwhelming, as a common problem. Patients’ physical movements were restricted and they reported often being subject to imposed treatments and routines that impacted
on their freedom (37). Patients also described changes in relationships with family and friends, which impacted their lives in numerous ways. Firstly, due to limited physical freedom patients reported seeing friends and family less and therefore missed out on opportunities for social support (37). Secondly, when patients did see family or friends they had negative experiences of feeling dependent and a sense of being a burden; this was particularly concerning if dependency was perceived by patients to put pressure on others health (37). Thirdly, patients in one study reported the concept of time to be a particular problem. They described finding it difficult to think about the future, the idea of their ‘time left’ and the fact that their lives were no longer ‘temporally aligned’ with their family and friends (37). Fourthly, patients described changes in communication with family and friends. Patients did not talk about their illness for several reasons including it being too painful for them or it being perceived as too upsetting for the other person to hear. When patients did talk about their illness they sometimes found little empathy and understanding in responses. Finally, some patients described feeling disempowered by being seen as ill in that their wishes were sometimes ignored and personal decisions made for them (37). One patient described how all of a sudden he ‘could not do a thing’ (p294) and that he had no emotional support (43). Patients were said to be effected emotionally by some of the described changes and losses, with reactions including difficulty getting up in the morning, not wanting to go on and one women described letting herself go (‘ I didn’t care if there was someone at the door, my hair was scruffy and I was really scruffy’, p 294, 43).

*Psychosocial aspects of attending specialist palliative day care*

1. Patients perspective of SPDC Environment
‘The place’ and to a lesser extent, “the food”, was consistently identified by patients as the most important thing about day care (35). In study 36 50% of patients rated ‘lunch time’ as one of the three most valued aspects of attending SPDC, though which particular aspects were not specified. In study 36 50% of patients also rated ‘access to staff’ within the top three most valued aspects. Patients went on to say that one of the benefits of SPDC was the ‘safe’ environment in that medical staff were available should anything go wrong (37). ‘Access to staff’ was a benefit of attending SPDC noted in study 40. Patients appreciated that there was a team of professionals available to monitor patients and pre-empt any problems; accessing staff also didn’t seem like too much of an imposition and easier than making an appointment with their GP. For some patients the availability of extra professionals at SPDC was their main reason for attending (40).

2. Change of scenery

Study 37 reported that attendance helped patients escape from reminders that their lives were ‘temporally bound’ and gave them a sense of hope for the future (37). This idea was also described in study 42; going to the hospice allowed relief from ‘tedium and/or difficulties’ within the home and reminders of tasks that patients were no longer able to perform. Patients felt able to escape the ‘sick role’, having a diversion from their thoughts and circumstances and reported increased feelings of self worth (42).

3. Person-Centred Care

The ‘person-centred’ nature of care provided was a recurrent theme within many of the papers reviewed. Person-centred care refers to a holistic approach to patient care that aims to consider all factors present in the individuals life including; illness, relationships, housing, employment and individual preferences. In study 36 61% of
patients valued SPDC because of the ‘welcome on arrival with tea and scones’ (36). Patients in study 42 reported feeling relaxed and comfortable in day care. They were welcomed, accepted, given time and shown consideration and understanding (42). This study also reported different styles of patients coping with their illness: ‘tolerating’ or ‘adapting’. The study reported that these two groups differed with regard to which aspects they found helpful and important within SPDC, for example the ‘tolerating’ group were reported to attend day care ‘to be cheered up and to have their attention diverted away from thoughts of their illness and its consequences (p. 122-123) whereas the ‘adapting’ group were reported to attend day care to ‘share their stories with others who they perceived as like themselves, to learn new skills and to talk about their illness and its effects on their lives’ (p. 123). Study 44 reported that four ethnic minority patients had very positive perceptions of the care received at SPDC (44). Finally studies 42 and 45 suggest value is placed on the patient-centred approach patients appreciating joint decision-making regarding their care (45) and having choices such as whether to attend, whether or not to talk about their illness and how to spend their time whilst at SPDC (42). Patients described how choices such as where to sit or what to have to drink were valued as they gave them a sense of control and therefore increased feelings of self worth (42).

4. Social Support

‘Meeting people’ was named as the most important aspect of SPDC by over 40% of patients interviewed in study 35 although specific aspects were not described. Study 39 reported patients valued peer support and used SPDC as a place to share information. They found that family and friends did not always understand their experiences but the support available from other patients helped them to ‘cope with problems and have some control and independence’ (39). Study 36 reported patients’ main benefit from
attending was meeting others in similar situations, with patients stating that strong friendships were forged (36). SPDC provided space where participants ‘were free to live in terms of representations of self that they adopt rather than (representations) defined by family and friends in the context of a life threatening illness’ (p. 123) (36). A sense of community within SPDC was enhanced through support, interaction and normalising experiences. Patients also reported hope in assessing how they were doing compared to other patients (37).

5. Isolation

‘Getting out’ was named as an important aspect of attending SPDC with 15% of patients reporting this at first interview and 24% at third interview (35) and appeared particularly important for those who were living alone with few opportunities to socialise (39). Patients reported SPDC as the highlight of their week, reducing feelings of isolation and giving a different outlook. Study 37 reported that all patients experienced a sense of social isolation, however, SPDC allowed them to ‘get out of their houses and feel free’ (37). Some patients felt distanced from the people they knew and described instances when friends had not respected their wishes: “Pat, for example, talked of how his desire not to have visitors while he was in hospital was not respected by a friend” (page 122, 37). They perceived other patients and staff understood their experiences and to have had similar experiences (37). Patients in study 36 reported that attending SPDC helped reduce feelings of isolation and study 43 reported the company of others as giving emotional support (43).

6. Communication

The opportunity to talk to others was frequently reported (36, 38-39, 42-43, 45-46). A ‘quiet time to chat’ was rated one of the most valued aspects of attending SPDC by 58% of patients. Patients found group discussions within day care beneficial although they
were sometimes emotionally charged (36). Patients valued having someone to talk to who showed genuine concern and interest (42), feeling particularly valued when listened to by someone who understood their experience of illness (42). Patients reported being able to speak openly and freely to each other (39) and to staff (43) about their feelings (36), personal issues (36) and how their illness affected their lives; something many patients felt unable to do at home as they were mindful of protecting their families (39). Study 38 reported that patients talked about a number of intimate aspects of their lives in SPDC, including symptoms, treatment, bereavement and personal mortality although often in a ‘light-hearted’ way. Explicit and implicit humour surrounding these intimate topics was used, with patients using expression, gesture and timing to keep the tone jovial. Finally, although patients appeared to value talking about their illness they were also reported enjoying having the opportunity to be themselves (43). They reported enjoyment in chatting about something not to do with health or SPDC, as this made them feel “normal” and accepted, as well as entertained (42).

7. Activities

The theme of ‘activities’ was frequently mentioned in the majority of studies (35-36, 39-43, 45-46). It was unclear as to what kind of activities were being undertaken i.e. art, crafts, relaxation, massage. Therefore for the purpose of this review the generic term of ‘activities’ will be used. Patients mentioned the importance of partaking in activities on both their social and psychological well being.

Activities were consistently rated as important by approximately 10% of participants in study 35 (35). Activities were also rated as one of the top three valued aspects of SPDC by 54% of participants with respondents stating they preferred craft activities versus “keep fit” or social outings (36).
Access to ‘complementary therapies (a definition or explanation outlining the term ‘complementary therapies’ was not provided in the paper) and other activities’ increased patients feelings of wellbeing and confidence, as well as promoting a positive attitude (39). Patients in one study reported that complimentary therapies helped them feel relaxed and less anxious (43). Patients reported therapeutic value in what were termed ‘diversional activities’ as they facilitated interaction with other patients leading to increased self-esteem and a sense of achievement (39). Patients described initially feeling anxious at participating in an activity but then they had felt surprised and proud at their unexpected achievements. Patients had used words such as ‘fantastic’, ‘wonderful’, ‘beautiful’ and ‘absolutely ideal’ to describe their experiences (43). Study 36 reported that patients felt enabled to find new activities, skills and entertainment regardless of limitations. Again patients valued the opportunity to discuss their feelings (36), experiences and concerns which they viewed as helping other patients and enhancing their own feelings of self worth (42). Even if they did not actively join in the activity they still enjoyed listening to others’ stories and comments (36) and found that creative groups were a means for making friendships, re-finding social outlets that had been lost and developing a sense of belonging (43).

Making items that could be sold to raise money for the SPDC service and making gifts for friends and relatives (42) gave patients ‘enormous pleasure’ and pride and patients described believing it was important to be ‘giving rather than taking’ (42).

Three studies looked specifically at effects of activities; ‘creative arts group’ (40), sculpting (46) and shiatsu (41). The studies have been divided into those looking at activities that are ‘done with’ patients (40,46) and activities ‘done to’ patients (41) due to potential difference in reported psychosocial experiences.

7.1 Activity done with patients
Studies 40 and 46 reported similar themes. Patients described pleasure, enjoyment, excitement and enthusiasm about their work. They felt surprise at the quality of their work and achievement about new skills and the finished product. There was emotional investment and physical involvement with the materials (46) and a sense of purpose (40). There was some anxiety about whether the work would be ‘good enough’ but patients described the sculpture project as a ‘challenge’ that they valued particularly as they didn’t know what the outcome would be (40). Both studies reported themes around the ‘permanence’ of the work remaining after they had died (46). Linked to this idea was the theme of ‘communication of identity’ where patients felt the sculptures could ‘represent’ them and ‘carry their identity’ (46). Study 40 reported themes around competition, mutual support and sharing skills with other patients. Finally both studies included themes around a sense of significance, describing “hope” (40), or “going beyond” (46); attempting to capture language such as ‘out of this world’ and ‘taken to our limits’ used to describe making the sculptures.

7.2 Activity done to patients

Study 41 describes the activity of Shiatsu which is a Japanese body complimentary therapy. This activity was more physical in nature, however patients described psychosocial effects of increased confidence, self-esteem, morale and positivity. Patients reported that Shiatsu improved their physical capability helping them regain some capacity for movement and control over their health in turn giving hope that they were not ‘just a victim of the disease’ (p. 237) and increasing mental clarity, concentration and decision making (41).

8. Negative psychosocial aspects of attending SPDC
Studies that asked explicitly about negative aspects of patients experiences did receive 
negative comments (35-36, 40, 43), however there were few critical comments. Patients 
reported wanting to attend more than once a week (43) and suggested that SPDC should 
be available ‘all day or should last until early evening’ (p. 466, 36). Twelve patients 
said that there were too few people attending SPDC and that they would like to see 
younger people allowed to access the service (it is unclear as to the specific ages of the 
patients who made the latter comment however participant ages ranged from 42-87 
years, 36). In one SPDC setting patients commented that they disliked a review process, 
as it was undertaken without them; they felt people were talking about them behind 
their backs (36). Patients in study 43 reported that a negative aspect of attending SPDC 
was the sadness they felt when someone they had become friends with died (43). Finally 
Diver et al (44) had a patient report that staff had not asked them about their culture and 
that this might signify a lack of cultural assessment within SPDC.

In relation to activities, patients in study 40 reported an anticlimax when the project 
ended. They therefore suggested that future exhibitions should last longer, be bigger, 
more permanent and that there should be more artwork for patients in wards (40). In 
study 36 27% of patients reported that they would like more craft orientated activities 
but one patient felt that the activities were for children and not adults (36).
Discussion

Results show that attending SPDC provides clear patient-perceived positive psychosocial experiences. These are summarised below and related to psychological and social theories.

*Change of Scenery and Person-Centred Care*

Physical removal from reminders of limitations appears to mentally free up patients from the psychological impact of their disease. Talcott Parsons (47) proposed the theory of ‘the sick role’ in which patients label themselves as sick and subsequently enact this role. Relief from previous responsibilities and an expectation of compliance with strict medical advice can cause distress. People are said to need responsibility and control to make their lives meaningful and satisfying (48). Within the review, patients valued being given choices and making decisions that reinstated a sense of control lost in many other areas of life. Perceived control (the belief that we can influence our environment therefore influencing our positive or negative experience of it) is associated with good physical and mental health (49). Ryan and Deci (50) proposed that “self determination” is needed to achieve personal growth, integrity and well being. Self-determination is when actions are carried out because they have intrinsic interest or value to the individual as opposed to controlled actions which are carried out because of payment or pressures outside the self. When a person’s control or free will is threatened, for example by disease, a response called ‘reactance’ can occur (51). ‘Reactance’ is an attempt to regain free will by, for example, not allowing others to tell one what to do or by increasing freedom such as providing choice. One example of this from reviewed studies is having choices such as where to sit or what to have to drink which patients reported gave them some control and therefore increased feelings of self worth (42).
Reduction in isolation

A strong theme was that attending SPDC reduced isolation on both physical and psychosocial levels. Patients valued feeling free, having a different outlook on life and feeling less isolated. One hypothesis is that patients within SPDC experience ‘social interdependence’; relying on other members of a group for feelings of connectedness, social and emotional reward and positive identity (52). ‘Self completion theory’ may also explain reduction in feelings of isolation (53) that is, when a valued aspect of their identity is threatened, people become motivated to seek social recognition of that aspect thus restoring a sense of self. It could be argued that illness, loss of function and disability threaten sense of self. Isolation resulting from physical decline provides a further threat, thus, social recognition via SPDC attendance has greater significance. In conjunction with this, Deci and Ryan (54) proposed a need for ‘relatedness’ within their theory of self-determination, that is, self-determination does not mean independence from others, rather, that people have an intrinsic need for genuine connection to others unbound by pressure or demand, therefore being self-determined but also intimate. This is reminiscent of Carl Roger’s theory of ‘unconditional positive regard’ whereby people gain self-esteem when accepted by others as having merit regardless of their behaviour (55). Patients from reviewed studies valued the acceptance, welcome and time given by staff and peers at SPDC. Finally, patients might experience a reduction in isolation and illness induced identity conflict by belonging to an ‘in group’. Patients from reviewed studies reported a sense of ‘community’ and ‘belonging’ which might have come from being part of a ‘SPDC group’.
Social support

Social support was mentioned frequently within the review in relation to peer support, sharing information, meeting people in similar circumstances and social comparison. McAdams (56) reported that people have a need for intimacy that is considered warm, close and communicative. House (57) described four kinds of social support: ‘emotional concern’; ‘instrumental aid’ (e.g. access to staff); ‘information’ and ‘appraisal’ (e.g. feedback from others regarding progress and how to make sense of what has happened). This was evident in one study (37) where patients used downward comparisons (comparing self with others less fortunate) to assess how they were doing compared to other patients. ‘Appraisal’ was also evident in patients reporting value in meeting others in similar situations and being listened to by someone who understood their experience of illness (58).

Communication

McAdams’ (56) definition of intimacy states a need for communicative interaction with others. Within the review communication was noted as important. Fiore, 1980, added a fifth form of social support to House’s existing four (57), i.e. ‘socialising’, citing beneficial effects derived from socialising itself, even simple conversation or recreation (59). This concurs with reports that SPDC patients liked chatting about non-health topics as this made them feel ‘normal’, accepted and simply entertained. The hypothesis that SPDC facilitates communication is further supported by Rogers theory; that when parts of the self become incongruent with our previous sense of self people may experience anxiety and need to accept their feelings and actions (55). This can be aided through the opportunity to communicate personal feelings in a non-judgemental and open environment; SPDC may provide this opportunity.
An additional conceptualisation could be related to Langley-Evans and Paynes’ finding that patients communicated about intimate aspects of their lives using humour (38). Humour has been reported to help people cope with stress (60). Therefore through use of light hearted jokes patients may be using humour as a mediator of stress. Another hypothesis is that of ‘equity theory’ which states that people are happiest with relationships in which the rewards and costs received and given are roughly equal (61). This may explain why patients reported feeling more able to speak freely with other patients than with their families, experiencing themselves as more equal to other SPDC patients and staff but as more ‘costly’ in their interaction with family and friends.

**Activities**

The psychosocial impact of ‘activities’ within SPDC are wide reaching. Activities appear to encapsulate all of the factors discussed previously including giving patients an opportunity to make friends, find mutual support, gain a sense of control over disease and a sense of belonging. Patients reported a sense of pride in being able to achieve a task regardless of the limitations of their illness and increased self-esteem and feelings of worth. A number of theories may be relevant to these findings. Self-esteem and worth are intrinsically linked; self-esteem referring to an individual’s positive or negative evaluation of themselves (52) thus contributing to their perception of self worth. When self-esteem is threatened by an event that is perceived as negative, people can try to minimise its impact on their sense of self (62). Patients in this review stated that they initially felt anxious about participating in an activity and whether their work would be good enough, suggesting a negative self-evaluation. However when carrying out the activities they described feeling surprise and pride at their unexpected achievements suggesting activities had a positive impact on individuals’ evaluation of themselves.
Another strategy employed when self-esteem is threatened is to minimise the negativity of the event (62). Self-affirmation theory suggests that people will reduce the impact of the threat to their self-esteem by affirming their competence on an unrelated dimension (63); humans have a need to achieve and feel competent (64). Therefore, the fact that patients found activities challenging and as requiring physical and emotional investment could be the reason for increased self-esteem and self worth. This hypothesis is also supported in that patients reported making things to raise money for the SPDC service and making gifts for friends and relatives gave them enormous pleasure and pride.

Interestingly two of the studies that looked specifically at art or sculpture within SPDC reported a theme around importance of making something permanent. Pattison (65) highlighted the need for those caring for the dying to help them acknowledge the reality of their impending loss which may be the process patients are experiencing whilst carrying out activities such as sculpture. Patients also reported a sense of significance and hope whilst carrying out activities. Carver and Scheier (66) have found evidence that hope provides important psychological and physical benefits for people facing the difficulties of diagnosis and treatment for cancer.

**Negative Comments**

There were few negative comments regarding attendance at SPDC, and those that existed related mainly to insufficient availability of SPDC services. Patients wanted to attend more often, wanted more people to attend and proposed increasing SPDC availability to all day and into the evening. These comments indicate that patients appear to value SPDC highly and want to increase its use. However, a criticism may that SPDC could foster a culture of dependence. Patients value the safe environment, access to the multi-professional team staff and gain reassurance from attending SPDC.
Anxiety theories (67) raise the concern that reassurance from attending SPDC may only cause short term reduction in anxiety as in the long term patients may not realise their ability to cope with their illness outside of SPDC.

**Self concept**

It can be argued that all psychosocial experiences described so far can be categorised under the umbrella term of ‘self concept’ which refers to an individual’s understanding of their personal qualities, developed throughout life using internal and external sources. ‘Self-concept’ can be one source to help an individual understand themselves. Understanding of self concept can also come from external sources, particularly reactions of others and social comparisons; patients placing value on peer support, sharing information and meeting people with similar experiences may be using others as a source of self concept.

When self concept is threatened people are said to respond by defending their sense of self. They may do this in two ways; by defending against the threat or by attacking head on (such behaviours are described as ways of coping). Two broad ways of coping have been outlined; emotion focused and problem focused (68). Emotion focused coping is seen as an attempt to regulate the negative impact of a stressor, in this instance, disease. Strategies include distancing, (trying not to think about the problem) or avoidance, (wishing the problem would go away or physically escaping from reminders). Evidence of emotion focused coping in SPDC can be seen in patients reporting valuing the change of scenery, being able to escape reminders of their physical limitations. This type of coping can be adaptive, serving to distract patients from stressors and giving them freedom. The second category of coping is problem focused coping, with efforts to alter or eliminate sources of stress. Research with cancer patients found problem
focused strategies include; fighting spirit (accepting diagnosis but with optimistic challenging) (69), reframing (positive reinterpretation of the illness) (70), information seeking (71), and expression of feelings which have all been shown to lower mood disturbances (72).

Self-esteem is an important mediator of self concept (52). The model of transition shown in Fig 2 suggests that change impacts an individuals’ self-esteem and is key to understanding how they may cope (73).

Figure 2.Hopson and Adams Model of Transition Showing Self-esteem Changes during Transitions

The model outlines stages that people may go through when adjusting to change, however not all people go through every stage at the same time, in the same order. In relation to SPDC patients may be referred during the depression phase when they are perceived as needing support (74) and have potentially been overwhelmed by the unfamiliar and negative expectations of the change (diagnosis of terminal and/or life limiting disease resulting in immobilisation), tried to deny that the change is happening (minimisation) and are now showing feelings in response to facing up to the
implications of the change. This review suggests that whilst attending SPDC people go through the later phases of self-esteem changes, particularly acceptance of reality, testing, searching for meaning and internalisation. These stages relate to the process of letting go of the old state of being, beginning to accept a situation, testing out new ways of coping and reflecting on how and why things are different. Finally people may reach an understanding of their new situation, internalising new meanings and accepting them as part of their new self. Evidence for this process occurring in SPDC can be drawn from the fact that patients report value in meeting others with similar experiences, seek social support, value the chance to talk about their feelings, experiences and concerns, enjoy the freedom of being able to be themselves and report increases in self-esteem and self worth.

Appraisal of the review

This review has several limitations. Most notable is the difficult nature of defining the term ‘psychosocial’, narrowing it down to three concepts (psychological, social and spiritual) may have lead to omission of key or useful papers. Further to this, there is a noteworthy lack of papers directly referring to spiritual issues. This may suggest a lack of research into this aspect, a need for the use of different terms such as ‘religion’ or ‘faith’, or it may reflect researcher bias in the review process. Interestingly all authors included in the review embarked on their own interpretative process whilst reporting findings. This can be seen as a strength in that this review has incorporated a multi professional approach but may also suggest the need and usefulness of more than one reviewer for future reviews. Also of note is that all reviewed papers utilised qualitative methodology and lack of quantitative research within this field is apparent. Although useful in providing depth and detail, qualitative papers do not provide generalisable results which may limit the scope for drawing wider inferences. However, homogeneity
in reports within the review suggests potential for generalisability of findings. Finally, inclusion of one article undertaken in Western Australia could have implications for cultural differences in reported psychosocial experiences; however it was beyond the scope of the current review to consider this.

Conclusion

This review aimed to systematically evaluate literature on patient perceived psychosocial experiences of attendance at SPDC. It has shown that patients attending SPDC value a person-centred approach which reduces isolation, increases social support, encourages communication and provides activities. These factors appear to influence an individual’s sense of control, support, purpose, achievement, coping, hope and self-esteem which are all part of an individual's self concept. Therefore patients attending SPDC place particular importance and value on the factors that contribute to construction and/or maintenance of their self concept. The nature of the meanings underlying interventions and factors most valued by patients is in need of further exploration. Future research could explore why patients value the psychosocial experiences reported in this review? For example, does it help them better cope with terminal illness; and how these experiences can be defined in a way that would be meaningful to clinical commissioners. Enhanced understanding of the underlying experiences of attending SPDC could also have implications in relation to referral into SPDC, which is also currently an under researched area. Once this has been done, clinicians can start to more effectively measure clinical effectiveness and devise justifiable interventions to help this patient group.
References


Coping with Terminal Illness: The Experience of Attending Specialist Palliative Day Care

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Abstract

Objective

The importance of services helping patients cope with terminal illness has been emphasised throughout Department of Health (2000) and NICE (2004) cancer guidance. However the question of whether services are achieving this aim has been sparsely researched to date; particularly in relation to Specialist Palliative Day Care (SPDC) services. The current study aims to begin to address this problem.

Design and Method

Utilising exploratory methodology (Interpretative Phenomenological Analysis – IPA) to allow for an in depth investigation of patients’ views of attending SPDC, eleven semi-structured interviews were carried out and analysed.

Results

Emerging themes suggest that SPDC provides an environment in which patients are helped to cope by facilitating acceptance of the reality of death, thereby freeing them to have ‘life’ as their focus.

Conclusions

The study does not claim to provide the definitive answer to what processes may underpin attendance at SPDC, however in such an under researched area it provides a much needed exploration which can be built upon or challenged by future research.
Introduction

When a person is deemed to be suffering with terminal illness, a whole host of challenges, physical, psychological and social, need to be managed. This has been acknowledged by health services and recent government guidance for cancer patients. Specifically, Department of Health (D.O.H) guidelines highlight the importance of palliative services providing supportive care to ensure that ‘... patients with cancer, with their families and carers, receive support and care to help them cope with cancer and it’s treatments at all stages (pg.8, National Institute for Clinical Excellence (NICE), 2004).’ This guidance places a strong emphasis on helping patients cope with the various stressors associated with having a terminal illness. One aspect of palliative services is Specialist Palliative Day Care (SPDC). SPDC is defined as “... a service, which enhances the independence and quality of life of patients through rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms and provision of psychosocial support” (National Council for Hospice and Specialist Palliative Care Services, Commissioning through partnership, 2000). SPDC has been shown to provide psychosocial and disease specific interventions that are beneficial to patients (Kernohan, Hasson, Hutchinson & Cochrane, 2006; Kennett & Payne, 2005). However, as highlighted in a recent review, there is currently a paucity of research exploring the reasons why particular interventions are beneficial (Bradley, Frizelle & Johnson, in submission). Further to this, it is unclear as to whether positive effects are due to enhanced coping or whether there are other mechanisms at play? Therefore the current study aimed to start the process of elucidating potential mechanisms, whereby SPDC provides benefit, through examination of patients’ experiences of SPDC and coping.
‘Coping’ is a term widely used in everyday language, however it is also a notoriously hard concept to define and arguably the most widely studied topic in contemporary psychology (Hobfoll, Schwrzera and Chon, 1998). (For a summary of the Concept of Coping see Appendix 8). One attempt to define the concept of coping comes from Lazarus and Folkman (1984) and is credited as the underpinning of recent developments in coping research (Livenh, 2000). Lazarus and Folkaman proposed the ‘Transactional Model of Stress and Coping’ (1984). The model begins with an individual appraising a situation as taxing or exceeding his or her resources (Folkman, Lazarus, Gruend, Delongis, 1986), it then suggests that in an effort to overcome this incongruence between environmental demands and individual resources coping occurs. Coping is said to be “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of that person” (Lazarus, 1990). It is argued that coping has two major functions: dealing with the problem that is causing distress (problem-focused coping) and regulating emotion (emotion-focused coping). The processes of appraisal and coping are said to be ‘transactional’ in that they are dynamic, bidirectional and mutually reciprocal. The model is outlined in Figure 1.

![Figure 1. The Transactional Model of Stress and Coping (Folkman and Lazarus, 1984).](image)
Previous research outlines the efforts to cope, more commonly known as coping strategies, employed by terminally ill patients. These include fighting (accepting diagnosis and optimistically challenging the illness, Greer, 1991), reframing (positive reinterpretation of the illness, Backman & Austing, 1993), information seeking (Lavery & Clarke, 1996), seeking social support (Stanton & Snider, 1993) and expression of feelings which has been shown to lower mood disturbances (Classen, Koopman, Angell & Speigal, 1996). However, despite these useful findings there is a paucity of research investigating whether services, such as SPDC, enhance an individuals’ ability to use these coping strategies in response to terminal illness.

In the absence of research investigating whether SPDC has an impact on a patients’ ability to cope and if so how, it is impossible to state whether these services are meeting D.O.H recommendations (2004). Therefore, the current study endeavours to begin to address this problem utilising exploratory methodology (Interpretative Phenomenological Analysis – IPA) to allow for an in depth investigation of SPDC patients’ views in relation to attendance at SPDC and the complex concept of coping.
Methodology

Design

The study employed qualitative methodology in which 1:1 semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA). IPA was chosen, as appose to other qualitative methods, due to its usefulness in examining the experiential-relevance of a theory, in this instance coping (for a Summary of IPA Theory see Appendix 9).

Participants

Eligible participants were those attending one of two participating charitably funded hospices in the North of England at time of recruitment. They were known to be directly experiencing a terminal illness (not specifically cancer), aged 18 years or over, able to provide written consent and able to undertake a semi-structured interview. Patients who were unable to speak English or complete a written consent form and/or semi-structured interview without assistance were not recruited (determined by the senior nurse following discussion with the care team).

Twelve participants were interviewed; however one interview was not included due to poor quality of the audio recording. Participants included six men and five women all aged between 63 to 88 years old with an average age of 75.5 years. All patients had a terminal illness with diagnoses including; multiple sclerosis, cancer and leukaemia.
Table 1. Showing interview number, pseudonym, gender and age of each participant

<table>
<thead>
<tr>
<th>Interview Number</th>
<th>Pseudonyms</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Janice</td>
<td>Female</td>
<td>64</td>
</tr>
<tr>
<td>2</td>
<td>Sue</td>
<td>Female</td>
<td>88</td>
</tr>
<tr>
<td>3</td>
<td>Sam</td>
<td>Male</td>
<td>83</td>
</tr>
<tr>
<td>4</td>
<td>Alfred</td>
<td>Male</td>
<td>63</td>
</tr>
<tr>
<td>5</td>
<td>Greg</td>
<td>Male</td>
<td>71</td>
</tr>
<tr>
<td>6</td>
<td>Carol</td>
<td>Female</td>
<td>73</td>
</tr>
<tr>
<td>7</td>
<td>Graham</td>
<td>Male</td>
<td>82</td>
</tr>
<tr>
<td>8</td>
<td>Steve</td>
<td>Male</td>
<td>75</td>
</tr>
<tr>
<td>9</td>
<td>Carl</td>
<td>Male</td>
<td>78</td>
</tr>
<tr>
<td>10</td>
<td>Lucy</td>
<td>Female</td>
<td>65</td>
</tr>
<tr>
<td>11</td>
<td>Sandra</td>
<td>Female</td>
<td>83</td>
</tr>
</tbody>
</table>

Data collection

Research and Development approval was obtained (See Appendix 10). Ethical approval to approach and interview patients was obtained (See Appendix 11). The study inclusion criteria and information leaflets providing details of the study were given to each participating SPDC centre to distribute to potential participants (See Appendix 12). If participants were willing to take part they informed a member of staff, who informed the researcher and the participant was approached at their next SPDC attendance. Written consent was obtained prior to commencing the interview (See Appendix 13). Following the interview all participants were given a debrief sheet to thank them and provide details should they wish to contact the researcher or discuss any aspect of the research process (See Appendix 14). Audio recordings of interviews and written consent forms were stored in keeping with ethical guidelines.
Participant demographic information (name, age and illness diagnosis) was collected prior to commencing 1:1 semi-structured interview. The interview schedule was developed following IPA guidelines (Smith & Osborn, 2003) and was used by the researcher to prompt and guide participants’ discussions (See Appendix 15). All interviews were audio recorded and transcribed verbatim.

Data Analysis

Transcribed interviews were checked for accuracy by comparing them to original recordings. The interview extracts were subjected to a five stage idiographic approach:

- Stage 1- The first transcript was read through fully to familiarise the author with the text.
- Stage 2- The author reread the transcript making notes in the left hand margin concerning anything interesting or significant in context.
- Stage 3- The author read the transcript for a third time noting, in the right hand margin, any emerging theme titles, (these being in the form of key words that captured a concept or quality present within the text).
- Stage 4- Potential theme titles were noted on a separate sheet and connections between them were formed. Potential groupings were noted as sub-ordinate themes accompanied by verbatim examples.
- Stage 5- Phases 1 to 4 were repeated for each transcript and links between transcripts made. Sub-ordinate themes were integrated and reorganised resulting in a master list of super-ordinate and sub-ordinate themes accompanied by a cross section of verbatim examples. The themes were then linked to potentially relevant theory. (Smith, Jarman and Osborn, 1999).
A worked example of the analysis process can be found in Appendix 16.

**Validation**

Despite acknowledgement that no single interpretation of the text would be definitively ‘right’, credibility checks were undertaken.

- A reflective diary was kept throughout the research process to increase insight into the potential influence of the author’s own beliefs and values and to document how the analysis developed.

- Phase two was carried out on a total of six extracts by the second and third author of this paper. Comments were incorporated into the analysis process.

- One full transcript was subject to IPA by two independent qualitative researchers. Interpretations and themes were discussed and compared to the authors’ themes. Feedback was incorporated into data analysis.
Results

Present from results were descriptions of the stressors of having and living with a terminal illness these included; Physical effects of illness and medication, Restrictions and frustration, Lack of control, Feeling like a burden, Other people’s opinions and Loss of identity. Patients appeared to utilise personal resources to cope with these stressors. These efforts to cope included; ‘acceptance’ of the realistic impact of their disease; ‘Best you can’ involving optimistically challenging limitations; ‘Here and now’ where patients chose to live for the moment in the view that that is all they can do; ‘fighting’ the impact of the disease and not letting it take over their lives. In addition to personal coping efforts there were four super-ordinate themes obtained specific to attendance at SPDC. Each of the four themes is presented, accompanied by postulated theory to illustrate potential links with wider research. Although they fit into the ‘Transactional model of stress and coping’ (1984), they also appear to represent broader human existential concerns that may be at the forefront of SPDC patients minds due to their diagnosis of a terminal illness. Therefore coping and existential theory are included in the description. Sub-ordinate themes with descriptive narrative and verbatim examples follow each super-ordinate theme to provide a more in-depth account of participants’ stories.

(For Complete Themed Data See Appendix 17).
Table 2. Summary of Super-ordinate and corresponding Sub-ordinate themes.

<table>
<thead>
<tr>
<th>Super-ordinate Theme</th>
<th>Sub-ordinate Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality of Death</td>
<td>Provision of Medical Care</td>
</tr>
<tr>
<td></td>
<td>Ease of Access</td>
</tr>
<tr>
<td></td>
<td>Experience of Staff</td>
</tr>
<tr>
<td></td>
<td>Professionals to Keep an Eye on Death</td>
</tr>
<tr>
<td>Focus on Life</td>
<td>Initial Views of SPDC</td>
</tr>
<tr>
<td></td>
<td>A Change is as Good as a Break</td>
</tr>
<tr>
<td></td>
<td>Focusing on life through the activities of SPDC</td>
</tr>
<tr>
<td></td>
<td>Focusing on life through the people at SPDC</td>
</tr>
<tr>
<td>Sense of Self</td>
<td>Unconditional Acceptance</td>
</tr>
<tr>
<td></td>
<td>The value of being cared about</td>
</tr>
<tr>
<td></td>
<td>Downward Comparison</td>
</tr>
<tr>
<td></td>
<td>Giving something back</td>
</tr>
<tr>
<td>Belonging</td>
<td>Companionship</td>
</tr>
<tr>
<td></td>
<td>Upward Comparison</td>
</tr>
</tbody>
</table>

Table 3. Description of Super-ordinate and corresponding Sub-ordinate themes.

Super-ordinate theme: Reality of death.

What distinguishes humans from other forms of life is our ability for self-awareness and reflection. This allows humans to learn from the past and plan or hypothesise the future, however this awareness comes with a cost. The very fact that humans have the awareness that they are alive means they also have the awareness that they are going to die (Becker, 1973). Most people live life without contemplating their
own death for any length of time. However in response to extreme negative personal events, such as life-threatening illness, people are more likely to be consciously confronted with the issue of their own mortality (Koole, Greenberg & Pyszczynski, 2006). The following sub-ordinate themes represent attempts patients make to cope with this existential concern by allowing them to acknowledge their own death but also minimise the power of their existential awareness. SPDC, and particularly the professional staff within it, appeared to provide an environment of ‘containment’ for patients, that is, they performed a parenting task of making sense of feelings of anxiety and modelling tolerating these feelings so that they become more bearable to experience (Bion, 1961).

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Provision of medical care.</th>
<th>The provision of medical care was highlighted as a positive aspect of SPDC.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>P- you know, errm they do all the blood tests as well,</td>
</tr>
<tr>
<td></td>
<td>I- right</td>
</tr>
<tr>
<td></td>
<td>P- take the red sauce and that has to be sent off to the doctors</td>
</tr>
<tr>
<td></td>
<td>and to err specialist you know if -there’s anything they’ll let them</td>
</tr>
<tr>
<td></td>
<td>know here</td>
</tr>
<tr>
<td></td>
<td>I- yeah</td>
</tr>
<tr>
<td></td>
<td>P- errm and then err if there’s anything that you know</td>
</tr>
<tr>
<td></td>
<td>anything to do anymore injections or anymore tablets to be taken</td>
</tr>
<tr>
<td></td>
<td>I- yeah</td>
</tr>
<tr>
<td></td>
<td>P- they can deal with that here as well</td>
</tr>
</tbody>
</table>
### Janice

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Ease of access</th>
<th>Having increased access to professionals with knowledge of disease seems particularly important as patients know medical or psychological support is available should they need it.</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>P-</em>... as I say that was a good, one of the good things rather than make an <em>ER</em> appointment to see a doctor, to mention I’m constipated and then going through the full…you know, it skips a sort of visit</td>
<td></td>
</tr>
</tbody>
</table>

### Alfred

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Experience of staff.</th>
<th>Patients drew strength from their perception that staff have dealt with these problems before and know what to do.</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>P-</em> They’ve dealt with this sort of illness</td>
<td></td>
</tr>
<tr>
<td><em>I-</em> Yeah</td>
<td></td>
</tr>
<tr>
<td><em>P-</em> you know a lot a lot of different people, long time</td>
<td></td>
</tr>
<tr>
<td><em>I-</em> yeah</td>
<td></td>
</tr>
<tr>
<td><em>P-</em> whereas its all new to me, you see</td>
<td></td>
</tr>
</tbody>
</table>

### Janice

| Sub-ordinate theme: Professionals to keep an | Through coming to SPDC patients appear to be able to pass the burden of having an awareness of impending death to the professionals caring for them. |
eye on death.  

\[ P- \text{ Well the thing is they check, they do such a good check here, I'm weighed, they keep a note of your weight} \]

\[ I- \text{ Mmm} \]

\[ P- \text{ And your pulse and that’s all kept for you} \]

\[ I- \text{ Yeah} \]

\[ P- \text{ In their books and things like that} \]

\[ \text{Sue} \]

Super-ordinate theme: Focus on life.

In conjunction with an existential fear of death is an existential desire to live (Koole et al, 2006). The super-ordinate theme ‘focus on life’ is an attempt to represent patients’ apparent desire to fight impending death and stay connected to life. Although it may be impossible to escape death completely, SPDC appears to provide an arena where patients are free to shift their focus away from death and embrace the activities and relationships of the living. Further to this, patients may be using SPDC to emotionally process the hazards of finding meaning to their lives whilst facing a terminal illness. Research has suggested that making meaning can play an important role in the coping process (Park & Folkman, 1997). Research has also suggested that finding meaning following a traumatic event can lead to personal growth and an enhanced appreciation of life (Janoff-Bulman & Yopyk 2004 as cited in Jones, 2008).

Sub-

| Patients repeatedly described an initial reluctance to attend SPDC due to the perception that it would be full of reminders of disease and |
theme: death. What they found was that SPDC was far more about living life
and finding enjoyment from the time they had left.

P- *One of the things I thought about when I was first coming here
was I didn’t want to come because I thought ohh it was going to be all
old people*

I- *Mmm*

P- *not feeling very good, moaning about their illnesses. It is
totally different.*

Greg

Subordinate theme: A change is as good as a break.

Patients report that SPDC takes them away from their home routine
and potential reminders of being ill. SPDC appears to allow patients to
have a change of scenery, but more than this, it appears to give them
something to look forward to and adds purpose to their week.

I- *and would you be able to pinpoint what that was that was
giving you the uplift?*

P- *Er, well it’s a complete change isn’t it?*

I- *Ah*

P- *I think it’s the complete change from everyday things isn’t it?*

Steve

Subordinate theme: Patients described how activities such as pottery, flower arranging and
creative writing enabled them to think about something other than
**theme:** Focusing on life through the activities at SPDC.

- *I* - Oh and what is it about doing things like that that helps
- *P* - It’s crafts, it’s simply because you are concentrating, instead of thinking about yourself
- *I* - Right
- *P* - You’re concentrating on what you are doing

**Sub-ordinate theme:** Focusing on life through the people at SPDC.

- *P* - ...its nice to be able T’ talk erm what they’ve done over the frontier of last week to this week
- *I* - Yeah
- *P* - You know, what they’ve been doing in life,
- *I* - Yeah
- *P* - Nice to listen to

---

Super-ordinate theme: Sense of Self.

When faced with a traumatic event, such as a terminal illness, research has shown...
that a person’s sense of identity can be threatened (Koole et al, 2006; evident in this study within the sub-ordinate theme of ‘loss of previous identity’). Rogers (1961, as cited in Bernstein et al, 2003) described an innate human drive towards growth and fulfilment of sense of self (coined ‘self-actualisation’) which can be slowed or blocked when the self becomes distorted. A sense of self is developed through unconditional positive regard, empathy and genuineness (1951).

Central to a persons’ sense of self is their self-esteem - the evaluation of one’s own self worth (Bernstein, Penner, Clarke-Stewart & Roy, 2003). In a recent review, the psychosocial experiences of attending SPDC were found to have a large effect on patients’ self-concept and in particular their self-esteem (Bradley et al, in submission); this was also apparent in this study. Specifically making ‘downward comparisons’ - ‘comparing ourselves to people who are worse than we are on a particular trait or ability’ (Aronson, Wilson & Akert, 2004) - have been shown to enhance self-esteem (Taylor, 1983).

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Unconditional acceptance.</th>
<th>Patients’ described how their decisions and behaviour were unconditionally accepted by staff and volunteers and patients appeared to value the freedom of not being judged or expected to comply with social etiquette.</th>
</tr>
</thead>
<tbody>
<tr>
<td>P- You, they never seem to get vexed with you not matter how long it takes you to do things.</td>
<td></td>
</tr>
<tr>
<td>I- Right so they just then allow you to take as long as</td>
<td></td>
</tr>
<tr>
<td>P- Oh yes. She says ‘you’re here to do what you want</td>
<td></td>
</tr>
</tbody>
</table>
### Specialist Palliative Day Care: Patients’ Perspectives

<table>
<thead>
<tr>
<th>I-</th>
<th>Ohh</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-</td>
<td>and if you don’t want to do it don’t bother’.</td>
</tr>
</tbody>
</table>

*Sandra*

<table>
<thead>
<tr>
<th>Sub-ordinate theme: The value of being cared about.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients repeatedly praised staff for being so helpful and good at looking after them. This may be linked to patients feeling like a burden to friends and family, but also a validation of themselves as being worthwhile through having people other than family and friends taking the time to care.</td>
</tr>
</tbody>
</table>

*P-*  
*I-*  
*P-*  
*I-*  

*Sam*

Such nurturing attitudes and behaviour seemed to provide patients with a sense of mental and physical strength, which stayed with them in their week outside SPDC.

*P-*  
*I-*  

*P-*  
*I-*  

*P-*  
*I-*  

*P-*  
*I-*
### Carol

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Downward comparison.</th>
<th>Patients frequently made reference to the positive effect of seeing other patients who were viewed as ‘worse’ than themselves.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>P-</em> Yeah, I mean it’s never easy is it to cope with an illness ermm but I think because of coming here you do see other people who are much worse than yourself and that helps you.*</td>
</tr>
<tr>
<td></td>
<td><em>I-</em> Mmm</td>
</tr>
<tr>
<td></td>
<td><em>P-</em> That helps them to realise you know oh my ‘what have I got to worry about? You know*</td>
</tr>
<tr>
<td></td>
<td><em>I-</em> Hmm</td>
</tr>
<tr>
<td></td>
<td><em>P-</em> I’m not half as badly off as they are’. Thank you God sort of thing.*</td>
</tr>
</tbody>
</table>

### Lucy

<table>
<thead>
<tr>
<th>Sub-ordinate theme: Giving something back.</th>
<th>This sub-ordinate theme appears to have two elements. Firstly patients seemed to be so appreciative of what SPDC provided them with that they wanted to show this by appreciation contributing money, time or effort from themselves. Secondly, on a deeper level, statements and behaviour such as the one outlined below may serve to maintain patients’ sense of usefulness which in itself may boost self-esteem.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>P-</em> ...Just cos And I must admit, if I get well enough and I can...*</td>
</tr>
</tbody>
</table>
cope with it, I’m going to volunteer for here so I can put something back.

Graham

Super-ordinate theme: Belonging

‘Existential isolation’ is a term used to portray the fundamental separateness of humans and their experience (Jones, 2008). Although other people may appear to be going through the same experience their perception may be different; due to the fact that we can never truly see things through another’s eyes (literally and metaphorically) there is a fundamental divide between people. Literature states that we are not necessarily conscious of this isolation (Pinel, Long, Landau, Alexander & Pyszczynski, 2006) and that the effort to belong and be socially connected is pervasive and strong (Baumeister & Leary, 1995). However in light of stressors such as ‘feeling like a burden’ and ‘opinions of others’, patients’ sense of themselves as isolated may also be important. To counteract this isolation patients appear to use other patients to provide them with a sense of ‘connectedness’ and shared experience; this may be an example of a phenomenon called ‘I-Sharing’. I-Sharing is the process of forming strong bonds with people due to a shared subjective experience as opposed to a shared objective experience; for example two people may feel a strong connection to each other after a travelling experience together however they may not know each others basic facts e.g. surname. This process can occur, or increase, in direct reaction to trauma in an attempt to address feelings of existential isolation (Tyler, 2001).

Sub-ordinate

Patients reported a sense of camaraderie that was quickly formed
<table>
<thead>
<tr>
<th>Theme:</th>
<th>...and appeared to have positive effects.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Companionship</td>
<td><strong>P</strong>- and the, the er, other er, fraternal side to it you know where you meet people who are pleased to see you.</td>
</tr>
<tr>
<td><strong>I</strong>- yeah</td>
<td><strong>P</strong>- friends in other words.</td>
</tr>
<tr>
<td><strong>Carl</strong></td>
<td></td>
</tr>
<tr>
<td>Sub-ordinate theme:</td>
<td>Comparing themselves with other terminally ill people seemed to provide patients with strength and hope; that if someone else can cope with the situation they will be able to as well.</td>
</tr>
<tr>
<td>Upward comparison</td>
<td><strong>P</strong>- And they're all doing in much the same sort of way or the net result is in the same way. I can't tell what's going on their minds but I mean the net result seems to be the same way which is good which makes you feel more ok, maybe I'm doing something right.</td>
</tr>
<tr>
<td><strong>Greg</strong></td>
<td></td>
</tr>
</tbody>
</table>

Reported Super and Sub-ordinate themes are the researcher’s interpretation of the text and have been organised as such; it is not considered that each is mutually exclusive. Figure 2 is one formulation of how experiences described within themes may be related.
Figure 2. Formulation of Patients' Experiences.

Discussion

Figure 2 represents a conceptualisation of data from this study. It is based upon Lazarus and Folkman's (1984) 'Transactional Model of Stress and Coping' with an emphasis on the bidirectional and mutually reciprocal nature of the model. Patients do appear to go through a process of appraising the impact of the stressor (terminal illness) and their perceived ability to cope with it. However, assessment of patients' appraisals was not the primary focus of this study. Therefore, detail with regards to appraisal is limited. What is clear however is the impact of attendance at SPDC on patients' coping. Patients appear to utilise SPDC in an effort to cope both through the act of attending and experiences whilst attending. However, it is at this point that findings from this research separate, although not exclusively, from primary coping literature. SPDC does appear to directly address stressors described to be associated with having a terminal illness, however the impact of SPDC seems to be wider than this. Parallels can be drawn with clinical therapy, specifically the distinction made between content (what is said in
the room e.g. whilst attending SPDC) and process (the underlying meanings that can be interpreted from the content e.g. the experience(s) of being at SPDC) (Latner, 2000), which is harmonious with the interpretative phenomenological method of analysis.

Throughout analysis the field of existential psychology proposed particular relevance. Specifically patients’ accounts appear to centre around the notion that an awareness of being alive also brings an awareness of inevitable death (Yalom, 1980) and that this awareness may have been bought to consciousness due to the experience of terminal illness. In an effort to cope with the uncomfortable awareness of death patients interchange between focusing on the reality of death and the desire to keep on living. Through this interchange patients may find that an increased awareness of death fosters an increased awareness of life.

In his Mindfulness Based Stress Reduction approach Kabat-Zinn (1990) likens rejection of stress to “sailing straight into the wind”. He goes on to say that “if you only know how to sail with the wind at your back, you will only go where the wind blows you”, however by becoming mindful of ones situation and inner resources one can “Orient ourselves in such a way that we can use the pressure of the problem to propel us through it” (Kabat-Zinn, 1990, pg 3). Therefore by acknowledging and accepting the stressor (terminal illness) patients may be better able to cope with it. Patients in this study described being present in the ‘here and now’ and accepting their situation, which can be likened to this way of being called Mindfulness. Mindfulness is defined as purposively paying attention in a non-judgemental way to the present moment (Kabat-Zinn, 1994). It is said to involve being actively engaged in immediate experience in a curious, open and accepting way (Bishop, Lau, Shapiro, Carlson, Carmody, Segal, Abbey, Speca & Velting Devins, 2004). Although mindfulness is optimally cultivated through meditation (Kabat-Zinn, 2005) it could be argued that SPDC facilitates an
enhanced focus on the present moment similar to being mindful. As outlined earlier, patients appear to value having the opportunity to focus on life and living whilst attending SPDC; particularly through engagement in activities and relationships with other patients and staff. These experiences seem to foster a greater sense of well being and patients reported feeling ‘replenished’ and ‘uplifted’ following attendance at SPDC. Therefore it could be argued that in the presence of death, patients not only experience an increased awareness of life but also a greater appreciation of life. This could be seen as an example of Post Traumatic Growth which is a process by which people experience a positive psychological change as a result of their struggle with trauma. Examples of post traumatic growth include reprioritising one’s life goals, feeling closer to loved ones and experiencing positive personality changes such as increased empathy and patience (Snyder & Lopez, 2009). Patients in this study describe a general appreciation of the positive aspects of human nature and companionship. They appear to value the ‘small’ things such as shared experience and being cared about which are often aspects of life that are taken for granted, particularly in Western society. In Western culture people are encouraged to be independent with a strong sense of identity that includes striving to get what you want and having the individual resources to get it. Western culture places a strong emphasis on individuals being separate (Germer, Siegel & Fulton, 2005). However patients within SPDC appear to be describing ways of being that are more related to Eastern culture which places more emphasis on being embedded in the clan, society and nature (Germer et al, 2005). Patients form strong bonds that take them out of themselves and allow them to focus on others. Patients also appear to live in the moment instead of striving towards a goal, which seems to promote a connectedness to life and greater appreciation of their current situation, both the bad and the good. The practice of Mindfulness was first introduced in Buddhist psychology to help alleviate
the suffering associated with existential concerns such as death (Germer et al, 2005).

Suffering was said to be caused by the way we relate to these unavoidable concerns, therefore, by following Western culture and relating to the fear of death by fighting it for example, by dyeing grey hair, having cosmetic surgery and so on, suffering may be increased. However by accepting the ‘reality of death’ (through attending SPDC) patients appear to be free to shift their focus between death and life. They use the provision of medical care and communication with professionals to acknowledge and cope with their impending death therefore allowing for less suffering and more psychological well-being.

The implications of this research are a commissioner’s nightmare. SPDC undoubtedly helps patients cope, however the term ‘coping’ is notoriously difficult to define due to its complex, individual and nebulous nature. SPDC also appears to help patients with unconscious existential concerns, particularly their awareness of death, however the tendency for such concerns to be unconscious makes them hard to quantify. What is clear from this research is that SPDC has a profound positive impact on patients and consequently the importance of continuing to provide and maintain such services is emphasised. In particular it is important for SPDC services to provide a person-centred approach to care that is non-judgemental, accepting and flexible to the individual and their constantly changing needs. SPDC services should provide an environment where the main focus is on the present as opposed to the past or the future, thus allowing patients to focus on living life moment by moment; which is also aided by involvement in activities and relationships with other patients and staff.

Further research into the efficacy of SPDC is vital. Of particular interest, given the conclusions of this study, could be research utilising experimental existential psychological techniques (Greenberg, Koole & Pyszczynski, 2004) to investigate the
non conscious processes at play for those patients attending SPDC. Research investigating the underlying processes of SPDC from a staff perspective could also provide useful insight.

Several criticisms of this research exist. There is potential bias in the research specifically in relation to patient recruitment. Given that the senior nurse deemed whether patients met the inclusion criteria it may be that only the most able patients were recruited, making the sample biased, this needs to be addressed in future research. Due to the use of IPA methodology, results are not generalisable to the larger population of patients attending SPDC. However, IPA methodology does provide a way of looking at experiences of patients in depth thus laying groundwork for further research. A further criticism of IPA methodology is that it is open to researcher bias, such as pre conceptions regarding the service SPDC provides. However one of the reasons IPA methodology was utilised is that it recognises the role of the researcher in the process of conducting and analysing the research. It therefore encourages a process of ‘bracketing’, which involves the researcher acknowledging their biases and then setting these aside in order to focus and reflect on participants experiences (Dowling, 2007).

Many themes developed were outside the scope of the current research. One such theme being ‘support outside of SPDC’ which stemmed from the extensive volume of data referring to the practical and emotional support patients received from family, friends and local community. The outside support received undoubtedly enhanced patients’ ability to cope and in an effort to show their gratitude many patients reported a benefit of attending SPDC as being that it allowed those providing them with support to have a break:
P- That's one of the main reasons why I go, so she has a bit of time free.

I- Yeah

P- She needs to have time free.

Thus there would appear to be a relationship between external support and SPDC support, with SPDC providing more structured support to patients and also allowing external support to be sustained.

Conclusion

The current research has provided a piece of the puzzle attempting to explore processes underpinning attendance at SPDC from a patient's perspective. It suggests that SPDC provides an environment in which patients receive help in coping with terminal illness by encouraging acceptance of the reality of death and therefore freeing patients to bring 'life' into the spotlight. The study does not claim to provide the definitive answer to what processes may underpin attendance at SPDC, however in such an under researched area it provides a much needed exploration of SPDC attendance which can be built upon or challenged by future research.
References


Specialist Palliative Day Care: Patients’ Perspectives


Specialist Palliative Day Care: Patients’ Perspectives


Appendixes
Appendix 1

Journal Guidelines for Systematic Literature Review
Manuscript Submission Guidelines:

Information for Contributors

Palliative Medicine is a highly ranked, peer reviewed scholarly journal

Palliative Medicine has a fully web-based system for the submission and review of manuscripts. All submissions should be made online at the Palliative Medicine SAGETRACK website

Note: Online submission and review of manuscripts is now mandatory for all types of papers.

New User Account

Please log onto the website. If you are a new user, you will first need to create an account. Follow the instructions and please ensure to enter a current and correct email address. Creating your account is a three-step process that takes a matter of minutes to set up. When you have finished, your User ID and password is sent via email immediately. Please edit your user ID and password to something more memorable by selecting 'edit account' at the top of the screen. If you have already created an account but have forgotten your details type your email address in the 'Password Help' to receive an emailed reminder. Full instructions for uploading the manuscript are provided on the website.

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Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the 'Get Help Now' button at the top right of every screen. Further help is available through ScholarOne's® Manuscript CentralTM customer support at +1 434 817 2040 x 167.

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Review your submission (in both PDF and HTML formats) and then click the Submit button.

You may suspend a submission at any point before clicking the Submit button and save it to submit later. After submission, you will receive a confirmation e-mail. You can also log back into your author centre at any time to check the status of your manuscript.

Please ensure that you submit editable/source files only (Microsoft Word or RTF) and that your document does not include page numbers; the Palliative Medicine SAGETRACK system will generate them for you, and then automatically convert your manuscript to PDF for peer review. All correspondence, including notification of the Editor's decision and requests for revisions, will be by email.

If you would like to discuss your paper prior to submission, or seek advice on the submission process please contact the Editorial Assistant, Debbie Ashby, at the following email address: Debbie.Ashby@bristol.ac.uk

Submitting a Revised Submission
Authors submitting revised manuscripts should follow the instructions above to submit through the SAGETRACK system. To create a revision, go to the 'Manuscripts with Decisions' option in your Author Dashboard and select 'create a revision in the 'Action' column. Authors of all revised submissions should, when prompted, provide information explaining the changes in your manuscript as this will be provided to reviewers.

Notes for Authors

Palliative Medicine publishes original articles, reviews, case studies and correspondence on any subject relevant to palliative care. The journal particularly encourages papers of interdisciplinary and nonmedical authorship. The principal criteria for acceptance of material are originality and quality. All material submitted for publication is assumed to be submitted exclusively to Palliative Medicine unless the contrary is stated. Before acceptance, papers will be refereed and may be statistically assessed. All authors will be sent a Transfer of copyright which must be signed before the paper is published.

Priority and time of publication are decided by the Editor, who retains the customary right to edit material accepted for publication.

When preparing your paper:

• Use the minimum formatting.

• Roman, bold and italic type can be used, but use only one typeface and size.

• Capitals should be used only where they are to appear in the finished text.

• The text should be ranged left and unjustified, with hyphenation cancelled.

• Indents, underlining and tabs should be avoided unless absolutely necessary.

• Headings and paragraphs should be separated by two carriage returns.

• There should be only one space between words and only one space after any punctuation.

The title page. Give the title of the paper and a running title if the main title is very long. Authors should include their names and initials, their posts at the time they did the work and their current appointments and qualifications. The name and address of the author to whom correspondence, proofs and offprint order are to be sent should be given, together with telephone and fax numbers if possible.

Supply up to six key words, to be subject headings from Index Medicus.

Structure. Manuscripts should be approximately as follows:

• review articles, 5 000 - 10 000 words;

• original papers, 1 500 - 3 000 words with up to six tables or figures;

• case reports, up to 900 words with one table or figure;

• letters, up to 600 words;

• book reviews, up to 150 words.
Scientific papers should be divided into abstract (approximately 150 words), introduction, methods, results, discussion, acknowledgements, and references. Case reports should be divided into abstract, introduction, case history, discussion, acknowledgements, and references.

Headings. In dividing articles under headings, please grade the headings by writing A, B, or C in the margin:

A - subheading
B - subsubheading
C - subsubsubheading

Please avoid using more than three levels of subheading.

Style.

(i) Generic names should be used for drugs. Authors should be aware of different drug names and availability in the UK, North America and Australia, and give alternative names or drugs in the text.

(ii) Scientific measurements should be given in SI units, but blood pressure should be expressed in mmHg and haemoglobin as g/dl.

(iii) For numbers, adopt a rule that all numbers under 10 should be written as words, except when attached to a unit of quantity (e.g. 1 mm or 3 kg), and that numbers of 10 or more should be written as digits, except at the beginning of a sentence.

(iv) Abbreviations should be kept to a minimum and must be clearly defined when used for the first time. Abbreviations should be typed with no full point.

(v) Avoid excessive capitalization. For the titles of books and articles, capitals should be used for the initial letter of the first word only. However, for the titles of journals and series, the initial letter of all principal words should be capitalized.

(vi) Use italics for emphasis only very sparingly.

Illustrations. All illustrations and graphs should be submitted in the form of completed artwork suitable for reproduction. They should be separate from the typescript with legends also on a separate sheet. Please indicate the position of all figures in the text. All figures should have the "TOP" marked on the reverse with a soft pencil. The name of the first author should also be clear. When graphs or histograms are submitted the numerical data on which they are based should be supplied.

Line diagrams. No illustrations, including captions, will be given more space than the text area of the journal (i.e. 156 mm x 195 mm). Figures should ideally be drawn for a reduction of one-third, i.e., 3:2 or 150:100 mm. Where possible, all figures should be drawn for the same reduction.

All lines in a drawing should be of even weight. Do not use too fine a tint as this will result in a blotchy appearance after reduction. All lettering should follow the journal's typographical style.

Any colour reproduction costs must be met by the author.

Photographs. Other illustrations should be black and white photographic prints (not negatives, transparencies or X-ray films), and should be trimmed to remove excess material. They should be high-quality glossy prints, showing as much contrast as possible. Patients in photographs should not be
identifiable and should have their eyes masked. Any identifiable photograph should be accompanied by
written permission from the patient, parent or guardian. Colour photographs can only be accepted if the
author bears the cost of reproduction.

Tables should be typed on separate sheets. Indicate in the margin of the text where tables should be
positioned. Each table should have an explanatory caption, and be clearly numbered.

Statistics. Numbers of patients or subjects should be given, with percentages in brackets. Means should
be expressed as the mean with standard deviation of the mean: where appropriate, authors should also
consider supplying the median. Care should be taken that all statistical methods are appropriate, and that
it is clear which methods were used for which analyses. Any statistical methods not in common use should
be supported by references or described in detail. Results of statistical tests should be reported as well as
the p values; where possible, confidence intervals should also be reported.

Ethics. Please state explicitly whether any study being reported to Palliative Medicine has the approval of
local ethical committees.

References should always be appropriate: more is not necessarily better. They should be numbered in the
order in which they appear in the text, and should be given in the ‘Vancouver style’ (1). In summary, for
articles give names and initials of all authors (unless seven or more, in which case give the first three only
then et al.), the title of the article, the journal title abbreviated according to Index Medicus, year of
publication, volume number and first and last page number; for chapters in books give authors, chapter
title, editors of the book, the book title, place of publication, publisher, year of publication and first and last
page number. For examples, see below.

1 International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to


4 Wade OL. Research ethical committee. In: Duncan AS, Dunstan GR, Welbourn RB eds. Dictionary of

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page will frequently cost as much, or more than, the original setting cost of the entire page.

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Appendix 2

Quality Assessment of Qualitative Research - Summary
Quality Assessment of Qualitative Research

The assessment of quality in qualitative research is a widely debated subject. Qualitative research exists in a variety of forms, stemming from a variety of approaches, as a result there is an underlying lack of agreement as to its nature and further to this; how (if at all) it can be subject to quality control. Pope and Mays (2000) note three broad arguments in the debate.

The first is to discard quality control in qualitative research completely. However, in light of the guidance published by the NHS Centre for Reviews and Dissemination (2001) advocating for an increase in recognition of the diverse types of evidence that can contribute to systematic reviews, it is argued that the battle for the use of qualitative research in systematic reviews is won and therefore the need to develop criteria for assessing quality in qualitative research is essential (Dixon & Fitzpatrick, 2001).

The second argument proposed by Pope and Mays (2000) is coined ‘subtle realism’ (Hammersley, 1992) and is based on the premise that although there are differences between the nature of quantitative and qualitative research they are both primarily concerned with the search to represent reality. Hammersley argues that there are similarities between qualitative and quantitative research which allow for direct quality comparisons to be made, particularly concerning validity and relevance.

Opposition to this standpoint comes from the third argument outlined by Pope and Mays (2000). This argument accepts the need to assess quality in qualitative research however direct application of quantitative quality criteria checklists are seen as inappropriate due to the fundamental differences in philosophy and aims between qualitative and quantitative research. Barbour (2001) argues that although checklists can be useful, they can also be too prescriptive and therefore result in ‘the tail wagging the
dog’. She argues that unless the checklists address the broader rationale and philosophy behind qualitative research they run the risk of losing the unique contribution these methods have to offer.

In 2003 the National Centre for Social Research was commissioned by the strategy unit in the cabinet office of the Government to develop a framework that would guide assessment of the quality of qualitative research. The framework was developed, in part, by a review of 29 existing frameworks largely developed in the medical and health service fields and by in-depth interviews carried out with government workers, funders of evaluation research, academics and practitioners involved in qualitative research and reporting quality. It is based on four guiding principles for the conduct of research, these being:

1. **Contributory** in advancing wider knowledge or understanding about policy, practice, theory or a particular substantive field.

2. **Defensible in design** by providing a research strategy that can address the evaluative questions posed.

3. **Rigorous in conduct** through the systematic and transparent collection, analysis and interpretation of qualitative data.

4. **Credible in claim** through offering well-founded and plausible arguments about the significance of the evidence generated.

The framework itself consists of 18 appraisal questions which are designed to focus on four methods: in-depth interviews, focus groups, observation and documentary analysis. There is an absence of scores or marks accompanying the framework as Spencer et al (2003) argue that scoring systems can be prescriptive rather than guiding. Instead they
emphasise that the framework is developmental and should be used flexibly with “judgement and discretion” at the heart of quality appraisal.
References


http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/qqe_rep.pdf
Appendix 3

Quality Assessment Framework - Revised Version
## Quality Assessment Framework - Revised Version

### Study being appraised: ............................................................

<table>
<thead>
<tr>
<th></th>
<th>a) Appraisal questions</th>
<th>b) Quality indicators (possible features for consideration)</th>
<th>c) Notes on study being appraised</th>
<th>d) Omitted (0), Poor (1), Good (2), Excellent (3).</th>
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</thead>
<tbody>
<tr>
<td>1. FINDINGS</td>
<td>How credible are the findings?</td>
<td>Findings/conclusions are supported by data/study evidence (i.e. the reader can see how the researcher arrived at his/her conclusions; the ‘building blocks’ of analysis and interpretation are evident)</td>
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<td>Findings/conclusions ‘make sense’/have a coherent logic</td>
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<td>Findings/conclusions are resonant with other knowledge and experience (this might include peer or member review)</td>
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<td>Use of corroborating evidence to support or refine findings (i.e. other data sources have been used to examine phenomena; other research evidence has been evaluated: see also Q14)</td>
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<tr>
<td>2. FINDINGS</td>
<td>How has knowledge/understanding been extended by the research?</td>
<td>Literature review (where appropriate) summarising knowledge to date/key issues raised by previous research</td>
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<td>Aims and design of study set in the context of existing knowledge/understanding; identifies new areas for investigation (for example, in relation to policy/practice/substantive theory)</td>
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<td>Credible/clear discussion of how findings have contributed to knowledge and understanding (e.g. of the policy, programme or theory being reviewed); might be applied to new policy developments, practice or theory</td>
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<td>Findings presented or conceptualised in a way that offers new insights/alternative ways of thinking</td>
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<td>Discussion of limitations of evidence and what remains unknown/unclear or what further information/research is needed</td>
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3. FINDINGS
How well does the evaluation address its original aims and purpose?

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<tr>
<th>How well does the evaluation address its original aims and purpose?</th>
<th>Clear statement of study aims and objectives; reasons for any changes in objectives</th>
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<tr>
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<td>Findings clearly linked to the purposes of the study – and to the initiative or policy being studied</td>
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<td>Summary or conclusions directed towards aims of study</td>
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<td>Discussion of limitations of study in meeting aims (e.g. are there limitations because of restricted access to study settings or participants, gaps in the sample coverage, missed or unresolved areas of questioning; incomplete analysis; time constraints?)</td>
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4. FINDINGS
Scope for drawing wider inference – how well is this explained?

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<thead>
<tr>
<th>Scope for drawing wider inference – how well is this explained?</th>
<th>Discussion of what can be generalised to wider population from which sample is drawn/case selection has been made</th>
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<td>Detailed description of the contexts in which the study was conducted to allow applicability to other settings/contextual generalities to be assessed</td>
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<td>Discussion of how hypotheses/propositions/findings may relate to wider theory; consideration of rival explanations</td>
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<td>Evidence supplied to support claims for wider inference (either from study or from corroborating sources)</td>
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<td>Discussion of limitations on drawing wider inference (e.g. re-examination of sample and any missing constituencies; analysis of restrictions of study settings for drawing wider inference)</td>
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5. FINDINGS
How clear is the basis of evaluative appraisal?

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<tr>
<th>How clear is the basis of evaluative appraisal?</th>
<th>Discussion of how assessments of effectiveness/evaluative judgements have been reached (i.e. whose judgements are they and on what basis have they been reached?)</th>
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<td>Description of any formalised appraisal criteria used, when generated and how and by whom they have been applied</td>
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<td>Discussion of the nature and source of any divergence in evaluative appraisals</td>
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<td>Discussion of any unintended consequences of intervention, their impact and why they arose</td>
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<td>6. DESIGN</td>
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| How defensible is the research design? | Discussion of how overall research strategy was designed to meet aims of study | Discussion of rationale for study design | Convincing argument for different features of research design (e.g. reasons given for different components or stages of research; purpose of particular methods or data sources, multiple methods, time frames etc.)
|  | Use of different features of design/data sources evident in findings presented | Discussion of limitations of research design and their implications for the study evidence |

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<th>7. SAMPLE</th>
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| How well defended is the sample design/target selection of cases/documents? | Description of study locations/areas and how and why chosen | Description of population of interest and how sample selection relates to it (e.g. typical, extreme case, diverse constituencies etc.) | Rationale for basis of selection of target sample/settings/documents (e.g. characteristics/features of target sample/settings/documents, basis for inclusions and exclusions, discussion of sample size/number of cases/setting selected etc.)
|  | Discussion of how sample/selections allowed required comparisons to be made |

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<th>8. SAMPLE</th>
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| Sample composition/case inclusion – how well is the eventual coverage described? | Detailed profile of achieved sample/case coverage | Maximising inclusion (e.g. language matching or translation; specialised recruitment; organised transport for group attendance) | Discussion of any missing coverage in achieved samples/cases and implications for study evidence (e.g. through comparison of target and achieved samples, comparison with population etc.)
|  | Discussion of access and methods of approach and how these might have Affected participation/coverage | Documentation of reasons for non-participation among sample approached/non-inclusion of selected cases/documents |

| 9. DATA COLLECTION | How well was the data collection carried out? | Discussion of:  
• who conducted data collection  
• procedures/documents used for collection/recording  
• checks on origin/status/authorship of documents  
Audio or video recording of interviews/discussions/conversations  
(if not recorded, were justifiable reasons given?)  
Description of conventions for taking fieldnotes (e.g. to identify what form of observations were required/to distinguish description from researcher commentary/analysis)  
Discussion of how fieldwork methods or settings may have influenced data collected  
Demonstration, through portrayal and use of data, that depth, detail and richness were achieved in collection |
| 10. ANALYSIS | How well has the approach to and formulation of the analysis been conveyed? | Description of form of original data (e.g. use of verbatim transcripts, observation or interview notes, documents, etc.)  
Clear rationale for choice of data management method/tool/package  
Evidence of how descriptive analytic categories, classes, labels etc. have been generated and used (i.e. either through explicit discussion or portrayal in the commentary)  
Discussion, with examples, of how any constructed analytic concepts/typologies etc. have been devised and applied |
| 11. ANALYSIS | Contexts of data sources – how well are they retained and portrayed? | Description of background or historical developments and social/organisational characteristics of study sites or settings  
Participants’ perspectives/observations placed in personal context (e.g. use of case studies/vignettes/individual profiles, textual extracts annotated with details of contributors)  
Explanation of origins/history of written documents  
Use of data management methods that preserve context (i.e. facilitate within case description and analysis) |
| 12. ANALYSIS | How well has diversity of perspective and content been explored? | Discussion of contribution of sample design/case selection in generating diversity |
| | | Description and illumination of diversity/multiple perspectives/alternative positions in the evidence displayed |
| | | Evidence of attention to negative cases, outliers or exceptions |
| | | Typologies/models of variation derived and discussed |
| | | Examination of origins/influences on opposing or differing positions |
| | | Identification of patterns of association/linkages with divergent positions/groups |
| 13. ANALYSIS | How well has detail, depth and complexity (i.e. richness) of the data been conveyed? | Use and exploration of contributors’ terms, concepts and meanings |
| | | Unpacking and portrayal of nuance/subtlety/intricacy within data |
| | | Discussion of explicit and implicit explanations |
| | | Detection of underlying factors/influences |
| | | Identification and discussion of patterns of association/conceptual linkages within data |
| | | Presentation of illuminating textual extracts/observations |
| 14. REPORTING | How clear are the links between data, interpretation and conclusions – i.e. how well can the route to any conclusions be seen? | Clear conceptual links between analytic commentary and presentations of original data (i.e. commentary and cited data relate; there is an analytic context to cited data, not simply repeated description) |
| | | Discussion of how/why particular interpretation/significance is assigned to specific aspects of data – with illustrative extracts of original data |
| | | Discussion of how explanations/theories/conclusions were derived – and how they relate to interpretations and content of original data (i.e. how warranted); whether alternative explanations explored |
| | | Display of negative cases and how they lie outside main proposition/theory/hypothesis etc.; or how proposition etc. revised to include them |
| 15. REPORTING | How clear and coherent is the reporting? | Demonstrates link to aims of study/research questions  
Provides a narrative/story or clearly constructed thematic account  
Has structure and signposting that usefully guide reader through the commentary  
Provides accessible information for intended target audience(s)  
Key messages highlighted or summarised |
|---------------|----------------------------------------|--------------------------------------------------|
| 16. REFLECTIVITY AND NEUTRALITY | How clear are the assumptions/theoretical perspectives/values that have shaped the form and output of the evaluation? | Discussion/evidence of the main assumptions/hypotheses/theoretical ideas on which the evaluation was based and how these affected the form, coverage or output of the evaluation (*the assumption here is that no research is undertaken without some underlying assumptions or theoretical ideas*)  
Discussion/evidence of the ideological perspectives/values/philosophies of research team and their impact on the methodological or substantive content of the evaluation (again, may not be explicitly stated)  
Evidence of openness to new/alternative ways of viewing subject/theories/assumptions (e.g. discussion of learning/concepts/constructions that have emerged from the data; refinement restatement of hypotheses/theories in light of emergent findings; evidence that alternative claims have been examined)  
Discussion of how error or bias may have arisen in design/data collection/analysis and how addressed, if at all  
Reflections on the impact of the researcher on the research process |
### 17. ETHICS

**What evidence is there of attention to ethical issues?**

- Evidence of thoughtfulness/sensitivity about research contexts and participants
- Documentation of how research was presented in study settings to participants *(including, where relevant, any possible consequences of taking part)*
- Documentation of consent procedures and information provided to participants
- Discussion of confidentiality of data and procedures for protecting
- Discussion of how anonymity of participants/sources was protected
- Discussion of any measures to offer information/advice/services etc. at end of study *(i.e. where participation exposed the need for these)*
- Discussion of potential harm or difficulty through participation, and how avoided

### 18. AUDITABILITY

**How adequately has the research process been documented?**

- Discussion of strengths and weaknesses of data sources and methods
- Documentation of changes made to design and reasons; implications for study coverage
- Documentation and reasons for changes in sample coverage/data collection/analytic approach; implications
- Reproduction of main study documents *(e.g. letters of approach, topic guides, observation templates, data management frameworks etc.)*

**Total:** 1
1
2  Appendix 4
3
4  Data Extraction Form
5
1 Data Extraction Form

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Appendix 5

Table of Itemised Quality Assessment Scores
### Table of Itemised Quality Assessment Scores

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**Total Score-Article**

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Appendix 6

Table of Descriptive Data
Table of Descriptive Data

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<th>Reference Number</th>
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<th>Author</th>
<th>Publication</th>
<th>Purpose of Study</th>
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<th>Methodology</th>
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<td>34</td>
<td>What is palliative day care? A patient’s perspective of five UK services.</td>
<td>Goodwin, D. M., Higginson, I. J., Myers, K., Douglas, H. R., &amp; Normand, C. E.</td>
<td>Support Cancer Care</td>
<td>To ‘describe palliative day care from the patient’s perspective’.</td>
<td>Included five palliative day care centres, which provided facilities for medical and nursing assessment and also for social and therapeutic activities.</td>
<td>102 at baseline, 59 after 6-8 weeks, and 40 after 12-15 weeks.</td>
<td>‘new referrals, mainly white, over 65 years old, retired, and with a cancer diagnosis’.</td>
<td>Three interviews were carried out, at baseline (within 2 or 3 visits to day care as it was not possible to identify patients before they attended day care), after 6-8 weeks, and after 12-15 weeks.</td>
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<td>35</td>
<td>Patient satisfaction with hospice day care.</td>
<td>Kernohan, G. W., Hasson, F., Hutchinson, P. &amp; Cochrane, B.</td>
<td>Support Cancer Care</td>
<td>To ‘report the findings of a survey of day care patients, which was undertaken for quality enhancement purposes’.</td>
<td>A day care unit which had been running since 1985. Day care is offered on 3 days of each week between 10 a.m. and 2 p.m.</td>
<td>10 men and 16 women Aged between 31 and 70 years, had a variety of cancer diagnoses and had attended day care for 1–24 months.</td>
<td>A questionnaire was developed based on previous satisfaction questionnaires, combined with the experience and knowledge of the staff. It consisted of 26 items including ‘several’ open-ended questions to encourage conversations about patients experiences and was administered by</td>
<td>28</td>
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The role of palliative day care in supporting patients: a therapeutic community space.

Fisher, C., O’Connor, M. & Abel, K.

International Journal of Palliative Nursing

To ‘explore palliative day care patients’ experiences in a Western Australian context; in particular, to explore their needs from, and understandings of, palliative day care’.

Palliative Day Care centre in Perth.

Eight patients (two males and six females) with ages ranging from 44 to 82 years were interviewed. The average age was 60 years.

Participants’ diagnoses included breast, stomach, lung, bladder, ovarian and renal primary cancers.

All lived in the northern suburbs of metropolitan Perth, and occupations (or former occupations) included: taxi driver, air steward, home duties, librarian, nurse and administrative assistant.

All participants were from Anglo-Celtic backgrounds.

a trained lay volunteer with no experience of working in an adult day hospice.
| 37 | Light-hearted death talk in a palliative day care context. | Langley-Evans, A & Payne, S. | Journal of Advanced Nursing | ‘Examine processes surrounding talk about cancer, illness and death amongst patients in a palliative day care unit’. | A day unit in large purpose built wing of hospice. Day care had been running for 6 months, two days a week from 10am to 3pm. | Fourteen patients, 7 men 7 women. Aged between 36-82, 1 with multiple sclerosis and the others with cancer. Also included two staff-trained nurse of sister grade managed unit, care assistant and eight volunteers. | Utilised participant observation methodology over a seven week period detailing events and conversations. Observation episodes ranged from 21/4 hours to 51/2 hours per day. | 36.5 |

<p>| 38 | A qualitative evaluation of the impact of palliative care day services: the experience of patients, informal carers, day unit managers and volunteer staff. | Low, J., Perry, R, &amp; Wilkinson, S. | Palliative medicine | To explore the experiences of people involved in UK palliative care day services (PCDS) and identify the important outcomes of this service. | Four palliative care day units, which were purposively sampled to reflect the wide range of PCDS service delivery in the UK. | Included 18 patients, who were ‘mainly females with a median age of 60 years and predominantly white British (16/18)’. The focus groups ranged from three to six patient participants. Also include 12 carers, 22 day care volunteers and 11 PDCS managers. | Qualitative approach using focus group methodology. Focus groups were facilitated by the research nurse and the Senior Research Fellow audio taped and transcribed verbatim for thematic content analysis. A separate focus group was conducted for patients, carers, volunteers and PCDS managers. | 29.5 |</p>
<table>
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<td>39</td>
<td>Participation in a creative arts project can foster hope in a hospice day centre.</td>
<td>Kennet, C. E.</td>
<td>Palliative Medicine</td>
<td>Gain insight into the creative experience of people with advanced terminal illnesses; • develop a clearer understanding of how a facilitative environment for creativity may be established; • develop day centre practice through attention to patients’ experiences.</td>
<td>St Christopher’s Hospice, London, offering a social model of care, aiming to facilitate an environment in which a range of social and creative opportunities is offered. Included 6 men and 4 women patients. Aged 23-80. Ethnic backgrounds included one black African patient, one Indian patient and the others white British. Eight patients had a diagnosis of cancer, two of motor neurone disease</td>
<td>In-depth, semi-structured, audio taped interviews were conducted. Duration of interviews varied from 15 to 40 minutes, according to participants’ stamina and ease of communication.</td>
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<td>40</td>
<td>Exploring the value of shiatsu in palliative care day services.</td>
<td>Cheesman, S., Christian, R., &amp; Cresswell, J.</td>
<td>Internationa Journal of Palliative Nursing</td>
<td>To ‘evaluate the effects of shiatsu therapy on clients attending hospice day services’ (p. 234).</td>
<td>St Helena Hospice Day Services Eleven participants were involved (8 female, 3 male) with a range from 32 years to 84 years. Diagnoses included AIDS, motor neurone disease, severe cardiac insufficiency and prostate.</td>
<td>Utilised unstructured interviews over a 26 week period of shiatsu treatment. Participants were interviewed five times; 2 weeks before their sessions began; on three</td>
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<td>41</td>
<td>Patients’ perceptions of hospice day care: a phenomenologic study.</td>
<td>Hopkinson, J. B., &amp; Hallett, C. E.</td>
<td>International Journal of Nursing Studies</td>
<td>To find out what was important to people about their day care experience</td>
<td>A Day care unit. Twelve participants, seven men and five women. The participants were aged 50-86, had attended day care for between three weeks and three years, had a variety of cancer diagnoses and came from poorer to more affluent social backgrounds. A phenomenological methodology, developed from authors nursing practice, personal experience of cancer and my understanding of Humanistic Nursing Theory. Interviews were conducted utilising open ended questions and lasting 30 to 90 minutes.</td>
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<td>42</td>
<td>Understanding Why Palliative Care Patients ‘Like Day Care’ and ‘Getting Out’.</td>
<td>Kennett, C. &amp; Payne, M.</td>
<td>Journal of Palliative Care</td>
<td>Build on previous research particularly patients use of everyday phrases such as ‘getting out’ ‘like day care’, understand significance of day care and perceptions of St Christopher’s Hospice- ‘creative living centre’ (psychosocial palliative day care)</td>
<td>34 participants, 23 male and 11 female. Aged between 40-95 Ethnic background included African-Caribbean, Asian and White British. Utilised data from six recorded ‘gold fish bowl’ teaching sessions for medical students. Patient and staff members sat in a circle facing each other with students and non members sit in outer circle. The groups were facilitated by one member of staff.</td>
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<td>43</td>
<td>The palliative care needs of ethnic minority patients attending a day care centre: a qualitative study.</td>
<td>Diver, F., Molassiotis, A., &amp; Weeks, L.</td>
<td>Internationa l journal of Palliative Nursing</td>
<td>To assess the cultural specific palliative care needs of ethnic minority patients</td>
<td>Day care unit in a hospice of a university hospital</td>
<td>Two males and two females</td>
</tr>
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| 44 | Interprofessional working in hospice day care and the patients’ experience of the service. | Lee, L. | Internationa l Journal of Palliative Nursing | Enhance understanding of day care through an in-depth qualitative case study. | A specialist day care unit attached to an inpatient unit in Nottinghamshire. | Seven patients, four females and three males. Ages ranged between 66 to 89 years. Time since referral ranged from four weeks to nine years. | Interviews with patients were carried out with length ranging from 10 – 25 minutes. Observations were also carried out and were participatory (five full days observing day care, taking part in day care activities and attending meetings) and non participatory (observing 20 patients for 1 hour and recording at 4 minute intervals patient activity or involvement with staff) in design. Documents were also analysed including; information leaflets, the | 34.5 |
| 45 | ‘Parting gifts’. Palliative care patients perceptions of making sculpture. | Shaw, B. | Palliative Care Today | Three year research programme to explore ‘art as a vital activity, as opposed to a pastime’ (p. 86). | Liverpool Marie Curie Centre Day Unit | Does not specify how many patients participated in the study however does state that 63% out of 42 patients attending the day unit over an 11 month period took part in the sculpture project. | Semi-structured questionnaires were used to collect patient responses. | 11 |
Appendix 7

Journal Guidelines for Empirical Paper
Notes for Contributors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via our online peer review system. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper.

5. Manuscript requirement

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. Please see the document below for further details:

![British Journal of Health Psychology - Structured Abstracts Information](image)

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
• In normal circumstances, effect size should be incorporated.
• Authors are requested to avoid the use of sexist language.
• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For guidelines on editorial style, please consult the [APA Publication Manual](link) published by the American Psychological Association.

6. Publication ethics

All submissions should follow the ethical submission guidelines outlined the the documents below:

![](image)

[Ethical Publishing Principles – A Guideline for Authors](link)

[Code of Ethics and Conduct (2006)](link)

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the [British Library Document Supply Centre](link). Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Copyright

On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form. To find out more, please see our [Copyright Information for Authors](link).
Appendix 8

Concept of Coping - Summary
Concept of Coping - Summary

Coping is arguably the most widely studied topic in contemporary psychology (Hobfoll, Schwartz and Chon, 1998). Therefore it is important that before this study was undertaken, an extensive search into previous coping studies was carried out. The following is a summary of the current theoretical literature on coping.

The study of coping originated from the psychoanalytic perspective (Freud, 1933). Freud argued that coping was an “unconscious mechanism of defence,” that is, the ego's struggle between ‘unpleasant ideas or feelings’; therefore coping is a defence against anxiety produced by psychic conflict. In 1948 Anna Freud went on to publish “The ego and the mechanisms of defence” which had wide impact on the medical and social sciences. It identified many types of defence that were unconsciously used as mechanisms of coping, for example repression, denial, projection and intellectualisation. Within academic psychology Freud’s theory produced a flood of empirical research most of it focusing on the defence of repression or projection. These studies seemed to flourish between the 1930s and 1960s however they eventually had their critics. These critics argued that repression, as an unconscious defence, did not exist and that it could be explained by differences in attentional processes and response suppression (Holmes, 1972). They also argued that projection, although existent could be better explained as the process of attribution (Holmes, 1978). However, research into defences still continued with the creation of a defensive hierarchy (Valliant, 1977) and the object relations theory that broadened the role of defence (Cramer, 2000). In a more recent paper, Cramer (2000) looked at the role of defence mechanisms in psychology today and concluded that defences provide a diagnostic template for understanding distress. She states that defence mechanisms and coping can both be seen as forms of adaptation. However Cramer also states that there are critical differences between
defences and coping (1998). Defence mechanisms are unconscious, unintentional, dispositional, hierarchical and associated with pathology, whereas coping is conscious, intentional, situationally determined, non-hierarchical and associated with normality. Due to these differences Cramer concludes that the two processes should be researched separately.

A conceptualisation of coping that developed from aspects of psychoanalytical theory is the coping style approach. This approach focuses more on the way people process information than the psychoanalytic perspective. Coping styles are viewed as behavioural traits that are stable over time (Beutler, Moos and Lane, 2003). Beutler et al (2003) go on to conclude that coping styles can be viewed as habitual and enduring patterns of behaviours that characterise the individual when confronted with any situation including those that may be novel, threatening or intense. Since coping styles are said to be characteristics of an individual that are consistent over time there has been a lot of debate as to whether coping styles are actually a form of personality. Beutler and colleagues comment that “it is very difficult to conceptualise a person’s personality without invoking some description of the characteristic way he or she deals with stressful events” (p. 7, 2003). Recently there has been growing research into the possible links between personality and coping (Suls, David & Harvey, 1996; Watson & Hubbard, 1996). Research has found links between coping and Eysenck’s proposed personality traits, which are even said to be stable over a seven year follow up (Costa, Sommerfield, McCrae, 1996). Research has also proposed that “coping is personality in action under stress” and found that neuroticism influenced coping efforts (p. 525, Bolger, 1990). Aldwin, Sutton and Lachman (1996) proposed that coping results in homeostasis or a return to prior routines or symptom levels. Their research found that major life stressors can have long lasting effects on an individual’s personality.
particularly in terms of factors such as mastery and self-esteem. Therefore coping can be seen as being linked to personality in that in times of extreme stress coping style may be forced to adapt which in turn may alter previously stable personality traits. Costa et al (1996) suggest that coping and personality are part of a continuum of adaptation. There have been suggestions that coping styles should be described as classes of behaviours rather than specific and precise behaviours, this has lead to researchers providing a dichotomy of coping styles. The earliest typology suggested was ‘repression-sensitization’ (Byrne, 1964). This dichotomy has further been used in the form of blunting/monitoring (Endler & Parker, 1990), introversion/extroversion (Beutler et al, 2003) and avoidance/approach, which is a frequently used categorisation of coping styles today (Aldwin & Yancura, 2003). There has yet to be universal agreement on global coping styles.

In 1984 Lazarus and Folkman published a book that would epitomize the technical meaning of coping. The theory suggests that stress involves a relationship between an individual and an environment that is appraised by the person as taxing or exceeding his or her resources and as endangering their well-being (Folkman, Lazarus, Gruend, Delongis, 1986). Therefore stress occurs when there is an incongruence between the environmental demands and the individual’s resources. This relationship is said to be transactional in that it is dynamic, bidirectional and mutually reciprocal. The theory suggests two processes that are critical mediators in this relationship, these being cognitive appraisal and coping. Folkman and Lazarus argue that cognitive appraisal involves the individual evaluating whether a situation is relevant to their well-being and if so in what way. Cognitive appraisal is divided into two types; primary and secondary. Primary appraisal is the process whereby the individual evaluates the significance or impact of the situation; examples of primary appraisal include that the situation is
irrelevant, benign, positive or stressful (threat, harm, challenge). The process of primary appraisal is influenced by many characteristics of the individual’s personality; such as values, commitments, goals and beliefs about themselves and the world. Secondary appraisal is the process where by the individual evaluates what, if anything, can be done to cope with the situation. They appraise the possibilities to overcome harm, prevent harm or to gain benefits from the situation. Various coping options are considered such as changing the situation, accepting it or seeking more information. Following cognitive appraisal Lazarus and Folkman’s theory states that coping occurs. Coping is said to be “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of that person” (Lazarus, 1990). They argue that coping has two major functions; dealing with the problem that is causing distress (problem-focused coping) and regulating emotion (emotion-focused coping). Several forms of problem- and emotion-focused coping have been identified (Folkman and Lazarus, 1985). Problem-focused coping involves active or planful coping methods; emotion-focused coping could include avoidance, withdrawal, disengagement, expressing emotion or suppression (Aldwin and Yancura, 2003). More recent attempts to conceptualise coping have added to Lazarus and Folkman’s original theory suggesting further forms of coping and describing ‘coping strategies’. Parker and Endler (1992) suggest a third coping strategy called ‘avoidance orientated coping’. Aldwin and Yancura (2003) suggest that there are five types of coping strategy that are not mutually exclusive but encompass problem-focused, emotion-focused, social support, religious coping and cognitive reframing. Seeking social support can take the form of asking for advice, emotional support or seeking justification for taking a particular perception or action (Thoits, 1986). Religious coping has not been extensively researched but could involve prayer and asking for advice, it is
Sometimes seen as a form of emotion-focused coping and research has suggested that it might help if stressors are uncontrollable (Aldwin & Yancura, 2003). Finally, cognitive reframing is said to be least understood. As a coping strategy, it is suggested to involve making meaning from an event or looking for the silver lining particularly in coping with extreme stressors such as trauma or major loss (Mikulincer & Florian, 1996).

With the conceptualisation of coping came a vast amount of research examining its use. The most widely used measure in studies examining coping is the Ways of Coping Checklist. This checklist was developed by Folkman and Lazarus (1980) and consists of a number of predictors portraying a coping thought or action that people may engage in when under stress. Respondents then indicate whether they have used such responses in a given stressful encounter. Following the development of this checklist, various measures have been modelled after it (Amirkhan, 1990; Carver, Scheier & Weintraub, 1989). Although these measures seemed to provide an economical and versatile means of comparing coping as it occurs across individuals and situations, recently such measures have come under extensive criticism. It is argued that “after two decades of coping checklist research, researchers are left with unfulfilled promises and little in the way of useful, generalizable findings” (Coyne & Racioppo, 2000). Auerback (1989) state that data obtained in coping research has limited theoretical and practical value as it examines unitary stressors rather than complex situations that present a number of stressors each with its own coping demands. Coyne and Racioppo (2000) argue at length on the failings of generic and ominous checklists, claiming that they result in a gap between coping research and clinical settings. They argue that research should be redirected towards understanding coping as it occurs in specific settings. This view is summarised by a paper providing an overview of the current state of literature in research on stress and coping (Lazarus, 2000). Lazarus concludes that there is merit in
recent research that examines coping using microanalytical, holistic methods that attend to individual differences that may help close the gap between research and clinical practice and shows that the field of coping research is maturing.

Coping with terminal illness

In relation to coping with terminal illness research has mainly investigated the stressor associated with cancer. However more recently there has been evidence that congestive heart failure (Horne & Payne, 2004), chronic obstructive pulmonary disease (Gore, Brophy & Greenstone, 2000), motor neurone disease (Kristjanson, Toye & Dawson, 2003) and multiple sclerosis (Wollin, Yates & Kristjanson, 2006) may have similar psychological effects. Such stressors include job discrimination, fears of death, interpersonal difficulties as well as stressors pertaining directly to health care and disease management (Meyerowitz, Heinrich & Schag, 1983). Morita, Kawa and Honke (2004) found that sources of distress in terminally ill cancer patients included feeling a sense of dependency, meaninglessness in present life, hopelessness, feeling a burden to others, loss of social role functioning, and feeling emotionally irrelevant. Similarly Moadel, Morgan and Fatone (1999) reported that cancer outpatients struggled with issues related to overcoming fears, finding hope, and finding meaning in life. McPherson, Wilson and Murray (2007) suggest that burden to others through physical, social and emotional hardship and the implications this has on self view are two major stressors that effect patients nearing the end of life. Gordon (2003) highlights the communication stressors that people living with serious progressive disease face, including receiving the diagnosis, choosing and starting treatment, modifying treatment in response to failure or disease progression, and arranging end of life care.
Livenh (2000) provides an overview of the various coping styles and coping strategies that have been studied in relation to cancer. Internal versus external control was reported to have an impact on coping with cancer, with patients that blamed others for the disease occurrence or lack of medical control more likely to show poor coping (Taylor, Lichtman & Wood, 1984). However Jenkins and Pergament (1988) reported that perceptions of control were differentially associated with measures of self-esteem where as perceptions of control from God were associated with higher self-esteem and less behavioural upset. Dispositional optimism was found to be positively related to coping and negatively related to psychological distress (Stanton & Snider, 1993). In relation to approach/avoidance coping styles Livenh’s review (2000) reported that an individual who adopted an avoidant coping style was more likely to suffer depression, physical symptoms and more psychological distress (2000). Among the coping strategies researched in relation to coping with cancer those specified as problem-solving, positively reinterpreting problems, using cognitive restraint and seeking social support were suggested as more adaptive. In particular Chen and colleagues (1996) found problem focused and fighting spirit (involving accepting diagnosis and optimistically challenging the illness) strategies to have a positive impact on mood. Schnoll, Harlow, Stolbach and Brandt (1998) found reframing to be adaptive. Ell, Nishimoto, Mantell and Hamovitch (1992) found self restraint or cognitive restraint and information seeking to be predictors of psychosocial adjustment. Finally expression of feelings has been shown to reduce mood disturbance (Classen, 1996). In contrast those coping strategies that involved wishful thinking, blaming oneself and adopting a fatalistic or resigned attitude were associated with more emotional distress and poorer adaptation to cancer. Denial as a coping strategy was also found to increase psychological distress (Carver, Pozo, Harris, Noriega, Scheier, & Robinson, 1993) and
avoidance was associated with heightened emotional distress (Nelson, Freidman, Baer, Lane & Amith, 1994).

While reviewed studies undoubtedly do not describe all stressors that are faced by terminally ill patients; they provide a useful insight into some of the issues terminally ill patients have to manage.
References


Appendix 9

Interpretative Phenomenological Analysis Theory- Summary
Interpretative Phenomenological Analysis Theory - Summary

Qualitative research aims to understand individual experiences. It is varied in specific methodology, however it places emphasis on the perspectives of each participant and acknowledges that individual viewpoints and practices will be diverse due to the variety of subjective interpretations. Qualitative research also puts emphasis on the appropriateness of methods and theories in relation to the field being studied. It is argued that within the field of death and dying much of the data is non-numerical and more concerned with the experience of dying people, rather than the generation of objective ‘truth’ (Owens & Payne, 1999). Therefore the current study naturally lends itself to a qualitative approach. Interpretative Phenomenological Analysis (IPA) is one such qualitative approach that tries to understand participants’ experiences and how they make sense of them. It is underpinned by three main theoretical stances.

Phenomenology

One such theoretical stance is phenomenology, which is concerned with the phenomena that appear in our consciousness as we engage with the world around us. Phenomenology was strongly influenced by Edmund Husserl’s attempts to construct a philosophical science of consciousness. Husserl argued that psychology, and other scientific disciplines, failed to examine the fundamental nature of their concepts, therefore leading to premature and unexamined abstract concepts being developed. Husserl claimed that because concepts were not grounded in the actual experience itself, they lacked clarity and appropriateness. Therefore all disciplines, including psychology, needed to return to the things themselves thus allowing each basic concept to be grounded in a rigorous method that would provide a firm basis to each discipline. Husserl particularly criticised strands of psychology, such as Wundt’s experimental
psychology, for steering away from the study of concrete experience. He argued that human experience is not, in general, a uniform response to a set of variables that are assumed to be in operation, rather that human experience is made up of a system of interrelated meanings, which Husserl coined ‘lifeworlds’ (Husserl, 1970). Therefore the natural scientific approach was viewed as inappropriate in studying human experience, as objects and subjects are part of a human’s experience of them, meaning that the two are inseparable and cannot be studied as casual variables. Husserl went on to suggest a branch of phenomenology called transcendental phenomenology, which aims to look at particular contexts within a particular time rather than to make generalised statements. For example an individual’s experience of an object will be influenced by factors such as the individuals’ context, location, angle of perception, mental orientation (e.g. purpose, views, ideals, emotions, aims). Therefore IPA views the individual as a conscious being whose experiences must be studied from the first person perspective in the context of their lifeworld.

**Hermeneutics**

A second influential theoretical stance within IPA is the notion of hermeneutics which is the theory of interpretation. Hermeneutics accepts that direct access to individual experience is not possible without the influence of the person who is trying to gain access. For example in human interaction/communication how do we know whether someone else understands the same meaning that we do from the language we use to try to make our meaning known? And how do we know that we understand the language in the same way that they did when they used it? Paul Ricoeur (as cited in Ashworth, 2000) distinguishes between two types of interpretation, these being meaning-recollection and suspicion. Meaning-recollection is concerned with interpreting as accurate experience as possible with the intention of informing others of
the nature of the participants’ experience, e.g. qualitative research. Suspicion is concerned with discovering a further reality found behind the thing being analysed, allowing for a deeper interpretation to be made that could possibly challenge the surface level account e.g. psychoanalysis. Hermeneutics is defined more generally by Palmer (1969) as

‘... something foreign, strange, separated in time, or experience, is made familiar, present, comprehensible; something requiring representation, explanation or translation is somehow ‘brought to understanding’ – is ‘interpreted’. (P. 14, Palmer, 1969).

Therefore although IPA aims to explore participant experiences from his or her perspective it accepts the impossibility of gaining direct access to a research participant’s life world. The approach also recognises the inevitable influence of the researchers own interpretations

*Symbolic-interactionism*

A third significant influence is symbolic-interactionism. Symbolic-interactionism is part of a movement within qualitative research called construction, which indicates an approach to investigating how individuals grasp their worlds. Constructionists, such as George Kelly, state that people do not act in accordance to the way the world is but in accordance to the way they construct it. Therefore there is no reality only people’s constructions of reality which are drawn from, and modified, in light of experience. Therefore it is only possible to grasp the meaning of an experience by relating it to the wide variety of constructs that surround it. For example, putting a piece of paper in a box might be considered meaningless unless put in the context of democratic elections and the action of putting a ballot paper in a box.
Symbolic-interactionism is an important source of constructionist thinking as it is concerned with how meanings are primarily constructed by individuals within personal and social worlds. For symbolic-interactionism, the meanings which individuals ascribe to events are of central concern, but those meanings are only obtained through a process of social engagement and a process of interpretation. Symbolic-interactionists, such as George Mead, argue that the mind and self are products of social interaction. Mead argued that as infant and caregiver interact before the infant knows ‘what they are doing’ or ‘who they are’ the development of thought is a social process that is attributed meaning through the gradual internalisation of how others in the situation will react. Therefore thought arises as a social process and the individualisation of thought develops at a later stage whilst largely utilising the symbolic system of language. Therefore, according to Mead, not only are the mind and self products of social interaction it is also this social interaction that constitutes society. Through symbolic-interaction individuals are both constructed and constructors.

IPA

In light of its influences IPA aims to explore an individuals’ lifeworld in the hope of capturing the quality and richness of individual experience. It aims to explore participants’ personal accounts or perceptions of an experience, as opposed to defining the phenomena or the person’s opinion. The approach places no importance on whether participants’ accounts are “right” or “realistic”, as IPA researchers believe that individuals can experience the same phenomena, but in vastly different ways (Willig, 2001). It is grounded in individual experience favouring methods such as semi-structured interviews. Although aiming to explore the individuals’ experience the approach accepts that direct access can not be achieved. IPA also accepts that the researcher has their own lifeworld and that their context, location, situation, mental
orientation etc will influence their interpretation of the individual. Therefore whilst “Participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003, pg. 51).

Through recognising the importance of the participant-researcher dynamic and that meanings occur as a process of their interaction (Smith, 1996) the IPA approach lends itself to semi-structured interviews. Often described as non-directive, this style of interviewing is less confining on participants’ responses than structured interviews or quantitative methods. It involves a careful balance between the researcher maintaining control of the interview and the participant having the opportunity to develop novel insights for the researcher. Through using semi-structured interviews it is possible to form a collaborative relationship with an individual and place a real emphasis on conducting research that is relevant to themselves and others. This may be particularly poignant for individuals dying from a terminal disease as, typically, they are already in a relatively powerless position as actions essential to their survival may be in the hands of physicians, nurses, family members and so on. Recent research has also found that patients suffering from a terminal illness gave several reasons for wanting to participate in research, including altruism, enhancement of a sense of personal value and the assertion of persisting autonomy (Terry, Olson, Ravenscroft, Wilss & Boulton-Lewis, 2006).
References


Appendix 10

Research and Development Approval
Removed for Hard Binding
Appendix 11

Local Research Ethics Committee Approval
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Removed for Hard Binding
Appendix 12

Participant Information Sheet
What is this study?

This study is interested in hearing about patient's experiences of coming to day care. It is also interested in how coming to day care may have helped, or not helped, a patient's ability to cope with their illness.

It wants to find out what kind of things help, and don't help, patients when they come to day care. Through asking patients for their opinion, this study is hoping to increase understanding of how patients cope with having their illness and also to inform day care services of how they can improve their care.

How can I help?

This study is asking people who come to day care to share their experiences of day care and the way in which day care has helped, or not helped, them cope with their illness. Each patient is unique and has their own story to tell; therefore we would really value the chance to talk to you so we can hear about your own experience.

What will I have to do?

To hear about your experiences you will be asked to come to a one-to-one interview with the researcher. This would take place at a time and location convenient to you.

During the interview the researcher will ask you some questions about coming to day care and how it has affected your ability to cope with your illness. However these questions will be very open-ended as we want to allow you time to talk about the experiences that are important to you.

The whole interview will last about an hour and will be audio taped. This tape will then be typed up by the researcher, who will look at what you have said, and try to gain a clear understanding of your experiences. Then, if you want, you can have written or verbal feedback to let you know what the study's findings were.
What about confidentiality?

We understand that some of what you say in the interview may be personal and private, and that you may not want others e.g. family, friends or people at day care, to know what you have said. Therefore all the information you give will remain strictly confidential and anonymous. Only the researcher will have access to the non-anonymised information and it will not be shared in any form.

The only time confidentiality would be broken is if you were to tell the researcher anything that would lead us to believe that the safety of you or anyone else is in danger. Any such action that would need to be taken would be discussed with you.

Will my treatment be effected by whether I take part or not?

No! You do not have to take part in this study. Even if you do initially agree to take part in this study, you can still withdraw from it at anytime without giving a reason. A decision not to take part (made at any point) will not affect the standard of care you receive.

Further Information

This leaflet aims to provide you with a brief overview of this study and how you could help.

If you are interested in taking part in this study or want to ask some more questions about it, you can ask the nurse that gave you this leaflet and they will let you know when the researcher is next visiting the hospice and available for a chat. Then if you want to take part, you will be asked to fill out a consent form and arrange a time to carry out the interview.

If you would prefer to contact the researcher directly, she will be more than happy to talk to you and answer any questions or concerns you may have. Her contact details are provided below:

Sarah Bradley
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
Hull
HU6 7RX
Telephone: 01482 464087
Email: S.Bradley@psy.hull.ac.uk

THANKYOU FOR TAKING THE TIME TO READ THIS.
Appendix 13

Participant Consent Form
Coping with Terminal Illness: The Impact of Attending Specialist Palliative Day Care

Declaration of Informed Consent

Please tick each statement that applies:

1. I confirm that I have read and understand the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. □

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. □

3. I understand that all information will be treated confidentially and stored anonymously, and will be used only for this study. □

4. I consent to use of audio-taping, with possible use of verbatim quotations. □

5. I understand that if I lose capacity to consent during this study I will be withdrawn however data already collected with consent would be retained and used in the study. □

6. I agree to take part in the above study. □

_________________ ________________
Name of Patient, Date, Signature

_________________ ________________ ___________________
Name of Chief Investigator, Date, Signature
Appendix 14

Patient Debrief Sheet
Participant Debrief Sheet

That is the end of the interview and your participation in the study. Thank you very much for agreeing to take part and for giving up your time. The researcher will now transcribe and analyse your interview tape and write up the study.

Should you wish to hear about the findings of this study please do not hesitate to tell the researcher, who will contact you when the findings are ready. You can either choose to receive written feedback or verbal feedback.

The researcher’s contact details are below:

Sarah Bradley
Hertford Building
University of Hull
Cottingham Road
HU6 7RX
Telephone: 01482 464 087
Email: S.bradley@psy.hull.ac.uk

Please remember that if you want to withdraw from the research at any point or you have any questions regarding the study, you can contact the researcher who will be more than happy to talk to you.

Should you have any complaints regarding your treatment during the study or any aspect of the study please contact the researcher directly or the researcher’s supervisor (Dorothy Frizelle at the address and telephone number provided above). Following these discussions should you still wish to make a complaint you are advised to follow the NHS complaints procedure and contact the Hull Patient Advice and Liaison Services (PALs) office on telephone number: 01482 335409.

Thank you again for taking part in this study.

Kindest Regards,
Sarah Bradley
Appendix 15

Participant Interview Schedule
Semi-Structured Interview Schedule

Topic 1 - understanding of coping
E.g. Can you start by describing to me what the word coping means to you?

Topic 2 – what have to cope with
E.g. Can you tell me a bit about what having an illness like yours means you have to cope with?

Topic 3 - experience of attending specialist palliative day care in relation to coping
E.g. How have you found coming to day care has an affect on you coping with your illness?
Is there anything specifically about the experience of coming to day care that affects your coping?
In what way/s has coming to day care helped you cope with your illness?
In what way/s has coming to day care not helped you cope with your illness?
How would your life be different without day care?
Appendix 16

Worked Example of Interpretative Phenomenological Analysis
Specialist Palliative Day Care: Patients’ Perspectives 152

Worked Example of Interpretative Phenomenological Analysis (IPA)

To outline the process involved in IPA methodology, an example, using a section of Transcript 1, will be worked through, highlighting the different phases of analysis, resulting in the collection of super and sub ordinate themes, with verbatim examples.

Participant Interview Excerpt

P- No its just about me trying to get on with life and just let life, no matter how much, its life, no matter how much a try ermm to do things, its still life threatening
I- Hmm
P- I know its never going to go away and I’m always going to have good days and bad days
I- Hmm
P- So I do look at it from that point of view as well, you know , your not going to say well I’m going to be well now, now I feel a good day, I’m going to be on top of the world
I- Hmm
P- Cos tomorrow I’ll probable feel a bit down
I- Hmm
P- You know
I- Does coming here help with ups and downs and the feeling..
P- Oh yes
I- Yeah
P- Well it gives you that break from your own life and it gives me a break from ****
I- Yes
P- And it gives us a chance to talk about other things
I- Yeah
P- And like I say do dominoes and have my hair done n
I- Oh really
P- Things like that
I- Yeah
P- you know yeah
I- oh that sounds great, so things like doing dominoes and having your hair done?
P- yeah, getting me hair done yeah
I- yeah
P- yeah and sometimes when your at home these are things that you can put of
I- mmm
P- where as when there’s a group of you, you sort of all fill in about each other
I- yeah
P- you know
I- yeah
P- that’s how I look at it
I- yeah, you mentioned that you could ask questions to the nurses as well,
P- yeah that’s right
I- see what’s going on, is there anything else that maybe the nurses do that helps you or effects your coping with your illness?
P- Ermm yeah sometimes when I say to them like you know like me ankles have swollen up is swelling up so
I- Right
P- Ermm I say to them well is it going to be permanent me ankles or will it go down, so she says well you can have a massage,
I- Yeah
P- So I get me ankles massaged once a week
I- Brilliant
P- And ermm that’s a load off, takes me mind of it, I think what we feel they’d help us
I- Yeah
P- Err certainly when your at home, you got to either ring a doctor or wait for a district nurse
I- Yeah
P- When I know that if I’ve got something to think about, or something to you know, want to talk to someone about, I can talk up here
I- Yeah
P- To the nurses and I know it won’t go any further
I- Yeah
P- You know, that’s another thing
I- So you can talk confidentially then?
P- That’s right yeah
I- Yeah
P- Yeah
I- Something about the ease of being able to talk to them because you maybe know that your coming here or your here already
P- Yeah
I- So their just on hand
P- They’ve dealt with this sort of illness
I- Yeah
P- you know a lot a lot of different people, long time
I- yeah yeah
P- whereas its all new to me, you see
I- yeah yeah
P- you know how to to cope with things but err I do, I need to cope with it reasonably well
I- yeah, something about their experience as well that helps you cope more fully
P- well they can, yeah, say well come on you know there is life after cancer you know and stuff like that, which there is
I- yeah
P- you know, you’ve got to just fight it
I- yeah
P- don’t let it take over your life you’ve got to be
I- yeah
P- fighting as best you can

Level one analysis

The transcript is read, for the second time, and notes are made in the left hand margin concerning anything interesting or significant about what the participant was saying.

Level one analysis for this transcript is as follows:

<table>
<thead>
<tr>
<th>Doing it herself-Within limitations</th>
<th>P- No its just about me trying to get on with life and just let life, no matter how much, its life, no matter how much a try ermm to do things, its still life threatening</th>
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<td>Specialist Palliative Day Care: Patients’ Perspectives 154</td>
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<td><strong>SPDC</strong></td>
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<td>-Break from illness role? ‘Can do’</td>
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<tr>
<td>-Change of scene</td>
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<td><strong>Medical</strong></td>
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<td><strong>Question not answered by nurse?</strong></td>
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<tr>
<td>But option given-something that might help Reassurance through solution</td>
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<tr>
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Specialist Palliative Day Care: Patients’ Perspectives

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<tr>
<th>Safety</th>
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<td>Reassurance</td>
<td>P-</td>
<td>They’ve dealt with this sort of illness</td>
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<td>Expert staff</td>
<td>I-</td>
<td>Yeah</td>
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<td>Desperation-</td>
<td>P-</td>
<td>you know a lot a lot of different people, long time</td>
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<td>perceived</td>
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<td>whereas its all new to me, you see</td>
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<td>and strength</td>
<td>I-</td>
<td>yeah</td>
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<td>Fighting spirit-</td>
<td>P-</td>
<td>you know, you’ve got to just fight it</td>
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<td>within limits</td>
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Level two analysis

Level two analysis involved reading the transcript for the third time noting, in the right hand margin, any emerging themes or repeated patterns found in the text. In this level of analysis links may begin to be made to theoretical concepts and is a generally higher level of analysis compared to level one.

| Doing it herself- | P-  | No its just about me trying to get on with life and just let life, no matter how much, its life, no matter how much a try erm to do things, its still life threatening |
| Within limitations | I-  | Hmm |
| Acceptance no control | P-  | I know its never going to go away and I’m always going to have good days and bad days |
| Not too positive-realistic | I-  | Hmm |
| Don’t raise expectations | P-  | So I do look at it from that point of view as well, you know , your not going to say well I’m going to be well now, now I feel a good day, I’m going to be on top of the world |
| Own life cannot function in the same way | I-  | Hmm |
| SPDC -Break from | P-  | Cos tomorrow I’ll probable feel a bit down |
|                 | I-  | Hmm |
|                 | P-  | You know |
|                 | I-  | Does coming here help with ups and downs and the feeling.. |
|                 | P-  | Oh yes |
|                 | I-  | Yeah |
|                 | P-  | Well it gives you that break from your own life and it gives me a break from **** |
|                 | I-  | Yes |

Retain independence
Acceptance
Change of scenery
illness role?  
‘Can do’  
- Change of scene
Life other than illness
Distraction
Harder at home?
Group support—provides the motivation for participation?
Individual opinion
Medical
Question not answered by nurse?
But option given—something that might help
Reassurance through solution
Access to staff—medical care
Easily accessible
Approachable
Confidential—someone other than partner/family—freedom to be honest

<table>
<thead>
<tr>
<th>P-</th>
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<tr>
<td>Something about the ease of being able to talk to them because you maybe know that your coming here</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P-</td>
<td></td>
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</tbody>
</table>
**Level three analysis**

Level three analysis involved organising emerging groups from each transcript into sub-ordinate themes with accompanying verbatim examples, thus allowing themes across all transcripts to be compared.

<table>
<thead>
<tr>
<th>Emerging Theme</th>
<th>Verbatim example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retain Independence.</td>
<td>P- No its just about me trying to get on with life and just let life, no matter how much, its life, no matter how much a try ermm to do things, its still life threatening JANICE, P11, L501-503</td>
</tr>
<tr>
<td>Coping Appraisal: Acceptance.</td>
<td>P- I know its never going to go away and I’m always going to have good days and bad days I- Hmm P- So I do look at it from that point of view as well, you know , your not going to say well I’m going to be well now, now I feel a good day, I’m going to be on top of the world I- Hmm P- Cos tomorrow I’ll probable feel a bit down JANICE, P11, L505-513</td>
</tr>
<tr>
<td>Change of Scenery.</td>
<td>P- Well it gives you that break from your own life and it gives me a break from **** JANICE, P11, L520-521</td>
</tr>
<tr>
<td>Focus on Life.</td>
<td>P- And it gives us a chance to talk about other things I- Yeah P- And like I say do dominoes and have my hair done n I- Oh really P- Things like that</td>
</tr>
<tr>
<td>Topic</td>
<td>Transcript</td>
</tr>
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<td>----------------------------------------------------------------------</td>
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</tbody>
</table>
| Group support.                                                       | P- yeah and sometimes when your at home these are things that you can put of  
I- mmm  
P- where as when there’s a group of you, you sort of all fill in about each other  
JANICE, P12, L534-538                                                                                                                                                                                                                                                                                                                                 |
| Medical Input.                                                      | P- Erm I say to them well is it going to be permanent me ankles or will it go down, so she says well you can have a massage,  
I- Yeah  
P- So I get me ankles massaged once a week  
JANICE, P12, L549-556                                                                                                                                                                                                                                                                                                                                 |
| Staff as Safety Net.                                                | P- And ermm that’s a load off, takes me mind of it, I think what we feel they’d help us  
JANICE, P12, L558-559                                                                                                                                                                                                                                                                                                                                 |
| Ease of Access.                                                    | P- Err certainly when your at home, you got to either ring a doctor or wait for a district nurse  
I- Yeah  
P- When I know that if I’ve got something to think about, or something to you know, want to talk to someone about, I can talk up here  
JANICE, P12, L561-566                                                                                                                                                                                                                                                                                                                                 |
| Confidential.                                                      | P- To the nurses and I know it won’t go any further  
I- Yeah  
P- You know, that’s another thing  
I- So you can talk confidentially then?  
P- That’s right yeah  
JANICE, P12-13,L568-572                                                                                                                                                                                                                                                                                                                                 |
| Reassurance from Staff Experience.                                 | P- They’ve dealt with this sort of illness  
I- Yeah  
P- you know a lot a lot of different people, long time  
I- yeah  
P- whereas its all new to me, you see  
JANICE, P13, L580-584  

P- well they can, yeah, say well come on you know there is life after cancer you know and stuff like that, which there is  
JANICE, P13, L590-592                                                                                                                                                                                                                                                                                                                                 |
| Coping Appraisal: Fighting Spirit.                                  | P- you know, you’ve got to just fight it  
I- yeah  
P- don’t let it take over your life you’ve got to be  
JANICE, P13, L594-596                                                                                                                                                                                                                                                                                                                                 |
| Coping Appraisal: Within Limits.                                    | P- fighting as best you can  
JANICE, P13,L598                                                                                                                                                                                                                                                                                                                                 |
Level four analysis

Once all transcripts had been analysed up to level three, level four analysis commenced. This involved grouping sub-ordinate themes and potential theoretical concepts across all transcripts into super-ordinate themes. If themes in one transcript were not supported by a number of others then that theme was disregarded. In addition any themes that after discussion were felt to not be strongly supported by the text were also disregarded. Through this process a master group of Super-ordinate was created, accompanied by sub-ordinate themes and supporting verbatim examples. The Complete Themed Data can be seen in Appendix 17.
Appendix 17

Complete Themed Data
<table>
<thead>
<tr>
<th>Physical effects of illness and medication</th>
<th>Restrictions and Frustration</th>
<th>Lack of Control</th>
<th>Feeling like a Burden</th>
<th>Other people’s opinions</th>
<th>Loss of Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>P: I’m particularly disappointed about my physical mobility</td>
<td>P: emmmm Just you know get me the things, you know, alright, it’s just daft little things you know I mean more to tell you I-yeah</td>
<td>I: The first question is, what does the word ‘coping’ mean to you?</td>
<td>P: Everything now, virtually everything I want to do, my wife has to do it for or help me. I: Yeah</td>
<td>P: You know which is helpful, and he’s he’s not embarrassed about situation, I: Yeah</td>
<td>P: it’s no good…to me I: yeah</td>
</tr>
<tr>
<td>STEVE, P3, L151</td>
<td>P: if I haven’t got it, I’ve got like a commode chair. I can get in eventually and use it, but what would take her ten seconds to go and get me I:yeah</td>
<td>P: Well it’s living with the knowledge that you’ve got an incurable illness, CARL, P1, L5-8</td>
<td>I: I know its never going to go away and I’m always going to have good days and bad days I: Hmm JANICE, P11, L507-509</td>
<td>ALFRED, 2-3, 99-101</td>
<td>I: some days I feel like sitting down and crying I:yeah</td>
</tr>
<tr>
<td>P: After all the bed pans and bed baths, they were horrible</td>
<td>P: would take me ten minutes I:yeah</td>
<td>P: Is there anything else that’s changed? P: Emmm, Everything changes really I:Really</td>
<td>P: you know what I mean I: Yeah</td>
<td>P: He’s still taken it quite well as you know as he can JANICE, 2, 56-59</td>
<td>P: thinking “oooh what have I come to?” GRAHAM, P3, L121-125</td>
</tr>
<tr>
<td>SUE, P3, L140</td>
<td>P: to half an hour something like that I:Yeah</td>
<td>P: Emmm, Everything changes really I:Really</td>
<td>P: you know what I mean I: Yeah</td>
<td>ALFRED, 3, 117-120</td>
<td>P: I think that’s why we’ve coped so good like. We have our separate lives. ALFRED, P2, L55-56</td>
</tr>
<tr>
<td>P: Now I know when I first started by the time I’d taken the tablets often I’d got to the weekend and the free week and I was feeling fine. Now it sort of runs right over and I get the odd day when I feel good and I: yeah</td>
<td>P: most days I feel sleepy like I do now. GREG, P5, L239-245</td>
<td>P: I know its never going to go away and I’m always going to have good days and bad days I: Hmm JANICE, P11, L507-509</td>
<td>P: but I can’t get in the car without her putting me in seat and I can’t get out of the car without her taking me out of the car. I: Right</td>
<td>ALFRED, 3, 107-110</td>
<td>I: It sounds like you were very active? P: Oh I was, so has knocked me off my perch I:Oh, yeah</td>
</tr>
<tr>
<td>P: because unfortunately the condition of the emmm leukaemia makes you very, very tired most of the time. I:Right</td>
<td>P: I just…even on the television on sitting up at night. I:Yeah</td>
<td>P: You know it’s not going to go away I:Hmm JANICE, P1, L15-16</td>
<td>P: So Sometimes I feel a bit guilty I: Mmm JANICE, P1, L15-16</td>
<td>P: I don’t know. I: Hmm</td>
<td>P: But that’s the only thing, I was always practical, SUE, P6, L258-261</td>
</tr>
<tr>
<td>CAROL, P1, L31-33</td>
<td>P: If it’s bad news I don’t want it on all day SANDRA, P5, L229-231</td>
<td>P: You know, if it had to be, if its gets to that point, then I’ll have to do I: Hmm</td>
<td>P: You know that that **** is taking on emmm a lot of responsibility looking after me I: Mm CAROL, 1, 34-38</td>
<td>P: Well I don’t know. I: Hmm</td>
<td>I:Ohh I think you’ve had to cope with since you’re diagnosis you had to give that up P: Yes, yes, yes</td>
</tr>
<tr>
<td>I:so it sounds as though, It seems</td>
<td>P: I’ve been such as walking and that, you can’t do the same as you used to, can you I:Right</td>
<td>P: When the chemotherapy stops for a time I don’t know what they’re going to next, when</td>
<td>P: I hate it when the house in my wheelchair via my wife to get to the buggy you</td>
<td>P: If I have to get her to the buggy you</td>
<td>I:Ohhh It sounds like it was an enjoyable job for you? P: It was, I loved it. Yes. I: Is that something that you’ve had to cope with since you’re diagnosis you had to give that up P: Yes, yes, yes</td>
</tr>
<tr>
<td>P: this makes you very, very tired most of the time. I:Right</td>
<td>P: HARRY, P2, L55-59</td>
<td>P: The first question is, what does the word ‘coping’ mean to you?</td>
<td>P: Everything now, virtually everything I want to do, my wife has to do it for or help me. I: Yeah</td>
<td>ALFRED, 2-3, 99-101</td>
<td>P: Is that something that you’ve had to cope with since you’re diagnosis you had to give that up P: Yes, yes, yes</td>
</tr>
</tbody>
</table>

**The stressors of having and living with terminal illness**
there are side effects of the illness so something you have to cope with?

P-Oh There are side effects. One of the worst things is that bread buns taste absolutely awful. I-Oh never

P-Oh I can’t eat bread buns. They taste all yukky and tasteless and I had some mushrooms the other day, and I love mushrooms but they didn’t taste of anything...

I-Oh what a shame

P-It does affect your taste buds

I-Right

P-and things like creamy milk, I love creamy milk I-mmm

P-but it doesn’t taste particularly creamy. It’s quite alright but it’s not great. But its just the way, but You’re going to get these side effects and apparently when they stop it’ll wear off

I-Oh right

P-so I look forward to enjoying those things again.

I-Yeah so its the side effects of the medication

P-Its the side effects of the medication quite honestly the side effects of the medication have more effect than the condition

I-Yeah

GREG, P3-4, L135-158

P-...I think mentally my limits, mentally they’re alright but it’s sitting down, that’s where

I-Right

P-an hour’s driving and I know I’ve done an hour’s driving er this is what limits me, the sitting down part

P-when you can’t do much, yeah (intake)

I-Can you tell me a bit about that?

P-Well I say when you’ve used out and erm (pause) you can’t do it.

I-Yeah

P-Jenny

HARRY, P2, L72-77

I-was just wondering Just let me know if this if you don’t want to answer this one but What kind of things do you have to cope with having MS?

P-Erm Mainly not being able to do what you want

I-Right

ALFRED, P2, L83-87

P-Yeah, cos All I do is sit down and basically do nothing but sleep which is a total waste of space and time; it’s so annoying

I-Yeah

P-And frustrating when you want to do things, you know

GREG, P2, L64-68

I-So its sounds as though there’s things to cope with physically regarding the disease so things that it’s affecting you in certain ways beside

P-Well it’s yeah it does restrict you in a lot of ways erm you don’t always feel like socialising

I-Yeah

JANICE, P3, L109-114

P- I find that it’s quite a long day getting up in the morning and just not being able to do things very much, not being able that starts easing off. I might feel a bit more like talking to people rationally.

I-Yeah

GREG, P5, L215-219

P-...but the majority of the time you just cope because you can’t do anything about it.

I-Yeah

ALFRED, P4, L151-153

P-You know cos you have your off days, day when you think oh I can’t go out in that weather today

I-Yeah

P-You know you have that feeling and then another day, erm you come back and be like were talking now

I-Yeah

P-And might enjoy it, you know

JANICE, P3, L115-122

P- because when I started with this condition, I didn’t know I’d got it. Hmmm I had no pain, no discomfort, ermm I just lost weight and then they found it, this thing and put me on chemotherapy since which time I’ve felt worse (laughs)

I-Oh yeah

GREG, P4, L159-164

P- I don’t think there’s anything else that er, that really concerns me

I-Yeah

P-about my future and er it’s the medical people that can hopefully keep on top of the illness so hopefully

I-Yeah

know.

I-Yeah

ALFRED, 3, 111-116

P-ermm but I know that he wants to do it and it’s he doesn’t object in any way

I-Yeah, yeah

P-to what he’s having to do but I do feel sometimes that ’I ought to be able to do that, I should I should be doing that’ you know.

CAROL, 1, 39-44

P-Not as much as he does for me, I feel that

JANICE, 6, 245

I-Right, right So you drive your wife crazy with it?

P-Yes, which is why I’m glad she’s getting a carer’s allowance because she damn well needs it

I-Yeah

JANICE, P3, L115-122

P-Is there anything else that you have to, that you could, springs to mind when I say with things you have to cope with.

P-Ermm well Just mainly that

I-Yeah

P-and going to the toilet, wife has to take me to the toilet.

I-Yeah

JANICE, P3, L201-219

P-Come back from the toilet you know err

I-Yeah

ALFRED, 4, 161-169

P-I think she’s quite glad to see the end of me…

I-Yeah

P-she’s getting a carer’s allowance because she damn well needs it

JANICE, 5, 201-219

P-You know

I-Yeah

ALFRED, 4, 161-169

P-You’ve cos with this, having this on all the time, sometimes its a bit embarrassing

I-Right

P-You know cos at meal sometimes you know

I-When your trying to yeah

P-Yeah trying to eat with it, I-Yeah

embarrassed by anything, he’s knows it has to be done, he don’t let me struggle.

JANICE, 2, 72-73

-...so I do miss most of all the physical activities

I-yeah

P-yes

STEVE, P2, L78-81

P- I used to enjoy gardening, now because of the limitations I can’t ‘as I enjoy it because of the limits of what I can do

I-Yeah

CARL, P3, L135-138

P-I mean I used to work. I used to to work for independent (con) living and err

I-Oh right

P- go to ladies in their own home who were on their own, make lunch for them and talk to them because they were lonely this sort of thing and I had to give it I had to give it all all up

I-Yeah

CAROL, P4, L159-172

P-I’m wondering if you Can mention anything else that you have to cope with, any other aspect of having leukaemia?

P-Ermm (pause) I think I think
I-you get stiffening
P- ah yeah, I’ve got to stand up
and sort of try and get the
motions you know
I-yeah
P- because it starts to get
numbish
I-yeah
P- it doesn’t become totally
numb but pins and needles start
to develop at the back of here
and here and certainly on the
right hand side and my back side
I-right
P- that’s where er, I notice my
I-yeah
P- problems are. Above there it’s
not too bad
I-right so obviously driving that
would affect it
P- yeah it’s physical, the
physical aspect rather than the
mental, the actions are ok, the
driving’s ok, it’s the physical
sitting down
I-yeah
P- and er, I’ve got er one of these
cushions in the car but really and
truly, I’ve yet to find one that’s
er, fits the bill
I-right
CARL, P2-3, L98-123
P- I take five in the morning
I-Five
P- And I’ve got er one more to
take at tea time and then two at
night for bed
I-Oh
SUE, P9, L409-414
P- because if I want to go for a
walk, I couldn’t because my legs
aren’t well they aren’t strong
enough but I was hoping to get
them stronger. But I might, well
I-Right
P- to do very much
I-yeah
P- until bedtime apart from
seeing friends
I-Mmm
P- and going out occasionally
STEVE, P2, L70-78
I-Yeah its like it’s Kind of
stopping you from doing things?
P-Well it makes you stop in and
watch telly and that, more than
what you used to and such as
that you know, you don’t err
I-Yeah
P- (pause) You can’t be involved
in doing gardening and
I-Mm
P-such as that, same as I used to.
I-Yeah
P-Yeah
I-Yeah,
HARRY, P2, L78-88
I think you might have covered
this a bit but I’m wondering...the
next question is what having
your illness means you have to
cope with. You’ve mentioned
some changes that things like
weeding and I was wondering if
there’s anything else that’s
changed or been affected by your
illness.
I-Well, holidays er, the horizons
there are non-existent really we
could never contemplate going
abroad or anything like that er
and our... where we go is how far
I can drive.
CARL, P2, L89-98
P- I tell them that I feel erm that
(pause) I want to do these things
I-Hmm
P- if that’s the case, which it
appears to me that it is the case
because I’m feeling reasonably
well
I-Mmm and you’ve been moved
to six weeks so that’s obviously
something
P- Yeah, mmm.
STEVE, P3, L109-119
P-And you know that its there
for you know well what word
can I use there till it decides to
do whatever it wants to do
I-Yeah
P-Its only moving slightly at the
moment as far as I know, but I
go and see the specialist in
September,
I-Mmm
P-Doctor **** and see if it’s
moving any different to what it
was when I saw him in June
I-Yeah
JANICE, P1, L17-26
P-...at the moment its like since
February, was it about February I
took real ill and they took me
into **** hospital they
transferred me to ****
I-Oh right
I-yeah
P I was in there five week
I-Right
P- Wit treatment and that
radiotherapy and then they
bought me back to **** and I
were in **** three weeks err so I
learnt how to cope with the
illness there cos there was a girl
there that came a and spoke to
me about it you know and asked
what I thought about the illness
and ermm why when they
scanned it,
I-Yeah
I say she can go the whole all
day if she wants you know,
I-Yeah
ALFRED,1,24-26
P- if she wants to go shopping or
things like that or if friends they
want to go to pictures or anything like that
I-yeah
P-err I can cope on my own ok.
I-Yeah
ALFRED, 1, 16-19
P-It means its ermrm It’s hard at
times obviously 24/7
I-Mmm
P-And I’ve tried to err I make
sure that I don’t affect our life
too much you know
I-yeah
ALFRED, 1, 11-15
P- You know I’m not errrm
I-Mmm
P- I’m not like dead demanding
attention all of the time or
anything like that you know
I-yeah
ALFRED, 1, 19-23
P-It’s about being fair. We both
my wife and I have been fairly
independent so I worked away a
lot on the north sea and abroad
and she’s copped on her own and
I’ve copped on my own
I-Mmm
ALFRED, 1, 41-45
P- she can give me some room, it
wont be long
I-Yeah
P- Neighbours pop in or my
daughter works in up at ****
village and the village
ALFRED, 1, 27-30
P-with bug brace on you know
JANICE, 14, 651-660
I-...So it sounds like some people
don’t know that you’re ill so they
treat you as you they normally would
and then the doctors know that
you’re ill so they treat you when they
come here.
P-Yeah
I-Yeah
P-Yeah
I-And what do you think of that and?
P-It’s alright.
LUCY, P7, L316-324
P-That’s the trouble, I do look
well.
I-Yeah
ALFRED, 1, 21-27
P-It is a problem that
I-Is it?
P- because people think you’re
quite normal and quite able to
do things
I-ohh yeah
P-but I know I can’t.
I-Ohh, so so that’s something
you have to cope with,
P-Yeah
P-people think that you’re ok
I-yeah
P- that your healthy?
I-Yeah
LUCY, P4-5, L198-211
P-...Yeah people do get well they
say ‘does anybody come to see
you’?
I-Yeah
I-Mmm
P-And that kind of talk and I
think ‘of course they do, loads of
people come to see me’.
I-Yeah
P- I’ve seen my sister and her
son-in-law, came the other day
you just don’t feel (pause) you
don’t feel—normal anymore
I-Mmm
P- and I say to myself that I’d
like to be how I used to be. I’d
like to be normal.
I-Yeah
P- What must it be like to be
normal and then somebody will
say to me ‘What is normal
anyway?’ you know
I-Yeah
P-What can you say is normal, I
suppose what I mean is to be
able to do the things I used to do;
to walk and to dance and and
have the energy you know to do
the things that I used to do.
I-Yeah
P-Mmm
I-Yeah to be normal for you
P-Yes
I-Yeah
I-yeah
CAROL, P3, L105-126
I-So the next question is in terms
of having cancer of the bone
narrow, can I ask you what kind of
things that means you have to
cope with? So it’s anything that
comes to mind that you’re
having to cope with at the
moment?
P-Er, yeah well I certainly miss I
myself as a very, very, very
active person prior to this
happening...
STEVE, P2, L58-63
P-...and it seemed to happen so
suddenly in April 2007
I-Yeah
P- you see, it happened so
suddenly really and I certainly
miss doing the physical things er
I’m on the top practically and then there’s a big dip down to the big beck
I-oh right, yes
P-well when your at the bottom
in a car you can’t see the four bed
roomed houses at the top, to me
drive, on the **** yeah
I-yeah
P-yeah
I-oh dear, so your, So that’s quite
a hill
P-it is
I-For your legs?
P-Mmm
I-yeah
P-so I wouldn’t be able to do that
but if you took me somewhere
like, like out here, I could walk
about a bit
SANDRA, P17, L805-822

I-…I’m wondering, first of all,
what does the word ‘coping’
mean to you?
P-Well its, To me it’s erm
keeping myself clean and tidy
after I’ve after I’ve have to rush
keeping myself clean and tidy
P-That’s how it goes.
I-yeah
I-Something you’ve had to
cope with,
P-yeah
I-Yeah yeah absolutely
ALFRED, P3, L130-136

I-…So when you were saying
about erm feeling like
this…yeah can you tell me a bit
more about that?
P-Well its (pause) I don’t know
how to explain it. And then I
think to myself well you know I
don’t join in and then I think
well you’ve done plenty of hard
work in years gone by (laughs)
I-Oh yeah
P-you’ve just got to, brought
your family up and you’ve just
got to think about yourself now
I-right
GRAHAM, P2, L55-65

I-…as the study is about coping I
was wondering if you could tell

JANICE, P2-3, L84-97
I-And Sounds as though things
are more gradual?
P-Its gradually
I-Gradual
P- going down generally.
I-yeah
I-I know I am I know for a fact
that I’m just slowly getting
worse.
I-Yeah,
LUCY, P3, L120-127

I-so How do you cope with these
feelings of guilt towards you
your daughter and ****?
P-Err I I tell them (sighs)
I-Yeah
CAROL, 2, 59-62
I-Erm How will that fit in in a
couple of weeks time when you
stop going?
P-I just sit here, she’ll just go
and like she’s doing now, talk on
the phone and go and do the
shopping. She’s been out she’s
been out this morning….
I-Right
P-To
I-Yeah you said she’d been
shopping this morning.
P-Yeah, And she’ll do things, as
long as she do things like that
LUCY, P16, L784-793

I-…So what else does your wife
help you with or else do you manage
with?
P-She just does everything
I-Ohh
P-and I get on with myself and
don’t do all the planning.
I-Yeah so people are around and
people are coming in.
P-yeah
LUCY, P8, L366-382

I-Oh lovely
P-and yesterday **** came to
see me
I-oh right
P- and took **** for shopping
and things
I-oh
P-at erm ****. Things are
happening, things are happening
all the time here.
I-Yeah so people are around
and people are coming in.
P-yeah
LUCY, L88-98

SPECIALIST PALLIATIVE CARE: PATIENTS’ PERSPECTIVES
with keeping yourself clean and…
P-Yeah it’s more hygiene isn’t it?
I-Yeah, Yeah and so is that something that that’s quite important to you?
P-Well you start getting a meal ready and all of a sudden, oh you’ve got to get from the kitchen through the dining room to the living room I-Yeah
P-right through to the bathroom and most times when it’s very bad you don’t really make it and that’s when you’ve got to think where am I going to cope with all this and you’ve got to cope. I-Mmmm, So you’ve just got to cope….
P-Yes
SANDRA, P1, L7-35
P-That’s another side effect that you have with this chemotherapy. I’ve noticed since I’ve been taking it, you look at my nails, the top the top couple of millimetres I-Mmm
P-is nice and smooth and the bottom couple of mm the bottom section is all rough and wrinkly that’s the period of time I’ve been taking the chemotherapy I-Hmm
P-and I’ve just sort of curious, I’d only noticed it yesterday and these nails particularly. It doesn’t affect those but the thumb nails particularly. They’re all bumpy and bumpy and wobbly at the bottom.
I-The bottom bit where there come through me what the word ‘coping’ means to you ****?
P-Well, To me, I can’t do as I used to do
GRAHAM, P1, L4-7
P-...and I can’t go out at the moment.
I-Right
P- I’ve got to be careful even just going outside the backdoor to.
I-Is that because of your nerve or is that?
P-Yeah and I’m wobbly I-Yeah, yeah
P-And that I don’t know erm
I-And so Not being able to leave the house.
P-Not being able,
GRAHAM, P1, L17-26
I-You mentioned that you can sometimes sit and cry when you’re thinking about yourself.
P-Not very often,
I-Oh right
P- it’s just like a cloud I-yeah
P-comes over me, ohh you know
I-yeah
P- I want to get up and get going I-Yeah
GRAHAM, P4, L155-164
P-It’s like walking. At one time I could walk for miles, now I can’t walk. Its Now I can walk from here to the toilet and back. I-To the toilet, that’ll that yeah
P-Or If my wife decides to go out for the day and takes me it takes me all my lifetime to get from here to that door and from that door to next door
LUCY, P3, L132-138
doesn’t look 73
I-Yeah
JANICE, P1-2, L44-51

P-սt’s just frustrating, I-Yeah
ALFRED, P3, L137-143
I-So you mentioned a lot about the physical things you have to cope with and maybe some changes that you’ve made in your life like not going shopping as often.
P-Well that’s it, because I was a shop assistant.
I-Oh yeah
P-And I During the war when they took the men, I went in to train as a grocer and each time I’ve been able to go out to work I’ve gone back into the trade.
I-Yeah
P-Hmm
I-Yeah, And so you erm so you used to work and do that, yeah?
P-Well .most of the days that have have been bad have been since then.
I-Right
SANDRA, P9, L432-446
<table>
<thead>
<tr>
<th>GREG, P9, L426-446</th>
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<tbody>
<tr>
<td>P-...I do have carers coming in.</td>
</tr>
<tr>
<td>I-Yeah, How often do they come?</td>
</tr>
<tr>
<td>P-Ermm They come night and morning and night.</td>
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<tr>
<td>I-Right</td>
</tr>
<tr>
<td>I-Right</td>
</tr>
<tr>
<td>P-...when I was got out of bed I had to wait in my nightie till the carers came and I’d lost the confidence going in the shower</td>
</tr>
<tr>
<td>I-Yeah</td>
</tr>
<tr>
<td>P-...because I’ve go in myself without this (zimmerframe) I stand in the shower</td>
</tr>
<tr>
<td>P-so the carers help me shower and they hold the shower head to wash all the dead skin off I-yeah and keep it clean</td>
</tr>
<tr>
<td>P-and then I can walk around. I can get dressed but I have to walk around with that knocking on that leg</td>
</tr>
<tr>
<td>I-Right</td>
</tr>
<tr>
<td>P-...until the district nurse comes later on.</td>
</tr>
<tr>
<td>I-Right, So one nurse showers you and then the other and then the district nurse comes....</td>
</tr>
<tr>
<td>P-To dress it,</td>
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<table>
<thead>
<tr>
<th>LUCY, P1, L35-43</th>
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</thead>
<tbody>
<tr>
<td>P-...and I get like err especially when I’m sitting and if I’m watching the television and it’s not very interesting but I put it on because for company although I do get some people. Sometimes you feel a bit out and my eyes start wandering, I think I’d have been able to meet then and if I’d have done that you know</td>
</tr>
<tr>
<td>I-Aww yeah so</td>
</tr>
<tr>
<td>P-And er you just feel, well I do you see</td>
</tr>
<tr>
<td>I-Mmm</td>
</tr>
<tr>
<td>P-You feel</td>
</tr>
<tr>
<td>GRAHAM, P1, L7-17</td>
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<tr>
<td>I-yeah, so you’ve had to cope with possibly not being able to...</td>
</tr>
<tr>
<td>P-...and I find it difficult to cope with</td>
</tr>
<tr>
<td>I-yeah</td>
</tr>
<tr>
<td>STEVE, P2, L82-85</td>
</tr>
<tr>
<td>P-I’m not always positive and I drive my wife nuts because I get cross and I get very crotchety</td>
</tr>
<tr>
<td>I-Yeah</td>
</tr>
<tr>
<td>P-...because these tablets they make me feel very crotchety, I’ve got a i’ve got always had a vile temper but it’s worse now</td>
</tr>
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</table>

I-...Are those things that she would have done in the past? |
Before ermm |
I-Mmm |
P-I used to do the gardening |
I-Yeah |
P- and now she does the gardening, I used to drive and now she does all the driving. |
I-Right |
P- I don’t drive at all now |
I-Yeah |

STEVE, P2, L82-85

I-Right
P-yes and err.
GRAHAM, P1, L26-50
P-...And I’ve got I’ve had this
cold you can probably tell I’ve
got a cold
I-Hmm Slightly yeah
P-And ermm, I went right off my
feet just after Christmas but I’m
getting back a bit now.
I-Right, Was that off your feet or
off your feed? I didn’t hear that.
P-Completely off my feet.
I-Off your feet?
P-And
I-Yeah
P-And then the crash nurse she
had to push me upstairs.
I-Right, so the crash nurses come
here, do they?
P-Yeah
I-Yeah
P-Yeah and shoved me in bed
erm
I-And make you rest.
P-Yeah and ermm I had a
catheter on for a while
I-Mmm
P-but I’m managing without that
now
I-yeah
P-and ermm (pause)
I-So
P-I sit
I-Yeah so as well as things going
gradually down it sounds as
though sometimes things go up
and down?
P-Yeah
LUCY, P4, L167-193
and it’s a very very short fuse.
GREG, P2, L54-59
P-I’m not quite sure why but I
lose my cool very quickly.
I-Hmm
P-Erm you you talk while
somebody She doesn’t keep
grasp hold of the idea of what
I’m getting at, I do you know i
sort of have a minor explosion
I-Right
P-which is totally irrational and I
feel sorry for it afterwards but it
just sort of blows,
I-yah
P-yah like a fuse.
GREG, P4, L179-188
I-Well Feel free to blow your
fuse here its fine?
P-No, it’s alright. You haven’t
touched any raw nerves or you
haven’t. I think it’s frustration. I
think what it is is the fact that I
know I’ve got a limited amount
of time
I-Mmm
P-and I want to get things sorted
out and explained and so
I-yeah
P-...and when people don’t
understand it, it sort of seems to
be wasting time.
I-Yea
P-IIii that seems to be something
towards it whether it is or not i
don’t know
GREG, P4-5, L198-209
P-I tell my wife, I say ‘oh the
telephone’s rang
I-Hmmm
P-‘two or three times’ by the
time she got to it its gone off
I-Yea
<table>
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<tr>
<th>Acceptance</th>
<th>Here and Now</th>
<th>Best You Can</th>
<th>Fighting</th>
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<tr>
<td>P-So I say I’ll have that slave next to me and I’ll answer it</td>
<td>P-Because it err when the problem actually arises I’ll deal with it then cause then they’ll actually be something concrete to get hold of.</td>
<td>P-So we have to have it all on a good run otherwise well I worry.</td>
<td>I...So you were saying it has two levels to it one being rational P-One’s emotional, one’s rational.</td>
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<tr>
<td>I-Yeah</td>
<td>I-Yeah</td>
<td>I-So you’ve worry</td>
<td>P-One’s emotional</td>
</tr>
<tr>
<td>P-You’ve just got to err grin and bear it as they say.</td>
<td>P- At the moment it’s too nebulous.</td>
<td>P-Well You’ve got to cope</td>
<td>I-Ones emotional</td>
</tr>
<tr>
<td>ALFRED, P4, L154-156</td>
<td>GREG, P6, L256-260</td>
<td>SANDRA, P3, L137-140</td>
<td>P-Everything has two levels to it, rational and emotional and that you’ve just got to deal with them separately at least I find that I have to deal with them separately.</td>
</tr>
<tr>
<td>P-...but what the hell, it’s I’ve done most of the things I wanted to do in my life so not that that’s very much. But no no I’m fine</td>
<td>P- but as to the future, who knows. That’s one of the things in the compartmental box</td>
<td>P- I don’t know if it would work for everybody</td>
<td>I-Yeah</td>
</tr>
<tr>
<td>GREG, P3, L101-103</td>
<td>I-yeah</td>
<td>P-but it certainly works for me.</td>
<td>GREG, P8, L377-379</td>
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<tr>
<td>P-Erm Rationally, I look at it and I say to myself yeah ok, I’m 72. I have probably 10 years left to live under normal circumstances, maybe a bit more, maybe a bit less so this has come along and its it shortened its only shortened it down a bit. It’s only brought the the finishing line a bit nearer</td>
<td>I-Mmm</td>
<td>P- generally I get by very well</td>
<td>I-Yeah</td>
</tr>
<tr>
<td>I-Mmm</td>
<td>I-Yeah</td>
<td>I-yeah</td>
<td>GREG, P2, L73-80</td>
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<tr>
<td>I-Mmm</td>
<td>P-back there.</td>
<td>P-yeah.</td>
<td></td>
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<tr>
<td>Erm</td>
<td>I-Yeah, shut that out That’s absolutely fine and that sounds like that’s the way you’re coping with it.</td>
<td>STEVE, P2, L92-94</td>
<td></td>
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<tr>
<td>P-Well, it’s my way of coping with it.</td>
<td>P-Don’t you think so?</td>
<td>P-Dont’ you think so?</td>
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<tr>
<td>GREG, P10, L463-470</td>
<td>I-Ermm in my experience I think that’s fine</td>
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<td>P- but for me I put put the emotions in the little box at the back of my mind and they pop up periodically and I deal with deal with them at that moment and then put them back there</td>
<td>P-Well well You’ve got to be positive.</td>
<td>P-Well well You’ve got to be positive.</td>
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<tr>
<td>I-yeah</td>
<td>I-Mmm</td>
<td>GREG, P2, L50-53</td>
<td></td>
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<tr>
<td>P-</td>
<td>P-Mmm</td>
<td>GREG, P2, L50-53</td>
<td></td>
</tr>
<tr>
<td>P-Mmm</td>
<td>P-</td>
<td>GREG, P2, L50-53</td>
<td></td>
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<tr>
<td>P-It’s a two level thing</td>
<td>P-Don’t you think so?</td>
<td>P-Don’t you think so?</td>
<td></td>
</tr>
<tr>
<td>One’s emotional, one’s rational.</td>
<td>I-Ermm (pause) Trying to keep positive. Coping is trying to keep positive</td>
<td>P-Ermm (pause) Trying to keep positive. Coping is trying to keep positive</td>
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<tr>
<td>I-Yeah</td>
<td>I-Mm</td>
<td>I-Mm</td>
<td></td>
</tr>
<tr>
<td>GREG, P2, L50-53</td>
<td>I-Yeah</td>
<td>I-Yeah</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P-Mm</td>
<td>P-Mm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I-Yeah,</td>
<td>CAROL, P1, L14-19</td>
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<td></td>
<td>I-In terms of anything to do with coping or to do with coming here?</td>
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<td></td>
<td>P-I cope as well as I can.</td>
<td>P-I cope as well as I can.</td>
<td></td>
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<td></td>
<td>I-Exactly. You’re doing a good job so far.</td>
<td>I-Exactly. You’re doing a good job so far.</td>
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<td></td>
<td>P-Yeah</td>
<td>P-Yeah</td>
<td></td>
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Coping effort- Personal Resources

Acceptance

P-So I say I’ll have that slave next to me and I’ll answer it
I-Yeah absolutely
LUCY, P5, L230-235

Here and Now

P-Because it err when the problem actually arises I’ll deal with it then cause then they’ll actually be something concrete to get hold of.
I-Yeah
P- At the moment it’s too nebulous.
GREG, P6, L256-260
P- but as to the future, who knows. That’s one of the things in the compartmental box
I-yeah
P- back there.
I-Yeah, shut that out That’s absolutely fine and that sounds like that’s the way you’re coping with it.
P-Well, it’s my way of coping with it.
GREG, P10, L463-470
P- but for me I put put the emotions in the little box at the back of my mind and they pop up periodically and I deal with deal with them at that moment and then put them back there
I-yeah
P- but I try and deal with it rationally.
GREG, P10, L476-481
P- I’m happy
I-Yeah
P- just to go from day to day.
STEVE, P3, L126-128
P-...You, you just sort of Basically, I’m here today, I’m walking,
GREG, P11, L506-507

Best You Can

P-So we have to have it all on a good run otherwise well I worry.
I-So you’ve worry
P-Well You’ve got to cope
SANDRA, P3, L137-140
P- I don’t know if it would work for everybody
I-Yeah
P-but it certainly works for me.
GREG, P8, L377-379
P- generally I get by very well
I-yeah
P-yeah.
STEVE, P2, L92-94
P-Don’t you think so?
I-Ermm in my experience I think that’s fine
P-Well well You’ve got to be positive.
I-Mmm
GREG, P2, L50-53
P-Ermm (pause) Trying to keep positive. Coping is trying to keep positive
I-Mm
P-Yeah
I-Mm
I-Yeah,
CAROL, P1, L14-19
I-In terms of anything to do with coping or to do with coming here?
P-I cope as well as I can.
I-Exactly. You’re doing a good job so far.
P-Yeah

Fighting

I...So you were saying it has two levels to it one being rational
P-One’s emotional, one’s rational.
I-Ones emotional
P-Everything has two levels to it, rational and emotional and that you’ve just got to deal with them separately at least I find that I have to deal with them separately.
I-Yeah
GREG, P2, L73-80

I-ok so the first question Could you start by describing to me a bit about -what ‘coping’ means to you?
P-It’s a two level thing – everything is a two level thing. One’s emotional, one’s rational.
I-Yeah
GREG, P1, L5-9

P-Coz I said I didn’t want a nurse coming in every day
I-Right
JANICE, P2, L79-80

...So you were saying it has two levels to it one being rational
P-One’s emotional, one’s rational.
I-Ones emotional
P-Everything has two levels to it, rational and emotional and that you’ve just got to deal with them separately at least I find that I have to deal with them separately.
I-Yeah
GREG, P2, L73-80

P-Coz I said I didn’t want a nurse coming in every day
I-Right
JANICE, P2, L79-80

I...I was wondering if you could start off by describing to me what the word coping means to you?
P-Coping?
I-Yeah.
P-Well going about normally which I mean, what you normally do, cooking, cleaning
I-Yeah
SUE, P1, L5-12

P-I try to keep going because I mean if you sit inside you all the time
SANDRA, P5, L209-210
I-Hmm
GREG, P4, L173-178

P-I've been sort of escaping all my life, if anything went wrong with myself it was *** you know you get the measles, you got that
I-Oh yeah
P-and yet I'm the one out of a family of ten that's lived the longest.
I-Yes
P-My dad lived til he was 88.
I-Right
P-Yes
I-Well yeah, You've done well.
P-Mmm
I-You are doing well.
I-I thought if I got to 60 that would do.
P-I-yeah, yeah, So
SANDRA, P10-11, L491-505

I-So describing coping, is that, is that, is there anything else that you want to say about, I know it's really hard to describe that word
P-Well
I-The word coping
P-The flat's ideal because well, oh the hospital send people down to view your home
I-Mmm
P-And I'm only two strides away from the bed to the toilet
I-That's good
P-So it's a small flat but it's very compact
I-Yeah
P-My living room is big and the kitchen I've got down to a height that I can use
I-Yeah
SUE, P2, L60-74

P-...You've got to accept that at the age of 79, I think we're all living longer than our parents and it's all due to medication. My favourite saying is 'your life span is dependent on three things; your genes, your er lifestyle, how much goes down your throat
I-Yeah
P- and er luck' (laughs)

P-...And I think I just don't make long term plans.
I-Right
P-err I deal with things day by day.
GREG, P1, L19-21

P-Let's run the chemotherapy through and then maybe I'll feel better and I can do something then.
I-mmm
GREG, P3, L132-134

I-So how do you cope with thinking about the future?
P-Yes, well I don't very much I think erm, er, yes, how do I think cope with thinking about the future
I-Mmm
P- well I, I, to be fair ****, I try not to think about it
I-yeah
STEVE, P3, L120-125

P-So I'll get on and live, I'll live today and I'll live tomorrow and then the day after tomorrow
I'll think about it.
I-Wow
P-That's the only way you cope with it
I-Yeah
P-otherwise you go under.
I-Mm
GREG, P1, L42-50

P-Basically I'll deal with that problem when I get there.
I-Mm
GREG, P1, L33-34

P-mm I can't think about what might happen as there's so many variables i mean what might happen, what could happen, how I'd feel, how I'd react, how my wife would react, how how my kids would react.err all those sorts of things
I-Mm
Bascially you just say, ok, shut it off. coz I can't answer those questions.

HARRY, P8, L355-359

P-And just live life as full as you can when you've got the the errr tumour that I have,
I-Yeah
P-Just live life as what you can to life,
I-Yeah yeah I like that
JANICE, P1, L10-14

P-...so I just get on with my life and I do the best I can and try not to blow my fuse
I-Yeah yeah
P-which I'm not very good (laughs) at being a male I can't cope with this.
GREG, P4, L193-197

P-So I just take in my stride and just relax
I-Yeah
P-And cope with it best I can
JANICE, P1, L38-40

P- as best I can. I try, I try and do my best, yes.
STEVE, P4, L154

P- but I do what I can.
I-Yeah, yeah,
GRAHAM, P4, L165-166

I-...The first question is as we were talking before was about coping
P-Right
I- and I'm just wondering what the word 'coping' means to you?
P-(pause) ermm yes I say managing
I-Yes
P-I manage,
I-So you manage
P-I manage, I do best to cope
I-Yeah
P-that's, I really do.
I-So it's managing
LUCY, P1, L5-17

I-...and so it's something about just managing and getting on with it.
P-Yeah, I do the best I can.

P-I sit down and do it and I'm gonna do as much as I can until I can't
I-Yes
P-Because you've gotta keep going
I-Mmm
P-And if you give up and sit about, there comes a time when you can't move
I-Mmm
P-That's what happens with a lot of people
I-Yeah, yeah
SUE, P23, L1091-1100

I-Yeah, so its sounds as though that's something you have to cope with is the the fact that you do have an illness that you don't want it to take over
P-I don't want it to take my life over I want to be able to continue although I'm not going to be able to do what I did normally
I-Mm
P-You sort of take some parts of your life,
I-Mm
P-You know, er, err
JANICE, P5, L227-236

P-...we still get to see things that we still visit relations and that sort of thing. We have no personal family so er, we can still get about
I-fantastic
P- I'm grateful for that
I-Absolutely
CARL, P2, L53-58

I-Do you have to cope with those up and down days, How do you cope with them? You know when sometimes your not feeling good
P-Well when you're feeling good I probably go and have a little walk on garden or things like that.
I-Yeah
P-And err
SANDRA, P4, L180-186

P-but ermm well, you need your space, I need my space
I-yeah
P-like you do even when your not ill
...So it sounds as though some side effects are quite common. 

LUCY, P2, L65-57

---

I-yeah
P: -cos you can live in the best way of life going but you could be run down by some mad man
I-Exactly
P: - driving a car so within those three things I’d say you’ve extended your life
I-absolutely, I like that phrase, I’ve not heard that before
P: - No,
I-Yeah
CARL, P3-4, L142-157

P-I’ve always, As I say, I’ve never been particularly emotional. Erm My wife says I’m not emotional at all, so its ridiculous
I-mm
P-ermmm but erm I think erm, GREG, P2, L85-89

P-and so I’ll get on and do what I’ve got to do until I get to the finishing line thats thats normal so that and I cope with it.
GREG, P1, L17-19

I...So it sounds as though some side effects are good and other things are not good.
P-Yeah, you just take it. You go with the good things and the bad things you just try and cope with.
GREG, P8, L354-357

I-Mmm
Is something that you have to cope with?
P-Yeah
I-Time
P-I attempt to, you’ve got to live with it,
I-Yeah
GREG, P5, L210-214

P-but you live with it.
I-Mmm
P-That’s what it’s for its to get getting things under control
I-You
P-and if it does that. fine.
I-Mmm

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I-Yeah
P: -Cos you can live in the best way of life going but you could be run down by some mad man
I-Exactly
P: - driving a car so within those three things I’d say you’ve extended your life
I-absolutely, I like that phrase, I’ve not heard that before
P: - No,
I-Yeah
GREG, P1, L35-41

I-...So the first question is around coping and I was just wondering if you could tell me what the word ‘coping’ means to you?
P-Coping? Yes, well it means managing with current circumstances doesn’t it...
STEVE, P1, L2-7

P-... I I I wish I I haven’t thought about next summer.
I-Mmm
P-I will, The next thing i think about is Christmas. If I get to Christmas then we’ll deal with summer next summer after this.
I-Yeah
P-But at the moment, you cannot, It’s the only way you cope with it.
GREG, P1, L21-29

P-and each day is a bonus day
I-hmm
P-you know so I look at it in that point of view as well
I-Yeah,
JANICE, P7, L307-310

P-So I do look at it from that point of view as well, you know , your not going to say well I’m going to be well now, now I feel a good day, I’m going to be on top of the world
I-Hmm
P-Cos tomorrow I’ll probably feel a bit down
I-Hmm
P-You know
JANICE, P11, L508-515

P-Other than that erm I know coping quite well with it really
I-yeah, I think that’s a good description, so its something about being able to get you through the week and cope as best you can
P-Can yeah and treat every day as it comes.
I-yeah
P-Do what I can do one day and I probably can’t do tomorrow, like if I go for a walk maybe
I-Best you can yeah.
LUCY, P2, L65-57

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I-yeah
P-both need your space
I-exactly yeah
JANICE, P8, L372-377

P- but the the vicar’s very good. Usually he he’ll ring and say do I want him to come and give me communion at home
I-oh right
P-and so what I’m going to do this weekend, with going into hospital on Monday, I’m going to ring him today and see if he can possibly come on Sunday so that I can have communion on ermm Sunday morning before I go into hospital.
I-Yeah
CAROL, P4, L173-182

P-I think sometimes you’ve got to push yourself,
I-Mmm
P-There’s no point in sitting back and letting it take you over,
I-Hmm
P- you know, like so actively might say, that wants doing that wants doing, oh no leave it.
I-Hmm
P-I think you’ve got to make yourself do these things
I-Yeah
P-otherwise you would get really housebound and that aint what I want
I-yeah
P-You know,
JANICE, P4, L149-162

I-So you’re still manage?
P-Yeah I’m alright. I put put some music on or something,
I-Oh do you
P-Yeah
I-Well that will be nice to sit and listen to music as well.
P-Yeah, It just switches itself off
I-Hmm
P-Its probably. I’ve had it on this morning, there’s probably lights, you can probably see lights
I-There’s a few lights I think yeah I’m not sure if its on, but Do you have a remote control for that as well?
P: If it gives me another couple of months or years or whatever it is I’ve got a couple more left, it’ll err do me
GREG, P4, L165-172

P: the low energy’s caused by the chemotherapy
I-right
P: and the chemotherapy’s working or seems to be
I-mm
P: so in that case that’s fine ok lets just get on with it.
I: Yeah
GREG, P3, L126-131

P:...erm when I got this I said to myself “Right, you’re 70 odd years old, you haven’t got an indefinite period of time in front of you anyway, all it’s done is made it a bit shorter so effectively all you can do is try and get all that stuff in the garage sorted out before you can (both laugh)
I: Yeah It’s a very rational way to look at absolutely
GREG, P10, L481-488

I:...How do you cope with that?
P:(pause) I think I think I think the thing is it’s happening gradually so you just...it’s erm...it’s just normal for me
I: Yeah
LUCY, P2, L95-99

I:...And ermm you mentioned about the problems with your sight and your voice. Do they help with that at all?
P: Not really, they can’t. They can’t
I: Mmm
P: They just know that I can’t and I know I can’t
I: Yeah
P: and that’s it.
I: Yeah,
LUCY, P12, L568-575

I:...erm So you’ve had to cope with things going gradually down by the sounds of things
P: Yeah

P: Tomorrow I think oh no I can’t managed that today
I: yeah
JANICE, P1, L27-37

I:...So are there any other ways you’ve found (patients pauses) or anything else that you need to cope with that you know you could think of finding a way for?
P: No I’m not aware of it.
I: Yeah
P: Erm What I do is ermm as I find the difficulty and I then deal with it.
I: Yeah, so when it comes up, the difficulty.
P: Yeah, Comes up
I: Yeah
LUCY, P6, L275-284

P: Yeah if I knew what to do!
I: Oh there’s a lot of buttons on that
P: Yeah
LUCY, P16-17, L794-807

I: Erm The next question is about here. And It’s about, you’ve mentioned what you’ve had to cope with in terms of ermm your physical health and things you do around the house and having to be a bit of a battler and you know not letting this
P: get on top of you.
I: Get on top of you, yeah.
GRAHAM, P7-8, L347-353

I: So what was it like when you first went if you didn’t know anybody?
P: Just normal. I just sat there
I: Yeah
P: and listened. I’m very good at listening. I am. I don’t always get it right but sometimes I just hear things
I: yeah, just take it all in
P: yeah
I: yeah
P: and then blurt something out
I: ohhh
P: yeah
LUCY, P15, L710-721

P:...Anger, yes but apart from that my my emotions are never very strong and so I just shut it off and deal with or I try and deal with it on a rational basis
I:mm
P: which I can do, that’s I rationalise it, no problem at all.
GREG, P8, L368-373

P:...Emotionally
I:mm
P: I just shut it off.
I: Right
GREG, P1, L29-32

P: It’s the only way its the only way because if you get emotional, it’ll wear you down;
I:mm
I- and ermm you’ve coped with that by it becoming a bit normal
P-yeah
I-yeah
P-It’s much more becoming normal yeah.
LUCY, P4, L160-167

...How do you cope with that?
P-Well I think it’s becoming normal to me.
I-Mmm
P-It’s becoming normal.
I-Yeah
LUCY, P3, L127-131

...and so ermm, this is a really hard question I think but how do you cope with the knowing that you’re going down? I mean it might be that you don’t P-accept it love. I-Right P-That’s the only word.
I-Yes, Accept it, yeah. Ok.
LUCY, P7, L337-344

...I was just wondering if there was anything else that you want to say about going to the hospice or about ermm how you cope with things with having MS?
P-It seems quite normal for me now.
I-Hmnm yeah
P-I’ve forgotten what it was like to be without it.
I-Hmnm and So it’s just normal?
P-Yeah, it’s become normal
I-Yeah And is going to the hospice normal as well?
P-Yeah
LUCY, P8, L860-870

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<th>Reality of Death</th>
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<tr>
<td><strong>Provision of Medical Care</strong></td>
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<td>P-...i mean look today i mean i guess if they hadn’t have been here i wouldn’t have been having this I-Yeah</td>
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P-Mm
I-Yeah there able to, is it an infusion
HARRY, P3, L114-119

P-So I have emrm an infusion, what they call an infusion
I-Yeah
P-Every six week and its err liquid that goes into me into a a vein
I-Right
P-That goes round me system that does calcium for me bones
I-Oh Brilliant yeah
P-And its awful, they said it strengthen my bones at the back of my neck
I-Mm
P-Not enough to do without a collar
I-Mm
P-But enough to be able to cope with a bit more
I-Yeah
P-Support you know
I-Right, so you get that done here?
P-Get this done here, once every six week yeah
I-Right
P-And they take me blood pressure and err temperature and things like that you know
JANICE, P15, L670-690

P-...And emrm oh I took my shoes and socks off one day and put it in this blue thing and all the little bubbles come on your feet. A foot spa.
I-Foot spa yes
P-Yes And then after they dry them they massage you with
I-Oh wow
P-with the cedar oil all over, But when she does my shoulders I have to sit down and be on the bed and I-And so lie down
P- and she works right up yes and right up where the pain comes.
I-Yeah
P-It’s the arthritis
I-Yeah
P-Of the old age.
SANDRA, P15, L725-739

...and ‘how’s it happening’.
P-So do you just talk about physical stuff or do you talk about
P-Yes, well we can talk about anything.
I-Yeah
P-Anything, Yeah ‘Have you got plenty of this at home, have you got plenty of that’ and ‘is your food alright’. Everything
I-Ohh everything
P-everything in general
I-yeah
P-and your medical as well.
SANDRA, P12, L558-573

P-...and at the same time somebody professional enough to look for the danger signs, danger signals I-s that in terms of symptoms?
P- that’s right yeah. If you’ve got a funny ache er, such as one here,
CARL, P4, L165-170

P-...it’s great, I’m sent here for them to keep an eye on you see
I-Oh
P-So, just to see, you know that I’m not overdoing things
I-Ah right, so this is about them keeping an eye on you
P-Yeah, that’s it, they weigh me, they check my pulse, sitting down, standing up and if you watch what’s going on in that room, I think there might be two of us having that done now, but that’s been right from the start
SUE, P7, L136-324

P-Mm, so you had to cope with being
I-Yeah so things like mobility and, and
P-That’s it, where now once a week I come here and you get a check here, while you wait, they take my blood pressure standing up and sitting down
I-Mm
SUE, P3, L141-147
P: Yes and the nurses are very very nice to you and the people who do the massage and that.
I: So you get massaged done as well?
P: Yes because I’ve got arthritis this side
I: Right
P: And across my shoulder and it’s old age my doctor tells me.
I: So they massage that
SANDRA, P10, L475-482
P: …er, I’m saying incurable. At the moment, there’s er, the medication I’m on relieves a lot of the symptoms and er, I’ve got no complaints in that respect er I’m certainly a lot better than I started out obviously due to medication er so er you know I’m grateful that there is such medication that will give you that
I: Mmm
CARL, P1, L8-14
P: …so she says well you can have a massage, I: Yeah
P: So I get me ankles massaged once a week
I: Brilliant
JANICE, P12, L553-557
I: …would you get that infusion done if you weren’t coming here?
P: I’d have to probably go to **** hospital for it
I: Right
P: Erm or somewhere else, maybe **** somewhere
I: Yeah
JANICE, P15, L691-696
P: I know that when I come up here, that err its two minutes while they insert the infusion
I: Right
JANICE, P15, L704-706
P: You know, erm they do all the blood tests as well, I: Right
P: take the red sauce and that has to be sent off to the doctors and to err specialist you know if - whole practice
I: Really
P: They sent me to **** hospital, **** hospital checked and they sent me to **** hospital
I: Oh right
P: To see a heart specialist, he checked and sent back a letter like that and they all agreed they were right, checked all the way around
SUE, P10-11, L492-504
P: That would probably be, it is for life
I: Yeah
P: So I see coming here that’s another good thing, I: Yeah
P: Its now not trailing backwards and forwards to work different journeys
I: Yeah
JANICE, P15, L697-703
P: But err I think that when you when you come here they can do all these things for you
I: Yeah
P: Which is erm helping them, and helping you at the same time
I: Yeah
P: Your not saying ooo I’ve got to got to **** ohh I’ve got to go ****
I: Yeah
P: Least you can get them done here, if things are err things are done under one roof you see
I: I see,
JANICE, P16-17, L757-768
I: I’m not sure what we would group it as but things like making it very accessible to to have the
P: Yeah
I: clinical side of things taken care of
P: Cos you see you have to have transport wherever you go
I: Yeah
JANICE, P16, L742-747
P: …as I say that was a good, one of the good things rather than make an er appointment to see a doctor, to mention I’m constipated and then going through the full…you know, it skips a sort of visit
I: Yeah
P: And she says well you know she does the best she can for them at that time so that’s why it hit her as hard like you know
I: Mmm
ALFRED, P, L333-340
P: They’ve dealt with this sort of illness
I: Yeah
P: You know a lot a lot of different people, long time
I: Yeah
P: Whereas its all new to me, you see
I: Yeah yeah
JANICE, P13, L580-585
P: … it really err put my mind at rest and that like you know so
I: Yeah
ALFRED, P6, L253-255
I: Is there anything else about here that, that affects you coping? Is there anything else about what you do here or choose here that affects you?
P: Well the thing is they check, they do such a good check here, I’m weighed, they keep a note of your weight
I: Mmm
P: And your pulse and that’s all kept for you
I: Yeah
P: In their books and things like that
I: Yeah
SUE, P10, L482-491
P: Well I stubbed my toe, oh must have been two or thee years age
I: Oh
P: My foot started to swell up again
I: Oh dear
P: But my daughter wanted me to call the doctor, but I said you’re only to call the doctor in an emergency if it’s a heart attack I said I’m not gonna fuss around like that but anyway they’ve checked it they’ve just said it’s just old age
I: Right
P: It’s probably just damaged toe, Rheumatism goes to your damaged parts
I: Yes
P: Now I’m bruised it, I bruised it so badly, I only knocked it against a table at home and it went black
I: Really
P: So it was that sort of colour my big toe
I: And they were able to check that here?
P: Oh they checked into everything and she checked it again today and she oh no it’s just old age
I: Yeah
P: So that’s
I: So
SUE, P9-10, L443-466
P: … usually there’s a doctor
I: Yes
P: Calling in and if you need to see the doctor, they send you
I: You can do
P: Well there’s two trained nurses, she’s had a look at the foot this morning and she said it’s just old age
there’s anything they’ll let them know here I-yeah
P-ermm and then err if there’s anything that you know anything to do anymore injections or anymore tablets to be taken I-yeah
P-they can deal with that here as well I-oh right, so it sounds as though they do a lot here? P-They do yeah I-I’ve ermm I’ve not tried describe at all but things like taking bloods and and giving you infusion and doing that P-Yeah
I-Would you call it management? Or? P-You can call it that yeah I would say so

JANICE, P16, L724-741

P-...And the doctor comes.
I-So as well as a fun day P-Mmm
I-there’s also the doctor P-to check up on that I-right
P-And they there was the physiotherapist I-Ahhh
P- and she does the massaging in here. And they also, have people that haven’t got the services and they can’t do their own bathing and that I-yeah
P-yeah well there’s a place for that. SANDRA, P15, L712-725
I-...what about the I’m interested in the services they provide here, what about the symptom management and the hairdresser and that kind of thing.
P-I haven’t used them. I have had some massage as I’ve got a bit of arthritis in my right knee and the lady came for two or three weeks massaging my right knee and there was a great improvement. I was very pleased I-Mmm
P-with that and most of the other facilities I haven’t used. Perhaps I should Greg, P9, L412-421

I-yeah
CARL, P5, L236-240
P-...I have everything I need and want when I come here, I have my pill box with me, they’ve never pre, all the tablets I’m taking now, they’s so many and some of them I could never pronounce I-Really
P-So I bring the pill box with me, so if anybody wants to know, it’s in my hand bag there I-Really
P-So if anybody wants to know what drugs I’m on they are there I-You show them P-Yeah
SUE, P7, L300-311
P-When I know that if I’ve got something to think about, or something to you know, want to talk to someone about, I can talk up here I-Yeah
P-To the nurses and I know it won’t go any further I-Yeah
P-You know, that’s another thing I-So you can talk confidentially then?
P-That’s right yeah I-Yeah
P-Yeah
JANICE, P12-13, L564-574
P-Like filling in the medication, changing and there always see ermm straight away, I-Yeah
P-Like if I’m running short, I’ll say I’m running short can you I-oh right
P-I can she’s sort of done that for me, you know I-So they will do that for you as well? P-Yeah, get me a prescription made up, yeah I-Yeah
P-I get to down to surgery you know they make up make me the same ermm Prescription up I-Yeah
P-You know, I-Do that here P-They can do that a swell yeah
**Initial Views of SPDC**

- I-and What did you think of it when you came here?
- P-I thought it was alright In the end,
- I-Mmm
- HARRY, P3, L146-148

- I-Is there anything that springs to mind when I ask you what
- P-It’s a good day out here.
- I-Yeah
- HARRY, P3, L106-107

**Focus on Life**

**A Change is as Good as a Break**

- P-It’s a good day out here.
- I-Yeah
- HARRY, P3, L106-107

- I-That what, I was just about to say it sounds really fun, yeah And so it brightens up your week?
- P-Oh Yeah it does.
- I-Yeah

**Focusing on life through the activities of SPDC**

- I-Oh and what is it about doing things like that that helps
- P-It’ crafts, it’s simply because you are concentrating, instead of thinking about yourself
- I-Right
- P-You’re concentrating on what you are doing
- I-Ah
- SUE, P17, L798-803

**Focusing on life through the people at SPDC**

- P-Well yeah, I’m hoping that by the time, as time goes on I won’t have to talk about the illness too much
- I-Yeah
- P-You know, cos I think some the more you talk about it the more you ermm you don’t feel down but you know that your poorly
- I-Yeah
P-I didn’t when I first started
I-Ohh
P-I didn’t think I would come
I-Really
P-But I, mmmm
HARRY, P3, L129-135

P-When they first asked I didn’t like the idea because watching television in these nursing homes you see all the elderly people just sat there dropping off to sleep and ohh I didn’t like that
I-Mmmm
P-And I said oh but that was in the days when I was just on my own
I-Yeah
P- waiting for my sister to come and my son and then of course err **** says ‘well why don’t you come and just look around’. I-Just look
P- She rang up one morning and my daughter was here looking after me. Just after the operation my daughter come in for a month to look after me. And she said ‘well could she come with her mother’ you see and me son was driving his car and all three of us. It was one Thursday and they said we could come at 10.30 and we were greeted with a cup of tea
I-Ohh
P- and we were going from room to room they were doing something in each room.
I-Yeah
P-And the garden was lovely and of course the weather was…
I-It makes such a difference. And so he wasn’t sitting and watching tele
SANDRA, P14-15, L681-707

P-One of the things I thought about when I was first coming here was I didn’t want to come because I thought ohh it was going to be all old people
I-Mmmm
P-not feeling very good, moaning about their illnesses. It is totally different.
I-Yeah
GREG, P11, L526-532

SANDRA, P14, L677-680
I-So errmm my next question is about coming here.
And you’ve mentioned things you have to cope with and you’ve mentioned really well about how you cope with them,
P-Mmmm
I-the adjustments you’ve made and the things that you do. Erm what about coming here? Does that have an affect on your ability to cope?
P-It brightens the week, definitely.
SANDRA, P10, L463-471
I-....Errmm my last question is if you didn’t come here, what what do you think would be different?
P-Well I’ll have to just have Every day would be the same won’t I.
I-Yeah
P- There wouldn’t be anything different at home you see
I-Yeah, yeah so something
SANDRA, P17, L797-804
I-Does coming here help with ups and downs and the feeling..
P-Oh yes
I-Yeah
P-Well it gives you that break from your own life and it gives me a break fro ****
I-Yes
JANICE, P11, L516-522
P-its it gets you away from the routine that I have at home
I-yeah
P-you know, which I think you need to do that, you need a break even if its just the one day a week
I-Mmmm
P-it does help,
I-so changes the routine that you have at home a bit,
P-yeah
I-the household routine
JANICE, P8, L358-366
P-It’s just a change of environment really. Its A

P-errmm, yeah in general its just gets you away from your own your own illness
I-oh right
JANICE, P8, L346-348
P-Yes and that was to keep your brain ticking over.
I-Ohhh
P-Oh And the flower arranging.
I-And the flower arranging
P-Yes
I-Keeping your hands going
SANDRA, P14, L660-665
I-Yeah. And so did you enjoy doing that this morning?
P-I’ve done that this morning. That’s twice they’ve been since I came last October and errmm I-And you enjoyed it?
P-I have enjoyed it and pottery.
I-Ohhh
P-We did the little nests for the birds for Easter to go in with these things but mine at home on the window ledge
I-Ohh you’ll have added to it.
P-Yeah
SANDRA, P13, L625-634
P-...and then the lady came for this creative writing
I-ohhh. You did some writing as well?
P-We we she brought a sheet and a board and She put letters down to start with. ‘What does this remind you of?’ or she’d open a box of things on the box with ribbon and stones
I-Ohh
P-and ‘what does it remind you of’, petals and things and you just gave her little bits and pieces all the way round and she’d turn it into a poem for you
I-really
P-But you helped
I-because you put
P-put the image of the thing there, yeah
I-And some of the words as well?
SANDRA, P13-14, L644-659
P-One of the ladies finished last week; creative

P-Yeah you know, so I try not to put it down as being poorly all the time
JANICE, P5, L220-228
I-Yeah, What kind of things do you talk about?
You mentioned you talk about things during the week, ermm you talk about I’m wandering if you talk about your actual disease or what
P-Ermmm not diseases, I mean I don’t know what’s wrong with everyone that’s here, some have had stroke some have tumours, you know
I-Yeah
P-But I think sometimes it does you good to get away from it as well
I-Mmmm
P-Instead of discussing the illnesses all the time
I-Yeah
JANICE, P10, L454-466
P-So but we don’t interfere with other peoples ermmm life’s, we don’t, there business I’ll put it that way
I-Right yeah
P-You know, we don’t need to know all their business as such,
JANICE, P9, L403-407

P-No we don’t talk about each other’s illnesses. We just ask how they are but don’t go into any detail.
SANDRA, P13, L600-603
I-Ohh well That’s interesting, so people don’t actually talk about their illnesses?
P-They don’t talk about their illnesses.
I-Mmmm
GREG, P11, L522-525
P-where as when there’s a group of you, you sort of all fill in about each other
I-yeah
P-you know
I-yeah
P-thats how I look at it
JANICE, P12, L539-544
I’m wondering therefore, with in light of what coping means to you and also what you’ve had to cope with

P: Mm
I: Since you were diagnosed with MS, I’m wondering what’s coming to day care and how that affects that?
P: Erm, when I when I erm Sister **** we have brilliant doctors and nurses, she asked me if I would go to **** Hospice. As soon as she mentioned hospice, I says...
P: I thought that’s the end of the road like so, so I refused to go for quite a while

I: Hmm

I: And then she started persuading me to come here

And for I would thing the first few weeks it’s quite traumatic when you come.

I: Really

P: You see other people. Well, Like I say, the word ‘hospice’

I: Hmm

ALFRED, P5, L227-246

I: Why did you think you wouldn’t come?

P: Well, I the doctor asked me to meet if I’d like to go, like you know

I: Yeah

P: And I said ay, I’d give it a try but er

I: Yeah but maybe you were a bit weren’t sure you wanted to come to start with

P: That’s right yeah, Hmm

I: Yeah

P: It’s err

HARRY, P3, L136-145

I: Hmm interesting what sticks in people’s minds about coming here

P: Oh yeah

I: Yeah

P: I think a lot of people are frightened to try, aren’t they

I: Hmm

I: Hmm, Why why do you think they’re frightened to try?

change is as good as a rest.

I: Mmm

GREG, P6, L281-283

P: Oh well yeah and er, er, as regards coming in

I: Mmm

P: Er it’s unfortunate that you have to come here when you’ve got a problem but it’s a big plus point in a week’s living is coming here both for the reception,

CARL, P4, L158-162

I: I’m wondering that seems like something you’ve had to cope with, that change

P: Yes

I: And I wondering how coming here effects that?
P: Well it’s the best day of the week

SUE, P9, L428-433

I: And would you be able to pinpoint what was that was that was giving you the uplift?

P: Er, well it’s a complete change isn’t it?

I: Ah

P: I think it’s the complete change from everyday things isn’t it, yeah

STEVE, P7, L321-326

I: I’m now wondering how, how coming to day care has affected your coping?

P: It’s marvellous, it’s the best day of the week

I: Oh

P: It’s really is because it’s the best day

I: Hmm

P: I really meant that,

SUE, P6-7, L293-300

P: Yes I do I do actually look forward to it

I: Oh

ALFRED, P6-7, L300-301

I: So it sounds like it means something to you, coming here?

P: Oh yeah. Yeah

I: Yeah

P: I look forward to it

Yeah

writing.

I: Oh wow, right

P: Have you heard of it?

I: I’ve heard of it but what what did they do?

P: She went around ‘pick a word, any word that comes to you’ and that and then something was said and she puts little bits you know to it well ‘what did your word mean?’ and she brought a container with bits of there was a piece of lace, a piece of tatty rag, a stone and lots of different things.

I: All sorts

P: We picked this particular week we picked something out of the basket that appealed to us and then she made it with our help, you know made a rhyme up. The last week she wrote ‘hospice’ down there

I: Oh like a

P: On a board

I: On a board, hospice

P: And ‘H. What does H, what comes to your mind

I: Oh wow

P: When you have H?” you know and every letter and then you had to make a verse. She was very helpful.

I: She sounds great and that

P: And keeping my mind

I: Keeping your mind active

P: Yes

I: Yeah and keeping you doing things.

GRAHAM, P9, L443-469

P: but it was, you don’t know really what you’re going to get hit with sometimes -(both laugh)

I: Right

P: You know but it’s always something interesting.

I: Yes, So you’re not quite sure what they’re going to give you or to do

P: No

I: Is that right, and that it’s always interesting?

P: Yes, yes. They just sort of well they said next week we’ve got a lady coming in to start creative writing so next week you’re doing some sort but you don’t actually know what’s happening.

I: And what it’s actually going to be like, yeah

P: Erm I don’t think that erm you need to talk about other people’s hobbies

I: Yeah

P: You know. What other people do in their spare time and

I: Yeah

P: Like like one lady just says to us oh she says I I can just sit down and just peel the potatoes I’ll do the potatoes now or I’ll get the veg ready you know emm for for a meal, just for something to do

I: Yeah

P: everybody’s so different in hobbies

I: Mmm

P: I know that isn’t a hobby that’s err something to make your meals, isn’t it?

I: Yeah, but its something that gives her something to do

P: Something to keep you occupied

I: Yeah

P: Yeah

JANICE, P11, L478-495

P: ...its nice to be able T’ talk erm what they’ve done over the frontier of last week to this week

I: Yeah

P: You know, what they’ve been doing in life,

I: Yeah

P: Nice to listen to

I: Yeah definitely

JANICE, P9, L407-413

P: Like I say we come up here, we always hanging out, What originally made us come here,

I: Mmm

P: When I first started, there was ladies and gentleman

I: Yeah

P: So the gentlemen used to come up here out of the out of the way of like work and that

I: (interviewer laughs)

I: Hide somewhere

P: (laughs)

P: The petticoat government like

ALFRED, P6, L259-269

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GRAHAM

"I'm going again," she said, "I told you!"

"I go once and if you don't like it you can..."

"And then erm there was a box of cards that one of the nurses had got they were samples like Christmas cards and things."

"I said I'm not going there, so she said "I know I-ah"

"I don't think so much but it look forward to...actually..."

"I quite look forward to coming here..."

"I-ah"

"Well, so you cut the front out and made an extra bit and put it together under;

"I-you didn't..."

"Yeah, and then there was some cards that had pop-up things and you know cutting the figures out and making Christmas cards..."

"I-ah wow..."

"And things like that..."

"GRAHAM, P9, L417-431"

"I-...I'm wondering whether coming here helps that.

"GRAHAM, P9, L101-102"

"I-...and you talked about not wanting to be erm housebound and not just wanting to watch television."
I: So it sounds as though you’re doing things?
P: Oh yeah, yes, yes
I: Yeah. And what is it about, you say you look forward to it and doing the activities. What is it about the activities that you look forward to?
P: Well, it’s keeping that (points to mind) going!
I: Oh yes, keeping your mind going.
GRAHAM, P9, L436-442

P: you know but err even just talking, different conversation err there’s all activities and things like that you know
I-right
P: play dominoes now and again you know
I-oh really
P: and I enjoy doing that
I-yeah.
JANICE, P8, L353-359

I-...So ermm what else do they do at the hospice?
P: We do err we play dominoes.
I-Yeah.
P: Yeah. And there’s and there’s two or three men they’ll either fall asleep and I say ‘right come on let’s play dominoes’
I-Ohh
P- so we’ll play dominoes
I-yeah
P: They enjoy that.
LUCY, P10, L454-464

worker’s alright and the volunteers, they’re marvellous.
I-Because they just volunteer don’t they?
P: Yes
I: They just come. And what’s marvellous about them? What’s marvellous about them? What do you find
P-Well, their personality really. I mean as soon as they see you there’s a smile.
I-Yeah
P: They aren’t grumpy or anything like that.
I-Ohh
SANDRA, P12, L574-591

P-Hmmm, They really are nice you know nice people and and understand you.
I-Right
CAROL, P7, L337-339

P: They’re just keep an eye on things and ermm they’re ermm I think they say things like ‘no swearing, no fighting’.
(both laugh)
I: It’s like you’re at the pub. Oh dear. So they look after you by the sounds of it?
P-Yeah and I’m thinking ‘well what about the staff attacking the patients’
(both laugh)
I-Should get them told
P-Yeah
I-Absolutely.
LUCY, P14, L684-695

P: Anything you can ask even if your whinging, they’ll give you as good as what you give them like so
I-Yeah
P: It really is.
ALFRED, P6, L297-300
## Sense of Self

### Unconditional Acceptance

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<tr>
<th>Unconditional Acceptance</th>
<th>The value of being cared about</th>
<th>Downward Comparison</th>
<th>Giving something back</th>
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<tr>
<td>P-but **** and **** and ****, they’re treat you really good. You know. You know They don’t treat you like an invalid.</td>
<td>P-And They’ve been good to me here, really good. I-Yeah mum</td>
<td>P-er, having said all that it could be a lot worse than it is, I’m grateful that I can do it I-yeah</td>
<td>P-...Just cos And I must admit, if I get well enough and I can cope with it, I’m going to volunteer for here so I can put something back. GREG, P8, L388-390</td>
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<td>I-I-Yeah ALFRED, P5, L247-250</td>
<td>P-(pause) err i like it here I-Erm is there anything HARRY, P5, L108-111</td>
<td>I-yeah CARL, P1, L35-37</td>
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<td>P-You, they never seem to get vexed with you not matter how long it takes you to do things. I-Right so they just then allow you to take as long as P-Oh yes. She says ‘you’re here to do what you want I-Ooh P-and if you don’t want to do it don’t bother’. I-Ooh right P-Yeah</td>
<td>P-... The drivers of the car that will bring us. They’re ever so good and helpful. I-because they're volunteers as well? P-Yes. I-They pick you up...? P-Yes, they pick us up and take us home. I-Mmm GRAHAM, P11, L518-524</td>
<td>P-... and when you look at people and see how bad you really can be, you’re grateful that you can still get about until lately you might say without any er, er need for er a wheelchair or anything like that CARL, P1, L15-18</td>
<td>I-...so when you say helping them? Do mean them as in, did you mean, because you said it it helps you and it also helps them, I’m just wondering who them is? P-Well you see I think it it’ll help them with their notes, I-Right P-You know when they’ve got to make the notes up and they’ve got everything gets under one roof I-Yeah P-You know whereas they’d have to make notes in **** notes in **** I-sure, so its the nurses that your thinking of? P-Coming I was referring to the nursing really I-Yeah yeah P-Yeah, so it just makes all the notes there you know I-Yeah</td>
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<td>I-Yeah, yeah. Now you mentioned that you erm that you can do what you want here. P-Yes. There’s ermm If there are things going on that you don’t don’t care to be interested in, you just either sit and read or go and sit with some of the others. SANDRA, P13, L614-618</td>
<td>I-They know what you can do and what you can’t do. P-Yeah I-And do they also know what you want help with? so P-Yeah. They’re quite good actually. I-Yeah LUCY, P12, L561-568</td>
<td>P-yeah you’re still in my case to get about, you only have to look around and see how bad it could be I-Right P- you know, you’re grateful for what you can do I-Mmm CARL, P7, L326-330</td>
<td>I-Yeah JANICE, P17, L768-782</td>
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<td>P-... If I want to go to sleep, I can go to sleep. If I I-Yeah GREG, P6, L278-280</td>
<td>P-What what er, She was in hospital on Tuesday working I-Was she P-but I didn’t know and I got sat down at the table and she she turned around and saw me well It was it was as if we hadn’t seen each other for ages. I-Ah, and it had only been less than a week? P-And yeah, and she said well ‘you’ll have to get yourself better’ and come I-Oohh SANDRA, P11, L537-545</td>
<td>P-yeah, it’s never easy is it to cope with an illness ermm but I think because of coming here you do see other people who are much worse than yourself and that helps you. I-Mmm CAROL, P8, 375-379</td>
<td>P-...I’ve got lavender bushes outside I-Oh</td>
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<td>P-Then if I don’t feel very, I feel, I feel a bit off today you know, soo they just well would you like to move to sit somewhere else on your own? you know I-Yeah</td>
<td>P-...some quite worse actually I-Mmm P- and I think psychologically it helps you to think that yeah, well perhaps **** things are not as bad as you might think they are sometimes I-yeah</td>
<td>P-...and that affects your coping? P- yeah, CARL, P7L 343-347</td>
<td>P-My daughter cuts it for me and I let it dry and I've made a little lavender bags I-Oh how lovely</td>
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<td>P-...I’ve come ever since you know, It’s been</td>
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<td>P-er, having said all that it could be a lot worse P-er, having said all that it could be a lot worse than it is, I’m grateful that I can do it I-yeah</td>
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P: have a bit of freedom from saying well no cos that would make me erm think well I am ill you know
I: Yeah
JANICE, P10, L440-446

P: I say the staff are absolutely fantastic.
I: Is there anything about what they do and it’s really hard to pinpoint but is there anything you can pinpoint about what the staff do that might affect your ability to cope?
P: Erm (pause) well I They don’t do they don’t do they every single thing.
I: Mmm
ALFRED, P6, L283-293

I: So you’re escaping?
P: Yeah and it’s just like stuck now a
Bu

P: I know where I live

I: What do you want a cup of this or a cup of that?
P: Oh, I think it’s helped a lot. Hmmm
HARRY, P5, L227-235

I: Right
CAROL, P8, L380-385

I: I can see you had a bit of freedom in there that do or not?
P: Oh yeah they can’t they can’t be nice. When you come in the drivers, I mean such as me walking with the frame from outside, the car, so the driver’s not there to help you because they’ve got to go back out for somebody
I: Mmm
P: but the carer’s they’re there they take your coat and ‘do you want a cup of this or a cup of that?’
I: Aw
P: ‘Do you want a glass of sherry’?
I: Yeah, yeah
P: You know oh they’re kindness itself
I: Aw
GRAHAM, P11, L534-547

P: I mean these people their’s their out of this world really
I: Mmm
P: and they they’re it’s mean do everything for you
HARRY, P3, L11-114

I: Is there anything else, there’s nothing else you’d like to mention about coping or about your illness or about coming here?
P: No er I couldn’t be treated better. There’s a guy who lives at ***** which isn’t very far from er where I live
I: Mmm
P: he picks me up from where I live he picks me up on a morning on his way here to help out. He’s a

STEVE, P4, L173-179

I: and just kind of maybe being able to compare yourself to them and your circumstances in comparison which might be helpful
P: Mmm
STEVE, P7, L308-311

P: That helps them to realise you know oh my ‘what have I got to worry about? You know
I: Mmm
P: I’m not half as badly off as they are’. Thank you
I: God sort of thing.
I: Yeah
CAROL, P8, L380-385

I: Can you tell me a bit about, what’s that and why that is? That’s a really hard question
P: It is
I: Yeah
P: It is erm (pause) because you’re erm in the company of other people who nine times out of ten are more seriously ill than I am
I: Right
CAROL, P7, L315-322

P: and er, sometimes I feel a fraud, you know, when I see people...there’s one person wheeled in and he just...he hardly speaks because the people who treat him you know, who look after him they have to put their ear up to his mouth and all he can do is......like that, that’s as much as he can do. He sits there with his eyes closed and his feet on a
I: Rest
P: Rest and er that’s all he does, now what sort of life is that
I: Yeah
P: I mean you’re grateful it makes you even more happy that it could be a lot worse than what it is, you’re grateful
CARL, P7, L331-342

P: Yeah like I say I’m sad for **** like you know he nuclear scientist was that one
I: Really
P: and know he’s just sat sitting the chair

P: We’re trying to do them a favour because they’re doing us
I: Yeah, So they’re kind of looking after you and providing things like activities and stuff and then you can also give something back?
P: Yes
GRAHAM, P14, L676-688

I: So what is this fair that’s happening?
P: Well it’s for, I don’t know exactly when it is because I’ve never been here at this time,
I: Yeah
P: Is erm to raise money for the funds.
I: Oh for the for the Hospice?
P: Mmm
I: Oh
GRAHAM, P14, L689-696

P: It is, it’s excellent and if I could just describe briefly the period I was in for three weeks
I: Mmm
P: it was excellent care, first class, excellent care.
I: Ah, brilliant
P: I’m just sorry that erm they have to rely so much on voluntary contributions
I: Yeah they do yeah
P: and if I could tell you this because of my circumstances, my wife and a friend and my sister last Friday, er, they have a Macmillan morning
I: Ah
P: a Macmillan coffee morning and my wife’s a pretty good cook and she made cakes, buns etc
I: Ah
P: and at the end of the day they sold raffle tickets, charged a pound for tea and coffee, they made together £550
I: Aahhh
P: which I thought was quite good
I: In one morning that’s fantastic
P: yes, it was good wasn’t it?
I: That’s amazing
P: they were delighted and so was I
I: Absolutely so that was, who was invited?
P: just friends, well as I say we have a large
I: You do have a large
P: circle of friends
then the time I get home and **** made a meal I might be ready for it then I-Yeh.
P: So do without a meal sometimes even when there’s even other people there or they say “do you feel you want to sit on your own and have your meal?” I-Yeh.
JANICE, P14, L635-650

P: ...But I insist on a thing that you put on that doesn’t make a mess. I-Because it can get quite messy with pottery and things yeah. So you put like an apron type of thing on?
I-Yeh.
P-Yeah.
I-I say where’s my apron?
P-Mmm
I-And they have one ready for you?
P-Yeah, everybody has an apron on LUCY, P17, L823-831

I- And ermm and if you didn’t want to do it, would you be able to say “no”?
P-You can drop out, Yes.
I-Yeah, yeah, Grahah, P11, L500-503

I-Do you get a choice if you didn’t want to do that, would that be ok or would you feel you had to…? P-Oh I enjoy doing that sort of thing I-And do you always do it? You said she’s come four times. Do you always join in?
P-Yeah, always yeah, I-Yeh.
P-always.
LUCY, P17, L832-839

volunteer and then I’m looked after first class here and then at three o’clock when he’s finished in the garden, he takes me home again. I couldn’t wish for a er, better treatment I-Yeh
P- so I mean there’s no improvement on that, perfection, there is no improvement on perfection I-absolutely
CARL, P8, L356-370
I- and how it might affect your ability to cope?
P-I don’t do anything myself, I mean they do everything for you. I-Yeh.
P-Yeh I-Thats sounds brilliant HARRY, P5, L202-206
P-...and they’re most helpful I-really
STEVE, P4, L179-181

I-So what is it you enjoy about doing that?
P-Well, we do it, when I said something to her, I said look at my nails, I’ve made an awful mess on this top here.
I-Ohh
P-On the tops of my nails, she says no but She says ‘no but your hands are getting work’ I-ahh
P-Ahhh
I-but you don’t notice P-logic in it you see
SANDRA, P13, L635-644

I-Can you perhaps think why people would not want to leave?
P-Well because they are looked after, you don’t have to cook your own meals I-Mmm
SUE, P22, L1086-1090
P-I just can’t fault them myself. None of them, Nothing’s any trouble or anything at all. I-Yeh
ALFRED, P6, L294-296

I’m not sure I’ve met **** but ermm P-Yeah he doesn’t say much at all. I-Right
P-He’s very quiet and ermm I don’t know whether the radiation’s got to him or what’s happened I-Mmm
ALFRED, P8, L367-376
P- and then I think especially when I’ve been to a place like **** **** Hospital I-right
P-I think I oh people years younger than me and they’re worse than me I-right
P- and that’s how I just look at it. I-Yeh
P-I can’t do anymore.
I-Yeah
P-So to places like **** **** and seeing those other people it seems like that helps?
P: Yes, yeah
I-Yeah
P- ‘cos I mean there’s kiddies going there and oh poor things and I think I-Yeh
P-oh, you know. I-Yeah
P-So there are days when it does get to you?
P-Well it does upset me when I see them, young people I-Mmm
P- you know going there and there cripples and things but you’ve got to put it out of your mind and think about yourself I-yeh
P-don’t you I-yeh
P-but you can’t help having thoughts about I-yeh
P-other people younger. GRAHAM, P3-4, L126-154

I-very generous group of friends P- yes they’re generous friends aren’t they? Yes, I-I would never have thought P- so we’re very pleased I-absolutely
P- I think it’s because of my circumstance that they were maybe so generous I-Yeh
P- but they are I-yeah, that’s a credit to you and **** definitely P- well, it’s a credit to the other people isn’t it for being so kind I-yeah, wow what a lovely story P- and we all appreciate what this place does us for us, particularly for me, I appreciate it Sarah, yeah.
STEVE, P7-8, L328-369

P-...And I said, we all said about our purses, ‘oh no’ she said ‘it’s free because don’t expect great big prizes you know’. Well I thought about it but its like having a sweepstake; you’ve got to pay something I-Mmm
P- and ermm ‘oh she said, money again.’ She’s like that. She said ‘well what do you suggest seeing as you brought it up?’ so I said ‘oh if we all give a little bit’ you know, I said it’s just a pleasure I-just a little bit yeah
P-she said ‘oh well, we don’t want much’ she said, what if we all put, because this was including the men who come on a Friday I-oh, ok, with everybody, yeah P-hmm so I said ‘well if we all put fifty pence in it would’ ‘oh,’ She said ‘that would help towards the costs of little bits we do’. I-Little bits
P-well To finish the cards of, I-ohh
P-so we put 50p in GRAHAM, P13-14, L630-650

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P: It’s ermm (sigh and pause) its such a relaxing place that makes me feel better.
I: Right
GREG, P8, L395-397

P: Ermm (long pause) for me it’s it’s ermm (pause) it’s uplifting and it’s ermm rejuvenating
I: Hmmm
CAROL, P7, L328-330

P: it makes you feel so much better.
CAROL, P11, L334

P: ...and ermm you go back home you know and you just feel replenished somehow and the next day, Saturday, I always have a good day on Saturday
I: Right
P: after being here on on the Friday,
CAROL, P7, L309-314

I: Would you say that affects your ability to cope as well?
P: Indeed it does oh most certainly. It lifts your spirits,
CARL, P7, L321-322

P: Yes, They make you feel ermm worthwhile.
I: Hmmm
P: Yeah
I: Yeah, It’s a wonderful thing to be able to do.
CAROL, P8, L353-356

P: ...and erm, yeah I do actually and it gives me a little uplift
I: ah
P: yes I’m sure, I’m positive of that. Yes, yes I am
STEVE, P7, L317-320

I: So you come once a week.
P: Yeah, ermm when I was at **** **** a while back, I was coming on the Thursday and **** once said could **** take me in for another day a week.
I: Mmm
P: I said, well I don’t know, I can’t answer that.
Anyway, they were in touch with each other and when I came the following Thursday, **** said to me I’m going to have you in two days a week, I said ‘oh lovely’ she said ‘only for four weeks though’.

I-Right
P- So for four weeks I was coming Thursday and Friday.
I-And why was that?
P-Well, **** thought it would boost me, give me a bit of a boost.
I-A boost in physical or mood or what kind of boost?

P-Well just mixing
GRAHAM, P8, L356-372

P-...and there are people who want to do this sort of thing and for no gain.
GREG, P8, L387-388

P-...and staff and everybody are so caring
I-hmm
CAROL, P7, L331-333

P-Hmm, Yes, yes, I think they do a wonderful job. I think It’s a gift.
I-Hmm
P-Its a gift
CAROL, P8, L357-360

I-So ermm something about the people who are here?
P-Ermm It’s the people. It’s not the place, it’s the people and people make it. They’re They’re nice people and they do nice things and they’re like being helpful.
I-Yeah,
GREG, P12, L408-412

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<tr>
<th>Belonging</th>
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<tr>
<td>P-Well yeah, I would say that and of course that lady that’s caring the jug now she used to live on the on</td>
<td>P-Nobody nobody moans about their illness. They get on and do their and enjoy their life and err their</td>
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the road where I live now just at the top, yes, ****
1- So There’s a real community in ****.
P- Yes
I- It sounds like everyone knows a bit about each other.
P- Yeah
SANDRA, P17, L828-834

P- Since I came here there’s err ****. She’s the one that wor
I- Oh lovely
SANDRA, P10, L471-474

P- You know, but we all talk quite well really you know
JANICE, P10, L453

P- Yeah, like I say its just camaraderie and you know,
ALFRED, P10, L467

P- And then when there’s a lot of you in the room having a quiet moment one of the err volunteers, she has
she says ‘oh shes we’ll have a game of bingo’
1- Ohhh
P- and someone says ‘are we having prizes?’ she’ll answer back ‘if you win a line you get one sweet’.
If you win the thing you get like a bar of chocolate you see
I- so If you get full house?
P- Yes, I- Ohhh
P- You see Everybody, it’s like a fun place.
SANDRA, P14, L666-676

P- We’re a good crack
I- Yeah
P- and we give as good as what we get and you think,
SANDRA, P6, L251-253

I- yeah ermm You mentioned the camaraderie between the lads. Is that -something that helps you cope
P- yes yeah
I- or affects your coping?
P- yeah it does ermm, They’ve been some nice lads,
ALFRED, P7, L326-330

P- ... and the, the er, other er, fraternal side to it you know where you meet people who are pleased to see you
I- yeah
P- friends in other words
I- yeah
CARL, P6, L248-253

getting on with coping coping with it.
I- Yeah
GREG, P11, L533-536

P- I sit there with two gentlemen
I- Yeah
P- and you know we discuss with each other how we’re getting along and we all seem to be sort of
improving generally
STEVE, P5, L217-221
P- ... but err but they’re coping and they’re cheerful and they’re dealing with it i think in the same way that
I’m dealing with it.
GREG, P11, L504-506

I- so has coming here i think i’ve asked this question already but just to make sure has coming here helped
with that rationality?
P- Yes because I’m dealing with other people who are dealing with it in a similar sort of way.
GREG, P10, L494-498

I- ah, so when you say you compare notes and talk to each other, is that with the other patients?
P- with the other patients, yeah
I- ah
STEVE, P5, L213-216

P- I mean, **** who came here just now, she’s dealing with it, she’s got cancer
I- Yeah
P- of some sort, I haven’t i don’t enquire. If she wants to tell me,
I- mm
P- she’ll tell me
GREG, P11, L498-504

P- And they’re all doing in much the same sort of way or the net result is in the same way. I can’t tell
what’s going on their minds but i mean the net result seems to be the same way which is good which
makes you feel more ok, maybe I’m doing something right.
GREG, P11, L537-541

P- then err you know you can sit long and thought the worse for yourself, their are people they coped with
it, well if they can cope I can cope,
JANICE, P8, L349-351

I- ... And ermm it sounds to me as though its something about all of you do it together.
P- We like doing it together
I- Yeah
P- which is nice because it’s company as well.
I- Yeah
GRAHAM, P11, L503-508
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P: And for me, yes it helps to mingle with people in a similar position to yourself
I: Right
P: some maybe not so bad,
STEVE, P 4, L 170-173

I: Erm yes, so erm, Is there something about the other patients that coming here is that helps at all?
P: (pause) the, All the people have something similar but we don’t talk about it,
I: Ahh
P: well not not in any detail and err we say ‘how are you’ ‘oh I’ve had a nice day’ and things like that
I: yeah
SANDRA, P11, L 518-525

I: yeah absolutely and do you think that’s affected your ability to cope?
P: It helps, it helps certainly. A problem shared is a problem halved. Is that right?
I: yeah that’s the saying
P: or something
I: yeah very much so
P: Mmm.
STEVE, P5, L 227-234

I: I wouldn’t say it’s for everybody. Some people are much more emotional and much less rational
I: And sometimes that works for them
P: and they’ll deal with it in their way
I: mmm
GREG, P10, L 471-475

I: yeah so you talk about some of your diseases and what, compare notes in terms of how you kind of progress...?
P: that’s right, we don’t write notes down **** (both laugh) no we don’t write them down, it’s a mental thing isn’t it
STEVE, P5, L 222-226

I: Yeah, absolutely, so something about talking to other people in terms of their erm their coping with something as well?
P: Yeah
I: Could that be something that...
P: I think that’s a help.
GREG, P11, L 511-516

I: I was going to say you exchange views don’t you, exchange views and compare notes, it’s important, it’s interesting isn’t it?
I: so is....
P: if only to progress
STEVE, P5, L 208-212

P: And it makes you think to yourself, Oh I never thought of that. I could do that you know. yeah

P- you talk to them
I-hmm
P- make lovely friends,
CAROL, P7, L323-325

P- actually do, I don’t mind coming at all coz err Like I say there’s some decent lads, **** and that and err
I- Hmmm
ALFRED, P6, L256-258

P- yeah. (pause) hmm I’ve met some good people in here.
I- Have you?
P- Hmmm yeah
I- Erm what its
P- I mean i know alot of them rest like
I- Hmm
P- but err good to get on with
HARRY, P3-4, L149-155

P- I think
I- Yeah
P- I really the world of **** and he’s a lovely bloke and **** as well.
I- Yeah
P- That’s the two I know ‘cos **** lives in the next village
I- Oh right
P- and I know **** ‘cos I’ve been coming here a couple of years
I- yeah
P- while he’s been here as well
I- yeah
ALFRED, P7-8, L344-356

P- I felt at ease as soon as they came in.
I- Yeah
P- just sat down and one of them said ‘oh that’s so and so, and that’s erm so and so she’s the loud one, you’ll hear her!’
I- (I laugh)
P- you know
GRAHAM, P15, L699-705

P- and you can talk to them as though you’ve known them for years
I- for years, yeah
GRAHAM, P11-12, L548-550

I- And so so does the you the fact that you know the hospice is something is quite sociable. Is that something that you enjoy or value?
P- Yeah quite. They’re getting to know me and I’m getting to know them.
I-Yeah, LUCY, P10, L476-480

P-...I enjoy it, and I enjoy the people as well, and we have a bit of chatter
I-Absolutely
P-Change them
LUCY, P18, L855-858

I-So have you been quite a quiet person in your lifetime?
P-Yeah, because I used, there’s ermm the chap there said to me he said ‘oh you must have been a builder!’ and I say ‘That’s right, I was a builder and I worked for myself. I can tell that by what he’s saying he said.’
I-Really?
P-Yeah
I-So he’s getting to know you
P-Yeah he’s getting to know me
LUCY, P15, L722-730

P-...and you felt as though you’ve known them a long, long time.
I-Yeah
P-You didn’t feel a stranger.
GRAHAM, P15, L705-708

P-And it’s like have a nice meal with somebody at the table,
I-Hmm
P-You know,
I-Yeah so you’ve talked about loads of things, about what you do here and the people here.
GRAHAM, P11, L530-534

I-...Who are they? Who are the volunteers?
P-Ohh they’re ermm thers all sorts, mostly ladies.
I-Right
P-Mostly ladies
I-Are they good to chat with?
P-They come and sit next to you because my hands are usually freezing…
I-What’s that about? Why?
P-Circulation
I-Circulation yeah
P-And my feet.
I-Yeah
P-They’ll come and say ‘oh you’re freezing!’
I-Ohh And do they rub and warm them up?
P-They might do, Yeah,
I-Yeah
LUCY, P14, L668-683

P-So when I get back I can just imagine, they’ll all be saying ‘oh it was a waste of time’ but what she did

I-Hmm, Have you got an example of that? I’m quite curious, with out trying to put you on the spot
P-Well really ermm, I go go for walks you know, Some of them seem to push themselves a bit more than what I do,
I-Oh right
P-Yeah, like the the next lady that I was speaking to she does she never sits down at all
I-Yeah
P-So but she’ll tell you that,
JANICE, P9, L414-424

P-I would rather stay with the group and I think it’s a good thing to be to be in a group
I-To be with others, yeah
P-All other people that’s got similarities of ermm you know varieties or interests, varieties of illness
I-Yeah
JANICE, P10, L447-452

P-I-No that’s brilliant, ermm I’m impressed by how well you articulate everything that that your coping with and being able to describe coping. I guess the next part of the interview is asking ermm how coming here has related to coping, to your ability to cope?
P-Oh yes,
I-Mm
P-I like coming here yes, I enjoy it yeah, and everybody else is so nice and it nice to see that there’s people err that you can talk to
I-Yeah
P-And you talk about their illnesses as well you know
I-umm
JANICE, P8, L333-345

P-I-Yeah, so you mentioned ermm about the conversations that you have here
P-yeah
I-and I’m wandering how they relate back to when you said that you were, that you had to cope with your friends being a bit different with you
P-yeah
I-does coming here relate to that?
P-Ermm not really no, here everybody else has their own problems
I-Mmm
P-Ermm you know like the one of the ladies here had a fall
I-Right
P-So she that’s the topic of today you know
I-Yeah
JANICE, P9, L388-402

P-while I’ve been coming there’s nobody who, for want of a word, ‘backed out’.
I-Hmm
P-You they’ve all been regulars.
I-Hmm
P-Some of have maybe missed coming if they’ve had appointments maybe with doctors or something
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**LUCY, P13, L624-630**

I...So that was some things about what you have to cope with and now I’m wondering whether going to the hospice helps with any of that?

P: Well I’m getting to know I’m getting to know and they’re getting to know me

I: Mmm

P: and they think ermm and they’re getting to know me

**LUCY, P7-8, L345-351**

I: Aww they seem it

**GRAHAM, P14, L697-698**

But err oh they’re a great bunch.

I: Hmm, You mentioned earlier about it being because of the atmosphere and the people and the staff

P: Hmm, Yes. I can’t, I’m sure that everybody you know, who comes will say the same.

**ALFRED, P8, L394-400**

I: Hmm, something about the people by the sounds of it

P: Mmm, yep

I: Yeah

P: Is it Good stock they say

I: Pardon

P: Good stock that you come from they say

I: Oh yeah absolutely

**ALFRED, P8, L394-400**

I: Yeah, yeah

**CAROL, P8, L367-371**

important but

I: Mmm

P: it’s just home from home.

I: Yeah and so does that suggest that other people enjoy it as well do you think?

P: Yeah, yeah.

I: Yeah.

**GRAHAM, P15, L711-725**

I: Mmm, something about the people by the sounds of it

P: Mmm, yep

I: Yeah

P: Is it Good stock they say

I: Pardon

P: Good stock that you come from they say

I: Oh yeah absolutely

**ALFRED, P8, L394-400**

I: Hmm, You mentioned earlier about it being because of the atmosphere and the people and the staff

P: Hmm, Yes. I can’t, I’m sure that everybody you know, who comes will say the same.

I: Hmm, yeah
**Appendix 18**

Reflective Statement
Reflective Statement

The following is a reflection of my individual research journey. It will include any pragmatic lessons learnt from the process of carrying out a large-scale research project. However in light of the qualitative nature of part of this research project I have also chosen to reflect upon the processes present whilst carrying out the research. In particular I will discuss the process of carrying out research with a terminally ill population and how biases and experiences have influenced this research project.

My research journey might best be described as slow and steady. I have learnt positive lessons about my ability to manage my own time and to work towards a long term goal. That is not to say that it has been an easy journey, in particular I have struggled with a feeling of not achieving anything despite putting in a lot of time and effort, however with steady dedication I have been able to consistently meet deadlines set by the course and myself. This is true of every deadline bar one, transcription of interviews. I was due to commence transcription in October of 2008 with the aim of being finished by February of 2009 thus allowing me ample time to analyse and write up my papers. However despite best intentions this did not happen. Initially I put this down to the time consuming nature of transcribing and my own lack of typing skills, however this didn’t seem to fit with my overall work ethic and attitude to this research project. I found myself asking why, when my motto throughout had been ‘keep on plodding’, had I allowed five months to pass without getting my transcription finished? The answer to this question that fitted most strongly for me was that I was avoiding becoming too involved with my interviews. Interpretative phenomenological analysis states that researchers should become ‘immersed’ in their data (Smith, Jarman, Osborn, 1999), however the idea of doing this filled me with great anxiety. I was frightened of what would be present in the interviews and whether I would be able to ‘handle’ it.
Fellow researchers had warned me when I proposed carrying out research with this population that I should ensure I had the necessary support to cope with what may come out. Even family and friends commented that I was doing something that not everyone would be willing to do by going to hospices (Specialist Palliative Day Care) and that it was somehow a sacrifice to myself. There appeared to be a general assumption that going to hospices and talking to terminally ill patients would be difficult and emotive for me. However, once I faced up to this fear I actually found the transcripts inspiring, which was also true of my experiences when spending time at the hospices.

On reflection I wonder if the assumption that I would be negatively affected by researching this population stems from a deeper assumption that what the patients themselves are going through is difficult and emotive. In hindsight it is clear to me now that I have held this assumption from the beginning of this research journey and that it has influenced the research in a number of ways. I have always maintained that I wanted this research to be ‘meaningful’ and ‘worthwhile’. Although I think this would be true of any research project I carried out, I feel this drive was especially strong in this instance due to the population involved. I was often conscious of the ‘fragile’ nature of these patients and the fact that they may not have a lot of time left. I didn’t want to bombard them with questionnaires and numbers that may not be beneficial to them. Therefore instead I chose to carry out qualitative research in an endeavour to be more personal and sensitive to this population who were going through a really tough time. Having carried out my systematic literature review I think this assumption may be shared by other researchers in the palliative care field. In relation to the papers I reviewed there was an average length of 8 pages, which when mentioned to peers was seen as ‘light work’. My patient information sheet when compared to peer equivalents is also noticeably shorter and more user friendly which I think reflects my assumption that
this population needs to be treat with ‘kid gloves’. Although this is a reasonable assumption and presumably made in good faith, it is an assumption all the same and could potentially cause problems for patients. By treating this population as ‘delicate’, we run the risk of disempowering them and socially excluding them from every day life. What became apparent both in my systematic literature review and empirical paper is that patients value the opportunity to maintain ‘normality’ whilst attending Specialist Palliative Day Care. Through communication, belonging, carrying out activities etc patients gained the opportunity to focus on life and break away from the assumption that they are invalids who need to be treated carefully. In light of this conclusion I have learnt the importance of being aware of the assumptions I am making about a population or setting and the influence these may have on my research and clinical work.

Vital to enhancing my awareness of any assumptions I was making, was the process of carrying out Interpretative phenomenological analysis. I had not carried out qualitative research before therefore I was initially struck by the uncertainty of not having a hypothesis to test or a questionnaire to administer. The freedom of qualitative research was incredibly daunting. For example, when developing the semi-structured interview schedule I felt a desire to fill the schedule with questions from previous coping literature, asking patients whether they utilised this strategy or that strategy. However on reflection I realised that this stemmed out of my fear of relying on participants accounts as this left me vulnerable to not producing ‘good enough’ research. I think this fear was strengthened by a self inflicted pressure to produce evidence that promoted Specialist Palliative Day Care and therefore wasn’t a ‘waste of time’ for the patients participating. Being aware of this bias helped me overcome it, as I was then able to ensure I grounded myself in the patients words and that I checked the
validity of results with my research and field supervisor. I think the fear of not producing ‘good enough’ research was also indicative of a parallel process present throughout the research. During the recruitment and analysis phases of the research project I had feelings of anxiety when away from the hospice or my transcripts. When thinking about the research in other areas of my life it became overwhelming, I worried about whether I was doing it right, whether I could face the hospice or whether I was strong enough to handle the transcripts. This left me wondering whether this could be paralleling patients’ experiences when they are away from the hospice. Further to this when I was at the hospice or analysing my transcripts this anxiety disappeared. I felt reassured and in control, I also felt this when talking to my supervisors. It is impossible to state whether my experiences truly parallel patients’; however they are interesting to consider in an effort to gain further insight into patients’ experiences.

Finally I wanted to acknowledge the problems I have had with endings in relation to this research. During the research I found myself wanting to carry out extra interviews, not wanting to stop analysing and being reluctant to finish the research project all together. The thought of ending evoked strong sadness in me as though I was betraying the patients by leaving them behind. I felt guilty for being healthy and being able to walk away from the hospice and from the awareness of death. I think this reflects the reality of what the patients are going through. For the patients there is no escape, the end for them is in sight. Whereas the healthy can defend against the reality of death through immersing ourselves in life, the terminally ill have to face death every day. As a healthy individual it was hard not to feel despair and hopelessness in response to this revelation; however I kept drawing strength from an interview excerpt in which the patient asked the nurse how she copes with patients dying? And the nurse said that she does the best that she can for the patient at the time and that she cannot do any
more. I hope that I have done the best that I can and that although I am leaving them
behind I have learnt a lot from having the chance to talk to them.

This area of research is undoubtedly emotive and difficult at times, however I
have found it to be incredibly rewarding and humbling and I look forward to further
clinical and research endeavours in the future.