Developing and evaluating a supportive nursing intervention for family members of people with lung cancer

May 2006

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Acknowledgements

The research team would like to thank all the patients, relatives and friends, and clinical staff that were involved in this project for the contribution they made to ensure its success at a time when they had many other demands on their time and energy.

We are grateful for the financial support from Guy’s and St. Thomas’ Charitable Foundation in the form of a grant and resources made available to us by the Florence Nightingale School of Nursing and Midwifery, King’s College London.

This report should be referenced as Plant, H., Sherwin, A., Moore, S., Medina, J., Ream, E., Richardson, A. May 2006. Developing and evaluating a supportive nursing intervention for family members of people with lung cancer. King’s College London.

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Developing a Supportive Nursing Intervention
Abstract

Background
Cancer engenders complex emotional and social reactions both in the patient and those close to them. Families may provide crucial support, yet their own distress may be as great as that of the patient. The NICE Guidance on Supportive and Palliative Care (2004) recommended the development of services to support family members. However, it remains unclear exactly what the family’s needs are, or how health care professionals might address them. This study aimed to develop and test the feasibility and acceptability of a supportive nursing intervention for family members of people with lung cancer.

Design
A concurrent mixed methods design that entailed the collection of qualitative and quantitative data before and after the inception of the intervention to examine the delivery process and outcome of the intervention.

Sample
Twenty-five family members of 20 people with lung cancer and 3 clinical nurse specialists (CNSs) participated in the study.

Intervention
Family members received an individualised supportive intervention from CNS. This involved an initial semi-structured ‘assessment of needs and experiences’ interview which allowed participants to articulate their concerns and explore how they were affected by their loved one’s cancer. At the end of the interview a tailored plan of ongoing support addressing informational, emotional, social and practical need was drawn up. Subsequent to this information and support were delivered by the nurse, both in person and over the telephone, for a period of 12-weeks.

Methods of data collection
Family members completed the Psychosocial Needs Inventory (PNI), 12-Item General Health Questionnaire (GHQ-12), Quality of Life Family Version Instrument (Family QoL), Carers’ Assessment of Managing Index (CAMI), and Family Inventory of Needs (FIN) at baseline and 12-weeks. A semi-structured telephone interview was undertaken three months from the inception of the intervention to determine participants’ views. The CNSs kept a log of the frequency and nature of all contacts and undertook two taped reflective sessions about their experiences during the study. A final taped focus group with the CNSs was undertaken to allow detailed discussion on the process, outcomes and utility of the intervention.

Results
The initial assessment on average lasted 60 minutes and the most common needs identified as a result of this were: need to explore uncertainty regarding the future (42%), treatment information needs (29%), point of contact/access to healthcare system (29%) and need for emotional support. One hundred and thirty four contact episodes occurred following the initial assessment and mean number of contact
episodes per carer was 6 (range 1-15), with most lasting 20 minutes or less and most likely to be initiated by a nurse, planned in advance and delivered by telephone.

Ten different elements to the intervention were identified, the most common included information/advice giving, active listening and monitoring carer well being. Overwhelmingly, family members expressed that ‘knowing someone was there’ had proved extremely valuable. The intervention served to: increase knowledge and meet needs for individually tailored information, facilitate communication between family members, improve emotional well being and facilitated coping, increase feelings of being supported and facilitate their role as carer.

Data collected through the questionnaires indicated a trend for more of a family member’s needs to be satisfied by the end of the intervention period. Scores on the GHQ revealed a significant reduction in overall distress (p<0.05) and scores on the Family QoL for physical, psychological and spiritual well-being, whilst not statistically significant, revealed a positive trend.

There were a number of aspects to the experience of nurses delivering the intervention. The work was perceived to be both challenging and rewarding. Overall, they perceived the intervention had served to meet the dynamic, diverse and unpredictable needs of family members, but had drawn considerably on their professional and personal resources. The nurses perceived that through closer communication with family members a smoother patient journey was achieved through supporting the carer and initiating timely and appropriate referrals for patients. Other opinions of nurses converged with those of family members. It appeared that the intervention provided information pertinent to carers needs, picked up on key concerns and enabled them to access the health care system particularly at times when either they or the patient were feeling vulnerable.

**Conclusions**

This study has demonstrated that experienced cancer nurses can deliver a supportive intervention for family members of people with lung cancer. A combination of emotional support and information, underpinned by assessment, lead to family members feeling well supported. This had a significant impact on their emotional well-being. The intervention should now be subject to further evaluation through the conduct of a randomised controlled trial. The training and supervision of nurses involved in delivering this type of intervention need to be addressed in future.
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1. Introduction

Cancer engenders complex emotional and social reactions both in patients and those close to them. Families provide crucial support, yet their own needs often go unrecognised and as a consequence can remain unmet. Close family members usually try to keep things going on a normal basis, consequently remaining ‘invisible’ (1).

Current UK policy has placed emphasis on the requirement for health care professionals to address the emotional, social and practical needs of the carers of people with cancer throughout the illness experience (2, 3). However, as the focus of professional care to date has remained quite naturally with the patient’s needs, it is not yet clear how best to achieve this. The NICE (3) guidance on supportive and palliative care for adults with cancer acknowledges that services for patients and carers are poorly developed and fragmented, and often targeted at those whose loved one is expected to die.

Family members watching their loved one experience the symptoms of cancer and its treatment can struggle to cope. Multiple issues come into play, including emotional strain, the physical demands of caring, uncertainty, fear, altered roles and lifestyles and matters of personal and sexual intimacy (4). While the emotional distress can be as great as that experienced by the patient (5, 6), it could be argued they have fewer opportunities to express their feelings.

There is a small amount of work looking at the needs of informal carers of people with lung cancer and the difficulties of meeting these needs from the perspective of healthcare professionals. Lung cancer remains one of the most challenging cancers both in terms of morbidity and mortality. It is the second most common cancer after breast cancer and the commonest cause of cancer death in the United Kingdom (7). The physical, psychological and social impact of lung cancer on patients and their family members is significant (1, 8). This is because most people diagnosed with lung cancer present with advanced disease (often very symptomatic) and die very quickly. Only about 7% of patients are alive five years after diagnosis and most people (about 75%) die within the first year (7). This leaves little time for patients and family members to come to terms with what is happening to them.

It is reported that carers of people with lung cancer feel isolated and invisible to professional carers (9). Furthermore, carers tend to subordinate their own distress and needs to those of the patient, needs they perceive as being more important and valid (1), leading to failure to provide the right support at the right time. Indeed one author (10) has gone so far as to say that current provision for informal carers can be described as crisis intervention, that services ignore successes and reward failure.

Where supportive interventions have been tested these have tended to use specialist services, such as psychology and psychiatry, to meet the needs of the most distressed carers (11, 12). These fail to address the broader experience of carers. Support at key transition points has been recognised as crucial, particularly at entry to the caring role (1).
Evidence suggests that carers suffer from a lack of information, minimal contact with health care professionals and ineffective support structures (1, 8). This may have significant consequences for both carers’ well-being, and that of patients, who often rely on the carer for physical and emotional support. There is however no literature recounting approaches for use in everyday practice that might serve to first assess and then meet needs for information and support for all, rather than those who are highly distressed, clinically depressed or anxious. The project that forms the subject of this report aims to begin to address this gap in the evidence.

The aim of the study was to develop and evaluate a supportive nursing intervention for carers of patients with lung cancer. As so little is known about the aspects of an effective intervention strategy for carers it was conceived as a feasibility study in which both the process of delivering, and outcome of, a newly developed supportive nursing intervention would form the focus of our enquiry.

The project was conceived by a group of individuals drawn from the practice and academic community. In particular the nurses in practice took the role of both researchers and subjects of research – in that they played a significant role in all aspects of the research process and were the individuals who delivered the intervention. Working together we developed the proposal, submitted an application for funding and subsequent to this executed the project that forms the subject of this report.
2. Literature Review

2.1 Introduction

The physical burden of cancer and its treatment may be exacerbated by the emotional, social, financial and practical issues, which affect both the patient and those who are close to them (12). With cancer care now being increasingly delivered on an outpatient basis the demands on the close family and friends to support the patient are ever more sophisticated and time consuming (13). Health professionals have recognised the importance of support for the family members of people diagnosed with cancer, both because of their own well-being as well as that of the patient (2, 3). However, family members are currently more often identified in terms of providing support rather than needing it (11). The focus of professional care still largely remains on the person with cancer, and ultimately this will always be the priority for the family as well (14, 15).

Research to date has not clearly identified the optimum nature and timing of support required by those close to someone with cancer or how this support should be most sensitively and effectively delivered (16). This review, whilst not being exhaustive will address recent debate and research relevant to the current project.

2.2 The experiences of those close to someone diagnosed with cancer

There are many factors that contribute to the way in which an individual experiences cancer in a close relative or friend. These include: their relationship to the person with cancer; the extent of the illness for example life threatening or chronic; their own health; their financial and social situation and particularly their gender (1, 4).

Several qualitative research studies have identified ways in which those close to a person with cancer may live through these difficult circumstances (17-20). These papers give a picture of close family members who despite their distress do not break down, managing to find ways of living with the illness to minimise the disturbance. This may require great emotional effort on the part of the relative, to manage the emotions of the patient as well we managing their own feelings which they may believe that they need to repress in order to protect the patient (4). Carers may often want to be seen as 'strong', 'positive, and 'carrying on as normal' with the need to manage feelings ‘in order to sustain a sense of control over events, to stave off the nightmare of death, loss and major life change and to promote healing’ (4), p. 538). Alongside this however, a ‘minority of cancer patients’ carers develop psychiatric disorders and a greater number develop high levels of emotional distress. These problems may become chronic but carers are unlikely to seek help’ (12), p.1518).

A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their partners confirmed a positive association between patient and close family psychological distress –partners were not found to experience significantly more or less psychological distress than the patient (5). Another study found that the emotional distress of the family can be as great or greater than that in
the patient (6). It is suggested that early intervention with support targeted at critical stages for both family and patient could prevent the later development of psychological distress (5). Discussing mental health issues positively influences the receipt of mental health services and could helpfully be pursued in this population (21).

A study which aimed to look at the concordance between the patient’s self report of quality of life and the family caregivers’ perception of the patient’s quality of life over time found that in general most caregivers were able to accurately rate the patients global quality of life, although this was least accurately for the psychosocial domains (22). The majority of participants in this study were married and the congruence of their reports reflects the partner’s close emotional and practical involvement with the patient’s experience and care. On the other hand cancer may put an almost intolerable strain on family daily routines, communication and relationships which without attention may be at threat of breaking down (23). Newly diagnosed cancer patients and their adult relatives who were able to openly express feelings and communicate information directly were found to have lower depression and anxiety (24). For adults with a parent with cancer changes in role and concerns about family relationships were central (25).

Cancer may put an almost intolerable strain on family daily routines, communication and relationships which without attention may be at threat of breaking down (23). Newly diagnosed cancer patients and their adult relatives who were able to openly express feelings and communicate information directly have been found to have lower depression and anxiety (24). For adults with a parent with cancer changes in role and concerns about family relationships were central (25).

The practical elements of having a close relative with cancer are also an important part of this experience and may be influenced by a number of variables. One study found that the most negative experiences were associated with low income, living with only the patient, a distressed relationship and a high level of patient dependency (26). A structured interview study aiming to describe care giving tasks among families of people with lung cancer found that providing emotional support was the most difficult and time consuming task, with transportation and monitoring symptoms also taking time (27).

The distress of those affected by the diagnosis of cancer in someone close may be manifest through a range of physical problems (28). Taking on the practical and emotional care work can be at great a physical cost. In a qualitative interview study half the sample interviewed had prolonged sleep disturbance and half also had disrupted eating habits, although this later resolved (1). Krishnasamy and Plant (28) utilising the work of Feigenberg (29) also describe the ‘exhaustion of uncertainty’ where those affected are ‘bombarded with fluctuating emotions, reactions and realities’.

The links between sleep loss and depression in family caregivers of people with cancer have been explored finding that progressive sleep deprivation affects emotions and ability to care (30, 31). When attempts were made to measure sleep quality it appeared to fluctuate widely over time responding to both internal and
external disturbances for example the patient’s current disease status and symptoms or the anxiety of the caregiver (30).

2.2.1 The needs of the family

Clark (10) comments that there needs to be a more precise understanding of the needs of informal carers, so that they can be supported effectively by public services. As a starting point it is contended that it is vital to distinguish and assess the carer needs as separate from those of the patient, with whose needs they may at times conflict (10). A study utilising a sociological approach and drawing on both qualitative and quantitative data to look at the psychosocial needs of cancer patients and their main carers found that 35% of participants had disability or long standing illness of their own (4). In this study, sub groups of carers who shared particular personal and social characteristics (for example young children) expressed similar needs with women and younger carers being most able to express their needs. The emotion work performed by the carers who took part in this research revealed that they put the needs and interests of the patient before their own (4). In another report on this same study the authors suggest that a clear recognition by health professionals of the carers’ involvement in the situation it will be easier for them to attend to their own needs alongside those of the patient (32).

Informal carers are more likely to have unmet needs if they are not the partner of the patient, or have other caring responsibilities and do not have others to call on for help (33). Those who do not live with the patient in particular may have unmet informational needs (34). The difficulties of negotiating the concerns of family members whilst respecting the needs of the patient, particularly if the informational needs about end of life issues for the family are different from those of the patient are inherent in palliative care (35). Through the use of focus groups and individual interviews these issues were explored, finding that terminally ill cancer patients and their caregivers have different needs for information about prognosis and end of life issues with the caregiver requiring more detailed information than the patient about the dying process. Open discussion and consistent information were considered important but it may not be possible to meet information needs of patient and family without having additional individual discussions (35). A further study with the families of palliative cancer found that communication was considered the most important factor in their experience but the respondents themselves did acknowledge that they required support (36).

There remains a lack of clarity about the informational needs of the family in the variable situations which they may encounter, it is unclear how these informational needs should be met and how the process of information exchange in the health care system can be improved (37). There is little information available about the cultural differences about preferences for information and support which may be present. Families frequently assume the role of caregiver with minimal preparation under sudden and extreme circumstances with variable guidance and support from the health care system (38). Meeting the needs of close the family of people with cancer is now not just an issue for health carers, but one which it is suggested needs to be addressed by society at large requiring creativity and energy from many disciplines (13).
2.3 Carers and caring

In the health, sociological and political literature the use of the term ‘carer’ to define those close to the patient (many of whom have chronic illness) remains commonly used and accepted – even if many of those who do provide care do not readily recognise themselves as belonging to a group of ‘carers’ (39).

‘Caring’ can be used to describe both practical and affective activities. ‘Caring for’ indicating the practical dimension of caring and ‘caring about’ the emotional dimension (40). However, for those close to someone diagnosed with cancer the caring dimensions are likely to be both practical and emotional with the potential to be exhausting and overwhelming. Care may involve practical help, giving drugs dealing with symptoms of cancer and providing emotional support (10). Furthermore, a person with cancer may find it hard to accept that their close family and friends have become defined as their ‘carers’ – particularly if they feel well. Schumacher (41) who interviewed patients and family during chemotherapy found self-care and care-giving were interconnected patterns of behaviour, with the requirements of the care-giving role waxing and waning during chemotherapy. The people with cancer who took part in her study ‘often vigorously resisted receiving help from others and strongly desired to maintain their self-care’ (41), p.263). If the intention is to increase professional support for the patient’s carers the very term itself might prove an obstacle implying that the ‘carers’ will be doing the caring. Furthermore, a lack of recognition of themselves as ‘carers’ has been identified in informal caregivers palliative care (11).

For the purposes of this current project we decided after deliberation to refer to those who participated as ‘family’ rather than ‘carers’ we found the Canadian Palliative Care Association definition as the most appropriate as follows; ‘those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract) and the family of choice and friends (not related biologically or by marriage/contract.)’ (http://www.chpca.net/home.htm) (42). Nevertheless the literature about carers provides helpful background context to this study and in reviewing these papers their terminology will be used.

One of the crucial issues when thinking about caring is highlighted by James (43), who argues that effective caring remains ‘invisible’ and it is often only recognised when things go wrong or become disordered. ‘Ignored and invisible’ is the title given to a research survey commissioned by the UK Carers National Association (44). Benner and Wrubel (45) also write that that those who provide care (they are writing particularly about nurses) ‘will feel the stress of being invisible’ (p368). So although it is widely acknowledged that families and carers do provide crucial support for patients, their importance and their own needs may go unrecognised by professionals (3). In cancer care despite a general belief in the need to support the family, the patient invariably receives more support and information than their close relatives (46). The family may remain unacknowledged because they may not perceive themselves as having needs and thus any contact with health professionals is likely to be couched in terms of how best to fulfil the patient’s needs (1).
Despite this, or rather perhaps because of this, there has been a growth of campaigning groups of carers from all areas of experience, though most notably chronic illness and disability (4, 44, 47). These have called for the carers’ contribution to society to be recognised both financially and practically. The majority of people in Britain who define themselves as carers are women (44, 48) and feminists have also argued the cause for this hidden domestic labour (39). These calls have to some extent been successful with the publication of a number of UK government policy documents (2). This however may not necessarily provide the mechanisms to filter down to the tricky day—to—day situations encountered by people with cancer and their carers, both lay and professional.

Caring can be both burdensome and rewarding. Current research reflects both these contradictory, but closely interwoven elements (4). Families require practical help to manage the situation, which if not received may lead them to feel overwhelmed. The actual activities that the caregiver may need to perform were less important than their own social circumstances in managing the situation, for example having poor social networks, restrictions on their daily activities or being young (49). However, it has also been acknowledged, ‘caring allows the person to focus on the event or the one cared for rather than on personal threat’ (45), p.3) and thus the caring itself may help people to live with the adversity of the situation. Semi-structured interviews at home revealed 60% of primary caregivers of advanced cancer patients were able to identify positive aspects of their role which possibly buffered the more negative aspects of the experience (50). The ‘emotion work’ involved in care-giving, particularly around the management of emotions – both of the patient and those close to them is key, particularly in cancer care (43, 51-53). If the family anticipate that professional support for them might remove some of their own ability and right to care then they can become suspicious and resentful (1). Any successful intervention to support the family will need to work collaboratively with family members to support and build on their own expertise and way of dealing with the illness.

2.4 Intervention studies aimed at supporting those close to someone diagnosed with cancer

Review of intervention studies aimed at supporting those close to someone with cancer or palliative illness identified few targeted interventions and a lack of evaluative studies conductive with small samples of carers (11). Moreover studies which have been conducted have suffered from low accrual and retention rates (54).

A further review of interventions with family caregivers of palliative care patients contends that few supportive interventions have been conducted or rigorously evaluated and comments that ‘there is an urgent need for new strategies to be designed and tested’ (50), p – In press). There is thus currently limited information on how to support the families of people with cancer with either their emotional distress or with the demands of providing care.

A number of approaches to developing and evaluating way of supporting close family of patient’s with cancer will now be briefly described.
2.4.1 Problem solving or educational group intervention

A supportive intervention in the UK which combined education and peer support focusing on the unmet needs of the informal cares of patients attending a home palliative care service was delivered over 6 weekly 90 minutes group sessions. The evaluation showed significant support and knowledge gained from participation. However, there was modest uptake for the group with those carers with the greatest perceived burden least willing or able to access this sort of intervention (16). A family caregiver cancer education programme, which addressed symptom management, psychosocial support and resource identification delivered to 187 participants in a small group format over three 2 hour sessions was evaluated immediately before and four months after participation (55). This confirmed the chronic and consuming nature of cancer caregiving and participation demonstrated that although caregiving tasks increased in intensity, the perception of burden remained the same and perceptions of their own health improved over time with an increase in the number of caregivers who said that they were well informed and confident about care giving (55).

The messages posted on an online support group accessible to the public for cancer caregivers were analysed for their content revealing the importance of hope, the experience of being on an emotional rollercoaster and their physical and emotional responses to their situation. All 38 participants of the group were women who appeared motivated to tell their story and vent their emotions to this group which, it is postulated may have facilitated their ability to continue with their caring responsibilities (although this was not measured) (56).

2.4.2 Telephone intervention

Much of the nursing support for the family of people with cancer is given over the phone in the clinical setting (57). A qualitative study looking at nurse interventionists conducting individual telephone calls to family caregivers or seriously ill cancer patients with the aim of enhancing the caregivers ability to cope with the stress resulting from the patient’s illness (58). The family are reported as being very appreciative of this support, but their satisfaction was not evaluated in any way. However, the authors comments that the caregivers would not initiate discussions about their own needs unless asked directly and were always more concerned to talk about the patient’s well-being.
2.4.3 One-to-one interventions (randomised studies)

A randomised study of a short term individual counselling program delivered by an oncology social worker over six sessions was designed to help spouses to cope with the stress of caring for their partner in the phase of the illness between initial diagnosis and treatment and terminal illness (59). These participants were found to be more distressed than the general population, but not as distressed as psychiatric out patients with low levels of caring activities. However, this intervention only appeared to be effective in a distressed sub sample of the participants. Another randomised study which looked at the effect of a family based intervention program over five contacts, providing information and support involving both the patient and their partner during the recurrent phase of breast cancer. The family members who received the intervention experienced significantly less negative appraisal of care giving at three months but this was not sustained at six months and there was no significant impact on quality of life (60). The response may be better sustained with a more intense ‘dose’ of the intervention, and ensuring outcome measure for psychosocial intervention studies are sensitive to the intervention goals (60).

A randomised study comparing health related quality of life (HRQOL) of family members who participated in a program of palliative care with conventional care in Scandinavia found that as they hypothesised HRQOL deteriorated over the terminal phase of the illness reaching a low point some time after death and then gradually improving. However, the expected increasing difference in scores between the control and the intervention group over time was only partially realised (61). A randomised study of care-givers of post surgical patients with cancer looked at how the carers’ experience was affected by having physical problems of their own and the impact of the patient receiving a home care intervention (62). This study showed that physical problems in the caregiver make them at increased risk of psychological morbidity, home care may be helpful in preparing them for what is to come (62). A further study which randomised patient and family dyads to a 10 contact, 20 week programme and aimed to assist in managing patient symptoms and reduce emotional distress did not indicate that this nursing intervention was effective in decreasing caregiver depression (63). On the other hand in a non-randomised study of a brief problem solving intervention for family caregivers of individuals with advanced cancer resulted in some improvements in emotional tension, care-giving confidence and positive problem solving orientation (64). Houts and colleagues proposed a prescriptive problem solving model for how care should be managed at home and for the kinds of information and training family caregivers should receive (65). Cancer pain management has also been addressed as an issue with which families need education and support (66, 67) but these models have not been fully evaluated.

Many of these studies suffer from a low participation and high attrition rate – possibly with the least distressed families (55, 59, 64). The participants except in studies of families of women with breast cancer are most likely to be female. Furthermore the findings from many of these studies are equivocal and it remains far from clear what is the best way to provide support for the families of people with cancer.
2.4.4 Barriers to effective supportive intervention

Even when support is available, close family of cancer patients may be hard for health care professionals to contact. A review of the literature to detail some of the common practice-based barriers to providing supportive care to family caregivers of patients receiving palliative care identifies three broad categories (68). These are: family-related challenges, including family functioning and incongruent patient and carer need, communication process barriers and health system barriers including lack of continuity of care and health professionals lacking skills and appropriate planning and evaluation. The carers of terminally ill patients may have limited contact with hospice staff for several reasons, these include, the carers visiting in the evening, relatives’ own unwillingness to approach staff and lack of time available to professionals – who spend the most time with the family when the patient is severely ill (14). There are several further factors which make communication between relatives of people with cancer and professionals difficult. These include the relatives invariably putting the needs of the person with cancer before their own, unfamiliarity with the health care setting – particularly if the relative is experiencing poor health and the relatives’ own ways of dealing with the illness, such as minimising the threat of the cancer and suppressing their own emotional expression along with often a strong need to care for the patient themselves (1).

Caregivers in palliative care were interviewed to look at why the needs that have been identified in caregivers in palliative care were not being met (11). Ambivalence among care givers about their own needs was identified and the authors recommend that any intervention should address their lack of identification with their role, enhance existing coping strategies and ensure that interventions are accessible and acceptable.

A further barrier is that the cancer patient themselves may not recognise that those around them may also need support during their illness. A survey of people with lung cancer and their informal and professional carers on perceptions of health care need, found that only 29% of the 209 patients questioned ‘stated that they believed their family or friend has particular needs in relation to their illness’ (8), p.91).

Health care professionals and researchers need to have an awareness of these obstacles that hinder the provision of support to family care givers, so that we can ‘begin to design and implement interventions that are clinically relevant and more likely to be effective’ (68), p.19).

2.4.5 Implications for the current study

A brief review of the current research about the close families of people with cancer reveals that those close to the patient will experience distress at varying levels dependent on their individual circumstances and have a high expectation (both from professional and from themselves) to provide some kind of care for the patient. ‘Deeply rooted within the core of palliative care philosophy is support for the family as well as the patient’ (68). Health professionals have a commitment to support the family but the best ways of doing so remain as yet unclear.
A review of the interventions to support the families of people with cancer to date suggest that interventions need to be tested that can be transported into standard care and should take account of the costs involved (54). It is also suggested that there should be larger randomised controlled studies with a clear theoretical base, consistently delivered interventions which utilise instruments which are sensitive to the effects of the intervention (54, 69).

Studies are needed to ‘identify and test interventions that will prevent or alleviate the stress and distress of caregiving’ (13), p. 6821). A meta-analysis of interventions with those caring for the elderly found that all interventions are likely to provide some support but psycho-educational and psychotherapeutic interventions showed the most consistent short-term effects, recommending the choice of intervention should depend on the goals wanted to be achieved (70).

The nature of professional support required to address support needs of family members during the initial and on-going experience of the cancer illness therefore remains unclear but is a pressing concern for practitioners, researchers and policy makers. Because of the protective nature of the relationships between cancer patients and their close family it may be more helpful to work at least some of the time with the patient and their relative separately. Any study will need to provide on-going support which is easy to access and flexible, maximising any pre-existing coping mechanisms and provide help over the whole experience; emotional, informational, practical and social.
3. Developing the Intervention

The previous chapter highlights the need for effective supportive interventions to improve the experience of care-giving for family members of people with cancer. Limited research suggests that interventions targeted at family members may improve outcomes but there is little guidance on the nature of such interventions. In this study, the authors have drawn upon key findings from the research literature to form the theoretical framework for the development of a supportive intervention for family members of people with lung cancer. These include:

1. The need to address the broader experience of family members rather than focussing solely on those who are most distressed
2. The need for interventions to target family members at key stages in the cancer pathway
3. The need to address the total impact of caring for people with cancer on family members’ emotional, social and physical well-being
4. The need to address family members’ information deficits in relation to the patient’s illness, symptom management, treatment plans and likely future outcome
5. The need to address and manage the uncertainty and fear associated with a cancer diagnosis, particularly lung cancer.

It was anticipated that the exact nature and content of the intervention would develop throughout the study process in response to the identified needs of family members and the nurse specialists’ perception of their need. However, it was anticipated it would incorporate the following key elements:

- Proactive; potentially preventing or reducing problems, rather than reactive; responding only when problems have already manifested
- Initiated by assessment of family member need
- Focussed primarily on the family member rather than the patient
- Providing individualised information and emotional, social and practical support.

This chapter outlines the initial development of the intervention.

3.1 Nature of intervention:

In defining and developing the intervention, the authors were keen to acknowledge that most family members do cope with the task of caring for a loved one with cancer and that most want to be seen as strong, positive and able to carry on as normal (4). Therefore, the main purpose of the intervention was to recognise and seek to build on and maintain the expertise, competence and well-being of family members. The model was educative and supportive; designed to work collaboratively with family members to identify any problem areas, reduce the emotional and physical cost of caring, and improve family members’ overall well-being and experience of caring.
The intervention was designed to explore and address the following key areas where family members are known to experience difficulties:

- The emotional strain of caring
- The physical demands of caring
- Managing uncertainty and fear about what may happen
- Altered roles, relationships and lifestyles.

The intervention adopted a 'person-centred approach'. This approach has its roots in counselling where Rogers (71) believed that three core conditions were essential for therapeutic relationships to be effective. These are empathy, genuineness and unconditional positive regard. Within nursing, this model has been translated in terms of techniques such as paying attention to detail, uncovering meaning in everyday situations, being attentive, available, reliable and true to promises, and understanding the importance of each person's own particular biography and how he or she is seeking to gain an understanding of what is happening to him or her (72).

The intervention was developed to target all family members of patients with lung cancer rather than those who were identified as having greater needs. The need for family members to be empowered so that they see their own needs as legitimate and have a sense of entitlement with regard to services was a key aim. In addition, because family members often find it difficult to voice their own concerns particularly in the patient’s presence (1), the intervention was targeted at the family member solely, rather than including the patient. Shifting the focus of care to include family members may ensure they feel less isolated and invisible, and overcome the obstacles that currently hinder support of family members.

The illness trajectory and survival for many patients with lung cancer is uncertain and frequently short. Unlike patients with other cancers, for example breast cancer, there is seldom a recovery period post-treatment during which patients are cured, in remission or remain well for long periods of time. Many patients suffer distressing symptoms from diagnosis and their condition may deteriorate rapidly. Therefore, identifying a definitive stage to target an intervention, where the needs of family members would be greater than at any other stage, is difficult. Currently, studies evaluating interventions with family members have focussed mainly on targeting the palliative phase of the cancer pathway. However, in this study it was felt that, given the known morbidity associated with lung cancer, most family members would enter into the caring role at diagnosis. Therefore, it was decided to target the intervention at, or near to, diagnosis. It was hoped that by targeting family members at an early stage in the patient’s pathway, the development of problems later in the disease trajectory might be prevented.

Consideration was also given to the optimal duration of the intervention. In previous research, interventions have been offered over a finite period of time or number of sessions, with the strongest effect obtained just after the intervention was delivered and lessening over time (54, 73). Booster sessions have been suggested as a way of extending the intervention effect for a longer period of time. In a disease such as lung cancer where survival is often short, it was felt that a 'one-size fits all' approach may not be appropriate. It was anticipated that family members would differ in the amount of support they needed depending on various factors, including their own
support structures, coping strategies and the patient’s illness trajectory. Therefore, a flexible, on-going and more responsive model of support was proposed rather than an intervention consisting of finite number of sessions.

3.2 Content of the intervention:

An audit of the nurse specialists’ current contact with family members during their routine care of patients with lung cancer (57) (see Appendix 14) suggested possible components of the intervention. This consisted of the nurse specialist acting as a key point of contact to:

- Provide expert information and advice regarding the patient’s disease, symptom management, investigation pathways, treatment options, medications, prognosis, diet, exercise, financial benefits, other sources of support, etc
- Assist family members in navigating the health care system and accessing help and advice where necessary
- Provide emotional support and monitor well-being of family member
- Assist family members to manage the uncertainty associated with patient’s disease and disease process
- Acknowledge and encourage family members’ care-giving role
- Provide social support including benefits advice
- Provide a source of continuity throughout the diagnostic, treatment and follow-up pathway.

The audit highlighted that contact may differ depending on the stage in the patient’s disease pathway and may continue after the patient has died.

It was anticipated that during this study, contact may differ from that reflected in the audit in response to the nurse specialists adopting a more proactive model of working with family members.

3.3 Design and delivery of the intervention:

The intervention was delivered by three hospital-based senior cancer nurses (two Lung Cancer Nurse Specialists and one Lead Nurse for Research and Development) with advanced communication, clinical skills and knowledge of the lung cancer pathway.

Initially, the intervention comprised two core components:

1. A standardised initial ‘Assessment of Needs’ interview
2. A tailored, individualised plan of on-going support.
3.3.1 ‘Assessment of Needs’ interview:

The ‘Assessment of Needs’ interview consisted of a face-to-face meeting with the family member and nurse specialist and lasted approximately one hour. The meeting was scheduled at a mutually convenient time, within the hours of the nurse specialist service, and held in a private room within the hospital. It did not include the patient. The interview was semi-structured and assessed the family member’s emotional, social, informational and practical need. It allowed the family member to explore the effect on them of their loved one having cancer and articulate any concerns. The main aim of the initial interview was to assess and, through discussion, plan with the family member how best to support their caring efforts. It was hoped also that it would serve a dual purpose in being therapeutic in its own right. Key skills employed by the nurse specialist during the interview included:

- Active listening
- Affirming, reassuring and supporting the family member’s role as carer
- Developing a relationship based on reciprocity
- Summarising and checking key issues discussed.

The interview was loosely structured and aimed to explore:

- Demographic details of the family member, for example name, contact details, relationship to patient, age, dependants, social roles etc
- Experience of what has happened thus far in patient’s pathway including the family member’s feelings and reactions to the patient’s situation
- Any deficits in information or understanding of what has happened and what is planned in the patient’s care pathway
- Any problems or concerns the family member has already identified
- Own health and physical/emotional well-being
- Social situation
- Social support network and coping strategies including previous coping patterns to any significant events in the past.

This interview allowed open consideration and discussion of the range of possibilities for a plan of support, based on well-grounded and shared understanding of the family member’s needs, resources and coping strategies. Any deficits in the family member’s understanding relating to the patient’s diagnosis or management were addressed during the interview where possible, or a strategy agreed to address these at a future time. At the end of the interview the following were identified:

1. Sources of further advice and support including the need for referrals to other health care professionals/agencies
2. Individualised, tailored plan of on-going support.

Following the interview, an assessment form was completed by the nurse specialist (Appendix 5). This served as both a data collection tool for study purposes and a clinical record summarising the interview and proposed plan of support.
3.3.2 On-going support:

A tailored, individualised plan of on-going support was agreed with the family member. The aim of this was to offer a range of services which matched the needs identified in the initial assessment interview and be sufficiently flexible to respond to changes in the care-giving experience over time. The family member could choose what level of on-going support they would like but were instructed that the level of support could change at any time depending on need. Previous research has identified that not all families need the same amount of intervention (54). Some family members have many resources and need less help; others have few resources and need more help. On-going support could be:

- Proactive: including regular, scheduled, face-to-face meetings or telephone calls between the nurse specialist and family member, or
- Reactive: where the family member is given the nurse specialist’s contact details and encouraged to make contact if they have any queries or concerns.

A tool was developed to record ongoing contact (Appendix 6).

3.4 Refinement of the intervention:

After two months, the nurse specialists held a reflective session to explore their experience of delivering the intervention thus far and discuss areas which might require refinement. During this session, it was acknowledged that the initial assessment interview was often emotional and the nurse specialist may be left with concerns over the family member’s emotional well-being. Therefore an additional nurse-initiated telephone contact was proposed and incorporated into the intervention. This took place approximately one week following the initial assessment interview. The purpose of this telephone contact was to check the family member’s well-being after the initial assessment and their satisfaction with the agreed plan for on-going support. In addition, it was hoped it would also serve to emphasise the intended supportive nature of the intervention and facilitate the family member to access the Nurse Specialist if this was required in the future.
4. Method

4.1 Introduction

This section provides a description of the methods used to carry out the study. It will include an outline of the design of the study, the sampling and data collection methods, and procedures for data analysis. It will conclude with a discussion of the ethical dimensions of the study.

4.2 Study aims

To date, little research has been conducted with family members of individuals with lung cancer which might be used to inform how nurses might address the emotional, social and practical needs of this group throughout the illness experience. Hence, this study aimed to develop and test the feasibility and acceptability of a supportive nursing intervention for family members of people with lung cancer. Broadly it sought to:

- Explore the needs and concerns of family members of patients with lung cancer
- Explore what sort of interventions are helpful for family members and what are not
- Explore the adequacy of chosen instruments to measure family members’ needs and the effect of the supportive nursing intervention on satisfaction with care received, emotional distress, quality of life and ability to manage and cope with the effects of cancer
- Develop tools to record nursing assessment of family members’ needs and nursing interventions
- Explore the potential of the supportive nursing intervention to effect change in key aspects of family members’ experiences and outcomes
- Explore the experiences of nurse specialists in delivering this sort of intervention

A description of the function and form of the intervention was presented in the previous chapter. Essentially through the execution of a feasibility study we sought to explore the perceptions of those receiving the intervention (the family members) and delivering the intervention (the specialist nurses) in terms of its process and outcome, in particular addressing appropriateness, acceptability, feasibility of the newly developed supportive nursing intervention.

4.3 Research design

As described above the study was concerned with evaluating the feasibility of a supportive intervention for family members of patients with lung cancer. In essence it was a pilot study and as such adopted a pre-test post-test mixed method design. It entailed the collection of both qualitative and quantitative data to examine both the delivery process and outcome of the intervention.
Developing a Supportive Nursing Intervention

The MRC framework paper on trials of complex interventions (74) acknowledges the specific difficulties in defining, developing, documenting and reproducing complex interventions (i.e. interventions that include several components). It has been recognised that problems often arise in the evaluation of complex interventions because researchers have not fully defined and developed the intervention. To counteract this it was suggested that the process of development and evaluation develop in a phased approach. Mindful of the MRC framework, and in view of the fact that very little intervention work with family members had been undertaken before, this study was conceived as a preliminary study - at the modelling phase of development. This phase concerns itself with identifying the components of the interventions and how they might influence outcome. It was envisaged that information collected would then be used to develop the optimum intervention (in effect its essential functions) and develop study design within the context of an exploratory trial. It also presented an opportunity for outcome measures for any future trial to be piloted to ensure they were relevant and encompassed measures of relevance.

The study adopted a mixed methods approach in that it collected and analysed both qualitative and quantitative data in a single study (75). This design was chosen on the assumption that collecting diverse types of data would best provide understanding of the research problem, converging data in order to provide a comprehensive analysis. It was anticipated that by bringing more than one source of data to bear we would be more successful in illuminating the process and outcome of the intervention. It employed a strategy of enquiry that involved concurrent data collection (gathered at the same time) to best understand our chosen research problem. Data collection involved gathering numeric information (i.e. family member outcome measures) as well as text information (family interviews, nurse specialist focus group and nurse records). As the priority for this study was to identify and understand the components of the intervention the qualitative aspect of the study took greater priority, and thus could be termed a concurrent nested strategy, where the quantitative was nested within the qualitative (see Figure 4.1). Our emphasis was on developing understanding of the active components of the intervention and its feasibility from both a service and user perspective. The quantitative aspect, namely the administration of standardised measures of outcome, were employed primarily to assess whether the selected instruments had the ability to sufficiently capture variables of interest and would perform satisfactorily within the context of a trial. Scores obtained would also give some indication of the intervention’s potential to invoke change. Integration of the data occurred at the data analysis and interpretation stage.
Furthermore, the study was undertaken in an iterative manner. At the mid point of data collection a review was scheduled\(^1\) in order to examine the process and outcome of the intervention and the need for any modifications. It was anticipated that this approach, a combination of qualitative and quantitative methods (see Figure 4.2), would serve to inform future study design and enable exploration of the many possible facets of the intervention.

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\(^1\) Recruitment & data collection ceased for a period of 6 weeks [Fri 19th Dec ’04 – Tues 18th Jan ’05 = 5 ½ weeks]
Figure 4.2. Research Design

<table>
<thead>
<tr>
<th>Qualitative Element</th>
<th>Pre-test Baseline (T1)</th>
<th>Post-test 3 months later (T2)</th>
<th>Process data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member interviews</td>
<td>Nurse specialist reflective meetings</td>
<td></td>
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<tr>
<td>Nurse specialist focus group</td>
<td>Nurse specialist contact records</td>
<td></td>
<td></td>
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<tr>
<td>Family member questionnaire</td>
<td>Satisfaction with intervention questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse specialist contact records</td>
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</tbody>
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Qualitative process and outcome data relating to the delivery of the intervention were collected. Throughout the study the nurses involved in delivering the intervention completed records of the initial assessment of family members, and subsequent contacts. Qualitative data were gathered via interviews with family members towards the end of the intervention period. A focus group was conducted with the nurses involved in delivering the intervention supplemented by reflective accounts.

The pre test (prior to delivery of the intervention) involved collection of data from family members through the administration of a series of standardised outcome measures:

- The Psychosocial Needs Inventory (PNI)
- The 12-Item General Health Questionnaire (GHQ-12)
- The Quality of Life Family Version Instrument (Family QoL)
- The Carers’ Assessment of Managing Index (CAMI)
- The Family Inventory of Needs (FIN)

The post test (3 months later) involved a repeat administration of these outcome measures.
4.4 Sample and setting

4.4.1 Setting

The intervention was conceived and developed by Nurse Specialists working within a cancer centre, as part of a multidisciplinary team, in a large London teaching hospital in South East England. This was also the location for the feasibility study.

4.4.2 Sample size

The size of the study was not determined through conduct of power calculations. The pilot study aimed to determine the feasibility of the recruitment and intervention process. Therefore, a sample size of family members of around 20 patients was sufficient for this purpose and considered reasonable within available resources and timescales.

4.4.3 Selection criteria

As the study sought inclusion of family members of around 20 patients diagnosed with lung cancer within the last two months, a convenience sample was drawn whereby the first 36 patients that met the inclusion criteria were approached either during an in-patient stay at an out-patient appointments.

In order to accomplish this, the Nurse Specialists identified patients from clinic attendance lists and patient notes, who fitted the inclusion criteria outlined below.

To be eligible patients had to:

- Have been diagnosed with lung cancer within the previous two months
- Be aware of their diagnosis of lung cancer
- Be able physically and emotionally to understand and cope with the research protocol
- Be able to speak and give informed written consent in English
- Be over 18 years old

Patients were excluded if they:

- Had been diagnosed with lung cancer more than two months previously
- Were physically or emotionally unable to cope with the research protocol (as judged by the clinical team - this was to avoid approaching people who would be unable to understand with the research process)

Family members of consenting patients were approached and, providing they fulfilled the inclusion criteria were invited to take part in the study. Therefore, recruitment of family members took place through patients.
To be eligible **family members** had to:
- Be aware of their family member/loved one’s diagnosis of lung cancer
- Be able physically and emotionally to cope with the research protocol
- Be able to speak English, give informed written consent, and complete a written questionnaire printed in English
- Be over 18 years old

**Family members** were excluded if they:
- Were unable to cope, both physically and emotionally, with the research protocol
- Family members with degenerative illnesses affecting cognition and comprehension (e.g. Alzheimer type disorders, severe mental illness)

### 4.5 Data collection

Data collected were concerned with both the process and outcome of the family member intervention, accessing the perceptions of those receiving and those delivering the intervention, namely the family members themselves and the Nurse Specialists involved in delivering the intervention. In the following section the nature of the data collection with the two different groups of individuals will be outlined.

#### 4.5.1 Family members

#### 4.5.1.1 Standardised outcome measures

One focus of the evaluation was to assess the suitability and ability of research instruments to capture the impact of the intervention on certain outcomes. It was anticipated that the key impacts of the intervention would be on experienced needs, family member satisfaction with support received, emotional distress, quality of life and ability to, and methods used to, manage and cope. Following review of the literature and discussion with experts in the field the following were selected:
1. The Psychosocial Needs Inventory (PNI)  
   To measure family members’ experienced needs and their level of satisfaction with support received

2. The 12-Item General Health Questionnaire (GHQ-12)  
   To measure family members’ level of emotional upset or distress

3. The Quality of Life Family Version Instrument (Family QoL)  
   To measure the family members’ perceived quality of life

4. The Carers’ Assessment of Managing Index (CAMI)  
   To measure the family members’ ability to manage and cope with the effects of the cancer

5. The Family Inventory of Needs (FIN)  
   To further measure aspects of family members’ experienced needs

The five instruments, which together formed the questionnaire booklet, administered at both baseline (T1) and 3 months later (T2) are detailed below.

4.5.1.11 Psychosocial Needs Inventory

The Psychosocial Needs Inventory (PNI), developed by Thomas et al (53), measures family members’ needs and their level of satisfaction with support received.

Family members rate a list of 48 statements pertaining to the psychosocial needs which carers sometimes have when facing illness. The 48 items have been re-grouped into the following seven psychosocial needs categories using a Cronbach’s alpha test for internal reliability (Cronbach’s $\alpha = 0.7$):

- Needs related to interaction with health professionals
- Information needs
- Needs related to support networks
- Identity needs
- Emotional and spiritual needs
- Practical needs
- Childcare needs

Family members rate each item - regarding importance and satisfaction of each need - along two 5-point scales: (1) ‘not at all important’ to ‘very important’ and (2) ‘not at all satisfied’ to ‘very satisfied’. An alternative choice can be made by ticking a ‘Does not apply to me box’.

The PNI was developed (including piloting) and through adapting the Home Caregiver Need Survey (HCNS) to a British context, and to the research requirements of Thomas et al (53). The HCNS had been developed as a result of a
series of studies carried out in Kansas/Missouri (76) looking to identify the needs of primary caregivers. Additionally, Thomas et al (53) carried out a literature review, and interviews, focus groups, and surveys with patients and carers which have further informed its adaptation.

Thomas et al (53) have acknowledged that this 'scale', as a whole, has not been subject to the usual kinds of validity and reliability tests as yet. It has proved, nonetheless, to be of considerable utility, and would benefit from psychometric testing in future. Discriminant validity has been established; i.e. the tool detected differences among needs at four critical moments of cancer trajectory.

Members of the team who played a part in developing the PNI, have reported on its use. For example, Soothill, et al (33) used the PNI to assess the unmet psychosocial needs of informal carers of cancer patients, finding that 43% of carers had significant unmet needs. Those with unmet needs were more likely to be family members of patients that were not their partner/spouse, family members likely to have other caring responsibilities, and family members less likely to have friends/relations to call upon for help. McIllmuray et al (77) also reported on the psychosocial needs of cancer patients using the PNI. The PNI has been used in the form of a self-completion questionnaire survey and suitable for use with both patients and informal carers (facilitating comparison, if appropriate)

For the purposes of this study, 4 PNI items were excluded. Following review by the project group, bearing in mind the target population and any overlap between the 5 instruments to be included in the questionnaire booklet, the following 4 items were removed:

- Support in dealing with any changes in the way others see me (Item 21)
- Support in dealing with changes in my body or the way I look (Item 23)
- Support in dealing with any changes in my sense of who I am (Item 24)
- Help in maintaining independence in the face of illness (Item 25)

4.5.1.1.2 General Health Questionnaire

The 12-item General Health Questionnaire (GHQ-12), developed by Goldberg & Williams (78) in London during the 1960s and 1970s, is the most commonly used international scale to measure emotional upset or distress. This tool was originally intended for use in general practice settings as a screening questionnaire for detecting independently verifiable general psychiatric morbidity (anxiety and depression). Patients rate a list of 12 items regarding their general health, over the past few weeks, along 4-point scales (Best – Worst).

Patients' ratings are then used to calculate an overall score, ranging from 0 to 12. This score is used the screen for whether an individual can be classified as a GHQ 'case', or is presenting 'caseness'. According to Goldberg & Williams (18) the patient could then be deemed to be at risk of suffering from a mental health problem. The most commonly used cut off point used by Goldberg & Williams (78) is that of GHQ 2/3, whereby all patients with an overall GHQ score of 3 or higher would be viewed as a GHQ 'case'.

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The GHQ is one of the most widely tested and used scales to assess psychological wellbeing, and is regarded as having strong reliability and validity. The test-retest correlations range from \( r = 0.51 \) to \( 0.90 \) (78). Internal consistency has been reported to range from \( \alpha = 0.77 \) to \( -0.93 \) (Cronbach’s \( \alpha \)). Split-half reliability was tested with 853 respondents, and the correlations were high at \( r = 0.95 \). Although slightly less sensitive, the GHQ-12 is as efficient as the 30-item version. The scale is designed for self-completion, and has been administered by postal survey and by interview.

4.5.1.1.3 Quality of Life Family Version Instrument

The Quality of Life Family Version Instrument (Family QOL), developed by Ferrell (79), measures the Quality of Life of a family member caring for a patient with cancer. This 37-item ordinal instrument can be grouped into the following QOL domains or subscales

- Physical Well Being
- Psychological Well Being
- Social Concerns
- Spiritual Well Being

The caregiver indicates the degree to which they agree/disagree with each statement, by means of an 11-point scale (0-10); 0 = worst outcome to 10 = best outcome.

The family version of the QOL tool is an adaptation of the patient version QOL tool. The instrument was revised and tested from 1994-1998 in a study of 219 family caregivers of cancer patients. Test-retest reliability of the whole instrument was found to be \( r = 0.89 \), with an internal consistency of Cronbach’s \( \alpha = 0.69 \) (Personal Correspondence; Betty Ferrell – 10th March 2004).

This instrument can be used in research/clinical practices to gain information about Quality of Life of caregivers. It can be administered by mail or in person. It has been used in the past to assess the impact of cancer pain education on family caregivers of elderly patients (79), to explore cancer pain management by family caregivers (66) and the experience of pain from the family caregivers’ perspective (80).

For the purposes of this study, 3 Family QOL items were excluded from the study’s questionnaire, following review by the project group. The following 3 items were removed:

- How distressing has the time been since your family member’s treatment ended? (Item 15)
- Are you fearful of a second cancer for your family member? (Item 18)
- Are you fearful of recurrence of your family member’s cancer? (Item 19)

4.5.1.1.4 Carers’ Assessment of Managing Index

The Carers’ Assessment of Managing Index (CAMI), developed by Nolan, Grant, and Keady (81), assesses the managing, coping, and needs of people caring for a family member or friend with mental health problems. The CAMI explores how useful
certain coping strategies are seen to be, and to build a picture of each carer’s unique coping efforts. Family members rate 38 carer-generated coping strategies using a 4-point scale; ‘I do not use this’ to ‘Very helpful’. These 38-Items were generated primarily from carers themselves, and shaped by theory and previous research (81, 82). The internal consistency of the tool has been reported to possess a Cronbach’s $\alpha = 0.85$ (82).

The CAMI can be used as part of an assessment interview, or it can be self-administered. On a self-administered basis, the instrument has been found to be easy to complete; and can be accomplished in a matter of minutes. The CAMI was primarily designed to provide an individual profile for each carer’s circumstances, but statistical evidence suggests that the instrument can be used for epidemiological purposes (to look at the prevalence of certain types of difficulties, satisfactions and coping patterns amongst populations of carers).

### 4.5.1.1.5 Family Inventory of Needs

The Family Inventory of Needs (FIN), developed by Kristjanson, Atwood & Degner (83), measures the perceived importance of care needs of families of patients with advanced cancer, and the extent to which these families felt their care needs have been fulfilled. This 20-Item tool has two subscales with established construct validity and internal structure. They are as follows:

- The FIN-Importance of Care Needs subscale – The internal consistency of this subscale was found to be Cronbach’s $\alpha = 0.83$ (83)
- The FIN-Fulfilment of Care Needs subscale – The internal structure of this subscale was established using cluster analysis (due to it being a dichotomous variable) (83)

Each of the 20 items are rated with a score of 0-10 (Not at all important to Very important), and then checked to indicate whether each need has been Met, Partly Met or Unmet (FIN modified in June 2004 to include ‘Partly Met’ option – Kristjanson L J; Unpublished).

This tool was developed based on the family needs literature and previous research, including that surrounding family satisfaction with advanced cancer care in the form of the FAMCARE Scale, developed to measure family satisfaction with advanced cancer care (84). The tool is designed for use in research and clinical settings. It has been modified to take the form of a version for husbands of women with breast cancer (85).

### 4.5.1.1.6 Pre testing of instruments

Pre-testing of the instruments was undertaken in order to ascertain acceptability. Four of the instruments (the PNI, the GHQ-12, the Family QOL, and the CAMI) were piloted with eight family members to ascertain their experiences of completing the tools, through use of a feedback sheet (Appendix 1).
Feedback resulted in the project team’s decision to include a further measure of outcome; that of family members’ needs; a key area flagged by family members during the pre test. The FIN was selected from the relevant literature and piloted with a further six volunteers.

The overall feedback from a total 14 volunteers lead to the project team deciding to:
- Remove a total of 7 questionnaire items (4 from the PNI and 3 from the Family QOL as detailed in earlier sections).
- Amend the layout of the instruments, in order to facilitate completion.

Feedback further informed the team of the feasibility of family members completing the outcome measures in a suitably convenient length of time – it took an average of 20mins.

4.5.1.2 Telephone interviews

The interviews aimed to determine family members’ use of the service Family member intervention, their views on it, their satisfaction and any factors inhibiting and facilitating its use. A semi-structured interview approach was adopted, using open-ended questions, in order to elicit views and opinions of the family members and guided by a topic guide (see Appendix 3).

The family member interviews were conducted over the telephone and tape recorded. This method was adopted to ensure minimum inconvenience to the family member, sparing them the need to fit the time and travel required for a face-to-face interview into an already busy ‘caring’ schedule. There was an option for a face-to-face interview if the family member was more comfortable with this. Of the 23 family members who agreed to be interviewed, 22 were interviewed over the telephone, and 1 chose to be interviewed face-to-face.

The interviews took place towards the end of family members’ involvement in the study, approximately 3-4 months after they were recruited and after they had completed the 2nd set of questionnaires (at T2 = 3months). The schedule included items allowing family members’ to describe their impressions of: their contact with the Nurse Specialist (NS); their main concerns and any influence their contact with the NS had on these; their level of information regarding the disease and their satisfaction with this; the ease of making contact with the NS; their preferred method of contact with the NS (telephone/face-to-face); the helpfulness of the service; their foreseeable support needs; and the suitability of the service provided. These interview items enabled the research team to gain insight into the perspectives and opinions of the family members regarding the intervention delivered by the Nurse Specialists.

The team were aware some patients might die within the study period. Indeed, sadly 4 patients did die during the course of the study. However, family members continued to access the intervention, if they so desired. These bereaved family members were approached and invited to take part in the interview by the relevant nurse specialist, and it was found acceptable to all 5 family members (of the 4 patients).
Each interview was designed to last approx 30mins, and conducted in the main by the RA. Interviews were conducted by a Nurse Specialist in a few cases (13% (N = 3/23). This occurred in cases where it was considered more appropriate for a very experienced nurse researcher to undertake the interview with family members at high risk of experiencing emotional distress i.e. In the case of distress resulting from bereavement.

4.5.2 Nurse Specialists

The Nurse Specialists providing the family member intervention kept a written record of the outcome of the ‘Initial ‘Assessment of Needs and Experiences Interview’ (i.e. the initial assessment) carried out with each family member. They also kept a record of all subsequent contact with family members.

Furthermore, on completion of the study, the Nurse Specialists took part in a taped focus group: This allowed detailed discussion of the process and outcomes of the intervention.

4.5.2.1 Initial assessment and further contact records

Documentation was specifically designed by the Nurse Specialists to collect process as well as outcome information, focussed on:

1. The outcome of the initial assessment carried out with each family member
2. A record of any subsequent contact with these family members

Through these two sets of written records, which the Nurse Specialists were asked to complete for each family member, it was anticipated we would be able to track the frequency and nature of contact and capture any significant issues associated with the process of intervention delivery. The records had a dual purpose in that they also served as a clinical record and were intend to capture a summary of family member experience to date, main needs of family member identified, resources/information supplied, referral made, and agreed management plan.

The *initial assessment* record documentation gathered demographic information on the family member and the patient, and details of the timing of the first contact (e.g. at the treatment stage). This documentation further allowed the recording of the experiences and needs expressed by the family member, and of the reflections of the Nurse Specialist throughout the assessment. (See Appendix 5)

The *further contact* record documentation enabled the Nurse Specialists to keep a record of the date, length, and form of subsequent contact (telephone/face-to-face). The documentation also allowed the recording of the object of the contacts/visits with the family members. It summarised what was covered, and to whom patients and/or family members were referred to. (See Appendix 6)

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2 Reviewed in reflective sessions outlined in the Intervention Section of this report
4.5.2.2 Focus group

On completion of the study, the NSs took part in a focus group. This allowed detailed discussion on the process and outcomes of the intervention, and the utility of the emergent ‘Assessment of Needs and Experiences Interview’ and fostering therapeutic discussion. Discussion also focused on take up of the service, and factors inhibiting and facilitating its use. The focus group was tape-recorded (For Focus Group Schedule see Appendix 7).

4.6 Study procedures

From the onset it was intended to schedule a mid way point of review of both study procedure and the family member intervention model. Therefore participants were recruited in 2 waves of recruitment, 3 months apart. Potential participants were identified through their nomination as the main person affected by their loved one’s lung cancer diagnosis. This process is outlined below.

4.6.1 Recruitment process

Recruitment was undertaken over a period of 7 months between October 2004 and April 2005. Patients whose family members were viewed as potential research participants and fitted the inclusion and exclusion criteria, were identified by the Nurse Specialists. Once identified the Nurse Specialists informed the Research Associate (RA) of potential patients and they were then approached either in the clinics or on the wards.

The RA provided patients with a written patient information sheet outlining the study (Appendix 8), along with an in-depth verbal explanation. Once patients felt they fully informed of the study protocol, the RA undertook the consent process with patients who were agreeable to their family member(s) being approached. This exchange transpired in a separate and private space (room, quiet hallway) in order to enable uninhibited questioning to take place.

Twenty-seven patients gave their written consent (Appendix 9) for their family members to be approached regarding their potential participation in the study.

In cases where the family member(s) of the consenting patients were not present in the ward / clinic: The RA provided the patient with a written information sheet, on the background of the study (Appendix 10), to give to their family member(s).

In cases where the family member(s) of the consenting patients were present in the ward / clinic: The RA provided family member(s) with the information sheet (Appendix 10), along with an in-depth verbal explanation. This occurred in a separate and private space in order for unrestricted questioning to occur, and for rapport to be

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3 This review informed adjustments to the nurse records, the shape and content of the intervention, and confirmed best practice for participant recruitment
developed (as the RA would be their key point of contact throughout their participation in the study).

*In both cases*, the family members’ contact details were taken, and family members given a minimum of 72 hours (3 days) to allow them time to make an informed decision and agree (or not) to take part in the study. After this time period had elapsed, the RA telephoned the family member(s) to address any queries or concerns; and ascertain their willingness / gain verbal consent to participate.

The RA undertook the consent process with family member(s) at a later meeting (e.g. at their following visit to the hospital) or by posting them a consent form (along with their 1st questionnaire and a SAE).

At this point, the participants had been identified, approached, and successfully recruited.

### 4.6.1 Consent process

The consent form completed by the patients, in order to gain access to their family member(s), comprised agreement for the research team to approach their family member(s) for potential recruitment to the study. Additionally, if their family member(s) was successfully recruited the patient understood that their condition and treatment might be discussed by their family member/friend with the Nurse Specialist where relevant. (See Appendix 9)

Family members recruited to the study consented to having an initial assessment, completing 2 questionnaires 3-months apart, and carrying out an interview to be tape-recorded, on the understanding that the tape would be destroyed at the end of the project.

### 4.6.2 Data gathering process

Following recruitment the RA posted the 1st questionnaire (at T1) made up of 5 instruments (Appendix 2) along with an informed consent form (Appendix 11).

The family members were instructed to return these items to the RA and once returned the RA informed the Nurse Specialists of the family members’ consent to participate; and forwarded the family members’ contact details.

This allowed the Nurse Specialists to contact each family member by phone to set up the first appointment for their initial assessment - the starting point of the family member intervention. The family members’ appointments were arranged for a face-to-face meeting with the Nurse Specialist at a time convenient to the family member. Alternatively, if a face-to-face meeting could not be arranged, the initial assessment was carried out over the telephone at a time convenient to the family member.

If the family member did not return the consent form (plus 1st questionnaire) by post to the RA before the initial assessment, OR did not take it with them to their first
appointment (for the initial assessment) with the Nurse Specialist, the family member was able to complete a new set of paperwork (consent form plus 1st questionnaire) upon arriving for the initial assessment, as the Nurse Specialist possessed spare copies.

The initial assessment was scheduled to last from 1hr - 1 ½ hrs. Details of this first meeting were recorded by the Nurse Specialist by means of the study documentation (outlined in the previous section). Following this initial assessment, the Nurse Specialist was available to be contacted by telephone or face-to-face for both support and information. The Nurse Specialist – by means of their record-keeping documentation – also recorded details of these subsequent contacts.

Three months after the completion of the 1st questionnaire (at T1) the RA sent a 2nd questionnaire to each family member, to be returned complete and returned (T2). The RA also contacted each family member and scheduled a tape-recorded interview, to be carried out over the telephone.

On completion of the study, a focus group with the Nurse Specialists was carried out to discuss the outcome of the intervention provided to the family members on the study.
4.7 Research governance

4.7.1 Ethics

In planning the research project, involving as it does a potentially vulnerable population of family members of patients with lung cancer, we anticipated we would meet a number of ethical challenges.

Principally, the intervention comprised educational, supportive and psychotherapeutic/psychodynamic elements. The research team did not envisage that the approach would place participating family members at risk of adverse effects; although there was potential for inconvenience and some disruption to daily life (e.g. in organising a meeting with the nurse specialist). This issue was addressed through the nurse specialist organising all meetings to fit in with visits to the hospital required by the patients’ treatment/follow up appointments.

In addition, participation in the study was not expected to put participants at risk of damage to their health, or cause any pain or discomfort. However, the research team were aware that participation, through completion of the questionnaires and interviews, and the intervention process, could emotionally distress family members, by encouraging the exploration of feelings and concerns regarding the patient's condition. In fact, it was hypothesised that the nature of the intervention, delivered by experienced cancer nurse specialists, would not only reduce emotional distress in family members, but family members might also feel positive through taking part in the study through the knowledge that it will generate. Research participants often voice that they like to make a contribution that may enhance the care of patients and their families in the future.

The research team aimed to keep the duration of participation (for questionnaire completion and interviews) to a minimum, in appreciation of using/taking up participant family members’ time; endeavouring to minimise any possible stress of participation.

The Nurse Specialists and stakeholders were also viewed as potentially benefiting from reviewing their regular working practices, and reflecting on how nurse specialists might enhance or improve cancer services.

A research proposal taking all these issues into account was submitted to, and given a favourable opinion by, the relevant Local NHS Research Ethics Committee [Guy's LREC Project Reference Number 04/Q0704/15] and associated Research and Development Committee.

As with all research, care was taken during the study to ensure family members’ (and patients’) details and responses were kept anonymous. To this end, patients completing the questionnaires were allocated a study number. Their name did not appear on any documentation other than the consent form and clinical records, which was stored away from other data that were generated.
The conduct and progress of the study was monitored and guided by a Project Group, which included researchers from King's College London and Nurse Specialists from the participating hospital. The group met at least every 6-8 weeks throughout the study.

4.7.2 Data protection

All data were stored in accordance with the Data Protection Act (1998). Therefore the single file linking the family member’s ID and information identifying the family member (e.g. family members names and contact details used to maintain contact during the 3 months of their participation) was stored on a computer and password protected with a code known only to the research team. No other documentation linking family members’ IDs and details of their identity (electronic or otherwise) were stored for this study.

In future presentations of quantitative or qualitative data, all family members will be referred to only by their study ID number. In this way comments are not attributable to any particular individual.
4.8 Data analysis

The analysis of quantitative and qualitative data (see Figure 4.3) was undertaken with the purpose of enabling in-depth understanding of the possible benefits that might be accrued from introducing an intervention such as this; and the conditions and resources that might be required for such a service to be to be introduced; and the perception involved for both those receiving and providing the intervention.

Figure 4.3. Analysis plan

As represented in Figure 4.3, all quantitative data resultant from the questionnaires completed by all family members, at T1 and T2, were submitted to descriptive tests, and inferential analysis to determine the relative efficacy of the intervention. All qualitative data attained from the telephone interviews with family members, and from the Nurse Specialists’ focus group, summarised and key quotes transcribed verbatim, were subject to Framework Analysis (86). Framework Analysis allows commonly held views and discrepancies in opinion to be described. In combination, the analysis outlined above was aimed at giving rise to complementary and insightful findings relating to the family member intervention.

4.8.1 Family member questionnaires

The data from the 5 outcome measures (described in section 4.5.1.1) recorded the impacts of the intervention on: needs and satisfaction; emotional wellbeing; quality of life; and both ability to and methods used to manage and cope. These data were gathered at T1 (baseline) and T2 (3 months), entered into an SPSS database and then submitted to inferential and statistical analysis with the use of Microsoft Excel and the SPSS statistical package.
Data from the Psychosocial Needs Inventory (PNI) were described including calculation of means, standard deviations and ranges for the applicability, importance and satisfaction of PNI items.

Data from the General Health Questionnaire (GHQ-12) were submitted to descriptive and inferential statistics. Firstly, tallies and frequencies were calculated and scores then compared at T1 and T2 using a paired sample t-test. GHQ-12 scores were also grouped according to ‘caseness’ or ‘non-caseness’ and compared at T1 and T2 using a 2x2 Chi-square test.

Data from the Quality of Life Family Version (Family QoL) were described through the comparison of mean subscale scores, and mean scores for individual items.

Data from the Carers’ Assessment of Managing Index (CAMI) were described by means of percentages and frequencies of the number of participants who used each coping item, and who found each item to be helpful.

The Family Inventory of Needs (FIN) data were described by tallying the number and percentage of items rated by importance, and calculating the average participant responses regarding whether each need item was met / partly met / unmet.

4.8.2 Family member interviews

All the participants who completed the final evaluation (n= 23) were happy to undertake a taped semi structured telephone interview (one took place face-to-face because the participant had a speech impediment). This included 5 bereaved family members who all remained keen to continue with the study. The usual length of the interviews was 20-30 minutes. The relevant details were transcribed verbatim.

The interviews transcripts were analysed using a thematic framework as described by Ritchie et al (86). Initially, two researchers familiarised themselves with the data by reading through a random sample of 12 interview script. From these, recurrent themes or concepts were identified. At this point, the two researchers collaborated on their findings and defined the initial themes. These themes were sorted and grouped under a smaller number of broader, higher order categories or ‘main themes’ and placed within an overall framework. There was little disagreement between the researchers about the emergent themes as all the interviews were reporting similar comments and experiences with their contact with the nurse specialists. After analysis of 8-10 transcripts both researchers felt confident that they were reaching data saturation.

The researchers then independently applied the framework to the data from all the 23 interview transcripts and then met to further collaborate in refining and describing the main themes. These results were then tabulated to display the themes and associated quotations from the text enabling a clear and accessible representation of the findings and further elaboration and definition of each theme (86). (For detail please see Appendix 4).
4.8.3 Nurse Specialists’ assessment and contact records

Data were available in the form of written documents completed by the three intervening nurses. Analysis was undertaken in three discrete phases. First, the initial needs assessments were analysed independently. Second, all subsequent contacts were analysed. Third, the context of each episode of contact was determined.

Analysis of the initial assessment (free text records) was undertaken to identify family members’ needs identified during the assessment interview. In order to gain an overview of these data a sample of six records were read and re-read by one member of the research team to identify initial themes. This familiarisation process included records from all three intervention nurses. An index was then drawn up requiring sorting and grouping of themes into a hierarchy providing both main and sub themes (86). Textual terms (staying close to language and terms used in data set) were used to capture the essence of the theme or sub theme. The framework was discussed with the research team to check it captured and ‘named’ needs in ways that reflected the understanding of the intervention nurses. The framework was then applied to the data from all 24 assessment interviews and the frequency of different types of needs calculated.

For each contact subsequent to the initial assessment a similar procedure was undertaken involving the free text nursing records to arrive at reason for contact, management plan and nature of intervention delivered. As before an index was created from a sample of six records by one member of the research team. After the validity of this index was checked with the wider team, it was applied to these data and frequencies calculated.

Finally, each family member record was summarised numerically to provide the context of the meetings and provide a description. This summarised the number of contacts with each family member, who made the contact, method of contact, initiator of contact following initial assessment, length of contact and interval between contacts. This was undertaken with Excel.

4.8.4 Nurse Specialists’ focus group

The aim of this element of the investigation was to understand the experiences of those that had delivered the intervention to family members of people with lung cancer. It sought to describe how these nurses worked with the family members, depict the essence of what was delivered and explore the benefits for family members and patients of this approach. Further, it sought to unpick the inherent challenges of instituting the family member intervention programme.

Data were collected through the conduct of a focus group with the three intervening nurses. This research method was adopted given focus groups’ propensity to generate rich data from providers of health care and their utility in studies that involve complex issues that entail many levels of feeling and experience (87). It was anticipated that the three nurses, given their differing backgrounds, and varying clinical experiences and exposure to research could have insightful and differing

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4 One of the 25 carers was not assessed due to the practicalities of the patients’ illness
Developing a Supportive Nursing Intervention

opinions. Lively discussion and debate frequently arises in focus groups as the social interaction typically stimulates greater discussion than arises with individual interviewing (88). Further it can allow complex issues to be clarified and elaborated upon and when working well allow new ideas to emerge (89).

The focus group was undertaken in a quiet room within the Trust and continued for over 1.5 hours. During this time participants articulately described their considered opinion. Conversation flowed freely as they explored issues in detail, provided examples to illustrate their points and sought to unpick the complex issues of how best to intervene with this group of family members. Their discussion was recorded by audio tape and field notes written to prevent loss of data.

Data were analysed in a series of stages. First the audio recording was replayed and a detailed transcription was constructed. Transcription was not verbatim, rather the sequence of the conversation and topics covered were recorded. These were illustrated by numerous verbatim quotes. This transcript was re-read and the tape listened to as two of the research team independently drew up an index of codes. These were compared to check for completeness and to provide a validity check. In the event, the two indexes were very similar. They were combined and the integrated index (Appendix 13) used to code the focus group data.
5. Results

5.1 Introduction

The results chapter is organised to provide a description of the impact of the Nurse Specialists’ intervention on family members’ experience of supporting a patient with lung cancer. It presents outcomes of analyses conducted on both qualitative and quantitative data provided by Family members and Nurse Specialists. Before coming to these findings, the chapter will begin with an overview of sample accrual and attrition, and a description of the demography of the different samples that provided data during the study (i.e. the family members and the nurse specialist).

5.2 Sample accrual and attrition

A total of 36 patients were introduced to the study and consented to the team accessing their family members. All 36 patients approached granted access to their family members. Forty-four family members of these 36 patients were approached over the period that data were collected (October 2004 to April 2005). Twenty-five of these family members (57%) agreed to participate.

The 19 family members (43%) that did not wish to participate commented that this was for a variety of reasons summarised by the following sentiments: ‘this is not the right time’, ‘I already have enough on my plate’ or ‘too much going on [with loved one’s illness]’, ‘it would be too destabilising to our way of coping with the illness at the moment’ or ‘it’s not my sort of thing’ (See table 5.1).
Table 5.1. Reasons for family members declining participation in the study

<table>
<thead>
<tr>
<th>Reasons for declining participation:</th>
<th>Total (N = 19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members felt that they had enough in their lives at the time:</td>
<td></td>
</tr>
<tr>
<td>- And they felt they had enough support from family members</td>
<td>(3)</td>
</tr>
<tr>
<td>- “It’s not the right time” / “Too much on my plate”</td>
<td>(3)</td>
</tr>
<tr>
<td>- “Enough reminders / focus on the disease”</td>
<td>(2)</td>
</tr>
<tr>
<td>- “Too much going on” - with patient’s illness</td>
<td>(2)</td>
</tr>
<tr>
<td>Family members were difficult to get in touch with, i.e. They never returned calls or the consent form.</td>
<td>(4)</td>
</tr>
<tr>
<td>“Not my sort of thing” / “not the kind of thing we do”. I.e. Participating in research</td>
<td>(3)</td>
</tr>
<tr>
<td>Family members said they would let the research team know if they were interested – They never did</td>
<td>(2)</td>
</tr>
</tbody>
</table>

The 25 family members that were recruited to the study over the 7-month data collection period were the family members of 21 patients. Of these 25 recruited family members, 23 provided completed the study questionnaire at baseline (T1) and then again at 3 months later (T2). The remaining 2 family members only provided data at T1. This was due to these family members’ personal life becoming considerably busy and stressful at T2 and they declined to complete it.

Please see Figure 5.1 for a diagrammatic representation of the accrual and attrition of the study family members (carers) sample.
Figure 5.1. Flow diagram of accrual and attrition

Patients approached and consented
N = 35

Carers accessed and approached
N = 44

Carers recruited
N = 25

Carers declined
N = 19

Data provided at T1
N = 25

Females
N = 23

Males
N = 2

Data provided at T2
N = 23

Females
N = 21

Males
N = 2

Bereaved
N = 5

Bereaved
N = 0

5.3 Demography of the family member sample

Demographic data were collected on all family members approached regarding the study, i.e. from both the 25 family members that agreed to part in the study and the 19 that did not. These are summarised in Table 5.2.
Table 5.2. Family member demographics

<table>
<thead>
<tr>
<th></th>
<th>Overall (N = 44)</th>
<th>Family members who declined participation (N = 19)</th>
<th>Family members recruited (N = 25)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>39 (89%)</td>
<td>16 (84%)</td>
<td>23 (92%)</td>
</tr>
<tr>
<td>Male</td>
<td>5 (11%)</td>
<td>3 (16%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td><strong>Age (years):</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average (SD)</td>
<td>Data not available</td>
<td>Data not available</td>
<td>54 (12)</td>
</tr>
<tr>
<td>Range (years)</td>
<td>Data not available</td>
<td>Data not available</td>
<td>30 – 72</td>
</tr>
<tr>
<td><strong>Relation:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter / Stepdaughter</td>
<td>18 (42%)</td>
<td>4 (21%)</td>
<td>14 (56%)</td>
</tr>
<tr>
<td>Wife / Partner</td>
<td>16 (36%)</td>
<td>9 (48%)</td>
<td>7 (28%)</td>
</tr>
<tr>
<td>Husband / Partner</td>
<td>5 (11%)</td>
<td>3 (16%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Other**</td>
<td>5 (11%)</td>
<td>3 (15%)</td>
<td>2 (8%)</td>
</tr>
</tbody>
</table>

**Others: Included a Daughter-in-law and a friend (recruited), and a sister, a son, and a niece (declined).**

Of the 25 family members who were recruited to the study the majority were female (92%) and the daughter or stepdaughter of the patient (56%). Their mean age was 54 (SD = 12). Of the 19 family members who declined participation, the majority were female (84%) and the wife or partner of the patient (48%). By the time the 3-month intervention period had elapsed (at T2) 5 of the family members (of 4 patients) were bereaved. These 5 family members were all female.

Of the 25 family members who participated in the study, 23 agreed to be interviewed. All 5 bereaved family members took part in the interview. 2/23 of those family members interviewed were male; 1/23 of the interviews took place face-to-face (vs. over the telephone); and 3/23 were conducted by one of the nurse specialists.

The 2 family members who declined to take part in the interviews had busy and stressful personal lives at the time, and therefore declined participation.

5.4 The family member experience

This was described and analysed through data recorded on family member-nurse contacts, data gathered through the interviews conducted with the family members, and through the questionnaires completed by the family members.
5.4.1 Nurse records

The data discussed in this section was derived from the records maintained by the nurses delivering the intervention. These recorded data on the initial assessment of the family members and all subsequent contacts between family members and nurse specialists.

5.4.1.1 Analysis of the initial assessment

The initial assessment (IA) was carried out for 24/25 of the family members. This was due to obstacles presenting themselves on the occasions that the 25th family member and the nurse attempted to schedule this. Following a number of these attempts, it became inappropriate to attempt to carry out the IA (this was mutually agreed by the family member and the nurse). Despite the IA not being carried out for the 25th family member, the nurse kept a record of the subsequent contacts with this family member, during the intervention period.

Of the 24 initial assessments that were carried out between the nurse specialists and the family members, 75% (N = 18) were carried out face-to-face, and remaining 25% (N = 6) were carried out over the telephone. A total of 26 hours and 28 minutes was spent on carrying out the initial assessments.

The mean duration of the initial assessment was approximately 66mins (range 30mins - 105mins), with most initial assessments (67%) lasting over 1hr.

The analysis of the needs on initial assessment lead to the following 12 needs being identified in the 24 family members with who the initial assessment was carried out:

1. A need to explore uncertainty re the future (Identified in 10, of family members assessed = 42%)
2. Information needs re treatment (N = 7; 29%)
3. Point of contact/access into the healthcare system (N = 7; 29%)
4. Emotional / psychological support (N = 6; 25%)
5. Information needs regarding the cause / management of symptoms (N = 5; 21%)
6. Information needs regarding the disease (N = 4; 17%)
7. Financial needs (N = 4; 17%)
8. A need to be kept informed (N = 4; 17%)
9. Information needs re other sources of support (N = 3; 13%)
10. A need to talk / tell their story (N = 2; 8%)
11. A need for practical advice / support (N = 1; 4%)
12. Information / advice needs for other health problems (N = 1; 4%)

No needs were identified for 4 of the 24 family members with whom the initial assessment was carried out (17% of family members)
5.4.1.2 Analysis of ongoing contacts

25 family members of 21 patients were recruited to the study over 23 weeks\(^5\). Following their recruitment they were each provided with the intervention over a 12-week period; commencing with an initial assessment.

During the 39 weeks that the study ran\(^6\), 134 contacts – following the initial assessments – were recorded between the nurse specialists and the family members\(^7\). Additionally, a total of 33 hours and 54 minutes\(^8\) was spent on nurse-family member contact over those 39 weeks.

The average number of days that elapsed between nurse-family member contacts was 12 days, with a range of 0 - 49 days. This range accounts for the fact that family members often had contact with the nurses on more than one occasion in the same day. The mean length of ongoing contacts was approximately 17 mins (range 1 min - 105 mins), with most contacts (85%) lasting 20 min or less (Figure 5.2).

**Figure 5.2. Percentage of contacts and their duration**

![Bar chart showing percentage of contacts and their duration](image)

The mean number of contacts per family member during the 12-week intervention period was 6, ranging from 1 to 15 contacts.

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\(^5\) Recruitment: 28/10/04 – 07/04/05 = 5 months & 1 week (23 wks). Involvement of carers in study: 16/11/04 (1st init assess) – 27/07/05 (Last exit interview) (37 wks)

\(^6\) The study ran for a total of 39 weeks (9 months – from the start of recruitment to the last exit interview)

\(^7\) Contacts following the 3-month intervention period were not included in these analyses

\(^8\) This amounts to approximately 1.7% of the Nurse Specialists’ working time / man hours (i.e. an average of 1 hr and 38 mins per week) [Based on 2 x 37.5 hrs (FT CNSs) + 22.5 hrs (PT Nurse Specialist) per week]. This time only accounts for the contacts, not any activity required to respond to carers’ queries and needs.
In recording the contacts, the following was documented: Whether the contact was an agreed follow up contact or not; who initiated the contact (nurse or family member); and the mode of contact (telephone, etc).

It was recorded that 75% of the subsequent contacts (N = 101) were agreed upon ahead of time, and therefore planned, while 25% were not (N = 33).

Sixty-seven percent (N = 90) of contacts were initiated by nurses (25% ad hoc and 42% planned (e.g. an agreed upon phone call to inform the family member of the outcome of a conversation with a consultant). Family members initiated 25% (N = 34) of contacts. The remaining 8% of contacts (N = 10) were mutually agreed upon (e.g. a face-to-face meeting).

Most contact (83% of occasions; N = 111) took place over the telephone; on 4% of these occasions (N = 5) an answer-phone message had to be left. 16% of contacts (N = 22) were face-to-face – on one occasion a patient was also present. Additionally, one contact (1%) took place by e-mail (see Figure 5.3).

**Figure 5.3. Percentage of contacts by form of contact**

![Bar chart showing percentage of contacts by form of contact]

In addition to looking at the medium by which contact occurred, the following were also explored:
- The reasons for contact
- The outcomes of contact
- The intervention styles delivered at each point of contact

These three aspects of the contacts were summarised into 3 lists (See Appendices 12a, 12b & 12c).
In analysing the reasons for the contacts between the family members and the nurses, the total contacts were coded/classified into ‘family member reasons’, ‘nurse reasons’ and ‘mutual reasons’ for contact (See appendix 12a).

It was found that the majority of all contacts (52%), were mutual or nurse reasons, as follows:

- For mutually planned (but not necessarily scheduled) meetings or contacts usually to provide information or emotional support - Such as for a planned follow-up call made by the nurse to inform the family member of the outcome of a discussion / test result / etc (12%); or a general inquiry/update regarding the family members well being (12%); or in order to carry out the initial assessment (12%).

- Or they were initiated by the nurses because they wanted to generally enquire about a family members’ well being (16%). Half of these particular contacts were incidental (i.e. the enquiry occurred due to contact with the patient).

The most common reasons for family members contacting the nurses – comprising 16% of the reasons for contact – were:

- To discuss the patients' treatment plan (4%)
- To review the current situation (4%)
- To obtain emotional support (4%)
- To gain information or advice (re. the patient’s condition; symptom management; or discharge arrangements) (4%)

The nurse-family member contacts usually resulted in a number of specific outcomes. The five most common outcomes of contact – constituting 89% of outcomes – were:

1. An agreement for the nurse to call the family member (at a specified or unspecified point) in the future – in order to update the family member on the patients' condition, enquire about the family member themselves etc (37%)
2. It being agreed that subsequent contact would be made by the family member as and when they wanted or needed help, support, or information (32%)
3. An appointment being scheduled for a face-to-face meeting (9%)
4. That the family member was unavailable when the nurse tried to make contact (8%)
5. An agreement to call again with the outcome of a discussion with the doctor, or having secured information from other health professional (e.g. discharge) (3%)
The nurse records provided a summary of the nature of each contact episode. A coding framework (Appendix 12c) was developed and applied to the records in order to elaborate on the nature of the intervention delivered by the nurses during their interaction with family members. This enabled the scope of the intervention, and the frequency with which different aspects of it were delivered, to be described.

Ten different elements were identified (Table 5.3). One hundred and thirty four contact episodes took place between family members and nurses. During these contact episodes the 10 elements were delivered in varying combinations. During the course of the 134 contact episodes, a sum total 453 units (comprised of 1 of the 10 elements) of the intervention were recorded as having been delivered (see Table 5.3).

Table 5.3. Frequency with which ten different elements of the intervention were delivered (N = 453)

<table>
<thead>
<tr>
<th>Elements of Intervention</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information / advice giving</td>
<td>171</td>
<td>37.3%</td>
</tr>
<tr>
<td>Listening</td>
<td>99</td>
<td>21.9%</td>
</tr>
<tr>
<td>Monitoring family member's well-being / maintaining continuity in nurse-family member relationship</td>
<td>54</td>
<td>11.9%</td>
</tr>
<tr>
<td>Helping family member 'navigate the system'</td>
<td>33</td>
<td>7.3%</td>
</tr>
<tr>
<td>Enabling expression of emotion</td>
<td>32</td>
<td>7.1%</td>
</tr>
<tr>
<td>Acknowledging and providing reassurance over role as family member</td>
<td>22</td>
<td>4.9%</td>
</tr>
<tr>
<td>Acknowledging and exploring patient’s condition</td>
<td>18</td>
<td>4%</td>
</tr>
<tr>
<td>Bereavement support</td>
<td>18</td>
<td>4%</td>
</tr>
<tr>
<td>Benefits</td>
<td>7</td>
<td>1.5%</td>
</tr>
<tr>
<td>Helping with decision-making</td>
<td>1</td>
<td>0.2%</td>
</tr>
</tbody>
</table>

The most common elements delivered during the contact episodes were Information/Advice Giving (171/453, 37.6%), Listening (99/453, 21.8%) and Monitoring the Family member’s Wellbeing (54/453, 11.9%).

The least common elements delivered related to giving Benefits advice (7/453, 1.5%), and Helping with Decision Making (1/453, 0.2%).
The majority of the Information / Advice Giving involved:

- Symptoms / symptom control – 21% of information / advice giving
- The treatment process – 15%
- Managing uncertainty (around living with someone with cancer/lung cancer) – 13%
- The disease process – 10%

The majority of ‘Listening’ carried out by the nurses was with respect to family members’ current or recent experience of the cancer experience (62%). A distinction was drawn between the element of ‘Listening’ and ‘Enabling expression of emotion’. The former encompassed listening to family members tell their story and that of the patient’s from their perspective, often through recounting a narrative which enabled the family member to make sense of a situation. The latter involved creating an environment that allowed people to share their distress, not only in words, but also the emotions they were experiencing, for example allowing the family member space to cry or get angry.

Table 5.4 shows the percentage of contact episodes (N = 134) on which each of the 10 elements were delivered. In a third of the contact episodes Information/Advice Giving, Monitoring of Family members Well Being and Listening took place.

**Table 5.4. Percentage of contact episodes on which each of the 10 elements were delivered (N = 134)**

<table>
<thead>
<tr>
<th>Elements of Intervention</th>
<th>N</th>
<th>Percentage*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information / advice giving</td>
<td>64</td>
<td>48%</td>
</tr>
<tr>
<td>Monitoring family member's well-being / maintaining continuity in nurse-family member relationship</td>
<td>52</td>
<td>39%</td>
</tr>
<tr>
<td>Listening</td>
<td>49</td>
<td>37%</td>
</tr>
<tr>
<td>Enabling expression of emotion</td>
<td>28</td>
<td>21%</td>
</tr>
<tr>
<td>Helping family member 'navigate the system'</td>
<td>20</td>
<td>15%</td>
</tr>
<tr>
<td>Acknowledging and exploring patient's condition</td>
<td>18</td>
<td>13%</td>
</tr>
<tr>
<td>Bereavement support</td>
<td>18</td>
<td>13%</td>
</tr>
<tr>
<td>Acknowledging and providing reassurance over role as family member</td>
<td>16</td>
<td>12%</td>
</tr>
<tr>
<td>Benefits</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>Helping with decision-making</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

* The percentages do not add up to a total of 100%, as these are calculated as a proportion of 134 contact episodes
The 3 elements most commonly delivered to family members (see Table 5.3 and Table 5.4), and the proportion of contact episodes on which they received these, were calculated for each individual family member. These can be seen in Figure 5.4. Data for family member 009 are not displayed in the figure as this individual had no follow up contacts with the nurse after the initial assessment. Figure 5.4 shows that 16 of these 23 family members received information and advice, on between 50%-100% of their contacts. In fact 2 family members received information and advice at all contact episodes (100% of the time). Eight of the family members were supported through active listening on 50% or more of their contacts with the nurse, and 12 of the family members were monitored regarding their well-being on at least half of (50%+) of their contacts. In total, 13 family members received all 3 of the most common elements at some point in the intervention period.
Figure 5.4. The 3 most common elements delivered to family members and the proportion of contact episodes on which these were received.

[Bar chart showing the proportion of contact episodes for the 3 most common elements: Information/Advice giving, Listening, and Monitoring carer’s well-being/maintaining continuity in nurse/carer relationship.]
5.4.2 Telephone interviews

The main focus of the semi structured interview with family members was to explore experiences of nurse specialist support. It also identified the families’ and family members’ concerns about a loved one living with lung cancer and their responses to this.

All the participants who completed the final evaluation (n= 23) were happy to undertake a taped semi structured telephone interview (one took place face-to-face because the participant had a speech impediment). This included 5 bereaved family members who all remained keen to continue with the study. The usual length of the interviews was 20-30 minutes. The relevant details were transcribed verbatim.

Four key themes emerged from the analysis of the interview transcripts. These were: therapeutic ingredients of the intervention, the structure of the intervention, participants’ key concerns and the outcome from the family members’ perspective.

The majority of the interview focussed on the therapeutic ingredients of the intervention

5.4.2.1 The therapeutic ingredients of nurse specialist support

The most striking feature of the interviews was the positive descriptions concerning interactions with the nurse specialists and how helpful family members found these. From the interviews, certain elements clearly emerged as important for this intervention. These have been described as the therapeutic ingredients. One aspect of the intervention pervades all the interviews – the fact that they knew that there was someone there who they could contact if they had need to. The other elements were not mentioned in every interview – some people for example did not require any practical help, but this was mentioned with such frequency that it seemed likely that this needed to at least be available within the framework of the intervention for it to be successful. These have been separated out into six separate sub- themes for clarity of presentation, although clearly there is some overlap between them all.

5.4.2.1.1 Knowing someone was there

This is an overarching theme that runs throughout the data and appears to have been most significant to the participants in this study. It was important to know that there was someone available and accessible to them who they could contact if they needed to;

‘I know I’ve got someone there to speak to if things get a bit too much’ (002)
‘She was just there. She was there for you and you knew she was there for you’ (022)

‘I think even if I just wanted someone to talk to, that knew me and knew what had happened, I feel that I could ring her’ (004a)
Twenty two of the interviews mention the importance of knowing that someone was there to support them (and the interview that did not was with a woman whose husband died only days after the initial assessment). This appears to have provided a security for the participants when they were feeling vulnerable and insecure. The frequency with which this is mentioned in the data can not be underestimated as it was not in direct response to a particular question and mentioned most often when asked what was helpful.

‘Just a real ease in the sense that we were very aware that we did have someone we could pick up the phone to at any time. To put our minds at rest if we had any problems or queries, questions whatever’ (011)

This did not necessarily mean that the participants were constantly contacting the nurse specialists but the knowledge that they could if they wanted to was very important. The nurse specialists worked approximately office hours and the participants on the whole did not expect them to be there all the time (although one woman did wish someone had been available at the weekend). What was important was the confidence that they would be responded to as soon as the nurse specialist was able;

‘If you rang her and she wasn’t available, you could leave a message and she would always call you back’ (004b)

5.4.2.1.2 Individually tailored information

There were several issues that were important with regard to the way in which the information was given by the nurses. Expert knowledge was important to several family members;

‘The honesty and her knowledge really. She was so knowledgeable because she was specialist purely in lung. As opposed to (the palliative care nurse) that was just, she wasn’t specialised, she just cares for you in general’ (011)

The information that was given by these nurses was different in quality from the information received from others for example the chemotherapy nurse or doctors. Some of this was because participants felt that it was at the right level and tailored to their needs;

‘lots of stupid questions but not being made to feel stupid. I felt that I could say almost any thing to her’ (002)

The specialist nurses supplemented and filled in gaps left by information given in other ways. Several expressed how they did not always find the written information helpful;

I think verbal is better. I mean when you’re trying to plough through loads of literature and such, it doesn’t always sink in. I think the personal approach is better’ (011)
Some of the information given was relatively straightforward and about treatment and side effects. However, other information was about difficult and emotionally complex issues such as future prognosis and what to expect;

‘So it was a huge relief really, it was part of the burden being taken off my shoulders because I knew what to expect as far as she was concerned’ (002)

The opportunity to ask questions and to feel at ease to ask questions was reported by fourteen of the participants as being helpful.

‘you never … felt that you were being stupid in asking her anything. Everything was dealt with in a very, very, nice way. You felt totally at ease with her’ (009)

‘It was literally having the advice and to know that if we did have a question we could just ring her. That’s worth its weight in gold really. Its enough really. It is nice to be able to just ring somebody and know you can get an answer from her’ (022)

5.4.2.1.3 Listening

One of the elements of the intervention that participants frequently commented on was the feeling of being listened to in a manner that conveyed that what they had to say was important and relevant. It also seems to have been important that they did not feel rushed. The nurses gave the impression of having time to listen to their concerns.

‘It didn’t feel like she was looking at her watch when she was with you. She would sit there’ (004b)

Again this seems to be emphasising how useful the participants found it to have somebody who was there for them. Listening to their stories appears to have been helpful in acknowledging their experience, giving the feeling of being understood, but also in creating the relationship between the nurse and the family member.

‘I thought she was actually interested in I myself as a person’. ‘I didn’t feel so much alone’. ‘it was a personal communication and that made all the difference’ (017)

‘I think she listened. She listened to what we had to say and she just sort of helped’ (014b)

The intervention was delivered both over the telephone and face-to-face. It was intended to be flexible to suit the needs of the individual so that they were able to make contact when it was helpful to them and not to suit the timetable of the clinic.

‘I felt at that particular time when I was talking to her, she was there at the right time’ (013)
5.4.2.1.4 Allowing expression of emotion

Much of the work that was done with the participants in this study was intensely emotional. For many, this was the most difficult experience that they had faced in their life and for others this brought back echoes of other difficult times that they had experienced.

‘I always feel good when I come out from seeing her. You sort of feel a bit positive. I know its not positive with my mum, but, you sort of feel better in yourself that someone’s listened to you… how you’re feeling…and, when I’ve had a cry, she’s been there… It’s been quite good’ (014a)

The environment or relationship created by the intervention allowed expression of emotion and provided opportunity for the nurse to help the relative manage or cope with these difficult feelings.

‘She was my way that I could … vent off steam if you like. She’d put things in perspective for me bit’ (002)

The fact that the intervention was longitudinal and intended to support family members throughout the course of the illness meant that they could anticipate being supported through the difficult times ahead.

‘When the cancer returns, that will be the next time that I’ll probably be ringing her and I think that will distress us again and we'll probably need that support and someone to talk to, just to calm us back down and bring us back to reality’ (022)

Several participants expressed how helpful it was to have someone to talk to without having to worry about the effect that their feelings and thoughts would have on them

‘I could say things to her that I couldn’t say to, well I felt I couldn’t say to other members of the family. I could say what I wanted to without fear of upsetting anyone’ (002)

This is particularly pertinent when family members are concerned with protecting others from their difficult emotions and so may find few places to openly express feelings and concerns.

‘it was quite nice to talk to someone as well who wasn’t involved within the family. Because you all tend to protect each other don’t you’ (031)

5.4.2.1.5 Personal attributes

The analysis on the telephone interview data unexpectedly produced a long list of personal attributes ascribed to the nurse specialists who were undertaking this work. These included; caring, kind, approachable, honest, open, available and accessible, concerned, knowledgeable, experienced, instilling confidence, competent, like a friend/family, interested, professional, natural, helpful, supportive and reassuring.
The intervention was delivered by three experienced cancer nurses, but each with different career histories, one of whom was not a lung cancer nurse specialist (although she had worked with lung cancer patients in the past). However, there was no clearly discernable difference in how the intervention was perceived by this small sample.

'I mean she is a very, very nice, very warm caring person and she comes over as very caring you know. She's got a lovely way with her. A nice manner and it is reassuring' (004b)

'It was invaluable. I'll never forget as long as I live. And I never realised as I say that there were people out there that were so kind and understanding' (029)

'We found her very caring, very informative. She was open to any questioning and, yes we found her very pleasant as well' (017)

It seems it was important for the nurses to have knowledge about lung cancer, the course of the disease and the patient and their relatives’ possible reactions to the illness. Also knowledge of how the health care system worked was an invaluable asset.

She must see this every day of her life.......I thought she (the patient) probably had a little bit longer than what she (the nurse) had told me, but she (the nurse) was spot on. She knew’ (004b)

'It was comforting to know that there was somebody professional who knew the medical side of things, had the experience of the illness on the other end of the phone' (019)

It was quite hard to define what it was about the way the nurses themselves worked in these roles that participants found so helpful. Experience was certainly important, although exactly what the nurse needed to be experienced in remains a little unclear, probably most crucially it was experience in dealing with difficult and complex human emotions that was fundamental to the success of working with these families

'And I feel you know that if I did have any, if I was really down myself I could have, I would prefer to chat with her than anybody who hadn’t got her experience' (017)

'But you know I don’t think we could get through without her (021)

5.4.2.1.6 Practical help and advice

Participants reported appreciating practical help and support from the nurses in a variety of ways. Nurse specialists were described as being a ‘go between’ between different professionals (004a) facilitating times of appointments and investigations. Eleven family members said that they had had help with benefits or grants.

The initial assessment covered the ways in which practical support might be available to the relatives and the nurses facilitated this happening.
‘and the first time she rang me on the telephone and went through lots of things we could, we may need as support, what was actually available, and she was extremely helpful’ (010b).

Two of the bereaved relatives particularly commented on how helpful they had found the practical support and advice given after bereavement.

‘She did ring me afterwards and offer help if I needed it. So it’s not as though you feel like’ oh well, that case is through, move on to the next one’ (004b)

5.4.2.2 The structure of the intervention

All participants responded very positively about their contact with the nurse specialist, with only some minor issues or suggestions about how the support provided could be changed.

All expressed satisfaction with the way the intervention was structured, although this varied dependant on individual social circumstances. Some preferred face to face contact, others preferred telephone contact and some a combination of the two. They appreciated that the contact was tailored to their individual needs to fit with their lifestyle and other commitments. They valued that the nurse specialists were flexible in their approach and would schedule to see them when they were up at the hospital – rather than making a separate appointment (unless they wanted it). Two participants requested telephone contact outside of normal working hours because of their own work commitments. No-one thought that a support group or a drop-in clinic would be helpful, although these were explicitly suggested as possible modes of support in the semi-structured interview. Perhaps as these lacked flexibility with regards to timing or seemed to be too formal as in the case of commitment to a group, which can be difficult at times of uncertainty.

5.4.2.3 Key Concerns

Obtaining information about the family’s key concerns about the illness experience was not the main focus of the telephone interviews however some of the issues raised when asked about their key concerns were very revealing about the relatives experience and provides helpful information when trying to further develop ways of supporting those close to a patient with lung cancer.

Although the majority of family members felt they had been given a lot of information, the key concern expressed by most family members was to know in detail about how the disease was going to progress. For the majority this was expressed as a need for individual information and detail about the disease process and prognosis in their particular situation. There appears to be a feeling expressed by some that healthcare professionals were holding back this kind of information and this occasionally included the nurse specialists who took part in the study.

‘Not knowing how everything was going to go is very difficult’ (004a)
For a few specifically knowing about how and when the patient would die was most important

‘How long before we’d lose mum’ (009)
‘What’s going to happen at the end’ (014b)

For others this is expressed as a concern about the patients’ well-being

‘My main concern was that she wouldn’t suffer, that she wouldn’t be in any pain at all’ (004b)
My main concern is what is what’s going to happen to him’ (017)

Furthermore, some family members also felt that information was hampered because of sensitivity and respect of the patient’s wishes.

‘My mum wouldn’t let us ask too many questions so we can’t really go into it’ (014b)

Despite the intervention attempting to meet the needs of the family members there was little or no mention of concern by participants for their own well-being, however perhaps not surprisingly several mention the patient’s well-being as their main concern.

5.4.2.4 Expressed outcome of the intervention for the family and family members

A number of outcomes for the family members participating in the study have been identified from the transcripts of the telephone interviews. These outcomes largely reflect what has been reported as the therapeutic ingredients of this intervention with the families. The outcomes have been identified as mapping to five areas.

5.4.2.4.1 Increased knowledge / met information needs

The need for information and to understand the information that they had been given was important for many participants. The interviews indicate that this need for information was largely met – except for some of the more existential questions about living with uncertainty;

‘Everything was answered. Everything we wanted to know’ (009)

5.4.2.4.2 Facilitated communication between family members

Participants acknowledged in the interviews how difficult communication amongst family members could be about issues so emotionally stressful. The nurses were able to facilitate some improvements in this;

‘Because sometimes when you’re very close to somebody, it somehow makes it more difficult to talk about things …And sometimes you find it’s, you know, your just a bit too close to the problem to discuss it. And it was nice to, we knew if we rang (the nurse specialist) she could help us sort through it’ (010b)
5.4.2.4.3 Improved emotional well-being/facilitated coping

To a varying degree, participants were able to articulate how distressed they were about their situation. Some of the initial refusals to take part in the study were because the project was perceived as potentially being ‘upsetting’. In fact although some participants did get upset during their contact with the nurse specialists, they acknowledged in the telephone interviews that seeing the nurse specialists had a positive impact on their emotional well-being and ability to cope;

‘It just seemed to take the stress out of it’ (009)
‘Put our minds at rest’ (011)
‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)

5.4.2.4.4 Increased feeling of being supported

It has been described earlier in this section how helpful participants found it knowing that there was someone who was dependable and who showed understanding of their situation there for them within the health care system. They reported that this led them to have a feeling of increased support;

‘I know she said that she would be there if ever I felt unable to cope. It’s reassuring. I think that was helpful’
‘It’s helped me in a way that I didn’t feel so much alone’ (017)

5.4.2.4.5 Facilitated family member’s role

The feeling of having support facilitated participants in their role as family member. There was someone who they felt that they could trust and rely upon to talk through issues that they were concerned about or finding difficult at home

‘Because she was there, she was supporting me and I could support him. I mean, I was, I didn’t feel completely lost’ (017)

5.4.3 Questionnaire data

This allowed the measurement of family members’ well being at two time points, approximately 3 months apart (at T1 and T2), by means of the questionnaire booklet made up of 5 instruments. The statistical analysis carried out to ascertain family members’ wellbeing was done on the data of the 23 that provided both sets of data.
5.4.3.1 Experienced needs and level of satisfaction with support received

Both the family members’ perceived needs, and the satisfaction of them, were measured using the Psychosocial Needs Inventory (PNI), made up of 44 needs statements which fall into 7 psychosocial needs categories, as follows:

- Needs related to interaction with health professionals (9 statements)
- Information needs (5 statements)
- Needs related to support networks (5 statements)
- Identity needs (1 statement)
- Emotional and spiritual needs (15 statements)
- Practical needs (8 statements)
- Childcare needs (1 statement)

The PNI required family members to rate 44 statements of psychosocial need regarding their importance, and the satisfaction of each need.

Before rating the 44 needs statements, family members indicated whether or not these applied to their situation. A summary of how applicable the 44 statements were to the family members (as rated by them) is presented in Table 5.5.

<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>29 (10.2)</td>
<td>27 (9.5)</td>
</tr>
<tr>
<td>Range</td>
<td>17-44 items</td>
<td>8-42 items</td>
</tr>
</tbody>
</table>

As displayed in Table 5.5, an average of 29 statements (66%) were applicable to their situation at baseline (T1). 3 months later (T2) 27 statements (61%) were, on average, applicable to them. Therefore family members found an average of 2/3rds of the statements of need to be relevant throughout their involvement with this study.

Overall, there was a marginal change in average number of applicable statements over those 3 months; 29 statements at T1 vs. 27 statements at T2.

Nevertheless, there was a large change when looking at the range of statements that were felt to be applicable to family members’ situation. At T1 at least 17 items (39%) were applicable to all family members’ situations, but at T2 as little as 8 items (18%) were relevant to all family members.

In addition to looking at scores at T1 and T2, average scores across the two time points showed that at least 16 of the 44 needs statements (36%) were found to be applicable to a minimum of 17 of the 23 family members (at least 75% of family members).
The needs that were applicable to all 23 family members (on average, across T1 & T2) were as follows:

- Information about medication and side effects*
- Information about treatment plans*
- Information about what to expect*
- Honest information
- Information given sensitively
- Health professionals who listen to me
- Health professionals who have time to discuss issues with me

These items fell into the ‘Information’* and ‘Health professional’ category of this tool.

Needs that were applicable to the least number of family members were:

- Help with child care (applicable to only 4 people)
- Help in considering my sexual needs (5 people)
- Help with housework (7 people)
- Opportunities for personal prayer (7 people)
- Support from people of my faith (7 people)
- Support from a spiritual advisor (7 people)

These were mostly items that fell into the ‘Emotional and Spiritual’ category of this tool, with the ‘help with housework’ need falling into the ‘Practical’ Category. (The PNI’s categories are defined later in this section)

The PNI further allowed the family members to rate the 44 needs statements (on 5-point Likert-type scales) regarding their importance and the level of satisfaction of each need.

For the purposes of analysis, the ratings of importance and satisfaction of these needs given by the 23 family members at T1 and T2 were collapsed into the 7 psychosocial needs categories.

The average importance of each need (Table 5.6) and satisfaction of each need (Table 5.7) mean (SD) scores were calculated for each category. Scores nearing 1 equate to family members’ rating of items as ‘not at all important’/‘not at all satisfied’, and scores nearing 5 equate to ‘very important’/’very satisfied’.
### Table 5.6. Average importance scores for each psychosocial needs category at baseline (T1) and 3 months later (T2)

<table>
<thead>
<tr>
<th>Psychosocial needs category – Importance</th>
<th>T1 Mean (SD)</th>
<th>T2 Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs related to interaction with health professionals</td>
<td>4.9 (0.3)</td>
<td>4.8 (0.2)</td>
</tr>
<tr>
<td>Information needs</td>
<td>4.8 (0.4)</td>
<td>4.7 (0.4)</td>
</tr>
<tr>
<td>Needs related to support networks</td>
<td>4.7 (0.4)</td>
<td>4.5 (0.5)</td>
</tr>
<tr>
<td>Identity needs</td>
<td>4.6 (0.9)</td>
<td>3.7 (1.2)</td>
</tr>
<tr>
<td>Emotional and spiritual needs</td>
<td>4.0 (1.2)</td>
<td>4.0 (0.7)</td>
</tr>
<tr>
<td>Practical needs</td>
<td>4.0 (1.1)</td>
<td>4.0 (1.0)</td>
</tr>
<tr>
<td>Childcare needs</td>
<td>2.8 (1.8)</td>
<td>3.0 (2.8)</td>
</tr>
</tbody>
</table>

As displayed in Table 5.6, the average importance scores for all categories at T1 and T2, except ‘childcare needs’, were high indicating the high importance of these needs to family members. Additionally, at T2 ‘Emotional and spiritual’ and ‘Practical’ needs remained equally important on average to family members. ‘Childcare’ needs appear to have become slightly more important at T2. Additionally, all other needs became marginally less important on average. This was with the exception of ‘Identity’ needs, which became markedly less important to family members at T2 (with a change of 0.9 points on a 1-5 scale).

### Table 5.7. Average satisfaction of need scores for each psychosocial needs category at baseline (T1) and 3 months later (T2)

<table>
<thead>
<tr>
<th>Psychosocial needs category – Satisfaction</th>
<th>T1 Mean (SD)</th>
<th>T2 Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs related to interaction with health professionals</td>
<td>4.2 (0.6)</td>
<td>4.4 (0.6)</td>
</tr>
<tr>
<td>Information needs</td>
<td>3.7 (0.9)</td>
<td>4.1 (0.8)</td>
</tr>
<tr>
<td>Needs related to support networks</td>
<td>4.2 (0.7)</td>
<td>4.3 (0.8)</td>
</tr>
<tr>
<td>Identity needs</td>
<td>3.2 (1.1)</td>
<td>3.4 (1.0)</td>
</tr>
<tr>
<td>Emotional and spiritual needs</td>
<td>3.2 (1.0)</td>
<td>3.4 (1.0)</td>
</tr>
<tr>
<td>Practical needs</td>
<td>2.9 (1.3)</td>
<td>3.7 (1.0)</td>
</tr>
<tr>
<td>Childcare needs</td>
<td>3.2 (1.8)</td>
<td>3.0 (2.8)</td>
</tr>
</tbody>
</table>
Table 5.7 displays the average satisfaction of the 44 needs for all categories at T1 and T2. I.e. The satisfaction with how well each of these needs had been met at each time point. At T2 ‘Childcare’ needs appear to have become slightly less satisfied for family members. All other needs became marginally more satisfied for family members on average. This was with the exception of ‘Practical’ needs, which became markedly more satisfied for family members at T2 (with a change of 0.8 points on a 1-5 scale). Additionally, ‘Information’ needs became more satisfied at T2 (with a change of 0.4 points on a 1-5 scale).

Perceived family member needs were further explored by means of the Family Inventory of Needs (FIN).

The FIN was administered to family members at T1 and T2 in order to measure aspects of family members’ experienced needs and whether these had changed as a result of the intervention. This instrument measures the degree of importance of each need to family members. Items that are considered important to family members were rated as Somewhat Important (scores of 1), Average Importance (scores of 2), Very Important (scores of 3) or Extremely Important (scores of 4). Further more family members are asked to indicate the degree to which need was met through indicating whether it was met, partially met or unmet.

Descriptive statistics firstly focussed on the importance of the 20 FIN needs items. See Table 5.8 below.

### Table 5.8. Number of needs found to be important by family members at T1 & T2

<table>
<thead>
<tr>
<th>Number of needs rated as being 'Somewhat' to 'Extremely' Important</th>
<th>No. (%) of respondents @ T1 (n = 22)</th>
<th>No. (%) of respondents @ T2 (n = 21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 15</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>15</td>
<td>1 (4%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>16</td>
<td>1 (4%)</td>
<td>-</td>
</tr>
<tr>
<td>17</td>
<td>1 (4%)</td>
<td>-</td>
</tr>
<tr>
<td>18</td>
<td>3 (14%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>19</td>
<td>3 (14%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>20</td>
<td>13 (60%)</td>
<td>12 (57%)</td>
</tr>
</tbody>
</table>

Note: missing values for 1 respondent @ T1 and 2 respondents @ T2

Table 5.8 showed that all family members found between 15 and all 20 of the needs to be important in some way at both T1 and T2. Therefore at least 15 items were somewhat, average, very or extremely important to family members over the 3-month intervention period. Additionally, 57% - 60% of family members found all 20 needs to be somewhat-extremely important (See Table 5.7).

On average, family members rated only 1 need as of ‘average importance’; this was the need to ‘have someone be concerned with my health’. Additionally, 1 need was rated as ‘very important’; this was the need to ‘be told about people who could help
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Apart from these 2 needs, all 18 of the remaining needs were rated as being ‘extremely important’. All needs were more than ‘somewhat’ important.

Descriptive statistics further focussed on whether or not the FIN needs items had been mostly met or unmet for family members (modal scores used). It is important to note that only items viewed as of average to extremely important were rated as to whether they had been met, partly met or unmet. See Table 5.9 below.

Table 5.9. Needs at T1 and T2 and whether or not they were met for most family members

<table>
<thead>
<tr>
<th>Needs</th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have my questions answered honestly</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Know specific facts concerning the patient's prognosis</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Feel that the health professionals care about the patient</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Be informed of changes in the patient's condition</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Know exactly what is being done for the patient</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Know what treatment the patient is receiving</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Have explanations given in terms that are understandable</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Be told about treatment plans while they are being made</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Feel there is hope</td>
<td>√</td>
<td>Partly</td>
</tr>
<tr>
<td>Be assured the best possible care is being given to the patient</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Know what symptoms the treatment or disease can cause</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Know when to expect symptoms to occur</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Know the probable outcome of the patient's illness</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Know why things are being done for the patient</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Know the names of health professionals involved in the patient's care</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Have information about what to do for the patient at home</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Feel accepted by the health professionals</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Help with the patient's care</td>
<td>Partly</td>
<td>√</td>
</tr>
<tr>
<td>Have someone be concerned with my health</td>
<td>Unmet</td>
<td>√</td>
</tr>
<tr>
<td>Be told about people who could help with problems</td>
<td>√</td>
<td>√</td>
</tr>
</tbody>
</table>
As can be seen in Table 5.9, 12 needs were fully met at all times (T1 & T2). In addition, when considering those needs that were at least “partly” met, 19 needs were met in some way at both time points.

In addition, 6 needs were only partly met at T1 and then they all went on to be fully met at T2. The same is true for the one need that had been unmet at T1 – That of someone being concerned with the family members’ own health.

There is only one need that went from being fully met at T1, to partly met at T2 – that of feeling that there was hope. Although it is not possible to ascertain it statistically, this last point could be explained by the fact that not only were 5/18 of the family members were bereaved at T2, but the remaining 18 family members were supporting patients who were now further into their illness and treatment; and suffering from the associated symptoms/side effects (a distressing time for both family members and patients).

5.4.3.2 Level of emotional upset or distress

This was measured by means of the 12-Item General Health Questionnaire (GHQ-12). The GHQ-12 was administered to family members at T1 and T2 to discern the impact that the intervention had upon family members’ emotional wellbeing. It was used to ascertain whether levels of distress associated with the caring role had changed as a result of the intervention.

Using the ‘GHQ method’ of scoring this instrument (78), a total GHQ score was calculated for each of the 23 family members at both T1 and T2. This total score could range from 0 to 12. In addition family members’ GHQ scores, ranging form 0 to 12, are used to screen for whether an individual could potentially develop/be at risk of a mental health problem, also known as mental health ‘cases’. This is determined by means of the most commonly used cut off point of GHQ 2/3 (78) (See section 4.5.1.1.2).

The number of family members who had a total GHQ scores ranging from 0 to 12 at baseline (T1) are displayed in Figure 5.5.
As can be seen in Figure 5.5, five family members were not classified as GHQ cases, having total scores equal to or lower than 2. The remaining 18 family members, with total GHQ scores of 3 or more, could potentially be suffering from a mental health problem.

Correspondingly, Figure 5.6 displays the number of family members who had a total GHQ scores ranging from 0 to 12 at the end of the 3-month intervention period (T2).
In contrast with T1, Figure 5.6 shows that around half of family members (12 out of 23), had an overall GHQ scores of 3 or more. Thus, it appears that fewer could be considered GHQ ‘cases’.

Inferential statistics allowed the significance of these differences in GHQ scores over time to be explored. Considering the average scores resulting from the GHQ method of scoring this tool (78), it was determined that at T2 there was a significant reduction in family member distress during the time they received the intervention from the nurse specialist. (See Table 5.10)

**Table 5.10. Changes in family member wellbeing**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Time 1 (N = 23)</th>
<th>Time 2 (N = 23)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total GHQ score, overall distress – Mean (SD)</td>
<td>5.83 (3.29)</td>
<td>4.00 (3.73)</td>
<td>&lt; 0.05*</td>
</tr>
<tr>
<td>GHQ cut off score – No. (%) of symptomatic cases</td>
<td>18 (78%)</td>
<td>12 (52%)</td>
<td>= 0.052†</td>
</tr>
</tbody>
</table>

* Significant at the p<0.05 level  
† Approaching significance at the p<0.05 level
In addition to average GHQ scores, Table 5.10 presents the percentage of family members screening positive for a possible mental health problem, also known as mental health ‘cases’. Considering this cut off point of 2/3, the number of family members presenting GHQ ‘caseness’ had decreased by 26% by T2. This difference neared significance.

5.4.3.3 Perceived quality of life

Perceived quality of life for family members was assessed by means of the Quality of Life Family Version Instrument (Family QoL). This was administered to family members at T1 and T2 to discern the impact that the intervention had upon family member perceived quality of life.

As described in the method section 4.5.1.1.3, only 34 of the original 37 items were included for completion by the family members. As several items had reverse anchors, the scores yielded by 18 items within this instrument were scored in reverse. Therefore, higher scores for each item indicated a positive response.

Firstly, scores for the 34 items were collapsed into 4 subscales commonly calculated for analysis purposes. These subscales are:

- The physical well-being subscale
- The psychological well-being subscale
- The social concerns subscale
- The spiritual well-being subscale

The mean scores within each of the four subscales were then calculated and compared between T1 and T2. This is represented in Figure 5.7.
As can be seen in Figure 5.7 overall physical, psychological and spiritual well being increased over the 3-month period. Additionally, the level of social concern decreased. However, although these trends are encouraging, none of the differences were significant at the p < 0.05 level.

Secondly, the research team examined the change over time expressed by participants in relation to each of the 34 individual items comprising the Family QoL. This is shown in Table 5.11.
Table 5.11. Average scores for the individual Family QoL items at T1 and T2

<table>
<thead>
<tr>
<th>Family QoL Items</th>
<th>Subscale</th>
<th>T1</th>
<th>T2</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>Physical well being</td>
<td>5.6</td>
<td>4.8</td>
<td>-0.9</td>
</tr>
<tr>
<td>Appetite change</td>
<td>Physical well being</td>
<td>6.6</td>
<td>7.6</td>
<td>1.0</td>
</tr>
<tr>
<td>Pain / aches</td>
<td>Physical well being</td>
<td>6.9</td>
<td>6.4</td>
<td>-0.5</td>
</tr>
<tr>
<td>Sleep change</td>
<td>Physical well being</td>
<td>5.1</td>
<td>6.0</td>
<td>0.9</td>
</tr>
<tr>
<td>Overall Phys Health</td>
<td>Physical well being</td>
<td>6.8</td>
<td>6.3</td>
<td>-0.6</td>
</tr>
<tr>
<td>Ease of coping</td>
<td>Psychological well being</td>
<td>4.5</td>
<td>4.7</td>
<td>0.1</td>
</tr>
<tr>
<td>Overall QoL</td>
<td>Psychological well being</td>
<td>7.0</td>
<td>6.9</td>
<td>-0.1</td>
</tr>
<tr>
<td>Happiness</td>
<td>Psychological well being</td>
<td>5.1</td>
<td>5.0</td>
<td>0.0</td>
</tr>
<tr>
<td>In control</td>
<td>Psychological well being</td>
<td>5.6</td>
<td>6.2</td>
<td>0.6</td>
</tr>
<tr>
<td>Satisfying</td>
<td>Psychological well being</td>
<td>6.0</td>
<td>5.8</td>
<td>-0.3</td>
</tr>
<tr>
<td>Concentrate / remember</td>
<td>Psychological well being</td>
<td>5.4</td>
<td>5.5</td>
<td>0.1</td>
</tr>
<tr>
<td>Useful</td>
<td>Psychological well being</td>
<td>7.1</td>
<td>6.3</td>
<td>-0.8</td>
</tr>
<tr>
<td>Distress initial diagnosis</td>
<td>Psychological well being</td>
<td>0.9</td>
<td>0.7</td>
<td>-0.3</td>
</tr>
<tr>
<td>Distress due to treatments</td>
<td>Psychological well being</td>
<td>2.7</td>
<td>1.8</td>
<td>-0.9</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Psychological well being</td>
<td>2.4</td>
<td>4.0</td>
<td>1.6</td>
</tr>
<tr>
<td>Depression</td>
<td>Psychological well being</td>
<td>5.7</td>
<td>6.1</td>
<td>0.4</td>
</tr>
<tr>
<td>Fear of spreading</td>
<td>Psychological well being</td>
<td>2.3</td>
<td>3.4</td>
<td>1.1</td>
</tr>
<tr>
<td>Overall psychological wellbeing</td>
<td>Psychological well being</td>
<td>7.1</td>
<td>6.7</td>
<td>-0.5</td>
</tr>
<tr>
<td>Distressing - illness for family</td>
<td>Social concerns</td>
<td>1.7</td>
<td>1.3</td>
<td>-0.4</td>
</tr>
<tr>
<td>Support</td>
<td>Social concerns</td>
<td>7.4</td>
<td>7.5</td>
<td>0.1</td>
</tr>
<tr>
<td>Interf - personal relationships</td>
<td>Social concerns</td>
<td>5.6</td>
<td>6.1</td>
<td>0.6</td>
</tr>
<tr>
<td>Interf – sexuality</td>
<td>Social concerns</td>
<td>7.4</td>
<td>7.4</td>
<td>-0.1</td>
</tr>
<tr>
<td>Interf – employment</td>
<td>Social concerns</td>
<td>7.8</td>
<td>8.2</td>
<td>0.4</td>
</tr>
<tr>
<td>Interf - activities at home</td>
<td>Social concerns</td>
<td>5.5</td>
<td>6.4</td>
<td>0.9</td>
</tr>
<tr>
<td>Isolation</td>
<td>Social concerns</td>
<td>7.7</td>
<td>8.2</td>
<td>0.5</td>
</tr>
<tr>
<td>Financial burden</td>
<td>Social concerns</td>
<td>6.6</td>
<td>7.5</td>
<td>0.9</td>
</tr>
<tr>
<td>Overall social well-being</td>
<td>Social concerns</td>
<td>6.6</td>
<td>6.8</td>
<td>0.2</td>
</tr>
<tr>
<td>Religious activities</td>
<td>Spiritual well being</td>
<td>3.5</td>
<td>2.4</td>
<td>-1.1</td>
</tr>
<tr>
<td>Personal spiritual activities</td>
<td>Spiritual well being</td>
<td>3.5</td>
<td>3.8</td>
<td>0.3</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>Spiritual well being</td>
<td>2.1</td>
<td>3.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Positive changes</td>
<td>Spiritual well being</td>
<td>4.6</td>
<td>2.6</td>
<td>-2.0</td>
</tr>
<tr>
<td>Purpose / mission</td>
<td>Spiritual well being</td>
<td>7.2</td>
<td>7.4</td>
<td>0.2</td>
</tr>
<tr>
<td>Hopeful</td>
<td>Spiritual well being</td>
<td>5.0</td>
<td>6.9</td>
<td>1.9</td>
</tr>
<tr>
<td>Overall spiritual well-being</td>
<td>Spiritual well being</td>
<td>5.5</td>
<td>7.2</td>
<td>1.8</td>
</tr>
</tbody>
</table>

As shown in Table 5.11, over the 3-month duration of the intervention, the majority of family members’ responses showed improvement. Of the total 34 items comprising the Family QoL instrument: 20 of the of family members’ experiences showed...
improvement, 13 showed a degree of decline, and 1 remained unchanged (on average).

Considering noteworthy experiences – the research team considered these to be chances of > 1 point – family members’ appetite showed a marked improvement. Additionally, family members’ anxiety and uncertainty showed an interesting decline, while family members’ fear of metastasis decreased. Family members also became more hopeful, and their overall spiritual well being increased. The only experience that showed no change whatsoever between T1 and T2 was that of ‘happiness’.

Throughout the intervention period it appeared that the amount of support received relating to spiritual activities decreased, and on completion of the study (T2) family members were less likely to feel that their family member's illness had made ‘positive changes’ in their life (when compared to T1).

5.4.3.4 Ability to manage and cope with the effects of the cancer

Family members’ ability to manage and cope with the symptoms and effects of their friend or family member’s cancer was ascertained by means of the Carers’ Assessment of Managing Index (CAMI). The instrument was administered to family members at T1 and T2 to discern the impact that the intervention had upon family members’ ability to manage and cope with the effect of their family member or friend’s cancer.

Through completing the CAMI, family members indicated:
- Whether or not they used each coping / managing strategy
- Whether or not they found the ones that they used helpful

Additionally, the modal rating of each strategy was calculated. This is represented in Table 5.12.

It must be noted that, in looking at the ‘helpfulness’ of each strategy (according to a percentage), this was calculated by the following division:

\[
\% = \frac{\text{# of family members who found each strategy quite/very helpful}}{\text{# of family members who actually used the strategy}}
\]

Therefore, the denominator changed accordingly.
**Table 5.12. Use and helpfulness of the family members’ (carers’) coping / managing strategies**

<table>
<thead>
<tr>
<th>Coping / managing strategies</th>
<th>No. (%) carers who used T1</th>
<th>No. (%) carers who used T2</th>
<th>No. (%) carers quite/very helpful T1</th>
<th>Modal response - Utility T1</th>
<th>No. (%) carers quite/very helpful T2</th>
<th>Modal response - Utility T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Establishing a regular routine and sticking to it</td>
<td>15 (65%)</td>
<td>11 (48%)</td>
<td>14/15 (93%)</td>
<td>9/11 (82%)</td>
<td>Quite helpful</td>
<td>Not used</td>
</tr>
<tr>
<td>2. Letting off steam in some way – shouting, yelling or the like</td>
<td>9 (39%)</td>
<td>13 (56%)</td>
<td>6/9 (75%)</td>
<td>10/13 (77%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>3. Talking over my problems with someone I trust</td>
<td>20 (86%)</td>
<td>22 (96%)</td>
<td>20/20 (100%)</td>
<td>22/22 (100%)</td>
<td>Very helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>4. Keeping a little free time for myself</td>
<td>15 (65%)</td>
<td>17 (74%)</td>
<td>14/15 (93%)</td>
<td>15/17 (88%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>5. Keeping one step ahead of things by planning in advance</td>
<td>18 (78%)</td>
<td>15 (65%)</td>
<td>17/18 (94%)</td>
<td>14/15 (93%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>6. Seeing the funny side of the situation</td>
<td>17 (74%)</td>
<td>17 (74%)</td>
<td>14/17 (82%)</td>
<td>13/17 (76%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>7. Realizing there’s always someone worse off than me</td>
<td>18 (78%)</td>
<td>20 (86%)</td>
<td>15/18 (83%)</td>
<td>18/20 (90%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>8. Gritting my teeth and just getting on with it</td>
<td>18 (78%)</td>
<td>18 (78%)</td>
<td>16/18 (89%)</td>
<td>16/18 (89%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>9. Remembering all the good times I used to have with the person I care for</td>
<td>18 (78%)</td>
<td>20 (86%)</td>
<td>16/18 (89%)</td>
<td>18/20 (90%)</td>
<td>Very helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>10. Finding out as much information as I can about the problem</td>
<td>19 (83%)</td>
<td>21 (91%)</td>
<td>18/19 (95%)</td>
<td>21/21 (100%)</td>
<td>Very helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>11. Realizing that the person I care for is not to blame for the way they are</td>
<td>15 (65%)</td>
<td>15 (65%)</td>
<td>14/15 (93%)</td>
<td>15/15 (100%)</td>
<td>Very helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>12. Taking life one day at a time</td>
<td>17 (74%)</td>
<td>18 (78%)</td>
<td>17/17 (100%)</td>
<td>17/18 (94%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>13. Getting as much practical help as I can from my family</td>
<td>22 (96%)</td>
<td>17 (74%)</td>
<td>20/22 (91%)</td>
<td>16/17 (94%)</td>
<td>Very helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>14. Keeping the person that I care for as active as possible</td>
<td>19 (83%)</td>
<td>17 (74%)</td>
<td>17/19 (89%)</td>
<td>15/17 (88%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>15. Altering my home environment to make things as easy as possible</td>
<td>8 (35%)</td>
<td>10 (43%)</td>
<td>6/8 (75%)</td>
<td>10/10 (100%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>16. Realizing that things are better now than they used to be</td>
<td>6 (26%)</td>
<td>6 (26%)</td>
<td>2/6 (26%)</td>
<td>3/6 (50%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>17. Getting as much help as I can from professionals and other service providers</td>
<td>17 (74%)</td>
<td>20 (86%)</td>
<td>15/17 (88%)</td>
<td>20/20 (100%)</td>
<td>Very helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>18. Thinking about the problem and finding a way to overcome it</td>
<td>16 (69%)</td>
<td>16 (69%)</td>
<td>15/16 (94%)</td>
<td>16/16 (100%)</td>
<td>Very helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>19. Having a good cry</td>
<td>19 (83%)</td>
<td>17 (74%)</td>
<td>14/19 (74%)</td>
<td>13/17 (76%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>20. Accepting the situation as it is</td>
<td>20 (86%)</td>
<td>21 (91%)</td>
<td>14/20 (70%)</td>
<td>18/21 (86%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>21. Taking my mind off things in some way, by reading, watching TV or the like</td>
<td>19 (83%)</td>
<td>18 (78%)</td>
<td>13/19 (68%)</td>
<td>15/18 (83%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>22. Ignoring the problem and hoping it will go away</td>
<td>4 (17%)</td>
<td>5 (22%)</td>
<td>1/4 (25%)</td>
<td>1/5 (20%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>23. Preventing problems before they happen</td>
<td>14 (61%)</td>
<td>18 (78%)</td>
<td>14/14 (100%)</td>
<td>15/18 (83%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>24. Drawing on strong personal or religious beliefs</td>
<td>7 (30%)</td>
<td>7 (30%)</td>
<td>7/7 (100%)</td>
<td>5/7 (71%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>25. Believing in myself and my ability to handle the situation</td>
<td>18 (78%)</td>
<td>21 (91%)</td>
<td>18/18 (100%)</td>
<td>21/21 (100%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>26. Forgetting about my problems for a short while by day-dreaming or the like</td>
<td>10 (43%)</td>
<td>12 (52%)</td>
<td>7/10 (70%)</td>
<td>9/12 (75%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
</tbody>
</table>

KEY: Text in **bold** is discussed in following text.
Table 5.12 continued…

<table>
<thead>
<tr>
<th>Coping / managing strategies</th>
<th>No. (%) carers who used T1</th>
<th>No. (%) carers who used T2</th>
<th>No. (%) carers quite/very helpful T1</th>
<th>No. (%) carers quite/very helpful T2</th>
<th>Modal response - Utility T1</th>
<th>Modal response - Utility T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>27. Keeping my emotions and feelings tightly under control</td>
<td>15 (65%)</td>
<td>17 (74%)</td>
<td>10/15 (66%)</td>
<td>11/17 (65%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>28. Trying to cheer myself up by eating, having a drink, smoking</td>
<td>13 (57%)</td>
<td>14 (61%)</td>
<td>10/13 (77%)</td>
<td>8/14 (57%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>29. Relying on my own experience and the expertise I have built</td>
<td>15 (65%)</td>
<td>17 (73%)</td>
<td>13/15 (87%)</td>
<td>14/17 (82%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>30. Trying out a number of solutions until I find one that</td>
<td>11 (48%)</td>
<td>14 (61%)</td>
<td>11/11 (100%)</td>
<td>13/14 (93%)</td>
<td>Not used</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>31. Establishing priorities and concentrating on them</td>
<td>16 (69%)</td>
<td>18 (78%)</td>
<td>16/16 (100%)</td>
<td>15/18 (83%)</td>
<td>Quite helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>32. Looking for the positive things in each situation</td>
<td>18 (78%)</td>
<td>19 (83%)</td>
<td>16/18 (89%)</td>
<td>18/19 (95%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>33. Being firm and pointing out to the person I care for what I</td>
<td>10 (43%)</td>
<td>6 (26%)</td>
<td>7/10 (70%)</td>
<td>4/6 (67%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>34. Realizing that no one is to blame for things</td>
<td>18 (78%)</td>
<td>18 (78%)</td>
<td>16/18 (89%)</td>
<td>16/18 (89%)</td>
<td>Very helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>35. Getting rid of excess energy and feelings by walking,</td>
<td>10 (43%)</td>
<td>14 (61%)</td>
<td>8/10 (80%)</td>
<td>12/14 (86%)</td>
<td>Not used</td>
<td>Quite helpful</td>
</tr>
<tr>
<td>swimming or other exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Attending a self-help group</td>
<td>3 (13%)</td>
<td>1 (4%)</td>
<td>1/3 (33%)</td>
<td>1/1 (100%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>37. Using relaxation techniques, meditation or the like</td>
<td>2 (9%)</td>
<td>1 (4%)</td>
<td>1/2 (50%)</td>
<td>1/1 (100%)</td>
<td>Not used</td>
<td>Not used</td>
</tr>
<tr>
<td>38. Maintaining interests outside caring</td>
<td>18 (78%)</td>
<td>16 (70%)</td>
<td>16/18 (89%)</td>
<td>16/16 (100%)</td>
<td>Quite helpful</td>
<td>Quite helpful</td>
</tr>
</tbody>
</table>

Summarising the data presented in Table 5.12, the five strategies that were most used over both time periods (T1 & T2) are presented in Table 5.13. These were used by at least 20 (85%) family members. Additionally, they were found to be either ‘quite’ or ‘very helpful’ by most family members.

Table 5.13. Most used CAMI managing and coping strategies

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Strategy</th>
<th>% family members who used this</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Talking over my problems with someone I trust</td>
<td>91%</td>
</tr>
<tr>
<td>20</td>
<td>Accepting the situation as it is</td>
<td>89%</td>
</tr>
<tr>
<td>10</td>
<td>Finding out as much information as I can about the problem</td>
<td>86%</td>
</tr>
<tr>
<td>13</td>
<td>Getting as much practical help as I can from my family</td>
<td>85%</td>
</tr>
<tr>
<td>25</td>
<td>Believing in myself and my ability to handle the situation</td>
<td>85%</td>
</tr>
</tbody>
</table>

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Other strategies found to be either ‘quite’ or ‘very helpful’ are presented in Table 5.14. These were used by at least 20 (80%) family members.

### Table 5.14. Helpful CAMI managing and coping strategies

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Strategy</th>
<th>% family members who found this helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Realizing there’s always someone worse off than me</td>
<td>85%</td>
</tr>
<tr>
<td>9</td>
<td>Remembering all the good times I used to have with the person I care for</td>
<td>85%</td>
</tr>
<tr>
<td>17</td>
<td>Getting as much help as I can from professionals and other service providers</td>
<td>80%</td>
</tr>
</tbody>
</table>

All above eight strategies (in Table 5.13 and 5.13) were most used and found most helpful, along with receiving modal ratings of being ‘quite helpful’ or very helpful’ at both T1 and T2.

The 5 strategies in Table 5.15 are those that were least used by the family members. These strategies were also those that were found least helpful by most respondents. Additionally, they were used by at fewer than 8 (30%) of family members.

### Table 5.15. Least used CAMI managing and coping strategies

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Strategy</th>
<th>% family members who used this</th>
</tr>
</thead>
<tbody>
<tr>
<td>37</td>
<td>Using relaxation techniques, meditation or the like</td>
<td>7%</td>
</tr>
<tr>
<td>36</td>
<td>Attending a self help group</td>
<td>9%</td>
</tr>
<tr>
<td>22</td>
<td>Ignoring the problem and hoping it will go away</td>
<td>20%</td>
</tr>
<tr>
<td>16</td>
<td>Realising that things are better now than they used to be</td>
<td>26%</td>
</tr>
<tr>
<td>24</td>
<td>Drawing on strong personal or religious beliefs</td>
<td>30%</td>
</tr>
</tbody>
</table>

Another strategy found least helpful by most respondents was item 33; “Being firm and pointing out to the person I care for what I expect of them” (used by 35% of family members). This item, along with those in Table 5.15, were least used and least helpful items in the list. They also received modal ratings of being ‘not used’ at both T1 and T2.

Regarding the number of strategies used on average by each family member, this varied dramatically, from family members using only 3 of the strategies to using all 38 strategies throughout the intervention ($\bar{x} = 24$ strategies; $SD = 8.32$; Mode = 30). Additionally, there were changes in number of strategies used by family members over time, although this was not statistically significant.
When the frequency with which individual strategies were used and their utility are explored over time, there are some apparent trends. Below are listed the strategies that increased in use by T2 by a minimum of 10% (see Table 5.16).

**Table 5.16. CAMI managing and coping strategies that increased in use by T2**

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Strategy</th>
<th>% increase in use</th>
</tr>
</thead>
<tbody>
<tr>
<td>35</td>
<td>Getting rid of excess energy and feelings by walking, swimming or other exercise</td>
<td>18%</td>
</tr>
<tr>
<td>2</td>
<td>Letting off steam in some way – shouting, yelling or the like</td>
<td>17%</td>
</tr>
<tr>
<td>23</td>
<td>Preventing problems before they happen</td>
<td>17%</td>
</tr>
<tr>
<td>25</td>
<td>Believing in myself and my ability to handle the situation</td>
<td>13%</td>
</tr>
<tr>
<td>30</td>
<td>Trying out a number of solutions until I find one that works</td>
<td>13%</td>
</tr>
<tr>
<td>17</td>
<td>Getting as much help as I can from professionals and other service providers</td>
<td>12%</td>
</tr>
</tbody>
</table>

Some of these strategies also appear to have become more helpful with time – these were strategy numbers 2, 17 and 35. Therefore, not only were these strategies increasingly used, they were also found to be increasingly helpful.

On the other hand, some strategies decreased in use by T2 and were used by up to 25% fewer people: These are presented in Table 5.17.

**Table 5.17. CAMI managing and coping strategies that decreased in use by T2**

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Strategy</th>
<th>% decrease in use</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Getting as much practical help as I can from my family</td>
<td>22%</td>
</tr>
<tr>
<td>1</td>
<td>Establishing a regular routine and sticking to it</td>
<td>18%</td>
</tr>
<tr>
<td>33</td>
<td>Being firm and pointing out to the person I care for what I expect of them</td>
<td>17%</td>
</tr>
<tr>
<td>5</td>
<td>Keeping one step ahead of things by planning in advance</td>
<td>13%</td>
</tr>
</tbody>
</table>

These strategies were the only 4 to decrease in use, and were also those that decreased in the number of family members to find them helpful.

To summarise, talking about the problems associated with the illness, accepting the situation, and having information about the problems, were the strategies that were most used and found most helpful. In addition it was found that stress relieving...
behaviours, problem solving behaviours, and information seeking behaviours carried out by the family members increased over time (by T2) and were found to have become more helpful strategies by T2.

5.5 The nurse experience

This was described as result of the focus group conducted with the Nurse Specialists.

5.5.1 Focus group

Twelve different themes were identified within the focus group data (Appendix 13). These related to topics ranging from ‘Personal experience of delivering the intervention’, to those describing its content, features and complexities, to its outcomes and future potential. These themes are woven together in the presentation of the findings below. These depict how those that provided the intervention perceived this experience, describe the content of the intervention that was delivered, and detail the differences in how it was delivered and used by family members. The findings also delineate its impact on both the family members and the service providing it, and present perceptions of its future utility.

5.5.1.1 The intervention: Meeting dynamic, diverse and unpredictable family member need

According to the intervening nurses, the family members’ concern and need was primarily influenced by the journey that the patient was following. It was explained that ‘if the patient’s pathway isn’t smooth, ideal, or something is going wrong then this is manifested in what the family member wants from you’. Contacts were initiated when there were changes in patients’ condition, or when patients and family members were struggling to access what they needed from the service including results of tests and scans or appointment times. Thus, typically need arose from disease or service-related issues pertaining to their loved ones. Shortfalls and issues with these contributed to family member distress and need, apparently over the processes involved with caring itself. It is possible that this was due to the newness of the diagnosis and family members’ relative naivety with regards to cancer services and the rapid/unpredictable disease process. Interestingly, had the family members been caring for someone with a chronic and fairly stable condition it is possible that need arising from the process of caring may have dominated service and disease-related issues.

The family members’ need was at the heart of, and drove, the intervention. Unsurprisingly, this need was very particular at any given time and the nurses tailored their approach and delivery accordingly. The needs referred to by the nurses fell within the following categories: emotional, psychological, practical, informational, needs for reassurance, and harboured need.
Emotional need was one form of need the nurses frequently addressed during the intervention, as was psychological need. The family members’ need for a confidante was clear from the nurses’ explanations of their role/actions. Family members needed a confidante, someone with whom they could establish a therapeutic relationship, who could listen to their story and contain the distress it conjured. The need to tell their story was commonplace amongst family members.

In some instances emotional need became intense and more akin to what the interveners perceived as psychological need. This arose on occasions when feelings that had been harboured re-emerged. Two interveners referred to family members who had ‘feelings that they were harbouring’. Feelings they had been concealing for many years, but that came to the fore due to the situation they were in and through having an opportunity to share these. In some instances strong emotions and feelings were vented. One nurse talked of a family member who had become shocked by the strength of their distress over their mother’s illness. They had clearly been estranged from feelings of fondness towards their mother but the sudden onset and gravity of her illness had rekindled these. These feelings were rehearsed with the intervener. Another revealed that that the psychological intervention they provided in a particular instance mirrored what they believed counselling should be. This concerned the nurse as it transgressed what they conceived the intervention should have offered.

Other types of support comprising the intervention were practical and informational/service-related support. Typically it appeared family members required information that was specific to their relatives’ circumstances and through the nurses’ insight into their case, combined with their extensive knowledge of the disease process and lung service, the interveners perceived they could provide family members with pertinent information rather than providing ‘platitudes’.

Some individuals sought and were provided reassurance. They required reassurance so that they could ‘check out an idea… “is this normal?” how they’re feeling or dealing with something.’ They wanted ‘reassurance that they’re doing the right thing… they wanted to run it by someone, just to make them feel a little bit easier in their minds.’ One intervener provided an example of a family member that rang them a lot to discuss the patients’ treatment and ongoing disease progress. They were very anxious, and the root of this anxiety appeared to be their uncertainty over whether they (the family member) had done the right thing.

However, the nurses talked of the difficulty associated with attempting to predict those family members that would prove needy. It appeared that such activity in the main proved futile because predictions were generally inaccurate, even when based on the initial assessment. It appeared that some family members voiced little need on initial assessment. The nurses suggested that this was because these family members sometimes had little conception at that time of either the interveners’ role and capacity to support them, or of the trajectory of their loved ones illness. Family member need was dynamic in its manifestation, expression and requirements for resolution.
5.5.1.2 Different models of delivery and uptake

Whilst the intervention was aimed at family members, the ethos underlying it differed between the intervening nurses. For one, the family member was central but for the others, most likely due to their clinical roles, the needs of patients and family members became difficult to tease apart. One nurse felt that she typically did not solely address family members’ needs. Either they were already ‘intimately involved’ with the patients and their care, or they sought to understand the patients’ history and treatment because they felt better able to support the family member armed with this understanding. It appeared to suit their favoured way of working, wishing to ‘portray an air of knowledge about what’s going on for the patient, to the family member.’ The third intervener explained that they had focussed attention only on the family members in some instances. They had done this for the purpose of the study, to explore how this affected both their way of working and the family members’ outcome. On the basis of this they determined that working in this manner had felt artificial. For them, it felt more natural when they were involved in the patients’ care. Further, they suggested that it was more difficult to develop rapport with family members when patients were not on their caseload. They also perceived that their contact over time following the assessment interview differed according to how much they were involved in the patients’ care. Typically when they were not greatly involved, interveners surmised that relationships with family members might not be optimised.

The interrelatedness of family member and patient need was apparent from the conversation within the focus group. One of the nurses explained that through addressing patient needs, those of the family member were attended to: ‘With my supporting the patient, it’s implicit that you’re supporting the family member’. The patients’ needs were recognised to be at all times ‘paramount’ by the interveners. Debate arose over whether family members and patients should be viewed as a dyad and an intervention shaped for the entire patient/family member unit. However, it was decided that there was great value in meeting with and addressing the family member’s needs independently from those of the patient.

A further question surrounded who could most optimally address family member needs, the clinical nurse specialists involved in the patients’ care or an individual outside the CNS service. The differential effects of these two different models could be explored to some extent in this study because two of the interveners were CNSs within the lung cancer service, whilst the other intervention nurse was an experienced cancer nurse from outside the service. The individual outside the service recognised that their focus was on the family member rather than the patient. They found that family members did ‘ring up and talk about overwhelming things’, and surmised that had they been within the service one particular family member would probably have rung up about her husband’s appointments another patient oriented issues and not and not her own dark times. It was felt that through not caring for the patient, this did ‘legitimise the family members’ needs. That they can phone with their stuff if they want to and are feeling anxious.’ When comparing the intervention that this nurse from outside the CNS service provided to that provided by the lung CNSs it was apparent that there was a difference. The former appeared to be primarily the provider of emotional support, whereas the latter’s emphasis
Developing a Supportive Nursing Intervention

appeared to be more on supplying information and practical advice, and on influencing the service. It appears that the interveners played to their strengths, but it is unclear whether the family members recognised these strengths and sought out such intervention, or whether moreover the interveners acted in the manner that suited them.

However, an inherent difficulty for the intervener working outside the service related to their difficulty in not having an intimate understanding of the lung cancer service which resulted in their having difficulty facilitating patients’ navigation through the health care system. This resulted in ‘frustration’ for them, and the realisation that this would have been less troublesome had they been able to ‘tie in more closely with the team’.

As might be expected the family members differed in the extent to, and manner in, which they utilised the interveners’ support. Typically the assessment interview was used to derive a plan for delivery of future support, the patterns this followed appeared to fall within three different categories: family member initiated, intervener initiated and a hybrid of both. Following initial contact some individuals opted to liaise with the nurse when issues or difficulties arose - the initiative was left with them to make contact. Others wished the nurse to call at particular points in the patients’ cancer journey, which they duly fulfilled. Other family members had ongoing dialogue with the interveners throughout the study notably when the nurse was providing ongoing support to their relative. Conversely, some family members appeared not to follow up the interveners’ offer of support and, bar the assessment interview, had little contact with them. However, these individuals were in the minority, more commonly there was regular contact both between family members and interveners, either in person or by telephone.

The severance of family member support was discussed during the group, in terms of when this should arise, and how this was initiated. Prior to the study commencing, the individuals providing the intervention decided that it would be inappropriate to necessarily withdraw family member support at the end of data collection. It was anticipated that some family members would need intervention on an ongoing basis, and the Research Team agreed that it would be unethical to sever family member contact when family members were likely to have become reliant on it.

In the event, contact declined naturally with some family members over time as telephone contact slowly tailed off. In some cases this mirrored patients’ decline and the increasing input of the palliative care team. However, on other occasions support continued following study completion and in some instances after the patients had died. One of the interveners provided support to a family member whose husband died shortly after commencing treatment. This family member had wished to continue with the study purely for emotional support. They appeared to have great need of someone to offer them time and support through their grief. In another case, a bereaved family member wrote to one of the interveners to enquire whether they could view their relative’s body with them. A third example of support sought by and provided to a bereaved family member was reflected on during the group. In this instance, the intervener was providing ongoing support to the family member until the role could be assumed by a bereavement counselling service. The intervener’s perceptions of this situation were that I think they feel I’m somebody… I am a contact
in the hospital. I think that’s probably quite important to them... They tells me they don’t cry, so when I ring her up they cry... The person referred to in this quote was bereaved suddenly, but there was a perception that had their relative died at home, or in a hospice, that there would have been more support for them within the community. This apparently left the intervener with a conundrum because whilst they may have wished to withdraw their support, alternative provision was not necessarily easy to organise. The intervener explained: Cruse Bereavement Care probably might not be able to see them for 3 months.

5.5.1.3 Outcomes of the intervention: smoothing bumps in the journey

The members of the focus group reflected on what the intervention offered family members, and described how it helped family members of patients with lung cancer to manage their situation better. They also teased out the features that characterised it. The overarching philosophy underpinning the intervention appeared to be the smoothing of patients’ and family members’ pathways or journeys. The members explained that the journey (rather than the outcome) could definitely be altered through family member intervention; for example through liaising more closely with families and expediting tests, scans etc. The way patients get access to care is much smoother and quicker.

Individuals in the group explained how they could often pre-empt need. An example was provided that illustrated this. One of the interveners had been supporting a family member whose relative was admitted to a different hospital whilst they were away from work. Another of the intervention team was aware that this was likely to be a time of difficulty for the family member and anticipated their need for support. However, they determined not to rush in and make contact on their colleague’s behalf. In the event the family member left a frantic message on the (absent intervener’s) telephone ‘I know you are away, but I can’t actually get any information from anywhere about what’s going on, can you please ring me as soon as you get back’ and that family member had rang the local hospital, she’d rang the medical team here, and just couldn’t access information or get help. So it does say something about accessibility, and also about pre-empting that need, because I was very aware that had I phoned her before the 48 hours ticked away, I could have pre-empted that anxiety.

All members of the focus group referred to the importance of accessibility. Easing family members’ access to the lung service, and providing them with a sense of availability (even when time was limited) was perceived as fundamental to the intervention’s success. As one of the group explained: You can’t be available 24/7 but you can give a sense of availability. This was achieved through lowering perceived barriers to the healthcare team, a process that was initiated at initial assessment interview, and continued throughout the intervention programme. Right from the beginning it was stressed that they were open to calls, to the extent that family members would sense they could phone regarding trivia. It was perceived that this openness was important as it reduced anxiety.

Further, the group perceived that through easing family members’ access to the lung service they were facilitating family members’ influence over patients’ situation and management. This engendered a sense of power or belief that they could alter the
process. Debate ensued over whether there was a risk that this could lead to
dependence on the interveners or provide a false sense of security as when outside
the Trust itself the interveners recognised they held little sway. Despite much
discussion, consensus was not reached over the relative merits of engendering
feelings of empowerment within one particular Healthcare Trust over not being self-
sufficient outside this environment – or whether the process led to empowerment or
dependency. It was agreed that this was a complex process.

However, it was clear that trust was central to the intervention process. It was
explained by one in the group: I think if they trust you as well… then you’re a safe
person… they know if they talk to you about something (concern) then it
(improvements to situation) can happen, whereas I think sometimes things feel a bit
insecure. If there is somebody they can trust, that they can tell or ask something…
it’s safe as well, they can check out an idea… is this normal? This process is
facilitated through continuity and familiarity as it helps when the family members have
a person that isn’t anonymous, there is confidence that they can orchestrate change.
When comparisons were drawn with other hospital personnel, the importance of
continuity became clearer. One member of the group explained: clerical staff,
secretarial staff, even - sometimes - medical teams, there doesn’t seem to be that
sort of same confidence (in them). They’re changing over time. It was perceived that
trust built up feelings of confidence in family members and lessened their feelings of
insecurity. However, it was apparent that this type of connectivity with family
members was not universal across those in receipt of the intervention. One member
of the group illustrated how family members cope very differently. They provided an
example where one gentleman felt what will be, will be. It will be sorted in time.
Don’t make a fuss. He appeared somewhat fatalistic in bearing and appeared
reluctant to engage with the lung cancer service or to attempt to control the situation.
Another gentleman similarly was reticent to take up the offer of support provided by
the intervention, and behaves as if everything is going on as normal. One intervener
portrayed their inability to engage with one gentleman: I’ve been explicit in offering
my service, and he’s not taken it up at all. Whether there was a difference in coping
styles and response between gender was debated within the focus group and agreed
that there was insufficient data on which to base judgement. Further, there were
women in the study that had equally proved distant to the support provided by the
intervention.

The focus group reflected on the contribution that the programme made, and
determined that the benefits it afforded were manifold but clustered with three
themes. It appeared that the intervention facilitated better coping at home, and both
facilitated place of death and prepared family members for bereavement. These
three will be considered in turn. The group were united in their views on the
intervention’s capacity for enhancing coping at home. It appeared that patients could
be cared for within their own homes, rather than requiring transfer to the hospital or
hospice for symptom management, through the action of the intervention provided to
family members. One intervener explained how one patient would undoubtedly have
been admitted to hospital had his wife not been accessing their guidance and
support. It was explained that the family member’s questions were so simple, but
she was very anxious about what was happening. She’d ask about things to do with
understanding medication and pain, sleeping, positioning, eating ... The intervener
explained that although the patient was finally admitted to a hospice, the intervention
had facilitated their staying at home until that point. This was clearly what the family member and patient had desired.

However, in another case the patient and family member wished the hospital to provide care as the disease took hold. The family member did not want their relative to die at home, as they felt they could not cope with this. Thus, instead of going home, the patient was discharged straight to a hospice. Thus, at the heart of this process is the mechanism for enabling choice regarding place of death, whether this is at home or in a healthcare setting. The intervener appeared well placed to inform, support and realise this choice. Further they seemed well placed to prepare them for their loved ones death. As one in the group explained what I did was maybe prepare them that things would deteriorate quite quickly; she had quite advanced disease. Their contribution, although the intervener may not perceive this as not being extensive, was clearly well received: and I didn’t even feel that I’d done very much for them. But you’ve obviously had an impact if they’ve sent you a card… the card was very nice and thanked me for my involvement.

Finally, the group agreed that where patients died, they had facilitated the bereavement process. As alluded to earlier, contact during this time was typically over the telephone, but was also through written correspondence. They provided an ongoing contact to the hospital that for some appeared important in the early stages of bereavement. There was a gap in the current service, particularly for patients where the palliative care team had not been involved before the patient’s death. It was explained I would have said there is no contact after death for ward patients like that, which must be pretty traumatic. It’s very difficult for them to be cut off from the hospital, and access someone to go through things with them. As a team, our consultants don’t actually encourage it. Our main consultant actively discourages it. Ringing up, sending a letter, meeting bereaved relatives. It’s something he finds very difficult.

The interveners appeared to offer family members continuity of support and advice over the patient’s treatment and disease pathway – smoothing the bumps as they arose. The intervention offered at any given time was driven by a complex interplay of patient and family member need. One necessarily impacts on the other. The intervention in some instances was a gap-filler, filling deficits in the current service, but in others augmented it. It was perceived that it could impact profoundly on family members’ ability to support patients at home, and determine place of death.

5.5.1.4 Personal experience: Dilemma and emotion

Conversation around how individuals personally perceived taking on a programme of care for family members proved very emotive. This was not a role that the intervening nurses would ordinarily undertake during their working day. Reference was made during the focus group to the difficulties associated with subsuming this within their usual, and typically over committed, working lives. One individual referred to this added working dimension as a burden, not least as it proved labour intensive through the additional responsibility it generated. At various times this new commitment to family members was referred to as different, frightening and unnerving. These strong emotions were alluded to particularly when the intervention appeared to progress/transgress beyond what had been anticipated at its inception. For example,
providing care that ‘mirrored counselling’. The nurse that found themselves in this situation perceived that they were in danger of moving outside their professional sphere of expertise and leaving them at risk of not meeting the family members’ psychological needs.

Dilemmas were alluded to when on occasion normal working practice had to be abandoned to prevent compromising the study design. This arose when the nurse specialists encountered patients who were unwell and in need of specialist nursing care, but were relatives of family members under another nurse’s intervention caseload. In some instances, the nurses did not see such patients for fear of ‘muddying the waters’ but they worried over whether such individuals had missed out as a result. Concern was not only voiced over patients not receiving the care they believed was required, but also regarding instances when the level of support promised to family members was not in the event delivered. This left the nurses feeling uncomfortable and dissatisfied. However, when the family member was in receipt of the planned intervention their involvement in its delivery was perceived as rewarding and intensely worthwhile. As one nurse expressed, they ‘loved it’; it appeared to embody their considerable knowledge, skills and expertise. To draw on this so effectively was clearly rewarding.

Emotional dilemma arose as they could see the benefit for family members and the sense of reward the intervention could provide them. However, the personal cost in terms of time and commitment was high and at times impossible to meet. Emotions then swung in the opposite direction when the intervention proved too time-consuming to deliver as planned. This resulted in one nurse taking documentation home to complete in their own time, whilst others voiced concern and guilt over this short fall. It is easy to understand how taking on the intervention and the negative feelings it evoked at times became viewed as burdensome.

5.5.1.5 Impacts on the service: blurring of roles

It was unsurprising that during the focus group the interveners referred to the demands that the intervention programme placed on the service. Although they determined that some aspects of what they provided was not far removed from their usual CNS role, it certainly had been extended as a result. As noted earlier, formally including family members on their caseload added significantly to workload. Further, it was felt that some family members were being chased up because they were study participants. It was deemed that this would not mirror practice, and created an artificial situation. The same was the case when one particular CNS provided the intervention to family members without being involved in the patients’ care. They perceived that it felt more natural when they were interfacing with both. Further, they hypothesised that family members would feel better supported where she was also involved with the patient’s care. Thus, the interveners recognised that the research process had altered their usual working practices, which was not necessarily to the benefit of all service users.

Further, through undertaking the research the interveners felt that at times they were adopting roles outside of their norm. As mentioned before one intervener was providing support akin to counselling, and another mentioned that ordinarily they
would refer such patients on for specialist support but under the auspices of the research determined not to.

The difficulties associated with undertaking the intervention programme as part of a research process was also discussed. It was recognised that combining research and practice is not easy. The documentation required for the research aspect was lengthy and appeared prohibitive for everyday practice. The initial assessments took between 30 mins and 1 hour 45 minutes, but their documentation proved hard to complete. Allowing yourself time to actually document all of that, and try to capture it. And when the phone’s ringing or you’ve got to go and see a patient on the ward… that can be quite stressful, knowing you’ve got to get all of this information down. Time has proved the constraining factor as they explained it has been hard to do justice to the study, in terms of reflection on what we’re doing and planning what we’re doing, following things up, documentation…it’s just been the time issue.

Discussion turned to what would need to be documented if the intervention had been introduced into practice but was not being evaluated. This will be considered in the next section that considers the future of such an initiative for family members.

5.5.1.6 Future

When considering the future of interventions for family members the focus group reflected on what the essential attributes of their programme had been that would need to be provided in future for it to be successful. Time was the most frequently referred to commodity. Without this, it appeared that it would be difficult to include a comprehensive programme for family members that would provide the accessibility that those in this study benefited from. Further, there was some concern over equity. The intervention would need to be available to all that needed it, and for this to be the case time would need to be dedicated to it. The group were concerned about this, for it appeared that within the lung cancer service that working with family members in this manner would not necessarily be valued. They determined that some of their contributions to family members, and the emotional and psychological support provided to them would be difficult to quantify. Further they stressed that they also feel as though this kind of work isn’t really valued. The reason put forward for this was that it does not help them meet set clinical targets and you feel that you’re investing a lot of time, but actually, you’re not getting through many things on your list for that day, because it is so labour intensive and it’s not valued by others, and you question the value yourself. Support for the family member gets lip service but you are not going to get peer reviewed on it… It is not something that is institutionally recognised as being a priority. It would appear that the challenge would be to introduce an approach that was less labour intensive yet produced evident benefits that the team could recognise. The group stressed that they would like it translated into practice but conceded that it could be an uphill battle. The minimum family member service that the group perceived they could deliver within current resources would comprise providing all family members with the contact details of the lung CNS team alongside details of how/when to contact them. The group did perceive that they would be unable to give the quality, depth of care and support to family members that they had during the study.

The group perceived that for the intervention to be successful, it would need to be delivered by an experienced cancer nurse, with knowledge of both lung disease and
of the local lung cancer services. It was stressed that family members contacting the
service need the intervening nurse to have a detailed understanding of the patient’s
history and be able to provide them with considered opinion and advice. They
explained that these people don’t actually need platitudes. Platitudes was the
terminology used because one intervener explained they (family members) often get
told things very much without a history… It would be very easy to take things at face
value and give off-pat answers and not meet people’s needs… they know that the
advice you are giving, based on the assessment… whatever’s been before, is a
considered one. They explained that some health professionals they encounter
because those people vary over time, haven’t got that history. So their advice
doesn’t seem as genuine, it does seem more like platitudes. The manner in which
this information and supported is provided was reflected on. Advanced
communication skills were perceived as important for the intervener to engage in
active listening, reflecting and probing. This type of attention was not without its
stresses and the group recognised that supervision was important for them to act in
this manner as we’ve talked about the burden time-wise, but there is a burden to
you… personally.

Finally, the group considered the type of documentation that would be required to
record family member intervention. Whilst consensus was not reached on this issue,
it was recognised that this would need future consideration and need to take account
of who would access this information, and with the current streamlining of patient
documentation would need to be concise.

The focus group came to a natural conclusion with some reflection on integrating the
approach into practice. To summarise, the group could foresee that this could be
difficult, but all perceived that it would be very valuable to see all family members
individually for around 20-30 minutes when their relative was referred to their service.
They did recommend that boundaries be placed around what they can offer within
the family member service. They perceived that their role with regards to family
members related to their supporting family members in relation to the patients’
ilness. It was decided that certain roles that had been adopted for the purposes of
the research: addressing family members’ own illnesses, addressing their financial or
social situations, or completing social security forms, were beyond the remit of the
intervention. It was clear that such functions were beyond those of CNSs caring for
patients with lung cancer. Indeed as one of the group explained once you open up
that door (to other issues) some patients are going to respond to that. Then you
have to deal with what is brought up after the floodgates are opened.
6. Discussion

This feasibility study sought to explore the needs and concerns of close family of people with lung cancer. The aim was to develop and evaluate a supportive nursing intervention which would effect positive change in the family’s experience. We also aimed to explore the adequacy of the chosen instruments to measure this and in addition to develop recording tools for nurses undertaking this kind of work. Furthermore we wanted to explore the nurses’ experiences of developing and delivering this intervention.

The project has demonstrated that experienced cancer nurses can successfully deliver a supportive intervention for the close family members of people diagnosed with lung cancer. The process of developing this intervention has been elaborated, and was found to be appropriate and practical for both nurses and family in the circumstances under which it was utilised in this study. The chosen instruments were successfully completed by participants and although the sample was small the trends were encouraging. The nursing records developed were useful as a clinical record but further refinement will make them easier to analyse retrospectively.

6.1 The motivation for this project

As has been illustrated in this study through the clinical encounters, the questionnaires and the telephone interviews those close to someone diagnosed with lung cancer are likely to be deeply distressed and have difficulty in expressing or even acknowledging this distress. They are also likely to face practical challenges for which they have no previous experience. They may have difficulty in fully comprehending the severity of this disease and the swiftness with which it debilitates their loved one. This reflects participating nurses’ previous clinical experience and the findings of other research in this field (4, 12).

In the UK Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004)(3) recommends research to determine families’ views about different services, patterns of care received, how services best meet their needs and cost-effectiveness of different models of providing support. However, the families of people with cancer have been found to be difficult to recruit to research studies with many barriers to providing effective support – even in palliative care (11, 50, 54). To date there is no research which successfully delineates the most appropriate way for nurses to provide effective support for families of cancer patients throughout their cancer illness. This current project was devised through a combination of perceived urgent clinical need, previous research experience in this field along with a compliance with the need for research in this area to enable the development of current national strategy.
6.2 The focus of the research

After reflection on current research findings and the clinical need for nursing support throughout the disease trajectory, the direction of this intervention has been different from other work aimed at supporting families and carers of people with cancer. Here we aimed to support the family right from the time of diagnosis – rather than focussing on the palliative phase of the illness. Families were not screened to identify who was the most distressed; the aim was to be available to all. The tendency for those close to someone with cancer is to try and protect the patient and not to express their own needs (1, 4). The intention of this study therefore was to see patient and family member separately to allow participating family members to be able to seek help for themselves and voice their own concerns without feeling the need to protect the patient. It was felt that this was the appropriate way to provide help for people close to someone diagnosed with lung cancer which has such short disease trajectory and high disease burden. We believed that this broad, inclusive approach was appropriate because this study was looking at nursing support for families, the aim being to identify areas of this work which will be generalisable to the cancer nursing workforce.

Furthermore the approach developed was intended to be flexible and responsive to individual need. It was proactive – particularly in the early stages when the relationship between the nurse and family member was developing. Some research studies have found it difficult to recruit family members to be involved in supportive interventions and it has been surmised that this might be because they may not be convenient or may be requiring families to adopt a different style of managing the illness (16, 59). In this study, the telephone was often used as a flexible mode of communication to follow up and maintain the relationship with the family member. This was sometimes early in the morning or in the evening at times convenient for the relative.

The intervention was initiated by a detailed assessment which involved listening to the family member’s story about their own experience of the illness. It then involved working collaboratively with the family to provide individualised emotional, informational, social and practical support in response to their need. So for example, in the telephone interviews the participants described being able to talk about their difficult feelings with the nurses in a way that they were unable to with anybody else. The nurses also interpreted information and filled in gaps in understanding and knowledge and they provided practical advice when family members were worried about issues at home. Some participants had only a few contacts with the nurses and others more – some had almost daily contact over a difficult period at home. In essence this was utilising a ‘person centred approach’ (71, 72). Although the data collection for the study was completed at three months, the relationships developed were usually on-going, becoming richer and potentially more useful to the participants as the disease progressed. Indeed for some we did believe that our support was keeping the patient out of hospital for longer – an aspect of this work which we would like to study further.
Throughout the study there was debate about how to refer to and define the people who we were aiming to support. Finally we decided to use the words ‘family’ or ‘close family’ to describe those who took part in this study, rather than ‘carer’, ‘informal carer’ or ‘significant other’ (we used the Canadian Palliative Care Association 1998 definition of family) (90). This was for a variety of reasons but principally because the participants in our research, at least initially, did not see themselves as carers and thus would not recognise or respond to this term. We also wanted to emphasise that that we wanted to be the ‘carers’ providing care and thus to call them the ‘carers’ did not seem correct. This use of the word ‘family’ is at odds with some of the other literature in this field which tends to use ‘carer’ (although much of this refers to chronic or palliative illness).

Initially we believed that we should provide the nursing intervention for all those family members who wanted to participate. However, on reflection we decided that in the current study format we would only be able to support one family member – ideally the one who was most affected by the illness and who had most responsibility for supporting the patient.

6.3 The intervention

The participant’s experiences of taking part in the research project - both the family participants and the participating nurses, were explored comprehensively by successfully utilising a concurrent nested mixed method strategy to collect the data. The priority was to identify and understand the components of the intervention. The family members were unanimously positive about their interactions with the nurse specialist and how helpful they found these.

The families’ experience identified through analysis of the telephone interviews clearly mirrors the description of the intervention revealed through analysis of the nurses’ discussions and documentation. There do not appear to be contradictions between what the nurse specialists believed that they were doing and what the family participants experienced. The main difference was that the nurses had an understanding of the role they were taking on with the families from the beginning, whilst the families only understood this through experience of contact with the nurses. The CNSs obviously already had extensive experience in working with families. However, with the majority of the family participants this developed into something more intense and interactive for the nurse specialist than in their usual working relationships with the family members.

It was at times perhaps inevitably difficult to separate the family member’s own needs from those of the patient. Indeed in the telephone interviews the families clearly expressed that patient’s the well-being was paramount and, if this was not attended to it was difficult to support the family. However, what appeared most helpful for the family members was knowing that someone was there for them who they could contact when they needed to – either because they needed it for themselves or to provide them with help to support the patient. Being listened to by someone who allowed them to express their emotions if they wanted to, and being provided with information which they could understand and practical help and support when they
needed it, appear to have been the most beneficial elements of the intervention described by the participants in the telephone interviews.

The families’ on-going need for support was not necessarily predicted by the initial assessment which was within a few weeks of the initial diagnosis. At this stage it appeared that some relatives were still unable to take in what this diagnosis might really entail, they were unfamiliar with the health care system and had no understanding about what they might need. Some appeared unrealistically hopeful about treatment despite what they had been told initially about the prognosis. Furthermore, in some of the interview transcripts there was a sense that they felt that there was more information available than was actually given by the doctors and nurses looking after them – particularly as the disease progressed. This is likely to reflect the difficulty that patients with cancer and their families experience with living with the acute uncertainty of a disease such as lung cancer. The wish for more precise information such as when and how the patient was going to die may never be satisfied. These existential worries are reflected in the fact that when asked about their own main concerns in the telephone interviews, the family members almost unanimously said that it was about the patient and wanting to know how the disease was going to progress. The nurses facilitated the family members being able to have time to talk about themselves and their deeper fears. Many of the relatives expressed how helpful this had been for them in the telephone interviews.

The frustrations of navigating the way through the healthcare system revealed in the nurses’ records reflects current research about patient experience e.g. arranging appointments, transport, co-ordinating availability of scan results with appointments (57). If this system is not working smoothly then it is difficult to work therapeutically with either patients or their family. The issues of navigating the system need to be addressed first otherwise the family’s worries about this will prevent them from being able to focus on other deeper concerns.

A further aim of this study was to explore the suitability and ability of the chosen quantitative research instruments to capture the impact of the intervention on certain outcomes and to ascertain if they had the ability to sufficiently capture variables of interest to perform satisfactorily within the context of a trial. The questionnaires were found to be acceptable to the participants who appeared to understand them and complete them relevantly. The sample size was too small to measure any statistical change but the trends were all very encouraging in terms of support received from the intervention.

6.4 Limitations

The telephone interviews indicated that it was initially difficult for the family participants to understand the concept of the research process. Many did not know what to expect, despite having a researcher dedicated to recruiting them and providing them with a detailed information sheet. These are a group of people who have been found to be difficult to recruit and this may be reflected in the fact that 43% of the family members of the patients who consented, declined to take part. This might also reflect the view expressed by some non-participants that taking part might de-stabilise their already fragile coping mechanisms. Furthermore, this was a
predominantly female sample (92%) because these were the people who attended the hospital with the patient and they were not necessarily always the person who was most affected by the illness (they were able-bodied, willing and probably a car driver). So this small study has not necessarily recruited a truly representative cross section of close family members of people diagnosed with lung cancer. Nevertheless, recruitment to the study was relatively quick and unproblematic and once recruited, participants were committed to the project and only two failed to complete the final research assessment and interview.

This was a small and convenient sample and therefore the quantitative research tools were only able to identify trends (which were promising). The participants on the whole completed the questionnaires well although they were not designed for use in bereavement and five participants were bereaved during the study. Furthermore as with any study looking at issues in palliative care it is important to note that these were a group of patients who were almost universally experiencing declining health.

The intervention was developed over the course of the study and therefore there were some inconsistencies and changes in the way it was practised. This development and refinement was a deliberate element of the research process which was designed to learn as much as possible about what we were doing. For example, after the midway break for reflection we decided to be more pro-active and telephone participants one week after the initial assessment rather than at one month. The intervention was also delivered by three nurses with quite different nursing career history and experience. This was dealt with by constantly talking together and reflecting on our experience. We followed the same set of guidelines for the intervention but practised as individuals. There was no perceivable difference of levels of satisfaction revealed by the telephone interviews.

The undertaking of the telephone interviews was also pragmatic. We did not have the funding or time for the analysis of a wide ranging open interview. However the analysis of these interviews has proved important in our understanding of what was most helpful and important for the participants in this study.

6.5 Taking this work forward

The research team involved in this study comprised nurse researchers skilled in evaluating new interventions and looking at experiences of cancer care and clinical nurses with considerable experience of caring for patients with lung cancer. These combined skills enabled the development, delivery and evaluation of an innovative nursing intervention as well as a further description of the experiences of the families of people with lung cancer and an assessment of the research tools which may be utilised to further evaluate this kind of work.

Defining the qualities and experience of nurses required to deliver the kind of support offered to families in this study is complex. This was conceived as a nursing intervention but reflection and discussion during the project have raised the issue of who would be best placed to do such work. From the interviews it appears that excellent communication skills are needed, a reasonable knowledge of lung cancer and its treatments, an understanding of the health care system and how to navigate
it. The most obvious group to fulfil this role would be the CNSs, however many CNSs already feel their role is over stretched. It is possible that a counsellor who had spent some time learning about lung cancer and its treatment could fulfil the requirement – although again, counsellors are a limited resource. In this study the three intervening nurses worked together closely peer supervising this sometimes highly emotionally work. In further work of this nature it is vital that there is provision for supervision for the health professionals providing support.

This study provides some clear indications of what minimum level of support for the families of cancer patients might be desirable. We would argue from the experience of undertaking the study that a contact person to make an initial one-to one assessment of the key family member and provide contact details is fundamental. It appears helpful to follow this assessment up after a week and then continue with a monthly phone call/contact. This project has indicated that there is a need to be proactive with family members who do not always voice their concerns. There was also an appreciation by participants of the flexibility of contact with the nurse specialists in order to fit in with their own disrupted home/work life.

Families maintain the well being of people with cancer providing emotional and practical help often putting their own lives into upheaval. At the same time they may also be profoundly emotionally distressed themselves. This feasibility study has rigorously evaluated one possible model of care which has been shown to be helpful and acceptable. The study has several limitations, however this is the first general (rather than specialist) nursing intervention to support the families of cancer patients in the UK and as such shows considerable promise. The importance of supporting this vulnerable group of people both for their own and for the patients’ wellbeing is now well recognised. This study provides the theoretical underpinning for a larger sufficiently powered trial to reproduce these findings and look how to most effectively translate this into everyday practice.
7. References


35. Clayton JM, Butow PN, Tattersall MH. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. Cancer 2005;103(9):1957-64.


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Appendix 1: Feedback Sheet – Used in piloting study questionnaire

Pre-Test Evaluation

[NOTE: This version will be printed out as one double-sided A4 sheet]

We would appreciate it if you could please take some time to give us some feedback on the questionnaire that you have just completed - Please refer to the attached copy of the questionnaire

Please complete all sections questionnaire

We anticipate this will take no more than 10 minutes to complete

1. How long roughly did it take you to complete the questionnaire (Minutes)

2. Did you have any difficulties understanding the questions? (Yes/No)
   If Yes, please list the item numbers of the questions that you found troublesome (e.g. B13), and let us know why:

3. How easy was it to fill in the sections of the questionnaire? (Tick)
   Please see the attached copy of the questionnaire
   
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<td></td>
<td></td>
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</tr>
<tr>
<td>Section D</td>
<td></td>
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</tbody>
</table>

   If you had any difficulties, please explain these:

4a. How clear was the appearance of each section of the questionnaire? (Tick)
   
<table>
<thead>
<tr>
<th>Section</th>
<th>Very Clear</th>
<th>Clear</th>
<th>Unclear</th>
<th>Very Unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section A</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Section B</td>
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<tr>
<td>Section C</td>
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</tr>
<tr>
<td>Section D</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

4b. If you found the appearance of the questionnaire difficult, please explain below:
   For example – with the size of the print, the spacing between the questions, etc
5. Did you have any other difficulties with the questionnaire? (Yes/No)
   If Yes, please give details:

6a. Were there any questions that you particularly disliked? (Yes/No)
   If Yes, please list the item numbers of the questions (e.g. B13), and let us know why:

6b. Were there any questions that you particularly found helpful or useful? (Yes/No)
   If Yes, please list the item numbers of the questions (e.g. B13), and let us know why:

7. Do you think that there is anything else that we should have included in our questionnaire – which we might have missed out? Do you have any suggestions? Please note these below:

Thank you very much for your comments and your time
Carer Questionnaire

Meeting the needs of close relatives and friends of patients with lung cancer and mesothelioma

Florence Nightingale School of Nursing & Midwifery
October 2004
Section A

In this section we would like to know about your needs as a carer, rather than those of the person you are caring for.

Below you will find a list of needs carers sometimes have when facing illness; we would like you to go through the list in two ways:

First, ask yourself: “How important has this need been to me, over the past few weeks?” Then circle the appropriate number on a scale from 1 to 5:

1 = Not at all important 2 = Not very important 3 = Neither important nor unimportant 4 = Important 5 = Very important

Second, ask yourself: “How satisfied has this need been for me, over the past few weeks?” Then circle the appropriate number on a scale from 1 to 5:

1 = Not at all satisfied 2 = Not very satisfied 3 = Neither satisfied nor unsatisfied 4 = Satisfied 5 = Very satisfied

If the statement does not apply to you, tick the box under “DOES NOT APPLY TO ME”

Now, please go through the list and make a selection for all of the statements:

<table>
<thead>
<tr>
<th>GETTING OR HAVING THE FOLLOWING:</th>
<th>DOES NOT APPLY TO ME</th>
<th>HOW IMPORTANT?</th>
<th>HOW SATISFIED?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A1. Information about medication and side effects</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A2. Information about treatment plans</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A3. Information about what to expect</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A4. Honest information</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A5. Confidence in the health professionals I meet</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A6. Information given sensitively</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A7. Health professionals who listen to me</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A8. Health professionals who have time to discuss issues with me</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>
### Developing a Supportive Nursing Intervention

#### GETTING OR HAVING THE FOLLOWING:

<table>
<thead>
<tr>
<th>Item</th>
<th>Does Not Apply to Me</th>
<th>How Important?</th>
<th>How Satisfied?</th>
</tr>
</thead>
<tbody>
<tr>
<td>A9. Health professionals who treat me with respect</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A10. Easy and quick access to doctors</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A11. Easy and quick access to health professionals other than doctors</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A12. Access to other sources of information</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A13. Advice on what services and help are available</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A14. Opportunities to participate in choices around treatment</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A15. Help with finding a sense of purpose and meaning</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A16. Hope for the future</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A17. Opportunities for personal prayer</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A18. Support from people of my faith</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A19. Support from a spiritual advisor</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A20. Help in dealing with the unpredictability of the future</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A21. Help in maintaining a sense of control in my life</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A22. Help with housework</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A23. Help with transport</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A24. Help with child care</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A25. Help in dealing with any tiredness</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A26. Advice about food and diet</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A27. Help with financial matters</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A28. Help in filling out forms</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A29. Help with any distressing symptoms</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>GETTING OR HAVING THE FOLLOWING:</td>
<td>DOES NOT APPLY TO ME</td>
<td>HOW IMPORTANT?</td>
<td>HOW SATISFIED?</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------</td>
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<td>----------------</td>
</tr>
<tr>
<td>A30. Support from family</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A31. Support from friends</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A32. Support from neighbours</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A33. Support from care professionals</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A34. Someone to talk to</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A35. Help with any loneliness</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A36. Help with getting out and about socially</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A37. Opportunities for meeting others who are in a similar situation</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A38. Help with any fears</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A39. Help with any sad feelings</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A40. Help with any anger</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A41. Help with any feelings of guilt</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A42. Help in considering my sexual needs</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A43. Help in dealing with the feelings of others</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A44. Time for myself</td>
<td>□</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>
Section B

In addition to the other questions you have answered we are interested in knowing how your health has been in general over the past few weeks.

Please answer all of the questions on this page simply by circling the answer which you think most applies to you:

In the past few weeks have you…?

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>B1</td>
<td>Been able to concentrate on whatever you're doing</td>
<td>Better than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B2</td>
<td>Lost much sleep over worry</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B3</td>
<td>Felt you were playing a useful part in things</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B4</td>
<td>Felt capable of making decisions about things</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B5</td>
<td>Felt constantly under strain</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B6</td>
<td>Felt you couldn't overcome your difficulties</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B7</td>
<td>Been able to enjoy your normal day to day activities</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B8</td>
<td>Been able to face up to your problems</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B9</td>
<td>Been feeling unhappy or depressed</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B10</td>
<td>Been losing confidence in yourself</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B11</td>
<td>Been thinking of yourself as a worthless person</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B12</td>
<td>Been feeling reasonably happy, all things considered</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
</tbody>
</table>
Section C

In this section we are interested in knowing how your experience of having a loved one with cancer affects your Quality of Life.

Please answer all of the following questions based on your life at this time.

Please circle the number from 0 - 10 that best describes your experiences:

**Physical Well Being**

To what extent are the following a problem for you:

C1. Fatigue
No problem

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>6</th>
<th>7</th>
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<th>9</th>
<th>10</th>
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</table>

C2. Appetite changes
No problem

<table>
<thead>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

C3. Pain or aches
No problem

<table>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<th>8</th>
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<th>10</th>
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</table>

C4. Sleep changes
No problem

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>10</th>
</tr>
</thead>
</table>

C5. Rate your overall physical health

Extremely poor

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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</tr>
</thead>
</table>

**Psychological Well Being Items**

C6. How difficult is it for you to cope as a result of your family member's disease and treatment?

Not at all

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<th>10</th>
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</thead>
</table>

C7. How good is your overall quality of life?

Extremely poor

<table>
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<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
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<th>9</th>
<th>10</th>
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</thead>
</table>
### Developing a Supportive Nursing Intervention

**C8. How much happiness do you feel?**

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
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<tbody>
<tr>
<td>Completely</td>
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</tr>
</tbody>
</table>

**C9. Do you feel like you are in control of things in your life?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<tbody>
<tr>
<td>Completely</td>
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</tr>
</tbody>
</table>

**C10. How satisfying is your life?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>6</th>
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</tr>
</tbody>
</table>

**C11. How is your present ability to concentrate or to remember things?**

<table>
<thead>
<tr>
<th>Extremely poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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</thead>
<tbody>
<tr>
<td>Excellent</td>
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<td></td>
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</table>

**C12. How useful do you feel?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>6</th>
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</thead>
<tbody>
<tr>
<td>Extremely</td>
<td></td>
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</tbody>
</table>

**C13. How distressing was your family member's initial diagnosis for you?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
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</tbody>
</table>

**C14. How distressing were your family member's cancer treatments (i.e. chemotherapy, radiation, BMT or surgery) for you?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
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</table>

**C15. How much anxiety do you have?**

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tbody>
<tr>
<td>Severe</td>
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</table>

**C16. How much depression do you have?**

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td></td>
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</tr>
</tbody>
</table>
C17. Are your fearful of the spreading (metastasis) of your family member’s cancer?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

C18. Rate your overall psychological well being?

<table>
<thead>
<tr>
<th>Extremely poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Excellent</th>
</tr>
</thead>
</table>

**Social Concerns**

C19. How distressing has your family member's illness been for your family?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely</th>
</tr>
</thead>
</table>

C20. Is the amount of support you receive from others sufficient to meet your needs?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Completely</th>
</tr>
</thead>
</table>

C21. To what degree has your family member's illness or treatment interfered with your personal relationships?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Completely</th>
</tr>
</thead>
</table>

C22. To what degree has your family member's illness or treatment interfered with your sexuality?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Completely</th>
</tr>
</thead>
</table>

C23. To what degree has your family member's illness or treatment interfered with your employment?

<table>
<thead>
<tr>
<th>No problem</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe problem</th>
</tr>
</thead>
</table>

C24. To what degree has your family member’s illness or treatment interfered with your activities at home?

<table>
<thead>
<tr>
<th>No problem</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Severe problem</th>
</tr>
</thead>
</table>

C25. How much isolation is caused by your family member's illness or treatment?

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Complete</th>
</tr>
</thead>
</table>
C26. How much financial burden resulted from your family member's illness or treatment?

None at all 0 1 2 3 4 5 6 7 8 9 10 Extreme

C27. Rate your overall social well being

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 Excellent

**Spiritual Well Being**

C28. Is the amount of support you receive from religious activities such as going to church or temple sufficient to meet your needs?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

C29. Is the amount of support you receive from personal spiritual activities such as prayer or meditation sufficient to meet your needs?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

C30. How much uncertainty do you feel about your family member's future?

None at all 0 1 2 3 4 5 6 7 8 9 10 Extreme

C31. Has your family member's illness made positive changes in your life?

None at all 0 1 2 3 4 5 6 7 8 9 10 Extreme

C32. Do you have a purpose/mission for your life or a reason for being alive?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

C33. How hopeful do you feel?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Extremely

C34. Rate your overall spiritual well being

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 Excellent
Section D

Finally, this section contains a series of statements which carers have made about the coping strategies they use.

Carefully read each statement and show if it applies to you by placing a tick in the space available:

<table>
<thead>
<tr>
<th>ONE WAY OF DEALING WITH DEMANDS OF CARING IS BY:</th>
<th>I do not use this</th>
<th>Not really helpful</th>
<th>Quite helpful</th>
<th>Very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1 Establishing a regular routine and sticking to it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D2 Letting off steam in some way – shouting, yelling or the like</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D3 Talking over my problems with someone I trust</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D4 Keeping a little free time for myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5 Keeping one step ahead of things by planning in advance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D6 Seeing the funny side of the situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D7 Realizing there’s always someone worse off than me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D8 Gritting my teeth and just getting on with it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D9 Remembering all the good times I used to have with the person I care for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D10 Finding out as much information as I can about the problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D11 Realizing that the person I care for is not to blame for the way they are</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D12 Taking life one day at a time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D13 Getting as much practical help as I can from my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D14 Keeping the person that I care for as active as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D15 Altering my home environment to make things as easy as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D16 Realizing that things are better now than they used to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D17 Getting as much help as I can from professionals and other service providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D18 Thinking about the problem and finding a way to overcome it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D19 Having a good cry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ONE WAY OF DEALING WITH DEMANDS OF CARING IS BY:  | I do not use this | Not really helpful | Quite helpful | Very helpful |
---|---|---|---|---|
D20 | Accepting the situation as it is |  |  |  |
D21 | Taking my mind off things in some way, by reading, watching TV or the like |  |  |  |
D22 | Ignoring the problem and hoping it will go away |  |  |  |
D23 | Preventing problems before they happen |  |  |  |
D24 | Drawing on strong personal or religious beliefs |  |  |  |
D25 | Believing in myself and my ability to handle the situation |  |  |  |
D26 | Forgetting about my problems for a short while by day-dreaming or the like |  |  |  |
D27 | Keeping my emotions and feelings tightly under control |  |  |  |
D28 | Trying to cheer myself up by eating, having a drink, smoking or the like |  |  |  |
D29 | Relying on my own experience and the expertise I have built up |  |  |  |
D30 | Trying out a number of solutions until I find one that works |  |  |  |
D31 | Establishing priorities and concentrating on them |  |  |  |
D32 | Looking for the positive things in each situation |  |  |  |
D33 | Being firm and pointing out to the person I care for what I expect of them |  |  |  |
D34 | Realizing that no one is to blame for things |  |  |  |
D35 | Getting rid of excess energy and feelings by walking, swimming or other exercise |  |  |  |
D36 | Attending a self-help group |  |  |  |
D37 | Using relaxation techniques, meditation or the like |  |  |  |
D38 | Maintaining interests outside caring |  |  |  |

Please add below any other coping methods you use and indicate how helpful you find them:
Section E:

This laid out section is about the needs of family members of cancer patients. Please show how important the following needs are for you as a family member:

First, complete the first column of the table, by noting your rating from 1-5 of each item

<table>
<thead>
<tr>
<th>(1) Not Important</th>
<th>(2) Somewhat Important</th>
<th>(3) Average Importance</th>
<th>(4) Very Important</th>
<th>(5) Extremely Important</th>
</tr>
</thead>
</table>

Second, if the need was important to you, and you gave it a rating of between 2 and 5, Place a tick in one of the shaded boxes to show how much that need has been met

For example:

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Rating from 1 - 5</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>E17 Feel accepted by the health professionals</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Now, please go through the list and make a rating and selection for all of the statements:

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Rating from 1 - 5</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1 Have my questions answered honestly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E2 Know specific facts concerning the patient’s prognosis</td>
<td></td>
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</tr>
<tr>
<td>E3 Feel that the health professionals care about the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E4 Be informed of changes in the patient's condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E5 Know exactly what is being done for the patient</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>E6 Know what treatment the patient is receiving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need to:</td>
<td>Rating from 1 - 5</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>-----</td>
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</tr>
<tr>
<td>E7  Have explanations given in terms that are understandable</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E8  Be told about treatment plans while they are being made</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>E9  Feel there is hope</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>E10 Be assured the best possible care is being given to the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E11 Know what symptoms the treatment or disease can cause</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E12 Know when to expect symptoms to occur</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E13 Know the probable outcome of the patient's illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E14 Know why things are being done for the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E15 Know the names of health professionals involved in the patient's care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E16 Have information about what to do for the patient at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E17 Feel accepted by the health professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E18 Help with the patient's care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E19 Have someone be concerned with my health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E20 Be told about people who could help with problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
WELL DONE!

YOU HAVE REACHED THE END.

PLEASE CHECK THAT YOU HAVE COMPLETED ALL THE QUESTIONS.

Please return this questionnaire, along with your signed Informed Consent form, by post or to the Lung Cancer Nurse Specialist on your first appointment.

Thank you for so generously giving your time to participate in this project.
Appendix 3: Family member interview schedule

Family members’ Interview Schedule

1. How did you find your contact with the nurse specialist? [General opening question]

2. In your own words, could you describe what – if anything – you got from your contact with <<insert NS name >>?

3.a. Can you remember, when you first came on to this study, what you expected of it?
3.b. Has this/your initial expectation been met?
3.c. If not, why not

4. Since your <<insert name >>’s diagnosis, what has been your main concern?

5. How much do you feel seeing <<insert NS name >> has helped you with your feelings of worry and concern? (In what ways?)

6.a How much information did you have about what was going on with <<insert name >>?
6.b Was this amount of information enough?
6.c How easy was this to understand?

7. In what ways did seeing <<insert NS name >> help you in practical terms with coping with <<insert name >>’s illness? I.e. financial, local support services, aids

8. In what ways did meeting <<insert NS name >> help you support <<insert name >> better?

9. In what ways did seeing <<insert NS name >> impact on the ways in which you were able to discuss issues to do with the illness with <<insert name >>?

10.a What further information would you have liked?
10.b How would you have liked it given? i.e. Information sheet, or by another health professional such as doctor?

11.a How easy was it to get in touch with <<insert NS name >> outside of your appointments?
11.b Did anything stop you from getting in touch?
11.c To what degree did you feel that the matter which you had wanted to discuss had been resolved?

12 What kinds of things do you think you might re-contact <<insert NS name >> about in future?
13.a How easy was it for you to arrange to meet <<insert NS name >>?
13.b How convenient was this?
13.c What would have been easier? E.g. meeting at your home?

14. The first time you met <<insert NS name >> was 3-4 months ago, was this introduction to the service at the right time for you?

15. Did/do you prefer your contact with <<insert NS name >> to be face-to-face or by telephone?

Optional / If appropriate:

16. In what ways, do you think, that seeing <<insert NS name >> impacted on your relationship with <<insert name >>?

17.a In what ways, if any, did seeing <<insert NS name >> help you prioritise issues within your own life?
17.b What ways did it help you find any balance between living with <<insert name >>’s illness and the rest of your work and recreational commitments?

Final questions:

18.a Overall, what did you find that <<insert NS name >> did or said that was helpful?
18.b What else might have been helpful?
18.c What did you find that they did or said that was not helpful?
18.d Can you give an example of what was unhelpful?

19.a It has now been about 4-5 months since diagnosis, what do you foresee your support needs to be in the next few months?
19.b How confident are you that these will be met?

20.a This study has been about developing new ways of offering help and support to carers. The main way we have done this has been by offering an appointment for an assessment of your needs and providing you with information. How suitable was this?
20.b What other ways do you think might have been more useful/helpful/better? E.g. Drop in clinics, telephone contact, email contact, at a group meeting, etc.

21. Do have anything further that you would like to add?

Thank you.
### Therapeutic Ingredients

<table>
<thead>
<tr>
<th>INFORMATION-GIVING</th>
<th>Mentioned by:</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>With expert knowledge</strong></td>
<td>004a, 004b, 011, 017</td>
<td>‘The honesty and her knowledge really. She was so knowledgeable because she was specialised purely in lung. As opposed to having been with the Ellenor Nurse that was just, she wasn’t specialised, she just cares for you in general. And M was so knowledgeable and she was able to answer absolutely everything we threw at her’ (011)</td>
</tr>
<tr>
<td><strong>With sensitivity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Right level (tailored to individual)</strong></td>
<td>004a, 004b, 019, 021</td>
<td>‘Its only now that I’ve been through the experience that the things that I was told I realise were right, if you like’ (004a) ‘You know some doctors can be a bit stuffy and a bit, they don’t, they talk in their own language. Whereas you know, M explained everything so that my mum understood, so that we understood as well’ (004b) ‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b) ‘Its nice to have someone to put your mind at ease, if you’ve got any problems which I she did. She was very clear when she spoke. She didn’t insult my intelligence or anything, but then on the other hand she didn’t blind me with technology. She just kept it very simple with regards to medical procedures and that sort of thing’ (019) ‘Very matter of fact but she’s very good at dealing with it in a way that’s not upsetting’ (019)</td>
</tr>
<tr>
<td><strong>Based on experience</strong></td>
<td>004a, 004b, 017</td>
<td>‘she’s got such a lot of experience and in that respect she knows what to say and is helpful’ (004a)</td>
</tr>
<tr>
<td><strong>Specific – with relevance to patient</strong></td>
<td>002</td>
<td></td>
</tr>
<tr>
<td><strong>Clarifying/interpreting info already received</strong></td>
<td>002, 004b, 014b, 014c, 019, 021, 024, 031</td>
<td>‘When I spoke to M, it was very easy to understand. I must admit when you deal with the doctors, sometimes it isn’t very easy to understand. They’re very, I found it, one instance I did find it, the doctor wasn’t very good at one time..sometimes they come out with words you don’t always understand’ (014c) ‘She’s explained things that I never understood, do you know and explained them to me in my sort of language which I did understand’ (021) ‘If I come away from there (hospital) and I feel I haven’t got what I want then I will phone up S and she will explain to me again what they’ve told me. If I don’t understand, I will get in touch with S (021)</td>
</tr>
</tbody>
</table>
| **Supplementing info (or filling in gaps)** | 004a, 009, 013, 014a, 014c, 016c, 022, 026, 031 | Doctors not having time to explain things – NS having specific knowledge that enabled her to fill that gap’ (004b) ‘she’d find out anything, if there was a problem’ (009) ‘From M we got quite a lot, because she sort of explained the type of cancer that mum had, which we
‘We were a little bit anxious because he (doctor) didn’t quite explain himself very well but S explained it. She phoned my mum and spoke to my mum and put my mum’s mind at rest. And then she actually phoned me and she was able to answer any anxieties that I had and helped in that way’ (019)

‘We didn’t get any information at all. None whatsoever. H gave us all the leaflets’ (022)

‘So it was a huge relief really, it was part of the burden being taken off my shoulders because I knew what to expect as far as she was concerned’ (002)

‘I got my questions answered. She told me what I needed to know, to allow me to prepare for myself’ (004b)

‘I asked her the questions, you know about how long she thought my mum had, and she did answer them (004b)

‘She would just tell me how it was. Like I kept saying to S is I don’t know how long they’ve got (both parents have lung cancer). But like she said that’s something we really cannot answer. But it’s the way she did it. Where the doctors was well, we don’t know. Its like she’s telling me the truth more than the doctors’ (021)

‘I think verbal (info) is better. I mean when you’re trying to plough through loads of literature and such, it doesn’t always sink in. I think the personal approach is better’ (011)

‘I feel even though we were given all the pamphlets and all the information and everything, but because we’ve always stood on our own two feet, we’ve never been ones for asking for help. It would have been nice if somebody had volunteered and said, well I hear you’re waiting for treatment or I’m so and so, is there any way that I can help’ (028)

‘She’s has actually helped a lot. She has talked us through things, that could happen. She’s answered questions that we’ve asked, that we’ve pondered with each other and we’ve asked M’ (014b)

‘Happy to answer any questions I had’ (019)

‘It was literally having the advice and know that if we did have a question we could just ring her. That’s worth its weight in gold really. Its enough really. It is nice to be about to just ring somebody and know you can get an answer from her’ (022)
| Carer felt at ease to ask questions | 002, 004b, 009, 010b, 014a, 014b, 010b, 014a | ‘able to ask lots of stupid questions but not made to feel. I felt I could say almost anything to her (002)
She felt ‘very comfortable and supported. It was a lot better than I thought it would be. She was so caring and everything. It was a lot easier to talk to her than I thought it would be’ (009)
‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b)
‘She did answer a hell of a lot of the questions’ (014a) |
| Demonstrates willingness to answer questions | 004b, 010b, 014a, 014c, 021, 029, 009 | ‘I got my questions answered. She told me what I needed to know, to allow me to prepare for myself’ (004b)
‘I asked her the questions, you know about how long she thought my mum had, and she did answer them (004b)
‘Some of the worries and concerns that I had you know she sort of went through them and explained, she was very good’ (014a)
‘Everything I sort of needed to know or wanted to talk to, she’s been there. She hasn’t been too pushy and she’s sort of kept her distance and you know when you needed her, she was there’ (021)
‘I could ask S anything’ (029) |
| Demonstrates availability to answer questions | 004b, 009, 021, 004b | ‘She said anytime I wanted any questions answering or if she could help with the social services side of it, then just contact her’ (004b)
‘She made it clear that I could ask her anything or ask her to find out anything’ (009)
‘If I’ve needed information I’ve got it. I mean you can’t go around phoning doctors willy nilly and asking for questions. So its someone to, you could do that’ (021) |
| Knowledge and experience to answer questions | 004a, 026, 004a | ‘I ask her questions and she give s me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026) |
| Answers appropriate/helpful | 004a, 004b, 009, 010b, 011, 018, 026, 004a | ‘Everything was answered. Everything we wanted to know’ (009)
‘I’m very confident. Even if she couldn’t answer the question, then she would maybe get in touch with someone that could’ (009)
‘and any questions asked were honestly and sympathetically dealt with’ (010b)
‘We did have lots of questions to ask her and she answered them very openly and honestly.’ 011
‘I do feel confident that I can ring up H and ask her if she can help…I get a proper answer an answer that satisfies the problem’ (018) |
## Therapeutic Ingredients

### Listening

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<tr>
<th>Description</th>
<th>Mentioned by:</th>
<th>Quotes</th>
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| Allows time and space        | 004b, 009, 013, 029 | ‘It didn’t feel like, she wasn’t looing at her watch when she was with you. She would sit there’ (004b)  
‘She made time and nothing was too much trouble’ (009)  
I know with the doctors you feel like they’re always so busy and there’s lots of people in the waiting room. You know that their time is very precious. So it’s just nice to sit down with M and you know it wasn’t all rushed and that you could be in there for how long you wanted to be in there. She had the time. It was just nice to have that chance to feel a bit more comfortable, a bit more easier. If you had anything you forgot, you wasn’t sort of rushed’ (009)  
‘It was just nice for me to have someone to talk to and she was just listening’ (009)  
‘It was just nice for her to listen’ (009)  
‘She just listened’ (009)  
‘I think she listened. She listened to what we had to say and she just sort of helped’ (014b)  
‘I felt at that particular time when I was talking to her, she was there at the right time’ (013) |
| Attentive                    | 009, 013, 014b, 029 | ‘It was just nice for me to have someone to talk to and she was just listening’ (009)  
‘It was just nice for her to listen’ (009)  
‘She just listened’ (009)  
‘I think she listened. She listened to what we had to say and she just sort of helped’ (014b)  
‘I felt at that particular time when I was talking to her, she was there at the right time’ (013) |

### Allows Expression of Emotion (Emotional Support)

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<tr>
<th>Description</th>
<th>Mentioned by:</th>
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</table>
| Allows time and space                | 004a,         | ‘She was my way that I could..vent off steam if you like. She’d put things in perspective for me a bit’ (002)  
‘I know that I’ve got someone there to speak to if things get a bit too much’ (002)  
I could say what I felt and I found that quite nice’ (009)  
‘and I think probably I’ve found that talking about my husband’s illness helped me and the fact that there’s someone there to listen. It was great’ (013)  
‘We just blurt everything to M. How we’re feeling, we just tell M everything. Not straight away, I’ve got to be honest with you, it did take a couple of visits, with each visit we did tell her a bit more and a bit more’ (014a)  
‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)  
‘When the cancer returns, that will be the next time that I’ll probably be ringing H and I think that will distress us again and we’ll probably need that support and someone to talk to, just to calm us back down and bring us back into reality’ (022) |
‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to talk to and when we’ve had a problem, I’ve got on to her. I was inclined to get on to her. She’s been a great help mentally in every which way. Like a couple of times I’ve felt really down when she’s rung and I’ve spoken to her and after I’ve been chatting to her for a while I feel a bit better’ (028)

Allows expression of difficult/sensitive issues

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<tr>
<th>Mentioned by:</th>
<th>Quotes</th>
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<tbody>
<tr>
<td>002, 004b, 022,</td>
<td>‘I could say things to her that I couldn’t say to, well I felt I couldn’t say to other members of the family. I could say what I wanted to without fear of upsetting anyone’ (002)</td>
</tr>
<tr>
<td></td>
<td>‘Just being able to talk to somebody about how you’re feeling and your fears’ (022)</td>
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</table>

Accepts expression of distress (normalises this)

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<thead>
<tr>
<th>Mentioned by:</th>
<th>Quotes</th>
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<tbody>
<tr>
<td>014a, 029,</td>
<td>‘and when I’ve had a cry, she’s been there. Its been quite good’ (014a)</td>
</tr>
<tr>
<td></td>
<td>‘I could get upset with S and I wouldn’t feel that I was doing anything wrong or being silly or all the, I wouldn’t feel like that’ (029)</td>
</tr>
</tbody>
</table>

### Therapeutic ingredients

<table>
<thead>
<tr>
<th>PERSONAL ATTRIBUTES/ATTITUDE OF NS</th>
<th>Description</th>
<th>Mentioned by:</th>
<th>Quotes</th>
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</thead>
<tbody>
<tr>
<td>Caring</td>
<td>Caring</td>
<td>004b, 010b, 017, 021, 028, 030</td>
<td>‘I mean M is a very, very nice, very warm caring person and she comes over as very caring you know. She’s got a lovely way with her. A nice manner and its reassuring’ (004b)</td>
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<td></td>
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<td>‘She’s very good. She’s very caring. She’s got a gentle way with her and any questions asked were honestly and sympathetically dealt with’ (010b)</td>
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<td>‘well somebody does care’ (017)</td>
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<td></td>
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<td></td>
<td>‘helpful to hear her voice and know that someone cared’ (030)</td>
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<tr>
<td>Kind</td>
<td>Kind</td>
<td>004b, 016c, 029, 030,</td>
<td>‘It was invaluable. I’ll never forget as long as I live. And I never realised as I say that there were people out there that were so kind and understanding’ (029)</td>
</tr>
<tr>
<td>Understanding</td>
<td>Understanding</td>
<td>004a, 016c, 021, 028, 029,</td>
<td>‘I felt I could ring her at any time really and she would understand’ (004a)</td>
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<td>‘I don’t know whether its because I’ve met her personally, but she seems to have a good rapport with me and been very understanding and was able to be very helpful at times when its got more stressful than other times’ (028)</td>
</tr>
<tr>
<td>Approachable</td>
<td>Approachable</td>
<td>004b, 009, 010b, 011, 013, 019, 021, 026, 028</td>
<td>She felt very comfortable and supported. It was a lot better than I thought it would be. She was so caring and everything. It was a lot easier to talk to her than I thought it would be’ (009)</td>
</tr>
<tr>
<td></td>
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<td>‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b)</td>
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<td></td>
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<td>‘Personality-wise, we got on very well and maybe that helps. I did feel we all bonded very very well together and I gained a great deal of support from that’ (011)</td>
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<td>‘She never made you feel like you were being a nuisance. Nothing was too much of a problem. When you spoke to her it was ok, which is a nice feeling’ (019)</td>
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<td>‘Everything I sort of needed to know or wanted to talk to, she’s been there. She hasn’t been too pushy and she’s sort of kept her distance and you know when you needed her, she was there’ (028)</td>
</tr>
</tbody>
</table>
Developing a Supportive Nursing Intervention

(021) ‘I really enjoyed the chat. I found talking to her really nice actually’ (026)

Honest 004b, 010b, 011 ‘Just being honest with me, supportive and very caring towards my mum’ (004b)

Open 011, 013 ‘She’s just been a very natural girl and very open and honest and extremely professional (011)’

Available/Accessible 002, 004a, 004b, 007, 009, 010b, 011, 013, 014a, 014b, 014c, 016b, 017, 018, 019, 021, 022, 024, 026, 028, 029, 031

‘Easy as anything. It was ‘as easy as picking up the ‘phone and making an appointment. No problem’ (002)

‘I know that I’ve got someone there to speak to if things get a bit too much’ (002)

‘I felt I could ring her at any time really and she would understand’ (004a)

‘I think even if I just wanted someone to talk to, that knew me and knew what had happened, I feel that I could ring her’ (004a)

‘If you rang her and she wasn’t available, you could leave a message and she would always call you back’ (004b)

‘She was always available if you need her’ (004b)

‘She made time and nothing was too much trouble’ (009)

‘It’s nice that I knew that I could contact her’ (009)

‘She made time and nothing was too much trouble’ (009)

‘It was nice to know that somebody was there we could talk to’ (010b)

‘If you felt that something was bothering you and you weren’t sure whether you were doing the right thing or not, you knew that she was there. You know during the weekdays in which, you know, if she wasn’t there, and you left a message she would very shortly come back to you’ (010b)

‘Just a real ease in the sense that we were very aware that we did have someone we could pick up the phone to at any time. To put our minds at rest if we had any problems or queries, questions, whatever’ (011)

‘I had a contact number for her. I had a bleep number. If she wasn’t available, she got back to us when she could. And in no way did she ever let me think that the call wouldn’t be welcome’ (011)

‘She’s been there for us and you know when we’ve met her, she listened to us and she’s given us answers back’ (014b)

‘Well the fact that she was there, she was on the other end of the phone if you wanted her’ (016b)

‘You do sort of feel that if you wanted to you could ring her at any time, which is good’ (016b)

‘Because she’s available, you know, she’s said she’s always there if I do get problems. And she makes a point of seeing us when we come up thee and having a chat. And as I say, she rings us at home’ (017)

‘I think she’s certainly done her bit in keeping in contact with us and she’s been there. She has been available and said she would be available if we ever wanted to be in touch with her. I can’t really say anymore than that. She’s sort of put herself at our disposal’ (017)

‘Well it’s nice to know that I can just pick up the phone to her, that is really important, if it is something serious, I will ask her if I can come and see her’ (018)
<table>
<thead>
<tr>
<th>Concerned</th>
<th>013</th>
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<tbody>
<tr>
<td>Knowledgeable</td>
<td>002, 004a, 011, 019, 022</td>
</tr>
<tr>
<td>Experienced</td>
<td>002, 004a, 004b, 017, 022, 028, 029</td>
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<tr>
<td>Instils confidence</td>
<td>017</td>
</tr>
<tr>
<td>Competent/good</td>
<td>002, 004a, 009, 010b, 014a, 017, 022, 028, 029, 031</td>
</tr>
<tr>
<td>Like a friend/family</td>
<td>002, 013, 022, 029, 030</td>
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<tr>
<td>Interested</td>
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<tr>
<td>Personal (interested in the person)</td>
<td>017, 019,</td>
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</table>

‘You just phone her up. Literally just phone up. If she’s not there, you leave a message and she gets back to you’ (021)
‘She was just there. She was there for you and you knew she was there for you’ (022)

‘It was comforting to know that there was somebody professional who knew the medical side of things, had experience of the illness, on the other end of the phone’ (019)

‘someone with loads of experience’ (002)
‘Somebody you can contact who obviously has experience’ (004a)
‘M must see this every day of her life…I thought she probably had a little bit longer that what M had told me, but she was spot on. She knew’ (004b)
‘And I feel you know that if I did have any, if I was really down myself I could have, I would prefer to chat with her than anybody who hadn’t got her experience’ (017)
‘I ask her questions and she gives me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026)
‘I think someone should ring up that relative or somebody each week, like H has done with me, to see how they are getting on. Because that, you know, you’re trying to cope and as good as your family are, I think probably an outsider is much better. And somebody that carers and know what she’s talking about’ (028)
‘Someone that obviously knew what we were going through’ (029)

‘and I must say it gave me more confidence’ (017)

‘I feel quite confident that if I do have any concerns and I do need anything, I’m sure H would be able to point me in the right direction. If not to send me the information. She’s come through all the times for us so far, so I’d imagine she’d continue (022)
‘There was no waiting. Bag it was done and that’s what we found with M. As soon as she, she always seems to get everything done, and for my dad it makes him feel like someone’s doing something’ (031)

‘I think she’s more like a friend now’ (002)
‘She had a lovely rapport with mum. I mean mum absolutely loved her. And most, well every night we were up there (hospital), at one point S would come in and she talked and she was like a family member’ (029)

‘I thought she was actually interested in myself as a person, a well as the patient, as a carer you could put it. Well I’m not a carer, I’m his wife. I feel that’s looking after my interests’ (017)
‘Because she was there, she was supporting me and could support him, I mean I was, I didn’t feel completely lost. And to get in touch with these associations that we were given at the beginning, you know, because we haven’t got in touch. But with S it was personal communication and that made all the difference you know. We could talk freely and laugh and joke and get friendly. And I think that was her support that helped me’ (017)
'That there was somebody there that could understand some of the things that perhaps I was feeling, or, it's a comfort to know that there is somebody who’s, not the consultant that's normally busy or his secretary, or whatever. Its someone a bit more personal.’ (019)

Professional 004b, 011, 016c, 019, 'She’s just very professional and it makes you feel that.. she was always available if you need her’ (004b)

Natural 011 'Most helpful’ (002) ‘Very, very supportive’ (010b)

Helpful 002,004a, 007,009, 010b, 014b, 014c, 016b, 017, 022, 018, 022, 026, 028, 029

Supportive 004b, 009, 010b, 011, 013, 018, 021, 028, 029, ‘I couldn’t have wanted anything else’ (004b) ‘very, very supportive’ (010b) ‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018) ‘But you know, I don’t think we could get through without her’ ((021) ‘she was just supportive in every way’ (029)

Reassuring 004b, 009, 014a, 016c, 021, 031 'She’s a lovely lady. I found her very supportive and I'm so glad she was there for my mum and me’ (009)

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<tr>
<th>Therapeutic ingredients</th>
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<tbody>
<tr>
<td><strong>PRACTICAL HELP</strong></td>
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<tr>
<td><strong>Description</strong></td>
</tr>
<tr>
<td>Not specified</td>
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<tr>
<td>Hospice</td>
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<tr>
<td>Liaised with medical staff/other hcps</td>
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<tr>
<td>Bereavement support</td>
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<tr>
<td>Benefits/Grants</td>
</tr>
<tr>
<td>Description</td>
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<td>----------------------------------------------------------------------------</td>
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<tr>
<td>Information about community services/social support for patient</td>
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<tr>
<td>Offered referral for carer counselling</td>
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<tr>
<td>Sorting out patient’s pain</td>
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<tr>
<td>Obtaining results of investigations</td>
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<tr>
<td>Organising appointments/transport</td>
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<tr>
<td>Advice about medication</td>
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<tr>
<td>Holiday advice</td>
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<tr>
<td>Advice about risk of infection</td>
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<tr>
<td>Advice about co-morbidity</td>
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<tr>
<td>Advice about treatment side-effects/symptoms</td>
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<td>Wig referral</td>
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| Therapeutic ingredients                                                                                                                                                                                                 |
| Description                                                                 | Mentioned by: | Quote                                                                                                                                                                                                 |
| Increased carers’ knowledge/understanding                                  | 002, 014c     | ‘I was able to be a source of information for them (other family members)’ (002)                                                                                                                                 |
| Facilitated communication between family members                           | 002, 010b, 011, 014a, 014b | ‘Because sometimes when you’re very close to somebody, it somehow makes it more difficult to talk about things than if its somebody that you’re, its just a neighbour or something’. And sometimes you find its, you know, you’re just a bit too close to the problem to discuss it. And it was nice to, we knew if we rang S she could help us sort through it’ (010b) ‘We did have lots of questions to ask her and she answered them very openly and honestly. Then it gave us the ability to chat and discuss things ourselves’ (011) ‘M helped with this communication (between family members) because she answered any questions we weren’t sure about’ (014b) |

Developing a Supportive Nursing Intervention
### Met information needs

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<tr>
<th>Source</th>
<th>Comments</th>
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| 002, 009, 014c, 026 | ‘Everything was answered. Everything we wanted to know’ (009)  
‘I find it very helpful and she answered all what I wanted to know at the time’ (014c)  
‘I ask her questions and she give s me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026)’ |

### Improved psychological status/coping

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<th>Source</th>
<th>Comments</th>
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| 002, 009, 011, 014a, 018, 019, 026, 028, 029 | ‘So it was a huge relief really, it was part of the burden being taken off my shoulders because I knew what to expect as far as she was concerned’ (002)  
‘It just seemed to take the stress out of it’ (009)  
‘Put our minds at rest’ (011)  
‘I always feel good when I come out from seeing M. You sort of feel positive. I know its not positive with my mum, but you sort of feel better in yourself that someone’s listening to you, how you’re feeling and when I’ve had a cry, she’s been there. Its been quite good’ (014a)  
‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)  
‘Nice to have someone to put your mind at ease’ (019)  
‘It made me feel better, let’s put it that way. Knowing that someone was there that I could talk to, which did make it a bit easy, being in this position, my position, sometimes you feel you’re helpless, but she did give me a lot of encouragement (026)  
‘It was just an enjoyable chat. I mean I came out of thee feeling a hell of a lot better about it than what I did when I went in’ (026)  
‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to talk to and when we’ve had a problem, I’ve got on to her. I was inclined to get on to her. She’s been a great help mentally in every which way. Like a couple of times I’ve felt really down when she’s rung and I’ve spoken to her and after I’ve been chatting to her for a while I feel a bit better’ (028)’ |

### Held/support carer

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<tr>
<th>Source</th>
<th>Comments</th>
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| 002, 004b, 013, 017, 028 | ‘someone there to speak to (002)  
‘I knew that I could call upon M if I needed some help (004b). That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b)  
‘Because I was meeting or speaking to her regularly and she became part of the situation in the end. But she was there for me, and I knew I didn’t phone her because I knew that if I needed her, there was a feeling that because I knew she was there, I didn’t always have to worry her’ (013)  
‘It’s helped me in a way that I didn’t feel so much alone’ (017)  
‘And I feel you know that if I did have any, if I was really down myself I could have, I would prefer to chat with her than anybody who hadn’t got her experience’ (017)  
‘I know she said that she would be there if ever I felt unable to cope. Its reassuring. I think that was helpful’ (017)  
‘When I’m at home, you get a bit low. And that’s where, H has rung up about once a week and she, that has made a big difference’ (028)  
‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to’ |
Facilitated carer’s role 002, 004b, 017, 019, 026, 028,

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<thead>
<tr>
<th>Description</th>
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<tbody>
<tr>
<td>‘I could take care of all the questions that she would need to ask me from her point of view’ (002)</td>
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<tr>
<td>‘My mum was profoundly deaf and so she didn’t hear the answers’ She (patient) relied on us to tell her stuff back. That’s how I knew and I could prepare’ (004b)</td>
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<td></td>
</tr>
<tr>
<td>‘I knew that I could call upon M if I needed some help. That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b)</td>
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<tr>
<td>‘It’s helped me in a way that I didn’t feel so much alone. Not knowing whether it was normal how he was feeling or whether it was something other people experienced. I think she was reassuring in how I felt’ (017)</td>
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<tr>
<td>‘Because she was there, she was supporting me and could support him. I mean. I was, I didn’t feel completely lost’ (017)</td>
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<tr>
<td>‘I spoke to H about my wife’s diabetes and things like that and she advised me on that as well. And I relayed back the information to my wife and it did help us both quite a lot because I know nothing at all about diabetes’ (026)</td>
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NOTES/OTHER COMMENTS

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<thead>
<tr>
<th>Description</th>
<th>Mentioned by:</th>
<th>Quote</th>
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<tbody>
<tr>
<td>Unexpected</td>
<td>002, 009</td>
<td>‘you don’t expect these back-up facilities’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exceeded expectations (009)</td>
</tr>
<tr>
<td>Outside the family</td>
<td>002, 009, 013, 014a, 022, 028, 031</td>
<td>‘I could say things to her that I couldn’t say to, well I felt I couldn’t say to other members of the family. I could say what I wanted to without fear of upsetting anyone’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Though I’ve got my sister, it was quite nice for someone not to be connected in the family’ (009)</td>
</tr>
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<td></td>
<td></td>
<td>‘Probably because it would upset, I couldn’t perhaps say too much to my daughter. So probably I was able to get some of my emotions out, which I wouldn’t have done perhaps to my daughter because it would upset her too much’ (013)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Sometimes when we’ve had a really rough ride with my mum, its really been hard..and you feel you’ve got no one to turn to because you know if you say anything to anyone in the family, its ‘oh you’ve got to understand she’s (patient) ill’. When I’ve gone to M and told M..M has sort of probably given me the answers that I want the family to give me’ (014a)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘It’s actually been nice to know that there’s somebody there to actually talk to outside the family’</td>
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</table>
and outside your friends. And you can actually say exactly what you want and feel. I have found that very, very helpful (022)
‘I think someone should ring up that relative or somebody each week, like H has done with me, to see how they are getting on. Because that, you know, you’re trying to cope and as good as your family are, I think probably an outsider is much better. And somebody that carers and know what she’s talking about’ (028)
‘It was nice to talk to somebody as well who wasn’t involved within the family
Carer burden
<table>
<thead>
<tr>
<th>002, 004b, 009, 013, 014, 017, 019, 024, 026, 031</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘that I was kind of doing it on my own, within the family’ (002-daughter-in-law)</td>
</tr>
<tr>
<td>‘I was still in shock, raw’ (004b)</td>
</tr>
<tr>
<td>‘because I’d heard some horror stories from people in the past’ (004b)</td>
</tr>
<tr>
<td>Son had a brain tumour – felt stressed unable to ‘go through it all again’ (009)</td>
</tr>
<tr>
<td>‘and the worry of your husband wears you out’ (013)</td>
</tr>
<tr>
<td>Find mum difficult to care for eg in a lot of pain but won’t take analgesia (014a)</td>
</tr>
<tr>
<td>‘It takes over your life’ (017)</td>
</tr>
<tr>
<td>‘I’m just in a quandary as to know what to do. All I want to do is to ease his ill-feeling. You know he gets very, at times, he gets very, very low, and unless I can do something form him, I get low myself as well’ (017)</td>
</tr>
<tr>
<td>‘I’m responsible for a lot of his well-being’ (017)</td>
</tr>
<tr>
<td>‘I’m sure as soon as he feels better, we’ll copy better’ (017)</td>
</tr>
<tr>
<td>‘So often you get overlooked. It’s the patient that gets the focus and the carer sort of gets overlooked. And at the end of the day, if the carers not feeling good about things or what have you, then they can’t care properly can they. So yeah its nice to know because obviously you do feel different emotions when you’re caring for somebody with an illness. Its nice to know you’re getting a bit of support there..I think its very, very important I think’ (019)</td>
</tr>
<tr>
<td>‘We have to live day by day, week by week. W can’t plan anything or you know we just have to wait and see how things turn out’ (24)</td>
</tr>
<tr>
<td>‘You just feel totally helpless’ (026)</td>
</tr>
<tr>
<td>‘There’s so much to take in, it has been quite hard to take everything in’ (031)</td>
</tr>
</tbody>
</table>

A contact
<table>
<thead>
<tr>
<th>002,004a, 004b, 009, 014a, 029, 031</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘The fact that someone is there. Somebody you can contact who obviously has experience’ (004a)</td>
</tr>
<tr>
<td>‘So it was reassuring to know that there was somebody out there that could help me if I needed it’ (004b)</td>
</tr>
<tr>
<td>‘I knew that I could call upon M if I needed some help. That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b)</td>
</tr>
<tr>
<td>‘She was always there’ (009)</td>
</tr>
<tr>
<td>‘Its nice that I knew that I could contact her’ (009)</td>
</tr>
<tr>
<td>‘Its nice to have a contact’ (031)</td>
</tr>
</tbody>
</table>

Wanting more info
<table>
<thead>
<tr>
<th>004a, 009, 013, 014b, 014c.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanted to know more about what to expect ‘time-scale’, treatment options (no treatment), and where cancer was (004a)</td>
</tr>
<tr>
<td>014b, 014c, 017</td>
</tr>
<tr>
<td>------------------</td>
</tr>
<tr>
<td><strong>Proactive</strong></td>
</tr>
<tr>
<td>014b</td>
</tr>
<tr>
<td>010b</td>
</tr>
<tr>
<td>016b</td>
</tr>
<tr>
<td>009</td>
</tr>
<tr>
<td>014a, 014b, 014c, 017</td>
</tr>
<tr>
<td>011</td>
</tr>
<tr>
<td>028</td>
</tr>
</tbody>
</table>
## Key concerns

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Mentioned by:</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future/how disease would progress</td>
<td>002, 004a, 004b, 009, 010b, 013, 014a, 014a, 014c, 016c, 017, 029, 031</td>
<td>'her progress and what her prognosis is' (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Not knowing exactly how everything was going to go' is very difficult (004a)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'if the tumour was going to spread' (009)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'My main concern is what’s going to happen to him, you know because it’s the future’ (017)</td>
</tr>
<tr>
<td>How &amp; when patient will die</td>
<td>009, 014b,</td>
<td>'How long before we’d lose mum’ (009)</td>
</tr>
<tr>
<td>Need for information/never enough</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concern for patient’s well-being</td>
<td>002, 004b, 007, 011, 014a, 017, 018, 019, 021, 026, 028, 029, 030</td>
<td>'there was a huge emotional support needed because she (patient) was dealing not only with her own illness but the emotional effect of her husband not being there and worrying about him’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'My main concern was that she wouldn’t suffer, that she would not be in any pain at all’ (004b)</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>004a,</td>
<td>'Not knowing exactly how everything was going to go’ is very difficult (004a)</td>
</tr>
<tr>
<td>Little expression of carer’s own needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other responsibilities</td>
<td>002, 018, 024</td>
<td>Father in law (patient’s husband) has alzheimers’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mother (patient’s wife) has dementia (024)</td>
</tr>
<tr>
<td>Availability of further support if needed/future care needs</td>
<td>010b, 031</td>
<td></td>
</tr>
<tr>
<td>Treatment effects</td>
<td>014c, 016c, 021, 029,</td>
<td></td>
</tr>
<tr>
<td>Treatment delays</td>
<td>028</td>
<td></td>
</tr>
<tr>
<td>Lack of information</td>
<td>028, 030,</td>
<td></td>
</tr>
<tr>
<td>Structure of Intervention</td>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td><strong>Face to face</strong></td>
<td>002, 013, 014a, 014b, 017, 022, 026, 029, 030, 028</td>
<td></td>
</tr>
<tr>
<td>‘could put a face to the voice’ (002)</td>
<td>I found it very helpful face-to-face, you have that personal feeling’ (017)</td>
<td></td>
</tr>
<tr>
<td>‘because then you can put the face to the name and it makes it a bit more personal as well’ (022)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Telephone</strong></td>
<td>004a, 010b, 011, 019, 021, 024, 031</td>
<td></td>
</tr>
<tr>
<td>Convenience – ‘because of the distance (004a)’</td>
<td>‘Well actually I never met S. Most of my contact with S was on the telephone. But my mother met her, and so did my brother and his wife, and they thought she was absolutely amazing, you know very, very supportive. As I did find on the ‘phone’ (010b)</td>
<td></td>
</tr>
<tr>
<td>‘When I spoke to her on the telephone it was, she was no less efficient and caring on the telephone than I’m sure she would have been face-to-face’ (010b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone contact preferred (working) (011)</td>
<td>It was telephone support. Unfortunately I never got to actually meet S. The one time I did go up with mum, S wasn’t there. But she phoned me the next day, herself, I didn’t ask her to. But she phoned me up to apologise that she didn’t meet me and asked me if I had any questions’ (019)</td>
<td></td>
</tr>
<tr>
<td>‘I’ve got to say I do find it easier to speak over the phone that face-to-face. There’s no one else around to, like worry about’ (21)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone contact more convenient (works) (24)</td>
<td>‘I suppose I felt closer to her when we’re together, you know and I could express myself better than on the ‘phone’ (029)</td>
<td></td>
</tr>
<tr>
<td>‘Phone contact was good. Because I think, sometimes as well you’ve got a lot of mixed emotions. And I think you tend to get a bit upset if its face-to-face. Whereas on the ‘phone, I think its sometimes a little bit easier to talk’ (031)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Either face-to-face or telephone</strong></td>
<td>004b, 014c, 018, 028</td>
<td></td>
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<tr>
<td>‘I don’t mind either way. I didn’t have no problems with talking to her over the ‘phone (works)’ (014c)</td>
<td></td>
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<tr>
<td><strong>Right time</strong></td>
<td>004a, 004b, 002, 007, 010b, 011, 013, 014a, 014b, 014c, 017, 018, 021, 022, 026, 029, 031</td>
<td></td>
</tr>
<tr>
<td><strong>Earlier</strong></td>
<td>009, 019, 022, 028, 030</td>
<td></td>
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<tr>
<td>‘It would have probably been nice shortly after my mum got diagnosed because we’re just, I think, we were in a state of shock’ (009)</td>
<td></td>
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<tr>
<td>Immediately after diagnosis (019)</td>
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<tr>
<td><strong>Out of hours</strong></td>
<td>010b, 018</td>
<td></td>
</tr>
<tr>
<td>‘The only down side …we needed to contact them quite urgently over the weekends, two different weekends, and we couldn’t get hold of anybody’ (010b)</td>
<td></td>
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</tr>
<tr>
<td><strong>Home visits</strong></td>
<td>026, 029</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5: Initial assessment record documentation

CARER INITIAL ASSESSMENT
(Front sheet not for data purposes)

Identification No: _________ Date _________

Name of carer:

Address:

Telephone No:

Mobile:

E-mail address:

Name of patient:

Hosp.No of patient:
CARER INITIAL ASSESSMENT

Identification No: __________ Date _____________

<table>
<thead>
<tr>
<th>Timing of first contact</th>
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<tbody>
<tr>
<td>Diagnosis</td>
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<tr>
<td>During treatment</td>
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<tr>
<td>Follow-up</td>
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<tr>
<td>Terminal phase</td>
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<tr>
<td>Face-to-face</td>
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<td></td>
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<tr>
<td>Telephone</td>
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<tr>
<td>Place of contact</td>
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</table>

<table>
<thead>
<tr>
<th>Age of carer</th>
<th>Sex of carer</th>
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<tr>
<td>Male</td>
<td>Female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to patient</th>
<th>Spouse</th>
<th>Partner</th>
<th>Son/daughter</th>
<th>Friend</th>
<th>Other (specify)</th>
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<tr>
<th>Dependents (include age)</th>
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<table>
<thead>
<tr>
<th>Other family members</th>
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<table>
<thead>
<tr>
<th>Social support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives with patient</td>
</tr>
<tr>
<td>Occupation</td>
</tr>
<tr>
<td>Occupation</td>
</tr>
<tr>
<td>Good</td>
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<table>
<thead>
<tr>
<th>Own health</th>
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</table>
Summary of carer’s experience relating to patient’s illness journey:

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Carer’s identified need(s):

________________________________________________________________
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Nurse Specialist’s perception of need(s):

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Resources/Information given:
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<table>
<thead>
<tr>
<th>Referral</th>
<th>Date</th>
<th>Reason</th>
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Agreed management plan:
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<table>
<thead>
<tr>
<th>Agreed contact</th>
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<tbody>
<tr>
<td>Telephone</td>
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<tr>
<td>None</td>
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</table>

<table>
<thead>
<tr>
<th>Duration of consultation</th>
<th>Place of consultation</th>
<th>Date &amp; time of next contact</th>
<th>Name of CNS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>
CNS reflection/assessment on intervention/contact

What went well?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
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Was there anything that was difficult?

__________________________________________________________________
__________________________________________________________________
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Carer’s satisfaction from interview (perceived)

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Any other comments?

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__________________________________________________________________
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__________________________________________________________________
# Appendix 6: Further contact record documentation

## CARER CONTACT SHEET

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>During treatment</th>
<th>Follow-up</th>
<th>Terminal phase</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Type of contact</th>
<th>Face to face, carer initiated</th>
<th>Phone contact, carer initiated</th>
<th>Face to face, CNS initiated</th>
<th>Phone contact, CNS initiated</th>
<th>Email contact, carer initiated</th>
<th>Email contact, CNS initiated</th>
</tr>
</thead>
</table>

### Place of contact if relevant

<table>
<thead>
<tr>
<th>Nature of intervention (tick all that apply)</th>
<th>Specify</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information-giving</td>
<td></td>
</tr>
<tr>
<td>Advice-giving</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td>Benefits advice</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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<td>Other</td>
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<table>
<thead>
<tr>
<th>Referral</th>
<th>Date:</th>
<th>Reason</th>
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</table>

Length of contact
Further comments on intervention/contact

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

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________________________________________________________________________

CNS reflection/assessment on intervention/contact

What went well?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Developing a Supportive Nursing Intervention
Was there anything that was difficult?

________________________________________________________________________
________________________________________________________________________
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________________________________________________________________________

Carer’s satisfaction from interview (perceived)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Other comments (continue overleaf if necessary)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix 7: Focus group schedule

Focus Group Discussion - Process

1. Welcome
2. Refreshments- whilst waiting for all participants to arrive.

Introduction

Welcome participants to group introduce primary and secondary researchers. Open group discussion by reaffirming confidentiality of group and guidelines/rules, including level of group confidentiality and right to withdraw at any time.

i) confidentiality
ii) views needed – describe what delivered, enhance the intervention in future & increase potency – no correct/incorrect points
iii) my role guide – will gently steer if necessary & keep on target
iv) try not to speak over each other, or have ‘aside’ conversations

Ice-breaker

Can you begin by telling us your name and one thing that you are looking forward to this year.

Group discussion as directed by guide (next sheet)

Summary of main points and ending questions

Second researcher who has been acting as an observer in the room summarises points

Activity

Please write down up to 5 elements of what you provided that you believe were most helpful to carers? Write down....

Most important at the top ranked 1, least at the bottom (up to 5)

Ending Question

Is there anything else you would like to add about the intervention and how it has been delivered and responded to?

Conclusion

Focus Group Discussion is concluded. Thanks to the participants for attending. Final reminder of confidentiality within researchers and group participants.
Guide

□ What has been your experience of supporting carers in this study?
   ○ What kind of needs were evident in the carers you were involved with?
□ How did these vary?
□ How successful were efforts to support them via intervening in the manner that you did? How helpful?
□ What were the outcomes?
   ○ What difference did this intervention make?
   ○ Carers managing the situation at home?
   ○ Patient care?
   ○ Bereavement care – where this arose
   ○ Service angle of having greater contact with carers?
□ What needs (if any) did study identify that you were unable to meet? Explain.
□ Did carer outcomes vary?
   ○ Did it make a difference who was intervening?
   ○ Did anyone in particular benefit from this approach?
   ○ Who tended to respond less well?
□ Who do you feel are the target group – did we reach these?
□ How achievable has it been within current resources?
□ What were the challenges encountered? Constraining factors?
   ○ Personal?
   ○ Process?
   ○ Service?
□ Were there times you felt you were in danger of breaking patient confidentiality?
   ○ If so, how dealt with?
□ How has it changed how you work with carers not on the study?
□ Is this way of working something you would like to continue after the study?
□ Will this be possible? Explain
□ How much was this approach specific to carers of those with lung cancer?
□ What might need to be different when working alongside carers of patients with other diseases?
□ Have you identified through providing carer support skills/training that may be necessary for you/other nurses to deliver care & support to informal carers of cancer patients?
Appendix 8: Patient information sheet

Patient information sheet

Meeting the needs of close relatives and friends of patients

with lung cancer and mesothelioma

Dear Mr/Mrs/Miss/Ms: _________________,

You are being invited to take part in the above study. Before you decide whether or not you would like to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully and discuss it with relatives, friends and your GP if you wish. We have added our telephone number and address at the end of this information sheet. Please contact us if you would like to discuss anything further.

What is the purpose of the study?

When cancer is diagnosed, it not only affects the person with cancer - it also affects families and friends. However, we recognise that health professionals do not always support family and friends very well. This study will identify ways in which health professionals may better support the family and friends of those with cancer.

With your permission, we would like to ask a close relative or friend who is particularly close to you if they would be willing to participate in this study. If they agree, we would arrange a meeting with them and a Cancer Nurse Specialist to help them explore their feelings and concerns as a close relative or friend of someone with cancer. We would then draw up a plan of support for them. This plan of support may involve:

- providing more information about the cancer and its treatment,
- seeing or telephoning them on a regular basis, or
- referring them to other agencies who may be able to help further.

Please be assured that we will not discuss any information about you that you have not agreed to.

We would also ask them to complete a questionnaire. This questionnaire would provide information about how they are feeling in themselves.

The study will last three months and after this time we would ask the family member or friend to complete the questionnaire again. Also, if they were willing, we would ask them to participate in an interview with the Researcher involved in the study. The interview will
identify what types of support have been helpful and assist us in planning care for family members and friends in the future.

At the end of the study, support from the Cancer Nurse Specialist will continue to be available for as long as your family or friend would like it.

It is entirely up to you, and your family member or friend, whether to take part in this study. If you decide to take part and later change your mind you are free to withdraw at any time without giving a reason. If you do not wish to take part or later withdraw from the study, please be assured that your care will not be affected in any way.

If you do consent to allow a family member or friend to take part, your medical records and information about you will be kept strictly confidential. Any information and data that we gather about your family member or friend will also be kept in the strictest confidence, and will be anonymous when reporting on the findings.

If you agree to a family member or friend taking part in this study, you will be given a copy of this information sheet and will be asked for your written consent, by signing an informed consent sheet.

This study is being conducted jointly by nurses at Guy’s and St Thomas’ NHS Hospital Trust and researchers from the Florence Nightingale School of Nursing and Midwifery, King’s College, London. It has been approved by the Research Ethics Committee of Guy’s Hospital.

‘Consumers for Ethics in Research’ (CERES) publish a leaflet entitled ‘Medical Research and You’. This leaflet gives more information about medical research and looks at some questions you may want to ask. This leaflet may be obtained from CERES, PO Box 1365, London N16 0BW.

Thank you very much for taking the time to read this information sheet. If you require any further information, please do not hesitate to contact any of these members of the study team:

Ms Jibby Medina
Research Associate
Florence Nightingale
School of Nursing & Midwifery
King’s College London
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Clinical Development Nurse
Cancer and Haematology Services
Guy’s & St Thomas’ Hospital NHS Trust
C/o Samaritan Ward
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Guy’s Hospital, St Thomas Street
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Telephone: 020 7188 4252
Hilary.Plant@gstt.sthames.nhs.uk

Ms Sally Moore
Lung Cancer Nurse Specialist
Guy’s & St Thomas’ Hospital NHS Trust
Palliative Care
Cancer & Haematology
New Guy’s House, Guy’s Hospital
St Thomas Street, London SE1 9RT
Telephone: 020 7188 4739
Sally.Moore@gstt.sthames.nhs.uk

Ms Amanda Sherwin
Lung Cancer Nurse Specialist
Guy’s & St Thomas’ Hospital NHS Trust
Palliative Care
Cancer & Haematology
New Guy’s House, Guy’s Hospital
St Thomas Street, London SE1 9RT
Telephone: 020 7188 4268
Amanda.Sherwin@gstt.sthames.nhs.uk
Appendix 9: Patient informed consent form

Patient Informed Consent Form

Title of Project:
Meeting the needs of close relatives and friends of patients with lung and mesothelioma

Name of Researcher: Dr Hilary Plant

I confirm that I have read and understand the patient information sheet dated 20th of May 2004 (Version 2) for the above study and have had the opportunity to ask questions. I also understand that my condition and treatment may be discussed by my family member/friend with the Nurse Specialist where relevant.

_________________________  ____/____/____  ____________________
Name of Participant: Mr/Mrs/Miss/Ms___________________________

_________________________  ____/____/____  ____________________
Name of Person taking consent
(If different from researcher)

_________________________  ____/____/____  ____________________
Researcher

Please initial box

Name of Participant: Mr/Mrs/Miss/Ms___________________________

Date

Signature

Date

Signature

Date

Signature
Appendix 10: Family member information sheet

Guy's and St Thomas' Hospital

Carers' information sheet

Meeting the needs of close relatives and friends of patients
with lung cancer and mesothelioma

Dear Mr/Mrs/Miss/Ms: ________________,

You are being invited to take part in the above study. Before you decide whether or not you would like to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully and discuss it with relatives, friends and your GP if you wish. We have added our telephone number and address at the end of this information sheet. Please contact us if you would like to discuss anything further.

What is the purpose of the study?

When cancer is diagnosed, it not only affects the person with cancer - it also affects families and friends. However, we recognise that health professionals do not always support family and friends very well. This is a feasibility study aiming to determine how best to offer supportive care to the family and friends of those with lung cancer, through better understanding carers’ needs and experiences.

Why have I been chosen?

You have been identified as a close relative or friend of someone with lung cancer or mesothelioma. We would like to invite approximately 20 people like yourself to participate in the study.

What will happen to me if I take part?

If you are willing to take part, we would arrange an initial meeting with one of our Cancer Nurse Specialist to talk about your experiences of knowing and living with a relative or friend with lung cancer or mesothelioma. We would also ask you to complete a questionnaire which provides us with information about how you are feeling.

Following the meeting with the Cancer Nurse Specialist, if you feel it would be helpful, a plan for on-going support will be offered to you. This plan of support may involve:

- providing more information about the cancer and its treatment
- meeting or telephoning you on a regular basis, or
referring you to other agencies who may be able to help further.

Alternatively, you may not wish for further support. The choice will be entirely up to you.

The study will last for three months. At the end of this period, we will ask you to complete the questionnaire again and, if you are willing, participate in an interview with our researcher. This interview will ask you about the types of support that you have found helpful. It will also ask you about whether you would have liked any other types of support. All information from the questionnaires and interviews will be confidential to the study team. At the end of the study, support from the Cancer Nurse Specialist will continue to be available for as long as you would like it.

**Do I have to take part?**

It is entirely up to you whether you take part in this study. If you decide to take part and later change your mind you are free to withdraw at any time without giving a reason. If you do not wish to take part or later withdraw from the study, please be assured that the care of your relative or friend will not be affected in any way.

**Are there any benefits or risks in taking part?**

We do not envisage that there will be any risks involved in taking part in this study. We hope that we will discover ways in which we can better support you.

If you do become distressed at any point during the research process, if you wish, an appointment will be arranged with the Cancer Clinical Nurse Specialist, or a referral arranged with another Health Care professional.

We hope that the findings of the study will improve our support of relatives and friends of people with cancer in the future.

If you do consent to take part, the information we gain from you will be analysed for the purpose of the study. However, all information which is collected about you during the course of the study will be kept strictly confidential, and any data that we gather from you will be kept completely anonymous when reporting on the findings.

This study is being conducted jointly by nurses at Guy’s and St Thomas’ NHS Hospital Trust and researchers from the Florence Nightingale School of Nursing and Midwifery, Kings’ College, London. It has been approved by the Research Ethics Committee of Guy’s Hospital.

‘Consumers for Ethics in Research’ (CERES) publish a leaflet entitled ‘Medical Research and You’. This leaflet gives more information about medical research and looks at some questions you may want to ask. This leaflet may be obtained from CERES, PO Box 1365, London N16 0BW.

If you agree to take part in this study, you will be given a copy of this information sheet and a copy of the consent form that you will be asked to sign.

**What happens with the result of this study?**

The findings of the study will be published and shared with other health professionals within Guy’s and St Thomas’ and elsewhere. This is likely to be in about 18 months’ time. If you would like a copy of the final report from the study, please let us know.
Thank you very much for taking the time to read this information sheet. If you require any further information, please do not hesitate to contact any of these members of the study team:

Ms Jibby Medina  
Research Associate  
Florence Nightingale School of Nursing & Midwifery  
King's College London  
Room 5.9 WBW  
Franklin Wilkins Building  
150 Stamford Street  
London SE1 9NN  
Telephone: 020 7848 3759  
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Dr Hilary Plant  
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Guy's Hospital  
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Palliative Care  
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Lung Cancer Nurse Specialist  
Guy's & St Thomas' Hospital NHS Trust  
Palliative Care  
Cancer & Haematology  
New Guy's House  
Guy's Hospital  
St Thomas Street  
London SE1 9RT  
Telephone: 020 7188 4268  
Amanda.Sherwin@gstt.sthames.nhs.uk
Appendix 11: Family member informed consent form

Oncology & Haematology
Directorate
Cancer Management Offices
4th Floor
Thomas Guy House

Guy’s Hospital
St Thomas’ Street
London SE1 9RT

Name of Participant:

Tel: 020 718 84266
Fax: 020 718 83606

Carer Informed Consent Form

Title of Project:
Meeting the needs of close relatives and friends of patients with lung cancer and mesothelioma

Name of Researcher: Dr Hilary Plant

Please initial box

1. I confirm that I have read and understand the information sheet dated 20th of May 2004 (Version 2) for the above study and have had the opportunity to ask questions

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

3. I agree to take part in the above study

4. I am happy for the interview to be tape recorded on the understanding that the tape will be destroyed at the end of the project

_________________________  ____/____/____  ____________________
Name of Participant  Date  Signature

_________________________  ____/____/____  ____________________
Name of Person taking consent (If different from researcher)  Date  Signature

_________________________  ____/____/____  ____________________
Researcher  Date  Signature
## Appendix 12: Lists summarising ongoing contacts

### 12a. Reasons for contacts

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Family member</th>
<th>Mutual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To generally enquire about carer’s well being</td>
<td>21. Discuss test results</td>
<td>41. Planned face to face follow up meeting</td>
</tr>
<tr>
<td>2. To make contact as requested (incl. previous message on answer phone from carer)</td>
<td>22. To gain information on patient’s condition</td>
<td>42. Planned follow up telephone call pre arranged</td>
</tr>
<tr>
<td>3. To find out outcome of GP visit</td>
<td>23. To alert to new symptom and get advice on how to manage (symptom control)</td>
<td>43. Initial assessment</td>
</tr>
<tr>
<td>4. To inform carer of date of patient investigation / appointment / admission</td>
<td>24. To inform nurse of date of appointment with psychological support</td>
<td>44. Planned follow up call (but not pre arranged)</td>
</tr>
<tr>
<td>5. To enquire about carers well being (incidental)</td>
<td>25. To alert to and discuss deteriorating condition</td>
<td>45. Post bereavement support</td>
</tr>
<tr>
<td>6. To inform and discuss outcome of referral</td>
<td>26. Discuss treatment plan / information relating to next steps in treatment plan</td>
<td>46. Support, advice and reassurance whilst carer managing palliative patient at home</td>
</tr>
<tr>
<td>7. To give information and clarify discharge planning process</td>
<td>27. To discuss and get advice on how to arrange admission to hospice</td>
<td>47. To review current situation</td>
</tr>
<tr>
<td>8. To inform of outcome of conversation with doctor</td>
<td>28. To get advice re discharge arrangements</td>
<td>48. To offer emotional support</td>
</tr>
<tr>
<td>9. To reschedule face to face meeting</td>
<td>29. Advice on symptoms arising as result of radiotherapy</td>
<td>49. To generally enquire about carer’s well being</td>
</tr>
<tr>
<td>10. Support, advice and reassurance whilst carer managing palliative patient at home</td>
<td>30. To inform nurse carer does not want patient told test result in event of bad news</td>
<td>50. To inform of outcome of conversation with doctor</td>
</tr>
<tr>
<td>11. Post bereavement support</td>
<td>31. To confirm email address</td>
<td>51. To inform and discuss outcome of referral</td>
</tr>
<tr>
<td>12. Discuss test results</td>
<td>32. Travel arrangements in order to receive treatment</td>
<td>52. To find out outcome of GP visit</td>
</tr>
<tr>
<td></td>
<td>33. To review current situation</td>
<td>53. To inform carer of date of patient investigation/appointment</td>
</tr>
<tr>
<td></td>
<td>34. To obtain emotional support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>35. Unclear – missed call</td>
<td></td>
</tr>
<tr>
<td></td>
<td>36. To change their appointment with the Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>37. Because they had concern about another family member</td>
<td></td>
</tr>
<tr>
<td></td>
<td>38. To make an appointment with the nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>39. Post bereavement support</td>
<td></td>
</tr>
</tbody>
</table>

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Developing a Supportive Nursing Intervention 152
12b. Outcomes of contacts

1. Carer not available

2. Subsequent contact left up to carer* [some say will get in contact as required and underline preference for no proactive contact from CNS, others say to say hello when in clinic with patient…]

3. Agreement to call

4. Agreement to subsequent meeting and booked

5. Planned face to face follow up meeting (but time and date not yet agreed)

6. Agreement to call again with outcome of discussion with doctor, or having secured information from health professional (e.g. discharge)

7. Encouraged to speak to hospice staff re discharge arrangements

8. Contact to be made with GP

9. Contact to be made with patient to undertake assessment

10. Referral to be made for psychological support

11. Agreement to bring symptoms to attention of doctor

12. Agreement for carer to call nurse with date of appointment / re tests results

13. Asked to contact carer (message left on answer phone)

14. Booked OPA* for patient to undergo review

15. Arranged 1-1 contact with carer (without patient)

16. Arranged to view body

17. Agreement for nurse to call again with date of patient’s next appointment

18. Agreed session with another family member

19. Initial assessment didn’t take place

20. Patient admitted to hospital

* Used when no plan/arrangement made
* Out patients appointment
12c. Intervention delivered on contacts

**A** Information/Advice giving
1 Symptoms/symptom control
2 Disease process
3 Treatment modalities
4 Medication
5 Additional resources/support services
6 Self management strategies (living with cancer)
7 Managing at home
8 Diet
9 Managing uncertainty (around living with cancer/lung cancer)
10 Giving/clarifying test results
11 Info-giving/clarifying management plan
12 Transport
13 Discharge planning
14 Advice regarding own health issues
15 Prognosis/future
16 Other

**B** Listening
17 Listening to current/recent experience of cancer experience
18 Allowing patient to explore the past to put current experience into context
19 Listening to family issue
20 Listening about own health

**C** Benefits
21 Benefits advice
22 Help with obtaining benefits

**D-23** Helping carer ‘navigate the system’

**E** Active intervention in patient’s care pathway
24 Chasing results of investigations
25 Transport
26 Appointments
27 Treatment plans
28 Other active intervention

**F** Liaison with other health care professional(s) regarding pt’s care/care needs
29 GP
30 Hospital doctor
31 Palliative Care Team
32 Ward nurses
33 Other (Specify)

**G-34** Acknowledging and providing reassurance over role as carer

**H-35** Enabling expression of emotion

**I-36** Monitoring carer’s well-being / maintaining continuity in nurse/carer relationship

**J-37** Acknowledging and exploring patient’s condition

**K-38** Helping with decision-making

**L-39** Bereavement support
Appendix 13: Focus group coding index

Coding frame for carer focus group conducted with interveners

1. Personal experience
   1.1 Sacrifice
   1.2 Reward

2. Focus of intervention
   2.1 Patient needs paramount
   2.2 Carer
   2.3 Interwoven

3. Content of intervention
   3.1 Emotional need
   3.2 Psychological need
   3.3 Informational/service need
   3.4 Reassurance need
   3.5 Relationship need
   3.6 Harboured need
   3.7 Dynamic need

4. Characteristics/features of intervention
   4.1 Time
   4.2 Accessibility
   4.3 Assessment
   4.4 Documentation

5. Delivery modes
   5.1 Proactive
   5.2 Reactive
   5.3 Artificial
   5.4 Individual versus family

6. Differential carer uptake
   6.1 Uncertainty over what intervener could offer
   6.2 Gender

7. Differential intervention delivery

8. Outcomes
   8.1 Lowering barriers
   8.2 Smoothed pathway
   8.3 Reduced anxiety
   8.4 Sense of trust
   8.4.1 Continuity
   8.4.2 Safety
   8.4.3 Sounding board
   8.4.4 History: overcoming platitudes
   8.5 Sense of control
8.5.1 Safety
8.5.2 Empowerment
8.5.3 Dependency
8.6 Better coping at home/more effective carer role
8.6.1 Reassurance over events; ‘Doing the right thing’
8.6.2 Understanding of symptoms and their amelioration
8.7 Preparing for death
8.7.1 Personal
8.7.2 Controlling place of death
8.7.3 Eased bereavement

9. Service impact/challenge
9.1 Intervention
9.1.1 Accommodation
9.1.2 Distortion of usual practice
9.1.3 Pandora’s box
9.1.4 Role blurring; counselling & supporting
9.2 Research in practice
9.2.1 Usual versus unusual CNS role

10. Ending the intervention

11. Vulnerable carers
11.1 Insufficient support networks
11.2 Complex/poor relation ship with patient
11.3 Illness within family
11.4 Unwillingness/resentment over caring role
11.5 Stereotypes

12. Future
12.1 Resourcing
12.2 Minimum
12.2.1 Individual face-to-face carer assessment
12.2.2 Contact person
12.2.3 Documentation
12.2.4 Organised peer supervision
12.3 Challenges
12.3.1 Time
12.3.2 Equity
12.3.3 MDT & service support – benchmarks
12.3.4 Measuring/quantifying
Appendix 14: Dissemination activities to date

Publications


Oral presentations


Posters


Richardson, A; Medina, J; Plant, H; Moore, S; Ream, E; Johnson, M & Sherwin, A (2004). Meeting the needs of informal carers of patients with lung cancer: A feasibility study. King's College London, Florence Nightingale School of Nursing and Midwifery, Postgraduate Research (PGR) Symposium, 25th June 2004
Appendix 1: Feedback Sheet – Used in piloting study questionnaire

Pre-Test Evaluation

[NOTE: This version will be printed out as one double-sided A4 sheet]

We would appreciate it if you could please take some time to give us some feedback on the questionnaire that you have just completed - Please refer to the attached copy of the questionnaire

Please complete all sections questionnaire

We anticipate this will take no more than 10 minutes to complete

1. How long roughly did it take you to complete the questionnaire (Minutes)

2. Did you have any difficulties understanding the questions? (Yes/No)
   If Yes, please list the item numbers of the questions that you found troublesome (e.g. B13), and let us know why:

3. How easy was it to fill in the sections of the questionnaire? (Tick)
   Please see the attached copy of the questionnaire
<table>
<thead>
<tr>
<th>Section A</th>
<th>Very Easy</th>
<th>Easy</th>
<th>Difficult</th>
<th>Very Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section C</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section D</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   If you had any difficulties, please explain these:

4a. How clear was the appearance of each section of the questionnaire? (Tick)
<table>
<thead>
<tr>
<th>Section A</th>
<th>Very Clear</th>
<th>Clear</th>
<th>Unclear</th>
<th>Very Unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section C</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section D</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4b. If you found the appearance of the questionnaire difficult, please explain below:
   For example – with the size of the print, the spacing between the questions, etc
5. Did you have any other difficulties with the questionnaire? (Yes/No)
   If Yes, please give details:

<table>
<thead>
<tr>
<th>6a. Were there any questions that you particularly disliked? (Yes/No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If Yes, please list the item numbers of the questions (e.g. B13), and let us know why:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6b. Were there any questions that you particularly found helpful or useful? (Yes/No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If Yes, please list the item numbers of the questions (e.g. B13), and let us know why:</td>
</tr>
</tbody>
</table>

7. Do you think that there is anything else that we should have included in our questionnaire – which we might have missed out? Do you have any suggestions? Please note these below:

Thank you very much for your comments and your time
Appendix 2: Study Questionnaire

[Prepared and printed with King's Logo]

Participant ID No □□

Carer Questionnaire

Meeting the needs of close relatives and friends of patients with lung cancer and mesothelioma

Florence Nightingale School of Nursing & Midwifery
October 2004
Section A

In this section we would like to know about your needs as a carer, rather than those of the person you are caring for.

Below you will find a list of needs carers sometimes have when facing illness; we would like you to go through the list in two ways:

First, ask yourself: “How important has this need been to me, over the past few weeks?” Then circle the appropriate number on a scale from 1 to 5:

1 = Not at all important  
2 = Not very important  
3 = Neither important nor unimportant  
4 = Important  
5 = Very important

Second, ask yourself: “How satisfied has this need been for me, over the past few weeks?” Then circle the appropriate number on a scale from 1 to 5:

1 = Not at all satisfied  
2 = Not very satisfied  
3 = Neither satisfied nor unsatisfied  
4 = Satisfied  
5 = Very satisfied

If the statement does not apply to you, tick the box under “DOES NOT APPLY TO ME”

Now, please go through the list and make a selection for all of the statements:

<table>
<thead>
<tr>
<th>GETTING OR HAVING THE FOLLOWING:</th>
<th>DOES NOT APPLY TO ME</th>
<th>HOW IMPORTANT?</th>
<th>HOW SATISFIED?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>NOT AT ALL IMPORTANT</td>
<td>VERY IMPORTANT</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A1. Information about medication and side effects</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A2. Information about treatment plans</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A3. Information about what to expect</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A4. Honest information</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A5. Confidence in the health professionals I meet</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A6. Information given sensitively</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A7. Health professionals who listen to me</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A8. Health professionals who have time to discuss issues with me</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>GETTING OR HAVING THE FOLLOWING:</td>
<td>DOES NOT APPLY TO ME</td>
<td>HOW IMPORTANT?</td>
<td>HOW SATISFIED?</td>
</tr>
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<tr>
<td></td>
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<td>A9. Health professionals who treat me with respect</td>
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<tr>
<td>A10. Easy and quick access to doctors</td>
<td>□</td>
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<tr>
<td>A11. Easy and quick access to health professionals other than doctors</td>
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<td>A12. Access to other sources of information</td>
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<td>A13. Advice on what services and help are available</td>
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<tr>
<td>A14. Opportunities to participate in choices around treatment</td>
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</tr>
<tr>
<td>A15. Help with finding a sense of purpose and meaning</td>
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<td>2</td>
</tr>
<tr>
<td>A16. Hope for the future</td>
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<td>A17. Opportunities for personal prayer</td>
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<td>A18. Support from people of my faith</td>
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<tr>
<td>A19. Support from a spiritual advisor</td>
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<tr>
<td>A20. Help in dealing with the unpredictability of the future</td>
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<tr>
<td>A21. Help in maintaining a sense of control in my life</td>
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<td>A22. Help with housework</td>
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<td>A23. Help with transport</td>
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<td>A24. Help with child care</td>
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<td>A25. Help in dealing with any tiredness</td>
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<td>A26. Advice about food and diet</td>
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<td>A27. Help with financial matters</td>
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<td>A28. Help in filling out forms</td>
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<td>2</td>
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<tr>
<td>A29. Help with any distressing symptoms</td>
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<td>HOW SATISFIED?</td>
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<td>A30. Support from family</td>
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<td>A31. Support from friends</td>
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<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A32. Support from neighbours</td>
<td></td>
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<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A33. Support from care professionals</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A34. Someone to talk to</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A35. Help with any loneliness</td>
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<td>1 2 3 4 5</td>
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<td>A36. Help with getting out and about socially</td>
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<tr>
<td>A37. Opportunities for meeting others who are in a similar situation</td>
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<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A38. Help with any fears</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A39. Help with any sad feelings</td>
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<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A40. Help with any anger</td>
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<td>1 2 3 4 5</td>
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<td>A41. Help with any feelings of guilt</td>
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<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A42. Help in considering my sexual needs</td>
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<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>A43. Help in dealing with the feelings of others</td>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>A44. Time for myself</td>
<td></td>
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</tbody>
</table>
Section B

In addition to the other questions you have answered we are interested in knowing how your health has been in general over the past few weeks.

Please answer all of the questions on this page simply by circling the answer which you think most applies to you:

In the past few weeks have you...?

<p>| | | | |</p>
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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>B1</td>
<td>Been able to concentrate on whatever you’re doing</td>
<td>Better than usual</td>
<td>Same as usual</td>
</tr>
<tr>
<td>B2</td>
<td>Lost much sleep over worry</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B3</td>
<td>Felt you were playing a useful part in things</td>
<td>More than usual</td>
<td>Same as usual</td>
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<tr>
<td>B4</td>
<td>Felt capable of making decisions about things</td>
<td>More than usual</td>
<td>Same as usual</td>
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<tr>
<td>B5</td>
<td>Felt constantly under strain</td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td>B6</td>
<td>Felt you couldn’t overcome your difficulties</td>
<td>Not at all</td>
<td>No more than usual</td>
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<tr>
<td>B7</td>
<td>Been able to enjoy your normal day to day activities</td>
<td>More than usual</td>
<td>Same as usual</td>
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<tr>
<td>B8</td>
<td>Been able to face up to your problems</td>
<td>More than usual</td>
<td>Same as usual</td>
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<tr>
<td>B9</td>
<td>Been feeling unhappy or depressed</td>
<td>Not at all</td>
<td>No more than usual</td>
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<tr>
<td>B10</td>
<td>Been losing confidence in yourself</td>
<td>Not at all</td>
<td>No more than usual</td>
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<tr>
<td>B11</td>
<td>Been thinking of yourself as a worthless person</td>
<td>Not at all</td>
<td>No more than usual</td>
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<tr>
<td>B12</td>
<td>Been feeling reasonably happy, all things considered</td>
<td>More than usual</td>
<td>Same as usual</td>
</tr>
</tbody>
</table>
Section C

In this section we are interested in knowing how your experience of having a loved one with cancer affects your Quality of Life.

Please answer all of the following questions based on your life at this time.

Please circle the number from 0 - 10 that best describes your experiences:

**Physical Well Being**

To what extent are the following a problem for you:

C1. Fatigue
No problem

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Severe problem

C2. Appetite changes
No problem

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Severe problem

C3. Pain or aches
No problem

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Severe problem

C4. Sleep changes
No problem

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Severe problem

C5. Rate your overall physical health

**Extremely poor**

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</table>

Excellent

**Psychological Well Being Items**

C6. How difficult is it for you to cope as a result of your family member's disease and treatment?

Not at all

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Extremely

C7. How good is your overall quality of life?

**Extremely poor**

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<tr>
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</thead>
</table>

Excellent
C8. How much happiness do you feel?
None at all: 0 1 2 3 4 5 6 7 8 9 10
Completely

C9. Do you feel like you are in control of things in your life?
Not at all: 0 1 2 3 4 5 6 7 8 9 10
Completely

C10. How satisfying is your life?
Not at all: 0 1 2 3 4 5 6 7 8 9 10
Completely

C11. How is your present ability to concentrate or to remember things?
Extremely poor: 0 1 2 3 4 5 6 7 8 9 10
Excellent

C12. How useful do you feel?
Not at all: 0 1 2 3 4 5 6 7 8 9 10
Extremely

C13. How distressing was your family member's initial diagnosis for you?
Not at all: 0 1 2 3 4 5 6 7 8 9 10
Extremely

C14. How distressing were your family member's cancer treatments (i.e. chemotherapy, radiation, BMT or surgery) for you?
Not at all: 0 1 2 3 4 5 6 7 8 9 10
Extremely

C15. How much anxiety do you have?
None at all: 0 1 2 3 4 5 6 7 8 9 10
Severe

C16. How much depression do you have?
None at all: 0 1 2 3 4 5 6 7 8 9 10
Severe
C17. Are your fearful of the spreading (metastasis) of your family member’s cancer?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
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<tbody>
<tr>
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C18. Rate your overall psychological well being?

<table>
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<tbody>
<tr>
<td>Excellent</td>
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Social Concerns

C19. How distressing has your family member's illness been for your family?

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<thead>
<tr>
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C20. Is the amount of support you receive from others sufficient to meet your needs?

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<thead>
<tr>
<th>Not at all</th>
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C21. To what degree has your family member's illness or treatment interfered with your personal relationships?

<table>
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C22. To what degree has your family member's illness or treatment interfered with your sexuality?

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C23. To what degree has your family member's illness or treatment interfered with your employment?

<table>
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C24. To what degree has your family member’s illness or treatment interfered with your activities at home?

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<tbody>
<tr>
<td>Severe problem</td>
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C25. How much isolation is caused by your family member's illness or treatment?

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
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<th>2</th>
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</table>
C26. How much financial burden resulted from your family member's illness or treatment?

<table>
<thead>
<tr>
<th>None at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
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C27. Rate your overall social well being

<table>
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<th>3</th>
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<tbody>
<tr>
<td>Excellent</td>
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**Spiritual Well Being**

C28. Is the amount of support you receive from religious activities such as going to church or temple sufficient to meet your needs?

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C29. Is the amount of support you receive from personal spiritual activities such as prayer or meditation sufficient to meet your needs?

<table>
<thead>
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C30. How much uncertainty do you feel about your family member's future?

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<tr>
<th>None at all</th>
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<td>Extreme</td>
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C31. Has your family member’s illness made positive changes in your life?

<table>
<thead>
<tr>
<th>None at all</th>
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<tr>
<td>Extreme</td>
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</table>

C32. Do you have a purpose/mission for your life or a reason for being alive?

<table>
<thead>
<tr>
<th>Not at all</th>
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<th>1</th>
<th>2</th>
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<tbody>
<tr>
<td>Completely</td>
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</table>

C33. How hopeful do you feel?

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<tr>
<th>Not at all</th>
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<tr>
<td>Extremely</td>
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</table>

C34. Rate your overall spiritual well being

<table>
<thead>
<tr>
<th>Extremely poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td></td>
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</tbody>
</table>
Finally, this section contains a series of statements which carers have made about the coping strategies they use.

Carefully read each statement and show if it applies to you by placing a tick in the space available:

### ONE WAY OF DEALING WITH DEMANDS OF CARING IS BY:

<table>
<thead>
<tr>
<th>Statement</th>
<th>I do not use this</th>
<th>Not really helpful</th>
<th>Quite helpful</th>
<th>Very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1 Establishing a regular routine and sticking to it</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>D2 Letting off steam in some way – shouting, yelling or the like</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>D3 Talking over my problems with someone I trust</td>
<td></td>
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<tr>
<td>D4 Keeping a little free time for myself</td>
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</tr>
<tr>
<td>D5 Keeping one step ahead of things by planning in advance</td>
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<tr>
<td>D6 Seeing the funny side of the situation</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>D7 Realizing there’s always someone worse off than me</td>
<td></td>
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<tr>
<td>D8 Gritting my teeth and just getting on with it</td>
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<tr>
<td>D9 Remembering all the good times I used to have with the person I care for</td>
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<tr>
<td>D10 Finding out as much information as I can about the problem</td>
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<tr>
<td>D11 Realizing that the person I care for is not to blame for the way they are</td>
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<tr>
<td>D12 Taking life one day at a time</td>
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</tr>
<tr>
<td>D13 Getting as much practical help as I can from my family</td>
<td></td>
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<tr>
<td>D14 Keeping the person that I care for as active as possible</td>
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<tr>
<td>D15 Altering my home environment to make things as easy as possible</td>
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<tr>
<td>D16 Realizing that things are better now than they used to be</td>
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<tr>
<td>D17 Getting as much help as I can from professionals and other service providers</td>
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<tr>
<td>D18 Thinking about the problem and finding a way to overcome it</td>
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<tr>
<td>D19 Having a good cry</td>
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</tbody>
</table>
Developing a Supportive Nursing Intervention

ONE WAY OF DEALING WITH DEMANDS OF CARING IS BY:

<table>
<thead>
<tr>
<th></th>
<th>I do not use this</th>
<th>Not really helpful</th>
<th>Quite helpful</th>
<th>Very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>D20</td>
<td>Accepting the situation as it is</td>
<td></td>
<td></td>
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<tr>
<td>D21</td>
<td>Taking my mind off things in some way, by reading, watching TV or the like</td>
<td></td>
<td></td>
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<tr>
<td>D22</td>
<td>Ignoring the problem and hoping it will go away</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D23</td>
<td>Preventing problems before they happen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D24</td>
<td>Drawing on strong personal or religious beliefs</td>
<td></td>
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<tr>
<td>D25</td>
<td>Believing in myself and my ability to handle the situation</td>
<td></td>
<td></td>
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<tr>
<td>D26</td>
<td>Forgetting about my problems for a short while by day-dreaming or the like</td>
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<tr>
<td>D27</td>
<td>Keeping my emotions and feelings tightly under control</td>
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<tr>
<td>D28</td>
<td>Trying to cheer myself up by eating, having a drink, smoking or the like</td>
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<tr>
<td>D29</td>
<td>Relying on my own experience and the expertise I have built up</td>
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<tr>
<td>D30</td>
<td>Trying out a number of solutions until I find one that works</td>
<td></td>
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<tr>
<td>D31</td>
<td>Establishing priorities and concentrating on them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D32</td>
<td>Looking for the positive things in each situation</td>
<td></td>
<td></td>
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<tr>
<td>D33</td>
<td>Being firm and pointing out to the person I care for what I expect of them</td>
<td></td>
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</tr>
<tr>
<td>D34</td>
<td>Realizing that no one is to blame for things</td>
<td></td>
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<td></td>
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<tr>
<td>D35</td>
<td>Getting rid of excess energy and feelings by walking, swimming or other exercise</td>
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<tr>
<td>D36</td>
<td>Attending a self-help group</td>
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<tr>
<td>D37</td>
<td>Using relaxation techniques, meditation or the like</td>
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<tr>
<td>D38</td>
<td>Maintaining interests outside caring</td>
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</table>

Please add below any other coping methods you use and indicate how helpful you find them:

<p>| | | | | |</p>
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</table>
Section E:

This laid out section is about the needs of family members of cancer patients. Please show how important the following needs are for you as a family member:

**First**, complete the first column of the table, by noting your rating from 1-5 of each item

<table>
<thead>
<tr>
<th>(1) Not Important</th>
<th>(2) Somewhat Important</th>
<th>(3) Average Importance</th>
<th>(4) Very Important</th>
<th>(5) Extremely Important</th>
</tr>
</thead>
</table>

**Second**, if the need was important to you, and you gave it a rating of between 2 and 5, place a tick in one of the shaded boxes to show how much that need has been met.

For example:

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Rating from 1 - 5</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>E17 Feel accepted by the health professionals</td>
<td>3</td>
<td></td>
<td>√</td>
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</tr>
</tbody>
</table>

Now, please go through the list and make a rating and selection for all of the statements:

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Rating from 1 - 5</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1 Have my questions answered honestly</td>
<td></td>
<td></td>
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<tr>
<td>E2 Know specific facts concerning the patient's prognosis</td>
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<tr>
<td>E3 Feel that the health professionals care about the patient</td>
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<tr>
<td>E4 Be informed of changes in the patient's condition</td>
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<tr>
<td>E5 Know exactly what is being done for the patient</td>
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<tr>
<td>E6 Know what treatment the patient is receiving</td>
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<td></td>
</tr>
<tr>
<td>I need to:</td>
<td>Rating from 1 - 5</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
</tr>
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<td>--------------------------------------------------------------------------</td>
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<tr>
<td>E7  Have explanations given in terms that are understandable</td>
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<tr>
<td>E8  Be told about treatment plans while they are being made</td>
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<td>E9  Feel there is hope</td>
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<td>E10 Be assured the best possible care is being given to the patient</td>
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<tr>
<td>E11 Know what symptoms the treatment or disease can cause</td>
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<tr>
<td>E12 Know when to expect symptoms to occur</td>
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<tr>
<td>E13 Know the probable outcome of the patient's illness</td>
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<tr>
<td>E14 Know why things are being done for the patient</td>
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<tr>
<td>E15 Know the names of health professionals involved in the patient's care</td>
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<tr>
<td>E16 Have information about what to do for the patient at home</td>
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<tr>
<td>E17 Feel accepted by the health professionals</td>
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<td></td>
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</tr>
<tr>
<td>E18 Help with the patient's care</td>
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<tr>
<td>E19 Have someone be concerned with my health</td>
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<tr>
<td>E20 Be told about people who could help with problems</td>
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</tbody>
</table>
WELL DONE!

YOU HAVE REACHED THE END.

PLEASE CHECK THAT YOU HAVE COMPLETED ALL THE QUESTIONS.

Please return this questionnaire, along with your signed Informed Consent form, by post or to the Lung Cancer Nurse Specialist on your first appointment.

Thank you for so generously giving your time to participate in this project.
Appendix 3: Family member interview schedule

Family members’ Interview Schedule

1. How did you find your contact with the nurse specialist? [General opening question]

2. In your own words, could you describe what – if anything – you got from your contact with <<insert NS name >>?

3.a. Can you remember, when you first came on to this study, what you expected of it?
3.b. Has this/your initial expectation been met?
3.c. If not, why not

4. Since your <<insert name >>’s diagnosis, what has been your main concern?

5. How much do you feel seeing <<insert NS name >> has helped you with your feelings of worry and concern? (In what ways?)

6.a. How much information did you have about what was going on with <<insert name >>?
6.b. Was this amount of information enough?
6.c. How easy was this to understand?

7. In what ways did seeing <<insert NS name >> help you in practical terms with coping with <<insert name >>’s illness? I.e. financial, local support services, aids

8. In what ways did meeting <<insert NS name >> help you support <<insert name >> better?

9. In what ways did seeing <<insert NS name >> impact on the ways in which you were able to discuss issues to do with the illness with <<insert name >>?

10.a. What further information would you have liked?
10.b. How would you have liked it given? i.e. Information sheet, or by another health professional such as doctor?

11.a. How easy was it to get in touch with <<insert NS name >> outside of your appointments?
11.b. Did anything stop you from getting in touch?
11.c. To what degree did you feel that the matter which you had wanted to discuss had been resolved?

12. What kinds of things do you think you might re-contact <<insert NS name >> about in future?
13.a How easy was it for you to arrange to meet <<insert NS name >>?
13.b How convenient was this?
13.c What would have been easier? E.g. meeting at your home?
14. The first time you met <<insert NS name >> was 3-4 months ago, was this introduction to the service at the right time for you?
15. Did/do you prefer your contact with <<insert NS name >> to be face-to face or by telephone?

Optional / If appropriate:

16. In what ways, do you think, that seeing <<insert NS name >> impacted on your relationship with <<insert name >>?
17.a In what ways, if any, did seeing <<insert NS name >> help you prioritise issues within your own life?
17.b What ways did it help you find any balance between living with <<insert name >>'s illness and the rest of your work and recreational commitments?

Final questions:

18.a Overall, what did you find that <<insert NS name >> did or said that was helpful?
18.b What else might have been helpful?
18.c What did you find that they did or said that was not helpful?
18.d Can you give an example of what was unhelpful?

19.a It has now been about 4-5 months since diagnosis, what do you foresee your support needs to be in the next few months?
19.b How confident are you that these will be met?

20.a This study has been about developing new ways of offering help and support to carers. The main way we have done this has been by offering an appointment for an assessment of your needs and providing you with information. How suitable was this?
20.b What other ways do you think might have been more useful/helpful/better? E.g. Drop in clinics, telephone contact, email contact, at a group meeting, etc.

21. Do have anything further that you would like to add?

Thank you
### INFORMATION-GIVING

<table>
<thead>
<tr>
<th>Description</th>
<th>Mentioned by:</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>With expert knowledge</td>
<td>004a, 004b, 011, 017</td>
<td>‘The honesty and her knowledge really. She was so knowledgeable because she was specialised purely in lung. As opposed to having been with the Ellenor Nurse that was just, she wasn’t specialised, she just cares for you in general. And M was so knowledgeable and she was able to answer absolutely everything we threw at her’ (011)</td>
</tr>
<tr>
<td>With sensitivity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right level (tailored to individual)</td>
<td>004a, 004b, 019</td>
<td>‘Its only now that I’ve been through the experience that the things that I was told I realise were right, if you like’ (004a)  ‘You know some doctors can be a bit stuffy and a bit, they don’t, they talk in their own language. Whereas you know, M explained everything so that my mum understood, so that we understood as well’ (004b)  ‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b)  ‘Its nice to have someone to put your mind at ease, if you’ve got any problems which I she did. She was very clear when she spoke. She didn’t insult my intelligence or anything, but then on the other hand she didn’t blind me with technology. She just kept it very simple with regards to medical procedures and that sort of thing’ (019)  ‘Very matter of fact but she’s very good at dealing with it in a way that’s not upsetting’ (019)</td>
</tr>
<tr>
<td>Based on experience</td>
<td>004a, 004b, 017</td>
<td>‘she’s got such a lot of experience and in that respect she knows what to say and is helpful’ (004a)</td>
</tr>
<tr>
<td>Specific – with relevance to patient</td>
<td>002</td>
<td></td>
</tr>
<tr>
<td>Clarifying/interpreting info already received</td>
<td>002, 004b, 014b, 014c, 019, 021, 024, 031</td>
<td>‘When I spoke to M, it was very easy to understand. I must admit when you deal with the doctors, sometimes it isn’t very easy to understand. They’re very, I found it, one instance I did find it, the doctor wasn’t very good at one time..sometimes they come out with words you don’t always understand’ (014c)  ‘She’s explained things that I never understood, do you know and explained them to me in my sort of language which I did understand’ (021)  ‘If I come away from there (hospital) and I feel I haven’t got what I want then I will phone up S and she will explain to me again what they’ve told me. If I don’t understand, I will get in touch with S (021)</td>
</tr>
</tbody>
</table>
| Supplementing info (or filling in gaps) | 004a, 009, 013, 014a, 014c, 016c, 022, 026, 031 | Doctors not having time to explain things – NS having specific knowledge that enabled her to fill that gap’ (004b)  ‘she’d find out anything, if there was a problem’ (009)  ‘From M we got quite a lot, because she sort of explained the type of cancer that mum had, which we
Developing a Supportive Nursing Intervention

<table>
<thead>
<tr>
<th>Question Type</th>
<th>Mentions</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>About disease &amp; symptoms</strong></td>
<td>007, 010b</td>
<td>“Helpful information following treatment for radiotherapy” (010b)</td>
</tr>
<tr>
<td><strong>About treatment &amp; side effects</strong></td>
<td>007, 010b</td>
<td>“So it was a huge relief really, it was part of the burden being taken off my shoulders because I knew what to expect as far as she was concerned” (002)</td>
</tr>
<tr>
<td><strong>About future/prognosis – what to expect</strong></td>
<td>002, 004b, 021</td>
<td>“I got my questions answered. She told me what I needed to know, to allow me to prepare for myself” (004b)</td>
</tr>
<tr>
<td><strong>Differs from written info</strong></td>
<td>011, 016c, 028</td>
<td>“I think verbal (info) is better. I mean when you're trying to plough through loads of literature and such, it doesn't always sink in. I think the personal approach is better” (011)</td>
</tr>
<tr>
<td><strong>Advice</strong></td>
<td>002, 009, 019, 026, 028</td>
<td>“and she'd just offer advice when I was unsure about things” (009)</td>
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</tbody>
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**Therapeutic ingredients**

<table>
<thead>
<tr>
<th>Description</th>
<th>Mentioned by:</th>
<th>Quotes</th>
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<tbody>
<tr>
<td>Opportunity to ask questions</td>
<td>002, 004b, 009, 010b, 014a, 014b, 014c, 016b, 017, 018, 019, 022, 024, 026</td>
<td>“She’s has actually helped a lot. She has talked us through things, that could happen. She’s answered questions that we’ve asked, that we’ve pondered with each other and we’ve asked M” (014b)</td>
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<tr>
<td></td>
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<td>“Happy to answer any questions I had” (019)</td>
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<td>“It was literally having the advice and know that if we did have a question we could just ring her. That’s worth its weight in gold really. Its enough really. It is nice to be about to just ring somebody and know you can get an answer from her” (022)</td>
</tr>
</tbody>
</table>
| Carer felt at ease to ask questions | 002, 004b, 009, 010b, 014a, | ‘able to ask lots of stupid questions but not made to feel. I felt I could say almost anything to her (002)  
She felt ‘very comfortable and supported. It was a lot better than I thought it would be. She was so caring and everything. It was a lot easier to talk to her than I thought it would be’ (009)  
‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b)  
‘She did answer a hell of a lot of the questions’ (014a) |
| Demonstrates willingness to answer questions | 004b, 010b, 014a, 014c, 021, 029, | ‘I got my questions answered. She told me what I needed to know, to allow me to prepare for myself’ (004b)  
‘I asked her the questions, you know about how long she thought my mum had, and she did answer them (004b)  
‘Some of the worries and concerns that I had you know she sort of went through them and explained, she was very good’ (014a)  
‘Everything I sort of needed to know or wanted to talk to, she’s been there. She hasn’t been too pushy and she’s sort of kept her distance and you know when you needed her, she was there’ (021)  
‘I could ask S anything’ (029) |
| Demonstrates availability to answer questions | 004b, 009, 021, | ‘She said anytime I wanted any questions answering or if she could help with the social services side of it, then just contact her’ (004b)  
‘She made it clear that I could ask her anything or ask her to find out anything’ (009)  
If I’ve needed information I’ve got it. I mean you can’t go around phoning doctors willy nilly and asking for questions. So its someone to, you could do that’ (021) |
| Knowledge and experience to answer questions | 004a, 026, | ‘I ask her questions and she gives me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026) |
| Answers appropriate/helpful | 004a, 004b, 009, 010b, 011, 018, 026, | ‘Everything was answered. Everything we wanted to know’ (009)  
‘I’m very confident. Even if she couldn’t answer the question, then she would maybe get in touch with someone that could’ (009)  
‘and any questions asked were honestly and sympathetically dealt with’ (010b)  
‘We did have lots of questions to ask her and she answered them very openly and honestly.’ 011  
‘I do feel confident that I can ring up H and ask her if she can help…I get a proper answer an answer that satisfies the problem’ (018) |
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<tr>
<th>Therapeutic ingredients</th>
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<tr>
<td>LISTENING</td>
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<td><strong>Description</strong></td>
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| Allows time and space   | 004b, 009, 013, 029 | 'It didn’t feel like, she wasn’t looing at her watch when she was with you. She would sit there’ (004b)  
'She made time and nothing was too much trouble' (009)  
I know with the doctors you feel like they’re always so busy and there’s lots of people in the waiting room. You know that their time is very precious. So it’s just nice to sit down with M and you know it wasn’t all rushed and that you could be in there for how long you wanted to be in there. She had the time. It was just nice to have that chance to feel a bit more comfortable, a bit more easier. If you had anything you forgot, you wasn’t sort of rushed’ (009) |
| Attentive               | 009, 013, 014b, 029, | 'It was just nice for me to have someone to talk to and she was just listening’ (009)  
'It was just nice for her to listen' (009)  
'She just listened’ (009)  
'I think she listened. She listened to what we had to say and she just sort of helped' (014b)  
'I felt at that particular time when I was talking to her, she was there at the right time’ (013) |

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<tr>
<td>ALLOWS EXPRESSION OF EMOTION (EMOTIONAL SUPPORT)</td>
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<tr>
<td><strong>Description</strong></td>
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| Allows time and space   | 004a,             | 'She was my way that I could...vent off steam if you like. She’d put things in perspective for me a bit’ (002)  
'I know that I’ve got someone there to speak to if things get a bit too much’ (002)  
'I could say what I felt and I found that quite nice’ (009)  
'and I think probably I’ve found that talking about my husband’s illness helped me and the fact that there’s someone there to listen. It was great’ (013)  
'We just blurt everything to M. How we’re feeling, we just tell M everything. Not straight away, I’ve got to be honest with you, it did take a couple of visits, with each visit we did tell her a bit more and a bit more’ (014a)  
'When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)  
'When the cancer returns, that will be the next time that I’ll probably be ringing H and I think that will distress us again and we’ll probably need that support and someone to talk to, just to calm us back down and bring us back into reality’ (022) |
| Encourages emotional expression | 002, 009, 013, 014a, 018, 022, 028 |  

‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to talk to and when we’ve had a problem, I’ve got on to her. I was inclined to get on to her. She’s been a great help mentally in every which way. Like a couple of times I’ve felt really down when she’s rung and I’ve spoken to her and after I’ve been chatting to her for a while I feel a bit better’ (028)

Allows expression of difficult/sensitive issues

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<tr>
<td>Caring</td>
<td>004b, 010b, 017, 021, 028, 030</td>
<td>‘I mean M is a very, very nice, very warm caring person and she comes over as very caring you know. She’s got a lovely way with her. A nice manner and its reassuring’ (004b) ‘She’s very good. She’s very caring. She’s got a gentle way with her and any questions asked were honestly and sympathetically dealt with’ (010b) ‘well somebody does care’ (017) ‘helpful to hear her voice and know that someone cared’ (030)</td>
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<tr>
<td>Kind</td>
<td>004b, 016c, 029, 030</td>
<td>‘It was invaluable. I’ll never forget as long as I live. And I never realised as I say that there were people out there that were so kind and understanding’ (029)</td>
</tr>
<tr>
<td>Understanding</td>
<td>004a, 016c, 021, 028, 029,</td>
<td>‘I felt I could ring her at any time really and she would understand’ (004a) ‘I don’t know whether its because I’ve met her personally, but she seems to have a good rapport with me and been very understanding and was able to be very helpful at times when its got more stressful than other times’ (028)</td>
</tr>
<tr>
<td>Approachable</td>
<td>004b, 009, 010b, 011, 013, 019, 021, 026, 028</td>
<td>She felt ‘very comfortable and supported. It was a lot better than I thought it would be. She was so caring and everything. It was a lot easier to talk to her than I thought it would be’ (009) ‘She never spoke to you in a derogatory way, you know as if you were, felt that you were being stupid in asking her anything. Everything was dealt with in a very, very nice way. You felt totally at ease with her. You felt you could discuss anything with her’ (010b) ‘Personality-wise, we got on very well and maybe that helps. I did feel we all bonded very very well together and I gained a great deal of support from that’ (011) ‘She never made you feel like you were being a nuisance. Nothing was too much of a problem. When you spoke to her it was ok, which is a nice feeling’ (019) ‘Everything I sort of needed to know or wanted to talk to, she’s been there. She hasn’t been too pushy and she’s sort of kept her distance and you know when you needed her, she was there’</td>
</tr>
<tr>
<td>Available/Accessible</td>
<td>002, 004a, 004b, 007, 009, 010b, 011, 013, 014a, 014b, 014c, 016b, 017, 018, 019, 021, 022, 024, 026, 028, 029, 031</td>
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<tr>
<td>Honest</td>
<td>004b, 010b, 011</td>
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<tr>
<td>Open</td>
<td>011, 013</td>
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- ‘I really enjoyed the chat. I found talking to her really nice actually’ (026)
- ‘I felt that she was really lovely. I could open my heart to her’
- ‘I think even if I just wanted someone to talk to, that knew me and knew what had happened, I feel that I could ring her’ (004a)
- ‘If you rang her and she wasn’t available, you could leave a message and she would always call you back’ (004b)
- ‘She was always available if you need her’ (004b)
- ‘It’s nice that I knew that I could contact her’ (009)
- ‘She made time and nothing was too much trouble’ (009)
- ‘It was nice to know that somebody was there we could talk to’ (010b)
- ‘If you felt that something was bothering you and you weren’t sure whether you were doing the right thing or not, you knew that she was there. You know during the weekdays in which, you know, if she wasn’t there, and you left a message she would very shortly come back to you’ (010b)
- ‘Just a real ease in the sense that we were very aware that we did have someone we could pick up the phone to at any time. To put our minds at rest if we had any problems or queries, questions, whatever’ (011)
- ‘I had a contact number for her. I had a bleep number. If she wasn’t available, she got back to us when she could. And in no way did she ever let me think that the call wouldn’t be welcome’ (011)
- ‘She’s been there for us and you know when we’ve met her, she listened to us and she’s given us answers back’ (014b)
- ‘Well the fact that she was there, she was on the other end of the phone if you wanted her’ (016b)
- ‘You do sort of feel that if you wanted to you could ring her at any time, which is good’ (016b)
- ‘Because she’s available, you know, she’s said she’s always there if I do get problems. And she makes a point of seeing us when we come up thee and having a chat. And as I say, she rings us at home’ (017)
- ‘I think she’s certainly done her bit in keeping in contact with us and she’s been there. She has been available and said she would be available if ever we wanted to be in touch with her. I can’t really say anymore than that. She’s sort of put herself at our disposal’ (017)
- ‘Well it’s nice to know that I can just pick up the phone to her, that is really important, if its is something serious, I will ask her if I can come and see her’ (018)
<table>
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<tr>
<th>Concerned</th>
<th>013</th>
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<tbody>
<tr>
<td>Knowledgeable</td>
<td>002, 004a, 011, 019, 022</td>
</tr>
<tr>
<td>Experienced</td>
<td>002, 004a, 004b, 017, 022, 028, 029</td>
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<tr>
<td>Instils confidence</td>
<td>017</td>
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<tr>
<td>Competent/good</td>
<td>002, 004a, 009, 010b, 014a, 017, 022, 028, 029, 031</td>
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<tr>
<td>Like a friend/family</td>
<td>002, 013, 022, 029, 030</td>
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<tr>
<td>Interested</td>
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<tr>
<td>Personal (interested in the person)</td>
<td>017, 019,</td>
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‘You just phone her up. Literally just phone up. If she’s not there, you leave a message and she gets back to you’ (021)
‘She was just there. She was there for you and you knew she was there for you’ (022)

‘It was comforting to know that there was somebody professional who knew the medical side of things, had experience of the illness, on the other end of the phone’ (019)

‘someone with loads of experience’ (002)
‘Somebody you can contact who obviously has experience’ (004a)
‘M must see this every day of her life…I thought she probably had a little bit longer that what M had told me, but she was spot on. She knew’ (004b)
‘And I feel you know that if I did have any, if I was really down myself I could have, I would prefer to chat with her than anybody who hadn’t got her experience’ (017)
‘I ask her questions and she give s me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026)
‘I think someone should ring up that relative or somebody each week, like H has done with me, to see how they are getting on. Because that, you know, you’re trying to cope and as good as your family are, I think probably an outsider is much better. And somebody that carers and know what she’s talking about’ (028)
‘Someone that obviously knew what we were going through’ (029)

‘and I must say it gave me more confidence’ (017)

‘I have every confidence in her’ (010b)
‘I feel quite confident that if I do have any concerns and I do need anything, I’m sure H would be able to point me in the right direction. If not to send me the information. She’s come through all the times for us so far, so I’d imagine she’d continue (022)
‘There was no waiting. Bag it was done and that’s what we found with M. As soon as she, she always seems to get everything done, and for my dad it makes him feel like someone’s doing something’ (031)

‘I think she’s more like a friend now’ (002)
‘She had a lovely rapport with mum. I mean mum absolutely loved her. And most, well every night we were up there (hospital), at one point S would come in and she talked and she was like a family member’ (029)

‘I thought she was actually interested in myself as a person, a well as the patient, as a carer you could put it. Well I’m not a carer, I’m his wife. I feel that’s looking after my interests’ (017)
‘Because she was there, she was supporting me and could support him, I mean I was, I didn’t feel completely lost. And to get in touch with these associations that we were given at the beginning, you know, because we haven’t got in touch. But with S it was personal communication and that made all the difference you know. We could talk freely and laugh and joke and get friendly. And I think that was her support that helped me’ (017)
‘That there was somebody there that could understand some of the things that perhaps I was feeling, or, it’s a comfort to know that there is somebody who’s, not the consultant that’s normally busy or his secretary, or whatever. Its someone a bit more personal.’ (019)

Professional 004b, 011, 016c, 019,  
She’s just very professional and it makes you feel that.. she was always available if you need her’ (004b)

Natural 011  
Most helpful’ (002)

Helpful 002, 004a, 007, 009, 010b, 014b, 014c, 016b, 017, 022, 018, 022, 026, 028, 029  
‘Very, very supportive’ (010b)

Supportive 004b, 009, 010b, 011, 013, 018, 021, 028, 029,  
I couldn’t have wanted anything else’ (004b)
very, very supportive’ (010b)
‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)
‘But you know, I don’t think we could get through without her’ (021)
‘she was just supportive in every way’ (029)

Reassuring 004b, 009, 014a, 016c, 021, 031  
She’s a lovely lady. I found her very supportive and I’m so glad she was there for my mum and me’ (009)

Therapeutic ingredients

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<tr>
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<tbody>
<tr>
<td>Not specified</td>
<td>002,</td>
<td></td>
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<tr>
<td>Hospice</td>
<td>004a,</td>
<td></td>
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</tbody>
</table>
| Liaised with medical staff/other hcps | 004a, 011, 014c, 029, 031 | Acted as a ‘go between’ between different professionals (004a)
She was our bit of contact because she could obviously get hold of doctors and knew where they were and so she was our sort of middle man between us and the consultant or registrar’ (029)
‘M was able to get them to see him (a specific doctor) all the following times because he knew dad’s case and knew what was going on’ (031)
| Bereavement support | 004b, 029, 030, | ‘She did ring me afterwards (death of patient) and offer help if I needed it. So it’s not as though you feel like ‘oh well, that case is through, move on to the next one’’ (004b)
‘She supported me after G died. She phoned me every week. Helpful to hear her voice and know someone cared. I never had a call from my GP and he was the one who got things going, arranged the blood test and xray’ (030)
<p>| Benefits/Grants | 007, 009, 010b, | For patient and carer (021) |</p>
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<tr>
<th>Description</th>
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<tbody>
<tr>
<td>Information about community services/social support for patient</td>
<td>010b, 031</td>
<td>'and the first time she rang me on the telephone and went through lots of things that we could, we may need as support, what was actually available, and she was extremely helpful' (010b) blue badge (031)</td>
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<tr>
<td>Offered referral for carer counselling</td>
<td>010b,</td>
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<tr>
<td>Sorting out patient's pain</td>
<td>011</td>
<td></td>
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<td>Obtaining results of investigations</td>
<td>016b</td>
<td></td>
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<tr>
<td>Organising appointments/transport</td>
<td>016b, 028,</td>
<td>'she helped us get the appointments early in the morning, from the middle of the afternoon and so that worked out better' (016b)</td>
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<tr>
<td>Advice about medication</td>
<td>018</td>
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<tr>
<td>Holiday advice</td>
<td>019</td>
<td></td>
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<tr>
<td>Advice about risk of infection</td>
<td>019</td>
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<tr>
<td>Advice about co-morbidity</td>
<td>026</td>
<td>Diabetes advice</td>
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<tr>
<td>Advice about treatment side-effects/symptoms</td>
<td>028</td>
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<tr>
<td>Wig referral</td>
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<tr>
<td>Increased carers’ knowledge/understanding</td>
<td>002, 014c</td>
<td>'I was able to be a source of information for them (other family members)' (002)</td>
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<tr>
<td>Facilitated communication between family members</td>
<td>002, 010b, 011, 014a, 014b</td>
<td>'Because sometimes when you’re very close to somebody, it somehow makes it more difficult to talk about things than if its somebody that you’re, its just a neighbour or something’. And sometimes you find its, you know, you’re just a bit too close to the problem to discuss it. And it was nice to, we knew if we rang S she could help us sort through it’ (010b) 'We did have lots of questions to ask her and she answered them very openly and honestly. Then it gave us the ability to chat and discuss things ourselves’ (011) 'M helped with this communication (between family members) because she answered any questions we weren’t sure about’ (014b)</td>
</tr>
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</table>
| Met information needs | 002, 009, 014c, 026 | ‘Everything was answered. Everything we wanted to know’ (009)  
‘I find it very helpful and she answered all what I wanted to know at the time’ (014c)  
‘I ask her questions and she gives me the answers and they’re the answers I needed. She does make you feel a little better about it. Having somebody that has, I suppose, not personal experience, but has seen it I suppose (026) |
| ? Improved psychological status/coping | 002, 009, 011, 014a, 018, 019, 026, 028, 029 | ‘So it was a huge relief really, it was part of the burden being taken off my shoulders because I knew what to expect as far as she was concerned’ (002)  
‘It just seemed to take the stress out of it’ (009)  
‘Put our minds at rest’ (011)  
‘I always feel good when I come out from seeing M. You sort of feel positive. I know its not positive with my mum, but you sort of feel better in yourself that someone’s listening to you, how you’re feeling and when I’ve had a cry, she’s been there. Its been quite good’ (014a)  
‘When I’ve had a bit of a panic I phone her up and she’s sorted me out’ (018)  
‘Nice to have someone to put your mind at ease’ (019)  
‘It made me feel better, let’s put it that way. Knowing that someone was there that I could talk to, which did make it a bit easy, being in this position, my position, sometimes you feel you’re helpless, but she did give me a lot of encouragement (026)  
‘It was just an enjoyable chat. I mean I came out of thee feeling a hell of a lot better about it than what I did when I went in’ (026)  
‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to talk to and when we’ve had a problem, I’ve got on to her. I was inclined to get on to her. She’s been a great help mentally in every which way. Like a couple of times I’ve felt really down when she’s rung and I’ve spoken to her and after I’ve been chatting to her for a while I feel a bit better’ (028) |
| Held/supported carer | 002, 004b, 013, 017, 028 | ‘someone there to speak to (002)  
‘I knew that I could call upon M if I needed some help (004b). That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b)  
‘Because I was meeting or speaking to her regularly and she became part of the situation in the end. But she was there for me, and I knew I didn’t phone her because I knew that if I needed her, there was a feeling that because I knew she was there, I didn’t always have to worry her’ (013)  
‘It helped me in a way that I didn’t feel so much alone’ (017)  
‘And I feel you know that if I did have any, if I was really down myself I could have, I would prefer to chat with her than anybody who hadn’t got her experience’ (017)  
‘I know she said that she would be there if ever I felt unable to cope. Its reassuring. I think that was helpful’ (017)  
‘When I’m at home, you get a bit low. And that’s where, H has rung up about once a week and she, that has made a big difference’ (028)  
‘Made me feel more positive, not such a wimp. I think just generally all around its somebody to
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talk to and when we’ve had a problem, I’ve got on to her. She’s been a great help mentally in every which way. Like a couple of times I’ve felt really down when she’s rung and I’ve spoken to her and after I’ve been chatting to her for a while I feel a bit better’ (028)

Facilitated carer’s role 002, 004b, 017, 019, 026, 028, ‘I could take care of all the questions that she would need to ask me from her point of view’ (002) ‘My mum was profoundly deaf and so she didn’t hear the answers’ She (patient) relied on us to tell her stuff back. That’s how I knew and I could prepare’ (004b) ‘I knew that I could call upon M if I needed some help. That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b) ‘It’s helped me in a way that I didn’t feel so much alone. Not knowing whether it was normal how he was feeling or whether it was something other people experienced. I think she was reassuring in how I felt’ (017) ‘Because she was there, she was supporting me and could support him. I mean. I was, I didn’t feel completely lost’ (017) ‘I spoke to H about my wife’s diabetes and things like that and she advised me on that as well. And I relayed back the information to my wife and it did help us both quite a lot because I know nothing at all about diabetes (026)

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<tr>
<td><strong>Description</strong></td>
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<tr>
<td>Unexpected</td>
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<td>Outside the family</td>
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</tbody>
</table>
and outside your friends. And you can actually say exactly what you want and feel. I have found that very, very helpful (022)
‘I think someone should ring up that relative or somebody each week, like H has done with me, to see how they are getting on. Because that, you know, you’re trying to cope and as good as your family are, I think probably an outsider is much better. And somebody that carers and know what she’s talking about’ (028)
‘It was nice to talk to somebody as well who wasn’t involved within the family

<table>
<thead>
<tr>
<th>Carer burden</th>
<th>002, 004b, 009, 013, 014, 017, 019, 024, 026, 031</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘that I was kind of doing it on my own, within the family’ (002-daughter-in-law)</td>
<td>‘I was still in shock, raw’ (004b)</td>
</tr>
<tr>
<td>‘because I’d heard some horror stories from people in the past’ (004b)</td>
<td>Son had a brain tumour – felt stressed unable to ‘go through it all again’ (009)</td>
</tr>
<tr>
<td>‘and the worry of your husband wears you out’ (013)</td>
<td>‘It was nice to talk to somebody as well who wasn’t involved within the family’ (014a)</td>
</tr>
<tr>
<td>‘It takes over your life’ (017)</td>
<td>‘It’s the patient that gets the focus and the carer sort of gets overlooked. And at the end of the day, if the carers not feeling good about things or what have you, then they can’t care properly can they. So yeah its nice to know because obviously you do feel different emotions when you’re caring for somebody with an illness. Its nice to know you’re getting a bit of support there..I think its very, very important I think’ (019)</td>
</tr>
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<td>‘We have to live day by day, week by week. W can’t plan anything or you know we just have to wait and see how things turn out’ (24)</td>
<td>‘You just feel totally helpless’ (026)</td>
</tr>
<tr>
<td>‘Its nice to have a contact’ (031)</td>
<td>‘There’s so much to take in, it has been quite hard to take everything in’ (031)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A contact</th>
<th>002,004a, 004b, 009, 014a, 029, 031</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘The fact that someone is there. Somebody you can contact who obviously has experience’ (004a)</td>
<td>‘So it was reassuring to know that there was somebody out there that could help me if I needed it’ (004b)</td>
</tr>
<tr>
<td>‘I knew that I could call upon M if I needed some help. That was, to me, that was the best bit of information that I could have, because if I hadn’t have had that support I would have been in a state of panic or even guilt that I wasn’t able to do enough for my mum, because I didn’t have the right tools to help her with’ (004b)</td>
<td>‘She was always there’ (009)</td>
</tr>
<tr>
<td>‘Its nice that I knew that I could contact her’ (009)</td>
<td>‘Its nice to have a contact’ (031)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wanting more info</th>
<th>004a, 009, 013, 014b, 014c, 014c.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanted to know more about what to expect ‘time-scale’, treatment options (no treatment), and where cancer was (004a)</td>
<td></td>
</tr>
</tbody>
</table>
| Proactive | 004b, 010b, 013, 016b, 017, 021, 022, 028, 031 | ‘She kept in contact with me’ (004b)  
‘She did ring me afterwards (death of patient) and offer help if I needed it. So it’s not as though you feel like ‘oh well, that case is through, move on to the next one’” (004b)  
‘because Mum was up at the hospital a lot and she would make a point of coming to see us’ (004b)  
‘And she used to ring off her own back. She would ring and ask how things were going. She didn’t wait until we contacted her all the time’ (010b)  
‘She’s ‘phoned me at regular intervals’ (013)  
‘She’d put herself out to come and see us (016b)’She actually put herself out twice to come and meet with us when he was having his radiotherapy’ (016b)  
‘And H keeps in touch to see how things are going and that’s good’ (016c)  
‘She’s rung up nearly every week which is, you know, very useful, talking to him and to me. So its, you know, very helpful’ (017)  
‘She’ll always find the time to see what time our appointment is and even if it’s a quick hello, she goes ‘have we got any questions’ and if we go ‘no’, you know she’ll always find the time to come and say hello’ (021)  
‘It is also very positive that nine times out of ten H pops by to say hello when she is up at the hospital’ (022)  
‘I think someone should ring up that relative or somebody each week, like H has done with me, to see how they are getting on. Because that, you know, you’re trying to cope and as good as your family are, I think probably an outsider is much better. And somebody that carers and know what she’s talking about’ (028)  
‘I mean she’s popped down and seen us when we’ve been in the clinic or up on the ward’ (028)  
‘She always comes and finds us when we’re at the hospital’ (031) |
<p>| Info to carer hampered by patient | 009, 014a, 014b, 014c, 017 |
| Helpful to have contact separate from patient | 011 |
| Being there |
| Timely or prompt |</p>
<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Mentioned by:</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future/how disease would progress</td>
<td>002, 004a, 004b, 009, 010b, 013, 014a, 014a, 014c, 016c, 017, 029, 031</td>
<td>'her progress and what her prognosis is' (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Not knowing exactly how everything was going to go' is very difficult (004a)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'if the tumour was going to spread' (009)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'My main concern is what's going to happen to him, you know because it’s the future’ (017)</td>
</tr>
<tr>
<td>How &amp; when patient will die</td>
<td>009, 014b,</td>
<td>'How long before we’d lose mum’ (009)</td>
</tr>
<tr>
<td>Need for information/never enough</td>
<td></td>
<td>'there was a huge emotional support needed because she (patient) was dealing not only with her own illness but the emotional effect of her husband not being there and worrying about him’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'My main concern was that she wouldn’t suffer, that she would not be in any pain at all’ (004b)</td>
</tr>
<tr>
<td>Concern for patient's well-being</td>
<td>002, 004b, 007, 011, 014a, 017, 018, 019, 021, 026, 028, 029, 030</td>
<td>'Not knowing exactly how everything was going to go’ is very difficult (004a)</td>
</tr>
<tr>
<td>Need for information/never enough</td>
<td></td>
<td>'there was a huge emotional support needed because she (patient) was dealing not only with her own illness but the emotional effect of her husband not being there and worrying about him’ (002)</td>
</tr>
<tr>
<td>Other responsibilities</td>
<td>002, 018, 024</td>
<td>Father in law (patient's husband) has alzheimers’ (002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mother (patient’s wife) has dementia (024)</td>
</tr>
<tr>
<td>Availability of further support if needed/future care needs</td>
<td>010b, 031</td>
<td></td>
</tr>
<tr>
<td>Treatment effects</td>
<td>014c, 016c, 021, 029</td>
<td></td>
</tr>
<tr>
<td>Treatment delays</td>
<td>028</td>
<td></td>
</tr>
<tr>
<td>Lack of information</td>
<td>028, 030</td>
<td></td>
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<tr>
<td><strong>Structure of Intervention</strong></td>
<td></td>
<td></td>
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<tr>
<td>-----------------------------</td>
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<tr>
<td><strong>Face to face</strong></td>
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</tbody>
</table>
| 002, 013, 014a, 014b, 017, 022, 026, 029, 030, 029, 030, 031 | ‘could put a face to the voice’ (002)  
‘I found it very helpful face-to-face, you have that personal feeling’ (017)  
‘because then you can put the face to the name and it makes it a bit more personal as well’ (022) |
| **Telephone**               |
| 004a, 010b, 011, 019, 021, 024, 031 | Convenience – ‘because of the distance (004a)  
‘Well actually I never met S. Most of my contact with S was on the telephone. But my mother met her, and so did my brother and his wife, and they thought she was absolutely amazing, you know very, very supportive. As I did find on the ‘phone’ (010b)  
‘When I spoke to her on the telephone it was, she was no less efficient and caring on the telephone than I’m sure she would have been face-to-face’ (010b)  
Telephone contact preferred (working) (011)  
It was telephone support. Unfortunately I never got to actually meet S. The one time I did go up with mum, S wasn’t there. But she phoned me the next day, herself, I didn’t ask her to. But she phoned me up to apologise that she didn’t meet me and asked me if I had any questions’ (019)  
‘I’ve got to say I do find it easier to speak over the phone that face-to-face. There’s no one else around to, like worry about’ (21)  
Telephone contact more convenient (works) (24)  
‘I suppose I felt closer to her when we’re together, you know and I could express myself better than on the ‘phone’ (029)  
‘Phone contact was good. Because I think, sometimes as well you’ve got a lot of mixed emotions. And I think you tend to get a bit upset if its face-to-face. Whereas on the ‘phone, I think its sometimes a little bit easier to talk’ (031) |
| **Either face-to-face or telephone** | 004b, 014c, 018, 028 | ‘I don’t mind either way. I didn’t have no problems with talking to her over the ‘phone (works)’ (014c) |
| **Right time**              |
| 004a, 004b, 002, 007, 010b, 011, 013, 014a, 014b, 014c, 017, 018, 021, 022, 026, 029, 031 | ‘It would have probably been nice shortly after my mum got diagnosed because we’re just, I think, we were in a state of shock’ (009)  
Immediately after diagnosis (019) |
| **Earlier**                 |
| 009, 019, 022, 028, 030      | ‘The only down side …we needed to contact them quite urgently over the weekends, two different weekends, and we couldn’t get hold of anybody’ (010b) |
| **Out of hours**            |
| 010b, 018 | |
| **Home visits**             |
| 026, 029 | |
### Appendix 5: Initial assessment record documentation

**CARER INITIAL ASSESSMENT**  
*(Front sheet not for data purposes)*

<table>
<thead>
<tr>
<th>Identification No:</th>
<th>Date</th>
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<tr>
<td>__________</td>
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<table>
<thead>
<tr>
<th>Name of carer:</th>
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<tbody>
<tr>
<td>__________________________</td>
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</table>

<table>
<thead>
<tr>
<th>Address:</th>
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<table>
<thead>
<tr>
<th>Telephone No:</th>
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<table>
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<th>E-mail address:</th>
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<table>
<thead>
<tr>
<th>Name of patient:</th>
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<tbody>
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<td>__________________________</td>
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<table>
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<tr>
<th>Hosp.No of patient:</th>
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<tr>
<td>__________________________</td>
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</table>
## CARER INITIAL ASSESSMENT

Identification No: __________ Date ______________

<table>
<thead>
<tr>
<th>Timing of first contact</th>
<th>Diagnosis</th>
<th>During treatment</th>
<th>Follow-up</th>
<th>Terminal phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face</td>
<td>Telephone</td>
<td>Place of contact</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Age of carer | Sex of carer
--- | ---
Male | Female

### Relationship to patient

<table>
<thead>
<tr>
<th>Spouse</th>
<th>Partner</th>
<th>Son/daughter</th>
<th>Friend</th>
<th>Other (specify)</th>
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### Dependents (include age)

<p>| |</p>
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### Other family members

<p>| |</p>
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### Social support

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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</table>

### Lives with patient

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Full/Part-time</th>
<th>Retired</th>
</tr>
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<tbody>
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</table>

### Occupation

<table>
<thead>
<tr>
<th>Good</th>
<th>Health problems (specify)</th>
</tr>
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<tbody>
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</table>

### Own health

<p>| |</p>
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</table>
Summary of carer’s experience relating to patient’s illness journey:

________________________________________________________________
________________________________________________________________
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Carer’s identified need(s):

________________________________________________________________
________________________________________________________________
________________________________________________________________
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________________________________________________________________
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Nurse Specialist’s perception of need(s):

________________________________________________________________
________________________________________________________________
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Resources/Information given:

________________________________________________________________
________________________________________________________________
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________________________________________________________________

Referral | Date | Reason
---------|------|--------

Agreed management plan:

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Agreed contact

<table>
<thead>
<tr>
<th>Telephone</th>
<th>Face-to-face</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Weekly</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Duration of consultation</th>
<th>Place of consultation</th>
<th>Date &amp; time of next contact</th>
<th>Name of CNS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional comments</td>
<td></td>
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</tbody>
</table>
CNS reflection/assessment on intervention/contact

What went well?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Was there anything that was difficult?

__________________________________________________________________
__________________________________________________________________
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__________________________________________________________________

Carer’s satisfaction from interview (perceived)

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Any other comments?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
### Appendix 6: Further contact record documentation

#### CARER CONTACT SHEET

<table>
<thead>
<tr>
<th>Carer No: _______</th>
<th>Date: ______________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>During treatment</td>
</tr>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

#### Type of contact

<table>
<thead>
<tr>
<th></th>
<th>Face to face, carer initiated</th>
<th>Phone contact, carer initiated</th>
<th>Face to face, CNS initiated</th>
<th>Phone contact CNS initiated</th>
<th>Email contact, carer initiated</th>
<th>Email contact CNS initiated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of contact if relevant</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

#### Nature of intervention (tick all that apply)  Specify

<table>
<thead>
<tr>
<th>Information-giving</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice-giving</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td>Benefits advice</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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<tr>
<td>Other</td>
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<td>Other</td>
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<td>Other</td>
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<tr>
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</table>

#### Referral

<table>
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<th>Reason</th>
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#### Length of contact
Further comments on intervention/contact

________________________________________________________________________
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CNS reflection/assessment on intervention/contact

What went well?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Was there anything that was difficult?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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Carer’s satisfaction from interview (perceived)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Other comments (continue overleaf if necessary)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix 7: Focus group schedule

Focus Group Discussion - Process

1. Welcome
2. Refreshments - whilst waiting for all participants to arrive.

Introduction

Welcome participants to group introduce primary and secondary researchers. Open group discussion by reaffirming confidentiality of group and guidelines/rules, including level of group confidentiality and right to withdraw at any time.

i) confidentiality
ii) views needed – describe what delivered, enhance the intervention in future & increase potency – no correct/incorrect points
iii) my role guide – will gently steer if necessary & keep on target
iv) try not to speak over each other, or have ‘aside’ conversations

Ice-breaker

Can you begin by telling us your name and one thing that you are looking forward to this year.

Group discussion as directed by guide (next sheet)

Summary of main points and ending questions

Second researcher who has been acting as an observer in the room summarises points

Activity

Please write down up to 5 elements of what you provided that you believe were most helpful to carers? Write down....
Most important at the top ranked 1, least at the bottom (up to 5)

Ending Question

Is there anything else you would like to add about the intervention and how it has been delivered and responded to?

Conclusion

Focus Group Discussion is concluded. Thanks to the participants for attending. Final reminder of confidentiality within researchers and group participants.
Guide

☐ What has been your experience of supporting carers in this study?
  o What kind of needs were evident in the carers you were involved with?
☐ How did these vary?
☐ How successful were efforts to support them via intervening in the manner that you did? How helpful?
☐ What were the outcomes?
  o What difference did this intervention make?
  o Carers managing the situation at home?
  o Patient care?
  o Bereavement care – where this arose
  o Service angle of having greater contact with carers?
☐ What needs (if any) did study identify that you were unable to meet? Explain.
☐ Did carer outcomes vary?
  o Did it make a difference who was intervening?
  o Did anyone in particular benefit from this approach?
  o Who tended to respond less well?
☐ Who do you feel are the target group – did we reach these?
☐ How achievable has it been within current resources?
☐ What were the challenges encountered? Constraining factors?
  o Personal?
  o Process?
  o Service?
☐ Were there times you felt you were in danger of breaking patient confidentiality?
  o If so, how dealt with?
☐ How has it changed how you work with carers not on the study?
☐ Is this way of working something you would like to continue after the study?
☐ Will this be possible? Explain
☐ How much was this approach specific to carers of those with lung cancer?
☐ What might need to be different when working alongside carers of patients with other diseases?
☐ Have you identified through providing carer support skills/training that may be necessary for you/other nurses to deliver care & support to informal carers of cancer patients?
Appendix 8: Patient information sheet

Guy's and St Thomas’ Hospital
NHS Trust

Patient information sheet

Meeting the needs of close relatives and friends of patients
with lung cancer and mesothelioma

Dear Mr/Mrs/Miss/Ms: ____________________ ,

You are being invited to take part in the above study. Before you decide whether or not you would like to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully and discuss it with relatives, friends and your GP if you wish. We have added our telephone number and address at the end of this information sheet. Please contact us if you would like to discuss anything further.

What is the purpose of the study?

When cancer is diagnosed, it not only affects the person with cancer - it also affects families and friends. However, we recognise that health professionals do not always support family and friends very well. This study will identify ways in which health professionals may better support the family and friends of those with cancer.

With your permission, we would like to ask a close relative or friend who is particularly close to you if they would be willing to participate in this study. If they agree, we would arrange a meeting with them and a Cancer Nurse Specialist to help them explore their feelings and concerns as a close relative or friend of someone with cancer. We would then draw up a plan of support for them. This plan of support may involve:

- providing more information about the cancer and its treatment,
- seeing or telephoning them on a regular basis, or
- referring them to other agencies who may be able to help further.

Please be assured that we will not discuss any information about you that you have not agreed to.

We would also ask them to complete a questionnaire. This questionnaire would provide information about how they are feeling in themselves.

The study will last three months and after this time we would ask the family member or friend to complete the questionnaire again. Also, if they were willing, we would ask them to participate in an interview with the Researcher involved in the study. The interview will
identify what types of support have been helpful and assist us in planning care for family members and friends in the future.

At the end of the study, support from the Cancer Nurse Specialist will continue to be available for as long as your family or friend would like it.

It is entirely up to you, and your family member or friend, whether to take part in this study. If you decide to take part and later change your mind you are free to withdraw at any time without giving a reason. If you do not wish to take part or later withdraw from the study, please be assured that your care will not be affected in any way.

If you do consent to allow a family member or friend to take part, your medical records and information about you will be kept strictly confidential. Any information and data that we gather about your family member or friend will also be kept in the strictest confidence, and will be anonymous when reporting on the findings.

If you agree to a family member or friend taking part in this study, you will be given a copy of this information sheet and will be asked for your written consent, by signing an informed consent sheet.

This study is being conducted jointly by nurses at Guy’s and St Thomas’ NHS Hospital Trust and researchers from the Florence Nightingale School of Nursing and Midwifery, King’s College, London. It has been approved by the Research Ethics Committee of Guy’s Hospital.

‘Consumers for Ethics in Research’ (CERES) publish a leaflet entitled ‘Medical Research and You’. This leaflet gives more information about medical research and looks at some questions you may want to ask. This leaflet may be obtained from CERES, PO Box 1365, London N16 0BW.

Thank you very much for taking the time to read this information sheet. If you require any further information, please do not hesitate to contact any of these members of the study team:

Ms Jibby Medina
Research Associate
Florence Nightingale
School of Nursing & Midwifery
King’s College London
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150 Stamford Street, London SE1 9NN
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Clinical Development Nurse
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Guy’s & St Thomas’ Hospital NHS Trust
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Guy’s Hospital, St Thomas Street
London SE1 9RT
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Ms Sally Moore
Lung Cancer Nurse Specialist
Guy’s & St Thomas’ Hospital NHS Trust
Palliative Care
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New Guy’s House, Guy’s Hospital
St Thomas Street, London SE1 9RT
Telephone: 020 7188 4739
Sally.Moore@gstt.sthames.nhs.uk

Ms Amanda Sherwin
Lung Cancer Nurse Specialist
Guy’s & St Thomas’ Hospital NHS Trust
Palliative Care
Cancer & Haematology
New Guy’s House, Guy’s Hospital
St Thomas Street, London SE1 9RT
Telephone: 020 7188 4268
Amanda.Sherwin@gstt.sthames.nhs.uk
Appendix 9: Patient informed consent form

Name of Participant: Mr/Mrs/Miss/Ms__________________

Oncology & Haematology
Directorate
Cancer Management Offices
4th Floor
Thomas Guy House

Guy’s Hospital
St Thomas’ Street
London SE1 9RT

Tel: 020 718 84266
Fax: 020 718 83606

Patient Informed Consent Form

Title of Project:
Meeting the needs of close relatives and friends of patients with lung and mesothelioma

Name of Researcher: Dr Hilary Plant

Please initial box

I confirm that I have read and understand the patient information sheet dated 20th of May 2004 (Version 2) for the above study and have had the opportunity to ask questions. I also understand that my condition and treatment may be discussed by my family member/friend with the Nurse Specialist where relevant

Name of Participant ______________________ Date /___/___ Signature ______________________

Name of Person taking consent (If different from researcher) ______________________ Date /___/___ Signature ______________________

Researcher ______________________ Date /___/___ Signature ______________________
Carers’ information sheet

Meeting the needs of close relatives and friends of patients

with lung cancer and mesothelioma

Dear Mr/Mrs/Miss/Ms: ____________________ ,

You are being invited to take part in the above study. Before you decide whether or not you would like to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully and discuss it with relatives, friends and your GP if you wish. We have added our telephone number and address at the end of this information sheet. Please contact us if you would like to discuss anything further.

What is the purpose of the study?

When cancer is diagnosed, it not only affects the person with cancer - it also affects families and friends. However, we recognise that health professionals do not always support family and friends very well. This is a feasibility study aiming to determine how best to offer supportive care to the family and friends of those with lung cancer, through better understanding carers’ needs and experiences.

Why have I been chosen?

You have been identified as a close relative or friend of someone with lung cancer or mesothelioma. We would like to invite approximately 20 people like yourself to participate in the study.

What will happen to me if I take part?

If you are willing to take part, we would arrange an initial meeting with one of our Cancer Nurse Specialist to talk about your experiences of knowing and living with a relative or friend with lung cancer or mesothelioma. We would also ask you to complete a questionnaire which provides us with information about how you are feeling.

Following the meeting with the Cancer Nurse Specialist, if you feel it would be helpful, a plan for on-going support will be offered to you. This plan of support may involve:

- providing more information about the cancer and its treatment
- meeting or telephoning you on a regular basis, or
referring you to other agencies who may be able to help further.

Alternatively, you may not wish for further support. The choice will be entirely up to you.

The study will last for three months. At the end of this period, we will ask you to complete the questionnaire again and, if you are willing, participate in an interview with our researcher. This interview will ask you about the types of support that you have found helpful. It will also ask you about whether you would have liked any other types of support. All information from the questionnaires and interviews will be confidential to the study team. At the end of the study, support from the Cancer Nurse Specialist will continue to be available for as long as you would like it.

**Do I have to take part?**

It is entirely up to you whether you take part in this study. If you decide to take part and later change your mind you are free to withdraw at any time without giving a reason. If you do not wish to take part or later withdraw from the study, please be assured that the care of your relative or friend will not be affected in any way.

**Are there any benefits or risks in taking part?**

We do not envisage that there will be any risks involved in taking part in this study. We hope that we will discover ways in which we can better support you.

If you do become distressed at any point during the research process, if you wish, an appointment will be arranged with the Cancer Clinical Nurse Specialist, or a referral arranged with another Health Care professional.

We hope that the findings of the study will improve our support of relatives and friends of people with cancer in the future.

If you do consent to take part, the information we gain from you will be analysed for the purpose of the study. However, all information which is collected about you during the course of the study will be kept strictly confidential, and any data that we gather from you will be kept completely anonymous when reporting on the findings.

This study is being conducted jointly by nurses at Guy’s and St Thomas’ NHS Hospital Trust and researchers from the Florence Nightingale School of Nursing and Midwifery, Kings’ College, London. It has been approved by the Research Ethics Committee of Guy’s Hospital.

‘Consumers for Ethics in Research’ (CERES) publish a leaflet entitled ‘Medical Research and You’. This leaflet gives more information about medical research and looks at some questions you may want to ask. This leaflet may be obtained from CERES, PO Box 1365, London N16 0BW.

If you agree to take part in this study, you will be given a copy of this information sheet and a copy of the consent form that you will be asked to sign.

**What happens with the result of this study?**

The findings of the study will be published and shared with other health professionals within Guy’s and St Thomas’ and elsewhere. This is likely to be in about 18 months’ time. If you would like a copy of the final report from the study, please let us know.
Thank you very much for taking the time to read this information sheet. If you require any further information, please do not hesitate to contact any of these members of the study team:

Ms Jibby Medina  
Research Associate  
Florence Nightingale School of Nursing & Midwifery  
King's College London  
Room 5.9 WBW  
Franklin Wilkins Building  
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Lung Cancer Nurse Specialist  
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Palliative Care  
Cancer & Haematology  
New Guy's House  
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Lung Cancer Nurse Specialist  
Guy's & St Thomas' Hospital NHS Trust  
Palliative Care  
Cancer & Haematology  
New Guy's House  
Guy's Hospital  
St Thomas Street  
London SE1 9RT  
Telephone: 020 7188 4268  
Amanda.Sherwin@gstt.sthames.nhs.uk
Appendix 11: Family member informed consent form

Oncology & Haematology
Directorate
Cancer Management Offices
4th Floor
Thomas Guy House
Guy’s Hospital
St Thomas’ Street
London SE1 9RT

Name of Participant:

Tel: 020 718 84266
Fax: 020 718 83606

Carer Informed Consent Form

Title of Project: Meeting the needs of close relatives and friends of patients with lung cancer and mesothelioma

Name of Researcher: Dr Hilary Plant

Please initial box

1. I confirm that I have read and understand the information sheet dated 20th of May 2004 (Version 2) for the above study and have had the opportunity to ask questions

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

3. I agree to take part in the above study

4. I am happy for the interview to be tape recorded on the understanding that the tape will be destroyed at the end of the project

_________________________  ____/____/____  ____________________
Name of Participant  Date  Signature

_________________________  ____/____/____  ____________________
Name of Person taking consent (If different from researcher)  Date  Signature

_________________________  ____/____/____  ____________________
Researcher  Date  Signature
Appendix 12: Lists summarising ongoing contacts

12a. Reasons for contacts

<table>
<thead>
<tr>
<th>Nurse</th>
<th>Family member</th>
<th>Mutual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To generally enquire about carer’s well being</td>
<td>21. Discuss test results</td>
<td>41. Planned face to face follow up meeting</td>
</tr>
<tr>
<td>2. To make contact as requested (incl. previous message on answer phone from carer)</td>
<td>22. To gain information on patient’s condition</td>
<td>42. Planned follow up telephone call pre arranged</td>
</tr>
<tr>
<td>3. To find out outcome of GP visit</td>
<td>23. To alert to new symptom and get advice on how to manage (symptom control)</td>
<td>43. Initial assessment</td>
</tr>
<tr>
<td>4. To inform carer of date of patient investigation / appointment / admission</td>
<td>24. To inform nurse of date of appointment with psychological support</td>
<td>44. Planned follow up call (but not pre arranged)</td>
</tr>
<tr>
<td>5. To enquire about carer’s well being (incidental)</td>
<td>25. To alert to and discuss deteriorating condition</td>
<td>45. Post bereavement support</td>
</tr>
<tr>
<td>6. To inform and discuss outcome of referral</td>
<td>26. Discuss treatment plan / information relating to next steps in treatment plan</td>
<td>46. Support, advice and reassurance whilst carer managing palliative patient at home</td>
</tr>
<tr>
<td>7. To give information and clarify discharge planning process</td>
<td>27. To discuss and get advice on how to arrange admission to hospice</td>
<td>47. To review current situation</td>
</tr>
<tr>
<td>8. To inform of outcome of conversation with doctor</td>
<td>28. To get advice re discharge arrangements</td>
<td>48. To offer emotional support</td>
</tr>
<tr>
<td>9. To reschedule face to face meeting</td>
<td>29. Advice on symptoms arising as result of radiotherapy</td>
<td>49. To generally enquire about carer’s well being</td>
</tr>
<tr>
<td>10. Support, advice and reassurance whilst carer managing palliative patient at home</td>
<td>30. To inform nurse carer does not want patient told test result in event of bad news</td>
<td>50. To inform of outcome of conversation with doctor</td>
</tr>
<tr>
<td>11. Post bereavement support</td>
<td>31. To confirm email address</td>
<td>51. To inform and discuss outcome of referral</td>
</tr>
<tr>
<td>12. Discuss test results</td>
<td>32. Travel arrangements in order to receive treatment</td>
<td>52. To find out outcome of GP visit</td>
</tr>
<tr>
<td></td>
<td>33. To review current situation</td>
<td>53. To inform carer of date of patient investigation/appointment</td>
</tr>
<tr>
<td></td>
<td>34. To obtain emotional support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>35. Unclear – missed call</td>
<td></td>
</tr>
<tr>
<td></td>
<td>36. To change their appointment with the Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>37. Because they had concern about another family member</td>
<td></td>
</tr>
<tr>
<td></td>
<td>38. To make an appointment with the nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>39. Post bereavement support</td>
<td></td>
</tr>
</tbody>
</table>
12b. Outcomes of contacts

1. Carer not available

2. Subsequent contact left up to carer* [some say will get in contact as required and underline preference for no proactive contact from CNS, others say to say hello when in clinic with patient…]

3. Agreement to call

4. Agreement to subsequent meeting and booked

5. Planned face to face follow up meeting (but time and date not yet agreed)

6. Agreement to call again with outcome of discussion with doctor, or having secured information from health professional (e.g. discharge)

7. Encouraged to speak to hospice staff re discharge arrangements

8. Contact to be made with GP

9. Contact to be made with patient to undertake assessment

10. Referral to be made for psychological support

11. Agreement to bring symptoms to attention of doctor

12. Agreement for carer to call nurse with date of appointment / re tests results

13. Asked to contact carer (message left on answer phone)

14. Booked OPA* for patient to undergo review

15. Arranged 1-1 contact with carer (without patient)

16. Arranged to view body

17. Agreement for nurse to call again with date of patient’s next appointment

18. Agreed session with another family member

19. Initial assessment didn’t take place

20. Patient admitted to hospital

---

* Used when no plan/arrangement made

* Out patients appointment
12c. Intervention delivered on contacts

A  Information/Advice giving
1  Symptoms/symptom control
2  Disease process
3  Treatment modalities
4  Medication
5  Additional resources/support services
6  Self management strategies (living with cancer)
7  Managing at home
8  Diet
9  Managing uncertainty (around living with cancer/lung cancer)
10 Giving/clarifying test results
11 Info-giving/clarifying management plan
12 Transport
13 Discharge planning
14 Advice regarding own health issues
15 Prognosis/future
16 Other

B  Listening
17 Listening to current/recent experience of cancer experience
18 Allowing patient to explore the past to put current experience into context
19 Listening to family issue
20 Listening about own health

C  Benefits
21 Benefits advice
22 Help with obtaining benefits

D  Helping carer 'navigate the system'

E  Active intervention in patient's care pathway
24 Chasing results of investigations
25 Transport
26 Appointments
27 Treatment plans
28 Other active intervention

F  Liaison with other health care professional(s) regarding pt's care/care needs
29 GP
30 Hospital doctor
31 Palliative Care Team
32 Ward nurses
33 Other (Specify)

G  Acknowledging and providing reassurance over role as carer

H  Enabling expression of emotion

I  Monitoring carer's well-being / maintaining continuity in nurse/carer relationship

J  Acknowledging and exploring patient's condition

K  Helping with decision-making

L  Bereavement support
Appendix 13: Focus group coding index

Coding frame for carer focus group conducted with interveners

1. Personal experience
   1.1 Sacrifice
   1.2 Reward

2. Focus of intervention
   2.1 Patient needs paramount
   2.2 Carer
   2.3 Interwoven

3. Content of intervention
   3.1 Emotional need
   3.2 Psychological need
   3.3 Informational/service need
   3.4 Reassurance need
   3.5 Relationship need
   3.6 Harboured need
   3.7 Dynamic need

4. Characteristics/features of intervention
   4.1 Time
   4.2 Accessibility
   4.3 Assessment
   4.4 Documentation

5. Delivery modes
   5.1 Proactive
   5.2 Reactive
   5.3 Artificial
   5.4 Individual versus family

6. Differential carer uptake
   6.1 Uncertainty over what intervener could offer
   6.2 Gender

7. Differential intervention delivery

8. Outcomes
   8.1 Lowering barriers
   8.2 Smoothed pathway
   8.3 Reduced anxiety
   8.4 Sense of trust
     8.4.1 Continuity
     8.4.2 Safety
     8.4.3 Sounding board
     8.4.4 History: overcoming platitudes
   8.5 Sense of control
8.5.1 Safety
8.5.2 Empowerment
8.5.3 Dependency
8.6 Better coping at home/more effective carer role
8.6.1 Reassurance over events; ‘Doing the right thing’
8.6.2 Understanding of symptoms and their amelioration
8.7 Preparing for death
8.7.1 Personal
8.7.2 Controlling place of death
8.7.3 Eased bereavement

9. Service impact/challenge
9.1 Intervention
9.1.1 Accomodation
9.1.2 Distortion of usual practice
9.1.3 Pandora’s box
9.1.4 Role blurring; counselling & supporting
9.2 Research in practice
9.2.1 Usual versus unusual CNS role

10. Ending the intervention

11. Vulnerable carers
11.1 Insufficient support networks
11.2 Complex/poor relations hip with patient
11.3 Illness within family
11.4 Unwillingness/resentment over caring role
11.5 Stereotypes

12. Future
12.1 Resourcing
12.2 Minimum
12.2.1 Individual face-to-face carer assessment
12.2.2 Contact person
12.2.3 Documentation
12.2.4 Organised peer supervision
12.3 Challenges
12.3.1 Time
12.3.2 Equity
12.3.3 MDT & service support – benchmarks
12.3.4 Measuring/quantifying
Appendix 14: Dissemination activities to date

Publications


Oral presentations


Posters


Richardson, A; Medina, J; Plant, H; Moore, S; Ream, E; Johnson, M & Sherwin, A (2004). Meeting the needs of informal carers of patients with lung cancer: A feasibility study. King's College London, Florence Nightingale School of Nursing and Midwifery, Postgraduate Research (PGR) Symposium, 25th June 2004