

## Nurses' experience of delivering a supportive intervention for family members of patients with lung cancer

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## **Nurses' experience of delivering a supportive intervention for family members of patients with lung cancer**

### **Abstract**

Families contribute to maintaining the well-being of people with cancer through providing emotional and practical support, frequently at significant cost to their own well-being, and often with little help from health care professionals. This paper describes nurses' experience of providing an innovative service to support the families of people with lung cancer. A process of group reflection by the three nurses involved in delivering the intervention has produced an autoethnographic account of taking part in this study. Three main themes relating to the nature and process of delivering the intervention were identified: 'meeting diverse need', 'differing models of delivery' and 'dilemma and emotion'. Supporting family members of patients with lung cancer can be immensely rewarding for nurses and potentially bring significant benefit. However, this kind of work can also be demanding in terms of time and emotional cost. These findings demonstrate the value of incorporating process evaluation in feasibility studies for articulating, refining and developing complex interventions. Determining the applicability and utility of the intervention for other practice settings requires further evaluation.

Key words: Supportive Interventions, Family Members, Lung Cancer, Nursing roles

## Introduction

The burden experienced by family members supporting people with lung cancer is well described (Persson & Sundin, 2008; Persson et al., 2008; Ostlund et al., 2010; Murray et al., 2010). Although meeting the needs of family members is recognised as an integral component of cancer services (National Institute for Clinical Excellence (NICE), 2004), how best to meet these may prove challenging for cancer teams. Little is known about the interventions that might prove to be effective and how to implement these into routine practice. In an earlier paper, we reported the main findings from a pilot study demonstrating the feasibility, acceptability and potential efficacy of a novel supportive intervention for family members of patients with lung cancer (Richardson et al., 2007). The study demonstrated that a combination of emotional support and information, underpinned by assessment, led to family members feeling well supported. This had a significant impact on their emotional well-being.

The Medical Research Council (MRC)'s guidance on developing and evaluating complex interventions suggests that study reports should provide a detailed description of the intervention to enable replication, evidence synthesis and wider implementation (Craig et al., 2008; MRC, 2008). The guidance also highlights the importance of process evaluation, that is exploration of contextual factors and the way in which the intervention under study is implemented. Recognising the importance of this approach, a process evaluation was nested in the original pilot study mentioned above. In light of these recommendations, this paper will describe the intervention and incorporate a brief overview of its development, nature and philosophical underpinnings before going on to present the findings from the process evaluation that focussed on exploring the experience of nurses involved in delivering the intervention.

The method adopted for the evaluation draws on reflexive and autoethnographic approaches to qualitative inquiry. Reflexivity and autoethnography are methodological approaches that value subjectivity and the use of introspection whereby the researcher becomes, or is part of, the phenomenon under investigation (Ellis & Bochner, 2000; Wall, 2006). In what Anderson (2006) terms 'analytic autoethnography', the researcher is a full member of the research group or setting, visible as a member in published texts, and committed to an analytic research agenda focussed on improving theoretical understandings of broader social ~~phenomenon~~phenomena. In this study, the nurses delivering the intervention acted as both 'researchers' and 'the researched' and moreover are co-authors of this paper. Using this methodological approach facilitated the authors' joint endeavour to better understand the contextual factors and processes involved in implementing the intervention into routine clinical practice.

## Developing the intervention

The intervention development process was ~~a collaborative one~~, steered by a team (the authors of this paper) of three nurse clinicians (Hilary Plant, Sally Moore and Amanda Cornwell) and three research academics (Alison Richardson, Jibby Medina and Emma Ream). At the time of the study, Hilary, Sally and Amanda worked at a large teaching hospital; Hilary as a practice development nurse, and Sally and Amanda as lung

cancer nurse specialists. Alison, Jibby and Emma worked within a nursing and midwifery faculty of a large London university; Alison as a professor of cancer and palliative care, Jibby as a research associate, and Emma as a senior lecturer in cancer and palliative care. The team came together in response to findings from Hilary’s doctoral thesis that family members of people with cancer feel unsupported in their role as ‘carers’ (Plant, 2000) and Alison’s work on the ‘Improving Supportive and Palliative Care for Adults with Cancer’ guidance (NICE, 2004).

The evidence base for the intervention was derived from existing literature exploring carers’ experience, not only within oncology and palliative care but also within the wider carer literature in relation to chronic illness. As a prelude to defining the nature of the intervention, the project team acknowledged most family members cope well with the task of caring for a loved one with cancer and want to be seen as strong, positive and able to carry on as normal (Plant, 2000; Thomas et al., 2002). Therefore, the main purpose of the intervention was to recognise, build on, and maintain the expertise, competence and well-being of family members. The model developed was educative and supportive and designed so nurses could work collaboratively with family members to identify problem areas, and enable and ~~facilitate~~ promote self-efficacy. It aimed to facilitate the process of caring whilst reducing its emotional and physical cost. It also aimed to improve family members’ overall well-being and experience of caring. The term ‘family member’ was defined as those closest to the patient in terms of knowledge, care and affection (Ferris et al., 2002) and included friends if the patient so wished.

The pilot study aimed to test the feasibility of delivering the intervention within routine clinical practice, and allowed for ongoing development, definition and refinement of ~~the intervention~~ it as the study progressed. The intervention aimed to address four main areas that Hudson et al. (2002) and Osse et al. (2006) identified that carers need support and guidance with. These are: patient comfort, information, practical care and emotional support (Table 1).

<b>Table 1: Areas of care underpinning the intervention</b>	
Patient comfort	Helping family members to feel competent in monitoring the patient’s physical condition and managing symptoms appropriately
Information	Providing information and explanations, particularly written, relating to the patient’s illness, medications and what might happen in the future
Practical care	Co-ordinating care from the different professionals involved in the patient’s care and enabling access to help from other agencies, including financial help and access to benefits
Emotional support	Providing an opportunity for family members to discuss their fears and uncertainties relating to the cancer diagnosis

### **Nature of the intervention**

The intervention comprised two core components:

1. A standardised initial ‘assessment of need’ interview
2. A tailored, individualised plan of ongoing support (Table 2).

<b>Table 2: Components of the intervention</b>	
<b>Assessment of need interview</b>	<b>Plan of ongoing support</b>
<ul style="list-style-type: none"> <li>• Initial meeting between family member and nurse (face-to-face or by telephone) without patient</li> <li>• Opportunity for family member to ‘tell their story’ of the patient’s illness</li> <li>• Opportunity for family member to explore impact of illness experience on them</li> <li>• Assessment of physical, social and emotional impact of patient’s illness on family member</li> <li>• Assessment of any information deficits/needs</li> <li>• Identification of:               <ul style="list-style-type: none"> <li>➤ Sources of further information/advice/support</li> <li>➤ Future point of contact</li> <li>➤ Tailored plan for on-going support</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Based on assessment of need interview</li> <li>• Family member chooses level of support/contact based on perceived need. Can be either:               <ul style="list-style-type: none"> <li>➤ Proactive (nurse-initiated) contact: including regular, scheduled contact between nurse and family member, or</li> <li>➤ Reactive (family member-initiated) contact: family member encouraged to make contact at times of concern or need</li> </ul> </li> <li>• Follow-up nurse-initiated telephone contact at one week to check family member’s well-being and satisfaction with agreed plan of support</li> <li>• Level of support flexible and able to respond to changes in the care-giving experience over time</li> </ul>

During the feasibility study, Hilary, Sally and Amanda delivered the intervention to twenty-five family members of people newly diagnosed with lung cancer. This work was undertaken alongside their normal clinical roles. A named nurse was identified as the key contact for each family member (and was the person who undertook the initial assessment) with cover for absences provided by the other nurses. The intervention was targeted near to diagnosis in order to support family members through the initial phase of adjustment and adaptation, and begin to prepare them for events or problems that could occur in the near or distant future. Timing the offer of intervention at this point was considered vital since most patients with lung cancer present with advanced disease, are often symptomatic, and frequently die very quickly, giving patients and family members little time to prepare and come to terms with what is happening to them (Krishnasamy et al., 2001; Cancer Research UK, 2010).

Consideration was also given to the optimal duration of the intervention. In previous research, interventions with family members have been offered over a finite period or

for a pre-specified number of sessions. The strongest effect has been observed immediately after intervention delivery with effect lessening over time (Mishel et al., 2002; Northouse, 2005). In this study it was anticipated family members may differ in the amount and timing of support need. Therefore, a flexible, responsive and on-going model of support was proposed. For study purposes data collection was scheduled to take place over a three-month period following recruitment, but the nurses who delivered the intervention continued to work with family members after this point and often continued until around the time a patient died.

### **Data collection and analysis**

Examining the experience of, and reflection about, delivering the intervention from the nurses' perspective was considered a key aim in order to establish the feasibility of incorporating the intervention into routine clinical practice. In order to capture this a group interview along the lines of a focus group was conducted towards the end of the study. It was facilitated by Emma who has extensive experience in conducting focus groups. Focus groups are group discussions which explicitly use interaction to explore people's views and experiences of a specific set of issues (Kitzinger, 1994). They can generate rich data from providers of health care and are useful in studies that involve complex issues that entail many levels of feeling and experience (Morse, 1994). Further, they can allow complex issues to be clarified and elaborated upon, and allow new ideas to emerge (Sim, 1998).

The group interview aimed to investigate the process of delivering the intervention. It sought to describe how the nurses worked with family members, depict the essence of what was delivered, and explore any perceived benefits for family members and patients of this approach. Further, it sought to unpick the inherent challenges of instituting the intervention. Data were analysed by Emma and Jibby in a series of stages. First, Jibby replayed the audio recording and constructed a detailed transcription. This was not verbatim. Rather the sequence of the conversation and topics covered were documented, and illustrated by numerous verbatim quotes. Emma then analysed the data using thematic analysis. The transcripts and analysis were returned to the nurses and emergent findings were discussed by the study team.

### **Findings**

Three main themes emerged from the group interview. These are discussed under the following headings and illustrated using verbatim quotes from the nurses involved:

1. Meeting diverse need: the content of the intervention
2. Differing models of delivery
3. Dilemma and emotion: the impact on the nurses

#### **1. Meeting diverse need: the content of the intervention**

Family member need was at the heart of, and drove, the intervention. Need was dynamic, diverse and often unpredictable.

#### ***Predicting need***

Predicting family members' future level of need from the initial 'assessment of need' interview proved difficult, even futile, because predictions were generally inaccurate. In some instances, family members who expressed the least need at the initial assessment later made the greatest use of the nurses' support. Clearly, it was difficult for family members to anticipate their need early in the patient's illness. For example, during the interview Amanda comments:

*'So one might think they don't need much support but in fact they are very, very needy. They've turned out to be very needy'.*

### ***Influences on need***

As the study progressed it became evident that family member need was primarily influenced by the patient's illness trajectory. Contacts with the nurses were initiated when there were changes in a patient's condition, or when patients and family members were struggling to access what they needed from the cancer service. Thus, typically, need arose from disease or service-related issues. Sally described it as:

*'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'.*

Therefore, with knowledge of the disease trajectory, the nurses felt they could preempt some needs if they acted proactively to 'smooth the patient's journey', for example by expediting tests, results and appointments, or by increasing telephone contact at significant time points, for example after the patient has received bad news or at the start of a new treatment. Amanda suggests that:

*'It reduces anxiety because you can, not make things happen, but you can facilitate things happening within their treatment, so you can smooth the pathway'.*

### ***Nature of need***

Family member need was described as emotional, practical and informational; often a combination of all three. Family members used the nurse as a confidante; someone with whom they could establish a relationship, who would listen to their story and contain the distress within it. Trust was central to the intervention process and was facilitated by the bond of the initial assessment, continuity and reliability.

*'I think if they trust you as well, then you're a safe person, they know they can talk to you about something, a concern' (Hilary).*

In some instances, emotional need became very intense. Two nurses referred to family members who had feelings associated with previous losses and childhood neglect they had been concealing for many years, which came to the fore due to the situation they were in.

*'The feelings they were harbouring had been there for many years, but because someone came along and sat with them and wanted to know how they were feeling, it brought up all their feelings from the past. This just gave them an opportunity to talk about it' (Amanda).*

### ***Skills required to meet need***

Emotional support varied and required not only sophisticated communication skills but knowledge and confidence in managing difficult aspects of the disease process. Emotional support and reassurance were often inseparable from giving practical support about how to manage certain situations. This is something which nurses are in an almost unique position to provide.

*'It's more than counselling because you help with the practical things as well. You may support them emotionally but intertwined with that is all this practical support'* (Amanda).

Some family members sought reassurance about how to deal with a situation and checked with the nurses if the ways in which they were dealing with, or responding to it emotionally, were 'normal'. For example:

*'Usually the carers want reassurance that they're doing the right thing, and they wanted to run it by someone, just to make them feel a little bit easier in their minds'* (Sally).

Provision of information and advice was an important element of the intervention. Typically, family members required information that was specific to their relative's circumstances. With insight developed through an ongoing relationship, combined with extensive knowledge of the disease process and lung service, the nurses perceived they could provide family members with meaningful information.

*'They know that the advice you're giving, or the assessment, is a considered one based on whatever has been before. Whereas some of the people they are meeting, because those people vary over time - haven't got that history - so their advice doesn't seem as genuine. It seems like platitudes'* (Sally).

### ***Apparent increased ability to cope at home***

The nurses were unanimous in their opinion that the intervention enhanced capacity for coping at home. They perceived it gave family members greater confidence to care for the patient in their own environment, rather than needing transfer to hospital or hospice for symptom management.

*'I think that empowering people as well, making them feel more supported, that hopefully, yes, you would be able to, they would be able to cope better at home'* (Amanda).

The nurses felt well-placed to inform, support and realise choice regarding preferred place of care and death. Hilary described two situations: One, in which she facilitated admission to a hospice as the family member did not feel they could cope with their loved one dying at home. The second, where Hilary felt the patient would undoubtedly have been admitted to hospital had his wife not been accessing her guidance and support. She described the family member's questions as *'so simple, but she was very anxious about what was happening. She would ask about things to do*

*with understanding medication and pain, sleeping, positioning, eating*'. Hilary explained that although the patient was finally admitted to a hospice for terminal care, the intervention had facilitated his staying at home until that point.

Thus, with expert knowledge of the disease process, the nurses were able to predict potential events and discuss preferred place of care at a timely point in the patient's illness. For example, Amanda describes a similar situation as:

*'What I did was maybe prepare them that things would deteriorate quite quickly; she had quite advanced disease'*.

## 2. Differing models of delivery

Reflective discussion during the interview suggested the approach the nurses took in delivering the intervention may have differed slightly, playing to their individual strengths. For Hilary, the family member was the sole focus of care. For Sally and Amanda, because of their role as nurse specialists, it proved more difficult to focus solely on the needs of the family member without also becoming involved in the patient's care. Sally and Amanda both felt that having an understanding and knowledge of the patient's disease history and management helped them develop rapport and support the family member better.

*'And that might be something about the way I work... wanting to portray an air of knowledge about what's going on for the patient to the carer. To make our relationship easier'* (Sally).

Hilary, whose role was outside the lung cancer service, recognised her focus was more clearly on the family member rather than the patient. Not having a direct care role with the patient emphasised the family members' needs, although swift acquisition of a working knowledge of the complexities of the lung service was necessary.

*'In a way, not looking after the patient does legitimise the carers' needs. That they can 'phone with their stuff if they want to and are feeling anxious'* (Hilary).

### ***Use of support by the family***

As might be expected, family members differed in the extent to, and manner in, which they made use of the nurses' support. The 'assessment of need' interview was used to derive a plan of delivery for future support. The patterns for this fell within three different categories following initial contact:

- Family member initiated - some individuals opted to liaise with the nurse when issues or difficulties arose; the initiative was with them to make contact
- Nurse initiated - others wished the nurse to call at particular points in the patient's cancer journey or at pre-arranged times

- A hybrid of both - some family members had ongoing dialogue with the nurses throughout the study, notably when the nurse was providing ongoing support to the patient.

Some family members appeared not to follow up the nurses' offer of support and, except for the initial assessment interview, had little contact with them. However, these individuals were in the minority. More commonly, there was regular contact between the family members and nurse, either by telephone or face-to-face.

### ***Ending the intervention***

Prior to the study commencing the nurses felt it would be inappropriate and ethically compromising to withdraw the intervention at the end of the data collection period (12 weeks). It was anticipated some family members would need support on an ongoing basis. In the event, the length of contact once data collection had been completed varied. For some, contact tailed off and ceased when the patient's care was transferred to palliative care services or when patients died. For others, contact continued even after the patient died, and for some the nature of the disease trajectory meant the greatest amount of work with the family was undertaken after the conclusion of the study.

### **3. Dilemma and emotion**

Taking on a programme of care for family members proved very emotive. The nurses felt their involvement in the study, and in delivering the intervention, was intensely worthwhile. It used the full range of their knowledge and skills, and they perceived great benefit for family members. This provided satisfaction and reward. In the nurses' words they 'loved it'. However, dilemmas arose because the personal cost in terms of time and commitment was high, and at times felt impossible to meet. Thus, emotions seemed to swing in opposing directions during the study.

*'I've personally, really, really loved it. It's been frustrating. Very difficult to fit in with my working life'* (Hilary).

Prior to the study, supporting family members was not a role the nurses felt a clear responsibility to undertake during their normal clinical work. For them, the formalised nature of this work seemed to extend their usual role. Reference was made to the difficulties associated with subsuming this aspect of care within their usual, and typically, over-committed working lives. At one point in the interview Sally referred to this added working dimension as a 'burden' and added:

*'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'*.

The nurses also expressed concern and guilt that the level of care they were able to provide at times fell short of the level of need they identified.

*'Then you might let yourself down if you don't give that good service. You identify need and then you feel you can't do anything to help that need'* (Sally).

The nurses recognised the impact the work had on them personally. 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 transgress beyond what had been anticipated at its inception. For example, when providing emotional support;

*‘Their support, that they were needing from me, I felt mirrored what counselling should be, rather than the support that should be coming from an intervention like this’ (Amanda).*

### ***Need for recognition***

Another dilemma the nurses expressed was a sense that some of their contribution to family members, particularly the emotional and psychological support, would be difficult to quantify. They acknowledged that much of their work with family members was hidden, and were unsure of the value other members of the lung service or the organisation would place on it. This created uncertainty in their own minds with regard to the value of the work; particularly when there were competing demands on their time. Hilary commented that:

*‘Although this is good for the people we have talked about, and their need is enormous, and we feel we might be able to have an impact in supporting them through this very difficult time, its not something that is institutionally recognised as being a priority’.*

### **Discussion**

Despite an increasing recognition of the need to support family members of patients with cancer, there are few accounts of how to deliver an approach suitable for integration into everyday practice. This paper provides insight into the experience of nurses delivering a supportive intervention for family members of people living with, and dying of, lung cancer in the context of a research study.

The study took place in a single hospital trust and involved only three nurses. The nurses involved were both delivering the intervention and carrying out the research. These aspects are limitations of the data presented in terms of familiarity and objectivity (Delamont, 2007). However, the purpose of this paper is not to make any claims for generalisability or transferability. Rather, with the MRC (2008) guidance in mind, to closely consider the process of the intervention and its impact on the nurses delivering ~~the intervention~~. Process evaluation can provide useful insights into why an intervention may achieve or fail to achieve its expected outcomes and is an important component of any feasibility work (MRC, 2008).

Despite the limitations cited, we believe the methodological approach used in this part of the study has been one of its strengths and has contributed to the overall success of the study. The nurses involved in delivering the intervention were all practising nurses and also full partners in the research process. Using a collaborative and reflexive methodological approach allowed them to influence the study design, and the initial and ongoing development of the intervention. This ensured its relevance and applicability to their practice setting enabling them to incorporate it successfully into

their current roles, albeit with the challenges identified. Importantly also, the nurses have been fully involved in reporting the study findings and thus able to highlight the most relevant implications for practice.

The intervention was initiated through a detailed assessment which involved listening to the family member's story of their own experience of the patient's illness. It then entailed working collaboratively with the family member to provide individualised emotional, informational, social and practical support in response to their need. The approach was proactive on the part of the nurses delivering the intervention, particularly in the early stages when the relationship between the nurse and family member was developing. Some participants had only a few contacts with the nurses and others more. Some had almost daily contact over difficult periods of time. In essence this utilised a 'person centred approach' (Rogers, 1961; Kitson, 1999) refined for a nursing role to allow for tailored information-giving and practical advice.

The level and nature of family member need was variable and unpredictable. The initial 'assessment of need interview' did not predict the level of future need. Rather, it served to develop rapport and trust, and thereby formed the basis for future therapeutic work. At this early stage it appeared that some relatives were unable to take in what the diagnosis might really mean. They were unfamiliar with the health care system and had no understanding about what they might need in the future. Therefore, need proved dynamic in its manifestation, expression and requirement for resolution. It was sometimes difficult to separate family member's own needs from those of the patient and it often manifested in response to significant events in the patient's pathway. Although data collection for the study was completed at three months, the relationships that developed were usually on-going, becoming richer and potentially more useful to participants as the disease progressed. This suggests that interventions may benefit from being responsive to individual situations rather than pre-defined for specific time-periods.

Those close to someone diagnosed with lung cancer are likely to be deeply distressed (Murray et al., 2010; Persson et al., 2008). They may experience difficulty in expressing or even acknowledging this distress in their usual encounters with health care professionals (Plant, 2000; Hill et al., 2003; Krishnasamy & Wilkie, 2007). In this study the nurses described a willingness on the part of the family members to talk to them about difficult feelings because they were given opportunity and encouragement to do so. Family members also lack confidence in their care-giving role because of the newness of the situation they find themselves in, and the swiftness with which the disease debilitates their loved one (Plant, 2000; Hudson et al., 2002). In this study, the nurses described that with appropriate, tailored support and reassurance, family member confidence could be enhanced.

The methodology we used in this project facilitated our reflection on the qualities and experience of professionals required to deliver the kind of support provided in this study. Initially, the model of support was conceived as a nursing intervention but consideration and discussion during the project raised the issue of who might be best placed to do such work. From the group reflection it appears that excellent communication skills, a reasonable knowledge of lung cancer and its treatments, and an understanding of the health care system and how to navigate it are needed. The most obvious group to fulfill this role would be cancer nurse specialists. It is possible

that a counsellor or social worker with knowledge of lung cancer and its treatment could fulfill the requirement also. Indeed, a model of family support provided by a professional with a social work background has been reported by Ryan et al., (2008). Further work exploring the optimum skills and experience needed for this type of intervention is therefore warranted.

Providing support for family members proved both rewarding and challenging for the nurses involved in the study. Incorporating the work into their already over-stretched roles placed a high demand on the nurses. This mirrors similar work where cancer nurses have been involved in developing new roles and innovative ways of working (Plant et al., 2000; Froggatt & Walford, 2005; Moore et al., 2006). The nurses in this study expressed great satisfaction; feeling they could make a significant difference to family members' experience of the illness. However, they felt constrained by a lack of time and uncertainty about the value placed on this support by the wider lung cancer team and organisation. These may be important factors in understanding why health professionals appear reluctant to formally take on family support in addition to their existing workload. Therefore, enhanced resources are required for professionals involved with this kind of work particularly with reference to additional time and supervision and a greater acknowledgement of its importance within mainstream service delivery.

## **Conclusion**

Families maintain the well-being of people with cancer through providing emotional and practical help, usually putting their own lives into upheaval. At the same time they may be intensely emotionally distressed themselves. The importance of supporting this vulnerable group of people both for their own and for the patients' well-being is now well-recognised. Overall, the pilot study has demonstrated that experienced cancer nurses can deliver a supportive intervention for family members of people with lung cancer. The intervention offered family members an on-going, reliable relationship and individualised support and advice as they needed it. This paper demonstrates that the exact nature of the intervention was driven by a complex interplay of patient and family member need, as well as the underlying focus of care of the nurse delivering the intervention. The on-going reflective process which allowed the nurses to articulate the impact of involvement with this study also illustrated that the nurses themselves require additional time and institutional support to undertake this work. They also needed detailed knowledge of the care required and what to anticipate in the lung cancer disease trajectory as well as sophisticated and flexible communication skills. Further evaluation is obviously required to determine its wider applicability and acceptability. We hope that sharing our experience of this early developmental work will assist other teams of researchers and clinicians who may be working in this area.

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