



What about the carers?: Exploring the experience of caregivers in a chemotherapy day hospital setting

S. Mcilfatrick^{a,*}, K. Sullivan^b, H. McKenna^a

^a*Institute of Nursing Research and School of Nursing, University of Ulster at Jordanstown, Shore Road, Newtownabbey, N. Ireland, BT 37 0QB, UK*

^b*North East Wales Institute of Higher Education, Plas Coch Campus, UK*

KEYWORDS

Chemotherapy;
Nursing;
Day hospital;
Phenomenology;
Caregivers' experience

Summary Interest in the concerns of cancer patients' carers has been growing steadily over the last decade reflected in key cancer service policy documents [DOH, 1995. A Policy Framework for Commissioning Cancer Services (Calman-Hine Report). London, HMSO; DOH, 2002. The NHS Cancer Plan]. Despite this acknowledgement, it can be argued that less is known about carers' experience in the cancer treatment context. Carers can be defined as someone who shares the experience of cancer with the patient. The aim of this study was to explore the lived experience of caregivers in a chemotherapy day hospital and how this compared with their experience of inpatient care. Using a phenomenological approach, face-to-face interviews were conducted with a purposive sample of ten caregivers. Data were analysed using Polkinghorne's [1995. Narrative Knowing & the Human Sciences. University of New York Press, Albany] two stages of narrative analysis. The findings indicated that the caregivers experienced similar transitions to the patients with regards to health-illness transition and organisational transitions. The caregivers adopted various roles in the day hospital such as *Companion* 'being with' their relative, *Protector* 'keeping an eye'; *Practical Caregiver* and assuming an *Advocate* Role. The findings of this study are important for cancer nursing practice as health professionals need to acknowledge the role of carers in the chemotherapy day hospital setting and facilitate their involvement in care.

© 2005 Elsevier Ltd. All rights reserved.

Zusammenfassung Das Interesse an den Problemen von Pflegepersonen, welche Krebspatienten betreuen, hat in den vergangenen zehn Jahren ständig zugenommen, was auch in den wesentlichen onkologischen Strategiedokumenten zum Ausdruck kommt (DOH, 1995; 2002). Obwohl diese Probleme inzwischen allgemein anerkannt sind, ist noch relativ wenig über die Erfahrungen der Pflegepersonen in der onkologischen Behandlungspraxis bekannt. Bei Pflegepersonen handelt es sich

*Corresponding author. Tel.: +44 28 90 368066; fax: +44 28 90 368202.

E-mail addresses: sj.mcilfatrick@ulster.ac.uk (S. Mcilfatrick), k.sullivan@newi.ac.uk (K. Sullivan).

definitionsgemäß um Personen, welche Erfahrungen, die mit Krebserkrankungen gemacht werden, mit den von ihnen betreuten Patienten teilen. Das Ziel dieser Studie bestand darin, die praktischen Erfahrungen von Pflegepersonen in einer Chemotherapie-Tagesklinik zu evaluieren und festzustellen, inwiefern sich diese Erfahrungen von denjenigen unterscheiden, die in stationären onkologischen Einrichtungen gemacht werden. In einem phänomenologischen Ansatz wurden in einer zielgerichteten Stichprobe von zehn Pflegepersonen persönliche Interviews durchgeführt. Die Auswertung der Daten erfolgte mit Hilfe der narrativen Analyse in zwei Phasen nach Polkingshorne (1995). Aus den Ergebnissen geht hervor, dass die Pflegepersonen ähnliche Transitionen erlebten wie die Patienten (im Hinblick auf Gesundheit-Krankheit-Transition und organisatorische Transitionen). In der Chemotherapie-Tagesklinik übernahmen die Pflegepersonen diverse Rollen: als *Partner*, die den Angehörigen „zur Seite standen“, als *Beschützer* mit einem „wachsamem Auge“, als *praktisch tätige Pfleger* sowie als *Fürsprecher*. Die Ergebnisse dieser Studie sind für die onkologische Pflegepraxis von Bedeutung, da im Gesundheitswesen tätige Personen akzeptieren müssen, dass ihnen die Rolle von Pflegepersonen zukommt und Hilfe bei ihrer Integration in die praktische Pflege benötigen.

© 2005 Elsevier Ltd. All rights reserved.

Introduction

It has long been recognised by medical sociologists and other health researchers that patients' illness experiences cannot be understood as individualised, socially isolated phenomena (Anderson and Bury, 1988; Kelly and Field, 1996). Rather, it is accepted that a serious illness such as cancer carries with it considerable psychological and social consequences for the family, carers and other close associates of the people with the disease (Thomas et al., 2002).

The nature of cancer care has changed dramatically in recent years. Earlier diagnosis and improvements in cancer care and treatment have impacted not only on people with cancer but also on the people *with* people with cancer, the carers, who may now live with the 'cancer patient' for many years. Interest in the concerns of cancer patients' carers has been growing steadily over the last decade. Key cancer service policy documents reflected this interest, acknowledging the presence of these 'significant others'. This is well expressed in the Calman-Hine Report (DOH, 1995) and the New NHS Cancer Plan (DOH, 2002):

The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of the professionals involved in cancer care (DOH, 1995, p. 6).

Patients, families and carers need access to support from the time that the cancer is first suspected through to death and into bereavement (DOH, 2002, p. 62).

Despite this acknowledgement Morris and Thomas (2001) argued that less is known about what informal caring actually involves in the cancer treatment context and about the difference that this makes to the overall health care endeavour. Rather, more attention has been paid to informal carers in the cancer palliative care literature (for example Rose et al., 1997; Beaver et al., 1999).

Literature review

Traditionally the concept of caregiver has been equated with that of family. While the term *family* has usually been defined as an individual of blood relationship (Ferrell, 1998), it is suggested that a broader definition is more appropriate and is best defined as those individuals considered as *family* by the patient. Thomas et al. (2001, 2002) defined the carer as 'someone who shares' the experience of cancer with the patient. However, Heaton (1999) suggested that the people health professionals might define as carers do not necessarily identify with this label, preferring to call themselves by more familiar titles, such as mother or daughter. It could be argued that people contest the term because of the connotations with which it is associated, for example, physical care which may not be appropriate for a patient who is in relatively good health.

The role of caregivers and the chemotherapy setting

Despite the extensive research on cancer and the family, little is known about the experience of the

caregiving role when a family member undergoes chemotherapy treatment. A research study by Schumacher (1996) investigated the caregiver role in an American grounded theory study of 19 family caregivers and 20 persons with cancer. Data, involving semi-structured interviews and observation, were collected three times across the course of chemotherapy at 7–10 days after the first three cycles of chemotherapy. The main findings revealed that

- a wider focus rather than an individualistic focus is more appropriate as the illness care is an area in which *both* the ill person and family caregiver participate,
- the caregiver role occurs vis-à-vis the health transition experienced by the ill person during chemotherapy treatment; and
- the caregiving role is not necessarily linear through predictable stages of development. Rather the caregiver role is fluid and ever changing.

Schumacher (1996) acknowledged a limitation in relation to the study sample, which consisted of primarily caregivers in traditional, well-educated, middle-class families. Another acknowledged limitation was that using interviews as the method of data collection could potentially have eliminated access to two important groups: (a) those caregivers who were overwhelmed with the time pressures imposed by caregiving and (b) patients who were too ill to be interviewed.

Eriksson (2001) carried out a survey in Finland with the aim of finding out what patients' relatives regarded as important factors of patient care during chemotherapy. The sample consisted of relatives of cancer patients ($n = 168$) from inpatient oncological wards. Sampling criteria included: at least 4 months since diagnosis, not in terminal phase; aged between 25 and 63 years; and receiving treatment for cancer. Findings indicated that relatives regarded both the content of care and the way in which it was provided as important. The most relevant factors were professional skill, trustworthiness of staff members and safety of care. Relatives regarded information about the patient's prognosis as less necessary than information about the patient's cancer, its treatment and the side effects of treatment. However, continuity of care appeared to be an issue for relatives. Two thirds (67%) of the relatives highlighted that the patients did not have their own primary nurses and that there was not much encouragement for the patients to take part in decision-making concerning their care. Some of the limitations of the study

include the response rate (50%) and the possible bias in sample selection. Some possible explanations for the response rate included: issues of confidentiality as the patients were still receiving care (it can be considered as potentially upsetting for relatives to participate in research about their next of kin) and the dependence of getting the patient's consent to approach relatives for the study.

To examine further the experience and psychosocial needs of carers, Thomas et al. (2001, 2002) conducted a large 3-year multi-method study in the UK on *the psychosocial needs of cancer patients and their main carers*. The study obtained its data from 644 returned postal questionnaires (carers $n = 262$; patients $n = 382$), 79 in-depth interviews with patients ($n = 47$) and carers ($n = 32$) and 39 structured interviews with a variety of health personnel involved in care services. To be eligible patients had to be over 18 years of age, diagnosed with one of four tumour types (breast, lymphoma, colorectal and lung), and close to one of four 'critical moments' (diagnosis, end of first treatment, first recurrence, move to palliative care only) in their cancer journey. Most carers in both the survey sample (75%, $n = 196$) and the interview sample (78%, $n = 25$) were spouses or partners. The results indicated that carers were engaged in both *care work tasks* and demanding *emotion work*.

Care work demands were an important feature of informal carers' experiences. Informal carers found themselves engaged in a range of new caring activities. These involved additional household labour tasks, personal care work (for example, assistance with washing and feeding), organisational work and the provision of transport. This work became more significant during periods when patients were in receipt of medical treatments, such as intensive chemotherapy and were at later critical moments in their cancer journey.

Emotion work was a crucial aspect of what informal carers did at all critical moments and carers worked hard to manage the emotions of the patient as well as their own feelings. This revolved around: 'being there' for the patient; 'being positive', maintaining hope and trying to maximise the sense of 'life carrying on as normal'. In doing this emotion work, carers, especially spousal carers, often symbolically shared in the illness and presented the struggle with cancer as a joint one.

Morris and Thomas (2001) further examined how carers negotiated their place in the medical setting and how carers identified their role in relation to the patient. They suggested that carers participated in a shifting process of 'carerhood' and

argued that there appeared to be a paradox between the carers' high levels of involvement, alongside their uncertainty about their position in the medical setting. The authors suggested that it would be beneficial for the patient–carer unit, rather than just the patient to be considered as the focus of care within the medical treatment setting. These studies help to elucidate caregivers' plan in the support of patients undergoing chemotherapy and hence provide a good rationale for exploring the lived experience of caregivers in a chemotherapy day hospital setting.

The study

The aim of the study was to *explore* caregivers' experience of a day hospital chemotherapy service in an acute general hospital in Northern Ireland and how this compared with their experience of inpatient care. This was addressed using a phenomenological approach. Van Manen (1990, p. 10) stated,

...phenomenology asks for the very nature of a phenomenon, for what makes a some-'thing' what it is—and without which it could not be what it is

Therefore, phenomenology is used to answer questions of meaning and is useful in understanding an experience as understood by those having it.

Sample

A purposive sampling technique was employed for the caregiver sample with the following inclusion criteria:

1. Over 18 years of age—the area of interest was adult services.
2. Have given their informed consent—this relates to the necessary ethical considerations.
3. Have been present with the patient during the chemotherapy treatment both as an inpatient and within the day hospital—this relates to the need for them to be able to discuss their experiences of being present with someone receiving chemotherapy treatment within a day hospital setting.

Ten caregivers, including wives ($n = 2$), husband ($n = 1$), mother ($n = 1$), daughters ($n = 3$) and sisters ($n = 3$) were selected for inclusion in this study.

Data collection

The research objective was to elicit narratives from the participants relating to their experience of day hospital chemotherapy. In order to generate narratives, Mishler (1986) and Reissman (1993) discussed the importance of asking the right kind of interview questions. For example, open questions are more likely to elicit narratives such as, 'tell me what happened'. For this study, focused questions were adopted linked closely to the cancer trajectory, with the participants being asked to reflect on their experience being with the patient in the inpatient unit and the day hospital. All the interviews took place within a relative's room in the cancer centre and were transcribed verbatim.

Ethical considerations

Ethical approval for the study was obtained from the University's Research Ethical Committee. The researcher employed a process of renegotiating consent to participate at various points throughout the data collection phase. Furthermore, consent was obtained from the patients before asking carers to participate in the study. Participants were informed that they could withdraw from the study at any time. With the consent of the participant, all interviews were audiotaped and transcribed. Assurances were provided regarding the confidential nature of the interview and the data and that the participants would not be identified in any way during the study.

Data analysis

A two-staged narrative data analysis approach was used for this study. This involved an analysis of the participants' narratives as a whole followed by an in-depth analysis of specific narratives and case studies. This was based on the work of Polkinghorne (1995). This process resulted in a description of themes that ran across the narratives alongside more in-depth narrative analysis in the presentation of a case study followed by a commentary.

The rigour for this study was addressed through the following: member checks with two of the caregiver participants; the use of thick description; ensuring a transparent audit trail in relation to all methodological decisions during the study; second checking of themed transcripts by the researcher's supervisors and employing a phase of 'blind' coding with two experienced cancer nurse researchers and a nurse researcher experienced with narrative analysis.

Findings and discussion

The study aim was to explore the caregivers' experience of day hospital chemotherapy and how this compared with inpatient care. This resulted in the development of a conceptual framework focused on transition (see Fig. 1) with the key constructs of *types*, *conditions* and *responses* to transition. This framework was adapted from Meleis et al. (2000) who suggested that transition is both a result of, and results in a change in lives, health, relationships and environments. It can be suggested that how human beings cope and adapt to transitions and how the environment affects that coping are fundamental questions for nursing and relates clearly to the aim of this study.

Types of transition

The two main types of transition identified were: *the health illness transition* associated with their loved one having cancer and receiving treatment and the *organisational transition* relating to the change from inpatient care to that of the day hospital.

Health/illness transition

The caregivers expressed emotional reactions similar to those expressed by their loved one when they received a *cancer diagnosis*. These reactions included shock, devastation and fear. It is accepted in the literature that a serious illness such as cancer carries with it considerable psychological and social

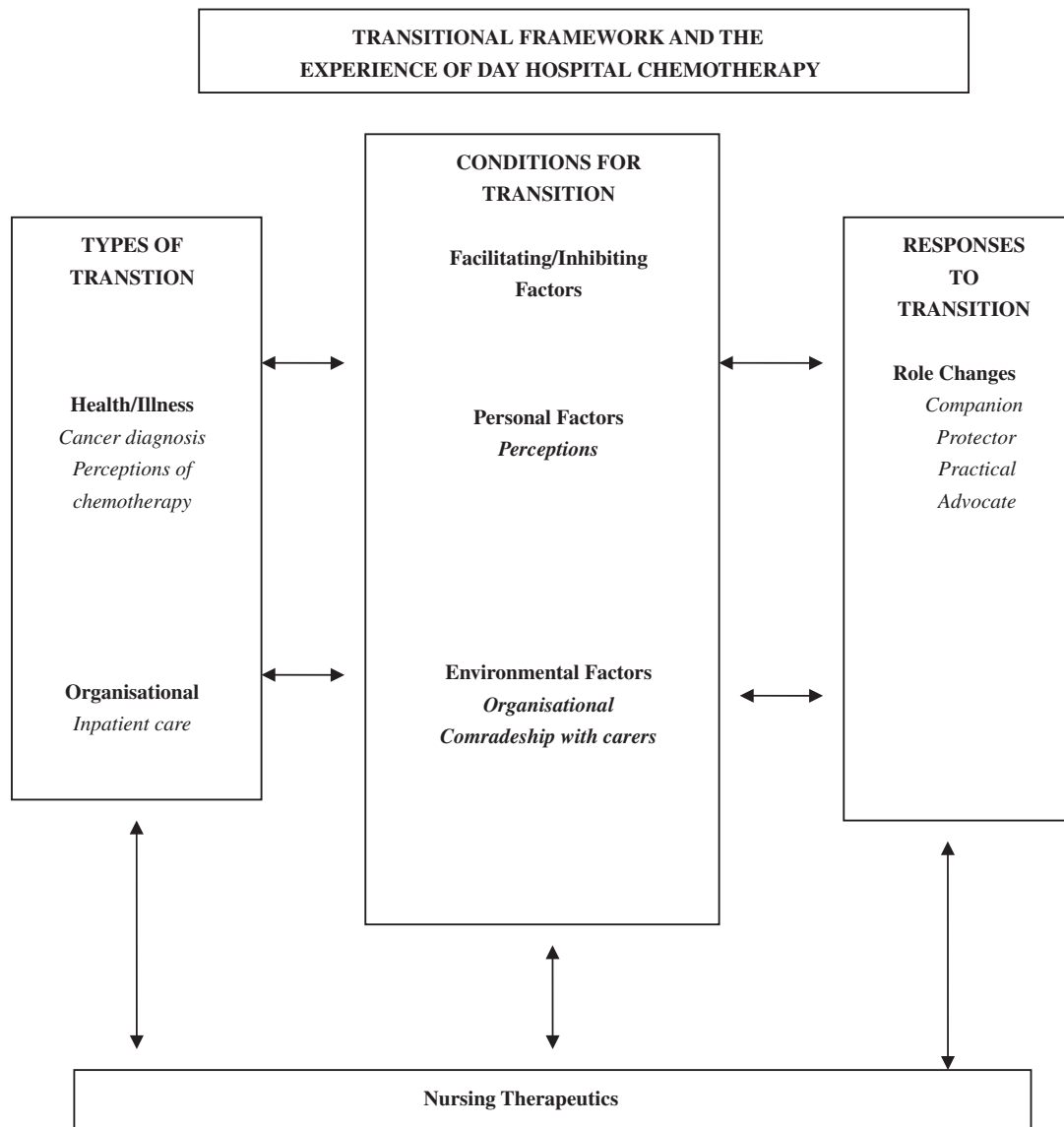


Figure 1 A transitional framework for the caregivers' experience of day hospital chemotherapy.

consequences for the family, carers and other close associates of the people with the disease (Thomas et al., 2002).

Rel 5 "Well it is a shock. Everybody will tell you that it is a shock and it is a shock.It was shock now" it was a shock. When I heard about it and I'd seen it on the television and I had read about people with cancer, but surely he was not talking about my wife, surely this can't be right".

The caregiver's *perception of chemotherapy treatment* was focused on the need to fight the disease and maintaining hope, coupled with feelings of fear:

Rel 17 "I suppose at the beginning when I heard about chemo then, I felt this was horrendous, I thought this was awful I need to be available for her to get her over this".

Organisational transition

The organisational transition was related to *the transition from inpatient to day hospital care*, and was considered positively and negatively. The main positive aspect was that the caregivers considered that the inpatient unit was not '*all doom and gloom*' as many of them had expected:

Rel 5 "...I thought people would be going about, you know, I thought that they would maybe be, the curtain would be around everybody's bed, and you would have to tiptoe in. You wouldn't be allowed to laugh, you know..."

The main negative aspect of the inpatient unit was the idea of '*seeing people who were ill*' and the subsequent shock that they experienced. One caregiver commented that she felt physically sick at seeing some people who were ill:

Rel 23 "...At the very beginning I saw somebody with a shaved head and they were together in the cancer ward and it was just very different to being on the general surgical ward and that was a shock and I felt physically sick, I really did, 'Oh God this is it'..."

Transition conditions

In order to understand the caregivers' experience it is necessary to uncover the personal and environmental conditions that impact on a transition. Some of these conditions included: the carers' perceptions of the day hospital; organisational factors; and comradeship with other carers.

Caregivers' perceptions of the day hospital

The caregivers described one of the more positive aspects of the day hospital as maintaining '*a sense of normality*' and not feeling that they were in hospital:

Rel 26 "It was like a hairdressers, you come in and sit down and they hand you a magazine and all these people are sitting there..."

Another positive aspect of the day hospital was *going home after treatment*. This was associated with maintaining their loved one as part of the household and being able to 'pamper' them allaying any potential feelings of guilt:

Rel 5 "Well, I like her to come home; psychologically it helps both of us. I keep an eye on her and I don't feel as guilty....I feel that if she is at home she's not isolated and that makes me feel better... I know she is there, I know she's actually still part of the house..."

However, *going home after treatment* was also viewed by some as a negative experience. Various caregiver narratives gave specific examples of some difficulties that were experienced at home and the perceived lack of 'back-up' and professional support available. The idea of going home after treatment was likened to the experience of being discharged home with a new baby and the fear and anxiety this provoked:

Rel 26 "I found it very frightening at the start, very frightening. I couldn't sleep. You know the way you have your first baby and you have the security of the hospital and then they say right you can goand all of a sudden you are left..."

The caregivers also considered that some of the negative aspects of the day hospital were the dehumanising elements of 'the system' and the lack of consideration for their relative as human beings. One relative likened the day hospital to a place for battery hens:

Rel 27 "I can only describe the day clinic as what a battery chicken feels like, that is what it reminds me of. Coming into a waiting area that is crammed with people with all shapes, sizes, ages, whatever..."

The dominance of this 'system' and the caregivers' need to learn to adapt to this system was also highlighted:

Rel 18: "...There is a system at work and they [nurses] are tied to it, they have got to get through so much and I suppose I feel for people a

bit on the emotional level because I feel that the psychological and emotional does tend to be the last thing on their list to be considered...”

Rel 23 “We have got used to coming here and used to the whole system and the way it operates...learning is the key word, it is a constant process of learning...”

Organisational factors

One of the main subcategories identified relating to organisational factors included *continuity of care* and was related to the use of the named nurse concept in the day hospital. This was seen as a very positive aspect of the care:

Rel 27 “I think people do need somebody to focus on... they focus on one person and the continuity of people is important. He would be fond of the nurse that would see him most of the time and that does help definitely and that makes a big difference...”

However, this subsequently led to a sense of disappointment whenever their relative's named nurse was not present. For example, Relative 26 commented:

I feel disappointed when she is not here because I know when she is here she is very efficient... I feel slightly disappointed when she is not here...

Comradeship with others

The caregivers identified other relatives and patients as a source of comradeship. The caregivers found that they developed a ‘bond’ and relationship with other carers, which helped them feel less isolated:

Then we met other people who were coming in for treatment and there was a bond formed very quickly so that was good...There is a sense of everybody is in this together...it was good for me too because I felt that we were brought into other people's lives and experiences and getting to know how they were dealing with things...

Transition responses

On exploring the caregiver's response to the transition from inpatient to day hospital it was noted that the caregivers adopted different roles and behaviours to help them to manage their new situation and environment. These roles can be described as *Companion*; *Protector*; *Practical Caregiver*; and *Advocate*.

The role of companion

The relatives considered that they wanted to share the experience with their loved one as far as was possible. For them this might have included simply ‘being with’ the patient:

Rel 10: “I told her, ‘you’ll never be on your own when you’re having this [treatment] you’ll never be on your own, I’ll always be with you’, because I didn’t know what she was going to have to go through.... I would sit here and get bored out of my skull but I feel it’s just a wee bit of moral support for her....”

The role of protector

The caregivers also highlighted the role of protector for their loved one. This could be related to practical issues associated with observing the administration of chemotherapy, as highlighted by the following comments:

Rel 18 “I’m just in the shadow to keep an eye, ... I mean there was one nurse that came in and didn’t even wash her hands and she was going to [patient], and I says *what!!!* I try not to interfere with [patient] but I had to that day, she was too weak”

Practical caregiver role

On occasions it was noted that the caregivers assumed a practical caregiver role within the treatment environment, especially in the day hospital. This was related to practical activities such as getting their relative a drink of water or something to eat and that this helped them to feel a part of the process.

Rel 18 “I mean if she wants anything the nurses are very busy and I would get her a drink of water or bring her a sandwich...”

Rel 27 “It maybe makes you feel that you are doing something, things like going to the kitchen and making tea just simple things like that...”

Advocate role

An advocate is defined as “someone who pleads a case on someone else's behalf” (*Concise Oxford Dictionary, 2002*). The caregivers in this study identified this role in light of helping the patient to get all the necessary information to make decisions. The caregivers considered that their relatives were being asked at times to make very difficult decisions regarding treatment options and they felt that they lacked the necessary information to make these decisions. This is highlighted in

the following comments:

Rel 23 "I get frustrated because I think you need to know everything before you can make these decisions and just because the doctor says something it doesn't mean to say that mummy doesn't have a say in it, she does, it's her body. I would have to put her aside or stop everything there and then and tell her you have the time to make the decision..."

It was noted from the findings of this study that the caregivers' roles were interchangeable, negotiated and adopted as necessary within the two settings. This negotiation of roles supports the work of Morris and Thomas (2001) who examined how carers negotiated their place in the medical setting, focusing on both the care work demands and the emotion work. The emotion work could relate to the roles of advocate, companion and protector and was a crucial aspect of what carers did at all critical moments. This revolved around 'being there' for the patient and trying to maximise the sense of 'life carrying on as normal' (Thomas et al., 2002). Furthermore, according to Plant (2001) the guardian or protective role can be considered both as a way of coping and a way of caring for caregivers. These findings are also congruent with the work of Schumacher (1996) who suggested that the patterns of caregiver involvement fluctuated across the course of chemotherapy including: monitoring and interpreting symptoms, making decisions, taking action, providing hands-on care, accessing resources, working collaboratively with the health care provider and negotiating the health care system. Both sets of authors (Morris and Thomas, 2001; Schumacher, 1996) concluded that it would be beneficial for the patient-carer unit, rather than just the patient to be considered as the focus of care within the medical setting helping. This would help to address the issue around 'facing it together' for carers and patients.

However, it is also important that the perceived dominance of the system is addressed both for patients and carers. Corner (2001) discussed the influence of 'the system' in a monograph entitled, 'Between you and me'. She argued that within the health care 'the system', comprising procedures and processes, dominates and is concerned more with itself rather than with the person for whom the processes and procedures have been designed. The end result can be a lack of attention to personalising care, with efficiency taking precedence over comfort, reassurance and emotional care.

The caregiver's story

During the interviews the caregivers recounted various stories regarding their experience in the day hospital and the change from inpatient care. A case study is presented to further elucidate the caregivers' experience of day hospital chemotherapy (see Box 1).

This case study helps to illustrate issues associated with '*communication and information giving*' and wider '*system issues*'. These themes were illustrated in the stories about receiving information on the treatment and about coping with her mother's nausea. This resulted in the caregiver needing to adopt '*new skills and roles*' to manage these situations, including the role of protector/monitor, advocate, and companion.

Limitations

The study was limited by the small sample size and the exploratory nature of the study. Therefore the limited generalisability of the findings must be acknowledged. However the intention of the study was to describe, explain and offer insights that could be developed and used in similar contexts.

Conclusion

The conceptual framework of transition provided a useful framework for exploring the caregivers' experience of day hospital chemotherapy, related to both *the health illness transitions* and the *organisational transitions*. The caregivers identified their need to be included in their loved one's experience of chemotherapy and highlighted that they constantly negotiated different roles in the treatment settings. Health care professionals in the day hospital need to acknowledge the role of carers and facilitate their involvement in care. Thus it is vital that the patient-carer unit, rather than just the patient is considered as the focus of care within the day hospital chemotherapy setting. Policy reforms have acknowledged the need to address patients' concerns and involve patients and families as 'users' of health care in decision making and planning (DOH, 2002). It is vital that this is more than rhetoric and that policy seeks to address ways of refocusing health care on the individual and their carers. Some recommendations for practice include the need to reorganise the 'physical' environment in these types of settings to facilitate the sense of comradeship which carers receive from each other and to be aware of the perceived

Box 1 Caregiver case study.

Anne is the daughter of a 71 year old woman diagnosed with oesophageal carcinoma attending the day hospital for chemotherapy. Anne accompanies her mother for all her treatments. Anne commences her research interview by recounting in detail the story regarding her mother's diagnosis of cancer. She recounts how they were given the information at that time and the exact words that were used. To illustrate the importance of how information is conveyed, Anne recounted a story. She stated that her mother was given some information about treatment that she was receiving. At the top of this information was the words treatment for '*advanced oesophageal cancer*'. Anne recalled the effect the word 'advanced' had on both her mother and herself. She stated that although they were aware of her mother's diagnosis they were greatly affected by seeing the word 'advanced' in print.

Another story related to the difficulty Anne experienced when she accompanied her mother for treatment. This was related to wanting to be there for her mother and yet having concerns and needs of her own and having a feeling that she was 'putting her own life on hold' to be with her mother. She highlighted her difficulty 'the system', with the example of a story about the difficulty in controlling her mother's nausea. Anne discussed how her mother was always suffering with nausea and sickness despite being reassured that there would be medication to control this. This caused Anne a lot of stress in coping with her mother at home. Finally, after some phone calls and discussion with health professionals her mother received some medication that seemed to help. However, whenever her mother returned for her next treatment Anne found that they had changed her mother's medication back to the old regime despite her reminding the staff that her mother needed the new tablet. This highlighted to Anne her role as being a Guardian and Advocate for her mother and the frustration of 'pushing' for things for her mother.

dominance of 'the system' in such settings. Furthermore it is vital that the concept of environment is perceived as much more than physical space but rather includes wider socio-cultural, interpersonal and organisational influences that impact on the day hospital setting.

Acknowledgement

The authors would like to acknowledge the Ulster Cancer Foundation who part-funded this research.

References

- Anderson, T., Bury, M., (Eds.), 1988. *Living with Chronic Illness: The Experience of Patients and their Families*. Unwin Hyman, London.
- Beaver, K., Luker, K., Woods, S., 1999. The views of terminally ill people and lay carers on primary care services. *International Journal of Palliative Nursing* 5, 266–274.
- Concise Oxford English Dictionary, 2002. The Concise Oxford English Dictionary. Oxford University Press, Oxford.
- Corner, J., 2001. *Between You and Me: Closing the Gap Between People and Health Care*. The Stationery Office, London.
- Department of Health, 1995. *A Policy Framework for Commissioning Cancer Services* (Calman-Hine Report). HMSO, London.
- Department of Health, 2002. The NHS Cancer Plan. <http://www.doh.gov.uk/cancer/cancerplan.htm> (assessed date 20/11/02).
- Eriksson, E., 2001. Caring for cancer patients: relative's assessments of received care. *European Journal of Cancer Care* 10, 48–55.
- Ferrell, B., 1998. The family. In: Doyle, D., Hanks, N., MacDonald, N. (Eds.), *Oxford Textbook of Palliative Medicine*, second ed. University Press, Oxford, pp. 355–480.
- Heaton, J., 1999. The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness* 21, 759–777.
- Kelly, M., Field, D., 1996. Medical sociology, chronic illness and the body. *Sociology of Health and Illness* 18 (2), 241–257.
- Meleis, A.I., Sawyer, L.M., Im, E., Hilfinger Messias, D.K., Schumacher, K., 2000. Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science* 23 (1), 12–28.
- Mishler, E.G., 1986. *Research Interviewing: Context and Narrative*. Harvard University Press, Cambridge.
- Morris, S.M., Thomas, C., 2001. The carer's place in the cancer situation: where does the care stand in the medical setting? *European Journal of Cancer Care* 10, 87–95.
- Plant, H., 2001. The impact of cancer on the family. In: Corner, J.B., Bailey, C. (Eds.), *Cancer Nursing: Care in Context*. Blackwell Science, Oxford, pp. 86–99.
- Polkinghorne, D.E., 1995. *Narrative Knowing & the Human Sciences*. University of New York Press, Albany.
- Reissman, C.K., 1993. *Narrative Analysis*. Sage Publications, London.
- Rose, K.E., Webb, C., Waters, K., 1997. Coping strategies employed by informal carers of terminally ill cancer patients. *Journal of Cancer Nursing* 1, 126–133.

- Schumacher, K.L., 1996. Reconceptualising family caregiving: family based illness care during chemotherapy. *Research in Nursing and Health* 19, 261–271.
- Thomas, C., Morris, S.M., McMurray, M.B., 2001. The Psychosocial needs of Cancer Patients and their Main Carers. Institute for Health Research, Lancaster University, Lancaster.
- Thomas, C., Morris, S.M., Harman, J.C., 2002. Companions through cancer: the care given by informal carers in cancer contexts. *Social Science and Medicine* 54, 529–544.
- Van Manen, M., 1990. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. State University of New York Press, New York.

Available online at www.sciencedirect.com

