



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

S. Mcilfattrick^{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 OQB, UK*

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

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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.

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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.mcilfattrick@ulster.ac.uk (S. Mcilfattrick), 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.

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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

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