

A STUDY TO EXPLORE THE EXPERIENCE AND SUPPORT NEEDS
OF OLDER CAREGIVERS CARING FOR FAMILY MEMBERS (OR
FRIENDS) WITH CANCER: INITIAL REPORT

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Introduction. Older people are often not provided with appropriate palliative care, and research has so far focused largely on younger adults, leading to a lack of understanding of the complex needs of older people with cancer and their family caregivers (ONS, 2007). Despite input from palliative care services, family members or friends are usually relied upon to provide major assistance with care in the home (Hudson et al, 2008a). In light of these and other factors, we set out to gain a more complete understanding of the experience and support needs of older family or other lay caregivers caring for an older partner, relative or friend with cancer at home. We also sought to evaluate the current role of formal health services in providing support for family members or other lay caregivers and to identify opportunities for working more closely with them to develop self-management and/or peer support strategies for palliative care and care towards the end of life.

Self-management is usually defined as people taking an active role in their own care. In this study the concept was also applied to the role of the family caregiver, and their contribution to the active management of their relative's condition and needs (Department of Health, 2004). Participants (people with cancer and their family or other lay caregivers) were all aged 65 years and over.

Our analysis of study data is helping to provide a more detailed model of the experience and support needs of older caregivers and their older relatives or friends with cancer. From the outset, the caregiver and person with cancer were approached as a single 'care partnership', or 'care partners' to reflect the reciprocal elements of the relationship.

Background. More than 50% of cancers are diagnosed in people aged 70 or over (Rosen et al, 2006), and ageing of the population is a major influence on the future need for cancer services (Edwards et al, 2002). As populations age, the number of individuals with chronic disease increases, as does the number with more than one chronic disease (Terret et al, 2009). One large American study found that 68.7% of cancer patients were diagnosed with at least one other chronic disease (Ogle et al, 2000). More than half of cancer deaths occur in people aged 75 and over (Cancer Research UK, 2010). One study conducted in Wales found that the increasing number of older people with cancer has led to a shift in place of death from the community to hospitals and care homes, and has led to a call for services for older people with cancer to be developed to meet this new level of need (Ahmad & O'Mahoney, 2007).

Despite age-related increases in cancer incidence, mortality and co-morbidity, and an expanding literature on the experiences of family caregivers of people with cancer and palliative care needs (see e.g. Thomas et al, 2010; Hudson et al, 2009; Hudson et al 2008a, 2008b), there continues to be little information about the palliative care needs of older people with cancer and their older family caregivers.

Despite the decrease in recent years in the proportion of people dying at home to around 22% (Gomes & Higginson, 2006), there are indications that until four weeks before their death, both people who die at home and people who die in inpatient settings spend a minority of their time (on average around 1.5 days per week or less) in inpatient care (Grande et al, 2003). The quality of care provided at home by family caregivers and others is therefore a major factor in the final year of life, irrespective of where people die. It is clear that with support from the health care team, family members and other lay caregivers are playing an increasingly important role in the provision of home health care (Stajduhar & Davies, 2005), either as a result of individual preference, or as a consequence of policy changes that encourage health care providers to manage patients in community settings (Rosen et al, 2006). The ability of family caregivers to cope with providing care at home, the risks of transferring responsibility, tasks and decision-making to family caregivers, and the importance of relationship-building for health care professionals and patients and caregivers in palliative care have all been highlighted as priority areas for further research (Stajduhar et al, 2008, 2010, 2011).

It is acknowledged that an increasing symptom burden does not prevent patients from adopting self-management approaches to maintaining quality of life and independence (McCorkle et al, 2011), and there is a developing body of work demonstrating the importance of lay knowledge and expertise in managing health care need in cancer and palliative care (e.g. Corner et al, 2005; Wright et al, 2006). Research, though, has yet to systematically learn from the experiences of older people caring for older relatives or friends with cancer. Despite the time that people with or affected by cancer spend at home towards the end of life, there is little evidence to show what self-initiated practical or social strategies are (or could be) used, what their value to the individual may be, or whether such strategies are recognised within current models of health care provision. In this study, we therefore talked to older people with cancer and their family caregivers to improve our understanding of need and how it is currently met, explore the practice of informal palliative care, and identify ways in which support for self-management may be more effectively managed and organised.

Peer education and support has been advocated as an approach to improving self-management in chronic conditions and as a means of improving well-being in older people (Sanders et al, 2006), and positive initial findings have recently been reported following the development of a peer education training programme in end-of-life care for older people and their carers (Seymour et al, 2010). The role of volunteers has also been positively evaluated (see e.g. Wilson et al, 2005). While few people with palliative care needs may currently receive support from volunteers (Emanuel et al, 1999), studies have shown potential benefits. Together with web-based resources to enable people to exchange information and personal experiences, which may have a range of positive effects including increased awareness about conditions, diagnoses and treatments, learning about living with cancer, social connections, support from others, and a means to tackle isolation (Roffe & Foster, 2005), peer education and volunteering offer

additional possibilities for supporting family or other lay caregivers with palliative care responsibilities.

Information from this study will help to lay the foundations for further work with stakeholders to develop new, or improve existing, interventions to support family and lay caregiving.

Study design and methods. In this 2-year longitudinal study, we used a combination of in-depth qualitative interviews and a structured measure of service use, taken and adapted from the Older Americans' Resources and Services Multidimensional Functional Assessment Questionnaire (OMFAQ) (Fillenbaum, 1988), to document and record the experiences of caregiving among older people with cancer and their partners or friends, all aged 65 years or over. In this way we were able to provide a detailed picture of the experience of caregiving, including met and unmet needs, the development and practice of lay expertise, and interactions with professional caregivers.

Interviews. We conducted a total of 55 in-depth interviews with 25 people with cancer and the partner or friend primarily responsible for providing care and support at home. All interviews were digitally recorded, unless participants requested the recording device to be turned off. Each person with cancer and their family caregiver was interviewed together on up to three occasions in their own home. A topic guide was used to ensure as far as possible that key issues were addressed consistently during the study (see Ritchie & Lewis, 2003). These included:

1. Background to care partnership
2. Health and illness trajectory
3. Current health-related needs
4. Self-management practice
5. Met and unmet needs
6. Peer support and e-health.

Opportunities were also taken to explore unexpected areas of interest that arose during interviews if they were relevant to the research aims and objectives.

Initial interviews were followed approximately 2-4 weeks later by a second interview. The third and final interview took place approximately 6 months after the first interview. In this way, we sought to gain an in-depth account of people's experiences of providing and receiving care and to explore changes over time. Interviews took place over a period of approximately 18 months, from December 2008 to June 2010. Overall, eleven (44%) people with cancer and their family caregivers were interviewed on three occasions, 8 (32%) were interviewed on two occasions, and six (24%) were interviewed once. The average length of first interviews was 90 minutes. Second interviews lasted an average of 108 minutes and third interviews an average of 123 minutes. In most cases, these figures include time taken to complete service use questionnaires, 48 of which were completed at the same time as in-depth interviews. Twenty-two sets of service use data were collected

during initial interviews, 16 during second interviews, and 10 during the final interview. On other occasions, service use questionnaires were omitted to avoid placing an excessive burden on participants.

Participants. Twenty-five pairs of participants, comprising one person with cancer and their nominated family or other lay caregiver gave written consent and were recruited to the study via community palliative care and district nursing teams over a period of approximately 12 months. The mean age of participants was 77.8 years (median 78 years, range 68-91 years).

People with cancer (i.e. care recipients) were considered eligible to participate in the study if they were:

- aged \geq 65years
- had a cancer diagnosis
- aware of their diagnosis
- receiving palliative home care/palliative day care services OR were on a GP-held Supportive Care Register
- living at home at time of enrolment to study
- able to nominate a family caregiver as co-participant
- an English speaker
- considered able to participate by a supervising clinician

Family or other lay caregivers were considered eligible to participate in the study if they were:

- aged \geq 65 years
- nominated by care recipient
- aware of the care recipient's diagnosis
- the family member (including significant others and close friends) who was providing the most care for the care recipient (and was not paid to do so)
- an English speaker

Overall, 17 (68%) care recipients were men and eight (32%) were women. Eighteen (72%) family caregivers or friends were women and seven (28%) were men. In 21 cases participants were spouses, in 3 they were partners and in one case, they were long-standing friends. The mean length of relationships, based on self-report, was 43.8 years (n= 21, range 9-67 years).

Participants (care recipients) reported a range of cancer diagnoses, including lung, prostate, gastrointestinal (oesophagus, pancreas and stomach), renal, bladder, head and neck and hematological tumours, and frequently also reported secondary cancers such as bone or lung metastases. Some family caregivers also reported having, or having had, cancers themselves.

Care recipients reported a wide range of symptoms, including pain, haematuria, breathlessness, cough, haemoptysis, oedema, sleep

disturbances, poor mobility, fatigue, weight loss, dysphagia, retching and vomiting, constipation, loss of appetite, panic attacks, anxiety, and low mood; self-reported comorbidities included diabetes, cardiovascular disease, COPD, infections, arthritis, and previous cancers.

Caregivers reported symptoms such as pain, breathlessness, poor mobility, sleep disturbances and anxiety, as well as comorbidities including diabetes, cardiovascular disease, arthritis and previous (or existing) cancers.

The individual circumstances of participants in the study varied widely, both materially and personally. For some, living space was restricted, with limitations on the extent to which modifications to the physical environment were possible, while for others living space was extensive enough to present its own problems in terms of maintenance and upkeep. It was not uncommon for participants to incur considerable costs through the private purchase of additional furniture or mobility aids. Participants' experience of morbidity and symptoms was such that in some cases, 'caregivers' were just as seriously affected as 'care recipients', blurring the boundaries between the two. For care recipients, concern for the circumstances in which their caregivers would find themselves in the future was often just as strongly expressed as the sense of loss anticipated by caregivers themselves. In these difficult and shifting circumstances, caregiving was approached with great commitment. At the same time, the cost of caregiving was apparent, both in the necessity of recognizing that illness was life-limiting, and in the self-denying work of providing intense and single-minded support for a partner or friend.

Indices of Multiple Deprivation (IMD). Indices of multiple deprivation were identified for the 25 households represented by the participants in this study to assess levels of relative deprivation in the sample. The English Indices of Multiple Deprivation are a method of measuring a broad concept of multiple deprivation comprising seven distinct domains: income deprivation, employment deprivation, health deprivation and disability, education skills and training deprivation, barriers to housing and services, living environment deprivation, and crime. These can be combined into a single overall Index of Multiple Deprivation, which can be used to rank every small area (around 1500 people) in England according to the deprivation experienced by the residents of that area.

Using the most recent (2010) version of the statistics provided by the Department for Communities and Local Government (Communities and Local Government, 2011), the 25 households in this study were ranked according to level of overall deprivation. This showed that 10/25 (40%) of households in the sample were located within the top 25% (least deprived) small areas in England; 4/25 (16%) of households were located in the top 25% (most deprived) small areas. Overall, 15/25 (60%) of households in the sample were located in the top 50% (least deprived) areas in England, and 10/25 (40%) were located in the top 50% (most deprived) areas. Households in this study were therefore located in areas with a wide range of levels of relative deprivation, from very low to very high.

Service Use. Service use data from the service use module of the OMFAQ (Fillenbaum, 1988) were collected following in-depth interviews with care recipients and caregivers, and then analysed descriptively using Microsoft Excel (© 2010 Microsoft Corporation). This included information on transportation, social and recreational services, mental health services, personal care services, nursing care, physiotherapy, supervision, checking services, homemaker-household services, meal preparation, and coordination, information and referral services.

24 questionnaires were completed in total by care recipients and 24 by family caregivers (n=48). Twenty-two pairs of participants completed the questionnaire at least once: ten of these (45.4%) completed the questionnaire on all three occasions, six (27.3%) completed it twice, and six (27.3%) completed it only once. These data help to provide a more detailed picture of everyday life for participants in this study.

Transportation. When asked how many trips they made on average each week using some form of transportation care recipients answered 'none' or 'less than one' on a total of 23/48¹ (48%) occasions; there were only four occasions (4/48, 8%) when care recipients indicated that they were making 4 or more rounds trips per week. In contrast, family caregivers answered 'none' or 'less than one' to this question on only 8/48 (8%) occasions, and '4 times a week or more' on 15/48 (31%) occasions. This suggests that care recipients, in particular, spent little time away from home, and it is worth noting that round trips reported included hospital and other health care-related travel. Moreover, while eleven of the 22 caregivers (11/22, 50%) who provided information said at some point that they had access to their own transport, only four care recipients (4/22, 18%) said that they did.

Social and recreational activities. Overall, 9 of the 22 (41%) care recipients and 10 of the family caregivers (10/22, 45%), who provided information indicated that at some point in the past six months they had participated in some form of planned social or recreational activities. Only three care recipients in total (3/22, 14%) and three family caregivers (3/22, 14%) reported participating in these activities more than once a week. Thus a minority of both care recipients and caregivers took part in planned recreational activities, and of those who did, few took part with any frequency.

Personal, family or emotional problems. No participants reported receiving treatment or counselling for personal, family, or emotional problems, although 2/22 (9%) caregivers indicated that they needed this kind of support. A minority did report taking prescription medicine for anxiety or depression (5/22, 23% care recipients; 1/22, 4.5% caregivers), although in some cases this was a long established practice. Qualitative data showing that some participants experienced care- or illness-related distress throw an interesting light upon these figures, and raise the possibility that carers

¹ No. of responses given in total, i.e. all questionnaires combined.

and/or care recipients may have a need for psychosocial support that is not fully accounted for in service use data.

Personal care. Seventeen care recipients (17/22, 77%) and one caregiver (1/22, 4.5%) indicated that they had received help with personal care (e.g. bathing, dressing, feeding, toilet care) at some point during the study. Eleven of the care recipients (11/17, 65%), and the one caregiver, identified unpaid family members as the sole source of this help, and in total fifteen care recipients (15/18, 88%) identified family members as one source of help alongside others including social care agencies. When asked how much time on average they received help with personal care per day, the most common response was 0.5-1.5 hours (17/30¹, 57%), followed by less than half an hour per day (7/30, 23%), and more than 1.5 hours per day (6/30, 20%). The time spent on personal care, in some cases more than 1.5 hours a day, and the proportion of care provided solely by a family member (65%), is worth emphasising here, given that in most cases the person in question was an older partner or friend, and that family members were also often identified as the sole source of support when care recipients needed someone to be with them all the time (see below).

Nursing care. Twenty of the 22 care recipients who provided service use data (20/22, 91%) indicated that they had received nursing care at some point during the study. In all cases, the source of nursing care was given as the NHS. Fourteen of these (14/20, 70%) reported that they received nursing care only occasionally (not every day) or received help with oral medicine only, although when asked for how long they had received nursing care, the most common response was more than three months (18/38¹, 47%), followed by one to three months (10/38, 26%) and less than one month (10/38, 26%).

Supervision and checking. Eleven (11/22, 50%) care recipients indicated at some point during the study that they needed someone to be with them all the time to look after them. In seven of these cases (7/11, 63%) family members were identified as the sole source of support. A further six (6/22, 27%), who did not indicate that they needed someone to be with them all the time, did however say on at least one occasion when responding to the service use questionnaire that they needed someone to check on them regularly (i.e. at least five times a week) by 'phone or in person to make sure they were alright. In each of these cases (6/6, 100%), family members were identified as the source of support.

Household chores. Twenty of the 22 care recipients who provided service use data (20/22, 91%) indicated that someone had to help them with routine household chores such as cleaning and washing clothes at some point during the study. Again it is noteworthy that for 14 of these (14/20, 70%), family members were identified as the sole source of support. For 18 care recipients (18/20, 90%) family members were either the sole source of support, or one of a number of sources including friends and social care

¹ No. of responses given in total, i.e. all questionnaires combined.

agencies. When asked how much time on average they received help with household chores per week, the most common response was at least nine hours (24/38¹, 63%), followed by less than four hours per week (7/38, 18%), and four to eight hours per week (6/38, 16%). Five family caregivers (5/22, 23%) indicated at some point during the study that they themselves needed help with routine household chores. Only one of these (1/5, 20%) identified family members as the sole source of support for these tasks.

Meal preparation. Eighteen (18/22, 82%) care recipients indicated at some point during the study that someone had to prepare meals for them because they were unable to. Nearly all of these (17/18, 94%) identified family members as their sole source of support with this activity. One other identified both family members and friends. One family caregiver (1/22, 4.5%) indicated that they also needed someone to prepare meals for them.

Systematic multidimensional evaluation. The OMFAQ includes an item on systematic multidimensional evaluation, which asks respondents if their overall condition, comprising their health, mental health and social and financial situation, has been reviewed recently by, for example, a doctor or a social worker. Only five care recipients (5/22, 23%) reported that they had been reviewed in this way at least once, together with two caregivers (2/22, 9%). One care recipient (1/22, 4.5%) and two family caregivers (2/22, 9%), who were not reviewed in this way, indicated that they thought it was something they needed.

Coordination, information and referral services. This item in the OMFAQ asks respondents if someone has provided them with information about the kind of help that is available to them or has put them in touch with someone who could help them. The majority of care recipients (21/22, 96%) and family caregivers (20/22, 91%) indicated on at least one occasion that they had received this kind of support. In every case (22/22, 100%) care recipients indicated that they had received this from health or social care agencies at some point, and in 17/22 cases (77%) this was the sole source identified. Similarly, 20/20 (100%) family caregivers identified health and social care agencies as one source of this kind of support, with 18/20 (90%) reporting this as the sole source. Qualitative data from the study suggests that it was often primary health care professionals who ensured that sources of support, or information about sources of support, were identified either to care recipients or to their spouses, partners or friends. While this suggests that assistance with mobilising sources of support was available, it is not clear from service use data alone if this support was the right kind of support, or how many of a variety of possible needs were addressed in this way.

Whilst most care recipients, and some caregivers, were visited by health care professionals at home, service use data as a whole show that older family caregivers themselves delivered significant amounts of essential personal care for their older partners or friends with cancer. For the

¹ No. of responses given in total, i.e. all questionnaires combined.

majority of care recipients, movement outside the home was limited, and for both caregivers and care recipients, participation in social or recreational activities was often infrequent. Family caregivers may themselves have been affected by long term or life-limiting conditions and associated symptoms. In this study, therefore, older family caregivers took substantial personal responsibility for the well-being of older partners or friends, and for the maintenance of households, against a background of increasingly restricted freedom of movement, particularly outside the home, and their own significant health concerns.

Qualitative data. The primary purpose of qualitative data collection was to identify key aspects of the experience of older caregivers caring for family members or friends with cancer, particularly their support needs when receiving palliative care. The 55 interviews conducted in this study provided in-depth, and in the majority of cases also longitudinal data: 19 of the 25 pairs of participants took part in at least two semi-structured interviews.

Our approach to data analysis was based on the process of microanalysis described by Strauss & Corbin (1998, 2008). In microanalysis, data are first examined and interpreted through line-by-line examination of participants' descriptions of relevant events. Events and actions are then classified into categories and sub-categories, and through a process of constant comparison of events and actions as they are identified in the analysis, the relationship between the different categories and their properties is established (Strauss, 1987). This relationship, which reflects the way in which key concepts in participants' accounts of their experiences are linked to form a whole, forms the basis of a theoretical explanation or model of the central phenomenon of the study, namely, the experience of family caregiving for older people with cancer.

The purpose of analysis was twofold:

1. To develop a model of family caregiving to inform understanding of the role of older people with cancer and their family members or friends in managing palliative care needs
2. To identify priorities for supportive interventions to enhance the experience of giving or receiving care, to be tested in future exploratory and definitive studies.

So far, analysis has highlighted a number of potential elements of a theoretical model of family caregiving. Using as a guide the framework described by Gibbs (2007) for structuring analytical codes into a model, we can tentatively say that a key causal condition of the experience of family caregiving is the sense of anticipated loss that affects caregivers and care recipients as a result of the illness confronting them. References to the nature of this loss are an important feature of the interviews, describing a situation in which the outcome of illness is acknowledged, but which also involves uncertainty and discomfort over timescale and the precise nature of unfolding events:

You know that one day she's not going to be here. (Caregiver, Ki1)

Life-limiting illness and its multidimensional consequences impose a series of requirements upon both caregiver and care recipient. A central, perhaps overriding, factor in shaping the way in which these requirements are fulfilled is the strong sense of obligation or duty felt by many family caregivers (as well as friends with this role) in this study. The force of this sense of duty is such that it appears to reflect a key aspect of individual identity:

I won't go and leave [spouse] because I look after him and nobody is looking after him but me. (Caregiver, Kg1)

Prominent among the requirements placed on caregivers and recipients are the following three categories:

- Care management
- Maintaining the household
- Relationships with health care professionals.

Care management represents a host of family caregiving activities, including those often carried out by social care staff, such as washing, dressing and meeting elimination needs, as well as those carried out by health care staff, including nurses, such as post-treatment (e.g. chemotherapy) care, managing and maintaining medical equipment (e.g. preventing blockages or malfunctions in urinary catheters or enteral feeding tubes and pumps), management and modification of dietary requirements, symptom management (e.g. pain, anxiety, breathlessness, sickness, constipation and/or diarrhoea), ordering, timing, administration and titration of medicines, and managing moving and handling needs, including falls:

It's such a problem getting him out to the toilet ... you've got to carry the bag, the bag gets in the way ... when you are trying to get out there, and he's got no strength. (Caregiver, Ka1)

The work included in this category extends to the management of hospital visits (e.g. for follow-up or treatment), transport needs, and comprehensive maintenance of records of care and treatment that in some cases were detailed and accurate enough to be used by health care professionals as part of assessment and decision-making processes:

You need that level of information and detail to be able to manage all of the demands effectively so you have to be very organised. (Caregiver, Kb1)

In the context of older age, and in the presence of multiple comorbidities, such daily caring tasks are in themselves demanding and often require a series of complex judgements and decisions. However it is perhaps the

strong sense of obligation and duty, taken together with the cumulative effect of numerous caring activities and responsibilities, that exerts the greatest influence on the experience of family caregiving, and comes to dominate everyday life.

Maintaining the household represents the work done not only in attending to the practical aspects of housekeeping, but also in preserving the sense of integrity and orderliness of a household or home. It refers both to the work of maintaining the internal equilibrium of a household through activities such as cooking, cleaning, washing, gardening, looking after pets, servicing, repairing, decorating and organising household contents, but also to activities that extend into a locality or neighbourhood, such as, for example, shopping, banking, collecting medicines and other goods, arranging services, and keeping appointments, that are an essential part of the work of keeping a household in good working order. Such activities may involve several phases of coordinated effort:

We can walk down to the bus stop ... and get a bus to [supermarket], and once we've loaded up, we get a taxi back ... so ... we don't actually carry bags on the bus... (Care recipient, Kf1)

We go to [supermarket], and we just get a few things there, things that we like, and we have a bag each... (Caregiver, Kf1)

They may also involve the caregiver in taking on an unaccustomed role:

[I] did the cooking ... or dusting [the] house and hoovering ... and launderette, and now, he has to do everything. (Care recipient, Ea1)

The work involved in maintaining the household, while often undertaken in part or in whole by care recipients or caregivers themselves, may also involve a process of negotiation to establish arrangements with other individuals, paid or unpaid, to provide household services. These include family members, friends, neighbours, people who have provided services in the past, or others (for example, shopkeepers or drivers). The process of negotiation can itself be seen as a form of work and may be both complex and difficult. It may need to be repeatedly undertaken, as is the case, for example, if an agreement with a shopkeeper to deliver goods is made through a series of one off, ad hoc arrangements, and it may involve the caregiver in convincing a provider to step outside the normal parameters of their role - as may be the case, for example, with a shopkeeper who does not offer a delivery service as standard, with someone who has been paid for one type of service in the past (e.g. gardening) but who is called upon to provide another (e.g. cleaning) now, or with a driver who is asked to make additional stops or to help with bags:

If we get a good taxi driver ... he'll stop outside and carry the bags to the front door, if you don't get a good taxi driver, he puts them on the grass. (Care recipient, Kf1)

Complex, repeated negotiations for the provision of goods and services, the necessity of splitting activities into several different constituent parts and of allocating joint or unaccustomed roles, and the frequent loss of a means of convenient transport outside the home, again in the context of increasing age and comorbidity, mean that activities directed at maintaining an orderly household often become a disproportionate and difficult regime for caregiver and care recipient alike.

Relationships with health care professionals played an important part in shaping the experience of family caregiving in this study. Spontaneous, sociable gestures by health care professionals were highly valued, and appeared to be perceived as going beyond expected professional boundaries:

When we had [bad weather] ... the phone rang ... it was [name] our doctor ... I am phoning up ... to see are you alright ... isn't that wonderful ... how many doctors ... would do that? (Caregiver, Kg1)

Care recipient: *...the doorbell rang ... so I answered the door and he came in and he said I've just come to check on you to see how you are...*

Caregiver: *He just came, which is good. (Kh1)*

In the following example, the speaker seems to find the relationship with the hospital consultant comfortable and sustaining (he refers to it elsewhere as a 'tonic') because professional boundaries have been relaxed ('he is one of you') and there is no fear of blame or criticism ('without fear ... I have said the right things'):

When you go to see him he is not ... very formal ... he is one of you ... can talk to him quite easily, no fears at all ... his team are as good as well ... the team you can talk to quite easily, without any fear of have I said the right things. (Care recipient, K11)

Relationships with health care professionals were complex and sometimes difficult, however, and played a varied part in shaping experience. Participants were sometimes involved in lengthy dialogues with clinicians which they felt should help resolve important existential or biographical questions, but were unable to move forward through this channel:

Care recipient: *I find it very frustrating that I ask ... questions ... and I get ... don't know...*

Caregiver: *...they are very nice and they say ... go away and live your life ... how can you live your life ... you can't plan anything. (Kb1)*

Caregiver: *...it just came ... out of the blue, go there for one thing and then come back finding something else ...*

Care recipient: *The ... advice we got, carry on as normal ... Now what ... is normal? (Ko1)*

In the same way that *care management* or *maintaining the household* represent a form of work on the part of people with cancer and their family caregivers, *relationships with health care professionals* have to be worked at, through a series of negotiations that may not always establish common ground.

Hospital appointments provided a sense of being watched over, but could also be experienced as inconclusive:

You felt as though you wanted to ... keep in touch, keep ... track of how it goes or how it progresses, although I don't suppose they will do anything. (Caregiver, Kn1)

They could be occasions when 'caregiver' became 'care recipient', and vice versa, if, for example, caregivers attended their own hospital appointments accompanied by their partner:

And what works us up is if [spouse] gets the late appointment like that ... we had to go back the next day [to collect medicines] ... it's not really great news when you are not 100% yourself ... but that's how it is ... if you get a late appointment ... it puts you on edge... (Care recipient, Kd1)

Time spent waiting for appointments could itself be a source of heightened uncertainty and discomfort, emphasising the precariousness of people's situations:

... you don't know what is going to happen ... you don't know what they are going to do and what's going to happen. (Care recipient, Kh1)

Outpatients' appointments were sometimes therefore both stressful and exhausting, and it was a relief, for some, not to have to continue to attend:

Very, very stressful it was ... for me personally ... I came back absolutely washed out. (Care recipient, Ka1)

For people in this study, relationships with health care professionals were part of the shifting ground of their everyday experience. Such relationships were sought after because they provided a source of support, which was particularly valued if it was offered in a way that suggests a kind of unconditionality; but they were also sources of feelings of heightened precariousness and apprehension:

That's been such a trauma, getting him to hospital. (Caregiver, Ka1)

In some cases, if important questions cannot not resolved through established routes, the work of keeping up relationships with health care professionals may itself become part of a burdensome schedule of daily activities.

A model of family caregiving. Day-to-day life for caregivers and recipients was shaped, in the broadest sense, by a powerful sense of anticipatory loss. At a more detailed level, day-to-day life is structured by the demands of care management, maintaining the household, and relationships with health care professionals. The effect is to put caregivers, in particular, who already experience a strong sense of duty and loyalty to 'be there' and 'do', at the centre of many converging lines of responsibility:

If I was not here to coordinate everybody there would be a problem ... in order to keep things going smoothly it has taken more time than I expected to try and get things coordinated. (Caregiver, Rd1)

The central, defining effect of these criss-crossing lines of duty and responsibility, which helps to explain what day-to-day life is like at this focal point, is to require each day to be strictly scheduled or timetabled to accommodate them:

I mean it is only since the [illness was identified] that the calendar is so full ... every day has got something written down on it ... doctors' appointments or having to go for a scan or something else ... every square is full up for one reason or another and most of them are connected one way or another with [spouse]'s health. (Caregiver, Kn1)

Keeping to such a disciplined and focused timetable over an uncertain timescale requires great strength and determination. It rests upon, and is mediated by, the relationship between caregiver and care recipient, and in particular upon a sense of duty and loyalty to spouse, partner, or friend:

I'm just glad I'm here for him ... and I'm strong enough to look after him... (Caregiver, Ka1)

Converging lines of caregiving responsibility have the effect, as indicated above, of requiring day-to-day life to be scheduled according to a strict timetable of health-related activities. As a consequence, the focus of daily life is upon an increasingly tightly bounded physical, functional and emotional space, more particularly as movement outside the home becomes more difficult, not only for care recipients, but also for caregivers, who may be unwell or lack mobility themselves and may not have access to independent means of transport.

At times, the intensity of this experience, in which physical, functional and emotional demands are highly concentrated and condensed, is hard to accommodate. Understandably, therefore, day-to-day life can be experienced as both stressful and distressing, like being on a 'treadmill':

You have to live with that hardship ... so I try to manage ... I was not ready ... and [in addition to] that, this pressure, and that pressure... (Caregiver, Ea1)

In these circumstances, the priority for intervention is to identify a means of providing support in a way that is consistent with the underlying model of the caregiving experience.

Summary and recommendations. Data from this study suggest that the experience of family caregiving is characterised by a sense of anticipated loss in the context of which ties of duty and loyalty exert a strong influence. Arising from this central experience are a range of caregiving strategies, notably care management, maintaining the household, and negotiating relationships with health and social care professionals, that focus on achieving a sense of equilibrium or containment across physical, functional and emotional domains. The desire to keep up with the responsibilities of caregiving, sometimes undertaken alone or in the context of a contracting circle of social contacts, leads to a careful scheduling of day-to-day life. Maintaining a sense of good governance within this concentrated and condensed physical and metaphysical space can be difficult, and may lead to a sense of being overwhelmed by the number and force of the demands experienced.

The responsibilities of caregiving, which are freely entered into and are often the unassailable token of shared lives and feelings, can sometimes be too great. In these circumstances, supportive interventions should focus on providing relief from the difficulty of accommodating and containing the full range and number of caregiving demands, and the tendency towards an increasingly tightly boundaried day-to-day life. Alongside, and building upon, existing health and social care services, which provide valuable guidance and support, there is also a need to offer new (or facilitate access to existing) socially oriented and community-focused contacts to provide caregivers and/or care recipients with an opportunity to step outside the day-to-day schedule of accommodating physical or functional challenges and containing stressful situations. Work is currently continuing in the Faculty of Health Sciences to refine the model of family caregiving and bring forward proposals for testable interventions, through further stakeholder consultation, conference presentations, and publications.

References

- Ahmad S, O'Mahony MS (2007) Shift in the burden of cancer towards older people - a retrospective population-based study. *International Journal of Clinical Practice*, 61, 6, 931-936.
- Cancer Research UK (2010). *Cancer mortality by age - UK statistics*. [<http://info.cancerresearchuk.org/cancerstats/mortality/age/>] (accessed 2 May 2011)
- Communities and Local Government (2011) *The English Indices of Deprivation 2010*. [<http://www.communities.gov.uk/publications/corporate/statistics/indices2010>] (accessed 8 April 2011)
- Corner J, Hopkinson J, Fitzsimmons D, Barclay S and Muers M (2005) Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. *Thorax*, 60, 314-319.
- Department of Health (2004) *Improving Chronic Disease Management*. [<http://doh.gov.uk>] (accessed 14 January 2011)
- Edwards BK, Howe HL, Ries LA, Thun MJ, Rosenberg HM, Yancik R, Wingo PA, Jemal A and Feigal EG (2002) Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on U.S. cancer burden. *Cancer*, 94(10):2766-2792.
- Emanuel EJ, Fairclough EL, Slutsman J, Alpert H, DeWitt B, Emanuel LL (1999) Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine*, 341(13), 956-963.
- Fillenbaum GG (1988) *Multidimensional Functional assessment of Older Adults*. Lawrence Erlbaum Associates, Hillsdale, New Jersey.
- Gibbs G (2007) *Analyzing Qualitative Data*. Sage Publications Ltd, London.
- Gomes B, Higginson I (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, 332(1012), 1012.
- Grande GE, McKerral A, Addington-Hall JM & Todd CJ (2003) Place of death and use of health services in the last year of life. *Journal of Palliative Care*, 19(4), 263-270.
- Hudson P, Quinn K, Kristjanson L, Thomas T, Braithwaite M, Fisher J, Cockayne M (2008a) Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliative Medicine*, 22, 270-280.
- Hudson P, Quinn K, O'Hanlon B, Aranda S (2008b) Family meetings in

palliative care: multidisciplinary clinical practice guidelines. *BMC Palliative Care*, 7:12.

Hudson P, Thomas T, Quinn K (2009) Family meetings in palliative care: are they effective? *Palliative Medicine*, 23, 150-157.

McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, Wagner EH (2011) Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA A Cancer Journal for Clinicians*, 61, 50-62.

Ogle KS, Swanson GM, Woods N, Azzouz F (2000) Cancer and comorbidity: redefining chronic diseases. *Cancer*, 88(3), 653-663.

ONS (Oncology Nursing Society & Geriatric Oncology Consortium) (2007) Joint position on cancer care for older adults. *Oncology Nursing Forum*, 34(3), 623-624.

Ritchie J, Lewis J (Eds) (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Sage Publications Ltd, London.

Roffe L and Foster C (2005) *Sharing Experiences of Cancer Online*. Macmillan Research Unit, University of Southampton.

Rosen R, Smith A and Harrison A (2006) *Future trends and challenges for cancer services in England: a review of literature and policy*. King's Fund, London.

Sanders C, Seymour J, Clarke A, Gott M and Welton M (2006) Development of a peer education programme for advance end-of-life care planning. *International Journal of Palliative Nursing*, 12(5), 214-223.

Seymour J, Kennedy S, Froggatt K, Almack K, Clarke A, Sanders C (2010) A training programme for volunteer peer educators in end of life care education for older people. *Palliative Medicine*, 24, 208.

Stajduhar K, Davies B (2005) Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine*, 19, 21-32.

Stajduhar KI, Martin WL, Barwich D, Fyles G (2008) Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing*, 31(1), 77-85.

Stajduhar K, Funk L, Jakobsson E, Ohlen J (2010) A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving. *Nursing Inquiry*, 17(3), 221-230.

Stajduhar KI, Funk LM, Roberts D, Cloutier-Fisher D, McLeod B, Wilkinson C, Purkis ME (2011) Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research*, 21(1), 117-

131.

Strauss AL (1987) *Qualitative Analysis for Social Scientists*. Cambridge University Press, Cambridge.

Strauss A, Corbin J (1998) *Basics of Qualitative Research*. Sage Publications, Thousand Oaks.

Strauss A, Corbin J (2008) *Basics of Qualitative Research*. 3rd Edition. Sage Publications, Thousand Oaks.

Terret C, Castel-Kremer E, Albrand G, Droz JP (2009) Effects of comorbidity on screening and early diagnosis of cancer in elderly people. *Lancet Oncology*, 10(1), 80-88.

Thomas K, Hudson P, Oldham L, Kelly B, Trauer T (2010) Meeting the needs of family carers: an evaluation of three home-based palliative care services in Australia. *Palliative Medicine*, 24(2), 183-191.

Wilson DM, Justice C, Thomas R, Shepsy S, MacAdam M, Brown M (2005) End-of-life care volunteers: a systematic review of the literature. *Health Services Management Research*, 18, 244-257.

Wright DNM, Hopkinson JB, Corner JL and Foster CL (2006) How to involve cancer patients at the end of life as co-researchers. *Palliative Medicine*, 20, 821-827.