Evaluating family support needs of people using Strathcarron Hospice services

Dr Liz Forbat
Dr Erna Haraldsdottir
Elaine McManus

The University of Stirling is recognised as a Scottish Charity with number SCO 11159
Strathcarron Hospice is recognised as a Scottish Charity with number SC0 06704

Title	Evaluating family support needs of people using hospice services
Authors	Liz Forbat, Erna Haraldsdottir, Elaine McManus.
Publication date	2010
Publisher	Cancer Care Research Centre (CCRC)
Place of publication	University of Stirling
Funded by	Strathcarron Hospice
Target audience	Strathcarron Hospice, service developers, palliative care service users
Description	This report presents the findings of a study which set out to identify the supportive needs of family members using Strathcarron Hospice
Contact details	CCRC Tel: 01786 849260 Email: elizabeth.forbat@stir.ac.uk

Acknowledgements

Executive summary

- Over two-thirds of cancer patients are cared for by two or more close relatives (1998), however, there are substantial gaps in the provision of supportive care.

- An interview study with 16 family members of people supported by Strathcarron Hospice was conducted to identify the support needs of families when someone is receiving palliative care from Strathcarron Hospice.

- Participants described the demanding role of being the main family carer and how this can at times be overwhelming and stressful.

- Many interviewees were not provided the information they needed to help them to cope with the responsibility and new experiences which come about in their role as a carer prior to accessing Strathcarron Hospice services.

- Relationships with healthcare professionals within the general healthcare system were often difficult and family members often felt taken for granted. Those interviewees who were also trained as nurses or worked in healthcare felt considerable role conflict from this duality.

- Healthcare professionals were not thought to provide adequate support, on the whole, for family members. Strathcarron Hospice's services, however, were considered to stand out somewhat from this pattern and participants reported feeling supported by the Hospice.

- Out of hours support was considered inadequate, with difficulties in accessing specialist support from NHS24, and limited knowledge of the role that the Hospice could have out of office hours.

- Family members readily identified the ways in which a palliative diagnosis impacted on them, not just the patient. Thus, there is a need to understand the entire context in which people experience and make sense of their illness, and particularly their interconnectedness and interrelationships with others.

- For many interviewees, there was a sense of a growing difficulty in relationships as a consequence of the multitude of changes which had occurred as a consequence of the illness.

- Unpaid carers were drawn into supporting a range of other family members. However, families often experienced considerable difficulties in communicating with each other, and received no support to facilitate this.

- Despite participants all having a relative who had been diagnosed with a life limiting condition, very little mention was made by interviewees of death or dying.

Key recommendations include the following points of action for Strathcarron:

1. Continue to adopt a systematic approach to assessing the needs of family members in relation to both practical and psychosocial support.
2. Facilitate access to external agencies which can provide specialist family therapy support to ensure that families are supported in processing the wider implications of the disease, and prevent complicated grief reactions in the future.
3. Offer education to healthcare professionals which draw on this study's findings regarding the impact of a life-limiting diagnosis on the wider family system.
4. Support primary care services to stay involved with families who are accessing specialist palliative care, and ensure that family members are informed of the likely disease progression and how to access out-of-hours support.
5. Conduct further research regarding the ways families talk about death and dying.

Table of contents

1   Background

1.1   Family functioning and life-limiting conditions

Over two-thirds of cancer patients are cared for by two or more close relatives (Ramirez et al., 1998), however, there are substantial gaps in the provision of supportive care (NCRI, 2004) for family members and the treatment of both the disease and the family (Hubbard et al., 2007; Kearney et al., 2007). The impact on family members of caring is vast; more than three-quarters (76%) of people looking after an ill, frail or disabled relative do not feel as though they have a life outside of their caring role (Help the hospices, 2010). The majority of research has sought to evidence the psychological impact of cancer, such as depression and anxiety, on spouses and children (Edwards and Clarke, 2003).

Developing appropriate supports for the family must be based on quality evidence about what happens when someone receives a diagnosis of a life-limiting condition. To date, limited research has explored the change in family relations during palliative care for bereaved relatives. Where research has focused on relationships in cancer care, it has typically been focused on spouses (Bakas et al., 2001), particularly partners of women with breast cancer (Thomas and Morris, 2002), daughters (Wellisch et al., 1992) and siblings of children with cancer (Madan-Swain et al., 1993). Such work has tended towards quantifying relationships (Persson et al., 2008; Wennman-Larsen et al., 2009), focusing on distress and describing bereavement (Grassi, 2007).

Thus, while previous studies have looked at the impact of palliative care on family members, these have often adopted quantitative methods (Payne et al., 1999) and do not focus on the family as the unit of analysis. Studies which have explored impact on family members have treated them individually, not seeing palliative care as impacting on relationships, but on individuals. This individualistic approach sits at odds with viewing relatives as part of the whole family system. Studies have therefore rarely considered how family members influence how supportive services are used (e.g. the uptake of home care services), or how services are perceived within the family system.

Rolland's (1994) 'Family Systems Illness Model' theorises systemic approaches to supporting families where an individual has an illness or disability. The model provides a framework for considering the multiple ways in which families may be impacted upon by ill-health, and suggests ways of navigating these changes. The model integrates belief systems about illness (which may be held at an individual, family, social or cultural level) with individual and family scripts and life-stages. Each of these is intimately connected with the illness experienced, and whether this is progressive/degenerative, relapsing/remitting, or chronic. Rolland's (2005) model has been described in relation to cancer, identifying in particular the need to consider life-cycles and belief systems as specific contexts for understanding the impact of serious illness on families.

As well as providing a framework for therapeutic work, Rolland (1994) suggests that life-limiting or life-threatening illnesses can instigate change at a relational level. He surmises "a serious health crisis can awaken family members to opportunities for more satisfying, fulfilling relationships with each other" (p10). A systemic understanding of illness suggests that cancer may precipitate centripetal and centrifugal forces (Rolland, 1994). Centripetal forces draw

family members in toward each other, and may take place at the onset of illness or during a phase of acute exacerbation; centrifugal forces, by contrast, are those which create distance between family members, and which may occur during chronic phases of the condition. Thus, relationships within the family can be affected by the disease's progression at a number of points, and not just be located during periods of dying and bereavement.

The needs of families will alter as a consequence of the course of the illness. Though not all life-limiting conditions have a clear medical trajectory, the work by Murray et al. (2005) in cancer, frailty/dementia, and organ failure has begun to map out likely courses of disease progression. Different disease courses (e.g. as described by Rolland as relapsing/remitting or chronic, etc.), set a precedent for differently tailored approaches to supporting families during palliative care. Organ failure and frailty/dementia are, for example, described by Murray et al. as having a range of peaks and troughs of functioning across the length of the disease (with consequent predicted patterns, then, of movement between centrifugal and centripetal impacts on relationships for many years prior to death). These disease pathways can be compared with the cancer trajectory which is characterised by a long period of high functioning with a rapid drop-off toward death, which might then have a less complex relational pattern in centrifugal and centripetal forces.

There is an increasing groundswell of work marrying medical research and systemic/family supportive care in palliative services (Ballard-Reisch and Letner, 2003; Mehta et al., 2009). Changes to family functioning have also been explored using a family-focused grief therapy intervention in a oncology palliative care population (Kissane et al., 2003). The investigators use the Family Relations Index to identify families who have adaptive and maladaptive relating styles, and report high levels of psychosocial morbidity associated with worsening family function. Specific typologies of family functioning are identified as related to poor outcomes, such as conflict, poor cohesion and limited expressiveness (Kissane et al., 1994). Such relating patterns result in significantly higher levels of psychological morbidity and poorer social functioning for family members. The authors identify the potential for the development of preventive interventions provided for families most at risk.

Other studies echo Kissane's findings, and have shown that poorer family/social networks are related to higher rates of disease progression and rates of death (Funch and Marshall, 1983; Reynolds and Kaplan, 2008). Indeed, survival has been linked to marital status, whereby people who are married have better outcomes than those who are single, divorced, widowed or recently separated (Sprehn et al., 2009). These results indicate that supporting family relationships from the point of diagnosis through the disease's progression has important impacts, not only on quality of life, but also on mortality.

1.2 Policy context

Family members play a vital role in caring for those who have long-term illnesses and their contribution is crucial to both patients and society. This recognition of carers is reflected within current health care policy emphasizing increased community care for those with long-term conditions (Scottish Government, 2008). Family members, caring for their relatives, both provide and need support. Recognition of their role and support needs should be seen as an important part of health care delivery (Harding and Higginson, 2003) and has been integrated into policy for over a decade (Department of Health, 1999).

The World Health Organisation (2004) sets out a definition of palliative care which includes a need to offer a support system to help the family cope during the patient's illness and in their own bereavement. This definition is reinforced with health policy (2008), as laid out in *Living and dying well* (Scottish Government, 2008), which emphasises a need to focus on the quality of life for both patient and family members. The action plan focuses on the need for reviews and assessments when there is a changing ability in the unpaid carer's ability to cope.

The Scottish Government has identified the need to provide services to support the physical and emotional needs of unpaid carers. Across Scotland, Local Authority expenditure on respite and support for unpaid carers varies between 1% and 20% of community care budgets (Scottish exec, 2006). Despite this financial investment and their valorised position in policy, research (Scottish Executive, 2001) shows that 75% of carers are unclear/do not know of available support services.

Improving service delivery indicates a number of areas where improvements to supportive services would benefit carers (Audit Scotland, 2009). Out-of-hours support, respite/short breaks, and support around/following bereavement are highlighted as particular areas where carers are under-supported. Out-of-hours support affects family members as the weight of responsibility rests on them to co-ordinate beyond 9-5 hours. Audit Scotland (2009) reported that respite and short breaks are rarely used, despite their ability to give necessary time-out for recuperation for family carers. Finally, a lack of specialist psychological support is cited by the report to explain the lack of adequate support around bereavement.

1.3   Service context

Strathcarron is an adult hospice, supporting people with life-limiting conditions. It is located in Denny, Stirlingshire. It serves Central Scotland communities throughout the NHS Forth Valley area including Stirling and Falkirk, and Cumbernauld and Kilsyth in NHS Lanarkshire. It covers a total of over a third of a million people. It has three levels of service: at home (a nurse-led service), a 24 bed in-patient unit, and day services, and is served by a multi-disciplinary team.

2 Methods

2.1 Research Question

What are the support needs of families when someone is receiving palliative care from Strathcarron Hospice?

2.2 Sample

The sample was identified by using a systematic sampling technique. This has been described as a superior method to random and opportunity sampling, due to its ability to ensure rigorous approach to identifying potential participants (Babbie, 2008). The Community Clinical Nurse Specialist caseload was identified, which includes a total of 289 patients. Patients were arranged chronologically by date of admission to the Hospice service and consecutively allocated numbers 1–5. Every fifth patient was selected and clinical advice was taken regarding whether an invitation to participate was appropriate. This method ensured that people who were recently bereaved were not approached. Where contact was not appropriate the previous patient (i.e. the fourth) was selected. This procedure was conducted three times in total.

In total, 141 letters were sent to family members of people using Strathcarron Hospice, resulting in 16 interviewees. In the first round, 57 patients were identified, and letters were sent out to their next of kin, which translated to nine responses. In the second round, 54 patients were identified, and this translated to five carers responding. At the third and final round, 30 patients were identified and two carers responded.

This sample size of 16 is considered adequate (Guest et al., 2006) to achieve data saturation (that is, the point at which no further new information arises from further interviews) in the context of qualitative analysis of the data.

Inclusion criteria
The principle inclusion criterion was individuals who were the relative of someone using Strathcarron Hospice's community and day care services. This focus on out-patients is in recognition of the different stage of illness of those using in-patient services, and the different level of service provision for in-patients. The majority of the Hospice's service users are on an out-patient basis, so focusing the study on this population was felt to address the needs of most users.

Second to this, potential participants should be able to communicate verbally in English. Though we recognise this second criterion may have excluded some respondents, due to the small-scale and restricted funding of the study there was no capacity to pay for the translation of materials or interpretation of interviews.

Finally, participants were also required to give written, informed, consent.

Exclusion criteria
Family members of patients recently referred for palliative care were excluded. The Hospice operates with a time-lag of approximately four weeks between referral and receipt of services.

Recruiting people in this time frame will not give an accurate reflection of people's experiences of the support provided and therefore these individuals were not invited to participate.

148 patients were excluded due to:
> Being a current in-patient
> Patient lives alone, no family/carer living locally
> Moving away from area
> New patient (not yet visited)
> Last days of life/died
> Clinical notes unavailable
> Patient was discharged

2.3   Interview topic guide development
Interview schedules were developed with input from Hospice staff, family members of Hospice users (not those using Strathcarron Hospice) and the academic partners.

2.4   Procedure
Following identification of the sample (as outlined above) an information sheet and invitation letter outlining details of the evaluation were sent to potential participants. The letter was addressed to "The family of [patient name]" so that the family members themselves were able to decide who was best placed to take part in the interview.

Potential participants were given one week to consider their involvement, and were asked to alert the Hospice if they were interested in taking part. A follow-up letter was sent as the minimum sample size was not achieved in the first round of invitations.

Process-informed consent was gained from participants. That is, consent was not considered a one-off event at the beginning of the interview, but was a topic which was returned to throughout the conversation to check that the participant was happy to continue with the interview.

The interviews were conducted by four experienced palliative care professionals who are Hospice staff (including two nurses and two educators). Interviews were conducted in the family members' home or the Hospice, or another location of their choice.

The use of Hospice staff to conduct interviews with service users had the potential to introduce some interview bias into the process, which was controlled for by: a) training of staff interviewers, b) not having staff interview people on their own caseload, c) debriefing of interviewers with Principal Investigator, d) clear statements for participants about the use of data not affecting their care, and e) audio-recording of interviews to enable analysis by the independent academic partner.

2.5   Ethical considerations
Ethical approval was granted by Fife and Forth Valley NHS ethics committee.

Talking about experiences of palliative care and supportive care needs was considered potentially distressing for family members. Interviewers all work within a Hospice and were familiar with the issues that arose and confident in handling them sensitively. People participating in the study were offered support by the Hospice, and also given the phone numbers of Cancerbackup, an independent support organisation in case the interview raised any issues which participants required additional support for. The evaluation team was led by an experienced researcher (LF) who has conducted a range of studies on sensitive topics.

To protect the anonymity of respondents, identifier numbers have been used throughout this report in place of names, and all other identifying details have been altered.

2.6   Analysis

Qualitative data was analysed inductively and thematically, assisted by the use of NVivo, a computer package for organising qualitative data. Transcripts were read and re-read and organized according to themes and classifying patterns which provided order to the data set. Sub-themes were then identified and the data further classified. This thematic, data-driven analysis drew on the approach discussed by Braun and Clarke (2006), which is informed by a position of theoretical freedom and flexibility. The rigour of the analytic process was augmented by drawing on two other members of the research team in group analysis of the data corpus and team discussion around individual transcripts. Within this team context the identified themes and patterns were further theorized to draw implications about their meaning and implications on service development.

The data were then further investigated, applying more fine-grained analysis drawing on constructionist and systems theory framework. This provided clear connections between the study data and the practice of family support (e.g. through family therapy theory).

Issues of validity have been long debated in relation to qualitative data, and how this sits in the context of the dominant quantitative positivist paradigm. As Huberman and Miles (2002) indicate, the core criteria for qualitative validity is that of 'descriptive validity', that is: "the factual accuracy of their (participants') account – that is, they (researchers) are not making up or distorting the things they saw and heard" (p45). Second, interpretative validity, as "a matter of inference from the words and actions of participants" (ibid., p49), that is to say the interpretation fits with the inferred intended meaning of the participants.

2.7   Service user involvement

This project involved family members of people who have used hospice services as advisors to the study. This rationale sits within the patient focus and public involvement policy directives and best practice in research:

> "It is essential that health research reflects the practicalities of care delivery. To that end, relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research." (Scottish Executive, 2006 p9)

Relatives of people who used hospices services helped to develop the interview questions.

3   Results

16 family members were interviewed (an overview of interviewees is presented in the appendix). Several overarching themes were identified in the data and are presented in the subsequent section, focusing on the experience of being a carer, access and uptake of support, relationships at the end of life and preparing for death.

3.1   Experiences of being an unpaid carer

3.1.1 The intensity of being an unpaid carer

Study participants spoke about the demanding role of being the main family carer, and how this can at times be overwhelming and stressful. Interviewees clearly demonstrated the constant pressure they are under as carers. One interviewee described the situation as 'a massive responsibility and every day being a bit of a struggle' (7); another felt a sense of having a breakdown (2). The burden of care was evident in nearly all interviewees' accounts, reflecting feelings of constant pressure and never being able to switch off (1). A woman looking after her husband with a neurological condition which meant she could not leave him out of sight, even when in the house, said:

> *"The hardest things about caring for someone with this illness, apart from the fact it's pretty devastating illness erm… you don't really relax." (8)*

Caring for a relative demands much time and energy being dedicated to the caring role. This was evident in many interviewees' accounts reflecting how their quality of life was affected as they had very limited time for themselves.

> *"I have been in my parents' house every single day looking after my dad, I feel like this has taken over my life."* (1)

> *"The hardest thing about being a carer is never having time to yourself, it's constant."* (4)

> *"I just want to do what everybody else does, I don't ever get that option."* (1)

The on-going pressure of being a carer and lack of ability to 'switch off' and have 'time out' either physically or mentally was reflected by many of those interviewed. The difficulty of having a mental break was particularly evident in an account from a woman who had been looking after her sister with advanced MS for a number of years:

> *"Although I actually go away home and I don't live that far from my sister actually, I don't know if it is a good thing or bad thing but I don't completely switch off sometimes … I go home and dream about her, you know, I dream about things going wrong, I dream, I worry, I worry."* (12)

For most participants, being a carer had become interwoven into their life and dominated their whole life experience.

3.1.2 Unpaid carers' need for information

Many interviewees spoke about how they were not provided the information they needed to help them to cope with the responsibility and new experiences which come about in their role as a carer prior to accessing Strathcarron Hospice services. Many interviewees' accounts reflected clearly a lack of communication. A mother who was looking after her son, in his early twenties who has lymphoma, spoke strongly about the lack of recognition of her information needs as a carer:

> *"I was just at the end of tether cause I just didn't know what was going on or the doctors they did not want to tell us anything, they just said 'Och, he is fine, he will get through it,' and I mean I know they deal with it every day and different things but I thought this has not happened to them, it's happening to me."(14)*

Lack of acknowledgement of carers' information and support needs was also reflected in an account from a man looking after his wife who had cancer, whilst he praised the care related to the treatment his wife had at the oncology centre he said:

> *"Doctors tend to talk to the patient … they don't tend to talk to the carer or the partner or the person looking after them … the carer is never supported ... Nobody ever asks you ... nobody sees the carer."* (5)

Despite the massive responsibility carers take on when looking after their relative, many of them were not included into the overall care. Many felt they lacked involvement in decision-making, as evidenced in an account of a woman looking after her husband with COPD:

> *"There was no after-care plan. My husband was sent home to me and I didn't know what to do with him … The doctor said to my husband, 'How far can you walk?' and he says, 'Oh, I can walk such and such,' and that is not realistic. They say to him, 'Can you do this?' and 'How do you do that?' and he says, 'Yeah, I can do that,' and then he came home and he couldn't do it."* (4)

In some instances there was a lack of dialogue between healthcare professionals and the family carer, often causing much distress to the family member trying to cope with decisions from health care staff.

> *"I had to take him to a hospital appointment back in July. To this day I don't know how I got my dad to hospital and I only took him because [consultant] secretary phoned me the day before and said [consultant] wanted to see him … I said, 'Why are we here?' and he said, 'I wanted to review your dad.' I didn't ask for appointment, as far as I am concerned he is end of stage he will be nursed at home."(1)*

3.1.3 The carers' role

Many interviewees spoke about healthcare professionals within the generalist healthcare setting who did not recognise the stress family members may be under as a result of their relative being ill. They reported healthcare professionals' expectations that a family member would take on the role of being the main carer without any discussion or guidance:

> "*It was like the doctor assumed I would take this responsibility and that responsibility and I again I feel they sort of a … not twist it because they don't do it intentionally but it is assumed you will do it because you are the next of kin … you are the one that's in the house.*"(4)

There was evidence that carers were expected to 'get on with it' without much recognition of the negative psychological impact the caring role may have on them:

> "*I didn't feel great it was just like a, 'get on with it' thing situation. Just take the chemotherapy and get on with it. So that was quite upsetting.*" (14)

There was also evidence that carers did not want to complain about care being a burden, yet accounts clearly described this kind of feeling:

> "*I am not doing it with a complaint... you know it's my mum ... I am happy to do it for her, but ... I can't cope with it … sometimes I can and sometimes I can't and sometimes I find it very frustrating.*" (7)

There was evidence that for some carers 'getting on with it' was their only option despite the situation being 'frustrating and depressing' (7). However, this also caused some carers to be under more stress than they could even recognize themselves.

> "*At first you think I will do it I can cope with this … and you just keep going, as you do, you don't realise what you are doing until you stop doing it … you just get into it gradually, don't you, and then gradually you are doing more and more and more.*" (8)

Carers play a vital role in looking after the patients and take on substantial responsibility. Despite this they are invisible within the healthcare system and meet a 'taken for granted attitude' that undermines the stress and strain they are under.

3.1.4 Role conflict

The carer literature is replete with studies that identify a critical tension between being a spouse and being a carer, with variations on the phrase 'I'm not a carer, I'm his wife' being widely reported. This was a theme within the data in this study:

> "*I think my husband sees me as a carer and I can't remember what I said once but when he answered me I said, 'Excuse me, I am your wife first and then your carer!'*" (4)

In many ways, the family members become professionalised in their relationship, acting as an intermediary between the patient and services. Care co-ordination was a key part of some family members' roles. The following interviewee highlights this issue, from her position as both a daughter and a nurse, where she found her professional identity began to be an important component to supporting her father and the rest of the family in the wake of his palliative prognosis. The length of the quote can be interpreted itself as a reflection of the complexity of the multiple systems involved in palliative care, and therefore, the burden of care co-ordination:

> "*I done it all myself but first of all when I was trying to find out about it, because I work in Glasgow, so I'm obviously with Greater Glasgow Health Board and this (Hospice) would be North Lanarkshire, so I contacted the nurses, who are obviously ... the lovely nurses that came in to see my dad every week, but when I contacted them back in February I had holidays and I took near enough three or four weeks off and says, that's it we're getting everything, the social worker , the OT, everybody in, and so I'd phoned and I thought, I'll phone the district nurses, I'm a district nurse, I know who to refer my patients to get benefits, benefit checks done and all the rest of it and when I had phoned and the nurse says to me 'Do you not just contact the benefits office?' And I says to her, 'Do yous not have people that come out?' I says 'Can you not give me an organisation as such?' she says 'No, and what's it for?' 'My dad's terminally ill', 'And how do I not know about him?' and I said 'Well, you'd have to take that up with the GP, I don't know why you don't know about him.' 'Well, how have I not had a referral to see him?' and I says 'Maybe because he's now… doesn't require any hands-on nursing care, he's got no wounds, he's nothing like that,' So (she) said 'Possibly that's why. What's wrong with him?' 'He's got liver failure' and I says 'Could you possibly put me in contact with the Macmillan nurses?'"* (1)

The speaker above draws attention to her nursing identity, which plays a critical role in positioning her as someone who is more knowledgeable than members of the general public. Yet, despite this knowledge, she struggles to make sense of the system and gain access for her father to appropriate support and benefits.

Thus, having a professional identity as a nurse aided some family members' ability to manage caregiving, but, as with the speaker above, had a powerful impact on creating complexities around the role of relative/carer and healthcare professional:

> "*My daughter has been very VERY good but one would expect that with her nursing background.*" (6)

> "B*ecause I am a nurse actually myself and I think that was, you know, the big factor that erm I have those skill, I have those skills from all the years of nursing.*" (12)

For this speaker, her professional identity meant that she implemented formal systems in her home to facilitate continuity of care:

> *"We have a very good system we, we have a handover book and we write down everything that's been happening during the shifts that have been on so that everybody knows if there's anything new I write it down everybody reads the book when they come in. We communicate everything."* (12)

However, this was not always a strength, and having a nurse in the family felt sometimes as though it precluded them from receiving as much support as other families. Thus role conflict was not a concern in its impact on family relationships, so much as it disrupted the smooth flowing of professionalised systems:

> *"The district nurses in the community don't really come in and out very much er because I am a nurse I think you know they are there if I need them but you know they don't come on a regular basis.*" (12)

3.2   Supporting people who care for their relatives at end of life

3.2.1 Support for unpaid carers

Many of the interviewees' accounts reported limited support from healthcare professionals prior to accessing Strathcarron Hospice services, and little recognition that they experienced caring as stressful. Some coped by taking a day at a time and hoping for the best:

> *"I don't think about the future, take one day as it comes … you just have to get on with it and that's I suppose my generation, you just get on with things … just hope for the best."* (9)

While there was evidence that some carers tried to gain control by seeking information and understanding of their concerns this was not met by much understanding by health care professionals:

> *"The doctor just made feel as though I was being so silly so she did, that I was making too much of a thing out of this, that was how they made us feel ... he got this condition, he is getting treated for it, get on with it and that's it and you think to yourself but how do you get on with that?" (14)*

Further, there were few resources available for carers:

> "*I said to the GP, 'My husband has COPD and I am trying to cope with it, is there any self help group?' and it was like, pass ….. my GP gave me antidepressant and I went back to her and said, 'They are not doing any good.' She said, 'When you are having a stressful day take double the dosage.' How did I know it was going to be stressful day? Every day is stressful*." (4)

It was only when the above carer got support from a private counsellor that she managed to gain insight into her own situation and felt supported and understood. Thus, proactively accessing a counsellor can be viewed as part of her self-management:

> *Interviewer:* What did you get from counselling that helped you that time?
>
> *Interviewee:* That I could not do everything, he made me feel that how I felt was natural, he made me realize that I had to take care of my own life. (4)

Carers often had to therefore take the initiative in organising supports for themselves. A woman looking after her husband with mesothelioma spoke about how she had accessed support through Princes Carers Trust and a Maggie's Centre, but had to seek all this out herself. She had identified key support she required:

> *"We have had a very, very good support, but it is support we have had to find out for ourselves."* (15)

It was noticeable that there was lack of resources that helped carers to cope with the intensity of the experience and the constant pressure they were under on a day-to-day basis:

> *"I don't think there are a lot of services out there to actually give something to the carer ... I know that the Hospice is trying to offer relaxation therapy to carers and I think that's good … I think that is a great step forward … if something can be done for the carers."* (10)

Others reached a point where they ceased being able to continue with all their roles:

> *"Yes, fine, cancer, I can cope with this, I am the strong woman, I can be this, do this, and I couldn't, so I got signed off sick again."(15)*

> *"I really felt ... really felt alone, I don't think anybody ...people didn't know what COPD was... by the summer I was so bad I was off work for four months....with... anxiety and depression."* (4).

It was evident in many interviewees accounts that their support needs were not recognised. For those who were trying to find ways to self-manage, this was not met with much understanding or support by healthcare staff.

3.2.2 Carers are reluctant to acknowledge own needs

Despite family members clearly putting in a great deal of time, energy and emotion into caring for their relative, they were very reluctant to express any needs of their own. Some interviewees wished to be seen as being able to cope and were reluctant to ask for help despite being under much stress and strain of the situation as reflected in an account from a daughter looking after her father:

> *"They say 'Just phone just phone if you need us,' and all the rest of it and maybe because I like to think I am a strong person I think what am I going to phone and say? 'I can't cope anymore?'"* (1)

When directly asked to describe what support needs they had for themselves, they often could only articulate support for the patient, reflecting a difficulty in identifying or articulating their own needs. The following exchange exemplifies this, drawing attention to how, when pressed, family members struggle to think beyond the medical model:

> *Interviewer:* *[Is there] a service that would be helpful for you to have that*
> *you're not currently having … would there be something that*
> *would be … ?*
> *Dad:* *For us or for her?*
> *Mum:* *For us.*
> *Interviewer:* *For you.*
> *Mum:* *As carers, … ehm ….*
> *Dad:* *Chiropody [laughs].* (11)

When family members' support needs were discussed, conversation quickly returned to the patient. The following family member realised half way through talking about her sister, the actual purpose of respite care:

> *Interviewee:* *The respite is not really her it's for me.*
> *Interviewer:* *Yes [laughs].*
> *Interviewee:* *Am forgetting. It's **my** respite. (12)*

This apparent difficulty in talking about their own desire for support is not related to a lack of perceived need, however, as the following extract demonstrates:

> *Interviewee:* *It's frustrating and depressing.*
> *Interviewer:* *And it also must be quite, you were saying depressing, isolating*
> *as well.*
> *Interviewee:* *Yes, it is also.*
> *Interviewer:* *And how do you cope with that on a day-to-day basis?*
> *Interviewee:* *Not very well, you just have to get on with it, really. (7)*

Family members found it positive to receive tailored support for themselves offered by the Hospice, and the opportunity to talk to others in a similar situation. The following quotation again illustrates how challenging interviewees found it to think of themselves as receiving a service, rather than their (unwell) relative:

> *"I came up here for a pampering day once recently. Not so long ago and I*
> *enjoyed that, they were, it was, it wasn't just pampering, it was, it was*
> *relaxation, and I had the chance to talk to any of the nurses and the physio and*
> *anybody and it was just wasn't for my sister, it was just for the carers. … Yeah,*
> *I was chatting to a few people that day. Even other people who were sitting,*
> *you know, who are also caring for people."* (12).

Another asked what support the Hospice had been to her, was unable to answer, and framed her response as being about support for her mother:

> Interviewer: How they [Hospice] have supported you, can you tell me more about … ?
>
> Interviewee: It's not so much about how they have supported me, but I think for mum it's good. (7)

Two further interviewees echoed this sentiment highlighting that Hospice service was for their relative, not for themselves:

> "Hospice visitors come to see my wife." (15)

> "She [Hospice staff member] comes up to see the wife." (5)

For some relatives, seeking support for themselves was difficult as this was felt to involve the patient in having to also seek support from those in a similar (illness) situation. Consequently, family members sometimes did not access supportive services because of their concern for how this would be experienced by the person they were caring for:

> "I've never ever went to carers' places or anything at all. Mainly, too is [my daughter] won't go to anything like that either for the simple reason she doesn't like listening to people talking about their illnesses." (2)

Taking on the carer identity would become too public in this situation. By positioning oneself publicly as a carer this forces a patient identity on the relative, a position which may be unwelcome and in itself lead to further relational tension.

Many of those interviewed talked about the difficulty in recognizing and acknowledging their own needs and it was clear that they found it hard to shift the focus from their relative and on to them selves.

3.2.3 Support from Strathcarron Hospice

The many accounts indicated above reflecting a lack of involvement of carers had all occurred prior to accessing Strathcarron Hospice services. Strathcarron's services were felt to be much more inclusive of carers. This was particularly evident in an account by a woman who was looking after her son. She spoke about the impact of having a visit from a Strathcarron Hospice home care sister:

> "That came as really pleasant surprise when I could ask all these questions that was there and somebody took the time to actually break down to terms that I could understand, so they did, which was brilliant because I felt so much better knowing a lot of things I was worrying about were really not, I mean it was nothing I had to worry about … 'Cause I think it was just not knowing, so it was the not knowing what to do for the best and panicking when I really didn't need to panic." (14)

Most interviewees were overwhelmingly appreciative of Strathcarron's services, and some wished they had been able to access the service earlier (4). Many interviewees said that it was

not until they came into the Hospice that they experienced a service that was focused on them, offering psychological support:

> *"(The) home care sisters came and they started to ask what sort of help I was getting … I actually cried because it was the first time anyone had asked about that kind of thing."* (8)

The psychological pressure of being a carer was not taken for granted by the Hospice staff and they deliberately provided opportunities for carers to express their feelings and concerns. This culture of support is reflected in an account of a woman looking after her husband:

> *"I can rant and rave on the phone to the home care sister and chaplain they just listen, sometimes it's just about the chaplain or home care sister sitting and saying, 'How do you feel? Do you feel like shit today? Well, it's normal because you have had a shitty week,' … then you say to yourself 'I am not insane, it's perfectly natural to lose my temper,' or sometimes just giving me a hug and saying to me 'You're being normal, this is normal, sane reaction,' because when things are all jumbled up in me and I had depression there were lots of feelings I had that I felt I should not have towards my husband, them listening has helped because I now realised how I feel, they have helped me to look at it from husband point of view."*(4)

Many of those interviewed spoke of the difference it made gaining support from Strathcarron Hospice, such as 'being heard' and 'listened to' (1). It was also evident that some of those interviewed felt able to discuss problems and issues of concern even when these may not easily be solved, as is evident in the account below from a woman looking after her husband:

> *"When you get here [to the Hospice] people are listening to you, they want to be told how, 'How can we help you?' they ask, they want to know what the problem is … they might not be able to solve it, they are not magicians."* (10)

There was also evidence of Hospice staff demonstrating attitudes that showed insight and understanding of the carer's situation that reflected willingness to engage with the carer and hear their concerns:

> *"I think the home care nurses [from the Hospice] have compassion, I think they are gentle and I think they have got an understanding of what you're going through … and you can get someone and talk to them there [at the Hospice] and you are not making an appointment and bothering, bothering someone, and they are happy to see you and you feel you are not putting anybody out."* (7)

An understanding of the need for psychological support was reflected in an account from a man looking after his wife. The whole interview focused on how he did not demand support but the need was still recognized by the home care sister:

> *Interviewee:*   *The home care nurse popped in one day because I didnae know I was suffering from stress at the time*

> Interviewer: So she picked that up?
> Interviewee: She picked that up just with a phone call, my voice
> Interviewer: From your voice
> Interviewee: My voice, yeah

Gaining support from Strathcarron Hospice also provided carers with a sense of security, as trust had been established between the service and the carers. This was especially evident in relation to peace of mind:

> *"It's hard to look to the future because I don't want to, you know, because your mind starts running wild but, eh, funnily, what I feel is that now we have made this connection with the Hospice I am not worried about it. I think there is a safety in it, knowing that whatever happens where will be somebody (in the Hospice) who knows what to do."* (10)

The interviewees indicated that they did not have such trust in services before gaining service from Strathcarron Hospice. The following account illustrates how important this was to one carer, whose husband was involved in a clinical trial:

> *"We were off the radar with the trial doctor and the consultant, who do you 'phone? I felt I was not being heard and I felt, you know, although I was 'phoning and it was difficult for me to 'phone, ehmm, it's not easy for people to keep 'phoning when they are not being heard, eh, eh, I mean, who do you ask? There was no one to ask, now I feel, as I said, that if something happened to my husband tomorrow morning and I 'phoned then something would be done, to me there is something very safe about someone coming from the Hospice. After the nurse from the Hospice was involved or the Hospice was involved, suddenly everyone picked up a notch. Suddenly we were on everyone's radar… suddenly we were heard, that's how I felt about it."*(1).

All of those interviewed were in receipt of services from Strathcarron Hospice at the time of the interview. Most interviewees were overwhelmingly appreciative of the service they got from the Hospice and it was clear that the service they gained was meeting a need that had not been met by statutory healthcare services. However, there was, for some carers, lack of knowledge that the home care service would also be available for family support as indicated by the following interviewee quote:

> Interviewer: *Maybe it's something when [name of husband] is coming to day care you could ask the CNS to visit you at home so that you actually get a bit of a time with her to look at your own needs.*
> Interviewee: *Yeah, yeah that is a good idea because I always thought it was for [name of husband].* (16)

Whilst most carers spoke about the relief they experienced as a result of gaining support from Strathcarron Hospice, a woman looking after her husband with COPD was not sure whether the Hospice could offer support when her husband needed to be admitted to the Hospice for end of life care. When asked who could provide support in the future, she replied:

"I think the future, I don't know if the Hospice would be able to provide support. Because I feel ... I would, in the sense that I feel ... don't get me wrong, he's looked after okay while he is in hospital, but a medical ward is not for someone requiring palliative care. It's far too busy. And I wouldn't like to think that he got really ill and was left in there on his own." (4)

The above speaker felt that neither hospital nor Hospice would be able to offer appropriate services at end of life. So, while some interviewee were able to identify the support provided by Strathcarron, there were apparent difficulties in recognising that services were available and appropriate for family members (rather than just the person with the diagnosis).

3.2.4 Breaks from caring

The need to have breaks from caring was recognised by many interviewees. This need is strongly depicted in the following quotation taken from an account by a daughter looking after her father, who identified how it helped her to maintain distance and focus on her own life:

"When I do switch off it's good, the more you do it the more you are able to cope rather then just be drowning in it, you need to step back, you need to be helped to do that." (12)

Those who had their relative accessing Day Care at Strathcarron Hospice spoke about the service being important for themselves because they were able to do what they wanted when freed temporarily from caring. A woman looking after her husband who was just about to start attending day care said: 'The day care will give me a day where I don't feel I have to rush back' (3). It is further described how the day care service increases quality of life for carers in an account from a woman looking after her husband, who has COPD:

"Day care opened it up for me and my husband because his illness is a very isolating illnesss, because they have offered him a day palliative care there is one day of the week if I want to go out and I don't have to look at my watch, I can meet people for lunch and it's not like I have to go back." (4)

While day services were seen as important for carers to maintain their own quality of life, one mother of a daughter with long-term conditions could not benefit from service. She identified this as being related to the lack of appropriate day care options for younger adults:

"She doesn't want to go to day care and it's not because they are not nice, but they are elderly ladies who have got cancer and my daughter said, 'They are lovely, mum, but I don't want to sit and listen to that, I just dinnae want to be in that older environment'".

A woman who had been looking after her sister with MS for many years spoke of the relief she had when the sister accessed direct payments:

"So my life changed a bit … through the social work my sister was discovering that there was other way of erm, through the independent living fund and direct payment with the new system that came in a few years ago where she could employ people … she did that few years ago now so she has other people

... there is now a team of us […] I have a wee bit of freedom now and I have my evenings and some weekends that I am free, so that is a wee bit better in that respect." (12)

The desire for a longer break was also spoken about by carers. The need for a more extensive break was particularly evident in an account from a wife looking after her husband with COPD:

"Sometimes I would feel like even if I am not on holiday but I still would like them [the Hospice] to offer to take my husband for couple of weeks' respite care … I feel like, embarrassed in the sense of saying, and, 'I am here but could you take him for a week?' and I feel that's bad because I am in the house." (4)

Despite carers recognizing the need they had for breaks from the demanding role of being a carer many of them were reluctant to acknowledge their own needs as discussed in section 3.2.2.

3.2.5 Practical support for unpaid carers and patients

It was evident from many interviewees that the experience of being a carer had been much more difficult prior to accessing Strathcarron Hospice. It was variable how much practical support had been offered to patients and their carers by statutory health services. For some, it was only when they accessed Strathcarron Hospice that financial and practical matters were checked:

"It was only when the home care sister from Strathcarron Hospice came involved she said to me, 'Are you coping financially?'" (4)

"I think it was the financial person from Strathcarron Hospice, she got him the blue badge ... and she filled in all the forms and that was really quite good … I find form-filling and things like that difficult, and for knowing who to contact." (3)

It was evident that the Hospice home care sister was knowledgeable about possible resources for support:

"We contacted Macmillan also and they said 'No,' that my son was not entitled to anything at all because he worked. So that was that knocked on the head, they would not even entertain him neither for anything. I was telling the home care sister about this and she got something sorted and she, I don't know what that charity was, but she got in touch with a charity that deals with young people and they got us £1000." (14)

Navigating through the system was particularly difficult for a woman looking after her father with liver failure. At the time of his diagnosis she had to find her way through the system to figure out what was available and where:

"I had to chase up everything ... my mum and dad have never had any benefits, they have worked all their lives and it's just pension. I am like, 'You can get

allowance attendance and that,' I got all the information … I done it all myself, I 'phoned the benefit office at [name of place], they gave me a date in April and this was February, I said, 'You know, the person who requires the benefit check could be dead in April'. 'That's the earliest date we got'. I said, 'Fine,' put down the phone." (1)

In some cases it was only because a carer had personal contacts that they would know were to seek out practical help such as wheelchair:

"My husband said 'If we want to go out anywhere I am stuck' … I said to my husband, 'What about a wheelchair?' Because I know they are available on the NHS, I work in the doctors' reception and I know where the wheelchair forms are." (15)

"I got him a wheelchair from the Red Cross when he was going to Stirling because it was such a long way to find when he was going right along all these corridors to see the doctor and then he would send you along in the other direction for an x-ray and then you had to go back to the other doctors that was quite tiring. I worked in the health centre, you see, so I just 'phoned [the Red Cross] and then I went down and they gave me it." (3)

Some interviewees reported better experiences in gaining practical support. This was more evident in people caring for relatives with cancer, who were offered financial and domestic help proactively from statutory services:

"Haematology are excellent, I would say … last time when mother was having her last lot of treatment the oncology nurse organized for, ehm … the Macmillan nurse to come and see us and we got a payment from Macmillan … and also she got home care so we get half an hour ironing once a week and we get 15 minutes to do bed change once a week … and we get half an hour housework once a week." (7)

Likewise, a wife looking after her husband with cancer had a good experience of nurse specialist services:

"He was in abject agony, and all he really had was co-codamol, you know … so … this time was very frightening and we had no backup at that point ... I took him to the Oncology Centre on Friday morning and the nurse specialist there took charge immediately and they immediately started him on ora-morph, she told me she would contact the local Hospice and she put everything into […] So we were, luckily got the right girl, the nurse specialists." (10)

For patients with non-malignant conditions, access to a specialist nurse was often difficult:

"There is actually an MS liaison nurse in the community out there who is over-worked, I think you know who, who we never see, I mean, if I do try and get her it's always answering machine or so [the Hospice] is always where I would turn now for any problem or anything." (12)

One woman looking after her husband with neurological disease described their experience of organised discharge:

> *"A meeting was set up with the day hospital in Stirling and a doctor was there, the sister, the OT, the speech therapist and us and as result of that meeting other things were put in place to help and that's when he got word he would go to Strathcarron for a day each week and the GP started to come on a monthly basis, to the house, social service helped us to apply for benefits … Attendance Allowance."*(8)

It was clear in interviewees' accounts that there is little consistency in practical support. Healthcare professionals varied considerably in how proactive they were in checking the need for support, and assisting patients and their carers in seeking what they were entitled to. In most cases this was a significant gap, which was addressed only when patients accessed Strathcarron Hospice.

3.2.6 Support from Primary Care

Carers' perceptions of the primary care service varied, and some respondents felt they had been let down by their GP and district nurses. This experience is reflected in an account from a mother looking after her daughter with long-term illness, who describes the support of the GP compared with support from the district nurses:

> *"I think my biggest problem is I have not had the best GP support, where I felt let down was with my GP … I don't know why it is … I think it's because she [daughter] has been ill for such a long, I think they are slightly bored … I think it would be nice if a GP was more supportive … if he just dropped in and said 'How are things going?' It is just as if you don't exist. The district nurses are in [the house] every day because they need to be there to do her pump. They are very good … the girls are very good, but I don't think they are there to actually support you, cause they have not got the time to do that … district nurses are all nice have not got anything bad to say about them at all … eh just I felt very lonely and isolated with my daughters illness."* (2)

For the above speaker, despite the involvement of the district nurse, she remained lonely and isolated. The staff appear to be task-oriented, rather than offering psychosocial support to the family, indicating an unmet need for this mother and daughter. A further interviewee felt that the district nurses and physiotherapists are not as involved as the carer would like:

> *"The district nurses in the community don't really come in and out very much … erm, physio, it's very hard to get a physio, I mean, I have a 'phone number for the physio now, in the community, but I quite often have to leave a message and maybe she only works three days so may[be] you don't see her until one or two weeks later."* (12)

Some of those interviewed spoke about primary health care professional's lack of insight into the patient's disease progression, causing the carer much distress:

> "Your GP comes out and, you know, she didn't seemed to know the enormity of what was going on for a man that had, ehm, prostate cancer for seven years, and had such a bad prognosis at the beginning. I mean, they didn't expect him to live but a year and he's had various treatments, he's had chemo last year you wouldn't need to be a brain surgeon to know that, you know, it had to be watched at that point. The GP wasn't that helpful, she gave him co-codamol, he was in abject agony and all he really had was co-codamol, you know … so … this time was very frightening and we had no backup at that point." (10)

By contrast, other interviewees reported feeling quite well supported by primary care practitioners.

> "The GP is in every three weeks and he is excellent, I mean, I don't know how we would have coped, he has been so good and so thorough and talks it through, erm, we really can't say enough about him." (9)

A woman looking after her son warmly described the relationship the district nurses had developed with her son:

> "He has become really fond of the district nurses because he got to know them now but they are actually teaching him to inject himself just now so he will miss them." (14)

Another participant described how although she did not gain emotional support from the district nurse, she was nevertheless grateful that she had been referred to the Hospice for further support:

> "The district nurse that was out one day to give him his [injection of medication] and I think she just saw the state that everybody was in and said, 'Look, do you want to speak to somebody from the Hospice?' If it hadn't been for the district nurse I wouldn't have known about the Hospice." (14)

The data clearly demonstrated that carers value support from Primary Care and when this is lacking they felt let down.

3.2.7 Out of hours support

Many interviewees spoke about how important it was to have a service that they could access any time that they needed help or advice. Some had accessed Strathcarron Hospice over the weekend and found that helpful:

> "The home care nurses from Strathcarron Hospice are all very, all very helpful I must say so … it's just, erm, it's just that assurance that there is somebody there, there is always somebody there …. Couple of times at the weekends I had

> to 'phone to the Hospice for some advice … you can even 'phone just for advice." (12)

However, it did not appear to be clear to everyone that they could contact the Hospice out of hours for advice. This is evidenced in the account below from a woman looking after her mother, who, when asked if there was anything that the Hospice could improve in terms of their services, replied:

> "*Yes, if there was an out-of-hours or a weekend thing with the Hospice.*" (7)

A further interviewee highlighted a lack of knowledge about out of hours care:

> "*I would really like somebody that I could 'phone if something goes wrong at night or weekends.*" (4)

Other interviewees said they were not sure who they would turn to as they knew that Hospice home carer sisters are only available during daytime hours:

> *Interviewee:*   *The home care sister said to me if you ever need me just phone. But I know that the she is only on to …*
> *Interviewer:*   *So you that you can get [home care sister] but only in office hours?*
> *Interviewee:*   *But there's nothing been ever said to me about how to get anybody at … like at night or the weekends*. (4)

Some interviewees had accessed NHS 24 when they needed help out of hours. One reported that this had been a very stressful experience:

> "*I phoned the 24-hour service, I phoned … you know, how you get the emergency number and they are hopeless, I found them hopeless, they obviously got a questionnaire they have go to ask you, right? And they started going through this thing, 'And how is her breathing?' I said, 'Look, her breathing is practically nil she can hardly breathe,' and ehm, 'What colour is she?' and I said, 'She is kind of gray, she cannae breathe and what I am trying to tell you is we need something done here quickly,' right? 'Have a look at her lips, are her lips blue?' Right? 'Is she sitting up? Can I talk to her?' I says, 'She cannae even breathe, so how can she talk to you?' Right? And all this kind of thing, and I just went, 'I am needing an ambulance, we are needing somebody here now!'*" (5)

> "*It was terrible and we ended up having a doctor in … NHS24 which… is … If I said what I really thought about NHS24 I'd probably swear … I think by the time you get through the channels and repeating yourself as someone … very stressful for me … very stressful for mother.*" (7)

Whilst many spoke about their lack of satisfaction with NHS24, one interviewee had good experience of phoning them for support:

"We had to phone [NHS 24] twice in the beginning when there was a great deal of pain during the night and they were quite good in coming and the other one was excellent." (9)

Some carers had a number to phone that would bypass the NHS:

"I have got a straight number right through to, ehm, local site that actually deals with it so I don't have to go through NHS24, I just phone them up, I am quite lucky there." (2)

However, as noted in the accounts above, not everyone had been given this number.

It was evident that many carers are unaware of where they can phone for support out-of-hours. In particular, while Strathcarron Hospice offers some services for carers out-of-hours, this was not known to all carers.

3.3 Relationships at the end of life

There is a need to understand the entire context in which people experience and make sense of their illness, and particularly their interconnectedness and interrelationships with others. As described in section 1.2, supporting relationships at the end of life has been identified in health policy as being central to providing quality care. Talk about relationships was apparent throughout the interviews, reflecting both the role of pre-existing relational ties which influenced the uptake of a carer position, and also the impact of caring on their relationship with the person with the diagnosis. Relationships often changed and shifted as the need for care became apparent. This is characterised by one family, where the patient's marriage ended, resulting in her parents undertaking a wide range of informal care-giving tasks:

> "She was first diagnosed eight years ago. I don't know if she used it [the Hospice] at that point because she was with her partner at that time. So we didn't have to come and stay with her." (11)

Another interviewee clearly signposts the impact on family members when a palliative diagnosis is given:

> "It's pretty much all-consuming really. I mean, it's not just debilitating for her but it's debilitating, it's very difficult for the, for the whole family but especially the ones closely there with her, erm, more closely, well, I've looked after, we're close as sisters anyway so erm, I just naturally sort of fell into the role." (12)

The above quotation thereby clearly illustrates the impact on entire family systems, and the power of relationships in determining the uptake of the role of unpaid carer. For several interviewees, taking on a caring role contributed to a major shift in lifestyle. The parents of one woman, for example, found themselves travelling 300 miles to look after their daughter. Another participant expressed the magnitude of responsibility on her:

> "Well, you just feel it's a massive responsibility, originally I had lived abroad and I more or less came back because my mum wasn't so well because I didn't want to be abroad, and my own health wasn't as good either … And I'm not so able because my illnesses are getting worse." (7)

Several interviewees spoke about their own health problems, which played significant roles in how they were able to support their relative, and access support themselves. One woman, for example, spoke of her diabetes and heart disease, while another spoke of her insomnia and arthritis, and also stated: *"it takes [it] out of me, with my M.E. in using up my energy."* (7) Another participant had experienced prostate cancer and incontinence as a side-effect of treatment, and reflected how this had contextualised his wife's illness: *"As I say, my experience before, I've learnt quite a lot."* (13).

Thus the caring responsibilities often weighed heavily on families, and struggles with ill health were often apparent for many people throughout the family system. Indeed, some interviewees clearly identified how change in one part of their family initiated changes elsewhere:

> "*So, sometimes when you've been out with friends and it's lifted your mood you come back and your husband brings you back down … So I would imagine it works both ways, each other's mood affects the other. So it's up and down.*" (4)

> "*I sometimes just feel, when anything about support, when people see the patient or that the person that has the illness that is going to maybe shorten their life that they just look at the bigger picture and see the carer, like. Or if how, if you had kids in the house with this restriction and how they are feeling with their illness it restricts them how it can effect maybe your kids' life, they don't want friends to maybe come into the house if their father or mother is wired up to a tube. And it's also very difficult to understand.*" (4)

For other interviewees, the impact of the disease was informed by the age and stage of the family members. The following interviewee places the disease in the context of his retirement, and the flexibility this affords him to be with his wife, unconstrained by work commitments:

> *Interviewer:* *How your wife's illness has affected both you and your family … what effect that has had on you?*
>
> *Interviewee:* *Eh … it hasn't … being retired it's not as though is it, would have affected me in terms of any trauma or any job I had to do. (6)*

There was a clear sense of reciprocity in many accounts between the unpaid carer and the person with the palliative diagnosis, which has been well documented in the literature (Brechin et al., 1998). The following speaker signposts this mutuality over the life-course of their relationship:

> "*The reason I started going to the gym was that I had a kidney transplant and I thought I must try and keep myself [fit], because I've always felt that what kept me going most of the time was that I was always able to eat … But … as I said to my husband, he had many years of me being ill and it's my turn to look after him.*" (3)

For other participants however, the onset of palliative care had led to, or exacerbated, relational difficulties.

3.3.1 Relationship difficulties

For many interviewees, there was a sense of a growing difficulty in relationships as a result of the multitude of changes which had occurred as a consequence of the illness. Difficulties emerged between both the person with the palliative diagnosis and wider family members. Similar debates have been well documented in the carer literature (Henderson and Forbat, 2002) around the shift in roles, whereby becoming an unpaid carer seemed to necessitate relinquishing or at least re-negotiating their role as spouse:

> "*It's very much different in a sense of a relationship is, erm, at times, I think that my husband just sees me as the carer and I can't remember what I said*

once but when he answered me I said, 'Excuse me, I am your wife first and then your carer!'" (4)

Relationship difficulties were present for some people, even before a palliative prognosis was given. The stress of a life-threatening disease itself seemed to trigger the end of relationships:

"She was with her partner for fourteen years, they were due to get married, erm, she took breast cancer, and he went off with someone else, so she had a breakdown." (11)

There was often an impact upon wider relationships, as the following quotation highlights, from a woman who describes the impact on her marital relationship, in the context of caring for a son with advanced cancer:

"I think that the relationship with my husband that sort of went away for a while there, so it did, but that's coming back again." (14)

For some, the strain of caring was visible in how people related to each other. The following quotation is taken from a woman who cares for her sister with MS. The patient compares the care she receives from her sister unfavourably with that received from a paid carer. The relative finds this intolerable, given how much time she has invested in caring:

"[My sister] said 'You're not gentle, er, the girl [paid carer] who'd just left she's so gentle, you're not gentle,' you know, and I was just like, I just, I never do it, I never and, I just went out and I just slammed the door behind me, because you know, I literally go there every morning … She's, she can be, you know we can just be as sisters are to each other [laughs]." (12)

Thus, while the above speaker signposts difficulties between them as a consequence of the lack of gentleness, she minimises this with reference to the cultural trope of 'what sisters are like', invoking a normalised sense of sisters struggling to always get along.

Interviewees also marked out how struggles in managing symptoms led to relational tensions:

"You sit and watch people gasping for breath and they can't breathe and you are giving them a nebuliser and it's not working, and they get ratty because they can't help you and you get ratty at them and resentful for what the disease has done to this person." (4)

Feeling taken for granted and with minimal escape from the pressures of work and unpaid caring also negatively impacts on relationships, with reverberations throughout the family system:

"That year I would go to my work at eight o'clock in the morning and not come home till six and it was only because I didn't just want to face my husband because the moment I got in the door it was 'Yap, yap ,yap, I've been on my own, I've been this, I've been that. It was like, 'Shut up.'" (4)

Other carers used the interview to reconstruct scenarios where they had become angry with their relative as a consequence of the pressure they were under in providing support:

> *"I turned to mummy and I just swore at her, I said, 'For so and so's sake, don't fucking get a chest infection, because I can't take it', and she went, 'Well, I don't want one and if I get one it's not my fucking fault,' … and I don't want to speak to my mother like that."* (7)

For other interviewees, relationship difficulties were present in wider parts of the family system that is, beyond the person with the diagnosis and the interviewee. This was often a product of other relatives feeling that the interviewee had invested 'too much' of themselves in caring:

> *"This taking for granted, she doesn't, she doesn't, you can be taken for granted really that you're the, you know, I'm the one that's always done it therefore I'm, to her I'm the one that's always going to be there, and it's presented a few difficulties for me and my husband."* (12)

> *"I get a row for spending too much time with her...you know ... she's just ... great to look after and ... it HAS been hard."* (2)

For the above two interviewees taking on care-giving roles had unsettled the balance of roles and relationships in the family, notably between spouses.

Some interviewees conceded that they found it hard to relinquish care, which resulted in strain in other areas of life:

> *"I find it very difficult to LEAVE [daughter] with anybody."* (2)

Further, for some families, the aetiology of the illness was a factor which added strain to family relationships. The following quotation comes from a mother who describes a suboptimal conversation with doctors and the subsequent role of blame within the family.

> *"At the beginning one of the doctors said that there was a chance that [son] could have picked this up in the womb so there was, er, that it could have been a gene. So something, it was something to that effect anyway, so that, that was like the, the blame so it was, where the blame came out, so it did. So we had quite a few weeks where we were arguing quite heavily over that. Everybody said it, 'You picked something up when you were carrying him, why didn't you know?' and all this sort of stuff."* (14)

3.3.2 Support in the context of other family members

Many of the interviewees spoke of how their role as carer involved far more than looking after the person with the diagnosis. Often they were drawn into supporting a range of other family members. This seemed to represent taking on the position of carer across the whole family. The following quotation comes from the daughter of a man with organ failure, talking about supporting her mum:

I'm there every day with my mum and I feel I'm maybe more supporting her in so far as I took the time off so that I didn't want my mum to become like a recluse so at least if I'm there I can say to her sometime during the day for her to go out and get a break ... but in turn, me doing that, I've become the recluse." (1)

Another participant, a mother caring for her son, highlighted the number of people in the family she was having to care for and the impact on her husband and his ability to work:

"It affected my husband a lot more than me I, I just felt as though if I'd have crumbled then the whole family would have just went to pot. So it would have, so I'd just sort of tried to keep everybody together and just keep a normal life, everyday going to work and then looking after [name of son 1] when I came home. My husband, he ended up having to sign off work, so he did." (14)

The impact of the illness is clearly marked as being on both the man's wife and daughter, indicating the truly systemic impact of a palliative diagnosis. The speaker goes on to indicate her role in supporting her siblings too, and managing their reactions to their father's declining health:

"I have got three brothers and there's times when he's really low and they're there and you ask them to help to do something with them and they're standing there like maybe there's … he goes through phases where he's maybe vomiting and they're like, [I will say], 'Can you give me a hand to hold him up?' and they're standing and they have tears down their face and I'm standing there and I'm looking, thinking 'For God's sake, he's only being sick … I've been away today and my mum's been in the house all day today, I can't leave her in the house all day tomorrow, but I'm like, why do I think like this? Why, [laughs], why do my brothers not think like this? Why am I thinking like this? Why [laughs], can I not have a full weekend away?" (1)

The interviewee marks out her very different position of responsibility to that of her brothers, and the role she sees herself as accommodating in supporting their mother. Thus, while there are other family members present, they have differential roles in providing care.

For other interviewees, the focus was on supporting their family by actively choosing not to involve them in active care-giving tasks. The following participant uses the first person singular (I) and plural pronouns (we) to illustrate that this is both her position, and that of others:

"My family's quite local but they're not in this town but they're not far away, if you know what I mean. And they're, they're very supportive ... but I don't want to, you know ... I don't want to play on them ... We want them to enjoy their lives, we don't want them sort of stuck. I don't want them on my doorstep every day. They've got to have their own life." (2)

In a small number of instances, the wider family provided invaluable support to the main carer:

> Interviewer: In terms of the extended family do you find that ... has the support mostly been around practical things around you and your husband or has there been any support to your extended family as well?
>
> Interviewee: As I say, my brother has come from [40 miles away] once a fortnight which has been really great. My daughter who lives in [20 miles away] comes the alternate Tuesdays, Tuesdays are when my brother comes, from her work. She takes a long lunch hour to let me go shopping for food. I go out once a month to a ladies' group and my daughter will come over and sit with her dad while I do that, so that's fairly regular and apart from that she is very willing to come any time we ask her. (8)

She goes on to reflect:

> "At first I was thinking that I had to do everything for him, that's my job, I'm his wife and all the rest of it. But then it dawned on me that I'm his wife but he is their father. And when my parents were ill I used to do stuff for them and nobody kept me out, so it gradually dawned on me that when they offer to do something, I should take them up on the offer, you know?" (8)

Thus, while an ongoing illness may result in exhausting family input, for some the length of time lived with the disease allowed for learning and reflection on the support needs of the main unpaid carer.

3.3.3 Communication with, and within, families

Communication emerged as a dominant theme in participants' talk, relating to the quality of the relationships at end of life. This included both relationships within the family, but also between family and healthcare professionals.

Within families, some participants reported dominant family scripts about communication patterns:

> "His upbringing is totally different to mine. His upbringing was very much that his parents didn't discuss things, especially not in front of him. They weren't very open towards him and he had a rather weird relationship ... well, they had a weird relationship compared to my family. So, when it comes that he's really miserable and has this really frightening thing in front of him, doesn't know how to communicate, he doesn't know how to put it into words." (4)

Families struggled to find ways of communicating with each other in a way that felt appropriate. Without support to find adaptive ways of expressing themselves, both patient and family members were restricted in their activities:

> "When she is out it is 'I've got a pain in my tummy, I've got a pain in my tummy, need a toilet, need a toilet', which is frustrating for her and frustrating for me. So the best thing is she just doesn't go out, really. It's frustrating

> *because you can't plan anything and … even for myself … ehm … whereas I have a friend in the city who said, 'Oh, you'll come through', well I've to wait to the last day to see how my mum is before I can go any place.*" (7)

Interviewees highlighted the ways in which both family members and patients worked hard on protecting each other through managing how and what they communicated with each other. Family members often recognised that the person with the diagnosis was holding back information, feelings and symptoms as a way of not overburdening carers with worry:

> "*I think he sometimes keeps things to himself because he doesn't want to worry me.*" (4)

> "*I know she worries about us, too.*" (11)

Family members also held back from talking about prognosis as a mechanism for protecting the patient from thinking about death. For some, recognising the independence of their relative meant that they shied away from organising an advance care package:

> *Interviewer:*   *She really needs someone in the house you feel, 24 hours?*
> *Dad:*   *Definitely, I think so.*
> *Mum:*   *So, I don't think she would agree with that.*
> *Dad:*   *Oh no, she wouldn't (laughs)!*
> *Mum:*   *She's such an independent lady.* (11)

Many relatives had physical health problems themselves, meaning that the patient identity was held by a number of people, not just the person using the Hospice. This led to families making decisions about who was, and was not, well placed to be involved in knowing about and taking part in care-giving:

> "*The daughter who would be able to help us unfortunately lives near [city], and she came up right away and she teaches and it isn't easy for her to come up. But she came up at the weekend right away and ehm … we, we rather try to protect the youngest daughter because she has MS.*" (9)

> "*I guess we all play the game of … you know … you know, you enter into this game, don't you, where you are all telling some slight untruth, ehmm … you hide things from one another … so that it doesn't seem as bad, perhaps … when they [the daughters] phone up and you say 'Oh yes, he has had a reasonable, yeah he's good today,' blah, blah, blah, you know, you try to hide it from one another, I think …. We all enter some sort of place where we are trying to minimise what is going on to one another, not minimise it, perhaps that's the wrong word, but it's not a denial thing, you know, we know he is ill.*" (10)

For some carers, adopting a stance of bravery and holding back emotions were presented as ways of coping:

"You are always trying to keep a face on it for him ... I sometimes go into the shower [to cry]." (3)

Being offered supportive listening from professionals was highly valued by family members, indicating the importance of clear communication in wider health systems:

"[The Macmillan nurse] will often phone me and say, 'Do you want me to come, do you want to meet up sometime?' Just to talk and I don't know, so many things come out when I do sit to talk … there, there's a lot of support." (12)

Building a relationship with health care professionals has been critical in providing supportive care to relatives. One family member describes this in terms of someone who knows the complexity of the medical condition, but also the patient and family member themselves:

Interviewee: *I want to speak to the nurse who has visited me and my sister you know, I know I can just 'phone up and leave a message and she'll 'phone back … So it's ...*
Interviewer: *Relationship isn't it ... ?*
Interviewee: *Yeah. (12)*

3.3.4 Relationships with friends

Maintaining relationships with friends was a struggle for many interviewees, yet was framed as an important component to their sense of self. Many interviewees reported a significant loss of friends through the course of the illness, leading to a smaller network and a sense that former friends have lost sight of the impact of the illness on the family ("*people forget*" 10).

There was a palpable sense that it was the family member's duty to reach out to friends to receive support, rather than friends being proactive. This leads to a difficult position for family members, desiring support but simultaneously not wishing to be needy:

Interviewer: *You have spoken a lot about people saying that you just have to pick up the 'phone.*
Interviewee: *But why don't they 'phone you?*
Interviewer: *Is that a hard thing to do to pick up the 'phone to people?*
Interviewee: *Yes, because you don't want to feel dependant on people (10).*

For those with friends who had offered support, this was clearly valued very highly, and seemed to be understood as related to a recognition that friends had a solid understanding of how intense care-giving can be:

"We've had good support from friends ... in saying to me, 'You have a day off ... don't you bother going over to the hospital,' or whatever … 'I'll take your wife over'… So we've got a good background of friends." (6)

With progressive degenerative illnesses, there was a shift in relationships with friends as well as within families (as discussed above). One speaker illustrated this by describing how her friends

had not been aware of the impact of her husband's COPD on them as a couple, until they experienced it themselves. The following quotation underlines the importance of this close experiential knowledge in understanding the impact of advanced disease on family relationships that even friends may be unaware of:

> *"… felt they [friends] didn't really understand … I feel a bit freer to be able to speak to them now and also up until then, until my husband really took ill, he really only showed me his nastier side and he didn't really show it to anybody else but of course, obviously, as the illness prolongs you can't hide that the same so other people they would say to me, 'He said such and such a thing to me,' and I said, 'Well, join the club, now you know what it's like.'"* (4)

Some interviewees spoke of how they found ongoing friendships strained, feeling increasingly distanced from a care-free lifestyle:

> *"I feel like it's kinda taken over my life, very much so, and I find that lately, like with maybe friends that'll I'll pop in to see are asking me, people ask me to go places, I just think, no, or friends that'll pop in, or even friends that phone me, that I find I cut conversations on the telephone very quickly and it's because, maybe I'm ignorant on it, I'm not interested in what you're doing and I think, actually I'm, like people say, 'Oh, I was out here and I was out there,' and it's not that I resent what, that they've got a life, it's just, just now, I'm not interested, I don't have a life. I think it's because I don't want to hear that they are having a good time because then they'll say to me, 'What have you been up to?' and 'I've been at my mum's I've been looking after my dad.'"* (1)

Isolation was a core component, then, to think about the relational impact of the disease process. Several interviewees made it clear that they had limited family support available to them. The following quotation comes from carers noted above, who chose not to ask friends for help, thus the following excerpt highlights how isolated they are:

> *"Very difficult because I'm completely on my own because our two daughters live abroad. One in [North America] and the other in [Asia]. But they have been home once or twice but we have no other relatives in this country, although I do have a sister who lives in Galloway but she is a semi-invalid."* (10)

Thus, while relationships within families were clearly impacted by the onset of illness, there was also clear evidence of the importance of considering wider relationship systems, including friendships.

3.4   Preparing for death

It was striking that despite participants all having a relative who had a palliative diagnosis and was using a Hospice, that throughout the interviews very little mention was made by interviewees of death or dying.

The following three extracts illustrate the most explicit references to death and dying in the data:

> " … and here I am again at the end of September and the, I am like 'Ow, is the man still here?' I am sure dad every night goes to bed and closes his eyes and says a wee prayer that he doesn't open his eyes again … I am sure that is what he wishes for and, God forgive me, every night I go to bed and I say the exact same." (1)

> "We don't want to know how long he has got or anything like that, erm, we just want to take each day as it comes … Monday was a very bad day emotionally for us both … but you know, we got through it and Tuesday was a better day … if we have three days on the trot where [he] is quite good that's what we are working for." (3)

> Interviewer: What stresses you about the situation, or is that a hard question to answer?
> Interviewee: No, not really, just maybe losing her you know? (13)

Interviewees demonstrated delicate footwork between recognising imminent death and choosing not to focus on it. The following quotation begins with a sentiment that both patient and family have no wish to know how long he has left, yet this is contradicted by a sense of 'proving' doctors wrong by outliving a predicted prognosis:

> "We don't want to know how long he's got or anything like that, erm we just want to take each day as it comes. That's what I said to him, he's a stubborn bugger, so he can prove them wrong [both laugh]." (3)

This speaker goes on to illustrate the duality of both knowing and not knowing:

> "I said to one of the nurses one time, 'If I could hang on to him for a year or so,' and the next day the doctor was in and he was talking to me ... he said, 'You do know we are talking weeks, maybe months,' and I said, 'I gathered that.' So I took it that the nurse had went back to him and said that she's living under ... false pretences, but I wasn't really, I was just ... not wanting to put a time limit on it." (3)

Other families struggled to communicate their understanding that the patient would not get better, the following two powerful quotes come from the same interview of parents caring for their daughter with metastatic brain cancer:

> Mum: I said, '[daughter], we won't be leaving here until you're capable,'
> Dad: 'Of looking after yourself.'
> Mum: 'Of looking after yourself more or less, cooking your own meals and cleaning.' She had a cleaner, she had employed a cleaner of her, she got, gets disability living allowance. (11)

> *"She won't hear the word 'terminal' used. Community CNS says, 'No, you're erm, chronic, chronically ill.' She's got her own thoughts, I know. She doesn't want to say to upset us, I know so that's something that's not discussed." (11)*

Thus, preparing for death and dying is impaired by difficulties in finding a common language to use that is acceptable to all family members and the healthcare team.

3.4.1 Living with a life-limiting illness is a systemic issue

Family members readily identified the ways in which a palliative diagnosis impacted on them, not just the patient. The following participant spoke eloquently about this throughout her interview:

> *"He [GP] asks the patient things ... I know that he probably thinks that it's not his job to think of the family ... But it's only once you've got someone who is really ill like my husband or with cancer or even in an alcoholic ... that the illness affects not just the person, it affects the close friends and family to that person and unless you actually put your hand up and say, 'I've had enough of this.'"* (4)

> *"Doctors only see the patient when they see them and it's right that they should obviously try and care for them, which is right, medically, but there's people in the background that are involved with this patient but they are just left to sort themselves out."* (4)

Many interviewees identified that they were not being kept in mind by healthcare professionals:

> *"Doctors tend to talk to the patient ... now this is, must be a thing that has come out ... I don't know if it's been through the ... they don't tend to talk to the carer or the partner or the person looking after them."* (5)

Thus, there is a sense that the biomedical approach to palliation is inadequate, since it marginalises the other people who are impacted by the condition. A psychosocial approach is implicitly supported, whereby family members are also identified as impacted.

Many interviewees spoke of how practical support and interpersonal care for the patient had a knock-on effect on them as a carer:

> *Interviewee:*   *The OT comes in and the physio they've been and erm ... our doctor comes in every three weeks and he is excellent in that we just need to ask for a visit and he'll come. He's been brilliant, I must say.*
> *Interviewer:*   *So it sounds like that you find the carers helpful because they're actually ... they free you up a bit of time?*
> *Interviewee:*   *In the mornings it saves washing and showering that's difficult because he gets wobbly on his legs.*

Interviewer: *So the practical side, you feel that bits of that does actually help you?*

Interviewee: *It does. (10)*

"She (social worker) has also, you know, tried to suggest that my brother is there and we do things together and there's more involvement from the family." (12)

Thus, where support is available, this too has a wider systemic impact, ensuring that when the patient is receiving adequate help this takes the pressure off family members.

Finally, some interviewees were very mindful of the stressful position that the patient occupies, since they may worry about the whole family in addition to their own health:

"They might say to the patient, but they've GOT to remember that the patient's under stress. Right? They're not only worried about themselves. They're worried about the families and how they're doing when they're not there." (5)

4   Discussion

This study highlights the impact of caring on family members due to the constant pressure of their role. Previous research has highlighted the need to recognise the impact of patients' illness on family members and support them in their caring role (Grande et al., 2009; Harding and Higginson, 2003). Despite such research, it is evident that family members are expected to take on the role of caring for their relative without adequate support, and they remain unseen and unheard within the statutory health care system.

The study highlights serious lack of support for carers within the general health care system. A lack of dialogue between health care professionals and carers was evident in the data, reflected by a lack of information regarding the disease progression, lack of involvement of carers in decision-making and lack of information about practical support. It was also evident that there was a lack of resources for carers to help them to protect and maintain their psychological wellbeing. Overall, there was a sense that family members found it difficult to talk about their own needs, with frequent references back to the patient, rather than themselves. Thus, despite over a decade of policy aimed at shoring up the status of the carer and positioning them as having a need for support in their own right, this remains to be translated into how family members are able to articulate their own needs, and a dominance of privileging the patient. Family members are invisible to healthcare professionals (Harding and Higginson, 2003).

Despite research (Andershed, 2006) demonstrating that information and communication helps relatives to manage much better with the caring role and maintain meaningful involvement, there was a clear lack of this. Many carers report feeling unseen and unheard, and there was evidence of an underlying assumption that health care professionals believe that family members are able to cope without much information or communication. Consequently, participants in this study reported feeling disconnected with clinical information which may affect their ability to care. The data demonstrate that carers attempted to self-manage in order to mitigate the negative impact of caring. However, there was little data in this study to support the idea that family members were supported in undertaking self-care. Thus, the findings fly in the face of the clear move in policy and practice to identifying and encouraging self-management (Department of Health, 2004; Department of Health, 2005; Scottish Executive, 2005).

Strathcarron Hospice provides services that are inclusive of the family and recognise the burden on carers. For example, the home care nurses, chaplain and medical team are all cognisant of the impact of caring on family members, and offer support through listening, demonstrating understanding of carers' feelings and concerns as well as offering practical support (including finding ways for financial support). Where Day Care, complementary therapies and the Carers' Day was accessed, carers found this valuable. Some carers were unaware of the availability of out-of-hours Hospice support and furthermore, some of them did not know that home care support was available to them as well as the patient.

The data strongly indicate struggles with the implications and ramifications of the palliative diagnosis on the whole family. The palliative diagnosis both intensified/exacerbated previous tensions in relationships, and created new difficulties. While little support was available to the

carer to manage their new role, there was even less support which took cognisance of the wider family system, and provided expert support to the family as a whole.

Finding it hard to relinquish care, a feature reported by many respondents, might be considered a difficulty which stems from what Rolland (1994) describes as centripetal forces. Particularly for chronic illnesses, there can be a tension when some family members revert to more centrifugal positions while others remain close and connected with the patient. Respondents clearly reported the difficulties where they were torn between the unwell person and other relatives.

Families manage their communication in a way that often prevents them from speaking with each other about the future (which, for many, will mean coping with death, dying and bereavement). There was ambivalence for many interviewees at taking on board a full understanding of their relative's likely prognosis, illustrating perhaps a position of 'unsafe uncertainty' (Mason, 1993).

This communication style presents significant difficulties with engaging in advance care planning since appropriate planning is predicated on being able to communicate clearly about wishes and needs at end of life. The avoidance of talking about and preparing for death and dying may lead to significant problems in bereavement, specifically risk of complicated grief. Indeed, in a cross-sectional pilot study Brintzenhofeszoc et al. (2001) identified significant relationships between the level of family functioning, psychological distress and grief reaction. Further evidence indicates that families with multiple stressors might also be at risk for increased complicated grief reactions (Tomarken et al., 2008).

4.1 Limitations

The study was unable to recruit the desired number of participants. Despite three rounds of recruitment to the study, the response rates were low. This may have resulted in an unrepresentative sample being achieved, despite the systematic approach to sampling undertaken. Thus, while data saturation has been achieved, and minimum numbers for qualitative analysis was reached (Guest et al., 2006), the opt-in system of sampling may have resulted in people with similar views taking part in the study.

The letter of invitation was addressed to 'the relative of', which left the decision of who would participate in the interview with the family. This sampling strategy resulted in 12 spousal carers, three filial carers and one sibling.

Though the approach of asking families to nominate the interviewee privileges their own knowledge and views on who would provide the most useful information for the study, it resulted in the recruitment of a broad range of family members. Literature focusing on caregiving, particularly in adult palliative care, has largely focused on spouses, which this study somewhat replicates. Unpicking the rationale for why an individual was identified as the appropriate person to be interviewed would have made an interesting and potentially illuminating addition to the data corpus.

5   Recommendations

A number of recommendations stem from this work, all of which would enhance current service provision to families within the general healthcare service and strengthen Strathcarron's services.

1   Strathcarron Hospice should continue to ensure that:
   ➢ The needs of the wider family are identified, documented and addressed.
   ➢ Service users are supported to understand that Hospice services are available support *all* family members, not just the patient.
   ➢ Families are made aware of what out-of-hours services are available and how to access these services as appropriate.
   ➢ Family members' methods of self management are identified and supported.

2   Access to specialist family therapy support should be made available, through referral to external agencies. This will ensure that families are supported to process the wider implications of the disease, as expert support would lead to better psychosocial outcomes for patient during the course of their disease, and for family members in their bereavement.

3   Education offered by Strathcarron Hospice, both internally and externally, should draw on this study's findings to inform healthcare professionals of the impact of a life-limiting diagnosis on the wider family system. Furthermore, education around palliative and end-of-life issues should aim to enhance healthcare professionals' assessment skills in relation to carers' need for practical and psychosocial support and enhance their ability to offer this support.

4   Strathcarron Hospice should, where appropriate, for example, through Gold Standard meetings:
   ➢ Highlight the ongoing need for the primary care service to maintain contact with patients and family members who are receiving input from palliative care specialists.
   ➢ Highlight carers' needs, in relation to understanding the disease progression in relation to their own information needs, and details of out-of-hours support.

5   Strathcarron Hospice should explore the possibility of conducting further research focusing on the ways families talk about death and dying, in order to support them to communicate with each other, as well as health care professionals, about these issues.

6 References

Andershed, B. (2006).'Relatives in end-of-life care- part 1: a systematic review of the literature the five last years, January 1999-February 2004', *Journal of clinical nursing*, Vol. 15, No. 1158-1169.

Audit Scotland (2009) *Review of palliative care services in Scotland*, Audit Scotland, Edinburgh.

Babbie, R. (2008) *The basics of social science research*, Belmont, CA.: Thomas Wadsworth.

Bailey, C., Wilson, R., Addington-Hall, J., Payne, S., Clark, D., Lloyd-Williams, M., Molassiotis, A., and Seymour, J. (2006).'The Cancer Experiences Research Collaborative (CECo): building research capacity in supportive and palliative care', *Progress in palliative care*, Vol. 14, No. 6, pp. 265-270.

Bakas, T., Lewis, R. R., and Parsons, J. E. (2001).'Caregiving tasks among family caregivers of patients with lung cancer', *Oncology Nursing Forum*, Vol. 28, No. 5, pp. 847-854.

Ballard-Reisch, DS. and Letner, JA. (2003).'Centering families in cancer communication research: acknowledging the impact of support, culture and process on client/provider communication in cancer management', *Patient Education and Counselling*, Vol. 50, No. 1, pp. 61-66.

Braun, V. and Clarke, V. (2006).'Using thematic analysis in psychology', *Qualitative Research in Psychology*, Vol. 3, No. 77-101.

Brechin, A., Walmsley, J., Katz, J. and Peace, S. (1998) *Care matters: Concepts, Practice and Research in Health and Social Care*, London: Sage.

BrintzenhofeSzoc, K., Smith, E., Zabora, R., and et al. (2001).'Screening to Predict Complicated Grief in Spouses of Cancer Patients', *Cancer Practice*, Vol. 7, No. 5, pp. 233-239.

Department of Health (1999) *Caring about carers: A national strategy for carers*, Department of health, London.

Department of Health (2004) *Chronic disease management: a compendium of information*, The Stationary Office, London.

Department of Health (2005) *Supporting people with long-term conditions. An NHS and Social Care model to support local innovation and integration*, The Stationary Office, London.

Edwards, B. and Clarke, V. (2003).'The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety', *Psychooncology*, Vol. 13, No. 8, pp. 562-576.

Funch, D. P. and Marshall, J. (1983).'The role of stress, social support and age in survival from breast cancer.', *Journal of Psychosomatic Research*, Vol. 27, No. 1, pp. 77-83.

Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne, S., and Todd, C. (2009).'Supporting lay carers in end of life: current gaps and future projects', *Palliative Medicine*, Vol. 23, No. 4, pp. 339-344.

Grassi, L. (2007).'Bereavement in families with relatives dying of cancer', *Currrent Opinion in Supportive and Palliative Care*, Vol. 1, No. 1, pp. 43-49.

Guest, G., Bunce, A., and Johnson, L. (2006).'How many interviews are enough?', *Field Methods*, Vol. 18, No. 1, pp. 59-82.

Harding, R. and Higginson, I. (2003).'What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness', *Palliative Medicine*, Vol. 17, No. 1, pp. 62-74.

Help the hospices. Hospice UK Online. http://www.helpthehospices.org.uk/media-centre/press-releases/carers-week/ viewed June 2010. 2010.

Henderson, J. and Forbat, L. (2002).'Relationship-based social policy: personal and policy constructions of 'care'', *Critical Social Policy*, Vol. 22, No. 4, pp. 669-687.

Hubbard, G., Knighting, K., Rowa-Dewar, N., Forbat, L., Illingworth, N., Wilson, M. and Kearney, N. (2007) *Peoples Experience of Cancer within the First Year Following Diagnosis*, University of Stirling, Stirling.

Huberman, M. and Miles, M. (2002) *The qualitative researcher's companion*, London: Sage.

Kearney, N., Hubbard, G., Forbat, L. and Knighting, K. (2007) *Developing Cancer Services: Patient and Carer Experiences.*, University of Stirling., Stirling.

Kissane, D. W., Bloch, S., Burns, W. I., Patrick, J. D., Wallace, C., and MacKenzie, D. (1994).'Perceptions of family functioning and cancer', *Psychooncology*, Vol. 3, No. 4, pp. 259-269.

Kissane, D. W., McKenzie, M., McKenzie, D. P., Forbes, A., O'Neill, I., and Bloch, S. (2003).'Psychosocial morbidity associated with patterns of family functioning in palliative care: baseline data from the Family Focused Grief Therapy controlled trial', *Palliative Medicine*, Vol. 17, No. 6, pp. 527-537.

Madan-Swain, A., Sexson, S. B., Brown, R. T., and Ragab, A. (1993).'Family adaptation and coping among siblings of cancer patients, their brothers and sisters, and nonclinical controls', *The American Journal of Family Therapy*, Vol. 21, No. 1, pp. 60-70.

Mason, B. (1993).'Towards positions of safe uncertainty', *Human Systems: The Journal of Systemic Consultation & Management*, Vol. 4, No. 189-200.

Mehta, A., Cohen, SR., and Chan, LS. (2009).'Palliative care: A need for a family systems approach', *Palliative and Supportive Care*, Vol. 7, No. 2, pp. 235-243.

NCRI (2004) *Supportive and palliative care research in the UK: Report of the NCRI strategic planning group on supportive and palliative care*, National Cancer Research Institute, London.

Payne, S., Smith, P., and Dean, P. (1999).'Identifying the concerns of informal carers in palliative care', *Palliative Medicine*, Vol. 13, No. 1, pp. 37-44.

Persson, C., Östlund, U., Wengström, Y., and Gustavsson, P. (2008).'Health Related Quality of Life in significant others of patients dying from lung cancer', *Palliative Medicine*, Vol. 22, No. 3, pp. 239-247.

Ramirez, A., Addington-Hall, J., and Richards, M. (1998).'ABC of Palliative Care. The carers. ', *British Medical Journal*, Vol. 316, No. 208-211.

Reynolds, P. and Kaplan, G. (2008).'Social connections and risk for cancer: Prospective evidence from the Alameda County Study', *Behavioral Medicine*, Vol. Fall, No. 101-110.

Rolland, JS. (1994) *Families, illness and disability: An integrative treatment model*, New York: Basic Books.

Rolland, JS. (2005).'Cancer and the family: An integrative model', *Cancer (supplement)*, Vol. 104, No. 11, pp. 2584-2595.

Scottish Executive (2005) *Delivering for health*, Scottish Executive, Edinburgh.

Scottish Executive (2006) *Research Governance Framework for Health and Community Care*, Scottish Executive, http://www.research.luht.scot.nhs.uk/ResearchGovernance/ResearchGovernanceFramework.pdf.

Scottish Government (2008) *Living and dying well: A national action plan for palliative and end of life care in Scotland*, Scottish Government, Edinburgh.

Sprehn, GC., Chambers, JE., Syakin, AJ., Konski, A., and Johnstone, AS. (2009).'Decreased cancer survival in individuals separated at time of diagnosis', *Cancer*, Vol. 115, No. 21, pp. 5108-5116.

Thomas, C. and Morris, S. M. (2002).'Informal carers in cancer contexts', *European Journal of Cancer Care*, Vol. 11, No. 3, pp. 178-182.

Tomarken, A., Holland, J., Schachter, S., and et al. (2008).'Factors of complicated grief pre-death in caregivers of cancer patients.', *Psychooncology*, Vol. 17, No. 2, pp. 105-111.

Turner, M., Payne, S., Gluth, J. and Lyons, J. (2009) *Mapping research activity in hospices in the United Kingdom: Project Report*, International observatory on end of life care, Lancaster University.

Wellisch, D. K., Gritz E.R., Schain W., Wang H., and Siau J. (1992).'Psychological functioning of daughters of breast cancer patients. Part II: Characterizing the distressed daughter of the breast cancer patient', *Psychosomatics*, Vol. 33, No. 2, pp. 171-179.

Wennman-Larsen, A., Persson, C., Ostlund, U., Wengstrom, Y., and Gustavsoon, JP. (2009).'Development in quality of relationship between the significant other and the lung cancer patient as perceived by the significant other', *European Journal of Oncology Nursing*, Vol. 12, No. 5, pp. 430-435.

World Health Organisation. WHO Definition of Palliative Care.
http://www.who.int/cancer/palliative/definition/en/ . 2004. World Health Organisation.

Appendix

Diagnoses and demographics

Interviewee	Patient	Carer	Diagnosis
1	Father	Female (daughter)	Liver Failure
2	Daughter	Female (mother)	Lung Failure
3	Husband	Female (wife)	Cancer
4	Husband	Female (wife)	COPD
5	Wife	Male (husband)	Cancer
6	Wife	Male (husband)	Cancer
7	Mother	Female (daughter)	Cancer
8	Husband	Female (wife)	Neurological Disease
9	Husband	Female (wife)	Cancer
10	Husband	Female (wife)	Cancer
11	Daughter	Male & Female (parents)	Cancer
12	Sister	Female (sister)	MS
13	Wife	Male (husband)	Cancer
14	Son	Female (mother)	Cancer
15	Husband	Female (wife)	Cancer
16	Husband	Female (wife)	Cancer