Nursing and Palliative Care

Research Article

ISSN: 2397-9623

Family caregivers' perceptions of an Irish palliative day-care unit: A qualitative descriptive study

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Abstract

Aim and objectives: To describe family caregiver's perceptions of a palliative day-care service.

Background: An emphasis on homecare for patients with advanced disease has meant that family caregivers' have greater responsibilities. Caregivers' can become vulnerable, prone to exhaustion, fatigue, anxiety, sleeplessness, weight loss, burnout, social isolation and general deterioration in health. Palliative day-care can alleviate carer stress and burden by providing care and supporting carers. Little evidence exists of caregivers' perceptions of palliative day-care units.

Design: A descriptive qualitative approach allowed the researchers to elicit family caregivers' perceptions of a palliative day-care unit in Ireland.

Methods: After ethical approval, family caregivers were purposively sampled (n=6) and interviewed (semi-structured). Interviews were transcribed and analysed using Braun and Clarke's (2006) thematic analysis framework.

Results: Three themes were identified: 'transition to palliative day-care', 'effects of caregiving' and 'support'. The study highlights participants' worries and fears within the transition to palliative care but that they welcomed the warm homely environment of palliative day-care. Participants' fears and anxieties alleviated as they were able to share their responsibility with palliative day-care staff who were a valuable source of help. Supports such as respite were valued however, other supports would also be desirable such as caregiver and bereavement support groups.

Conclusions: Overall the study highlights the importance of palliative day-care in supporting caregivers' and further supports required. Services need to respond to caregivers' need for education, support and information around their family member's medical/nursing care, emotional/spiritual/social support and services available to assist them to provide care.

Relevance to clinical practice: This paper reports on the findings of a study which explored caregivers' experiences of palliative day-care. Broadening the support available to caregivers' during and after their time engaged with palliative day-care is a necessity and should address bereavement and caregiver support groups.

Introduction

Over the past two decades therapeutic options for patients with active disease have shifted to outpatient facilities and patients survive longer, which has led to an expansion of the caregiver role and the development of palliative day centres [1]. The World Health Organization (2002) position paper on palliative care emphasizes that family members should be supported during the caring process. With increased longevity palliative day-care is in a favourable position to provide support to families (National Institute for Health and Clinical Excellence – NICE 2004) [2]. An emphasis on home care for patients with advanced disease has meant that family caregivers' are taking on greater responsibilities [3]. The role of the caregiver has become an essential and expansive one, incorporating many tasks of care which can vary from assisting with activities of daily living, medication management and administration, provision of nutritional support, physical care, emotional support, providing transport to appointments and household management [1]. Thereby care giving for this group can be difficult and caregivers' can become vulnerable and prone to exhaustion, fatigue, anxiety, sleeplessness, weight loss, burnout, social isolation and general deterioration in health [4,5].

Professional healthcare support for family caregivers' of palliative care patients is a core tenant of international palliative care philosophy [6]. In order to achieve the best quality of life for patients, it is fundamental to understand their feelings and those of their family [7]. Palliative day-care services aim to support people with progressive illness who wish to be cared for in their own homes, patients may attend the day hospice usually once per week, accessing the multidisciplinary palliative care team during that time [8]. In general, hospice day-care centres provide a supportive environment for people with life limiting illnesses and their families.

The development of palliative day-care can promote the provision of community care, responding to patients and relatives decision to provide care at home and forming an essential link between primary and secondary care [9]. Palliative day-care programmes offer out-of-home supervised activities and socialisation for patients and offer families relief from day-to-day care responsibilities, to enhance the functional independence and quality of life of clients who attend, and enable clients to remain in a home/community setting for as long as

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***Key words:** caregiver, day-care, palliative care, support, transition*

Received: March 29, 2018; **Accepted:** April 20, 2018; **Published:** April 24, 2018

possible [10]. Patients who access palliative or hospice day centres in the main have either a malignant or non-malignant/neurological condition. The facility of day-care provides a combination of medical, social and respite care alongside complimentary therapy, hairdressing, luncheon and attention to personal needs i.e bathing [11,12]. The respite achieved through palliative day-care is a significant important provision, as a common cause of admission to in-patient facilities is the inability of the family caregiver to cope with the stress and exhaustion of looking after a patient at home [13].

Background

Families are complex, and illness of a family member threatens their integrity, thus the diagnosis of a life-threatening illness can exert extreme stress on a family, as someone within the family must assume the role of caregiver [14,15]. With a shift in services to outpatient facilities caregiver roles are expanding [1]. While caring for a loved is rewarding it can also be stressful and exhausting [16,17] with feelings of grief and loss associated with impending death [18,19]. Many factors increase caregiver vulnerability; care burden, restricted activities, fear, insecurity, loneliness, disrupted sleep patterns, facing death and lack of support [17,20]. To support caregivers' palliative day-care centres aim to promote independence and enhance quality of life through management of symptoms and rehabilitation, and provide psychological support in order to reduce stress, anxiety and depression and increase self-esteem and confidence through providing multidisciplinary holistic care and a sense of community [15,21,22]. Referral occurs to provide social interaction, psychological support, carer respite and monitoring/management of symptoms [8].

The nurse in palliative day-care empowers family caregivers' [23], establishes an engaged relationship [1,23], provides information, knowledge and skills [23,24], affirms self-worth [23], and provides reassurance and hope [1,25]. Effective communication utilising verbal and non-verbal skills, personal attributes and knowledge is necessary when supporting caregivers' [4,26]. Family caregivers' have identified that communication regarding the dying process is important to enable them prepare mentally and feel confident in providing physical and emotional care to their loved one [26]. Clayton, *et al.* [27] note that as the patient's illness progresses, caregivers' generally want more information while patients' seek less.

The provision of palliative day-care can bring a sense of normality into the world of caring [28], enabling caregivers' do things that most people take for granted [29]. It also provides opportunities to have time for themselves [15] and contributes to a positive improvement in quality of life [15,29]. To facilitate this healthcare systems should have appropriate supportive mechanisms in place for caregivers' as well as the patient such as; caregiver educational programs, respite services, spiritual and psychological counselling and caregiver support groups [30,31]. The true benefit of palliative day-care for caregivers' can be the ease of access to palliative care health professionals [15]. This helps caregivers' deal with the fear of the unknown and has an overall influence on the caregivers' well-being [32]. For caregivers' there is always room for hope even if the outcome is the death of a loved one [33]. Hope has a positive impact on the coping ability and quality of life of palliative patients' and their family members' [25]. Keeping hope alive is expressed through the nurse's attitude to the whole situation that involves focusing on the present and making the most of the moments given [34,35]. The introduction of meaning based therapeutic approaches could strengthen the patient and caregivers' spiritual resources enabling them to overcome the fear of experiencing and expressing grief [31,36]. There is a need for an understanding of the kind of support palliative day-care provides [37] and creates the focus of this study.

Methods

Aim: To describe family caregiver's perceptions of a palliative day-care service.

Research design: In accordance with the study aim a qualitative descriptive approach was chosen to emphasise the dynamic, holistic and individual aspects of human experience with the purpose being to describe and understand [38,39]. Qualitative research is congruent with the philosophical underpinnings of the interpretive paradigm focusing on human experience whilst attempting to capture the meaning people attribute to them in the context they occur [39,40]. Choosing qualitative descriptive research allows for exploration and description of phenomena in real-life situations [41]. Ethical approval was obtained from the Health Service Research Ethics Committee and access was gained from the Director of Nursing in the service.

Participants and recruitment: A purposive sample of eighteen potential participants were invited to participate by mailing an information leaflet, information sheet and invitation letter. Nine participants responding to the initial contact however, six participants volunteered to participate and proceed with the interview. Participants' were family caregivers' of patients' who attended the palliative day-care unit within the past three years and were at least six months post bereavement. Participants ranged in age from 30-75 years and comprised of two males and four females. Three participants were caregivers' to their spouse and three were caregivers' to a parent. Written informed consent was obtained, confidentiality was protected and participants' had the right to withdraw at any time without prejudice.

Data collection: Data were collected by interviews using a semi-structured qualitative approach in a venue of the participant's choice, lasting 40-55 minutes and audio-recorded to allow for transcription. Interviews were aimed at exploring the participant's perceptions of palliative day-care units and were transcribed verbatim and as analysis progressed questions related to emerging themes were added.

Data analysis: The first author conducted the interviews, and the process of data analysis followed Braun and Clarke's [42] thematic analysis framework. This involved six steps: familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. Two members of the research team reviewed the transcripts independently, and findings were compared and discussed until consensus reached.

Results

Three key themes emerged from the data: 'transition to palliative day-care', 'effects of caregiving' and 'support'. Themes were formulated by placing meaning on the participants' statements and organising the meanings into themes. The themes and subthemes are highlighted in Table 1.

The transition to the palliative day-care unit

The transition to the day-care unit appears to have a dual influence, pre-engagement with day-care brought emotions to the fore for both the patient and the caregiver. Once patients entered day-care the transition was affected by the atmosphere within the environment and carers hope reignited.

Emotions pre-engagement

Participants described their feeling of denial, disbelief, anxiousness, apprehension and worry when their family member was referred to palliative day-care. These feelings stemmed from the participants belief

Table 1. Research themes and essences

Theme	Essence
Transition to palliative day-care	Emotions pre-engagement Hope Palliative day-care atmosphere
Effects of caregiving	Responsibility of caring Caregivers' stress Physical effects of caregiving Rewards of caring
Support	Essence of day-care Respite Additional and future support needs

that their family member would get better and their worry of how their family member would react about going to a palliative day-care unit.

It was the first time that I had realised (name) wasn't going to get better, I thought is this man crazy, we don't need palliative care she's going to get better. I suppose my fear was that she wouldn't have liked it we were worried about how she would react because I didn't know how she would feel about coming into a unit like this (p 3).

Hope

Hope emerged throughout the discussions as a concept that changed and developed over time. From the initial loss of hope when the person was first referred to the development of hope through access and availability of support in the palliative day-care unit to enabling the person to be cared for at home and die with dignity.

At first any hope seemed to be gone but then our hope as a family was that we would have help when we needed help as (name) wanted to be at home, we did what we could but we couldn't do everything so it was nice to know that you could get help without it being in your face (p2).

Palliative day-care atmosphere

The warm peaceful empathic atmosphere of palliative day-care helped alleviate participants' fears and worries and they were in favour of the environment not resembling a hospital environment.

When we walked in we couldn't believe it and everywhere you go seems so nice, I mean there was warmness about it, and it doesn't feel like a hospital that is what I liked about it. Yes I was a little bit frightened I'll be perfectly honest because I thought it would be like a hospital and she had enough of that at that stage obviously it was a completely different thing, totally more relaxed, it felt very open, it was very spacious, I felt more you know there was a homely atmosphere about it, it was very relaxing, peaceful, it's just a very comfortable warm empathetic place and that's beautiful (p 4).

Effects of caregiving on the carer

Caregiving did place a burden and responsibility on carers which caused stress, exhaustion and night time waking, these stemmed from not only the aspect of caring but also the sense of helplessness. While caregiving is demanding participants did appreciate and value the fact that they were able to provide care to their family member at home.

Responsibility of caring

The responsibility of the caregiving role was identified by participants' as falling to one family member (themselves) and having palliative day-care alleviated some of this responsibility and enabled them to continue.

I found it difficult that my other sisters and brother didn't pull an awful lot of weight, she stayed here with me and I went to (place name) all the time with her, I did everything, it was nice to get a break and help, not that I wanted (name) to die but it was a heavy weight and having the palliative day-care helped alleviate some of the responsibility (p5).

Caregivers' stress

Most participants' described being stressed as a result of caregiving at some stage during their loved ones illness. This stress often started at diagnosis where uncertainty was an issue and re-emerged when physical care was required or communication was an issue. However, while stress was evident the aspect of loss of self and the stress that caused for the palliative person was a major factor driving participants' stress.

One of the most difficult things was the lack of communication, when he wasn't able to tell me what he wanted to say, knowing that he was screaming from inside, why couldn't we hear what he was thinking, and not getting it out, that was hell on earth, that was the worst, because he was a talker he loved discussing and all of a sudden that was taken from him, yeah and the fact that you had to do everything for him, I didn't mind doing it, but I know that a person feels that their dignity is gone when someone has to do everything in the line of toiletry care, that was very stressful for me but more so because I know it was stressful for him (p6).

Physical effects of caregiving

The physical effects of caregiving were described by the participants' as; fatigue, exhaustion and burnout often as a result of a lack of sleep. Also participants reported that it took them along time to recover following their role as caregiver to a loved one.

There was many a time when he was gone to bed and gone to sleep and I used to say thanks be to god, I won't see him now till the morning, and that's an awful thing to say but I was holding this in and I often didn't sleep at night, you know, worrying and pure exhaustion, it wasn't that I didn't love him, it was because there was nothing left in me it was the biggest thing I have ever experienced, the hardest thing I've ever experienced (p1).

I'd say I was burnt-out completely afterwards and I had to do a lot of self-care, I had kind of let a lot of that go, I would have let a lot of my own self-care go cos you are just so focused on them and I'm just getting back into nurturing myself after it and I gave myself a lot of space to come back to myself but I had to get a lot of help though (p3).

Rewards of caring

While the caregiver role brought responsibility, strain and stress participants' did appreciate being able to provide such care to their relative in the home and found this to be rewarding and opportunistic in mending past relationships.

I actually became quite possessive of her care, I wanted to care for her and enjoyed having that time with her, unbelievably I actually found the last times here with mom were the closest times we ever had. You know it's kind of like, as if you get a warning to make up for all times in the past (p4).

Support

Support was described by participants throughout the study and while they recognised palliative day-care as a support to provide information, respite and enable them to cope they also highlighted areas where further support is required.

Essence of day-care

Palliative day-care helped caregivers' in several ways as it increased their confidence, provided enlightenment, helped them to cope and was a source of advice. This was achieved through the process of shared care where caregivers' felt included and part of the decision making process.

I did feel a lot more confidence here because I got to rely on the nurses, yeah we did rely on the nurses a lot, but I don't think we could have managed without it, I could have a cup of tea or coffee and sit down and talk to somebody and I didn't feel quite so isolated whereas I did when I went away, I did feel a bit isolated, I must admit I felt that there was always help, you know, even if it was only to make a phone-call, I knew that there was help at the end of the phone the nurses were very helpful if I had questions and I did and I felt supported in every decision (p2).

Respite

Respite was frequently discussed by participants where patients generally attended one day per week. This time created individual space for both the caregivers' and the patient however while participants' were glad to avail of this support others were not keen to avail of it as they preferred to spend as much time as possible with their loved one.

There wasn't a lot of respite until we came to palliative day-care, and I used to look forward to seeing the nurses, I felt that you were sharing the load if you know what I mean, and yes certainly it helped, I mean the fact that I left her in safe hands, I never had to worry about her for a little while, and I could go off and do a bit of shopping or get a little rest, or get a break from it, I know it doesn't sound nice but you just need to restock the batteries if you know what I mean as you're living with it all the time, twenty-four hours a day, and we knew she was happy there (p6).

On the other hand two participants' were not keen to avail of respite services associated with the unit.

All I wanted to do was be with Mom, I didn't need time away, I needed time to be with her, I didn't want to be losing out that time that we had, you know, and I suppose deep down, I probably knew that the time was limited, but I suppose that we grasped with the straws (p1).

Recommendations for future needs for the service

While participants' felt supported by palliative day-care they did identify that this support was limited to once or twice a week and unavailable at weekends. In addition participations identified a need for greater support to deal with certain conditions and that caregiver support would be helpful. After the caring process participants did identify a greater need for bereavement support.

We were only there twice a week, I suppose looking back, maybe if you had, I don't know how to put it now without feeling bad or putting it bad, but you know, there was a time where the caregiver could go to each other and kind of you know spill their guts about their fears and whatever, maybe it would be a good idea as I presume, I wouldn't have been the only one that would have a feeling like that, maybe the option of coming into a meeting some evening or something like that with other carers would be interesting to hear their point of view, I would have liked if it was part of the whole palliative care thing, also a few workshops and maybe not everyone would be interested in that, I suppose, I would have been particularly interested in that how to remain calm, how to deal with certain situations and conditions maybe just how to maybe support them more without burning yourself out, and perhaps a workshop or more training about death and dying (p5).

The thing about is, even when your loved ones pass away or something, like that maybe if there was a group session after you know sort of because you have this care and you just have this crutch and someone dies then all of a sudden that's gone, you're out of the loop again and you are dealing with all the emotions that you had while the illness, of guilt, saying could I have done something else and whatever, and it's all cut off then so your love is gone and the crutch you have is cut away and you are kind of left then, the pillar and supports are gone, maybe that aspect of it, there might be something, after care for the carers, you know (p6).

Discussion

In this study caregivers' and patients' alike experienced a wide range of fears and anxieties regarding the final stages of the disease similar to those documented by Whitehead, *et al.* [43]. The impending death of a loved one can give rise to a wide range of emotional experiences which occur before death and are collectively known as anticipatory grief. Emotions experienced in this study ranged from denial and disbelief to worry, anxiety and apprehension and are also similar to the five stages of grief noted by Kubler-Ross [44]. Duhamel & Dupuis [45] argued that family members may not believe that the patient is terminally ill because they do not believe that they have the capacity to deal with such an eventuality. Transition to palliative day-care can be a difficult time for both the patient and caregiver provoking significant worries for both groups and often the transition causes a realisation that a loved one may not be cured from their illness [46]. Within this study the transition into palliative day-care was more than a physical process and represented the individual's passage from one set of hope to another [47]. Maintaining a sense of hope is central for both caregivers' and their loved ones' [34]. Proot, *el at.* [17] postulates that hope in the sense of realistic hope, (not for a cure) is important to reduce fear, for example hope that their loved one will have a good peaceful death, or that they will live a bit longer.

Benzein [48] highlights that from the family caregivers' perspective, the higher the age of the person, the lower the level of hope and the stronger the experience of hopelessness and fatigue. However, findings from this research study do not correlate with those of Benzein [48] as hope varied significantly between participants' and the experience of fatigue was encountered by both younger and older participants. Participants described hope as being able to access help which would allow them to continue caring at home and keep despair away. The supportive environment of palliative day-care stems from it been seen as a homely warm empathetic atmosphere which helped alleviate participants' fears and anxieties and participants' value the fact that it did not resemble a hospital environment [15,49]. This home like environment was important to participants' as it created a link between person-centred care and the physical environment and acknowledge in other research [50,51]. Thoughtful environmental design is a therapeutic resource promoting well-being and functioning among patients' [52] and improves well-being and quality of life of caregivers' [10,53-55]. Findings from this study highlight the effects of caregiving in that participants' describe the responsibility entailed within the role of caregiver and portrayed that the responsibility of this role was challenging. Caring for a terminally ill relative can be a very stressful time for the caregiver [56] and caring for a terminally ill loved one involves both physical and mental burdens [17]. Where caregivers' often bear an un-measurable emotional burden for their work, where sadness, guilt, anger, resentment and a sense of inadequacy are common and understandable reactions [57,58]. Some of the common physical effects of caring reported in this study included fatigue, lack of sleep, exhaustion and burnout. These correlate with Carter & Chang [59] who demonstrated 95% of caregivers' experienced severe sleep problems and more than 50% exhibited symptoms at a level of risk for clinical depression.

Sleeplessness contributes to anxiety and demoralisation for caregivers' [4] and feelings of guilt are often described by caregivers' as caring can be overwhelmingly both mentally and physically and creates exhaustion with caregivers' expressing feelings of anger, frustration and guilt for losing patience with the care recipient [18]. This places caregivers' under stress [60] and often results in caregivers' neglecting themselves to put the needs of the ill person ahead of their own, minimising the severity of their own problems and sacrificing or delaying their own health care needs [57,61]. Thereby caregivers' should enforce self-care practices such as maintaining one's health and well-being, actively seeking support and maintaining some activity apart from the caregiving role to maintain their physical and emotional well-being.

Palliative day-care provides caregivers' with support mainly in the form of direct contact with a specialist palliative care team [53] and respite helping them to cope by gaining confidence in their role [10,15,51,55]. In addition this study highlights caregivers' expressed that they valued being able to access advice and help when required and that respite was seen as a key support to allow them do everyday activities. Milberg & Strang [62] identify that distracting activities such as walks, reading and household chores are helpful as engaging in such activities; caregivers' were able to think of something other than the caring situation and could take a rest from it. However, further support is required for example a caregivers' support group. Where carers' would be able to discuss their role and issues important to them with other carers in a safe environment and enable them to recognise that they were not alone in their situation and that other carers were facing similar problems [15,58]. Caregivers' support groups can also have an educational focus to support caregivers' prevent against feelings of powerlessness and helplessness, including after the death of the patient [30,62]. Bereavement support for family caregivers' is mandated by international guidelines for palliative care [63]. Providing bereavement support groups would provide an opportunity for caregivers' to meet others going through similar emotional experiences and learn from other people's coping strategies and have people to talk to who were not family members [64]. Within this study following a bereavement some of the participants' could not recall receiving any contact from the palliative care service involved while other participants' expressed that they found it too difficult to return to the unit after their loved one had died. Thereby, not only the provision of bereavement support needs to be considered but also the location of this service needs to be considered with the provision of optional bereavement support group on and off site being available.

While participants' reported negative and challenging aspects of the caregiver role they did however appreciate being able to provide such care to their relative and considered the time together and their role was rewarding. Acting as caregiver can be gratifying for family members and the opportunity to provide care can be seen as a gift where caregivers' felt grateful, blessed honoured and privileged to provide care [18,58]. Creating a sense of togetherness, relationships deepened and personal growth [65] which caregivers' do willingly, in spite of the difficulties experienced [66]. What must be remembered is that caregiving is a dynamic process and it is logical that caregivers' perceived burden and psychosocial concerns will be different at various phases of the caregiving process [65].

Overall caregivers' viewed the palliative day-care as a flexible service that meets the needs of patients' and caregivers' to enable them to stay at home [67], operating within a combined model (social {socialisation and preventative services} and nursing {assessment, treatment and rehabilitation services}) which focused on individual needs [68]. Essentially palliative day-care through providing services based on individual needs ensures therapeutic activities are provided for patients' and this careful planning creates a sense of accomplishment for staff and most importantly contributes to patients' well-being and quality of life [69,70]. Through providing support to patients' in a holistic manner family caregivers' are included and report; satisfaction with the service received [71], responsive communication and a partnership approach [72] and a sense of freedom, relaxation and lowering of stress [73,74]. However, while palliative day-care has an important role [75] there often remains a difficulty in balancing patient preferences and needs [10].

Conclusion

Palliative care provision presents challenges for services to support both patients and their caregivers' and to do this, services need to consider a pragmatic view of the issues and develop realistic, proactive and responsive strategies. However, to achieve this nurses need to listen to the voices of patients and their caregivers' in order to achieve the aim of providing a seamless service that is needs based. This study described family caregivers' perceptions of palliative day-care identifying the transition to palliative day-care as a worrying and fearful time for caregivers'. Noteworthy, is that the principles of normalisation [76] were evident in the relaxed warm homely environment which was appreciated as caregivers' do not wish for a hospital like environment. The role of caregiver is difficult and places responsibility on caregivers' and to effectively function within this role caregivers' require support. While support is provided by palliative day-care (accessible, information, respite, someone to talk to) there is a need for further support such as caregiver support groups and bereavement support groups.

Contributions

Study design: LR, MB, OD; data collection: LR; data analysis LR, MB and manuscript preparation: LR, MB, OD.

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