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Participating in the personal care of a person with a life-limiting illness within the hospice inpatient setting; the informal caregiver's perspective.

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Abstract

Utilising semi structured interviews this descriptive qualitative research study examined informal caregivers' perspectives of participating in the personal care of a person with a life-limiting illness within one hospice inpatient setting.

Ten principal, informal caregivers of hospice inpatients were recruited by means of purposive sampling using posters displayed in the hospice inpatient unit. Thus, participation was entirely "opt- in". A flash card was displayed at the beginning of each interview to determine a definition of personal care. Field notes and digital audio recording were utilised to capture data collected.

Data were thematically analysed and demonstrated that informal caregiver's perceptions of personal care included everything that allowed the patient to remain the person they were. Informal caregivers reported an acceptable balance between being able to carry out personal care and hospice nursing staff involvement, despite no discussions being carried out to establish their wishes. Prior experiences of informal caregiving, and individual caregiver preparedness, contributed to negative and positive feelings about participating in personal care. Informal caregivers reported additional support and education needs associated with being able to participate in the personal care of patients on discharge and in the future.

The emergent themes provide palliative care practitioners with direction for professional practice and research around supporting informal caregivers participating in personal care. Healthcare professionals need to clarify terminology of personal care by having dialogue with informal caregivers and act on this accordingly. But, not all informal caregivers want conversations. Consequently, healthcare professionals should approach this topic sensitively. Healthcare professionals ought to be asking informal caregivers if they wish to participate in personal care. Hospice nurses need to engage, support and educate informal caregivers with

personal care. Furthermore, they should help to maintain and develop the skills of those informal caregivers who want to continue to play this role and not allow them to become deskilled.

Introduction

Palliative care is recognised as an approach that focuses on enhancing quality of life of individuals and their families who are facing any advanced, life-limiting illness (World Health Organisation (WHO), 2008, National Council for Palliative Care (NCPC), 2015). The National Institute for Health and Care Excellence (NICE) (2017) stresses that physical, emotional, psychosocial and spiritual support are imperative for effective palliative care. Hospices specialise in providing palliative care to patients and their families and their models of care delivery reflect the fundamental aims of palliative care. By virtue of the range of services they provide and their location within communities, hospices are well-placed to support and complement the care that patients already receive from family members or friends playing an informal caregiver role.

Currently, there are estimated to be over six million informal caregivers in the UK (759,000 in Scotland) (Carers Scotland, 2019), with that figure forecast to rise as the population ages and "formal" service provision declines (Cavaye and Watts, 2016). No informal caregiver statistics appear to be available for separate institutional settings. However over three hundred patients were admitted to one hospice inpatient setting (the research site) last year, and each would presumably have had at least one (and possibly two) main informal caregivers. Hence, the research site cared for and supported at least three hundred informal caregivers in the last year.

The significance of informal caregivers has been recognised in various countries (Stoltz et al, 2006). In Australia, for instance, there are five times more family caregivers than paid carers (Australian Institute of Health and Welfare, 2003). Meanwhile Carers Scotland (2019) has estimated that informal caregivers save the Scottish economy £10.3billion (which is close to the cost of providing all NHS services in Scotland). In Canada, family members provide 80–90% of care in the home environment (Romanow, 2002).

Family care-giving in institutions has received significantly less attention, but is nonetheless common in some countries. For instance, in Greece, informal care has been shown to occur in most hospitals (Sapountzi - Krepia et al, 2008). Bellou and Gerogianni (1991) and Sapountz – Krepia et al (2008) have suggested that this level of family involvement is encouraged by the provision of flexible visiting hours. In the local health board connected to this study, the introduction of flexible visiting hours has been associated with improved patient satisfaction (Trueland, 2014). However there is no known evidence to suggest a link with the provision of personal care by informal caregivers and flexible visiting hours. The hospice concerned with the current study also offers open visiting. Again, no analysis of its impact on personal care provision by informal caregivers has been attempted, hence, the importance of this study.

La Cour et al (2009) and Strohbuecker et al (2011) have shown that informal caregivers who assisted with a patients' personal care at home and continued to do so within the hospital environment managed to retain a sense of control, dignity and autonomy. However no such correlation has been demonstrated in the hospice setting. Instead, Tiberini and Richardson (2015) found that personal care is delivered almost exclusively by hospice nurses without taking into account informal caregivers' capability or desire to be involved.

The study described here was undertaken to add to the rather limited knowledge base around the role of informal caregivers after the recipient of their care has been admitted to a hospice in-patient setting. It aimed to capture the views, attitudes and preferences of informal caregivers regarding participating in the personal care of a patient during a hospice stay, employing an interviewing technique to gather data. The principal focus was on answering the following research questions:

• What are the views, attitudes and preferences of informal caregivers about participating in the personal care of a loved one during a hospice stay?

• What are the prior experiences of informal caregivers in terms of participating in the personal care of a loved one?

• What advantages and disadvantages do informal caregivers identify in terms of participating in the personal care of a loved one during a hospice stay?

Methodology

Ethical approval was gained from the University of the West of Scotland, local health board and the researcher's employer prior to this research being carried out. A qualitative approach was chosen on the basis that human behaviour is best interpreted by exploring interactions between people in order to make sense of the world (Gerrish and Lacey, 2010, Polit and Beck, 2014). Because a straightforward description of a readily-observed phenomenon was required, a qualitative, descriptive approach was employed (Sandelowski 2000). Given the relatively transient nature of the hospice informal caregiver population, it was decided that in-depth, one to one, semi-structured interviewing was most fitting for the research proposed.

The research was carried out at a hospice north of Glasgow which was established in the 1980's. The hospice is an independent charity delivering tertiary care, part-funded by the NHS and partly by the hospice charity. The in-patient unit, which was the specific site for this research study, looks after twenty four patients and their families at any one time.

The study population consisted of informal caregivers of patients within the hospice inpatient setting. Inclusion criteria included the following: Participants should be at a stable period of time in the patients' illness; Ability to speak English (since no translation facilities were available); Over the age of sixteen years; Not known to the researcher and Capacity to consent.

Recruitment of participants was completely "opt-in", using posters in the ward setting. Any person who expressed an interest in the study on the basis of reading the poster was given a copy of the Participant Information Sheet by a member of the ward team. Thereafter, each individual was approached by a member of the research team to ascertain if they were still interested in taking part. If so, a suitable date was agreed for an interview to take place.

The Interviews were based around the following prompts:

* What are your views/experiences of participating in a loved one's personal care?

* What are your views of informal caregivers participating in a loved one's personal care whilst in the hospice setting?

* What is your experience of participating in your loved one's personal care in the hospice setting?

* How much personal care have you participated in since your loved one's admission?

* How would you feel if it were possible for informal caregivers to participate more in care?

* Can you tell me if you think there are any advantages or disadvantages to participating in a loved one's personal care in the hospice setting?

* Can you tell me your views/experiences of seeing your loved one's personal care being carried out by hospice staff?

* Can you tell me your views of healthcare professionals encouraging informal caregivers to maintain their role of participating in a loved one's personal care when they are admitted to the hospice?

A flash card was displayed at the beginning of each interview so that there was agreement on the definition of personal care between the author and participant. Published definitions of personal care are not adequate (Department of Health, 2001). Therefore, over time, the author had previously asked non participating informal caregivers out with this study and during general day to day discussion what personal care meant to them. These results had been used to develop the flash card. Field notes and electronic audiotaping were utilised to record information (Tubey et al, 2015).

Results

Ten informal caregivers were interviewed, consisting of eight women and two men. Of the eight female participants, six were daughters, one was a wife and another was a friend of the patient. Of the two male participants, one was a husband of a patient while the other was a partner. All participants were of Caucasian origin.

Interview transcripts were transcribed verbatim and analysed using the six-step thematic analysis of Braun and Clarke (2006). This led to the emergence of four themes and nine subthemes as shown in Table 1. Each of these is discussed below and illustrated by verbatim quotes.

Table 1. Themes and sub-themes emerging from the analysis of interview transcripts.

1. Breadth and Depth (a). All rounded; (b). The spectrum.

2. Moulding Care (a). Keeping things normal; (b). Offered, not imposed.

3. The Recall (a). Crossing the line; (b). Preparedness.

4. The Timeline (a). What's happening to my life; (b).Dipping in and out; (c). Still a learning process.

Participants emphasised the breadth and depth of what personal care meant to them, giving varying accounts which contained physical, social, emotional, psychological and spiritual elements:

anything from(…) personal grooming to keeping sort of interest in certain activities going, making sure they are comfortable, maybe having familiar things from home. (Participant 5, lines 96-120)

I would do her personal care for her, things like banking, that's quite personal. Even things like getting wee birthday, wee Christmas presents. To me, that's personal care because you're looking after who my mum technically is. (Participant 4, lines 194-221)

Subtheme 1(a). All rounded: This sub-theme emerged when informal caregivers described how they had to meet the full range of needs of the person.

Personal care is making sure the person, all their needs are catered for. It's treating somebody just as if they were at home (…) looking after themselves at home. (Participant 1, lines 66-67)

It's everything from actual personal physical care up to the sort of spiritual, it's the whole, holistic package. I think it makes the person remain the person they are. (Participant 7, lines 37-38, 49-50)

Subtheme 1(b). The spectrum: A wide spectrum of informal caregivers' understanding of personal care was evident. In contrast to the understanding of personal care in the literature, all participants regarded personal care as having more than just a physical element.

(…) feel like a woman again, feminine, (…) as though she still is a part of life. (Participant 2, lines 838-859, 881-884)

My role is very much is the psychological support, so you're a confidant (…). (Participant 10, lines 69-90)

Indeed, the informal caregivers recognised the "personal" element and the inappropriateness of having a "one size fits all" approach to personal care.

I don't think it's something you could do a policy on. (…) very, very personal. (Participant 3, lines 558-562)

Theme 2. Moulding care:

This theme emerged from the informal caregivers' disclosures about how their wishes about their role influenced the care that patients received in the hospice setting, with some participants wishing to do as much as they possibly could and others recognising their own limitations.

You bring as much of home as you can to her. (Participant 5, lines 449-458)

Me doing it that's no dignity, (…) that's taboo. (Participant 8, lines 567-578)

Subtheme 2(a). Keeping things normal: The desire (on the part of informal caregivers) to keep things normal for patients had a significant influence on the care informal caregivers provided, with several participants emphasising its importance. Participants stressed the importance of maintaining as much normality around personal care in the hospice setting as possible whilst trying to mirror the routine that was followed at home.

It's an extension, (…) of almost the same that happens at home, (…) a way of continuing that. (…) just the wee touches that are them. (Participant 7, lines 189-245)

Trying to let her lead the process to an extent, so that she's comfortable with what's happening and not imposing anything new on her. (Participant 7, lines 124-133)

Additionally, several informal caregivers discussed their striving to maintain normality in their own lives.

I would still try and lead a kind of normal life, (…) wondering if I'd come back and find him alive. I've lived, lived on a knife edge but still doing everything possible to keep life normal. (Participant 1, lines 252-261)

Subtheme 2(b). Offered, not imposed: This subtheme provides more information about how informal caregivers' perceptions about their role moulded their participation in personal care in the hospice.

I'd hold the mirror so she could brush her own hair. Then, ultimately, she was holding the mirror while I'd brushed her hair (…) ultimately, I was holding the mirror and brushing her hair. (,,,). She would just do her usual routine (…) made her feel good (…) she was still taking care of herself. (Participant 2, lines 1032-1039)

(…) depend very much on what I was required to do. (…) Beyond that, no, and he'd be mortified, I couldn't do that to him even if I could do it. (Participant 3, lines 389-433)

Theme 3. The recall:

Within this theme, informal caregivers recalled their experiences of crossing a line or boundary, with previous caregiving roles influencing their feelings about participating in personal care in the hospice setting. Additionally, they explored their preparedness to participate in this care.

(…) people have to go back to their lives and the rest of the world doesn't stop (…), so it's kind of getting that balance. (Participant 6, lines 603-615).

Subtheme 3(a). Crossing the line: Many informal caregivers identified the responsibilities of and lack of alternatives available to them in previous caregiving roles as factors that influenced their desire (or not) to participate in personal care in the hospice.

(…), huge responsibility is put on (…) you can't even get out the house (…) can't leave that person. So (…) anything that can be done to enhance. (Participant 1, lines 746-753)

Because my professional knowledge, I wasn't asked I was expected to (…) I didn't feel I could say no (…). It crosses a line and I didn't speak out. (Participant 10, lines 180-187)

One individual recalled a previous caregiving role positively, but also understood where the boundaries of her present participation in personal care ended.

(…) an absolute privilege to build that love through my personal care. (…). With my mum, no I stood back from that. (…) thinking ahead, I probably will stand back when John (pseudoymn) dies. No, that's where my personal care has ended. (Participant 1, lines 525-526, 602-604)

One participant reported that fears and reservations from a previous caregiving role had been alleviated, and expressed confidence about participating in the patient's personal care in the hospice.

(…) I was a coward, (…) not now. (Participant 4, line 15)

Subtheme 3(b). The preparedness: The preparedness (or not) of informal caregivers to participate in personal care in the hospice environment led to the "preparedness" subtheme emerging. All participants spoke particularly about their preparedness to allow hospice nurses to take over at least some of the patient's personal care which they had previously been doing.

(…) it's quicker to make a pot of soup yourself than it is to teach children (…) it will be the same (…) in some aspects of personal care, it's not necessarily going to make it more efficient for your staff. (…) For the first few days when the family are tired, I think the last thing they want is doing it badly. (Participant 10, lines 346-354)

Families step back (…) I think that's okay because I certainly feel that if someone wanted to be involved or the patient wanted the family to be involved, the hospice would facilitate that and there wouldn't be a problem with it. (…) families are probably in need of that rest and that break just as much as the person. So, (…) I think the families are relieved that that aspect has been taken care of by someone else. (Participant 10, lines 160-174)

Further, two informal caregivers found that their preconceptions about hospice care influenced their preparedness to get involved.

I'd say that probably doesn't happen at the moment because traditionally the expectation in a hospice, I think, is that family visit and bring grapes but that's where it ends. (Participant 10, lines 278-280)

Informal caregivers in particular spoke about the struggle they went through as they prepared to hand over the responsibility for care to the hospice nurses.

It's a very fine line, (…) when you come in and somebody takes over, that's difficult. That had been my responsibility for all those months. (Participant 1, lines 325-347)

Theme 4. The Timeline: This theme produced a further three subthemes. The first of these was 'What's happening to my life' (past) which explored the negative impact of the caregiver role, pre-admission, on decision-making around participating in personal care. The second subtheme captured the experiences of the informal caregiver's participation in the hospice and is called 'dipping in and out' (present). Thirdly, the informal caregivers' understanding of their role as 'still a learning process' (future) led to the emergence of the third subtheme.

(…) It's your own feelings that comes into it, it's a personal thing, (…), everybody's got their own way of looking at everything, tackling everything, stress wise and all the rest of it. (Participant 8, lines 258-260)

Subtheme 4(a). What's happening to my life: All ten participants talked about how negative experiences of the caregiver role prior to the patient's admission to the hospice had impacted on their decisions regarding participating in personal care in the hospice.

I would get angry, (…) annoyed (…) do I need to cut back on my work? (…) what's happening to me? (…) my life? Then, the guilt would step in. So, it's a vicious circle, but normal feelings. A roller coaster of emotion. (Participant 1, lines 263-272)

Carers become carers with no training whatsoever. You wouldn't allow an auxiliary to come on a ward with no training whatsoever (…) relatives just start to pick this role up and really don't know what they are doing (…). (Participant 7, lines 421-427)

Subtheme 4(b). Dipping in and out: Informal caregivers had different experiences of participating in personal care in the hospice. One reported that she was able to communicate with the nurses regarding the patients' wishes.

I would be able to say what her regime (…) was and you felt we were able to support them as well and help my mum as well. (Participant 4, lines 1123-1133)

However the other nine reported that no discussion had taken place, although they were generally positive about the balance eventually reached.

(…) staff will pick that up through body language. Yeah, seeing that if a family want involved and they all know whether to pull back or move forward. (…) They can read a room, it's like a stage. (Participant 1, lines 696-711)

Being able to "dip in and out" was a strong feature of the informal caregivers' evidence.

And you were able to dip in and out, but I didn't have to do it. (Participant 4, lines 1392-1396)

It's a privilege to take care of her (…) you wouldn't not do it and in some respects actually it also takes some of the burden off the staff because the staff in here work really hard, so if you can come in and even do the wee odd bits and pieces. (Participant 7, lines 200-226)

All ten participants also described how a fine balance was reached between their own participation and that of the nurses.

The staff appreciate see you do that and just allow you to do it. A fine balance. (Participant 1, lines 424-427)

When I came in, the nurse's didnae (…) take over. I got her into her bed and everything (…) I thought, they let me do that there and it was like I (…) settled her in. (Participant 4, lines 581-593)

One participant however identified benefits to having strict role boundaries covering participation with personal care.

Sometimes mum won't ask the nurse for help, she'll ask us instead (…) sometimes it's good to have strict roles as well. (…) We'll (…) wait and ask a nurse. I think it's an individual thing. (Participant 6, lines 907-928)

Furthermore, three informal caregivers made reference to there being limits to participating, although there was no real consensus as to what the limits consisted of.

There's stuff that seems to be rules. You're allowed to do what you need to do and my sense is that anything that wasn't done would be picked up sensitively and quietly. Nobody asks you what have you done or are you gonny do, you're just allowed to (…). They let me do that and that's quite important (…), it's just what I would normally do, that's not just taken off you (…). (Participant 4, lines 788-808)

I was comfortable enough to do what I could do, but sensible enough to know I wouldn't have done anything that if I felt it was inappropriate, I would asked first, I kind of know where the boundaries are. (Participant 7, lines 395-399)

One informal caregiver expressed her unawareness of what she was allowed to do.

I don't think we knew if we could do anything. So, I didn't know whether and I never thought to ask, to say (…) I think sometimes when someone goes into hospital or a hospice, we think, Oh, they've got to be there, we're not allowed. (Participant 3, lines 568-576)

Additionally, one informal caregiver highlighted that the hospice nurses defined the boundaries.

I think one of the things that's funny in a way that if they're coming in to reposition her in the bed but you've got to get up and out the room. I've been with her 46 years. There's not an area that hasn't been seen at some stage in our time. (Participant 9, lines 189-196)

Subtheme 4(c) Still a learning process: This subtheme emerged from comments about what can still be learned about participating in the personal care of the patient in the hospice setting. Two informal caregivers understood the importance of further discussions around participating with personal care.

I think it would be nice to have that conversation especially if they have been very involved and the conversation would be about you can continue to take part in the caregiving if you want and if your loved one wants that but you don't have to. I think that whole thing about you might actually (…) (Participant 10, lines 234-238)

(…) It would be a discussion both in terms what that caregiver wanted, prepared to do and setting boundaries from the hospice perspective so that they don't come in and cause you problems. (Participant 7, lines 387-390)

Nevertheless, several of the informal caregivers spoke about the challenges that hospice nurses may face when aiming to have open conversations with informal caregivers.

(…) The professional judgement about the individual whether encouraging them was good to keep the connections going although it's a bad thing cos the individual then felt they were under pressure even when the person was in a care setting. To actually have to do something

where they just need the break. I have seen that with families where they get to the real end of their rag, particularly if it's only one individual that's doing the care. (Participant 7, lines 355-367).

Nonetheless, one participant emphasised the importance of having open discussions around participating with personal care in the hospice.

I could see you could get really interfering relatives which might be an absolute pain to the nursing staff, so I think you would have to be boundaries to it, a discussion about it not just coming in there and doing things. (Participant 7, lines 301-307)

Discussion

The terms "personal care" and "personal hygiene" are often used interchangeably by professional care providers (Department of Health, 2001, Peate and Lane, 2015). However although they acknowledged the physical and hygiene elements to personal care, the informal caregivers in this study placed particular emphasis on "breadth and depth" of the caregiver's role and the "all rounded" nature of that care. This awareness of the holistic nature of personal care was consistent with the definition of palliative care where "the spectrum" of psychological, social, emotional and spiritual aspects are equally significant to ensuring the patient is maintained as the person they are, despite advancing illness" (WHO, 2008). O'Hare et al (2017) and Zeng et al (2017) acknowledge the complexities that are associated with adopting the informal caregiving role and looking after a person's holistic as well as personal care needs. The "not one size fits all" approach to personal care is described as a synonym of person centred care. This "made to measure" perspective (Van der Cingel et al, 2016) was a consistent feature of the informal caregiver reports in this study.

Florin et al (2005) and Uitterhoeve et al (2008) found that informal caregivers in other inpatient settings seldom offer personal information on what really matters to them, therefore, the significance of also exploring the informal caregiver's viewpoint on personal care remains imperative. Furthermore, Healthcare Improvement Scotland (2017) determine person-centred care as co-ordinated with "what matters to you?" This focus enables personal care goals by giving opportunity to involve people who matter most.

Widely across Scotland, informal caregivers express a desire for continuity, partnerships and shared decision-making (Scottish Government, 2010, Hagedoorn et al, 2019), therefore, it comes as no surprise that the theme of "moulding care" emerged in this study. Moreover, the informal caregivers in the current study expressed a desire to be in partnership with hospice nurses when deciding about their participation in personal care.

As already discussed, particular emphasis was placed by interviewees on "keeping things normal" in connection with participating in personal care. Johnston et al (2012) and Richardson et al (2015) have reported that patients regard maintaining normality as pivotal to them, albeit, no other studies have explored personal care specifically. The current study argues that it is imperative to preserve a patients' usual practices of self-care to maintain their sense of self (Ekman et al, 2004, McClement et al, 2004, Johnston et al, 2012) which contributes to "everything that makes the person remain who they are".

The informal caregivers in this study experienced negative and positive reactions in caregiving situations, yet the latter do not appear to have received much attention until recently (Andren

and Elmstahl, 2005). Savage and Bailey (2004) and Stamataki et al's (2014) findings coincide with the informal caregivers in this study, expressing willingness and contentment to "keep things normal" for the patient. Agreeing with this, Stamataki et al (2014) discovered that it was important for carers to keep their life as normal as possible throughout the patients' illness. Nevertheless, the author remains aware of the impact of maintaining that normality. Interestingly, Molassiotis et al's (2011) study of the experiences of patients and informal caregivers living with cancer described the same feeling of "living on a knife edge".

The informal caregivers in this study understood the high levels of dependence on personal care that patients experienced. Regardless of dependency, they displayed a consistency around their perceptions of personal care being "offered, not imposed". Interestingly, they also had a coordinated focus analogous to the rehabilitative palliative care approach, where they attempted to provide sufficient support to empower individuals to live as fully as possible, within the limitations of advancing illness (Hospice UK, 2017). Likewise, they found individual ways to give patients greater independence, autonomy, choice and dignity whilst participating in their personal care in the hospice environment. Although not specifically in the hospice setting, Beanlands et al (2005) and Chang and Yu (2013) found positive attitudes expressed by informal caregivers when they were able to provide autonomy and choice around personal care to patients.

As evidenced in the recall theme, the informal caregivers explored crossing the line from previous caregiving roles to their current situation of participating in personal care in the hospice setting. Taylor (2010) and Cobb et al (2016) discovered that previous caregiving experiences are valuable in preparing informal caregivers for their current caregiving situation. Consistent with Taylor (2010) and Cobb et al (2016), this study found only a minority of informal caregivers expressing positive feelings about the impact of previous caregiving roles. Most found that experiences of previous caregiving negatively affected their preparedness to participate in personal care in the hospice environment. Funk et al (2010) and Hudson et al (2011) acknowledge that informal caregivers frequently feel inadequately prepared for taking over care responsibilities in a new environment (Stajduhar and Cohen, 2009). Nevertheless, none of these studies were carried out in a hospice environment.

The informal caregivers in this study revealed that their own understanding and expectation of hospice care was a restriction on participating in personal care, albeit some acknowledged the need for respite from their caring role. Consistent with this finding, Haesler et al (2007) found that family members faced difficulty in handing over the responsibility for a patient's personal care to healthcare professionals. Conversely, some of the informal caregivers in this study suggested that although they had been participating in personal care at home, it was not their place to do this in the hospice. Egan and Abbott (2002) have challenged palliative care professionals to step back and allow informal caregivers and patients to direct them as to the particular balance they want.

There is considerable variation in how people react to their caregiver experiences, therefore, the need for discussion around informal caregiver wishes and preferences remains crucial. In support of this, Foley et al (2005) have concluded that the role of the hospice nurse is to provide support, education, respite and other services so that informal caregivers can manage their responsibilities around participating in personal care. Preparedness facilitates the transition experience and related to this is knowledge about what informal caregivers expect during a transition and what strategies may be helpful in managing participation with personal care, something that could be supported by nursing interventions (Meleis et al, 2000). Additionally,

Cagle and Kovacs (2009) emphasise that hospice staff can help informal caregivers feel better prepared to deal with the many unknowns of participating in personal care, while also reassuring them that they are not expected to handle these alone.

A plethora of literature reveals that informal caregivers' needs can be neglected or rarely valued (Bevans and Sternberg, 2012, Meneguin et al, 2016) and whilst no other studies have focused on the hospice setting, these findings are consistent with the informal caregiver's rollercoaster of emotions expressed in this study (Given and Reinhard, 2017). However, although it is supported by the informal caregivers' testimonies in the current study, guidance on carers giving personal care and support remains fragmented (Given and Reinhard, 2017). Burton et al (2012) discovered that caregivers report low levels of preparedness for providing care and often indicate they do not have the knowledge and skills needed to do so. The focus on "preparedness" in this study suggests this remains a prominent concern.

The World Health Organisation (2008) defines palliative care as an approach that aims to prevent and relieve suffering by early identification and impeccable assessment of problems. The process involves offering informal caregivers the opportunity to discuss significant issues, taking into account all possible care options, as well as the patients' and informal caregivers needs and preferences (Verschuur et al, 2014). An abundance of studies have detected the need for effective communication between informal caregivers and healthcare professionals (Yedidia and Tiedemann, 2008, Levesque et al, 2010, Stirling et al, 2010). Yet, the informal caregivers in this study highlighted that no discussions occurred around their wishes or preferences regarding participating in personal care. Consequently, this would appear to be a fundamental way in which the aims of palliative care are not being met. Additionally, personal care wishes are so diverse that unless discussion takes place, personal care needs cannot be fully assessed and respected. The participants here did hint at the existence of a partnership with hospice nurses which was mostly non-verbal and yet was quite effective at assessing informal caregivers' wishes to participate. O'Shea et al (2014) report that a co-operative approach to care in which families and staff have agreed roles is vital. Nevertheless the informal caregivers in this study appeared to appreciate being able to "dip in and out" of participating in personal care with no clearly defined roles established.

Although informal caregivers' participation in personal care can benefit both patients and informal caregivers (Bauer, 2006), caregivers are often confused about boundaries in the inpatient environment (Janzen, 2001, Bauer, 2006). Some informal caregivers acknowledged strict roles whilst others were unsure what boundaries existed, if any. This study suggests that informal caregivers believe that hospice nurses set the boundaries and perceive that those boundaries affect their preparedness to participate in personal care.

Bramble et al (2009) have argued that effective communication is imperative to enable informal caregivers to fulfil their role in care. Moreover, O'Shea et al (2014) recommend that the respective roles of informal caregivers and staff need to be outlined at the point of admission to care, although this study did not involve a hospice setting. Several informal caregivers in this study made reference to the potential challenges and detriment to informal caregivers should overt discussion regarding their participation in personal care in the hospice setting occur. Nevertheless others found these conversations beneficial and recognised that participating in the personal care of a patient in the hospice setting is "still a learning process".

Conclusions

It is important to reiterate that the person responsible for the collection of the data presented here also works in the hospice where the study took place. It is acknowledged that the credibility of this researcher could be questioned. However this risk was minimised by adhering to good research practice and practicing reflexivity (Polit and Beck, 2014). This research was performed in a single inpatient hospice environment with particular attention paid to the perspective of adult informal caregivers. Accordingly, the findings may not be generalizable to wider populations. Nevertheless, the emerging themes identified here may provide palliative care practitioners with direction for professional practice and research.

Despite the author examining an under-researched area of the informal caregiver perspective, the results echo the demands in the literature to seek out and explore what matters to informal caregivers to ensure they remain partners in shaping patients' care.

While this research was unique in exploring informal caregivers' perceptions of participating in personal care in the hospice environment, there are close links with research carried out in other settings regarding the positive experiences of informal caregivers respecting the patient's choice and autonomy when participating in care. Further, this study contributes interesting findings around informal caregivers' preparedness to participate in personal care following the transition to the hospice. The available literature has not explored attitudes towards participation in personal care in the hospice, therefore these findings add new information to the evidence base.

The findings coincided with the plethora of literature that highlights the need for effective communication between informal caregivers and healthcare professionals and while the literature recommends that discussions about roles should take place at the point of admission, some informal caregivers of hospice patients are not calling for this. This study found that informal caregivers feel ill-equipped where practical support from healthcare professionals is fragmented, and were uncertain as to the boundaries that affect their participation in personal care. A lack of discussion around participation with personal care in the hospice environment was strongly evident. Hospice nurses clearly need to engage, support and educate informal caregivers around participating in personal care. Furthermore, healthcare professionals should help maintain the skills of those who want to care and not disempower them. It is apparent that healthcare professionals need to use clear terminology and to have dialogue with informal caregivers about their perceptions of personal care. It should be remembered, however, that not all informal caregivers want to have these conversations. Therefore healthcare professionals should approach this topic sensitively.

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