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Carer Experience Supporting Someone With Dementia and Cancer: A Narrative Approach

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Abstract

In this article, we examine the challenges of informal carers supporting someone with dementia and cancer within the United Kingdom. Interviews were conducted with seven informal carers using a narrative approach to examine the construction of their experiences. Our findings demonstrate how informal carers navigate a path through complex cancer treatments and support their relative. A cancer diagnosis often requires multiple treatment visits to an oncology center, and this can be challenging for carers. They find that they need to coordinate and manage both health professionals and their relative in terms of getting access to appropriate services and support. This process can be particularly challenging in the presence of a cognitive impairment that often demands effective communication with different agencies. Carers frequently experienced multiple challenges including dealing with the stigma that is characteristic of the dementia experience and the added complexity of negotiating this within a cancer care context.

Keywords

cancer; carers; dementia; narrative; qualitative; narrative analysis; Europe.

Introduction

People living with dementia may present with a number of co-morbidities, cancer being one. Cancer is a common disease of older age with 36% of all cancers affecting people older than 75 years (Office of National Statistics, 2010). There are more than 815,000 people living with dementia in the United Kingdom, affecting one in 14 of the population more than 65 years of age (Alzheimer's Society, 2014). The worldwide prevalence of people with dementia in 2010 was 35.6 million (Alzheimer's Disease International, 2010) and for cancer in 2012, it was 14.1 million (Cancer Research UK, n.d.). The probability of co-occurrence of both dementia and cancer in the same patient increases with age and is associated with a poorer survival rate post diagnosis (Chang et al., 2014; Gorin, Heck, Albert, & Hershman, 2005; Kimmick, Fleming, & Sabatino, 2014; Patnaik, Byers, Diguseppi, Denberg, & Dabelea, 2011; Raji, Kuo, Freeman, & Goodwin, 2008; Robb, Boulware, Overcash, & Extermann, 2010). Importantly, a dementia diagnosis is associated with increased odds of being diagnosed at an unknown stage of cancer or at autopsy, and an increased likelihood of not receiving any cancer treatment (Baillargeon et al., 2011; Gupta & Lamont, 2004). Gorin et al. (2005) found that patients with dementia were 52% less likely to have surgical resection, 41% less likely to have radiation, 39%

less likely to have chemotherapy, and 2.7 times more likely to receive no treatment than those without a diagnosis of dementia. These statistics clearly evidence the disparity in terms of how treatment and support is offered to those with and without these conditions. Courtier et al. (2016) undertook a single site, case study design to explore the experiences of cancer treatment in people with dementia. The findings suggest that the exploration of memory loss was superficially based on patient or carer disclosure. Patients were found to underplay the importance and extent of memory problems in cancer consultations, and staff found assessment challenging. There appeared an avoidance to explore memory without an obvious therapeutic gain. There was a lack of communication of a dementia diagnosis in referrals to cancer centers and a concern that patient disclosure would adversely affect treatment decisions. There were issues related to monitoring side effects and carer communication. This required subtle negotiations between staff and

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the person with dementia particularly surrounding decision making. These findings were confirmed in a systematic review (Hopkinson, Milton, King, & Edwards, 2016), indicating that, compared with cancer patients who do not have dementia, people treated for cancer with preexisting dementia are diagnosed at a later or unknown stage, and receive less treatment with more treatment complications and poorer survival. This highlights the challenge for carers in advocating and negotiating treatment implications with their relative and health professional. There was a clear lack of proactive communication and support from staff to carers, and carers appeared not to seek support themselves.

Within the United Kingdom, family carers are integral to supporting someone with dementia with two thirds of people with dementia living at home (Knapp, Comas-Herrera, Somani, & Banerjee, 2007). Receiving a dementia diagnosis can be a challenging process. For carers, this can be a convoluted experience. There is a reluctance to diagnose by general practitioners due to a fear of stigma (Werner, Goldstein, & Buchbinder, 2010), time limitations that negatively affect on their ability to formally assess people, and diagnostic uncertainty (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Koch & Iliffe, 2010). Carer burden can be significant within the context of a cancer diagnosis (Li, Mak, & Loke, 2013). There is a general acknowledgment within the cancer literature of the invisibility of carer identity (Seal, Murray, & Seddon, 2015; Smith, 2009), both of which significantly and negatively affect carers. There are also significant unmet needs of the carers, such as anxiety and depression, fatigue, financial difficulties, issues with work, and social isolation (Hubbard, Illingworth, Rowa-Dewar, Forbat, & Kearney, 2010; Heckel et al., 2015). The burden of care can be a time-consuming activity with repeated outpatient appointments, difficulties with accessing appropriate transport, and carrying out added domestic work associated with the conditions (Stenberg, Rowland, & Miaskowski, 2010). Within the context of dementia care, these time-consuming extra activities involving cancer treatment can add to the burden associated with changing role patterns, the continuous nature of caregiving required, and the lack of control and uncertainty of the situation (Schoenmakers, Buntinx, & Delepeleire, 2010).

Caregiver grief at their relative/friend's deterioration was also a feature of this process, with caregiver grief scores highest among carers providing support for patients with profound dementia (Warchol-Biedermann et al., 2014). There is evidence of poor communication with formalized care providers leading to unmet needs at home (Egdell, 2013). The loss of cognitive abilities of the care recipient meant some of the positive narratives in cancer care, such as facing the cancer together, personal growth, and becoming stronger by spending time together

(Li & Loke, 2013), do not apply within a dementia context. This was particularly evident in the presence of carer depression, an issue affecting quality of life generally for carers of people living with dementia (Bruvik, Ulstein, Ranhoff, & Engedal, 2012).

The wider cultural context for caregivers is often situated within a common cultural frame that views people living with dementia as having lost a sense of personhood, as Davis (2004) comments, "Dementia, even in the early stages, represents a fraying of the self" (p. 375). The framing of memory loss has typically been through a biomedical discourse of loss (Beard & Fox, 2008) with dementia characterized as the slow goodbye and leading to the destruction of self in spite of literature portraying individuals living well with dementia (Basting, 2009; Beard, Knauss, & Moyer, 2009; MacRae, 2010). People with dementia have been characterized as the living dead (Aquilina & Hughes, 2006) and zombies (Behuniak, 2011), with these perceptions pointing to what Agamben (1998) refers to as a space without rights located between life and death. Maintaining a sense of personhood within dementia care and preventing what Sweeting and Gilhooly (1997) describe as a "social death" for people living with dementia has been an integral part of the work of Kitwood (1997). Within his concept of personhood, standing or status is bestowed on one human being by another and is situated relationally as we are social beings. It moves from a reductionist approach based on a biomedical model to examine the psychosocial process that prevent "positive person work" (Kitwood, 1997, p. 43) and how this can be challenged. These issues may also characterize the experience of people with cancer with the stigma of diagnosis and the communication challenges affecting perceptions of personhood (Gillies & Johnston, 2004). Within this background, there is little research exploring the carer experience of navigating cancer care within the context of a dementia diagnosis, and to our knowledge, no study has explored these challenges.

Aim

The aim of this study was to explore the experience of carers who have supported a relative with cancer and dementia using a narrative approach.

Method

Sample/Data Collection

We recruited seven caregivers; five were recruited via a psycho-oncology unit at a regional cancer center. This unit had a designated dementia lead. As a Patient

Identification Centre (PIC), the psycho-oncology team identified relevant participants and gave out the information sheets. Two participants were recruited via snowballing technique(s). We attempted to present the narratives of participants who had previously supported their relatives throughout treatment through to those who are presently supporting their relative. Lived experience is not linear but situated between a past and future. Narratives are never neutral recalls of facts and events; there are no “unsponsored texts” (Harris, 1989) without intentionality and purpose, and therefore, we were interested in how participants reconstructed their narrative through the course of time. We cannot objectively know what someone’s narrative construction was at a specific time of the events. We can, however, observe how claims of identity are positioned retrospectively and examine this in relation to other participant narratives that may be interpreting events experienced more currently within the context of supporting someone living with dementia and cancer. All the participant’s relatives were diagnosed with dementia within a community setting through general practitioners or referral via a memory clinic. The psycho-oncology team had contact with some carers who had previously received support and maintained ongoing contact after their relative had been discharged or died. This allowed recruitment of participants who had been through the whole treatment journey with their relative. We attempted to recruit a purposive sample of caregivers who represented different familial relationships. Our sample included daughters, partners, brothers-in-law, and siblings. The intention was to examine any positional or narrative differences between participants with different familial relationships. Recruitment and semistructured interviews using an interview guide took place between July 2014 and March 2015. Informed consent was sought from all the carers, and they were interviewed by one of the research team, G.W., a nurse with experience in cancer care. All participants were interviewed at home and interviews lasted between 40 and 60 minutes. The interviews (with permission) were recorded and transcribed verbatim. Pseudonyms were used throughout this article. The inclusion criteria were carer/supporter of someone living with memory problems/dementia and diagnosed with cancer, able to provide informed and written consent, able to speak and understand English, and able to participate in an interview for up to 60 minutes at a place of their choosing.

Ethical Approval

This study received ethical approval from both an National Health Service research ethics committee (Research Ethics Committee reference 13/NW/0717) and University Ethics Committee.

Table 1. Analytical Framework.

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1. Why was the narrative developed that way and told in that order?
 2. In what kinds of stories does the narrator place himself or herself?
 3. How does he or she strategically make preferred identity claims?
 4. What other identities are performed or suggested?
 5. What was the response of the listener/audience, and how did it influence the development of the illness narrative and interpretation of it?
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Source. Riessman (2003, p. 9).

Analysis

A performative narrative approach was used to interpret the data. A fundamental tenet of a performative narrative approach is to position our lives as storied with identity narratively constructed. There are multiple truths, constructed by tellers who are socially and historically located (Riessman, 2003, 2008). Language actively constructs the self, and it is through relationships that talk becomes the site of self and identity work through a process of co-construction between speaker and listener. Emphasizing this performative element does not suggest that these identities are inauthentic but acknowledges that they are situated and achieved within social relationships. The analysis takes the position(s) of participants and asks what can be learnt from storytellers. Within this process, it becomes a much more case-centered approach (Riessman, 2008) in generating the detailed stories of experience and holistic rather than breaking down the data into analytical codes or categories. Nevertheless, this case-centered method can generate theoretical concepts and observations about general processes that can be transferable. The interview dialogue has been further analyzed and interpreted by working on a set of questions developed by Riessman (2003; see Table 1) and McCormack (2004), and iteratively revising both the questions and the understanding of the data. So in the process of reviewing the transcripts, attention was paid to what is said; for example, the words that have common understandings and also how it is said, so whether it was an active/passive voice or speech functions (questions, comments, statements) or occurrence of internal dialogue (I said, then I said). The context of the situation is also important, so, for example, what can we learn from the participants’ response to my open question and to any wind-up questions? Finally, the context of culture is significant so, for example, what cultural constructs does each person draw on to position themselves within an interview? By this process, common underlying narratives generated from participants’ stories can be explored and contextualized.

Validation/Rigor

Validation, particularly for narrative approaches, should involve questions such as the following: What are the warrants for my claims? Could other investigators make a reasonable judgment of their adequacy? Would they be able to determine how my findings and interpretation(s) were “produced,” and on that basis decide whether they were trustworthy enough to be relied upon for their work (Mishler, 1990)? One of the primary roles of the researcher is to demonstrate via the visibility of the work in the form of texts how it was analyzed (Sandelowski, 1986). In this sense, transparency is an integral part of trustworthiness and validation. The transcript material was viewed by the research team and subsequent discussion and critical reflection as to both interpretation and meaning took place throughout the project (DeFina, 2009). The transcripts were examined from two levels of positioning (Bamberg, 1997), one in relation to the context of what the story was designed to be about, the other with respect to the coordination of the interaction between speaker and audience. We can then situate the ideological positions (or master narratives) within which participants position their sense of self. Rather than a formalized coding process, this analysis examines how participants position and construct the characters within the reported events, how the participant positions himself or herself to the audience (the researcher) and to themselves. This becomes the construction of their identity to the listener. Therefore, issues such as how language is employed to make claims that the participant holds to be true and relevant above and beyond the local conversational situation is an important area of analysis (Bamberg, 2006).

Results

Recruited caregivers had different familial relationships, and our sample included daughters, partners, brothers-in-law, and siblings. The issues and narratives generated did not appear to be significantly different depending on the familial relationship identified. Interestingly, throughout the interviews, support from the psycho-oncology team was not a significant feature of the narratives explored by the participants. The participants were between 50 and 70 years of age, and the care recipients' cancers were diverse, with two living with more than one cancer. These included bladder, prostate, lung, esophageal, sarcoma, and penile. Through participant reporting, there was a range of dementia stages of the participants relatives, with some having limited mental capacity and advanced dementia (the relatives of Susan, Betty, Lynne, and Alan), to those who had insight into their cognitive impairment (the relatives of Susan, Alice, and Lauren). Two relatives had vascular dementia, one a mixed dementia, and the others had Alzheimer's disease. The participants were the primary carer givers for their relative.

Communication With Health Care Professionals: Maintaining Carer Identity

Communication was challenging for the participants, as both health professionals and the relative living with dementia often minimized their role as the carer and their crucial importance in the life of that person. Participants described situations where their relative disputed their assessment of the impact of cognitive impairment on coping with cancer treatment. The participants described situations in clinic where they had to either attempt to interject to challenge the narrative presented or attempt to see a health professional independently of their relative with dementia. This often required a series of complex communication strategies or possible attendance at further appointments to present a realistic assessment of the context of care. The participants often felt marginalized by health professionals who simply were failing to appreciate the complexities of the coexisting conditions and the impact that having dementia can have in terms of accessing appropriate treatment and support.

Betty, in her 70s, had lost her partner 4 years previously to both prostatic and esophageal cancer. For Betty, the years have solidified a series of painful events and appear to present what are characterized in the literature as “atrocious stories” (Stimson & Webb, 1975). These stories present criticism of how a doctor (and by extension a health professional) did behave, to show how they should behave. It reflects how those in a relatively powerless situation can attempt to redress the balance by emphasizing their own human and sensible qualities in comparison with the absurdity or stupidity of the more powerful. Betty accomplishes this by appealing to the reasonable standards of the everyday world that she assumes are shared by the listener. An example of this positioning was evident in the following extract relating to the physical deterioration of her partner following surgery for his esophageal cancer:

Betty: I tried to get him to go in scooter because his legs had gone.

Interviewer: ok, ok.

Betty: I, I think it was because he wasn't eating but err to this day I don't know why.

Interviewer: mm.

Betty: his legs and I was having to go the doctor, I was having to put him in a taxi, with the taxi driver, err helping me, the doctors busy telling me how well his doing, I'm telling the doctor no, his going down the hill, no he isn't I said his losing weight, I said his not eating and of course.

In this interaction, Betty presents and establishes her identity as a carer in attempting to address the symptom her partner is experiencing. Her use of “gone” conveys the serious nature of his mobility issues, and Betty tentatively asserts that his nutritional needs could be the causal link to his immobility. These were just more questions to the list of unanswered questions Betty asks the audience within her narrative. Betty presents an atrocity story in which she reaffirms the problem with her partner’s legs but situates this outside of formalized care, with the taxi driver having to help. Betty remains an outsider, and she further exonerates this by describing a doctor contesting her knowledge as a carer through challenging her judgment about her partner’s progress. The significance of atrocity stories is the way tellers construct moral character and present the rationality of their actions (Baruch, 1981). Betty asks the audience how can the doctor not see the reality of this situation? The nature of the challenge is such that Betty is not the expert in terms of her partner’s condition and that the health care professional is. The nature of the interaction renders her experience silent.

Decision Making and Maintaining Personhood

Maintaining personhood was a key driver for the participants, and although this is a contested concept (Clark, 2002; B. McCormack, 2001), the definition from Kitwood (1997, p. 8) of the “standing or status bestowed upon one human being by others in the context of a relationship” provides a frame to interpret carer ethical concerns. Attempting to advocate through the decision-making process for their relative was challenging. Decision making was a key area and complicated by issues of their relatives’ mental capacity. Lynne relays the trouble involved with her brother’s radiotherapy for lung cancer and his refusal to attend the daily appointments. This meant that treatment was not continued. Lynne presents the response from the consultant at the memory clinic:

Lynne: . . . when we went back to the memory clinic she just had to say how is he getting on about his lung cancer, I said nothing, I said he refused treatment in January and nothing’s been done. She said you are joking, I said . . . no. She said do these people not understand that his got memory problems and he’s not, you know, somebody else should say. I said I’ve been trying, I said, since they stopped, I said even the cancer nurse has never been and inquired and his still got the cancer, why isn’t the Macmillan nurse coming round and seeing him?

Her narrative highlighted how the health professionals accepted at face value much of what her brother said without a realistic acknowledgment and assessment of his capacity to make informed decisions. Both Lynne and Alan (her husband) present narratives exploring the difficulties

of trying to convey the reality of the situation, whether this be to staff from the memory clinic or within the oncology center. This frustration at health professionals’ inability to work with carers was highlighted by Lauren, whose father has bladder cancer, as she comments:

However, as a carer you’re not going to get a history or a . . . or a lot of sense sometimes and so if you constantly ask the person with dementia, Alzheimer’s, it’s great to be inclusive but at the same time often what they’re saying is not what the reality.

The decision-making process of carers appeared to be imbued with a sense of realism in terms of both quality of life and prognosis, typified by Jane who was supporting her parents who were both living at home with dementia. Her father was also diagnosed with esophageal cancer. Jane was aware of the prognostic script that was unraveling before her; her father had survived cancer but his dementia was slowly robbing him of the insight he retained. As the dialogue below illustrates,

Jane: . . . it goes through your mind, you think, well if they had told him they’d have to keep him in a month, 3 and a half weeks, he probably wouldn’t have had the treatment, then part of you thinks . . . And this is horrible, you’ve got to die of something and that would have been quicker than this that’s happening to him now.

Interviewer: yeeah.

Jane: because this that’s happening to him now is horrendous.

Interviewer: yeah.

Jane: and it’s happening to mum and you see them go and slip away a bit at a time.

Jane presents a different but potentially better scenario, a hypothetical narrative (Riessman, 1990). One that involves no radiotherapy but threatens her identity as a carer and daughter. Jane contrasts the prognostic outcomes of dementia and cancer to the listener (the interviewer) and asks the question, “which is quicker?” Jane presents the current situation as grounds to morally justify this position. Jane asks the listener to address the dilemma about treatment, “should he have cancer treatment or not?” It is a hypothetical dilemma but demands an answer to maintain moral adequacy. Ochs and Capps (2001) highlight the teller–listener relationship, with tellership involving the extent and kind of involvement of conversational partners in the actual recounting of a narrative. Jane animates her narrative in response to a listener’s interaction, and the tellability of a reported event is important to make a rhetorically effective point.

Negotiating Cancer Care

The importance of a key contact person was also a significant factor in good coordination of care. One participant Lauren described the embarrassment she felt because of her father's angry behavior in the outpatient clinic. This was generated by a constant requirement to reiterate his previous medical history. The stigma associated with his inability to recall such information was a key issue and at times required her father to proactively challenge the medic(s), insisting they look at his medical notes for the background information. Lauren also described a situation where she dropped her father off in outpatients for a presurgical assessment. As she comments,

Lauren: having the same question over and over again, every time we go to theatre and we have the pre-assessment thing.

Interviewer: mm.

Lauren: which is an hour, dad has twice missed his pre-assessment and the nurses have phoned me, even though I took him to [name of local hospital] on both occasions. His missed it because he didn't know where he's supposed to wait and the signage as usual wasn't clear and the nurse was stupid enough not to go round the corner and find him. He was round the corner and she phoned me and gone where's your father and I said he's there, I took him myself. Well his not here.

Her father also had a hearing impairment so he did not hear his name, and the participant had to return to the hospital to find her father just round a corner to the clinic. This sort of experience demonstrates how without an overt awareness and attention to the needs of this population key appointments and therefore access to treatment and support can be missed. Other participants specifically position this requirement to recall medical and personal information throughout the cancer treatment journey, as a particular challenge. For example, two participants describe their care recipient attending a pre-op assessment only to be asked the same information in the anesthetic room. In this situation, they were anxious and did not have the cognitive abilities to answer the questions appropriately.

The issues related to negotiating treatment were explored in the research interview by Alan (in the presence of his wife Lynne) when he described the reasons why his brother could not have radiotherapy as an outpatient. In particular, they present his erratic sleeping pattern, which often meant he would be asleep when the ambulance arrived. Alan and Lynne retold the discussion with the oncologist in an outpatient setting:

Alan: I said there's no one to get him ready, if an ambulance comes he could be in bed I said.

Interviewer: so Doctor Smith was saying the cost is the thing.

Alan: yes and he wouldn't bring him in and then he said to me, I said why won't you bring him in, he said I only bring people in who are very ill and I said you're joking.

Lynne: cancer [laughing].

Alan: do you know what you've just said. Now he had four people with him and I said do you know what you've just said err so you're saying cancer's not a serious thing, I, I [indignant voice] didn't mean that, yes but you've just said that, I said, I'm trying to tell you it's his dementia, you know.

Interviewer: yeah.

Alan: it's not his fault he wouldn't come every day, you could start off with 20 treatments is a lot with somebody knocking on his door, even now he has a problem with carers getting in or when we go to see him.

In this dialogue, Alan presents the problems that are experienced by his brother-in-law who lives alone and would have no one to prompt him to be ready when transport arrives, and therefore, would miss it. Alan presents this having experienced the problems before, and queries whether the common sense answer would surely be to keep his brother-in-law as an inpatient. Alan positions his challenge to the consultant, supported by Lynne who laughs reinforcing and demonstrating the absurdity of considering people with cancer as not very ill. Alan positions the consultant as "back tracking" imitating the consultant's indignant assertion "I didn't mean that." Alan positions the dementia as the unacknowledged context that demands inpatient treatment. Complex and lengthy cancer treatments require more adaptation of treatment regimens and protocols to accommodate people with cognitive impairments.

Discussion

These data suggest that there was significant strain and carer burden for the participants and reflect the established literature on dementia and cancer (Hubbard et al., 2010; Li et al., 2013; Schoenmakers et al., 2010). The impact of a cancer diagnosis for the participants appeared of secondary importance to the ongoing challenges that managing the day-to-day support for their relative required. The extra burden appeared in both the ethical challenge of assessing quality of life with the potential burden of cancer treatment, and the logistics of managing the diagnostic, treatment, and follow-up requirements of cancer care.

The participants within this study were concerned with maintaining the personal integrity of their relative with dementia. The carers attempted to position them in ways that maintained identity in situations where the dementia could threaten and contest their identity. The findings of Courtier et al. (2016) also reflect this, and the negotiating required for carers relied on effective honest communication to articulate the complexities of the situation. Finding the opportunity to have these discussions was challenging for our participants. The stigma associated with dementia was exacerbated by the multiple and complex cancer treatment pathways that often challenge both carer and their relative with dementia. The literature suggests that post diagnosis survival is poor (Chang et al., 2014; Kimmick et al., 2014; Patnaik et al., 2011) and therefore more research into the experience and issues pertinent for this population is of importance. There appeared an inflexibility in adapting cancer treatment pathways to meet the needs of people with cognitive impairment, and this was further compounded by carer exclusion within this journey. Carers are the ones who attempt to forge connections and link past to present. Health professionals need to support this process and create systematic ways to include carers throughout the cancer treatment journey. This is of particular importance as anticipatory grief is common in supporting someone with dementia and associated with carer depression (Chan, Livingston, Jones, & Sampson, 2013; Kisely, Sadek, MacKenzie, Lawrence, & Campbell, 2008). Indeed, compared with other long-term conditions, there is evidence that carers of people living with dementia experienced twice as much anticipatory grief as, for example, cardiac disease carers (Ross & Dagley, 2009). The carers' experience is different from supporting someone with cancer as they are exposed to multiple losses during different phases with related guilt and anticipatory grief a common feature. They had also often said their farewells prior to the advanced stage, and these appear different to the cancer carer experience (Albinsson & Strang, 2003). Albinsson and Strang (2003) suggest that staff experienced in dementia care are more responsive and act as a go between for patient and family and are more expert at supporting the maintenance of familial ties than non-specialist staff. The participants in this study were therefore not only exposed to loss and grief in relation to cancer but also anticipatory grief as they support their relative with dementia.

Decision making was an important issue and highlights the challenges of substitute decision making within the context of dementia and cancer care. The carers in this study often felt excluded. This reflects the wider literature that carers of those people living with dementia often felt excluded from decisions made in hospital, and those who felt unsupported by professionals found decision making more difficult (Livingston et al., 2010; Lord, Livingston,

& Cooper, 2015). Decision making with the person living with dementia is complex, requiring carer negotiation and nuanced communication that often needed adaptation dependent on the severity of the cognitive impairment (Miller, Whitlatch, & Lyons, 2016). There was often a continuum with a gradual transition from supported decision making to substitute decision making (Samsi & Manthorpe, 2013). Conveying complex treatment information about cancer occurred without meaningful health professional engagement. There was limited information giving or involvement, even when one participant had lasting power of attorney for their relative with dementia, and hence a legal right to be informed. This highlights some of the legal issues confronted with decision making and capacity. Within England and Wales, the Mental Capacity Act (MCA) 2005 codified existing clinical practice to specific decision making on behalf of adults lacking capacity. There is evidence that this legal framework is still inconsistently applied in practice (Hinsliff-Smith et al., 2017), and claims to confidentiality and data protection, as well as bureaucracy and rigidity, also meant carers' ability to make decisions was sometimes compromised. These issues had a psychological cost for carers often centering on role conflict, carer guilt, and family conflict (Livingston et al., 2010).

The framing of dementia and cancer within a biomedical context can present wider challenges for carers. This framing can be particularly problematic with the therapeutic nihilism associated with dementia and the tendency of biomedical approaches to focus on the individual to the exclusion of wider social networks (Chaufan, Hollister, Nazareno, & Fox, 2012; Frank, 2012; Mattingley, 2010). The family/carers appeared to be sidelined as superfluous to the healing process. At best, they can provide sociomedical information to inform a clinical approach, and at worst, they are deemed as untrustworthy historians, whose input may be perceived as unreliable, irrelevant, and a hindrance to the discourses of medical care. Notions of personhood would seem to need further exploration, and Nolan, Davies, Brown, Keady, and Nolan (2004) use the framework developed by Mulrooney (1997; as cited in Nolan et al., 2004) to move away from concepts of personhood based on an understanding of autonomy as independence and individualism. For caregivers, respect for personhood is associated with both a value for interdependence and investment in caregiving as a choice. It would seem important to acknowledge the "multiple voices" that exist within caregiving relationships and developing strategies in which carers, health professionals, and people living with multiple comorbidities can be meaningfully involved within different complex environments. Dementia care is often provided within these dementia care triads. The interplay of conversational and social practices undertaken by dementia

care triad members can position each other in certain ways (Adams & Gardiner, 2005). "Negotiating the balance" and working through interactions that may advocate for a carers relative, or antagonize their position in terms of decision making and choice, was a key issue for the participants (Quinn, Claire, McGuinness, & Woods, 2012). This narrative competence (Charon, 2004) is an area that requires acknowledgment by health professionals. Charon (2006) examines narrative knowledge within a health care context and suggests that such an approach requires candid reflection and an active listening to the stories that frame one's life. She characterizes the differences in approach between patient/carer and health professional, with the former perceiving illness within the narrative framing of their whole life, whereas the latter tend to designate illness within discrete, isolated events framed as biological puzzles, requiring expert medical or behavioral interventions. The narratives of medicine often focus on "restitution" (Frank, 1995) in which the clinical drive is to get the patient back to the healthy state prior to a cancer diagnosis. This can be particularly challenging for carers as dementia remains a palliative condition. The power of positive thinking is often a popular media and cultural driver in relation to cancer care (Ehrenrich, 2001, 2009). This silences other stories and particularly those carers supporting someone with dementia and cancer. Bell (2012) refers to the teachable moment within cancer survivorship and argues that the perceived shock of a cancer diagnosis can be constructed as a positive avenue for self-management (Henshall, Greenfield, & Gale, 2017) and lifestyle modification, the remaking of self. The cultural frames of trauma associated with cancer calls people to act; it is not neutral and compels a person to demonstrate an ethical and moral position. The remaking of self, articulated by Bell (2012), appears inappropriate within the context of dementia. There are no teachable moments because of the foreclosure of a narrative future. There appears to be no remaking of self that applies to dementia. When Susan tentatively explored whether her father should have had cancer treatment, she was contemplating the foreclosure of his narrative future. It becomes an ethical challenge to make meaningful quality of life decisions about cancer treatment. Would it have been better for him to die more quickly from cancer than the slower cognitive deterioration that dementia brings? Lauren again was concerned about any major surgery her father may be offered for bladder cancer and was mindful of his quality of life with a co-existing dementia.

In response to these findings, health professionals need to examine the stigma associated with dementia and reflect on how to communicate effectively with carers. Health care professionals within oncology need to create more adaptable treatment pathways that are more responsive to those with cognitive impairment. To tailor this

person-centered approach, carers need to be included with the context of treatment as issues of informed consent, quality of life, and person-centered care cannot be adequately explored without the wider inclusion of the network of people who make us who we are.

Limitations

There are some limitations to this study; in particular, recruitment via the psycho-oncology team meant that most of these participants were identified as requiring extra support, and this may be indicative of an atypical treatment journey for the participant's relative. We also know that a large percentage of people are living with an undiagnosed dementia, and therefore, this study would not capture that experience for carers. We also did not account for all familial relationships (particularly primary male carers), and therefore, we may not have captured narratives positioned differently to the participants in this study. Our sample size is small, but this is an exploratory study and the thick description generated provided rich data. As far as we are aware, these data are the first sources of insight into carer experiences in relation to cancer and dementia and a valuable foundation for future research.

Conclusion

The challenges of carers of those living with dementia and cancer predominately focus on the inflexibility of a system that does not cater for vulnerable patients with cognitive impairment. Complex treatment regimens require complex levels of support, and the exclusion of carers in the planning and implementation of cancer treatments creates an intolerable burden. Engaging with carers requires engagement with their narrative lives and an opening up of alternative narrative cultural frames that do not marginalize their lives or those of their relatives. Health and social care staff need to develop narrative competence (Charon, 2004) in terms of recognition and acknowledgment of stories that shape and interpret peoples' lives. Narrative care can ultimately open up the storied lives of carers and their relatives in a way that engages with the meaning(s) to which we attach the disease processes that confront us. In doing so, this becomes a joint venture in creating hope, opening up silences and examining the contexts in which we live.

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References

- Adams, T., & Gardiner, P. (2005). Communication and Interaction within dementia care triads. *Dementia*, 4, 185–205. doi:10.1177/1471301205051092
- Agamben, G. (1998). *Homo Sacer: Sovereign power & bare life*. Stanford, CA: Stanford University Press.
- Albinsson, L., & Strang, P. (2003). Differences in supporting families of dementia patients and cancer patients: A palliative perspective. *Palliative Medicine*, 17, 359–367. doi:10.1191/0269216303pm669oa
- Alzheimer's Disease International. (2010). *World Alzheimer's report 2010: The global economic impact of dementia*. London: Author. Retrieved from https://www.alz.org/documents/national/World_Alzheimer_Report_2010.pdf
- Alzheimer's Society. (2014). *Dementia UK update* (2nd ed.). London. Retrieved from https://www.alzheimers.org.uk/download/downloads/id/2323/dementia_uk_update.pdf
- Aquilina, C., & Hughes, J. C. (2006). The return of the living dead: Agency lost and found? In J. C. Hughes, S. J. Louw, & S. R. Sabat (Eds.), *Dementia: Mind, meaning and the person* (pp. 143–161). Oxford, UK: Oxford University Press.
- Baillargeon, J., Kuo, Y.-F., Lin, Y.-L., Raji, M. A., Singh, A., & Goodwin, J. S. (2011). Effects of mental disorders on diagnosis, treatment and survival of older adults with colon cancer. *Journal of American Geriatrics Society*, 59, 1268–1273. doi:10.1111/j.1532-5415.2011.03481.x
- Bamberg, M. G. W. (1997). Positioning between structure and performance. *Journal of Narrative and Life History*, 7, 335–342. doi:10.1075/jnlh.7.42pos
- Bamberg, M. G. W. (2006). Stories: Big or small: Why do we care? *Narrative Inquiry*, 16, 139–147. doi:10.1075/ni.16.1.18bam
- Baruch, G. (1981). Moral tales: Parent's stories of encounters with health professionals. *Sociology of Health & Illness*, 3, 275–295. doi:10.1111/1467-9566.ep10486851
- Basting, A. D. (2009). *Forget memory: Creating better lives for people with dementia*. Baltimore: Johns Hopkins University Press.
- Beard, R. K., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23, 237–245. doi:10.1016/j.jaging.2008.01.002
- Beard, R. L., & Fox, P. J. (2008). Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss. *Social Science & Medicine*, 66, 1509–1520. doi:10.1016/j.socscimed.2007.12.024
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society*, 31, 70–92. doi:10.1017/S0144686X10000693
- Bell, K. (2012). Remaking the self: Trauma, teachable moments and the biopolitics of cancer survivorship. *Culture, Medicine, and Psychiatry*, 36, 584–600. doi:10.1007/s11013-012-9276-9
- Bradford, A., Kunik, M., Schulz, P., Williams, S., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Disease Association Disorders*, 23, 306–314. doi:10.1097/WAD.0b013e3181a6bebc
- Bruvik, F. K., Ulstein, I. D., Ranhoff, A. H., & Engedal, K. (2012). The quality of life of people with dementia and their family carers. *Dementia and Geriatric Cognitive Disorders*, 34, 7–14. doi:10.1159/000341584
- Cancer Research UK. (n.d.). Worldwide Cancer Statistics. Retrieved from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/worldwide-cancer#heading-Zero>
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*, 28, 1–17. doi:10.1002/gps.3795
- Chang, C.-K., Hayes, R. D., Broadbent, M. T. M., Hotopf, M., Davies, E., Moller, H., & Stewart, R. (2014). A cohort study on mental disorders, stage of cancer at diagnosis and subsequent survival. *BMJ Open*, 4(1), e004295. doi:10.1136/bmjopen-2013-004295
- Charon, R. (2004). Narrative & medicine. *New England Journal of Medicine*, 350, 862–864. doi:10.1056/NEJMp038249
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford, UK: Oxford University Press.
- Chaufan, C., Hollister, B., Nazareno, J., & Fox, P. (2012). Medical ideology as a double-edged sword: The politics of cure and care in the making of Alzheimer's disease. *Social Science & Medicine*, 4, 788–795. doi:10.1016/j.socscimed.2011.10.033
- Clark, P. G. (2002). Values and voices in teaching gerontology and geriatrics. *The Gerontologist*, 42, 297–303. doi:10.1093/geront/42.3.297
- Courtier, N., Milton, R., King, A., Tope, R., Morgan, S., & Hopkinson, J. (2016). Cancer and dementia: An exploratory study of the experience of cancer treatment in people with dementia. *Psycho-Oncology*, 25, 1079–1084. doi:10.1002/pon.4212
- Davis, D. H. J. (2004). Dementia: Sociological and philosophical constructions. *Social Science & Medicine*, 58, 369–378. doi:10.1016/S0277-9536(03)00202-8
- DeFina, A. (2009). Narratives in interview—The case of accounts: For an interactional approach to narrative genres. *Narrative Inquiry*, 19, 233–258. doi:10.1075/ni.19.2.03def
- Department of Health. (2005). *Mental Capacity Act*. London: Her Majesty's Stationary Office (HMSO).
- Egdell, V. (2013). Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. *Ageing & Society*, 33, 888–907.
- Ehrenrich, B. (2001, November). Welcome to Cancerland. *Harper's Magazine*, 43–53.
- Ehrenrich, B. (2009). *Bright sided, how the relentless promotion of positive thinking has undermined America*. New York: Metropolitan Books.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness and ethics*. London: The University of Chicago Press.
- Frank, A. W. (2012). *Letting stories breathe: A socio-narratology*. London: The University of Chicago Press.
- Gillies, B., & Johnston, G. (2004). Identity loss and maintenance: Commonality of experience in cancer and dementia. *European Journal of Cancer Care*, 13, 436–442. doi:10.1111/j.1365-2354.2004.00550.x

- Gorin, S. S., Heck, J. E., Albert, S., & Hershman, D. (2005). Treatment for breast cancer in patients with Alzheimer's disease. *Journal American Geriatric Society*, *53*, 1897–1904. doi:10.1111/j.1532-5415.2005.00467.x
- Gupta, S. K., & Lamont, E. B. (2004). Patterns of presentation, diagnosis and treatment in older patients with colon cancer and comorbid dementia. *Journal American Geriatric Society*, *10*, 1681–1687. doi:10.1111/j.1532-5415.2004.52461.x
- Harris, R. (1989). How does writing restructure thought? *Language & Communication*, *9*, 99–106. doi:10.1016/0271-5309(89)90012-8
- Heckel, L., Fennell, K. M., Reynolds, J., Osborne, R. H., Chirgwin, J., Botti, M., . . . Livingston, P. M. (2015). Unmet needs and depression among carers of people newly diagnosed with cancer. *European Journal of Cancer*, *51*, 2049–2057. doi:10.1016/j.ejca.2015.06.129
- Henshall, C., Greenfield, S., & Gale, N. (2017). The role of self-management practices as mechanisms for re-establishing normality in cancer survivors. *Qualitative Health Research*, *27*, 520–533. doi:10.1177/1049732316651252
- Hinsliff-Smith, K., Feakes, R., Whitworth, G., Seymour, J., Moghaddam, N., Dening, T., & Cox, K. (2017). What do we know about the application of the Mental Capacity Act (2005) in healthcare practice regarding decision-making for frail and older people? A systematic literature review. *Health and Social Care in the Community*, *25*, 295–308. doi:10.1111/hsc.12310
- Hopkinson, J. B., Milton, R., King, A., & Edwards, D. (2016). People with dementia: What is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review. *Psycho-Oncology*, *25*, 1137–1146. doi:10.1002/pon.4185
- Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L., & Kearney, N. (2010). Treatment decision-making in cancer care: The role of the carer. *Journal of Clinical Nursing*, *19*, 2023–2031. doi:10.1111/j.1365-2702.2009.03062.x
- Kimmick, G., Fleming, S. T., & Sabatino, S. A. (2014). Co-morbidity burden and guideline-concordant care for breast cancer. *Journal of American Geriatric Society*, *62*, 482–488. doi:10.1111/jgs.12687
- Kisely, S., Sadek, J., MacKenzie, A., Lawrence, D., & Campbell, L. A. (2008). Excess cancer mortality in psychiatric patients. *Canadian Journal of Psychiatry*, *53*, 753–761. doi:10.1177/070674370805301107
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.
- Knapp, M., Comas-Herrera, A., Somani, A., & Banerjee, S. (2007). *Dementia: International comparisons*. London: Personal Social Services Research Unit. Retrieved from <http://www.pssru.ac.uk/pdf/dp2418.pdf>
- Koch, T., & Iliffe, S. (2010). Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: A systematic review. *BMC Family Practice*, *11*, Article 52. doi:10.1186/1471-2296-11-52
- Li, Q. P., & Loke, A. Y. (2013). The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research. *Psycho-Oncology*, *22*, 2399–2407. doi:10.1002/pon.3311
- Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013). Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review*, *60*, 178–187. doi:10.1111/inr.12000
- Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., . . . Cooper, C. (2010). Making decisions for people with dementia who lack capacity: Qualitative study of family carers in UK. *British Medical Journal*, *341*, c4184. doi:10.1136/bmj.c4184
- Lord, K., Livingston, G., & Cooper, C. (2015). A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, *27*, 1301–1312. doi:10.1017/S1041610215000411
- MacRae, H. (2010). Managing identity while living with Alzheimer's disease. *Qualitative Health Research*, *20*, 293–305. doi:10.1177/1049732309354280
- Mattingley, C. (2010). *The paradox of hope: Journeys through a clinical borderland*. London: University of California Press.
- McCormack, B. (2001). Autonomy and the relationship between nurses and older people. *Ageing & Society*, *21*, 417–446. doi:10.1017/S0144686X01008303
- McCormack, C. (2004). Storying stories: A narrative approach to in depth interview conversations. *International Journal of Social Research Methodology*, *7*, 219–236. doi:10.1080/13645570210166382
- Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, *15*, 1141–1157. doi:10.1177/1471301214555542
- Mishler, E. G. (1990). Validation in inquiry-guided research: The role of exemplars in narrative studies. *Harvard Education Review*, *60*, 415–442. doi:10.17763/haer.60.4.n4405243p6635752
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond "person-centred" care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(S1), 45–53. doi:10.1111/j.1365-2702.2004.00926.x
- Ochs, E., & Capps, L. (2001). *Living narrative: Creating lives in everyday storytelling*. London: Harvard University Press.
- Office of National Statistics. (2010). *Cancer statistics registrations: Registrations of cancer diagnosed in 2008, England* (No. 38). London: National Statistics.
- Patnaik, J. L., Byers, T., Diguiseppi, C., Denberg, T. D., & Dabelea, D. (2011). The influence of comorbidities on overall survival among older women diagnosed with breast cancer. *Journal of the National Cancer Institute*, *103*, 1101–1111. doi:10.1093/jnci/djr188
- Quinn, C., Claire, L., McGuinness, T., & Woods, R. T. (2012). Negotiating the balance: The triadic relationship between spousal caregivers, people with dementia and admiral nurses. *Dementia*, *12*, 588–605. doi:10.1177/1471301212437780
- Raji, M. A., Kuo, Y.-F., Freeman, J. L., & Goodwin, J. S. (2008). Effect of a dementia diagnosis on survival of older patients after a diagnosis of breast, colon or prostate cancer: Implications for cancer care. *Archives of Internal Medicine*, *168*, 2033–2040. doi:10.1001/archinte.168.18.2033

- Riessman, C. K. (1990). *Divorce talk: Women and men make sense of personal relationships*. London: Rutgers University Press.
- Riessman, C. K. (2003). Analysis of personal narratives. In J. A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns* (pp. 331–346). London: Sage.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. London: Sage.
- Robb, C., Boulware, D., Overcash, J., & Extermann, M. (2010). Patterns of care and survival in cancer patients with cognitive impairment. *Critical Reviews in Oncology/Hematology*, 74, 218–224. doi:10.1016/j.critrevonc.2009.07.002
- Ross, A., & Dagley, J. C. (2009). An assessment of anticipatory grief as expressed by family caregivers of individuals with dementia. *Alzheimer's Care Today*, 10, 8–21.
- Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics*, 25, 949–961. doi:10.1017/S1041610213000306
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8, 27–37. doi:10.1097/00012272-198604000-00005
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia: A systematic literature review. *Maturitas*, 66, 191–200. doi:10.1016/j.maturitas.2010.02.009
- Seal, K., Murray, C. D., & Seddon, L. (2015). The experience of being an informal “carer” for a person with cancer: A meta-synthesis of qualitative studies. *Palliative & Supportive Care*, 13, 493–504. doi:10.1017/S1478951513001132
- Smith, P. (2009). The family caregiver’s journey in end-of-life care: Recognizing and identifying with the role of carer. *International Journal on Disability and Human Development*, 8, 67–73. doi:10.1515/IJDHD.2009.8.1.67
- Stenberg, V., Rowland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19, 1013–1025. doi:10.1002/pon.1670
- Stimson, G., & Webb, B. (1975). *Going to see the doctor: The consultation process in general practice*. London: Routledge.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19, 93–117. doi:10.1111/j.1467-9566.1997.tb00017.x
- Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., & Maseda, A. (2014). What causes grief in dementia caregivers? *Archives of Gerontology and Geriatrics*, 59, 462–467. doi:10.1016/j.archger.2014.05.013
- Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer’s patients. *Qualitative Health Research*, 20, 159–169. doi:10.1177/1049732309358330

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