

Original Article

Cite this article: DiGiacomo M *et al.* (2024) “You’re the only thing he comes out [of his room] for”: A qualitative study of engagement between Laughter Care Specialists and families of people with dementia in long-term care. *Palliative and Supportive Care*, 1–6. <https://doi.org/10.1017/S1478951524000579>

Received: 30 November 2023

Revised: 28 February 2024



Accepted: 17 March 2024

Keywords:

Dementia; long-term care; family carer; person-centered; palliative care

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“You’re the only thing he comes out [of his room] for”: A qualitative study of engagement between Laughter Care Specialists and families of people with dementia in long-term care

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Abstract

Objectives. Family involvement in the lives of people who have dementia and live in long-term care is important, but family members may face challenges communicating and connecting with their loved one as dementia progresses. A type of therapeutic humor (Laughter Care) delivered by trained specialists aims to engage people with dementia who reside in long-term care through creative play and laughter. This study aimed to explore the perceptions of Laughter Care Specialists (LCSs) regarding families’ engagement with the program.

Methods. Semi-structured interviews were conducted with LCSs ($n = 8$) and analyzed inductively using thematic analysis.

Results. Family members were reported to initially have varied degrees of openness toward Laughter Care, but often become more accepting after observing positive engagement with the person with dementia. Family members were perceived to benefit from the program through witnessing the person with dementia enjoy joyous and light interactions, learn new ways of communicating and connecting with the person with dementia, and engage in positive interactions at end of life.

Significance of results. Laughter Care may provide family members with novel ways of communicating and connecting with people who have dementia at end of life as well as comfort into bereavement.

Introduction

In Australia, more than two-thirds (68.1%) of long-term care residents have moderate to severe cognitive impairment and 54% have a dementia diagnosis (Caughey *et al.* 2020). Continuing contact with family members is important to people with dementia living in long-term care facilities to maintain relationships and a sense of identity (Harmer and Orrell 2008). Frequent visits from family members have been associated with improved quality of life of residents (Verloo *et al.* 2018), whereas less frequent visits are associated with higher rates of behavioral problems (Arai *et al.* 2021).

Despite a person with dementia residing in long-term care, family members may continue their caring roles and this role will evolve over time (Cooke *et al.* 2023; Gaugler and Mitchell 2022). Whilst visiting, family carers of people with cognitive impairment engage in more care-related tasks than carers of people without cognitive impairment (Cohen *et al.* 2014) and are particularly involved in managing the behavioral and psychological symptoms of dementia (BPSD) which can include apathy, depression, agitation, anxiety, aggression, disinhibition, and delusions (Tjia *et al.* 2017). Non-pharmacological interventions are recommended as first-line management for these issues (Guideline Adaptation Committee 2016). It is thought that such symptoms may develop as a result of unmet needs for meaningful activity, socialization, and comfort (Cohen-Mansfield 2013).

Regardless of care setting, family members of people with dementia may experience anticipatory grief and ambiguous loss as they observe a gradual deterioration and psychological loss

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of their loved one (Blandin and Pepin 2017). Their family member may become “less known” to them and their personalities can change (Blandin and Pepin 2017). They may grieve a loss of interpersonal connection and ability to engage in joint activities (Sanders and Corley 2023), due to loss of communication capabilities (Young *et al.* 2011).

Not all people living with dementia in long-term care facilities have family that visit regularly due to barriers including distance, access to transport, financial difficulties, ill health, or emotional difficulty seeing their relative with dementia in long-term care (Miller 2019). Adult children may feel ambivalent around visiting and avoid the situation altogether (Dupuis 2002). Family who cope through avoidance express more pain and emotional distress in their roles than those able to accept the situation (Dupuis 2002). Family visits tend to be longer and more frequent when their family member had less severe cognitive impairment (Fukahori *et al.* 2007). Some families report that visits can be difficult when their family member has advanced dementia due to losses in communication, recognition, emotional expression, and interaction with their environment (Piechniczek-Buczek, 2007). This suggests a need to make visits more positive in long-term care facilities to benefit both people with dementia and their families. Despite people with dementia emphasizing the importance of familial involvement in their care, information is limited on interventions that support this in long-term care (Backhaus *et al.* 2020).

Humor therapy is one type of non-pharmacological intervention used to promote health and well-being “by stimulating a playful discovery, expression, appreciation of the absurdity or incongruity of life’s situations which may enhance health or be used as complementary treatment to facilitate healing/coping, whether physical, emotional, cognitive, social, spiritual” (Association for Applied and Therapeutic Humour 2020). While there are various types of humor therapies (Linge-Dahl *et al.* 2018), this study centered on “Laughter Care” (The Humour Foundation 2023) which is an intervention that involves Laughter Care Specialists (LCSs), previously referred to as elder clowns. LCSs have formal performance training and substantial experience as professional performers as well as training in the skills, principles, and techniques required to work with people with dementia in aged care facilities. They use various individualized, often improvised techniques including music, dance, storytelling, puppetry, conversation, and humor to promote engagement (Warren and Spitzer 2011). LCSs wear a red nose, no stage makeup, and 1950s-style clothing (Kontos *et al.* 2016). The red nose signifies that the LCS is someone with whom residents can have fun and be playful (The Humour Foundation 2023).

While all people living in participating long-term care homes can engage with LCSs, individual visits are mainly centered on persons with dementia. Also, long-term care home staff help to identify individuals to visit, such as people who receive few visitors, who are perceived to be withdrawn or down. They also advise whether a resident would not like to participate (e.g., due to aversion to clowns).

There is a growing evidence base around this approach that demonstrates it has capacity to meet a person with dementia’s needs for meaningful connection and engagement. While research into this program has shown statistically significant reductions in agitation (Low *et al.* 2013), improvements in quality of life, reductions in BPSD (Kontos *et al.* 2016), and decreased use of psychotropic medications (Leow *et al.* 2016) in people with dementia in long-term care, little is known about the mechanisms that these outcomes are achieved and possible broader impacts of the program. While we are increasingly understanding the techniques used by LCSs

to engage with people with dementia, we do not know how they engage with or support family when visiting long-term care, if at all. This study aimed to explore the perceptions of LCSs regarding families’ engagement with the program.

Methods

Using a social constructionist lens, we undertook a qualitative study using in-depth semi-structured interviews to better understand engagement from the perspectives of the LCSs.

We recruited LCSs working for The Humour Foundation in Australia. Laughter Care is delivered in metropolitan and regional long-term care facilities of moderate to large size (61–100 residents). All LCSs were invited to participate through an email listserv. Two subsequent email reminders sought additional participation over the study period after which it was assumed people had declined to participate and reasons were not asked. Ethical approval for this study was granted by the University of Technology Sydney Human Research Ethics Committee (ETH21-6698). Written informed consent was obtained from participants prior to interviews.

Eight participants completed individual 1-hour, in-depth, semi-structured interviews using videoconferencing between June and September 2022. The interviewer (MD) was an experienced female qualitative researcher and social scientist with no prior relationship to participants. Participants had no prior knowledge of the interviewer. Interview topics included perceptions regarding interactions with visiting family members of people who lived in long-term care facilities with dementia. The interview guide was pilot tested with the project investigator team. Interviews were audio-recorded with permission of participants and professionally transcribed. Following transcription, identifying material was removed and names were replaced with pseudonyms. Data were concurrently collected and analyzed which enabled awareness of sufficient information power (Malterud *et al.* 2016). With this in mind, when a 50% response rate ($n = 8$) was achieved and reminder invitations elicited no additional participants, recruitment ceased.

Data were analyzed using inductive thematic analysis (Braun and Clarke 2006). Two analysts (MD, SR) double-coded transcripts independently using NVivo software and developed an initial coding tree comprised of descriptive codes. Meetings were held to discuss any discrepancies in interpretation and generate a coding framework comprised of categories and sub-categories of similar codes. One analyst (SR) coded the remaining transcripts. Categories and sub-categories were refined and themes developed through iterative analysis. Participants were invited to review a summary of findings; 2 affirmed content and no changes were suggested.

Findings

Participants were 5 women and 3 men with an average of 7 years of experience as an LCS. Three overarching themes reflected the ways in which LCS engaged with family members visiting their loved one with dementia in long-term care: the journey from resistance to valuing; working together to facilitate engagement; and supporting end of life interactions and bereavement.

The journey from resistance to valuing

Some LCSs reported that some families do not want to be involved in interactions or do not want their loved one involved in the program. LCSs perceive resistance to be due to a lack of understanding

of the principles of the program and/or perceptions that LCSs infantilize residents. These preconceived notions may block acceptance of the LCS.

Sometimes you have family who see it and think 'that is so not appropriate' ... 'My family member's not a child, they don't need a clown.' (Kim, 7 years' experience)

Family members may hold preconceived notions of the role of a clown in health care, with many associating the clown with pediatrics. Participants discussed a need to educate family members on program principles so they understand the program and can make informed decisions regarding involvement. When there was resistance from the family, the LCS respected their wishes. However, where such family members had the opportunity to witness the positive impact that the person-LCS relationship had on their family member, they became more open to these visits.

His wife was really very offended about the idea of the clown and told me, very, very succinctly: 'This is not going to be a thing ... one time ... I remember him coming towards me and I thought ... What is going to happen? ... I was playing 'Singing in the Rain' ... he came up to me and he started dancing. That was when I realised that he actually wants to [engage]. And his daughter realised and then she would support this and eventually the wife realised, and the family said to me, "you're the only thing he comes out [of his room] for."' (Kim, 7 years' experience)

While the LCS reports initial rejection or hesitance of family members, gradual acceptance usually occurred after the family was able to witness how their loved one enjoyed themselves in the company of the LCS. Whether just observing or contributing to interactions, seeing their loved one have fun with the LCS was valued as it was sometimes the sole motivation to interact with others.

On Thursdays, when I go to a memory care unit, this man's son visits him but [when I offer to let them have time alone,] he goes 'no, no,' and he just sits at the back there because he knows his Dad is having a good time with Tucker. (Frank, 5 years' experience)

Rather than avoid times when the LCS is at the facility, the following participant explained that the opposite is often true of family members.

People's families love them, but they are traumatized quite often [from the symptoms of dementia]. So, a lot of families come in on the days that I'm working to see their loved one in the way that's more enjoyable. (Joe, 10 years' experience)

Being able to see their family member having a positive experience may support their own feelings of well-being after witnessing loss of everyday functioning and diminished quality of life. The LCS interaction may be a brief respite from the carer role and an opportunity to see just their loved one rather than focus on the dementia.

Participants reported that some families invite the LCS to spend time with the family at end of life. At times, this invitation is the result of an ongoing relationship that has been developed over time between the family and the LCS. The following excerpt exemplifies the family's journey from resistance to valuing the LCS at the person's end of life:

When he was dying, they invited me in to spend time. So, we went from 'don't go near him' to actually 'you're of value, and we want to include you in our experience,' which is really beautiful, and it took a long time and it isn't about putting any pressure ... because you've got to respect the families, they know their loved one. (Kim, 7 years' experience)

Working together to facilitate engagement

Family members and LCSs work in partnership to ensure engagement and interaction with people living with dementia in long-term care. Family members play a key role by providing information about the resident's history, which informs the techniques that LCS choose in interactions.

If the family member is there, you can do almost like a hand-over memory. Where they can talk to you a bit about what their loved one's life has been up to this point ... then you've got all those reference points ... then you use that every week ... so those conversations can continue, and you keep that intimacy like a family member would. (Kim, 7 years' experience)

Seeking this information from family members acts to both enable them to share their history and knowledge of the person and be recognized as important holders of information that supports their family member's inclusion and experience of person-centered care. It was perceived that families found value in being able to speak with participants about their loved ones.

In the end, we really got somewhere very close and very special. He sent me a lovely card saying, 'I thoroughly enjoyed the 'jousting matches' between you and my mother.' And he said it was just so great. (Joe, 10 years)

LCSs also supported families to connect and communicate with one another. They created an atmosphere of light-heartedness where families could enjoy the present moment, create memories, and continue to develop bonds.

I went up to the room, and Edith's there with the daughter, the granddaughter, the great grand-daughter, Emily. I've gone, "Edith, do you want to hear the song that Emily and I have been singing?" ... and we sang 'You are my Sunshine.' And now, remember, Edith is non-vocal ... and we finished and I've gone, "Oh, Edith, how good was Emily?" And Edith said, "Yes, I know, isn't she wonderful?" (Frank, 5 years)

The ability to create meaningful interaction can be particularly impactful following loss of cognitive and verbal function when families may need new ways of connecting with their loved one. LCSs model effective communication and engagement skills to promote interaction and maintain connection.

They don't know how to talk to their mother ... but then they see the way that I talk to their mother. So, get on the same level, move in close, talk really slowly and clearly in a musical kind of way ... and then the mother lights up. And they just go, "Oh, did you see that? She smiled." Or "she really likes you" ... the mother doesn't really understand a lot of what I'm saying, but she knows I'm amplifying things. I'm amplifying the expressive range and the attention, my eye contact is really good. I'm slowing things down. I'm really connected. I'm really relaxed in my own presence. I'm not worried about anything. I'm really present, I'm really here, I'm with the person. Then the family member, the loved one, just goes, "that's how you do it". (Joe, 10 years)

In the above example, the LCS shares their skills with family members to empower them to engage with their loved one in new ways and get positive responses when they may have perceived this as impossible. In addition to demonstrating communication techniques, LCSs adopt a strength-based approach to highlight possibilities with regard to interaction with their loved one, rather than focusing on ways in which their relationship has been lost or diminished.

The relatives are always seeing what's not there whereas we're seeing what's there. That's what we're paid to do, is to see what's there and to work with that. So, people always look a bit shinier when we're around because we

know how to interact and how to just catch the smallest look or tiny finger movement and we're onto it. (Shane, 6 years' experience)

Supporting end of life interactions and bereavement

Some family members may not have known the LCS or were not aware of their relationship with the person with dementia, requiring new relationships to be built with the family at the end of the resident's life.

If I see a resident, maybe I've seen them for three years, and then I see a family member towards the end when their relative becomes palliative. All of a sudden, the family's there. They don't know me. So it can be a little bit strange because this is my good friend in the bed and they don't necessarily know that we have a long relationship, but usually they're quite receptive because I'll tell them, "oh, you know I have all this information about their mother" So, there's some connection in that way and real warmth around coming to the end of that person's life. (Robyn, 7 years)

During these visits, LCS focus on providing comfort to the resident and the family.

[Their] Mum was in the very final stages and I spent quite a bit of time and the daughter just talked to me about her life and her mother's life, and sharing, and we sang to her mom together. And it was really beautiful. (Kim, 7 years)

Some interactions between LCSs, residents, and/or families that occurred toward the end of life were described as impacting feelings during early bereavement. One LCS explained that he had leveraged his friendship with a resident to promote the man's communication with his daughter prior to his death.

... he ends up telling [the daughter] that he was proud of her and that he loved her and then she was satisfied. And she's in tears and she's just going, "thanks" Apparently, they embrace He dies shortly after. The husband of the daughter comes in to meet me ... and he's going, "I don't know how you got through to [him]. But you got through to him and it's changed everything. He was on the phone saying goodbye to people and saying all the things that people needed to hear in his last week. And we can't believe it. He was a very different person". (Joe, 10 years)

This example demonstrates that the LCS supports communication and connection between the resident and family. Another example of family seeking out the LCS following the death of their loved one suggests that the LCS was likewise valued by the family.

One woman passed away and then the family rang me up ... the whole family had gathered after the funeral ... and they all wanted to talk to Oscar one by one because their mother, auntie, grandmother, great-grandmother had talked about nothing other than Oscar for the last three years They loved it. They would write me notes. Kids would draw me pictures. They were saying things like, "my mother eats more when you are there. And she talks more - she's making stuff up." (Joe, 10 years)

In early bereavement, family members connected with the LCS and affirmed positive impacts on their loved one.

Discussion

This study aimed to explore the perceptions of LCSs regarding engagement with families of people living with dementia in long-term care facilities. LCSs reported that some families were initially resistant to Laughter Care, but accepted it over time when they saw its value. Some families worked with LCSs to support engagement with their person. Toward end of life, some LCS provided families

comfort and support as well as opportunities to share memories in early bereavement. Although Laughter Care is primarily delivered to facilitate engagement of people with dementia, findings suggest there may also be benefits for family members who witness or contribute to engagement between their loved one and the LCS.

Previous research has shown there are positive associations between quality of families' collaboration with health-care professionals (e.g., perceptions of care provision, information provision, communication, support) and emotional well-being of family carers post-bereavement (Matthys *et al.* 2023). Although not registered health professionals, LCSs ascertain and address psychosocial needs of people living in long-term care facilities, apply supportive measures, and promote health to meet needs and expectations of individuals their families over time. When health-care workforce shortages were not the norm, long-term care staff may previously have been in positions to engage more with residents and families (Aged Care Royal Commission 2021). In the current context, the LCS is someone who engages, brings lightness to the facility, and can bring families comfort in knowing their loved one is being visited, is engaged, responding positively to interactions, possibly having fun. The individualized nature of engagement may also allow families to witness their loved one in interactions that reflect their personality, which may also bring comfort to families. The LCS can also be a person with whom family members can talk about their relative and develop an ongoing relationship due to sustained contact. The program provides an opportunity for family members to actively collaborate with the LCS to provide psychosocial care to the person with dementia. Some family members wish to maintain both their caring role and their relationship with their person following transition into long-term care (Cooke *et al.* 2023). This may be particularly important for family members of people with dementia, where caregiving can be challenging (Xiao *et al.* 2014). As dementia can be traumatizing for family members (McCormack *et al.* 2017), it may be beneficial for them to witness their loved one engage in positive interactions. In this study, there were no reported adverse effects of Laughter Care for family members. However, LCSs should be mindful of the needs, feelings, and attitudes of family members when interacting with their loved ones.

Impact on communication and relationships

For family members of people with dementia, anticipatory grief may arise as they experience multiple losses personally (e.g., loss of companionship) and for the person with dementia (e.g., loss of personhood) (Chan *et al.* 2013). Communication between people with dementia and their family members can become increasingly difficult as symptoms progress (Young *et al.* 2011). Good communication between family members and people with dementia can involve improvisation, creativity, and imagination and should be flexible, adaptive, and respectful (Basting 2013; van Manen *et al.* 2021). Family members may not always possess such skills, however, research has demonstrated that such capacity can be built (Howell *et al.* 2022). This study provided descriptions of LCSs demonstrating for family members new ways of communicating with the person with dementia as their disease progresses, which allows them to receive positive responses from their family member, which in turn may facilitate relationship development despite losses in communication capabilities. Strategies enacted by the LCS have been demonstrated to support communication with people with dementia (Bender *et al.* 2022; Dementia Australia 2023; Wilson *et al.* 2012). Learning new approaches to communication

with the care recipient indicates that the family member is adapting and progressing through grief (Blandin and Pepin 2017).

Impact on end of life and bereavement

Findings from this study indicated that LCSs may also have the capacity to improve interactions at end of life, bringing comfort to the person with dementia and their family as death approaches. The LCS can facilitate memory sharing, reflecting on the resident's life, and possibly give families new memories. Following the death of the person with dementia, most prominent grief symptoms of family members are feelings of separation and yearning (Givens et al. 2011). Currently, there is limited empirical evidence of delivery of formal support to bereaved carers of people who died with dementia in long-term care (Arruda and Paun 2017). Pre- and post-death interventions for families of people with dementia aim to improve bereavement outcomes, yet many of these are for home-based carers rather than families of people living in long-term care facilities (Arruda and Paun 2017). Such interventions may not be routinely provided in long-term care due to a lack of funding. Given that pre- and post-death support may mediate symptoms of depression, anxiety, and guilt in bereavement in carers of people living with dementia in long-term care (Arruda and Paun 2017), Laughter Care seems a promising intervention. This study demonstrated that LCSs facilitate grieving family members to have continuing bonds with the decedent by providing opportunities for families to continue discussions about the decedent and share memories. Continuing bonds have been shown to provide comfort to bereaved people in grief (Hewson et al. 2023).

Limitations

In this study, we did not include the perspectives of family members, but rather sought descriptions from LCSs. Although LCSs may have a bias toward perceiving that families might benefit from this program, they have a unique perspective in that they engage with multiple stakeholders, are observers as well as participants in interactions, and have a unique non-staff/nonfamily member role in long-term care environments. They described positive and negative perceptions that family members expressed as well as verbatim elicitations depicting what family members see as important and meaningful outcomes of interactions with LCSs. In future research, perspectives should be obtained from family members to better understand the impact of this program.

We interviewed in-depth a small number of LCSs, yet they represented 50% of the total number of these professionals at the time of the study, who all had at least 5 years' experience. As there have been no other reports of how LCSs engage with family members of people living with dementia in long-term care who participate in Laughter Care, these are novel findings.

Conclusion

Laughter Care is a program that may provide family members with novel ways of communicating and connecting with the person with dementia before death as well as provide comfort at end of life and into bereavement. Potential benefits for families include improved communication skills and relationships with people with dementia and positive bereavement outcomes.

Funding. This work was supported by a Sydney Partnership for Health, Education, Research, and Enterprise (SPHERE) Palliative Care Clinical Academic Group Seed Grant.

Competing interests. Authors DS, TW, and KP are employed at The Humour Foundation. There are no other competing interests.

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