

Usefulness and acceptability of an animation to raise awareness to grief experienced by carers of individuals with dementia

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Abstract

Aim: Many carers of individuals with dementia experience high levels of grief before and after the death of the person with dementia. This study aimed to determine the usefulness, acceptability, and relevance of an animation developed to raise awareness to grief experienced by carers of people with dementia.

Methods: This research had a single group intervention study design. We contacted carers of people with dementia over the phone or email. Participants evaluated the animation through an online or paper-based survey. We used descriptive statistics and analysed qualitative data using thematic analysis. We required a sample of 40 carers to adequately power the study with a target of 75% of carers finding the animation useful, acceptable, and relevant.

Results: 31/78 carers approached evaluated the animation. Ninety-four percent of participants found the animation relevant to their situation, meeting our target. However, we fell short of this target for usefulness (68%) and acceptability (73%). The qualitative responses suggested that participants felt the animation could help improve the understanding of grief among carers, family, friends, and healthcare professionals. Carers also shared that the animation would be most useful for carers of newly diagnosed people with dementia.

Conclusion: Most carers of people with dementia in this study reported that the animation was useful, acceptable, and relevant. Dissemination of the resource may be useful for the majority of carers, with the caveat that a few carers may find it distressing and need to be referred for further support.

Introduction

Caring for an individual with dementia poses an increased risk of experiencing grief before and after the death of the person with dementia (Blandin & Pepin, 2017). Grief is defined as a natural emotional reaction to the loss of a loved one through death that involves various psychological and physical symptoms (Stroebe, Hansson, Schut, & Stroebe, 2008). Symptoms of grief differ in quality and intensity largely due to cultural differences (Stroebe et al., 2008).

Pre-death grief is the carer's response to perceived losses as a result of dementia-related psychological and physical changes that occur before the individual with dementia has died (Lindauer & Harvath, 2014). Pre-death grief is also referred to in the literature as dementia grief, a specific kind of anticipatory grief that occurs in reaction to many changes that occur throughout the course of the disease.

Dementia grief is influenced by the unique deteriorations in communication and memory that occur among people with dementia (Blandin & Pepin, 2017). Problems with language impede interactions between the carer and person with dementia, which results in changes to the relationship (Blandin & Pepin, 2017; Noyes et al., 2010). Carers display elevated levels of dementia grief as the dementia advances (Adams & Sanders, 2004; Blandin & Pepin, 2017) and this can affect their physical and mental health (Lindauer & Harvath, 2014).

Dementia grief may be experienced by carers as disenfranchised grief when the loss is not acknowledged by the carer's social group or society in general (Doka, 2008). Carers who have not experienced a physical death may not have their losses recognized by friends or family and therefore may not receive adequate social support (Doka, 2008). Also, as no death has occurred, carers may not feel that it is right for them to grieve while the person with dementia is still living.

Complicated grief is a prolonged, severe type of post-death grief characterized by long duration, high intensity, inability to resume everyday life, and yearning for the lost person (Blandin & Pepin, 2017; Shear, 2010). About 20% of dementia carers experience complicated grief after the death of the person with dementia (Blandin & Pepin, 2017; Holland, Currier, & Gallagher-Thompson, 2009). Carers who have higher dementia grief prior to the death of the person with dementia are at increased risk of complicated grief after the death (Romero, Ott, & Kelber, 2014).

A systematic review by Wilson and colleagues (2017) sought to determine the impact of psychosocial interventions that aim to reduce grief pre- and post-death for carers of people with dementia. They only identified three studies that used intensive psychosocial interventions to reduce grief. The authors concluded there was insufficient evidence to guide care interventions for these carers (Wilson et al., 2017).

Acknowledging that it is common and acceptable to grieve may be a useful step for carers in processing grief and overcoming feelings of guilt while caring for someone with dementia (Martz & Morse, 2017; Strang et al., 2006). In addition, audio-visual techniques may be a useful, low-cost method of communicating health messages such as normalizing dementia grief (Schubbe et al., 2020). Though there is limited evidence to suggest that audio-visual interventions may be effective for dementia carers, studies have looked at their efficacy in other health domains. For example, Houston and colleagues (2020) tested the impact of an animation on comprehension of colorectal cancer screening probabilities to determine effective risk communication strategies (Houston et al., 2020). They found that video with animated pictographs, video with static pictographs, and audio-booklet with static pictographs all improved content knowledge (Houston et al., 2020).

Another study aimed to investigate what features of spoken health animations improved information recall and attitudes (Meppelink, van Weert, Haven, & Smit, 2015). The results showed that among those with low health literacy, animations combined with spoken messages significantly improved recall (Meppelink et al., 2015). They concluded that spoken animation is an effective way to communicate health information among people with low health literacy (Meppelink et al., 2015).

In addition, Murray and colleagues developed an interactive 3D computer animation and an action plan help sheet to encourage physical activity among young people with asthma (Murray et al., 2016). The intervention was regarded as highly acceptable and meaningful to stakeholders (Murray et al., 2016). The authors concluded that it is feasible to develop high quality visual interventions that effectively capture health information in an acceptable and engaging format (Murray et al., 2016).

Developing an animation to raise awareness of dementia grief

We developed an animation using content from a previous study that explored preparation for end of life and pre-death grief in carers of people living with dementia; the Experiencing Loss and Planning Ahead Study (ELPAS). ELPAS was a cross-sectional, mixed methods study of 150 family carers of people with dementia who participated in face-to-face interviews from January 2018 through January 2019, sixteen of whom also participated in audio recorded qualitative interviews. We gathered information such as demographic data and grief scores. Details about recruitment and methodology for this study are reported elsewhere (Moore et al., 2020).

We held a workshop with a multi-disciplinary panel of experts and stakeholders to present the findings from ELPAS facilitated by the ELPAS researchers (KM, SC). The 11

attendees included a clinical psychologist, three admiral nurses (dementia specialist nurses), one dementia navigator (link staff who provide information and support to people with dementia and their carers), five bereaved carers, and one representative from the Alzheimer's Society. One of the healthcare professionals was also current carer. The workshop members discussed consolidating information about carer grief to create a resource for carers. The panel decided that this resource should be an animation which would be brief, engaging and easy to understand for a broad and diverse audience. The aim of the animation would be to raise awareness about carer grief before the death of a person with dementia among a wide audience – carers, their social networks and people who worked with and supported family carers. As the resource is only brief, it did not intend to help carers manage or process grief but rather raise awareness and highlight options to access grief support.

Using the feedback gained from the workshop participants, we developed a script for the animation which included quotes from the ELPAS audio recorded interviews. One of the authors (SC) created imagery for the animation using the animation software Vyond. We sent the script to the workshop members for additional feedback. Once the script was finalized, we sent the draft animation and audio recordings to a filmmaker to professionally edit the audio and match it to the visual animation. We then sent the final draft version back to workshop members for final feedback and revision.

Aim

Due to the high levels of grief experienced by carers of individuals with dementia as well as the dearth of evidence supporting the efficacy of psychosocial interventions to manage grief among these carers (Wilson et al., 2017), attention should be placed on development of acceptable and efficacious interventions. In response to this need, the present study aimed to

determine the usefulness, acceptability and relevance of the animation we previously developed to raise awareness to grief experienced by carers. We hypothesized that 75% of carers would find the animation useful, acceptable, and relevant, a benchmark used in other research with family carers of people with dementia (Rapaport et al., 2020).

Method

We used a single group intervention study design with family carers of people with dementia to evaluate the ELPAS animation.

Ethics approval

Ethics approval was obtained through the London - South East Research Ethics Committee (Reference 17/LO/1881) and the University College London Research Ethics Committee (Reference 11755/001). The study was approved by the Health Research Authority (Sponsor Reference Number 17/0477).

Developing the evaluation survey

We developed an evaluation survey that covered usefulness, acceptability, and relevance of the animation, as we were unable to find an existing tool that met our requirements (Appendix). We sent the evaluation survey questions to four bereaved carers to ensure the survey was understandable and feasible for carers to complete. Their feedback resulted in minor modifications to the evaluation questionnaire.

The evaluation consisted of 13 multiple choice and 14 open-ended questions (Appendix). The evaluation asked if the participant felt that the animation was relevant to them and related to their own personal experiences of caring. In addition, it examined if the participant felt the animation was helpful to their situation and whether it was distressing. The evaluation also questioned if the participant believed the animation was trustworthy, clear, and easy to

understand. Additionally, it asked if the animation would be useful in helping family and friends and healthcare professionals understand what they were experiencing as a carer. The evaluation also asked if the animation was helpful in finding further information or support for carer grief. We asked participants to elaborate on some of their responses in open-response form.

Participants

To recruit participants to complete the evaluations, we contacted participants from the ELPAS study as described above (Moore et al., 2020). During the initial ELPAS interview, participants had the option of consenting to be contacted about future related research studies within the next two years. We classified the 150 participants from those with the highest to the lowest grief scores on the Marwit-Meuser Caregiver Grief Inventory (Marwit & Meuser, 2005). The Marwit-Meuser Caregiver Grief Inventory is an 18-item grief inventory that provides a total grief score (score range 18-90, with higher scores indicating higher grief) (Marwit & Meuser, 2005). We prioritized contacting those with higher grief scores first because we believed the animation would be more relevant for those with higher levels of grief. If carers were not eligible or we couldn't contact them, we worked down the list of participants and this included participants with lower levels of grief. Given we were contacting carers between 1-2 years since they had participated in the original ELPAS interview, we decided it would not be appropriate to contact carers who had been caring for someone with advanced dementia or were considered at end of life at the time of the ELPAS interview. We also did not contact carers who were highly stressed in the prior interview or had been interviewed more than two years earlier. We excluded these carers from the present study because we did not want to cause additional stress.

We contacted participants over the phone or via email to establish they were still providing care for their relative and to gain verbal consent to receive the animation and

evaluation. Eligible participants also indicated consent on the evaluation survey. We gave participants the option to complete the evaluation online through a program called Opinio or on paper and to return it through the mail. Those who opted to complete the paper version were sent a DVD of the animation.

Data analysis

Statistical analyses were conducted using the SPSS software package (Version 26). We performed descriptive statistics and reported the responses to the evaluation questionnaire as well as the demographic characteristics of the sample. These demographic characteristics were derived from the original ELPAS interviews conducted in 2018 and 2019. Based on expected values of 75% (95% CI = 59-87%) for the proportion of carers finding the animation relevant (very or somewhat), helpful (very or somewhat) and acceptable (not causing any distress), we calculated that we would require feedback from at least 40 carers to calculate these values with reasonable precision (for 75% value, the 95% Confidence interval with this sample size would be 59-87%). We chose this level to indicate that the majority benefited from the resource rather than only 50% where the benefits would be equivocal.

We used NVivo (Version 12) to analyze the open-text qualitative data on the evaluation questionnaire. Text data were imported into NVivo and analyzed using thematic analysis (Braun & Clarke, 2012). Two raters (CS, KM) read the transcripts and CS developed an initial coding scheme that was discussed with KM and SC. The researchers discussed the codes and continued to develop themes that emerged from the data. Once all open-text responses were coded, the first author reviewed all thematic categories and created subcategories to identify additional themes. When reporting qualitative responses from participants, we applied new ID numbers that were not the original participants' ID numbers in the study.

Results

Participant characteristics

The evaluations were completed from January through March 2020. We attempted to contact 78 carers. Of those 78, 18 carers shared that the person with had dementia passed away, three had no access to a computer or DVD player, and nine did not answer the phone. Of the 48 carers who we contacted and were eligible to complete the survey, 31 completed the evaluation, yielding a response rate of 65%.

The mean age of participants was 64.2 years ($SD=8.9$), ranging from 52 to 83 years of age. Most participants were female (85%) and either wives (42%) or daughters (42%) to the person living with dementia. Twenty-seven (87%) participants were White British, 2 (7%) were White Other, 1 (3%) was Asian British, and 1 (3%) was African. The scores on the Marwit-Meuser Caregiver Grief Inventory showed that the mean grief score of the sample was 66.23 ($SD=9.36$). The demographic characteristics are presented in Table 1.

Participant responses to the evaluation questionnaire

Ninety-four percent of participants found the animation very (68%) or somewhat (26%) relevant to their situation, meeting our 75% target level. Sixty-eight percent described the animation as very helpful (26%) or somewhat helpful (42%) to their situation just falling under our 75% target level but exceeding 50%. The remaining 29% indicated it was neither helpful nor unhelpful (See Table 2). Seventy-three percent of carers reported the animation was not at all distressing, which was our criteria for acceptability. Seven carers (23%) reported it was a little distressing, and one (3%) felt it brought on a lot of distress. We found that 87% of carers indicated that the animation would be helpful for other carers as well as healthcare professionals.

We found that 6 (19%) participants reported the timing of the animation was right for them, 10 (32%) felt it would have been more helpful at diagnosis, 14 (45%) felt it would have been more helpful the first year after diagnosis, and 1 (3%) felt they were not ready for the animation and it would have been more helpful in the future. When asked whether the animation would be useful in helping their family and friends understand what they are experiencing as a carer; 14 (45%) of carers reported it was very useful, 6 (19%) somewhat useful, 7 (23%) not sure, 2 (7%) it was not very useful, and 2 (7%) it was not at all useful.

Qualitative Findings

The total number of participants who responded to each open-text qualitative question on the evaluation questionnaire can be found in Table 3 (ranging between 9-26 responses). We present the themes below identified in these open-ended responses.

Improved carers' understanding of grief

Many participants found the animation useful in helping carers better understand grief. Participants expressed that watching the animation allowed them to label what they were feeling as grief and realize that grief can occur before the death of their loved one.

'You have covered many aspects of the isolation and sadness we all feel, but also some of the less known emotions - like grief. It's a new way of thinking about grief, and it's useful for us to have a name for what we feel, day after day. It really is a kind of grief, but the word always seemed to me too strong for what I felt, and now I feel I can own it in a way, and acknowledge that there are ways of feeling grief even if there isn't a death.'

Participant ID #1, female caring for spouse

Shared experience with other carers

In addition, participants felt that the animation helped them understand that there were other carers who were going through similar experiences. The carers explained that knowing this allowed them to feel a sense of community with other carers.

‘[The animation helps] knowing that others are experiencing the same sense of loss of the person and the resentment that can produce.’

Participant ID #5, female caring for parent

‘Listening to how others feel, makes you feel you are not on your own.’

Participant ID #6, female caring for parent

Informing healthcare workers, family, and friends

Participants reported that the animation could allow healthcare professionals, family and friends to better understand the feelings and needs of carers. Participants indicated that healthcare professionals in particular often focused solely on the mental and physical health needs of the person with dementia, and therefore overlook the carer’s needs.

‘It could reinforce the role of carers and the hidden implications on their mental wellbeing. With healthcare professionals the focus is always entirely on the sufferer and, in my experience the carer is treated as a resource or source of communication for the sufferer at best and ignored for the most part.’

Participant ID #2, female caring for parent

Some participants shared that family and friends do not understand what the experience of caring for a person with dementia is like. They felt that the animation may be used to show family and friends how to support carers more effectively.

‘Friends and family ... may not know what it is like to live with a person who has dementia and the feelings of loss and grief a carer experiences while the person is still alive. They may hesitate to start a conversation in case it upsets the carer, but the animation would give them the confidence to say that they would like to listen if the carer felt ready to talk’

Participant ID #3, female caring for spouse

Timing of the animation

In contrast, some participants believed that the animation was less useful to their situation. For example, some carers believed that the timing of the animation was not right for them because they had been caring for a person with dementia for many years. As a result, the animation did not provide new information for those carers. They felt the animation would have been more useful to watch at diagnosis or one-year post diagnosis.

‘I feel that this animation would be useful in the early stages following diagnosis to support families who are trying to make sense of the changes in their loved one’

Participant ID #7, female caring for parent

‘I felt there was nothing in the messages that I didn’t know already. Maybe the animation would be helpful for people new to caring’

Participant ID #8, female caring for parent

More emphasis on grief support resources

In addition, a few carers expressed that they would have preferred that the animation put more emphasis on support resources. Some participants said the slide that discussed additional resources was displayed too briefly. Others said that they wished the animation discussed more about how to manage and cope with grief in the dementia context.

‘The last part of the animation showing the contact details of helpful organisations was not on the screen long enough to be useful.... this should be provided as a pdf file that could be saved so that it could be accessed again without having to watch the animation again.’

Participant ID #9, female caring for spouse

Distress brought about by the animation

Many of the carers who did not find the animation distressful had been caring for their loved one for an extended period of time. Those participants postulated the animation may cause more distress among new carers.

‘I did not find the animation distressing. My mother was diagnosed over 10 years ago ... if I had not been through the whole process, I can see it may affect new carers slightly before they can see how helpful it would be.’

Participant ID #6, female caring for parent

‘It may be distressing for some people who have just found out the close relative has been diagnosed [with] dementia.’

Participant ID #10, male caring for spouse

The one participant, a female caring for her husband with young onset dementia, who had reported the animation to be very distressing indicated that this was related to:

‘The relationship of the image of two daisies and people’

Participant ID #4, female caring for spouse

Further comments from this participant indicated that they also felt the animation was not helpful due to ‘the image of older dementia sufferers’ and the ‘lack of young dementia sufferers.’

Images in the animation

Participants provided mixed feedback on the images in the animation. Some carers explained that the images were clear and appreciated that the animation portrayed diverse carers. On the other hand, other participants did not favor some of the images. For example, a few participants felt that some of the images were distracting and hard to follow.

‘I found the way the coloured background flickered (or toggled between two phases) very distracting.’

Participant ID #3, female caring for spouse

Relevance of the animation

Participants felt that the animation was relevant to their experience of caregiving. Many participants related most to the experience of losing the person they once knew as a result of psychological and physical changes brought on by the disease. They reported that the animation captures effectively the difficulty of grieving aspects of the relationship before the death of their loved one.

‘That your relationship with the person with dementia changes radically.’

Participant ID #11, female caring for parent

‘Living with a different person now....not able to hold an intelligent conversation....’

Participant ID #12, female caring for spouse

Disseminating the animation

When asked who participants felt the animation should be targeted to, they believed that it would be useful to show it to carers, employers, family members, and health care professionals. They shared the most efficient ways to promote the animation including care homes, GPs, libraries, memory services, mental health clinics, public transportation advertisements, social media, universities, and workplaces.

Discussion

We aimed to evaluate the usefulness, acceptability and relevance of an animation co-designed with carers and healthcare professionals. The majority of carers reported the animation to be useful, acceptable, and relevant. The qualitative responses also supported benefit of the animation, as many felt that the animation could help carers recognize grief and see that other

carers go through similar experiences. Participants thought the animation could help healthcare professionals, family and friends better understand grief and how best to open a supportive dialogue with carers. They also felt the animation may be more suited for carers in early stages of caring, either at diagnosis or one-year post diagnosis of dementia. In addition, they felt that more emphasis should be put on the support resources so that carers can easily discern who they should reach out to.

We compared the mean grief score in our sample to that of other studies that used the 18-item Marwit-Meuser Caregiver Grief Inventory to assess grief among carers of people with dementia. We targeted carers with higher grief and this was evident as scores for our sample (mean=66) were higher than other studies, showing means of 57 (Marwit & Meuser, 2005; Ott, Kelber, & Blaylock, 2010). Many participants in our sample had been caring for a person with dementia for several years, and therefore may have experienced multiple losses throughout the unpredictable disease trajectory that exacerbated grief (Lindauer & Harvath, 2014; Meichsner & Wilz, 2018).

Limitations

This study has several limitations. Because we derived participants' demographic information from the original ELPAS interviews, it is possible that some demographic variables may have changed in the time between the first interview and the evaluation. For example, participants may have had different living situations or grief scores by the time they completed the evaluation questionnaire. In addition, as we were unable to recruit our target sample of 40 due to COVID-19 because we felt it would put additional stress on carers to continue to contact them for the study, we are unable to be confident that our findings could be generalizable to the larger population of carers of individuals with dementia. However, we fell just short of the 75%

target in acceptability and usefulness, questioning the overall value of the resource. As participants had been involved in an interview about grief and loss 1-2 years before the evaluation, they may have been more likely to have thought about and processed grief. Therefore, this might have made the animation less useful to them.

Implications

Finding the target audience for the animation may come with challenges. For example, it's difficult to determine the appropriate timing of the animation given that some carers of individuals with advanced dementia shared the animation may be more appropriate for carers of individuals newly diagnosed with dementia (Moore et al., 2017; Moore, Goodison, & Sampson, 2019). In addition, a carer from a diverse background who cared for a person with early onset dementia expressed that the animation was not useful or relevant. Studies have demonstrated that individuals from diverse cultural backgrounds experience and express grief in different ways (Rosa & Fuentes, 2020; Stroebe et al., 2008; Sun, Ong, & Burnette, 2012), and this may have impacted the way the participant received the animation. Additionally, it is also possible that early onset dementia may be a different carer experience that could have also influenced how this participant received the animation (Kobiske, Bekhet, Garnier-Villarreal, & Frenn, 2019).

Future research should investigate the usefulness and acceptability of the animation among carers of newly diagnosed people with dementia. Also, future studies should develop interventions to target dementia grief tailored for different types of carers, such as adult children and spouses. Finally, this animation was developed as a method for raising awareness of grief, rather than helping carers manage their grief. Further research is needed to identify strategies and interventions to help carers who are struggling to adjust to their grief while caring for a friend or relative.

Despite the need for future research, many participants found the resource helpful for carers as well as family, friends, and healthcare professionals, so we have published the animation online for broader dissemination and access. We incorporated minor changes in response to participant feedback. We addressed graphical issues and flashing images as well as increased the time spent on the page for accessing services. The revised version is accessible at this link: <https://youtu.be/X6QXP22N6tg-> or with contextual information and links to services here: <https://www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research-department/research/centre-dementia-palliative-care-23>. Based on carer suggestions it may also be useful to show the animation in settings such as care homes, GPs, and social media. The resource is a cost-effective way of raising awareness of carer grief and possibly giving permission to carers to accept feelings of grief and perhaps seek psychological support either via informal social networks or through formal counselling or peer support.

Conclusion

We developed an animation to raise awareness to grief experienced by carers of individuals with dementia. Although this study was not adequately powered and we could not determine statistically whether carers felt the animation was useful, acceptable, and relevant, participant responses to the animation were overall favorable. Dissemination of the resource may be useful for the majority of carers, with the caveat that a minority of carers may find it distressing and need to be referred for further support.

The Authors declare that there is no conflict of interest.

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