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The right to mourn in dementia: To tell or not to tell when someone dies in dementia day care

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ABSTRACT

People with dementia (PwD) attending dementia day care often experience the death of others. Little research exists regarding whether PwD should be informed of the death, and if so, how? In this qualitative research, the authors explored, through semistructured interviews, the beliefs and practices of 52 staff members of adult day centers for PwD about these issues. Themes that emerged are that many staff members feel their clients have emotional capacity to mourn, despite their cognitive impairments. There are many different ways to tell PwD about the death of others. Each case should be judged individually. Eighty percent of staff feels sad when a group member dies and 92% desires more training on how to enable their clients to grieve. Research is needed on mourning and PwD, staff training, and ways to help staff with the burden of their own grieving. These methods may improve quality of care and decrease staff burnout.

The challenges surrounding the mourning experience of persons with dementia (PwD) can be illustrated in the following case study: Mr. Richards passed away at the age of 80. His wife of 40 years, Hillary, had dementia for the past 7 years. The family, after being advised by their family doctor, decided not to tell Hillary of her husband's death, not to take her to the funeral and not to include her in any of the family mourning rituals. Over a year later she has still not been openly informed of her husband's death. The family did not consult with the staff in the dementia day care center that Mrs. Richards attends to hear their insight on the matter. The staff therefore has to acquiesce to the family's requests not to inform Mrs. Richards of her husband's death. As a result, staff members are often confronted with Mrs. Richards's enquiries as to the whereabouts of her husband, however they are equally aware that informing her each time of his death will become a recurring stressful event. This case study exemplifies the complex situations that can arise when PwD lose those who were close to them.

Despite PwD's decrease in social cognition capacity (Cosentino et al., 2014; Smid & Adoni, 2015) as well as their decreased conscious reflection, comprehension, and verbal expression, all abilities used in the mourning process, research shows that PwD, even in advanced stages, can and do experience emotions such as loss (Boyle, 2014).

Disenfranchised grief is the grief experienced by those who incur a loss that is not openly acknowledged, publicly mourned, or socially supported (Doka, 2002). These losses are not recognized by others close to the person who experienced the loss. In a sense, the person is not given the right to mourn. Being isolated in bereavement can make it much more difficult to mourn and reactions are often stronger. The mourner is deprived of the catharsis shared grief brings (Doka, 2002). Could it be that when PwD are not informed or included in the grieving process or when their grief is not at all acknowledged by others, they may experience disenfranchised grief? Although PwD may not be capable of clearly expressing their feelings of loss, some researchers (Rando, 1993; Rentz, Krikorian, & Keys, 2005) have suggested that perhaps select unconventional behaviors seen in a PwD (e.g., unusual or increased manifestations of agitation or restlessness) may be the manifestation of their grieving for loved ones who have died. These behaviors may not be properly identified by professional or family caregivers as mourning behaviors, but rather as difficult behaviors. Because those around them don't realize they are mourning they may fail to validate and support the PwD's grief (Doka, 2004). However, despite the theoretical understanding of grieving capacity in PwD, there are few empirical studies that explore caregivers' beliefs, attitudes, and practices, as well as their needs, in dealing

with the issues arising from the death of someone in the social circle of PwD (Gataric, Kinsel, Currie, & Lawhorne, 2010; Tan, O'Connor, Howard, Workman, & O'Connor, 2013). These questions are especially relevant to staff members working in adult day care with PwD who, because of the common occurrence of a death of a group member, must regularly decide whether to and how to inform the remaining group members (Moore, Geboy, & Weisman, 2006).

Staff members in dementia day care facilities are regularly confronted with dilemmas which necessitate answers to many of the following questions: Do group members with dementia have the capacity to understand that someone in the group has died? Would they want to know if a fellow group member will no longer attend the group? Should the staff inform the whole group and if so, how? Which of the staff members should take on this responsibility? And, finally, do group members have the right to mourn for their fellow group member who has died? The aims of this study were to explore the pertinent beliefs, attitudes, and practices of staff members working in dementia day care related to the above questions. We hoped to be able to define future research agendas based on our preliminary assessments using grounded theory analysis, and begin a dialogue about current methods in the hope of generating guidelines on good practice for adult day care staff regarding grieving of PwD.

Methods

Setting

The research was conducted with staff members of the adult day care centers of MELABEV—Community Clubs for Eldercare in Jerusalem, Israel. This nonprofit organization runs adult day care centers in the greater Jerusalem area, caring for over 400 community dwelling people with varying levels of dementia. Groups are conducted in the mother tongue of clients. Each group of clients has a group leader (usually a social worker, psychologist, or nurse), recreation workers, and volunteers. There are also specialized expressive arts therapists who facilitate the groups' therapeutic activities. In this article, we refer to all these different types of staff members collectively as "staff."

Staff recruitment and demographics

Approval for this research was obtained from the Helsinki Ethics Committee of the Shaare Zedek Medical Center, Jerusalem, Israel. The total pool of staff members was 100. The research project was presented

to staff members at a routine yearly staff meeting. During this meeting, each staff member also received a written description of the study and a consent form to be signed if they wished to participate. This information was also sent by e-mail to all staff members. Telephone contact followed to arrange times for interviews. Of the 100 staff members, 52 (52%) staff agreed to be interviewed. All were female.

Instruments

The staff questionnaire was constructed through consultation with multidisciplinary professionals and was based on relevant literature in the areas of death, dying, and dementia (Grief & Myran, 2006; Gruetzner, Ellor, & Back, 2012; Johansson & Grimby, 2013). The questionnaire contained a total of 40 questions.

The questionnaire included both closed and open ended questions grouped in the following areas:

1. Staff background data
 - a. Demographics: age, marital status, place of birth.
 - b. Education: level and training including if they received training in end of life care.
 - c. Personal experience with death (not related to work): including who died, how they were told, how did they react to the loss, was their grief acknowledged?
2. Current practices in the day care center in the event of a group member or staff's death.
3. Staffs' beliefs regarding what should be done when someone from the group dies: Do PwD want to be told? Should a person with dementia be told when someone else dies? If they should be told, by whom? With whom? Where? When? And how?
4. Staffs' beliefs and observations about clients' grief associated behaviors.
5. Staffs' personal feelings when a group member dies.
6. Staffs' interest in learning more about grieving and dementia care?
7. Open ended question regarding any areas not covered in the semi-structured interview.

Semistructured face-to-face interviews with staff members using the questionnaire, were conducted in one of the MELABEV centers in a private, quiet setting. Interviews lasted from 20 to 60 min. All interviews were conducted by the same interviewer and coded to ensure anonymity.

Analysis

Following the methodology of grounded theory all interviews were thematically coded individually by two of the authors with the aid of two additional researchers.

This was done to reduce researcher bias. Our aim was to formulate major themes grounded in staff self-reports in order to develop action strategies and build theory and hypothesis for further research (Strauss & Corbin, 1990). Quotes from the interviews that illustrate the identified themes were selected and are included as qualitative examples later on in the article. All quotes included in the article were given by staff members either in the “other” option in any question, or as the answer to the open ended final question “Is there anything else you would like to add?”

Results

Staff sociodemographic data

The average age of the 52 staff members interviewed was 52 ($SD = 14$). All were female. Seventy-seven percent were married, 11% were divorced, 10% single, and 1% widowed. In terms of educational level, 94% of the staff members interviewed had 13+ years of schooling, and the rest reported having between 8–12 years of schooling. They had much experience working in the field of aging in general with 81% working more than 6 years in the field and more than 50% having worked more than 5 years in Melabev with PwD. Yet, more than half (61%) of the staff had not had specific training in end of life issues. Most staff members (88%) have had some personal experience with death.

Current practices in the day center in the event of a group member or staff members' death

Staff members reported numerous rituals to honor, memorialize and remember the dead, currently done with the group when staff deem it appropriate. These varied from group to group and from group member to group member. Ceremonies included the use of candles, passing around a picture of the deceased person, posting a picture of the person, talking about the person, asking if someone wants to say something about the person, reminiscing about the person, relating stories about the person's participation in the group, saying a prayer for the person, performing an activity with the group that the deceased enjoyed, sharing eulogies that were given at the funeral and presenting a memorial lecture. One staff member added a unique

suggestion of something not done: “I would want to show them a film about someone who died at their age, in order to prepare them [for when someone dies].”

Staffs' beliefs regarding what should be done when someone from the group dies

Staff members had several different approaches regarding whether to tell the PwD when someone else dies. Some staff members said the PwD should always be told, others said they should never be told, and some recommended a tailored approach.

The major responses to questions related to staffs beliefs as to what should be done when a group member of adult day care dies are presented in Table 1.

More than half of the study group (60%) felt that it is important to tell the group about the death of a group member. Not all staff members thought these questions could be answered by yes or no and in the “other” option added answers of their own (that were not included in the list of multiple choices). As seen in the table, many of these answers were “it depends.” The “it depends” answer was qualified by such statements as it depends “on the group,” “on who died,” or “on their relationship with the deceased.”

To tell or not to tell?

Always tell. Two thirds of the staff said one should always tell a PwD if someone dies. The following responses by staff members exemplify this perspective:

“They don't want to know details, but they must know the fact it happened.”

“If they notice the person isn't there, they may ask. I think they should be told, even if they don't understand. Many years ago, we didn't tell them and the staff changed that.”

“We tell them everything. Maybe they will forget. But a lack of memory doesn't stop them from being told and knowing.”

“They ask and show emotion; they worry when someone is missing.”

Never tell. Several staff members felt that the PwD should not be told. Responses that highlighted this perspective included:

“Why create emotional havoc [for the PwD].”

“What purpose does this serve?”

Table 1. Staffs' beliefs related to telling.

Question	Yes tell	Don't tell	It depends
Do you think it is important or useful to inform the group about the death of a group member?	60%	13%	26%
What should be done when a client asks about someone who has recently died?	71%	4%	25%

A personalized approach for telling. A quarter of staff members gave the response: “it depends.” It appears that they recognize a social structure and connectedness within the group of PwD. This in turn affects their choice of whether to inform the group of a members’ passing away. For example, staff mentioned that the practice in the group would “depend” on how well the other group members knew the deceased. This indicates that staff members acknowledge the heterogeneity among PwD and endeavor to treat them individually and approach each case individually. This personalized approach is highlighted by the following staff quotes:

“[We should tell] when the people know and remember who has died.”

“They may notice that someone is missing.”

“It depends on the personality of the client who died and the relationship the group had with him.”

“Although it’s different each time, I definitely think something should be said. Some people are larger than life for the others in the group whereas some group members have just arrived and are not well known by the others.”

“I think there are times when there is no point to tell the people when they are very deep in their own world, in their own bubble. On the other hand when the client does have some orientation to his surroundings—one must tell him.”

“They can sense the change, the loss.”

“On a certain level; depending on the relationship between clients and the deceased, there is a thought: why is he missing?”

Some staff members suggested that when telling, the staff must “follow the groups’ needs” and “not force information.” Others said, “One should tell the first time the person asks, but need not put them through the loss repeatedly if they continue to ask.” Some stressed that the message should be “kept simple and that there is no need to go into the details surrounding the death.” Another respondent reminded everyone that “one should never lie [to them].”

Who should tell?

When asked the closed ended question, “If the group should be told, do you feel you are the ‘right person’ to tell the group that someone died?,” 44% said yes they felt they were the right person, whereas the rest did not.

The staff members were also asked an open-ended question regarding who they felt would be appropriate for telling the group other than themselves. In response, 27% said the group leader, 19% said the staff member closest to the group, 11% any trained staff member, 11% any staff member, 5% said the social worker 5% said no one should, whereas 22% gave no response.

Staffs’ beliefs and observations about clients’ grief associated behaviors

Staff members’ beliefs concerning clients’ ability and wish to know that someone died are presented in Table 2. In the question whether group members can understand that someone has died those who answered “it depends” qualified it by saying that it depends on the relationship to the deceased or that it depends on their cognitive ability.

Staff believe that PwD maintain many emotional capacities despite advanced cognitive decline. This can be seen in the following quotes:

“This is an emotional memory. So yes, they can remember the feeling of loss.” “Even if the head forgets the heart doesn’t.”

“They have to have a place for expressing emotions. If you don’t commemorate [the loss of a group member] and just ignore the death when people see that someone’s not there, they feel that when they pass away the same will happen to them—no one will care.”

“Although she’s in the group for people with more advanced dementia, she’s aware of others, and [she related to] the death of her late husband.”

Staffs’ personal feelings when a group member dies

Burden of grieving

Staff reported that working on a regular basis with people who may be close to death is challenging and, that although the death of members is a relatively common occurrence, the burden of grief remains. Staff members reported that they become attached to their clients and have difficulty coping with their deaths. This is highlighted in the following quotes:

“This is the downside of the job—we get attached.”

“The staff is not prepared for the frequency [of group members dying].”

Table 2. Staffs’ beliefs about clients’ grieving abilities.

Question	Yes	No	Depends	Don’t Know
Do you think group members can understand that someone has died?	46%		On client’s cognitive ability 44%	
Do you think group members want to know if someone died?	44%	6%	On relationship to deceased 10%	13%
			37%	

“I feel that our clients sometimes lead us and are more ready for these issues than we are. They want to talk about death and express it. We have to learn how to let them express these feelings and the staff has to be more comfortable with itself—allowing them to express the fear, depression, even their own readiness, their frustration with their lives, with pain and sadness. I don’t think we are so good at that because of our own discomfort.”

Emotional support

When asked “How do you react when someone from the group dies?” a large percentage (80%) of staff members reported being sad. Within the choice of “other,” 9% of the staff reported feeling “relieved,” 7% said it depended on the relationship with the client, 2% reported that it makes them think about the meaning of life, and 2% said they didn’t know. No staff members selected the answers “I have no feelings, that’s part of the job” or “I don’t feel like going to work.”

However, more existential grieving emotions were also described by the staff in answers they gave to other questions on the interview. For example some staff members mentioned being scared, having fears of death, thinking about their own mortality, and having a hard time discussing topics related to death.

The following quote points to staffs’ need for emotional support:

“In terms of staff response to this topic, each person is responsible for dealing with the death of clients on her/his own terms. So much of this topic is about fears or anxieties and other personal issues of the staff members and less about the actual state of being of the client. This is not to say that clients don’t deal with issues of anxiety, fear, sadness, etc. But when the staff member is asked about this topic, it triggers their personal feelings on the subject, their own fears related to dying, more than we realize. The bottom line is, why is someone afraid of dying?”

Staffs’ interest in learning more about grieving and dementia care

Ambivalence

Some staff members reported being unsure as to the best course of action as well as what was expected of them when a group member passes away. They felt the need for formal guidelines. The following excerpts highlight this ambivalence and lack of guidance:

“Some [clients] will notice and ask [about a missing client]. I talk about it [the death]. But we don’t have a formal policy although I think we should.”

“I used to think I had all the answers [that they] should be told ... Now I don’t know, not sure if it’s healthy for them to know. Otherwise, they detach more quickly.”

“It’s hard to know if we are doing it right. We never know what reaction we will get from a client.”

This ambivalence can be exacerbated further when family members think differently than the staff. For example when staff members want to tell the PwD about a death (of a family member) and family members tell them not to.

Need for more training

The vast majority (92%) of staff members felt a need for more training about mourning and PwD. This can be seen from the following quotes:

“I don’t feel qualified to tell them, but it’s important to train us for this in case we need to.”

“Staff want to do the ‘right thing’, but don’t know exactly what to expect.”

Discussion

Half of all the staff members volunteered to be interviewed for this research study. We would have liked more staff members to participate. This lower participation rate could be because the staff are very busy, the times that the interviewer was available to do interviews was not convenient for all staff members, or those who chose not to participate might be reluctant to discuss issues related to death and mourning.

Those staff members who were interviewed were educated, and had many years of experience working with older adults and PwD. A high percentage 60% felt that PwD should be told when someone dies. This percentage rises to 71% when referring to a PwD who asks a direct question about the whereabouts of someone who has recently died (Table 1). Staff members related their decision to three major concepts; the belief that PwD maintain emotional capacity even in the face of significant cognitive deficits (“Even if the head forgets the heart doesn’t”) the uniqueness of each PwD (“It depends on the personality of the client who died.” “Some people are larger than life for the others in the group”) and the existence of a social personhood (Buron, 2008) amongst PwD in adult day care (“It depends on the relationship the group had with him”).

Our research demonstrates that staff members regard PwD in their groups as autonomous individuals with unique personalities that contribute differently to the group dynamics. Each individual’s presence in the group affects the rest of the group in different ways.

They understand that group members develop relationships within the group. This was demonstrated in studies by some researchers who have found that some PwD do have remaining capacities for social cognition and are able to make friends (Sabat, 2012). Similar studies have shown that social stimuli promote engagement even in persons with advanced dementia (Cohen-Mansfield, Thein, Dakhel-Ali, Regier, & Marx, 2010).

Staff members see the personhood of group members (Palmer, 2013). There are many definitions for personhood. The one that fits with this staff's behaviour seems to be that of Kitwood "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being ... implying recognition, respect and trust" (Kitwood, 1997). The staff uses person-centered care with the PwD being the focus (Kitwood & Bredin, 1992). This is exemplified by their way of relaying information about the death of another group member, or conducting memorial services for someone who has died. It is evident by the common use of the answer "it depends." The staff who participated in this study, believe that many of the questions and issues raised were too complex to merit a yes or no answer. Rather, their response is often personalized to each group member depending on their cognitive abilities and their connectedness to other group members. Ultimately, the majority of staff believe that the group members should be told but "the how" must be crafted and personalized to the group members and the group as a whole.

Staff members often created a ritual acknowledging the death of a group member. The ritual of death acknowledgement varied depending on the staffs' perception of the social personhood of the person who died within the PwD group and of the needs of other group members. For that reason many different types of rituals were reported.

Another important issue that was explored was the level of preparedness and confidence felt by staff members when relating to PwD and mourning. One finding of this study that we would like to highlight relates to the uncertainty and insecurity that staff members felt about their own ability to cope with these situations. Although 44% felt they were suited to inform the group about a death, 56% felt others were better suited. Furthermore, 92% requested more training in this area. Although 56% of staff reported that they do notify the group in some way, the lack of practical guidelines leaves the staff with questions as to what is the most appropriate way to share the news with the group members in their care. Interventions aimed specifically at increasing staff self-efficacy and competence in these areas of dementia care, could be very beneficial in giving

staff the clarity they need and reducing burnout at work (Duffy, Oyebode, & Allen, 2009). It might also be worthwhile to explore adapting models for training medical professionals on the best practices for relating "bad news" into a specialized curriculum for adult day-care staff working with PwD. The training could include a combination of lectures, interactive techniques such as demonstrations, role play, panels, and audience feedback on the staff's actual skills (Rosenbaum, Ferguson, & Lobas, 2004). The curriculum may include guidelines on a range of practices from which the leader should choose when telling PwD about the death of another group member. The choices would be based on the members remaining in the group, the person who died, and the staff member's comfort. It would also provide suggestions of the considerations to be taken into account when choosing a course of action. Further training and clear guidelines could possibly give staff more confidence and help them deal with their reported ambivalence as to what really is the best practice in this area of dementia care (Horwath & Morrison, 2005). Further research is needed in the area of staff training for dealing with loss and grieving in adult day care.

Because 80% of staff members reported being sad when a group member passed away, it is also important to investigate methods to help them cope with their own grieving burden. These methods may help improve the quality of care and decrease staff burnout and turnover rates (Rickerson et al., 2005).

Conclusion

The aims of this study were to explore the pertinent beliefs, attitudes, and practices of staff members working in dementia day care. We hoped to be able to define future research agendas based on our preliminary assessments using grounded theory analysis, and begin a dialogue about current methods in the hope of generating guidelines on good practice for adult day care staff regarding grieving of PwD. Key themes that emerged are that many staff members felt their clients are autonomous and have emotional capacity to perceive the death of certain group members despite their cognitive impairments. There are many different ways to tell PwD and each case should be considered individually, taking into account the social connectedness of the group to the person who died, and tailoring the grieving ritual to the group's needs. As one staff member summarized, "Maybe it is important to check more 'how to tell' [and not if to tell] since it is different from person to person."

Interview data indicated that a high percentage, 80%, of staff members feel sad when a group member dies and would benefit from a safe place to deal with these

issues, as mentioned by a staff member: “The staff sometimes needs to work on the sadness and that’s totally overlooked.” Other findings relate to the uncertainty and insecurity that staff members felt about their own ability to cope with these situations. Although 44% felt they were suited to inform the group about a death, 56% felt others were better suited. Likewise, 92% of the staff expressed the need for more training for how to best enable their clients to grieve successfully. They may benefit from formal practical guidelines in this area of dementia care and training to boost their self-efficacy and competence. Staff support and training emerged as areas where further program development and guidelines are needed. Additional research in this area would be essential to develop the knowledge base for such program developments.

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