Abstract

GUIDE BOOKLET: A LOOK AT BEREAVEMENT SUPPORT FOR PEOPLE WITH DEMENTIA

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This project began out of a need to find resources to support people with dementia who are bereaved due to the death of a loved one that received hospice services. Although it was found that a considerable amount of research has been conducted to address the needs of people who care for those with dementia, it became evident during the literature review that specific findings on supporting the bereaved with dementia is lacking. In an effort to contribute to the conversation, this project begins with briefly addressing the concept of grief, and the condition of dementia. The literature review focuses on understanding the phenomena associated with the population under consideration, challenges to providing quality care, and working to understand the subjective experiences of the bereaved with dementia so that communication skills can be enhanced and a better framework for research can be developed. This paper continues with an explanation of the materials and methods for developing a guide booklet as a supportive and educational resource offered within a hospice setting. Additionally this paper offers a sustainability plan for revising, updating and building upon the project. This paper closes with a discussion of the project limitations and recommendations for further research.
Acknowledgements

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# Table of Contents

Abstract .................................................................................................................................. ii
Acknowledgements.............................................................................................................. iii
List of Tables ....................................................................................................................... v
Introduction ......................................................................................................................... 1
  Literature Review ........................................................................................................... 3
Materials and Method ........................................................................................................ 10
Results ............................................................................................................................... 12
Sustainability Plan ............................................................................................................ 13
Discussion ......................................................................................................................... 15
References ......................................................................................................................... 17
List of Tables

Table 1. Guide Booklet Sustainability Plan for Year Two ........................................ 13
Introduction

Death is a significant part of life and each person who loses a loved one to death experiences grief in individual ways; there is no single unique way to grieve. When a person with dementia loses a loved one to death, the experience of grief can become particularly complex. People who have dementia need a great deal of care and support in daily life. The caregivers of the bereaved with dementia also need relevant information to help in the understanding of how to help with the processing of grief.

The Alzheimer’s Association has put forth that dementia is a term used to describe a person who is experiencing loss of memory and other mental functions, which when severe enough can be disruptive to daily living (Alzheimersassociation.org, n.d.). Although dementia can stem from diseases like Alzheimer's, Parkinson's or Huntington's (i.e., neurodegenerative diseases) it is also found in relation to medical conditions like strokes (i.e., vascular damage) or vitamin deficiencies (Alzheimers.net, n.d.). Dementia affects 35.6 million people worldwide and it's estimated that there are 7.7 million new cases each year (World Health Organization, 2012). The effects of dementia can have a significant impact on a person's memory, thinking, behavior and ability to do daily activities. Caregivers of people with dementia are also impacted and can experience guilt, grief, frustration and anger (Alzheimer Society Canada, n.d.). When faced with the death of a loved one who was once receiving hospice care, surviving members who have dementia and the people who care for them often endure complex challenges for coping with grief.
The project that was undertaken and is discussed in this paper aimed to fulfill an unmet need within the hospice community. To that end, content for a guide booklet has been developed and designed to act as an educational resource to support the bereaved who have dementia, as well as to provide support for their caregivers (e.g., family members, friends, etc.). The intention of the guide booklet is to provide basic information about grief, loss, coping with loss and how to improve communication with the bereaved that have dementia. The guide booklet will also serve as a foundation to expand upon for the community partner for which it is being developed, Yolo Hospice of Davis, California.

The approach to developing the project relied heavily on the review of the Literature and collaboration with the community partner, both of which provided a platform for the context of the booklet’s content. Gaining a better understanding of the perspectives of people who have dementia has served as an influence while research was conducted and content was developed. Subject areas that were under consideration included but were not limited to: grief, dementia, grief in people with dementia, coping with loss and communication skills when engaging with people who have dementia.

The anticipated outcome of the project serves to offer an increase in available resources for people who need support in caring for those with dementia who are grieving the loss of a loved one that has died while receiving hospice care. Preliminary plans for assessing the outcome of the project include seeking feedback from the community partner. The community partner will be asked if those who access the booklet offer any comments or feedback and if any modifications would be useful. Suggestions and
comments from staff will also be invited and assessed. If implementation of the booklet is well received, the question of making it available as a resource on a larger scale to include additional hospice agencies will be considered.

**Literature Review**

People who are bereaved and have dementia need emotional support. Thus far, the review of the literature has revealed a consensus that this population has been underrepresented concerning the allocation of bereavement services. In order to gain a better understanding of this social problem, several aspects of the issue were investigated. Literature reviews included: 1) the phenomenology of bereavement among older adults with cognitive impairment; 2) challenges in providing care for the bereaved with dementia; 3) grief from the perspective of the person with dementia; and 4) a potential framework for future research.

**The bereaved with dementia: understanding the phenomena.** Grief and Myran (2006), describe bereavement as being an experience of deprivation resulting from death. The work of Grief and Myran (2006) explores the clinical issues found in settings where older adults who have cognitive impairments and dementia are in bereavement. They support the consensus that little is known about the effects of grief on older adults with dementia. Further, Grief and Myran (2006) propose that people with dementia often encounter difficulties in communicating, where verbal expressions are a challenge and participation in support groups becomes thwarted. Another challenge faced by those with
dementia is recollection of the death of a loved one, which can exacerbate emotional frustrations when requests for the whereabouts of a loved one are repeated.

Working to gain an understanding of the clinical issues surrounding people with dementia who are bereaved requires a common language amongst professionals. Grief and Myran suggest that the data from their case studies serve as a starting point to categorize the distress of bereaved people with dementia and provide a framework for managing the issues in a clinical setting. At the time of their work, Grief and Myran emphasized the lack of literature regarding psychotherapy for bereaved adults with cognitive struggles. The data they generated resulted in observations that offer a phenomenological approach to categorization, which included:

- Understanding the frequency of distress
- Relationship the distress is connected to
- Awareness of death taking place
- Presence of psychosis
- Severity of cognitive impairment
- Provisional diagnoses (e.g., dementia with Lewy bodies, vascular dementia, etc.)

(Grief and Myran, 2006, pg. 212).

A marked point of concern rose by Grief and Myran (2006) is the absence of ethical guidelines when it comes to helping professionals on how to disclose the death of a loved one to a person who has dementia. They offer that education of staff in nursing homes, and those fulfilling the roles of nurses, physicians and social workers is scant. Grief and Myran’s solution to developing a framework for managing care is somewhat limited in that it applies on a case-by-case basis. Gaining an understanding of how each person experiences his or her grief based on conditions of memory impairment can help to identify individual needs and care. Grief and Myran conclude their article by
encouraging investigation of broader literature to include therapeutic approaches for the bereaved with cognitive impairment.

**Challenges: providing care for the bereaved with dementia.** Caring for bereaved people with dementia and their families presents with challenges. To help address these challenges, a symposium on grief and dementia took place in 2008 in Dayton, Ohio. The idea of the symposium stemmed from a planning committee that had come together at the suggestion of a geriatrics nurse who worked in a hospital setting. The nurse raised the issue of staff being ill prepared to care for the bereaved with dementia and their family (Gataric, Kinsel, Currie and Lawhorne, 2010). The authors generated a report from the symposium on grief and dementia in 2010 with the objective to describe the intersection of dynamics between professionals and families who receive care.

Death and the experience of loss for survivors is a unique experience. Understanding both the perceptions of people who are grieving and of those who are providing support is paramount to quality of care. The symposium set out to explore perceptions of grief as well as therapeutic approaches for support and how to best integrate them into a continuum of care (Gataric, et.al, 2010). The symposium revealed that communicating the news of the death of a loved one to a person with dementia comes with uncertainty for both professionals and family members. It was also found that a lack of understanding regarding the grieving process for a person who has dementia could lead to insensitivity from professionals.
The subject of helpful interventions calls for attention to an individual's unique experience. The symposium emphasized the importance of determining the comprehension levels of the person with dementia (e.g., strength of attachment to the deceased). Interventions were identified as being in two categories: practical support and spiritual engagement (Gataric, et.al, 2010). In the former, helpful resources included Alzheimer’s support groups, respite services, home health care, educational outreach and services from several professional disciplines (e.g., nurse practitioners, social workers). Concrete examples of useful techniques were reported: repetition of information, manicures, hand massages, play, and singing. Spiritual or affective interventions included prayer, life review, engagement with clergy, playing hymns and playing music from childhood, which was found to reduce distress (Gataric, et.al, 2010). To the extent that the person with dementia is capable, practicing inclusion as much as possible for funeral arrangements, celebration of life plans and other activities or rituals can also play an effective role in easing distress.

**Grief from the perspective of the person with dementia.** Although there is a significant amount of research on care giving for people with dementia and the associated challenges, there is a paucity of work being done to reflect the subjective experiences of losses and grief for people with the dementia (Rentz, Krikorian & Keys, 2005). The work of Rentz et al., emphasizes that when people with dementia experience grief and cannot communicate associated feelings to others in a successful manner, there can be missed opportunities for intervention. Rentz, et al., provide a discussion of the biological tenets relating to neurocognitive deficits and the processing of the grief experience. They posit
that grief is possible and to be expected in people with dementia at both early and advanced stages.

An essential question addressed in the work of Rentz et al., stems from acknowledging the importance of effective communication with people experiencing bereavement and dementia. The mode of communication and the coping mechanisms of the person are in need of deeper understanding and conceptual frameworks need to be developed in order to provide support. Interviews and reports of selected case studies presented by Rentz et al., revealed communication struggles for family and the person with dementia. Some individuals with dementia may repeatedly ask the whereabouts of a deceased loved one. Over time, the frustrations associated with hearing the news again can become emotionally exhausting for the person and family members. An ethical question arises when some families decide to tell the person with dementia the loved one is away and will be back later versus telling the truth and risking any potential consequences this may carry.

Rentz, et al., pose a plethora of unanswered questions in their article. Once again, this points to the consensus regarding the lack of research on the subject. Understanding the perspective of the bereaved person with dementia calls for more extensive research on physiological changes, perceptual experiences, degrees of awareness, coping mechanisms and grief processing and modes of communication. Until the body of research grows, appropriate interventions can come in the forms of education, psychological and behavioral therapies, and in some cases pharmacological approaches.
How to proceed: a potential framework for future research. People who have dementia and are coping with loss are influenced by several factors: the stage of dementia, the relationship with the deceased person, how often he or she was in contact with that person, and their own personal style of grieving (Pathways, n.d.). The work of Mast (2009), sets out to understand what it is people with dementia experience. Mast argues that relying on people with dementia to provide verbal reports for research has culminated in widespread skepticism. Mast is yet another author who contributes to the consensus that little research has been done to explore the subjective experience of the person with dementia. Learning about the early stages of dementia lends an opportunity to discover the inner experiences of the person who experiences it.

Two factors introduced by Mast that can be examined when trying to understand the dementia experience are awareness and variability over time. First, self-reports of awareness are often more favorable than those that come from the caregivers of people with dementia. The author cautions that this point of disagreement does not imply the reports to be any less reliable or invalid. Concerning the factor of variability over time, Mast argues that this may be true for populations across studies whether they have dementia or not. Of particular interest regarding the factor of variability over time, moment-to-moment reports by those with dementia have shown reliability within the given time periods of study (Mast, 2009).

Spending time and providing care for bereaved people with dementia offers an opportunity to live in the moment. Working to understand their perspectives, how they perceive their environments and how they define their lived experiences will aid
caregivers, family members and professionals alike to provide quality care. Further research on the subjective experience of people with dementia is undoubtedly needed. As the body of research grows it is predicted that an enriched framework of care and support will develop.
Materials and Method

The Alzheimer's Scotland - Action on Dementia organization (2011), recognizes the lack of resources for people who help care for those who have dementia and are bereaved. This organization has developed an information sheet in partnership with the University of the West of Scotland to facilitate providing this needed care. The guide booklet developed for the current project has incorporated some of the techniques suggested to be useful by the partnership (e.g., person-centered care, validation therapy and reminiscence work).

The guide booklet created from the project serves as a tool for helping people understand the lived experiences of the bereaved who have dementia. The booklet will act as an accessible reference for friends, families, caregivers, as well as those who work in the helping professions. The elements of the booklet were identified through discussion with the community partner and include:

- An overview of grief and bereavement as processes
- Adjusting to and adopting to loss
- Ways to provide support to the bereaved who also have dementia
- Ways to improve communication between the bereaved with dementia and the people who care for them

The booklet can be printed on heavyweight white paper, folded in half and secured with a simple stapled binding. Making the booklet available as a digital document can be a potential medium for publishing as well. It is estimated that the
foundation of the booklet will be 10 pages in length and be written for an audience with at least an 8th grade education.
Results

The research conducted for this project has resulted in the creation of a basic foundation for a booklet with content directed at supporting people who are bereaved and have dementia. The content of focus was defined through discussions with the community partner and exploration of literature reviews. It was determined by agreement with the community partner that the booklet will serve as a framework for agency staff and potentially incoming Interns to further develop the project so that it may reflect more specific needs of the agency and its clients.

The implications of the project have further emphasized current positions regarding the lack of research and information available to people who need to understand and provide support for the bereaved with dementia. Continued advocacy for implementing agency policy to support the target population is needed. Lobbying efforts to encourage funding for research on understanding the subjective experiences of the bereaved with dementia are called for so that their needs can be met and quality of care can be improved.
Sustainability Plan

Recommendations for sustaining the ongoing development of the guide booklet are outlined in Table 1. Efforts proposed to sustain the project include utilization of an electronic format for publication whenever possible. This will reduce the costs of printing and save valuable resources (e.g., paper, labor and time). To ensure the continued quality and efficacy of the guide booklet, it is proposed that an annual review of the content be conducted.

Surveying the most recent research and incorporating it into the guide will keep it up to date with the newest developments. Seeking feedback from clients, staff and others who may access the resource could also be instrumental in the revision process. Recruiting a current intern at the agency to implement the updates and further develop the project would serve the learning experience of the intern and conserve resources for the agency.

<table>
<thead>
<tr>
<th>Component/Method</th>
<th>Action Steps</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain feedback from staff regarding relevancy of content in the booklet.</td>
<td>Create a survey to address factors concerning efficacy of booklet from agency perspective.</td>
<td>Initiate September of 2015.</td>
</tr>
<tr>
<td></td>
<td>Analyze data; determine what is useful, what needs improvement and revise as required.</td>
<td>Initiate October of 2015.</td>
</tr>
<tr>
<td>Collect current and up-to-date information on the relevant aspects of topic.</td>
<td>Conduct additional literature research. Recruit expert input regarding relevant aspects of topic.</td>
<td>Develop over November and December of 2015.</td>
</tr>
<tr>
<td>Consider seeking feedback</td>
<td>Conduct a small-scale</td>
<td>Design and implement over</td>
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<tr>
<td>Component/Method</td>
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<tr>
<td>from other users of the booklet.</td>
<td>research study where an approved survey is given to users for feedback.</td>
<td>January through May of 2016.</td>
</tr>
<tr>
<td>Revise and update the first edition of the</td>
<td>Compile data from staff, updated research and end-users. Revise content of</td>
<td>Develop over June through</td>
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<tr>
<td>guide booklet.</td>
<td>the guide booklet.</td>
<td>December of 2016.</td>
</tr>
<tr>
<td>Generate print and electronic versions of the</td>
<td>Consult with agency for reproduction capabilities; focus on electronic</td>
<td>January of 2017.</td>
</tr>
<tr>
<td>updated booklet.</td>
<td>version if resources are limited.</td>
<td></td>
</tr>
<tr>
<td>Implement annual revisions and subsequent</td>
<td>Outline a proposal and action-plan for agency; suggest recruitment of</td>
<td>September of 2017.</td>
</tr>
<tr>
<td>editions of the guide booklet.</td>
<td>Interns for sustaining the project.</td>
<td></td>
</tr>
<tr>
<td>Expansion</td>
<td>Contact other hospice agencies and introduce the guide booklet for</td>
<td>December of 2017.</td>
</tr>
<tr>
<td></td>
<td>integration into existing collection of resources.</td>
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Table 1. Guide Booklet Sustainability Plan for Year 2
Discussion

The project under discussion was developed with the intention to focus on providing support for people who have dementia and are experiencing grief, as well as for those who are in the role of caregivers. This very specific population is likely to require specialized support in the form of communication strategies, which may differ from those who do not have dementia and are experiencing grief. Therefore, the guide booklet may not be inclusive of all individuals experiencing grief. Further, the booklet is not likely to address every possible challenge faced by the population of focus. It will serve as an ancillary resource to other forms of support available at an agency providing hospice services. Lastly, the expertise of the current author is limited to personal experience as a caregiver of people with dementia, as a volunteer and Intern in hospice settings and as a candidate for graduation from the Master's of Social Work program at Humboldt State University. The guide booklet does not claim to provide all solutions to the presenting challenges; it aims to offer guidance based on research and presents with an interpretation of the author's personal, academic and pre-professional perspectives.

The limitations of the project include a restricted amount of time to develop the first edition of the guide booklet. Although several perspectives of the topic have been addressed, the depth and magnitude of the research could be enriched with a greater amount of time to work on the project. The initial version of the booklet has resulted in creating a foundation from which agency staff can build upon. The initial version is also
suitable as a beginning point for an incoming Intern to build upon the project based on the specific needs of the agency.

Although the undertaking of the project found that there is a paucity of research on the subject of providing support for people with dementia who are bereaved, it was also discovered that there is a great deal of potential for improved quality of support for this population. Researchers and practitioners are finding ways to enhance communication skills by studying the subject of the project from a multitude of perspectives, considering the subjective experiences of the target population and re-thinking frameworks to approach the study and practice of providing improved quality of care.

It is with optimism that the current author sees the potential for improved bereavement support for this population as more facets of its subjective experiences and creative communication skills are researched, understood and implemented. Social workers in particular are often found working in hospice settings as medical social workers and they come in contact with people who have dementia that are bereaved. With continuing efforts of researchers to expand knowledge concerning the subjective experience of the population in question, and with the implementation of agency policy to provide educational resources to those who care for the subject population of this project, people with dementia who are bereaved will stand a greater chance of receiving quality care when navigating the processes of grief.
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