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Chronic Grief Management for Dementia Caregivers in Transition: Intervention Development and Implementation

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Abstract

Research reveals that Alzheimer's disease (AD) caregivers (CGs) do not relinquish their role after placing a family member in long-term care. Caregivers report increased emotional upset around the time of placement, with sustained losses over time leading to chronic grief. Chronic grief increases caregivers' risk for depression and suicide. There are no documented interventions designed to decrease CGs chronic grief post placement. The Chronic Grief Management Intervention (CGMI) builds on existing evidence to target caregiver chronic grief in the transition of a family member into long-term care. The intervention is structured into three major components: 1) knowledge, 2) skill in communication and conflict resolution, and 3) chronic grief management skill. The 12-week intervention was pilot tested with thirty four caregivers for feasibility and preliminary effects on caregiver skill, knowledge, chronic grief, and depression. This article presents a general study description while focusing on the development and implementation of the CGMI.

Keywords

dementia caregivers; chronic grief; long-term care

Introduction

Family caregivers provide care for persons with Alzheimer's Disease (AD) for an average of 8–10 years. As care demands increase over time, AD caregivers suffer long-term mental and physical health effects (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Schulz et al., 2003; Schulz et al., 2004). Chronic grief and depression are common caregiver mental health effects that become exacerbated in the transition of a family member with AD into long-term care (Marwit & Meuser, 2002; Sanders & Adams, 2005; Walker & Pomery, 1996). After placement, family caregivers continue to experience chronic grief that is exacerbated by conflict with long-term facility staff and increased guilt (Butcher, Holkup, Park, & Maas, 2002; Maas et al., 2004; Paun & Farran, 2006; Ryan & Scullion, 2000; Specht et al., 2000). Although a few interventions have been tested with family caregivers in long-term care facilities (Maas et al., 2004; McCallion, Toseland, & Freeman, 1999; Pillemer, Hegeman, Albright, & Henderson, 1998), none focused specifically on caregivers' chronic grief. The Chronic Grief Management Intervention described in this article builds on existing evidence to specifically target AD caregiver chronic grief in the transition of a

family member into long-term care. The intervention was pilot-tested for implementation feasibility and effects on caregiver mental health outcomes.

Background

Dementia caregiving interventions have focused predominantly on caregiver burden, using a stress and coping framework and targeting home-based AD family caregivers. Multi component interventions including educational materials, skill training, and a form of counseling or psychoeducation were found to reduce caregivers' burden, depression, and anxiety symptoms (Schulz, Martire, & Klinger, 2005). Further recommendations call for dementia caregiver interventions to borrow from strategies designed for hospice care, in which caregivers are being helped to deal with their loved ones' deterioration and impending death, and are being empowered to help alleviate their suffering (Schulz et al., 2005).

A growing body of literature is shifting attention toward conceptualizing caregiver grief as a defining aspect of the dementia caregiving experience. Meuser and Marwit (2001) found that AD caregivers experience "real grief" that is equivalent in intensity to death-related grief. Their stage-sensitive model of caregiver grief identified the differences between spousal and adult-child AD caregivers. Spousal caregivers differed from their adult-child counterparts in that they displayed lower levels of denial and focused on losses they were experiencing as a couple such as loss of intimacy, companionship, and friendship networks (mild and moderate AD stages). After placing their family members in long-term care facilities (severe AD stage), both spousal and adult-child caregivers expressed guilt and regret over placement, with grief continuing to intensify after the care recipients' deaths. Similarly, a descriptive study by Ott, Sanders, and Kelber (2007) revealed that spouse caregivers experienced increased grief and depression after transitioning their family member with AD into long-term care.

Studies exploring the relationship between grief and depression in AD caregivers have found that grief was a significant predictor of caregiver depression, especially in the late stages of AD (Adams & Sanders, 2004; Sanders & Adams, 2005). In one study, grief accounted for 63% of the variance in depression scores in a sample of 100 AD caregivers (Walker & Pomeroy, 1996). Meuser, Marwit, and Sanders (2004) proposed a causal pathway for grief in dementia caregiving to be used in assessing and intervening with AD caregivers. They argued that grief interplays with what they coined "the depression-stress-burden constellation," and that individual, situational, and cultural factors may also contribute to the grief response. Although they acknowledge that their model offers more than one potential target for intervention, Meuser and colleagues agree that a grief intervention may in turn affect "the depression-stress-burden constellation" along with enhancing coping and promoting caregiver well-being.

To date, a few studies have pilot-tested grief interventions for AD caregivers. A psychoeducational group intervention was specifically designed to address loss and grief in caregivers of persons in the middle and late stages of AD (Sanders & Sharp, 2004). Weekly sessions were offered to one small group (n=10) of home-based caregivers over a five-week period. Compared to the control group (n=7), caregiver grief levels increased in the intervention group from pre- to post-test. The authors caution that these paradoxical findings may be due in part to the small sample size; and they suggest that caregivers may need more than five weeks to begin processing their losses.

"Easing the Way," a highly individualized, multi component intervention targeting grief in home-based AD caregivers was pilot-tested with 20 spouse caregivers over eight months (Ott, Kelber, & Blaylock, 2010). Twelve caregivers who continued caring for their spouse with AD at home showed significant improvement from baseline to completion in measures

of grief, depression, anxiety, positive states of mind and self-efficacy. The eight caregivers whose spouses entered a long-term care facility or had died during the study did not sustain the intervention effects; in fact their grief levels returned to baseline levels and depression scores increased. These findings are significant in that they support emerging evidence that post-placement AD caregivers continue to experience new losses and guilt, as well as conflict with nursing home staff, and require continued support (Kiely, Prigerson, & Mitchell, 2008; Maas et al., 2004).

Only a few studies have tested interventions for AD family caregivers whose family members transitioned into a long-term care facility. In a randomized trial, McCallion, Toseland, & Freeman (1999) compared a family nursing home visit education group with a regular family nursing home visit group (N=66). Findings indicated that the education group promoted improved communication between primary visitors, residents and staff. Similarly, Pillemer, Hegeman, Albright, & Henderson (1998) tested a “Partners in Caregiving” program designed to address communication and conflict-resolution issues that arise between caregivers who had placed relatives with AD in nursing homes and staff caring for them (N=55). Their results suggest positive changes in the staff-caregiver interaction and an increase in caregiver overall satisfaction with nursing home care.

Maas and colleagues (2004) tested the “Family Involvement in Care (FIC)” intervention (N=183) designed to increase collaboration among family caregivers and long-term care facility nursing staff in the care of residents diagnosed with AD. Their findings indicated that caregivers who received the FIC intervention experienced a decrease in stress levels while their counterparts in the control group reported higher levels of loss and role captivity. In addition, nursing staff in the intervention group reported their own improved attitudes toward family caregivers of facility residents diagnosed with AD.

A number of gaps in the existing literature are apparent: 1) there is no specific intervention to target AD caregivers’ chronic grief in the process of transitioning their family members in long-term care and 2) chronic grief was measured as an outcome in only two small intervention studies with home-based caregivers. Inspired by existing evidence and using as a model the *Guide to Support Family Caregivers Through the Alzheimer’s Disease Trajectory: Grief and Personal Growth* (Ott, Reynolds, Schlidt, & Noonan, 2006) we created the multi component *Chronic Grief Management Intervention* (CGMI). The intervention was pilot-tested for feasibility and preliminary effects on caregiver knowledge, communication and conflict resolution skills, and management of chronic grief and depression. Thirty four AD caregivers who were within their first year after placing a family member into a long-term care facility received the 12-week group-based intervention. This article presents a general study description while focusing on the development and implementation of the CGMI.

Intervention Development

In developing this intervention, we used three conceptually-related models (Meuser et al., 2004; Pearlin, Mullan, Semple, & Skaff, 1990; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001) to develop an adapted model that places chronic grief at the center of the AD caregiving experience. We conceived the CGMI as a mediator between caregiver/care recipient background and contextual factors (Meuser et al., 2004; Pearlin et al., 1990; Whitlatch et al., 2001), exacerbators of grief as defined by Maas and colleagues (2004) and outcomes such as caregiver depression and chronic grief (Meuser et al., 2004).

Existing evidence from 1) dementia caregiving interventions, 2) dementia caregiver chronic grief, and 3) interventions in long-term care settings literature informed the structure and the content of the CGMI. In addition, *A Guide to Supporting Family Caregivers Through the*

Alzheimer's Disease Trajectory: Grief and Personal Growth (Ott et al., 2006) that was used with home-based dementia caregivers, served as a model for our intervention manual.

In an earlier descriptive study (Paun & Farran, 2006) we found that in the process of transitioning from home-based to long-term care caregiving, dementia caregivers expressed their need to 1) know more about end-stage AD and long-term care facilities, 2) become more competent in communicating with staff and administrators in these facilities, and 3) receive more emotional support. The efficacy of knowledge and skill interventions with dementia caregivers is well documented in both home-based and long-term care facility studies (Sörensen, Pinquard, & Duberstein, 2002). Emotional support interventions (individual and/or group format) were also found to preserve dementia caregivers' mental health (Gaugler, Roth, Haley, & Mittelman, 2008; Mittelman, Roth, Coon, & Haley, 2004; Mittelman, Roth, Clay, & Haley, 2007).

Based on existing evidence, we structured the intervention into three major components: 1) knowledge, 2) skill in communication and conflict resolution, and 3) chronic grief management skill/processing loss. The first three sessions focused on knowledge and progressed with three additional sessions that focused on communication skills. In addition to content-related benefits, these first six sessions allowed time for trust building among group members and created a foundation for processing loss. We learned from existing literature on chronic grief that AD caregivers needed more time set aside specifically for processing loss, thus the following six sessions were dedicated to specific topics related to losses sustained in the process of transitioning from home to institutional caregiving.

The content of the 12 weekly group sessions was designed to accomplish the study's purpose of increasing caregivers' knowledge and skill related to dementia caregiving in the long-term care facility environment and to decrease their chronic grief and depression. Table 1 illustrates intervention target areas and specific content. The first three group sessions included the following content focusing on increasing caregivers' knowledge:

- 1) Introduce group members, review group rules, and present a brief overview of the study. Provide a review of AD stages with emphasis on late/end stage changes: cognitive, behavioral, and emotional. Stimulate discussion of caregivers' personal experiences with their family members' cognitive, behavioral, and emotional changes. (Meuser et al., 2004; Paun & Farran, 2006).
- 2) Initiate discussion of long-term care facility's philosophy of care, structure, regulations, policies, and personnel roles. Encourage caregivers to share personal experiences with facility's philosophy of care, structure, regulations, policies, and personnel roles (Maas et al., 1994, 2004; Paun & Farran, 2006; Specht et al., 2000).
- 3) Promote discussion of long-term care facility and community resources available to further support the caregivers after placement. Encourage caregivers to share personal experiences with resources they had used in the facility and the community (Ott et al., 2007).

The next three group sessions included the following content focusing on increasing caregivers' skill in communication and conflict resolution, as well as hands-on care/activities:

- 4) Review and role-play effective communication techniques between caregivers and facility staff, their family members, other residents in the facility and their family members (McCallion et al., 1999; Pillemer et al., 1998).

- 5) Review conflict scenarios and role-play conflict resolution techniques using an assertive approach (Maas et al., 1994, 2004; Pillemer et al., 1998).
- 6) Discuss and role-play caregiver involvement with hands-on care for family member and participation in facility activities (Maas et al., 1994, 2004; McCallion et al., 1999; Specht et al., 2000).

The following six group sessions focused on assisting caregivers to process chronic grief related to multiple losses sustained in the process of transitioning their family member into long-term care. For this part of the intervention we used Rando's (2000) six mourning processes and existing literature that addressed loss and grief in the context of dementia caregiving (Adams & Sanders, 2004; Farran & Kuhn, 1998; Kuhn, 2001; Loos & Bowd, 1993; Ott et al., 2006; Ott et al., 2007).

- 7) Discuss/recognize losses associated with family members' advancement through the stages of dementia and transition into a long-term care facility. Encourage caregivers to share what facilitated or hindered acceptance of these losses.
- 8) Discuss caregivers' reactions to separation (relational, physical, emotional, intellectual) and explore what facilitated or hindered acceptance of separation from family members who transitioned into long-term care facilities.
- 9) Stimulate caregivers' reminiscing about their relationship with family members prior to and after their transition into long-term care. Encourage caregivers to recall defining moments in their relationships with family members. Encourage caregivers to reflect on what facilitated or hindered acceptance of the relationship in its present state.
- 10) Encourage caregivers to discuss relinquishing old attachments and assumptions about what the relationship with their family member might have been. Encourage caregivers to reflect on what facilitated or hindered acceptance of their present state of attachment to their family member.
- 11) Encourage caregivers to share strategies they have used to readjust to a life where their family members are no longer cared for in the home environment. Discuss what facilitated or hindered adjustment to not having full control over family members' care.
- 12) Encourage caregivers to share strategies they have used to reinvest in new attachments, goals, and pursuits. Discuss what facilitated or hindered reinvesting. Process group closure.

The manual containing the 12 sessions used large font, appealing graphics, and colorful images. Deliberate attention was given to writing the content at a sixth grade reading level. To make the manual user-friendly, we separated each session by a tag indicating the session number. We have added resource materials at the end of sessions one through six. Each session contained questions posed to stimulate discussion on the topic at hand. Caregivers were invited to use the empty notes page included at the end of each session to document their thoughts/feelings if they felt so inclined.

Intervention Implementation

After we received Institutional Review Board approval from the parent institution and from two long-term care facility systems that required a peer-review of the study, we pilot-tested the intervention with a total of 34 caregivers. The intervention sample included predominantly female caregivers (85%) and care recipients (64%). The majority of caregivers were Caucasian (91%), adult children (68%), of an average age of 60.7 years

(10.65 sd), with a mean 15.7 (3.11 sd) years of education. Care recipient mean age was 83.4 (6.46 sd), with an average of 7.2 (6.80 sd) months since transitioning into long-term care, and receiving an average of 2.9 (2.27 sd) visits per week from their family caregivers.

Prior to beginning the intervention implementation, the PI and two group co-leaders met for a full day of orientation to: 1) become familiarized with the manual, 2) role-play possible scenarios, 3) discuss strategies to monitor group dynamics, and 4) practice with the recording devices. Meetings were scheduled over 12 consecutive weeks on days and at times mutually agreed upon and were hosted by facilities located in the inner city (one) and suburban (seven) areas. The meetings lasted an average of 60–90 minutes and were conducted in conference rooms where there was minimal potential for disturbance from wandering residents.

Each first meeting was initiated with caregivers and group leaders introducing themselves and caregivers sharing briefly about their family member's condition. Group leaders gave a brief description of the study and reviewed group rules emphasizing confidentiality and respect for each other. Each last meeting included group process closure.

Lessons Learned

The intervention content did not pose major challenges during implementation. In our 3 and 6-month follow-up questionnaire, caregivers reported that they found the topics very helpful and timely for their current circumstances and were satisfied with the additional resources included in the manual. Although the first six sessions were planned to initiate discussions on more concrete topics (knowledge and communication skills) to allow caregivers time to become comfortable with each other, they consistently brought into discussion their losses and especially their guilt as early as session three. We realized early into implementing the intervention that caregivers needed time to vent their overwhelming feelings first and then address the topics at hand. We made efforts to balance caregiver needs with treatment fidelity and made sure that content was never missed or neglected in any of the sessions.

Group dynamics varied, as some groups were more homogeneous than others with respect to family relationships and race, and the groups varied in size from three to six caregivers. Overwhelmingly, group members bonded early on and were comfortable enough to share their innermost feelings and at times cry openly. One spouse and one daughter from two different groups had lost their family members around session three, thus no longer meeting the eligibility criteria for the study. Faced with this ethical dilemma, the PI discussed the issue with the group members and with the two individual caregivers, offering them the option to return to the weekly meetings when they felt comfortable. Both caregivers chose to return missing only one or two sessions, and their peers were extremely supportive. The intervention content was not affected. The sessions immediately following these caregivers' return were extended another 30 minutes beyond the usual length of time (60–90 minutes), to allow additional processing. These caregivers contributed meaningfully to the groups they were attending, adding new perspectives on end-stage AD and the use of hospice as a reliable source of support. Both caregivers completed the intervention.

We found that CGMI was feasible both as treatment delivery and treatment receipt. Although attending weekly meetings posed some scheduling challenges especially for the younger caregivers juggling family responsibilities and young children, the overall average attendance of 10 out of 12 sessions indicated that the time commitment was feasible. The program evaluations at 3 and 6 months revealed that caregivers found the CGMI very helpful and that they would have liked to receive the intervention over a period longer than 12 weeks. Overall, caregivers found the manual well developed and some made occasional suggestions for improvement to group co-leaders.

Limitations and Future Directions

Our findings are limited by the relatively small sample size and the small percentage of African American caregiver participants (9%). Although we started with a fairly mixed pool of facilities, we successfully recruited from mostly suburban areas, with only one intervention facility located in the inner-city. Caregiver knowledge and skill levels at baseline may have varied depending on prior caregiver exposure to resources in the community and in the facility itself. For example, all suburban facilities where we conducted the intervention were offering monthly guest presentations on a variety of AD related topics and held regular family caregiver general support groups.

Anecdotal reports suggest the CGMI has positive clinical implications. For example, staff in the facility where we conducted three consecutive CGMI groups informally observed that caregivers who participated in the study: 1) experienced fewer conflict episodes with staff, 2) required less time to be reassured by staff, and 3) overall, appeared to be more satisfied with the care provided to their family members. In addition, administrators in the same facility expressed an interest in having a social worker trained in implementing the CGMI, so they could continue offering chronic grief support to family caregivers of their residents.

We are confident that implementation of CGMI is feasible in long-term care settings. Preliminary data suggest that CGMI affected positively AD caregiver knowledge and helped decrease caregivers' sense of guilt. These effects were sustained at three and six month measurement points. Because these findings present modest statistical significance, the CGMI should be further tested with a larger sample, in inner-city facilities. In addition, a new study should test facility staff satisfaction with the intervention and perform cost analyses to explore the financial impact of CGMI.

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Figure 1.
Adapted Model for Caregiver Chronic Grief in the Long-Term Setting

Table 1**Chronic Grief Management Intervention Content**

Session #	Target Area	Content
1	Knowledge	AD late/end stage changes: cognitive, behavioral, emotional
2	Knowledge	LTCF philosophy, structure, regulations, policies, and personnel roles
3	Knowledge	LTCF and community resources for the CG and the CR post placement
4	Communication Skills	Communication techniques with LTCF staff, CR, other residents and their family members
5	Conflict-Resolution Skills	Conflict-resolution techniques (CR, LTCF staff, other residents, and their family members)
6	Hands-on Care Skills	Hands-on care for CR and participation in LTCF activities
7	Grief Management Skills	Recognize losses
8	Grief Management Skills	Process reaction to separation (relational, physical, emotional, intellectual)
9	Grief Management Skills	Recollect and re-experience the relationship with the CR
10	Grief Management Skills	Process relinquishing old attachments and assumptions.
11	Grief Management Skills	Process readjusting into the new without forgetting the old
12	Grief Management Skills	Discuss reinvesting in new attachments, goals, and process group closure.

AD= Alzheimer's Disease; CG=caregiver; CR=care recipient; LTCF=long-term care facility