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Effectiveness of A Grief Intervention for Caregivers of People with Dementia

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Running head: CAREGIVER GRIEF INTERVENTION EFFECTIVENESS

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ABSTRACT

In this article, we report on the structure and effectiveness of a grief management coaching intervention with caregivers of individuals with dementia. The intervention was informed by Marwit and Meuser's Caregiver Grief Model (2002) and considered levels of grief, sense of empowerment, coping, and resilience using five methods of delivery. Results indicate that the intervention had significant positive effects on caregivers' levels of grief and increased their levels of empowerment, coping, and resilience. The intervention was found to be effective across caregivers' characteristics as well as across five delivery modalities. Through description of this intervention, as well as outcome, this research contributes to the body of knowledge about caregivers' disenfranchised grief and ways to effectively address it.

Approximately 500,000 Canadians currently have dementia and estimates forecast a doubling of this number within twenty years (Alzheimer's Society of Canada, 2010). Services to support individuals with dementia are fragmented and not evenly available across the country. Where services do exist, health care professionals may have limited understanding of, or training in, dementia care (Ibid, 2010). Recently more emphasis has also been on professionals' need to understand the experience of patients with illness and families who provide the primary care of individuals with dementia. Due to the extended trajectory of caring for an individual with dementia, this may become a "career", extending well into caregivers' senior years (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995).

The toll that caregiving an individual with dementia takes on the family and its members has been well documented. This includes a higher reported rate of chronic psychological and physical symptoms including a decrease in well-being and life satisfaction stemming from depression, stress, burden, fatigue, family conflict, feelings of anger, guilt, frustration, loneliness, and isolation, as well as loss and grief (Acton & Kang, 2001; Clipp & George, 1993; Epstein-Lubow, Davis, Miller & Tremont, 2008; Gaugler, Kane & Newcomer, 2007; Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007). These symptoms place the physical, mental, and financial health of the caregiver, and their ability to continue to care for their family member, at risk (Mittelman, 2002). While there are many similarities across caregiving contexts, caregivers of people with dementia face unique challenges, including experiencing nearly twice the amount of loss compared with caregivers of a non-demented person (Ross & Dagley, 2009).

DISENFRANCHISED GRIEF

Grief in dementia caregiving originates from progressive losses, including the quality of the relationship, roles, control, well-being, intimacy, health status, social interaction, communication, and opportunities to resolve issues from the past (Loos & Bowd, 1997; Sanders & Saltz-Corley, 2003). These losses may include hopes and expectations for the future, social networks, and other critical sources of identity and support (Adams, McClendon & Smyth, 2008). Caregivers of persons with dementia experience loss of the person they knew, even while providing care. Within this context, caregivers may begin their bereavement long before the person they are caring for dies.

While some health care providers and researchers conceptualize this process as “anticipatory grief” (Ponder & Pomeroy, 1996), being a witness to the gradual ‘death’ of a loved one’s personal identity and memory from dementia brings a unique form of grief that is associated with present and expected losses preceding bodily death, and being witness to this process is distinct from anticipatory grief of death (Boss, 1999; Doka & Amber, 1989). These experiences may be more accurately described as “ambiguous loss” (Boss, 1999), “latent grief” (Dempsey & Baggo, 1998), and “relational deprivation” (Pearlin, Mullan, Semple & Skaff 1990). How caregivers are able to cope and adapt to relationship and role changes and losses is determined in large part through their ability to manage their grief around these losses (Silverburg, 2007).

The intensity of grief changes throughout the caregiving journey, with grief increasing as the disease and associated impairments worsens (Sanders & Adams, 2005). Although this process of bereavement may be so severe that it is experienced as the death of the person that was, these losses are often not appreciated by others and there are few social mechanisms that allow this

kind of bereavement while the person is still alive (McEvoy, 2007; Walker, Pomeroy, McNeil & Franklin, 1994). If this grief is not acknowledged or validated, it can become disenfranchised grief and its effects on the caregiver may become debilitating. Consequently, many caregivers not only experience ambiguous loss but also disenfranchised grief. Disenfranchised grief is defined as "the grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka & Aber, 1989). Disenfranchised grief occurs when the relationship, the loss and/or the griever, is not recognized. This unresolved grief may then add to, and complicate, perceived caregiver burden (Doka, 2010; Large & Slinger, 2013). Increasing the possibility of disenfranchised grief is that these losses may not be recognized or they may be minimized by both caregivers and health care providers (Adams & Sanders, 2004; Silverburg, 2007). Grief in dementia caregiving may also be mistaken as symptoms of caregiver burden or labelled as stress or depression (Dempsey & Baggo, 1998; Molley & Mast, 2009; Sanders & Saltz-Corley, 2003; Hughes, Lloyd-Williams & Sachs, 2010).

While caregivers may be provided with practical support, information, and education about stressors that accompany the tasks of care, their emotional needs receive comparatively little attention through health care services (Meuser, Marwit & Sanders, 2004). In turn, lack of knowledge and identification of grief in dementia caregiving further disenfranchises the caregiver's grief. Growing awareness of the toll that dementia care can have on family caregivers has resulted in increased interest by researchers and health care providers in identifying interventions and training programs aimed at assisting caregivers in managing their grief. However, there remains relatively little information as to how to address grief associated with caring for those with progressive cognitive decline or dementia (Marwit & Meuser, 2005). Further, there remains an absence of policies and practices detailing best practices for supporting

these caregivers (Large & Slinger, 2013). Consequently, additional research is needed in developing interventions to support caregivers of people with dementia who are experiencing high levels of grief. To better support caregivers of those with dementia, health care providers need to normalize the emotional issues related to loss, including recognizing and responding to these changes through the development of supports for early awareness (Doka 2010; Meuser & Samuel, 2001). Discussion of effective, and innovative, interventions addressing grief associated with caregiving for a person with dementia may indicate ways in which services can both support caregivers and improve the quality of life for the care receiver. Better understanding of disenfranchised grief among family caregivers may reduce caregiver strain, and hence the health and economic burden placed on them. Additionally, it may delay admission for the person with dementia into long-term care, thereby reducing system burden (Hebert, Dubois, Wolfson, Chambers & Cohen, 2001).

Coaching Intervention

Coaching, as an approach, has developed from a variety of fields including counseling, management consulting, and psychology (Hadikin 2004, Starr 2003). Defined broadly, coaching is a practice that encompasses “the art of facilitating the performance, learning, and development of another” (Downey, 1995: 15). Unlike therapy, coaching focuses on building capacity and problem-solving based “on where you are now, and where you want to get to, and [that] the only place you can start is from where you are now” (O’Donovan & Martin, 2000:13). Consequently, coaching is outcome orientated and a highly individualized and person-centered endeavor, where “individuals focus on the skills and actions needed to successfully produce their personally relevant results” (International Federation of Coaching, 2013). Through questioning, objective feedback, information, support, and structure, the coach creates opportunities for clients to have

insights and see possibilities for action that are then responsibility of clients to carry forward into action (McGee & Tuokko, 2005).

For this study a coaching intervention to caregivers of people with dementia was carried out by Registered Clinical Counselors with extensive knowledge and experience with coaching, dementia, the demands of caregiving, and grief. Five methods of delivery were used: (1) individual face-to-face, (2) individual by telephone, (3) face-to-face group, (4) telephone group, and (5) online group. Six possible sessions and two follow-up sessions were provided. Session content included: 1) Introduction to Transitions, 2) Dimensions of Grief, 3) Living with Grief, 4) Honoring Grief, 5) Maintaining Self, and 6) Enhancing Resilience. Two “Follow-up and Check-In Sessions” were also offered. Based on the counselors’ assessments of the participants, and dependent on intervention modality, coaches were responsible for: 1) assessing the amount of coaching required, and 2) drawing from themes that emerged from each session to inform the following session.

Recruitment of participants followed ethical approval by the University of Victoria. Recruitment strategy was contingent upon location within British Columbia using local media and referrals from the Alzheimer’s Society of British Columbia. Individuals were placed in the intervention or control group based on time of recruitment and the intervention participants were further divided into one of five intervention groups based on physical proximity to the clinicians, group timing, and adequate knowledge of, and access to, technology. All participants regardless of control or intervention designation were encouraged to participate in all existing education and support programs available. Those participating in either of the individual face-to-face or individual telephone coaching sessions received on average six sessions of one hour based on the clinician’s

assessment. Those participating in the group interventions received six sessions of one and a half hours; group size did not exceed eight participants.

Methods

A controlled study using a mixed method design was used with two groups – a control group and an intervention group – to examine and compare the effectiveness of five forms of a coaching intervention on participants' levels of grief, sense of empowerment, coping, and resilience. The intervention group was comprised of 123 participants and 77 participants comprised the control group. To be eligible for the research, participants had to identify whether caring for a family member with Alzheimer's Disease, or dementia. The intervention group received a brief coaching intervention informed by Meuser's and Marwit's Caregiver Grief Model (2002).

Data collection

This study utilized pre- and post-test for both intervention and control groups, employing the following five data collection instruments:

1. *The Demographic and Caregiving Characteristics Questionnaire*. A nine-item questionnaire developed by McGee and Tuokko (2005) designed to gather participant demographic and caregiving characteristics including the stage of the relative's dementia.
2. *The Caregiver Grief Inventory*. Developed by Marwit and Meuser (2002), this inventory is a factor analysis to identify 50 items for measuring the grief experience of family members caring for a relative with a dementia. The instrument divides grief into three components useful for both assessment and intervention: personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation.

3. *The Empowerment Questionnaire*. This 52-item questionnaire, developed by Man (1998), was adapted for this project by McGee and Tuokko (2005). The adapted version assessed how well family caregivers perceived themselves to be in control of, and able to master, various stressful life situations. This instrument reflects empowerment as both process and outcome, experienced at the individual, family and community levels, and included the following conceptually-derived four components: a) efficacy - skills/abilities and strategies; b) support - outlook/attitude, belief system, and supports; c) knowledge - knowledge of, and access to, information and external resources; d) aspiration - anticipation and preparation for future caregiving; and 5) community - influence over conditions that impact people who share neighborhoods, workplaces, experiences or concerns.
4. Shortened version of *The Brief COPE* (Carver, 1997). This 28-item instrument assessed 14 conceptually different coping strategies by having respondents indicate what they generally do when they experience stressful events in their life and how often they do it. The 14 conceptual components include: self-distraction; active coping; denial; substance use; use of emotional support; use of instrumental support; behavioural disengagement; venting; positive reframing; planning; humor; acceptance; religion; and self-blame.
5. *The Resilience Scale* (Wagnild & Young, 1993). This 25-item instrument measured the degree of individual resilience, considered a positive personality characteristic that enhances individual adaptation. Factor analysis of the instrument was conducted indicating two factors of personal competence and acceptance of self and life.

Data Analysis

Statistical descriptions of participants in each intervention group were compiled. T-tests were used to examine the relationship between participant outcomes between Time 1 and Time 2.

Multivariate analyses were conducted to examine the relationship among: (1) participant outcomes (i.e., levels of grief, sense of empowerment, coping, resilience), (2) participant characteristics (e.g., relationship, age, location of care, stage of dementia, etc.), and (3) methods of delivering intervention. All subscales on the four instruments were collapsed.

Results*Participant characteristics*

In Table 1 caregiver characteristics for intervention and control groups as well as the total group are summarized. There were significant differences in education between groups, ($X^2=13.69$, $df=4$, $p=.008$) with those in the control group having higher educational levels. Significantly more participants in the control group were caring for a spouse compared to participants in the intervention group ($X^2=10.29$, $df=4$, $p=.036$). However, overall the t-tests and chi-square tests to assess for differences resulted in few significant differences between the control and intervention groups, suggesting they can be considered homogenous.

Table 1: Participant characteristics by group

	Total (n=200)	Control (n=77)	Intervention (n=123)
Caregiver age (mean)	64.4	66.2	63.3
Months caregiving (mean)	48.3	53.7	45.0

Gender of caregiver			
Female	158 (79.0%)	59 (76.6%)	99 (80.5%)
Male	42 (21.0%)	18 (23.4%)	24 (19.5%)
Marital status			
Married	163 (81.9%)	68 (88.3%)	95 (77.9%)
Never married	13 (6.5%)	3 (3.9%)	10 (8.2%)
Common-law	7 (3.5%)	1 (1.3%)	6 (4.9%)
Separated	4 (2.0%)	1 (1.3%)	3 (2.5%)
Divorced	9 (4.5%)	2 (2.6%)	7 (5.7%)
Widowed	3 (1.5%)	2 (2.6%)	1 (0.8%)
Education			
Some high school	20 (10.1%)	12 (15.6%)	8 (6.6%)
High school graduate	58 (29.1%)	27 (35.1%)	31 (25.4%)
University graduate	62 (32.1%)	15 (19.5%)	47 (38.5%)
Technical/business college graduate	33 (16.6%)	16 (20.8%)	17 (13.9%)
Other	26 (13.1%)	7 (9.1%)	19 (15.6%)
Employment status			
Full-time	25 (12.8%)	6 (7.8%)	19 (16.0%)
Part-time	28 (14.3%)	10 (13.0%)	18 (15.1%)
Retired	125 (63.8%)	54 (70.1%)	71 (59.7%)
On leave from work	12 (6.1%)	4 (5.2%)	8 (6.7%)
Unemployed	6 (3.1%)	3 (3.9%)	3 (2.5%)
Gender of care recipient			
Female	90 (45.5%)	30 (39.5%)	60 (49.2%)
Male	108 (54.5%)	46 (60.5%)	62 (50.8%)
Care recipient age (mean)	78.0	77.2	78.5
Relationship			
Spouse	122 (61.9%)	57 (75.0%)	65 (53.7%)
Parent	65 (23.0%)	18 (23.7%)	47 (38.8%)
Other	10 (5.1%)	1 (1.3%)	9 (7.5%)

Outcome measures

A reliability analysis of outcome measures was undertaken using a total score for each of the outcomes measures calculated at Time 1 and Time 2 for each participant (Table 2). For the

coping, empowerment, and resilience scales, higher scores reflect strengthened for coping, empowerment, and resilience. For grief, however, higher scores represent greater grief.

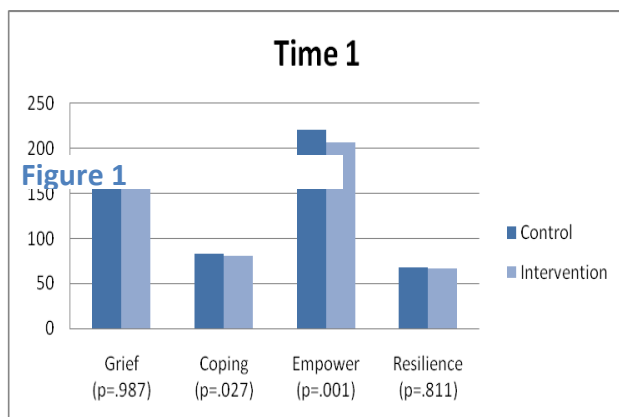
Table 2: Reliability analysis of outcome measures (Chronbach’s alpha)

	Time 1	Time 2
Grief	.956	.964
Coping	.760	.731
Empowerment	.944	.947
Resilience	.912	.916

Differences in outcomes between groups

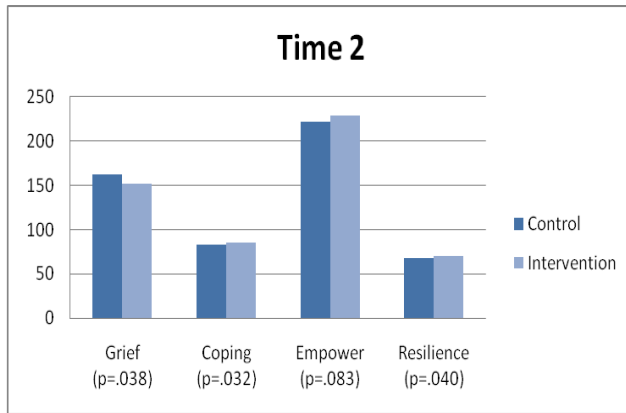
To examine the differences between groups for each of the 4 outcome measures, independent t-tests were conducted at Time 1 and Time 2.

At Time 1 (Figure 1) there were significant differences between the control and intervention groups for coping ($t=2.23$, $df=195$) and empowerment ($t=3.36$, $df=196$) scores and these differences favored the control group. In other words, at Time 1 caregivers in the control group were better able to cope and exhibited greater empowerment than those in the intervention group. However, at Time 2 (Figure 2), the significant differences were reversed to favor the intervention



group except empowerment, (grief: $t=2.089$, $df=191$; coping: $t=-2.160$, $df=192$; resilience: $t=-2.071$, $df=195$).

Figure 2



Differences within groups

Paired t-tests were used to examine for any differences in outcome scores between Time 1 and Time 2 for both the control and intervention groups (Figures 3 - 6).

For the control group, there was no significant difference in any of the scores from Time 1 to Time 2 and, in fact, grief and coping scores actually declined over the course of the study period. For the intervention group, grief ($t=4.036$, $df=116$), coping ($t=6.608$, $df=117$), empowerment ($t=9.057$, $df=118$), and resilience ($t=5.281$, $df=119$) scores all improved significantly from Time 1 to Time 2.

Figure 3

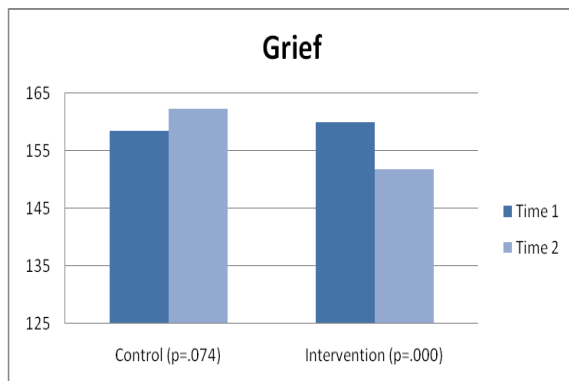


Figure 4

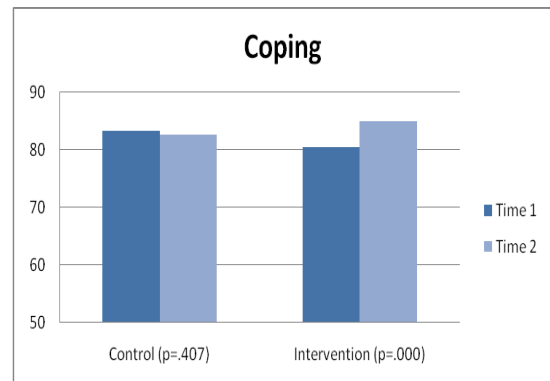
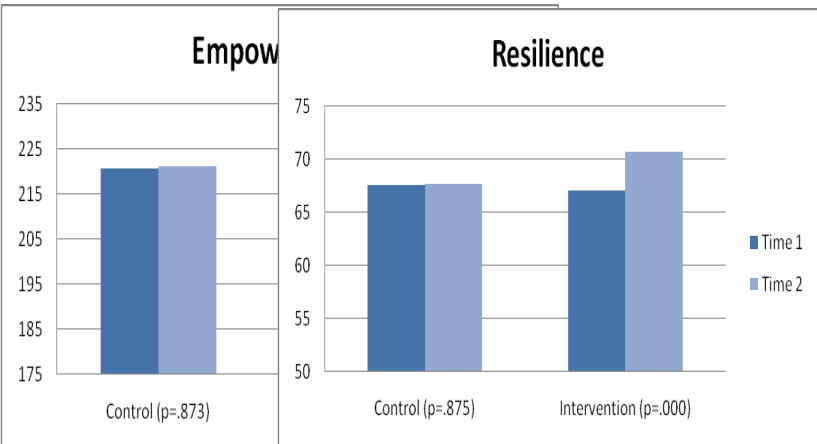


Figure 5

Figure 6



Impact of intervention

Analysis of covariance (ANCOVA) models was used to determine if the intervention had an impact on the four outcome measures. The dependent variable in each case was the Time 2 score. Time 1 scores were entered into the models as covariates along with age of caregiver, age of care recipient, gender of caregiver, gender of care recipient, months providing care, married, university graduate, working full-time, retired, caring for spouse, and caring for parent.

To assess whether there was an interaction between the group variable (control/intervention) and the Time 1 score, a preliminary ANCOVA was run that included an interaction term (Time 1 score X group). The interaction in all four models was not statistically significant which satisfies the homogeneity of regression assumption and therefore the final ANCOVA models were run without the interaction included.

The results of the ANCOVA models suggest that the group variable is statistically significant for each of the 4 outcome measures. The following summarizes the ANCOVA results of the 4 models:

Grief: The main effect for the intervention group was significant ($F=16.35$, $df=181$, $p=.003$) suggesting that they exhibited less grief at Time 2. The Time 1 grief score ($p=.000$) and not having a university education ($p=.047$) also predicted less grief at Time 2.

Coping: The main effect for group was significant ($F=17.57$, $df=182$, $p=.001$) suggesting that those in the intervention group exhibited better coping at Time 2. The Time 1 coping score ($p=.000$) also predicted better coping at Time 2.

Empowerment: The main effect for group was significant ($F=25.58$, $df=186$, $p=.000$) suggesting that those in the intervention group exhibited greater empowerment at Time 2. The Time 1 empowerment score ($p=.000$) and not working fulltime ($p=.021$) also predicted greater empowerment at Time 2.

Resilience: The main effect for group was significant ($F=10.70$, $df=185$, $p=.009$) suggesting that those in the intervention group exhibited greater resilience at Time 2. The Time 1 resilience score ($p=.000$) also predicted greater resilience at Time 2.

Additional analyses

Additional T-test analyses were conducted to discern any differences between spouse and adult children caregivers for each of the outcomes measures (Table 3). Results suggest that there are no differences between the 2 types of caregivers with the exception of the Time 2 grief scores ($t=2.805$, $df=178$, $p=.006$). The significant difference suggests that spouse caregivers are more likely to exhibit worse grief at Time 2 than adult children who are providing care.

Table 3: Outcome measure means by spouse/adult child

	Spouse	Adult child
Grief Time 1	161.76	154.58
Coping Time 1	81.39	81.54
Empowerment Time 1	213.33	210.75
Resilience Time 1	67.87	66.63
Grief Time 2	161.49	146.58
Coping Time 2	83.17	85.18
Empowerment Time 2	223.68	226.88

Resilience Time 2

68.89

71.08

Additional analysis of variance (ANOVA) was used to examine if intervention outcome measures varied by delivery modality (Table 4). There were no significant differences between the different intervention groups for any of the outcome measures.

Table 4: Outcome measure means by method of delivery

	Individual face-to-face	Individual phone	Group face-to- face	Group phone	Group online
Grief Time 1	160.15	163.34	162.38	148.00	155.41
Coping Time 1	80.56	82.67	78.56	80.11	80.52
Empowerment Time 1	202.21	207.04	204.39	209.86	208.96
Resilience Time 1	65.25	67.00	68.45	68.61	66.54
Grief Time 2	141.54	154.14	162.44	147.36	148.73
CopingTime 2	87.15	86.45	82.66	85.58	83.68
Empowerment Time 2	237.65	222.40	224.25	224.03	234.25
Resilience Time 2	70.64	70.72	70.45	72.32	69.41

Discussion

Caregivers in the control group appeared initially (Time 1) to have better coping and empowerment than those in the intervention group. However, by Time 2, those in the control group expressed reduced coping skills and increased grief. It may be that completing the battery of measures raised awareness among study participants about the issues they faced, but in the

case of those in the control group, this was not mitigated through the intervention. These caregivers (and those in the intervention group) were however able to access usual support services from the Alzheimer Society of British Columbia.

The findings indicate that coaching resulted in increased coping and resilience, and less grief, for participants who received the intervention, compared to those who did not. However, while results at Time 2 for the intervention group showed improvement for empowerment, their scores were not significantly higher than those of the control group at Time 2. As empowerment is both a process and an outcome, it is possible that caregivers in the intervention group needed more time to experience and integrate the effect of improved coping skills into their self-perception. Further, while individual level factors such as coping skills may be mitigated by coaching, empowerment may be more strongly determined pre-existing internal characteristics (e.g., self efficacy) and by external factors such as availability of social support and resources.

Participants in the intervention group, who expressed higher coping, empowerment, and resilience levels, and lower grief levels at the outset of the study, also experienced greater improvements in all areas following the intervention than did other participants. It is possible that participants who were higher functioning/less distressed prior to the intervention may have had more innate strengths and/or energy to bring to the coaching sessions than the other participants, thus benefitting more.

There were no differences in the effectiveness of the coaching intervention for spousal or adult child caregivers on coping, empowerment, and resilience. However, although the grief experienced by spousal caregivers was significantly less at the end of the coaching intervention, their grief levels remained higher than those of adult child caregivers. This could be because

spousal caregivers in our study were full time caregivers and therefore spent more time witnessing the decline in the care receiver than non-full time adult children. Further, it is possible that the bond between the spousal caregiver and their spouse could be more intense than the parent child bond, resulting in more entrenched grief for spouses (Meuser & Marwitt, 2001).

The coaching intervention used in this study, regardless of delivery method, was equally effective in increasing participants' coping, empowerment, and resilience, and reducing grief. This finding was surprising as participants did not necessarily receive the intervention via the modality of their choice due to logistical factors. Further, although we expected that spouses and older adults would feel less positive about online coaching than adult child caregivers, the ability to manage technology was the more relevant factor. Several online participants, and one of the coaches, expressed surprise about the intimacy and group cohesion that they were able to achieve online. While many of the participants who received the online or telephone coaching appreciated that they did not have to leave home for the intervention, some who received the telephone intervention expressed concern about being overheard by the care receiver. Many participants who engaged with a face-to-face group stressed the importance of the social aspect of being among peers. Given these findings, we suggest that although practical and individual preferences for a specific delivery method should be accommodated as much as possible, it does not appear to be the determining factor in the success of the intervention.

Limitations

The coaching intervention developed for this study is a model that relied on the ability of a clinician, skilled in dementia care, grieving, and coaching to tailor the intervention to the address the unique needs of each participant. Consequently, we suggest that skilled delivery is a crucial

component of the intervention's effectiveness, and that the positive effects on participants' coping, empowerment, resilience, and grief was heavily dependent on the expertise of the clinician providing the service. Few health care providers have the specialized training, knowledge, and direct practice skills, which may limit the generalizability of this intervention.

This study has several other limitations. Participants were self-selecting, and may differ from other caregivers of those with dementia. One possibility is that volunteers for both groups had increased coping capacities compared to those who did not participate, expressed through their ability to seek out caregiver support. An alternative interpretation is that volunteers for both groups had decreased coping capacities compared to those who did not participate, expressed through a need to seek out caregiver support. Although we did not gather data on ethnicity, the overwhelming majority of participants were Caucasian, most were female, had adequate or above average incomes, and all lived in one region of the country. Consequently this study lacks diversity in ethnicity and socioeconomic background data that likely would influence caregivers' grief, resilience, coping, and empowerment and the effectiveness of interventions.

Implications and Future Directions

Results from this study suggest that online and telephone coaching interventions can be an important and cost-effective way to increase support for caregivers who are home bound or limited by geographic or travel issues. Further this study found that a number of approaches to coaching caregivers in naming and understanding their grief are effective in providing knowledge, tools, and strategies that improved coping and resilience. Of particular interest was the finding that all intervention groups had improved results although participants were not given

a choice of approach. These findings suggest that the needs of rural caregivers, and others who have challenges in participating in traditional face-to-face interventions, can be effectively met. However, individuals differ in learning and coping styles and would benefit in being offered a variety of options and flexibility in meeting their needs and preferences.

Planning to meet the health needs of an aging population has increased focus on community care options and the related role of caregivers. The unit of care must expand beyond the identified client and caregiver's capacity and skills to give care to promote the latter's health emotionally and physically. Organizational policies to embed this expectation and tools to assess the caregiver needs and to provide evidence informed interventions are needed. Beyond the organizational efforts, public engagement in appreciating the value of family care givers to the health care system as well as understanding the grief associated with providing care to a person with dementia are needed. Through broader community recognition and support, the hidden toll on families can be lessened, such as we now witness with cancer diagnoses (Clipp & George, 1993).

The experience of clients and families in health situations requires a reframing approach to transform how we provide health services (Bahita & Rifkin, 2010). Utilizing a reframing lens allows us to better understand how the caregiving of family members with dementia is not merely a functional 'burden' but also a disenfranchised grief impact, related to the unique progressive losses in the lived experience of dementia. Both foundational clinical education and continuing education programs need to emphasize this fundamental reorientation and provide the required knowledge and skills.

Caregivers offer practical and emotional support to some of society's most vulnerable and dependent individuals – those with dementia and neurocognitive-related decline. In order to do this effectively, caregivers themselves require practical and emotional support. The findings of this study support existing research that renders grief visible and addresses its disenfranchised nature as not only beneficial, but necessary, to the wellbeing of these caregivers (Doka, 2010; Large & Slinger, 2013; Meuser & Samuel, 2001; Silverburg, 2007). Although this study contributes to the emerging body of evidence on how to address grief associated with caring for those with progressive neurocognitive decline or dementia, there remains relatively little information about intervention effectiveness especially in diverse populations. Further longitudinal research about caregivers is needed to determine if grief issues change and if results sustain over longer periods of time. Additional research is also needed to determine if early grief and loss interventions with caregivers has an impact on hospital or long-term care utilization over time, thereby reducing system burden.

References

Acton, G. & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health*, 24(5), 349-360.

Adams, K. B., & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions, and depressive symptoms across stage of disease: A mixed-method analysis. *Dementia: The International Journal of Social Research and Practice*, 3, 195–210.

Adams, K., McClendon, M. & Smyth, A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7(3), 301-319.

Alzheimer's Society. Of Canada. (2010). Rising Tide: The impact of dementia on Canadian society. Retrieved from:

http://www.alzheimer.ca/~ /media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.ashx

Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S. & Whitlatch, J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.

Bhatia, M. & Rifkin, S. (2010). *A renewed focus on primary health care: Revitalize or reframe?* *Globalization and Health*, 6(13). Retrieved from:

<http://www.globalizationandhealth.com/content/6/1/13>

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine*, 4(1), 92-100.

Clipp, E. & George, L. (1993). Dementia and cancer: A Comparison of spouse caregivers. *The Gerontologist*, 33(4), 534-541.

Dempsey, M. & Baago, S. (1998). Latent grief: The unique and hidden grief of carers of loved ones with dementia. *American Journal of Alzheimer's Disease*, 13, 84-91.

Doka, K. J. (2010). Grief, multiple loss, and dementia. *Bereavement Care*, 29(3), 15-20.

Doka, K. J. & Aber, R. A. (1989). *Psychosocial loss and grief*. In K. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp.187-211). Lexington, Mass: Lexington Books.

Downey, M. (1999) *Effective Coaching*. Orion Business Books, London

Epstein-Lubow, G., Davis, J., Miller, I. & Tremont, J. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*. 21(3): 198-203.

Gaugler, J. E., Kane, R. L. & Newcomer, R. (2007). Resilience and transitions from dementia

caregiving. *The Journal of Gerontology*, 67(1), 38-44.

Hadikin, R. (2004) *Effective Coaching in Healthcare*. Books for Midwives, Elsevier, Oxford, UK.

Hebert, R., Dubois, M., Wolfson, C., Chambers, L. & Cohen, C. (2001). Factors associated with long-term institutionalization of older people with dementia: Data from the Canadian study of health and aging. *The Journal of Gerontology: Series A, Biological Science and Medical Science*, 56(11): M693-9.

Hughes, J.C., Lloyd-Williams, M. & Sachs, G.A. (eds.) (2010). *Supportive care for the person with dementia*. Oxford: Oxford University Press.

International Coaching Federation. (2013). *What is Coaching?* Retrieved from:

<http://coachfederation.org/need/landing.cfm?ItemNumber=978&RDtoken=53162&userID=>

Large, S. & Slinger, R. (2013). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative analysis. *Dementia*, 0(0): 1-20.

Loos, C. & Bowd, A. (1997). Caregivers of persons with alzheimer's disease: Some neglected implications of the experience of personal loss and grief. *Death Studies*, 21(5), 501-514.

Man, D. W. K. (1998). The empowerment of Hong Kong Chinese families with a brain damaged

family member: Its investigation and management. *Brain Injury*, (12), 245-254.

Marwit, S. J., & Meuser, T.M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with AD. *The Gerontologist*, 42(6), 751-765.

Marwit, S. J., & Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29(3), 191–205.

McEvoy, A. (2007). Dying in pieces. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 11–13.

McGee, P. & Tuokko, H. (2005). Partners in care: Empowering caregivers through coaching.

Retrieved from:

http://www.coag.uvic.ca/resources/publications/reports/Partners_in_Care.pdf

Mesuer, T. and S. Marwit. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41 (5), 658-670.

Meuser, T., Marwit, S., & Sanders, S. (2004). *Assessing grief in family caregivers*. In K. Doka (Ed.), *Living with grief: Alzheimer's disease* (pp.169-196). Washington, DC: Hospice Foundation of America.

Mittelman, M. S. (2002). Family caregiving for people with Alzheimer's disease: Results of the

- NYU spouse caregiver intervention study. *Journal of the American Society on Aging*, 26 (1), 104-106.
- Molley, C. & Mast, B. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49 (3), 388-396.
- O'Donovan, G. & Martin, C. (2000). *The Thirty Minute Life Coach*. The Coaching Academy, Portsmouth, UK.
- Papastavrou, E., Kalokerinou, A., Papacostas, S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing*, 58(5), 446-457.
- Pearlin, L., Mullan, J., Semple, S. & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Ponder, R. J., & Pomeroy, E. C. (1996). The grief of caregivers: How pervasive is it? *Journal of Gerontological Social Work*, 27, 3-21.
- Ross, A., & Dagley, J. C. (2009). An assessment of anticipatory grief as experienced by family caregivers of individuals with dementia. *Alzheimer's Care Today*, 10, 8-21.
- Sanders, S. & Adams, K.B. (2005). Grief reactions and depression in caregivers of individuals

with Alzheimer's disease: Results from a pilot study in an urban setting. *Health and Social Work*, 30(4), 287-295.

Sanders, S. & Saltz-Corley, C. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with alzheimer's disease. *Social Work in Health Care*, 37(3), 35-53.

Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, assess and assist. *Omega*, 54(3): 215-235

Starr, J. (2003). *The Coaching Manual*. Prentice Hall Business, London.

Wagnild, G.M., & Young, H.M. (1993). Development and psychometric evaluation of the resiliency scale. *Journal of Nursing Measurement*, 1(2), 165-178.

Walker, R. J., Pomeroy, E. C., McNeil, J. S., & Franklin, C. (1994). Anticipatory grief and Alzheimer's disease: Strategies for intervention. *Journal of Gerontological Social Work*, 22, 21-39.