



Developing and pilot-testing a Finding Balance Intervention for older adult bereaved family caregivers: A randomized feasibility trial



Lorraine Holtslander^{a, b, *}, Wendy Duggleby^c, Ulrich Teucher^d, Dan Cooper^e, Jill M.G. Bally^f, Jessica Solar^g, Megan Steeves^h

^a College of Nursing, University of Saskatchewan, 4216 E Wing Health Science Building, 104 Clinic Place, Saskatoon SK S7N 2Z4, Canada

^b Honorary Associate Professor, University of Witwatersrand, Johannesburg, South Africa

^c Nursing Research Chair Aging and Quality of Life Professor, Faculty of Nursing, Level 3, Edmonton Clinic Health Academy, 11405 87 Avenue, University of Alberta, Edmonton, AB T6G 1C9, Canada

^d Department of Psychology, College of Arts and Sciences, University of Saskatchewan, Saskatoon, SK S7N 5E5, Canada

^e Palliative Care Services, Regina Qu'Appelle Health Region Regina, SK S4T 1A5, Canada

^f College of Nursing, University of Saskatchewan, Health Sciences Building, E-Wing, 104 Clinic Place, Saskatoon SK S7N 2Z4, Canada

^g College of Nursing, University of Saskatchewan, E-Wing, 104 Clinic Place, Saskatoon SK S7N 2Z4, Canada

^h College of Education, University of Saskatchewan, 3047 Education Building, Saskatoon, SK S7N 5E5, Canada

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ABSTRACT

Purpose: This study aimed to test the feasibility of a psychosocially supportive writing intervention focused on finding balance for older adult bereaved family caregivers of advanced cancer patients.

Method: The Finding Balance Intervention (FBI) was tested for feasibility, acceptability and potential influence on increasing hope, coping and balance through a multi-method pilot study employing a randomized trial design with 19 older adults with an average age of 72 years. The intervention group received the FBI and a follow up visit from an RN-RA. The control group received the FBI at a second visit. The FBI, a theory-based intervention was developed from grounded theory qualitative data, applying Delphi methods to design a self-administered, psychosocially supportive, writing intervention for older adults who had lost a spouse after caregiving.

Results: Feasibility was assessed and specific modifications identified. The FBI was easy to use, acceptable and of benefit. The FBI offered validation of emotions and ways to discover new ideas to find balance, which may enable bereaved caregivers to move forward on a unique journey through grief. The treatment group showed a statistically significant increase in restoration-oriented coping and higher oscillation activity.

Conclusions: The results suggest the FBI was easy to use, acceptable and of benefit. A full scale study, with specific modifications to the design, is needed to test the effectiveness of this innovative intervention.

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1. Introduction

Family caregivers often experience an intense trajectory of events while caregiving for a person with advanced cancer. Deaths from cancer occur mainly in older people, since the median age range for cancer deaths is estimated to be 70–74 years (Canadian

* Corresponding author. College of Nursing, University of Saskatchewan, 4216 E Wing Health Science Building, 104 Clinic Place, Saskatoon SK S7N 2Z4, Canada.

E-mail addresses: lorraine.holtslander@usask.ca (L. Holtslander), wduggleb@ualberta.ca (W. Duggleby), ulrich.teucher@usask.ca (U. Teucher), dancooper@accesscomm.ca (D. Cooper), jill.bally@usask.ca (J.M.G. Bally), jessica.solar@usask.ca (J. Solar), megan.steeves@usask.ca (M. Steeves).

Cancer Society Statistics, 2015). The caregiving experience has implications for health and well-being in bereavement, especially as an older adult caring for a spouse, a population at great risk during bereavement (Stroebe et al., 2007) due to significant additional losses including personal health, support networks, and often, financial strain (Williams et al., 2014). Many experience prolonged distress (Thomas et al., 2013), risk of suicide (Erlangsen et al., 2004), depression (Holtslander and McMillan, 2011), loss of meaning in life (Brandstätter et al., 2014), substance abuse, physical and emotional disability (Schulz et al., 2008), and even death (Christakis and Iwashyna, 2003). Although support from palliative care services for bereaved family members is mandated by international guidelines (World Health Organization, 2002), the needs

of family caregivers during bereavement have mostly been neglected, even though they are heavily relied upon to be caregivers (Canadian Hospice Palliative Care Association, 2004). Older adults who have lost a spouse after caregiving are at high risk of negative outcomes, nevertheless, support for caregivers in bereavement is generally lacking (Hudson, 2013).

2. Background

After caregiving for a family member with advanced cancer, the person who becomes bereaved carries many unresolved concerns, including painful memories, guilt, regret and disappointment that leaves them at risk of complicated bereavement (Topf et al., 2013). At 6 months post-death, more than one-third of palliative family caregivers were experiencing distress; even further predicted by the loss of a spouse and the intensity of caregiving (Thomas et al., 2013). If not addressed, bereaved caregivers may be at risk for long-term and overwhelming health and quality of life impacts. Many family caregivers will be older adults, who are known to face great difficulties during bereavement, including intense and prolonged suffering (Stroebe et al., 2007) and distressing grief over varying lengths of time (Chentsova-Dutton et al., 2002). This challenge for the entire health care system will continue to increase due to the world's aging population, often described as a "tsunami of aging" that is expected over the next 20–30 years. Clearly, the death of a spouse to advanced cancer, after an exhausting and difficult caregiving experience, suggests the need for supportive psychosocial interventions to promote positive outcomes.

2.1. Supportive interventions for bereaved cancer caregivers

There is a lack of effective, evidence-based interventions specific to the needs of bereaved family caregivers (Holtslander, 2008); most interventions consist of support groups, memorial services, mailings, phone calls, and referrals. A systematic review of 74 studies of bereavement interventions revealed a lack of rigorous, non-pharmacologic, evidence-based interventions to offer bereaved caregivers (Forte et al., 2004), mostly due to theoretical heterogeneity and methodological inadequacies. A more recent systematic review of intervention research with bereaved spousal caregivers of a person with advanced cancer, found only 4 studies of bereavement interventions with this population; these studies were all more than 10 years old, and none had a strong theoretical component (Gauthier and Gagliese, 2012).

In a series of intervention studies within hospice care, an individualized approach recognized the highly diverse needs of bereaved spouses (Caserta et al., 2015). A study with 298 bereaved adults tested a group-based intervention and identified the need for individually targeted and delivered interventions; allowing each person to identify unique restoration oriented activities for themselves (Lund et al., 2010). Writing in a diary showed promise in helping older women who were bereaved caregivers of a spouse with advanced cancer find hope (Holtslander and Duggleby, 2008) and research has also demonstrated the impact of writing to generate significant health improvements (Pennebaker and Chung, 2011). A convenient, self-administered, focused writing intervention, developed and tested through research, would provide an evidence-based tool for any member of the health care team to offer to the bereaved family caregiver.

2.2. Finding balance in bereavement

In a previous study by the lead author, older bereaved family caregivers stated that finding balance meant dealing with overwhelmingly difficult emotions and experiences after a frequently

exhausting caregiving experience. Some bereaved caregivers were able to move forward easily, while others struggled a great deal (Holtslander and Duggleby, 2009). Negative emotions and thoughts, memories of caregiving, and a lack of support were key challenges. In other words, the inability to find balance prevented the participants from moving forward. In a grounded theory study with 10 older adults, participants described the importance of finding balance and the difficulties they had with the emotions, thoughts, and activities of grief (Holtslander et al., 2011). Similar concepts were found in the literature to support finding balance, including a study of 163 bereaved widowed people (Caserta and Lund, 2007) which revealed that having a balance between the processes of loss and restoration activities was associated with more positive outcomes of bereavement. Similar, individually delivered interventions for bereaved caregivers focused on finding balance have not previously been developed or tested. As well there are very few evidence-based interventions designed specifically for this highly burdened population to promote positive outcomes after caregiving ends (Hudson, 2013; Hudson et al., 2012). A theory-based psychosocial intervention would potentially address some of the needs of bereaved family caregivers (Evans et al., 2013). The purpose of this article is to describe the development of an innovative intervention and to report the results of a pilot study to determine the feasibility and acceptability of the intervention and study procedures prior to conducting a definitive study of effectiveness (Evans et al., 2013), paying attention to benefit and methodology.

3. Developing the Finding Balance Intervention (FBI)

The steps required to develop interventions for end of life care include: a) the development and refinement of the intervention theory, b) identification of the active components to detect change and c) evaluation of outcomes prior to a definitive trial (Evans et al., 2013).

3.1. Refinement of the Finding Balance Intervention theory: adaptation of the Dual Process Model

The Dual Process Model (DPM) of coping with bereavement as presented in a seminal article by (Stroebe and Schut, 1999), describes everyday life experiences of adaptive coping as a back and forth **oscillation** between both **loss** (including grief work, denial, and intrusion of painful emotions) and **restoration** processes (including doing new things, distraction and seeking new identities). The essence of adaptive grieving is found in accommodating the loss while also engaging in activities to promote restoration. The DPM was the basis for the development of the scale chosen to evaluate the Finding Balance Intervention (FBI), the Inventory of Daily Widowed Life (IDWL), developed through research with 161 older bereaved spouses (Caserta and Lund, 2007). The oscillation between restoration and loss processes has shown considerable promise in facilitating positive adjustment outcomes (Lund et al., 2010). The balance and timing of these activities in moving through grief remains to be determined, but creative, individualized approaches, including writing about their experiences, have shown the most promise in helping those at most risk (Neimeyer, 2014). Stroebe and Schut (2010) recommend the development of interventions applying the DPM be tested in trials with broader aspects of personal functioning such as sense of control, self-efficacy and emotional equilibrium. The DPM, a relatively new, cyclical model, provided the theoretical framework for the development and testing of the FBI and hope, grief, and the IDWL were chosen to measure outcomes.

In order to identify the active components to detect change, a

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