

Article

**Evidence-Informed Primary Bereavement Care:
A Study Protocol of a Knowledge-to-Action Approach for Systems Change**

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Abstract

Using a systems change approach to knowledge-to-action, the purpose of this study is to increase organizational and practitioner uptake of an evidence-informed primary bereavement care guideline in home and community care through a researcher-knowledge-user partnership. Guided by the Consolidated Framework for Implementation Research, a single case study design will be used to examine system change in its natural context. The project integrates an organizational change initiative and a research study. Multiple data collection and analysis strategies will be used to explore and map the interactive synergistic process of interconnected decisions and actions. Iterative cycles of analysis and feedback will incite knowledge-user reflection and action, shape and substantiate findings, use data in a timely fashion to inform and guide next steps, and ensure ongoing monitoring and evaluation of the process.

Keywords: bereavement care, evidence-base guideline, integrated knowledge translation, nursing, system change, case study

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Background

Need for Improved Primary Bereavement Care

Bereavement is defined as “the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to life [surrounding] the death of a loved one” (Christ, Bonnano, Malkinson & Rubin, 2003, p. 554). Experiences of loss, grief, and bereavement are unique, dynamic, and wide-ranging in spite of the ubiquitous presence and commonality of death in our lives (Moules, Simonson, Prins, Angus, & Bell, 2004; Stroebe, 2001; Stroebe, Schut, & Stroebe, 2007). Although death—both expected and unexpected—is a certainty, the responses of family members and other loved ones are not (Attig, 2010; Moules, Simonson, Fleiszer, Prins, & Bob, 2007). Nevertheless, grief occurs in recognizable patterns. Guidelines or guiding principles for “bereavement care” are scarce despite the need for health-care providers to offer meaningful support to individuals and families following the death of a loved one (Genevro & Marshall, 2004). Although it is still unclear which groups of individuals are most vulnerable, there is agreement that a loved one’s death affects the health and well-being of all who are bereaved (Stroebe et al., 2007). Empirical studies have revealed increased morbidity and mortality for the bereaved following the death of a loved one (Christakis & Alison, 2006; Li, Olsen, Vestergaard, & Obel, 2010; Li, Vestergaard, Obel, Cnattingus, Gissler, & Olsen, 2011; Moon, Glymour, Vable, Liu, & Subramanian, 2014; Shah, Carey, Harris, DeWilde, Cook, & Victor, 2013; Shah, Carey, Harris, DeWilde, Victor, & Cook 2013). The bereaved can suffer from a range of physical, emotional, social, and financial concerns. These include heightened risk of depression, somatic complaints, medication and substance abuse, and absenteeism and disability days (Aziz & Steffens, 2013; Christakis & Iwashyna, 2003; Lang, Gottlieb, & Amsel, 1996; Lang, Goulet, & Amsel, 2004; Liu, 2014; Shah et al., 2013; Stroebe, 2001). These sequelae can lead to increased use of health services and incur a variety of costs, which are potentially preventable. Yet, to date, the focus of bereavement care has centered on those who present with complications, rather than on primary prevention and health promotion (Genevro & Marshall, 2004; Wimpenny et al., 2006). The human and financial costs of providing evidence-informed primary bereavement care should be set against the likely weightier personal and societal costs of preventable complications (Wimpenny et al., 2006).

“Primary bereavement care” is defined as capturing and creating opportunities to be with and to support individuals and families in their experiences of grief and mourning surrounding the death of a loved one (Lang, Duhamel, Aston, Fleiszer, Gilbert & Sword, 2012, p. 11). This care includes several levels of upstream preventive and health promoting-type interventions aimed at supporting bereaved individuals, families, and communities. Across health and social service settings, primary bereavement care includes the following: actively and openly acknowledging and validating both the death of the loved one and experiences of bereavement; providing appropriate and discerning “anticipatory guidance” about grief reactions; ensuring a network for continuity of care and appropriate resources such as time, staffing, experts/teachers, funds, and physical space for the bereaved; and developing and implementing bereavement care-centered initiatives and policies (Attig, 2010; Lang et al., 2012; Robinson, 1996) “A compassionate approach by all professional and non-professional staff is consistently reported by the bereaved as having a positive impact on their bereavement” and, conversely, approaches which do not relay such compassion can impact negatively (Wimpenny et al., 2006, p. 177).

Given their usual involvement around a death and their common presence across levels of health systems, nurses are strategically positioned to improve services and to better support grieving individuals and families. Nurses are also ideally situated to lead and motivate other team members to improve their knowledge, skills, and attitudes around primary bereavement care. Yet, as with other professionals, nurses often feel ill-prepared and have identified the need to know how to care more effectively for the bereaved (Granger, George, & Shelly, 1995; Lang et al.,

2012; Tse, Wu, Suen, Ko, & Yung, 2006). However, it is important to recognize that providing primary bereavement care also requires systems support and is not simply a clinical practice improvement issue.

There are numerous examples of system-level factors that create either an absence or a fragmentation of support for the bereaved. First, there is no health-care funding for primary bereavement care in Canada. The Canada Health Act covers medical care for an end-of-life/palliative client and their family/caregivers over a period of several months (Romanow, 2002). However, when the client dies, the current system ceases to remunerate or support any further care for the bereaved by health-care organizations and providers—unless the bereaved present themselves back into the system (e.g., emergency department, mental health clinic, substance abuse program) with a grief-caused health problem. This funding gap contributes to a lack of consistent follow-up care for those who are bereaved, even in high risk situations. Second, primary care for the bereaved is not addressed by nor falls under the mandate of any particular segment of the health and social system, professional group, or governmental jurisdiction. This contributes to lack of continuity of care for the bereaved and often leads to disjointed secondary and tertiary bereavement services in addition to the lack of primary care services altogether. Even in the domain of end-of-life care, which is centered on the care of the dying, bereavement support is typically curtailed due to resource restrictions and an absence of national care standards for the bereaved. These systems problems have further implications related to a broadened patient safety perspective in health care that considers the safety of more than just patients (Lang, Edwards, Fleiszer, 2008). Patient safety is increasingly understood as multidimensional and characterized by physical, emotional, social, and functional aspects intricately linked to family members, caregivers, and providers (Lang et al., 2008). In addition to safety risks for the bereaved, there are also increased safety risks for providers as a result of ethical dissonance and burnout that can come from caring for dying or bereaved individuals and families (Lang, Duhamel, Fleiszer, Sword, Gilbert, Aston, 2010). These examples and their implications for increased safety risks point to the need for multiple systems-level interventions, in addition to direct care improvements.

Development of a Primary Bereavement Care Guideline

A seminal report highlighted “the need for improved linkages between bereavement research and practice in order to determine and promote the most appropriate and meaningful care for [the] bereaved” (Genevro & Marshall, 2004). Research suggests that evidence-informed guidelines can be a valuable part of knowledge translation (KT) and systems change initiatives (Davies, Edwards, Ploeg, & Virani, 2008; Francke, Smit, De Veer, Mistiaen, 2008; Hakkennes & Dodd, 2008; Thomas et al., 2000). As part of a program of research integrating home care safety, bereavement care, and KT, a study was conducted to develop an evidence-informed guideline for primary bereavement care (Lang et al., 2012). The guideline consists of practice, education, research, and policy/community development recommendations for care providers and their organizations. The recommendations resulted from a multimethod study that included a comprehensive review of the literature, an interprofessional expert panel, and a series of focus groups conducted with community and acute care nurses, healthcare managers, and bereaved family members. This initial guideline development study was a precursor to the study described in this protocol. Participants involved in the development of the guideline affirmed that the guideline presented an appropriate set of competencies that all nurses, as well as other professionals, health-care workers, and even volunteers, should and could incorporate into practice. Participants also described significant systemic and organizational barriers such as inflexible funding structures, inappropriate staffing models, and lack of debriefing and mentorship initiatives that might ultimately impede the translation of this evidence into practice (Lang et al., 2012; Lang et al., 2010). This article describes a planned study that aims to explore

the implementation process of the bereavement care guideline in practice, taking into consideration the need for a systems-based approach.

Gap in Knowledge about Implementation and Systems Change

Too often, promising planned change initiatives are followed by disparate implementation efforts producing results that remain disappointing at best (Institute for Healthcare Improvement, 2003). There are estimates that at least half of attempted changes in health-care systems are not successfully implemented; those that are often do not yield the results that were anticipated (Brousselle & Champagne, 2011). Furthermore, there is a gap in the empirical literature regarding the implementation of evidence-informed practice and system changes. Only a small proportion of empirical studies reflect the complex interaction between aspects of professionals' practices, organizational change processes, and the contexts within which newly implemented innovations unfold. Moreover, implementation as a crucial phase of the change process as well as the use of guidelines as vehicles for stimulating change, are still not well understood nor sufficiently described to guide organizations in making evidence-informed practice and system changes (Contandriopoulos, Lemire, Denis, & Tremblay, 2010; Damschroder, 2009; Greehalgh, Robert, Bate, MacFarlane, & Kyriakiou, 2005).

Methodology

Knowledge-to-Action Approach

The Canadian Institutes for Health Research (CIHR), a major health services research funding organizations, established a "Knowledge-to-Action" (KTA) grant competition. This program was initiated in recognition of the gap in knowledge about implementation as well as the limited use of research findings in practice. The KTA initiative funds projects that "bridge a knowledge-to-action gap, and in so doing, increases the understanding of knowledge application through the process" (CIHR, n.d., para 4). It requires partnering researchers and knowledge users to be fully engaged and involved throughout project conception to completion and beyond. Given that practice does not change without leadership support (Gifford et al., 2013; Ploeg, Davies, Edwards, Gifford, & Miller, 2007), it is important to engage people within the organization who understand how the system can support practice and where to make changes in order to have an effect. Strong reciprocal relationships among researchers, practitioners, as well as clinical and policy decision makers are central to the effective short- and long-term adoption of evidence into practice. These types of relationships are assumed to be the basis for building capacity for systems change (Graham et al., 2006; Lindstrom, 2003; Lomas, 1997; National Centre for the Dissemination of Disability Research, 2006). "Partnership not only moves knowledge to action – the researcher generates and the knowledge-user acts and both are changed as a result" (CIHR, n.d., para 8). This approach is a form of "integrated knowledge translation" wherein both research and change occur.

Study Context

Victorian Order of Nurses (VON) Canada, a nursing-led not-for-profit national home and community care organization, identified the need to improve the care provided to bereaved individuals and families in the communities it serves. VON championed the initial project to develop the primary bereavement care guideline (Lang et al., 2012). The implementation of the guideline within VON was the planned next step, given the organization's commitment to improving primary bereavement care. The following study was developed based on the relevant and pervasive need to improve primary bereavement care in Canada, narrow the the gap in research about knowledge-to-action processes, and advance the six-year partnership between the research team and VON. Hence, this project was conceived and developed collaboratively by the research team members and the "knowledge users" from VON. The core knowledge-user team

consists of national leaders who are part of VON's Practice, Quality, and Risk Team as well as leaders from the local VON Tri-County site in Nova Scotia (the site that will participate in this project).

Study Purpose and Research Questions

Using a systems change approach to knowledge-to-action, the purpose of this study is to increase organizational and practitioner uptake of an evidence-informed primary bereavement care guideline in home and community care through a researcher-knowledge-user partnership. The specific research questions included the following:

1. What is the process of translating evidence-informed recommendations from the guideline into action?
2. How does a researcher-knowledge-user partnership influence the translation of the guideline?
3. What are the impacts at multiple levels of the system of this knowledge-to-action approach?

The project integrates an organizational change initiative and a research study. The organizational change will be supported by several multi-stakeholder meetings as well as two large collaborative forums. The research study will entail the use of multiple data sources. In addition to observations and document reviews, a series of individual and group interviews will be conducted over the course of the two-year project. The organizational change and research study processes are described below.

Design and Methods

A single case study design (Anthony & Jack, 2009; Stake, 1995; Yin, 2009), will be used to examine system change in its natural context. Multiple data collection and analysis strategies will be used to explore and map the "interactive synergistic process of interconnected decisions and actions" (Graham & Logan 2004). Ethics approval for the project was granted by the ethics review boards of VON Canada and each of the investigators' respective universities. Written informed consent will be obtained from all participants prior to their participation.

Theoretical Framework

A systems perspective suggests that "issues, events, forces, and incidents should not be viewed as isolated phenomena but seen as inter-connected, inter-dependent components of a complex entity" (Iles & Sutherland, 2001, p. 17). This perspective reflects the interdependent systems of organizations; the need for shared values, purposes, and practices within and between organizations; and the requirement for multiple interventions to integrate the perspectives of a range of stakeholders across a wide system (Edwards, Rowan, Marck, & Grinspun, 2011; Greenhalgh et al., 2005; Iles & Sutherland, 2001; Sterman, 2006). The focus extends beyond how to diffuse an innovation throughout a system, to how systems adaptively respond to planned and unplanned change in ways that enable them to effectively evolve, adapt, and renew over time (Sterman, 2006). Introducing new practice changes such as the recommendations from the guideline into busy practice environments with numerous competing demands is challenging and often met with resistance (Bero, Grilli, Grimshaw, Harvey, Oxman, & Thomson, 1998; Davies, Edwards, Ploeg, Virani, 2008; Davies, Edwards, Ploeg, Virani, Skelly, & Dobbins, 2006; Edwards, Marck, Virani, Davies, & Rowan, 2007). Implementation of a new guideline can be particularly challenging in home care where providers do not work within a common physical space, but rather are spread out across different homes, neighborhoods, and communities. Furthermore, as we have identified, primary bereavement care requires interventions at multiple levels of the health and social systems. Successful adoption of research into practice is also

largely a function of the interactions between the evidence, the contexts, and the facilitation processes utilized (Kitson, Harvey, & McComack, 1998; Kitson et al., 2008; Rycroft-Malone et al., 2002; Rycroft-Malone et al., 2004). Thus, effectively managing system change involves targeting multiple system levels with multiple change strategies.

This study is guided by the Consolidated Framework for Implementation Research (CFIR) (Damschroder, 2009). The authors of this framework synthesized Greenhalgh and colleagues' (2005) seminal work on implementation of innovations in health service delivery organizations with the work of 18 other models, theories, or frameworks used to translate research findings into health services practice (e.g., Ottawa Model of Research Use, PARiHS framework) (Graham & Logan, 2004; Kitson, 1997; Rycroft-Malone et al., 2002). The CFIR presents strong conceptual and empirical support to guide implementation and to structure this knowledge-to-action study. The framework comprehensively addresses the innovation, process, context and players, and is flexible to the change strategy preferences of our user partners at VON Canada.

CFIR has five major domains: (a) the characteristics of the intervention (e.g., evidence strength, quality, complexity) must be adaptable to the setting without loss of integrity; (b) the dynamic interface between outer setting (e.g., patient needs and resources) and inner setting (e.g., the organization's structural characteristics and readiness for implementation) influences the translation process; (c) individuals are active players who can facilitate or impede the intervention; (d) players' characteristics, both individual (e.g., knowledge, beliefs, and self-efficacy) and social (e.g., professional and organizational norms), influence the success of change interventions; and (e) the implementation process (e.g., planning, engaging, executing) requires multiple, nonsequential levels of active change. This framework informs the study design and methods. The distinction between the two main components of the project, namely, the implementation of the guideline within the setting and the research study activities, are portrayed in Table 1 and are described in greater detail below.

Table 1

Knowledge-to-Action Organizational Change and Research Study

Organizational change	Research study
Implementation of guideline	Data collection, analyses, and translation
This is a collaborative process between VON and research team, with VON leading this aspect of the project.	This is a collaborative process between VON and research team, with the research team leading this aspect of the project.
Pre-forum activities (0-3 months)	Baseline (at 0 months)
<i>Goal:</i> to conduct planning meetings with VON core leadership team, other employees, and research team; to establish goals and determine responsibilities for Forum #1	<i>Individual interviews</i> <i>Goal:</i> to glean an understanding of status of bereavement care at VON, from the leadership perspective; to anticipate the challenges of guideline implementation <i>Participants:</i> 5 members of VON "core leadership team"
Forum #1	
Guideline implementation "kick off" (at 3 months)	<i>Focus groups</i> <i>Goal:</i> to provide a baseline of different perspectives of the current status of bereavement care at VON
<i>Goal:</i> to gather ideas and solidify plans for guideline implementation	

Organizational change	Research study
<p><i>Participants:</i> VON core team, research team, and 20 others (e.g., VON nurses, managers, administrators, volunteers; bereaved; external stakeholders)</p> <p>* sources of research data: research team member field notes; worksheets and flip charts from small and large group work</p>	<p><i>Participants:</i> 5 homogeneous groups (nurses, personal support workers, managers, volunteers, bereaved)</p>
<p>Forum #2</p>	<p>Mid-Process (at 8-9 months)</p>
<p>Guideline implementation “follow-up” (at 15 months)</p>	<p><i>Focus groups</i></p> <p><i>Goal:</i> to share experiences of the change amongst different stakeholders; to address challenges to improving bereavement care</p> <p><i>Participants:</i> 2 heterogeneous groups (nurses, personal support workers, managers, volunteers, bereaved)</p>
<p><i>Goal:</i> to assess if and how the implementation has begun to impact practice change and the care provided</p>	<p>Project conclusion (at 17-18 months)</p>
<p><i>Participants:</i> same as Forum #1, if possible</p> <p>* sources of research data: research team member field notes; brainstorming/planning flip charts from small group work</p>	<p><i>Individual interviews</i></p> <p><i>Goal:</i> to uncover the impacts of the knowledge-to-action process and the resultant changes in bereavement care, from the leadership perspective</p> <p><i>Participants:</i> same 5 members of VON “core team”</p>
<p>Post-forum activities (16+ months)</p>	
<p><i>Goal:</i> to plan for next steps; to work on sustaining/spreading changes</p>	<p><i>Focus groups</i></p> <p><i>Goal:</i> to examine the impacts of the knowledge-to-action process and the resultant changes in bereavement care</p> <p><i>Participants:</i> 5 homogeneous groups (nurses, personal support workers, managers, volunteers, bereaved)</p>

Setting

VON leaders proposed the Tri-County site in Nova Scotia, Canada, as the ideal setting within which to begin this initiative. This site serves three counties in a large, predominantly rural area at the southwestern end of Nova Scotia. This site is fitting because of its provincial contract for providing home and community care services involving 75 nurses, as well as for its active palliative and supportive care program that provides over 2000 palliative care visits per month. Furthermore, stakeholders from this site were involved in the development of the guideline and the site leadership team remains highly passionate and committed to improving bereavement care in their community.

Data Collection

As part of the research component of the project, interviews will be a main source of study data. Semistructured interview guides (Tables 2 and 3) are informed by the study objectives and the CFIR. All interviews will be digitally recorded and transcribed verbatim.

Table 2

Focus Group Interview Guide

Focus Group Interview Guide

At the beginning of each focus group, there will be an introduction by the facilitator(s). This introduction will include a preliminary discussion of terms (i.e., meaning of bereavement—encompasses experiences before, during, and after the death of a loved one) that may be used in proceeding questions, the format of the focus groups, and a review of the consent form. The facilitator(s) will also give participants a chance to ask any questions prior to commencement of the focus groups.

- Give out name tags.
- Introduce facilitators.
- Review purpose of study and purpose of focus group.
- Explain goal to tap into their experience and opinions about bereavement care.
- Review and sign of consent forms. Emphasize that there will be no names or identifying information in the final report and that comments shared are confidential.
- Explain that after a question is asked, we will go around the circle, so everyone has a chance to share their thoughts. If more time is needed to think or to pass on the question that is fine.
- Assure that there are no right or wrong answers.
- Describe how notes may be taken during the discussion to guide follow up on issues.
- Remind participants to feel free to get up for refreshments.

- Staff warm-up question: Please tell us your name, how long you have been working at VON, and something interesting about yourself.

- Bereaved warm-up question: Please tell us your name, where you are from, and something else that is interesting about yourself.

Before implementation (0 months)

In five minutes or less:

- (Bereaved only) Tell us about one or more meaningful experiences you had during the care that VON provided to you and your loved one (before, during, after).
- (Bereaved) What helped you in your bereavement? What, if anything, was not helpful? Are there any changes you would like to see in how bereavement care is provided through the VON?
- (Staff only) Tell us about one or more meaningful experiences you had providing bereavement care since your time with the VON.
- (Admin) Tell us about what you know of bereavement care provided through the VON.
- (Admin) Tell us about your involvement/engagement with bereavement care.
- (Staff only) What works well in your bereavement care practices now? What is challenging? How would you want to change it?
- (Admin) Tell us about how institutional practices support or create challenges for your bereavement care practices.
- (Staff) Tell us about how your workplace supports or creates challenges for your bereavement care practices.
- (All) Is there anything you came here wanting to say but didn't get a chance?

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- Have we missed anything?
 - Any closing thoughts/comments/questions?

After implementation (Last 2 focus groups)

- (Bereaved only) Tell us about your experiences with bereavement care.
 - (Staff only) Tell us about your bereavement care practices now since the guideline was introduced. Are you practicing differently because of the guideline? Why or why not?
 - (Staff only) Tell us about your practices with clients.
 - (Staff only) Tell us about how institutional practices support or create challenges for your bereavement care practices.
 - In your opinion, what changes, if any, have been made to improve bereavement care?
 - Can you provide any specific examples of the guideline implementation and how you felt it was or was not successful?
-

Focus group interviews (Table 2) will provide an interactive venue for eliciting a variety of stakeholder perspectives about implementation. The interaction will prompt exchanges and insights between all participants and interviewers that would not have been possible through individual interviews (Krueger & Casey, 2000; Ulin, Robinson, & Tolley, 2005). Using purposive and snowball sampling to identify potential participants, homogenous focus groups will be conducted with nurses, personal support workers, managers, volunteers, and bereaved family members respectively. Each group will consist of approximately 6 to 8 participants (Krueger & Casey, 2000) and will be held before the first large stakeholder meeting (Forum #1; see Table 1). Data from the focus groups will provide a baseline about the current status of bereavement care, identify facilitators and barriers to providing evidence-informed bereavement care, and elicit potential strategies for implementing system changes. A second set of these homogeneous focus groups will be held after the final forum (Forum #2; see Table 1). These will examine the knowledge-to-action process, the resulting changes, and the remaining opportunities and challenges to continued improvement.

Five heterogeneous focus groups will be held between Forums #1 and #2. Participants will include representatives from each of the five original groups (i.e., nurses, personal support workers, managers, volunteers, bereaved family members). The purpose of the heterogeneous focus groups will be for stakeholders to share their perspectives with each other and to monitor the progress of the initiative. Although homogeneity of participants in focus groups is a common method used in research (Krueger & Casey, 2000), this mixed approach will be used to extend knowledge-to-action through interactions between different categories of participants. Participants will be able to broaden their appreciation for the perspectives of the other stakeholders and subsequently consider these within their respective contexts as the initiative unfolds. The researchers are skilled focus group facilitators, with previous in-depth knowledge of the study content and context.

In addition to the focus groups, members of the VON national core leadership team, who are considered organizational leaders of change in their executive and senior management positions, will participate in two sets of individual interviews (Table 3). The first set will be conducted at the beginning of the study, where the goal will be to glean an understanding of the status of bereavement care at VON from the leadership perspective, and to anticipate the challenges and levers for implementing the guideline. The second set of individual interviews will be conducted toward the end of the study, where the goal will be to uncover the impacts of the knowledge-to-action process and the resultant changes in bereavement care, from this leadership perspective.

Table 3

Individual Interview Guide

Individual Interview Guide

Before implementation (0 months)

- Tell us about your bereavement care practices now. What works well? What is challenging?
- What, if anything, would you want to change about the current bereavement care practices? How would you want to change it?
- Who do you feel needs to be involved in changing bereavement care practices?
- Tell us about how institutional practices support or create challenges for your bereavement care practices.
- What similar changes have you been involved with at VON and what lessons learned can be applied or built on for this project?

After implementation (12-13 months)

- Tell us about your bereavement care practices now since the guideline was introduced. Are you practicing differently because of the guideline? Why or why not?
- Tell us about how institutional practices support or create challenges for your bereavement care practices.
- Can you identify how the change and implementation process might be applied more broadly across VON?
- Are there any other recommendations you would make to help move the guideline into the bereavement care system?

In addition to interviews, additional sources of data will be collected. During team meetings and forums (described further below), digital recorders will be used to capture discussions focused on the guideline and the implementation process. During forums, work sheets and flip charts will be used to record brainstorming and discussions. Organizational and project documents (e.g., agendas, presentations, preliminary findings reports) will be collected in order to trace the history around and the context for the knowledge-to-action process. Research team members will keep descriptive and reflective notes documenting observations and impressions about the process.

Building on the collaborative relationship with the knowledge users throughout the development of this initiative, the research team will meet regularly throughout the course of the project. For example, a face-to-face planning meeting with the VON core team will be held to establish goals and determine responsibilities for Forum #1. A series of teleconferences will also be held to exchange emerging findings, identify opportunities and challenges, and plan contextually-sensitive implementation and system change activities. At the end of the project, a meeting will be held to plan for next steps, particularly around sustaining and spreading changes for the improvement of primary bereavement care.

A critical element of this integrated KT effort will be to hold two knowledge exchange forums. These will be held 18 months apart and are intended to serve as an important opportunity for exchange between VON employees, community stakeholders, and research team members. VON's core leadership knowledge-user team, along with the variety of other stakeholders, will participate at the forum. VON will lead this aspect of the project. Forums will include a variety of individuals (VON nurses, managers, administrators, volunteers; bereaved individuals; and some external stakeholders, such as funeral home directors, social workers, physicians, bereavement coordinators, health-system funders, and spiritual/religious professionals). We estimate 40

attendees per forum. The inclusion of participants from all levels of VON is expected to promote a supportive, synergistic environment in which the most context-sensitive bereavement-related KT activities can be planned and initiated. Furthermore, including the experience of stakeholders from external settings such as funeral directors, spiritual leaders, and family support group members is anticipated to contribute additional innovative and strategic avenues toward knowledge-to-action that will help to link the VON initiatives with potential changes within the larger system.

The purpose of the forums will be to (a) critically discuss the components of the proposed guideline and adapt recommendations to fit the local context, (b) identify and support key champions/opinion-leaders, (c) select multidimensional KT implementation strategies, and (d) identify and document facilitators and barriers related to implementation. Forum agendas will be developed jointly by the core VON leadership group and the research team prior to each meeting. Forums will be formally evaluated (formative and summative) by all participants. Feedback will be used to modify the approaches used.

The philosophy underpinning the forums is to serve as the foundation of “a learning collaborative” in which participants will learn from each other, create innovative strategies for the implementation of the guideline, and together, ultimately, improve bereavement care. “Learning collaborative” is a multistakeholder structure within an organization aimed at improving quality of care and often producing dramatic results (Bodheimer, 2007; Institute for Healthcare Improvement, 2003). An evidence-based guideline implementation toolkit (Registered Nurses’ Association of Ontario, 2012) will be used to guide the work of the forums. The first forum will gather ideas and plan for implementation; the second will assess how the implementation has impacted system changes and the care provided. The forums will facilitate small and large group discussions about issues related to the guideline and its implementation, as well as opportunities for sharing of experiences, feedback, and problem solving strategies. The diversity of participants is expected to cultivate strategic and complementary alliances for knowledge-to-action around primary bereavement care.

Researchers will contribute to the translation process by (a) providing timely feedback of findings from forums, interviews, and focus groups; (b) problem-solving with implementation groups during exchange periods; (c) contributing financially to the release of a project facilitator and staff participants from their usual work within VON; and (d) assisting in the development of a support structure, a learning collaborative, as an outcome of the integrated knowledge-to-action methods proposed. The researchers will promote stakeholder collaboration from the beginning and will aim to support the synergy of researcher-user interaction throughout the project toward evidence-informed bereavement care.

Data Analysis

Data analysis will begin as data are collected. Preliminary and increasingly finalized findings will be conveyed back in subsequent researcher-knowledge-user interactions including teleconferences, meetings, focus groups, and the final forum. The purpose of these iterative cycles of analysis and feedback will be to incite knowledge-user reflection and action, shape and validate findings, use data in a timely fashion to inform and guide next steps, and ensure ongoing monitoring and evaluation of the process. This collaborative and participatory approach represents a departure from more traditional designs in that researchers and knowledge-users, together will co-construct interpretations rather than the initiative remaining exclusively driven by the researchers.

An interpretive descriptive method of analysis will be used. Interpretive description is an approach developed to generate disciplinary knowledge capable of informing clinical practice (Thorne, 2008) and is therefore appropriate to this integrated KT study. Study data will be

organized and managed with NVivo qualitative software. Drawing on the main components of the study framework as a guide (Thorne, 2008), constant comparison techniques will be employed to cluster the data into sufficiently distinct and comprehensive categories. The intent will be to highlight both complementary and divergent perspectives about the knowledge-to-action process and multiple changes across the system.

Discussion

Although this single case will provide the opportunity to investigate in an in-depth fashion one initiative within one organization, the transferability of the findings could be strengthened through comparisons with other initiatives or organizations. Multiple data sources, a theoretical framework, and collaborative multistakeholder process will be used to confirm and challenge the interpretation of key findings.

Several strategies are planned to address some potential threats to the success of this project. One potential obstacle to this study is the possibility that this initiative will become a burden for this large busy organization, which is constantly negotiating many competing demands on administrators, staff, and clients. Furthermore, the nature of home care is that everyone is spread out geographically, making it challenging to bring people together. In addition, in the guideline development process and planning stages for this project, stakeholders outlined a range of systemic and organizational barriers to providing primary bereavement care. These included insufficient and inflexible remuneration, inappropriate staffing models, lack of debriefing and mentorship, as well as time constraints and multiple competing priorities. Nonetheless, the strong support experienced to date from VON's President/CEO right through to the directors, managers, and frontline staff is an indication that such potential challenges may be mediated. Flexibility and adaptation will be of key importance in this collaborative study given the often unpredictable events and situations that inevitably arise in the life of an organization. To help address some of these impediments, project funding will be provided to support a facilitator for this project and to liberate staff. The forums and focus groups will be conducted at a convenient time and place for participants, perhaps piggybacking on to preplanned organizational activities to minimize time and cost expenditures. The development of a learning collaborative and the fostering of relationships between multiple stakeholders are anticipated to assist with longer-term support and mentorship around the provision of bereavement care.

VON Canada is the largest national not-for-profit charitable home and community care organization, with most of its sites engaged in palliative and end-of-life care. VON Canada considers therapeutic relationships and supporting families (core competencies to bereavement care) to be a foundation for their "Care and Service Model" (Victorian Order of Nurses Canada, n.d.). VON Canada has identified improving the delivery of quality services for bereaved individuals and families as a high priority. This is fitting for this home care organization for several reasons: (a) it is at the interface between acute care and the community and therefore well placed to identify the conduits for ensuring continuity of care across sectors; (b) its clinical and program emphasis on the elderly, palliative care, and chronic care management; (c) regardless of where or in what setting they lose their loved one, bereaved individuals and families ultimately grieve at home; (d) VON is recognized as a pioneer and champion in the field of caregiver/family information, support, and education; (e) VON is characterized by a learning culture which aims for excellence, innovation, and integration; research and evidence is used to inform practice and organizational decision-making and to proactively influence policy at the organizational and health system level; and (f) as a nongovernmental organization with extensive experience in the policy arena, VON can champion this innovation for bereaved Canadians.

VON Canada has been an active partner in the Principal Investigator's program of research for over a decade. The Principal Investigator's position as an embedded researcher in this national home and community care organization has been important in the development of research and implementation of evidence-based practice change. VON's commitment to having a nurse researcher as part of its organizational structure highlights the dedication to ensuring that research evidence will inform home care practice and, in turn, that practice will inform research. There has been an underlying assumption in the KT literature that users and producers traditionally reside in two separate communities (Phelps, 2005; Phelps & Hase, 2002). The colocation within an organization of research producers and knowledge users is an under-studied aspect of KT to which this study can also contribute.

The knowledge-user partners range in positions across all system levels. For example, this project includes the President/CEO, National Directors and Vice Presidents, managers and front line staff, in addition to other key stakeholder across the system locally, regionally, and nationally. This breadth of involvement provides the potential for scaling up and spreading of this initiative. VON Canada's long-term goal for this system innovation is to be a champion of the process to reach a national consensus for a standard of care for primary bereavement care across the nation. This standard of primary bereavement care will be based on a philosophy of prevention and health promotion. Given the evidence for potential negative health impacts following the death of a loved one, and the documented need for support (Bonanno & Kaltman, 2001; Christakis & Alison, 2006; Christakis & Iwashna, 2003; Lang et al., 1996; Lang et al., 2004; Lilard & Waite, 1995; Schulz, Boemer, Shear, Zhang, & Gitlin, 2006; Wimpenny et al., 2006), it is clear that bereavement care must be integral to health-care agendas and services. It requires a large system change through effective KT strategies, with key stakeholders across sectors and provinces. The knowledge user partners are strategically positioned and committed to realizing the study objectives and to undertaking future initiatives. They also have the potential to disseminate the outcomes and evidence on a broad and influential scale.

In order to improve the care to bereaved Canadians in a sustainable fashion, there is a need to reach out to and partner with resources outside of the health-care system including funeral homes and to the bereaved themselves. It is anticipated that implementation of the primary bereavement care guideline will have benefits for the health-care workforce as well as for the bereaved. Some benefits to providers include a reduced level of stress, lower incidences of anxiety and depression, reduced substance abuse, lower employment turnover, and fewer sick days. Some benefits to the bereaved include reduced use of medical and other health and social services, reduced leaves of absence from work, as well as improved health and quality of life.

Results from this study will be published in a health services and policy peer-reviewed journal. The notion of primary bereavement care will be introduced to the public health community through conference presentations. This diverse team will transfer the knowledge from this project to other health and social issues for which large system change is sought. It is also anticipated that the project findings will have significant impact by augmenting the practice recommendations that are part of the guideline with more specific and significant organizational and policy change recommendations. As part of this project, VON is positioned to be a model community of practice for primary bereavement care, wherein local research-user interaction is maximized. This project is anticipated to yield empirical and theoretical evidence about the process of researcher-knowledge user partnerships as well as the process initiating systems transformations related to primary bereavement care in the community.

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Appendix A: Individual Consent

Evidence-Informed Primary Bereavement Care: A Knowledge-to-Action Approach

Interview Consent Form

STUDY PRINCIPAL INVESTIGATOR:

Ariella Lang, RN PhD

Research Scientist, *VON Canada*

Assistant Professor, School of Nursing *McGill University*

Professeure associée, Faculté des sciences infirmières *Université de Montréal*

RESEARCH TEAM:

Andrea Fleiszer, RN BSc BN PhD(c), McGill University

Amin Mawani, PhD, FCMA, York University

Megan Aston, RN PhD, Dalhousie University

Susan Cadell, PhD, Wilfrid Laurier University

Catherine Butler, RN, BA, BScN, MHA, VON Canada

You are being invited to participate in a research study led by Dr. Ariella Lang about improving bereavement care. Prior to agreeing to participate and before signing this consent form, please take the time to read and understand the information that follows.

STUDY PURPOSE

The main purpose of this research study is to increase organizational and practitioner uptake and application of a Primary Bereavement Care Guideline focused on improving the provision of primary bereavement care for individuals and families at home and in the community around the death of a loved one. The knowledge gained through this research project will be used to inform future practice and policy development. In addition, it aims to have a significant impact on providers' knowledge, skills and attitudes about caring for the bereaved, while also seeking benefits for the bereaved.

PARTICIPATION

Your participation in this study is voluntary and confidential. It will consist of your participation in two 30-60 minute audio-recorded semi-structured interviews (the first at the beginning and the second at the end of the study). The goal of the first baseline interview will be to gain an understanding of the bereavement care status at VON, particularly from the leadership perspective, and to anticipate the levers for and challenges of implementing the Primary Bereavement Care Guideline. The goal of the second or end of project interview will be to: uncover the impacts of the knowledge-to-action process; discuss the resultant changes in bereavement care; and, identify how the change and implementation process might be applied more broadly across VON. At the time of your interview, you will also be asked to complete a brief demographics form.

The most important thing about your participation is that we hear what you have to say. There are no right or wrong answers. Your participation is completely voluntary, and you may refuse to answer any questions during the interview and/or withdraw from the study at any time. You may also request that the data that is collected from you be excluded from the study findings. Participating in, or withdrawing from the study will not affect your employment at VON in any way.

CONFIDENTIALITY

The information gathered from you will be used only for the purposes of this research. Only the researchers and research staff involved in this study will see the transcripts and study records. All information will be kept confidential. Your name will not be recorded alongside your responses. A unique identification number will be assigned to your interview data. Your individual results will not be shared with anyone outside of the research team. Only group results will be presented or published publicly. Your words may be quoted in reports of this research; however, you will not be identified by name. It is possible that you may be identifiable by virtue of your unique position in this organization. If so, you will be offered the option of reviewing portions of your interview transcript and of excluding any text that you do not wish quoted. The Research Ethics Boards overseeing this study may request and inspect information from the study to make sure that it is being conducted properly. In this case, the members of these ethics committees will also adhere to strict confidentiality policies.

CONSERVATION OF STUDY DATA

All participant information, demographics forms, as well as recordings and transcripts of your interview(s) will be kept in the research team members' locked offices. Electronic versions of your data will be stored on the research team members' password-protected computers. The raw data from this study will be kept for a minimum of 10 years from the time of collection. Secondary analysis of the data collected may be performed as part of future studies conducted at VON related to the Primary Bereavement Care Guideline program.

RISKS & BENEFITS

Other than the time it takes to participate, it is unlikely that you will experience any discomfort or inconvenience as a result of your participation. Your participation in this study will not necessarily benefit you directly. However, your participation will help to develop knowledge that may help improve bereavement services and help families locally and across Canada.

ETHICAL CONSIDERATIONS

If you have any questions concerning the study, you may contact Dr. Lang at the telephone number or email address below. If you have any concerns about how the study is being conducted you may contact the VON Canada Research Ethics Committee Chair directly at (phone number).

If you are interested in participating in this study, please contact the Research Project Coordinator at (phone number) or at (email). She will further explain the study and answer any questions that you may have.

CONSENT FORM

<u>Title of Project:</u> Evidence-Informed Primary Bereavement Care: A Knowledge-To-Action Approach		
Consent questions (to be completed by the research participant):		
	<u>Yes</u>	<u>No</u>
I have had the opportunity to ask questions and discuss this study:	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I am free to withdraw from the study at any time, without having to give a reason and without affecting my employment:	<input type="checkbox"/>	<input type="checkbox"/>
I am willing to participate in an audio-taped interview:	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the secondary analysis of the data collected from me as part of future related studies conducted by members of the research team:	<input type="checkbox"/>	<input type="checkbox"/>

_____	_____	_____/_____/_____
Signature of Participant	Name (Printed)	Year/Month/Day
_____	_____	_____/_____/_____
Signature of Witness	Name (Printed)	Year/Month/Day

I, _____, would / would not [please circle one] like to be contacted when the results of the study are available.

Please contact me at:

NAME: _____

ADDRESS: _____

EMAIL: _____

Appendix B: Focus Group Consent

Evidence-Informed Primary Bereavement Care:
A Knowledge-to-Action Approach

Focus Group Consent Form

STUDY PRINCIPAL INVESTIGATOR:

Ariella Lang, RN PhD

Research Scientist, *VON Canada*

Assistant Professor, School of Nursing *McGill University*

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Catherine Butler, RN BA BScN MHA, VON Canada

You are being invited to participate in a research study led by Dr. Ariella Lang about improving primary bereavement care. Before agreeing to participate and before signing this consent form, please take the time to read and understand the information that follows.

You are being invited to participate in this study because:

- 1) You are > 18 years of age,
- 2) You are a volunteer / community member who works with bereaved individuals, OR are employed at VON and work with the bereaved, OR have experienced the death of family member, OR are employed by Nova Scotia Health and your work in some way involves the bereaved, AND
- 3) You are able to participate in an English focus group.

STUDY PURPOSE

The main purpose of this research study is to increase the use of a developed Primary Bereavement Care Guideline (PBCG) at an organizational and practitioner level. This guideline is aimed at improving bereavement care for individuals and families at home and in the community around the death of a loved one. The knowledge gained through this research project will be used to inform future practice and policy development. In addition, it aims to have a major impact on providers' knowledge, skills and attitudes about caring for the bereaved, while also seeking benefits for the bereaved.

PARTICIPATION

Your participation in this study is voluntary and confidential. It will consist of your participation in a 1.5 to 2 hour face-to-face audio-recorded focus group with you and others involved in some way with bereavement care. During the focus group you will be asked to participate in a discussion about your perception of bereavement care at VON. We want to hear what you have to say. There is no right or wrong answer.

Your participation is completely voluntary, and you may refuse to answer any questions during the focus groups and/or withdraw from the study at any time. You may also request that the data that is collected from you be excluded from the study findings. Participating in or withdrawing from the study will not affect your employment or relationship with VON in any way.

CONFIDENTIALITY & ANONYMITY

For the purposes of this research related to the Primary Bereavement Care program, only the researchers and research staff involved in this study will see the transcripts and study records. All information will be kept confidential. Your name will not be recorded alongside your responses. Only group results will be presented or published publicly. Your words may be quoted in reports of this research; however, you will not be identified by name. The Research Ethics Boards overseeing this study may request and inspect information from the study to make sure that it is being conducted properly. In this case, the members of these ethics committees will also adhere to strict confidentiality policies.

Anonymity will not be possible among the members of the focus groups. The researcher will ask other members of the focus group to keep what you say confidential, but please note that the researcher cannot guarantee they will do so.

CONSERVATION OF STUDY DATA

All participant information, demographics forms, as well as recordings and transcripts of the focus groups will be kept in the research team members' locked offices. Electronic versions of your data will be stored on the research team members' password-protected computers. The raw data from this study will be kept for a minimum of 10 years from the time of collection. The data collected might be used in future related studies conducted at VON and related to the Primary Bereavement Care program.

RISKS & BENEFITS

During the focus group, you will be asked to speak about your feelings, thoughts, and experiences related to bereavement and bereavement care. Discussing these things may cause you to feel emotional discomfort. The focus groups will be conducted by facilitators who are experienced in facilitating such discussions. These group moderators will be attentive to the need to mediate any potentially harmful interactions between participants. The moderator will establish "ground rules" for the focus groups and remind all participants of these rules if respectful communication is breached. You may refuse to answer any question at any time during the focus group. In case of harm or serious discomfort during the focus groups, contact information for professional counseling will be offered to you.

Your participation in this study will not necessarily benefit you directly. However, your participation will help to develop knowledge that may help improve bereavement services and help families locally and across Canada.

ETHICAL CONSIDERATIONS

If you have any questions concerning the study, you may contact Dr. Lang at the telephone number or email address below. If you have any concerns about how the study is being conducted you may contact the VON Canada Research Ethics Committee Chair directly at (phone number).

If you are interested in participating in this study, Research Project Coordinator at (phone number) or at (email). She will further explain the study and answer any questions that you may have.

CONSENT FORM

Title of Project: Evidence-Informed Primary Bereavement Care: A Knowledge-To-Action Approach		
Consent questions (to be completed by the research participant):		
	Yes	No
I have had the opportunity to ask questions and discuss this study:	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I am free to withdraw from the study at any time, without having to give a reason:	<input type="checkbox"/>	<input type="checkbox"/>
I am willing to participate in an audio-taped focus group:	<input type="checkbox"/>	<input type="checkbox"/>
I agree the data collected from me might be used in future related studies conducted by members of the research team	<input type="checkbox"/>	<input type="checkbox"/>
I am interested in participating in another mixed focus group with nurses, managers, home support workers, family members and volunteers:	<input type="checkbox"/>	<input type="checkbox"/>

_____/_____/_____
Signature of Participant Name (Printed) Year/Month/Day

_____/_____/_____
Signature of Witness Name (Printed) Year/Month/Day

I, _____, would / would not [please circle one] like to be contacted when the results of the study are available.

Please contact me at:

NAME: _____

ADDRESS: _____

EMAIL: _____