Self-Administered Intervention for Caregivers of Persons With Alzheimer’s Disease

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Abstract
The purpose of this article is to describe the development and feasibility testing of a Transition Toolkit to support caregivers of persons with Alzheimer’s disease (AD) in dealing with transitions. Using the Medical Research Council (MRC; UK) guidelines for complex intervention development, Step 1 was to develop a theoretical understanding of the likely processes of change, by reviewing existing evidence and theory, and conducting new primary research. Based on Step 1, the intervention was developed with the Alzheimer’s Society experts (Step 2), followed by concept mapping of the critical inputs of the intervention with the theoretical understanding (Step 3). A feasibility study was then conducted with 20 caregivers of persons with AD (Step 4) using a mixed methods concurrent design. The preliminary findings of the pilot study were positive with the participants describing the Transition Toolkit as acceptable, easy to use, and having the potential to help deal with transitions.

Keywords
caregivers, Alzheimer’s disease, intervention, development, feasibility

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Introduction

Approximately 34 million people will be diagnosed with Alzheimer’s disease (AD) and related dementias by the year 2025 worldwide and the majority of their care will be provided by family members (World Health Organization, 2011). Family members who become caregivers experience multiple concurrent transitions that impact their own quality of life (Duggleby, Swindle, Peacock, & Ghosh, 2011). For example, studies of caregivers caring for persons with AD suggest that the experience of care giving can affect their physical and mental health (Donelan, Falik, & Deroches, 2001; Fast, Eales, & Keating, 2001; Gilliland & Bush, 2001; Gruenfeld et al., 2004). Given the growing body of literature on the negative impact of care giving on physical and mental health (Donelan et al., 2001; Fast et al., 2001; Gilliland & Bush, 2001; Gruenfeld et al., 2004) and the reliance on caregivers to provide care to the increasing numbers of persons with AD in Canada (Alzheimer Society of Canada, 2010), there is a critical need to find ways to support caregivers.

Several interventions have been developed to support family caregivers of persons with AD, however when evaluated they have very minimal effects and are costly in nature as they require the presence of a trained professional (Zarit & Feema, 2008). The purpose of this article is to describe the development and feasibility testing of a self-administered intervention to support caregivers of persons with AD dealing with transitions. The purpose of the feasibility study was to determine if the intervention was easy to use, feasible, and acceptable to family caregivers of persons with AD.

Problem

Examples of interventions for family caregivers that have been evaluated include extensive training sessions on how to give care for persons with AD or coping and stress reduction guided by a health care professional (Andren & Elmstahl, 2008; Ducharme et al., 2011; Marriott, Donaldson, Tarrier, & Burns, 2000). Systematic reviews of interventions for caregivers of persons with AD suggest that interventions targeting caregivers have had minimal effect (Brodarty, Green, & Koschara, 2003; Cooper, Balamurali, Selwood, & Livingston, 2007; Peacock & Forbes, 2003; Pinquart & Sörensen, 2006; Sellwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Thompson et al., 2007; Zarit & Femla, 2008). The authors of these reviews suggest that: (a) interventions should be flexible and tailored (customized to the characteristics of clients; Zarit & Femla, 2008), (b) involve active participation...
Most interventions for family caregivers have been based on caregiver stress and burden theories with a focus on strain and depression (Ducharme et al., 2011). One effective intervention for caregivers of newly diagnosed persons with AD utilized transition theory to develop the intervention (Ducharme et al., 2011). Although the intervention has promise it is costly and time intensive as it consists of 90 min psycho-educational individual sessions once a week for 7 weeks (Ducharme et al., 2011). However, transition theory may be a useful framework for the development of interventions for the caregivers of persons with AD.

Transitions, as they are disruptive, result in uncertainty and distress. During this time, individuals are at risk for changes in their health (Ducharme et al., 2011). Transition theory suggests that transitions are processes triggered by change (Meleis, 2010; Olsson & Ek, 2002) during which a new situation or circumstance is incorporated into a person’s life (Kralik, Visten, & van Loon, 2006). The transitions experienced by caregivers of persons with AD may include changes to their environment, roles and relationships, physical and mental health, isolation, and taking on new tasks (Adams, 2006; Duggleby et al. 2011). Transition theory provides a framework to understand the complex nature of the caregiving experience and as such was chosen to be the framework for this study.

The Medical Research Council (MRC) in the United Kingdom has published guidelines to direct the development of complex interventions (Medical Research Council [MRC], 2000, 2006). There are four recommended steps, which were undertaken in the present study. Step 1 was to develop a theoretical understanding of the desired change by drawing on existing evidence and theory, which was supplemented by new primary research. The intervention was then developed based on this first step by experts (Step 2), followed by concept mapping of the critical inputs of the intervention based on the theoretical understanding (Step 3). Then an assessment of the feasibility of the intervention was completed (Step 4). These steps are detailed below.

Step 1: Theoretical Understanding and Conceptual Framework

There are several developmental theories that focus on transitions that occur as a person ages (Meleis, 2010). There are also transition theories which focus on nondevelopmental life changes such as health and economic changes (Bridges, 2001; Meleis, 2010; Selder, 1989). Most of the current
theories however, do not reflect the experience of informal caregivers. One transition conceptual model “Navigating Unknown Waters” (Duggleby et al., 2010) was developed for informal caregivers of persons with advanced cancer. In this model, multiple complex transitions were proposed to occur concurrently. The processes delineated in the model, acknowledging the situation, connecting with others and redefining normal, helped caregivers deal with transitions. The model has the potential to inform the AD caregiving journey; however, the model had not been validated with caregivers of persons with AD.

It was important to adapt the “Navigating Unknown Waters model” as the experience of caring for persons with AD is considered to be unique as the disease itself is central to the experience (Galvin, Todres, & Richardson, 2005). In step one a mixed methods study was conducted to inform the adaptation of the “Navigating Unknown Waters” model to reflect the experience of caregivers of persons with AD (Duggleby et al., 2011). The details of the study procedures and findings are reported elsewhere in Duggleby et al. (2011). Several of the concepts from the model were shared by family caregivers of persons with AD and those with advanced cancer; however, there were some differences. In Figure 1 the highlighted concepts reflect the specific concepts that were added to the “Navigating Unknown Waters” model to adapt it to reflect the transition experiences of caregivers of persons with AD.

**Step 2: Development of the Intervention**

Based on the adapted transition model and working with the Alzheimer Society of Alberta/North West Territories and the Alzheimer Society of Calgary, a Transition Toolkit for caregivers of persons with AD was developed. Principles guiding the development of the Toolkit were developed by the research team and collaborators to reflect the recommendations from the systematic reviews of interventions for persons with AD and the mixed methods study findings in Step 1. The following principles that guided the development of the Toolkit were:

1. The intervention was self-administered by family caregivers of persons with AD and focused on the caregivers themselves.
2. The intervention was flexible allowing for the person to use it in the way they wish.
3. Providing education was an important component of the intervention. Participants described their educational needs in the mixed methods study conducted in Step 1.
(4) Resources such as websites and contact information for services were part of the intervention to facilitate connecting family caregivers of persons with AD. Providing a list of resources may increase access to information and services. Contact information of local community services, as well as provincial and national services, were part of the intervention.

(5) Descriptions of what caregivers of persons with AD might expect to happen was also part of the intervention. In the mixed methods study in Step 1 caregivers described their most significant changes were often unexpected.

(6) Time and energy may be an issue for family caregivers, so the activity instructions were worded to say “begin” an activity, not to complete it.

(7) Reading levels were designed at a grade five reading level and pictures used as much as possible so a diverse public, that is those with less than 8 years of formal education, would be able to read the Toolkit.

(8) Caregivers chose what they would like to share with others and what they wish remained private.
Intervention

The intervention was based on the adapted “Navigating Unknown Water’s” model for the purpose of supporting caregivers of persons with AD (principle #1). The toolkit was in the form of a binder with the flexibility to add to the binder (principles #2). The instructions for the Toolkit reflect choice. It can be used whenever or however the person would like to use it. It can be shared or be private (principle #8). Moreover, it has instructions for each section so that it can be used by the caregivers themselves (self-administered; principle #1).

The Transition Toolkit has 5 sections. The first section entitled “About Me” has 6 activities (e.g., what helps me, my goal as caregiver, what is my backup plan) to help family caregivers of persons with AD deal with transition processes. The activities were worded to encourage persons using the toolkit to begin the activities, not necessarily to finish them (principle #6). The second section is entitled “Common Changes” contains examples of transitions experienced by other family caregivers of persons with AD. This section was developed to address principle #5, as it has descriptions of what they might expect. Each example of “common changes” includes verbatim quotes from data in the Step 1 study. A section entitled “Contacts” was developed with the intent of helping to connect with the community and other resources (principle #4). In this section there is space to write down the names and phone numbers of important people in their own lives, such as doctors, home care nurses, spiritual leaders, and so on. Some relevant contacts are also provided in the binder, such as contacts for the Alzheimer Society, income tax, employment insurance, and so forth.

Based on the information needs expressed by participants from the study in Step 1, the “Frequently Asked Questions” and “Resources” sections were developed (principle #3). Data from the Step 1 study were formulated into questions. These questions were then answered by experts from the Alzheimer Society. The final section is entitled “My Important Health Information.” The instructions for this section suggest that a short summary of the medical history, updated list of medication, and copies of most recent test results and advanced directives of the person they are caring for, be placed in a plastic folder (provided) that can be removed whenever it is necessary to take to the hospital or doctor’s office.

Step 3: Concept Mapping of the Intervention

One way to ensure that the Transition Toolkit was based on the adapted conceptual model was to conceptually map the intervention activities with the
theory. Hardeman et al. (2005) suggested that concept mapping ensures that the intervention includes essential elements. Figure 2 illustrates the concept mapping of each of the activities and sections to the concepts from the conceptual model.

**Step 4: Feasibility Study**

The purpose of this feasibility study was to evaluate the Transition Toolkit for ease of implementation, feasibility (able to be used), and acceptability (would be used).

**Design/methodology.** A mixed methods concurrent descriptive design was used, in which quantitative data (evaluation survey) and qualitative data were collected from four focus groups of caregivers of persons with AD. This study received ethics approval from a university health research ethics board.

**Sample.** The Manager of Education and Support, Alzheimer Society of Alberta and Northwest Territories, and the Support Service Intake Coordinator, Alzheimer Society of Calgary, asked potential participants who met the study inclusion criteria if they would be willing to participate in the study. Inclusion criteria were: (a) caring for a person with AD, (b) 18 years of age or older, and (c) English literacy. If they agreed a letter of invitation outlining the study was given to potential participants and they were contacted by a research assistant who explained the study to them. Twenty-two participants were approached and 20 participants agreed to participate. Participants were then mailed a package that included information on the focus group sessions, a demographic form, and a copy of the interview questions.

**Data Collection Procedures**

Four focus groups of five participants each completed two group interviews held in the Alzheimer Societies’ conference rooms. At the first group interview, a trained moderator obtained written informed consents from all the participants and provided them with a copy. All participants then completed a demographic form. Open-ended questions regarding significant transitions guided the first focus group interview. Examples of questions include: Describe the most significant changes you have experienced since becoming a caregiver and what influences these changes? The purpose was to gather further qualitative data on transitions to enrich our understanding of transitions in this population. Following the interview, each member of the focus group was given a Transition Toolkit, with instructions on how to use it by the moderator.
Over a 2-week timeframe, study participants utilized the Toolkit. After that period, they were asked to evaluate the Toolkit, using an evaluation questionnaire which they brought with them to the second focus group. One week later, the participants completed an evaluation form and an open-ended audio-taped evaluation interview. A written evaluation questionnaire, based

Figure 2. Concept mapping.
on the program evaluation frameworks of McKenzie and Smeltzer (1997) and Timmreck (1995), was used to assess: (a) ease of use, (b) acceptability, and (c) feasibility of the Toolkit. The evaluation form consisted of six questions asking participants to rate their agreement using a Likert-type scale of five responses: fully disagree to fully agree. Room for comments was included with each question.

The second focus group was an evaluation of the Toolkit. The interview guide included questions such as: “what did you like best,” “what did you like least,” and “any suggestions for revisions.” The guide also explored the effectiveness of the Toolkit by asking if the participants found it useful for dealing with their transitions. The group interviews lasted approximately 45 to 60 min, and were audio taped.

Analysis
Quantitative data were entered into SPSS v. 19 and analyzed using descriptive statistics. All qualitative data were managed using Nvivo software and analyzed using Krippendorff’s content analysis techniques (Krippendorff, 2004). Content analysis involved reading the transcripts as a whole several times to identify common patterns in the data. Using an iterative process the common patterns were then categorized to form themes. Trustworthiness of the data was achieved by using the participant’s actual words as much as possible and keeping an audit trail of decisions.

Findings
Sample
Twelve of the participants were female and eight were male, with a mean age of 65.75 (SD = 16.7) years. Eight of the participants were daughters, eight were husbands, and four were wives. They reported caregiving for approximately 43.5 (SD = 29.4) months and ranged from 1 to 8 months. Their average reported health status was 3.00 (SD = 1.08) on a scale with a maximum score of 5. The person they were caring for had a mean age of 83.3 (SD = 7.39) years and 60% were female (n = 12; male n = 8).

Evaluation of Transition Toolkit
The results from the evaluation questionnaire and focus group interviews suggested that the Toolkit was easy to understand and use, and potentially
Effective in helping participants deal with transitions. The evaluation questionnaire asked participants to rate their agreement with statements using a scale from 1 to 6, with 1 being fully disagree to 5 which was fully agree. Participants were also asked to provide written comments for each statement.

**Ease of use.** The participants agreed and strongly agreed that the directions were clear (mean 4.20 [SD = 0.86]) and expectations were clear (mean 4.00 [SD = 1.07]). These findings were supported by the qualitative data from the questionnaire and the focus group interviews. For example, one participant said: “Yeah. I—I like the way that the material has been outlined, like the Frequently Asked Questions and those sorts of things.” Another said: “I—I think it’s very well balanced. It’s going to be a valuable tool for me.” Another said: “I agree. I thought it was very—it’s—the format is simple. It’s, the information is easily accessible. You don’t have to do a lot of reading, really you don’t. It’s pretty concise.”

**Feasibility.** Participants agreed that the Toolkit was feasible. They had energy (mean 3.93 [SD = 1.10]) ability (mean 3.876 [SD = 1.19]) and time (mean 3.67 [SD = 0.72]) to carry out the activities. These scores also suggested that some of the participants were neutral or disagreed about whether they had the energy or time to complete the activities. In the focus groups, the issue of having the energy to use the Toolkit was raised. As one participant explained: “Yeah, I think it’s a good reference book for a caregiver. I think the difficulty I see for any caregiver is to use it. Uh, I think when you really get bogged down with caregiving you don’t seem to have the energy or concentration to read through the manual.” As well the time frame of 2 weeks for the feasibility study was too short. The participants recommended that it would be most appropriate to give the Toolkit to those who were caring for persons newly diagnosed with AD, as they would have a longer time period to use the Toolkit. For example as one participant said: “[the Toolkit] . . . would be most helpful at the beginning of the process that is, when someone is newly diagnosed.”

**Acceptability.** The data suggested that the Toolkit does help care partners deal with significant transitions (mean 4.33 [SD = 0.82]). As well the participants agreed that they would like to use the Toolkit (mean 4.33 [SD = 1.05]) and recommend the Toolkit to others (mean 4.60 [SD = 0.91]). As one participant said: “I feel this is a very worthwhile resource. I would have liked to have it been made available when we first [started] this journey. I will be using it during the remainder of my journey. Thank you very much.” Another said: “I certainly did read it & let some of the comments resonate around in my soul. Caregiving is so isolating sometimes. I get validation and strength from knowing my feelings & thoughts are neither ‘crazy’ nor uncommon.”
Additional comments made by participants suggest that they liked the “About Me,” “Frequently Asked Questions,” “Resource section,” “Behavior Tracking Chart,” “Common Changes to Expect,” the pamphlets, the pockets, and online resources. While the Toolkit represented a good resource, participants felt that it would need to be supplemented with some type of support (e.g., counseling, support groups, such as provided through the Alzheimer Society). As well they recommended that it would be useful also as an online format, to increase its accessibility and to facilitate its use by those who prefer to use computers rather than hand writing their activities.

Discussion

The findings from the feasibility study suggest that the Transition Toolkit is easy to use, feasible, and acceptable, as well as having the potential to help family caregivers of persons with AD deal with transitions. The Transition Toolkit was developed with the intent of being a self-administered intervention. The participants ratings of agreement that the directions were clear and the Toolkit was easy to use, suggest that the Toolkit can be used alone by individuals. As well, it could be utilized by community agencies such as the Alzheimer Societies, to deal with the participants’ recommendations that additional support is often needed.

The qualitative data from the mixed methods study in Step 1 and in the present feasibility study (Step 4) enriched our understanding of transitions in several ways. It helped in the adaptation of the conceptual model to guide the study, and was used to determine the essential components of the intervention. As well, the data were important in developing certain aspects of the interventions. For example, the qualitative data were the foundation for determining what information would be included in the “Common Changes” and “Frequently Asked Questions” sections. The qualitative data added to our understanding of the feasibility study results, by confirming or not confirming the findings. Furthermore, the participants’ recommendations were insightful in terms of wanting the Toolkit as soon as possible after diagnosis and the need to have resources for support if required. Others have suggested that qualitative methods can provide insight and understanding of patient experiences and that interventions can be derived from this understanding (Gamel, Grypondak, Hargeveld, & Davis, 2001; Morse, 2000). In our experience the qualitative data were essential for every process of developing and feasibility testing the Toolkit.

In the process of concept mapping the concepts outlined in the adapted situation-specific transition theory were compared with the specific
components of the intervention. By completing this step we were able to ensure that the intervention was theory driven and included the critical components to support family caregivers of persons with AD. Intervention concept mapping has also been successfully utilized in the development of an intervention program for family caregivers of persons with AD (Ducharme et al., 2009).

The positive results from this feasibility study suggest that utilizing the MRC guidelines in developing a complex intervention (Transition Toolkit) has merit. It is a systematic process that guided the development of the intervention based on the theoretical framework of a situation-specific transition model. Systematic development of interventions, based on theory, has been found to be the basis for effective caregiver interventions (Zarit & Femia, 2008). Utilizing the MRC guidelines also resulted in the tailoring of the intervention to family caregivers of persons with AD. Tailoring of interventions is the process of designing interventions so they reflect the language and experience of the person who is using it (Sidani & Braden, 2011). Tailoring of interventions often results in individuals viewing the intervention as highly personally relevant (Sidani & Braden, 2011). Participants become more engaged in the process and have more positive outcomes.

Limitations

There are several limitations related to the sample, as the majority were older women and wives and had been caregiving for at least 1 year. The participants recommended that the Toolkit be used as soon as possible following diagnosis so that it could be used throughout the caregiving experience. However, none of the participants were in the early stages of caregiving. A more diverse sample of new to caregiving participants would be beneficial in determining the feasibility of the Transition Toolkit at that time. This was a feasibility study and the MRC guidelines suggest that the next step for the research team would be to further evaluate and understand the intervention.

Application

This Transitions Toolkit has the potential of providing nurses who work most closely with family caregivers of persons with AD (e.g., home care nurses) with an intervention that is easy to use, feasible, and accessible. Although the Transition Toolkit has been pilot tested with potential positive results, future research is needed to further evaluate the Toolkit before use in practice.
Furthermore, since the toolkit is based on transitions theory it is related to what nurses do on a daily basis—that is to assist patients and families experiencing transitions (Meleis, 2010). Therefore, the toolkit is consistent with the aims of nursing practice.

Very little literature is available that provides examples of developing interventions (Campbell et al., 2007), making it difficult to fully understand how a systematic process like the MRC guidelines work. This article addresses this gap in the literature by outlining a process that can be used by nurses to develop and tailor interventions in practice. This is important given that some nurses (e.g., clinical nurse specialists or nurse practitioners) are in a position to develop interventions that support the people they provide care to. With the expected increase in the number of persons with AD it is imperative to find ways to appropriately support their family caregivers; nurses are in a position to do this given their work with families and their skills in developing effective interventions.

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