

Pilot Study of a Transitional Intervention for Family Caregivers of Older Adults*

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RÉSUMÉ

Objectif: Évaluation (faisabilité, acceptabilité, pertinence et bienfaits potentiels) d'une intervention de transition pour proches aidants. **Méthode:** L'intervention visait à fournir du soutien émotionnel, de l'information sur les ressources communautaires et du soutien au développement des capacités d'adaptation pour les proches aidants de patients de 65 ans et plus qui avaient reçu leur congé suite à une hospitalisation de courte durée. L'approche méthodologique a impliqué un seul groupe, qui a été évalué lors d'un pré-test et d'un post-test effectué trois mois après le début de l'intervention. **Résultats:** Quatre-vingt-onze dyades patients-proches ont été recrutées. Soixante-trois (69 %) proches aidants ont reçu les cinq séances d'intervention (tel que prévu) et 60 (66 %) proches aidants ont complété le test final. Une diminution significative de l'anxiété et de la dépression des proches aidants et un taux de satisfaction élevé ont été notés après l'intervention. **Discussion:** Cette intervention de transition pour les patients plus âgés et leurs proches aidants devrait faire l'objet d'une évaluation plus poussée, de préférence avec un groupe de contrôle, en tant qu'intervention autonome ou comme une composante d'une intervention de transition complète.

ABSTRACT

Objective: To conduct a formative evaluation of a transitional intervention for family caregivers, with assessment of feasibility, acceptability, appropriateness, and potential benefits. **Methods:** The intervention aimed to provide emotional support, information on community resources, and information and support for development of coping skills for the caregivers of patients aged 65 and older who were to be discharged home from an acute medical hospital admission. We used a one-group, pre- and three-month post-test study design. **Results:** Ninety-one patient-caregiver dyads were recruited. Of these, 63 caregivers (69%) received all five planned intervention sessions, while 60 (66%) completed the post-test. There were significant reductions in caregiver anxiety and depression following the intervention, and high rates of satisfaction. **Discussion:** This transitional intervention should be further evaluated, preferably with a control group, either as a stand-alone intervention or as one component of a comprehensive transitional intervention for older patients and their caregivers.

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Introduction

Problem Description

Discharge back home from an acute-care hospitalization for older patients is often followed by adverse outcomes such as death, decline in physical and cognitive function, readmission to hospital, and admission to long-term care (McCusker, Kakuma, & Abrahamowicz, 2002). This transition can be challenging and stressful for family caregivers, who are often required to take on additional care responsibilities at home, particularly when community support services are unavailable or inadequate to meet patient care needs (Graham, Ivey, & Neuhauser, 2009). Transitional interventions from hospital to home aim to prepare and support patients and caregivers during this period (Allen, Hutchinson, Brown, & Livingston, 2014) and to reduce readmissions to hospital (Verhaegh et al., 2014).

At our university-affiliated community hospital in Montreal (Quebec), staff expressed an interest in improving the information and support provided to family caregivers of older medical in-patients preparing for discharge back home. At the time of the study (2016), the Quebec health care system was undergoing reorganization accompanied by significant personnel and budget cuts. Focus groups were, therefore, conducted with nursing and allied health professional staff on the general medical wards to better define the need for a caregiver intervention, and to determine whether and how such an intervention could be integrated with current practice. Although staff supported the need to address immediate emotional and informational needs of caregivers, they felt themselves unable to take on this additional role due to limited resources and heavy caseloads focusing on direct patient care and discharge processes. Existing care protocols require that hospital staff refer most caregivers with needs to front-line community centers; however, waiting lists for emotional and other psychosocial support are often over a year long. Consequently, staff recommended that the intervention should be mainly independent of usual care so as not to increase their burden of care. However, staff on participating units agreed to help in identifying potentially eligible patients and caregivers and introducing the intervention to them.

Available Knowledge

Meta-analyses of caregiver interventions, most delivered in community settings, generally support the effectiveness of complex multicomponent interventions (e.g., education, coping skills training, counseling), delivered either via the telephone or web, to alleviate caregiver distress (Gallagher-Thompson & Coon, 2007; Lins et al., 2014; Ploeg et al., 2017). Fewer studies are available to guide the development of transitional interventions for caregivers. Mainly descriptive research indicates that transitional interventions can be improved if they address family inclusion and education, communication between health care workers and family, and ongoing support for family after discharge (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). Goals of family caregivers are unique and potentially incongruent from those of the patient (Coleman & Min, 2015). Caregivers may have important needs of their own, for emotional support to alleviate the burden of caregiving, and for assistance in navigating the health care system (Manderson, McMurray, Piraino, & Stolee, 2012). This lack of congruency between caregiver and care receiver is often seen during visits to family doctors, and such conflict may interfere with provision of care to the patient (Yaffe & Klvana, 2002). If caregiver needs are not met, caregivers may experience an acute deterioration in their own health-related quality of life (Sewitch, Yaffe, McCusker, & Ciampi, 2006). Caregiver distress and burden may lead to patient hospital readmission (Longacre, Wong, & Fang, 2014) or to long-term care admission (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016).

A meta-analysis of 15 randomised controlled trials of transitional interventions for older adults that integrated caregivers in the intervention concluded that these interventions are associated with a 25 per cent reduction in 90-day readmissions (Rodakowski et al., 2017). Although not well-described, most interventions appeared to have multiple components, and included connections to community resources, caregiver needs assessment, and some form of post-discharge follow-up. Caregiver transitional interventions are needed in which the components are adapted to the local context and are sufficiently well-described to allow for replication.

Rationale

The focus of this project was on the family caregivers of patients aged 65 and older who were recruited from the wards of an acute care hospital and who were expected to return home rather than being placed in long-term care. In an earlier study, we identified three types of unmet need of these family caregivers for (a) information about their family member (e.g., clear explanations), (b) support for their caregiving role (e.g., having access to support for their own needs), and (c) reassurance (e.g., that the patient is receiving the best possible care) (McCusker et al., 2018). Based on these needs, and on the principles identified in the previous section, we designed a transitional intervention that aimed to provide (a) emotional support to the caregiver, (b) information on community resources suitable for the patient and/or the caregiver, and (c) information on skills development with the end goal of promoting caregiver empowerment. To enhance feasibility and potential sustainability, we planned for the intervention to be delivered by a trained layperson partly by telephone.

Specific Aims

The main goal of this study was to conduct a formative evaluation of the intervention. Formative evaluation aims to ensure that a program is feasible, appropriate, and acceptable before it is fully implemented; this is in contrast to an outcome evaluation that assesses outcomes (Centers for Disease Control and Prevention [CDC], 2014). Specifically, we aimed to determine (a) *feasibility*, by assessing the proportions of patients and family caregivers who were interested in receiving the intervention, enrolled in the project, completed 3-month follow-up, and completed the study measures; (b) *acceptability*, by assessing (1) the proportion of caregivers who completed the intervention, (2) the caregiver and patient characteristics associated with intervention completion, and (3) caregivers' and staff's satisfaction with the intervention; and (c) *appropriateness* of the intervention, by describing the needs expressed by caregivers, and ensuring that appropriate intervention components were used to address each need (McCusker et al., 2018; Proctor et al., 2011). A secondary goal was to assess potential outcome benefits of the intervention by assessing: (a) changes in caregivers' mental and physical health and perceived burden of care from pre- to post-intervention; and (b) caregiver contacts with recommended resources during the follow-up period.

Methods

Context

The study was conducted in a university-affiliated community-based hospital located in an area of Montreal that serves a multicultural population (St. Mary's

Hospital Centre, 2014). The study took place on two medical wards that provided general medical care primarily to an older population. One ward was a clinical teaching unit focusing on complex acute care; the other provided mainly longer-term and post-stroke care.

Design

This was an uncontrolled pre-post study of a caregiver intervention provided during the transition back home. The study was intended as a formative evaluation whereby modification to the intervention could be made during the course of the study.

Intervention

The intervention was delivered by a trained caregiver advocate (CA), a non-professional bilingual (English, French) male aged 36 with some personal experience with family caregiving, with counseling experience acquired in another country. Two team members (EA and MH) were responsible for selection of the CA. The role of the CA was to provide emotional support, information about community resources, and information and support on coping skills. Emotional support was provided through active listening, reassurance, and encouragement. Information about community resources included written materials appropriate for the patient and/or caregiver sourced from clinical partners, community groups, and websites of caregiver advocacy groups. Coping skills information and support included prioritization, problem-solving, emotional self-care, and tips on improving communication with health care providers. All intervention materials were available in either English or French.

Training and supervision were provided by co-authors MH, who has 20 years of experience as a social worker within the hospital setting, and EA, director of a community organization providing support and resources to families coping with mental illness. Some training techniques used were (a) role-playing interviews; (b) improving active listening techniques; (c) discussing case scenarios dealing with difficult/challenging situations; (d) reviewing recordings of interviews to discuss and improve on the approach used by the CA when recruiting participants; and (e) discussing limit-setting strategies, healthy boundaries, and working with the unit head nurse to cultivate a more integrated/collaborative role for the CA as part of the team. Over the course of the study, the CA met regularly with supervisors to review progress and discuss individual cases. The CA also reported back more generally on his work to the study investigators during regular meetings.

The intervention was planned to be delivered one-on-one in three core sessions provided at weekly intervals and lasting up to 30 minutes. During these sessions,

the CA focused on identifying caregiver needs and offering tailored information and resources. Two follow-up sessions lasting up to 15 minutes were provided at 2-week intervals, during which the CA asked the caregiver about use of recommended resources and answered any questions about information provided previously. All three intervention sessions could be delivered either face-to-face or over the telephone, depending on the availability of the CA and the caregiver. In some cases, caregivers requested additional sessions; a maximum of one additional core session was permitted.

The CA was guided by an intervention manual, the written resource materials as described above, and contact lists of relevant community agencies and caregiver support groups. Initially, few suggested scripts were used. The CA started the sessions by asking caregivers open-ended questions about their needs related to the hospitalization and return home of the patient. The manual guided the CA to suggest appropriate resources based on broad categories of needs (e.g., home care, transportation, equipment, caregiver mental health). During the course of the study, various improvements and specifications were made to the manual in response to problems noted during supervision and to address specific caregiver needs (Table 1). At the end of the study, the intervention manual was substantially revised with the help of an experienced occupational therapist. The goal of the revision was to standardize

the intervention for use in training and supervision of other CAs in future studies by providing suggested scripts for emotional support (Greene & Burleson, 2003); incorporating Specific, Measurable, Achievable, Realistic, and Time-framed (SMART) goal-setting (Siegert & Taylor, 2004); adding structured agendas for each session; and a revised list of resources. This revised manual was tested with seven caregivers for feasibility and acceptability, then modified based on the results.

Evaluation Methods

Between January 2016 and December 2016, the CA recruited patient-caregiver dyads on the participating wards unless patients were in isolation. Patient inclusion criteria were as follows: (a) patient age 65 or older, (b) presence of a self-identified family caregiver, (c) ability to read or speak in either English or French, and (d) expectation that the patient would be discharged home. Patients were invited to participate in the study to help researchers explore ways to help caregivers. Interested patients capable of providing informed consent were invited to sign the consent form, and designate a family caregiver who could be invited to participate in the study. Patients judged to be not capable or too sick to consent for their own participation were invited to assent to their caregiver's being contacted. The research assistant (RA) then contacted caregivers either in person or by telephone while the

Table 1: Summary of changes made to intervention

| Intervention Component | Change Made |
|---|---|
| <i>Changes made during the course of the study</i> | |
| First contact scripts | • Suggested script provided |
| Selecting a single caregiver | • Defined caregiver as the person most involved in the patient's care and/or the person with the greatest needs |
| Completing the needs assessment | • Added option for self-completion at home |
| Needs codes | • Standardized definition of needs and corresponding codes |
| Intervention options | • Added code for grieving |
| Length of core sessions | • Created list of potential resources/interventions for each need code |
| Length of follow-up sessions | • Reduced from 30–50 mins to 20–30 mins |
| Informational resources | • Reduced from 10–20 mins to 10–15 mins |
| | Added: |
| | • Care strategies for dementia |
| | • Ways to avoid caregiver burnout |
| | • Grieving guide and resources |
| | • Coping with stress |
| <i>Changes made after the study</i> | |
| Tools for the coach | • Created an "Exploring Needs & Actions Workbook" including: <ul style="list-style-type: none"> ◦ Structured worksheet to guide the needs assessment discussion and allow the CA to make structured notes on identified needs ◦ Worksheets to help CA guide the caregiver to select priority needs and build an action plan with the caregiver based on the needs |
| | • Created detailed agendas and scripts for each of the contacts |
| | • Included new guidelines in the CA manual around: <ul style="list-style-type: none"> ◦ provision of emotional support, ◦ using SMART (Specific, Measurable, Achievable, Realistic, and Time-framed) actions |
| Intervention options | • Revised list of potential resources/interventions for each need code |

patient was still hospitalized or shortly after the patient's discharge back home. Interested caregivers were invited to enroll in the study through engaging in formal signed consent either in person or by email/mail. Patients and caregivers completed questionnaires upon completion of the consent process, administered by the RA and/or self-administered according to their preference. Questionnaires were completed in hospital prior to discharge or at home, shortly after discharge (depending on what was most convenient for the respondents).

At follow-up (3 months after enrollment), an independent research assistant, blinded to how many intervention sessions had been completed, mailed caregivers a questionnaire and telephoned those who had not returned the questionnaire to remind them.

At the end of the study, focus group meetings were held with staff from the participating units to ascertain their perceptions of, and experiences with, the intervention.

Measures

Patient Measures

Socio-demographic measures from the patient chart included age, sex, hospital unit, and hospitalization at the same hospital in the previous 2 years. The Charlson Comorbidity Index was computed from these diagnoses and included diagnoses from the current admission (D'Hoore, Bouckaert, & Tilquin, 1996). The six-item Blessed Orientation-Memory-Concentration (BOMC) test was used to assess cognitive status (Katzman et al., 1983). Scores can range from 0–28, a score of 10 or more indicating moderate-to-severe impairment (Katzman et al., 1983). Among patients whom staff considered competent to participate, we used the Hospital Anxiety and Depression Scale (HADS). Each scale has seven items with total HADS scores ranging from 0 to 21. A cut-point of 8 or more on each subscale was used to identify significant anxiety or depression symptoms; these cut-points give a specificity of 0.78 and sensitivity of 0.9 for anxiety; and a specificity of 0.79 and a sensitivity of 0.83 for depression (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Caregiver Measures

Baseline caregiver socio-demographic characteristics included age, sex, relationship to patient, co-residence, level of education, family income, language spoken at home, employment outside the home, duration of caregiving, and whether caregiving duties were shared. The Older Americans Resources and Services (OARS) Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL) scales (Fillenbaum, 1988) elicited caregiver reports of the patient's functional status, using as reference period the 2 weeks before admission to hospital (McCusker, Bellavance, Cardin, & Belzile, 1999).

The scores for each scale range from 0 (completely dependent) to 14 (completely independent). Caregivers were asked how often they provided support to the patient for six areas: nutrition, exercise, symptom monitoring, management of medical care, basic activities of daily living, and instrumental activities of daily living (Rosland, Heisler, Choi, Silveira, & Piette, 2010). Response options ranged from 0 = never to 4 = almost every day. The scale was computed as the mean frequency of support based on a high internal consistency coefficient (0.83). The 12-item Zarit burden scale, with a score ranging from 0 to 48 and an internal consistency greater than 0.80, was used to assess burden of caregiving (Bedard et al., 2001). Measures of the caregiver's physical and mental health status were the HADS (described above) and the SF-12 Physical Component Summary (PCS) and Mental Component Summary (MCS), which are well-validated and widely used (Ware, Kosinski, & Keller, 1996).

At follow-up, satisfaction with the intervention was measured with the Client Satisfaction Questionnaire (CSQ), an eight-item questionnaire that has been validated as an outcome measure for mental health interventions (Attkisson, 1987). Each item has a 4-point response scale. The mean scores range from 1 to 4, a higher score indicating greater satisfaction. If the caregiver reported that they did not have time to complete the questionnaire, the RA attempted a short telephone follow-up which included two questions from the CSQ, with yes/no response options: "Did you get the kind of support you expected?" and "If a friend were in need of similar help, would you recommend the support program to him or her?"

Caregivers were asked whether the CA had been helpful in four areas: listening to and understanding needs; responding to needs; providing information on community resources; and helping to select community resources. They were asked whether, since entering the study, they had contacted any community resources or support groups, and which ones. Finally, caregivers were asked two open-ended questions: "Were there any things that you expected from the support program but did not receive?" and "Is there anything you would like to tell us about your experience with this program?"

Analysis

In order to examine potential selection bias at various stages of recruitment and follow-up, we conducted several analyses. First, we compared the baseline patient characteristics of eligible dyads in which the patient enrolled in the study but the caregiver did not. We also recorded the reason, if available, in which eligible patients and caregivers did not enroll. Second, among the participating dyads,

we tested differences in baseline patient and caregiver characteristics between intervention completers and non-completers, and between those who completed the follow-up and those who did not. All of the above analyses used chi-square, t-test, or Kruskal-Wallis tests (Sheskin, 2004).

Differences in the two CSQ questions between intervention completers versus short telephone follow-up completers were tested with Fisher's exact test. For those measures administered at both baseline and follow-up (HADS, SF-12, Zarit burden), we tested changes over time between baseline and follow-up questionnaires, using the paired t-test (Sheskin, 2004). Except for caregiver income, observations with missing data (< 10%) were discarded from the analysis. For caregiver income, missing data (21%) was treated as a separate category.

Comments from the open-ended questions were coded to summarize their central meaning and compared to identify the main themes related to the acceptability of the intervention.

Ethical Considerations

The study protocol was approved by the hospital's Research Ethics Committee. Patients or caregivers who had HADS scores of 11+ for either anxiety or depression were informed that their answers suggested the presence of severe symptoms. With the patient's consent, the attending physician and treating team were informed of these findings. Caregivers were also provided with the telephone number of a caregiver support hotline.

Results

Feasibility

The study flow chart is shown in Figure 1. Among the 732 patients aged 65 and older, expected to be discharged home, 287 (39%) had no family caregiver, 60 (8%) had been discharged before they were contacted, and the remainder did not meet other study eligibility criteria. Of the 317 eligible patients invited to be in the study, 135 enrolled (43%) and of these, 91 (67%) had a caregiver who agreed to participate. Seventy-six per cent of caregivers consented before patient discharge; the median time between patient admission and caregiver consent was 10 days. Among the 226 eligible dyads that did not enroll in the study, 149 (66%, 125 at patient enrolment stage and 24 at caregiver enrolment stage) indicated that either the patient or the caregiver thought there was no need for a caregiver support intervention.

The 44 patients who were eligible but whose caregivers did not enroll (data not shown) differed significantly from the 91 who participated with regard to four patient

characteristics: a lower co-morbidity index [mean (*SD*) 2.4 (2.1) vs. 3.3 (2.9)]; lower prevalence of a dementia diagnosis (14% vs. 36%); lower proportion that completed the baseline assessment (23% vs. 56%); and lower severity of depression symptoms among those assessed [mean (*SD*) 4.5 (1.4) vs. 8.5 (3.3)]. These differences are consistent with a lower need for additional support among non-participants.

Among the 91 enrolled caregivers, 60 (66%) completed the 3-month follow-up; an additional 12 caregivers completed the short telephone follow-up. Selected characteristics of the patients and caregivers in the 91 dyads enrolled are shown in the first column of Table 2. The second and third columns show the same characteristics among intervention completers ($n = 63$) and follow-up completers ($n = 60$) respectively. Among the 91 dyads enrolled, patients had a mean age of 82.4, and most had no hospital admissions during the previous 2 years. Mental health problems were common among patients: about half had either a chart diagnosis of dementia or were moderately to severely cognitively impaired; of those assessed for depression and anxiety, most met HADS thresholds for either of these conditions.

Caregivers were predominantly female, the majority were co-resident spouses or adult children, had been caregiving for at least three years, and did not work outside the home. Mental health problems were frequent among caregivers, the majority met HADS thresholds for anxiety (78%) and depression (59%). Levels of perceived burden were also high, and both SF-12 scores were low, particularly the MCS score indicating impaired mental health-related quality of life.

Among the 60 caregivers (66%) who completed the full follow-up questionnaire, there were significant differences from those who did not complete this questionnaire ($n = 31$) with regard to patient depression and perceived burden; among completers, patients were more depressed and caregivers had higher Zarit burden scores compared to those who did not complete it.

Acceptability

Overall, 63 out of 91 caregivers (69%) were considered to have completed the intervention as planned, having received at least three core intervention sessions (52% requested a 4th core session) and two follow-up sessions. Three of 91 caregivers received no intervention at all. Thirty-seven per cent of caregivers received their first intervention session after the patient had already been discharged home. Among the 63 caregivers (69%) who completed the intervention, there were significant differences from those who did not complete the intervention ($n = 28$) in five of the variables shown in Table 2: patient age (younger), co-morbidity score (higher),

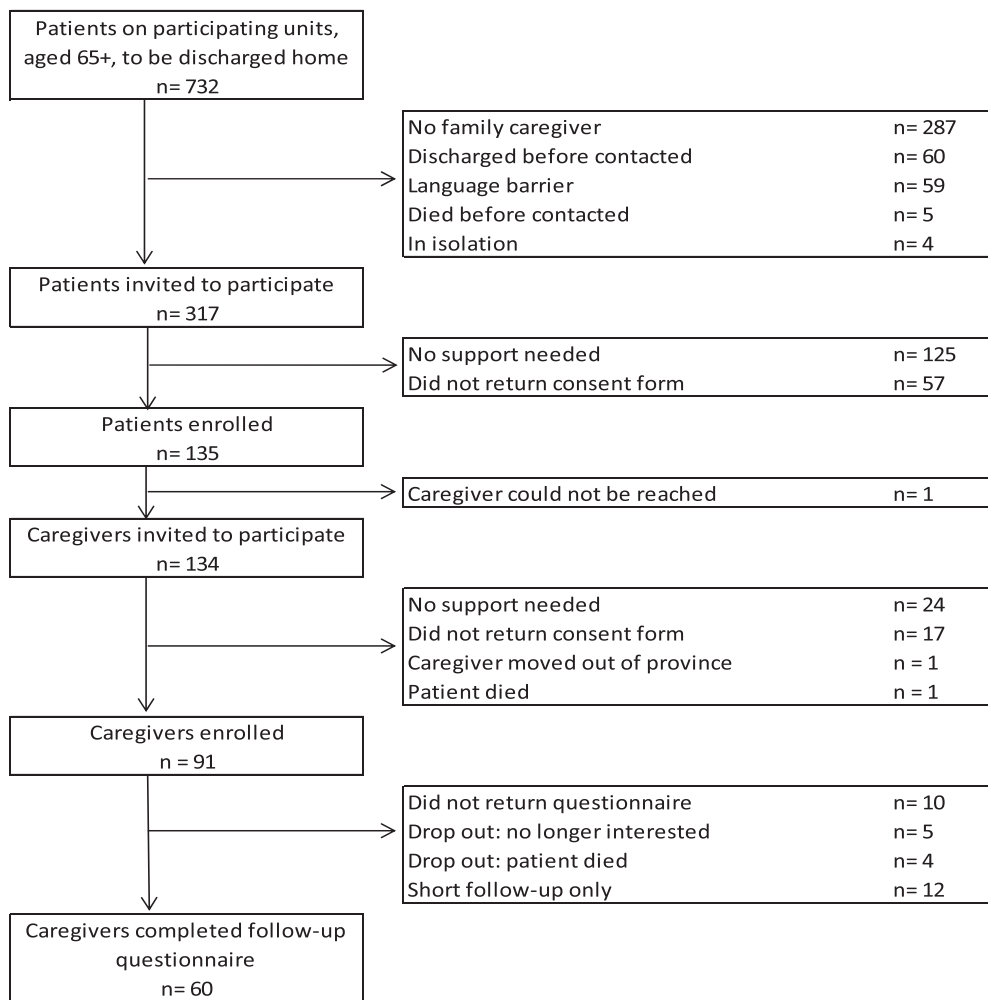


Figure 1: Study flow chart

household income (lower or missing), mental health (more anxious and depressed), and MCS score (lower).

Table 3 shows caregiver perceptions of the intervention at follow-up. CSQ scores were high (mean of 3.4 out of 4). Eighty-five per cent or more of caregivers found two aspects of the intervention helpful: listening and understanding needs, and information on community resources. Less frequently endorsed were responding to needs (72%) and helping to select community resources (64%). In comparison to follow-up completers, those who completed the short telephone follow-up reported lower rates of receipt of expected support, 18 per cent ($n = 11$) versus 82 per cent ($n = 54$) respectively (Fisher exact test $p < .001$), but no significant difference in the percentage that would recommend the program to others.

Responses to the open-ended questions were generally positive, indicating appreciation for the information provided (e.g., "Good to get the information for when I need it ..."; "It helps just knowing who to call if and when I need help"); and for the emotional support (e.g., "[the CA] reminded me to take care of myself";

"I got answers about different things to do to help with anxiety and stress and worries."). The main negative comments were that the intervention did not go far enough (e.g., "Wanted more concrete solutions", "[I needed] help in the house, meals brought ... just emotional support is not enough"; or expressions of frustration in following up on contacts with community resources (e.g., "It's hard to contact organizations and doctors myself", "Didn't have time to contact resources", "Called a lot of community resources but many didn't respond, were closed, couldn't help me.").

In the informal focus group meetings held with staff from the participating units at the end of the study, staff gave positive feedback with regard to the CA's role and reported that caregivers had expressed satisfaction with the additional support they received. They recognized that the work of social workers and nurses focusing on direct patient care and discharge processes could be complemented by the emotional and informational support provided by the caregiver advocate. The staff appreciated having timely support for the caregivers on site.

Table 2: Characteristics of dyads (n = 91), intervention completers (n = 63) and follow-up completers (n = 60)

| Characteristics | Overall (n = 91) | Intervention Completers (n = 63) | Follow-up Completers (n = 60) |
|---|------------------|----------------------------------|-------------------------------|
| Patient: | | | |
| Age, mean (SD) | 82.4 (7.5) | 81.1 (7.5) ^a | 81.9 (7.6) |
| Female, n (%) | 48 (53) | 34 (54) | 34 (57) |
| Hospitalization in the previous 2 years, n (%) | 29 (32) | 24 (38) | 16 (27) |
| Hospital length of stay (days), median [Q1–Q3] | 16 [9–35] | 17 [11–36] | 17 [8.5–34.5] |
| Comorbidity Index (0–37), mean (SD) | 3.4 (2.9) | 3.7 (3.2) ^a | 2.9 (2.2) |
| Dementia diagnosis, n (%) | 33 (36) | 22 (35) | 20 (33) |
| Patient assessed, ^c n (%) | 51 (56) | 26 (41) | 25 (42) |
| Moderate severe cognitive impairment, ^d n (%) | 20 (39) | 16 (43) | 13 (37) |
| Anxiety symptoms ^e (0–21), mean (SD) | 7.8 (3.2) | 8.1 (3.4) | 8.2 (2.8) |
| Depression symptoms ^e (0–21), mean (SD) | 8.5 (3.3) | 8.9 (3.3) | 9.1 (3.2) ^b |
| Caregiver: | | | |
| Age,* mean (SD) | 63.8 (13.7) | 62.8 (13.2) | 62.6 (14.4) |
| Female,* n (%) | 70 (79) | 50 (81) | 46 (78) |
| Post high school certificate or university degree,* n (%) | 52 (58) | 33 (54) | 36 (60) |
| Household income, n (%) | | | |
| < \$40,000 | 30 (33) | 24 (38) ^a | 19 (32) |
| + \$40,000 | 42 (46) | 23 (37) ^a | 27 (45) |
| Missing | 19 (21) | 16 (25) ^a | 14 (23) |
| Relationship,* n (%) | | | |
| Spouse living with patient | 35 (39) | 24 (39) | 23 (38) |
| Non-spouse living with patient | 24 (27) | 17 (27) | 15 (25) |
| Non-spouse not living with patient | 31 (34) | 21 (34) | 22 (37) |
| Has been the patient's caregiver since 3+ years, n (%) | 62 (69) | 43 (69) | 39 (66) |
| Currently working outside the home, n (%) | 39 (43) | 27 (42) | 25 (42) |
| Patient independence (reported by caregiver) | | | |
| Basic activities of daily living (BADL: 0–14), mean (SD) | 9.6 (3.8) | 9.4 (3.8) | 9.2 (3.9) |
| Instrumental activities of daily living (IADL: 0–14), mean (SD) | 6.2 (4.2) | 6.3 (4.1) | 6.4 (4.3) |
| Frequency of support provided (0–4), mean (SD) | 2.3 (1.0) | 2.4 (1.0) | 2.3 (1.0) |
| Zarit burden score (0–48), mean (SD) | 19.5 (11.4) | 20.6 (10.9) | 21.3 (11.9) ^b |
| Anxiety symptoms ^e (0–21), mean (SD) | 10.7 (4.6) | 11.9 (4.3) ^a | 11.1 (4.6) |
| Depression symptoms ^e (0–21), mean (SD) | 8.5 (4.8) | 9.6 (4.6) ^a | 9.0 (4.5) |
| SF-12 perception of health score | | | |
| Mental component summary (0–100), mean (SD) | 37.8 (12.4) | 34.7 (11.0) ^a | 37.2 (12.2) |
| Physical component summary (0–100), mean (SD) | 42.2 (11.7) | 41.6 (12.2) | 42.9 (11.2) |

Note. ^a Significant difference from intervention non-completers ($p < .05$); ^b Significant difference from follow-up non-completers ($p < .05$); ^c Patients too sick, confused or distraught were not assessed; ^d Blessed Orientation-Memory-Concentration; ^e HADS: Hospital Anxiety and Depression Scale.

* Number of missing values for caregiver variables: Age (5), Sex (2), Education (2), Relationship (1)

Q1:1st quartile, Q3:3rd quartile.

Appropriateness

Core sessions lasted a mean of 20 (SD 12.1) minutes, with a median duration of 17.0 minutes. Follow-up sessions lasted a mean of 18.2 (SD 14.9) minutes, with a

Table 3: Caregiver evaluation of intervention at follow-up

| Variables | n | % mean (SD) |
|------------------------------------|----|-------------|
| Satisfaction: CSQ-8 score (1–4)* | 59 | 3.4 (0.6) |
| Helpful aspects of intervention: | | |
| Listening and understanding needs | 58 | 90 |
| Responding to needs | 58 | 72 |
| Information on community resources | 58 | 85 |
| Helping select community resources | 58 | 64 |

Note. * Higher scores indicate greater satisfaction.

median of 11.5 minutes. Most frequently discussed needs (at one or more sessions) among 88 caregivers were (a) caregiver mental health (60%), (b) emotional burden (50%), (c) home care (30%), (d) communication with health care providers (24%), (e) caregiver physical health (11%), (f) transportation (9%), and (g) social support (7%). Table 4 shows which interventions were offered for each of the needs most frequently discussed.

Potential Benefits

Table 5 shows the changes from baseline to 3 months. There were significant declines in HADS anxiety and depression scores, but no significant changes in SF-12 and Zarit scores. Among 58 caregivers who completed the final questionnaire, 23 (40%) reported using community

Table 4: Interventions offered for most frequent needs

| Variables | Emotional Support | Information About Community Resources | Coping Skills Information and Support |
|--|---|--|--|
| Mental health | Active listening Reassurance | Local support groups Psychosocial services through CLSCs | Websites on depression and anxiety Skills building tools (depression self-care worksheets, relaxation audio) |
| Burden | Encouragement to follow-up Active listening | Respite services through CLSCs | Caregiver handbooks (normalising experiences, highlighting importance of emotional and physical self-care) Support with problem-solving |
| Homecare | Reassurance Encouragement to follow-up Active listening | Home adaptation and support with personal hygiene through CLSCs Meal delivery programs Subsidized private homecare services like cleaning and help with shopping | Support with problem-solving Prioritization |
| Communication with health care professionals | Active listening | | Written tip sheet on improving communication Support with problem-solving |
| Caregiver physical health | Active listening Reassurance Encouragement to follow-up | Family physicians Local support groups | Disease or condition-specific websites Support with problem-solving Prioritization |
| Transportation | Encouragement to follow-up | Adapted public transit programs | Support with problem-solving |
| Social support | Active listening | Local support groups | Caregiver handbooks (normalising experiences, highlighting importance of social support) Support with problem-solving |
| | Reassurance Encouragement to follow-up | | |

Note. CLSCs = local community health and social service centres.

resources since entering the study. Most of these caregivers contacted services related to obtaining practical support for patient care; 22 per cent contacted emotional support services for caregivers.

Discussion

In this article, we have reported on a formative evaluation using an uncontrolled pilot study of an innovative transitional intervention for family caregivers of older medical patients who were discharged home from an acute care medical hospital stay.

The feasibility of the intervention is supported by its uptake by caregivers, despite high rates of anxiety, depression, and burden. Overall, among patients approached who had a family caregiver, 29 per cent of dyads enrolled in the project. Non-participation appears to be due primarily to lack of perceived need. Our analyses of potential selection bias suggest that participation was higher in older adults with multimorbidity and mental health conditions (dementia and depression). These patients needed more support from their family caregivers, and the caregivers themselves were more

Table 5: Changes from baseline to follow-up in caregiver outcomes (n=60)

| Variables | Baseline | Follow-up | Paired t-test |
|--|-------------|-------------|---------------|
| | Mean (SD) | Mean (SD) | p-value |
| Hospital Anxiety and Depression Scale (HADS) ^a (n = 57) | | | |
| Anxiety symptoms (0–21) | 11.0 (4.6) | 8.8 (5.1) | 0.002 |
| Depression symptoms (0–21) | 9.0 (4.6) | 7.4 (4.4) | 0.015 |
| SF-12 perception of health score ^b (n = 55) | | | |
| Mental Component Summary (MCS: 0–100) | 36.8 (12.2) | 40.1 (13.4) | 0.091 |
| Physical Component Summary (PCS: 0–100) | 42.8 (10.7) | 43.0 (11.8) | 0.867 |
| Zarit burden score (0–48) (n = 54) | 21.6 (11.9) | 20.4 (11.6) | 0.455 |

Note. ^a Higher score indicates greater severity of symptoms; ^b higher score indicates better perception of health, as compared to a national average of 50.

likely to experience emotional distress, depression, and burden of care (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; McCusker, Latimer, Cole, Ciampi, & Sewitch, 2007, 2009). Importantly, it appeared that caregivers with greater needs for support were more likely to participate and to complete the intervention.

The participation rate was lower than that reported in other studies involving caregivers of hospitalized elders (Coleman, Ground, & Maul, 2015; Dellasega & Zerbe, 2000; Li et al., 2012; Lim, Lambert, & Gray, 2003). However, the majority of non-participants (66%) cited lack of perceived need for additional support. Indeed, based on patient data available on non-participants, rates of dementia and co-morbidity were significantly lower than among participants. Thus, the intervention appears to have reached those in greatest need. Another factor may have been the multicultural population served by the hospital; ethnic minority groups are often less interested in receiving additional home care and support services as they prefer to manage this care on their own (Greenwood, Habibi, Smith, & Manthorpe, 2015). Alternative ways of reaching this population should be explored, such as offering a single session to discuss possible needs, and focusing on providing information on resources rather than direct support.

The acceptability of the intervention is supported by high rates of post-intervention caregiver satisfaction. Hospital staff also reported that caregivers they had spoken to appeared to be satisfied with the intervention. The qualitative results suggest that the acceptability of the intervention might be greater if the CA actively advocates for the caregiver – for example, by obtaining information directly from health care professionals and assisting with making appointments and obtaining needed services.

The appropriateness of the intervention is supported by intervention components that addressed caregiver needs, and the complementarity of the intervention with clinical services offered by the health care professionals working with the patients.

The potential benefits of the intervention on the caregiver are suggested by the significant decline in the severity of symptoms of depression and anxiety, as found in previous research on caregiver interventions (Adelman et al., 2014). However, without a control group we cannot conclude that these changes are attributable to the intervention. There were no significant changes in physical or mental health quality of life or in perceived burden, also consistent with most other caregiver intervention research (Adelman et al., 2014).

There has been a dearth of studies of carefully conducted transitional interventions for caregivers that provide detailed information on the intervention. An exception

is a transitional nurse-led intervention that emphasized activation, and was associated with significant increases in caregiver self-efficacy to manage tasks such as medication management and communication with care providers (Coleman, Roman, Hall, & Min, 2015). In contrast to the Coleman intervention, the intervention we developed and tested in this study was designed to be delivered by a trained non-professional to increase its sustainability. A disadvantage was that it did not address medication issues. Non-professionals have been used successfully as mental health self-management coaches (McCusker et al., 2015). Telephone coaching by lay or professional health workers can be a cost-effective method of supporting self-management for various chronic diseases (Wennberg, Marr, Lang, O'Malley, & Bennett, 2010) and for depression (McCusker et al., 2015). The formative nature of the evaluation allowed us to make improvements during the intervention that focused mainly on standardizing and scripting each session, and on increasing the resources corresponding to caregiver needs. At the request of hospital staff, the intervention was designed to be independent of usual hospital discharge practices. However, if staff were willing, the intervention principles could be integrated, perhaps with greater effectiveness, into hospital discharge procedures, as one component of an enhanced, supportive transitional care intervention for patients and caregivers. Capacity would need to be built to deliver such an intervention.

Limitations

There are several limitations of the study. First, this uncontrolled pilot study focused primarily on indicators of the intervention process rather than effectiveness outcomes. The formative nature of the evaluation aimed to make needed improvements before the intervention was evaluated rigorously. Further evaluation of the intervention should involve a comparison group, ideally in a randomized controlled trial. Second, the results of the follow-up may not be representative of the sample enrolled; indeed, the perceptions of the intervention among 11 caregivers who did not complete the full follow-up questionnaire were less positive than among the 60 completers. Third, the follow-up period of 3 months may not be sufficient to detect improvements in quality of life or perceived burden of care.

Conclusions and Next Steps

We conclude that the intervention developed and tested in this study, with modifications suggested by the formative evaluation, merits further research, ideally in a randomized controlled trial, to rigorously assess its effectiveness on caregiver and patient health and service utilization outcomes.

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