Condition-Specific Pamphlets to Improve End-of-life Communication in Long-term Care:Staff Perceptions on Usability and Use

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ABSTRACT

Objectives: This paper reports findings on the usability and staff use of five condition- specific pamphlets of high prevalence in LTC: dementia, heart failure, chronic obstructive pulmonary disease, renal failure, and frailty. The pamphlets were created in response to residents', families', and staff's recommendations for activating early reflections and communication about end-of-life care.

Design: A mixed-method (qualitative and quantitative) survey design was used. Step one collected survey data on the usability of the pamphlets. Step two collected survey data on pamphlet use.

Settings and Participants: Two nurses with specialized palliative care training, two resident /family representatives, ten condition-specific specialists, and 33 LTC palliative leads reviewed the pamphlets for usability prior to distribution. 178 LTC home staff in four participating LTC homes reported on pamphlet use.

Measures: Specialists and resident /family representatives were asked to provide open comments and LTC home palliative leads were asked to complete a survey on the accuracy, readability and relevance of the pamphlets. After six months of distribution, all staff in participating LTC homes were asked to complete a survey on pamphlet use, usefulness, and comfort with distribution.

Results: The pamphlets were reportedly accurate, relevant, and easy to understand. Following six months of availability, most staff in LTC had read the pamphlets, found the information useful, and planned to share them. However half of the staff questioned their role in pamphlet

distribution and most had not distributed them. Regulated staff (i.e. staff affiliated with a regulated profession) expressed more comfort sharing the pamphlets than care aides and support staff.

Conclusions/Implications: Condition-specific pamphlets appear to hold promise in providing residents and families with relevant information that may activate early reflections and conversations about end-of-life care. However, structured implementation strategies, training and discussions are required to improve staff comfort with distribution, and explore roles in distribution and follow-up.

INTRODUCTION

Long-term care (LTC-sometimes referred to as a skilled nursing home or care home) is a major site of death for older persons with advanced chronic conditions.[1-3] Yet, the majority of older persons do not enter LTC with the primary goal of receiving end-of-life care, and consequently staff face the challenge of deciding when and how to initiate end-of-life discussions.[4-7]

An important aspect of delivering holistic end-of-life care within LTC includes prompting families and residents to reflect on, discuss, and sometimes document preferences, wishes and values for future end-of-life care.[8-9] These opportunities, referred to broadly as advance care planning (ACP), can reduce distress associated with in the moment decision making, and support perceptions of good end-of-life care for all parties.[9-14]

Despite the known benefits, ACP is rarely activated in LTC settings.[7] Barriers include: reinforcing the stigma that LTC accelerates deterioration and death, uncertainty regarding when

and how to introduce the topic, and lack of available tools to help direct reflections and discussions for conditions of high prevalence in LTC.[7, 15]

To help staff (a) introduce the topic of disease-progression and (b) name condition-specific issues warranting reflection and discussion, our interdisciplinary team developed five condition-specific pamphlets for conditions of high prevalence in LTC: dementia, heart failure, chronic obstructive pulmonary disease (COPD), renal (kidney) failure, and frailty. [16]

The idea to develop condition-specific pamphlets first evolved following analyses of 19 focus groups conducted with staff, residents, and families as part of a larger initiative aimed at strengthening a palliative approach to care.[15] Analyses of these discussions revealed a desire for condition-specific pamphlets. All parties believed that such pamphlets could address barriers to ACP communication in LTC by, normalizing the importance of thinking about and discussing future care, and offering tips regarding what to anticipate, reflect on and discuss for particular conditions. This paper reports findings on the perceived usability of the pamphlets and explores how, if at all, they were used by staff. Residents' and families' use of the material are reported elsewhere.[17]

METHODS

This study used a mixed-method design that incorporated qualitative and quantitative survey data in two steps. In step one, data was collected from condition-specific and palliative care specialists, as well as resident/family representatives to explore the accuracy, readability, and relevance of the pamphlets. This step was used to improve the usability of the pamphlets prior to distribution and evaluation. In step two, data was collected from LTC staff in four participating LTC homes where the pamphlets were distributed. This step explored staff use of and comfort with the pamphlets.

The four LTC homes wherein pamphlets were reviewed and distributed were located in urban settings in Southern Ontario Canada. These homes were purposefully selected to represent the mix of contexts found in LTC homes across Canada [18]. They included for profit (three) and not for profit (one) facilities; ranged in size from large (two -169 and 206 beds respectively), medium (one -120 beds) and small (one -60 beds); included contexts with high staff turnover (two) and low staff turnover (two); and comprised of religious-based (one) and secular facilities (three).

The two steps described in this paper were conducted in accordance with the standards of the *Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans* (2010). Procedures related to informed consent, data management, and dissemination were approved by the Office of Research Ethics Boards at X and X University.

Step 1: Usability of Pamphlets

Sampling and Data Collection

We developed five paper-based 8 X 11 threefold pamphlets for medical conditions considered by staff to be most pertinent to their contexts and noted in the literature to be of high prevalence in LTC.[16]

Four graduate students in nursing and social work helped to develop the pamphlets in consultation with evidence-based clinical resources [19-20] and the patient education literature.[21-24] Based on recommendations from these resources, the students elected to include general information on the relevance of a palliative approach to care in LTC care (e.g. providing information on the importance of ACP) alongside frequently cited condition-specific information (e.g. signs and symptoms of advanced stages of a condition; resources for further condition-

specific information). Questions to prompt further reflection and discussion were also included because this direction has been found to be an important precursor to activating discussions with clinicians. [25-26] All pamphlets shared a similar structure.

Once developed, two registered nurses with combined expertise in palliative care and the LTC home sector, and two specialists associated with each of the five conditions (one nurse and one physician for each, totaling 10 condition specialists) were purposefully selected and electronically invited to provide open written comments on how well both palliative care and the conditions were described, and to review the resources named in the pamphlets. The palliative specialists reviewed all pamphlets and the condition specialists reviewed those pamphlets associated with their expertise. One resident representative and one family representative known to the team, were also asked to review the pamphlets. Finally LTC Palliative leads (regulated staff, care aides and support staff who received palliative care training as part of a larger initiative)[15] were asked to complete a seven-item paper based survey inquiring about the applicability of the pamphlets to a LTC context (e.g. easy to understand, use of non-medical language, and relevance of suggestions made). Responses to all items were scored on a Likert scale ranging from (1) strongly disagree to (5) strongly agree. The survey also invited staff to include open comments on recommended changes, and positive aspects of the pamphlets.

Analysis

We created a list of all comments provided by condition experts, palliative specialists, and resident and family representatives and categorized them into strengths, weaknesses, and suggestions. Comments categorized as weaknesses or suggestions were addressed prior to distribution to LTC palliative leads for review.

We re-categorized the scale items on pamphlet usability completed by LTC palliative leads as overall agreement (strong agreement and agreement) to report them as percentages and frequencies. We conducted a conventional content analysis to categorize the open survey comments provided by LTC palliative leads.[27] Comments that emerged most frequently across respondents and/or that appeared to elaborate on trends noted in the quantitative findings were used to guide further pamphlet revisions.

Results

Two registered nurses with specialized palliative care training, 10 condition specialists and two resident/family representatives reviewed the pamphlets representing a 100% response rate. Their feedback suggested the information was accurate and well-described. Some provided preferred resources that were added prior to distribution to LTC palliative leads for review.

Thirty-three of the 55 eligible LTC palliative leads across four participating LTC homes completed the survey, representing a 60% response rate. Respondents included 20 regulated staff (16 nurses, 1 social worker, 1 physiotherapist, and 2 dieticians) 8 care aids, and 4 support staff (2 dietary aides, and 2 activity aides). One respondent did not identify their role within LTC. Table 1 presents staff responses to survey items.

[Insert Table 1]

Most staff agreed the pamphlets were easy to understand, used non-medical language, and included actions that were clear and manageable. Fewer staff felt the pictures and graphs were useful, key points were easy to identify, and the font was easy to read.

Open comments reinforced and expanded on these quantitative findings. First, many staff suggested that the pamphlets were “very helpful for people with a non-clinical background”, and included relevant information that is “typically not that well explained to families in LTC home

settings". However, some staff also suggested the pamphlets were "too busy" and should include "less text, more pictures and more point form". Finally, several staff noted that relatives of LTC home residents should be referred to as family /friends rather than caregivers. The resident and family representatives were consulted on this recommendation and agreed with the suggestion. Consequently, most sections of the pamphlets were re-written in point form, more pictorial representations were added, and references to caregivers were changed to family/friends. The final iteration of the pamphlets had a reported readability index suggestive of grade seven level capacity as measured by the Flesch-Kincaid, Gunning-Fog and SMOG readability instruments (see: Blinded for Review).

Step 2: Evaluation of Pamphlets

Sampling and Data Collection

Over a period of six months, the pamphlets were made available to residents, and families/friends in the four participating LTC homes via bulletin displays or through distribution by staff. At study end, all staff were invited to complete a series of questionnaires on all components of the team's larger intervention program which included one survey specifically evaluating staff's perceptions and use of the pamphlets.

The pamphlet survey inquired about pamphlet use, perceived usefulness and comfort distributing the pamphlets. Questions on pamphlet use included three items: awareness, reading, and distribution of the pamphlets. Responses were dichotomized as yes (1) or no (0). Those who had either read or distributed the pamphlets were asked to identify which pamphlets they had read/distributed.

Questions on perceived usefulness and comfort included six items. Items on usefulness were: usefulness of the information to self, usefulness of the information to residents/families,

and perceived harmfulness of the information. Items on comfort were: plans to distribute in the future, comfort distributing to families/friends, and feeling that one is the appropriate person to distribute the information. Responses to these six items were scored on a Likert scale ranging from (1) strongly disagree to (5) strongly agree. Two open ended questions on reasons for use or non-use of the pamphlets were also included.

Analysis

Descriptive statistics were calculated to provide an overview of sample characteristics, overall use, and reactions to the pamphlets. For descriptive purposes, strongly agree and agree responses for the Likert scale items on perceived usefulness and comfort were grouped together to represent agreement for an associated item and are reported as percentages and frequencies.

A principal components factor analysis with varimax rotation was conducted for the six items developed to capture perceived usefulness and comfort to examine if they clustered around these two pre-conceived domains.[28] This allowed us to conduct Analysis of Variance comparing means for perceived usefulness and comfort by occupational group: regulated staff, care aides and support staff. We used Chi Square tests to examine differences in pamphlet use by occupational group for dichotomous variables. The level of statistical significance between groups was specified to be $p<0.05$. Statistical analyses were performed using SPSS v23.

Answers to open ended questions were categorized using a conventional content analysis and then tabulated as frequencies and percentages.[27]

RESULTS

178 of a possible 697 staff completed the surveys; a response rate of 26%. Table 2 provides specific information about the study sample, pamphlet use, and distribution amongst staff.

[Insert Table 2]

Respondents were evenly distributed between care aides, support staff, and registered staff resembling the mix-ratios of staff in LTC.[29- 30] The registered staff respondents included 45 nurses, four social workers, four dieticians, three physiotherapists, one spiritual counsellor, and one physician. The support staff included 16 activity aides, 16 dietary aides, 16 maintenance staff, five physiotherapy assistants, and four clerks. Participants were largely female, had completed college degrees or higher, and had an average of 10 years of experience working in LTC.

Most staff were aware that the pamphlets were available, and had read at least one of the pamphlets, but fewer had distributed the pamphlets. Of those who read the pamphlets (n=105), the dementia pamphlet was read most frequently, followed by the heart failure pamphlet.

Registered staff were more aware of the pamphlets, X^2= 12.96(2), p=0.002; read more of the pamphlets, X^2= 18.15 (2), p=0.00; and distributed more pamphlets, X^2= 16.35(2), p=0.00, than care aides, and support staff .

Most staff who had read the pamphlets suggested that the information was useful to residents and families (83, 79%), planned to share the pamphlets in the future (76, 72%), and felt comfortable sharing the information (82, 78%). Only four of them felt the information would be harmful (4, 3.8%). Despite expressed comfort only half felt they were the appropriate person to share the pamphlets (53, 50.5%) (results not shown in a table).

Prior to proceeding with our exploratory factor analysis, we conducted the Kaiser Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity. KMO is used to measure whether values have enough in common to warrant a factor analysis. Historically, values of 0.7 are considered adequate for proceeding with a factor analysis.[31] Barlett's test of sphericity tests the hypothesis that items are unrelated and therefore unsuitable for further structure detection. Small values $p < 0.05$ indicate that a factor analysis may be useful.[32-33] For our six items the p-value for Barlett's test of Sphericity was < .01; and KMO was = .80.

We conducted our factor analysis with the 105 respondents who read the pamphlets. Our factor analysis provided evidence for a two-factor solution (eigenvalues greater than one) which explained 70.89% of the variance.

[Insert Table 3]

Table 4 shows the results of mean comparisons by staff group for perceived usefulness and comfort distributing pamphlets. There were no significant differences found between occupational groups based on perceived usefulness (p=0.90). A significant difference was found between occupational groups related to their comfort with pamphlet distribution ($p = 0.03$). Registered staff reported higher mean comfort (Mean=12.43, SD= 2.92) than care aides (Mean=11.06, SD= 2.68) and support staff (Mean=10.73, SD= 3.03). Post hoc comparisons using Tukey's test suggested that this overall difference was based on the mean difference between registered staff and support staff (p=0.05).

Open comments revealed some important information about pamphlet distribution and their use. Of the 54 participants who answered why they had used the pamphlets, almost half (26, 48%) suggested they used them for self-education while only a fifth (9 17%) suggested they used them to educate residents and families. The remaining comments were more general in nature

suggesting the pamphlets were useful and informative (without specifying for whom). Comments categorized as *pamphlets used for self-education* included: “they helped me to increase my own knowledge”; “I wanted to know more about certain ailments and dying”; and “I wanted to be more aware about palliative care”. Comments categorized as *pamphlets used for educating families and residents* included: “I wanted to educate families and residents to empower them to make the right decisions”; “Families seem more confident with information they can read as opposed to trying to recall something they have been told”; and “Family members benefit from education. It helps them make reasonable decisions”.

DISCUSSION

Our study suggested that pamphlets are a promising method for information sharing with residents, families, and staff on what to expect and discuss regarding end-of-life care. Most staff completing the survey had read at least one of the pamphlets, had suggested the information was relevant to families and residents, and few worried about doing harm by distributing the information. Pamphlets in high demand were those addressing dementia and heart disease; two conditions of high prevalence [16, 34] that have been identified as particularly challenging for staff in LTC to address.[35-36]

Despite the high number of staff who perceived the pamphlets to be relevant, fewer staff had distributed them. The most frequent reason for non- distribution was uncertainty about whether it was their role to do so. This was especially true of care aides and support staff. These findings may reflect a tendency in LTC to question care aides’ and support staffs’ roles in end-of –life care. While studies suggest that care aides and support staff provide between 70-90% of all patient care in LTC, studies have also shown that these integral interdisciplinary team members

feel disempowered to communicate their observations on resident functioning to registered staff. [28, 37-41] Although it goes beyond the role of support workers and care aides to discuss prognoses with residents and families, providing them with resources and ideas regarding what they may want to discuss with one another and the health care team fits well within the caring labour they are expected to conduct.[39-42]

Our former work on residents' and family/friends' reactions to receiving condition-specific pamphlets suggested that the pamphlets offer welcome opportunities for reflection but could require staff follow-up to activate discussions between residents and families/friends.[17] Previous research also suggests that residents and families/friends are open to receiving written information on end-of-life from most staff in LTC including care aides, and/or staff who know them well.[43] Our current findings add that role uncertaintly may pose an important barrier to pamphlet distribution and follow up. Taken together these findings point to the importance of delineating the role care aides and support staff can play in pamphlet distribution and implementing a procedure to ensure follow-up by registered staff.

While clarifying roles and procedures may prove helpful to address the barrier of role confusion, it is also possible that staff's' discomfort distributing the pamphlets was related, in part, to their lack of comfort engaging in end-of-life conversations. More specifically some staff may have feared that distributing a pamphlet could place them in an uncomfortable position of fielding questions they felt ill equipped to handle. Interdisciplinary end-of-life communication training that incorporates care aides and support staff may be particularly relevant to increase comfort in this regard, because it can help to improve staff knowledge and comfort managing intense emotions whilst also providing staff with the opportunity to discuss perceived power differentials, overcome issues of trust and reflect on scopes of practice.[44-45]

There are a variety of tools and processes that may be helpful in developing more structured procedures for pamphlet distribution and follow up. For example, the Palliative Performance Scale which is a scale developed to identify when patients may benefit from end – of –life care, or the 'surprise question' which prompts staff to use their clinical judgment to identify residents who could foreseeably die within a particular time frame, could be used to identify residents and families who would benefit from receiving a pamphlet [46-47]. Both of these triggers can be reliably used by care aides and support staff in LTC. Once a pamphlet has been provided, team huddles, rounds, or written records can communicate that pamphlet distribution has occured and follow up is warranted. Weekly on site physician visits, interdisciplinary care conferences, or daily bed-side nursing check-ins are all possible avenues for post distribution support and follow up.[48-49]

STUDY LIMITATIONS:

The findings from this study should be viewed in light of the following limitations. First, our factor analysis can only be considered exploratory because our sample size was small. Second, staff member perceptions were based on a self-selected sample whose experiences may not be transferable to other staff in LTC. Finally, this study was conducted in four LTC homes located in urban settings in one Canadian province limiting the generalizability of study findings to other jurisdictions. This limitation was partly addressed by our mix of LTC homes.[17]

CONCLUSIONS/RELEVANCE

Condition-specific pamphlets appear to hold promise in activating early reflections and conversations about end-of-life care. Such resources ensure a basic common understanding of illness related end-of-life trajectories that can prepare residents and families for more detailed discussions with staff. They also provide opportunities for all staff in LTC to play a role in

295 priming residents and families for such discussions and have been found here and elsewhere to
296 be acceptable means of transmitting information and supporting dialogue. [50] However, training
297 and facility wide deliberations may be required to, discuss staff roles in pamphlet distribution,
298 improve staff comfort engaging in end-of-life communication, and establish a consistent system
299 of pamphlet distribution and follow up.
300

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The authors have no conflict of interests to declare

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