Family care conferences in long-term care: Exploring content and processes in end-of-life communication

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ABSTRACT

Objective: End-of-life (EoL) communication in long-term care (LTC) homes is often inadequate and delayed, leaving residents dying with unknown preferences or goals of care. Poor communication with staff contributes to families feeling unprepared, distressed, and dissatisfied with care. Family care conferences (FCCs) aim to increase structured systematic communication around goals and plans for the end of life. As part of the Strengthening a Palliative Approach to Care (SPA–LTC) project, FCCs were implemented in four LTC sites in Ontario, Canada. The purpose of this substudy was to examine FCC content and such guiding processes as documentation and multidisciplinary staff participation.

Method: A total of 24 FCCs were held for residents with a Palliative Performance Scale score of 40% (nearing death). Data were collected from conference forms (i.e., Family Questionnaires, Care Plan Conference Summaries), site-specific electronic chart documents, and fieldnotes. Directed content analysis of data was informed by the Canadian Hospice Palliative Care Association's Square of Care Model, which describes eight domains of care: disease management, physical, psychological, social, practical, spiritual, EoL, and loss/bereavement.

Results: The FCCs addressed an average of 71% of the content domains, with physical and EoL care addressed most frequently and loss/bereavement addressed the least. Two goals and five interventions were documented and planned on average per FCC. Examination of the processes supporting EoL communication found: (1) advantages to using FCC forms versus electronic charts; and (2) high levels of multidisciplinary participation overall but limited participation of personal support workers (PSWs) and physicians.

Significance of Results: Communication around the end of life in LTC can be supported through the use of FCCs. Description of content and FCC processes provides guidance to persons implementing FCCs. Recommendations for tailoring conferences to optimize communication include use of specific conference forms, increased bereavement discussion, and further engagement of PSWs and physicians.

KEYWORDS: End of life, Conferences, Family meetings, Long-term care, Palliative care

INTRODUCTION

Approximately 30% of deaths in developed countries occur in long-term care (LTC) facilities, with rates anticipated to rise as the population ages (Broad et al., 2013). It is therefore important to build capacity in LTC to address end-of-life (EoL) issues in order to open communication between staff, residents, and families (Cherlin et al., 2005; Towsley et al., 2015). Unfortunately, communication about EoL issues is often inadequate in LTC due to many barriers, including a lack of systematic mechanisms to support

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EoL conversations and staff discomfort or uncertainty about when and how to discuss dying (Bollig et al., 2016; Brazil et al., 2006; Johnson & Bott, 2016).

The present paper reports findings on the use of family care conferences (FCCs) aimed at activating information sharing, decision making, and communication of EoL preferences within LTC (Hudson et al., 2008; Parker et al., 2013). Part of a larger study entitled "Strengthening a Palliative Approach to Care in LTC" (SPA−LTC) (Kaasalainen et al., 2016; Sussman et al., 2017), the present paper explores content discussed during FCCs and the processes that guided discussions and care planning.

BACKGROUND

Communication between staff, residents, and families about EoL concerns can serve to optimize resident quality of life and minimize suffering (Kaasalainen et al., 2016; World Health Organization, 2014). However, families consistently report that communication about the end of life in LTC is insufficient, with families disappointed by the amount of contact and discussion with LTC staff (Hennings et al., 2010; Shanley et al., 2011; Sussman et al., 2017; Thompson et al., 2012; Wright et al., 2008). In a study of 440 bereaved family members of LTC residents, 40% felt uninformed about the resident's health, and 50% felt that they were not given information on what to expect at the EoL (Biola et al., 2007). Communication between physicians and families was perceived as particularly lacking (Vohra et al., 2006).

Poor communication about EoL issues has detrimental effects on residents, families, and staff (Fosse et al., 2014; Towsley et al., 2015). Residents with undefined EoL preferences are at heightened risk for aggressive EoL care, while families can suffer difficulty with decision making and feel unprepared for their relative's death, with lasting negative effects on bereavement (Hebert et al., 2009; Hennings et al., 2010; Hudson et al., 2015; Martin et al., 2016; Parker et al., 2015; Reinhardt et al., 2015). Lastly, staff often experience moral distress when providing care to residents who have not communicated their EoL preferences (Bollig et al., 2016).

Conferences at the end of life have been purported to create an avenue for systematic, structured, meaningful communication around EoL care (Hudson et al., 2008; Parker et al., 2015; Temkin-Greener et al., 2015). Parker and colleagues (2015) developed guidelines for the implementation and documentation of FCCs in LTC and found that conferences appear to be an effective mechanism for addressing family concerns and improving satisfaction with EoL care (Parker & Hughes, 2010). Phillips et al.

(2013) identified moderately strong evidence that conferences improve the provision of the palliative approach to care in LTC, and consequently the need for description of FCC processes, timing, and multidisciplinary participation to support transferability. Moreover, research is needed to explore the extent to which FCCs address holistic EoL care (i.e., beyond the biomedical aspect) and support care planning. Therefore, the purpose of our present substudy is to explore and describe: (1) FCC content, including concerns discussed and care planned; and (2) the processes including documentation and multidisciplinary participation that guide EoL communication in FCCs.

METHODS

Design

A qualitative descriptive design with directed-content analysis was utilized to summarize the content of FCCs implemented at the end of life (Sandelowski, 2000; Hsieh & Shannon, 2005). Qualitative description describes a phenomenon using plain language with minimal application of theory, which supports replication and implementation of complex interventions. Descriptive data were organized using a template of domains (i.e., codes) supplied by the Canadian Hospice Palliative Care Association (CHPCA) Square of Care Model (CHPCA, 2014; Hsieh & Shannon, 2005). Study approval was granted by the Hamilton Integrated Research Ethics Board and by McGill University.

Setting

FCCs were initiated in four urban Ontario LTC homes selected for the SPA−LTC project, representing a content mix of conditions impacting intervention implementation (Kaasalainen et al., 2016). Sites differed by funding model, size, and philosophy (i.e., secular/faith-based). Variability existed between residents' socioeconomic status, medical complexity, and family involvement. Prior to the SPA−LTC project, all sites had established "annual care conferences," which occurred on a yearly basis between the resident, family member, physician, and LTC staff person (e.g., the director of care). Annual care conferences included discussions and information sharing around residents' current health status. Planning for the end of life was not the goal or regular practice within the meetings. In addition, Sites 2 and 3 conducted family meetings on an as-needed basis, often when a person transitioned to actively dying. Baseline data collected from the SPA−LTC project reported that staff perceived discomfort and barriers to discussing EoL issues with

residents and family members (Kaasalainen et al., 2017; Kaasalainen, 2017; Sussman et al., 2017).

Sampling and Recruitment

All residents and their family members residing in one of the four participating homes who were English-speaking and scored 40% or less on the Palliative Performance Scale (PPS) (i.e., nearing death) were invited to participate in the SPA−LTC project (Anderson et al., 1995; Kaasalainen et al., 2016; Parker et al., 2013). A total of 39 residents were selected by LTC staff from the total sample to have an FCC. Staff perceived that EoL care planning was needed for these residents and that the families would benefit from improved communication and more information.

Family Care Conferences

Staff Training

A member of the research team (D.P.) presented an educational seminar to multidisciplinary LTC staff (e.g., nursing, social work, recreation therapy, personal support workers, dietary) at each site. Using PowerPoint, the presenter described the PPS as a trigger for conferences and the FCC forms/documentation; and shared the video "All on the Same Page," depicting a reenacted FCC from the Palliative Approach Toolkit (Residential Aged Care Palliative Approach Toolkit, 2016). Multidisciplinary Palliative Care Champion Teams were also developed as part of the SPA−LTC project at each site and received special training regarding FCCs. Palliative Care Champion Teams comprised an average of 14 ($SD = 5.19$) members (including a range of staff from nursing, housekeeping, dietary, social work, and recreation) and met monthly for the duration of the study with a research assistant (RA) for the purpose of developing capacity for the palliative approach, supporting implementation and enhancing the sustainability of the project (Virag, 2016).

Facilitation and Documentation

An LTC staff facilitator, usually someone with a leadership role (e.g., director of care or social worker) led conferences lasting 30 to 60 minutes in a meeting room. Physicians were encouraged to attend FCCs in case healthcare consent for treatments was needed (Wahl, 2011). Sites were provided with five paper FCC forms to facilitate this process. The main forms included the Family Questionnaire and the Plan of Care Conference Summary. Description of the purpose, content, person responsible, and time of completion for each form/document is summarized in Table 1. Forms aimed at stimulating family and staff

member reflection on the resident's preconference health, foster multidisciplinary communication/collaboration, guide holistic discussion, and provide a record of care planning during the conference (Parker et al., 2013; 2015).

The tasks of the staff FCC facilitator were as follows: (1) to invite residents (if able) and their family members to attend an FCC; (2) to schedule the meeting; (3) to provide family members with a Family Questionnaire form; (4) to send a formal invitation to the resident's physician for the FCC; (5) to invite multidisciplinary staff to attend the scheduled FCC and/or communicate their concerns for the resident on the Staff Communication Sheet; and (6) to request family/resident's consent for an RA to attend the conference. If granted, RAs attended along with staff. Homes were encouraged to use FCC forms, though some sites employed site-specific electronic documents (e.g., PointClickCare software), which allows categorical "checks" to indicate assessments and provides space for narrative charting. Electronic document categories were similar to FCC forms and are summarized in Table 1. A designated category for EOL concerns/care is not present in electronic and is a distinct difference from FCC forms.

Data Collection and Content Analysis

Data and descriptive demographics of the participants were collected from the FCC forms and electronic documents. RAs were permitted to attend 11 (46%) of the FCCs, where they recorded observations of content, context, dynamics/interactions, and atmosphere/mood on a structured fieldnote template. Data were extracted through directed content analysis by two independent researchers (P.D. and A.T.) using the CHPCA Square of Care Model domains as codes (Crabtree & Miller, 1999; Hsieh & Shannon, 2005). The Square of Care guides palliative care to minimize suffering and maximize quality of life within eight domains: disease management, physical, psychological, social, practical, EoL, spiritual, and loss/bereavement (CHPCA, 2014). Directed content analysis allowed researchers to examine the extent to which FCCs addressed model domains (CHPCA, 2014; Durepos et al., 2017).

Researchers compared analyzed data and reached intercoder agreement through discussion (i.e., researcher triangulation), calculated descriptives, and code frequencies in SPSS (v. 22.0, SPSS Corporation, Chicago) (Patton, 2015; Sandelowski, 2000). A third researcher (C.H.) completed a final review of the results. The data were subcategorized as goals and planned interventions to examine care plans developed during the FCCs. Goals included priorities/preferred outcomes, while planned interventions/actions

Table 1. *Documents used for EOL communication in family care conferences*

Document	Purpose	Person completing	Time completed	Content categories
Family care conference forms				
Family Questionnaire	Family voice, communicate concerns	Resident family member/ friend	Preconference; discussed during conference	Questions/concerns Level of worry Likert-type scale
Physician Invitation	Engage physician	Facilitator	Preconference	Conference date and time
Staff Communication Sheet	Staff voice, communicate concerns	Any staff member (e.g., PSW, RN, housekeeping)	Preconference; discussed during conference	Staff concerns/suggestions for resident's care
Planning Checklist	Systematic organization	Facilitator	Preconference	Persons invited/attending Form completion checklist
Plan of Care Conference Summary	Record/guide structured conference discussion and care planning	Facilitator	During conference; to guide care postconference	Purpose of conference Wishes for EOL Key issues: social/psychological needs, assessments/investigations, others Plan of care action plan: goals/preferred treatments, actions, person responsible, review date
Site-specific documents				
Paper Chart	Document resident status, care, events	Registered staff (e.g., RN, SW, physician)	Pre-, postconference	Free narrative
Electronic (e.g., PointClickCare)	Document resident status, care, events	Registered staff (e.g.. RN, SW, physician)	Pre-, postconference	Reason for conference Goals of care Resident/family concerns Nursing/ pharmacy/dietary/recreation/social work/ pastoral concerns

Documents utilized by staff and families to guide EOL communication, document concerns, and communicate care plans.
PSW = unregistered personal support worker; RN = registered nursing staff.

included provision or change of services, education, and/or care practices. The process/method of documentation (FCC forms vs. site-specific electronic documents) was noted to explore the extent to which the forms supported communication. Themes and patterns emerged through comparative analysis of extracted data (Sandelowski, 2000). Data extracted from forms and documents were compared to fieldnote observations as a form of data source triangulation to increase the validity of our findings (Patton, 2015).

RESULTS

A total of 24 FCCs were held across sites between December of 2015 and August of 2016 (see Table 2). The majority of residents were female (62.5%), with an average age of 86 years, had lived in LTC for 7 years, and 92% had dementia. Residents' PPS scores were less than 40% during the FCCs, indicating a shift of function toward the end of life. The FCCs were attended by one or two family members, most of whom were adult children (see Table 3). Only one resident participated in an FCC.

Palliative Care Content

A total of 41 documents were collected from 24 FCCs and analyzed using the Square of Care domains (see Table 4). Structured fieldnotes contributed to understanding content, context, dynamics, and mood during FCCs. Content analysis of documents showed that FCCs addressed a total of 71% of the CHPCA domains, with an average of 5.54 ($SD = 1.74$) domains discussed per FCC. The most discussed domains were: (1) physical issues 24 (100%) (e.g., pain and nutrition); (2) EoL care 22 (92%) (comforts like music during death, visitors, withdrawal of medications, EoL symptom management, funeral planning); and

Table 2. *Characteristics of resident sample*

Characteristic	Family care conferences ($N = 24$)	
	n (%)	Mean (*SD*)
Sex		
Male	9 (37.5)	
Female	15 (62.5)	
Age at enrolment, years		86.0 (9.08)
Length of stay in LTC, years		6.67 (3.20)
Dementia diagnosis	21 (87.5)	
PPS score prior to FCC		38.26 (8.87)
Duration from FCC to death in weeks		7.11 (9.90)

FCC = family care conference; LTC = long-term care; PPS = Palliative Performance Scale.

(3) social care 21 (88%) (support for families and recreation for residents). The least discussed domain was loss/bereavement 4 (17%) (e.g., plans and support for grief). An average of 2.0 ($SD = 2.23$) goals were identified, and 5.04 ($SD = 5.03$) interventions were planned per FCC. Site 4 addressed the most domains ($M = 6.67$, $SD = 1.03$) and had the highest documented number of goals ($M = 4.17$, $SD = 1.94$) and the most interventions planned ($M = 9.17$, $SD = 3.33$) per FCC (see Table 5).

Disease Management

Disease management—referring to the resident's diagnosis, prognosis, or disease progression—was discussed in 17 (71%) FCCs (CHPCA, 2014). Progressive decline was documented in 15 (63%) FCCs and prognosis addressed in 6 (24%). On two occasions, families were documented as asking, "Is [resident's name] dying?" (Site 3). Dementia was the most commonly discussed diagnosis, addressed in 6 (25%) FCCs. One spouse hoped to "slow the onset of dementia" and recorded this goal on her Family Questionnaire. Planned interventions included "trial [of] a cognitive enhancer" (Site 4).

Physical Care

Discussion of such physical concerns as pain, function, and nutrition occurred in 24 (100%) of the FCCs, highlighting the focus on this domain (CHPCA, 2014). On the Family Questionnaire, one daughter documented concern for her mother's "inability to swallow, respond to others, or indicate she is in pain" (Site 1). Many families and staff stated that the goal was for residents to be "pain-free," which prompted such planned interventions as "Nursing to assess regularly for pain. Use Abbey Pain Scale. Speak to MD re: palliative pain meds when needed" (Site 4).

Psychological Care

Psychological concerns pertaining to behavior, emotions, and coping were addressed in 16 (67%) of the FCCs (CHPCA, 2014). In one conference, staff documented concerns regarding a resident's behaviors: "Becomes agitated [and] attempts to get out of bed . . . when his wife is not in to visit him" (Site 4). The resident's wife indicated that her husband "loves the outdoors" (Site 4). A goal was added to improve the resident's mood/behavior by planning outside time with the recreation staff.

Social Care

Social concerns—including relationships, environment, and family support—were discussed in 21

Table 3. *Family care conference attendance: Staff discipline and family relationship to resident*

Staff discipline/role	Site 1 (n = 5) n (%)	Site 2 (n = 5) n (%)	Site 3 (n = 8) n (%)	Site 4 (n = 6) n (%)	All sites (N = 24) n (%)
Nursing	5 (100.0)	3 (60.0)	8 (100.0)	4 (66.7)	20 (70.8)
Social work, program manager	4 (80.0)	4 (80.0)	0 (0.0)	6 (100.0)	14 (58.3)
Recreational therapy	1 (20.0)	4 (80.0)	0 (0.0)	6 (100.0)	11 (45.8)
Dietary	1 (20.0)	5 (100.0)	0 (0.0)	3 (50.0)	9 (37.5)
Director of care	2 (40.0)	0 (0.0)	1 (12.5)	6 (100.0)	9 (37.5)
Physiotherapy	0 (0.0)	1 (20.0)	0 (0.0)	2 (33.3)	3 (12.5)
PSW	0 (0.0)	3 (60.0)	0 (0.0)	0 (0.0)	3 (12.5)
Researcher*	0 (0.0)	2 (40.0)	4 (50.0)	5 (83.3)	11 (45.8)
Staff per FCC, Mean (SD)	3.2 (2.12)	4.8 (1.62)	2.0 (1.70)	4.8 (1.92)	3.5 (1.8)
Disciplines per FCC, Mean (SD)	3.0 (1.22)	5.4 (1.14)	1.5 (0.76)	6 (2.25)	4.0 (2.1)
Relationship to Resident					
Daughter-in-law	3 (60.0)	2 (40.0)	5 (62.5)	2 (33.3)	12 (50.0)
Son	2 (40.0)	3 (60.0)	2 (25.0)	2 (33.3)	9 (37.5)
Wife	0 (0.0)	0 (0,0)	0 (0.0)	3 (50.0)	3 (12.5)
Resident	0 (0.0)	0 (0.0)	0 (0.0)	1 (16.7)	1 (4.2)
Husband	0 (0.0)	0 (0.0)	0 (0.0)	1 (16.7)	1 (4.2)
Other	0 (0.0)	0 (0.0)	2 (25.0)	0 (0.0)	2 (8.3)
Family per FCC, Mean (SD)	1.0 (0.0)	1.4 (0.64)	1.1 (0.35)	1.5 (0.62)	1.3 (0.53)

M = mean; *n* refers to number of FCCs attended by 1 or more persons from that discipline/role/relationship to resident; Other = 1 grandson, 1 sister; PSW = personal support worker (i.e., unregistered nurse's aid); *SD* = standard deviation; Researcher not included in calculation of mean staff attendance per FCC.

(88%) of the FCCs (CHPCA, 2014). One staff person reported, "Family wants [resident] to maintain her usual activities as much as possible … up out of bed … among other people rather than isolation in her room" (Site 1). The staff plan was to "continue to invite resident to church services, should she like to attend" (Site 2).

Spiritual Care

Spiritual care was addressed in 16 (67%) of the FCCs, indicating the importance and acceptance of this domain, which refers to existential being, religious practices, and rituals (CHPCA, 2014). Spiritual care was discussed most frequently in FCCs (83%) at the faith-based LTC home (Site 4). Care by spiritual advisors (e.g., a rabbi) and rituals were mentioned in 12 (50%) of the FCCs. One family requested "Jewish prayers to be said … specific prayers that she would like [to be] read" (Site 4). These requests were added as goals and interventions to the resident's care plan: "Rabbi to meet with [resident], find out where her shawl is located, and what prayers" (Site 4).

Practical Care

Practical care—including activities of daily living, mobility, and hygiene—were addressed by 16 (67%) of the FCCs (CHPCA, 2014). Hygiene and mobility were common concerns for people with dementia. One resident's daughter reported on the questionnaire, "What do we do if she refuses [baths]?" (Site 4). During the FCC, staff recorded this goal: "resident was a very clean person prior to health crisis, and family want to uphold her cleanliness" (Site 4). Care was planned: "look into purchasing an appropriate [shower] chair … and they will also speak to the PSWs about bathing and daily care" (Site 4).

EoL Care

Care provided in the last days or hours and care of the body after death were discussed in 22 (92%) of the FCCs (CHPCA, 2014). "Comfort measures" to control symptoms during dying were frequently documented: "[family] agreed to give medication regarding pain management and would like scopolamine for end-of-life symptoms" (Site 3). In 4 (17%) of the FCCs, families withdrew disease medications: "Only medications for comfort measures will continue" (Site 3); similarly, another stated, "No pain, no pipes, just comfort with no suffering" (Site 4). Families also discussed preferred locations for care and for the end of life, explaining, "transfer to the hospital for treatable conditions, but not for life-saving measures" (Site 4), and "Mom cannot die in the [hospital] hallway" (Site 1).

Preferences regarding the resident's environment at the end of life were discussed in 7 (33%) of the

Table 4. *EoL communication and documentation across family care conferences*

Square of Care domain	Content	FCC forms $n = 17$ Mean (*SD*)	Site-specific, electronic documents $n = 9$ Mean (*SD*)	Total per FCC $N = 24$ Mean (*SD*)	Total addressed $N = 24$ n (%)
Disease management	Addressed				17 (70.8)
	Goals	0.06 (0.24)	0	0.04 (0.2)	
	Planned interventions	0.12 (0.49)	0.4 (0.70)	0.17 (0.64)	
Physical	Addressed				24 (100.0)
	Goals	0.29 (0.47)	0.3 (0.67)	0.38 (0.65)	
	Planned interventions	0.82 (0.89)	1.2 (1.55)	0.75 (0.8)	
Psychological	Addressed				16 (66.7)
	Goals	0.35 (0.49)	0.22 (0.42)	0.41 (0.59)	
	Planned Interventions	0.65 (1.17)	0.44 (0.84)	0.77 (1.15)	
Social	Addressed				21 (87.5)
	Goals	0.35 (0.49)	0.22 (0.42)	0.36 (0.49)	
	Planned interventions	0.50 (0.82)	0.4 (0.70)	0.45 (0.74)	
Spiritual	Addressed				16 (66.7)
	Goals	0.12 (0.33)	0.11 (0.42)	0.13 (0.34)	
	Planned interventions	0.47 (0.80)	0.56 (1.27)	0.61 (0.84)	
Practical	Addressed				16 (66.7)
	Goals	0.24 (0.56)	0.22 (0.42)	0.30 (0.56)	
	Planned Interventions	0.35 (0.71)	0.5 (1.27)	0.61 (1.03)	
End of life	Addressed				22 (91.7)
	Goals	0.35 (0.61)	0.44 (0.70)	0.49 (0.73)	
	Planned interventions	1.47 (1.66)	1.67 (2.05)	1.83 (1.87)	
Loss/grief	Addressed				4 (16.7)
	Goals	0	0.1 (0.32)	0.04 (0.21)	
	Planned interventions	0	0 (0.67)	0.13 (0.46)	
Total domains					136 (70.8)
Domains per FCC				5.54 (1.74)	
Goals per FCC		1.88 (2.0)	1.4 (1.65)	2.0 (2.23)	
Planned interventions per FCC		4.41 (4.06)	4.6 (5.32)	5.04 (5.03)	

Domain addressed = content including concerns discussed categorized as present or not present. FCC forms = paper documents developed specifically for FCCs; used for 17 FCCs. Goals = documented priorities/preferred outcomes. Planned interventions = documented treatments/activities to be provided/changed, such as: support services, education, care practices. Site-specific electronic documents = computerized resident charts supported by software, such as PointClickCare, used for 9 FCCs.
Total domains overall calculated based on potential to address 192 domains.

Table 5. *EoL communication and content in family care conferences per site*

Characteristic	Site 1 $n = 5$ FCCs Mean (*SD*)	Site 2 $n = 5$ FCCs Mean (*SD*)	Site 3 $n = 8$ Mean (*SD*)	Site 4 $n = 6$ Mean (*SD*)
Domains addressed	5.6 (2.19)	6.2 (0.45)	4.25 (1.75)	6.67 (1.03)
Goals	2.6 (2.88)	1.2 (1.3)	0.5 (0.76)	4.17 (1.94)
Planned interventions	7.0 (7.97)	3.8 (2.77)	1.5 (1.41)	9.17 (3.33)

Directed content analysis with data extracted from FCC forms and site-specific documents.

FCCs, with goals such as a peaceful setting and plans to play preferred music. Many families were concerned that the resident would die alone and requested space to sleep in the resident's room. Planning included, "1:1 [staff] for nights and volunteers when family is not in" (Site 4). Some families specified after-death care goals and interventions: "at the time of death, family would like to clean the body; bed bath will be done" (Site 4).

Loss/Bereavement

Family grief and emotions were occasionally mentioned in fieldnote observations. However, loss and bereavement were discussed minimally in 4 (17%) of the FCCs, with no discussion of bereavement planning. On one form, one facilitator reported,

> Nursing staff was very understanding and aware that this is a hard time for the family. The nurses remained sensitive … The son … really tried not to allow his emotions to show … [Staff plan] to follow up with him as time passes. (Site 3)

Conference Processes

Multidisciplinary Participation

Each FCC was attended on average by 3 to 4 staff members representing 4 disciplines, with nursing comprising the highest attendance rate (see Table 3). Social workers, recreation therapists, and dietary were additional frequent attendants, providing evidence for multidisciplinary participation and collaboration. Physicians attended 8 (33%) and PSWs (i.e., unregistered nursing aids) attended 3 (13%) of the FCCs. Multidisciplinary attendance was highest at Site 4, with staff from 6 disciplines attending each FCC on average. Diverse staff participation may have contributed to the high number of content domains ($M = 6.67$, $SD = 1.03$) addressed per FCC at Site 4 (see Table 4).

Documentation

Conference documentation varied across sites (supplementary data available from the author; see Supplementary Materials). The Family Questionnaire and Plan of Care Summary forms were used most frequently. Overall, Site 4 demonstrated the highest intervention fidelity, completing an average of 3 FCC forms for all 6 (100%) conferences, and documented more goals and planned interventions per FCC than other sites. Site 3 used an FCC form for 88% of conferences, whereas Sites 1 and 2 used FCC forms for only 33% of the conferences.

Across all sites, more goals were documented on FCC forms ($M = 1.88$, $SD = 2.0$) than on electronic documents ($M = 1.4$, $SD = 1.7$) (see Table 4). Often, staff only recorded the resident's code status in Goals of Care electronically. Alternatively, more planned interventions were documented electronically ($M = 4.6$, $SD = 5.32$) than on FCC forms ($M = 4.41$, $SD = 4.06$).

Summary

FCCs implemented as part of the SPA–LTC project supported EoL communication with: (1) content consistently addressing the majority of domains in the Square of Care Model; and (2) documented preferences, goals, and planned interventions for each resident.

DISCUSSION

Our study provides insight into the content and processes of FCCs used to support systematic EoL communication in the SPA–LTC project. Our findings are in line with staff-, family-, and resident-reported perceptions that EoL communication is enhanced through the SPA–LTC process (Kaasalainen, 2017). FCC content strengths included physical and EoL care, while discussion of loss/bereavement care for families and discussion around prognosis emerged as limitations.

Previous studies of FCCs and family meetings have not explored content against the model of palliative care or examined the processes of documentation and multidisciplinary participation used to communicate EoL concerns, goals, and interventions (Parker et al., 2015). Our study therefore provides valuable insights for the persons who are implementing and tailoring FCCs.

Physical care has consistently emerged as the predominant focus of FCCs and documented palliative care (Gunhardsson et al., 2007; Parker et al., 2015). The focus on physical needs could restrict care to a biomedical model, although families may wish to discuss funeral arrangements, family disagreements, the meaning of illness, or belief in an afterlife (Della Santina & Bernstein, 2004; Gunhardsson et al., 2007). Families have reported that questions go unasked because they (1) feel overwhelmed; (2) are unsure of whom to ask; or (3) are concerned about appearing ignorant (Hebert et al., 2008). In a retrospective study on EoL care provided to persons dying in LTC, documented care was largely focused on physical care and symptom control (Høgsnes et al., 2014). Spiritual and bereavement care for families was not documented, which raises concerns that if goals and interventions within these domains are

not addressed during FCCs they may not be provided in practice (Voyer et al., 2014).

In comparing the content of FCCs to the Square of Care Model, we identified areas of strength and areas for improvement. Similar to the literature, the focus was on physical needs and care for residents. However, on average, FCCs addressed 5.5 of 8 (71%) of the domains, suggesting holistic EoL communication (CHPCA, 2014; Høgsnes et al., 2016; Della Santina & Bernstein, 2004). Furthermore, the families in our study specified important EOL preferences beyond resuscitation status, describing preferred environmental, visitation, and preferences for after-death care (Berger, 2010; Tulsky, 2005). The majority of FCCs also addressed spiritual care, making it an area of strong focus. A study of family meetings as a tool for spiritual care reported that meetings can assist families in identifying existential purpose and meaning, and in feeling less alone, thus reinforcing their importance during LTC (Tan et al., 2011).

Discussion of residents' prognosis occurred in only 6 (25%) of the FCCs. Prognosis is a significant area known to cause concern for families of persons receiving palliative care, an area where increased awareness can prompt families to resolve interpersonal conflicts, complete unfinished business, and plan for the end of life (Hebert et al., 2008; Della Santina & Bernstein, 2004). LTC staff should plan to share information regarding prognosis, even if uncertain, during FCCs. The lack of discussion about loss/bereavement during FCCs in our study is also troubling. In one qualitative study of bereavement care for older persons in healthcare settings, some staff felt that facilitating families' anticipatory grief was part of their role (Stephen et al., 2013). However, some staff were uncomfortable discussing bereavement because of their limited ability to provide support without resources, while families sometimes preferred to remain focused on the dying person. These barriers may have been factors in our FCCs as well. Families involved in LTC have unique bereavement needs related to long-term caregiving and the loss of relationships with LTC staff following the resident's death (Romero et al., 2014; Schulz et al., 2003). To assess family concerns and provide bereavement support during FCCs, staff will most probably require education on these topics (Hudson et al., 2008; Temkin-Greener et al., 2015).

Documentation is essential for staff communication, something that can promote continuity of care (Urquhart et al., 2009; Voyer et al., 2014). Electronic documentation is perceived as efficient and associated with a higher quality of care. However, a review of electronic documentation in LTC revealed both benefits and burdens, with efficiency and quality of documentation related to users' computer proficiency

(Meißner & Schnepp, 2014). Communication may be enhanced or impaired by electronic documentation depending on its accessibility or its usability by varying staff.

The sites in our study employed variable methods of documentation to guide discussions and communicate FCC care plans. Potential advantages to both methods were observed. More interventions were recorded in electronic documents (potentially prompted by the extensive number of categories) than on FCC forms. However, the absence of an EoL category may have inhibited documentation of detailed preferences for EoL care.

We can glean from our study that there are multiple benefits to using FCC forms for documentation and communication. The frequent documentation of goals with relative interventions on FCC forms was a major advantage provided by using FCC forms. The negotiation of common goals with staff assists families in maintaining realistic and feasible expectations for care (Della Santina & Bernstein, 2004). Communicating the purpose and priorities for care also allows staff to provide interventions accordingly, optimizing family and resident satisfaction. Use of the Family Questionnaire also provides a unique advantage by documenting the "voice of the family." And, lastly, the paper format of FCC forms is less likely to create a barrier to access to care plans for staff such as PSWs who do not routinely use computers as part of their role.

Multidisciplinary attendance at FCCs promotes collaboration and holistic care, extending beyond a biomedical model, and is associated with positive outcomes in palliative care (Della Santina & Bernstein, 2004; Goldsmith et al., 2010; Hudson et al., 2008). Such benefits as increased patient satisfaction, dying in a preferred location, improved physical symptoms, decreased hospitalization, and enhanced continuity of care are associated with use of multidisciplinary care teams for EoL palliative care (Leclerc et al., 2014).

A valuable member of the care team is the PSW, who provides up to 80% of hands-on care in LTC in such countries as Canada and Australia (Berta et al., 2013; Fryer et al., 2016). However, PSWs are not formally trained in models of inter-professional collaboration in these countries and have reported feeling that their voices go unheard in LTC (Fryer et al., 2016; Kontos et al., 2009). Conversely, families and LTC staff request increased involvement and EoL communication from physicians (Biola et al., 2007; Fosse et al., 2014; Vohra et al., 2006). Family members often do not know who the physician responsible for the resident is, and few receive a prognosis from a physician (Hennings et al., 2010).

The multidisciplinary attendance of FCCs in our study was high. However, attendance of PSWs and

physicians was low. Barriers to PSW participation could include a heavy workload or lack of an invitation to attend the FCC (Berta et al., 2013; Fryer et al., 2016). Valuable information could be gathered from PSWs, who often have intimate knowledge about residents and experiential expertise (Berta et al., 2013). Low physician engagement is in line with findings in the literature of poor physician–family communication in LTC, possibly due to workload problems (Biola et al., 2007; Hennings et al., 2010). The highest physician attendance in our study was at Site 4, which may have supported their comprehensive development of care plans.

STRENGTHS AND WEAKNESSES OF OUR STUDY

The strengths of our study include the methodological rigor and credibility achieved through triangulation (Patton, 2015; Sandelowski, 2000). The limitations of the study include the small sample size and inclusion of only English-speaking families, which limit the transferability of our findings. To increase the validity of our findings, we utilized data source triangulation, comparing FCC content recorded on form/documents to RA fieldnotes, and we found no disparities (Patton, 2015). However, it is a limitation that fieldnotes were obtained for only 11 (46%) of the FCCs, which may mean that the content analysis of documents/forms does not fully reflect all the content discussed. Furthermore, according to researcher fieldnotes, electronic documentation was often completed retrospectively (e.g., days, weeks, and even months after the FCCs), potentially limiting their validity.

CONCLUSIONS

In summary, we explored the strengths and limitations in content and processes guiding FCCs to enhance EoL communication. Content strengths included: (1) holistic discussions addressing the majority of CHPCA domains with particular attention to physical and EoL care; and (2) evidence of comprehensive care planning. Discussion surrounding prognosis and loss/bereavement was limited, providing an important point about future FCC tailoring. The processes that supported EoL communication during FCCs included: (1) use of FCC forms for documentation with categorical headings to guide discussions, communicate goals, and planned interventions; and (2) multidisciplinary attendance to support holistic care planning and collaboration. Future research should focus on making FCC forms available in electronic format for LTC homes preferring this system, developing strategies to engage PSWs and physicians

in FCCs, and assessing whether care planned during FCCs is followed through on and influences outcomes.

SUPPLEMENTARY MATERIALS

To view supplementary materials for this article, please visit https://doi.org/10.1017/S1478951517000773.

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