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# Family Care Conferences in Long-Term Care: Exploring Content and Processes in End of Life Communication

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**Family Care Conferences in Long-Term Care:**
**Exploring Content and Processes in End of Life Communication**

SHORT TITLE: Family Care Conferences in Long-Term Care

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Manuscript Pages: 25
Tables: 5

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## Abstract

**Objectives:** End of life (EOL) communication in long-term care homes (LTC) 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 unsatisfied with care. Family Care Conferences (FCC) aim to increase structured, systematic communication around goals and plans for EOL. As part of the 'Strengthening a Palliative Approach to Care' (SPA-LTC) project, FCCs were implemented in 4 LTC sites in Ontario, Canada. The purpose of this sub-study is to examine FCC: a) content, and b) guiding processes such as documentation and multidisciplinary staff participation using mixed methods.

**Methods:** Twenty-four FCCs were held for residents with a Palliative Performance Scale of 40% (nearing death). Data was collected from conference forms (i.e., Family Questionnaires, Care Plan Conference Summaries) and site-specific electronic chart documents. 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:** FCCs addressed an average of 71% of content domains with physical and EOL care addressed most frequently, and loss/bereavement addressed the least. Two goals and 5 interventions were documented and planned on average per FCC. Examination of processes supporting EOL communication found: i) advantages to using FCC forms vs. electronic charts, and ii) high level of multidisciplinary participation overall but limited participation of Personal Support Workers (PSWs) and physicians.

**Significance of Results.** Communication around EOL in LTC can be improved through the use of FCCs. Description of content and FCC processes provides guidance to persons implementing

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FCCs. Recommendations for tailoring conferences to optimize communication include use of specific conference forms, increased bereavement discussion, further engagement of PSWs and physicians.

Keywords: end of life, conferences, family meetings, long-term care, palliative care

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## Introduction

Approximately 30% of deaths within developed countries occur in long-term care (LTC) with rates anticipated to rise as the population ages (Broad, 2013). Therefore it is important to build capacity in LTC to address end of life (EOL) issues to open communication between staff, residents and families (Cherlin et al., 2005; Towsley et al., 2015). Unfortunately communication about EOL is often inadequate in LTC due to barriers including: a lack of systematic mechanisms to support EOL conversations and staff discomfort or uncertainty around when and how to discuss dying (Bollig et al., 2016; Brazil et al., 2006; Johnson & Bott, 2016).

This papers reports findings on the use of Family Care Conferences (FCCs) as a mechanism for 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 aimed at 'Strengthening a Palliative Approach to Care in LTC' (SPA-LTC)(Kaasalainen et al., 2016; Sussman et al., 2017), this paper explores content discussed during FCCs, and processes guiding discussions and care planning in FCCs. Findings support tailoring and transferability of FCCs to enhance EOL communication.

## 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; WHO, 2014). However, families consistently report that communication about EOL 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 residents in LTC, 40% felt uninformed about the residents' health and 50% felt they were not given information on what to expect at EOL (Biola

et al., 2007). Communication between physicians and families is perceived as particularly lacking (Vohra et al., 2006).

Poor communication about EOL has detrimental effects for 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 preferences for EOL (Bollig et al., 2016).

Conferences at EOL 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 moderate evidence that conferences improve the provision of a palliative approach to care in LTC, and consequently need for description of FCCs 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 biomedical) and support identification of EOL preferences to assess and tailor conferences. Therefore, the purpose of this sub-study is to explore: (1) FCC content including concerns discussed and care planned; and (2) processes including documentation and multidisciplinary participation guiding EOL communication in FCCs.

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## Methods

### Design

A qualitative descriptive design was utilized to summarize the content of FCCs

implemented at EOL (Sandelowski, 2010). Qualitative description describes a phenomenon

using plain language with minimal application of theory, which support replication and

implementation of complex interventions. Descriptive data was 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

from Hamilton Integrated Research Ethics Board and McGill University.

### Setting

FCCs were initiated in 4 urban Ontario LTC homes selected for SPA-LTC, 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.

### Sampling and recruitment

All residents and their family members residing in 1 of the 4 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 SPA-LTC (Anderson et al., 1995; Kaasalainen et al.,

2016; Parker et al., 2013). A total of 39 residents were enrolled and those considered appropriate

by staff were invited to participate in an FCC to discuss EOL issues.

### Family Care Conferences

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. The presenter described: the PPS as a trigger for conferences, FCC

forms/documentation; and shared the video "All on the Same Page" displaying a re-enacted FCC

from the Palliative Approach Toolkit (http://www.caresearch.com.au/PAToolkit). A

facilitator, usually someone with a leadership role (e.g., Director of Care) led conferences lasting

30-60 minutes in a meeting room. Physicians were encouraged to attend FCCs in case health care

consent for treatments was needed (Wahl, 2011).

Sites were provided with 5 paper FCC forms to facilitate the process: i.e., guide

discussion, stimulate reflection on the resident's health, foster multidisciplinary

communication/collaboration, record concerns and plan care (Parker et al., 2013; Parker et al.,

2015). FCC forms included: a 'Family Questionnaire' provided to families pre-conference to

record concerns and communicate a 'Level of Worry' on a Likert-scale from 0-10; a 'Plan of

Care summary' completed by the facilitator during the FCC with categories: 'Issues, Goals,

Actions and Person Responsible'; a 'Staff Communication Sheet' for staff to document concerns

pre-conference; a 'Physician Invitation'; and a 'Planning Check-List'.

Multidisciplinary staff, family members and residents (if able) were invited to FCCs, as

well as a Research Assistant (RA) with permission. Homes were encouraged to use FCC forms,

however some sites used site-specific electronic documents (e.g., 'Point-Click Care' software),

which allows categorical 'checks' to indicate assessments and provides space for narrative

charting. Electronic document categories were similar to FCC forms and included: Reason for

Conference, Goals of Care, Resident/Family Concerns, Nursing/Pharmacy/Dietary concerns,

Recreation/Social work and Pastoral Care. A designated category for EOL concerns/care in

electronic documents was a distinct difference from FCC forms.

**Data Collection and Content Analysis**

Data and descriptive demographics of participants were collected from FCC forms, electronic documents and RA field notes used to confirm content, understand conference dynamics/interactions and atmosphere/mood. All data was 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 8 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 inter-coder agreement through discussion (i.e. triangulation), calculated descriptives and code frequencies in SPSS 22.0 (Patton, 2015; Sandelowski, 2010). A third researcher (C.H.) completed a final review of results. Data was sub-categorized as goals and planned interventions to examine care plans developed during FCCs. Goals included priorities/preferred outcomes while planned interventions/actions included the provision or change of: services, education or care practices.  The process/method of documentation (FCC forms vs. electronic document) was noted to explore the extent to which the forms supported communication. Themes and patterns emerged through comparative analysis of extracted data (Sandelowski, 2010).

## Results

A total of 24 FCCs were held across sites between December 2015 and August 2016 Table 1). Residents were female by majority (62.5%), an average of 86 years old, had lived in LTC for 7 years and 92% had dementia. Residents' PPS was less than 40% during FCCs,

indicating a shift of function to EOL. FCCs were attended by one or two family members, most

of whom were adult children (see Table 2). Only one resident participated in a FCC.

**Palliative Care Content**

A total of 41 documents were collected from 24 FCCs and analyzed using the 'Square of

Care' domains (see Table 3). Field notes contributed to understanding content (beyond

documentation), dynamics and mood during FCCs. Content analysis showed FCCs addressed a

total of 71% of 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%), i.e., pain and nutrition; 2) EOL

care 22(92%), i.e., comforts like music during death, visitors, withdrawal of medications, EOL

symptom management, funeral planning; and 3) social care 21(88%), i.e., support for families

and recreation for resident. The least discussed domain was 8) loss/bereavement 4(17%), i.e.

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 (M6.67, SD 1.03); had

the highest documented number of goals (M4.17, SD1.94) and the most interventions planned

(M9.17, 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%) conferences. On two

occasions families were documented as asking, "is xxxx dying?"(Site 3). Dementia was the most

commonly discussed diagnosis, addressed in 6(25%) FCCs. For example, a 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 physical concerns including pain, function and nutrition occurred in 24(100%) of FCCs highlighting focus on this domain (CHPCA, 2014). On the 'Family Questionnaire' a 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 the goal was for residents to be "pain free" which prompted planned interventions such 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 behaviour, emotions and coping were addressed in 16(67%) of FCCs (CHPCA, 2014). In one conference, staff documented concern regarding a resident's behaviours, "[he] 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/behaviours by planning outside time with recreation staff.

**Social Care:** Social concerns including relationships, environment and family support were discussed in 21(88%) of FCCs (CHPCA, 2014). For example, a staff person documented, "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). Staff planned, "…continue to invite resident to church services, should she like to attend"(Site 2).

**Spiritual Care:** Spiritual care was addressed in 16(67%) of 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., rabbi) and rituals were mentioned in 12(50%) of all FCCs. Family requested, "Jewish prayers to be said…specific prayers that she

would like 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 FCCs (CHPCA, 2014) Hygiene and mobility were common concerns for people with dementia. A resident's daughter cited on the questionnaire, "What do we do if she refuses [baths]?"(Site 4). During the FCC staff recorded the goal, "[the] 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 PSW's about bathing and daily care… "(Site 4).

**EOL Care:** Care provided in the last days or hours, and care of the body after death was discussed in 22(92%) of 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 FCCs families withdrew disease medications, "Only medications for comfort measures will continue" (Site 3) and similarly others stated "No pain, no pipes, just comfort with no suffering"(Site 4). Families also discussed preferred locations for care and for EOL 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 EOL were discussed in 7(33%) of FCCs with goals such as a peaceful setting and plans to play preferred music. Multiple families were concerned 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 documented in field notes. However, loss and was discussed minimally in 4(17%) of FCCs with no discussion of bereavement planning. In one field note an RA documented:

"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 staff representing 4 disciplines, with nursing comprising the highest attendance (see Table 2). 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 FCCs. Multidisciplinary attendance was the 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 5).

**Documentation:** Conference documentation varied across sites (see Table 3). 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 1 FCC form for 88% of conferences, whereas Sites 1 and 2 used FCC forms for only 33% of conferences. The 'Family Questionnaire' and 'Plan of Care summary' forms were used most frequently.

Across all sites more goals were documented on FCC forms (M1.88, SD 2.0) than on electronic documents (M1.4, SD1.7)(see Table 5). Often staff only recorded the resident's code status in 'Goals of Care' in electronically. Alternatively, more planned interventions were documented electronically (M4.6, SD5.32) than on FCC forms (M4.41, SD 4.06).

**Summary**

FCCs implemented as part of SPA-LTC demonstrated value as a mechanism for 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. Processes of multidisciplinary participation and documentation during FCCs appear to support open communication between staff and families and encourage holistic discussion and planning beyond a solely biomedical focus. FCC content strengths included physical and EOL care while discussion of loss/bereavement care for families, and discussion around prognosis emerged as limitations.

## Discussion

This study provides insight into the content and processes of FCCs used to improve EOL communication in SPA-LTC. Previous studies of FCCs and family meetings have not explored content against a 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). This study therefore provides valuable insight to persons 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 afterlife (Della Santina & Bernstein, 2004; Gunhardsson et al., 2007). Families have reported questions go unasked because they a) feel overwhelmed, b) are unsure who to ask or c) are concerned about appearing ignorant (Hebert et al., 2008).  In a retrospective study of EOL care provided to persons dying in LTC, documented care was largely focused on physical care and symptom control (Hogsnes, 2016). 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 literature, focus was on physical needs and care for residents. However, on average FCCs addressed 5.5/8(71%) of domains suggesting holistic EOL communication (CHPCA, 2014; Hogsnes et al., 2016; Santina & Berstein, 2004). Furthermore, families in our study specified important EOL preferences beyond code status describing the preferred environment, visitation and preferences for after-death care (Berger, 2010; Tulsky, 2005). The majority of FCCs also addressed spiritual care making it an area of strength. A study of family meetings as a tool for spiritual care reported that meetings can assist families to identify purpose and meaning and feel less alone, reinforcing its importance during FCCs (Tan, 2011).

Discussion of residents' prognosis occurred in only 6(25%) of FCCs. Prognosis is a significant area known to cause concern for families of persons receiving palliative care and increased awareness can prompt families to resolve interpersonal conflicts, complete unfinished business and plan for EOL (Hebert et al., 2008; Della Santina & Bernstein, 2004). LTC staff should plan to share information regarding prognosis 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, 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 in LTC have unique bereavement

needs related to a long-term caregiving, and loss of relationships with LTC staff following

resident death (Romero et al., 2014; Schulz et al., 2003). To assess family concerns and provide

bereavement support during FCCs staff may require education on this topics (Hudson et al.,

2008; Temkin-Greener et al., 2015).

Documentation is essential for staff communication promoting continuity of care

(Urqhart 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 benefits and burdens, with efficiency and quality of documentation related to users'

computer proficiency (Melbner & Schnepp, 2014). Communication may be enhanced or

impaired by electronic documentation depending on accessibility or usability by varying staff.

Sites in our study used variable methods of documentation to guide discussions and

communicate FCC care plans. Potential advantages to both methods were observed. More

interventions were recorded on electronic documents (potentially prompted by the extensive

number of categories) than on FCC forms. However, absence of an EOL category may have

inhibited documentation of detailed preferences for EOL care.

From our study we can glean 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 to using FCC forms. The negotiation of

common goals with staff assists families in maintaining realistic 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 'family

voice'. And lastly, the paper format of FCC forms is less likely to create a barrier of access to

care plans for staff such as PSWs who are not using computers.

Multidisciplinary attendance at FCCs promotes collaboration and holistic care extending

beyond a biomedical model with associated with positive outcomes in palliative care  (Della

Santina & Bernstein, 2004; Goldsmith et al., 2010; Hudson et al., 2008). Benefits such 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 countries such as Canada and Australia (Berta et al., 2013; Fryer et al., 2016).

PSWs however are not formally trained in models of inter-professional collaboration in these

countries and have reported feeling their voices are 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 high workload or

lack of FCC invitation (Berta et al., 2013; Fryer et al., 2016). Valuable information could be

gathered from PSWs who often have intimate resident knowledge and experiential expertise

(Berta et al., 2013). Low physician engagement is in-line with literature findings of poor

physician-family communication in LTC, possibly due to workload (Biola et al., 2007; Hennings

et al, 2010). The highest physician attendance in our study was at Site 4 and may have supported

their comprehensive development of care plans.

Strengths of our study included methodological rigor and credibility achieved through

triangulation (Patton et al., 2015; Sandelowski et al., 2010). Study limitations include the small

sample size and inclusion of only English-speaking families, which limit transferability of

findings. Content analysis relied upon documentation, which may not have captured all content

discussed. Furthermore, according to researcher field notes, electronic documentation was often

completed in retrospect (e.g. days /weeks or even months after FCCs) potentially limiting

validity.

In summary, in this study we explored strengths and limitations in content and processes

guiding FCCs to enhance EOL communication. Content strengths included: 1) holistic

discussions addressing the majority 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 insight for FCC tailoring. Processes supported EOL

communication during FCCs including: i) use of FCC forms for documentation with categorical

headings to guide discussions, communicate goals and planned interventions, and ii)

multidisciplinary attendance to support holistic care planning and collaboration. Future research

should focus on making FCC forms available in an electronic format for LTC homes preferring

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this system, developing strategies to engage PSWs and physicians in FCCs, and assessing if care

planned during FCCs is followed through and influences outcomes.

## Acknowledgements and Disclosures

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Table 1
*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) |

*Note. LTC* = Long-term Care; *PPS* = Palliative Performance Scale; *FCC* = Family Care Conference

Table 2

*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 MGR | 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) |

*Note:* M = mean; SD = standard deviation; 'n' refers to number of FCCs attended by 1 or more persons from that discipline/role/relationship to resident. *PSW* = Personal Support Worker (i.e. unregistered nurses' aid); *Program MGR* = Program Manager; Other = 1 Grandson, 1 Sister. Researcher not included in calculation of mean staff attendance per FCC.

Table 3

*Documentation for EOL Communication in Family Care Conferences*

|  | Site 1<br>n = 5 FCCs | Site 2<br>n = 5 FCCs | Site 3<br>n=8 FCCs | Site 4<br>n=6 FCCs | All Sites<br>N = 24<br>FCCs |
|---|---|---|---|---|---|
| Family Care Conference Forms: |  |  |  |  |  |
| Family Questionnaire | 3 | 1 | 7 | 3 | 14 |
| Physician Invitation | - | - | - | 1 | 1 |
| Staff Communication Sheet | - | - | - | 4 | 4 |
| Planning Checklist | - | - | - | 6 | 6 |
| Plan of Care Summary | 1 | - | - | 6 | 7 |
| Site-Specific Documents: |  |  |  |  |  |
| Paper Chart note | 1 | - | - | - | 1 |
| Electronic, ex. Point Click Care | 3 | 5 | - | - | 8 |
| Total Documents | 8 | 6 | 7 | 20 | 41 |

*Note.* Documents utilized by staff to guide EOL communication, document concerns and communicate care plans.

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) |

*Note.* Domain addressed = content including concerns discussed categorized as present or not present; FCC Forms: paper documents developed specifically for FCCs; used for 17 FCCs. Site-specific electronic documents: computerized resident charts supported by software such as Point Click Care; used for 9 FCCs. Goals: documented priorities/preferred outcomes. Planned interventions: documented treatments/activities to be provided/changed such as: support services, education, care practices. 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) |

*Note.* Directed-content analysis with data extracted from FCC forms and site-specific electronic documents, supporting information provided by researcher field notes.