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

Published in:
Palliative and Supportive Care

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
Link to publication record in Queen's University Belfast Research Portal

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

SHORT TITLE: Family Care Conferences in Long-Term Care

Please address all correspondence to the first author:
Pamela Durepos
Faculty of Health Sciences, 3N25F
McMaster University
1280 Main St. West
Hamilton, ON
L8N 3Z5
Email: lapospm@mcmaster.ca

Abstract

Objectives: End of life communication in long-term care 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 negatively effecting bereavement. Family Care Conferences aim to increase structured, systematic communication around goals and plans for end of life. Family Care Conferences were implemented as part of the 'Strengthening a Palliative Approach to Care' (SPA-LTC) project in four LTC sites in Ontario, Canada. The purpose of this sub-study is to evaluate: a) content, b) processes, and c) interdisciplinary engagement using mixed methods.

Methods: Twenty-four Family Care Conferences were held for residents with a Palliative Performance Scale of 40% (nearing death) considered appropriate by staff. Data was collected from conference forms (i.e., Family Questionnaires, Care Plan Conference Summaries) and site-specific electronic charts. Through directed-analysis, data was analyzed using the Canadian Hospice Palliative Care Association's 'Square of Care' model which includes eight domains of care: Disease Management, Physical, Psychological, Social, Practical, Spiritual, EOL, and Loss/Bereavement.

Results: Findings showed on average each conference documented 69% of domains with physical and end of life care content discussed the most, and loss/bereavement documented the least. Use of Family Care Conference forms had benefits over electronic documents including: higher documentation of goals and designated category for end-of-life care. FCCs were attended by an average of four disciplines supporting holistic content although Personal Support Workers and physicians attended minimally.

Significance of Results. Communication around end-of-life care in long-term care settings can be improved through implementation of Family Care Conferences. Description of issues/content addressed and processes provide guidance to persons facilitating Family Care Conferences. Recommendations for tailoring conferences to optimize communication include use of specific conference forms, increased bereavement discussion, further engagement of Personal Support Workers and physicians.

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

Introduction

Approximately 20-30% of deaths within developed countries occur in long-term care homes (LTC) with rates anticipated to rise as the population ages (Broad, 2013). Within this context, it is important to build capacity in LTC to address end of life (EOL) issues (Cherlin et al., 2005; Towsley et al., 2015). One aspect of quality EOL care is open communication between staff, residents, and families (Wright et al., 2008). Yet communication about EOL is often inadequate in LTC. Barriers include lack of systematic mechanisms to support EOL conversations and staff discomfort around when and how to activate discussions about dying (Bollig et al., 2016; Brazil et al., 2006; Hennings et al., 2010; Johnson & Bott, 2016 Ng et al., 2016; Towsley et al., 2015).

This papers reports findings on the use of Family Care Conferences (FCCs) as a mechanism for activating information sharing, supported decision-making and conversations about 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 aims to describe how FCCs may improve communication about EOL care in LTC.

Background

Communication between staff, residents, and families about EOL issues can serve to optimize resident quality of life and minimize suffering (Kaasalainen et al., 2016; WHO, 2014). Unfortunately, families consistently report that communication about EOL issues in LTC is inadequate (Hennings et al., 2010; Shanley et al., 2011; Sussman et al., 2017; Thompson et al., 2012; Towsley et al., 2015; Wright et al., 2008). A recent systematic review of families' experiences supporting a dying relative in LTC found participants were disappointed by the

amount of contact and communication they had with LTC staff (Hennings et al., 2010). Similarly in a study of 440 bereaved family members of persons in LTC, 40% felt uninformed and 50% felt they were not given information on what to expect (Biola et al., 2007). Communication between physicians and families is perceived as particularly problematic (Biola et al., 2007; Vohra et al., 2006).

Delayed and inadequate conversations about EOL care has detrimental effects for residents, staff and families (Bollig et al., 2016; Hennings et al., 2010; Fosse et al., 2014; Sussman et al, 2017; Towsley et al., 2015; Wright et al., 2008). Residents without opportunity to discuss EOL preferences are at heightened risk of aggressive and invasive EOL care (Hennings et al., 2010; Hudson et al., 2008; Martin et al., 2016; Parker et al., 2015; Sussman et al., 2017). Families who are not provided with opportunities to discuss their relatives' prognoses, illness trajectories and health changes (Fosse et al., 2014; Hebert et al., 2008) suffer uncertainty, experience difficulties with decision-making, and feel unprepared for their relative's death (Hennings etal, 2010; Hudson et al., 2015; Parker et al, 2015; Shanley et al., 2011). For some, negative outcomes impact bereavement (Hebert et al., 2009; Reinhardt et al., 2015; Thompson et al., 2012; Wright et al., 2008). Staff lacking tools, mechanisms and support to activate EOL conversations may provide care without knowing resident preferences and consequently experience moral distress (Bolig et al., 2016).

Conferences at EOL have been proported to create an avenue for systematic, structured, meaningful communication around EOL care in LTC (Hudson et al., 2008; Parker et al., 2015; Temkin-Greener et al., 2015). Parker and colleagues (2015) who developed guidelines for when and how to implement and document FCCs, found that conferences at EOL appear to be an effective mechanism for addressing families' concerns and improve family member satisfaction

with EOL care in LTC. Others have noted that FCCs without prescribed structures and protocols generate mixed results in LTC (Reference). Research is needed to explore the extent to which FCC at EOL encourage holistic conversations about EOL care and support comprehensive documentation. Hence, the purpose of this sub-study is to explore: (1) the types of issues discussed in the conferences; and (2) the plans that were documented as a result of the conferences.

Methods

Design

A qualitative descriptive design was utilized to summarize the content of FCCs implemented at EOL (Sandelowski, 2010). Descriptive data was organized using a pre-existing template of domains (i.e. codes) supplied by the Canadian Hospice Palliative Care Association 'Square of Care' Model (CHPCA, 2014; Hsieh & Shannon, 2005). Qualitative description is ideal when looking to support replication and implementation of complex interventions. Using an organizing template allows comparison of study data to an existing model (Hsieh & Shannon, 2005). Study approval, was granted by the Hamilton Integrated Research Ethics Board and McGill University.

Setting

FCCs were initiated in four urban Ontario LTC homes selected as cases for SPA-LTC, representing a context mix of conditions known to impact the implementation of interventions (Kaasalainen et al., 2016). Sites differed by funding model, size and philosophy (i.e. secular versus faith-based). Variability existed between socioeconomic status, medical complexity and family involvement with residents.

Sampling and recruitment

All residents and/or their decision-makers residing in one of the four participating homes, who were English speaking and scored 40% or less on the Palliative Performance Scale (PPS) were invited to participate in the larger study (Kaasalainen et al., 2016; Parker et al., 2013). A total of 39 residents were enrolled, and as per the study protocol enrolled residents scoring 40% on the PPS (i.e. indicating a transitional stage of illness to EOL) were invited to participate in an FCC to discuss EOL issues.

Family Care Conferences

A member of the research team (D.P.) provided an educational seminar at each LTC site showing the video "All on the Same Page" from the Palliative Approach Toolkit from the University of Queensland in Australia to educate LTC staff about FCCs (http://www.uq.edu.au/bluecare/the-palliative-approach-toolkit). Study sites were provided with five forms for FCCs to guide discussions, stimulate pre-meeting reflection, support interdisciplinary communication, and offer a framework for documenting issues and plans of action (Parker et al., 2013; Parker et al., 2015). While all homes were encouraged to use the forms provided, some elected to use site-specific electronic documentation (i.e. 'Point-Click Care' software), which allowed categorical 'checks' to indicate assessments and space for narrative charting. Categories in electronic documents shared similarities with FCC forms including: Reason for Conference, Goals of Care, Resident/Family Concerns, Nursing/Pharmacy/Dietary concerns, Recreation/Social work and Pastoral Care. However, an EOL category was absent in contrast to FCC forms.

FCC forms included: a 'Family Questionnaire' provided pre-conference to record questions, concerns and communicate a 'Level of Worry' rated from 0-10; a 'Plan of Care Conference summary' completed by the FCC facilitator during the conference with headings of

'issues, goals, actions and person responsible'; a 'Staff Communication Sheet' for staff to document concerns pre-conference; a 'Physician Invitation' to be faxed requesting the physician's attendance; and a 'Planning Check-List' with invited attendants and tasks for planning. Interdisciplinary LTC staff and residents (if able) were invited to attend FCCs, along with a research assistant (RA)(with permission). Physicians were encouraged to attend in case health care consent to treatments were needed (Ontario Long-Term Care Homes Act, 2007; Wahl, 2011). A facilitator, usually someone with a leadership role (e.g., Director of Care) led conferences lasting 30-60 minutes in a meeting room.

Data Collection and Content Analysis

Data was collected and extracted from FCC forms, site-specific documents (electronic) and RA field notes. RAs completed field notes using a form developed by researchers to capture dynamics, atmosphere, tone and discussion points. Demographic data regarding residents and family members was also collected.

Data was extracted and analyzed using organizational template analysis (i.e. directed content analysis) where predetermined codes are applied to the data with allowance for development of new codes if needed (Crabtree & Miller, 1999; Hsieh & Shannon, 2005). This method allowed data to be compared to the CHPCA 'Square of Care' model to guide palliative care, to assess if recommended areas of palliative care content were addressed and communicated in FCCs (CHPCA, 2014; Durepos et al., 2017).

The 'Square of Care' model describes eight domains to guide discussion including: disease management, physical, psychological, social, practical, EOL, spiritual and loss/grief care (CHPCA, 2014). Two independent researchers used these domains as codes determining the frequency with which CHPCA domains were discussed. Researchers later reached inter-coder

agreement through discussion (i.e. triangulation) (Patton, 2015; Sandelowski, 2010). Data was sub-categorized as goals and planned interventions to identify a communicable care plan. Goals included priorities and preferred outcomes while planned interventions (i.e. treatments/actions planned during the FCCs) included the provision of support services, education or care practices. The format of documentation (i.e. FCC form/site-specific document) was also noted to determine the extent to which the forms themselves support comprehensive conversations. Themes and patterns emerged through comparative analysis within the extracted data (Sandelowski, 2010). FCC descriptives and code frequencies were calculated using SPSS 22.0 and Excel.

Results

A total of 24 FCCs were held across the four study sites with participants between December 2015 and August 2016 (see Table 1). Residents were female by majority (62.5%), 86 years old, lived in LTC for 7 years and 92% had dementia as a diagnosis. Resident's PPS was on average less than 40% during FCCs, indicating a shift from a transitional phase of function to EOL. Each FCC was attended by an average of four staff representing four disciplines, with nursing representing the highest attendance (see Table 2). Physicians attended 33% of FCCs and Personal Support Workers (PSW) or nursing aids attended 13% of FCCs. On average FCCs were attended by one or two family members most of whom were adult children (see Table 2). 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 as codes (see Table 3). Field notes contributed to understanding FCC processes. Content analysis showed that an average of 5.54 (SD 1.74) domains were discussed in each FCC. The most discussed domains were: physical issues (100%), i.e., pain and nutrition; EOL care

(92%), i.e., comforts like music during death, presence of visitors, withdrawal of medications, EOL symptom management, funeral planning; and social care (88%), i.e., support for families and recreation for resident. Loss and grief (17%), i.e. plans and support for bereavement was the least discussed area of content. An average of 2.0 (SD 2.23) goals were identified and 4.96 (SD 4.79) interventions were planned in FCCs.

Disease Management: Disease management refers to discussion of residents' diagnoses, prognosis and disease progression (CHPCA, 2014). Overall, disease management was discussed in 17(52%) FCCs. Progressive decline was documented in 15 FCCs and prognosis mentioned in 6 conferences. On two occasions families were documented as asking, "is xxxx dying?" (Site 3). Dementia was the only 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'. Related, 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 demonstrating the perception of physical needs as critical. On the 'Family Questionnaire' a family member shared concern for "my 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 care includes behaviour, emotions and coping (CHPCA, 2014). Psychological care was addressed by 16 (67%) of FCCs. In one conference, staff were concerned about a resident's psychological responsive 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 identified 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 issues include relationships, environment, and family support (CHPCA, 2014). Social concerns were raised in 21 (88%) of discussions. For example, a staff person documented, "Family wants [resident] to maintain her usual activities as much as possible (i.e. up out of bed...among other people rather than isolation in her room... (Site 1). Staff commonly documented, "...continue to invite resident to church services, should she like to attend" (Site 2).

Spiritual Care: Spiritual care refers to transcendental being, religious practices and rituals (CHPCA, 2014). Addressed in 16 (67%) of FCCs, spiritual care was raised by families and staff indicating both the domain's importance and acceptance. Spiritual care was most often (83%) discussed at the faith-based LTC home (Site 4). Care by spiritual advisors (i.e. rabbis, priests, chaplains, etc) and rituals were mentioned in half 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 to the resident's care plan with planned intervention for, "Rabbi to meet with [Resident] find out where her shawl is located and what prayers" (Site 4).

Practical: Practical care refers to activities of daily living, mobility and hygiene (CHPCA, 2014). Addressed by 16 (67%) of FCCs, hygiene/grooming and mobility were common concerns particularly 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 family articulated their goal, "[the] resident was a very clean person prior to health crisis and family want to uphold her cleanliness..." (Site 4). A corresponding intervention 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).

End-of-Life Care: EOL care refers to care provided in the last days or hours, and care of the body after death. EOL care was discussed in 22 (92%) of FCCs. '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 four (17%) of FCCs families withdrew medications, "Only medications for comfort measures will continue – son does not feel that all of her medications are necessary at this point" (Site 3). Some families planned to transfer residents, "…to the hospital for treatable conditions, but not for life-saving measures" (Site 4). Others stated, "No pain, no pipes, just comfort with no suffering" (Site 4) as a goal. Another family expressed, "Mom cannot die in the [hospital] hallway" (Site 1) when discussing preferred location of death.

Preferences regarding the resident's environment were discussed in 33% of FCCs with goals such as a peaceful setting and interventions like preferred music playing. Many families requested sleeping space in the resident's room to keep them from dying alone. Staff planned interventions, "Provide 1:1 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 / Grief: Family grief and emotions were occasionally observed and documented in field notes. However, loss/grief and was discussed minimally in four (17%) 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).

Documentation Processes

Documentation varied across with four sites (see Table 3). Overall Site 4 demonstrated the highest intervention fidelity completing an average of three FCC forms for 100% of conferences, Site 3 used one FCC form for 88% for conferences, whereas Sites 1 and 2 relied upon site-specific electronic documentation with additional use of FCC forms for 33% of conferences. The most used FCC forms included the 'Family Questionnaire' and 'Plan of Care Conference' summary.

Across all sites more goals were documented on FCC forms (1.71) than on site-specific electronic documents (1.56) (See Table 4). Often staff only recorded the resident's code status in 'Goals of Care' in electronic documents. Alternatively, more planned interventions were documented electronically (5.7) than on FCC forms (4.41). Overall, Site 4 documented more goals (4.17) and planned interventions (9.17) than any other site, had the highest mix and number of staff attending (including Advance Practice Nurses) and family members.

Summary

FCCs implemented as part of SPA-LTC demonstrated communication of goals, interventions and discussion of palliative care content in comparison to the 'Square of Care' model. Documentation implies that FCCs are meeting their primary aim of facilitating EOL communication and planning between staff and family members, with content focused on physical and EOL care. Discussion of loss/grief and bereavement care for family members emerged as the greatest limitation.

Discussion

This study provides insight into the content and processes of FCCs implemented as part of the SPA-LTC study to improve EOL communication. Previous studies of FCCs and family meetings have not assessed content against a framework of palliative care or evaluated the relationship of FCC documentation methods to communication of issues, goals and interventions (Parker et al., 2015). This study therefore provide valuable insight to persons implementing FCCs.

Physical care concerns have consistently emerged as the predominant focus of FCCs and documented palliative care (Gunhardsson et al., 2007; Hogsnes et al., 2016; Parker et al., 2015). This focus on physical needs could allow neglect of psychological, social, spiritual and bereavement needs (Gunhardsson et al., 2007; Hogsnes et al., 2016). Families may also wish to discuss what death looks like, how to arrange for a funeral, how to handle family disagreements and the meaning of illness and the afterlife (Hebert et al., 2008). Family members have reported questions go unasked because they feel a) overwhelmed, b) are unsure who to ask or c) are concerned over 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 domains suggesting holistic communication (CHPCA, 2014; Hogsnes et al., 2016). Furthermore, in our study families detailed EOL preferences beyond code status to preferred environment (e.g. music), family

visitation (e.g., sleep privileges) and preferences for after-death care (e.g., maintain resident in place until family arrives)(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 participants in identifying purpose and meaning, reflecting on the ailing person's life and feeling less alone (Tan, 2011).

The lack of discussion of loss, grief and bereavement care during FCCs in our study is 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 disinclined to discuss bereavement because of their limited ability to provide support without resources, while families sometimes preferred to remain focused on the dying person (Stephen et al., 2013). These barriers may have been factors in our FCCs as well. Families of residents in LTC have unique bereavement needs related to a long-time spent caregiving and loss of relationships with LTC staff upon resident death (Romero et al., 2014; Schulz et al., 2003). FCCs should prompt staff to assess and document families' coping and concerns for bereavement as part of palliative care (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). Incorporating a 'Family Questionnaire' as part of FCCs incorporated the family voice into the documented care process. Standardized forms should prompt assessments, organize and communicate data while allowing individuality (Wang & Yu, 2014). However, effective communication is dependent upon essential components being in place and accessible (Voyer et al., 2014).

Electronic documentation is perceived as efficient and associated with a higher quality of care. However, a systematic review of electronic documentation in LTC revealed benefits and burdens, with efficiency and quality of documentation related to users' computer proficiency (Melbner & Schnepp, 2014). A Cochrane review of the impact of nursing documentation methods for communication on patient outcomes also reported inconsistent results (Urqhart et al., 2009). Communication may be enhanced or impaired by electronic documentation depending on accessibility. For example, most PSWs do not use computers in their role which limits their access to electronic-only care plans.

In keeping with a flexible case-study approach, sites in our study selected variable methods of documentation. Site 3 and 4 relied exclusively on FCC forms whereas Sites 1 and 2 utilized electronic documentation within their organizations necessitating electronic documentation of FCCs for consistency. Despite similarities, analysis of FCC care plans revealed benefits to using FCC forms. Although more interventions were recorded on electronic documents (likely prompted by the large number of categories), absence of an EOL category may have inhibited detailed preferences for EOL care

An advantage to using FCC forms included communication of a higher proportion of goals linked to interventions, creating a comprehensive plan. Use of the 'Family Questionnaire' FCC form likely prompted open communication and affirmed importance of the 'family voice'. Paper format is also less likely to create a barrier of access for LTC staff not using computers. Site 4 documented the highest number of addressed domains, goals and interventions using only FCC forms, illustrating their value. From our study we can glean that there are benefits to using specific FCC forms for documentation and communication.

Documented attendance of all parties at FCCs is also essential to telling the story of what occurred. Interdisciplinary collaboration promotes holistic care extending beyond a biomedical model and is associated with positive outcomes in palliative care (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 interdisciplinary care teams for EOL palliative care (Leclerc et al., 2014).

A valuable member of the interdisciplinary 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 countries and have reported feeling unheard in LTC (Fryer et al., 2016; Kontos et al., 2009). Conversely, physicians are requested to increase their involvement and communication (Biola et al., 2007; Hennings et al., 2010; Fosse et al., 2014; Vohra et al., 2006). Family members are frequently unaware of the physician in charge of the resident and few receive a prognosis from a physician although families report wanting to communicate with physicians (Hennings et al., 2010).

The interdisciplinary attendance of FCCs in our study was high with an average of four disciplines represented at each FCC, however, attendance of PSWs and physicians was low. Possible barriers to PSW participation could include high workload and lack of invitation (Berta et al., 2013; Fryer et al., 2016). Valuable resident information could be gained from PSWs with intimate knowledge of residents 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 barriers of 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 researcher and source triangulation (Patton et al., 2015; Sandelowski et al., 2010. A limitation of this study is the small sample size of FCCs and confinement to English-speaking families. Each of these factors limits transferability of findings. Content analysis was based 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 the validity of documentation.

Conclusion

In this study we aimed to assess the palliative care content and processes of FCCs implemented as part of SPA-LTC. Contributions were made including the identification of strengths and gaps in content areas. Implications include the use of specific forms developed for FCCs. The interdisciplinary nature of palliative care was highlighted in this study and was linked to greater identification of goals and interventions demonstrating the value of collaboration. Future research should focus on strategies to engage PSWs and physicians in FCCs, assess if goals and interventions established during FCCs are followed through and influence outcomes.

Table 1

Characteristics of Residents 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)

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

	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 (%)
Staff Discipline					
MD	2 (40.0)	2 (40.0)	1 (12.5)	3 (50.0)	8 (33.3)
Recreational Therapy	1 (20.0)	4 (80.0)	1 (12.5)	6 (100.0)	11 (45.8)
Dietary	1 (20.0)	5 (100.0)	0 (0.0)	3 (50.0)	9 (37.5)
Physiotherapy	0 (0.0)	1 (20.0)	0 (0.0)	2 (33.3)	3 (12.5)
Nursing (RN/RPN)	5 (100.0)	3 (60.0)	6 (75.0)	4 (66.7)	17 (70.8)
PSW	0 (0.0)	3 (60.0)	0 (0.0)	0 (0.0)	3 (12.5)
DOC/ADOC	2 (40.0)	0 (0.0)	1 (12.5)	6 (100.0)	9 (37.5)
Social Work, Program MGR	4 (80.0)	4 (80.0)	0 (0.0)	6 (100.0)	13 (54.2)
Staff Attending M(SD)	3.2(SD2.12)	4.8(SD1.62)	2.0(SD1.70)	4.8(SD1.92)	3.5(1.8)
Disciplines Attending M(SD)	3.0(SD1.22)	5.4(SD1.14)	1.5(SD0.76)	6(2.25)	4.0(2.1)
Relationship to Resident					
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)
Wife	0 (0.0)	0 (0,0)	0 (0.0)	3 (50.0)	3 (12.5)
Daughter/in-law	3 (60.0)	2 (40.0)	5 (62.5)	2 (33.3)	11 (45.8)
Son	2 (40.0)	3 (60.0)	2 (25.0)	2 (33.3)	7 (29.2)
Other[1]	0 (0.0)	0 (0.0)	2 (25.0)	0 (0.0)	2 (8.3)
Family Attending M(SD)	1.0(SD0.0)	1.4(SD0.64)	1.1(SD0.35)	1.5(0.62)	1.3(SD0.53)
Researcher Attending M(SD)	0 (0.0)	2 (40.0)	4 (50.0)	5 (83.0)	11(46.0)

Note: PSW = Personal Support Worker; *RN* = Registered Nurse; *RPN* = Registered Practical Nurse; *DOC/ADOC* = Director / Assistant Director of Care; *Program MGR* = Program Manager; Other[1] = 1 Grandson, 1 Sister

Table 3

Documents Utilized to Communicate Family Care Conference Information at Each Site

	Site 1 n = 5 FCCs	Site 2 n = 5 FCCs	Site 3 n=8 FCCs	Site 4 n=6 FCCs	All Sites N = 24 FCCs
Family Care Conference Forms					
Family Questionnaire	3	1	7	3	13
Physician Invitation to FCC	-	-	-	1	1
Staff Communication Sheet	-	-	-	4	4
Planning Checklist	-	-	-	6	6
Plan of Care Summary	1	1	-	6	8
Site-Specific Documents:					
Paper Chart note	1	-	-	-	9
Electronic Chart Record, ex. Point Click Care	3	5	-	-	-
Total Documents					41

Table 4

Palliative Care Communication and Documentation during Family Care Conferences

Square of Care Domain	Characteristic	FCC Forms n=17 Mean (SD)	Site-Specific Document n=9 Mean (SD)	Total N=24 Mean (SD)
Disease Management				
	Issues Discussed			17 (70.8)
	Goals	0.06 (0.24	0	0.04. (0.28)
	Planned Interventions	0.12 (0.49)	0.33 (0.48)	0.17 (0.38)
Physical				
	Issues Discussed			24 (100.0)
	Goals	0.29 (0.47)	0.33 (0.7)	0.38 (0.65)
	Planned Interventions	0.82 (0.89)	1.22 (1.5)	1.04 (2.0)
Psychological				
	Issues Discussed			16 (66.7)
	Goals	0.35 (0.61)	0.22 (0.42)	0.33 (0.56)
	Planned Interventions	0.64(1.17)	0.44 (0.84)	0.63 (1.10)
Social				
	Issues Discussed			21 (87.5)
	Goals	0.35 (0.49)	0.22 (0.42)	0.25 (0.44)
	Planned Interventions	0.47 (0.80)	0.33 (0.48)	0.5 (0.78)
Spiritual				
	Issues Discussed			16 (66.7)
	Goals	0.11(0.33)	0.11 (0.32)	0.29 (0.55)
	Planned Interventions	0.47 (0.80)	0.56 (0.53)	0.5 (0.59)
Practical				
	Issues Discussed			16 (66.7)
	Goals	0.23 (0.56)	0.22 (0.42)	0.25 (0.53)
	Planned Interventions	0.41 (0.71)	0.44 (0.96)	0.5 (0.83)
End of Life				
	Issues Discussed			22 (91.7)
	Goals	0.35 (0.61)	0.44 (0.70)	0.46 (0.72)
	Planned Interventions	1.47 (1.67)	1.67 (1.51)	1.63 (1.69)
Loss / Grief				
	Issues Discussed			4 (16.7)
	Goals	0	0	0
	Planned Interventions	0	0	0

Domain Issues Discussed per FCC	Mean (SD)			5.54 (1.74)
Goals Documented per FCC	Mean (SD)	1.71	1.56	2.0 (2.23)
Planned Interventions Documented per FCC	Mean (SD)	4.41	5.7	4.96 (4.79)

Note. Issues discussed refers to researcher's dichotomous classification of content as present or not present on any document according to the Canadian Hospice Palliative Care Association 'Square of Care' domains. Goals refer to identified priorities and preferred outcomes. Planned interventions refer to treatments, activities planned during Family Care Conferences (FCC), to be provided, changed or removed from the resident's care plan such as: addition of support services, provision of education, change to current care plan. FCC Forms refer to paper/hard copy documents developed by researchers specifically for the intervention. FCC Forms were utilized in 17 conferences. Site-specific documents refer to electronic (8) and paper resident charts (1). Site-specific documents were utilized in 9 FCCs.

References

1. Berger, J. T. (2010). What about process? Limitations in advance directives, care planning, and noncapacitated decision making. *The American Journal of Bioethics*, *10*(4), 33-34.

2. Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). They know!—Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine*, *30*(5), 456-470. DOI: 1177/0269216315605753.

3. Brazil, K., Bédard, M., Krueger, P., Taniguchi, A., Kelley, M. L., McAiney, C., & Justice, C. (2006). Barriers to providing palliative care in long-term care facilities. *Canadian Family Physician*, *52*(4), 472-473.

4. Broad, J., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. (2013). Where do people die? an international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health, 58*(2), 257-267. doi:10.1007/s00038-012-0394-5

5. Canadian Hospice Palliative Care Association. (2013). *Model to guide hospice palliative care: based on national principles and norms of practice*. Canadian Hospice Palliative Care Association.

6. Crabtree B & Miller W (eds). *Doing Qualitative Research* 2nd ed. Thousand Oaks, CA: Sage; 1999.

7. Durepos, P., Wickson-Griffiths, A., Hazzan, A. A., Kaasalainen, S., Vastis, V., Battistella, L, Papaioannou, A. (2017). Assessing the palliative content in dementia care guidelines: A systematic review. *Journal of Pain and Symptom Management, In press.*

8. Fosse, A., Schaufel, M. A., Ruths, S., & Malterud, K. (2014). End-of-life expectations and experiences among nursing home patients and their relatives—a synthesis of qualitative studies. *Patient Education and Counseling*, *97*(1), 3-9.

1. Goldsmith, J., Wittenberg-Lyles, E., Rodriguez, D., & Sanchez-Reilly, S. (2010). Interdisciplinary geriatric and palliative care team narratives: collaboration practices and barriers. *Qualitative Health Research*, *20*(1), 93-104.

2. Gunhardsson, I., Svensson, A., & Berterö, C. (2007). Documentation in palliative care: Nursing documentation in a palliative care unit—A pilot study. *American Journal of Hospice and Palliative Medicine*.

3. Høgsnes, L., Danielson, E., Norbergh, K., & Melin☐Johansson, C. (2016). Healthcare professionals' documentation in nursing homes when caring for patients with dementia in end of life – a retrospective records review. *Journal of Clinical Nursing, 25*(11-12), 1663-1673. doi:10.1111/jocn.13184

4. Hebert, R. S., Schulz, R., Copeland, V., & Arnold, R. M. (2008). What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *Journal of Palliative Medicine*, *11*(3), 476-483.

5. Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management*, *37*(1), 3-12.

6. Hsieh, H-F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research,* 15(9), 1277-1288.

7. Hudson, P., Quinn, K., O'Hanlon, B., & Aranda, S. (2008). Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *BMC Palliative Care*, *7*(1), 1. DOI: 10.1186/1472-684X-7-12

8. Hudson, P. L., Girgis, A., Mitchell, G. K., Philip, J., Parker, D., Currow, D., ... & Brand, C. (2015). Benefits and resource implications of family meetings for hospitalized palliative care patients: research protocol. *BMC palliative care*, *14*(1), 1. DOI: 10.1186/s12904-015-0071-6

9. Johnson, S., & Bott, M. J. (2016). Communication with Residents and Families in Nursing Homes at the End of Life. *Journal of Hospice & Palliative Nursing,* 18(2), 124-130.

10. Kaasalainen, S., Sussman, T., Neves, P., & Papaioannou, A. (2016). Strengthening a Palliative Approach in Long-Term Care (SPA-LTC): A New Program to Improve Quality of Living and Dying for Residents and their Family Members. *Journal of the American Medical Directors Association*,*17*(3), B21.

11. Kontos, P. C., Miller, K. L., & Mitchell, G. J. (2009). Neglecting the importance of the decision making and care regimes of personal support workers: A critique of standardization of care planning through the RAI/MDS. *The Gerontologist*, *50*(3):352-362.

12. Martin, R. S., Hayes, B., Gregorevic, K., & Lim, W. K. (2016). The effects of advance care planning interventions on nursing home residents: A systematic review. *Journal of*

the American Medical Directors Association, *17*(4), 284-293. DOI: 10.1016/j.jamda.2015.12.017.

13. Ng, C. W. L., Cheong, S. K., Raj, A. G., Teo, W. S. K., & Leong, I. Y. O. (2016). End-of-life care preferences of nursing home residents: Results of a cross-sectional study. *Palliative Medicine,* 30(9), 843-853.

14. Ontario Long-Term Care Homes Act (2007). Toronto, ON: Ontario Ministry of Health and Long-Term Care.

15. Patton, M. (2015). *Qualitative research and evaluation methods.* Washington, DC. Sage.

16. Parker, D., Clifton, K. L., Tuckett, A. G., Reymond, L., Prior, T., McAnelly, K., ... & Glaetzer, K. (2013). Are we addressing the issues raised by families at palliative care case conferences in residential aged care? In *4th Annual Uniting Care Queensland Research Conference 2013*

17. Parker, D., Clifton, K., Tuckett, A., Walker, H., Reymond, E., Prior, T., ... & Glaetzer, K. (2015). Palliative care case conferences in long☐term care: views of family members. *International Journal of Older People Nursing.* DOI: 10.1111/opn.12105

18. Phillips, J. L., West, P. A., Davidson, P. M., & Agar, M. (2013). Does case conferencing for people with advanced dementia living in nursing homes improve care outcomes: evidence from an integrative review?. *International Journal of Nursing Studies*, *50*(8), 1122-1135. DOI: 10.1016/j.ijnurstu.2012.11.001

19. Rhondali, W., Dev, R., Barbaret, C., Chirac, A., Font-Truchet, C., Vallet, F., ... & Filbet, M. (2014). Family conferences in palliative care: a survey of health care providers in France. *Journal of Pain and Symptom Management*, *48*(6), 1117-1124.

20. Reinhardt, J. P., Boerner, K., & Downes, D. (2015). The positive association of end-of-life treatment discussions and care satisfaction in the nursing home. *Journal of Social Work in End-of-Life & Palliative Care, 11*(3-4), 307-322. doi:10.1080/15524256.2015.1107805

21. Residential Aged Care Palliative Approach Toolkit. Retrieved from http://www.uq.edu.au/bluecare/the-palliative-approach-toolkit

22. Romero, M. M., Ott, C. H., & Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of person's With Alzheimer's disease: A prospective study. *Death Studies, 38*(6), 395-403.

23. Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description?. *Research in Nursing and Health*, *23*(4), 334-340.

24. Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., ... & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, *349*(20), 1936-1942.

25. Temkin-Greener, H., Ladwig, S., Caprio, T., Norton, S., Quill, T., Olsan, T., ... & Mukamel, D. B. (2015). Developing Palliative Care Practice Guidelines and Standards for Nursing Home–Based Palliative Care Teams: A Delphi Study. *Journal of the American Medical Directors Association*, *16*(1), 86-e1.

26. Thompson, Genevieve N,PhD., R.N., McClement, Susan E,PhD., R.N., Menec, V. H., PhD., & Chochinov, Harvey M,M.D., PhD. (2012). Understanding bereaved family members' dissatisfaction with end-of-life care in nursing homes. *Journal of Gerontological Nursing, 38*(10), 49-60. doi:http://dx.doi.org/10.3928/00989134-20120906-94

27. Towsley, G. L., Hirschman, K. B., & Madden, C. (2015). Conversations about end of life: perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine*, *18*(5), 421-428.

28. Tulsky, J. A. (2005). Beyond advance directives: importance of communication skills at the end of life. *JAMA*, *294*(3), 359-365.

29. Vohra, J. U., Brazil, K., & Szala-Meneok, K. (2006). The last word: Family members' descriptions of end-of-life care in long-term care facilities. *Journal of Palliative Care*, *22*(1), 33.

30. Voyer, P., McCusker, J., Cole, M. G., Monette, J., Champoux, N., Ciampi, A., ... & Richard, S. (2014). Nursing documentation in long-term care settings: new empirical evidence demands changes be made. *Clinical Nursing Research*, *23*(4), 442-461.

31. Wahl, J. (2011). Long Term Care Homes Act 2007: Implications for Palliative Care. Toronto, ON: Advocacy Centre for the Elderly.

32. Wong, S.L., Gilmour, H., & Ramage-Morin, P.L. (2016) *Health Reports: Alzheimer's Disease and Other Dementias in Canada*. Retrieved from: http://www.statcan.gc.ca/pub/82-003-x/2016005/article/14613-eng.htm**End of Life 2011_reportEN-kaV02.indd**

33. World Health Organization. (2014). Strengthening of palliative care as a component of integrated treatment throughout the life course. *Journal of Pain & Palliative Care Pharmacotherapy*, *28*(2), 130-134.