

**Bereaved Family Members' Satisfaction with End-of-Life Care
within Four Ontario Long Term Care Homes**

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ABSTRACT

Background: Understanding bereaved family members' perspectives on end-of-life care offers long term care (LTC) homes a valuable quality improvement opportunity to better meet the needs of residents and families at end of life.

Method: The study adopted the Family Perception of Care Scale (FPCS) is a 27-item survey that collects information about bereaved family members' perceptions of and satisfaction with end-of-life care in LTC. It has four domains; 1) Resident care, 2) Family Support, 3) Communication, 4) Rooming, and provided room for comments (Vohra, Brazil, Hanna, Abelson, 2004). In conjunction with the "Improving Quality of Life for People Dying in LTC homes" research (www.palliativealliance.ca) the FPCS was mailed to 152 family members of residents who died during 2012 in four Ontario long-term care homes. Eighty-six surveys were returned (57% response rate). Quantitative data were analyzed using SPSS and qualitative data were analyzed thematically.

Results: The overall satisfaction score was 83/100; indicating family members were generally satisfied with the end- of- life care. Satisfaction did not significantly differ between homes. Important items for satisfaction were location of death, pain management, dignity, being informed about resident's health and feeling welcomed in the home. Scores were higher for rooming (86) and communication (86) and lower for resident care (82) and family support (76). Survey comments were organized into the four domains of the FPCS. Extensive open-ended comments made by 63% of respondents showed their desire to share their experiences and contribute to quality improvement.

Conclusions: Results indicate that the structural characteristics of the home are less important to family satisfaction than resident care, such as pain control, dignity, communication and relationships. Participants were more satisfied when the resident died in the long term care home than when the death occurred in hospital. This finding suggests a need for more resident and family education on the benefits of advance care planning and receiving palliative care in the LTC home. Furthermore, indicators of family satisfaction with end-of-life care need to be included more predominantly in LTC satisfaction surveys for quality improvement. Family member satisfaction and perceptions have policy implications and can guide education and training in long term care homes.

BACKGROUND

This research was a sub study of a five-year (2009-13) participatory action research study titled “Improving Quality of Life for People Dying in Long-Term Care Homes”, also known as Quality Palliative Care in Long-Term Care (QPC-LTC). The QPC-LTC project was funded by the Social Sciences and Humanities Research Council (SSHRC) as a Community University Research Alliance,(for more project details see www.palliativealliance.ca). The QPC-LTC project (2009-13) had the following goals: to improve the quality of life for residents dying in long term care; to develop interprofessional palliative care programs; to create partnerships between long term care homes, community organizations and researchers; to create a toolkit for developing palliative care in long term care homes that can be shared nationally; to promote the role of the Personal Support Worker in palliative care. It was completed through the collaboration and active participation of a large team of researchers and four key partners; Lakehead University, McMaster University, the Municipalities of Halton and Niagara and St. Joseph’s Care Group. The four long term care study sites for the project included Bethammi Nursing Home and Hogarth Riverview Manor in Thunder Bay, and Allendale Village in Milton and Creek Way Village in Burlington all Ontario Long Term Care homes. The principle Investigator, Mary Lou Kelley, is a Professor of Social Work and Gerontology at Lakehead University and at the Northern Ontario School of Medicine.

RATIONALE

Long term care homes, also known as nursing homes, are increasingly becoming a prevalent location of death in Canada and elsewhere in the developed world. Currently in Ontario, 18.2% of residents living in long term care homes die annually (Canadian Institute of Health Information, 2012). The majority of these residents die experiencing some form of

cognitive impairment. Declining cognitions often inhibit residents from reporting on their own quality of life, therefore researchers turn to bereaved family members to discover what contributes to quality care at end of life (Kaasalainen, Brazil, & Kelley, 2012).

As long term care homes continue to be a major location of death into the future, their role in providing end-of-life care will continue to gain importance. Residents in long term care would benefit by receiving specialized palliative care in the last year of life to address their psychological, social and spiritual needs as well as manage pain and symptoms (Kelley, 2012). Ongoing quality improvement programs in long term care homes that measure family satisfaction are thus important to improving quality of palliative and end-of-life care for Ontario residents.

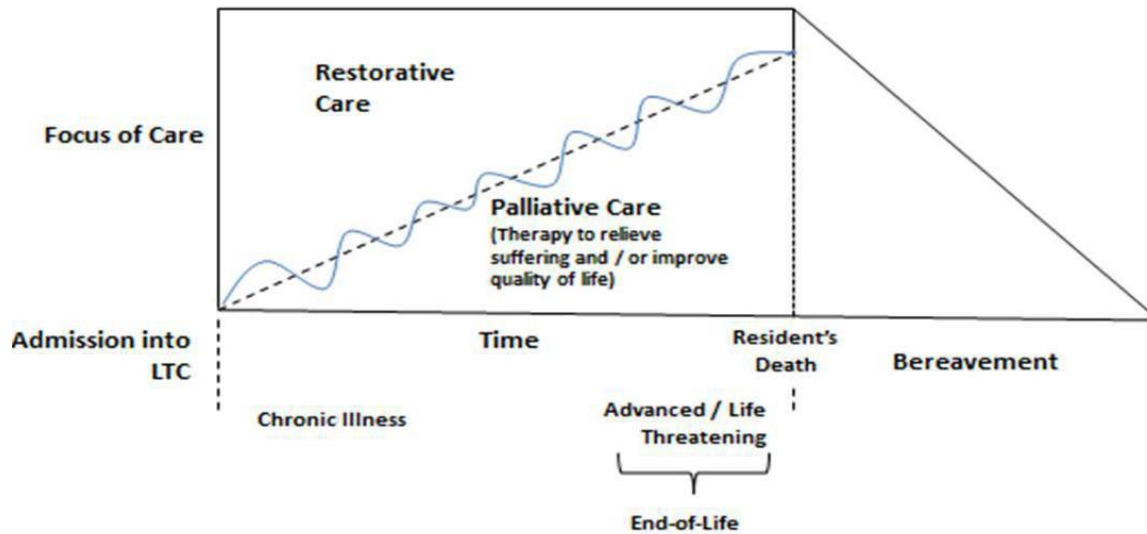
LITERATURE REVIEW

WHAT IS QUALITY PALLIATIVE AND END-OF-LIFE CARE?

The Way Forward: A Roadmap for the Integrated Palliative Approach to Care, a document drafted by the Quality of End-of-Life Coalition of Canada (2013) uses the World Health Organization's definition to outline the palliative approach to care as:

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (p.13)

Furthermore, the QPC-LTC Alliance states that palliative care is an interdisciplinary, client centered approach that focuses on maintaining quality of life and symptom control that begins when a resident is admitted into long term care and then gradually transitions into end-of-life care (Figure 1).

Figure 1: Transition from Admission to Death

(see: www.palliativealliance.ca)

When investigating family members' satisfaction with end-of-life care, it is important to discover what the standards are for quality palliative and the end-of-life care. The Canadian Hospice Palliative Care Association's (CHPCA) National Norms of Practice (2013), introduces a framework entitled; *The Square of Care* that emphasizes providing care that includes as the range of issues regularly faced by individuals and their families: disease management, physical, psychological, social, and spiritual issues, practical end-of-life and death management issues, and grief and loss. *The Square of Care* also outlines the essential steps necessary to deal with these issues which are; assessment, information sharing, decision-making, care planning and delivery. CHPCA states "all programs should strive to achieve the norms of practice at all times" and "organizations should use the norms of practice to guide the development of their standards of practice" (CHPCA, 2013, p.12).

Quality palliative care is also addressed in the framework for palliative care in long term care developed by the QPC-LTC project. Included in this framework is an audit tool entitled *Quality Palliative Care in Long-Term Care: Self-Assessment Checklist*. Homes are encouraged to utilize this tool to assess their own delivery of quality palliative care. Using this audit tool, homes can identify key structures, processes and outcomes for palliative care that exist or require development. Relevant for the purpose of this research is that one of the important outcome measures is resident and family satisfaction (Palliative Alliance, 2014).

FAMILY SATISFACTION WITH END-OF-LIFE CARE IN LTC

What do families see as quality care at the end of life? Several authors identify aspects of quality end-of- life care from the point of view of family members. Heyland, et al. (2006) identify: trust in the physician, prevention of unnecessary life support, effective communication, continuity of care and life completion. Additionally, Kaarbo (2011) identify individualized and patient-centered care as good end-of-life care , with family identifying the following as important; pain and symptom management, clear decision-making and staff being involved with the patient on a personal level Gelfman, Meier, & Morrison (2008), stated that families valued factors such as alleviation of physical suffering, the prevention of death-prolonging procedures, and reduction in caregiver burden at end of life. Further, Allan, Norgrove, & Heyland (2011), discovered that bereaved family members saw physical care, symptom management and emotional care as important to quality care at end of life. Additionally, Funk, Stajduhar, Cohen, Heyland, Williams (2012), determined that family members looked at the relationship that care providers had with the patient when assessing their satisfaction with care at end of life. Family members desired and preferred relationships that exhibited respect for patient dignity, wishes and decisions (Funk et al., 2012). Munn and Zimmerman (2006) identified that family members also

looked at the importance of structural factors of care such as staffing numbers, training, and consistency and the elements of the physical space; such as the space being clean and comfortable.

On the contrary, Thompson, McClement, Menec, & Chochinov (2012), pointed out what it meant for a family member to be dissatisfied with care. Families receiving confusing or inadequate information from nursing staff about care as well as families feeling that the care received at end of life was not what was expected were indicators that there was dissatisfaction with end-of-life care.

An examination of the literature about the experiences of bereaved family members identifies that similar indicators of satisfaction exist in the long term care setting as they do in other care settings such as a ICU, hospital, hospice and home settings (Nanda, Bourbonniere, Wetle, & Teno, 2010; Rhodes, Mitchell, Miller, Connor, & Teno, 2008; Akazawa et al., & Furukawa, 2010). Predominantly these studies point to the importance families place on comfort care for their loved ones. Results from a study by Akazawa et al., (2010) outlined care strategies recommended by bereaved family members for the care of terminally ill patients in palliative care units. These strategies include eliminating pain and other symptoms, quickly dispose of soiled material and support a patient's efforts to care for themselves. Another study of bereaved family members' satisfaction with hospice care services (Rhodes, et al., 2008), found key practices led to a participant rating the care as “excellent”: being regularly informed, receiving emotional support, and having a consistent team providing care.

Overall, literature on the perceptions of bereaved family members relating to the satisfaction of end-of-life care in long-term care reveals common themes. These include: communication and knowledge sharing (Hennings, Froggatt, & Keady, 2010, Kaarbo, 2011, Liu,

Guarino, & Lopez, 2012; Sheild, Wetle, Teno, Miller, & Welch, 2010; Thompson, Menec, Chochinov, & McClement, 2008) being told when their loved one would die (Thompson et al., 2008; Katz et al., 2001; Liu et al., 2012), and staff competencies and relationships (Hennings et al., 2010; Flock & Terrien, 2011; Kaarbo 2011 Sheild et al., 2010). Less common indicators of the experiences of family also are identified such as the experience some family members have losing their close relationship with staff (Sheild et al., 2010).

A study that researched satisfaction with the care of the dying in a nursing home found that communication and information sharing were key contributors to quality of care at end of life in long term care and that a failure to recognize imminent death was an indication of dissatisfaction (Thompson et al., 2008). Similarly, Kaarbo (2011) examined the experiences that family members had immediately prior and after death found that information sharing and communication were key to their satisfaction with end-of-life care. Furthermore, Munn, Dobbs, Meier, Williams, Biola, & Zimmerman, (2008), in a study that looked at the end-of-life experience of staff, family and residents in long term care, found that a good death, normalcy of end-of-life issues, relationship characteristics, hospice involvement, and recommendations for care were common themes that contribute to the enhancement of end-of-life care.

Vohra, Brazil, Hanna, and Abelson (2004), conducted one of the most comprehensive Canadian studies that examined family perception of end-of-life care in six Ontario long term care homes using an instrument they developed for that purpose. The study surveyed 231 family members of residents who died within 6 Ontario long term care facilities (62% response rate). The majority of respondents were daughters of residents who had died at the average age of 87. Findings revealed that overall family members were satisfied with the care received at the end of life. Family members prioritized pain control, comfort care and care with dignity and sensitivity

as important to excellent end-of-life care. Family members also valued being informed of when death was at hand. The lowest satisfaction scores were associated with staffing levels and information sharing and involvement if family members. Finally, family members were more satisfied with the care they received in the long-term care home at end of life than in the hospital. The authors (Vohra, Brazil, Szala-Menoek, 2005) also reported on the survey comments according to 2 themes; (1) appreciation for care and (2) concerns with care. The *appreciation for care* theme included subthemes: psychosocial support, family care, and spiritual care. The *concerns with care* theme included the subthemes: physical care, staffing levels, staff knowledge, physician availability, communication, and physical environment. Both studies point to a need for improvement in end-of-life care provision in long term care facilities, and point to continuing education among staff as a route to such improvements. (Vohra, Brazil, Szala-Menoek, 2005).

The potential implications from researching bereaved family members' perceptions and experiences of end-of-life care in long term care can be relevant to competence building, policy implications and a reminder for continuous evaluation of the appropriateness of practice models in long term care homes (Kaarbo, 2011; Liu, Guarino & Lopez, 2012). Also, an understanding of the experience of family members should be considered in order to improve on the care for those who die in long term care homes (Wetle, Shield, Teno, Miller, & Welch, 2005).

Much of the research to date done on family members' satisfaction and their perception of care at end of life has not been conducted within a long term care setting (Thompson et al., 2008). There have been multiple research studies done on the perception of end-of-life care through the lens of family member in ICU, hospital, hospice and home settings (Nanda et al., 2010; Rhodes et al., 2008; Akazawa et al., 2010). But according to Thompson et al., (2008),

these settings are significantly different from a long-term care or nursing home. This research will contribute to this literature by studying family satisfaction with end-of-life care in four Ontario long term care homes.

ENGAGING BEREAVED FAMILY MEMBERS IN EVALUATING SATISFACTION WITH RESIDENTS' EOL CARE

Engaging bereaved family members in evaluating the end-of-life care experiences of residents' is a valuable method for quality improvement in long term care homes.

A brief look at what the literature says about the process of engaging bereaved families was conducted to guide the methodology of this study and insure minimal risk to families. This literature is also relevant to undertaking ongoing quality improvement efforts in long term care homes.

Various studies spoke to the issue of when the appropriate time is to survey bereaved family members following a death. Addington-Hall & McPherson (2001) reviewed the available information on conducting after-death interviews and surveys and found that there is no consistency in timing from study to study. In a study that set out to describe the perspectives family members had on the care their loved ones received in ICUs across Canada (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003), a questionnaire was sent to family members 3 to 4 weeks after a patient's death. The study received a 62 % response rate and the authors stated that the short interval between death and data collection might have helped to control for recall bias (Heyland et al., 2003).

Furthermore, a study that looked at relative's perceptions of end-of-life care in two Norwegian nursing homes used a questionnaire (Kaarbø, 2011) that was administered through a structured interview approximately 8 weeks after the death had occurred. The authors cited that

although the topic is a sensitive one, the “eagerness to contribute to service improvement was impressive” which indicated a sense of “solidarity with future patients and families” (Kaarbø, 2011, p.1130).

Stroebe, M., Stroebe, W., & Schut, H. (2003) recommend ways in which one can maintain a respectful and thoughtful manner when recruiting bereaved family participants. Allowing the bereaved person a chance to refuse participating and opportunities to withdraw at any point during the study as well as an assurance of anonymity and confidentiality are ways in which we can insure that bereaved individuals are approached in a way that eliminates any perceived risks (Stroebe et al., 2003) An additional study advocates researchers use a common sense approach to gauge an appropriate time when a participant will want to talk about the death of a loved one (Williams, Woodby, Bailey, & Burgio, 2008).

In summary, there is no consistency in recommendations of timing to engage bereaved families from study to study (Addington-Hall & McPherson, 2001). However, the studies did not indicate any undue harm done to participants because of their chosen time criteria. Also, there does not appear to be consistent guidelines for the ethics of studying bereaved people. But suggestions found in the literature such as using indirect methods that allow refusal, recognizing inappropriate dates, maintaining confidentiality and harnessing the experience and common sense of the researcher are all conducive to the method was used for this study (Williams et al., 2008, Stroebe et al., 2003).

RESEARCH OBJECTIVE

The specific objective of this research was to evaluate bereaved family members’ perceptions and satisfaction with end-of-life care in long-term care facilities. It was conducted in

the four long term care homes in Ontario that were participating in the QPC-LTC project and formed part of the overall assessment of the larger research

METHODOLOGY

ETHICS

Ethical approval for this research was received from Lakehead University, McMaster University, the Municipality of Halton and St. Joseph's Care Group. The researcher adhered to the Tri-Council ethics guidelines that underpinned the larger QPC-LTC project and completed the Tri-Council Policy ethics tutorial.

METHOD

Data for this research were collected via a survey of bereaved family members who were identified as the powers of attorney (POA) for personal care of the residents who died. A POA for personal care is an individual identified by the resident as a substitute decision maker "who will provide consent or refusal of consent for care and treatments" when the resident is not mentally capable to do that for themselves. This person may be chosen as part of advance care planning, however, if no one is identified by the resident, the Ontario Health Care Consent Act provides a ranking system for people who will be designated to take on this responsibility (Ontario Health Care Consent Act, 1996). The legal POAs of residents who had died were known by the long term care home managers where the research was completed.

MEASURE

The Canadian survey instrument used in this study was adopted from Vohra, et al., (2004) who developed and tested it as a measure of family satisfaction with end-of-life care based on the 2001 Norms of Practice for Hospice Palliative Care and related research.

The Family Perception of Care Scale (FPCS) (Appendix A) is a survey that assesses family members' perception of at end-of-life in long term care (Vohra et al., 2004) by collecting quantitative and qualitative data. The survey contains 27 items. The first 25 items are evaluated on a 7 point Likert scale that ranges from strongly disagree to strongly agree. The two remaining items on the scale include a section where family members can indicate priority items, and lastly a section allocated for additional comments. The survey was validated by Vohra et al., (2004) through a developmental phase in which telephone interviews were done with bereaved family members who had a loved one die in long term care. The total score for the scale ranges from 26 – 175; 26 being a negative perception and 175 being the highest possible positive perception. The items are also categorized according to four different subscales: 1) Resident Care 2) Family Support 3) Communication 4) Rooming. This allows for a satisfaction score to be created for each subscale. The study done by Vohra et al., (2004) which utilized the FPCS, demonstrated that the survey has “face and content validity as well as good internal consistency” (p. 302).

SAMPLE

Survey respondents were individuals who had a family member die in one of the 4 Ontario long term care homes participating in the QPC-LTC project within 2012 and were identified as the deceased's power of attorney for personal care. No surveys were sent to the deceased's power of attorney for personal care sooner than one month, or later then one year after death.

DATA COLLECTION

Senior management of each of home identified residents who had died in 2012. Senior management then identified an employee to aid in the implementation of the survey. Two

Personal Support Workers, and two Social Workers were identified to help in administering the survey. All survey participants remained anonymous to the researcher.

Each long term care home informed the researcher of the number of residents that had died and the researcher then prepared coded packages for each home, which included an information letter (Appendix B), the Family Perception of Care Scale, addressed return envelope and postage. The long-term care home employee obtained the addresses for the resident's power of attorney for personal care and then addressed the packages. Surveys were mailed out by long-term care homes as per ethical guidelines and returned directly to the researcher. One week after the surveys were mailed the long term care home staff also mailed out a follow up letter, further explaining the survey that family members received (Appendix C). A total of 152 surveys were mailed out to all POAs for personal care of all residents who died during 2012 in the four long term care study sites. Collection of responses took place between January 2013 and April 2013. Surveys were coded to allow for the researcher to track the responses. The researcher informed the long term care home staff member the code for surveys that were returned. After two weeks, the long term care home staff member made a follow up call to non-respondents to encourage participation. Individual respondents were anonymous however each long term care home was identified through the code assigned.

ANALYSIS

Surveys were analyzed using SPSS software and qualitative data were manually analyzed to identify and group common themes. Findings were reviewed and verified by two members of the research team.

RESULTS FROM THE FAMILY PERCEPTION OF CARE SCALE

Eighty-six surveys were returned resulting in a response rate of 57% (n=86). The surveys from all four-study sites were initially analyzed separately so that a report could be provided to each home for use in their own quality improvement program (Appendix D). Results were then integrated for the purpose of analysis for this research report.

The demographic information compiled gives a brief but informative picture of the residents who had died and the POA/family members that were invested in their care. Table 1 illustrates the characteristics of the 86 residents and family members. The majority of residents were female (68.6%) and their average age was 89. Most (76.7%) of the deceased residents had lived in the long-term care home for 12 months or more prior to their death. Of the 86 deaths in that year, 74 residents died in the long-term care home and 12 had been transferred to hospital where they subsequently died. The results of the survey also revealed that the average age of respondents (POA/family members) was 63 and the most common relationship to the resident was a son or daughter (79%).

Table 1: Family and Resident Characteristics (n=86)

Resident Characteristics		
Gender of Residents	Female	20 (70%)
	Male	26 (30.%)
Average age of residents	89	
Length of stay	Less than 3 months	8 (9.3%)
	3 months but less than 6 months	5 (5.8%)
	6 months but less than 12 months	7 (8.1%)
	12 months or more	66 (76.7%)
Place of death	Long Term Care	74 (86%)
	Hospital	12 (14%)
Respondent Characteristics (POA/Family member)		
Gender of respondents	Female	63(73%)
	Male	23 (27%)
Average age of respondents	63	

Relationship to resident	Daughter	42(48.8%)
	Son	26(30.2%)
	Wife	7(8.1%)
	Other	11 (13%)

Following the analysis of Vohra et al., (2004), family member satisfaction was calculated by summing the total score from all the items of the FPCS and calculating the mean scores and standard deviation for each subscale.

Table 2 reveals the mean subscale scores as well as the mean total score of the FPCS. Overall, respondents were satisfied with the end-of-life care their family member received. The mean total score was 143 (SD32.34) out of a possible 175 or 83%. Scores were higher for rooming and communication and lower for resident care and family support. The greatest range in satisfaction scores was related to resident care (SD 14.27).

Table 2: Overall Scores

Subscale Scores for the Family Perception of Care Scale (n=86)						
Subscale	Minimum	Maximum	Mean	SD	Maximum Possible	%
Resident Care	12	77	63	14.27	77	82
Family Support	6	42	32	8.29	42	76
Communication	8	42	36	6.7	42	86
Rooming	2	14	12	3.08	14	86
Total Scale	28	175	143	32.34	175	83

The mean for each of the 25 items on the scale is shown in Table 3. Again the largest range in satisfaction is evident in the area of resident care and the least in rooming. The lack of variation in satisfaction with rooming is interesting in that the 4 long term care homes varied

from being new homes with private rooms for all residents and older homes where 2 or 3 residents shared a room. Overall family members were satisfied with each item with a mean overall score of 5.81 (maximum score 7) and subscale scores ranging from 5.5 to 6.07 (Table 4).

Table 3: Item and Subscale Means

Question	Mean
Subscale- Resident Care	
The staff treated my family member with dignity	6.2
The staff spent enough time with my family member	5.62
The staff provided comfort to my family member	6.01
The staff were sensitive to the needs of my family member	5.98
There was a plan of care tailored specifically to the needs of my family member	5.66
The staff put decisions I made into action quickly, in regards to my family members care	5.66
My family members pain was eased to the greatest extent possible	6.16
Other symptoms were eased to the greatest extent possible	6.04
There was someone there for my family member to talk to	5.38
There were enough staff to deal with my concerns	5.37
Overall, I am satisfied with the end-of-life care that was given to my family member	5.78
Subscale total mean	5.8
Subscale- Family Support	
The staff informed me about care options during my family member's last days	5.58
The staff involved me in the planning of care	5.68
The staff welcomed me to stay with my family member	6.02
The staff helped me to be involved in the care of my family member	5.89
Chaplaincy services were at hand for my family member	5.15
The staff asked about the rites and rituals of my family member	4.68
Subscale total mean	5.5
Subscale- Communication	
The staff were friendly to me	6.4
The staff kept me informed about my family member's health	6.21
The staff kept me updated based on what I wanted to know	6.22
The staff spoke to me in a way that was easy to grasp	6.44
The staff described what to expect as my family member became close to death	5.52
The staff informed me when they thought death was at hand	5.62
Subscale total mean	6.7
Subscale- Rooming	
My family member was placed on the appropriate floor/unit	5.97

My family member's room offered privacy	6.05
Subscale total mean	6.01

Table 4: Subscale Means

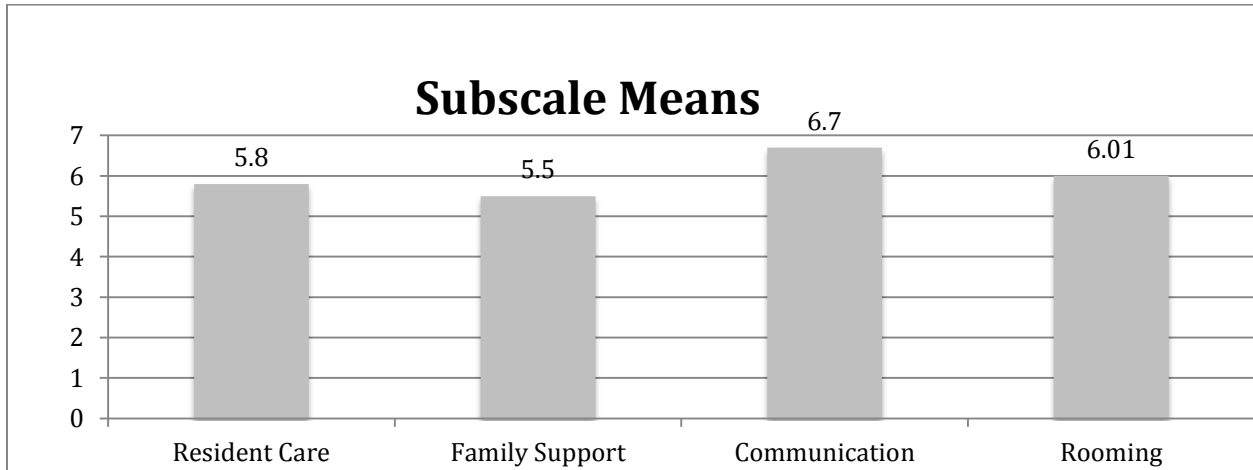


Table 5 reveals the items of the FPCS with the highest and lowest scores. High scores were related to communication, specifically the ways in which LTC home staff communicated with family members and the information that was shared. Lowest scores were related to the subscales of resident care and family support, in particular spiritual and religious concerns as well as staffing levels.

Table 5: Highest and Lowest Rated Items

HIGHEST	Mean
Q8: The staff spoke to me in a way that was easy to grasp	6.4
Q1: The staff were friendly to me	6.4
Q7: The staff kept me updated based on what I wanted to know	6.2
LOWEST	Mean
Q22: The staff asked about the rites and rituals of my family member	4.68
Q21: Chaplaincy services were at hand for my family member	5.15
Q3: There were enough staff to deal with my concerns	5.37

The FPCS surveys were compared across study sites. A one-way analysis of variance was conducted to examine whether family members satisfaction with end-of-life care differed among the four long term care homes. The ANOVA was not significant, $F(3, 82) = 1.74, p = .17$. There were no statistically significant differences among the mean total scores across all four homes (Table 5). Table 6 illustrates the subscale means across each study site.

Table 5: Total Mean Scores for Each Study Sites

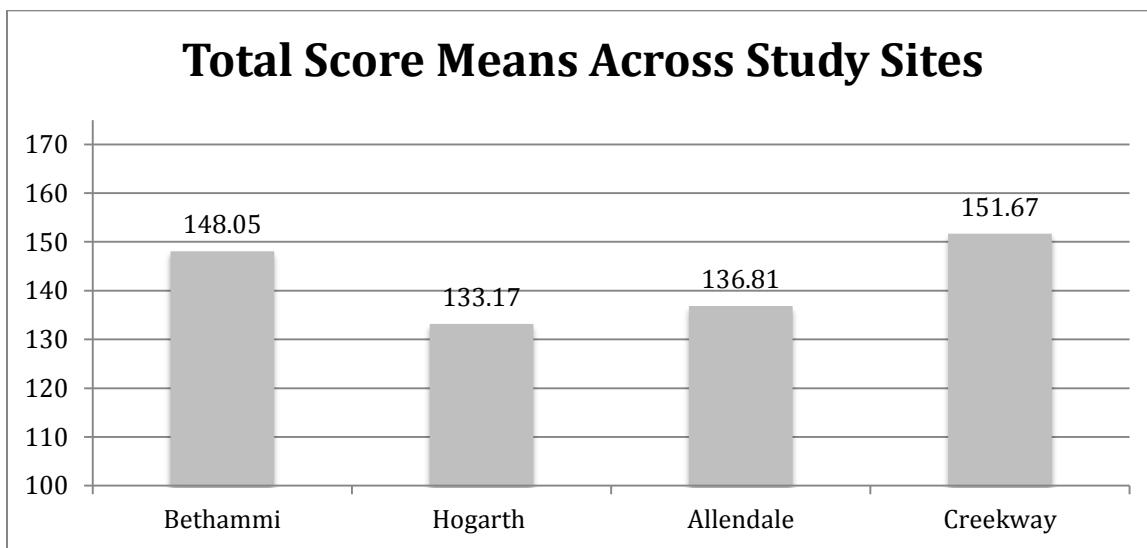
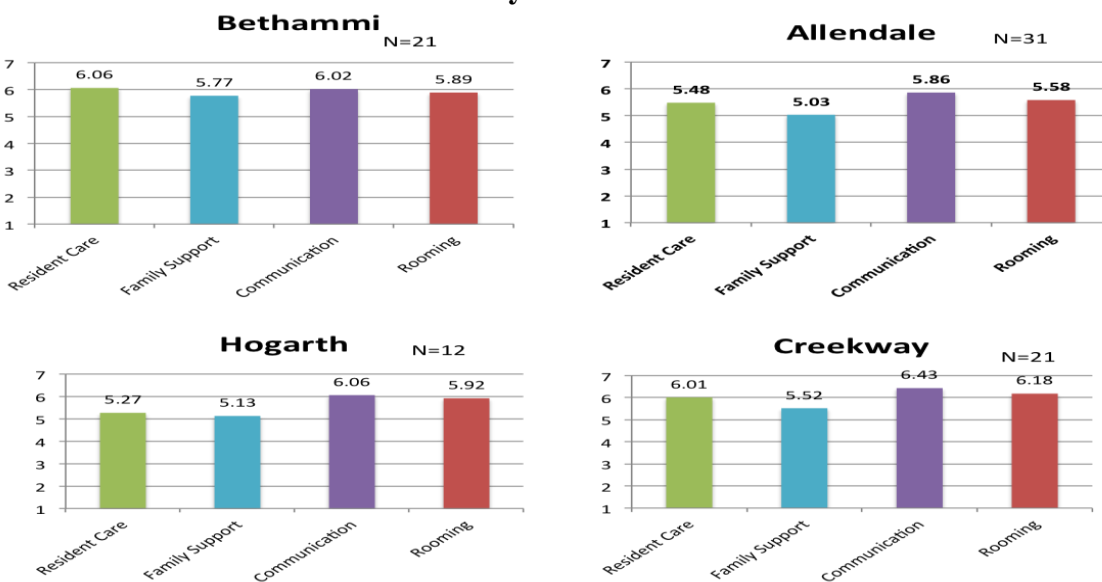


Table 6: Subscale means for each study site



Family members were asked to list the three items on the FPCS that they felt were most important to end-of-life care in long-term care (Table 7). The four items listed the most frequently are found in the resident care and family support subscales. From the choices of family members, it is clear that pain and symptom management is a priority in their satisfaction with end-of-life care. Following this item, residents receiving care with dignity and being relieved of any uncomfortable symptoms were identified as the priorities. Family members also considered being informed and welcomed as important components to quality end-of-life care.

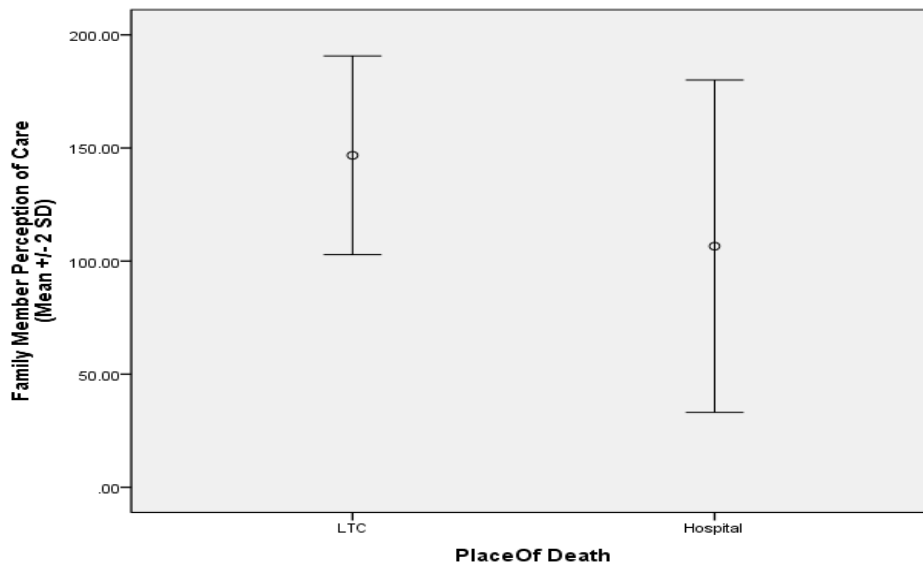
Table 7: Most Important FPCS Items

Question	n (%)
Q14: May family member's pain was eased to the greatest extent possible.	36 (14)
Q2: The staff treated my family member with dignity	32 (12)
Q15: Other symptoms were eased to the greatest extent possible. (E.g. difficulty breathing, coughing, swelling or weakness)	15 (6)
Q6: The staff kept me informed about my family member's health.	13 (5)
Q17: The staff welcomed me to stay with my family member.	13 (5)

The results of the FPCS were analyzed to determine whether the place of the resident's death (long term care vs hospital) was associated with family member satisfaction. An independent-samples *t* test was conducted to evaluate whether there was a difference in participants' satisfaction with end-of-life care depending on whether their family member died in hospital or long-term care. The difference in satisfaction score was statistically significant, $t(22) = 3.25$, $p = .004$. Participants whose family member died in long-term care were more satisfied with end-of-life-care ($M = 146.75$, $SD = 21.96$) than those whose family members died in hospital ($M =$

106.58, $SD = 36.73$). This represents a large, and practically significant effect (Cohen's $d = 1.33$). Table 8 shows the range of means of the two samples.

Table 8: Range of scores- Long Term Care vs. Hospital



QUALITATIVE RESULTS

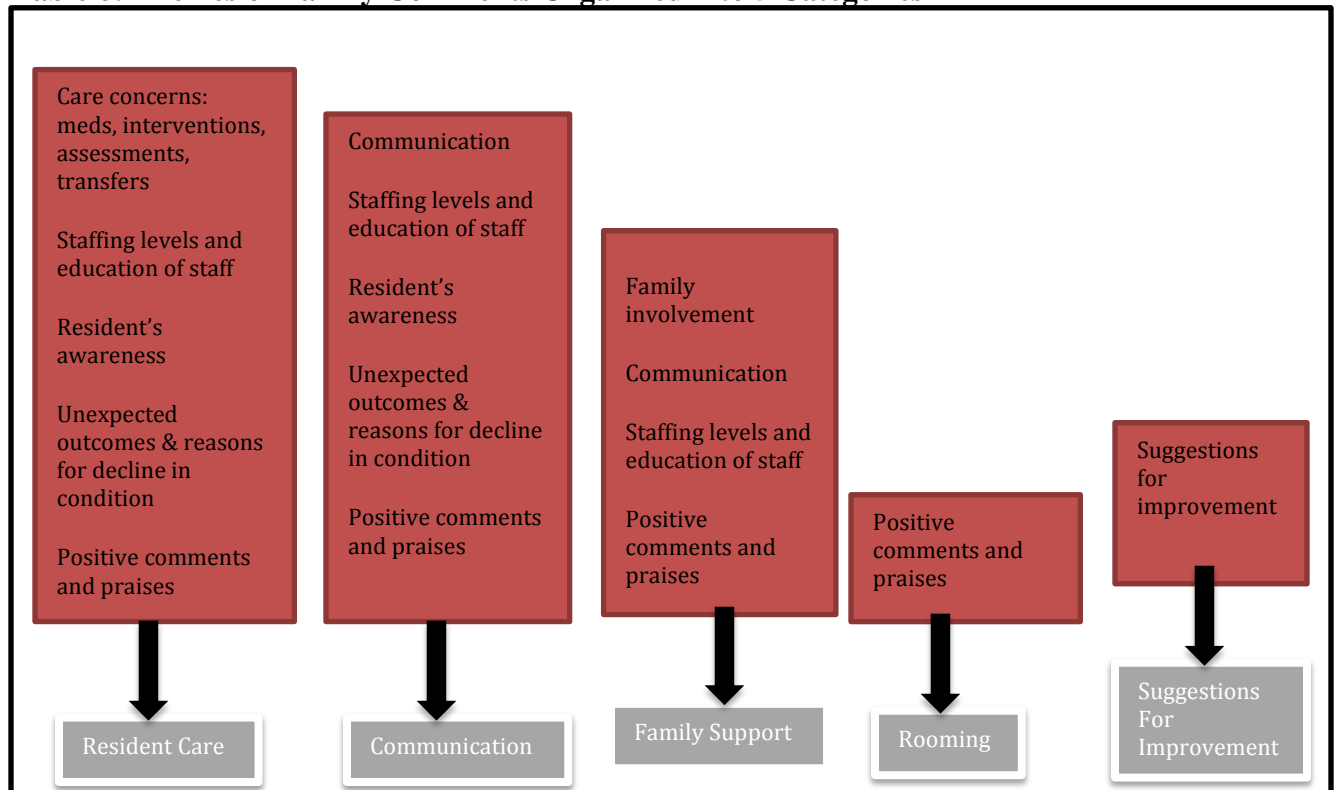
The FPCS also contained one open ended question at the end which invited family members to leave additional comments. Family members were provided a full page to respond to these questions. Fifty-four out of 86 (63%) of the respondents provide comments. Comments reflected both positive and negative experiences. Highlights from comments were grouped into the 4 subscales of the Family Perception of Care Scale. Comments ranged from short 16 –word comments to large 460 word descriptions of their experience.

ANALYSIS. Qualitative content analysis was used when looking at the comments written at the end of the FPCS. According to Zhang & Wildemuth (2009), qualitative content analysis is a method used to “condense raw data into categories or themes based on valid

inference and interpretation” (p. 2). It allows researchers to comprehend the story the data is telling in a subjective and scientific manner. The process of qualitative analysis uses inductive reasoning, which allows for the researcher to capture themes as they emerge from the data and constantly examine and compare how these categories fit in with the story being told. The process used to interpret data for this paper was coding the data and developing categories directly from the raw data (Zhang & Whitemuth, 2009).

In this instance the researcher transcribed the comments into a word document in order to easily code them. The transcription was then put through three levels of qualitative coding. This coding was done in a collaborative setting in which consultation was done with the Principle Investigator of the QPC-LTC project until there was an agreement on how the data should be interpreted. Level one coding consisted of separating the ideas contained in each comment. Level two of coding separated the comments into seven themes that had emerged from the data. Finally, the seven themes were grouped into the 4 subscales identified by the FPSC; (1) *Resident Care*, (2) *Family support*, (3) *Communication*, (4) *Rooming*. Some themes were relevant to more than one category. The theme *Suggestion for improvement* was added to level 3 coding (Table 8).

Table 8: Themes of Family Comments Organized into 5 Categories



Resident care. Comments regarding resident care focused on staff attitudes, knowledge and education and a need for more staff training. The following quote expresses a family member’s perspective of the need for more staff training:

“Some staff need to be more sensitive to last days. Appropriate training would be helpful”

Comments on resident care also reflected concern for broader issues affecting Long Term Care including Staff shortages, changes, availability and time constraints.

“It was my observation the resident to staff ratio is just too high to provide this level of care.”

“My concern is that LTC is the poor cousin”

There were also positive comments praising the care provided to their loved ones at end of life as evident in the comment below:

“I was very impressed with the comprehensive, interdisciplinary palliative care provided to my mother”

Communication. Comments regarding communication focused on the information family receive from staff, staff’s understanding of resident’s wishes and how staff respond to family member requests. A desire for more effective communication was evident in the comment below:

“It was never discussed what her wishes may have been, nor did it occur to me to bring it up. Perhaps this information could be included during the intake process.”

There was a dissatisfaction stated due to family requests not being followed up as well as a desire for family to be more informed about changes in care and resident conditions. Both a satisfaction and dissatisfaction with communication was evident in family members’ comments;

“The advice we received advising us of what to expect made our grieving less painful. Thank you all”

“If anything could be improved I would as to be informed immediately about any medication change and why”

Family support. Respondents stated that comfort for families and family involvement is important. Comments regarding family support touched on the importance of family being able to be there for their loved ones; feeling welcomed and comfortable while their relative reached end of life;

“family members were welcomed and kept well informed”

Family members also indicated that without family member support, residents would not fare as well as their counterparts who had family present;

“for residents without family or someone to be with them, sadly they would have been all alone at this critical time in their lives”

These comments also described what role family members have in supporting their dying relatives such as being involved in decision making, and bringing issues to the attention of the staff. There were comments praising the support received from staff that helped to alleviate family suffering. Respondents stated that providing emotional comfort for families and family involvement is important.

“Not only were the staff concerned about my mom, but they were also sensitive to the needs of myself and other members of my family”

Rooming. Comments indicated that if there was dissatisfaction with the structural environment that family still felt comfortable with the environment because of the professional and friendly atmosphere;

“[the home] was not the newest/most modern, but it was THE most comfortable, friendly and professional”

Family members appreciated being offered privacy near end of life stating concerns about the lack of privacy in semi-private rooms and dynamics with roommates;

“he found it difficult to sleep, as the other gentleman kept the television on all night which interrupted his sleep... Rest is important to all of us, and every person has a right to expect that”

In contrast however, some respondents appreciated being able to stay in their room at end of life.

Suggestions for improvement. Also contained in the feedback were suggestions for improvement. Respondents suggested an increase in staff consistency, an increase in staff knowledge concerning medication; end of life and after death processes and other care needs.

“Perhaps it would be more beneficial to have staff that knew her best assigned to her in the last days/weeks and newer staff assigned to newer patients”

Also suggested was an increase in privacy and more diverse food choices.

“Provide ethnic meals and events to acknowledge our diversity.”

DISCUSSION

Results from the FPCS indicate that satisfaction is most highly related to perceived resident pain control, family support and relationships and resident dignity. Comments from family members indicate that families are also aware of the impact of broader health system and structural issues effecting long term care facilities such as staffing, time constraints and funding. Noteworthy were the lack of comments regarding rooming which suggest that even though long term care homes may offer a new and modern space, the priority for most families remains communication, family support and concerns with resident care. In the 4 long term care homes participating in this research, there were a range of environments from exclusively private rooms to older facilities with shared rooms. Regardless, the physical environment did not emerge as a key priority in satisfaction with end-of-life care.

The results from this study are consistent with findings from Vohra et al., (2004), which used the FPCS within 6 Ontario homes ten years ago. Family members in 2013 were not more satisfied than in 2004. The similarity of the findings further validates the FPCS as a tool that can adequately capture family members perception of and satisfaction with care at the end of life in long-term care homes. However, the similarity may lead one to reflect that the 10 year space between the two studies has seen minimal attention given to improving the experiences of family members of family members as they care for a loved one in long term care. While levels of satisfaction were generally good overall, the areas of greatest concern have not improved.

Researching bereaved family members’ perceptions and experiences of end-of-life care in

long term care can be relevant to competence building, policy implications and a reminder for continuous evaluation of the appropriateness of practice models in long term care homes (Kaarbo, 2011; Liu, Guarino & Lopez, 2012). Also, an understanding of the experience of family members should be considered in order to improve on the care for those who die in long term care homes (Wetle et al., 2005).

Policy Implications

Researching bereaved family members' perceptions and experiences of end-of-life care in long term care has implications for required policy and practice models in long term care homes (Kaarbo, 2010; Liu, Guarino & Lopez, 2012). Currently, in Ontario, there is a policy focus on promoting dying at home and this includes LTC homes. Data from this study, which showed that a home death in LTC was very satisfying to families, demonstrates the ability of LTC homes to provide quality end-of-life care for residents and the benefits of dying in long term care needs to be more well-known in the public. Also, at a health system level, avoiding unnecessary end-of-life hospital transfers improves efficiency and reduces overall costs.

In Ontario there are gaps in the policies that aim to improve dying in long term care. In the Ministry of Health and Long-Term Care's Long-Term Care Homes Act of 2007, the only provision given to palliative care is that specialized training programs must be available to staff who provide care to residents (Long Term Care Homes Act, 2007) The Act's regulations state, "every licensee of a long-term care home shall ensure that every resident receives end-of-life care when required in a manner that meets their needs" (2010). This overarching policy does not guide practice nor does it indicate that family should be included in determining what is deemed quality care.

The comments from family members in this study highlight their perception that low

staffing levels are hindering desired communication and support. In Ontario there is no mandatory, minimum care standard that Ontario long-term care homes are legislated to meet, and staffing and care levels in Ontario's nursing homes are below the national average (CUPE, 2013). The need for adequate staffing to make quality palliative and end-of-life care a reality and is something that family members see as an important indicator to quality care at the end of life. With the growing number of people set to enter long-term care homes in the next twenty years, there is an increasing need to enhance staffing levels for palliative care measures. If staffing numbers and care hours standards are first of all necessary to carry out proper palliative care in long-term care settings, and second of all an indicator of family satisfaction, then adequate staffing needs further recognition in Ontario long-term care policies.

Furthermore, the Ontario Senior Strategy (2012) put the focus on increasing funding to home care services over the next three years, but I argue, with long term care becoming a common site for death among the Ontario population it cannot be ignored by provincial funding agencies (Sinka, S., 2012). According to the Quality Hospice Palliative Care Coalition of Ontario (2011), palliative care can be delivered wherever Ontarians can die including, long-term care homes. Long-term care homes currently have a lack of health care staff with consistent and standardized education and expertise in palliative care. In order to improve the delivery of palliative care long-term homes need to improve their understanding of the role they play in delivering palliative care. The focus on improvements in long-term care homes should look to enhance the palliative care experience for residents and their families (Quality Hospice Care Coalition of Ontario, 2011).

Advance Care Planning and Education

Participants were more satisfied when the resident died in the LTC home than when the death occurred in hospital. This suggests the need for more resident and family education on the benefits of receiving palliative care in the LTC home, the “appropriateness” of hospitalization at the end of life and the importance of advanced care planning early in the illness trajectory (Vohra et al., 2004). According to Ramsbottom & Kelley (2014), “Implementing effective advance care planning can improve patient and family satisfaction with care and increase the likelihood that people will die in their setting of choice”(p.1). Lack of discussion with the resident and the resident’s substitute decision-maker, most commonly a family member, about end-of-life wishes can lead to unnecessary transfers to the acute hospital (Ramsbottom & Kelley, 2014).

Furthermore the Palliative Alliance states that a long-term care homes would benefit from having a resource team available to provide palliative care information and education to residents and families (Palliative Alliance, 2014). Additionally, Quality Hospice Palliative Care Coalition of Ontario (2011) states that all settings of death need to improve information provided to caregivers such as developing “a simple pamphlet and supporting toolkit for caregivers that raise awareness and provide guidance” (p.39).

Quality improvement

Quality improvement programs in LTC should collect the identified key satisfaction indicators routinely from bereaved families. Results from this research show that bereaved family members are able to offer valuable information that has the potential to be utilize by administrators on long term care homes. Good survey response rates with extensive open-ended comments made by 63% of respondents in this research demonstrated family members’ desire to share their experiences on this topic. This indicates that homes should routinely invite family

members to return to the home after the death of a family member to aid in quality improvement. Including bereaved family members in assessing care delivery may not only help the home to understand their role and practice at end of life but also provide the bereaved family members an opportunity to reconnect with the home as well as receive grief and bereavement support from professionals and peers. Also, as stated by Kaarbø, (2011) family members are eager to contribute to the provision of care, indicated a sense of “solidarity with future patients and families” (Kaarbø, 2011, p.1130). Long term Care homes should utilize the FPCS to routinely evaluate family members perception of the care provided to their loved ones.

Future research

Further investigation into understanding family perceptions of quality care at the end of life would benefit from a larger sample in order to more confidently generalize the results from the FPCS. Further development of the FPCS to assess for the influence of other variables such as dementia, nature of the relationship with the POA, frequency of POA visits, could provide an even more comprehensive picture of the experience. Also, an examination into the perceptions of end-of-life care from various cultural perspectives needs to be integrated into the research on bereaved family members.

Using the FPCS in a large scale controlled intervention study in which one group of LTC homes offers palliative care programs while the others do not, can help to evaluate the benefits of formalized palliative care programs that are recently being implemented into long term care homes. Furthermore, investigating the role of social work in the homes studied could help to define the role of social work with families in long term care homes as well as highlight whether or not differences exist in satisfaction with end-of-life care in homes in which have a social worker position.

Limitations

This study sample may not be representative of all long-term care homes in Ontario. The four homes that participated were involved in the QPC-LTC project since 2009, which aims at improving quality of life for people who are dying in long term care. It is possible that lower satisfaction scores would be found in homes that did not have such initiatives being implemented. However, the initiatives facilitated by the QPC-LTC project were predominantly organizational and policy orientated, direct family and resident inclusion was very minimal.

Moreover, the respondents were powers of attorney for personal care that were contacted to complete the FPCS. This individual may not have been the person in the resident's life in the best position to speak to the day-to-day end-of-life care experience. Although they are legally connected to the resident there is a potential that family dynamics or history may have placed a good friend or other relative in a more appropriate position to speak to the care provide to their loved one.

CONCLUSION

Research into the experiences of bereaved family members and what they consider to be quality care has the potential to expand LTC homes ability to respond appropriately to the needs of residents receiving palliative care and approaching end of life. Results of the FPCS can not only influence how the homes provide their care but also can aid in the creation of more comprehensive policies to enhance long term care homes ability to provide quality care at the end of life. Most importantly, including family members in quality improvement and program development practices insures that family members are represented as an important part of the unit of care in long term care recognizing that they "have their own

unique perspectives of the care delivered to their loved ones at the end of life” (Thompson, et al., 2008, p. 42).

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APPENDIX A: THE FAMILY PERCEPTION OF CARE SCALE

**Family Perception of Care
(Family Member)**

Section 1 – Personal Information:

1. What year was your friend or relative born?

2. Did your friend or relative die in the long term care home?

Yes

No

3. If they died in a place other than the long term care home. Where did this occur?

Hospital

Hospice or palliative care unit

Other – please specific

4. If they died in a place other than the long term care home how long before they died where they transferred?

Less than 24 hours

More than 24 hours but less than a week

Between one and two weeks

More than two weeks but less than one month

More than one month

5. When did your family member pass away? If possible provide date/month/year.

6. What gender was the person who died?

Male

Female

7. How long had they lived in the long term care home?

Less than 3 months

3 months but less than 6 months

6 months then less than 12 months

12 months or more

8. What is your relationship to the person who died?

Husband

Son

Wife

Daughter

Partner

Daughter in law

Sister

Son in law

Brother

Niece

Grand daughter

Nephew

Grand son

Friend

9. In what year were you born?

10. What is your gender?

Male

Female

Section 2 – Your Experience

Instructions:

Please circle the number that best describes how you feel about the **care given to your family member during his/her last 4 weeks of life**. There are no right answers to any of these questions. Please circle only one response. In the survey, “staff” refers to anyone who was providing care at the long-term care facility.

	Strongly Disagree	Disagree	Mildly Disagree	Neutral	Mildly Agree	Agree	Strongly Agree
1. The staff were friendly to me.	1	2	3	4	5	6	7
2. The staff treated my family member with dignity	1	2	3	4	5	6	7
3. The staff spent enough time with my family member.	1	2	3	4	5	6	7
4. The staff provided comfort to my family member.	1	2	3	4	5	6	7
5. The staff were sensitive to the needs of my family member.	1	2	3	4	5	6	7
6. The staff kept me informed about my family member's health.	1	2	3	4	5	6	7
7. The staff kept me updated based on what I wanted to know.	1	2	3	4	5	6	7
8. The staff spoke to me in a way that was easy to grasp.	1	2	3	4	5	6	7
9. The staff described what to expect as my family member came closer to death.	1	2	3	4	5	6	7
10. The staff informed me about care options during my family member's last days.	1	2	3	4	5	6	7
11. The staff involved me in the planning of care.	1	2	3	4	5	6	7

BEREAVED FAMILY MEMBERS SATISFACTION WITH EOL CARE 44

12. There was a plan of care tailored specifically to the needs of my family member.	1	2	3	4	5	6	7
13. The staff put decisions I made into action quickly, in regards to my family member's care.	1	2	3	4	5	6	7
14. My family member's pain was eased to the greatest extent possible.	1	2	3	4	5	6	7
15. Other symptoms were eased to the greatest extent possible. (E.g. difficulty breathing, coughing, swelling or weakness).	1	2	3	4	5	6	7
16. The staff informed me when they thought that death was at hand.	1	2	3	4	5	6	7
17. The staff welcomed me to stay with my family member.	1	2	3	4	5	6	7
18. The staff helped me to be involved in the care of my family member.	1	2	3	4	5	6	7
19. My family member was placed on an appropriate floor/unit.	1	2	3	4	5	6	7
20. My family member's room offered privacy.	1	2	3	4	5	6	7
21. Chaplaincy services were at hand for my family member.	1	2	3	4	5	6	7
22. The staff asked about the rites and rituals of my family.	1	2	3	4	5	6	7
23. There was someone there for my family member to talk to.	1	2	3	4	5	6	7
24. There were enough staff to deal with my concerns.	1	2	3	4	5	6	7
25. Overall, I am satisfied with the end of life care that was given to my family member.	1	2	3	4	5	6	7
26. Please list, in order, the three questions in this survey that you think are the most important for excellent end of life care.	1. Question #1 _____ 2. Question #2 _____ 3. Question #3 _____						

If you feel that there are factors that are important to end of life care that are not covered on this survey, please print them, along with any additional comments below. Feel free to continue your comments on a separate page if need be.

**Thank you for completing this survey
to help us understand your views.**

APPENDIX B: INFORMATION LETTER TO FAMILIES



St. Joseph's Hospital
Corporate Office
P.O. Box 3251
35 Algoma St. N.
Thunder Bay ON P7B 5G7
Tel (807) 343-2431
Fax (807) 345-4994

Balmoral Centre
667 Sibley Dr.
Thunder Bay ON P7B 6Z8
Tel (807) 623-6515
Fax (807) 623-4988

Behavioural Sciences Centre
300 Lillie St. N.
Thunder Bay ON P7C 4Y7
Tel (807) 623-7677
Fax (807) 623-7697
Toll Free 1-888-423-5862

Hogarth Riverview Manor
300 Lillie St. N.
Thunder Bay ON P7C 4Y7
Tel (807) 625-1110
Fax (807) 623-4520

Lakehead Psychiatric Hospital
P.O. Box 2930
580 Algoma St. N.
Thunder Bay ON P7B 5G4
Tel (807) 343-4300
Fax (807) 343-4373

Sister Margaret Smith Centre
301 Lillie Street N.
Thunder Bay, ON P7C 0A6
Tel (807) 684-5100
Fax (807) 622-1779

St. Joseph's Health Centre
710 Victoria Ave. E.
Thunder Bay ON P7C 5P7
Tel (807) 624-3400
Fax (807) 624-3401

St. Joseph's Heritage
63 Centre St.
Thunder Bay ON P7A 4J2
Tel (807) 768-4400
Fax (807) 768-8820

www.sjcg.net

INFORMATION LETTER FOR BEREAVED FAMILY SURVEY

2013

I am contacting you as you are the power of attorney for personal care of a resident who lived in Hogarth Riverview I know that your family member has recently died and I am very sorry for your loss and the loss of your family. Given your recent experience, I am hoping that you are willing to share your perceptions of the care you and your family member received in the long term care home towards the end of life.

At the long term care homes, we have a goal to improve palliative and end of life care delivery. To help achieve our goal, we have partnered with the Palliative Care in Long-Term Care Alliance based at Lakehead University, led by Dr. Mary Lou Kelley. We have been working since 2009 with this Alliance on a project to develop palliative care programs in our homes. Our project is being sponsored by the Social Sciences and Humanities Research Council (SSHRC) of Canada and is being conducted by Dr. Mary Lou Kelley of Lakehead University and a team of researchers from across Canada and internationally.

In the next few weeks, we will be sending you a copy of a questionnaire in which we will ask you about your experiences with the care of your family member living in LTC. The survey will take about 30 minutes to complete and will be mailed to you along with a stamped self-addressed envelope addressed to Dr. Kelley. You can return the completed survey directly to her at Lakehead University. The survey will be totally anonymous. No identifying information you or the resident will be collected. Only the administrator of the long term care home who sent you the survey will know that you received a survey.

Completing this survey is completely voluntary, and you may choose not to participate. If you think that another family member is more appropriate to complete the survey please feel free to pass it along to that person. A staff member of the long term care home will make one follow up call about two weeks after you receive the survey to ensure you received the survey and answer any questions you may have about it.

Care **Compassion**
Commitment

All information gathered throughout this project will be kept strictly confidential and accessed only by the research team. The survey results will be provided to the long-term care home management in a way that protects the anonymity of individual participants. As a participant in the study, we will be happy to provide you with a report that summarizes the survey results.

This study has been approved by the Research Ethics Boards of Lakehead University and St. Joseph's Care Group. If you have any concerns regarding your rights as a research participant, or wish to speak to someone other than a research team member about this research project, you are welcome to contact the:

Chair, Research Ethics Board	St. Joseph's Care Group	580 N. Algoma St.	Thunder Bay, Ontario P7B 5G4	Phone: 807-343-4300 ext. 723	Email contact for Chair: REB_Chair@tbh.net
Chair, Research Ethics Board	Lakehead University	955 Oliver Rd	Thunder Bay, Ontario P7E 5E1	Phone: 807-343-8283	Email contact for Chair: research@lakeheadu.ca

Should you have any questions about this study, please feel free to contact me at chow@tbh.net or (807) 768-4408 or Dr. Mary Lou Kelley at (807) 766-7270 or mkelley@lakeheadu.ca. Thank you for your interest and involvement in this project. We look forward to working with you and others at [name of facility].

Sincerely,

ST. JOSEPH'S CARE GROUP

Paulina Chow, BAdmin, CHE
Vice President, Long-Term Care Services

APPENDIX C: FOLLOW UP LETTER TO FAMILIES

Dear Family Member and/or Power of Attorney:

This package is in follow up to the recent information letter you received from Paulina Chow, VP of on Long Term Care Services. You are the power of attorney for personal care of a resident who lived in Hogarth Riverview Manor. I know that your family member or friend has recently died and I am very sorry for your loss. Given your recent experience, I am hoping that you will complete this survey to share your thoughts on the care you and your family member or friend received towards the end of life at Hogarth Riverview Manor.

St. Joseph's Care Group is working with the Palliative Care in Long-Term Care Research Alliance based at Lakehead University to improve palliative care and end of life care in long term care homes in Thunder Bay and nationally. The experience and opinions of friends and family members closest to the residents receiving care are extremely important and valuable to meet our goal. This survey is being given to family members and friends of residents who recently died in four long term care homes in Ontario. If you think it is more appropriate for another family member or friend to complete the survey instead of you please feel free to pass it along to that person.

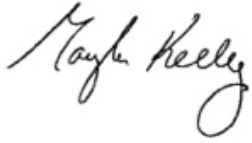
Completing the Family Perception of Care survey is voluntary, and you may choose not to complete it. If you complete the survey, you will remain anonymous and your name will never be used in any report or presentation. All answers to the surveys will be summarized together by the research team at Lakehead University before they are shared with the managers and staff of Hogarth Riverview Manor and other long term care homes. The research team does not know the identities of those who complete the surveys.

The survey can be returned in the enclosed addressed envelope. The survey will take about 30 minutes to complete. A staff member from Hogarth Riverview Manor will make one follow up call approximately two weeks to confirm you received the survey and answer any questions you may have about it.

A summary of the survey findings will be shared with participants in person through an advertised meeting and on the project website (www.palliativealliance.ca) upon completion of the project. Should you have any questions about this survey, please feel free to contact me at (807) 766-7270.

On behalf of the Quality Palliative Care in Long Term Care Alliance research team I would like to thank you for your contribution and involvement.

Sincerely,

A handwritten signature in cursive script that reads "Mary Lou Kelley". The signature is written in black ink and is positioned to the left of the typed name.

Dr. Mary Lou Kelley
Professor
School of Social Work

APPENDIX D: INDIVIDUAL HOME REPORTS

Quality Palliative Care in Long Term Care (QPC-LTC) Alliance
Results from Family Perceptions of Care Survey (Family Member)
Allendale (2013)

What is this report?

This report is one of a series that communicates the results of surveys completed in Allendale Long Term care Home during February and March 2013.

The objective of this survey was to collect information about family members' perceptions of end-of-life care in long-term care facilities.

59 surveys were sent out and 31 family members returned this survey (52%). The results from the survey were entered into a statistical program called SPSS for analysis.

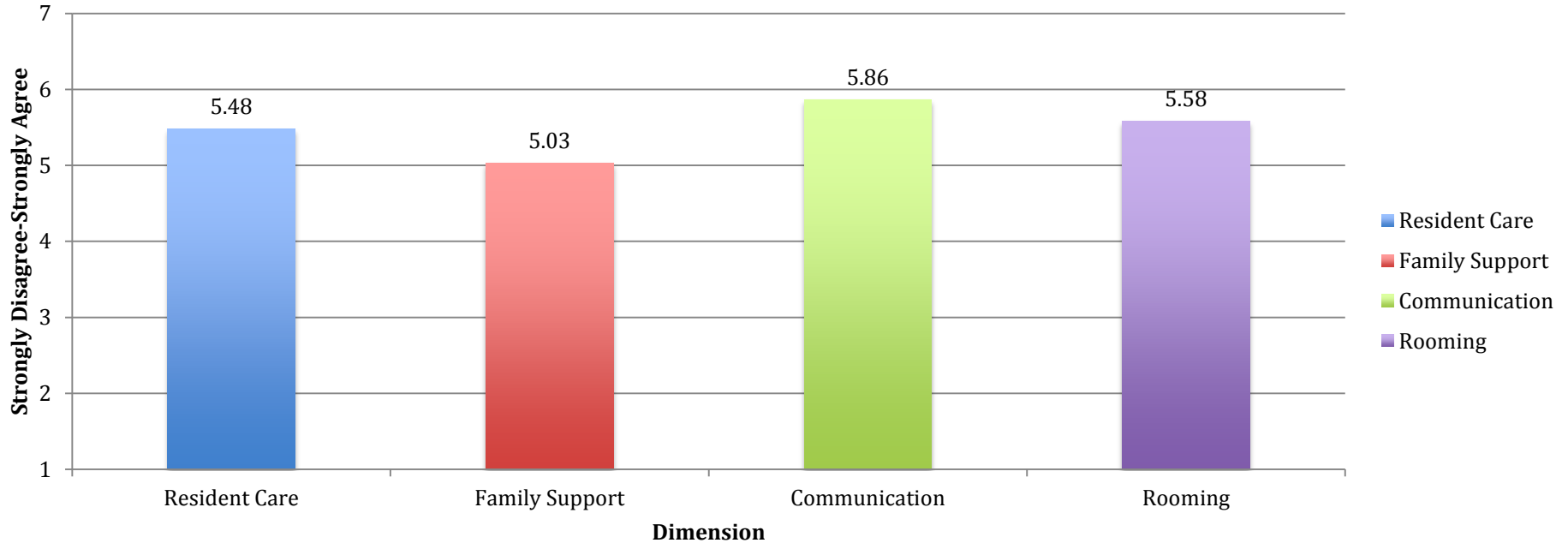
What is the Family Perceptions of Care survey?

The *Family Perception of Care* survey assesses family members' perceptions of end-of-life care in long-term care facilities. The Survey has four dimensions: 1) Resident Care, 2) Family Support, 3) Communication and 4) Rooming.

These dimensions are defined in the table below:

Subscale	Definition	Example
Resident Care	Family members' opinions of care provided to the resident.	"The staff treated my family member with dignity".
Family Support	Refers to care provided by the LTC facility that is directed towards family members to assist them with decision making, and to provide education, emotional, and spiritual support.	"The staff informed me about care options during my family member's last days".
Communication	Concerning the timelines, comprehensiveness, and clarity of the communication between staff and the family member.	"The staff kept me informed about my family member's health".
Rooming	Family members' perception of appropriated placement of the resident in the facility, and privacy.	'My family member's room offered privacy'

Average for each Dimension



Summary of Demographic Information

Age range of Respondents=
39-84

Respondents stated their relationship to their family member:

Daughter:	16 (52%)
Son:	9 (29%)
Wife:	3 (10%)
Granddaughter:	1 (3%)
Sister:	1 (3%)
Daughter in Law:	1 (3%)

Respondents indicated where their family member died:

In Allendale: **26 (84%)**
In Hospital: **5 (16%)**

Respondents indicated how long their family member lived in Allendale:

Less than 3 months:	2 (6%)
3 months but less than 6 months:	3 (10%)
6 months but less than 12 months:	6 (19%)
12 months or more:	20 (65%)

Family members were asked to rank what questions they considered to be the most important. The most frequently stated answer was:

Question #14 - My family member's pain was eased to the greatest extent possible

The last section of the survey asked for general comments. Comments were made by 23 of respondents, which reflected both positive and negative experiences.

Highlights from comments when grouped into the subscales include.

RESIDENT CARE

“staff are overworked and not cared enough by the region”

“my concern regards the awareness of health providers who failed to notice his condition”

“I was very impressed with the comprehensive, interdisciplinary palliative care provided to my mother”

FAMILY SUPPORT

“It is totally necessary for families to be involved in care. We were lucky we could do this. For the residents who did not have family around it was sad”

“they [staff] did a great job and kept my mom comfortable and fed as she came each day...before my dad died”

“it would have been helpful to have a better understanding of what to expect in the last day or so.”

COMMUNICATION

“The advice we received advising us of what to expect made our grieving less painful. Thank you all”

“it would have been helpful to have a better understanding of what to expect in the last days or so”

“the staff continuously kept me informed of his condition”

ROOMING

“he found it difficult to sleep, as the other gentleman kept the television on all night ... Rest is important to all of us, and every person has a right to expect that”

“It's a pretty beak place to go and die”

Quality Palliative Care in Long Term Care (QPC-LTC) Alliance

Results from Family Perceptions of Care Survey (Family Member) Bethammi Nursing Home (2013)

What is this report?

This report is one of a series that communicates the results of surveys completed in Bethammi Nursing Home during February and March 2013.

The objective of this survey was to collect information about family members' perceptions of end-of-life care in long-term care facilities.

32 surveys were sent out and 21(67%) family members returned this survey. The results from the survey were entered into a statistical program called SPSS for analysis.

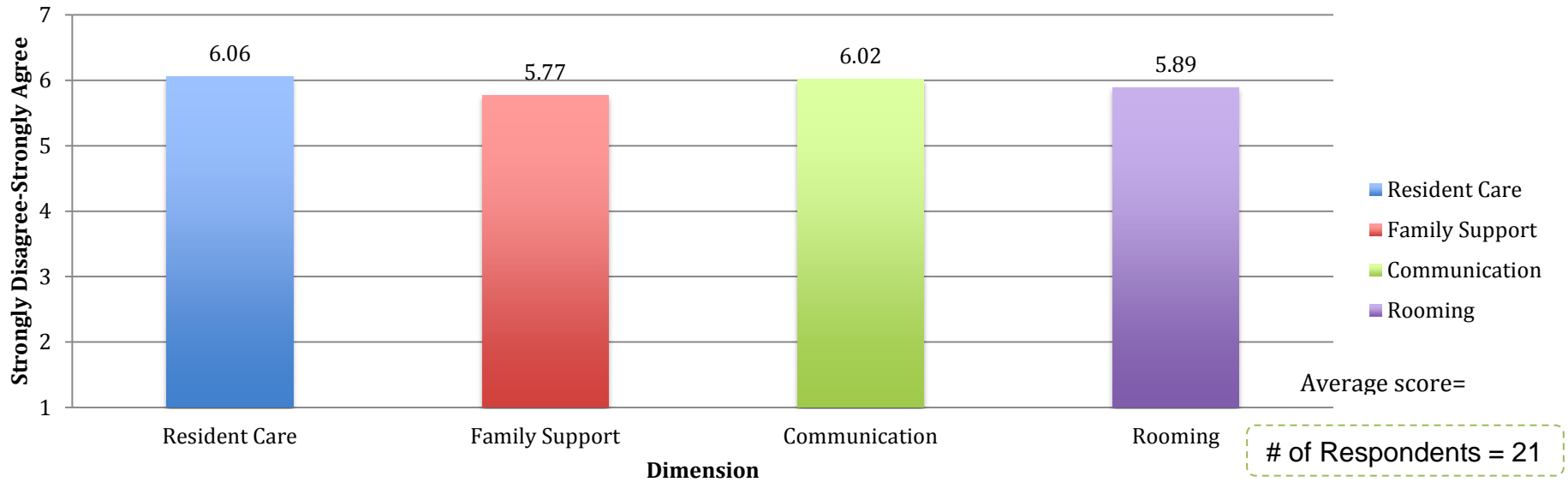
What is the Family Perceptions of Care survey?

The *Family Perception of Care* survey assesses family members' perceptions of end-of-life care in long-term care facilities. The survey has four dimensions: 1) Resident Care, 2) Family Support, 3) Communication and 4) Rooming.

These dimensions are defined in the table below.

Subscale	Definition	Example
Resident Care	Family members' opinions of care provided to the resident.	"The staff treated my family member with dignity".
Family Support	Refers to care provided by the LTC facility that is directed towards family members to assist them with decision making, and to provide education, emotional, and spiritual support.	"The staff informed me about care options during my family member's last days".
Communication	Concerning the timelines, comprehensiveness, and clarity of the communication between staff and the family member.	"The staff kept me informed about my family member's health".
Rooming	Family members' perception of appropriated placement of the resident in the facility, and privacy.	'My family member's room offered privacy'

Average for Each Dimension



The mean total score = 149 out of a possible 175
 Percentage of Satisfaction = **85%**
 15/21 scored 80% or higher

Summary of Demographic Information

Age range of Respondents=
50-84

Respondents stated their relationship to their family member:

Husband:	1 (5%)
Wife:	1 (5%)
Daughter:	10 (48%)
Son:	7 (33%)
Sister:	1 (5%)
Friend:	1 (5%)

Respondents indicated where their family member died:

In Bethammi: **17 (81%)**
 In Hospital: **4 (19%)**

Respondents indicated how long their family member lived in Bethammi:

Less than 3 months:	2 (10%)
3 months but less than 6 months:	0 (0%)
6 months but less than 12 months:	0 (0%)
12 months or more:	19 (90%)

Family members were asked to rank what questions they considered to be the most important. The most frequently stated answer was:

Question #14 - My family member's pain was eased to the greatest extent possible

The last section of the survey asked for general comments. Comments were made by 12 (57%) of respondents, which reflected both positive and negative experiences.

RESIDENT CARE

“The staff at Bethammi did their best to provide additional care and to improve his quality of life”

“Only concern I had was the sometimes small number of staff who had to care for so many high needs people”

“Provide ethnic meals and events to acknowledge our diversity[to improve quality of life]”

“Some staff need to be more sensitive to last days. Appropriate training would be helpful.”

COMMUNICATION

“I would have appreciated staff to be more direct and specific about approaching end of life.”

“It was never discussed what her wishes may have been, nor did it occur to me to bring it up. Perhaps this information could be included during the intake process.”

“family members were welcomed and kept well informed.”

ROOMING

“Our only regret is that it is an overcrowded and old facility”

“Bethammi nursing home was not the newest/most modern, but it was THE most comfortable, friendly and professional”

“My mother was moved to a private room 1 week prior to her passing. It would not have been as

FAMILY SUPPORT

“The staff brought us comfortable chairs for us and snacks in case we were going to be there. We were also offered supper if we wished”

“[the staff] moved a patient out of room so ----- could have quiet which I could appreciate.

Quality Palliative Care in Long Term Care (QPC-LTC) Alliance Results from Family Perceptions of Care Survey (Family Member) Creekway Long Term Care (2013)

What is this report?

This report is one of a series that communicates the results of surveys completed in Creekway during February and March 2013.

The objective of this survey was to collect information about family members' perceptions of end-of-life care in long-term care facilities.

43 were sent out 21 family members returned this survey (48.8%). The results from the survey were entered into a statistical program called SPSS for analysis.

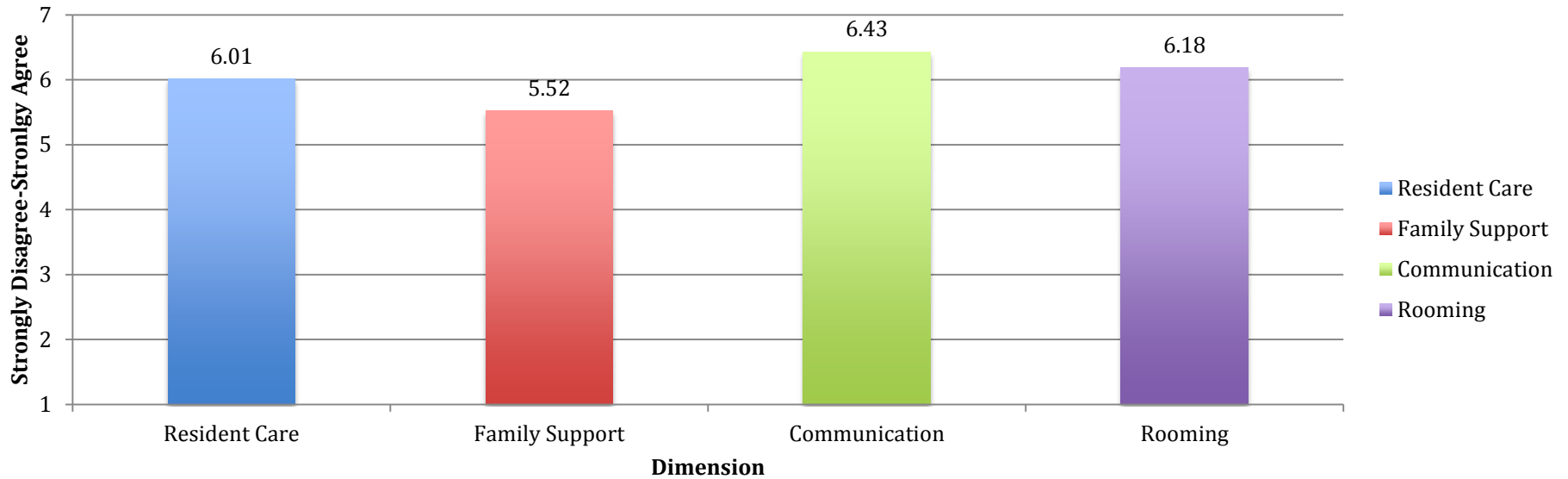
What is the Family Perceptions of Care survey?

The *Family Perception of Care* survey assesses family members' perceptions of end-of-life care in long-term care facilities. The survey has four dimensions: 1) Resident Care, 2) Family Support, 3) Communication and 4) Rooming.

These dimensions are defined in the table below.

<i>Subscale</i>	<i>Definition</i>	<i>Example</i>
<i>Resident Care</i>	Family members' opinions of care provided to the resident.	"The staff treated my family member with dignity".
<i>Family Support</i>	Refers to care provided by the LTC facility that is directed towards family members to assist them with decision making, and to provide education, emotional, and spiritual support.	"The staff informed me about care options during my family member's last days".
<i>Communication</i>	Concerning the timelines, comprehensiveness, and clarity of the communication between staff and the family member.	"The staff kept me informed about my family member's health".
<i>Rooming</i>	Family members' perception of appropriated placement of the resident in the facility, and privacy.	'My family member's room offered privacy'

Average for Each Dimension



Summary of Demographic Information

Age range of Respondents= **50-78**

Respondents stated their relationship to their family member:

Daughter:	12 (57%)
Son:	7 (33%)
Friend:	1 (5%)
Daughter in Law:	1 (5%)

Respondents indicated where their family member died:

In Creekway: **21 (100%)**
 In Hospital: **0 (0%)**

Respondents indicated how long their family member lived in Creekway:

Less than 3 months:	3 (14%)
3 months but less than 6 months:	2 (10%)
6 months but less than 12 months:	0 (0%)
12 months or more:	16 (76%)

Family members were asked to rank what questions they considered to be the most important. The most frequently stated answers were:

**Question #2- The staff treated my family member with dignity
and
Question #14- My family member's pain was eased to the greatest extent possible**

The last section of the survey asked for general comments. Comments were made by 13 (62%) of respondents, which reflected both positive and negative experiences.

Highlights from comments when grouped into the subscales include (there were no comments pertaining to rooming):

RESIDENT CARE:

“the level of staff stayed the same yet the residents needed more care”

“I have nothing to say except how excellent they were treated right until the end with pride, comfort and dignity.

My friend felt totally cut off from the world. I really believe she just gave up. Even though she had COPD she would fight it-but no longer cared anymore.”

FAMILY SUPPORT:

“Not only were the staff concerned about my mom, but they were also sensitive to the needs of myself and other members of my family.”

It was so nice to know that my Mom was so highly thought of during her time at Creek Way and that my family and I were not going through this alone

“the kitchen staff brought us our meals and a “comfort cart” with coffee tea, fruit ect. Without even being asked.”

COMMUNICATION

“[the doctor] was only a phone call away”

“If anything could be improved I would as to be informed immediately about any medication change and why.”

“I was impressed by the caring comments and provisions that they provided me during that period ”

Quality Palliative Care in Long Term Care (QPC-LTC) Alliance

Results from Family Perceptions of Care Survey (Family Member) Hogarth Riverview Manor (2013)

What is this report?

This report is one of a series that communicates the results of surveys completed in Hogarth Riverview Manor Long Term care Home during February and March 2013.

The objective of this survey was to collect information about family members' perceptions of end-of-life care in long-term care facilities.

18 surveys were sent out and 12 (66.7%) family members returned this survey. The results from the survey were entered into a statistical program called SPSS for analysis.

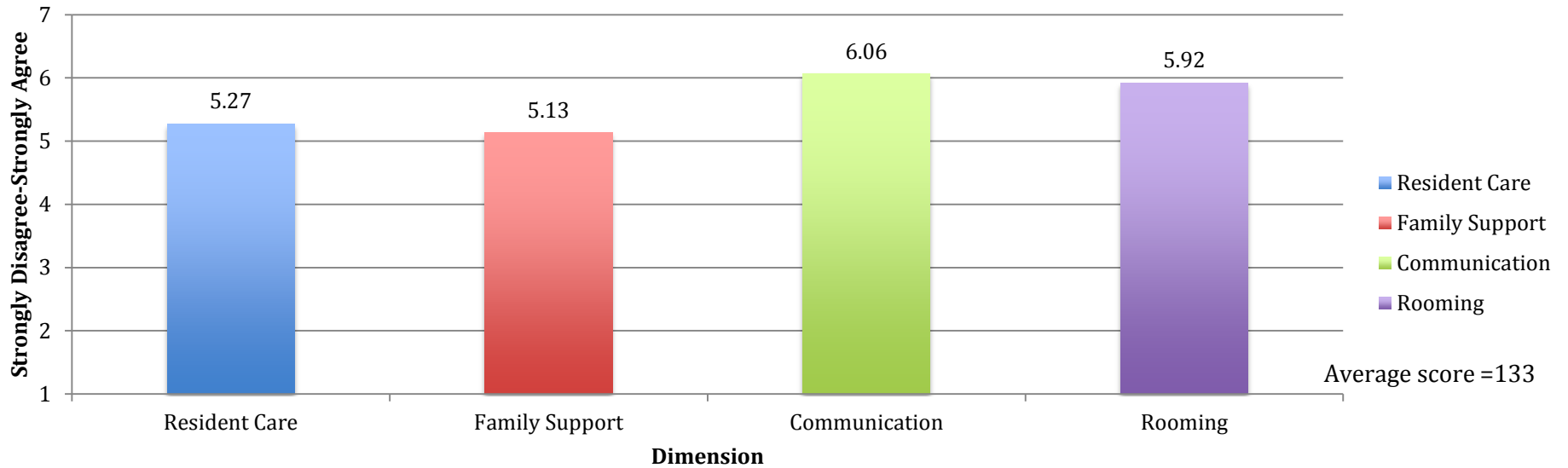
What is the Family Perceptions of Care survey?

The *Family Perception of Care* survey assesses family members' perceptions of end-of-life care in long-term care facilities. The survey has four dimensions: 1) Resident Care, 2) Family Support, 3) Communication and 4) Rooming.

These dimensions are defined in the table below.

<i>Subscale</i>	<i>Definition</i>	<i>Example</i>
Resident Care	Family members' opinions of care provided to the resident.	"The staff treated my family member with dignity".
Family Support	Refers to care provided by the LTC facility that is directed towards family members to assist them with decision making, and to provide education, emotional, and spiritual support.	"The staff informed me about care options during my family member's last days".
Communication	Concerning the timelines, comprehensiveness, and clarity of the communication between staff and the family member.	"The staff kept me informed about my family member's health".
Rooming	Family members' perception of appropriated placement of the resident in the facility, and privacy.	'My family member's room offered privacy'

Average for each Dimension



Summary of Demographic Information

Age range of Respondents= 53-88

Respondents stated their relationship to their family member:

Daughter:	4 (33%)
Wife	3(25%)
Son:	3 (25%)
Husband:	1 (8.3%)
Daughter in Law:	1 (8.3%)

Respondents indicated where their family member died:

In Hogarth: 9 (75%)
 In Hospital: 3 (25%)

Respondents indicated how long their family member lived in Hogarth:

Less than 3 months:	1 (8.3%)
3 months but less than 6 months:	0 (0%)
6 months but less than 12 months:	1 (8.3%)
12 months or more:	10 (83%)

Family members were asked to rank what questions they considered to be the most important. The most frequently stated answers were:

- **Question #2- The staff treated my family member with dignity**
- **Question #17- The staff welcomed me to stay with my family member**

Some of the highlights from the comments when grouped into the subscales include:

The last section of the survey asked for general comments. Comments were made by 8 (67%) of respondents, which reflected both positive and negative experiences.

RESIDENT CARE:

“Staff be better trained on options and medical practices related to end of life care”

“What I noted for the most part was that staff did not have enough time to address the many medical, let alone emotional needs of my father.”

“Just because someone has dementia that doesn’t mean they don’t feel the disrespect”

“I was deeply moved by the care and compassion shown to my father and myself”

COMMUNICATION:

“I again explained to them that all we wanted was to keep him comfortable and allow him to pass away in peace in his home”

“There should be more communication between nurses and staff”

“End of life options must be done with family members on a personal face to face basis with a palliative care professional”

FAMILY SUPPORT:

“for residents without family or someone to be with them, sadly they would have been all alone at this critical time in their lives”

“We were able to sit with him over the next 24hours and watch him pass away peacefully”