

**FAMILY PERCEPTIONS AND SATISFACTION  
WITH END-OF-LIFE CARE IN LONG-TERM CARE FACILITIES**

by

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## **ABSTRACT**

The purpose of this study was, first, to further our understanding of the experience of dying in a long-term care (LTC) facility from the perspective of family members and second, to identify the relationships between the various factors which may influence satisfaction with end-of-life care. Using a sequential mixed methods design, a convenience sample of 87 family members completed a survey interview using a modified version of the Toolkit of Instruments to Measure End-of-life Care (TIME) Nursing Home Version in the first phase of the study. Findings from the parametric and non-parametric analyses indicated that family satisfaction with end-of-life care was best predicted by contact and communication with nursing staff, feeling that care provided at the end of life met expectations, staff providing consistent care, feeling that the health care aide listened to their concerns about care and that respondents felt they had received enough emotional support. Being transferred to hospital in the last month of life, dying in a place other than the LTC facility, and respondent age and employment status were all associated with significant mean differences in satisfaction scores. In the second phase, three focus groups were conducted to further explore areas of satisfaction and dissatisfaction with end-of-life care. Focus groups provided confirmation of the findings of the first phase of the study and were instrumental in developing a list of ten recommendations for improvements in end-of-life care delivery. Recommendations for future research are made based on the study results.

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## **DEDICATION**

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## TABLE OF CONTENTS

CHAPTER ONE .....	3
Statement of the Problem.....	3
Introduction.....	3
Purpose of the Study .....	6
Research Questions.....	7
Definition of Terms.....	8
Significance of the Study .....	9
Summary .....	11
CHAPTER TWO - LITERATURE REVIEW .....	12
Conceptual Model.....	12
Measuring Quality .....	12
Quality Health Outcomes Model .....	13
Review of the Literature .....	17
Outcome Measure .....	17
Family Satisfaction with End-of-life Care.....	17
Client Factors .....	22
Individual Characteristics .....	22
Transfers to Acute Care .....	26
Family Characteristics .....	27
System Factors .....	28
Healthcare Provider Factors.....	28

Organizational Factors.....	31
Interventions .....	33
Quality End-of-life Care .....	34
Pain and Symptom Management .....	39
Advance Care Planning .....	41
Communication and Interaction.....	42
Summary .....	45
CHAPTER THREE - OVERVIEW OF THE STUDY.....	48
Introduction.....	48
Study Design.....	48
Characteristics of Mixed Methods Design.....	48
Type of Mixed Methods Design and Model.....	49
LTC Facilities in Winnipeg .....	50
Recruitment.....	51
Ethical Considerations .....	54
CHAPTER FOUR - PHASE I QUANTATATIVE SURVEY METHODOLOGY AND	
RESULTS .....	57
Introduction.....	57
Phase One Methodology.....	57
Data Collection Procedures .....	57
Measures .....	59
Outcome and Interventions.....	61

Domains .....	63
Information and decision-making .....	63
Advance care planning.....	64
Coordination of care. ....	65
Control and respect. ....	65
Physical comfort. ....	66
Surrogate emotional support.....	66
Self-efficacy of family.....	67
Overall ratings.....	67
Nursing contact and communication. ....	68
Health care aide (HCA) contact and communication. ....	68
Outcome – Family Satisfaction with End-of-Life Care.....	69
Global satisfaction. ....	69
Client Factors .....	69
Resident Characteristics.....	70
Age.....	70
Gender.....	70
Diagnosis of Alzheimer’s disease or dementia.....	70
Medical conditions.....	70
Cultural identity .....	70
Religious affiliation. ....	71
Education attainment .....	71

Length of time resided in current LTC facility.....	71
Characteristics of Resident’s Death.....	71
Date of death.....	71
Place of death.....	71
Death a surprise.....	72
Sudden death.....	72
Died in a place wanted to.....	72
Registered with WRHA Palliative Care Program.....	72
Transferred to hospital while residing in LTC.....	72
Transferred to hospital in last month of life.....	73
Respondent Characteristics.....	73
Age.....	73
Gender.....	73
Relationship to resident.....	73
Cultural identity.....	73
Religious affiliation.....	73
Educational attainment.....	74
Employment status.....	74
Income.....	74
Description of current health.....	74
Visitation patterns.....	75
Expectations for end-of-life care.....	75

Time to interview from resident’s death..... 75

Systems Factors ..... 75

    LTC characteristics..... 75

    Staffing..... 76

    Facility size..... 76

    Proprietary status..... 76

    Religious affiliation..... 76

    Physical environment..... 76

Subsequent Psychometric Assessment of the Survey Instrument and Factor

    Analysis ..... 77

    Data Coding and Assessment..... 77

    Reliability Assessment..... 79

    Factor Analysis ..... 81

Data Analysis Plan..... 84

PHASE ONE- RESULTS ..... 88

Demographic Characteristics..... 88

    Descriptive Analyses of Demographic Characteristics ..... 88

        Family respondent..... 88

        Resident..... 91

    Characteristics of the Death of the Resident..... 92

    System Factors ..... 93

        LTC facility..... 93

Descriptive Statistics of Results on Modified TIME Instrument .....	94
Client Factors .....	94
Family Expectations of Care.....	94
Interventions .....	96
Care and Concern for the Resident .....	96
Physician Contact and Communication .....	98
Consistent Care of the Resident.....	99
Family Knowledge and Confidence.....	100
Advance Care Planning .....	102
Nursing Contact and Communication.....	103
Health Care Aide Contact and Communication.....	105
Pain and Symptom Management .....	105
Spiritual, Psychosocial and Bereavement Support .....	107
System Factors .....	109
LTC Environment .....	109
Outcome .....	110
Satisfaction with End-of-life Care .....	110
Testing for Relationships between Client, Intervention, System Factors and Overall Satisfaction.....	112
Client Factors .....	112
Resident and family characteristics. ....	112
System Factors .....	117

LTC environment.....	117
Interventions .....	118
Correlations Between TIME Subscales and OSAT .....	121
Multivariate Analysis.....	123
Summary .....	128
<b>CHAPTER FIVE - PHASE II: FOCUS GROUP METHODOLOGY AND RESULTS</b>	
.....	130
Focus Group Questions.....	132
Focus Group Data Analysis .....	132
Phase Two: Focus Group Findings.....	135
Demographic Characteristics of Focus Group Participants.....	135
Dissatisfied Focus Group Results .....	137
Characteristics of a Good Death .....	137
Focus Group Themes: Dissatisfied with Care .....	139
Lack of Knowledge in End-of-life Care .....	139
Lack of Communication .....	142
Inadequate Physician Contact.....	144
Lack of Process or Policy for End-of-life Care .....	145
Consequences of Dissatisfaction with Care.....	147
Recommendations.....	148
Satisfied Focus Group Results.....	151
Characteristics of a Good Death .....	151

Focus Group Themes: Satisfied with Care .....	152
Support and Attention .....	152
Communication and Information Sharing .....	154
System Factors: Staffing, Physician Presence, and Transfers to Hospital.....	156
Recommendations .....	159
Summary .....	161
CHAPTER SIX - DISCUSSION AND CONCLUSIONS .....	163
Family Satisfaction with End-of-life Care in Long-Term Care.....	163
Communication and Interaction with Care Providers.....	164
Pain and Symptom Management .....	169
Physician Presence and Contact .....	172
Staffing and Staff Education .....	174
Psychosocial, Spiritual and Bereavement Support .....	176
Hospital Transfers and Location of Death .....	178
Advance Care Planning .....	179
Demographic Characteristics of the Respondent and Resident .....	182
Summary .....	182
Study Limitations.....	184
Recommendations.....	188
Implications and Recommendations for Further Research.....	190
Conclusion .....	192
REFERENCES .....	194

APPENDIX A	LTC FACILITY DIRECTORS STUDY INFORMATION.....	225
APPENDIX B	PARTICIPANT STUDY INFORMATION.....	229
APPENDIX C	ETHICAL APPROVAL LETTERS.....	232
APPENDIX D	TELEPHONE SCREENING TOOL.....	236
APPENDIX E	VERBAL (TELEPHONE) CONSENT FORM.....	239
APPENDIX F	FACE-TO-FACE SURVEY CONSENT FORM.....	241
APPENDIX G	MODIFIED TIME QUESTIONNAIRE.....	245
APPENDIX H	FOCUS GROUP CONSENT FORM.....	271

## LIST OF TABLES

Table 1. Quality Care Domains for Persons Near the End of Life .....	37
Table 2. Variables Examined in the Study .....	60
Table 3. Reported TIME Domains and Reliabilities .....	63
Table 4. Internal Consistency Reliability Analysis of TIME Instrument .....	80
Table 5. Results of Factor Analysis .....	83
Table 6. Descriptive Statistics for Family Respondent (N= 87).....	90
Table 7. Descriptive Statistics of Decedent .....	92
Table 8. Characteristics of Residents Deaths.....	93
Table 9. Physical Environment of the LTC Facility .....	109
Table 10. Satisfaction Ratings .....	111
Table 11. Results of T-Tests for Resident and Respondent Variables and Overall Satisfaction.....	113
Table 12. Results of T-tests between Characteristics of Resident's Death and Mean Overall Satisfaction Score .....	116
Table 13. Results of ANOVA Testing.....	117
Table 14. LTC Facility Characteristics and Overall Satisfaction Scores .....	118
Table 15. Results of T-Tests for Individual Intervention Questions and Overall Satisfaction.....	120
Table 16. Correlations between Overall Satisfaction and TIME Subscale Scores.....	122
Table 17. Regression Analyses of Significant Respondent Characteristics .....	124
Table 18. Regression Analysis for Variables Characterizing Resident's Death and	

Satisfaction with End-of-life Care .....	124
Table 19. Regression Analyses for Contact and Communication Variables and Overall Satisfaction with End-of-life Care .....	125
Table 20. Summary of Regression Analysis for Variables Predicting Satisfaction with End-of-life Care for Residents in Long-Term Care Facilities .....	127
Table 21. Focus Group Demographic Characteristics (N= 14) .....	136

## LIST OF FIGURES

Figure 1. Quality Health Outcomes Model – modified (reproduced with permission)....	16
Figure 2. Flowchart of Study Protocol.....	52
Figure 3. Resident's Death a Surprise .....	95
Figure 4. Care and Concern for the Resident.....	98
Figure 5. Contact with Physician in Resident's Last Week of Life .....	99
Figure 6. Information Provided by LTC Staff .....	101
Figure 7. Advance Care Plan (ACP).....	103
Figure 8. Pain and Symptom Experience of the Resident .....	107
Figure 9. Staff Discussion about Spiritual and Emotional Issues.....	108

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1. Quality health outcomes model; Figure 2 illustration; Mitchell, PH, Ferketich, S, Jennings, BM. (1998). *Journal of Nursing Scholarship*, 30(1); pp. 44
2. After-death Bereaved Family Member Interview - Nursing Home version; Teno, J.; 2001; URL: <http://www.chcr.brown.edu/pcoc/linkstoinstrumhtm.htm>

## CHAPTER ONE

### Statement of the Problem

#### *Introduction*

Health experts and policy planners have acknowledged that the demand for and need to provide excellent palliative care to a growing population is an emerging health concern in the 21<sup>st</sup> century. Much of this increased demand stems from the fact that individuals are living longer with diseases that significantly impact their quality of life. Additionally, Canada is on the cusp of experiencing an aging of its population in proportions never experienced before. Statistics Canada has projected that by 2026, 21% of Canadians will be aged 65 and over, resulting in one out of every five people being a senior (Statistics Canada, 2005b).

With the aging of the population and advances in medical technology, many individuals will be diagnosed and live longer with once fatal diseases, resulting in an increased need for support from informal and formal care services. While most seniors report their overall health to be relatively good, 83% of all individuals aged 65 and older report being diagnosed with at least one chronic health condition (Lindsay, 1999). Though not all elderly persons will develop disease and disability, approximately 40% of all elderly individuals will live in a nursing home for some period of time (Logue, 2003). Therefore, while Canada experiences a growing cohort of individuals who are not only older but may have some level of disease burden, a greater demand will be placed on formal care services such as long-term care facilities (LTC) to provide care at the end of life.

As an increased number of older adults make a LTC facility their home, these institutions will be faced with providing quality end-of-life care to an escalating number of dying persons. A study examining the patterns of health care use by Manitobans at the end of life, Menec and colleagues (2004) found that 47% of all adult deaths occurred in an acute care hospital, whereas 24% occurred in a LTC facility, 7% in one of the two speciality palliative care units in Winnipeg, 6% while a person received home care and 16% in other locations (Menec et al., 2004). Other researchers have also noted that increasingly more people are dying outside the hospital setting and in the community; either at home or in a LTC facility. A study conducted in Nova Scotia specifically examining the place of death for adult cancer patients noted a shift in the location of death from the hospital to the community over a 5-year period (Burge, Lawson, & Johnston, 2003). They noted that the proportion of deaths that occurred out of hospital rose by 52% from 19.9% to 30.2%. This variability in location of death is not isolated to Canada. A study examining trends in the location of death in the U.S. noted that 58% of persons died in hospital, 22% at home, and 20% in a nursing home (Weitzen, Teno, Fennell, & Mor, 2003).

The research evidence on the state of dying in LTC is relatively sparse. What evidence is available documents residents dying with poorly managed symptoms, in isolation and without much support being provided to their family members; this despite the belief by many nursing home staff that residents they cared for died with dignity and that they would characterized the death as a good death (Hanson & Henderson, 2000; Sloane et al., 2003). Though research has been conducted examining the care of the dying

LTC resident, much of this literature has been descriptive and exploratory in nature, conducted with U.S. samples and often with the focus on eliciting the perspectives of health care providers. What is lacking is an understanding of family members' perceptions of the quality of care provided to their loved one residing in a LTC facility at the end of life and how satisfied they were with that care.

Palliative care espouses that the patient and his or her family are the unit of care (Ferris et al., 2002). Research with families of individuals with life-limiting illnesses has identified that attending to the care needs of families is paramount (Kristjanson, 2003). Care needs can be described not only in terms of the specific needs of families such as receiving timely information about the resident's condition but also in terms of resident care needs that are important to families such as physical comfort (Kristjanson, 2003). What is noted however is that many of these identified needs go unmet. This may not only result in distress and suffering but also some research points to the finding that those families whose needs are met are more satisfied with care (Medigovich et al., 1999). For this reason, it is imperative that family members feel that their needs are being met at the same time that care is being provided to their loved one. Additionally, it is the reason why it is important to elicit from family members their perceptions of the care their loved one received at the end of life.

Much of the research to date on family satisfaction and their perception of care at the end of life has been conducted within the hospital or hospice/in-patient palliative care unit environment; environments which are significantly different than that of LTC facilities. The little empirical work that has been conducted into family perceptions of

end-of-life care provided in LTC offer conflicting results; some substantiate findings that care is less than optimal whereas others have noted high levels of satisfaction with the care provided. However, some studies have very small sample sizes (Goodridge, Bond, Jr., Cameron, & McKean, 2005) or have failed to examine other potential confounders to satisfaction such as expectations of care (Vohra, Brazil, Hanna, & Abelson, 2004). Due to the paucity of research in this area and the recognition that LTC facilities will increasingly be expected to provide excellent care at the end of life to a growing cohort of individuals, a study examining family members' perceptions and satisfaction with the quality of end-of-life care delivered to their loved one was warranted.

### ***Purpose of the Study***

The purpose of this sequential, mixed methods study was to examine the quality of dying in LTC facilities using family informants. In this regard a thorough understanding of the experience of dying in a LTC facility and the relationship between the various factors which may influence satisfaction with end-of-life care may be achieved. In the first phase of the study, quantitative data was collected using a validated tool to measure the relationship between the needs, perceptions of care, family/resident and system characteristics and satisfaction with care provided at the end of life. In the second phase, qualitative focus groups were conducted to probe significant results obtained in the first phase of the study and to explore aspects of satisfaction or dissatisfaction with end-of-life care in more depth.

### *Research Questions*

When conducting mixed methods research, there is a need for both qualitative and quantitative research questions to help narrow the focus of broad purpose statements (Creswell, 2003). Three main research questions that guided this study were:

1. What are family members' perceptions of the quality of end-of-life care and their satisfaction with end-of-life care in the long-term care setting?
2. What do family members identify as areas for improvement in the quality of end-of-life care provided in long-term care facilities?
3. What are the associations between resident and family characteristics, systems characteristics, quality of care and family satisfaction with end-of-life care?

Based on these research questions and the research literature, several hypotheses were postulated including:

1. Family members who are female, older, have lower education levels and income levels will report less satisfaction with care (i.e. identify more areas for improvement).
2. Families will be less satisfied with care received at the end of life for residents who are transferred to hospital and die in hospital.
3. Families who identify unmet needs and/or areas for improvement in care will be less satisfied with care.
4. Family members will report more satisfaction with care when an advanced care plan for the resident is in place.

For the second phase of the study, research questions emerged from the findings

of the first phase. In probing the issues surrounding satisfaction or dissatisfaction with care in small focus groups, broad questions were posed in order to freely explore these phenomena. For example, initially questioning began by having participants describe their experiences of end-of-life care in LTC facilities. Additional questioning focused on exploring aspects of care that either met or failed to meet their expectations and how end-of-life care could be improved.

### ***Definition of Terms***

Family Member - A useful term ‘functional families’ has been proposed to include those individuals that the dying identify as significant to them rather than being solely based on biology (Kristjanson, 1986). Defining family as ‘whom ever is significant’ to that resident appears to have congruence with the philosophy of palliative care. In order to address this concern in the current study which used a retrospective approach, if the individual identified as next of kin on the resident’s record did not feel they played a significant role in the last month of the resident’s life, they were asked to nominate who they felt was a significant person involved with the resident. In this manner, a family member can be represented by a biological relative, a legal relative, significant other or friend.

Long-Term Care - defined as places that provide basic nursing care, assistance in or supervision of activities of daily living and under the supervision of a registered nurse (Manitoba Health, 2005).

End of Life: refers to individuals whom have progressive illnesses that are expected to end in death and for which there is no treatment which can cure the underlying disease

process or substantially alter the outcome of the disease (IOM, 1997).

End-of-Life Care – is care provided to individuals with serious life-limiting illnesses or those experiencing chronic disease complications, where the aim of care is on comfort and not cure (Lynn & Forlini, 2001). Throughout the literature, “end of life” is defined in various ways. Some have described a period of time when palliative care is provided to patients, while others have used the term to describe the actual end of a person’s life. In this study, end of life refers to care provided in the last month of a resident’s life.

Personal Care Home – a facility that provides residents with “personal care” in the regards of (a) basic nursing care under the supervision of a registered nurse, or (b) personal assistance in the activities of daily living, or (c) supervision of activities of daily living, together with goods and services that are specified in provincial regulations as goods and services that are provided as personal care. This may include: meals, including special and therapeutic diets, routine medical and surgical supplies, prescribed drugs, and related preparations approved by the minister, routine laundry and linen services, and physiotherapy and occupational therapy in institutions approved by the minister for such services, and other goods and services approved by the minister (Government of Manitoba, 2002).

Resident – a person who lives in a personal care home (Government of Manitoba, 2002).

### ***Significance of the Study***

“How people die remains in the memories of those who live on” – Dame Cecily Saunders

There is a general recognition for the need to develop meaningful quality measures for end-of-life care. Indeed, Field and Cassel (1997) urge that quality efforts

aim to broaden the understanding of the important elements of end-of-life care for all recipients of care: in this case resident's and their family caregivers. Thus, LTC facilities will benefit from critically examining the care elements and organizational factors that are perceived as indicators of quality from multiple perspectives. However, as it is difficult to ascertain the opinions of residents at the end of life, it is important to solicit the views of their representatives and partners in care; their family members. Several factors coexist to make family satisfaction a significant quality measure. Families play an important role as caregivers in end-of-life care (Zarit, 2004). Additionally, family members frequently serve as both formal and informal proxy decision makers for residents (Guyatt et al., 1995; Levin et al., 1999; Shalowitz, Garrett-Mayer, & Wendler, 2006). As a result, health care providers such as LTC facilities need to recognize families as part of the recipient of care in need of support and information and who have their own unique perspective on care delivered (Zarit, 2004).

It is also imperative to explore the impact of satisfaction of future health outcomes for bereaved family members. A limited number of studies have noted that dissatisfaction with care can be associated with depressive, complicated, and prolonged grief symptoms (Cherlin et al., 2004; Hull, 1990; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Therefore, it is important to understand what factors are the dominant drivers of satisfaction and dissatisfaction with care in order to develop intervention studies to reduce any undue suffering experienced by the resident and their family members and thus the likelihood of complicated grief reactions.

***Summary***

The research problem the study sought to address, the purpose of the study, the research questions, and the significance of the research for health professionals interested in understanding family expectations and satisfaction with end-of-life care within the context of long-term care facilities were described in this chapter.

## CHAPTER TWO - LITERATURE REVIEW

### Conceptual Model

Overall this study is guided by the concepts of quality end-of-life care, satisfaction and perceptions of care. Though Patrick, Engelberg and Curtis (2001) have explicated a conceptual framework for evaluating the quality of dying and death, it focuses on a linear assessment of outcomes and requires the prospective assessment of patient preferences for dying and death. As such, the more generic Quality Health Outcomes Model (Mitchell, Ferketich, & Jennings, 1998) guided the exploration of the relationships between satisfaction, family/resident influence, system and quality end-of-life care. Before describing this model, a brief overview of the issues inherent in measuring quality will be conducted.

### *Measuring Quality*

In order to evaluate quality of care at the end of life, the variables that comprise the different domains must be operationalized into measurable components. One means to achieve this goal is to categorize the variables according to the structure, process and outcomes of care model (Donabedian, 1980). Structural elements emphasize the role of material resources, human resources, and the organizational structure in influencing quality of care. Processes of care are the ‘set of activities that go on within and between practitioners and patients’ (Donabedian, 1980, p.79). These activities are what health care providers, institutions and patients themselves actually do during the delivery of care. Donabedian (1980) stressed that the process of care can be defined by normative behaviours reflective of good practice. These norms are derived from professional

standards or from the ethics and values of society and reflect current best knowledge derived from science. When conducting process evaluations therefore, one dimension researchers need to assess is whether the care provided reflects the appropriate use of the most current evidence.

Finally, outcomes of care reflect the cumulative effect of care on the patient and family. Outcomes of care in care of the dying must extend beyond traditional outcomes such as infection rates and survival, to include quality of life, achieving symptom control, patient and family perceptions and satisfaction with care, dignity and control over decision making (Donaldson & Field, 1998; Stewart, Teno, Patrick, & Lynn, 1999). Failure to include these outcomes would result in an inadequate assessment of many of the domains of quality end-of-life care deemed important by patients, families and health care providers. This was noted in a recent study by Forbes-Thompson and Gessert (2005) who, in using the structure, process, and outcomes model to describe the linkages between these variables within the nursing home environment, used resident quality of life while approaching death and resident satisfaction with care as their main outcome variables.

### ***Quality Health Outcomes Model***

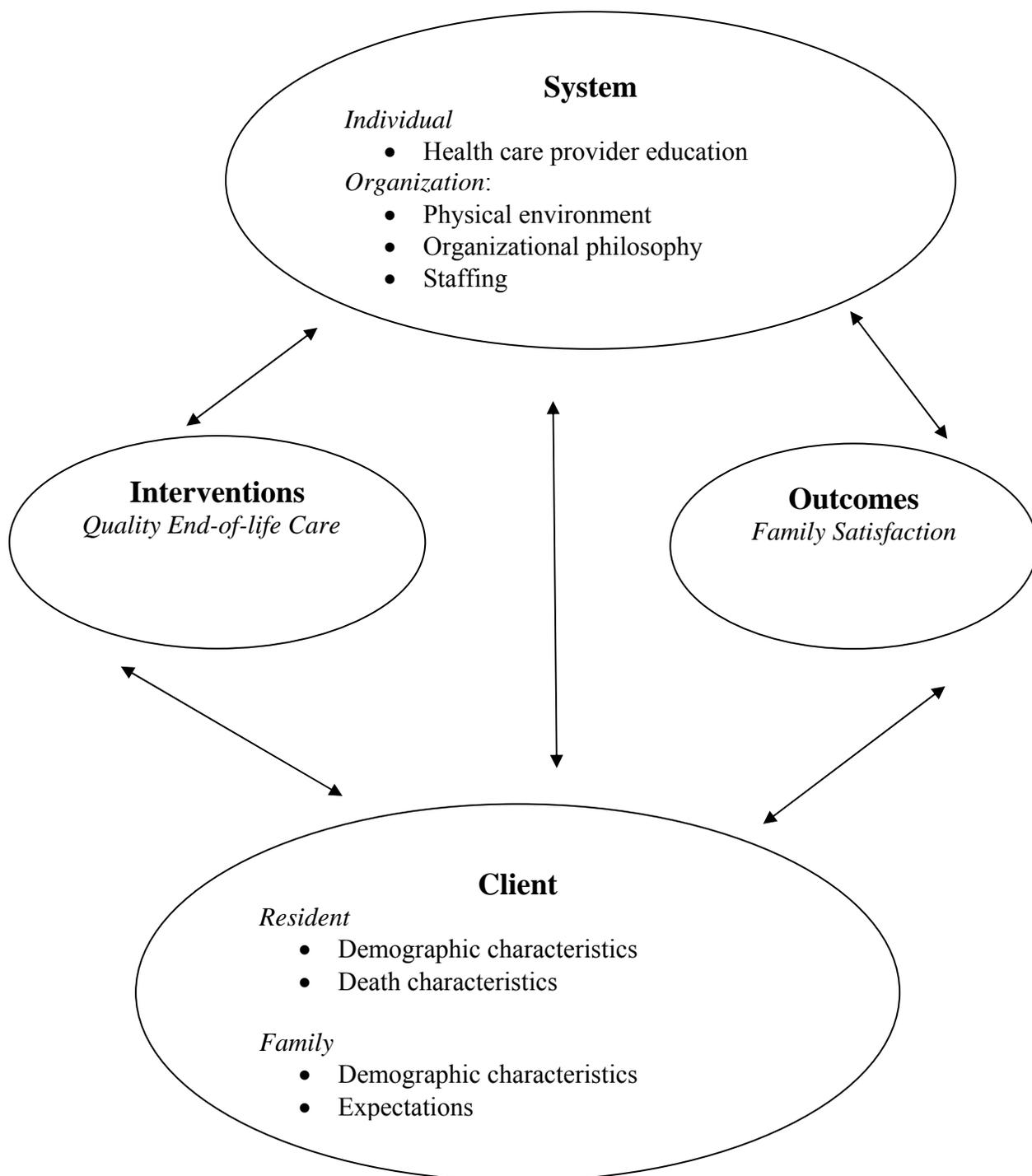
Expanding on Donabedian's (1966) framework of evaluating quality care, the Quality Health Outcomes Model (QHOM) moves from a linear model to one which suggests reciprocal directions of influence in order to acknowledge the dynamic relationships and mediating effects between clients, the context in which care is provided, interventions (i.e. processes of care) and outcomes (Mitchell et al., 1998). For example,

effective symptom management within a LTC facility will be moderated by nursing knowledge (individual system characteristic) and resident characteristics such as having a cognitive impairment or not (client factor). Thus if the family is not satisfied with the symptom management their loved one received, we must examine multiple levels of influence and not simply the failed intervention itself. This model therefore allows a greater depth and breadth of factors to be explored in assessing the outcome of satisfaction with care rather than solely focusing on processes and structures of care.

In the QHOM, system factors are those items traditionally associated with structural elements of care including staffing, education, organizational values and characteristics, and the physical environment. Client factors include patient and family demographics and characteristics such as health status, disease processes, social support, preferences and expectations of care. In the current study, characteristics related to the resident's death such as location of death and transfers to hospital at the end of life are captured under this domain. Interventions are direct and indirect clinical processes (Mitchell et al., 1998), which may include technical aspects of care, symptom management, decision-making, information sharing, and communication styles and processes. Though this model specifically measures the outcome of quality of care, it must be acknowledged that quality as it pertains to end-of-life care is comprised of processes that are captured under the classification of interventions. In this regard, the outcome of interest for the current study is family satisfaction with care. Models incorporating similar structural and process factors suggest that patient and family satisfaction with care are legitimate outcomes of these relationships (Forbes-Thompson

& Gessert, 2005). This QHOM model is represented in Figure 1 found below.

Figure 1. Quality Health Outcomes Model – modified (reproduced with permission).



In summary, the QHOM model provides an integrative way to classify the various factors which may influence family satisfaction with care, thus allowing for the interrelationships among the factors to be examined in order to understand the nature of any causal relationships between these factors and their impact of family satisfaction with quality of end-of-life care.

### **Review of the Literature**

Ensuring that residents dying in LTC settings receive high quality end-of-life care is of paramount importance. However, many factors influence the delivery of such care and many of these intervening factors may also influence family member's evaluation of and satisfaction with such care. The purpose of this section is to present the research literature on the dying experience in the LTC setting and the various factors that influence the delivery of quality end-of-life care. This section will be organized using the conceptual framework presented in the previous section. Specifically the literature will be presented under the broad headings of outcomes, client factors, system factors and interventions. Furthermore, client and system factors will be subdivided into individual, family or organization factors.

### **Outcome Measure**

#### ***Family Satisfaction with End-of-life Care***

Though some people will face death alone, most individuals with a life-limiting illness will have the support of significant others around them. Accordingly, family members observe and evaluate the care delivered to their loved one and are often active participants in the care. As palliative care ascribes to the philosophy that families are

part of the unit of care (Johnston & Abraham, 1995), family members will themselves be recipients of care in the form of emotional support, health education, and bereavement follow-up. Thus as participants, observers, and recipients of care, family members are in an excellent position to evaluate the quality of care received by the resident and themselves.

One of the most frequently used measures to assess the quality of care are satisfaction ratings. Adopted from the marketing and management disciplines, satisfaction is widely accepted to be a legitimate measure of health care quality (Ross, Steward, & Sinacore, 1995). Satisfaction ratings are thought to reflect three variables: (1) personal preferences; (2) expectations; and (3) the realities of the care received (Sitzia & Wood, 1997). It is thus believed that satisfaction ratings are a composite measure of the care received and a general reflection of the respondent.

Much of the research to date has examined satisfaction with care from the patient or consumer's perspective or in terms of general medical care (Linder-Pelz, 1982b; Pascoe, 1983; Ross et al., 1995; Tasso et al., 2002). This body of work has noted that the strongest predictor of overall satisfaction tends to be the nature and quality of the interaction between the patient and the health care provider, and also includes the amount of patient involvement in decision-making and the sharing of information (Coyle & Williams, 1999). Thus it appears that interpersonal aspects of care, specifically empathy and communication, are significant factors influencing quality care assessments. Some authors have noted that this emphasis on the 'caring' of health care as fundamental to satisfaction ratings rather than technical competence may be because a basic level of

competence is assumed by recipients of care and only when this competence appears to be severely compromised will patients report dissatisfaction with care (Sitzia & Wood, 1997).

Though many of the issues surrounding the concept of patient satisfaction may be similar for families and the provision of palliative care, the issue of determining which aspects of care are important to family member's satisfaction with end-of-life care is of concern. Similar to patient satisfaction research, previous research has found that family satisfaction with end-of-life care is associated with the performance of healthcare providers (e.g. competence, effectiveness, accuracy), human and empathetic attitudes of professionals, the degree of information sharing and/or involvement in treatment decision-making, and organization related factors (e.g. cleanliness, cost) (Fakhoury, McCarthy, & Addington-Hall, 1996; Fakhoury, 1998; Kristjanson et al., 1996; Morita, Chihara, & Kashiwagi, 2002).

Others have explored the relationship between unmet needs and satisfaction with end-of-life care. Needs described as being important to family caregivers include patient care needs (e.g. symptom control, comfort care, psychosocial and spiritual support) and the family's own personal needs such as receiving information and social support (Kristjanson, 2003). Some studies have suggested that when families feel that their needs have been met, they are more satisfied with care (Medigovich, Porock, Kristjanson, & Smith, 1999). Dawson's study (1991) found a significant negative correlation between overall satisfaction and unmet need scores ( $r = -0.69$ ,  $p=0.0001$ ) as well as a positive correlation between overall satisfaction and being satisfied with the amount of

psychosocial support provided by the nurse. In Teno and colleagues (2004) study of the care received in the last 48 hours before death, family members who reported the nursing home as the last place of care identified higher unmet needs for pain, concerns that the resident was not always treated with respect, concerns about physician communication and information received about what to expect while the patient was dying, and concerns about the amount of emotional support provided to themselves and their loved one. Overall, care received in the nursing home was significantly rated as the lowest in terms of assessment of the quality of care (41.6% versus 70.7% for home hospice, 46.8% hospital, 46.5% home care with nursing services) (Teno et al., 2004).

Another relationship that has been examined in the literature has been the influence of expectations on ratings of satisfaction. Much of the theoretical work in the area of consumer satisfaction has pointed to the fact that dissatisfaction with care occurs when there is incongruence between expectations of care and the perceptions of care provided (Fox & Storms, 1981; Linder-Pelz, 1982a). Expectations have generally been thought of as internal standards or aspirations, but as Sitzia and Wood (1997) identify, the paucity of empirical work in this area leaves us with little foundation on which to further our understanding of the concept of expectations. However, Linder-Pelz (1982) defines expectations as the ‘belief that a given response will be followed by some event; an event has either a positive or negative valence or affect’ (p.582). Thibault and Kelly (cited in Linder-Pelz, 1982) discuss expectations as when “people evaluate circumstances in relation to those they believe others achieve or in relation to those they have themselves experienced in the past”(p.580).

In examining the effect of expectations on satisfaction with end-of-life care, theoretical work into developing and testing theories of family satisfaction has been met with mixed results. Within the discipline of palliative care, Kristjanson (1991) tested four theories of satisfaction and noted that the discrepancy theory provided the most explanatory power accounting for 68% of the variance in family satisfaction with care. Discrepancy theory indicates that expectations and perceptions will predict the level of satisfaction with care. However, Medigovich and colleagues (1999) noted that only 29% of the variance in family care satisfaction with home hospice care could be explained by discrepancy theory alone. These researchers found that family perceptions of care, family functioning and age explained 54% of the variance in satisfaction scores.

One of the reasons for this difference may be that like the concept of satisfaction, expectations are difficult to conceptualize and thus, measure (Aspinal, Addington-Hall, Hughes, & Higginson, 2003). This raises the issue that assessing satisfaction with care may be imprecise and 'messy' since concepts cannot be clearly conceptualized. Indeed much research literature exists which explicates the difficulties in the measurement of satisfaction as an outcome measure of care (Aspinal et al., 2003; Fakhoury et al., 1996; Kristjanson, 2003). One of the main criticisms in using satisfaction as an outcome measure is that responses on satisfaction surveys have very little variability and a skewed distribution towards high satisfaction (Pascoe, 1983; Ross et al., 1995). Some have concluded that this is simply because families and patients have such low expectations of care although there is inconclusive evidence that a relationship exists between satisfaction and the fulfilment of expectations (Aspinal et al., 2003). Others have

explained that high satisfaction results from respondents feeling indebted to health care professionals, fear of retribution if they complain, feeling that they are powerless to change the situation or that providers are ‘doing the best they can with limited resources’ (Kristjanson, 2003; Sinding, 2003). It has however raised the question as to whether satisfaction is a normally distributed phenomena or one in which a ‘threshold’ operates resulting in the majority of people being satisfied and a minority reporting dissatisfaction with care (Kristjanson, 2003). Others have expressed that interpreting satisfaction ratings is difficult since it is not clear whether respondents actually want improvement in that area or whether they feel this is an acceptable outcome (Morita et al., 2004).

Despite these concerns, measuring satisfaction with the quality of care is an important assessment tool to understand the experience of family members. In order to overcome some of the inherent measurement issues, some authors suggest using a direct approach to questioning, use multi-item scales, and wording questions in the positive rather than negative direction (Aspinal et al., 2003; Kristjanson, 2003; Medigovich et al., 1999; Ross et al., 1995). It is also imperative that any assessment of satisfaction with palliative care assesses the areas deemed important to residents and their family members. Many of these items have been described in the literature and are captured in models of quality end-of-life care which will be addressed in the following section.

### **Client Factors**

#### ***Individual Characteristics***

One of the main challenges in providing end-of-life care in LTC facilities are that residents have chronic health concerns, many of which are not acknowledged as terminal conditions. Thirty-nine percent of all Canadians die each year in LTC (Fisher, Ross, &

Maclean, 2000), and death in this population occurs as a result of many different disease processes. Reynolds and colleagues (2002) in describing the prevalence of symptoms and needs of dying residents in the last three months of life noted that the most frequent causes of death were pneumonia (19%), coronary artery disease (19%), congestive heart failure (19%), cancer (17%) and stroke (10%). This concurs with findings from others who note that residents have a lower prevalence of deaths from malignant disease and are more likely to die from chronic neurological, cardiac and pulmonary diseases (Fisher et al., 2000; Menec et al., 2004); diseases not typically associated with being terminal. This impacts on the provision of palliative care in two ways. First, due to the difficulty in accurately prognosticating life expectancy in many of these chronic conditions, patients may not be eligible for enrolment with formal palliative care programs (i.e. a diagnosis of six months or less to life) (Miller, Teno, & Mor, 2004). Secondly as Sidell and Komaromy (2003) describe, in order to implement a plan of palliative care, the patient must be recognized as dying. Reaching such a conclusion prospectively has been identified as difficult, mainly due to the unpredictability of the resident's disease course and lack of a significant marker indicating the beginning of the terminal phase. However, this characterizes many of the disease trajectories present in the LTC environment; a slow decline with periods of crises and less well defined terminal phases (Shugarman, Lorenz, & Lynn, 2005). Indeed, for many persons with chronic, non-cancer diseases, the last months of life are punctuated with increasing disability and functional decline, high rates of co-morbidity, and fluctuating exacerbations of their primary disease or the development of infections (Jaul & Rosin, 2005). However, often

these 'signals' so to speak are not recognized as being part of the general decline towards death. As such, it is often not clear when active oriented treatment should be curtailed and a plan of comfort care adopted.

One such group of persons in LTC who are especially vulnerable to receiving ongoing interventions are those persons dying from dementia (Sachs, Shega, & Cox-Hayley, 2004). Mitchell and colleagues (2004) noted that nursing home residents dying with advanced dementia were 2.21 times more likely of having a feeding tube, 2.5 times more likely to have laboratory tests performed 30 days before they died, 1.8 times more likely of being in restraints and 1.7 times more likely of having pressure ulcers than those residents dying of terminal cancer. Those dying from dementia were also eight times less likely to have a do not resuscitate (DNR) order than those residents dying from cancer. These findings are troubling in light of the fact that many of these aggressive interventions are characterized as factors contributing to a 'bad' death and as a result may cause suffering and a decreased quality of life in the final months and weeks before death.

Studies examining the profile of LTC residents reveal that over time, the population within LTC facilities has changed, resulting in residents being admitted who are older, frailer and have higher levels of physical and cognitive disabilities (Nolan & Davies, 2000); this implies that those admitted for care are presenting with complex care needs, multiple co-morbidities resulting in disabilities and frailty (Lindsay, 1999; Miller et al., 2004). Lindsay (1999) reports that 95% of institutionalized seniors report having a chronic health condition which caused some level of activity restriction in 80% of those

persons. Those residents already in LTC are becoming frailer as they age and older persons entering LTC are increasingly at a higher level of dependence and thus require extensive care (Komaromy, Sidell, & Katz, 2000). Together these factors have resulted in LTC residents being more dependent for care and requiring a higher intensity of nursing and personal care. The Institute of Medicine's report on the quality of long-term care in the United States noted that nursing homes provide substantial care to persons living with severe mental or cognitive problems and those with other disabling health problems (Institute of Medicine, 2001). Providing care to residents with high dependency and care needs is resource intensive (Clare & De Bellis, 1997), a potential problem in light of the fact that many LTC facilities face significant nursing shortages and high staff turnover, two factors which will be addressed in another section.

The nature of dying in older people who have chronic health concerns other than cancer has been recognized as very different from that of cancer. As such, the care needs and symptom burden experienced by these populations may be quite different. Luddington et al., (2001) conducted a literature review to examine the palliative care needs of patients with non-cancer diseases. They identified that several studies noted that patients with non-cancer diseases were more likely not to get relief from physical distress than those with cancer (57% versus 26%), that patients with non-cancer diseases tend to suffer symptoms for a longer period of time due to the slow progression of the disease and that dyspnea and pain in the last week of life were prevalent in this population (Luddington, Cox, Higginson, & Livesley, 2001). Additional studies have documented that patients with non-cancer disease suffer from less symptoms requiring palliative care

than cancer patients (Casarett, Hirschman, & Henry, 2001). However, one must wonder if this occurs because of the difficulty in assessing symptoms in a person with cognitive impairment or that many of the symptoms experienced by residents are erroneously attributed to being normal consequences of aging and as such, not acknowledged by health care providers as requiring further assessment or treatment. For many residents, therefore, the chronic nature of their illness trajectory “disguises the dying process, making it difficult to plan and provide end-of-life care” (Forbes, 2001, p.39). A consequence of this prognostic difficulty may be that residents are transferred to acute care facilities near the end of life.

### ***Transfers to Acute Care***

Family members have noted that transferring their loved one to a hospital to die or receive treatment is an outcome many wish to avoid (Wilson & Daley, 1999). Despite this desire, hospitalizations near the end of life do occur. Two studies in particular have documented the frequency of transfer from LTC facilities to hospital in the last six months and year of life, respectively (Menec et al., 2004; Travis, Loving, McClanahan, & Bernard, 2001). Menec and colleagues (2004) noted that of the 36.8% of residents who had at least one hospital transfer in their last six months of life, the average length of stay for a hospitalization was 6.4 days and 16.3% died in hospital. This is worrying since Vohra et al., (2004) found that family members were less satisfied with care when their loved one who had resided in a LTC facility died in hospital. The study by Travis et al., (2001) sheds light on possible reasons for transfer to hospitals in the last year of life. These researchers noted that accidental injury, acute conditions (e.g. pneumonia), and

chronic disease exacerbations, most frequently cardiopulmonary failure, were the three main reasons for a resident being transferred to an acute care hospital. Though 19 of the 41 residents had an admission to hospital, 26.8% of the entire sample had between one to three emergency room visits, most frequently for falls that resulted in a laceration (Travis et al., 2001). They also noted that demented persons had slightly higher rates of hospitalization than non-demented residents, though the difference was not statistically significant ( $t = -1.53$ ,  $p = 0.067$ ). However, the main contrast between those who had a hospital transfer to those without was the explicit documentation on the resident's chart clearly stating the wishes of the resident and/or family revealing that open communication between all actors involved had occurred and that staff was committed to honoring those wishes.

### ***Family Characteristics***

Some investigators have explored the relationship between the personal characteristics of the respondent and their ratings of satisfaction with care. Key variables that have been identified as having a relationship with satisfaction include: a) age – older adults tend to rate higher levels of satisfaction; b) gender – women are often more satisfied than men; c) education level – those with less education tend to be more satisfied than the more educated; d) income – those with less income are more satisfied than those with higher income and e) health status – those who state their health is poor tend to express more dissatisfaction with care delivered to their family member (Fakhoury et al., 1996; Fox & Storms, 1981; Kristjanson et al., 1996; Kristjanson et al., 1997; Medigovich et al., 1999; Sitzia & Wood, 1997). However, other researchers have

noted no association between family and resident characteristics and satisfaction with care (Vohra et al., 2004). Limited research has been conducted on other factors which may impact on family satisfaction with care including ethnicity, religious affiliation or strength of religious beliefs, frequency of contact or visitation patterns, family functioning or social support and grief reactions (Fakhoury et al., 1996; Howell and Brazil, 2005; Kristjanson et al., 1996; Talbot, 1995; Vohra et al., 2004). Due to the contradictory nature and the paucity of literature in this area, it is important to assess these variables in future studies on family satisfaction ratings in order to assist in bridging this gap in knowledge.

### **System Factors**

#### ***Healthcare Provider Factors***

As a substantial number of individuals make a LTC facility their final home, health care providers in these facilities will require adequate knowledge and skill in caring for dying persons. Knowledge of the principles of palliative care, adequate educational preparation and the attitude towards death of the health care provider have all been noted to have direct correlations with the quality of care delivered to dying patients (Brockopp, King, & Hamilton, 1991; Proctor, Grealish, Coates, & Sears, 2000; Reissetter & Thomas, 1986; Wendt, 2001). It is troubling to note therefore, that deficiencies in the knowledge and perceived competency of LTC personnel to provide end-of-life care have been described in the literature. One study in particular that interviewed 30 nursing home administrators noted the main obstacle in providing high quality end-of-life care was the educational deficits of staff, physicians and families themselves regarding palliative care principles (Rice et al., 2004).

In assessing the educational needs and concerns of nursing home staff regarding end-of-life care, Ersek and colleagues (2000) discovered that both certified nursing assistants and licensed nursing staff identified several core areas in which they lacked competence. Participants identified symptoms management, communication and interaction, goals of care discussions, and role delineation as areas they felt inadequately prepared for and in which they required further education (Ersek, Kraybill, & Hansberry, 2000). Similar deficiencies in knowledge have been noted specifically in the area of pain assessment and management and the principles of palliative care (Ersek et al., 2000; Forbes, 2001; Jones et al., 2004; Raudonis, Kyba, & Kinsey, 2002). Using the Palliative Care Quiz for Nurses, a 20-item instrument measuring general palliative care knowledge with a group of licensed practical nurses and registered nurses working in LTC, Raudonis, Kybe and Kinsey (2002) found substantial knowledge deficits in all three conceptual categories (palliative care philosophy, symptoms, and psychosocial care) measured by the instrument. This lack of palliative care knowledge is not solely limited to direct care providers. In a survey of directors of personal care homes, Komaromy, Sidell and Katz (2000) found that only 34% were familiar with the hospice philosophy. When questioned about the needs of dying individuals, most participants focused on pain management, maintenance of dignity and ensuring that the person did not die alone; no mention was made of providing family support or spiritual care (Komaromy et al., 2000).

What compounds the concern regarding the lack of educational preparation is that when individuals feel inadequately prepared, discomfort in providing care and feelings of inadequacy ensue (Forbes, 2001). Many providers report ‘not knowing what to say’ to

dying patients and observations of care providers noted that they either withdraw from dying patients or care becomes task-oriented in nature (Forbes, 2001; Kayser-Jones, 2002). This observation has raised concerns by nursing home administrators regarding the impact that educational preparation has on the standard of end-of-life care provided to dying residents (Avis, Jackson, Cox, & Miskella, 1999), especially in light of the staff mix found in many LTC facilities.

Those with the least educational preparation often provide the majority of direct patient care in LTC facilities. As frontline caregivers, nursing aides generally have some secondary education and on the job training or a five month course at a career college (Government of Canada, 2005). This limited educational preparation focuses on the basic physical care of the patient such as bathing, feeding, and repositioning along with assisting nursing staff to provide the day-to-day care of the patient. The lack of formal educational preparation in care of the dying of this provider group has been noted to translate into significant misconceptions about the philosophy of palliative care and feelings of discomfort in providing care to dying persons (Forbes, 2001; Jones et al., 2004).

Physicians are also perceived as lacking skills in providing excellent end-of-life care. Though a study examining the end-of-life care perspectives of LTC physicians found that most were familiar in providing care to dying persons (Bern-Klug et al., 2004), others have noted that nursing staff identify that physicians are reluctant to order regularly prescribed pain medication (Wilson & Daley, 1998). Indeed, nurses noted they perceived physicians' and pharmacists' fears of addiction were powerful deterrents to

obtaining adequate analgesia to control resident's pain (Ersek et al., 2000).

### ***Organizational Factors***

Many LTC facilities pride themselves on their ability to create a home like environment for their residents. This is important in light of research documenting the effects of the physical environment on resident's cognitive functioning, physical well-being and social interaction (Lawton, 1980 cited in Kayser-Jones et al., 2003).

Additionally, in interviews with families and service providers on the elements that influence quality end-of-life care, ensuring privacy, an inviting atmosphere, and the physical environment ranked highly (Brazil et al., 2004; Keegan et al., 2001; Komaromy et al., 2000; Stewart et al., 1999). In an ethnographic study examining the care of the dying in LTC, privacy and space emerged as important themes (Kayser-Jones et al., 2003). When the environment was noisy and when basic supplies for care were lacking, family felt their loved one was not valued nor respected.

A second factor, the proprietary status and institutional size of a LTC facility, may influence the provision of quality end-of-life care to their residents. The general argument made is that non-profit facilities provide better care because their revenues can be used to improve patient care rather than pay shareholders (Hughes & Marcantonio, 1993). One finding in a Canadian study was that in not-for-profit facilities, staffing levels and the mean number of hours spent with residents by both direct-care and support staff was significantly higher (McGregor et al., 2005). It must be noted that some have argued that using proprietary status to classify LTC facilities in Canada is artificial since both

receive the same level of funding from government and therefore may not be as profit driven as those in the U.S. market (Sullivan cited in Berta et al., 2005).

No examination of the relationship between facility size and the care of residents was conducted but studies in the U.S. have noted that facility size can affect quality of care. It is also interesting to note that no studies examining the religious orientation of the LTC facility and quality of care could be found. Thompson-Forbes and Gessert (2005) noted however, that institutional philosophy and leadership values permeated all aspects of care and significantly impacted evaluations of the quality of life at the end of life in nursing home residents.

Final organizational factors identified in the literature in terms of their potential influence on quality care are staffing levels and staff mix. Inadequate staffing levels and high staff turnover are frequently cited reasons by administrators, staff, and family members as to why quality care is not achieved within a LTC facility (Clare & De Bellis, 1997; Ersek & Wilson, 2003; Rantz et al., 2004). Kayser-Jones and colleagues (2003) noted that inadequate staff and lack of certified nursing assistant supervision negatively impacted resident care, most frequently in that the basic care of patients was neglected such as oral care, bathing, repositioning, and providing adequate fluid and food. When there is high staff turnover and staffing shortages the continuity of care is disrupted and health providers are not able to develop strong relationships between themselves and the resident. As such, subtle changes in cognitively impaired patients that may signal increasing pain or the ability to provide important feedback to physicians is impeded. Indeed, in a qualitative study with physicians (n=12), staff shortages and high turnover

were seen to be significant factors that resulted in staff ‘not knowing the patient’ and contributed to disruptions in previously established patterns of communication between staff members (Bern-Klug et al., 2004).

Inadequate staffing can also lead to task oriented care, whereby staff do not have time to provide the ‘extras’ such as psychosocial or individualized care. When care of residents becomes task oriented, it fails to meet resident and family needs and as such, care is of lower quality (Swagerty, Lee, Smith, & Taunton, 2005). When nurses do not have time to sit and ‘be with’ the dying resident as is the case when staffing is less than optimal, nurses express significant stress and feelings of guilt over providing poor quality care (Ersek et al., 2000; Wilson & Daley, 1998). Hanson and colleagues (1997) noted that family members made the least number of positive comments about care providing in nursing home. Negative comments focused on the lack of physician support and poorly educated or inattentive staff (Hanson, Danis, & Garrett, 1997). However, a Canadian study noted high levels of satisfaction with the care provided in six not-for-profit LTC facilities except in the areas of family support, involvement in care planning and decision-making, and staffing levels (Vohra et al., 2004).

### **Interventions**

Interventions, as described in the Quality Health Outcomes Model (Mitchell et al., 1998), encompass processes of care. When examining the determinants of quality end-of-life care as put forth by patients, family members, health care providers and experts, many of the domains which they describe as important are processes of care and as such, are captured under the classification of interventions within this model. To facilitate

discussion, a brief overview of how quality end-of-life care has been defined and the various domains that it encompasses will be presented. This is followed by a more in-depth description of the various processes of care, which have been noted to impact significantly on satisfaction with end-of-life care.

### ***Quality End-of-life Care***

In order to begin to measure quality of care at the end of life, it is essential to first define what is meant by quality. This is not a simple task, due to the familiar yet abstract use of the term in everyday language (Thompson & McClement, 2002). As a first step to unpacking this concept, examining what is meant by a good death provides insight into the elements underscoring quality care. The Institute of Medicine (1997) defines a good death as “one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards” (pg. 24). Emanuel and Emanuel’s (1998) model of a good death consists of eight modifiable dimensions which encompass physical symptoms, social relationships and support, hopes and expectations, psychological and cognitive symptoms, economic demands and caregiving needs, and spiritual and existential beliefs. These domains were further supported by Mak and Clinton’s (1999) review of the literature on what defines a good death. These works highlight the multidimensional nature of quality care at the end of life and the importance of providing care that incorporates and responds to patient and family needs. However, many of the initial works conducted in this area focused on the development of core

categories through literature reviews and expert opinion and tended to reflect a cancer perspective to death and dying.

It has been argued that cancer patients, due to the more immediacy of death, have different end of life tasks and concerns than those with dying from more chronic diseases and disabilities (Lynn & Forlini, 2001). Cancer patients tend to focus on the completion of life's tasks, spirituality, and ensuring symptom control. Though symptom control remains important to those dying from non-malignant diseases especially in terms of reducing cognitive decline, minimizing swallowing difficulties and issues with immobility, there remains an emphasis on ensuring normality in the face of functional decline; trying to continue working, participating in on-going activities, and sustaining relationships (Lynn & Forlini, 2001). The implications of these different tasks near the end of life is that many earlier models failed to delineate from non-cancer patients their perceptions and needs for quality end-of-life care. Thus researchers, in addition to responding to the call for a more patient-centred approach to models of care, have undertaken the task to better understand the underpinnings of quality of care from a variety of perspectives. As such, the perspectives of patients dying from congestive heart failure, chronic obstructive pulmonary disease, end-stage renal disease, HIV, and with cognitive impairments in addition to cancer have been solicited. Along with seeking to understand what constitutes a good death from the perspectives of patients, family members, care providers, and experts have also been integrated into models of care. These efforts have resulted in models that capture the domains of quality end-of-life care that are important to individuals dying from life-limiting illnesses. Table 1 outlining the

various domains of quality end-of-life care is provided below. These various quality of care paradigms, though divergent in some areas, share many commonalities including a focus on: symptom control, communication and knowledge of preferences for care, care of the family, and quality of life at the end of life.

Table 1. Quality Care Domains for Persons Near the End of Life

<b>Authors</b>	<b>Study</b>	<b>Results: Domains of Quality Care</b>
Steinhauser et al. (2000)	Participants: Cancer, COPD, CHF, end-stage renal (n=340); Recently bereaved (6 months-1 year) family (n=332); Physicians (n=361) and other care providers (n=429)  Method: Cross-sectional, stratified random national survey	Pain and Symptom Management Preparation for the End of life Sense of Completion Treatment Preferences Being Treated as a Whole Person Patient's Relationships with HCP
Singer, Martin & Kelner (1999)	Participants: dialysis patients (n=48); HIV patients (n = 40); residents of a long-term care facility (n = 38)  Method: Qualitative study	Adequate pain & symptom management Avoiding inappropriate prolongation of dying Achieving a sense of control Relieving burden Strengthening relationships
Patrick, Engelberg, & Curtis (2001)	Participants: Persons dying from AIDS (n=52); end-stage COPD (n=16); other illnesses (n=47)  Method: Literature review Qualitative interviews and focus groups	Symptoms and Personal Care Preparation for Death Family Treatment Preferences Whole Person Concerns Moment of Death
Keegan et al. (2001)	Participants: Bereaved (8 months to 24 months) family members (n=155)  Method: Critical Incident Technique	Symptom control Access to services Bereavement support Communication & information Personalized care and staff attitudes towards person and family Privacy
Brazil et al. (2004)	Participants: Direct care providers (n=79) in LTC facilities  Method: Focus groups to examine what made a death 'good' versus 'bad' and the strategies for improving the care of dying residents.	Responding to resident needs Creating a homelike environment Supports for families Providing quality care processes Recognize death as a significant event Sufficient institutional resources

Table 1 (Continued)

<b>Authors</b>	<b>Study</b>	<b>Results: Domains of Quality Care</b>
Cherlin et al. (2004)	<p>Participants: Primary family caregivers (n=12) of patients with terminal cancer enrolled in hospice</p> <p>Method: In-depth interviews to identify 'outstanding practices' by clinicians in the last six-months of the patient's life</p>	<p>Respect for the patient</p> <p>Non-abandonment</p> <p>Care of the Family</p> <p>Facilitation of the family process</p> <p>Follow-up after patient's death</p>
Lynn (1997)	<p>Participants: a position statement made by the Ethics Committee of the American Geriatrics Society and 44 other organizations</p>	<p>Physical and emotional symptom management</p> <p>Support of function, autonomy, personal dignity, and self-respect</p> <p>Advanced care planning</p> <p>Aggressiveness of care near death</p> <p>Patient and family satisfaction</p> <p>Overall quality of life</p> <p>Family burden</p> <p>Survival time</p> <p>Provider continuity and skill</p> <p>Bereavement services</p>
Keay et al.,(1994)	<p>Participants:</p> <p>Conducted a literature review examining nursing home medical care for the terminally ill to determine domains for quality indicators. These indicators were refined from input by geriatricians and medical directors</p>	<p>Documentation of pt wishes or advance directive</p> <p>Pain acknowledged and controlled</p> <p>Relief of Dyspnea</p> <p>Psycho-social support</p> <p>Bereavement follow-up</p> <p>Hygiene</p> <p>Symptom control</p>
Teno et al., (2001)	<p>Participants: Experts; Bereaved family members (n=42)</p> <p>Method: literature review</p> <p>Focus groups</p>	<p>Provide desired level of physical comfort &amp; emotional support</p> <p>Promote shared decision-making</p> <p>Focus on the individual</p> <p>Attend to the needs of the family</p> <p>Ensure coordinated care</p>
Howel & Brazil, (2005)	<p>Meta-synthesis to develop a common conceptual framework of quality EOL care using patient and family perspectives.</p> <p>Qualitative studies only</p> <p>35 articles retrieved, 7 met study criteria.</p>	<p>Pain and symptom control</p> <p>Dying process not prolonged</p> <p>Prepared for death</p> <p>Support of family and friends</p> <p>Supported decision making</p> <p>Spiritual support and meaning</p> <p>Holistic and individualized care</p> <p>Death in a supportive environment in a location of choice</p>

### ***Pain and Symptom Management***

Providing relief from pain and other distressing symptoms is the hallmark of excellent palliative care (Ferris et al., 2002). It is therefore troubling to find that many studies document significant inadequacies in the management of pain and other symptoms in dying residents. Residents of LTC by their very nature, have multiple potential sources that may cause pain such as arthritis, diabetic neuropathies, and cardiovascular disease processes. The prevalence of pain reported in the general nursing home population ranges between 45% to 80% (Ferrell, 1995). The persistence of pain was noted in a nationwide U.S. study which documented that of those residents reporting pain on their first assessment, 41.2% were still in pain 60 to 180 days later and that 14.7% of residents reported pain on two physician assessments (Teno, Weitzen, Wetle, & Mor, 2001c). Compounding the adequate treatment of pain is that many residents of LTC have functional impairments either visual, auditory, motor and/or cognitive disorders that impede the ability to assess pain accurately (Ferrell, 1995). However, the effects of unrelieved pain can have severe negative consequences on residents including depression, impaired mobility, and decreased quality of life (Ersek & Wilson, 2003).

When specifically examining those residents who were identified as dying, pain is often reported as being present and inadequately controlled. Kayser-Jones's (2002) ethnographic study of dying in nursing homes noted that pain was not assessed, monitored or managed by staff members. When speaking with residents, they often described their pain as severe and one woman stated her pain was 'more painful than childbirth' (Kayser-Jones, 2002). It appears that many dying residents experience pain;

one study of family members, nurses and health care aides reported 86% of residents had pain in the last three months of life and that 53% had moderate to severe pain (Reynolds, Henderson, Schulman, & Hanson, 2002). However, in a study of nursing home administrators, 64% stated that they had no problems in their facility with pain control and that staff could 'read' and understand the pain experiences of end-stage dementia patients (Moss, Braunschweig, & Rubinstein, 2002). Another issue in ensuring adequate pain management is that reports of pain differ between health professionals. Generally, nursing home staff tend to underestimate pain severity and ratings and nurses aides tended to perceive that residents had more pain than nurses or physicians (Flacker, Won, Kiely, & Iloputaife, 2001).

Unfortunately the presence of symptoms in residents near the end of life is not limited to pain. In one study, researchers noted that patients dying in the nursing home reported more symptom distress and worse functioning on all scales of the EORTC QLQ-C30 questionnaire than those dying in hospital and at home (Jordhoy et al., 2003). Family members were similarly dissatisfied with the control of symptoms in nursing home as compared to assisted living facilities (Sloane et al., 2003). Of presenting symptoms, dyspnea was most frequently identified by family members as being poorly managed (Hanson et al., 1997; Teno et al., 2004). A chart review of 185 decedents' last 48 hours of life revealed that dyspnea was not treated in 23% of cases, whereas noisy respirations and delirium were not treated in 49% and 38% of cases, respectively (Hall, Schroder, & Weaver, 2002). Hanson and colleagues (1997) identified that individuals with congestive

heart failure were most frequently perceived by family members to have the highest rates of unrelieved symptoms.

### ***Advance Care Planning***

One of the most cited difficulties in the nursing home population is the issue of prognostication. Due to the fact that many residents of LTC facilities have chronic, non-cancer illnesses, illnesses that are typically characterized by periods of exacerbation and lack of a clearly defined ‘dying period’, health care providers often cite the difficulty in knowing whether a resident is actually dying. This lack of a clear terminal phase has been identified as a reason for the lack of formal palliative care services being provided in this population along with the fact that many residents are not identified that they are dying until death is actually very near (Brandt et al., 2005). Failing to acknowledge that diseases such as Alzheimer’s are a terminal illness often results in lines of communication between providers and family members being closed and therefore discussions pertaining to advanced care planning may not occur. A nationwide U.S. study found that only 13% of residents had living wills, 51% had directives for do not resuscitate (DNR) orders and only 8% had directives outlining their preferences regarding hospitalization and artificial nutrition (Teno et al., 1997a).

When an environment exists whereby patients and their family members have not had the opportunity to meaningfully discuss the terminal nature of the disease and expected complications or outcomes, implementing an appropriate plan of care is not possible. U.S. studies examining the enrolment of LTC residents in hospice care has

revealed that residents were typically enrolled in hospice only 2 to 7 days before death (Happ et al., 2002). Similar studies point to the fact that hospice care only reaches 1% of the nursing home population and of those nursing home residents who die, 20% received hospice care, most for stays of less than a week (Miller et al., 2004; Zerzan, Stearns, & Hanson, 2000).

One reason cited for the difficulty in providing formal palliative care services to LTC residents is the requirement of physicians to provide a certification that the resident has a terminal prognosis of six months or less; a prognostication which is difficult to make with most disease states affecting LTC residents. Yet when residents receive formal hospice care, family respondents report improved symptom management and a decrease in the need for hospitalizations (Baer & Hanson, 2000). Additionally, hospice care has been illustrated to reduce the use of invasive interventions (e.g. feeding tubes, intramuscular medications), improve the use of daily analgesic medication for pain and reduce the number of hospital transfers at the end of life (Miller, Mor, & Teno, 2003).

### ***Communication and Interaction***

A significant factor that seems to emerge in the literature that affects interaction and communication among residents, staff and family is the lack of physician presence in LTC facilities. Wilson and Daley (1998) note that physicians often only visit once a month, leaving nursing staff with little support and much of the responsibility in the day to day management of patient care. Travis et al., (2002) describes this behaviour by physicians as the ‘practice of medicine by telephone’, which contributes to a reduced

effectiveness in communication between all actors involved. Physicians themselves acknowledged their unwillingness to spend more time in nursing homes but the authors in the study did not delve into why this unwillingness exists (Hanson, Henderson, & Menon, 2002). The remoteness and lack of availability of physicians has been cited by families as contributing to their dissatisfaction with the care received in LTC (Hanson et al., 1997; Sloane et al., 2003). Most often this translates into feelings that information is not shared in a timely manner, that advanced care planning may not occur and that symptoms may not be relieved as quickly as warranted.

The interactions between the resident, family and nursing staff must also be explored. Though early studies examining the care of the dying found that many care providers, who experienced significant death anxiety, isolated the dying individual and withdrew from providing care (Quint, 1967) a slightly different picture emerges in the context of LTC. Since for many individuals the LTC facility is their home and many reside there for a relatively long period of time before the die, nursing staff report a different perception of their level of involvement and responsibility for providing care. Care providers describe strong emotional attachments and connectiveness to residents, often likening themselves as surrogate 'family' (Wilson & Daley, 1998). These feelings of attachment to the residents permeates all aspects of care and in many cases helped care providers develop individualized care plans to meet residents' needs (Ersek et al., 2000). These emotional bonds enhanced and provided meaning to the work of the staff and were a key driver in striving to provide quality end-of-life care. However, these strong

connections also greatly increased their feelings of grief when a resident dies (Ersek et al., 2000).

Though there is a sense among the general population that LTC facilities are a 'dumping ground' for the elderly, research conducted in the field over the last 30 years should dispel this myth (Ross, Carswell, & Dalziel, 2001). To the contrary, when family visitation patterns have been examined, these studies illustrate that visiting by family members occurs frequently and regularly (Friedmann, Montgomery, Rice, & Farrell, 1999; Keefe & Fancey, 2000). Visitation is one of the most common means of sustaining on-going family relationships and providing a link for the resident to the outside world. Researchers have noted the positive effects of family member visitation on resident's well-being and on spousal relationships (Greene & Monahan cited in Keefe & Fancey, 2000). In addition, family members continue to report feeling responsible for the resident's physical and emotional well-being along with a strong sense of responsibility and ongoing worry about the quality of care after PCH admission (Ryan & Scullion, 2000).

The provision of care by family members to their elderly relatives does not end with admission to PCH, indeed both empirical and anecdotal evidence points to quite the contrary. What does change however, is how families perceive their caregiving role within this new environment. Many will enter a period of adjustment involving the redefinition and adaptation of previous caregiving roles as they strive to continue to provide care to their loved one (Keefe & Fancey, 2000; Kelley, Swanson, Maas, & Tripp-Reimer, 1999; Ross et al., 2001). Many families report feeling relief that they are no

longer responsible for the 24-hour care and for many, feelings of responsibility for care remains. The process of family caregiving within the PCH environment requires family members to establish new and meaningful roles and relationships not only with their loved one but with the staff of the PCH (Janzen, 2003).

The dyadic relationship between staff and families within the LTC setting has received little empirical attention to date. However, the little evidence that does exist has focused on the conflicts that may arise when health care providers fail to acknowledge the experience and expertise of the family member, when staff are insensitive to family needs, or when roles overlap or have been rigidly defined (Duncan & Morgan, 1994; Hertzberg & Ekman, 2000; Schwartz & Vogel, 1990). Studies examining relationships between family and staff have provided two typologies depicting the several types of relationships that exist including: collegial, professional, friendship, distant, and tense (Gladstone & Wexler, 2002) or conventional, competitive, collaborative, and carative (Ward-Griffin, Bol, Hay, & Dashnay, 2003). The nature of the relationship that ensues between family member and health care provider is influenced by the nature of family involvement and degree of family centeredness espoused by the nurse (Ward-Griffin et al., 2003). Despite times of conflict between family and care providers, overall families report positive relationships with staff that develop as a result of participation in care decisions, the sharing of experiences and establishing trust (Gladstone & Wexler, 2002).

### ***Summary***

Much of the evidence of care of the dying in LTC is descriptive and exploratory in nature, conducted with nursing home residents, staff and bereaved family members.

Three studies conducted in the U.S. provide profound insight into the realities of the dying experience faced by LTC residents. Forbes's qualitative study (2001) describing the care at the end of life for 13 nursing home residents, found the process of dying to be described by both staff and residents as cold, lonely and painful. Observations noted that staff generally lacked the skills to adequately assess and relieve physical discomfort, a problem compounded by the finding that many staff expressed discomfort with death, therefore limiting their ability to respond to the changing physical and psychosocial needs of the residents. Furthermore, the work environment was task driven and there appeared to be problems with teamwork and communication among staff members (Forbes, 2001).

Many of these findings were echoed in the study by Kayser-Jones and colleagues (2003) which conducted participant observation and in-depth interviews with residents (n=35), their families (n=52), nursing staff (n=66) and physicians (n=36) to examine the factors that influence end-of-life care in a LTC facility. Data analysis revealed an troubling picture of end-of-life care, one that was characterized by a lack of privacy, lack of basic nursing care such as oral hygiene, bathing and adequate food or fluids, inadequate staffing and supervision, and the development of pressure ulcers (Kayser-Jones et al., 2003). Similarly, Hanson and colleagues (2002) noted that in their focus group study of certified nursing assistants, nurses and physicians, participants commented that death was perceived to be characterized by psychological suffering; that many of the residents suffered from loneliness, indignity of dependency and unwanted changes in physical appearance. These three studies highlight some of the inherent issues

in providing quality end-of-life care to individual's dying in LTC and the factors that are important to measure in the quest to further improve and understand quality care at the end of life and family member's satisfaction with such care.

## CHAPTER THREE - OVERVIEW OF THE STUDY

### *Introduction*

The purpose of this chapter is to provide an overview of the study. The first section of this chapter outlines the design used in the study and provides a background on the nature of mixed methods research. Subsequent sections describe the characteristics of LTC facilities in Winnipeg, and how participating facilities were approached. The chapter concludes with ethical considerations taken when conducting the research study.

### **Study Design**

#### *Characteristics of Mixed Methods Design*

Historically, research theorists have argued against the integration of both qualitative and quantitative research methodologies in the same study, resting their arguments on the ideological incompatibility of the methods. This ‘incompatibility thesis’ stemmed from the notion that the core philosophical foundations (constructivism versus positivism) of each method were so divergent that compatibility between the methods was impossible (Teddlie & Tashakkori, 2003). However, the emergence of several seminal works pushing the development of mixed methods as a separate research field replete with its own paradigmatic view (i.e. pragmatism) has led to the general acceptance of mixed methods as an alternative research methodology.

Some may question what the advantage is of combining quantitative and qualitative methods in the same study. The main strength in using a mixed methods design “is that it enables the researcher to simultaneously answer confirmatory and exploratory questions, and therefore verify and generate theory in the same study”

(Teddlie & Tashakkori, 2003, p.15). Additionally, it has been noted that mixed methods are superior to single approach designs in that mixed methods research: (1) provides stronger inferences; (2) provides the opportunity for presenting a greater diversity of divergent views; and (3) can assist in answering research questions that the other methodologies cannot (Teddlie & Tashakkori, 2003). In this manner the mixed methods research design allows for a phenomenon to be explored in greater depth and breadth than one would be able to when only a single method is employed.

### ***Type of Mixed Methods Design and Model***

To meet the objectives of this study, a two phase sequential explanatory mixed methods design was used. When using a sequential approach, the researcher uses the findings from one method to elaborate on the findings from another method (Creswell, 2003). The sequential explanatory strategy involves collecting and analyzing quantitative data in the first phase followed by the collection and analysis of qualitative data in phase two. One of the main reasons for using such a design is to use qualitative findings to assist in the interpretation of the quantitative results (Creswell, 2003). Additionally, it allows for the generalization of findings to the population of interest and assists in the development of a more detailed view of the phenomena at the individual level. In this manner, concepts can be tested and then followed by the development of detailed descriptions with a select group of individuals. Though the method has many strengths including its ease of implementation, the main weakness of the design is the potential for data collection to take a long time. To overcome this limitation, a six-month time frame was established for data collection.

### *LTC Facilities in Winnipeg*

In Winnipeg, there are currently 38 personal care homes accounting for 5,503 beds which are licensed by the Manitoba Personal Care Home Program to provide long-term personal and health services (Manitoba Health, 2006). A 98.5% occupancy rate is reported for licensed facilities in the Winnipeg region (Manitoba Health, 2006). The size of the LTC facilities ranges from 16 to 314 beds. Approximately 70% of beds in LTC facilities are in single rooms (Winnipeg Regional Health Authority, 2006). The annual total deaths of LTC residents are approximately 1400 persons (Menec, 2005).

Residents are admitted to a facility based on a paneling process. An assessment of their level of dependency and need for assistance with activities of daily living, the degree of behavioural problems, personal safety, and availability of informal support comprises the process (Doupe et al., 2006). Residents are assessed on a scale ranging from level one (minimal dependence on nursing time) to level four (maximum dependence in four or more activities). LTC residents who are assigned a level of care of 1 are thought to require about 0.5 hours of nursing care in a 24 hour period whereas those assigned levels 3 and 4 are thought to require at least 3.5 hours of nursing care during this time (Doupe et al., 2006). The majority of individuals admitted to a PCH are classified as either level 3 (39.1%) or 4 (33.4%), indicating a high level of dependency (Manitoba Health, 2006).

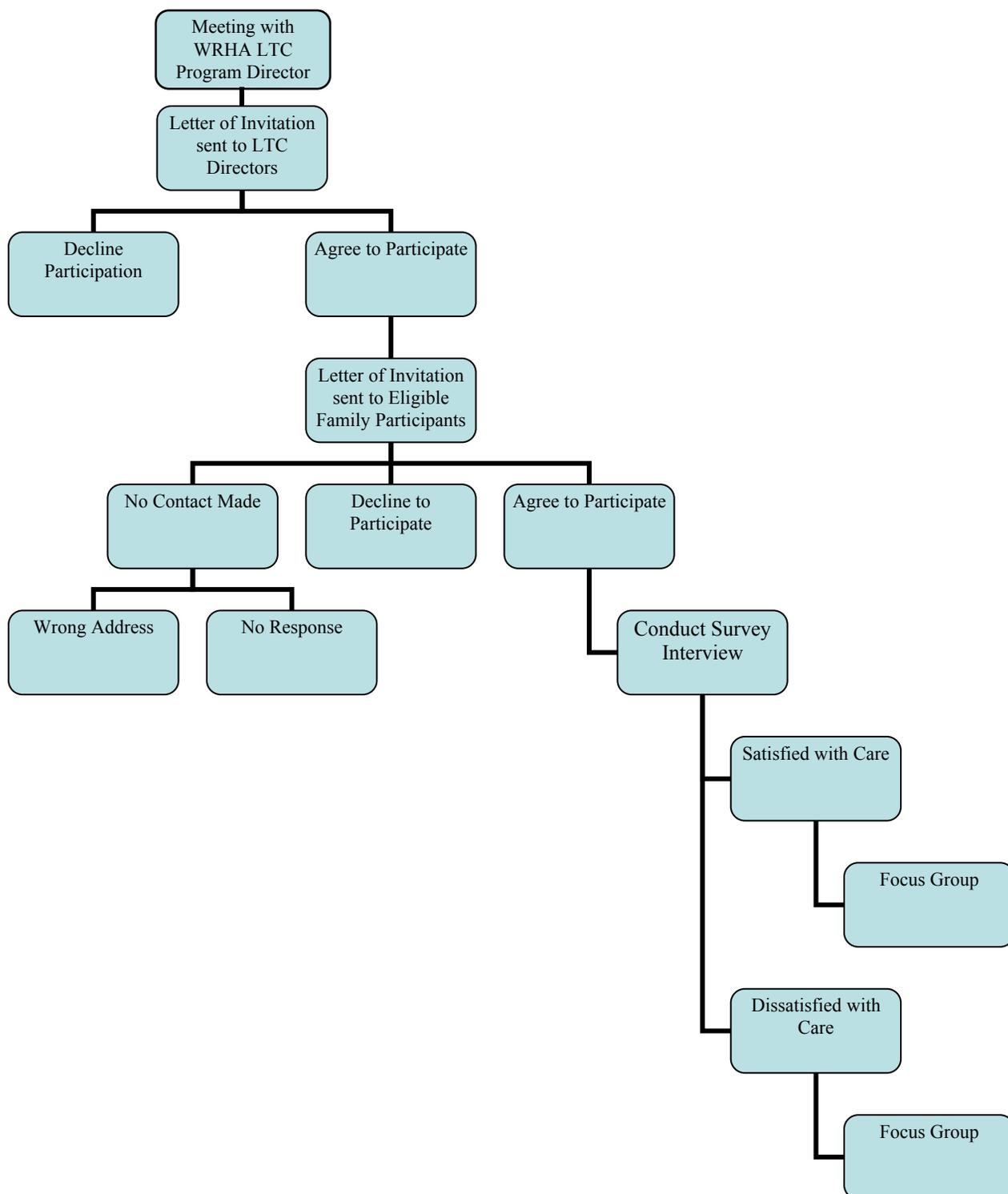
LTC facilities in Manitoba are either classified as proprietary (i.e. for profit) or non-proprietary (i.e. not-for-profit) facilities. All proprietary facilities in Manitoba are free-standing facilities whereas non-proprietary are either free-standing or juxtaposed to

another healthcare facility (Doupe et al., 2006). There are 14 proprietary and 24 non-proprietary facilities in Winnipeg.

### ***Recruitment***

Figure 2 illustrating the sequential steps used in this study can be found below:

Figure 2. Flowchart of Study Protocol



An initial meeting with the WRHA Personal Care Home (PCH) Program Director was undertaken to discuss the nature of the project and to develop a strategy to optimize the participation of the LTC directors. The Director of the WRHA PCH Program presented the study proposal at a LTC directors meeting and solicited interested participants. Five LTC directors expressed interest at that meeting and their contact information was forwarded to the investigator. The remaining 32 LTC directors were mailed a letter outlining the nature of the project and a brief study proposal (Appendix A). A week following the mailing, a phone call was made to each director to assess their interest and willingness to participate in the study. An additional nine directors expressed a desire to participate. A meeting was conducted with each director to review the study protocol and to answer any questions they may have had. Several facilities required ethical review of the project by their internal review board. One facility felt that after their ethical review they could not participate in the project and a second facility did not have the staff to facilitate the mail out. In total, 12 LTC facilities participated in the project. Additionally, the survey instrument, LTC cover letter and letter of invitation were translated into French per the request of two facilities who participated in the study.

In order to comply with the Manitoba Personal Health Information Act (PHIA), participating LTC facilities extracted from their files the names of residents who had died either in their facility or in hospital during the previous four to ten months, and the primary contact for that resident, excluding public trustees. A standardized cover letter from the facility (on facility letterhead) and a letter from the researcher outlining the nature of the study and how to participate in the project was included in each mailing

(Appendix B). A total of 417 letters were mailed to primary contacts by the participating facilities; 13 were returned as undeliverable which reduced the number of letters distributed to 404.

### **Ethical Considerations**

Prior to the initiation of data collection, permission to conduct this study was obtained from the Ethical Review Committee, Faculty of Medicine at the University of Manitoba and the access/ethics committees of the various LTC facilities involved (Appendix C). There are two groups that are the participants within this study who must be assured confidentiality; the individual family members and the resident, and the various participating LTC facilities.

Family member participants in both phase one and two were assigned a unique identifier so that names or any other identifying information did not appear on the questionnaires or focus group memos. This unique identifier also enabled the investigator to link data from phase one to phase two if an individual participated in both phases of the study. All potential participants received information in writing outlining the nature of the study and the confidentiality of their responses. Each participant signed a consent form or gave verbal consent in the case of telephone interviews prior to data collection in either phase of the study. Consent forms, questionnaires, and memos of the focus groups were kept in a locked cabinet housed within the Centre on Aging, at the University of Manitoba which is a secure, alarmed environment. Lists with the names of participants used during the recruitment process were locked in a cabinet separate from the data. The digital voice recordings of the focus groups were kept on a password protect personal

computer owned by the investigator. Data will be kept for a maximum of seven years, upon which time it will be destroyed. The destruction of data will be done by using the services of a confidential shredder.

Additionally, each participating LTC facility was assigned a unique identifier for sampling and when collecting data related to systems characteristics. This information was kept in a locked, secure cabinet within the Centre on Aging. Data are reported as aggregate data only; no facility was analyzed individually, no facility was identified individually or by name, and data with cell sizes less than five was not reported. In this regard, PCH directors were assured that no individual facility was identified or analyzed alone, and that my final dissertation and subsequent presentations provides a broad picture of family satisfaction with end-of-life care provided in the LTC environment and is not an assessment of their individual facilities performance.

Collecting data from bereaved family members has raised the concern that it might cause them emotional distress to participate in research studies. Takesaka, Crowley and Casarett (2004) addressed this issue in a sample of families (n=296) who were asked to rate how distressing participating in a study on end-of-life care had been for them. The data for this analysis were compiled from secondary data analysis from 4 studies (1 mailed survey and 3 telephone surveys). Twenty-two percent reported that study questions had been distressing (mild to moderate) with those who were younger themselves (OR, 0.97), being a younger patient (OR, 0.97) and patients with a cancer diagnoses (OR, 3.71) reporting significantly higher distress (Takesaka, Crowley, & Casarett, 2004). However, benefits to participating in research have been reported by

participants who voiced that by completing questionnaires and interviews, they are able to voice issues and needs they deem important that may otherwise go undetected (Dean & McClement, 2002).

## **CHAPTER FOUR - PHASE I QUANTITATIVE SURVEY METHODOLOGY AND RESULTS**

### ***Introduction***

This chapter describes the procedures, measures used, data analysis plan, and results of the first phase of the study.

### **Phase One Methodology**

#### ***Data Collection Procedures***

A total of 404 letters were distributed by the 12 participating LTC facilities to bereaved family members. In order for a family member to be eligible for participation, they had to be 18 years of age or older, understand and speak English, the resident must have died within the past 10 months, and they had to have had contact with the resident in their last month of life. Visitation patterns were one other factor that was measured in order to ensure that the family member had observed the care of the resident (Vohra et al., 2004). Although the research literature suggests that bereaved individuals suffer no distress in participating in surveys as soon as two weeks after the death of their loved one (Casarett, Crowley, & Hirschman, 2003), the current study solicited family members who had a relative die within the preceding four to 10 months in order to minimize recall bias. Due to scheduling difficulties, 13 interviews were conducted more than ten months after the death; however the average time since death was 7.6 months with a range from 3 to 16 months.

Those individuals who wished to participate were instructed to call the Centre on Aging at the University of Manitoba to indicate their interest in participating in the study. Calls were answered by the research coordinator of the Centre on Aging who recorded

their name, date called, phone number and the best time to reach the caller. If the coordinator was not able to answer the call, callers were asked to leave their contact information on a confidential answering service. The research coordinator would contact the investigator with the caller's information and contact with potential participants was generally made within 48 hours of their calling the centre. Information regarding the potential participants was recorded in an Excel spreadsheet.

Studies conducted with bereaved family members report response rates of around 60% (Kristjanson et al., 1997; Morita, et al., 2004; Vohra, et al., 2004). The response rate of the current study did not achieve such projections. A total of 87 primary contacts participated in the study for a response rate of 22%. Therefore, results are interpreted with caution.

During the initial contact, potential participants were thanked for their interest in participating in the study and a brief description of the study was reviewed. Participants were asked if they had any questions about the study and it was determined if they met the study criteria using a brief screening tool (See Appendix D). Once the participant was deemed eligible to participate, a date, time and how they would like to conduct the interview (either by phone or face to face) was established by the researcher. Several participants wished to conduct the interview during the initial call whereas the majority were contacted at a later date and time. During the subsequent contact, consent was obtained verbally after reading a brief script to the participant (Appendix E). In the case of face-to-face interviews, a consent form was reviewed with the participant and their witnessed signature obtained at that time (Appendix F). Seventy-six interviews were conducted by phone and 11 were conducted face-to-face. Though conducting face-to-face

interviews are preferred, giving a participant the option of conducting the interview over the telephone has been shown to improve response rates (Fowler, 2002). Several of the face-to-face interviews were conducted with couples (n=2) or with another family member present (n=2). In these cases, informed consent was obtained from all present but the perspective of the primary contact was recorded, though qualitative comments from all participants were noted and recorded. Chi-square analyses revealed no differences between those who participated in telephone versus the face-to-face interviews in terms of respondent or resident demographic characteristics.

Once informed consent was obtained, the interview was conducted using the modified TIME instrument (Appendix G) described in the measures section. The survey was read to participants by the researcher and was personalized to reflect the gender of the decedent. Comments were not actively solicited by participants however, all comments made by the participant during the interview were recorded verbatim. On average, the interviews lasted 48 minutes with a range from 25 to 80 minutes. All interviews were conducted in English. At the conclusion of the interview, participants were thanked for their time and offered the opportunity to participate in a focus group. Those participants from out of the province were not invited to participate in the focus groups. Participants were also asked if they would like a summary of the findings mailed to them once the study was completed.

### **Measures**

The following section details the various measures used to evaluate the dependent and independent variables in this study. Table 2 below classifies all variables of interest and how they were measured in the current study.

Table 2. Variables Examined in the Study

<b>Outcome</b>	Overall Satisfaction with Care: measured by mean composite score OSAT (range 0 to 10)	
<b>Interventions</b>  <b>Modified TIME Instrument</b>	<ul style="list-style-type: none"> <li>Care and Concern for the Resident: measured by composite score</li> <li>Physician Contact and Communication: measured by composite score DRCOMM</li> <li>Consistent Care: measured by composite score</li> <li>Family Confidence: measured by composite score</li> <li>Advance Care Planning (PLAN): measured by composite score</li> <li>Nursing Contact and Communication: measured by composite score RN-C</li> <li>HCA Contact and Communication: 0=yes; 1=no</li> <li>Pain and Symptom Management: 0=yes, 1=no</li> <li>Psychosocial, Spiritual, and Bereavement support: 0=yes, 1=no</li> </ul>	
<b>Client (Demographics and Characteristics of the Death)</b>	<b>Decedent</b>	<b>Family</b>
	<ul style="list-style-type: none"> <li>Age at death: continuous</li> <li>Gender: male=0; female=1</li> <li>Religious affiliation: protestant=1; catholic=2; other or none=3</li> <li>Medical conditions: none to 5 =0; more than 6=1</li> <li>Diagnosis of dementia: yes=0; no=1</li> <li>Length of time being a resident in the facility: continuous</li> <li>Place of death: other=0; PCH=1</li> <li>Transfers to acute care facilities: yes=0; no=1</li> <li>Death sudden or expected: yes=1; no=0</li> <li>Registered on the WRHA palliative care program: no=0; 1=yes</li> </ul>	<ul style="list-style-type: none"> <li>Age: continuous</li> <li>Gender: male=0; female=1</li> <li>Religious affiliation: protestant=1; catholic=2; other or none=3</li> <li>Relation to the decedent: son/daughter=0; all other=1</li> <li>Education level: High school or less=0; some university or university graduate=1</li> <li>Employment status: employed=0; retired/unemployed =1</li> <li>Income: \$59,000 or less=1; more than \$60,000=0</li> <li>Health status: fair/poor=0; good/excellent=1</li> <li>Visitation: daily=1; 2 to 5 times/week=2; other=3</li> <li>Expectations for care met: no=0; yes=1</li> <li>Time to interview: continuous</li> </ul>
<b>System (PCH Environment)</b>	<b>Individual</b>	<b>Organization</b>
	None at this time	<ul style="list-style-type: none"> <li>LTC-E: composite score (range: 1 to 50)</li> <li>Facility size: under 120 beds=0; 121 to 250 beds=1; over 251 beds=2</li> <li>Proprietary status: non-profit=0; proprietary=1</li> <li>Religious affiliation: no=0; yes=1</li> </ul>

## **Outcome and Interventions**

A survey comprised of a modified version of the instrument developed by Teno and colleagues (2001b) was used to collect data for this study. The Toolkit of Instruments to Measure End-of-life Care (TIME) is an after-death bereaved family member interview that is tailored for administration based on the setting of care. For this study, the module developed for use in evaluating nursing home care was administered. The 38 questions measure whether the care provided to the resident met the needs and expectations of family members along with an overall measure of their satisfaction with care. Developed on the conceptual model of patient-focused, family-centered medical care, this tool assists in assessing and improving quality of care in seven different domains of care including: (1) physical comfort & emotional support; (2) inform & promote shared decision making; (3) encourage advance care planning; (4) focus on the individual; (5) attend to emotional & spiritual needs of the family; (6) provide coordinated care; and (7) overall rating of patient-focused, family-centered care. Permission to use the TIME instrument has been granted and a copy of the modified instrument is found in Appendix G.

Assessment of these domains is done through a variety of questions and different response categories including: (a) ratings on a scale of 0-10; (b) 4-point scales ranging from “always” to “never”; (c) 3-point scales (e.g. reports of receiving “less than was needed/more than was needed/just the right amount” of care); and (d) yes/no and yes/no/don’t know response options. Asking questions in this manner reflects a move away from simply assessing satisfaction by having individuals rate their care on a

ranking scale, to a means of using patient centred reports (PCR); a way of asking questions about processes of care in which expectations or acquiescence responses do not confound the answers (Teno et al., 2001b). The tool is scored by summarizing PCRs into problem scores; problem scores sum the negative responses to the individual questions within that domain (Connor, Teno, Spence, & Smith, 2005). Therefore, a high problem score indicates concerns with the quality of care and unmet needs.

A domain score is calculated by dividing the problem score by the number of survey questions used to calculate the problem score. The authors suggest that an overall mean problem score or domain score greater than 0.20 indicates an opportunity to improve the quality of care (Teno et al., 2001b). For the “overall satisfaction” domain, the five overall rating questions of the tool are summarized, giving a composite score of overall satisfaction with the quality of care score ranging from 0 through 50.

The authors report (2001a) that the instrument has been tested with bereaved family members (n=156) between three to six months after their relative died in a nursing home, an out-patient hospice or in a hospital. The problem scores of the instrument are reported to have moderate correlation (i.e. from 0.44 to 0.52) with the overall rating of satisfaction measured on a five-point scale from “excellent” to “poor”. Based on that information, the following reliabilities are reported by Teno et al. (2001a) for each of the domains:

Table 3. Reported TIME Domains and Reliabilities

Domain	Number of Items	Cronbach's Alpha
Information and decision-making	8	.77
Advance care planning	3	.58
Coordination of care	4	.68
Control and respect	6	.80
Physical comfort	5	Not available due to a problem with a skip pattern
Surrogate emotional support	4	.58
Self-efficacy of family	3	.74
Overall ratings	5	.87

### ***Domains***

***Information and decision-making.*** This domain is comprised of a set of eight questions. The first three questions assessed the amount of contact and the nature of communication respondents had with the physician in the LTC facility. These questions included the following: “In that last week, was there ever a problem understanding what any doctor was saying to you about what to expect from treatment? yes=0, no=1, skipped=7”; “In that last week, did you feel that the doctors you talked to listened to your concerns about [resident’s] medical care? yes=1, no=0, skipped=7”; In that last week how much information did the doctors provide you about [resident’s] medical condition would you say less information than was needed=1, just the right amount=0, more than was needed=2 or skipped=7”. One question was asked “In that last week was there ever a decision made about (his/her) care without enough input from him/her or his/her family? yes=0, no=1.

Three questions are included in this domain which assess the amount of information respondents received and included: “At any time while [resident] was in the nursing home did you or your family receive any information about what to expect while (he/she) was dying? yes=1, no=0”; “At any time while [resident] was in the nursing home did you or your family receive any information about what to do at the time of (his/her) death? yes=1, no=0”; and “At any time while [resident] was in the nursing home did you or your family receive any information about the medications that would be used to manage (his/her) pain, shortness of breath, or other symptoms? yes=1, no=0”. Each of these questions was followed by a set of questions asking whether the respondent would have wanted to receive information regarding those respective areas.

The final question in this domain asked respondents “In [resident’s] last week, how often were you or other family members kept informed about [resident’s] condition? always=3, usually=2, sometimes=1, or never=0”. This variable was dichotomized based on the frequency distribution into always=1, usually, sometimes, or never=0.

***Advance care planning.*** Nine questions on the TIME questionnaire assessed issues of advance care planning, though not all are included in the calculation of the domain score. These questions included whether the resident or family had specific wishes or plans about the types of medical care they did or did not want while dying (yes=0, no=1); if the resident had an advance care plan or health directive naming someone to make decisions about medical treatment (yes=1, no=0) or giving directions for the kind of medical treatment they would want if they could not speak for (him/her) self (yes=1, no=0). The remaining set of questions assessed if the medical staff had

discussed the wishes of the resident/family for medical treatment (yes=1, no=0, skipped=7), if the medical staff had talked to them about ensuring care was consistent with those wishes (yes=1, no=0, skipped=7), if the resident had discussed his/her advance care plan with the physician while under the care of the nursing home (yes=1, no=0) and if the nursing home had respected their or the resident's wishes as stated in the advance care plan (yes=1, no=0). A final question assessed "In that last week was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes? yes=0, no=1, skipped=7".

***Coordination of care.*** Four questions comprised this domain including "In that last week, how often did any doctor give confusing or contradictory information about [resident's] medical treatment, always=3, usually=2, sometimes=1, never=0, skipped=7". Respondents were also asked "In that last week was there always a doctor in charge of [resident's] care, yes=1, no=0". Respondents were asked the follow-up question, "In that last week was it always clear to you which doctor was in charge of (his/her) care, yes=1, no=0". One question regarding pain management is included in this domain "In that last week, was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else? yes=0, no=1." Finally, respondents were asked, "In the last week was there any problem with the doctors or nurses not knowing enough about [resident's] medical history to provide the best possible care? yes=0, no=1".

***Control and respect.*** Six questions comprise this domain. The first three questions asked respondents to rate from 'always=3' to 'never=0' whether the resident

had been treated with respect, kindness, and if his/her personal care needs had been taken care as well as they should have been. These variables were dichotomized for analyses based on their frequency distribution (never, sometimes, usually=0, always=1). One questions asked “In [resident’s] last week, how often did you have concerns about [resident’s] personal care needs being met when you were not there? Always=3, usually=2, sometimes=1, or never=0”. This was dichotomized (always, usually, or sometimes=0; never=1) for analyses based on the frequency distribution of the variable. The final two questions in this domain assessed adequacy of staffing and are described under the LTC environment in this chapter.

***Physical comfort.*** Though only five questions are included in the calculation of this domain score, eleven questions, two of which were added to the TIME, asked respondents about the symptom experience of residents in their last week of life. These questions focused on assessing the presence of pain, difficulty breathing, feelings of anxiety and sadness and the subsequent management of these symptoms. The questions added by the investigator were “In that last week, did [resident] have any other symptoms that caused (him/her) distress or discomfort? yes=0, no=1”. The second question used to probe the nature of the symptom/distress. Comments were recorded verbatim.

***Surrogate emotional support.*** A series of four questions asked respondents about the spiritual and emotional support they had received in the resident’s last week of life. These questions included: “In [resident’s] last week, how much support in dealing with your feelings about [resident’s] death did the staff taking care of (him/her) provide you? less support than was needed=0, right amount=1”; “In [resident’s] last week, did any staff

taking care of [resident] talk about how you might feel after their death? yes=1, no=0”; “In [resident’s] last week, did any staff taking care of [resident] suggest someone you could turn to for help if you were feeling stressed? yes=1, no=0”; and “In [resident’s] last week, did someone from the nursing home talk with you about your religious or spiritual beliefs? yes=1, no=0”. Though not included in the domain score, follow-up questions are asked to assess whether the questions about their religious/spiritual beliefs were done in a sensitive manner (yes=1, no=0) and whether they had as much contact of that kind (spiritual support) as they wanted during the resident’s last week (yes=1, no=0).

*Self-efficacy of family.* These three questions assessed how confident the respondent felt in their knowledge of what to expect when the resident was dying, what to do after the resident’s death, and their knowledge of the medications which might be used to manage symptoms. Possible responses included ‘very confident=3’, ‘fairly confident=2’, and ‘not confident=1’. For analyses based on frequency distribution of the responses, these variables were dichotomized into ‘very or fairly confident=1’ and ‘not confident=0’.

*Overall ratings.* Respondents were asked to rate the care received in the resident’s last week of life in five areas on a scale of 0=worst care possible to 10=best care possible. These questions included how well the staff communicated about the resident’s illness and likely outcomes of care, how well the staff provided medical care that respected the resident or the family’s wishes, that staff ensured symptoms were controlled to a degree that was acceptable, how well the staff ensured that the resident died with dignity, that is died on his/her own terms, and how well staff provided

emotional support to the respondent and the resident's family and friends. A sixth question asked respondents to rate the overall care the resident had received in the last week of their life on a scale of 0=worst care possible to 10=best care possible.

***Nursing contact and communication.*** A series of eight questions was added to the TIME instrument to assess respondent's interaction with and information received regarding the medical care of the resident from registered nurses in the facility. Four of the questions used the original wording of the TIME questions assessing physician contact, replacing 'doctor' with 'nurse' in the question. A fifth question was asked assessing whether respondents felt the nurse acted on their concerns about the resident's care. All questions were answered by either 'yes=0, no=1, had no concerns=2' or 'less than was needed=1, more than was needed=2, or just the right amount=0'. All variables were recoded into dichotomous variables with higher scores indicating better care. An index of the questions was created based on an assessment of the inter-item correlations. The score on the RN-C ranged from '0=poor' to '5=excellent'. The RN-C Cronbach's alpha reliability was .74.

***Health care aide (HCA) contact and communication.*** Two questions were added to the TIME questionnaire. The first question asked respondents "In that last week/while under the care of the nursing home, did you feel that the HCAs you talked to listened to your concerns about [resident's] care? yes=0, no=1, had no concerns=2". This variable was recoded into 'did not feel listened too=0' and 'felt listened too or had no concerns=1'.

The second question asked respondents ""In that last week/while under the care

of the nursing home, how often did any HCA give confusing or contradictory information about [resident's] care – always=3, usually=2, sometimes=1 or never=0”.

This variable was recoded based on mean scores and frequency distributions into ‘received confusing information=0’ and ‘never=1”.

### ***Outcome – Family Satisfaction with End-of-Life Care***

A dependent variable index OSAT was created by computing the mean for valid responses on the five overall rating scales of the TIME, with respondents having had to answer a minimum of two of the five questions. On the Overall Satisfaction composite, scores could range between 0 (lowest) and 10 (highest), with higher scores indicating higher satisfaction with end-of-life care. The Cronbach’s alpha reliability was .84.

***Global satisfaction.*** An overall global satisfaction question was added to the end of the survey interview. This question asked participants “Overall, how satisfied were you with the end-of-life care that was given to your family member? Very satisfied, satisfied, undecided, not satisfied or very dissatisfied”. Using a single item to assess overall satisfaction with care has been included in surveys and in questionnaire development (Kristjanson, 1993; Vohra et al., 2004). When the correlation between the single item and a multi-dimensional satisfaction scale purporting to measure family satisfaction has been calculated, moderate correlations have been noted (between 0.6 and 0.78) (Castle, 2004; Kristjanson, 1993).

### **Client Factors**

A brief demographic questionnaire is incorporated into the TIME tool; however it includes items that are specific to the health care context of the United States. As such,

several questions were replaced with questions that reflect the realities of Canadian health care. The wordings for these questions were modified from the questions asked on the Canadian Census (Statistics Canada, 2005a).

### ***Resident Characteristics***

***Age.*** Respondents were asked the resident's date of birth. Age was calculated by subtracting date of death from date of birth. Age was treated as a continuous variable in all analyses.

***Gender.*** Gender was defined as male=0, female=1.

***Diagnosis of Alzheimer's disease or dementia.*** Respondents were asked if the resident had had Alzheimer's disease or dementia (yes=0, no=1).

***Medical conditions.*** Respondents selected from a list of 16 common medical conditions was including: cancer, chronic heart problems, congestive heart failure, high blood pressure, diabetes, COPD or lung disease, kidney problems, chronic digestive problems, arthritis, osteoporosis, stroke, partial or complete paralysis, visual or hearing impairments, back problems, depression or anxiety, and Parkinson's disease. A category of other was included in which participants indicated which other medical conditions the resident may have had. A dichotomous variable based on the frequency distribution of the variables was created and included those who had indicated the resident had Alzheimer's disease or dementia: less than five medical conditions=0, six or more=1.

***Cultural identity.*** Respondents were asked "What cultural group did [resident] most identify with?" A list of ten possible responses was included including a 'choose not to answer' category. Since 97.7% of respondents indicated they were Caucasian, it

was not included in any of the analyses.

**Religious affiliation.** Respondents were asked “What religious affiliation did [resident] most associate with? Protestant=1, Catholic=2, Jewish=3, Islam=4, Hindu=5, Buddhist=6, None=7, Other=8, Choose not to answer=98”. Based on the frequency distribution and to adequate representation for statistical analysis the variable was recoded into ‘Protestant=1’, ‘Catholic=2’ and ‘No religion or other=3’.

**Education attainment.** Respondents were asked “What was the highest level of schooling [resident] completed? Less than high school=1, high school graduate=2, some university, college or technical institute=3, university, college or technical institute graduate=4, advanced degree=5, and don’t know=97”. The variable was dichotomized based on the frequency distribution into ‘high school or less=0’ and ‘some university or university graduate=1’.

**Length of time resided in current LTC facility.** To assess this variable, respondents were asked “How long has [resident] been a resident at this facility?” All responses were converted to months. The measure was included as a continuous variable in the analyses.

### ***Characteristics of Resident’s Death***

**Date of death.** Respondents were asked “Can you tell me when [resident] died?” Date of death was used to calculate respondent age.

**Place of death.** Respondents were asked “Where did [resident] death take place?” Respondents who indicated the death did not occur in the LTC facility were asked if the death at occurred ‘in hospital’. If stated ‘yes’ then respondents were asked if the resident

had died ‘in the ICU (yes/no), in an emergency department (yes/no), or in an in-patient palliative care unit (yes/no). Other possible location of death included at home, in a hospice, in transit to a medical facility, somewhere else or don’t know. This variable was coded as place of death PCH=0, death elsewhere=1.

***Death a surprise.*** Respondents were asked “When [resident] died was it a surprise to you? (yes=0, no=1)”. Follow-up probes were used to further explore responses and comments were recorded verbatim.

***Sudden death.*** A variable was created based on the description of whether the respondent felt the resident’s death had been a surprise or not and the researcher’s expertise. A death was classified as sudden if the resident had been found deceased or died in their sleep with no apparent problems the day before or if the died from a myocardial infraction with no history of heart problems. This variable was dichotomized (sudden death: yes=0, no=1).

***Died in a place wanted to.*** Respondents were asked “Did [resident] die in a place where (he/she) wanted to? (yes=1, no=0). If respondents indicated ‘no’, follow-up probes were used to elicit where they felt the resident would have wanted to die and comments were recorded verbatim.

***Registered with WRHA Palliative Care Program.*** The question “Was [resident] registered with the WRHA palliative care program?(yes=1, no=0)” was asked of respondents.

***Transferred to hospital while residing in LTC.*** Respondents were asked “Was [resident] ever transferred to hospital while residing in the LTC facility? (yes=0, no=1).

***Transferred to hospital in last month of life.*** If respondents indicated the resident had been transferred to hospital while a resident at the LTC facility, they were asked “Was this in the last month of (his/her) life? (yes=0, no=1)?” Probes were used to solicit the reason for transfer and comments were recorded verbatim.

### ***Respondent Characteristics***

***Age.*** Respondents were asked “How old were you on your last birthday?” Age was treated as a continuous variable in all analyses.

***Gender.*** Gender was defined as male=0, female=1.

***Relationship to resident.*** Respondents were asked “What was your relationship to [resident]?” Responses included: husband or wife=1, common-law partner=2, son or daughter=3, son-in-law/daughter-in-law=4, grandchild=5, father or mother=6, father-in-law/mother-in-law=7, brother or sister=8, brother-in-law/sister-in-law=9, friend=10, or other=11. Based on the frequency distribution of the variable and to ensure adequate representation for statistical analyses, the variable was coded into a dichotomous variable: son/daughter=0, all other relations=1.

***Cultural identity.*** Respondents were asked “What cultural group did you consider yourself to belong to?” A list of ten possible responses was included including a ‘choose not to answer’ category. Based on the frequency distribution of this variable, it was not included in any of the analyses.

***Religious affiliation.*** Respondents were asked “What religious affiliation do you most associate with? Protestant=1, Catholic=2, Jewish=3, Islam=4, Hindu=5, Buddhist=6, None=7, Other=8, Choose not to answer=98”. Based on the frequency

distribution and to adequate representation for statistical analysis the variable was recoded into 'Protestant=1', 'Catholic=2' and 'No religion or other=3'.

***Educational attainment.*** Respondents were asked "What was the highest level of schooling you have completed? Less than high school=1, high school graduate=2, some university, college or technical institute=3, university, college or technical institute graduate=4, advanced degree=5, and don't know=97". The variable was dichotomized based on the frequency and mean responses into 'high school or less=0' and 'some university or university graduate=1'.

***Employment status.*** Respondents were asked "Are you currently...employed full-time=1, employed part-time=2, self-employed=3, stay at home parent/caregiver=4, unemployed=5, on disability=6, retired=7, other=8, choose not to answer=98". Based on the frequency distribution of responses, the variable was recoded into a dichotomous variable: employed=0, unemployed/retired=1.

***Income.*** Participants indicated their total household income by selecting from categories that ranged from "less than \$20,000/year" to "more than \$80,000/year" in \$20,000 increments. Based on the frequency distribution of the income variable, it was collapsed into more meaningful dichotomous category: '\$59,000 or less= 1' and 'over \$60,000 =0'.

***Description of current health.*** Self-rated health was measured with a question commonly used in gerontological research, "How would you describe your current health [poor=1, fair=2, good=3, very good=4, excellent=5]. Based on frequency distribution of the variable and to ensure adequate representation for statistical analysis the variable was

recoded into a dichotomous variable: poor/fair=0, good/very good/excellent=1.

**Visitation patterns.** Respondents were asked “How often did you visit [resident] in (his/her) last month of life?” Possible responses included ‘1=daily’, ‘2=two to three times a week’ ‘3=four to five times a week’ ‘4=once a week’ ‘5=once every couple of weeks’ ‘6=once in the month’ ‘7=live out of province’ and ‘97=don’t know’. Based on the frequency distribution of responses, the variable was recoded into ‘1=daily’ ‘2=two to five times a week’ and ‘3=other’.

**Expectations for end-of-life care.** To assess family members’ expectations of end-of-life care, two questions were asked of participants at the end of the survey interview, prior to asking the demographic questions. The first question asked “Was the care that the resident received in the last week of their life, what you expected? yes=1, no=0”. The second question used probes to follow-up on participants’ responses to solicit an understanding of how care met or failed to meet their expectations.

**Time to interview from resident’s death.** A variable was created to measure the length of time from the date of the resident’s death to when the interview was conducted. This continuous variable was included in testing the third research question.

### **Systems Factors**

**LTC characteristics.** There are several systems’ characteristics of interest that have been identified in the literature that have the potential to influence family satisfaction with care. These include staff education levels, staff mix and staffing levels, facility size, proprietary status, religious affiliation, and the physical environment of the facility. It was anticipated that each participating LTC facility would provide information

on their staff mix, education and staffing levels. However, many facilities failed to provide the researcher with this data or the manner in which it was reported was very inconsistent across facilities. Therefore, this type of data was not collected for this study.

**Staffing.** Two questions on the TIME instrument asked respondents “In that last week, was there enough help available to meet (his/her) personal care needs like bathing, dressing, feeding, and going to the bathroom? yes=1, no=0” and “In that last week was there enough help with medications and getting dressings changed? yes=1, no=0”.

**Facility size.** Information on facility size was obtained from the WRHA website and confirmed with the director of the facility. Based on mean responses and frequency distribution, this variable was categorized as ‘under 220 beds=0’, and ‘over 221 beds=1’ and used in the assessment of research question three.

**Proprietary status.** Information on proprietary status was obtained from the WRHA website and confirmed with the director of the facility. This dichotomous variable (proprietary =1, non-profit=0) was used in the assessment of research question three.

**Religious affiliation.** Information on religious affiliation was obtained from the director of the facility. This dichotomous variable (yes=0, no=1) was used in the assessment of research question three.

**Physical environment.** Characteristics of the physical environment was assessed by family members using items from the Nursing Facility Family Satisfaction Questionnaire (Castle, 2004). Specifically the items pertaining to autonomy and privacy

(2 questions;  $\alpha = 0.76$ ) and the physical environment (3 questions;  $\alpha = 0.81$ ) were used. These five Likert-scales ranging from 'very poor=1' to 'excellent=10' measured how homelike the facility was, the cleanliness of the facility, the temperature of the resident's room, the privacy of the residents room and how homelike the resident's room was. The LTC-E scale was created by summing the five questions. The score on the LTC-E ranged from 4.40 to 9.80 and had a Cronbach's alpha reliability of .78. Permission to use these questions was granted and they can be found as part of the modified TIME instrument in Appendix G.

### ***Subsequent Psychometric Assessment of the Survey Instrument and Factor Analysis***

#### ***Data Coding and Assessment***

Data was coded and entered into the Statistical Package for the Social Sciences (SPSS) version 11.0. Data coding became relatively complex due to the skip patterns utilized in the TIME instrument. Based on the original coding provided by the TIME developer, frequencies were run on the data which revealed large amounts of missing data related to skipped questions. Based on the frequency distributions of several variables (physician contact and communication, advance care planning, and physical comfort), questions were recoded to ensure adequate representation for statistical analysis. For example, a series of questions pertaining to communication with the physician required the interviewer to skip four questions regarding the nature of communication and contact of participants who stated they had not spoken to a physician in the last week of the resident's life. Since only 15 participants had spoken to a physician in that time period, these four questions had 72 missing responses. To

overcome this, the perspective was taken that those participants who had not communicated with the physician had experienced a problem or unmet need, corresponding to the theoretical underpinning of the questionnaire (Teno, Casey, Welch, & Edgman-Levitan, 2001a) and as such, their responses were recorded in the series of questions to reflect a problem with care. Overall, positive experiences with care were coded as a 1 and negative experiences as 0. Thus higher scores indicated a more positive experience with end-of-life care.

The OSAT variable which is the dependent variable of this study was created by summing the scores on the five overall rating scales of the TIME as instructed by the developer of the instrument. Due to missing data, however, the approach was taken that respondents had to have answered at least two of the five questions and a mean response was calculated.

Once data was recoded and the dummy variables and dependent index created, frequencies, descriptive statistics (mean, median, standard deviations, minimum, maximum), and histograms were re-run on all data collected on the survey to further ensure proper coding of the data had been conducted, to examine the distribution of the data and to check for outliers.

***Reliability Assessment***

The TIME instrument consists of eight domains, calculated by summing the scores of the individual questions comprising that domain. The internal consistency reliability of the eight domains captured on the TIME was evaluated using a correlation matrix and reliability test (Cronbach's alpha), the results of which are found in the Table 4.

Table 4. Internal Consistency Reliability Analysis of TIME Instrument

Domain	Number of Items	Cronbach's Alpha (standardized)	N
Information and decision-making	8	.68	72
Advance care planning	3	.55	62
Coordination of care	4	.48	82
Focus on Individual	6	.83	87
Physical comfort	5	-.26	75
Surrogate emotional support	3	.42	86
Self-efficacy of family	3	.71	83
Overall ratings	5	.84	69

Based on the poor alpha values, an exploratory factor analysis was undertaken to examine the structure of TIME instrument.

### ***Factor Analysis***

With exploratory factor analysis, the researcher aims to uncover the coherent, independently correlated subset of variables from a larger group of variables (Tabachnick & Fidell, 2007). In this manner, a larger number of variables can be reduced to a smaller number of factors as well as provide an understanding of the underlying process which may define the subset of factors. In this factor analysis, the first step taken was to review the frequencies, mean, median, standard deviation, skewness and kurtosis for each of the 31 variables involved in the unmodified TIME questionnaire. Three variables exhibited negative skewness and kurtosis. These variables were reflected and both log and square root transformation was assessed. Transformation did not reduce the kurtosis or skewness in any of the three variables and therefore the original variables were retained. It is acknowledged that the factor solution is enhanced when variables assume normality. However Tabachnick and Fidell (2007) do indicate that when normality fails, the solution may be degraded but is still valuable especially when factor analysis is used descriptively to summarize relationships with a large number of variables as is the case in the current study.

All 31 variables (n=47) were entered into the analysis, resulting in 11 factors with eigenvalues greater than 1.00. The scree plot of the eigenvalues suggested a 5 factor solution as did interpretation of the meaning of the items loading on the factors. Factors 6 and 7 were indexed by only two items each, and several variables failed to load on any factor. The five factors together accounted for 55 percent of the variance. The first factor accounted for 18 percent of the variance with the following factors adding 12, 9, and 7 percent respectively of the explained variance. It must be noted that though reduced to

five factors, they closely approximate those on the original TIME instrument, thus lending credibility to the findings. In addition, a good factor solution is evidenced by squared multiple correlations (SMCs) which range between 0 and 1 (Tabachnick & Fidell, 2007). The five factor solution produced larger SMCs ranging from .504 to .96 indicating that the observed variables account for substantial variance in the factor scores.

Internal reliability assessments were conducted on the five factors and based on preliminary assessment, some variables required deletion in order to improve the factor's reliability. As a result, factor one was reduced by one item (from 8 to 7), and factor five was reduced to two items (from 4). The factor analysis was rerun based on the elimination of these factors and the final results are reported in the table five below:

Table 5. Results of Factor Analysis

<b>Factor</b>	<b>Items</b>	<b>Factor loadings</b>	<b>Eigenvalues</b>	<b>Percent of variance</b>	<b>Cronbach's alpha</b>
<b>I. Care and Concern for the Resident</b>	D22 – treated with respect	.884	5.691	18.36	.83
	D23 – treated with kindness	.844			
	D21 – personal care needs addressed	.693			
	E1 – kept informed	.551			
	E2 – concern about needs met when not present	.473			
	D24 – enough ADL help	.608			
	D25 – enough medication help	.613			
<b>II. Physician Contact and Communication</b>	C1b –doctor listened	.974	3.82	12.3	.96
	C1a – problem understanding doctor	.974			
	C1c- doctor provided enough information	.854			
	C1d – doctor provided confusing information	.955			
<b>III. Consistent Care</b>	D15 – correct amount of pain medication administered	.721	2.80	9.0	.79
	D15a – pain treatment contradicted	.863			
	D19 – no resident of family input in decisions	.628			
	D18 – problem knowing medical history	.653			
	D4 – provision of inconsistent care	.682			
<b>IV. Family Confidence</b>	D26b – confident knew what to expect when person dying	.635	2.45	7.9	.81

	D27b – confident knew what to do at time of death	.590			
	D27a – requested information on what to do at time of death	.842			
	D26a – wanted information on what to expect with death	.768			
<b>V. Advance Care Planning</b>	D3 – care consistent with wishes	.787	2.36	7.6	.89
	D2 – discussed wishes with a health professional	.765			

New domain variables were created by summing the individual variables based on these factors. The five new composite variables were re-examined to ensure proper coding and to inspect general characteristics such as the mean, median, standard deviation, skewness and kurtosis.

### **Data Analysis Plan**

The analysis of the data was handled using SPSS (version 11.0). To determine whether the data met the assumptions for correlation and multiple regression as outlined by authors Tabachnick and Fidell (2007) and Norusis (2004), several tests were conducted.

Assumption: *Data contain no outliers.* To examine and eliminate outliers, frequencies were run on the data. In cases where outliers were noted, the original questionnaire was reviewed. In all cases, outliers were due to data entry error and were corrected.

Assumption: *No missing data.* Since the survey was read to participants by the investigator, missing data was minimal. Missing data was generated due to respondents

selecting “don’t know” as a response. In such cases, case-wise deletion was employed for missing cases. Missing data became problematic in the creation of the dependent index “Overall Satisfaction (OSAT)” which required the scores of the five questions on the TIME instrument assessing domains of satisfaction with care to be summed and a mean response calculated (items F1 through F5). In the case where a participant responded “don’t know” to one or more of the five items, the result was that dependent index would be missing, which would have resulted in only 69 of 87 participants being included in the analyses. To overcome the problem of missing values, the dependent index was calculated using participants who had valid response on a minimum of two of the five responses, resulting in analyses being based on 84 participants.

Assumption: *Data satisfy the assumptions of univariate and multivariate normality, linearity, and homoscedasticity.* In testing univariate normality and linearity, histograms and normal probability plots of all the independent variables were assessed to examine the distribution of the data and to check for outliers. For multivariate analyses, due to the large number of independent variables and the small sample size, a regression model was created using the independent variables which were found to be significant in inferential testing. A plot of the residuals and predicted values was evaluated. After reviewing the scatterplot, it was determined that the dependent variable met the all the assumptions.

Assumption: *Multicollinearity is not present in the independent variables.*

Multicollinearity occurs when the independent variables being tested are highly correlated (Tabachnick & Fidell, 2007), often indicating that one or more of the variables is a duplication of another. This assumption was tested by examining the tolerance

statistics examining the proportion of variability for that variable that is not explained by its relationships with the other variables in the model (Norusis, 2004). As the tolerance levels of the independent variables were not close to zero, a sign of excessive duplication, there appeared to be no indication of multicollinearity within this data.

Data analysis was conducted both within and across each phase of the study. Qualitative comments obtained by participants during the survey interview were recorded verbatim. Analyses of the comments consisted of grouping frequently occurring comments together under the question headings. Comments are used in the text for illustrative purposes and were chosen because they represented a frequently occurring opinion or issue.

### ***Demographic Factors***

Descriptive statistics were used to describe the sample. Summary statistics were calculated for the responses on the demographic questionnaire in order to describe the decedent and the participant. The gender, age, cognitive status, medical conditions, length of time residing in the PCH and where death occurred were calculated as frequencies and means, where appropriate. Similarly, the characteristics of the family participant are reported as frequencies and means.

**Research Question #1: What are family members' perceptions of the quality of end-of-life care and their satisfaction with end-of-life care in the long-term care setting?**

In order to provide insight into answering research question one, the mean, median and standard deviation of the individual problem, domain and composite scores on the TIME instrument and the single-item satisfaction question were calculated.

**Research Question #2: What do family members identify as areas for improvement in the quality of end-of-life care provided in long-term care facilities?**

This research question was answered by calculating the mean, standard deviation and confidence intervals of the various problem scores where a lower mean score indicates more opportunities for improvement

**Research Question #3: What are the associations between resident and family characteristics, systems characteristics, quality of care and family satisfaction with end-of-life care?**

To address the third research question and the hypotheses of this study, inferential statistics were used. In order to test for differences between groups, the demographic characteristics of the resident and the family participant were compared to family satisfaction as assessed by the OSAT score, using t-test statistics. T-tests were also used to compare quality of care assessment on the TIME instrument to overall satisfaction. Additionally, hypotheses exploring the influence of variables such as death in hospital, advance care plan in place, whether expectations were met, and systems' factors were compared to family satisfaction using t-tests. Pearson's and Spearman's correlation

coefficients were calculated to study the relationships between satisfaction, resident/family characteristics, quality of care and systems factors.

Finally, multiple regression models were developed to identify which factors are not only associated with satisfaction with care but those that are most usefully in predicting the outcome. Multiple regression models were developed using a stepwise approach due to the large number of independent variables in the study and small sample size. In this manner, only significant variables were entered into the final regression model

## **PHASE ONE- RESULTS**

The results of the first phase of the study will be presented in several sections. First, demographic characteristics of the study participants, the decedents and the participating LTC facilities will be presented. Using the conceptual framework guiding this study, results from the modified TIME questionnaire will be reported along with the qualitative comments made by respondents during the survey interviews. Results from the inferential statistics testing the hypotheses of the study will be addressed, followed by the results of multiple regression analyses.

### **Demographic Characteristics**

#### ***Descriptive Analyses of Demographic Characteristics***

***Family respondent.*** The demographic characteristics of the study participants are shown in Table 6. Of the 87 participants in the study, 59 (67.8%) were female and 28 (32.2%) were male. Participants ranged in aged from 30 to 90 years ( $M= 61.06$ ,  $SD= 11.4$ ). Most individuals were either son's, daughter's or a son-in-law or a daughter-in-law

to the decedent (73.5%) with the remainder of participants either being a husband/wife (9.2%), brother/sister/in-law (9.1%), friend/neighbour (5.5%), or grandchild (2.3%). Not surprisingly given the age of participants, 48.3% were retired and 51.7% were employed in some capacity. The majority of respondent's reported a total household income of more than \$60,000 (59.4% of responses), corresponding to the high education level reported by participants (70.9% of responses had some university or higher). The majority of participants lived in Winnipeg (80.5%) but 9.2% (n= 8) lived in rural Manitoba and 10.3% (n= 9) lived out of the province or country. In turn, 33.3% (n= 29) indicated they had visited the resident daily, 20.7% (n= 18) two to three times a week, 25.3% (n= 22) four to five times a week, and the remainder either once a week (10.3%) or once that month or less (10.3%). When asked about their religious affiliation, respondents identified most frequently being Protestant (41.9%), followed by none or other (34.9 %), and Catholic (23.3%). Additionally, the majority rated their health as good to excellent (86.2%) with 13.8% indicating that their health was fair or poor.

Table 6. Descriptive Statistics for Family Respondent (N= 87)

<i>Characteristic</i>	<i>Number</i>	<i>Percent</i>
<b>Gender</b>		
Female	59	67.8
Male	28	32.2
<b>Age</b>		
<54 years	24	27.6
55 to 64 years	33	37.9
>65 years	30	34.5
<b>Education Level</b>		
High school graduate or less	25	29.1
Some university or university graduate	61	70.9
Not reported	1	1.1
<b>Employment Status</b>		
Retired or unemployed	42	48.3
Employed	45	51.7
<b>Income</b>		
<\$59,000	30	40.5
>\$60,000	44	59.5
Not reported	13	14.9
<b>Religious Affiliation</b>		
Protestant	36	41.9
Catholic	20	23.3
Other/None	30	34.9
Not reported	1	1.1
<b>Relationship to Resident</b>		
Husband or wife	8	9.2
Son or daughter	57	65.5
Son in law or daughter in law	7	8
Grandchild	2	2.3
Brother or sister or in-law	8	9.1
Friend/other	5	5.7
<b>Visitation</b>		
Daily	29	33.3
2-5 times a week	40	46
Other	18	20.7
<b>Respondent Location</b>		
Winnipeg	70	80.5
Rural Manitoba	8	9.2
Out of province/country	9	10.3

**Resident.** When examining the characteristics of the decedents, 60.9% (n= 53) were female and 39.1% (n= 34) were males. The mean age at death was 86.8 years (SD 7.3) with a range from 57 to 100 years. Respondents reported that the resident had on average less than five medical conditions (57.5%) with 42.5% having six or more medical conditions. These included a wide variety of neurological disorders (e.g. epilepsy, neuropathy, migraines), skin conditions (e.g. psoriasis, chronic wounds), circulatory problems (e.g. peripheral vascular disease, arterlerosclerosis), bowel and bladder problems (e.g. incontinence) and mental illness (e.g. bipolar disorder, schizophrenia, obsessive compulsive, alcoholism). Cancer had affected 21 (24.2%) residents. Respondents identified dementia or Alzheimer's disease as being a medical condition for 47 (54%) of the residents. In contrast to respondents, most decedents were reported to have a high school education or less (72.3%). The majority of decedents were identified as having a Protestant religious affiliation (49.4%), followed by Catholic (25.3) and no religious affiliation (25.3%). Demographic details of the decedent are reported in Table 7.

Table 7. Descriptive Statistics of Decedent

<i>Characteristics</i>	<i>Number</i>	<i>Percent</i>
<b>Gender</b>		
Female	53	60.9
Male	34	39.1
<b>Age</b>		
<80 years	17	19.5
81 -90 years	42	48.3
>91 years	28	32.2
<b>Education Level</b>		
Less than high school	43	49.4
High school graduate	17	19.5
University or college	23	26.4
Don't know	4	4.6
<b>Religious Affiliation</b>		
Protestant	43	49.4
Catholic	22	25.3
Other/None	22	25.3
<b>Dementia or Alzheimer's</b>		
Yes	47	54.0
No	40	46.0
<b>Medical Conditions</b>		
< 5	50	57.5
>6	37	42.5

### *Characteristics of the Death of the Resident*

The majority of residents (n= 75) died in the LTC in which they resided. Of the 12 residents who did not die in the LTC, 11 died in the hospital (12.6%) and one died in transit to the hospital. For those who died in hospital, 3 died in the Emergency department. The median length of time residing in LTC was 24 months, with a range from two-weeks to 144 months (12 years). Most residents had been under the care of the LTC in their last week of life (83.9%), however 14 residents (16.1%) had not. When examining the last month of life, 26 residents (29.9%) were identified as being transferred to a hospital, or had moved from another LTC (n= 2). The median length of

time spent in this other place was 3 days, with a range from 12 hours to 6 years. A wide range of reasons for transfer to hospital were given including myocardial infarction/chest pain, pneumonia, dehydration, breathing problems, falls/fracture, gastrointestinal bleeding, and blood testing. When asked if the participant felt the resident died in a place he or she wanted, 33.3% reported “no”. Most often, home or at the LTC facility were the place it was felt the resident would have wanted to die. Only 5.7% of decedents had contact with the WRHA palliative care program.

Table 8. Characteristics of Residents Deaths

<i>Characteristics</i>	<i>Number</i>	<i>Percent</i>
<b>Place of Death</b>		
PCH	75	86.2
Hospital	11	12.6
In transit to hospital	1	1.1
<b>Transferred to Hospital in Last Month of Life</b>		
Yes	26	29.9
No	61	70.1
<b>Died in Preferred Place</b>		
Yes	43	49.4
No	29	33.3
Don't know	15	17.2
<b>Registered with WRHA Palliative Care Program</b>		
Yes	5	5.7
No	82	94.3
<b>Mean Number of Months Resident in PCH</b>	29.6 months	

### *System Factors*

*LTC facility.* Twelve LTC facilities participated in the study, with a range of 0 to 24 participants responding from each facility. Facilities ranged in size from 78 beds to 314 beds (M= 219.2, SD= 65.8) and there were more non-profit (n= 8) than proprietary (n= 4) facilities. Non-denominational facilities were slightly more prevalent (n= 7) than

those with a religious affiliation (n= 5). The majority of the LTC facilities were located in the suburbs of the city of Winnipeg.

### **Descriptive Statistics of Results on Modified TIME Instrument**

The following sections, organized under the headings of the conceptual framework, will describe the findings on the individual questions, along with the mean domain scores of the modified TIME instrument.

#### **Client Factors**

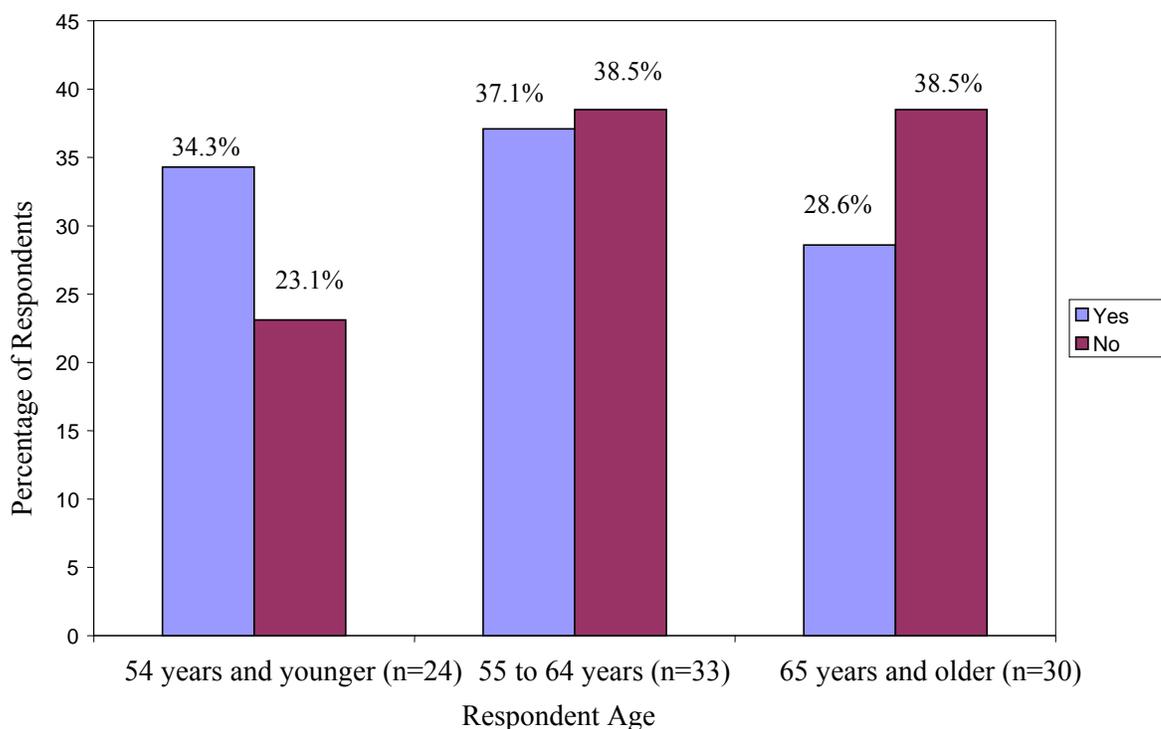
##### ***Family Expectations of Care***

When respondents were asked if the resident's death had come as a surprise to them, 40.2% (n= 35) stated "yes" and 59.8% (n= 52) indicated "no". Respondent age does appear to impact their perceived suddenness of the death (See Figure 3). For example, 23.1% of respondents who were less than 54 years of age indicated the death was not a surprise whereas 38.5% of respondents aged 65 years and older felt it was not a surprise. For many respondents, the resident's death came very suddenly, and was qualified with statements such as "we were expecting it but not at that time, not so soon". Others expressed that because the resident had recovered in the past from illness, they "felt she was healthy enough to recover". Two respondents aptly stated:

"It hit you like a ton of bricks when it happens, even though you know they are sick and not going to get better, it is still a shock. Death is final, you can't visit or hug anymore, can't turn around and see them".

"Even though her quality of life was not great and she was very ill, in my mind I was thinking if she would sleep away it was ok. But in reality when it happens you are never prepared."

Figure 3. Resident's Death a Surprise



For those respondents for whom the death did not come as a shock or surprise, their comments reflected recognition of the pattern of deterioration and decline in function over time. Comments noted that the resident started having difficulty swallowing, they stopped eating, became more tired, and less enthusiastic about activities that once brought them pleasure. These changes became the “red flags for the family” that death may be approaching. Others noted the sense that for many residents, they were “living on borrowed time” and that death arrived after a “very gradual and slow release”.

Based on the descriptions provided by the respondent of the resident’s last week of life and the clinical judgement of the researcher, only 14.9% (n= 13) of these deaths were classified as a ‘sudden death’. Sudden deaths were those where the resident

appeared healthy the day before and either suffered a myocardial infarction (no history of heart disease) or was found deceased either in the dining room, in bed or had died in their sleep.

Most respondents (n= 62, 71.3%) indicated that the care the resident had received in their last week of life was what they had expected. Comments revealed that this opinion was based on the facilities past performance and previous experience with death and dying. Others felt that care was “better than expected” and that staff had really rallied around the resident and family in the last week. One woman stated “[the care] exceeded my expectations. It is what you hope for; the staff loved her and treated her like their mother”. When care failed to meet expectations, it was often a result of feeling that the care was not personalized or that the resident had been abandoned. Several respondents noted that we are “kinder to animals” and that the care became very mechanical and impersonal. Some felt that the LTC staff did not deliver on what they had promised in regards to end-of-life care and ensuring the resident died without pain or suffering. One respondent stated:

“She suffered and they didn’t help her, they left her in her room and because I was in the room, they never came and checked on her... She was just another number.”

## **Interventions**

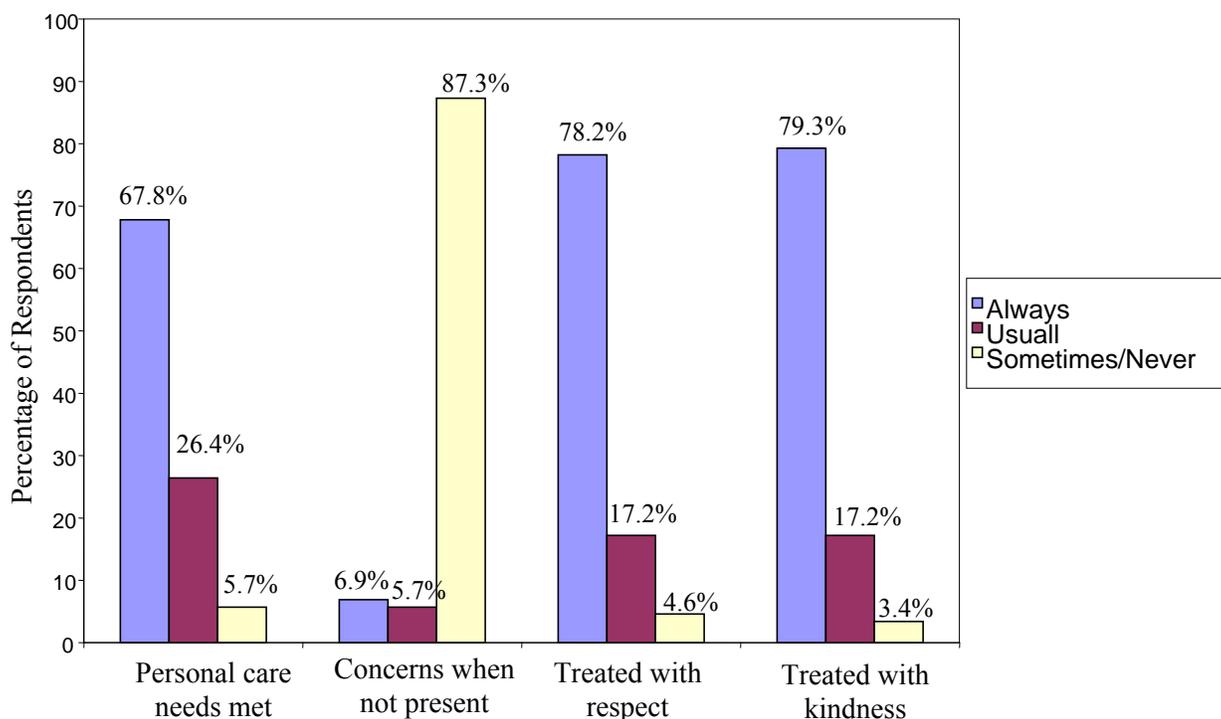
### ***Care and Concern for the Resident***

When assessing how well the personal care needs of the resident were addressed, 67.8% (n= 59) stated ‘always’, 26.4% (n= 23) stated ‘usually’ and 5.7% (n= 5) indicated that they were met ‘sometimes or never’ (See Figure 4). However, 31.0% (n= 27) felt that there was not enough staff available to meet the personal care needs of the resident but

only 17.2% (n= 15) believed there was not enough staff to help with medications. Quite a few of the respondents indicated they had hired companions to visit or stay with the resident. The majority of respondents (70.1%) stated that they ‘sometimes’ had concerns about the personal care needs of the resident not being met when they were not present, with 17.2% ‘never’ having concerns and 12.6% having concerns ‘usually or always’. One respondent, echoing the sentiment of some, stated “how do you know when you’re there they aren’t putting on a show when you visit”. Others indicated that they did not want to raise issues or concerns with staff for fear of retribution. As one individual stated “those things can come back to kick you in the pants.”

Most respondents felt that the resident was ‘always’ treated with respect and kindness (78.2% and 79.3%, respectively). No respondent felt that the resident was ‘never’ treated with respect or kindness, however, 4.6% and 3.4% responded that ‘sometimes’ or ‘usually’ the resident was treated with respect and kindness, respectively. Comments made by the respondents ranged from feeling staff “pampered” the resident to a feeling that resident’s “were neglected not because they wanted to but [they are] just too busy”. It was also interesting to note that many respondents made a link between staff liking the resident and the resident “not being a complainer, easy going, or didn’t ask for much”. The mean response on the NRCARE domain was .76 (SD.29), reflecting that 24% had an unmet needs in this domain.

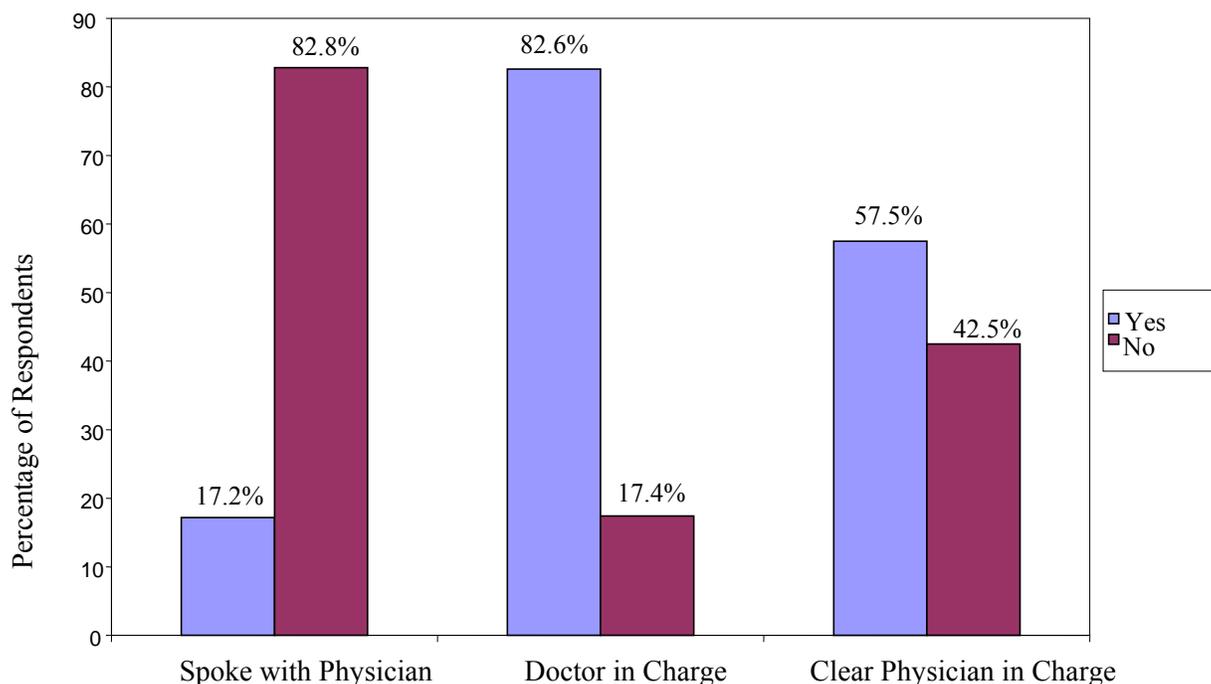
Figure 4. Care and Concern for the Resident



### ***Physician Contact and Communication***

The majority of respondents indicated they did not talk with the decedent's physician in the last week of the resident's life (n= 72, 82.8%). Additionally, 42.5% (n= 37) did not know who the physician was in charge of the care and 17.4% (n=15) did not believe there was even a physician in charge of the resident's care. For those 15 respondents who had spoken with the physician regarding the resident's care, none had a problem understanding what the physician told them about what to expect regarding the care of the resident. A few of the respondents (n= 3, 20.0%) felt they did not receive enough information regarding the resident's medical condition, but the majority felt the physician listened to their concerns about the resident's medical care (n= 12, 80.0%).

Figure 5. Contact with Physician in Resident's Last Week of Life



Respondents made comments that the physician was “very elusive” or that “only by luck do you see them or talk with them”. Respondents felt they did not have a relationship with the physician or that for some, the physician’s were “very reluctant to talk with relatives.” Questions or concerns for the physician that respondents had were most frequently communicated to the nurse or there was the general impression that the nurse alerted the physician to problems. The mean score for the physician domain was .16 (SD .35). This reflects that 84% reported an unmet need or had a problem with care in the physician domain.

### ***Consistent Care of the Resident***

Most respondents (n= 74) felt the staff in the LTC facility knew enough about the resident’s medical history to provide the best possible care. However, 14.9% (n= 13) expressed concern. Most of this concern came when residents were transferred to the

hospital. Many respondents made comments that they sensed that not enough information was transferred back to the facility when a resident returned from the hospital. Another comment reflected a lack of communication amongst staff; comments were made by several respondents that “information never seemed to trickle down to all the caregivers.”

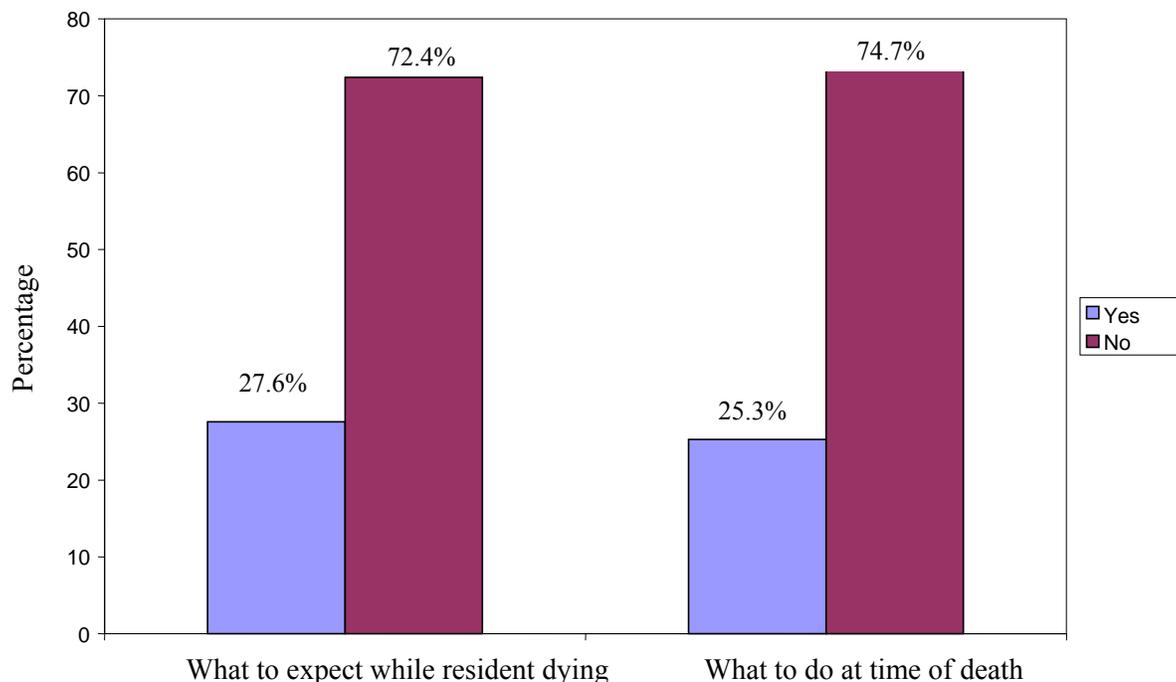
In regards to decision making, 86.2% did not feel that a decision had been made without enough input from them or the resident but nearly 10.3% indicated they ‘didn’t know’ if this had occurred and 3.4% expressed concern that a decision had been made without their input. Of those respondents who indicated the resident or themselves had specific wishes for the kind of care they did or did not want to be provided when dying, 88.9% (n= 63) felt that care was consistent with those wishes. Most respondents also indicated that when pain management was discussed, they had not received contradictory information from the staff (88.9%) and that the resident had received the right amount of pain medication to control their pain (71.7%). The mean score on the CRESID domain was .89 (SD .21). This reflects that 11% of respondents had unmet needs in this domain.

### ***Family Knowledge and Confidence***

When respondents were asked if they had ever received information about what to expect when the resident was dying, nearly three-quarters (72.4%) indicated they had not received this type of information. Similarly, three-quarters of respondents (74.7%) also had not received information regarding what to do at the time of the resident’s death (See Figure 6). However, when asked if they would have wanted information in either of these two areas, only 26.4% and 25.3% stated ‘yes’ respectively. Respondents reported feeling fairly or very confident that they knew what to expect when the resident was dying (34.5% and 46.0%, respectively) or that they felt fairly or very confident they knew what

to do at the time of the resident's death (23.0% and 58.6%, respectively).

Figure 6. Information Provided by LTC Staff



In regards to information on the types of medications used to manage symptoms the resident may have experienced, 57.8% (n= 48) stated they had received this type of information and 32.5% (n= 27) would have wanted more information. The majority of respondents felt either fairly (39.8%) or very confident (45.8%) they understood the medications that would be used to manage symptoms at the end of the resident's life. Comments made by the respondents reflected an assumption that staff would provide information on what to expect and what to do at the time of death "if they knew we needed it". Some respondents, who they themselves had a health care background, indicated how helpful and essential this was in their ability to make decisions and ask the staff questions. Others reflected on the need for a brochure or other material that would outline what to expect when a parent dies. The mean score on the FCON domain was .78

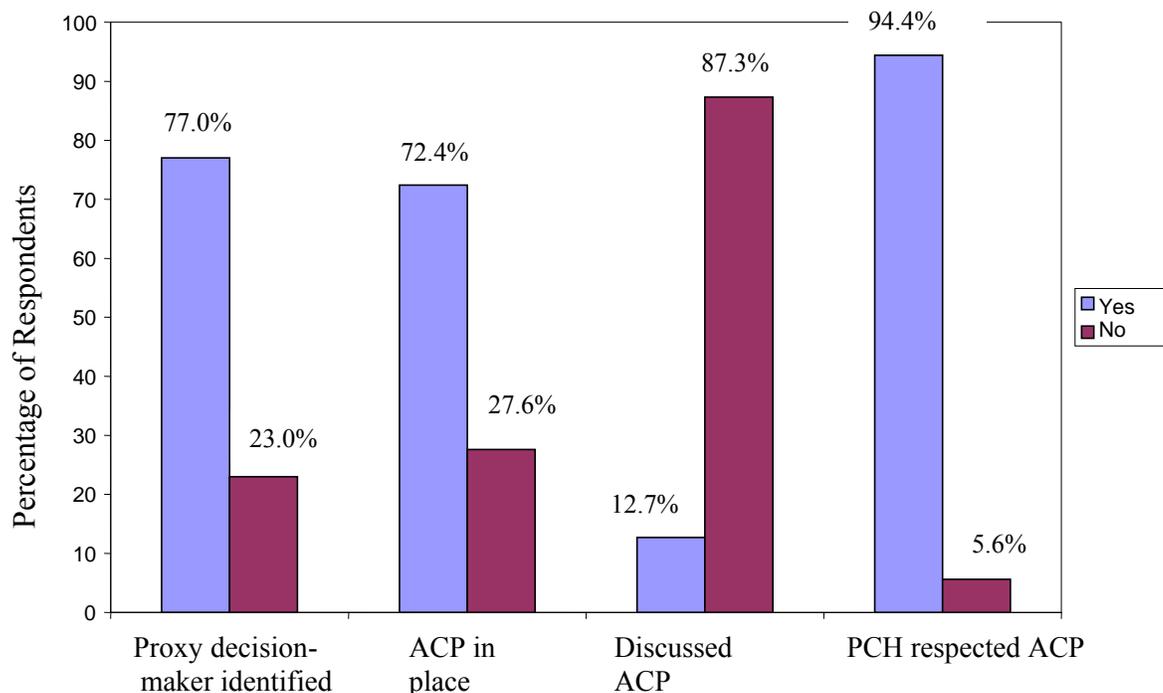
(SD .34), reflecting that 22% of respondents identified unmet needs in this domain.

### ***Advance Care Planning***

When asked whether or not the resident had had specific wishes or plans about the types of treatment he/she did or did not want when dying, 63.2% (n= 55) indicated 'yes'. Six respondents (6.9%) did not know if they had wishes and 29.9% (n= 26) indicated the resident had no wishes. Some respondents indicated that because the resident had had Alzheimer's disease or dementia, it was difficult to ascertain wishes; in this case the family was asked if they had wishes about the types of treatment they did or did not want the resident to receive when dying. Of the 20 respondents posed this question, there was an equal division between those who stated they had specific wishes regarding the resident's care and those who did not. When respondents who indicated they or the resident had specific wishes regarding care (n= 65) were asked if the physician or medical staff (including nurses) had ever discussed these wishes, 79.0% (n= 49) stated 'yes'. Additionally, 79% (n= 49) indicated that staff talked with them to ensure the care provided was consistent with those wishes and 88.9% (n= 56) felt that the care provided was consistent with the previously stated wishes.

Most respondents indicated that the resident had an Advance Care Plan (ACP) or health care directive naming a proxy decision maker (yes= 67, 77.0%) or giving directions for the kind of medical treatment they would want if they could not speak for him/her self (yes= 63, 72.4%). When asked if they had discussed this plan with the resident's physician, 87.3% (n= 62) stated 'no'. However of those with an ACP, 94.4% felt the LTC had respected it.

Figure 7. Advance Care Plan (ACP)



Some respondents commented that the levels of care used in ACP planning were “unclear” and “difficult to understand”. A few respondents indicated that the LTC staff had given them the form to fill out “without any explanation or discussion”. One respondent felt that the nurse “was disappointed in the choice [for my mom] to have treatment” whereas another noted that the “nursing home really pushed the DNR [do not resuscitate] on us and used really graphic language when they talked about it.” Nearly all respondents indicated that the discussion of ACP took place on admission and a review of the plan was done at an annual meeting. However, many commented that a more frequent revisiting of the plan would be beneficial or there was a need to review the plan when the resident’s condition changed. The mean score on the ACP domain was .58 (SD .47). This reflects that 42% of respondent’s had unmet needs in the area of ACP.

### ***Nursing Contact and Communication***

When exploring the respondents contact and communication with the nurse,

98.9% (n= 86) stated they had talked to a nurse in the resident's last week of life. Several respondents (n= 21, 24.1%) indicated that it was difficult to identify which nurse was responsible for the resident's care but most believed there was always a nurse responsible for care (n= 83, 95.4%). Only 3.4% (n= 3) indicated they had a problem understanding what the nurses were saying to them regarding what to expect from care.

Overwhelmingly, respondents felt that the nurses listened to their concerns about the resident's care (n= 82, 94.2%); however, 10.3% (n= 9) felt that the nurses did not respond or act on those concerns. Additionally, 18.4% (n= 16) indicated they had received less information than they wanted regarding the resident's medical condition and that 15.1% (n= 13) felt the nurse had given them confusing information regarding care.

Comments made by respondents during the interview reflected the feeling that nurses were reluctant to provide them with information or that they did not receive information proactively. For example, comments such as "they [nurse] didn't say very much; you had to seek them out; go looking for information" were frequently given. For many respondents, this resulted in them expressing a strong sense of advocacy in order to ensure issues were brought to the nurse's attention or to ensure that "things get done". Another common comment was that it appeared that either the nurses did not know the resident was dying or they did not want to talk to the family about death or dying. Respondents stated, "no one came out and said how sick he was", "they [nurses] never came out and said she was dying", or "there was no explanation of what was going on; never used the dying word". The mean score on the nursing domain item was .89 (SD

.21), reflecting that 11% identified unmet needs or areas for improvement with nursing contact and communication.

### ***Health Care Aide Contact and Communication***

Respondents felt that health care aides (HCA) played an important role in the day-to-day care of the resident, however, comments reflected the perception that the HCA's were not 'allowed' to discuss aspects of the resident's care with the respondent. Therefore, 81.6% (n= 71) indicated that a HCA had never given them confusing information, but 11.5% (n= 10) felt they could not answer this question. Most respondent's felt that the HCA's did listen to them if they had concerns about the care of the resident (n= 61, 77.2%).

Comments from respondents reflect a feeling that HCA's are very rule oriented and do not deviate from their scheduled tasks. Some respondents stated "they [HCA] didn't want to talk to you about anything" or "they [HCA] seemed quite angry and distant". Since many of the HCA's working in LTC facilities are ethnic minorities, some respondents reflected on language barriers and cultural issues that affected the respondent's ability to communicate with the HCA's. Communication issues between the nurses and HCA's was also noted by many respondents, who felt that often care issues "did not trickle down" and so often aides appeared not to know a resident was dying and would still be trying to get them up out of bed or feed them.

### ***Pain and Symptom Management***

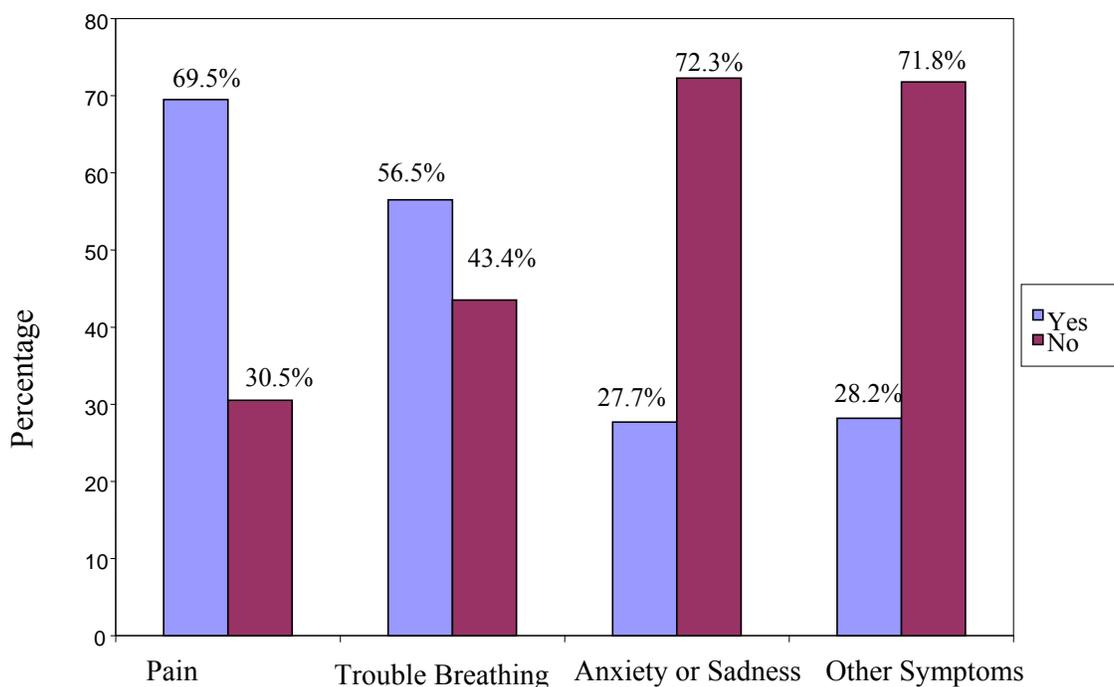
When exploring the symptoms experienced by the resident in their last week of life, 69.5% (n= 57) of respondents indicated that the resident had pain and that 94.5% (n= 52) were receiving medication to alleviate the pain. Refer to Figure 8 below. Several

respondents (n= 15, 31.3%) indicated they had not understood the explanation provided by the medical staff regarding how the resident's pain would be treated and 11.8% (n= 6) felt that staff provided contradictory information regarding pain management. Nearly one-quarter of respondents (n= 14, 26.4%) felt the resident had received too little pain medication to manage their pain. A frequent comment regarding pain management was made in relation to the reluctance of staff to give medication on a regular basis. As one respondent noted:

“I was ready to load her in the car and take her to ER because they weren't there for her. [We] just couldn't get continuity between shifts for morphine administration [it was ordered on an as needed basis only]. So many times [I] went into the room and she would be waiting for the next pill and [the staff] saying they would come when they knew she needed it. I wouldn't leave because I knew she wouldn't get her meds [if I wasn't there].”

Nearly half of the residents (n= 48, 56.5%) had trouble breathing in the last week of life and some (n= 18, 27.7%) had experienced feelings of anxiety or sadness. For those indicating a problem, respondents did believe that the resident had received enough help for the troubled breathing (right amount= 38, 79.2%) or their feelings of anxiety/sadness (right amount= 12, 70.6%). Several respondents (n= 24, 28.2%) indicated that the resident had experienced 'other symptoms' in the last week of life; the most frequently cited other troubling symptom was restlessness, confusion or agitation. However, pain with repositioning, difficulty swallowing, dry mouth, nausea, hunger pains, bleeding, itchiness, depression and loneliness were also cited as troubling symptoms.

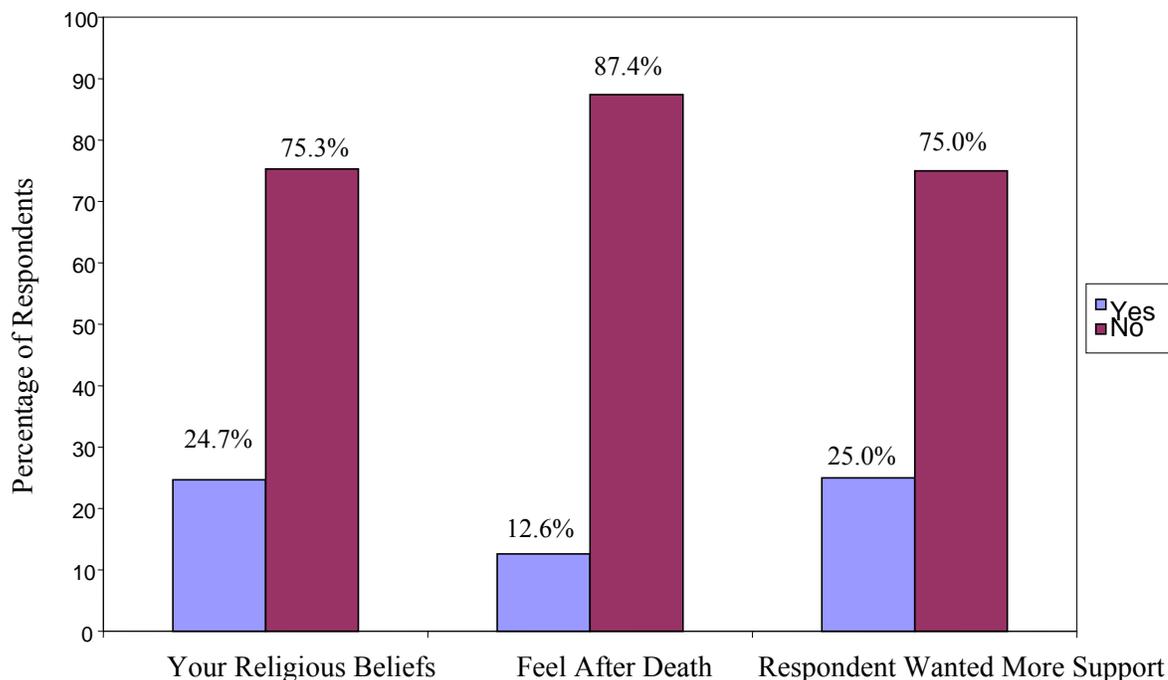
Figure 8. Pain and Symptom Experience of the Resident



### ***Spiritual, Psychosocial and Bereavement Support***

Three-quarters (75.3%) of respondents indicated that no one from the LTC facility had talked to them about their religious or spiritual beliefs. For those for whom a staff member discussed their beliefs (n= 21, 24.7%), all had felt it had been done in a sensitive manner and that they had as much contact of that kind as they had wanted. The majority of respondents indicated that they had received the right amount of support from the staff in dealing with their feelings about the resident's death (n=71, 82.6%) but that few had discussions with staff before the resident's death about how they might feel when the resident had died (n= 76, 87.4%). Most respondents indicated they would not have wanted staff to talk with them about how they might feel after the death (n= 57, 75.0%).

Figure 9. Staff Discussion about Spiritual and Emotional Issues



Comments indicated that dying and death was a personal experience and a few of the respondents stated they just “wanted to be in the moment and not think about death”. Most agreed that they would benefit from staff talking with them about what to expect but that “the staff are over-worked and no one has time to sit down and do this”. Additionally, respondents felt that it would be beneficial to talk to staff about what to expect with death or how they might feel but many qualified this by stating “I don’t need it but I can see how it might help someone else.” Many of the respondents (n= 71, 81.6%) indicated they had not received information from the LTC staff regarding someone they could turn to for help if they were feeling stressed.

The comments made by many respondents reflected a general sentiment that they themselves did not expect to receive emotional or spiritual support. For example,

participants stated “I didn’t ask for any and didn’t get any” or that “it didn’t occur to me that we should receive support”. Some stated that “I expect staff can look at a family and assess if they need help or not”. Others expressed that staff provided “unlimited support” and that they “were very concerned for us”. Staff members showed concern by providing tea and coffee or offering to sit with the resident while family went home to shower or out for a meal. As one respondent noted:

“no one said anything, they just seemed to be around a little bit more; [you] could sense they were a bit more attentive in the last few days.”

### System Factors

#### *LTC Environment*

Table 9 provides a summary of the findings on the individual questions regarding the assessment of the physical environment.

Table 9. Physical Environment of the LTC Facility

Question	Mean	Median	SD	Min.	Max.
H1. How would you rate how homelike the facility was?	7.1	8.0	1.96	1.0	10.0
H2. How would you rate how clean the facility was?	8.3	9.0	1.58	1.0	10.0
H3. How would you rate the temperature of your loved one’s room?	8.1	8.0	1.48	4.0	10.0
H4. How would you rate how able you were to make your loved one’s room homelike?	8.5	9.0	1.85	2.0	10.0
H5. How would you rate the privacy of your loved one’s room?	8.1	9.0	2.06	2.0	10.0
LTC-E Domain Score	8.03	8.4	1.31	22.0	49.0

The majority of respondents had few complaints about the LTC environment

expect when it came to the resident's room. Most of the LTC facilities represented did not have private rooms and thus, most residents had shared a room. Though seemingly contradictory to the above results, comments generally reflected that respondents felt that "at this stage of life, people should not have to share a room".

### **Outcome**

#### ***Satisfaction with End-of-life Care***

On the OSAT composite score, the median response was 8.8 (SD 1.85) indicating a high level of satisfaction with end-of-life care. Scores ranged from 18 to 50 for those 69 respondents with responses on all five items. On the single item satisfaction rating scale, just over half of the respondents (n= 47, 54.0%) were 'very satisfied' with the end-of-life care that was provided to the resident. Twenty-seven (31.0%) of respondents were 'satisfied' and 11.5% (n= 10) were 'not or very dissatisfied'. Three respondents were undecided. The mean score on the single item rating scale was 4.25 (SD 1.05).

Table 10 found below illustrates the results on the six rating scales, five of which comprise the overall satisfaction domain (items F1 to F5) and the OSAT domain score. The item F6 is not included in the calculation of the domain score as per coding instructions by Teno (2004).

Table 10. Satisfaction Ratings

Question	N	Mean (SD)	Median	Min.	Max.
F1. How well did the staff who cared for [resident] communicated with (him/her) and the family about the illness and the likely outcomes of care?	80	7.5 (2.5)	8.0	0	10.0
F2. How would you rate how well those taking care of [resident] provided medical care that respected (his/her) or your wishes?	83	8.6 (1.5)	9.0	3.0	10.0
F3. How well did those taking care of [resident] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?	79	8.3 (1.9)	9.0	0	10.0
F4. How well did those taking care of [resident] make sure that (he/she) died with dignity, that is died on (his/her) own terms?	79	8.8 (1.9)	10.0	0	10.0
F5. How well did those taking care of [resident] do at providing emotional support to you and [resident's] family and friends?	81	7.9 (2.4)	9.0	0	10.0
F6. What number would you give the overall care that [resident] received in their last week of life/under the care of the nursing home?	86	8.3 (1.8)	9.0	1.0	10.0
OSAT Domain (F1 to F5)	84	8.1 (1.8)	8.8	1.5	10.0

The comments made by respondents in regards to the areas being assessed by the satisfaction domains were reflective of previous comments made throughout the interview. Some respondents made the comment that staff “didn’t know [resident] was dying” as a means to explain their response. Others noted that staff “always communicated about the present” or that they “never came out and said dying”. Again the conception that staff intuitively knew what the respondent wanted was pervasive as stated by the following respondent:

“I think they realized from what I said that I understood what was going on. They didn’t talk because I didn’t ask. I know they knew I understood it was terminal.”

## **Testing for Relationships between Client, Intervention, System Factors and Overall Satisfaction**

The following section details the analyses undertaken to answer the third research question and the hypothesis of this study. T-tests, ANOVAs and correlation analyses examine these relationships. This section concludes with the building of a multiple regression model.

### ***Client Factors***

***Resident and family characteristics.*** Few demographic characteristics of either the resident or respondent resulted in significant differences in mean scores on the OSAT (Table 11.). Respondents employment status was the only variable in which significant differences existed; those who were retired or unemployed had higher mean satisfaction ratings ( $M=8.71$ ,  $SD=1.19$ ) than those who were employed ( $M=7.72$ ,  $SD=2.20$ ), [ $t(82)=-2.543$ ,  $p=.011$ ]. All tests conducted were two-tailed.

Table 11. Results of T-Tests for Resident and Respondent Variables and Overall Satisfaction

<b>Characteristic</b>	<b>Mean (SD)</b>	<b>T-test</b>
<b>Resident</b>		
<b>Dementia or Alzheimer's disease</b>		
Yes	8.28 (2.01)	t(82)=-.471, p=.639
No	8.09 (1.67)	
<b>Total # of medical conditions</b>		
<5	8.49 (1.72)	t(82)=1.754, p=.083
6 or more	7.79 (1.97)	
<b>Respondent</b>		
<b>Gender</b>		
Male	8.46 (1.41)	t(82)=.897, p=.372
Female	8.07 (2.03)	
<b>Relation</b>		
Son or daughter	7.97 (2.09)	t(82)=-1.578, p=.119
All other relations	8.63 (1.21)	
<b>Geographic location</b>		
Winnipeg	8.15 (1.91)	t(82)=-.500, p=.619
Rural or other	8.40 (1.63)	
<b>Employment status</b>		
Employed	7.72 (2.20)	t(82)=-2.543, p=.011*
Retired/unemployed	8.72 (1.19)	
<b>Education level</b>		
High school or less	8.19 (1.88)	t(81)=.037, p=.971
Some university or university graduate	8.17 (1.86)	
<b>Income</b>		
More than \$60,000	8.21 (1.97)	t(70)=.259, p=.797
\$59,000 or less	8.08 (1.71)	
<b>Health status</b>		
Fair to poor health	8.53 (1.49)	t(82)=.663, p=.509
Good to excellent health	8.14 (1.91)	

To test the relationship between respondent age and overall satisfaction, Pearson Correlation was used and a weak ( $r=.233$ ) but significant correlation was noted ( $p=.033$ ). Correlations were computed between the length of time an individual had been a resident ( $r=.051$ ,  $p=.645$ ), the number of days spent at place of transfer ( $r=.291$ ,  $p=.201$ ) and the time from the resident's death to the interview ( $r=-.146$ ,  $p=.186$ ) and overall satisfaction score; none were significant.

If we therefore, examine the first research hypothesis “family members who are female, older, have lower education levels and income levels will report less satisfaction with end-of-life care”, only employment status and age appeared to have a relationship with satisfaction.

Significant differences in mean scores were noted in the characteristics of the resident’s death (Table 12). To explore the second research hypothesis “families will be less satisfied with care received at the end-of-life for resident’s who are transferred to hospital and die in hospital”, two t-tests were conducted. In the first, there was a significant difference in mean score on the overall satisfaction composite between those resident’s who had died in the LTC facility (M=8.39, SD=1.68) and those who died elsewhere (M=6.84, SD=1.68), [t(82)= -2.68, p=.009].

When examining if being transferred to hospital in the last month of life affected mean satisfaction ratings, the subset of individuals who had ever had a transfer to hospital during their tenure at the LTC facility was first analyzed. No significant differences in mean score were noted [t(45)=-1.496, p=.071]. However, when all residents were included in the analysis regardless if they had ever had a transfer to hospital during their stay or not, respondents of residents transferred in their last month of life had significantly lower mean satisfaction scores (M=7.54, SD=1.98) than those who had never been transferred (M=8.47, SD=1.75), [t(82)=-2.139, p= .035]. Chi-square analyses was conducted to test whether having an advance care plan or proxy decision maker would affect a resident being transferred to hospital. Though no difference was noted in being transferred to hospital in general, those with an advance care plan [ $\chi^2$  =4.02, df=1, p=.045] or a proxy decision maker [ $\chi^2$  =7.82, df=1, p=.005] were less likely

to be transferred to hospital in their last month of life than those without.

A feeling that the resident died in a place they wanted to ( $M=8.76$ ,  $SD=1.40$ ) resulted in respondents having higher mean satisfaction scores compared to those who felt the resident did not die in a place they had wanted too ( $M=7.41$ ,  $SD=1.85$ ), [ $t(68)=-3.454$ ,  $p=.001$ ]. Similarly when death came as a surprise, respondents had lower mean satisfaction scores ( $M=7.65$ ,  $SD=2.04$ ) than those who stated the death was not a surprise ( $M=8.55$ ,  $SD=1.65$ ), [ $t(82)=-2.250$ ,  $p<.027$ ]. When the care provided met expectations, respondents had significantly higher mean satisfaction ratings ( $M=8.85$ ,  $SD=1.23$ ) than when care did not meet expectations ( $M=6.45$ ,  $SD=2.12$ ), [ $t(82)=-6.437$ ,  $p<.000$ ]. Being known to the WRHA palliative care program did not produce differences in mean satisfaction score.

Table 12. Results of T-tests between Characteristics of Resident's Death and Mean Overall Satisfaction Score

Characteristic	Yes	No	Result
	M (SD)	M (SD)	
LTC death	8.39 (1.80)	6.84 (1.68)	t(82)=-2.68, p=.009**
Transferred to hospital in last month (whole sample)	7.54 (1.98)	8.47 (1.75)	t(82)=-2.14, p=.035*
Transferred to hospital in last month (of those ever transferred) (n=47)	7.54 (1.98)	8.39 (1.91)	t(45)=-1.49, p=.142
Died in place wanted too	8.76 (1.40)	7.41 (1.85)	t(68)=-3.45, p=.001**
Death a surprise	7.64 (2.04)	8.55 (1.65)	t(82)=-2.25, p=.027*
Care what expected	8.85 (1.23)	6.46 (2.12)	t(82)=-6.44, p=.000**
Known to palliative care program	7.69 (1.83)	8.23 (1.86)	t(82)=.626, p=.533

\* t test p<.05 \*\* t test p<.01

To test for mean differences between three groups, one-way ANOVA was used (Table 13). Though frequency of visitation produced a trend in decreasing mean overall satisfaction score with more frequent visitation (daily, M=8.07, SD=2.09; 2 to 5 times a week, M=8.09, SD=1.59; other, M=8.64, SD=2.03), no significant differences were noted [F(2, 81)=.600, p=.551]. When religious affiliation for both the resident and respondent was assessed for affect on the overall satisfaction score, no significant differences were noted.

Table 13. Results of ANOVA Testing

Characteristic	Mean (SD)	ANOVA
<b>Visitation pattern</b>		
Daily	8.07 (2.09)	F(2, 81)=.600, p=.551
2 to 5 times a week	8.09 (1.59)	
Other	8.64 (2.03)	
<b>Resident religion</b>		
Catholic	8.15 (1.71)	F(2, 81)=1.649, p=.199
Protestant	8.50 (1.88)	
None or other	7.59 (1.88)	
<b>Respondent religion</b>		
Catholic	7.89(1.98)	F(2, 80)=.264, p=.769
Protestant	8.26 (1.87)	
None or other	8.24 (1.81)	

### *System Factors*

**LTC environment.** To explore the relationship between the LTC environment (composite score) and overall satisfaction, a Pearson correlation coefficient was calculated. The correlation between the LTC environment score and overall satisfaction was moderate ( $r=.461$ ) and significant ( $p=.000$ ).

A series of t-tests were conducted to examine the relationship between LTC factors, namely facility bed size, proprietary status, and religious affiliation with satisfaction. None of the relationships were significant and the findings are reported in Table 14 below.

Table 14. LTC Facility Characteristics and Overall Satisfaction Scores

Characteristic	N	Mean	SD	Result
<b>Number of Beds</b>				
Under 220	41	8.15	2.21	t(82)=2.66, p=.847
Over 221	43	8.23	1.46	
<b>Religious Affiliation</b>				
Yes	22	8.13	1.77	t(82)=-.202, p=.840
No	62	8.22	1.76	
<b>Financial Status</b>				
Proprietary	18	8.02	2.14	t(82)=.441, p=.661
Non-Profit	66	8.24	1.78	

### *Interventions*

The relationship between the individual questions not included in the composite scales relating to pain and symptom management, communication, and the spiritual, emotional and bereavement support provided to families were examined for potential differences in overall satisfaction scores (Table 15). When examining the effect of the symptom experience of residents as reported by the respondents on overall satisfaction rating, the presence of pain (M=7.94, SD = 1.96) and other symptoms (M=7.46, SD=1.87) resulted in borderline significant differences in satisfaction scores. If the resident had experienced difficulty breathing, or feelings of anxiety or sadness, there was no significant effect on satisfaction score.

When interaction and communication with health care providers such as the physician, nurse and health care aide were examined for their effect on satisfaction rating, lack of a clear understanding of who the nurse responsible for the resident's care was (M= 7.19, SD=2.46) and feeling that the health care aide did not listen to the respondent's care concerns (M= 5.93, SD=2.95) were two variables in which significant

difference in mean satisfaction score were noted.

Finally, when the spiritual, emotional and bereavement support provided by staff to the respondents was examined for their effect on satisfaction, individuals who felt they had not received enough emotional support ( $M= 6.14$ ,  $SD= 2.39$ ) compared to those who felt they had received enough support ( $M= 8.63$ ,  $SD= 1.38$ ) showed significant differences [ $t(81)=-5.469$ ,  $p=.000$ ]. Likewise, individuals who had staff talk with them about how they might feel after their loved one died reported higher satisfaction ratings ( $M= 9.68$ ,  $SD= 354$ ) than those who had not talked to a staff person ( $M=7.97$ ,  $SD= 1.87$ ), [ $t(82)=-2.984$ ,  $p=.004$ ]. These findings are interesting in light of respondents comments' that they did not want to talk about how they might feel after the death with staff; a finding that will be explored further in the next chapter.

Table 15. Results of T-Tests for Individual Intervention Questions and Overall

## Satisfaction

<b>Symptom Experience</b>	<b>N</b>	<b>M (SD)</b>	<b>Result</b>
<b>Pain present</b>			
Yes	55	7.94 (1.96)	t(78)=-1.966,
No	25	8.80 (1.40)	p=.053
<b>Receiving pain medication</b>			
Yes	51	7.98 (2.02)	t(81)=.925,
No (includes no pain)	32	8.52 (1.56)	p=.202
<b>Trouble breathing</b>			
Yes	48	7.91 (2.09)	t(81)=-1.682,
No	35	8.60 (1.42)	p=.096
<b>Anxiety or sadness</b>			
Yes	18	8.35 (1.68)	t(61)=.141,
No	45	8.28 (1.84)	p=.888
<b>Other symptoms</b>			
Yes	24	7.46 (1.87)	t(81)=-2.499,
No	59	8.54 (1.74)	p=.014*
<b>Communication</b>			
<b>Spoke with physician in last week of life</b>			
Yes	15	8.51 (1.49)	t(82)=-.715,
No	69	8.13 (1.93)	p=.476
<b>Clear who RN</b>			
Yes	65	8.49 (1.54)	t(82)=-2.799,
No	19	7.19 (2.46)	p=.006**
<b>Felt the HCA listen to concerns</b>			
Yes	66	8.60 (1.24)	t(74)=-5.078,
No	10	5.93 (2.95)	p=.000**
<b>HCA gave confusing information</b>			
Yes	6	8.02 (2.15)	t(72)=-.534,
No	68	8.38 (1.56)	p=.595
<b>Spiritual, Emotional and Bereavement Support</b>			
<b>Spiritual talk</b>			
Yes	20	8.77 (1.61)	t(80)=-1.677,
No	62	7.97 (1.91)	p=.097
<b>Talk how you would feel after death</b>			
Yes	11	9.68 (.354)	t(82)=-2.984,
No	73	7.97 (1.87)	p=.004**
<b>Enough emotional support</b>			
Yes	68	8.63 (1.38)	t(81)=-5.469,
No	15	6.14 (2.39)	p=.000**
<b>Offered help if stressed</b>			
Yes	16	8.45 (1.94)	t(82)=-.620,
No	68	8.13 (1.84)	p=.537

\* t test p&lt;.05 \*\* t test p&lt;.01

### *Correlations Between TIME Subscales and OSAT*

Correlation analyses were conducted to further examine the relationships between the various domains on the TIME derived by factor analyses such as care and concern for the resident, physician contact and communication, consistent care of the resident, family confidence, advance care planning, and nursing contact and communication, and overall satisfaction (Table 16). Overall satisfaction scores were significantly correlated with all but two of the subscale domains. There existed a strong positive correlation ( $r=.723$ ,  $p<.01$ ) between nursing contact and communication and overall satisfaction. Additional strong positive correlations were found between overall satisfaction and care and concern for the resident ( $r=.628$ ,  $p<.01$ ), consistent care ( $r=.544$ ,  $p<.01$ ), and family confidence ( $r=.397$ ,  $p<.01$ ). It was interesting to note that both advance care planning and physician contact and communication were not correlated to overall satisfaction ratings or any other of the subscale scores and may be due to the large number of variables included in this study. The failure of advance care planning to be significantly related to satisfaction ratings thus leads to the rejection of our fourth hypothesis where it was stated “family members will report more satisfaction with care when an advance care plan for the resident is in place”.

Nursing contact and communication was the only other subscale which had strong positive relationships with the most other subscales: consistent care ( $r=.451$ ,  $p<.01$ ); care and concern for the resident ( $r=.651$ ,  $p<.01$ ); and family knowledge and confidence ( $r=.274$ ,  $p<.05$ ). Possible reasons for these significant relationships will be discussed in the following chapter.

Table 16. Correlations between Overall Satisfaction and TIME Subscale Scores

<i>Subscale</i>	1	2	3	4	5	6	7
1. Overall Satisfaction	1.0						
2. Physician Communication	.097	1.0					
3. Nursing Communication	.723**	.149	1.0				
4. Consistent Care	.544**	.150	.451**	1.0			
5. Care and Concern for the Resident	.628**	.148	.651**	.335**	1.0		
6. Family Confidence	.397**	.113	.274*	.194	.218*	1.0	
7. Advance Care Planning	.092	.170	.040	-.064	-.007	.069	1.0

\*Correlation significant at the .05 level (2-tailed)

\*\*Correlation significant at the .01 level (2-tailed)

### **Multivariate Analysis**

Multiple regression analyses were performed to further explore the independent and joint effects of the various client, system, and intervention factors on satisfaction with end-of-life care. The regular method of multiple regression was used as there are no available theories to determine which variables had greater importance; thus, all variables had equal weight when entered into the regression analysis. However, the development of the multivariate models was largely based on the previous inferential analyses, with significant variables entered into the analyses in the same format as used previously. Therefore variables such as death in the LTC facility, transferred to hospital in the last month of life, and enough support with feelings were entered as dichotomous variables. Due to the small sample size, the final regression model was built from the significant findings of several smaller regression analyses. Variables were forced into the model as clusters. The number of observations included in the final multiple regression model was 75.

The first two variables regressed were the two respondent variables which were found to be significantly related to OSAT score; age and employment status. As noted in Table 17, when entered into the model, neither was significant and the model only accounted for 8% of the variance ( $R^2$  of .080,  $p < .05$ ,  $F = 3.53$ ). They were therefore excluded from further analyses.

Table 17. Regression Analyses of Significant Respondent Characteristics

<i>Variables</i>	B	SE-B	$\beta$	95% CI	
				Lower	Upper
Age	0.00172	0.022	0.107	-0.026	0.061
Employed (vs. retired/unemployed)	0.756	0.499	0.205	-0.236	1.75

Since many of the variables relating to the characteristics of the resident's death were found to significantly affect mean satisfaction score, a separate multiple regression analysis was conducted with only these variables (Table 18). When these five variables were regressed separately (n=70), the model was significant ( $R^2$  of .375,  $p < .001$ ,  $F = 7.691$ ). Two of the variables were significant: end-of-life care was what the respondent expected and if the respondent felt the death was a surprise.

Table 18. Regression Analysis for Variables Characterizing Resident's Death and Satisfaction with End-of-life Care

<i>Variables</i>	B	SE-B	$\beta$	95% CI	
				Lower	Upper
LTC death (vs. other location)	.225	.662	.048	-1.096	1.54
Died in a place wanted to (vs. not)	.690	.372	.198	-.053	1.43
Care what expected (vs. not)	1.36	.452	.348**	.457	2.263
Death not a surprise (vs. yes)	.820	.364	.238*	.092	1.55
Not transferred to hospital (vs. yes)	.107	.492	.029	-.877	1.09

\* $p < .05$ ; \*\* $p < .01$

To further explore the impact that contact and communication with staff had on respondents satisfaction ratings, a separate regression analysis was conducted with only those variables relating to communication and care of the resident. These variables were

entered together as they reflect quality of care variables. Eight variables were entered into the analyses (n=75), resulting in a highly significant model:  $R^2$  of .748,  $p < .001$ ,  $F = 24.47$ . Five of the seven variables were highly significant (Table 19).

Table 19. Regression Analyses for Contact and Communication Variables and Overall Satisfaction with End-of-life Care

<i>Variables</i>	B	SE-B	$\beta$	95% CI	
				Lower	Upper
RN communication and contact	2.92	.756	.344**	1.4	4.4
RN clear (vs. unclear)	.389	.285	.091	-.18	.958
HCA listened (vs. not)	.885	.375	.169*	.137	1.634
Talk how feel after death (vs. not)	.798	.341	.152*	.117	1.479
Enough support with feelings (vs. not)	.952	.349	.202**	.256	1.648
Consistent care	1.56	.585	.191**	.394	2.731
Care and concern for the resident	.936	.512	.154	-.086	1.958
Family confidence	.436	.374	.084	-.311	1.184

\* $p < .05$ ; \*\* $p < .001$

Finally, the impact of the LTC environment on satisfaction with end-of-life care was explored with a linear regression model. This simple model was significant with an  $R^2$  of .213,  $p < .001$ ,  $F = 22.172$ .

Using the significant findings from the three previous models, the final multiple regression analysis model (Table 20) was significant with an  $R^2$  of .774,  $p < .000$ ,  $F = 28.201$ ; 77.4% of the observed variability in overall satisfaction with end-of-life care was explained by the independent variables. Significant factors contributing to overall satisfaction with end-of-life care of this regression model are care meeting expectations, nursing contact and communication, feeling that the health care aide listened to the

respondent's concerns about care, the respondent felt they had received enough support with their feelings, and the provision of consistent care to the resident. Three variables were no longer significant in the final model and may be an indication of a type 2 error or that these variables are correlated with the other independent variables.

Table 20. Summary of Regression Analysis for Variables Predicting Satisfaction with End-of-life Care for Residents in Long-Term Care Facilities

<i>Variables</i>	B	SE-B	$\beta$	95% CI	
				Lower	Upper
Care what expected (vs. not)	.836	.290	.207**	0.257	1.42
Death not a surprise (vs. yes )	-.108	.239	-.030	-0.585	0.368
RN communication and contact	2.99	.655	.353**	1.692	4.306
HCA listened (vs. not)	1.095	.345	.208**	0.406	1.78
Talk how feel after death (vs. not)	.589	.321	.112	-0.053	1.23
Enough support with feelings (vs. less than needed)	.970	.308	.206**	0.356	1.58
Consistent care	1.29	.578	.158*	0.139	2.45
LTC environment	.179	.098	.129	-0.017	0.375

\*p<.05; \*\*p<.01

### *Summary*

The findings from the first phase of the study indicate that family members are generally satisfied with the care that a resident receives at the end of their life as noted by a median score of 8.8 on the OSAT domain. Indeed with a single item satisfaction rating, 54% were 'very satisfied' with the end-of-life care provide to the resident, with 11.5% being 'not or very dissatisfied'. Most family members (71.3%) felt that care at the end of life had met their expectations. Based on domain scores however, areas of unmet needs or problems with care were identified. These include 84% of respondents identifying problems or unmet needs with physician contact and communication, 42% with advance care planning, 24% with care and concern for the resident, 22% with family knowledge and confidence, 11% with consistent care of the resident, and 11% with nursing contact and communication. Nearly one-quarter of respondents (26.4%) felt the resident had received inadequate management of their pain.

Based on the results of the inferential and multivariate analyses, the research hypotheses may be answered as follows:

1. Of the demographic characteristics of the respondent, only age and employment status were associated with mean satisfaction scores; as age increased, satisfaction increased and those who were retired were more satisfied with end-of-life care.
2. Respondents of residents who had been transferred to hospital in the last month of life had lower mean overall satisfaction scores than those individuals who had never been transferred to hospital or for whom the transfer occurred any time except the last month of life.

3. Respondents of residents who died in hospital or in transit to the hospital were less satisfied with care as reported on the overall satisfaction score than those respondents where the resident died in the LTC facility.
4. No relationship existed between having an advance care plan in place and respondent satisfaction scores. However, having an advanced directive or a proxy decision maker reduced the likelihood of transfer to hospital in the last month of the resident's life.
5. The multiple regression model that best predicts satisfaction with end-of-life care in the LTC facility includes feeling that care provided at the end of life met expectations, having contact and communication with nursing staff, feeling that the health care aide listened to the respondent's concerns about care, that the respondent felt they had received enough support with their feelings and that the staff provide consistent care to the resident.

## **CHAPTER FIVE - PHASE II: FOCUS GROUP METHODOLOGY AND RESULTS**

Phase two of the data collection involved conducting separate focus groups for those that responded they were satisfied with care and those that were dissatisfied with the care the resident received in the last month of life. Making the groups homogeneous in this manner facilitated discussion, created group cohesion and served to respect the divergent experiences of each group (Fern, 2001). A list of potential participants was compiled from the information collected and recorded in the Excel spreadsheet after each interview. A list of those who expressed dissatisfaction with care (n=10) and those who were satisfied (n = 35) and whom expressed a willingness to participate in a focus group was generated. The objective was to have six to ten participants per focus group and to ensure that each LTC facility had at least one representative in a focus group. Participants were classified by LTC facility and randomly drawn to ensure representativeness; this approach was solely for the satisfied group where a larger pool of willing participants was available. Potential participants were contacted two weeks before the scheduled group with the date, time and location of the focus group and participants were asked if they would be interested in participating. If a person stated no, an alternate was found for the group based on the facility. Similarly, if a potential participant could not be reached after two phone call attempts, the next participant on the list was selected.

The day before the focus group, all who stated they would participate were contacted to remind them of the meeting and to ensure they were still available to participate. A total of three focus groups were conducted; one with those expressing dissatisfaction with care (n=6) and two with the satisfied group (n=4 respectively). All

participants in the dissatisfied group who stated they were going to attend did whereas each satisfied group had one and two participants respectively who did not attend. Using a small group size assisted in making participants feel more comfortable, were easier to facilitate, and are more suited to situations where a more in-depth understanding of phenomena are warranted (Morgan, 1998).

The objective of the focus groups was to have participants further elaborate on their perceptions of the end-of-life care received by their family member in the facility and to explore areas for improvement in the quality of care. Additionally, focus groups are ideal forums for developing recommendations around key issues. It is for these reasons that this study used focus groups over individual in-depth interviews (Krueger, 1998).

When participants arrived at the respective groups, they were greeted by the researcher and directed to the room where the group was meeting. Once in the room, a research assistant had them review and sign consent forms and answered any questions they may have had (see Appendix H). These groups were moderated by the investigator using a guide developed from the first phase of this study and the research literature. Each group started by having participants introduce themselves and briefly sharing with the group one thing about the resident they wished us to know about them. Some ground rules were reviewed with the group such as not interrupting and being respectful of others' opinions'. After the introductions, the digital audio recorders were started and the research assistant took detailed notes of the conversation. Focus groups lasted 78 minutes on average. At the completion of the evening, all participants were thanked for their time and given a \$5.00 gift certificate for Tim Hortons, a Canadian coffee chain. At the end of

each focus group, the investigator and research assistant debriefed and began to generate themes around significant topic areas which were discussed.

***Focus Group Questions.*** The approach taken in the focus group was to use a structured format with predefined questions in order to meet the goal of this phase of the study (Morgan, 1998); that is to further understand what influences satisfaction and dissatisfaction with end-of-life care. The focus groups were structured around a series of four questions which asked: (1) What in your mind is 'good dying' or a 'good death'; (2) Thinking about your experience now, what were the positive experiences you had; (3) What could the LTC facility have done better; and (4) We are trying to improve end-of-life care in care homes, what advice do you have to share. Probes were used to further discussion and ensure topics such as physician contact, sharing of information, feeling adequately prepared for the death, transfers to hospitals at the end of life were covered. An open ended "Have we missed anything" question was asked at the end of the group discussion to ensure participants had the opportunity to share their experiences.

### ***Focus Group Data Analysis***

In the second phase of data analysis, a case-oriented analysis (Onwuegbuzie & Teddlie, 2003) was used to enrich the findings of the first phase of the research study. A case oriented approach "considers the case as a whole entity, looking at the configurations, associations, causes, and effects within the case"(Onwuegbuzie and Teddlie, 2003, p.363). To conduct this type of assessment each case, those who were satisfied and those who were dissatisfied, was analyzed separately using content analysis. Content analysis consists of reading the transcript or listening to the tape in its entirety and identifying significant topics of discussion (Morse & Field, 1995). These topics then

become the primary categories. For example, statements related to recommendation for improvement in end-of-life care become a category. Once the entire transcript was coded in this manner, all data that related to that category were identified. Similar categories were clustered into smaller more representative patterns of experience. These patterns helped to form a comprehensive picture of the collective experience. These cases were then used to describe and further understand the regression models developed in the first phase of the study. Additionally, the focus groups were forums to develop key recommendations for improvement in the quality of end-of-life care delivery, and are reported for each case.

Conventional analysis of audio-recorded data involves transcription of the data into text. Some authors argue that by converting audio into text, aspects of the conversation are lost such as voice intonation, speed and volume, thus leading to potential misinterpretation of the speaker's meaning (Hutchinson, 2005). As such, this project sought to analyze the focus group data through the use of digital audio-editing software to save selected audio bytes from the digital audio recordings of the focus groups into the various themes.

Recordings of the focus groups were created using a Sony<sup>®</sup> IC Recorder, a digital audio recorder which uses Memory stick technology (Sony Corporation, 2000). Each focus group recording was saved to the computer as 16-bit wave (WAV) files and burned to CD-ROM for back-up purposes. To assist in the coding of the digital data, GoldWave v.5.18, an audio-editing application was selected based on correspondence with a researcher (A Hutchinson, personal communication) who had used the technology. This program was also selected for its functionality, cost and being user friendly. GoldWave

allows for the precise selection, copying and saving of segments of the audio recordings in various file formats.

Coding of the audio recordings began by the investigator listening to the entire recording and noting significant topic areas discussed and to generate preliminary themes. The second listening of the recording involved selecting precise parts of the audio recording, copying and saving them as a separate audio file in the mp3 format using the GoldWave program. The mp3 format was selected, as it requires less memory to be stored than wave files. The audio-editing application permits the use of markers to accurately determine the beginning and end of the selection. To ensure the new audio file could be traced to its position in the original recording, notes were kept of the marker locations measurable to a fraction of a second. Each audio byte mp3 file was imported into an Excel spreadsheet where it was assigned a code based on the experience it represented and the content of the discussion. Once the entire audio file was coded as described above, codes were analysed and grouped into categories based on their characteristics. The detailed notes taken during the focus group and those developed in the debriefing sessions after each group assisted in establishing the codes and categorical themes. The two focus groups conducted with those who were satisfied were combined to represent the collective experience. Selected segments of the categories were transcribed for presentation in the results section. When transcribed, superfluous language (e.g. um's, ah's) and identifying characteristics were deleted. Recommendations for improving the delivery of end-of-life care in LTC are presented for the respective groups.

## **Phase Two: Focus Group Findings**

The following paragraphs report the findings of the focus groups conducted with those respondents who self-reported as either being satisfied or dissatisfied with end-of-life care. The demographic characteristics of the participants are first reported followed by the description of the experiences of those who were dissatisfied and satisfied with care. The chapter concludes with the presentation of the recommendations generated by each focus group for improving in the quality of end-of-life care provided in LTC facilities.

### ***Demographic Characteristics of Focus Group Participants***

The demographic characteristics of the focus group participants are reported in Table 21. The majority of focus group participants were female (n= 12, 85.7%) with the mean age of respondents being 56.57 years. Most participants had a university education (n= 11, 78.6%) and had an average household income of over \$60,000/year (n= 7, 50.0%). To ensure that focus group participants were representative of the overall sample, the demographic characteristics of the focus groups were tested using cross-tabulations with chi squared tests of significance. No significant differences between the focus group participants and the overall sample in terms of the age, gender, relationship to the resident, employment status, religious affiliation, visitation patterns, income or health status were noted.

Table 21. Focus Group Demographic Characteristics (N= 14)

<i>Characteristic</i>	<i>Number</i>	<i>Percent</i>
<b>Gender</b>		
Female	12	85.7
Male	2	14.3
<b>Age</b>		
Mean Age	56.57 years	45 years to 68 years
<b>Education Level</b>		
High school graduate or less	3	21.4
Some university or university graduate	11	78.6
<b>Employment Status</b>		
Retired or unemployed	5	35.7
Employed	8	57.1
Other	1	7.1
<b>Income</b>		
<\$59,000	5	35.7
>\$60,000	7	50.0
Not reported	2	14.3
<b>Religious Affiliation</b>		
Protestant	6	42.9
Catholic	4	28.6
Other/None	4	28.6
<b>Relationship to Resident</b>		
Son or daughter	9	64.3
Son in law or daughter in law	3	21.4
Friend/other	2	14.3
<b>Visitation</b>		
Daily	8	57.1
2-5 times a week	4	28.6
Other	2	14.3
<b>Reported health</b>		
Excellent or good	12	85.7
Fair or poor	2	14.3

### **Dissatisfied Focus Group Results**

The experiences reported by those who had been identified as being dissatisfied with care reflected a strong underlying component of unmet needs for both the family and resident and that care failed to meet expectations. These unmet needs were driven by several concerns including a lack of communication, staff lacking knowledge in end-of-life care, the lack of adequate pain management, a lack of acknowledgment that the resident was in the dying phase, inadequate physician contact and support, and a lack of policy or process for providing end-of-life care. The sentiment of unmet expectations was intertwined throughout and was expressed by the participants as a sense of being let down by the LTC staff and administration in their failure to deliver what had been promised. As a consequence of sensing the care did not meet their expectations, participants expressed feelings of anger, frustration, the sense that they had “let the resident down”, regret, and a strong sense of sadness. These themes will be illustrated further in the following paragraphs but will be prefaced by the initial findings from the discussion on what it means to have a good death.

#### ***Characteristics of a Good Death***

The respondents identified four main characteristics that comprised their conception of what it means to have a good death. The first component was dignity. Dignity encompassed the notion of having not experienced any suffering and that the dying process had gone smoothly. For all respondents, death with dignity meant you died suddenly, often in your sleep. Achieving dignity during the dying process however, was seen as a difficult task for residents in LTC as participants sensed that residents suffered

from a multitude of indignities from the onset of admission. As one participant, to the agreement of all, eloquently stated:

...so you can't even have a good death if the life you're living is not good at that point. And to often someone goes into a nursing home and it's all downhill from there. The indignities absolutely astounded me. Where my dad was, everyday after people finished eating, they were either put back into bed or tied into chairs around the outside of the halls, even though they are not supposed to use restraints, they still do, or they're tied into a geri-chair or wheelchair. The T.V. is on with no sound, that one used to really get to me...your whole world is half a room, that's just wrong. The women, I never have felt so bad for these poor women. No make-up, no hair done, no bra. I mean how can they feel good about themselves, even if they are cognitively impaired, I'm sure there is still some shred of dignity in there somewhere, if people would just be a little bit more kind to them, think of these things. I know it sure isn't how I want to go.

Secondly, a sense of respect for the resident and the dying process was paramount in having a good death. Respect involved providing personalized care and treating the resident as a human being. For many, this meant calling the resident by their name or talking to the family member about the resident. For example one woman stated:

I know at night time when I was there, I was sleeping there, there was a night person who came in and she was wonderful. She talked to my mother all the time. She called her by her name while she was changing her and cleaning her.

A second part of respect involved feeling that the LTC facility took pride in providing excellent end-of-life care to its residents. A respondent, who had received a booklet about the palliative care process from a staff member, commented on the quality of the material and how she perceived it reflected on how the facility must view end-of-life care:

...the information that came to us was in the form of a 100 pages, photocopied pamphlet that was sort of like this, with askew staples that felt to me like a very casual approach to something that's not casual, that

somehow that belittled her, like give me you best stuff, don't give me this, that I wouldn't hand to anyone. It was just sort of an indication of how they were thinking about this process.

Thirdly, control and trust that persons will deliver what they promised emerged as components of a good death. As one participant summarized:

A good death is achieved by having some measure of control and trust in the integrity and quality of the process, and in those that are managing the process around you. [For] a good death, people should deliver what they promised and you should be able to trust in that right to the end.

Finally, the acknowledgment that the resident is dying and that the plan of care changes accordingly was expressed as a cornerstone to having a good death.

...A good death is, one way is when it happens quickly, the alternative is when it's a known process that's happening that it is acknowledged that things are in place to look after the last weeks.

Many of the components described by participants of a good death were reflections of what failed to happen in their experiences with end-of-life care delivered in the LTC facility. These experiences are captured and reported below.

### **Focus Group Themes: Dissatisfied with Care**

#### ***Lack of Knowledge in End-of-life Care***

A feeling that staff in LTC did not have adequate preparation in the care for the dying was manifest in two ways. Firstly, respondents felt that there had been a failure to recognize that the resident had been in the terminal phase of their illness and as such, the plan of care had not been altered. This may also correspond to the finding that for 40.2% of respondents the resident's death had been a surprise. One respondent stated:

There's the good death where it's sudden, it's a surprise...but when it's not like that, it's having it acknowledged that now we are in a different process, this is the way it was before something has happened, and this is

the way it is now, and now it is a different process and everybody kinda acknowledges that this is a dying process and the patient gets what's appropriate for this new process and the family gets what's appropriate for the new process...

A consequence of failing to acknowledge that the resident was dying often resulted in the provision of inappropriate care such as trying to get the resident to eat, putting them in a bedside chair, or getting them up for activities. "They were trying to make her [mother] jump through hoops that she was hopelessly not up to doing, like sitting up to eat, like it was horrible". Some however, did not blame staff for failing to recognize the resident was in the dying phase; rather they placed blame on the physician for not being present, feeling that "if they [physician's] don't come around, I'm not sure they [staff] can make that decision [that they are dying]".

The second manner in which a lack of knowledge was manifest was in the perception that staff, including physicians, lacked the skills necessary to provide adequate symptom management. This is important in light of the fact that 69.5% of respondents reported that the resident had experience pain in the last week of life and that 26.4% felt they had received inadequate medications to control the pain. For many, achieving good pain control for the dying resident had been a significant struggle. Respondents questioned whether the 'myth of addiction' still existed among health professionals as one reason why staff and physicians were reluctant to give opioids. One respondent noted that it seemed physicians lacked the skill or knowledge of "the whole arsenal of medications that are out there [to treat pain]. T3's [Tylenol #3], that's what they were giving her, T3's, they were fighting hell with a pail of water." Others discussed how differences existed between care providers on different shifts; whether the resident

received their pain medication depended upon who was providing care on that particular shift. The result for many was that they “didn’t trust” that the resident would receive their pain medication and thus, they would have to direct care. As one respondent summarized:

...and where it broke down was those folks who then needed to be able to administer the pain medication. She was on a morphine on demand, when you can’t speak for yourself and I couldn’t be there, I mean it was just me, so there was the rest of the life that needed living, I was there whenever I could, which being a portion of very day, so when I walked out of that place, I knew she wasn’t going to be okay because I wasn’t there to speak for her, for those people who had the responsibility, she shouldn’t have even had to ask for that morphine, it was to be every hour...

When staff lack the knowledge in how to provide care to the dying, families reported that staff looked to them to direct care; a task which they felt grossly inadequate to do. As one participant stated:

The other thing that bothered me about my mother was that they asked us how we wanted her to get the morphine, I had no clue, you know. For days they were trying to give her other pills...but they wanted to know [should we stop], and they were trying to get her to swallow them, after a couple of days they asked us if they should be bringing her food, and like we don’t know the process, I don’t know when she needed that...you know it’s just all those little things that I thought they should have had, someone should have been making that call...

Additionally, it was perceived that it was not the family member’s role to know how to provide care and that families expected staff to “do their job and provide good care”.

There’s always opportunity for choice and when you choose to do the right thing, or you can choose to be average or you can choose, and so there was someone in a bed who was counting on you to just be even average, just know how to tell time and know that for her it was time for her morphine, that’s all it took. We were prepared and I was there for the loving care, that part was mine and I owned that. But what I couldn’t own was making her pain free.

For some, there was the sentiment that staff were not to blame for inadequate knowledge and thus poor care; it was perceived that they lacked the tools to provide care or that “their hands are tied” in the care they can provide.

[resident] had the good fortune of being really well liked by the caregivers she had, she really liked them, they really liked her. They wanted to look after her, their hands were tied, they couldn't, they knew she needed more pain management, the people who were actually on the floor doing it didn't have any other option than to follow the protocol of that nursing home, and asking through the chain of command, which was trying to find some elusive doctor who has a contract to look after these people... and they certainly didn't know or give any evidence that they knew there was a palliative care resource in the region to trigger, have show up and allow them to use the appropriate medication which the physician didn't want to allow them to use...but the people on the floor, the people looking after her shift after shift, they seemed to know what was going on, they just didn't have the tools to deliver what they want to deliver, which was pain management. And it was rough on them and so it was just tearing them apart to see what was happening to her and us as well, but it was difficult for the nurses and caregivers.

### ***Lack of Communication***

Breakdowns in communication occurred on several different levels. Participants expressed feeling that they had not received adequate communication around the nature of the resident's illness and what to expect. For example to the agreement of many in the group, one respondent stated “the deficiency that affected me was we really didn't have a sense of how long this process was going to be and someone could have helped us out on that”. Many of the respondents had experienced a lack of communication around what changes to expect as the resident approached death and how to prepare for the impending death. These findings parallel those noted in phase one where nearly three-quarters (72.4%) of respondents had indicated not receiving information on what to expect while

the resident was dying. As one respondent replied:

Q- Did you feel that health care professionals adequately talked about or prepared you for the process or change in process?

A- Not at all. At no time did anyone in the nursing home talk to you about process, about what was happening to my mother, you know, or anything...but no one talked to us about process. The administration never came to us, never explained to us what my mom was going [through], to happen.

Information related to what to do after the resident's death was similarly lacking.

This finding is again reflective of those of the first phase where 74.7% of respondents did not receive information about what to do at the time of the resident's death. Many simply had felt it was an understanding on their part that the room was needed by someone else and that they would have to clean out the room as quickly as possible. However, for several participants, this information had not been clearly conveyed or provided in a manner that had been sensitive. As one respondent reported:

They need to explain to families once that person dies this is what the process is. We're going to take everything out of the room within 12 hours, and you'll never see it again for the most part, and if you want something then you better take it then. They don't tell you that, I mean my mom was told 24 hours, you have 24 hours. The next morning which was nine hours later I went in to get something and she [nurse] was like we just put all of his clothes in these garbage bags, I guess someone else needed the room.

Respondents also reported that it appeared that communication "did not trickle down" to all care providers. Part of this resulted in a lack of continuity in care provided between shifts, especially around pain management. Similarly, concerns were raised about the lack of apparent communication between nurses and physicians. It was generally acknowledged that to communicate with the physician a family member often

went through the nurse. However this did not ensure an expedited process. As one individual noted:

the process seems to be that the nursing staff flags someone who needs attention from the doctor but even there, there was a three week period where she [mother] was congested and it still took a long time still to even see the physician.

### ***Inadequate Physician Contact***

Throughout the discussion, respondents expressed frustration over their lack of access and the inability to contact the doctor to discuss their concerns about the resident. This was noted in phase one where 82.8% of respondents did not talk with a physician in the last week of the resident's life. For example one respondent stated:

I mean I never knew when the doctor was going to be there...and I'd try and get a hold of the doctor in the nursing home and I think that's probably the biggest problem is that you can't get a hold of them because their not there or their with a patient or whatever; yeah it's pretty hard to get a doctor and get his time.

For many, inadequate contact with the physician had been an ongoing issue, not one that had only started at the end of the resident's life. A common frustration was that when entering LTC, contact with the resident's community physician was severed and they were assigned a new physician, often disrupting a relationship that had developed over many years.

It seems as soon as you go through the nursing home doors you become someone else's patient so all of you past relationships go away and you seem, you're just cut-off from all that and at the time when its so critical to be able to rely on those relationships and on the history that you formed with these people. When you need it the most it's gone.

A result of this disruption and lack of contact with the physician was a sense that there was no continuity of care nor was a relationship formed between the family

member and the new physician. Not having an established relationship with the physician caused respondents to feel that the physician lacked an understanding of the resident's past medical history and complicated decision making at the end-of-life.

Well why should it be any different then what you've experienced through your whole life. You have a doctor, you go see the doctor, you consult with them, you establish a relationship. Why can't you do that in a nursing home setting? I guess it's really important to have that relationship with the physician established because when the crunch time comes, there are issues, and if you can't (a) get a hold of that doctor or if there's no established process so that you attend the appointments or the interactions that doctor has with your family member, then you've got nothing to fall back on.

### ***Lack of Process or Policy for End-of-life Care***

All respondents commented that it appeared in their respective facilities there had been no clear process in place for providing end-of-life care. As a result, care had been fragmented and often fraught with problems.

...there was no intrinsic process in that building; there was no process, no thing that kicked in to get a palliative care team involved, resolving the medication problems, all the things. It was sort of a battle to get anything good to happen.

In some cases, the care that had been promised, such as ensuring the resident would not die in pain, did not come to fruition. Though the respondents had thought they understood what comfort care entailed, it did not materialize as it had been discussed.

Q – Did you understand what comfort care means?

A – I thought I understood what it should have been; it wasn't happening that's for sure

Q- So you had a concept but what was happening...

A- what was happening was not the reality, was not what was expected.

Respondents had wanted someone to be in charge of the resident's care and to

ensure that end of life policy or procedure was followed.

...like looking back on it, we got through it but I was so angry after, she shouldn't have had to go through that, there should have been some policy, some process, a checklist you know and somebody should have been in charge of that checklist everyday, you know checked it off.

Part of the discussion in how to improve end-of-life care centred on ensuring adequate education and training in such care. However, training of staff is not enough. As one individual stated:

Nursing homes have to have palliative programs in place but you can have people with training and no protocol and you're still sort of in the same situation. You have people in the building who know how to do things but there's no protocol to move a person into it. So you need to establish that nursing homes have to have a palliative stream integral to their business with the full expectation that people are going to die in your building fully supported by a protocol, maybe have a checklist that caregivers follow.

Many of the respondents placed the responsibility on the failure to achieve a good death on "the top"; respondents blamed administration for the lack of clear palliative care policy in the facilities. Respondents continued to allude to the fact that their dissatisfaction with end-of-life care was not caused by the day to day staff but rather that it was perceived that "if the top didn't care, so the staff didn't care":

... in my experience, from the top down they didn't care, so their staff wasn't trained, their staff didn't know what to do because if the top people didn't show any consideration at all, then the rest of the staff doesn't.

Additionally some felt that the facility administrators had lacked empathy or did not view excellence in end-of-life care as their facilities priority.

I think most people [who] go there, eventually pass away...I'm amazed that the death word is not part of their business. Funeral homes don't mind talking about death. There are acknowledged segments of society who are

in the business of giving people the best service as part of this process, why can't that be something they're equally proud of as their hot meals.

### *Consequences of Dissatisfaction with Care*

When respondents were dissatisfied with the care the resident had received at the end of life, several consequences ensued. For some, a strong sense of regret was present; regret that they somehow failed the resident in their most vulnerable time.

I had this sense, of not failure, but I didn't deliver what I promised her because we had this conversation [about being pain free], and I promised her and there's the huge sense that I let her down and I hate that; I think I'll always feel regret for what happened in that week.

When care had failed to meet their expectations, respondents described the feeling that they "needed to be there all the time to ensure that things got done". This sense of advocacy or lack of trust permeated many of the discussions. Respondents noted that frequently, achieving good end-of-life care required "the right person being on shift and if you fight for it".

Others expressed that once the resident had died, they needed to get out of the facility as quickly as possible and "get the smell off me". This had implications for further contact with the facility staff. Respondents who returned to the facility after the resident's death had contact "with those that really mattered, who had made a difference" but tended to avoid contact with certain people. However, many did express the desire to inform staff about issues that had arisen during the resident's stay but were never given the chance to provide such feedback.

I think it's a fabulous idea, to have some sort of exit interview. I think it's tremendous for those people who are interested in that opportunity. I think you should have an opportunity to decline, so it should be assumed yes, unless you say no, I'm cool, I don't need do, then that's fine.

Though not a direct consequence of being dissatisfied with care, it is noteworthy that a few respondents reported feeling afraid to complain about the care, as they were worried about retribution by staff towards the resident.

...I would ask [about why she hadn't received pain medication] then I was frightened because I didn't want to be seen as the trouble making relative that somehow might then impact her care

-that's not unusual at all

-I was scared

-absolutely, anytime my mother went she wouldn't say a word, nothing

Q- so you did fear retribution?

A- absolutely, absolutely. Not on ourselves but on our loved ones, it was always a consideration and we know people got fed up with us because we were there all the time but I mean that's what we had to do

-but if they did their job properly, they wouldn't have to feel that way.

### ***Recommendations***

In order to generate a list of recommendations, focus group participants were asked "We are trying to improve end-of-life care in care homes, what advice to you have to share?" Much of the discussion with this group of participants focused on the need to develop programs and policies in end-of-life care. Programs included the mandatory training of all staff in end-of-life care, pain management, how to communication with families on what to expect when the resident is dying, and the after-death process (i.e. removal of personal items from the facility). However, training of staff is not enough. As one individual stated:

Nursing homes have to have palliative programs in place but you can have people with training and no protocol and you're still sort of in the same situation. You have people in the building who know how to do things but there's no protocol to move a person into it. So you need to establish that nursing homes have to have a palliative stream integral to their business with the full expectation that people are going to die in your building fully

supported by a protocol, maybe have a checklist that caregivers follow.

Respondents stressed the importance of having protocols in place to guide the delivery of end-of-life care. This might include a checklist, as mentioned above, which would ensure that the resident had an appropriate plan of care in place and the supports necessary to deliver such care. These protocols and policies would in turn help to establish 'indicators of success' another key recommendation in ensuring excellent end-of-life care identified by participants. Respondents indicated that LTC facilities need to have a clear understanding of what constitutes success in end-of-life care and how they are measuring whether or not care met these indicators. As one participant stated, in reference to her experience with her family member not receiving adequate pain management:

Where it broke down was with those folks who needed to deliver the pain management...How do they know within their business plan if they've succeeded in meeting their objectives and what are their objectives?

Respondents expressed that these protocols or standards of care needed to become a condition of facility licensing or part of their accreditation. As part of the accreditation process, respondents felt it was important for their voice to be included in an audit of the facility. Respondents commented that they want the opportunity to provide feedback on the facility's performance in the form of an exit interview.

I think it's a fabulous idea, to have some sort of exit interview. I think it's tremendous for those people who are interested in that opportunity. I think you should have an opportunity to decline, so it should be assumed yes, unless you say no, I'm cool, I don't need to, then that's fine.

These interviews may be done either by phone or as a paper survey which would then be

mailed back to the facility. If done by phone, respondents felt that they should be done by an independent company, not a staff member of the particular LTC. Respondents stated there needs to be some assurance that the facility will act on their comments and concerns.

...because if I am taking time out to talk to them, I expect them to reciprocate and tell me about what they did, and their action plan; I expect them to report to me what they did.

Respondents remarked on the need to improve physician continuity within LTC facilities. The group suggested that LTC facilities need to explore the use of alternative models of care including the use of advance practice nurses or physician assistants who would be on-site, 24-hours a day, seven-days a week as a support for nursing staff.

I don't think you're ever going to get the doctors to change because of their schedule, their work demands, and not enough doctors but what I think that these homes' could do like I know the military has physician assistants and they're fully trained...this person can prescribe and you know look after people and I think if each facility had someone like that in their midst that staff could go to because I don't think we're ever, ever going to get doctors in a nursing home to put in the effort or the time. I think we have to find a solution, you know sort of in the middle.

Another area that respondents expressed concern was for those residents who did not have any family to advocate for them or to visit with them. They recognized that nursing staff were often too busy to spend time with residents and that a volunteer would be someone who could be a companion for the resident. Participants identified that volunteers could play a much larger role within LTC facilities.

Finally, participants identified that in order to provide quality care at the end of life, LTC facilities must embrace a philosophy of palliative care within their respective

facilities. Each facility needs to develop a philosophy of quality end-of-life care which must be supported by the administration. As one participant noted:

...in my experience, from the top down they didn't care, so their staff wasn't trained, their staff didn't know what to do because if the top people didn't show any consideration at all, then the rest of the staff doesn't.

### **Satisfied Focus Group Results**

The experiences expressed by those who self-reported as being satisfied with the end-of-life care the resident had received are in sharp contrast at times, to the experiences of those in the dissatisfied group. However, similarities do occur between the two groups. It is interesting to note that for this group of individuals, it was often difficult to keep the discussion focused on the end of life, since many "had no complaints about the care at the end, but I do have complaints about the rest of their stay". Discussions centred on the problems that had occurred throughout the resident's tenure and required constant probes to bring the conversation back to the last month of the resident's life. Based on this discussion, a picture does emerge of the experience of the care received by the resident and the respondent which will be presented in the following paragraphs. The conversation around what it means to die well or to experience a good death will first be presented.

#### ***Characteristics of a Good Death***

Discussion of what it means to have a good death centred around three areas. Firstly that death occurred quickly, after having lived a long life. For many, the best kind of death was one in which you died in your sleep. Secondly, compassion was an important aspect of a good death and "something that everyone would like at the end".

Finally, a good death involved having human contact and presence; not dying alone.

As a respondent stated:

...[good dying is ] people being there to talk with the person or even just sit with them, or rub their back, or anything, just that human contact is very, very important.

### **Focus Group Themes: Satisfied with Care**

#### ***Support and Attention***

It was interesting to note that a common perception was that care improved at the end of the resident's life, with many respondents reporting that care providers "became more attentive" and "they just were around more; I didn't have to go looking for them".

One respondent noted:

Something that struck me, as he got sick...you didn't have to go look for them...they sort of made a point of stopping to say he had a good day or his eating became very bad at the end, oh he ate today or ate well, or we just put him down and half the other times you'd have to go stand at the nursing desk or search to find someone, to even ask for something you need not even how his day was but I need something now so that was interesting. Yeah, you didn't have to go looking for them, they just offered it.

Respondents also commented on how caregivers became focused on their well-being, often checking in on them to see how they were doing or if they needed anything.

...and the nurses had their pattern of coming in and checking and they would check in on me, make sure I was ok, and give me a sandwich or whatever I needed or wanted, it was there for me...

Other times, respondents noted that people would just come into the resident's room and share a story about the resident with the family or offer to sit and talk with them. These acts of kindness resonated with all the participants.

...when she [mother] was going through her dying process, people would

come in and they would sit with me and they would talk with me and that was the hairdresser, that was the lady who brought the dogs, and you know, so it wasn't just the nursing staff... it was wonderful for the family to have someone show us that kindness.

Many noted that they felt caregivers had treated the resident with respect, kindness, and dignity at the end of their life, things that had been a struggle to ensure throughout the resident's stay in LTC. This is reflected in the findings of phase one where 78.2% and 79.3% of respondents report the resident was 'always' treated with respect and kindness.

Often, respondents noted that if their loved one was cognitively impaired or had lost the ability to communicate, the LTC staff strove to provide compassionate care and to respond to the resident's needs.

...my mother-in-law at the end couldn't speak and couldn't swallow, for the last year she couldn't speak but her eye's spoke to you. It was just wonderful. The staff knew what she wanted, they were so attuned to her needs by her body movements, whether she squirmed or was uncomfortable...

Though few had been in a LTC facility with a designated palliative care program, those who had received this type of care noted how it had ensured that care of the resident had gone well at the end of their life:

The nursing staff were more than welcoming, and things had improved greatly over the years that he had been there, when he did pass away, they were actually the most supportive group I had come across probably in a long time. I mean everything worked out really, really well...when he did pass away and they implemented the palliative care measures, it was just a wonderful, a wonderful scene. I mean everyone came streaming through and they all said good-bye to him, and I thought that was marvellous. And there was the palliative care team and they just came in and they implemented it, and they told him exactly what was going to happen, they weren't going to feed him, no more pills, and the morphine started coming and he passed away within about 48 hours so it was just, you just have to

finally make that decision that you're going to let that person go and not have to struggle any more...so I was very pleased. I don't know what a perfect death would be but in a personal care home that was pretty good I think. I was very happy... I'm glad that they implemented it. I guess there is more of a standard. I think it could be quite shoddy probably sometimes at the end if one nurse wants to do it one way and one nurse wants to do it the other way.

### ***Communication and Information Sharing***

In contrast to the experiences reported by the dissatisfied group, most respondents had had discussions with care providers about what to expect at the end of life and the type of care that would be provided. In this manner, many had felt prepared for the resident's death and knew their loved one "was probably dying".

...my sister and I were called in with the head nurse and she went through everything with us...and she went through it and told us what to look for and what to expect and they kept in close contact with us, if there was ever anything, a change in my mom they would call me at home. So they were wonderful that way.

Q – and you said that happened about...

R – about 6 weeks before she passed away.

These discussions had not only occurred between themselves and health care professionals but also between the respondent and the dying resident. Some respondents had taken opportunities to discuss future care with the resident to ensure that their wishes were known and followed. Phase one noted that 63.2% of respondents knew the resident had specific wishes about the types of care they did or did not want when they were dying.

Before she lost her speech, the one thing I was absolutely insistent upon and told the nurse, it's time to get the doctor in here and time to make sure he clearly understands her wish not to be tube fed...the whole entourage, the social worker, the nurse, the doctor and I together went and asked her directly and got that ironed out for the last time... and they honoured her

wishes.

Care planning did emerge as an experience for which some respondents had had detailed discussions with care providers, most frequently the head nurse or social worker, around what comfort care entailed and the various levels of care.

To me they [the levels of care] were clear because they sat me down and they told me; I went through it with my mother and said what do you want to do; they did [explained the levels of care] and they gave examples you know in this situation what would happen if they were this level or that level and we changed the level as time progressed.

Others had not had such discussions and there existed confusion around the language used in the advance care planning documents or how a resident's living will would mesh with the standard health authority forms. Some had also wished to have further discussion with care providers on what to expect at the end of life.

There's one time when I look back on my mom's life, where she probably would have died at that point had I not taken her into the hospital and it would have been nice if someone would have been there to coach me or tell me things or explain things to me because with what happened in the hospital at this point I never would have taken her...telling me that the things my mother was going through was actually that she was dying.

One of consequence of not having discussions around end-of-life care planning or what to expect at the end was a sense of guilt; had they done enough or did they hasten the resident's death by stopping certain interventions such as medications. This guilt weighed heavily on some respondents and they suggested the importance of counselling family around decision making, especially for those whose loved one has dementia.

Even to this day, the feelings of did I kill my mother, because we had said we were going to discontinue her medications, and my sister and I, and we talked about that, was this something we did, could she have had more time, and that is where I would like to have counselling about, somebody to talk to you about the guilt you're going to have.

A few individuals had received information packages around what to expect during the dying process and they commented on how helpful this had been. Indeed those in the groups who had not received this type of information expressed how they wished someone had given them something to read about the dying process.

A common area where further information was wanted was on the after-death process; information on when the resident's belongings had to be cleared from the facility. This is similar to both findings from the dissatisfied focus groups and the first phase of the study. Respondents implicitly understood that the room needed to be cleared out as soon as possible as it was needed by someone awaiting admission. However, having a care provider sensitively communicate this information would have been welcomed.

...or after the dying what was really hard is they need the rooms desperately so our sort of told you have to be out by tomorrow...but there's a need to tell us that sensitively.

***System Factors: Staffing, Physician Presence, and Transfers to Hospital***

Many of the issues classified under the broad theme of system factors were not issues that developed only in the resident's last month of life. Rather these issues had emerged over the course of the resident's stay. For many respondents however, these issues comprised sources of great frustration and were worrisome problems. Though respondents commented on the proverbial problem of LTC facilities being short staffed, they also praised the staff for their kind and compassionate care, especially the care provided by the health care aides.

I found the best staff were the nursing aide type people. I liked them the

best, they were absolutely wonderful. The nurse's I have to say I didn't like as well which was really surprising to me because I felt the care and the compassion came many times more from the little people...

Q- the one's who had the...

R- the hands on, direct care.

Though generally content with the care delivered by the LTC staff, respondents did confide that they worried about the care their loved one received when they were not present. This concern was noted in phase one where 70.1% 'sometimes' had concerns about personal care needs being met when they were not present. Part of the perceived solution was to "get to know the staff" and the importance of being a presence within the facility was stressed. The fear of retribution from the staff towards the resident if they complained about the care was present within this group as well.

I think they were very, very good. They kept her very clean [as she was incontinent] but of course I don't know, I was coming there a lot too so, I always found that if you turned up a lot they were more careful about things...you don't know that for sure but certainly you think we need to have somebody there all the time and that may be a harsh thing for some very caring people, but on the other hand I guess it's human nature that you pay attention if somebody else is paying attention.

Respondents perceived staff such as pastoral care, social workers and recreation professionals as being an essential aspect of the holistic care provided to the residents. However, it was noted by some that these professionals were often the first to be let go when budget cuts were necessary, much to the perceived detriment of the resident's care.

The lack of access to physicians and the severing of ties with the resident's previous community physician were again noted as a major issue with entering a LTC facility. Most often respondents experienced that the LTC appointed physician appeared not to have a full understanding of the past medical history of the resident.

...they know nothing about the parent, and they're in there for such a short time, we never really had a chance to talk with them...it's absolutely ridiculous, dealing with strangers all the time, and they cut off the general practitioner, the family doctor who knows so much of the background, who could have advised us since we had that close relationship.

Additionally, it was questioned why physicians were the only LTC staff who were not present at caregiver meetings; meetings that are held periodically to discuss the care of the resident with family members.

The common perception was that residents had to have care provided to them by the LTC appointed physician, however one participant had chosen not to do this and expressed the advantages she had perceived to this arrangement.

...they [her parents] ended up with a great physician and we never went with an in house personal care physician...and his doctor offered to follow him.

Q- How did you negotiate that with the nursing home?

R- we just said, and they needed to make sure she would be available.

[Early on] she was us down and went through what living wills are, explained what my dad was going to go through at the end...she was huge for understanding the process.

The final system issue that was raised was the ability of LTC facilities to provide certain treatments to residents thereby diminishing the need to transfer them to a hospital. Respondents indicated that the transfer to hospital was very traumatic for residents, especially if they had dementia. This is worrisome in light of the finding that 55.2% of residents were transferred to hospital during their stay in LTC and that 29.9% were transferred in their last month of life:

It's very traumatic to move. I know with my mom, even when she was slipping in and out at first, very traumatic if something did happen and they would say "well we're taking her to X hospital", and just taking her out of there, taking her out of her home, it's very traumatic for them...

I think one of the things is that, is the limitations that they can't give an IV or anything like that and it just means a trip to the hospital which is pretty stressful for something it seems to me that if the paramedics can do that [give IV] on the way to the hospital, why can't someone go into the nursing home because it's very traumatic for the person to be moved out where they're not known...

### ***Recommendations***

The respondents of the satisfied focus groups, in answering the question “We are trying to improve end-of-life care in care homes, what advice to you have to share?” had discussion around five topic areas. The first area of discussion was on the need to clarify the language used in advance care planning. These participants indicated that there is confusion around the differences between a living will, advance directive and an advance care plan and knowing which directs the care the resident will receive. Participants also recommended that there needs to be a mechanism to ensure the wishes of residents with living wills are adequately captured by an advance directive.

What I found with the form was it was very difficult to figure out where it fit [i.e. living will], figure out what category ... because they [LTC facility advance care plan documents] don't exactly match up with the legal document [living will]... We need clarification on who is going to listen to what.

Respondents discussed the need to improve physician continuity once the resident enters a LTC facility. These participants indicated that a mechanism is required which will either improve the communication between the resident's previous family physician and their newly appointed physician or the option is made available for residents to retain their previous physician. This improvement in service delivery was seen as a critical aspect in the care of residents.

...it's absolutely ridiculous that your dealing with strangers all the time

and they cut off the general practitioner, the family doctor who knows so much of the background...you have to start all over again and it is a little late when you are 90 to be starting all over again [establishing relationships].

Respondents indicated that an important recommendation to ensure excellent care at the end of life was to improve available resources. For many this meant that facilities would have information booklets on what to expect at the end of life along with access to pastoral care services, and having a designated room to which a roommate could be moved during the last days of the resident.

Respondents expressed the need to provide bereavement follow-up and offer counselling after decision making. Respondents commented that no consistency seems to exist on whether a facility offers bereavement follow-up, with few participants indicating they had received follow-up. Those who had this contact appreciated it and found it reflected compassion on behalf of the LTC facility. A few participants had found decision making especially around stopping medications difficult and recommended that facilities provide counselling and on-going support for those family member's who are required to make end of life decisions on behalf of the resident.

Q – when do you see wanting this counselling?

A-when you're making the decision. Because when you make the decision it's almost like a relief because you've finally made the decision. But then after the decision [you start wondering] is this the right thing [I did]...and having information about the consequences of the decision, you've made the decision and these are the things that are going to happen...sometimes you are feeling, did I do enough?

Finally, participants expressed that there is a need for facilities to explore ways to avoid hospital transfers. They suggested that an examination of alternative models of care

and determining which interventions might be possible to provide in the LTC facility are was to begin to possibly eliminate non-emergent hospital transfers.

...one of the things, and I don't know how you overcome it, is the limitations that they can't give an IV or anything like that, and it just means a trip down here [to the hospital] for an IV which is pretty stressful. You know for some things it seems to me that [could be changed]... the paramedics gave the IV, while it seems if the paramedics can do that, why can't someone with that kind of training go into the nursing home? Because it is very traumatic to the person who has to be moved out, to somewhere else where they are not known...so maybe there's another step in here someplace for some other level of care.

### *Summary*

The picture that emerged from the discussions with each focus group was of very disparate experiences of end-of-life care. For those who were dissatisfied, the care the resident had received at the end of life failed to meet expectations, resulting in unmet needs for the resident and a sense of being let down in the respondent. The respondents were let down either by the LTC facility failing to have a policy to guide the provision of palliative care and thus care failed to adequately meet the resident's needs, or by the promises made by the LTC staff never materializing. As such, much of the respondents' energies were focused on acquiring care for the resident either through diligent, round the clock supervision or through the use of personal connections to bring outside resources into the facility to ensure the resident received adequate care. Feelings of guilt, anger and frustration continued to be experienced by respondents for the lack of perceived care delivered in the facility. However, respondents were always quick to point out that the day-to-day staff were excellent and not to blame for the inadequacies in care but rather it was the lack of guidance and strong administrative will in ensuring excellence in

palliative care which resulted in poor end-of-life care.

This is contrasted with the experiences of those who had been generally satisfied on the survey interview. This group's experience focused on the attention the staff paid to them and the care and concern expressed towards the resident. Though many respondents did have complaints about the care provided to the resident throughout their stay in the LTC facility, the prevailing sentiment was that once the care providers acknowledged the resident was dying, they became more attentive to the needs of the resident and the family. Thus a striking difference between the groups was in the recognition that the resident was dying and that this triggered the implementation and execution of an appropriate plan of care. This finding helps to further explain the multiple regression model and the significant role that contact and communication plays in satisfaction with end-of-life care. These findings will be discussed further in the next chapter.

## **CHAPTER SIX - DISCUSSION AND CONCLUSIONS**

The overall objective of this study was to contribute to the understanding of the factors which shape and influence family satisfaction with end-of-life care in the LTC setting. The findings of this research reinforced that the factors influencing satisfaction are multi-faceted; different relationships in varying degrees of significance between variables emerged through the statistical and qualitative analyses. However, communication regarding care of the resident, receiving emotional support, and having care expectations met all of which are mediated through established trusting relationships, were the significant predictors of satisfaction. The following discussion will explore these findings within the context of existing empirical literature. Additionally, the study's limitations will be identified and recommendations for future research will be discussed.

### **Family Satisfaction with End-of-life Care in Long-Term Care**

This study adds to the small but growing body of literature examining family satisfaction with end-of-life care and in particular care delivered at the end of life in LTC facilities. The current study found that 77.4% of the observed variability in overall satisfaction with end-of-life care was explained by feeling that care provided at the end of life met expectations, having contact and communicating with nursing staff, feeling that the health care aide listened to the respondents' concerns about care, that the respondents felt they had received enough support with their feelings and that the staff provide consistent care to the resident.

Few studies have explored predictors of family satisfaction with end-of-life care.

Three studies examined the impact that expectations and perceptions have on family satisfaction assessment using the FAMCARE scale (Kristjanson et al., 1997; Medigovich et al., 1999; Morita et al., 2004). Kristjanson and colleagues (1997) noted that discrepancy theory, a theory which identifies that family satisfaction is best predicted by the difference between care expectations and care perceptions, was the best predictor of family satisfaction, accounting for 57% of the variance. Meanwhile, Medigovich and colleagues (1999) noted that 54% of the variance in family satisfaction could be explained by care perceptions alone; that is the more families understand about the patient's care, the more satisfied they are. Morita et al (2004) found that expectations were weakly but significantly correlated with satisfaction. These findings resonate with those of the current study which found that care at the end of life that met family expectations was part of the model that best predicted overall satisfaction with care.

In the final study exploring predictors of family satisfaction with end-of-life care, Dawson (1991) identified that overall satisfactions was negatively correlated to unmet basic needs. These needs included: the need for information, ability to talk about concerns and fears to health professionals, being informed when the patient was dying, being present at the time of death, having time to say good-bye, symptoms begin controlled, and talking with health care providers after the death. He also noted that the psychosocial support received from the nursing staff was positively correlated to overall satisfaction, a finding that is echoed in the current model and focus group findings.

### ***Communication and Interaction with Care Providers***

The current study extends existing knowledge by providing further evidence of

the importance of communication and interpersonal relationships with LTC staff in shaping family satisfaction with end-of-life care. Illuminating the findings from phase one, the experiences which emerged from the focus groups point to the importance of involving family members in decision making, communicating what to expect at the end of life and providing emotional support to families through this difficult time.

Respondents reported that only 27.6% had received information on what to expect when the resident was dying, 25.3% had received information on what to do at the time of the resident's death, and 12.6% had a staff member talk to them about how they might feel after the resident died.

Of the four studies examining family satisfaction with end-of-life care in nursing homes, all to some degree report similar findings to the current study in regards to the important role that communication plays in shaping family satisfaction (Engel, Kiely, & Mitchell, 2006; Sloane et al., 2003; Teno et al., 2004; Vohra et al., 2004). Engel, Kiely and Mitchell (2006) noted that respondent variables related to higher satisfaction were those that involved communication: being counselled about the resident's prognosis, having a discussion longer than 15 minutes about advance directives with a health care provider and having comfort care as the primary goal of care. Indeed in Sloane et al's (2003) study, satisfaction with care was lower in nursing homes than other settings of care, and related to how included family members felt in care and treatment decisions. Teno and colleagues (2004) noted that when end-of-life care was received in the nursing home, the area of second highest concern expressed by bereaved family members concerned not receiving enough information on what to expect when the resident was

dying. Though Vohra et al (2004) found that describing what to expect, involvement in planning of care and being informed of care options were not rated as important for excellent end-of-life care by families, being informed about when death was near was very important.

The findings of this study also confirm other work done, which explored family satisfaction with end-of-life care delivered in a variety of settings: home care, in-patient palliative care units, hospital, and hospices. Common to this body of literature is again the role that communication, specifically the sharing of information in a timely and sensitive manner, plays into family assessments of satisfaction (Aspinal et al., 2003; Connor et al., 2005; Marco, Buderer, & Thum, 2005; Rogers, Karlsen, & Addington-Hall, 2000; Talbott, 1995). From the discussions with the focus group participants in the current study, the role that information sharing especially around what to expect when the resident was dying, played a significant role in respondents feeling they had witnessed excellent care. This meshes with comments made throughout phase one of the study which revealed that respondents often felt nurses 'guarded' information and were not always forthcoming in delivering information in a timely manner; both of which impacted how respondents perceived the quality of care. Studies examining communication between LTC staff and family members corroborate these findings that it is perceived that staff are not proactive in delivering information (Caron, Griffith, & Arcand, 2005; Hertzberg, Ekman, & Axelsson, 2001; Vohra, Brazil, & Szala-Meneok, 2006).

Others have noted that dissatisfaction with care was often related to reported

inadequacies in the quantity of information shared (Ringdal, Jordhoy, & Kaasa, 2002; Shiozaki et al., 2005), the manner in which information is delivered (Rogers et al., 2000; Talbott, 1995) and feeling unable to express concerns and fears to health care providers (Dawson, 1991). Connor and colleague's (2005) study of satisfaction with hospice care noted that 10-29% of respondents identified a need for improvement in attending to family's information needs. Others have noted that the inadequate provision of information, insensitive communication by physicians, and the lack of communication between decision makers all significantly influence the experience of dying (Kayser-Jones, 2002; Travis et al., 2002; Yabroff, Mandelblatt, & Ingham, 2004). From these studies it would therefore appear that family satisfaction with end-of-life care is influenced by provider behaviours especially in terms of communication and empathy.

Studies examining provider behaviours essential to providing quality care at the end of life consistently identify compassionate, humanistic behaviours as paramount (Cherlin et al., 2004; Forbes, 2001; Goodridge et al., 2005; Heyland et al., 2006; Kristjanson, 1989; Wilson & Daley, 1999). The works identifying critical nursing behaviours in the care of the dying have delineated key behaviours espoused by expert nurses which are essential to providing excellent care at the end of life (Degner, Gow, & Thompson, 1991; McClement & Degner, 1995). In particular, the work by Wowchuck (2004) exploring these behaviours within the context of LTC noted three major categories of nurse behaviours: care of the dying resident; care of the dying resident's family; and care of the institutional family. Many of the behaviours encapsulated in these categories involved effective communication, providing education and facilitation of

decision making, ensuring resident comfort, and fostering a homelike environment.

These behaviours underscore the need for trusting relationships between care providers, family members and recipients of care (Caron et al., 2005; Cherlin et al., 2004; Kayser-Jones et al., 2003).

As respondents in the current study spoke of the importance of staff responding to their needs and taking the time to sit and talk with them, Wilson and Daley (1999) and Cherlin et al (2004) noted that these actions were identified by families as key caring behaviours. When staff members are empathetic to family members either by listening to their concerns, answering questions or by providing information in a clear, direct manner, families feel valued and are more satisfied with care. In Gladstone and Wexler (2000) study, families value staff members who exhibit these behaviours. Many of these behaviours, often identified as evoking patient-centred communication and interaction (Wanzer, Booth-Butterfield, & Gruber, 2004) have been identified as key factors in patient and family satisfaction and can result in improved psychosocial well-being (Hull, 1989; Stewart, 1995).

That provider behaviour especially around empathetic attitudes and communication would prove to be so significant a factor in shaping family assessments of care resonates with the body of literature examining determinants of quality care. Donabedian (1980) identifies that those who deliver quality care do so by providing technically competent care, involving the application of the science and technology of medicine, and interpersonal care. Interpersonal care is the caring aspect of health care encompassing empathy, compassion, and providing individualized care that meets

socially acceptable norms, values, and expectations. Thus the quality of the resident/family/provider interaction focuses on several elements including an assessment of the quality of communication, the ability to maintain trust, and the health care provider's ability to respond to individuals with empathy, honesty, concern and sensitivity (Blumenthal, 1996). Though not mutually exclusive, Donabedian (1980) postulates that technical competence is assumed to be generally present in all providers and as such, individuals are more likely to focus on provider behaviours when shaping perceptions of the quality of care. When patient and relatives perspectives of 'good' and 'not so good' quality of care was assessed, individualized, patient-focused care relating to their needs and provided in the context of a caring relationship was deemed as 'good' quality care (Attree, 2001). Similar assessments have been made in the LTC setting where the quality of the interaction between the provider, resident and family has been found to greatly influence the care experience (Caron et al., 2005; Furman et al., 2006; Hanson et al., 2002; Kayser-Jones, 2002). Some researchers have noted that families rate the quality of care high when health care providers show concern and compassion, are sensitive, take the time to listen to them, treat dying person and the family as individuals and treat the family as part of the unit of care (Andershed, 2006; Fakhoury et al., 1996; Kristjanson et al., 1996; Morita et al., 2002). These behaviours were consistently identified by focus group participants and in the analysis of the survey data as paramount to being satisfied with care delivered at the end of a resident's life.

### ***Pain and Symptom Management***

Respondents in the current study commented on how important pain management

was to ensuring excellent care at the end of life especially in light of the fact that 69.5% of residents had pain in their last week of life. Though respondents' overall mean satisfaction scores did not differ significantly whether the resident experienced pain or not, many in the focus groups discussed the impact of inadequate pain management not only on residents' suffering but on their suffering and subsequent dissatisfaction with care. Other studies have noted the importance of pain management as a significant factor in family satisfaction with care (Casarett et al., 2003; Keay et al., 1994; Singer, Martin, & Kelner, 1999; Steele, Mills, Long, & Hagopian, 2002; Steinhauser et al., 2000; Vohra et al., 2004). It remains troubling therefore, that achieving adequate management of pain in nursing homes was identified in the current study as an on-going issue as well as in the literature (Ferrell, 1995; Kayser-Jones, 2002; Reynolds et al., 2002; Teno et al., 2001c). The current study found that 26.4% of respondents felt the resident had received inadequate management of their pain.

One of the difficulties with achieving palliation of pain in LTC residents is that assessing pain in cognitively impaired residents can be challenging. However, what was identified by respondents in the current study as a major barrier to pain management was the manner in which pain medications were ordered; on an 'as needed' basis rather than a scheduled administration. This meant that respondents felt compelled to be present at all times to ensure the residents received their medications when it was required, as many had limitations in cognitive status and mobility, thereby impairing residents' ability to notify the nurse they needed medication. WHO guidelines and expert palliative care practitioners agree that practicing in an evidence-based manner involves 'round the

clock' dosing of analgesia, not on an 'as needed basis' (Jovey, 2002; Librach & Squires, 2001; WHO, 2007). Respondents in the current study often questioned whether staff and physicians did not prescribe or administer opioids in a scheduled manner for fear of addiction or due to a lack of their knowledge of pain management; both these concerns have been noted in the literature as barriers to the palliation of pain in LTC residents (Cramer, Galer, Mendelson, & Thompson, 2000; Kayser-Jones et al., 2006; Watson, Hockley, & Dewar, 2006).

An interesting finding was that this study noted that the 28.2% of respondents who reported the resident experienced 'other' symptoms had lower overall mean satisfaction scores than those who indicated that the resident had no 'other' symptoms. Most studies exploring satisfaction with care have focused only on the symptoms of pain, dyspnea, anxiety or depression (Hanson et al., 1997; Teno et al., 2001a; Vohra et al., 2004) not the constellation of symptoms of delirium, agitation and restlessness; symptoms most frequently reported in the 'other' category in the current study. The difference in mean satisfaction score thus may be due to the troubling nature of these 'other' symptoms which are often perceived to cause substantial distress to individuals. Studies examining the symptom experience in terminally ill patients noted that restlessness, agitation or delirium is a common symptom experienced by residents at the end of life (Casarett et al., 2003; Hall et al., 2002; Ley, 1989). It was also noted that next to noisy breathing, delirium was the symptom most frequently not treated in residents at the end of life (Hall et al., 2002). Additionally, the symptoms respondents reported as troubling such as swallowing difficulties, loneliness or hunger pains, are not ones

normally considered by palliative care experts as those requiring amelioration.

Loneliness has been a frequently cited issue for nursing home residents and comments have been made that residents need meaningful activities even at the end of life (Kayser-Jones, 2002; Reynolds et al., 2002; Stillman, Strumpf, Capezuti, & Tuch, 2005). That residents in the current study experienced a wide range of symptoms is not unexpected due to the prevalence of chronic disease conditions they experienced. This different constellation of symptoms concurs with other studies examining symptom prevalence in non-cancer populations residing in LTC, which note that lack of energy, dry mouth, drowsiness, pain and loss of appetite tend to be experienced frequently (Brandt et al., 2005; Cartwright, Hickman, Perrin, & Tilden, 2006).

### ***Physician Presence and Contact***

Infused throughout the current study were comments related to the ‘absence’ of physicians and frustration over the limited contact family members had with them. This finding has been identified by others (Ersek & Wilson, 2003; Hanson et al., 1997; Kayser-Jones, 2002; Vohra et al., 2006). One researcher in particular coined the term to describe this phenomenon as physicians being “missing in action” within LTC facilities (Shield et al., 2005). Though identified as a problem and concern by focus group participants, results from the survey failed to demonstrate a significant difference in mean overall satisfaction scores based on physician contact and communication; yet nursing contact and communication was a significant predictor of satisfaction. These findings may be the result of a couple of factors. Firstly, few respondents actually had contact with the physician in the resident’s last week or month of life. In the current study 17.2%

of respondents identified they had spoken with the physician. It was also troubling to note that 42.5% could not identify who the resident's physician was. One retrospective chart review study of the last 48 hours of LTC residents' lives, noted that documented physician visits ranged from zero to four per patient; 37% of residents received no visit, 37% had one, 29% were visited twice, 5% three times and 2% four times (Hall et al., 2002).

Secondly, when examining why family members were upset with the lack of physician contact, often the issue raised was the lack of continuity in care when the resident entered the nursing home. It was therefore the severing of long established relationships with the community physician and having limited opportunity to form new bonds with the appointed LTC physician that was upsetting to family members. The lack of familiarity of physicians with the residents was a source of frustration and concern for respondents; a finding that was echoed by Wetle, Shield, Teno, Miller and Welch (2005). Much of this concern emerges from the lack of established trusting relationships with LTC physicians, an essential aspect to ensure ongoing communication, adequate care planning, and knowledge of resident and family needs, values and wishes for end-of-life care (Andershed, 2006; de Haes & Teunissen, 2005; Furman et al., 2006; Royak-Schaler et al., 2006).

Finally, respondents often expressed concern with the timeliness of assessment regarding medical problems. As residents entering LTC facilities are frailer and sicker than in the past (Forbes, 2001; Komaromy et al., 2000; Nolan & Davies, 2000), they will require on-going medical management of a plethora of chronic disease conditions. Indeed

the profile of residents in the current study pointed to residents having on average at least five chronic medical conditions, with 42.5% having six or more. Additionally, the public perceives that LTC facilities are healthcare institutions and as such expect considerable physician presence (Shield et al., 2005; Wilson & Daley, 1998). In Kayser-Jones' (2002) study, a frequent finding was that when a resident is dying, family expect the physician at the bedside and report feeling abandoned when they fail to visit. Similar sentiments were expressed by respondents in the current study.

### ***Staffing and Staff Education***

The effect of adequate staffing levels on the quality of care especially at the end of life has received some attention in the literature (Forbes-Thompson & Gessert, 2005; Kayser-Jones et al., 2003; Miller et al., 2004). In their systematic review of staffing and quality in nursing homes, Bostick et al (2006) conclude that there is definite evidence for the relationship between total staffing levels and improved quality of care. This association is especially strong when comparing licensed staff to the quality care delivered. Kayser-Jones and colleagues (2003) and Forbes-Thompson and Gessert (2005) both found that residents were at higher risk of developing pressure ulcers and resident basic comfort and care suffered when staffing levels were inadequate. Though the current study found no significant relationship between staffing levels and overall satisfaction, comments in both the survey and focus group identified inadequate staffing, especially in terms of health care aides, as a frequent concern by respondents. Respondents often justified lapses in care when staffing levels were noted to be inadequate as staff 'doing the best they can'. Respondents were always quick to report that the day-to-day staff, the

health care aides, nurses and activity workers, were exceptional but it was the circumstances in which they had to work which restricted their ability to provide the best care possible. This justification and rationalization of care inadequacies has been identified by others (Sinding, 2003; Shield et al., 2005; Vohra et al., 2006) and may be one possible way that respondents act in order to reconcile care expectations with current realities of care (Williams, Coyle, & Healy, 1998).

The current study concurs with others which highlight the importance of LTC staff receiving education in the care of the dying. Most nurses and health care aides receive little training in end-of-life care principles and practices. A recent study of nursing home nurses in the U.K. found that most had received no formal training in bereavement support, non-malignant conditions, or managing symptoms of fatigue or cachexia (Whittaker et al., 2006). Additionally, they reported little familiarity with the concepts of palliative care. Similar gaps in knowledge have been reported by others (Brazil & Vohra, 2005; Ersek & Wilson, 2003; Raudonis et al., 2002; Rice et al., 2004; Vohra et al., 2006; Watson et al., 2006). Respondents in the current study acknowledged that at times it appeared staff, including physicians, lacked the educational preparation especially around issues of pain and symptom management, to adequately care for dying residents. These family observations concur with reports by direct care providers themselves who have identified feeling inadequately prepared to care for dying residents (Ersek et al., 2000). Brazil and Vohra (2005) noted that pain and symptom management and communicating to family members were the two priorities for continuing education for LTC staff identified by facility directors.

There was some sentiment expressed by respondents that providing education and training in end-of-life care practices was not a panacea; LTC facilities required the administrative will, support and policies in order to provide high quality care to their dying residents. In their examination of the impact of institutional philosophy on care delivery, Forbes-Thompson and Gessert (2005) identify the importance of leadership and the impact that philosophy has on the policies and priorities used to manage the day to day functioning of the nursing home. The institutional philosophy of a facility directly affects the structures, processes and outcomes of that facility. Indeed Hoffmann and Tarzian (2005) note that a significant factor in the use of hospice services by nursing homes can be accounted for by nursing home administrator's support of these services and institutional culture.

### ***Psychosocial, Spiritual and Bereavement Support***

Respondents reported receiving a range of bereavement support from having the funeral service in the facility, to receiving a card from the staff several months after the death, to no contact at all. Though there is a dearth of studies examining bereavement support in the LTC environment, what can be gleaned is that few LTC facilities have formal structures in place to offer bereavement services (Katz, Sidell, & Komaromy, 2000; Murphy, Hanrahan, & Luchins, 1997). Some studies report that staff find supporting residents' families stressful (Forbes, 2001; Kayser-Jones, 2002; Whittaker et al., 2006) and have received little formal training in providing bereavement care (Avis et al., 1999; Froggatt, Poole, & Houlst, 2002). This might be the reason why few staff discuss sensitive issues; in the current study only 12.6% of respondents reported

receiving information on how they might feel after their loved one died. In the work by Wowchuck (2004) examining critical nursing behaviours in the care of dying residents it is interesting to note that providing psychosocial, emotional or spiritual support to family members did not emerge as a critical behaviour. However, the current study demonstrated that feeling emotionally supported is a significant part of family satisfaction with end-of-life care.

The opportunity to discuss the resident's care and to receive follow-up from the LTC facility was important to respondents especially those who were dissatisfied with care. Respondents indicated that receiving either a phone call or card from the facility conveyed caring and concern on behalf of the facility staff. This follow-up contact from staff after a death is highly valued (Cherlin et al., 2004; Keegan et al., 2001). For many respondents in the current study it was also important for them to convey to the facility staff and administration what they were doing right and areas for improvement in care delivery. Providing such opportunities for bereaved family members not only is reflective of patient/family centred care but also a means for facilities to receive valuable feedback on their performance (Hockley, 2002; Institute of Medicine, 2001). It may also provide positive emotional benefits to family caregivers as well. In their study, Emanuel, Fairclough, Wolfe and Emanuel (2004) interviewed terminally ill patients and their caregivers to assess if such discussions caused additional stress or burden. Follow-up interviews were conducted two to six months after the initial interview. Among bereaved caregivers, 41.4% found the interviews helpful and caused them little stress. This may imply some therapeutic benefit from having the opportunity to have such discussions.

### ***Hospital Transfers and Location of Death***

Little empirical evidence exists examining the effect of hospital transfer at the end of life on family satisfaction, this despite the fact that nearly 40% of residents are hospitalized at least once in the last six months of life (Menec, 2007). The number of residents who are hospitalized ranges from 46.3% during their last year of life (Travis et al., 2001) to 58% in the last month of life (Ramroth, Specht-Leible, Konig, & Brenner, 2006). The current study found that 55.2% of residents had a transfer to hospital at some point during their stay, with 29.9% being transferred in their last month of life; family respondents reported lower satisfaction with care for those residents who had been transferred to hospital in their last month of life. The current study found that hospital transfer at the end of life did impact respondents' assessments of satisfaction with care: those who had been transferred to hospital in the last month of life had lower mean OSAT scores than those individuals who had never been transferred or for whom the transfer had occurred at a time other than the last month of life. Other studies have indirectly examined the impact of hospital transfer on satisfaction (Vohra et al., 2004) but no study could be found which directly examined this relationship.

One retrospective study of family members evaluating the quality of death and dying in the community noted that satisfaction with care was lower for those who felt the individual had not died where they had wanted to die and for those who had not died at home (i.e. anticipated location of death) (Curtis et al., 2002). This finding and those of the current study may imply that the lower ratings of satisfaction with care for those who are transferred to hospital in the last month of life is related to care not meeting

expectations and in the failure to achieve desired location of death. This is illustrated in a study by Evans, Cutson, Steinhäuser and Tulsky (2006) of patients receiving home hospice whom were transferred to an in-patient facility. Though the caregivers reported a desire to provide care for the individual at home, a transfer to an acute care facility ensured that specific goals of care were met, and therefore the achievement of a good death. For these respondents, satisfaction with care was not reduced by the transfer to hospital but was associated with clarifying the goals of care, providing personalized care, following treatment preferences and the environment of care.

It was predicted that family members of residents who died in a location other than the LTC facility would report lower satisfaction ratings than those residents who died in LTC. Similar to the very limited research examining this hypothesis, the current study supports previous work in this area. It was found that family members were less satisfied with end-of-life care if the resident died in a location other than the LTC facility. Vohra and colleagues (2004) in examining family perceptions of end-of-life care in LTC facilities noted that when a resident died in the LTC facility, family members were significantly more satisfied than if the death occurred in hospital. Indeed, in their study, this was found to be the best predictor of family satisfaction with end-of-life care (Vohra et al., 2004).

### ***Advance Care Planning***

Though previous research on advance care planning is divided in terms of its effect on the quality of care (Ditto et al., 2001; Molloy et al., 2000; Teno et al., 1997b; Teno, Stevens, Spornak, & Lynn, 1998), it was hypothesized that having an advance care

plan would improve respondents satisfaction with end-of-life care. The fact that this study's findings did not support this hypothesis is consistent with the limited empirical research on advance directives (AD) and satisfaction. In their national mortality survey, Teno and colleagues (2007) examined the association between ADs and the assessment of the quality of care by respondents of individuals who died in nursing homes, hospitals or at home. They noted that having an AD was not associated with higher overall satisfaction scores. However, those respondents who reported the decedent had not completed an AD were more likely to report concerns with physician communication and expressing unmet information needs in regards to what to expect during the dying phase.

The randomized controlled trial by Molloy et al (2000) designed to improve completion of ADs in nursing homes and assess resident and family satisfaction with involvement in decision making, found no significant difference in satisfaction scores as measured by a battery of instruments developed by Guyatt et al (1995) between the control and intervention groups. What did emerge was that nursing home residents who had completed an AD had significantly fewer hospitalizations, lower number of hospital days and lower health care costs than those in the control group.

When the current study explored whether the presence of an AD affected hospital transfer, both the presence of a proxy decision maker and the presence of an AD significantly reduced the likelihood of transfer in the last month of life.

In the study by Curtis and colleagues (2002) evaluating the quality of dying and death (QODD) from the perspective of bereaved family members, the presence of a living will or durable power of attorney for healthcare was not associated with improved QODD

scores. However having a discussion of preferences when dying, and having medical care provided in the last week/month of life that was consistent with those preferences for care were significantly related to higher QODD scores. Similarly, Engel, Kiely and Mitchell's (2006) evaluation of satisfaction with end-of-life care for nursing home residents with advance dementia found a relationship between the length of time of AD discussion and satisfaction. Using the Satisfaction with Care at the End-of-life in Dementia (SWC-EOLD) scale, health care proxies who reported having spent more than 15 minutes discussing advance directives with a care provider and for whom the primary goal of care was comfort had greater satisfaction scores.

From the limited research it would therefore appear that the relationship between completed ADs and family satisfaction is tenuous at best and that the presence of a written document alone does not guarantee respondent satisfaction. Rather, the role of ADs are to be a catalyst and tool to ensure open, ongoing communication between all parties in order to discuss goals of care, treatment preferences, and to elicit the values and wishes of the resident (Kolarik, Arnold, Fischer, & Tulskey, 2002; Leland, 2001). Indeed, Singer, Martin and Kelner (1999) noted that frequently individuals value ACP for its social function and the process itself. Therefore, individuals value ACP for its role in improving communication and lowering family burden in decision making not necessarily in ensuring improved medical outcomes. Thus the objective of ACP is as Emanuel and colleagues (1995) noted, about the process of structuring periodic discussions to elicit values and goals with the presence of proxy decision makers.

### ***Demographic Characteristics of the Respondent and Resident***

In an attempt to shed light on the contradictory nature of the research literature on demographic characteristics and their impact on satisfaction assessment, this study examined several variables including respondent age, gender, employment status, income, religious affiliation, health status, and visitation patterns. As noted in other studies (Fox & Storms, 1981; Medigovich et al., 1999), older age was associated with higher mean satisfaction scores in the current study. Though income, a variable identified by some as affecting satisfaction scores (Fox & Storms, 1981), may be associated with one's employment status, no other studies have found that those who are retired report higher levels of satisfaction, as noted in this study.

When resident characteristics were examined, no demographic characteristics were found to be related to satisfaction scores. However, for those respondents who reported that the resident had the presence of 'other' symptoms lower mean satisfaction scores were reported. This finding is congruent with other studies which have noted the importance of symptom management on satisfaction assessment and the quality of end-of-life care (Engel et al., 2006; Howell & Brazil, 2005; Steinhauser et al., 2000; Singer et al., 1999; Vohra et al., 2004).

### ***Summary***

The current study and many of the studies mentioned here point to the larger issue of the importance of reconceptualising dying from a defined event to an ongoing, evolving process. One of the main criticisms in the current study and echoed in the literature is the failure of LTC staff to recognize that the resident was dying (Travis et al.,

2002; Watson et al., 2006). As many residents have non-cancer diagnoses with illness trajectories that are less predictable than those with cancer, it is more difficult for health care providers to recognize when a resident is dying (Lynn, 2005; Miller et al., 2004; Sidell & Komaromy, 2003; Travis et al., 2002). Indeed many residents may be conceptualized as dying from chronic diseases and frailty; conditions characterized by their lack of significant markers that an individual is entering the terminal phase of life (Komaromy et al., 2000; Lynn, 2005). Often a hospitalization or repeated health crises are the sentinel events which trigger such recognition (Miller et al., 2004). Consequently, when a resident is not recognized to be dying, an appropriate plan of care can not be enacted and followed, resulting in unmet resident and family needs (Wetle et al., 2005). It also helps to explain the paucity of residents who qualify for hospice services; the current study noted 5.7% of residents had contact with the regional palliative care program, a finding reported by others (Casarett et al., 2001; Jones, Nackerud, & Boyle, 1997; Miller et al., 2004; Zerzan et al., 2000).

In order to achieve excellent care for dying residents requires an alteration in our conception about when an individual enters the end of life. Both Engle (1998) and Pattison (1977) encourage us to shift our thinking from one which solely focuses on end-of-life care during the last few weeks of life, to one which focuses on the chronic living-dying interval; that period of time between when one becomes aware of one's impending death and death itself. This living-dying interval may last for years as is the case for those dying from dementia and frailty to days or weeks for those with more chronic diseases punctuated by acute events (Engle, 1998). Others have advocated for the 'mixed

management' approach to care for nursing home residents whereby both palliative and curative care are not viewed as mutually exclusive but rather there is a recognition that interventions may be required by residents at different points in time which may prolong life, may palliate or do both (Hoffmann & Tarzian, 2005; Institute of Medicine, 1997). Froggart and Payne (2006) even suggests that we conceptualize end of life as occurring in three stages: living and losses experienced upon entering a care home; the actual dying and death; and the bereavement period.

Regardless of the approach adopted, it is imperative that the care provided to dying residents and their family members be guided by empirical evidence in order to limit undue suffering and distress. When care is recognized as inadequately meeting resident needs, respondents in the current study engaged in vigilant, advocacy behaviours; behaviours similarly reported by others (Swagerty et al., 2005; Wetle et al., 2005). Respondents reported significant levels of stress, anger, and frustration when care failed to relieve perceived resident suffering. The impact of psychological responses of pre-death experiences on grief reactions has received little attention. However, Carr (2003) reports that widowed individuals' evaluations of their spouses' end-of-life care were a significant influence on their psychological distress six months after the loss. Having no bereavement-related psychological problems has also been found to be significantly related to being more satisfied with nursing and general practitioner services (Fakhoury et al., 1996).

### **Study Limitations**

This study has several important limitations that caution the reader to carefully

interpret the current results. First, the low response rate and therefore, small sample size of the study can not be overlooked. As there is a direct relationship between a study's sample size and the power of statistical tests to detect statistically significant differences between groups (Hassard, 1991; Munro, 2005), the current study may have lacked power and committed type II errors by failing to detect relationships. Thus non-significant results may be related to the inadequate sample size. Having too few subjects per independent variables in the multiple regression analyses may also result in unstable prediction equations (Munro, 2005). An attempt was made to overcome this limitation by building the final multiple regression model in a stepwise manner and reducing the number of variables in the model by including only significant variables from the previous models. Additionally in the factor analysis, correlation coefficients may be less reliable when estimated from smaller samples (Tabachnick & Fidell, 2007).

Secondly, the sample may not have been representative of the range of family member experiences in care due to the manner in which respondents had to indicate they wished to participate. By having to have respondents contact the researcher to express their interest in participating, self selection may have occurred. Therefore, those who experienced extremes in care may have been more willing to participate than those for whom care was 'uneventful'. However, there is some confidence in the representativeness of the current sample in that other satisfaction studies have noted that 20% of respondents are usually dissatisfied with care (Kristjanson, 2003); the current study notes 15% were dissatisfied with care. Additionally, this study's profile of respondents is comparable to the characteristics of those included in a number of related

study samples examining family satisfaction with LTC (Engel et al., 2006; Teno et al., 2004; Vohra et al., 2004; Wetle et al., 2005).

Thirdly, respondents' recall of events may change over time and thus contribute to respondent recall bias. In examining the timing of assessments, McPherson and Addington-Hall (2004) used a repeated-measures design to assess the change in the perception of patient symptoms by proxies over time in a very small sample of respondents (n=13). They noted changes in the interpretation of events over time leading them to conclude that assessments of anxiety, pain and depression become less severe and are seen to have occurred less frequently with the passing of time. Additionally, proxies become less certain about the occurrence of symptoms the patient experienced as time passes.

Other researchers have noted similar changes in proxy responses over time, with proxies tending to polarize their responses in retrospective assessments; they tended to report either mild or severe assessments and patient anxiety was recalled as being less severe whereas their own anxiety was recalled as more severe (Higginson, Priest, & McCarthy, 1994; Hinton, 1996). For example, Hinton's (1996) study examined the accuracy of recall in 71 caregivers four months after they and the patient had been given regular interviews throughout the duration of care. In the post-bereavement interviews which had the caregiver assess care for the entire caregiving period, pain was generally rated as more severe retrospectively along with constipation. When asked to assess the quality of care, retrospective accounts of satisfaction increased, with 72% reporting care as excellent (up from 59%) (Hinton, 1996). These studies have lead researchers to

conclude that changes occur during the bereavement period which alter the interpretation of events. To improve recall, tying the occurrence of symptoms to a specific event made it easier for proxies to recall the occurrence of that symptom, lending support to the literature regarding the effects of saliency and memorability (McPherson & Addington-Hall, 2004). This study sought to limit recall bias by limiting end-of-life care evaluations to the last week of life and to conduct interviews a minimum of four months to a maximum of 10 months after the death of the resident.

Finally, the effect of emotions on recall of past events cannot be ignored. There is limited research on the impact that emotions have on how past events are interpreted and recalled by the person. However it is known that terminal illness greatly impacts family members and their own grief, guilt, burdens and stressors may shape assessments of care (Carr, 2003; Covinsky et al., 1994; Hinton, 1996). Research into the influence of emotion on memory has noted that there is a mood-congruent memory effect (Bower, 1981). For example, it has been noted is that those persons with anxiety pay more attention to negative stimuli since it corresponds more closely to their state of mind. The findings are inconclusive for persons with depression; however, there is evidence to suggest that memories are adversely affected by depression, with negative memories being more easily recollected than pleasant memories (Bradley, Mogg, & Millar, 1996). The other finding is that highly emotional events are more easily recalled than neutral ones (Addington-Hall & McPherson, 2001). This corresponds to the idea that the more salient an event is, the more easily it is recalled and thus reported. However, as events become more frequent in a person's life, they become normalized and underreported. It is

therefore the more unusual events that become salient and are more readily recalled. These findings may help to explain some of the differences in symptom assessment post-bereavement made by proxies (Higginson et al., 1994; Hinton, 1996). For example, a particularly severe episode of pain that was poorly controlled may be recalled more easily than the times when pain was controlled effectively. This is due to the manner in which some memories are stored and recalled. It would appear that normal, everyday events tend to be stored as generic memories, which are a summation of events into a concise whole (McPherson & Addington-Hall, 2003). As such, people tend to provide estimates of events rather than specifically recalling what occurred. This is especially true for persons with depression and those with decreased memory capabilities (McPherson & Addington-Hall, 2003). In this manner, proxies may form judgements about the care delivered based on specific episodic events and therefore, negative memories could theoretically have an effect on bereaved family members' retrospective evaluations of care. As a whole, the limited research in this area implies that evaluations of care can in part be influenced by the psychological and physical health state experienced during the bereavement period rather than being a direct reflection of the care itself. Thus care evaluations may reflect the mood, needs and opinions of the bereaved individual.

### **Recommendations**

The respondents of the respective focus groups developed a list of ten recommendations to improve care of the dying in the LTC environment. These recommendations include:

- 1. Develop programs and policies in end-of-life care** - includes mandatory training of all staff in end-of-life care, pain management, and how to communicate with families on what to expect when the resident is dying and the after-death process (i.e. removal of personal items from the facility).
- 2. Develop indicators of end-of-life care success** - LTC facilities need to have a clear understanding of what constitutes success in end-of-life care and how they are measuring whether or not care met these indicators.
- 3. Embrace a philosophy of palliative care in facilities** - a philosophy of quality end-of-life care needs to be developed for each facility and must be supported by the administration.
- 4. Provide clarity around the language used in advance care planning** – confusion exists around the differences between a living will, advance directive and an advance care plan and which directs the care the resident will receive. There needs to be a mechanism to ensure the wishes of residents with a living will are captured by an advance directive.
- 5. Improve physician continuity** – both groups suggested this recommendation. One group suggested exploring the use of alternative models of care including the use of advance practice nurses or physician assistants who would be on-site, 24-hours a day, seven-days a week as a support for nursing staff. The other group suggested that a mechanism to either improve communication between the resident’s previous family physician or the ability to retain one’s previous physician is seen as a critical aspect in the care of LTC residents.

- 6. Improve resources available for end-of-life care** - this recommendation reflected the need for information booklets on what to expect at the end of life along with access to pastoral care services, and having a designated room which a roommate could be moved during the last days of the resident.
- 7. Provide bereavement follow-up and offer counselling after decision making** - most respondents had not had any bereavement follow-up but those who had this contact appreciated it and found it reflected compassion on behalf of the LTC facility. Counselling and on-going support is needed for those family members who are required to make end of life decisions on behalf of the resident.
- 8. Provide an exit interview for all family members** - respondents want the opportunity to provide feedback on the facility's performance.
- 9. Increase the use of volunteers** -respondents expressed concern for those residents who did not have any family to advocate for them or to visit with them. They recognized that nursing staff were often too busy to spend time with residents and that a volunteer would be someone who could be a companion for the resident.
- 10. Explore ways to avoid hospital transfers** - examine alternative models of care and which interventions might be possible to provide in the LTC facility in order to eliminate non-emergent transfers to hospital.

### **Implications and Recommendations for Further Research**

This study provides useful research on family satisfaction with end-of-life care in LTC facilities. Family satisfaction with end-of-life care was found to be best explained

by a model which resonated with the qualitative findings of this study. Accounting for 77.4% of the variance in family satisfaction the final regression model included: contact and communication with nursing staff, feeling that care provided at the end of life met expectations, staff providing consistent care, feeling that the health care aide listened to their concerns about care and that respondents felt they had received enough support with their feelings. Many of these variables were also identified by focus group participants as playing a significant role in their assessment of and satisfaction with care delivered at the end of life.

The findings of this study resonate with many of the models of quality end-of-life care described in the literature including ensuring adequate pain and symptom management, timely and responsive communication, education, holistic and individualized care, preparation for death, and bereavement support (Brazil et al., 2004; Cherlin et al., 2004; Ferrell, 2005; Heyland et al., 2006; Howell & Brazil, 2005; Keegan et al., 2001; Kristjanson, 1989; Patrick, Engelberg, & Curtis, 2001; Steinhauser et al., 2000; Singer et al., 1999). These variables, many of which are modifiable, provide guidance for developing interventions to improve care of the dying and subsequently, family member satisfaction with care. Interventions aimed at improving provider comfort with communication, establishing goals of care discussions, providing emotional and instrumental support, and bereavement care all are important factors to improving family satisfaction with care. Attention must be paid to providing continuing education in pain and symptom management for all LTC facility staff, including physicians. Additionally, facilities must strive to adopt institutional philosophies which embrace palliative care as

an integral part of excellent care of their residents.

As much of family satisfaction with care focused on the importance of provider communication, it is critical that future researcher should focus on determining when family caregivers would like to receive information, how this information should be delivered, and the timing of goals of care discussions. This is especially important due to the disconnect between respondents stating they did not perceive they needed further information and the finding that it is a significant predictor of satisfaction with care.

If LTC facilities continue to use a model of care which requires recognition of a terminal phase of illness, then further research is needed in determining sentinel events which would trigger the enactment of appropriate palliative care measures.

Another critical component of family satisfaction that requires further research is the role that dissatisfaction with care has on the grief and bereavement experience of family caregivers. It became clear through respondents' comments, that many felt guilt, regret and anger even a year after the death when care had failed to meet expectations. Exploring the impact of such psychological distress on caregivers' health outcomes is an important but relatively unexplored area of research.

### **Conclusion**

In summary, this study sought to explore family perceptions and satisfaction with end-of-life care delivered in LTC facilities. The TIME instrument (Teno, 2004; Teno et al., 2001b) was modified to include nursing variables, LTC facility factors, family expectations of care, and resident and family demographic factors. Factor analysis revealed the questionnaire had a five factor structure. Administered to 87 bereaved

family respondents, results indicated that satisfaction with end-of-life care was best predicted by contact and communication with nursing staff, feeling that care provided at the end of life met expectations, staff providing consistent care, feeling that the health care aide listened to their concerns about care and that respondents felt they had received enough support with their feelings. Being transferred to hospital in the last month of life, dying in a place other than the LTC facility, and respondent age and employment status were all associated with significant mean differences in satisfaction scores. Interestingly, having an advance care plan in place or physician contact and communication were not significantly related to satisfaction. Focus groups provided confirmation of the findings of the first phase of the study and were useful in developing recommendations for improvements in end-of-life care. It is hoped that these findings will provide direction for quality improvement projects in LTC facilities and guide future investigation in the examination of interventions aimed at improving family satisfaction with care at the end of life.

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**APPENDIX A      LTC FACILITY DIRECTORS STUDY INFORMATION**

## PCH Directors Cover Letter

Dear [PCH Director],

This letter is being sent to solicit your facility's participation in my doctoral dissertation study of End of Life Care in Long-Term Care Facilities. This study is seeking to explore family members' experiences and satisfaction with the care provided to their loved one at the end of life.

Your participation in this project would involve mailing a letter to family members whose loved one was a resident in your facility and who has died in the past four to ten months. Family members are required to phone the investigator indicating their desire to participate in a survey interview lasting approximately 30 minutes.

The goal of this project is to further our understanding of how end of life care is delivered in the last month of life in long-term care facilities using family informants. In order to obtain a representative sample, your facilities participation would be very beneficial. Be assured that no individual PCH will be identified or analyzed alone. My final dissertation and subsequent presentations will provide a broad picture of family satisfaction with end of life care provided in the PCH environment and is not an assessment of individual facility performance.

I would like the opportunity to further discuss my study with you and to answer any questions that you may have. I will follow-up this letter by calling you in the next week to address any concerns or if you are interested in participating in this project, please call me at xxx-xxxx or email me (xxxxx@xxxx.xx).

I thank you in advance for your time and consideration.

Kind regards,

Genevieve Thompson, RN MN  
PhD Student, Dept. Community Health Sciences  
University of Manitoba

PCH Directors Study Information  
Family Perceptions and Satisfaction with End of Life Care in Long-Term Care Facilities

**Background to the Project:** Though some people will face death alone, most individuals with a life-limiting illness will have the support of significant others around them. Accordingly, family members observe and evaluate the care delivered to their loved one and are often active participants in the care. As palliative care ascribes to the philosophy that families are part of the unit of care, family members will themselves be recipients of care in the form of emotional support, health education, and bereavement follow-up. Due to the paucity of research in this area and the recognition that LTC facilities will increasingly be expected to provide excellent care at the end of life to a growing cohort of individuals, a study examining family members' perceptions and satisfaction with the quality of end of life care delivered to their loved one is warranted.

**Purpose of the Study:** The purpose of this mixed methods study is to examine the quality of dying in LTC facilities using family informants. In this regard a thorough understanding of the experience of dying in a LTC facility and the relationship between the various factors, which may influence satisfaction with end of life care may be achieved.

**Methodology and Procedures:** In the first phase of the study, quantitative data will be collected using a validated tool to measure the relationship between the needs, perceptions of care, family/resident and system characteristics and satisfaction with care provided at the end of life. In order to comply with PHIA regulations, participating PCH's will mail the letters inviting individuals whose relative was a resident of that particular PCH and who died within the past 4 to 10 months to participate in the research study. Using an opt-in approach, those individuals wishing to participate will be required to phone the investigator indicating their interest in participating in the study. Once the participant is deemed eligible to participate, the participant will be given the option of either conducting the survey interview by phone or face-to-face at a location that is convenient for the participant.

In the second phase, focus groups will be conducted to probe significant results obtained in the first phase of the study and to explore aspects of satisfaction or dissatisfaction with end of life care in more depth. Focus groups will consist of 6-10 individuals. The total number of focus groups will be dependent upon the number of persons interested in participating and the achievement of data saturation. However at a minimum, four focus groups will be conducted; two groups for those who are satisfied and two groups for those dissatisfied.

**Ethical Considerations:** Ethical approval has been obtained from the Bannatyne Campus Research Ethics Board. All potential participants will receive information in writing outlining the nature of the study and the confidentiality of their responses. Each participant will be required to sign and submit a consent form prior to data collection in either phase of the study. Additionally, each participating PCH will be assigned a unique

identifier for sampling and when collecting data related to systems characteristics. Data will be reported as aggregate data only; no PCH will be analyzed individually, no PCH will be identified individually or by name, and data with cell sizes less than five will not be reported. In this regard, no individual PCH will be identified or analyzed alone, and that my final dissertation and subsequent presentations to the PCH will provide a broad picture of family satisfaction with end of life care provided in the PCH environment and not be an assessment of their individual facilities performance.

Collecting data from bereaved family members has raised the concern that it might cause them emotional distress to participate in research studies. Little research exists exploring this issue. However, benefits to participating in research have been reported by bereaved participants who indicated that by completing questionnaires and interviews, they were able to voice issues and needs they deemed important that might otherwise go undetected.

**APPENDIX B      PARTICIPANT STUDY INFORMATION**

## LTC Cover Letter to Potential Participants

Dear [insert family member of recently-deceased resident]:

I am writing to make you aware of an opportunity to participate in a research project of Genevieve Thompson, RN, who is a doctoral student at the University of Manitoba. [LTC FACILITY NAME] is helping to facilitate her research because we believe it holds promise of improving the care that can be given to residents in the last days of their lives.

This is purely an invitation to consider participating. There is no obligation. I hope you will kindly take the time to read the attached information about Ms Thompson's study and how she would like you to participate. If you have questions about this study, please contact Ms Thompson directly at 474-8754. If you have questions about [LTC FACILITY] or its role in this study, please feel free to get in touch with [name, position and contact number].

Kind Regards,

Director, LTC FACILITY



**APPENDIX C      ETHICAL APPROVAL LETTERS**

U of M

Riverview

Deer Lodge

**APPENDIX D TELEPHONE SCREENING TOOL**

## INDRODUCTION & SCREENING

Hello, may I speak to (NAME),

My name is [interviewer name] and you indicated that you would be interested in participating in a study about the experience of [RESIDENT'S NAME] at the end of (his/her) life and your own experience during that time. I realize that this is a difficult time for you, (NAME), but I wonder if I might ask you some questions. Is this a good time for us to talk?

- Yes
- No (if no, When would be a better time for me to contact you? \_\_\_\_\_)

First of all I need to ask you the name of the individual who was a resident in the LTC Facility: \_\_\_\_\_

What was your relationship? \_\_\_\_\_

In what LTC were they a resident? \_\_\_\_\_

1. Would you say you are one of the people who knows the most about how (RESIDENT) was doing during (his/her) last month of life?
  - Yes (go to question 3)
  - No
2. Who would know more about (RESIDENT) in (his/her) last months of life than you?

\_\_\_\_\_ (alternative person)

2a. What is this person's relationship to (RESIDENT)?

2b. We may want to interview (ALTERNATIVE PERSON), do you happen to have (his/her) full name and address? \_\_\_\_\_

3. Are you over the age of 18?
  - Yes (GO TO QUESTION 4)
  - No (thank respondent for their time)
4. Are you able to communicate comfortably in English?
  - Yes (GO TO QUESTION 5)
  - No (thank respondent for their time)
5. How would you like to conduct the interview?

a) in your home: When would be a convenient time and date we could conduct the interview? \_\_\_\_\_

b) over the phone: Is now a good time for you to conduct the interview?

Yes (read brief script for consent)

No: When would be a better time and date to conduct the interview with you? \_\_\_\_\_

**APPENDIX E      VERBAL (TELEPHONE) CONSENT FORM**

## INFORMED CONSENT (telephone)

## [SCRIPT TO BE READ PRIOR TO THE COMMENCEMENT OF THE INTERVIEW]

To make sure you have all the information about the study, I am going to read you a few sentences.

The purpose of the study is to gain an understanding of family members' experiences and satisfaction with the care provided to their loved one at the end of life.

The interview will last approximately 30 minutes and be scheduled for a time that will be convenient for you. During the interview you will be asked to recall the care provided to your loved one during their last month of life. You may decline to answer any questions and you may withdraw from the study at any time. If you decide not to participate, it will not affect you in any way.

There are no known risks to participating in this study and there are no costs associated with your participation in this investigation. The possibility does exist that the recounting of some of your experiences during the interview may be emotionally upsetting for you. In that event, please understand that you are free to stop the interview and discuss your feelings with the researcher, or a support person of your choosing.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of the respondent. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers to be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not answer, just tell me and I will skip it.

Do you have any questions about who is doing the study or anything else related to the study?

May we proceed with the interview?

- Yes [CONTINUE THE INTERVIEW – GO TO QUESTION A]
- No [THANK RESPONDENT AND TERMINATE INTERVIEW]

**APPENDIX F      FACE-TO-FACE SURVEY CONSENT FORM**

## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: “Family Perceptions and Satisfaction with End of Life Care in Long-Term Care Facilities.”

Principal Investigator: Genevieve Thompson, 338 Isbister Building, University of Manitoba, R3T 2N2, (204) 474-8754.

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

The purpose of the study is to gain an understanding of family members’ experiences and satisfaction with the care provided to their loved one at the end of life. The study is being conducted by Genevieve Thompson, a PhD student in Community Health Sciences from the University of Manitoba. The study has been approved by the Research Ethics Board of the University of Manitoba and the research ethics boards of the Personal Care Home’s participating in this project. The project has received funding from the Manitoba Health Research Council.

If I agree I will participate in a survey interview conducted over the telephone or in my home. The interview will last approximately 30 minutes and be scheduled for a time that will be convenient for me. During the interview I will be asked to recall the care provided to my loved one during their last month of life. I may decline to answer any questions and I may withdraw from the study at any time. A total of 320 people may participate in this study.

I understand that there are no known risks to participating in this study and there are no costs associated with my participation in this investigation. The possibility does exist that the recounting of some of my experiences during the interview may be emotionally upsetting for me. In that event, I understand that I am free to stop the interview and discuss my feelings with the researcher, or a support person of my choosing. Although I may derive no direct benefits from my participation, I have been informed that the knowledge gained through this study will contribute toward improving the care provided to dying individuals residing in personal care homes.

I understand that my participation in the study is considered confidential. I will be assigned a code number, and my name will not appear on any documents. This will protect my identity and the identity of my loved one. All information collected is also considered to be confidential. During the course of the study, the data collection forms will be stored in a locked cabinet and will only be reviewed by the researcher. The consent forms will be stored in the same manner, in a separate location. At the completion of the study, the data collection forms will be retained for a period of seven years, following which they will be destroyed.

The results of the study will be published as a PhD dissertation and may be published in the form of a journal article. This project is being supervised by Dr. Verena Menec, Faculty of Medicine, Dr. Harvey Chochinov, Faculty of Medicine and Dr. Lesley Degner, Faculty of Nursing.

I understand that I may contact the researcher, Genevieve Thompson, at (204) 474-8754 or the Thesis Committee Chairperson, Dr. Verena Menec at (204) 474-9176. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

I have read this consent form. I have had the opportunity to discuss this research study with Genevieve Thompson. I have had my questions answered by her in language that I understand. The risks and benefits have been explained to me. I believe I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. I understand that I will be given a copy of the consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

My signature below indicates that I am informed and that I agree to participate in this investigation.

---

Participant's signature

Date (day/month/year)

---

Participant Printed Name

In order to further understand the experience of dying in a long-term care facility and to develop recommendations for improvement in the delivery of care, we are seeking to conduct small discussion groups. These groups would consist of 6-10 individuals who have had similar experiences to you. The focus group will last approximately 1 hour.

- I agree to participate in a Focus Group at a later date.
- I do not agree to participate in a Focus Group at a later date.

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and knowingly given their consent.

Printed Name: \_\_\_\_\_

---

Researcher's signature

---

Date (day/month/year)

**APPENDIX G      MODIFIED TIME QUESTIONNAIRE**

ID# \_\_\_\_\_  
PCH ID# \_\_\_\_\_

TOOLKIT OF INSTRUMENTS TO MEASURE END OF LIFE CARE  
After-Death Bereaved Family Member Interview Guide  
NURSING HOME VERSION - Modified

INTERVIEW COVER SHEET

DATE OF INTERVIEW: \_\_\_\_\_

START TIME: \_\_\_\_\_

END TIME: \_\_\_\_\_

INTERVIEW FORMAT:     \_\_\_\_\_ PHONE  
                                  \_\_\_\_\_ IN PERSON

FAMILY MEMBER INTERVIEWED:     \_\_\_\_\_ ALONE  
  \_\_\_\_\_ OTHER MEMBER PRESENT  
(SPECIFY)

DATE OF ADMIT TO PCH: \_\_\_\_\_

RESIDENT DATE OF DEATH: \_\_\_\_\_

Resident Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

INTERVIEWER INITIALS: \_\_\_\_\_

INTERVIEWER COMMENTS

## CHECKING THE FACTS

“Would you like to tell me a bit about your (mom, dad, spouse...) before we start?”

A. Where did [PATIENT’S] death take place? [INTERVIEWER – IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

<input type="checkbox"/> AT HOME →	Was that in the patient’s own home [ ], or in your home [ ], or in someone else’s home [ ]
<input type="checkbox"/> IN A HOSPITAL →	Was that in the Intensive Care Unit, <input type="checkbox"/> YES <input type="checkbox"/> NO (GO TO NEXT) Was that in an Emergency Department, <input type="checkbox"/> YES <input type="checkbox"/> NO (GO TO NEXT) Was that in a palliative care unit? <input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> NURSING HOME	
<input type="checkbox"/> HOSPICE →	Do you mean an inpatient hospice unit? <input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> IN TRANSIT TO A MEDICAL FACILITY	
<input type="checkbox"/> SOMEWHERE ELSE →	SPECIFY:
<input type="checkbox"/> DON’T KNOW	

A1. Can you tell me when (resident) died? \_\_\_\_\_ / \_\_\_\_\_

A2. Was [RESIDENT] under the care of the nursing home during the last 7 days of (his/her) life

YES (code = 1)

NO (code = 0)

A5. We’re interested in finding out where [PATIENT] spent the last 30 days of (his/her) life. Let’s start with where (he/she) was 30 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (30 DAYS BEFORE): \_\_\_\_\_ NUMBER OF DAYS: \_\_\_\_\_



- Partial or complete paralysis (Code = 12)
- Visual or hearing impairments (Code = 13)
- Back problems (Code = 14)
- Depression or anxiety (Code = 15)
- Parkinson's disease (Code = 16)
- Other \_\_\_\_\_ (Code = 17)

G3. "When [RESIDENT] died, was it a surprise to you?"

- YES (Code = 0)
- NO (Code = 1)

**-if answer YES, follow-up probes to assess why they were surprised  
(e.g. what made [RESIDENT'S] death such a surprise to you)**

B6. To the best of your knowledge, what did [RESIDENT] die of? \_\_\_\_\_

B7. Did [RESIDENT] die in the place where (he/she) wanted to?

- Yes (Code = 1)
- No (Code = 0)

B7a. Where would have (he/she) wanted to die? \_\_\_\_\_

B8. Was [RESIDENT] registered with the WRHA palliative care program?

- Yes (Code = 1)
- No (Code = 0)

B9. What cultural group did [RESIDENT] most identify with?

- Caucasian (White) (Code = 1)
- Native American (Code = 2)
- Southeast Asian (i.e. Vietnamese, Cambodian, Loatian) (Code = 3)
- Black or African-Canadian (Code = 4)
- South Asian (i.e. East Indian, Pakastani) (Code = 5)
- Filipino (Code = 6)
- Arab (Code = 7)
- Chinese (Code = 8)
- Japanese (Code = 9)
- Latin American (Code = 10)
- Other: \_\_\_\_\_ (Code = 11)
- Choose not to answer (Code = 98)

B10. What was the highest level of schooling [RESIDENT] completed?

- ] Less than high school (Code = 1)
- ] High School Graduate (Code = 2)
- ] Some University, Community College, or Technical Institute (Code=3)
- ] University, Community College or Technical Institute Graduate (C = 4)
- ] Advanced Degree (Master's or PhD) (Code = 5)
- ] GED (Code = 6)
- ] Don't Know (Code = 97)

B11. What religious affiliation did [RESIDENT] most associated with?

- ] Protestant (Code = 1)
- ] Catholic (Code = 2)
- ] Jewish (Code = 3)
- ] Islam (Code = 4)
- ] Hindu (Code = 5)
- ] Buddhist (Code = 6)
- ] None (Code = 7)
- ] Other:\_\_\_\_\_ (Code = 8)
- ] Choose not to answer (Code = 98)

INTERVIEWER CHECK: DETERMINE FROM THE PREVIOUS ANSWER IF PATIENT WAS UNDER CARE OF THE NURSING HOME DURING THE LAST 7 DAYS OF HIS/HER LIFE; CHOOSE 'IN THAT LAST WEEK'. IF NO – CHOOSE 'WHILE UNDER THE CARE OF THE NURSING HOME'

## DOMAIN QUESTIONS

**C1.** (In [RESIDENT'S] last week/While [resident] was under the care of nursing home), did you talk with any of [RESIDENT'S] doctors yourself?  
  YES (Code = 1)  
 NO (SKIP TO C2) (Code = 0)

**C1a.** (In that last week/While under care of the nursing home), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?  
 YES [**CODE = 0**]  
 NO [**CODE = 1**]

**C1b.** (In that last week/While under care of the nursing home), did you feel that the doctors you talked to listened to your concerns about [RESIDENT'S] medical treatment?  
  
 YES [**CODE = 1**]  
 NO [**CODE = 0**]  
 HAD NO CONCERNS [**CODE = 2**]

**C1c.** (In that last week/While under care of the nursing home), how much information did the doctors provide you about [RESIDENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?  
 LESS THAN WAS NEEDED [**CODE = 1**]  
 JUST THE RIGHT AMOUNT [**CODE = 0**]  
 MORE THAN WAS NEEDED [**CODE= 2**]

**C1d.** (In that last week/While under care of the nursing home), how often did any doctor give confusing or contradictory information about [RESIDENT'S] medical treatment - always, usually, sometimes, or never?  
  
 ALWAYS [**CODE = 3**]  
 USUALLY [**CODE = 2**]  
 SOMETIMES [**CODE = 1**]  
 NEVER [**CODE = 0**]

**C2.** (In that last week/While under care of the nursing home), was there always a doctor in charge of [RESIDENT]'s care?

YES [CODE = 1]

NO [CODE = 0]

C2a. (In that last week/While under care of the nursing home), was it always clear to you which doctor was in charge of (his/her) care?

YES [CODE = 1]

NO [CODE = 0]

**C3.** (In [RESIDENT'S] last week/While [resident] was under the care of nursing home), did you talk with any of [RESIDENT'S] nurses yourself?



YES (Code = 1)

NO (SKIP TO C2) (Code = 0)

**C3a.** (In that last week/While under care of the nursing home), was there ever a problem understanding what any of the nurses were saying to you about what to expect from treatment?

YES [CODE = 0]

NO [CODE = 1]

**C3b.** (In that last week/While under care of the nursing home), did you feel that the nurses you talked to listened to your concerns about [RESIDENT'S] medical treatment?

YES [CODE = 1]

NO [CODE = 0]

HAD NO CONCERNS [CODE = 2]

**C3c.** (In that last week/While under care of the nursing home), did you feel that the nurses you talked to responded or acted on your concerns about [RESIDENT'S] medical treatment?

- YES [CODE = 1]  
 NO [CODE = 0]  
 HAD NO CONCERNS [CODE = 2]

**C3d.** (In that last week/While under care of the nursing home), how much information did the nurses provide you about [RESIDENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- LESS THAN WAS NEEDED [CODE = 1]  
 JUST THE RIGHT AMOUNT [CODE = 0]  
 MORE THAN WAS NEEDED [CODE= 2]

**C3e.** (In that last week/While under care of the nursing home), how often did any nurse give confusing or contradictory information about [RESIDENT'S] medical treatment - always, usually, sometimes, or never?

- ALWAYS [CODE = 3]  
 USUALLY [CODE = 2]  
 SOMETIMES [CODE = 1]  
 NEVER [CODE = 0]

**C3f.** (In that last week/While under care of the nursing home), was there always a nurse in responsible for [RESIDENT]'s care?

- YES [CODE = 1]  
 NO [CODE = 0]

**C3g.** (In that last week/While under care of the nursing home), was it always clear to you which nurse was responsible for (his/her) care?

- YES [CODE = 1]  
 NO [CODE = 0]

**C4.** (In that last week/While under care of the nursing home), did you feel that the health care aides you talked to listened to your concerns about [RESIDENT'S] care?

YES [CODE = 1]

NO [CODE = 0]

HAD NO CONCERNS [CODE = 2]

**C4a.** (In that last week/While under care of the nursing home), how often did any health care aide give confusing or contradictory information about [RESIDENT'S] care - always, usually, sometimes, or never?

ALWAYS [CODE = 3]

USUALLY [CODE = 2]

SOMETIMES [CODE = 1]

NEVER [CODE = 0]

NOTE: IF PERSON HAS DEMENTIA, ASK IF FAMILY HAD WISHES ABOUT MEDICAL CARE.

**D1.** Did [RESIDENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?



YES [Code = 1]

NO (SKIP TO D5) [Code = 0]

DON'T KNOW (SKIP TO D5) [Code = 97]

**D1A.** Did you or other family members have specific wishes or plans about the types of medical treatment that you did or did not want provided?



YES [Code = 1]

NO (SKIP TO D5) [Code = 0]

DON'T KNOW (SKIP TO D5) [Code = 97]

**D2.** To the best of your knowledge, did [RESIDENT]'s doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about (his/her) wishes about medical treatment?



YES [CODE = 1]

NO [CODE = 0]

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?



- [ ] YES [CODE = 1]  
[ ] NO [CODE = 0]

D4. (In that last week/ While under care of the nursing home), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?



- [ ] YES [CODE = 0]  
[ ] NO [CODE = 1]

D5. Did [RESIDENT] have a Advance Care Plan or Health Directive naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?



- [ ] YES [Code = 1]  
[ ] NO [Code = 0]  
[ ] DON'T KNOW [Code = 97]

D6. Did [RESIDENT] have a Advance Care Plan or Health Directive giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?



- [ ] YES [Code = 1]  
[ ] NO [Code = 0]  
[ ] DON'T KNOW [Code = 97]

INTERVIEWER CHECK: DOES D5= YES OR D6 =YES?

- [ ] YES  
[ ] NO (SKIP TO A8)

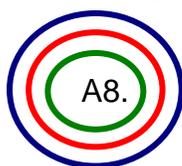
D7. Had you or [RESIDENT] discussed (his/her) Advance Care Plan with a doctor caring for (him/her) while under care of the nursing home?



- [ ] YES [Code = 1]  
[ ] NO [Code = 0]

- D8.** Did the nursing home respect you or your {resident}'s wishes as stated in (his/her) Advance Care Plan?
- YES [Code = 1]  
 NO [Code = 0]

Now I want to ask some specific questions about when [RESIDENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the nursing home.



About how many days or weeks before (he/she) died did [RESIDENT] lose consciousness?



\_\_\_\_\_ DAYS OR \_\_\_\_\_ WEEKS

NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE PATIENT WAS UNDER THE CARE OF THE NURSING HOME?

- YES (SKIP TO D18)  
 NO

**D9i.** Did [resident] experience pain (in that last week/while under the care of the nursing home)?

- YES [Code = 0]  
 NO (SKIP TO D16) [Code = 1]  
 DON'T KNOW (SKIP TO D16) [Code = 97]

**D12.** (In that last week/ While under care of the nursing home), was [RESIDENT] on medicines to treat (his/her) pain?

- YES [Code = 1]  
 NO (SKIP TO D15) [Code = 0]  
 DON'T KNOW (SKIP TO D15) [Code = 97]

**D12a.** (In that last week/ While under care of the nursing home), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?



- YES [CODE = 1]  
 NO [CODE = 0]

**D15.** (In that last week/ While under care of the nursing home), did [RESIDENT] receive too much, too little, or just the right amount of medication for (his/her) pain?



- TOO MUCH [CODE = 2]  
 TOO LITTLE [CODE = 1]  
 RIGHT AMOUNT [CODE = 0]

**D15a.** (In that last week/ While under care of hospice/hospital/nursing home), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?



- YES [CODE = 0]  
 NO [CODE = 1]

**D16.** (In that last week/ While under care of the nursing home), did (he/she) have trouble breathing?



- YES [Code = 0]  
 NO (SKIP TO D17) [Code = 1]  
 DON'T KNOW (SKIP TO D17) [Code = 97]

**D16b.** How much help in dealing with (his/her) breathing did [RESIDENT] receive - less than was needed, or about the right amount?



- LESS THAN WAS NEEDED [CODE = 0]  
 RIGHT AMOUNT [CODE = 1]

**D17.** (In that last week/ While under care of the nursing home), did (he/she) have any feelings of anxiety or sadness?



- YES [Code = 0]
- NO (SKIP TO D20) [Code = 1]
- DON'T KNOW (SKIP TO D20) [Code = 97]

**D17b.** How much help in dealing with these feelings did [RESIDENT] receive - less than was needed or about the right amount?

- LESS THAN WAS NEEDED [**CODE = 0**]
- RIGHT AMOUNT [**CODE = 1**]

**D20.** (In that last week/ While under care of the nursing home), did (he/she) have any other symptoms that caused (him/her) distress or discomfort?



- YES [Code = 0]
- NO [Code = 1]
- DON'T KNOW [code = 97]

D20a. What were those symptoms? \_\_\_\_\_

**D18.** (In that last week/ While under care of the nursing home), was there any problem with doctors or nurses not knowing enough about [RESIDENT'S] medical history to provide the best possible care?



- YES [**CODE = 0**]
- NO [**CODE = 1**]

**D19.** (In that last week/ While under care of the nursing home), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?



- YES [**CODE = 0**]
- NO [**CODE = 1**]
- DON'T KNOW [Code = 97]

D21. (In that last week/ While under care of the nursing home), how often were [RESIDENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

①

- ALWAYS [CODE = 3]
- USUALLY [CODE = 2]
- SOMETIMES [CODE = 1]
- NEVER [CODE = 0]

D22. (In that last week/ While under care of the nursing home), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

①

- ALWAYS [CODE = 3]
- USUALLY [CODE = 2]
- SOMETIMES [CODE = 1]
- NEVER [CODE = 0]

D23. (In that last week/ While under care of the nursing home), how often was [RESIDENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

- ALWAYS [CODE = 3]
- USUALLY [CODE = 2]
- SOMETIMES [CODE = 1]
- NEVER [CODE = 0]

D24. (In that last week/ While under care of the nursing home), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

- YES [CODE = 1]
- NO [CODE = 0]

D25. (In that last week/ While under care of the nursing home), was there enough help with medications and getting dressings changed?

①

- YES [CODE = 1]
- NO [CODE = 0]

D26. At any time while [RESIDENT] was in the nursing home did you or your family receive any information about what to expect while (he/she) was dying?

<input type="checkbox"/> YES [Code =1]	D26a. Would you have wanted (some/more) information about that? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]
<input type="checkbox"/> NO [Code =0]	D26a. Would you have wanted (some/more) information about that? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]

D26b. How confident were you that you knew what to expect while [RESIDENT] was dying - very confident, fairly confident, or not confident?

II

- VERY CONFIDENT [CODE = 3]  
 FAIRLY CONFIDENT [CODE = 2]  
 NOT CONFIDENT [CODE = 1]

D27. At any time while [RESIDENT] was in the nursing home did you or your family receive any information about what to do at the time of (his/her) death (funeral plans etc)?

<input type="checkbox"/> YES [Code =1]	D27a. Would you have wanted (some/more) information about that? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]
<input type="checkbox"/> NO [Code =0]	D27a. Would you have wanted (some/more) information about that? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]

**D27b.** How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

II

- VERY CONFIDENT [CODE = 3]  
 FAIRLY CONFIDENT [CODE = 2]  
 NOT CONFIDENT [CODE = 1]

**D28.** At any time while [RESIDENT] was in the nursing home did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

<input type="checkbox"/> YES [Code =1]	<b>D28a.</b> Would you have wanted (some/more) information about the medicines? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]
<input type="checkbox"/> NO [Code =0]	<b>D28a.</b> Would you have wanted (some/more) information about the medicines? <input type="checkbox"/> YES [CODE = 0] <input type="checkbox"/> NO [CODE =1]

**D28b.** How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

II

- VERY CONFIDENT [CODE = 3]  
 FAIRLY CONFIDENT [CODE = 2]  
 NOT CONFIDENT [CODE = 1]

These next questions are about your experience (during [RESIDENT'S] last week/while under care of the nursing home).

**E1.** (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the nursing home), how often were you or other family members kept informed about [RESIDENT'S] condition – always, usually, sometimes, or never?

- ALWAYS [CODE = 3]  
 USUALLY [CODE = 2]  
 SOMETIMES [CODE = 1]  
 NEVER [CODE = 0]

**E2.** (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the nursing home), how often did you have concerns about [RESIDENT'S] personal care needs – such as bathing, dressing, and changing bedding-being met when you were not there - always, usually, sometimes, or never?

①

- ALWAYS [CODE = 3]  
 USUALLY [CODE = 2]  
 SOMETIMES [CODE = 1]  
 NEVER [CODE = 0]

E4. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the nursing home), did someone from the nursing home talk with you about your religious or spiritual beliefs?

<input type="checkbox"/> YES [Code =1]	E4a. Was this done in a sensitive manner?  <input type="checkbox"/> YES [Code =1]	E4b. Did you have as much contact of that kind as you wanted in [RESIDENT'S] last week/ while [RESIDENT] was under care of the nursing home ? <input type="checkbox"/> YES [CODE = 1] <input type="checkbox"/> NO [CODE = 0]
	<input type="checkbox"/> NO [CODE = 0]	
<input type="checkbox"/> NO [CODE = 0]		

**E6.** (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the nursing home), how much support in dealing with your feelings about [RESIDENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?



- LESS THAN WAS NEEDED [CODE = 0]  
 RIGHT AMOUNT [CODE = 1]

- E7.** (In [RESIDENT'S] last week/ While [RESIDENT] was under the care of the nursing home), did a doctor, nurse, or other professional staff taking care of [RESIDENT] talk about how you might feel after [RESIDENT'S] death?

<input type="checkbox"/> YES → [Code =1]	<b>E7a.</b> Was it done in a sensitive manner? <input type="checkbox"/> YES [CODE = 1] <input type="checkbox"/> NO [CODE = 0]
<input type="checkbox"/> NO → [Code =0]	<b>E7b.</b> Would you have wanted them to? <input type="checkbox"/> YES [CODE = 1] <input type="checkbox"/> NO [CODE = 0]

- E8.** (In [RESIDENT'S] last week/ While [RESIDENT] was under the care of the nursing home), did a doctor, nurse, or other professional staff taking care of [RESIDENT] suggest someone you could turn to for help if you were feeling stressed?

YES [CODE = 1]  
 NO [CODE = 0]

Ratings [CODE for ratings = the number 0-10 chosen by the respondent]

Now we would like you to rate some aspects of the care [RESIDENT] received (in the last week/while (he/she) was under care of the nursing home. For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

- F1.** (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the nursing home), how well did the doctors, nurses, and other professional staff who cared for [RESIDENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F2. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the nursing home), how would you rate how well those taking care of [RESIDENT] provided medical care that respected (his/her) wishes?

*R*

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F3. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the nursing home), how well did those taking care of [RESIDENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

*R*

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F4. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the nursing home), how well did those taking care of [RESIDENT] make sure that [RESIDENT] died with dignity - that is, died on (his/her) own terms?

*R*

[ 0 1 2 3 4 5 6 7 8 9 10 ]

F5. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the nursing home), how well did those taking care of [RESIDENT] do at providing emotional support for you and [RESIDENT]'s family and friends?

*R*

[ 0 1 2 3 4 5 6 7 8 9 10 ]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [RESIDENT] received in [RESIDENT'S] last week of life/ while [RESIDENT] was under care of the nursing home)?

*R*

[ 0 1 2 3 4 5 6 7 8 9 10 ]

Section G. Expectations/Satisfaction
--------------------------------------

G1. Overall, how satisfied were you with the end of life care that was given to [RESIDENT]?

- Very satisfied (5)
- Satisfied (4)
- Undecided (3)
- Not satisfied (2)
- Very dissatisfied (1)

G2. "Was the care that [RESIDENT] received in the last month/week of (his/her) life, what you expected?"

- YES (1)                       NO (0)

-If answer NO; Follow-up probes to assess what expectations were of the care (e.g. how did you envision the care at the end of [RESIDENT'S] life)

Section H. Environment
------------------------

H. The following set of questions ask you to rate the **Physical Environment of the Personal Care Home** where [RESIDENT] resided.

On a scale of 1 to 10, with 1 being very poor and 10 being excellent:

H1. How would you rate how homelike the facility was.

Very Poor				Neutral					Excellen t
1	2	3	4	5	6	7	8	9	10

H2. How would you rate how clean the facility was.

Very Poor				Neutral					Excellen t
1	2	3	4	5	6	7	8	9	10

H3. How would you rate the temperature of your loved one's room.

Very Poor				Neutral					Excellen t
1	2	3	4	5	6	7	8	9	10

H4. How would you rate how able you were to make your loved one's room homelike.

Very Poor				Neutral					Excellen t
1	2	3	4	5	6	7	8	9	10

H5. How would you rate the privacy of your loved one's room.

Very Poor				Neutral					Excellen t
1	2	3	4	5	6	7	8	9	10

Section I. Demographics
-------------------------

We would like to know a few things about you to help us better understand your answers.

I1. Are you:  Male (Code = 0)

Female (Code = 1)

I2. How old were you on your last birthday? \_\_\_\_\_ YEARS OLD

I3. What is the highest level of schooling you have completed?

Less than high school (Code = 1)

High School Graduate (Code = 2)

Some University, Community College, or Technical Institute (Code = 3)

University, Community College or Technical Institute Graduate (Code = 4)

Advanced Degree (Master's or PhD) (Code = 5)

Don't Know (Code = 97)

I4. What was your relationship to [RESIDENT]?

Husband or wife (Code = 1)

Common-law partner (opposite-sex) (Code = 2)

Common-law partner (same-sex) (Code = 3)

Son or daughter (Code = 4)

Son-in-law or daughter-in-law (Code = 5)

Grandchild (Code = 6)

Father or mother (Code = 7)

Father-in-law or mother-in-law (Code = 8)

Brother or Sister (Code = 9)

Brother-in-law or sister-in-law (Code = 10)

Friend (Code = 11)

Other – specify: \_\_\_\_\_ (Code = 12)

I5. Are you currently...

Employed full-time (Code = 1)

Employed part-time (Code = 2)

Self-employed (Code = 3)

Stay at home parent/caregiver (Code = 4)

Unemployed (Code = 5)

On disability (Code = 6)

Retired (Code = 7)

Choose not to answer (Code = 98)

I6. What religious affiliation to you most associated with?

- Protestant (Code = 1)
- Catholic (Code = 2)
- Jewish (Code = 3)
- Islam (Code = 4)
- Hindu (Code = 5)
- Buddhist (Code = 6)
- None (Code = 7)
- Other: \_\_\_\_\_ (Code = 8)
- Choose not to answer (Code = 98)

17. What ethnic group do you consider yourself to belong to?

- Caucasian (White) (Code = 1)
- Native American (Code = 2)
- Southeast Asian (i.e. Vietnamese, Cambodian, Loatian) (Code = 3)
- Black or African-Canadian (Code = 4)
- South Asian (i.e. East Indian, Pakastani) (Code = 5)
- Filipino (Code = 6)
- Arab (Code = 7)
- Chinese (Code = 8)
- Japanese (Code = 9)
- Latin American (Code = 10)
- Other: \_\_\_\_\_ (Code = 11)
- Choose not to answer (98)

18. How would you describe your current health?

- Excellent (Code = 5)
- Very Good (Code = 4)
- Good (Code = 3)
- Fair (Code = 2)
- Poor (Code = 1)

19. How often did you visit [RESIDENT] in (his/her) last month of life?

- Daily (Code = 1)
- Two to three times a week (Code = 2)
- Four or Five times a week (Code = 3)
- Once a week (Code = 4)
- Once every couple of weeks (Code = 5)
- Once in the month (Code = 6)
- Live out of province (Code = 7)
- Don't know (Code = 97)

110. Now to help us make statistical comparisons, would you mind telling us what your total household income from all sources was for 2005?

- Less than \$20,000 (Code = 1)

- \$21,000 to \$39,000 (Code = 2)
- \$40,000 to \$59,000 (Code = 3)
- \$60,000 to \$79,000 (Code = 4)
- More than \$80,000 (Code = 5)
- Don't Know (Code = 97)
- Choose not to answer (Code = 98)

I11. Is there anything else that you would like me to know about [PATIENT'S] care in the last few days of life?

At end of the interview, ask "Would you like to participate in a focus group at a later date and time".

- Yes
- No

**\*\*Thank you for your time and participation in this project. \*\***

**APPENDIX H      FOCUS GROUP CONSENT FORM**

RESEARCH PARTICIPANT INFORMATION AND FOCUS GROUP CONSENT  
FORM

Title of Study: "Family Perceptions and Satisfaction with End of Life Care in Long-Term Care Facilities."

Principal Investigator: Genevieve Thompson, 338 Isbister Building, University of Manitoba, R3t 2N2, (204) 474-8754.

I \_\_\_\_\_ agree to participate in the above titled research project. The purpose of the study is to gain an understanding of family members' experiences and satisfaction with the care provided to their loved one at the end of life. The study is being conducted by Genevieve Thompson, a PhD student in Community Health Sciences from the University of Manitoba. The study has been approved by the Research Ethics Board of the University of Manitoba and the Winnipeg Regional Health Authority. The project has received funding from the Manitoba Health Research Council.

If I agree I will participate in a focus group of 6-10 individuals who have had similar experiences to mine. The focus group will last approximately 1 hour. During this group, I will be asked to recall the care provided to my loved one during their last month of life. I may decline to answer any questions and I may withdraw from the study at any time.

I understand that there are no known risks to participating in this study and there are no costs associated with my participation in this investigation. The possibility does exist that the recounting of some of my experiences may be emotionally upsetting for me. In that event, I understand that I am free to leave the group and discuss my feelings with the researcher, or a support person of my choosing. I will receive reimbursement for my parking or transportation costs for participating in the focus group. Although I may derive no direct benefits from my participation, I have been informed that the knowledge gained through this study will contribute toward improving the care provided to dying individuals residing in personal care homes.

I understand that my participation in the study is considered confidential. I will be assigned a code number, and my name will not appear on any published documents. This will protect my identity and the identity of my loved one. All information collected is also considered to be confidential. During the course of the study, the data collection forms and focus group tapes will be stored in a locked cabinet and will only be reviewed by the researcher and her thesis committee Chairperson. Names and identifying information will not appear on the transcripts. The consent forms will be stored in the same manner, in a separate location. At the completion of the study, the data collection forms and focus group tapes will be retained for a period of seven years, following which they will be destroyed. When participation in focus group discussions, everything that is said in the focus group is to be held in confidence and not to be repeated outside the focus group.

The results of the study will be published as a PhD dissertation and may be published in the

form of a journal article. This project is being supervised by Dr. Verena Menec, Faculty of Medicine, Dr. Harvey Chochinov, Faculty of Medicine and Dr. Lesley Degner, Faculty of Nursing.

I understand that I may contact the researcher, Genevieve Thompson, at (204) 474-8754 or the Thesis Committee Chairperson, Dr. Verena Menec at (204) 474-9176. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

I have read this consent form. I have had the opportunity to discuss this research study with Genevieve Thompson. I have had my questions answered by her in language that I understand. The risks and benefits have been explained to me. I believe I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. I understand that I will be given a copy of the consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

My signature below indicates that I am informed and that I agree to participate in this investigation.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date (day/month/year)

\_\_\_\_\_  
Participant Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and knowingly given their consent.

Printed Name: \_\_\_\_\_

\_\_\_\_\_  
Researcher's signature

\_\_\_\_\_  
Date (day/month/year)