LONG-TERM CARE NURSES’ PERCEPTIONS OF FACTORS THAT INFLUENCE THEIR END-OF-LIFE DISCUSSIONS WITH SURROGATE DECISION MAKERS

by

Diane Marie Walter

Copyright © Diane Marie Walter 2017

A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2017
THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the Dissertation Committee, we certify that we have read the dissertation prepared by Diane Marie Walter entitled “Long-Term Care Nurses’ Perceptions of Factors that Influence Their End-of-Life Discussions with Surrogate Decision Makers” and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

Pamela G. Reed, PhD, RN, FAAN
Date: February 28, 2017

Janice D. Crist, PhD, RN, FNGNA, FAAN
Date: February 28, 2017

Cindy Rishel, PhD, RN, OCN
Date: February 28, 2017

Final approval and acceptance of this dissertation is contingent upon the candidate’s submission of the final copies of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

Dissertation Director: Pamela G. Reed, PhD, RN, FAAN
Date: February 28, 2017
STATEMENT BY AUTHOR

This dissertation has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this dissertation are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the copyright holder.

SIGNED: Diane Marie Walter
ACKNOWLEDGMENTS

I thank God for all the blessings He has given me. There are several individuals I wish to acknowledge for their contribution to this dissertation. I would like to thank Dr. Pamela Reed for being my doctoral advisor and mentor, for sharing her knowledge and being my constant calmness. Your never-ending support and encouragement have inspired me to accomplish more than I ever thought possible. I offer my sincerest gratitude.

My committee members Dr. Cindy Rishel, Clinical Faculty and Dr. Janice Crist, Associate Professor, who challenged me to think in new and exciting ways and whose motivation and support have enabled me to achieve this milestone. Thank you for sharing your time and expertise.

My friends and colleagues near and far who have offered support and words of encouragement throughout this journey. Faby Bowles, thank you for always being “my person” through the good days and the not so good days.

I once heard that it takes a village to raise a child; I may not know if this is true or not, but I do know that it has taken the support of “my” clinical associates and adjunct faculty who graciously worked extra hours and ensured coverage in all educational settings so I could complete this dissertation. I am forever indebted to each of you! In addition, although “my” students (present and past) say I inspire them; it is they who have inspired me and I thank them for the never-ending support and words of encouragement.

My family—my brother Dan, my daughters Amber and Brandi, my grandchildren McKenzie, Preston, Tiffanie, Carson, and Taylor, and my mother Kay Lundeen Taylor—thank you for your never-ending love, support, and understanding. Danny—I still believe I am the one who has been blessed by having a brother, best friend, and colleague wrapped into one amazing individual. There is a special place in heaven for you! My girls and grandbabies—you are my inspiration always and forever! Mom—I appreciate you allowing me to spread my wings and fly.

Mi Familia—the Sesma’s—thank you for “adopting” me and offering me unconditional love, support, encouragement, and familia fun throughout this journey. I could not have accomplished this without you!! May God continue to bless each of mi familia members (near and far).
DEDICATION

This dissertation is dedicated in loving memory to three beloved people who have meant and continue to mean so much to me. Although they are no longer of this world, their memories continue to influence my life. First, My Daddy Gene Taylor whose love for me knew no bounds and, who taught me the value of hard work and perseverance. I will always be “The Nebraska Farmer’s Daughter.”

Next, my big sister Debbie Taylor Kirk who loved me, and took the role of being my first girlfriend and confidant although we were five years apart in age. Please know that I acknowledge and am thankful for your selfless sacrifices that allowed me to be my free-spirited self.

Finally, my niece Karen Pauline Taylor (K.P.) who determined my career path for me by making Aunt Diane promise to become a nurse and take care of people like her. I can only hope and pray that I have fulfilled “The Promise” made over 25 years ago.
### TABLE OF CONTENTS – *Continued*

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample</td>
<td>48</td>
</tr>
<tr>
<td>Procedure</td>
<td>49</td>
</tr>
<tr>
<td>Survey Process</td>
<td>50</td>
</tr>
<tr>
<td>Data Collection</td>
<td>50</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>51</td>
</tr>
<tr>
<td>Rigor and Trustworthiness</td>
<td>53</td>
</tr>
<tr>
<td>Quantitative Data</td>
<td>53</td>
</tr>
<tr>
<td>Internal validity</td>
<td>53</td>
</tr>
<tr>
<td>External validity</td>
<td>54</td>
</tr>
<tr>
<td>Qualitative Data</td>
<td>54</td>
</tr>
<tr>
<td>Credibility</td>
<td>54</td>
</tr>
<tr>
<td>Transferability</td>
<td>55</td>
</tr>
<tr>
<td>Dependability</td>
<td>55</td>
</tr>
<tr>
<td>Confirmability</td>
<td>55</td>
</tr>
<tr>
<td>Summary</td>
<td>56</td>
</tr>
<tr>
<td>CHAPTER 4: RESULTS</td>
<td>57</td>
</tr>
<tr>
<td>Description of the Sample</td>
<td>58</td>
</tr>
<tr>
<td>Research Question 1</td>
<td>59</td>
</tr>
<tr>
<td>Research Sub Question 1a. What Personal Factors of the Long-Term Care Nurse Influence Their Communication with the End-of-Life Surrogate Decision Maker?</td>
<td>60</td>
</tr>
<tr>
<td>Research Sub Question 1b. What Characteristics of the End-of-Life Surrogate Decision Maker Influence the Long-Term Care Nurse’s Ability to Communicate with Them?</td>
<td>62</td>
</tr>
<tr>
<td>Research Sub Question 1c. What Contextual Factors Influence Long-Term Care Nurse’s Communication with the End-of-Life Surrogate Decision Maker?</td>
<td>64</td>
</tr>
<tr>
<td>Research Sub Question 1d. What Situational Related Inputs are Instrumental in Communicating with the End-of-Life Surrogate Decision Maker?</td>
<td>66</td>
</tr>
<tr>
<td>Additional Analyses</td>
<td>67</td>
</tr>
<tr>
<td>Quantitative Content Analysis</td>
<td>68</td>
</tr>
<tr>
<td>Theme 1: Selected or Appointed as Surrogate Makes a Difference</td>
<td>68</td>
</tr>
<tr>
<td>Theme 2: Strong Trusting Bonds Between Nurse-Resident and Nurse-Family</td>
<td>69</td>
</tr>
<tr>
<td>Theme 3: Being Too Close to See Resident’s Wishes</td>
<td>70</td>
</tr>
<tr>
<td>Theme 4: Interdisciplinary Team Agreement</td>
<td>71</td>
</tr>
<tr>
<td>Theme 5: Living Will as a Communication Roadmap</td>
<td>71</td>
</tr>
<tr>
<td>Theme 6: Peaceful Environment</td>
<td>72</td>
</tr>
<tr>
<td>Theme 7: The Need to Create Emotional Distance</td>
<td>72</td>
</tr>
<tr>
<td>Research Question 2</td>
<td>73</td>
</tr>
<tr>
<td>Summary</td>
<td>74</td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS – Continued

**CHAPTER 5: DISCUSSION** ..................................................................................................................76

Nurses’ Experiences Communicating with End-of-Life Surrogate Decision Makers ..........76

Personal Factors of Nurse ....................................................................................................................77
  Spiritual and Religious Beliefs ........................................................................................................77
  Nurse Self-Confidence ......................................................................................................................78

Nurses’ Perceptions of Characteristics of Surrogate Decision Makers ..................................79

Contextual Factors ...............................................................................................................................81

Situational Related Inputs ..................................................................................................................82

Support Desired by Long-Term Care Nurses ..................................................................................85

Implications for the Conceptual Framework: Bringing Together Quantitative and Qualitative Results .................................................................86

Study Limitations and Strengths .......................................................................................................88

Implications for Practice and Education ..........................................................................................89

Implications for Future Research ......................................................................................................91

Conclusions ......................................................................................................................................92

APPENDIX A: IRB APPROVAL ..........................................................................................................93

APPENDIX B: DISCLOSURE STATEMENT FORM .........................................................................95

APPENDIX C: RECRUITMENT POSTING .......................................................................................98

APPENDIX D: QUALTRICS SURVEY .............................................................................................100

REFERENCES ......................................................................................................................................108
LIST OF FIGURES

FIGURE 1.  EOL Transactional Communication Model in LTC. .............................................22
FIGURE 2.  Mixed-Methods: Convergent Design.....................................................................45
FIGURE 3.  Conceptual Model of Factors that Promote End-of-Life (EOL) Discussion Between the Long-term Care (LTC) Nurse and EOL Surrogate Decision Maker.87
LIST OF TABLES

TABLE 1. Sample Demographic Data .................................................................59
TABLE 2. Importance Ratings of Personal Factors of Nurse ................................61
TABLE 3. Importance Ratings of Characteristics of Surrogate Decision Maker ..........63
TABLE 4. Importance Ratings of Contextual Factors ...........................................65
TABLE 5. Frequency of Situational Related Resident Characteristics Reported by the Long-Term Care Nurse as Instrumental in Communicating with the End-of-Life Surrogate Decision Maker .................................................................67
TABLE 6. Frequency of Types of Support Desired by Long-Term Care Nurses ............74
ABSTRACT

Background: Long-term care nurses are in a pivotal position to be augmenting the quality of life for residents and improving the death and dying experience for residents, their family members and surrogate decision makers. Currently there is a paucity of literature that acknowledges the experiences of long-term care nurses and their involvement with end-of-life decision making and care.

Purpose: To describe long-term care nurses’ perceptions of factors that influence their communication with end-of-life surrogate decision makers and the kind of support they need to support this discussion.

Method: A descriptive study using mixed-methods convergent design was used to obtain responses from a sample of 30 long-term care nurses. An online survey included questions to obtain quantitative data and open-ended questions for short responses. Results from both sets of data were brought together and compared during the analysis phase.

Results: The findings of this study highlight the personal factors of the nurse, the characteristics of the surrogate decision maker, contextual factors, situational related inputs, and the support desired by long-term care nurses. Participants rated factors according to importance in their experiences of communicating with surrogate decision makers. Seven themes were inductively derived from the analysis: 1) selected or appointed as surrogate makes a difference, 2) strong trusting bond between nurse-resident and nurse-family, 3) being too close to see resident’s wishes, 4) interdisciplinary team agreement, 5) living will as a communication roadmap, 6) peaceful environment, and 7) the need to create emotional distance. Long-term care nurses also identified the types of support they seek or need to be effective in communicating
with end-of-life care surrogate decision makers.

Conclusion: As the numbers of the older population continue to increase, the demand for nurses to develop expertise in caring for dying residents and communicating with them, their family members, and surrogate decision makers will increase. Understanding their experiences and providing support to long-term care nurses may strengthen their capacity to communicate about death and dying and their delivery of quality end-of-life care to residents.
CHAPTER 1: STATEMENT OF THE PROBLEM

One in five deaths in the United States occurs in long-term care facilities (including nursing homes), where the annual mortality rate for older adults is 25% (Teeri, Leino-Kilpi, and Valimaki, 2006; A. Torke, Alexander, & Lantos, 2008; A. Torke, Petronio, Purnell, Sachs, Helft, & Callahan, 2012). These numbers will increase since the proportion of persons 65 years of age and older is expected to double over the next few decades (Teeri et al., 2006). Importantly, behind these statistics are long-term care nurses as the primary professional involved in communicating with residents and their surrogate decision makers about end-of-life care options. Family members often are designated as surrogates to make end-of-life care decisions when a resident is deemed incompetent and/or incapacitated (Kelly, Rid, & Wendler, 2012; A. Torke et al., 2012). There is insufficient research-based understanding of the long-term care nurse communication with surrogate decision makers during the end-of-life process. Further, nurse-surrogate, nurse-patient/resident and physician-surrogate communication has been more commonly studied in acute care settings, with the majority of studies on end-of-life communication focus on the surrogate decision makers. Thus, the focus of this study is long-term care nurses facing difficult challenges in facilitating surrogate decision-making, particularly when they may find themselves “in the middle” of competing values of residents, their family members, surrogate decision makers, and other healthcare team members and the facility as they engage in end-of-life care decisions (Edwards, McClement, & Read, 2013).

Other elements associated with challenges for long-term care nurses discussing end-of-life care with surrogate decision makers include situational inputs (distracting stimuli, interpersonal space, timing) and the long-term culture such as regulatory and financial barriers.
that include the six-month prognostic criterion for hospice benefits, federal policies
“emphasizing rehabilitation care, and reimbursement incentives for procedural skills and
restorative care” (Reb, 2003, p. 36; Zerzan, Stearns, & Hanson, 2000). Discussions about end-of-
life care can elicit apprehension and produce strong emotions in healthcare providers as well as
residents and their family members (Baile, De Panfills, Tanzi, Moroni, Walters, & Biasco, 2012).

**Statement of the Research Purpose**

The purpose of this mixed-methods research study is to describe long-term nurses’
experiences in communicating with end-of-life surrogate decision makers. The study is designed
to reflect the voice of long-term care nurses regarding their experiences, feelings and beliefs
regarding end-of-life decision making. The results obtained from this study may inform nurses
about factors that facilitate or inhibit communication with end-of-life surrogate decision makers.
The long term goal is to contribute to knowledge that may be used to influence quality of
resident end-of-life care as well as nurses’ work satisfaction.

**Background and Significance**

This section provides background and significance of this area of study, including
descriptions of terms used in this study (i.e., long-term care settings, end-of-life care, and
surrogate decision makers).

**Death and Dying in Long-Term Care**

Today, long-term care facilities are termed skilled nursing facilities (SNFs), but were
historically referred to as nursing homes. These facilities have provided care to persons with
chronic diseases and co-morbidities. Advances in medical technology in the United States have
increased individuals’ life span, which has amplified the number of persons living with chronic
progressive diseases (NHPCO, 2012). The population of age 65 years and older numbered 44.7 million in 2013 and this has been mirrored by the increase in these individuals residing in long-term care facilities (DHHS, 2014; NHPCO, 2012). It is estimated that one in five deaths of those who are 65 years or over occurs in this setting every year and approximately 37,800 of these individuals, known as residents, die receiving palliative or hospice care (Munn, 2012; A. Torke et al., 2008; A. Torke et al., 2012; Van Soest-Poortvliet, van der Steen, Zimmerman, Cohen, Munn, Achterberg et al., 2011; Waldrop & Kusmaul, 2011). The proportion of deaths in the United States occurring in long-term care facilities has steadily increased over the past two decades and is expected that the proportion of deaths will continue to reach 40% by 2020 as the “baby boomers” continue to age (Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Temkin-Greener, Zheng, Xing, & Mukamel, 2013; Zimmerman, Cohen, van der Steen, Reed, van Soest-Poortvliet, Hanson et al., 2015).

Although numerous deaths occur in this setting, there is a growing concern about the inadequate use of palliative and hospice care along with the quality of end-of-life care being provided to residents. The actual patient experience of death and dying is not well documented in the literature, because Institutional Review Boards consider those who are in the death and dying process a vulnerable population. This lack of existing evidence has spurred researchers to focus on facilitators and inhibitors associated with end-of-life care in this setting and other healthcare settings.

In today’s health care system, nurses are being called upon to do more than just comfort a dying person; they are discussing end-of-life care options with patients or residents, their family members, surrogate decision makers, and other health care providers (Barnes, Gardiner, Gott,
Payne, Chady, Small et al., 2012). Long-term care nurses are in a position to have a pivotal role in augmenting the quality of life for residents and improving the death and dying experience for residents, their family members and surrogate decision makers using the End-of-Life Transactional Communication Model in Long-Term Care (Figure 1). This model’s foundation is based on passages of communication, feedback loops, personal factors, contextual factors, and situational related inputs.

**Long-Term Care Settings**

Long-term care settings have been labeled as nursing homes, long-term care facility, old-folks home, and skilled nursing facility. Often this serves to confuse persons as to what services are provided. The classification used for this study is found in the definition section of the State Operations Manual: Appendix PP-Guidance to Surveyors for Long Term Care Facilities by the Centers for Medicare and Medicaid:

“Skilled nursing facility” is defined as an institution (or a distinct part of an institution) which is primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons, and is not primarily for the care and treatment of mental diseases: has in effect a transfer agreement (meeting the requirements of § 1861 (1)) with one or more hospitals having agreements in effect under § 1861; and meets the requirements for a SNF [skilled nursing facility] described in subsections (b), (c), and (d) of this section. (CMS, 2015).

It is relevant to note that institutional policies are often reflective of state and federal mandates; this poses a problem for residents who would like to receive palliative care or hospice care in a long-term care facility. Currently the structure of the Center for Medicare and Medicaid Services (CMS) payment systems does not provide incentives for this type of care for residents; whereas, it does for rehabilitative care (Reb, 2003; Zerzan et al., 2000). Long-term care facilities are paid according to CMS’s Minimum Data Set (MDS) 3.0 quality measures user’s manual
based on the functionality of a resident (CMS, 2012). This is problematic because residents of long-term care facilities have chronic disorders and co-morbidities. Long-term care nurses are called upon to provide high quality of care with minimal financial support to cover the residents’ needs (Weissert & Frederick, 2013). Medicare offers higher reimbursement schedules for skilled nursing services versus supportive services for residents, which means that residents may not be receiving the best possible evidence-based end-of-life care and that long-term care nurses may be experiencing feelings of guilt for not being able to provide the level of care the residents deserve (Palmer, Quinn Griffin, Reed, & Fitzpatrick, 2010).

Another characteristic of the long-term care setting is that the nursing staff is comprised of registered nurses, licensed practical or licensed vocational nurses, and nursing assistants. It is customary that both registered nurses and licensed practical or licensed vocational nurses are classified as charge nurses and are actively engaged in coordination of care and educating residents and their family members about healthcare options; whereas, nursing assistants perform the tasks of assisting residents with their activities of daily living (Harrington, Carrillo, Dowdell, Tang, & Woleslagle Blank, 2011).

End-of-Life Care

End-of-life care is defined as providing care for persons who have an advanced, progressive, and incurable illness or disease. It is the period of time when the illness or disease will cause death (Wiener & Tilly, 2003). In general, there are two types of care that fall under the umbrella of end-of-life care.

1. Palliative Care: Is an approach that improves the quality of life of patients and their families facing the issues related to a life-threatening illness, by minimizing suffering
through early identification and impeccable assessment treatment of pain and symptoms that may be physical, psychosocial and spiritual (WHO, 2016).

2. Hospice Care: is a special type of care in which medical, psychological and spiritual support are provided to patients and their loved ones with a focus on controlling pain and other symptoms of illness so patients can remain as comfortable as possible near the end of life (NIH, 2012).

The type of end-of-life care people receive is influenced by whether the individual wants to continue to receive curative treatment or not. If someone is seeking curative treatment they will receive palliative care; whereas, hospice care is designed for someone who is no longer seeking curative treatment and a physician determines that the person has a life expectancy of six months or less if the illness follows its normal progression (NIH, 2012).

**Surrogate Decision Makers**

A surrogate is an individual who makes treatment decisions for the resident. This person may or may not be designated as a surrogate by a resident living in the long-term care facility. In the long-term care setting, residents’ family members tend to become designated surrogates to make end-of-life care decisions when a resident is deemed incompetent and/or becomes incapacitated (Kelly et al., 2012; A. Torke et al., 2008; A. Torke et al., 2012). Surrogate or proxy decision making has come to be the norm regarding termination of treatments and the initiation of end-of-life care for incompetent or incapacitated residents in this setting (A. Torke et al., 2008).

In an intensive care unit (ICU) study conducted by E. A. Boyd, Lo, Evans, Malvar, Apatira, Luce et al. (2010), family surrogate members report ambivalence regarding end-of-life care decisions. Surrogate decision makers reported that their knowledge of the patient’s
prognosis by what the physician states, the patient’s strength as an individual, their will to live, and the surrogate’s own observations of the patient’s physical appearance influence their end-of-life care decisions (p. 1270). Bearing witness to the changes the patient is experiencing and a lack of communication with healthcare providers have been reported to influence the surrogate decision makers’ end-of-life decision making as to what approach to take on behalf of the dying patient (Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009)

**Significance of Study to Nursing**

There is a paucity of research-based understanding of the long-term care nurse-surrogate decision maker’s communication during the end-of-life experience. Physician-surrogate, nurse-patient/resident and nurse-surrogate communication has been more commonly studied in acute care settings with the majority of these studies focusing on the surrogate decision makers’ perceptions and experiences. In 2014 there were 1.4 million older persons residing in long-term care settings in the United States and this population will continue to burgeon as the “baby boom” generation reaches the age of 65 (DHHS, 2014; Teeri et al., 2006; Towsley, Hirschman, & Madden, 2015).

Amongst long-term care professionals, nurses are often involved with end-of-life decision making discussions with residents and their family members or surrogates. The nature of the relationships between long-term care nurses, residents, and their family members or surrogates is crucial to residents’ quality of life including end-of-life care (McGilton & Boscart, 2007). End-of-life communication is one of the most difficult and stressful events for healthcare providers that has been identified to cause “death anxiety,” fear of caring for those who are dying and death-dying communication apprehension, which contribute to the reluctance of nurses to
engage in end-of-life discussions (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013; Pagano, 2016; Peters, Cant, Payne, O'Conner, McDermott, Hood et al., 2013). Delays in, poor, or avoidance of end-of-life communication with residents, their family members or surrogates leads to residents’ wishes for treatment, non-treatment, or withdrawal of treatment not being fulfilled or being initiated at the last minute (Lowery & Pear, 2012; Majerovitz, Mollott, & Rudder, 2009). This leads to poor quality of end-of-life care that may adversely affect all individuals involved in the death and dying experience.

With one in five deaths occurring in the long-term care setting in the United States and nurses frequently being the initial point of contact for end-of-life surrogate decision makers, it is warranted to support the voice of long-term care nurses regarding their experiences, feelings and beliefs regarding end-of-life decision making. Findings from this study may inform researchers about factors that facilitate or inhibit communication with end-of-life surrogate decision makers and contribute to the body of nursing knowledge influencing the quality of resident end-of-life care as well as nurses’ work satisfaction.

**Underlying Philosophy**

Epistemological beliefs of this study were grounded in constructionism, with interpretivism, its perspective for research and practice. This philosophic view emphasizes that meaning is constructed out of one’s life experiences through researcher-participant interaction and between person and the environment (Crotty, 1998; C. Wilson & Clissett, 2010). Constructionism portrays the world in terms of the interpretations a person makes of one’s environment (Crotty, 1998; Lincoln & Guba, 1985). Moreover, constructionism proposes that
reality is partly socially constructed through persons who are dynamic and active agents who give meaning to their environment.

My worldview, as a constructionist, has developed over time as the result of my personal and professional experiences. My professional experience has contributed to my worldview as I have spent over 25 years working in and educating others about long-term care and end-of-life care. It was during these experiences that I came to believe there is no one true or single reality for an individual, but that each individual creates a reality that is “true” for him/her.

Nursing and other human sciences strive to understand the world from the insider’s (participant’s) realm in order to gain an appreciation of how the insider interacts with his/her world. As a constructionist, I believe that the researcher is unable to be detached completely from the participants during a qualitative research study as there are constant subtle interactions taking place. The researcher’s perspectives may influence interpretation of the data, although steps are taken, as described in the methodology, to control for this influence.

**Conceptual Framework**

The End-of-Life Transactional Communication Model in Long-Term Care is the conceptual framework for this study.
Background of Model

Communication is “the act or process of using words, sounds, signs, or behaviors to express or exchange information or to express your ideas, thoughts, feelings, etc., to someone else” (Merriam-Webster, 2015). Communication in the above conceptual framework is primarily interpersonally (with others), but is influenced by intrapersonal (within one’s self) characteristics and can be considered as a transaction of information between a sender and a receiver (Arnold & Boggs, 2016; Kourkouta & Papathanasiou, 2014). Furthermore, communication may be in the form of a linear model or a transactional model. A linear model is the most basic of communication in which there is a sender, the message, a receiver, and environment (Carter, 2016). A transactional model theorizes that communication is an interpersonal communication that is shared between the sender and receiver and they influence each other during conversation.
This researcher drew upon the patterns of knowing to associate the concepts in the End-of-Life Transactional Communication Model in Long-Term Care. According to Carper (1978), there are four patterns of knowing rooted in nursing practice. Empirical ways of knowing is knowledge that can be observed, is objective and draws upon supportable data from science. Personal knowing is considered subjective, concrete, and existential. Often this pattern is considered relational as it is about the nurse knowing himself or herself and being able to connect with the human aspects of others. Aesthetic knowing is called the “art of nursing” because it is the nurse’s ability to blend scientific and personal knowledge to form a deeper appreciation of situations. Ethical ways of knowing refers to the moral aspects of nursing and knowing what is right and wrong according to nursing professional standards and codes. The emancipatory ways of knowing was introduced by Chinn and Kramer (2011) and includes a nurse’s mindfulness of social justice support issues as well as social problems that affect the delivery of healthcare to individuals, their family members, and communities as a whole.

Using the empirical way of knowing the long-term care nurse determines what healthcare options, based on scientific knowledge, to communicate to the end-of-life surrogate decision maker as applicable to the resident’s condition. Through personal ways of knowing the long-term care nurse has an understanding of diverse cultural backgrounds, values and beliefs that allows for connecting with surrogate decision makers on a humanistic level.

**Passages of communication.** Passages of communication are comprised of both verbal and non-verbal communication. Verbal communication involves the use of language (written or spoken), including sign language. Non-verbal communication includes facial expressions, body
language (crossing arms or looking away), gestures, and tone of voice (Carter, 2016). Aesthetic knowing is the blending of scientific and personal knowledge that may heighten a long-term care nurse’s ability to remain cognizant of both verbal and non-verbal communication that influences or inhibits the discussion of end-of-life care options with a surrogate decision maker.

**Feedback loops.** The feedback loops consist of how the sender interprets the receiver’s response to the message that was sent. Did the message have the desired effect on the receiver and vice versa? The “art of nursing” may also be used during the feedback loops to decide whether the long-term care nurse’s information was accurately interpreted by the surrogate decision maker.

**Influential Factors to be Studied**

Several factors may be identified as influencing the long-term care nurse’s experience in communicating with surrogate decision makers. These factors broadly are personal and contextual factors.

**Personal Factors of the Nurse**

Long-term care nurse’s professional and personal background factors in the End-of-Life Transactional Communication Model in Long-Term Care (e.g., age, gender, ethnicity, religious background, level of education, knowledge, professional experience) have been noted in studies to either facilitate or inhibit a nurse’s ability to communicate about end-of-life care. Studies have presented other factors such as encounters with death and dying, one’s own attitude towards death and dying, death anxiety, emotional labor secondary to job stress, ethnicity, spiritual beliefs, and ethics as being significant in a nurse’s ability to engage in end-of-life care discussions and caring for residents who are dying (Bottorff, Steele, Davies, Porterfield, Garossino, & Shaw, 2000; Gama, Barbosa, & Vieira, 2012; Henoch, Browall, Melin-Johansson,
Danielson, Udo, Johansson Sundler et al., 2014; Karimi, Leggat, Donohue, Farrell, & Couper, 2014; Mohamed Ali & Ayoub, 2010; Peters, Cant, Payne, O'Connor, McDermott, Hood et al., 2013; Roman, Sorribes, & Ezquerro, 2001; Weigel, Parker, Fanning, Reyna, & Brewer Gasbarra, 2007). It is important to note that researchers have not come to a consensus as to which factors are instrumental in influencing a nurse’s ability to engage in end-of-life care discussions with residents, their family members, surrogate decision makers and other interdisciplinary health care team members.

**Surrogate Decision Maker Characteristics**

Family members who acted as surrogates described three principle ways they became the end-of-life decision maker. Once it became apparent by family members that their loved one could no longer make decisions then a member of the family “simply assumed” the role of decision maker (Elliott, Gessert, & Peden-McAlpine, 2009). Elliott et al. (2009) describe the other two principle ways as “delegated role” where the long-term care resident appointed an individual to be the proxy or by “self-appointed” where a family member just took on the responsibility without being appointed. Family surrogates implied that their decisions for treatment or refusal of treatment were based on whether the treatment was short or long-term, what the resident had previously said while competent, the resident’s values and beliefs, and the reliance on the resident’s spirituality (Buckey & Molina, 2012; Elliott et al., 2009; Emanuel & Emanuel, 1992; Hayley, Cassel, Snyder, & Rudberg, 1996; Kelly et al., 2012; A. Torke et al., 2008; A. Torke et al., 2012). The way in which the individual came to be the surrogate decision maker can facilitate or inhibit communication in the end-of-life decision making process.
Contextual Factors

Factors that may influence the communication experience include the long-term care culture and Advance Care Planning (e.g., living will, advance directive).

Long-Term Care Culture

This researcher assumes the belief that long-term care nurses are members of a unique culture. There are specific institutional, state and federal rules, regulations, and policies associated with the long-term care culture. Institutional policies are often reflective of state and federal mandates, this may pose a problem for long-term care nurses who would like to encourage residents and their surrogate decision makers to use palliative and hospice care. Currently the structure of the Center for Medicare and Medicaid Services (CMS) payment systems does not provide incentives for this type of care for residents; whereas, it does for rehabilitative care (Reb, 2003; Zerzan et al., 2000). Long-term care facilities are paid according to CMS’s Minimum Data Set (MDS) 3.0 quality measures user’s manual based on the functionality of a resident (CMS, 2012). This may be problematic because residents of long-term care facilities have chronic disorders and co-morbidities.

Long-term care nurses are called upon to provide high quality of care with minimal financial support to cover residents’ needs (Weissert & Frederick, 2013). Medicare offers higher reimbursement schedules for skilled nursing services versus supportive services for residents, which means that residents may not be receiving the best possible evidence-based end-of-life care and that long-term care nurses may be experiencing feelings of guilt for not being able to provide the level of care the residents desire and/or deserve (Palmer, Quinn Griffin, Reed, & Fitzpatrick, 2010).
Additional factors that may influence the communication process include role relationships, level of understanding about resident’s healthcare status by the long-term care nurse and the surrogate decision maker, the healthcare team and family (surrogate) involvements, and surrogate decision maker characteristics. The words symmetric (equal) and asymmetric (nurse “superior” to surrogate) are germane in role relationships. The long-term care nurse assumes the complementary role of clinical expert and consultant to attain mutually determined end-of-life care goals.

In the symmetric role, the long-term care nurse works with the surrogate as a partner on developing mutually well-defined goals and the resources to achieve them (Arnold & Boggs, 2016). Levels of understanding by the sender and receiver are based on their individual perceptions of terminology or words used. Healthcare team and family involvements mean how engaged each party is in advocating for the resident’s needs to be met. Ethical ways of knowing are utilized as the long-term care nurse takes into consideration professional standards and codes when discussing end-of-life treatment goals with the surrogate decision maker. The long-term care nurse is able to use emancipatory ways of knowing through mindfulness of social and political topics that affect communication with the end-of-life decision maker and the delivery of care to resident.

**Advance Care Planning**

Advance care planning frequently influences both the long-term care nurse and surrogate decision makers concerning end-of-life care communication. The Patient Self-Determination Act (PSDA) of 1990 mandates healthcare providers that accept Medicare and Medicaid reimbursements to give residents upon admission information about advance directives (ADs)
including (a) the right to participate in and direct their own health care decisions; (b) the right to refuse or accept treatments; (c) the right to prepare an AD, and (d) information on the provider’s guidelines that govern the use of these rights (Resnick, Schuur, Heineman, Stone, & Weissman, 2009). Nurses in the long-term care setting play a significant role in meeting the mandates of PSDA in respect to advanced care planning since they have regular and substantive interactions with residents, their family members and surrogates (Gittler, 2011). Residents, their family members and/or surrogates generally regard long-term care nurses with trust and are more comfortable engaging in conversations about ADs, living wills (LWs), and end-of-life decision-making with them than other healthcare providers (Gittler, 2011; Mitty, 2012). These conversations often lead to the completion of an AD or LW by residents “to ease their family’s financial and emotional burden” (Mitty, 2012, loc. 18229). A resident’s AD or LW serve as a guide to long-term care nurses as they communicate the dying resident’s wishes for treatment or non-treatment with surrogate decision makers.

**Situational Related Inputs**

Situational related inputs include distracting stimuli that can be environmental, physical, and/or psychological (Arnold & Boggs, 2016). Environmental may include the environment and background noise such as the location the conversation is taking place in, televisions, others talking loudly, and radio. Physical includes not feeling well, tired, anxious, and being worried. Psychological includes preconceived bias about what the sender is about to say and/or the response the receiver will give. Interpersonal (physical) space is the distance between the sender and receiver. The timing may be related to the time of day or associated with the medical/nursing phase the resident is currently experiencing.
Research Questions

Several research questions were derived from the conceptual framework. Terms used in the questions were described in the framework.

1. What are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers?
   a. What personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker?
   b. What characteristics of the end-of-life surrogate decision maker influence the long-term care nurse’s ability to communicate with them?
   c. What contextual factors influence long-term care nurse’s communication with the end-of-life surrogate decision maker?
   d. What situational related inputs are instrumental in communicating with the end-of-life surrogate decision maker?

2. What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers?

Summary

This chapter describes the research study and provides the background, significance, underlying philosophy, and conceptual framework. There is a lack of research-based understanding of the long-term care nurse-surrogate decision maker’s communication during the end-of-life experience. Communicating about end-of-life care can be a time of vulnerability for long-term care nurses, residents, and surrogate decision makers. Findings from this study will begin to fill identified gaps in nursing knowledge. This study provides background information
about end-of-life care in the long-term care setting and lays the groundwork for future studies.
CHAPTER 2: REVIEW OF THE LITERATURE

Literature is available that describe nurse communication skills in palliative and end-of-life care, death and dying, and surrogate decision making. However, there is not literature specific to long-term care nurses communicating about end-of-life care issues with surrogate decision makers. It is important for long-term care nurses to be able to discuss death and dying with surrogate decision makers in order to provide quality end-of-life care to residents.

Nurses’ Personal Factors

Nurses who are 50 years of age or older and those who have more experience were more positive when caring for persons who were dying as compared to nurses who are between the ages of 20 to 29 (Henoch et al., 2014; Roman et al., 2001). According to Gama, Barbosa, & Vieira (2012) there is no statistical differences related to age and work experience. It is important to note that the majority of nurses in this study were on the medical and hematology units and not nurses who work in long-term care facilities, palliative and hospice care units where end-of-life care is generally seen and takes place.

With respect to gender and education level, researchers tend to be split as to the amount of influence these factors have a nurse’s ability to engage in end-of-life decision making discussions and caring for individuals who are dying. Female nurses have a tendency to be more positive about caring for persons who are dying as compared to their male colleagues who reportedly become apprehensive (Roman et al., 2001; Weigel et al., 2007). The higher the level of education has been found to influence nurses and their capabilities to participate in end-of-life care (Dunn, Otten, & Stephens, 2005; Gama et al., 2012; Henoch et al., 2014; Mohamed Ali & Ayoub, 2010). This researcher has worked with nurses of differing educational levels and agrees
with previous studies that nurses who have a higher education are more apt to engage with residents, their family members, surrogate decision makers and interdisciplinary health care team members about end-of-life care options.

Encounters with death and dying provide foundations for nurses to acquire skills and knowledge that are applicable in caring for residents and their family members (Adesina, DeBellis, & Zannettino, 2014). Factors related to knowledge are experiences with death and dying, education level, additional end-of-life care training, past and present contact with terminally ill individuals, death occurrences within one’s family and death occurrences within one’s work setting (Dunn et al., 2005; Peters, Cant, Payne, O’Connor, et al., 2013). Personal and professional experiences “enables connecting with, tuning in, and engaging” (Seno, 2010, p. 380) in end-of-life decision making discussions and care. Deaths are characteristically considered “good” or “bad” by the nurse and usually influence future contact the nurse has with dying residents (Adesina et al., 2014). A “good” death is normally when a resident’s pain and symptoms are controlled and a “bad” death is characteristically when a resident’s pain and symptoms are not managed well. Nurses incorporate death and dying experiences from their personal and professional lives and these experiences have been shown to have a positive or negative impact on nurses (Dunn et al., 2005; Sinclair, 2011).

A paucity of literature involving long-term care nurses and their involvement with end-of-life care decision making discussions addresses the concept of a nurse’s attitude towards death and dying. Researchers described attitude towards death and dying in terms of nurses being involved in medical end-of-life decision-making, death anxiety, and nurses’ attitudes in regards to caring for dying individual (Albers, Francke, de Veer, Bilsen, & Onwuteaka-Philippsen, 2014;
Dunn et al., 2005; Leclerc, Lessard, Bechennec, Le Gal, Benoit, & Bellerose, 2013; Nia, Lehto, Ebadi, & Peyrovi, 2016; Peters, Cant, Payne, O’Conner, et al., 2013; Peters, Cant, Payne, O’Connor, et al., 2013). Death anxiety may be denied or avoided by nurses since it is expected that nurses will be caring for persons throughout the life continuum from birth to death. It is notable that a nurse’s attitude towards death may affect their ability to be empathetic and the quality of care they give (Nia et al., 2016).

Nurses’ death and dying experiences as well as their involvement or lack of involvement in end-of-life discussions and decisions has been associated with nurses’ attitudes toward death and dying in several studies. Nurses’ work settings seem to play a role in their attitudes too (Albers et al., 2014). According to Peters et. al., (2013), “attitudes are formed as a result of a favorable or unfavorable evaluation of a person, object, or thing” (p. 14). Nurses’ attitudes have a tendency to change over time related to their death and dying experiences. If nurses have a negative encounter with death and dying, they may end up with a fear of death or experience death anxiety (Dunn et al., 2005). Positive death and dying encounters have a tendency to evoke an acceptance of the dying process in nurses along with an acceptance of death (Dunn et al., 2005).

The spiritual domain includes spirituality and religiosity. Spirituality can be broadly defined as one’s belief in or experience of self-transcendence; whereas, religiosity is typically represents organized practices and beliefs that facilitates a closeness to a higher being (Bjarnason, 2009; Decker & Reed, 2005; Haisfield-Wolfe, 1996; Hunnibell, Reed, Quinn-Griffin, & Fitzpatrick, 2008; Lacey, 2006; Nolan & Mock, 2004).

In a study by Cevik and Kav (2013), nurses who reported having a strong religious belief
or solid spiritual background were less likely to fear or avoid communicating with residents, their family members, surrogate decision makers and other interdisciplinary health care team members about death and dying. Conversely, nurses in this study who reported not having a belief in a higher being, God, or denied having a strong religious belief were more likely to fear death and avoid death and dying.

Ethical considerations related to end-of-life care include the following principles: (1) Autonomy emphasizes the right for residents to make decisions regarding their care without being pressured by others. In long-term care the challenges to autonomy may be a resident’s impaired mental capacity, surrogates making end-of-life care decisions, and subtle coercion by others who may feel the resident is a burden financially or emotionally, (2) Beneficence means to “do good” and what is in the best interest of the resident, (3) Non-maleficence means to “first, do no harm” such as not doing a treatment that will cause harm and not benefit the resident, and (4) Justice refers to the duty to treat residents fairly and equally without bias, but based on medical need (Ensign, unknown; Gibson & Ferrini, 2010; Mueller, Hook, & Fleming, 2004).

This researcher having worked in long-term care and hospice believes that these factors may influence a nurse’s capability of discussing end-of-life and providing care to those going through the death and dying process; nonetheless, not each nurse is influenced by the aforementioned factors. Like the residents, their family members, surrogate decision makers and interdisciplinary health care team members’ factors that may facilitate or inhibit long-term care nurses are different based on individuality.
End-of-Life Communication

There is a dearth of research about end-of-life care communication in the long-term care setting, but there is an abundant amount of literature about end-of-life communication in other settings. Furthermore, recurring themes prominent in the literature related to communication include that of effectiveness, communication as related to different dyads, interventions, and strategies to enhance communication, and end-of-life care communication. End-of-life communication takes place amongst a variety of dyads that include, but are not limited to: (1) nurse-resident, (2) nurse-surrogate decision-maker, (3) nurse-physician, (4) nurse-social worker and (5) social worker-resident. Each dyad has a different dynamic based on each provider’s role when discussing end-of-life care issues.

Communication about end-of-life care and death and dying often elicits apprehension in health care providers as well as residents, their family members and surrogate decision makers (Pagano, 2016). People’s cultures are prominent in shaping how one lives and dies, and there is great diversity amongst customs and rituals observed by people during the death and dying process (DeSpelder & Sachwartz, 2014). DeSpelder and Sachwartz (2014) posit, “death is a universal human experience, yet our response to it is shaped by our cultural environment (p. 85). Death is considered a taboo topic in the United States dominant Anglo culture (Pagano, 2016; Taylor, 2011); whereas, the Latino culture view death as a significant part their national identity and “embrace” death (Gutierrez, 2010). Two other aspects connected to communication in the long-term care setting are health care professionals’ uncertainty about prognosis and when to choose to initiate end-of-life care discussions and who should initiate these conversations. This has been an unending debate in the long-term care setting. Yet, interdisciplinary health care team
members associated with long-term care agree that end-of-life care discussions should be an ongoing process since residents’ medical and nursing needs change over time (Clayton, Butow, & Tattersall, 2005; Sleeman, 2013; Stone, Kinley, & Hockley, 2013). It is vital for health care providers in the long-term care setting to realize that we are all on the same side, meaning all stakeholders want the best quality of care for the resident and that communication is the cornerstone of meeting the needs of residents, their family members or surrogate decision makers (Fan, 2015; Majerovitz et al., 2009).

According to Galushko, Romotzky, and Voltz (2012) there are three key points linked to challenges in end-of-life care communication: (1) health care professionals should be aware of opposing views about end-of-life care and to initiate these discussions in an honest and sensitive manner; (2) awareness of one’s own values, beliefs, and emotions as they influence discussions with residents and families; (3) interdisciplinary team work requires being respectful of others’ approaches and ensure all members know their responsibilities. Seriously ill and terminally ill patients and their family members report that having honest and sensitive communication about end-of-life care options is important (D. Boyd, Merkh, Rutledge, & Randall, 2011; Galushko et al., 2012). Other noteworthy qualities researchers have reported include that of health care professionals being nonjudgmental, compassionate, flexible, respectful, have a sense of humor, showing tolerance, and active listening (Taylor, 2011).

The dyad of nurse-physician communication affects the quality of end-of-life care residents receive in the long-term care setting. In nursing and medical programs, alike, there is a small amount of time devoted to educating nurses and physicians about end-of-life care communication. One reason given for ineffective communication between nurses and physicians
is “the well-entrenched hierarchical authority structure and sexism” (Robinson, Gorman, Slimmer, & Yudkowsky, 2010, p. 206). Suggestions to improve the nurse-physician is for physicians to acknowledge the importance of the nursing profession and nurses’ roles in providing quality of care and end-of-life communication with residents, their family members, or surrogate decision makers and for nurses to provide straightforward and accurate information to physicians (Burke, Boal, & Mitchell, 2004; Robinson et al., 2010). In today’s technological advanced society, nurses and physicians may want to discuss what form of communication works best. Some prefer fax, text messaging, email, telephone (cell or landline), or via pager (Burke et al., 2004). Knowing this preference should enhance the quality of communication between the nurse and physician, which theoretically would enhance the quality of end-of-life care residents receive.

Long-term care social workers are often the first interdisciplinary team member to discuss advance directives with residents and their support persons. Social workers are challenged to provide expertise and guide residents, their family members or surrogate decision makers in end-of-life care options and communicate their wishes regarding end-of-life care are communicated to the various interdisciplinary team members (NASW, 2004; Reinhardt, Boerner, & Downes, 2015). Furthermore, social workers are often called upon to act as mediator between all interdisciplinary team members, the resident, family members or surrogate decision makers (Munn & Adorno, 2008). According to Munn and Adorno (2008) social workers in the long-term care setting describe becoming involved in the end-of-life care process “when their presence was requested (invited) typically by the nursing staff” (p. 347). This late “invitation” impedes effective and timely end-of-life communication, which affects the quality of care residents
receive during the dying process (Nedjat-Haiem, Carrion, Gonzalez, Ell, Thompson, & Mishra, 2016).

This researcher’s clinical experiences as a long-term care and hospice nurse aligns with studies that stress communication is essential to quality end-of-life care for residents in the long-term care setting and the best possible death and dying experience for all stakeholders.

**Factors Unique to the Long-Term Care Culture**

Factors unique to the long-term care culture include role relationships, level of understanding and health care team and family involvement. The relationship between long-term care nursing staff, residents and their family members or surrogate decision makers is unique as often times the nursing staff become extended family (McGilton & Boscart, 2007). Roles are reshaped in the long-term care setting and these roles are habitually influenced by family history, relationships between nursing staff and residents, and family members’ desire to participate in caregiving (Caron, Griffith, & Arcand, 2005). This may complicate nurses’ ability to discuss end-of-life care as they may experience reactions similar to that of the resident’s family member or surrogate decision maker (van Riesenbeck, Boerner, Barooah, & Burack, 2015).

Level of understanding encompasses that of the long-term care nurse, the resident, the resident’s family member or surrogate decision maker. Factors that contribute to level of understanding include each person’s knowledge about death and dying, responsibilities, and what the needs are during this timeframe (Austin, Goble, Strang, Mitchell, Thompson, Lantz et al., 2009). Other aspects of this for long-term care nurses include understanding of their facility’s policies, state and federal regulations, and hospice guidelines.

Over the years family involvement with residents in long-term care at the end-of-life has
become multidimensional and includes visiting, monitoring interactions between staff and resident, providing hands-on and emotional care, and advocacy (Williams, Zimmerman, & Williams, 2012). Similarly, long-term care nurses’ involvement in end-of-life care has become equally multidimensional by performing hands-on care, observing interactions between resident and others (i.e., resident family members and nursing assistants), being an advocate for residents and their family members, and serving as the primary health care team member involved in end-of-life care communication.

**Surrogate Decision Making**

Many long-term care residents in America require a surrogate decision maker to make end-of-life care decisions for them due to impaired cognition or incapacitation. According to Silveira, Kim, and Langa (2010) more than a quarter of elderly Americans may require surrogate decision making prior to death. A growing body of evidence has pointed to end-of-life surrogate decision making as a stressful event due to the advances in biomedical technology. The lines between life and death have become blurred since these technologies have allowed health care providers to prolong life (Buckey & Molina, 2012; D. Wilson, 2011).

Although residents in the long-term care setting may have an advance directive in place declaring their wishes for treatment or non-treatment, end-of-life surrogate decision makers struggle what is in the best interest of the resident (Wendler & Rid, 2011; D. Wilson, 2011). Surrogate decision makers may be greatly influenced by their moral, emotional, and interpersonal considerations (D. White, Martin Cua, Walk, Pollice, Weissfeld, Hong et al., 2012). Surrogate decision makers “face emotional, psychological, interpersonal, and moral barriers” when making end-of-life decisions for another individual (D. B. White, 2011, p. 252).
Factors instrumental in decision making reported by surrogates in studies include straightforward, honest, and frequent communication with health care providers, feeling emotionally supported by health care providers, the resident having a living will, spirituality, understanding of prognosis, and acceptance of futility (E. A. Boyd et al., 2010; Buckey & Molina, 2012; A. Torke et al., 2012; D. Wilson, 2011).

Family surrogates implied that their decisions for treatment or refusal of treatment was based on whether the treatment was short or long-term, what the resident had previously said while competent, the resident’s values and beliefs, and the reliance on the resident’s spirituality (Buckey & Molina, 2012; Elliott et al., 2009; Emanuel & Emanuel, 1992; Hayley et al., 1996; Kelly et al., 2012; A. Torke et al., 2008; A. Torke et al., 2012; A. M. Torke, Sachs, Helft, Montz, Hui, Slaven et al., 2014). According to the grounded theory analysis conducted by Buckey and Molina (2012), four themes emerged when surrogates or proxy decision makers discussed honoring patient care preferences. These include “(1) the emotional impact of the decision-making process on the surrogate; (2) the difficulty of watching a loved one’s health deteriorate; (3) the importance of having a Living Will (LW) or other written/verbal instructions; and (4) the reliance on spirituality as a means of coping with the surrogate experience” (p. 257). Persons who acted as a surrogate decision maker have described feelings of being emotionally distraught over the decision made as well as being sad and stressed over watching their loved one deteriorate. Although a living will or advance directive being in place helped to clarify the resident’s wishes, surrogates still experience guilt and other “negative” emotions associated with the decisions made. Spirituality served as a means of surrogates to cope with the experience of making end-of-life decisions (Buckey & Molina, 2012). Another source of comfort for proxy or
surrogate decision makers while making treatment decisions was knowing their loved one’s preferences secondary to their previous lifestyle (Elliott et al., 2009).

**Support for Long-Term Care Nurses**

A common misconception is that long-term care nurses are used to death and dying because “death is part of the job” (Marcella & Kelley, 2015, p. 1). This researcher has heard numerous times “you should be used to people dying; after all you work in a nursing home.” Although death may be viewed as part of the job for nurses in long-term care; nurses experience the burden of grief and the grief experience is individualistic (Marcella & Kelley, 2015). The repeated exposure to death and dying and possible unresolved grief make long-term care nurses vulnerable.

It is noteworthy that long-term care nurses are prone to self-neglect as they care for dying residents and their family members or surrogate decision makers. In the United States 75.5% of licensed nurses in long-term care facilities terminate employment due to compassion fatigue and burnout. This turnover rate strongly threatens quality of end-of-life care in long-term care facilities (Lombardo & Eyre, 2011; Portnoy, 2011). As a protective mechanism nurses may “switch off” their emotions in order to protect themselves; however, this may adversely affect the quality of end-of-life care residents receive (Heaslip & Board, 2012).

Information obtained from studies suggest that long-term care facilities look into creating health promotion programs, decreasing nurses’ workloads, education and training specific to end-of-life care, encourage support groups consisting of nursing staff, communication skills coaching, and end-of-life care simulation (Chu, Wodchis, & McGilton, 2014; Donoghue, 2010; Heineman, 2010; Zhang, Punnett, & Gore, 2014).
Summary

This chapter describes the extant literature significant to the End-of-Life Transactional Communication Model in Long-Term Care. While long-term care facilities have historically been noted for providing care of persons with chronic diseases and co-morbidities which resulted in death; there is a growing concern about the inadequate use of palliative and hospice care in this setting (NHPCO, 2012). Nurses’ personal factors that have been reported to influence a nurse’s ability to engage in end-of-life care discussions include age, gender, education level, years of experience, and one’s own attitude towards death and dying (Bottorff et al., 2000; Gama et al., 2012). Communication about death and dying often elicits apprehension in health care providers as well as residents, their family members and surrogate decision makers and occurs between and amongst different dyads (Pagano, 2016). It is essential to have effective communication in order to provide the best possible end-of-life care for residents.

Notable communication skills for nurses are active listening, awareness of non-verbal communication, being empathetic and showing supportiveness (Carter, 2016; Dahlin, 2010). As reported by McGilton and Boscart (2007) the relationship between residents and long-term care nurses is unique in nature as they become each other’s family. More than a quarter of elderly Americans may require surrogate decision making prior to death (Silveira et al., 2010). Surrogate decision makers suggest four themes that influence the decisions they make for the dying resident: “(1) the emotional impact of the decision-making process on the surrogate; (2) the difficulty of watching a loved one’s health deteriorate; (3) the importance of having a Living Will (LW) or other written/verbal instructions; and (4) the reliance on spirituality as a means of coping with the surrogate experience” (p. 257). Long-term care nurses are prone to self-neglect,
burnout, and vulnerability from a lack of support by the administration of the facility they work in. This review of literature supports a focus on personal and contextual factors that may influence the long-term care nurse’s experiences in order to gain a better understanding of long-term care nurses’ experiences in communicating with end-of-life surrogate decision-makers.
CHAPTER 3: METHODOLOGY

“It is the province of knowledge to speak, and it is the privilege of wisdom to listen.” ~ Oliver Wendell Holmes

This chapter introduces the research design and methods used for the study. Mixed methods research is a methodology for conducting research that comprises collecting, analyzing, and integrating both qualitative and quantitative research methods. The purpose of using this form of research is that the combination of the two allows for a better understanding of the research problem where either research approach alone cannot (Creswell, 2015; Curry & Nunez-Smith, 2015; Wolf, Delao, Perhats, Clark, Moon, Baker et al., 2015). Mixed methods research methodology is increasingly being used in nursing research to strengthen the depth and breadth of understanding the phenomenon of interest (Doorenbos, 2014). For this study a convergent design with merged integration was used to describe the experiences of long-term care nurses’ communicating with end-of-life surrogate decision makers (Figure 2). Convergence means that the qualitative and quantitative components of the study are conducted simultaneously to gather data and the integration of the two is by merging the sets of data during the analysis phase (Curry & Nunez-Smith, 2015, Loc. 886). Both qualitative data and quantitative data are obtained in mixed methods to assist in addressing the research questions in a more thorough manner and to facilitate gaining a fuller understanding of participants’ perspectives regarding their experiences.
For this study, quantitative and qualitative data were collected simultaneously using a survey with Likert-type questions and both closed-ended questions for quantitative data and open-ended questions for qualitative data. Descriptive and quantitative content analysis were used to analyze the data. Analysis was systematic and organized to ensure ease of locating and tracing results back to the context of the data. After both types of data were analyzed separately, the findings of each were merged with the qualitative results being used to inform the quantitative results. All themes were examined with the primary investigator’s dissertation chair to confirm validity and reliability of procedure, analysis, and findings.

**Qualitative Research**

Qualitative research is a form of social inquiry and is emancipatory in nature as it focuses on the beliefs, insights, and experiences of individuals, the way they make sense of their
experiences, and the world in which they live. Munhall (2012) describes qualitative research as “giving voice to people, to hearing people’s own personal narrative and using the language of our participants” (p. 4). Qualitative methods draw from principles of the naturalistic paradigm, inferring a commitment to studying something in its natural environment (Denzin & Lincoln, 2011). Naturalistic approaches are used when the researcher wants to obtain in-depth information about a phenomenon, when little is known about the phenomena of interest, or when a new perspective is needed (Tarzian & Cohen, 2012; Tripp-Reimer & Kelley, 2012). Furthermore, qualitative approaches have been viewed by some as being congruent with nursing as it relates to patient-centered, holistic and humanistic care (Parahoo, 2014). According to Denzin and Lincoln (2011), “qualitative methods are stressed within the naturalistic paradigm not because the paradigm is anti-quantitative but because qualitative methods come easily to the human-as-instrument” (p. 117). This methodology is appropriate for the purpose and design of this study because little is known about the antecedents of long-term care nurses and communication with end-of-life surrogate decision makers.

**Qualitative Descriptive Methodology**

Qualitative descriptive research was used to elicit participants’ experiences, feelings and beliefs regarding communication about end-of-life care with surrogate decision makers. This methodology is appropriate for the purpose and design of this study because little is known about the antecedents of long-term care nurses and communication with end-of-life surrogate decision makers (Sandelowski, 2000b, 2010).
Quantitative Research

Quantitative research methods give emphasis to objective measurements and the mathematical, statistical, or numerical analysis of data collected through questionnaires, polls, and surveys. Quantitative research focuses on collecting numerical data and generalizing it across groups (if appropriate) or to explain a particular phenomenon (Field, 2013; Levine, 2012; Muijs, 2011).

Human Subjects Protection

This research study meets the definition of clinical research. The Human Subjects framework and disclosure statement form follow the guidelines set forth by the University of Arizona. Institutional Review Board (IRB) approval was obtained prior to the recruitment of volunteer participants (Appendix A & B).

Participants were informed that there may be no direct or immediate benefits to them for participating in the study; however, they will be contributing to the understanding of long-term care nurses’ experiences about communicating with end-of-life surrogate decision makers. Equally, while the study posed no physical risks, participants were informed in the disclosure statement that questions on the survey may bring up memories of stressful or difficult interactions regarding end-of-life discussions. If this occurred, this investigator had a list of possible resources for participants to contact for emotional support.

The participants will not be personally identified in any reports or publications that may result from this study. This investigator and her dissertation committee members were the only individuals who had access to the information provided by the participants. Written narratives were identified by pseudonym initials and not participants’ initials and all data sources were kept
in an encrypted digital file, stored in a fireproof locked cabinet at the researcher’s home (Yuma, Arizona). All data will be kept for a period of 3 years and then be shredded.

Sample

Studies that combine both qualitative and quantitative approaches involve additional considerations (Creswell, 2015; Curry & Nunez-Smith, 2015; Sandelowski, 1995, 2000a). Either approach may prevail or have equal priority in study sampling as well as data collection and analysis (Sandelowski, 2000a, p. 248). Ideally quantitative research involves probability sampling to permit statistical inferences; whereas, qualitative involves purposeful sampling (Sandelowski, 2000a, p. 248). However, according to Neuendorf (2002) a researcher may use purposive or judgment sampling using content analysis by “making a decision as to what units he or she deems appropriate to include in the sample” (p. 88). In qualitative studies, the number of participants required to conduct the study ranges widely from as little as 10 to as many as 50 depending on the study type (Sandelowski, 1995). The conventional thinking is that data collection will cease upon theoretical saturation, meaning that no new themes are emerging from the data obtained (Corbin & Strauss, 2008; Sandelowski, 2000b, 2010).

Purposive or judgment sampling was used as it is a technique for the identification and selection of participants or informants who have knowledge of the phenomenon of interest and are willing to sharing their experiences with the researcher (Creswell, 2013; Holloway & Wheeler, 2010; Munhall, 2012). This type of sampling satisfied both the quantitative and qualitative dimensions of this study (Neuendorf, 2002). This researcher’s goal was to obtain a minimum of approximately 30 long-term care nurses with a maximum of 50 long-term care nurses to participate in this study to be able to provide thick descriptions where transferability of the
findings could be expected for a group similar to this study sample. Licensed practical or vocational nurses (LPN/LVN) and registered nurses (RN) with at least 1 year of long-term care experience who read/speak English and reside in the United States were invited to participate in the study. Inclusion in this study did not exclude specific ages, genders, ethnicities, races, or religions. Nurses who were without any long-term care experience were excluded from participating in this study.

In qualitative research, actual sample size is not contingent on the number of informants, but the number of incidents that informants can provide to generate enough data that will achieve a level of saturation (Corbin & Strauss, 2008; Creswell, 2013; Glaser & Strauss, 2012). Therefore, the sample was selected to understand the phenomenon.

**Procedure**

Three recruitment strategies were identified for this study with the primary strategy being online social media. Online recruiting was used to reach long-term care nurses throughout the United States. Rationale for using online social media is that numerous nurses and other healthcare professionals communicate through this method (Ressler & Glazer, 2010). The social media network of Facebook was used for recruitment. Permission was obtained from the American Association of Directors of Nursing Services (AADNS) to use their page (https://www.facebook.com/AADNS.LTC) to recruit volunteers. This researcher also placed the recruitment posting on her Facebook page (https://www.facebook.com/mmangel924) with a request for volunteers to contact the primary investigator directly. The second was through word of mouth, other volunteers may be recruited. The third was the primary investigator, as a former long-term care nurse, requesting her numerous acquaintances and colleagues to share the flyer
Volunteers for the study contacted the primary investigator either by phone or email expressing an interest.

**Survey Process**

The primary investigator sent an “invitation to participate” email with the link to the survey to study volunteers who expressed an interest in participating. The survey began with the inclusion criteria and if all criteria were met, the participant was able to continue the remainder of the survey that showed study details that focused on the participant’s experiences of communication about end-of-life care in the long-term care setting, and factors that may facilitate or inhibit end-of-life communication with surrogate decision makers.

By responding to the survey in the Qualtrics Survey Software online program (Qualtrics, Provo, Utah) (Appendix D), respondents indicated their willingness to participate and gave their informed consent.

**Data Collection**

Data collection in qualitative descriptive studies is characteristically focused on discovering the *who, what, and where* of happenings or experiences (Sandelowski, 2000b, 2010). Data were collected through the survey where participants answered closed-ended questions (quantitative data) and wrote short responses to the open-ended questions (qualitative data).

Open-ended questions were aimed at encouraging participants to engage in dialogue about their experiences of communicating with end-of-life surrogate decision makers. See Appendix D for study survey. The survey questions were based on this investigator’s inquiry to understand the phenomenon of the communication process between long-term care nurses and end-of-life
surrogate decision makers. The questions were designed to answer the study’s research questions:

1. What are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers?
   a. What personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker?
   b. What characteristics of the end-of-life surrogate decision maker influence the long-term care nurse’s ability to communicate with them?
   c. What contextual factors influence long-term care nurse’s communication with the end-of-life surrogate decision maker?
   d. What situational related inputs are instrumental in communicating with the end-of-life surrogate decision maker?

2. What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers?

   **Data Analysis**

   Quantitative content analysis was the approach used to analyze qualitative data, in particular a ‘directed’ approach to analysis, guided loosely by a conceptual framework (Hsieh & Shannon, 2005; Morgan, 1993). Analysis was descriptive rather than interpretive. Quantitative content analysis involves primarily deductive reasoning while qualitative analysis involves inductive reasoning (Neuendorf, 2002; Sandelowski, 2000a, 2010). Although the qualitative data obtained from the participants as guided in part by the conceptual framework, analysis allowed for unexpected ideas and themes to be found. Categories were formed first based upon the conceptual framework, consistent with the ‘directed’ approach to content analysis (Hsieh & Shannon, 2005;
Morgan, 1993). Codes were created within each category from analyzing words and phrases from the participants’ written narratives they provided in responses to each open-ended question. Analysis was ongoing, systematic, and organized to ensure ease of locating and tracing results back to the context of the data. For those qualitative data that do not readily fall under preconceived categories as guided by the conceptual framework, the following steps in analysis were followed: Phases of content analysis include the selection of a unit of analysis (words and phrases from the written narratives), data immersion, data organization, data abstraction, and evaluation of trustworthiness (Elo & Kyngas, 2008).

Memos were also used to describe how the codes fit the text and to increase the auditability of the analysis processes. Data were managed and organized using ATLAS.ti version 7.5.16. Each narrative was reviewed and compared to make sure all pertinent codes and code definitions were included. Narratives, codes, and categories were examined with this researcher’s dissertation chair and other committee members who have experience in qualitative methods to confirm data extraction.

This researcher collated and analyzed quantitative data using SPSS data analysis software version 24 and Qualtrics Survey Software. Descriptive statistics include: frequencies, distribution, measures of central tendency, mean, median, mode, and standard deviation. Descriptive statistics provided a meaningful summary about the characteristics of the participants in the study (Field, 2013; Triola & Triola, 2006; Trochim, Donnelly, & Arora, 2016).

In the mixed-methods research of convergent design, the merging of the qualitative and quantitative data were brought together and compared in the analysis phase (Creswell, 2015; Curry & Nunez-Smith, 2015).
Rigor and Trustworthiness

Quantitative Data

Rigor in quantitative studies is determined by examining the quality of the research through internal and external validity (Claydon, 2015; Creswell, 2015; Curry & Nunez-Smith, 2015).

Internal validity. The degree to which the findings of the study represent a “true” reflection of the population under study is internal validity (Claydon, 2015; Curry & Nunez-Smith, 2015; Field, 2013; Shadish, Cook, & Campbell, 2002; Trochim et al., 2016). Fowler (2014) ascertains there are four reasons for threats to validity when using a survey or questionnaire and each pertains to participants inaccurately completing the survey or questionnaire. First, participants may not understand a question. If a participant conjectures a different meaning from a question, then an error is likely to happen. Researchers should strive to write questions that are easily understood and provide definitions as needed to clarify. Second, participants may not have the required knowledge to answer a survey question accurately (Fowler, 2014). This may happen if a question requires the participant to provide a detailed response about a particular time frame. Third, participants may not remember enough about what is being asked or have difficulty recalling the communication event if it was a long time ago. Finally, participants may not want to answer a specific question on the survey because it is too sensitive or intrusive (Fowler, 2014). These areas of concern have been addressed by: 1) definitions of acronyms being provided to ensure meanings are the same for all participants; 2) the sample consists of long-term care nurses who have knowledge about the subject matter; 3) questions pertaining to the recall of events have been given a specific number for the time frame (e.g., 6
months, 12 months); and 4) using the online survey format minimizes the sense of judgment that may be felt by a participant and offer more confidentiality and anonymity.

Personal background data through the demographic questions was obtained from the participants to determine if something in their background influenced their responses in a way that was not relevant to the long-term care nurse role such as spiritual/religious beliefs.

**External validity.** The degree to which the findings of the study can be generalized to other persons in other places and at other times is external validity (Curry & Nunez-Smith, 2015; Field, 2013; Shadish et al., 2002; Trochim et al., 2016). To improve external validity, this researcher along with committee members evaluated the questions for clarity, absence of bias, and ease of reading. For this mix-methods study the focus was being able to provide thick descriptions where transferability of the findings can be expected for a group similar to this study sample versus generalizability.

**Qualitative Data**

Lincoln and Guba (1985) posit that trustworthiness of a research study is important to evaluating its worth. In qualitative studies, trustworthiness means the methodological soundness and adequacy of the data (Holloway & Wheeler, 2010, p. 300). Trustworthiness is achieved through credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

**Credibility.** In qualitative studies credibility corresponds with that of internal validity in quantitative studies. It means that participants and others can recognize the meaning; hence, the “truth” of the findings (Denzin & Lincoln, 2011; Holloway & Wheeler, 2010; Lincoln & Guba, 1985). This is done to determine if the findings represent a true representation of the data collected from the participants. For this study member checking was used to ensure that
participants felt that the analysis was a true and fair depiction of their perspective (Denzin & Lincoln, 2011; Holloway & Wheeler, 2010; Lincoln & Guba, 1985).

**Transferability.** Transferability is similar to the generalizability in quantitative designs. It means there is an ability to transfer the findings of the study to another group, a similar situation, and may have applicability in other contexts (Denzin & Lincoln, 2011; Holloway & Wheeler, 2010; Lincoln & Guba, 1985; Thomas & Magilvy, 2011). This was accomplished by maintaining thick descriptions of the research content, data, and assumptions through a clear audit trail.

**Dependability.** Dependability refers to the findings being consistent over time and that they may be replicated or repeated (Creswell, 2013; Denzin & Lincoln, 2011; Lincoln & Guba, 1985). This may be accomplished by conducting external audits, which is having a researcher not associated with the study examine the processes and the findings. The primary investigator’s advisor reviewed the process.

**Confirmability.** Confirmability demands intellectual honesty and openness, often called reflexivity, from the researcher and can be achieved through an audit trail (Creswell, 2013; Denzin & Lincoln, 2011; Lincoln & Guba, 1985; Thomas & Magilvy, 2011). An audit trail of “raw” data, memos, and notes was maintained so others could recognize how interpretations and study decisions were made (Lincoln & Guba, 1985; Sandelowski, 2000b, 2010; Weiler & Crist, 2009; Zhang & Wildemuth, 2009). The audit trail should be clear and allow for showing the steps taken throughout the entire research process. The investigator’s advisor reviewed a sample from the audit trail, including the process of interpreting data to form themes.
Summary

This chapter presented the method for this study. The study method was described and the procedures for human subject protection were listed. The sampling procedure, the process of data collection, data analysis, and methods to ensure trustworthiness were described.
CHAPTER 4: RESULTS

The purpose of this mixed-methods study was to describe long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers. This chapter presents the results of the study including participant demographic information and is organized to respond to the following research questions:

1. What are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers?
   a. What personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker?
   b. What characteristics of the end-of-life surrogate decision maker influence the long-term care nurse’s ability to communicate with them?
   c. What contextual factors influence long-term care nurse’s communication with the end-of-life surrogate decision maker?
   d. What situational related inputs are instrumental in communicating with the end-of-life surrogate decision maker?

2. What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers?

The results are organized by the two research questions. The quantitative findings are presented first followed by the qualitative findings. After reporting the quantitative and qualitative findings separately for each research question in this chapter, the merged findings are discussed for each research question overall in chapter five with the qualitative findings informing the quantitative findings.
Description of the Sample

The sample consists of 30 nurses who successfully completed the online Qualtrics platform survey for this mixed-methods study. Data from an additional three nurses who met inclusion criteria, were deleted using the listwise deletion method due to missing data in more than one question on the survey needed to answer the research questions. Listwise deletions is a default method for handling missing data with SPSS analysis software and it is commonly used by statisticians (El-Masri & Fox-Wasylyshyn, 2005; Schlomer, Bauman, & Card, 2010).

Table 1 details demographic characteristics and data of the sample. Participants ranged in age from 30 to 65 years with a mean age of 45.6 years (SD = 11.2). Participant gender recognition breakdown was 26 females, 3 males, and 1 other. The ethnic background of the sample was Caucasian (28) and Hispanic (2). Most participants reported identifying with a religion. One-third of the participants reported having attained a Bachelor’s degree as their highest degree obtained. Many participants listed their employment status as full-time. Years of working in the long-term care setting ranged from 1 to 44 years with a mean of 16.6 years (SD = 10.6). In the twelve months prior to taking the survey, long-term care nurses had a mean score of 23.38 times (SD = 9.27) related to engaging in end-of-life discussions with surrogate decision makers.
TABLE 1. Sample Demographic Data (N = 30)

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (mean ± SD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39 years old</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>40-49 years old</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>50-59 years old</td>
<td>8</td>
<td>26.6</td>
</tr>
<tr>
<td>60-69 years old</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
<td>86.7</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>28</td>
<td>93.3</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Identify with Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24</td>
<td>80</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td><strong>Highest Degree</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational/Technical Training (LPN/LVN)</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Associate’s</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>Master’s</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>28</td>
<td>93.3</td>
</tr>
<tr>
<td>Part-time</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>PRN (as needed)</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Years of Experience in Long-Term Care (mean ± SD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10 years</td>
<td>10</td>
<td>33.2</td>
</tr>
<tr>
<td>11-20 years</td>
<td>12</td>
<td>39.9</td>
</tr>
<tr>
<td>21-30 years</td>
<td>4</td>
<td>13.2</td>
</tr>
<tr>
<td>31-40 years</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>41-50 years</td>
<td>1</td>
<td>3.3</td>
</tr>
</tbody>
</table>

Research Question 1

The first overall research question focused on what are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers. Analysis of three sub-questions (1a to 1c) was done to answer this question.
Research Sub Question 1a. What Personal Factors of the Long-Term Care Nurse Influence Their Communication with the End-of-Life Surrogate Decision Maker?

A frequency analysis was completed to determine the respondents’ ratings of importance on each of five personal factors: (1) self-confidence in role as long-term care nurse, (2) knowledge about end-of-life, (3) educational level, (4) previous experience with death and dying, and (5) spiritual/religious beliefs about death and dying. The predominant personal factor ratings among the sample (N = 30) were 73.3% (very important) for a nurse’s knowledge about the end-of-life and 66.7% (very important) for self-confidence in role as long-term care nurse. Other factors, in order of importance, include previous experiences with death and dying, spiritual/religious beliefs about death and dying, and the nurse’s education level. See Table 2 for other importance ratings of long-term care nurses’ personal factors that influence their communication with end-of-life surrogate decision makers.
TABLE 2. Importance Ratings of Personal Factors of Nurse

<table>
<thead>
<tr>
<th>Personal Factors</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-confidence in role as long-term care nurse</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Quite Important</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>Very Important</td>
<td>20</td>
<td>66.7</td>
</tr>
<tr>
<td>No Response</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Knowledge about end-of-life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Quite Important</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>Very Important</td>
<td>22</td>
<td>73.3</td>
</tr>
<tr>
<td>No Response</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>Quite Important</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td>Very Important</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No Response</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Previous experience with death and dying</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td>Quite Important</td>
<td>14</td>
<td>46.7</td>
</tr>
<tr>
<td>Very Important</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>No Response</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Spiritual/Religious beliefs about death and dying</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Quite Important</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td>Very Important</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>No Response</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

In addition, two participants offered other responses to the question about personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker. These were categorized as follows, using the actual phrases from each respondent:

CX: “Life experiences, Reiki.”

DT1: “Philosophy re: end-of-life.”
Research Sub Question 1b. What Characteristics of the End-of-Life Surrogate Decision Maker Influence the Long-Term Care Nurse’s Ability to Communicate with Them?

A frequency analysis was completed to evaluate the importance of six surrogate decision maker characteristics. Participants rated the importance of the following characteristics: (1) confidence in the long-term care nurse, (2) knowledge about end-of-life, (3) education level, (4) previous experience with death and dying, (5) spiritual/religious beliefs about death and dying, and (6) level of understanding. The predominant surrogate characteristics ratings among the sample (N = 30) were 50% (very important) for level of understanding, 43.3% (very important) for confidence in the long-term care nurse and 40% (very important) for spiritual/religious beliefs about death and dying. The end-of-life surrogate decision maker’s education level was 46.7% (not important). Table 3 displays the remaining rated surrogate decision maker characteristics as the participants perceived their importance.
In addition, three participants offered other responses to the question about the characteristics of the end-of-life surrogate decision maker that influence the long-term care nurse’s ability to communicate with them as follows, using the actual phrases from each respondent:

NA: “Family involvement/dynamics.”

DT1: “Philosophy re: end-of-life.”
JF: “Stress is a huge factor.”

**Research Sub Question 1c. What Contextual Factors Influence Long-Term Care Nurse’s Communication with the End-of-Life Surrogate Decision Maker?**

A frequency analysis was completed to evaluate the importance of six contextual factors specific to long-term care. Participants rated the importance of the subsequent factors: (1) Current structure of Center for Medicare/Medicaid Services (CMS) payment system, (2) the Medicare Hospice Benefit (MHB), (3) hospice services/providers contracted by facility, (4) no contracted hospice services/providers, (5) the Omnibus Reconciliation Act (OBRA) focus on rehabilitation (rehab) versus custodial care, and (6) staff views on hospice being in facility. The predominant contextual factors ratings among the sample (N = 27) were 60% (very important) for staff views on hospice being in facility and 36.7% (very important) for hospice services/providers contracted by facility. OBRA focus on rehabilitation versus custodial care and the current CMS payment system were both 43.3% (not important). Table 4 details all contextual factors rated by study participants.
In addition, the participants offered other responses to the research sub question 1c: *What contextual factors influence long-term care nurse's communication with the end-of-life surrogate decision maker?*

NA: “Their [institutional staff] previous experiences and knowledge base.”

CX: “Referrals to all local hospice for the family to decide upon.”

WQ: “Staff afraid to give medications as ordered or as needed by the dying patient-afraid

<table>
<thead>
<tr>
<th>Contextual Factors</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current CMS payment system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>13</td>
<td>43.3</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>8</td>
<td>26.7</td>
</tr>
<tr>
<td>Quite Important</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Very Important</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>The MHB</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Quite Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Very Important</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td><strong>Hospice services/providers contracted by facility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Quite Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Very Important</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td><strong>No contracted hospice services/providers contracted</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Quite Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Very Important</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>OBRA focus on rehab vs. custodial care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>13</td>
<td>43.3</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Quite Important</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Very Important</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Staff views on hospice being in facility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Important</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Quite Important</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Very Important</td>
<td>18</td>
<td>60</td>
</tr>
</tbody>
</table>
they will ‘kill’ the patient prematurely.”

Research Sub Question 1d. What Situational Related Inputs are Instrumental in Communicating with the End-of-Life Surrogate Decision Maker?

The study participants’ responses to this question were analyzed using descriptive statistics and content analysis of an open-ended question. The situational related input of resident characteristics that were cited the most frequently were stage of illness, cognition, pain, and anxiety. See Table 5 for complete list of characteristics cited by participants.
Additional analyses were done to examine the relationships among the importance ratings of the factors (personal, surrogate characteristics, and contextual) perceived by LTC nurses as influential in their communication with end of life surrogate decision-makers. Because the data were considered ordinal level, Spearman rho correlations ($r_s$) were calculated to explore the relationships among all factors that addressed the first research question of what are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers (Coolidge, 2013; Lane & Brown, 2015).

### TABLE 5. Frequency of Situational Related Resident Characteristics Reported by the Long-Term Care Nurse as Instrumental in Communicating with the End-of-Life Surrogate Decision Maker.

<table>
<thead>
<tr>
<th>Resident Characteristics</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage of Illness</td>
<td>13</td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>1</td>
</tr>
<tr>
<td>Pain</td>
<td>3</td>
</tr>
<tr>
<td>Cognition</td>
<td>6</td>
</tr>
<tr>
<td>Anxiety</td>
<td>3</td>
</tr>
<tr>
<td>Multiple Hospital Visits</td>
<td>1</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>1</td>
</tr>
<tr>
<td>Goals of Care</td>
<td>1</td>
</tr>
<tr>
<td>Philosophy of Life</td>
<td>1</td>
</tr>
<tr>
<td>Unexpected Events</td>
<td>1</td>
</tr>
<tr>
<td>Unfinished Business</td>
<td>1</td>
</tr>
<tr>
<td>Guilt</td>
<td>1</td>
</tr>
</tbody>
</table>
Regarding sub question 1a. *What personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker*, there was a positive correlation between two personal factors, the nurse’s *self-confidence in role* as a long-term care nurse and the nurse’s *knowledge about end-of-life*, \( r_s = .487, n = 30, p = .006 \). Also, with sub questions 1a. *What personal factors of the long-term care nurse influence their communication with the end-of-life surrogate decision maker* and 1b. *What characteristics of the end-of-life surrogate decision maker influence the long-term care nurse’s ability to communicate with them*, there was a positive correlation between the variables of the nurse’s self-confidence in their role as a long-term care nurse and the surrogate decision maker’s confidence in the long-term care nurse, \( r_s = .532, n = 28, p = .004 \).

**Quantitative Content Analysis**

Seven themes were derived from the analysis of data from the participants’ responses to survey questions. Inferences drawn from the data were both *deductively*, from the responses to questions that came directly from the conceptual framework, and *inductively* in the identification of additional themes within the findings from responses to the questions.

**Theme 1: Selected or Appointed as Surrogate Makes a Difference**

One theme was generated from data obtained for sub question 1b. In response to “please explain why you agree or disagree that the way or reason by which someone became a resident’s end-of-life surrogate decision maker influences the surrogate decision maker’s ability to discuss end-of-life option.” Participants had similar ideas regarding how an individual became the resident’s end-of-life surrogate decision maker influenced discussions about end-of-life care options. Participants shared that how an individual became the resident’s surrogate decision
maker may influence the end-of-life discussions in either a positive or negative way. A surrogate who is appointed by the court system and does not know the resident may have additional educational needs that the long-term care nurse must address such as the resident’s history versus a surrogate decision maker who is a loved one and knows this history.

HP: “The way someone became the surrogate is important cause it can sometimes affect the motives of the surrogate.”

PL: “If the surrogate is a loved one chances are they have discussed end of life options.”

WQ: “If the surrogate is appointed by a court or legal firm, the person may be much more hesitant to allow the resident to die naturally at the end of their life.”

HJ: “I agree there is truth to this statement. If there were conversations by the resident and the surrogate prior to the end of life stage, the surrogate may be more comfortable with feeling confident with the decision made.”

Four themes were generated from data obtained related to research sub question 1c. The four themes are – strong trusting bonds between nurse-resident and nurse-family, being too close to see resident’s wishes, interdisciplinary team agreement and living will as a communication roadmap:

**Theme 2: Strong Trusting Bonds Between Nurse-Resident and Nurse-Family**

Long-term care nurses voiced that relationships are instrumental and positively influence communication about end-of-life care options with surrogates. Establishing strong trusting relationships is important, they are created through encounters with residents’ family members and through the day to day care of the resident.

MY: “Strong bonds are developed between a nurse and the residents and sometimes they
open up about what they want when the time comes near to end of life.”

ZA: “If a nurse has a good trusting relationship, the resident will value the opinion of the
nurse on the topic of end of life.” “If a nurse has a good trusting relationship with the
resident’s family, the resident’s family will value the opinion of the nurse on the topic of
end of life.”

PL: “There is a trust that is forged with day to day care.”

DT1: “The family needs to trust the care and opinion of the health care provider.”

BV: “If the family member has trust in the staff member it is much easier to explain how
things are going and options that are available.”

**Theme 3: Being Too Close to See Resident’s Wishes**

Participants described that a family member who is serving as the end-of-life surrogate
decision maker who is too close to the resident often negatively impacts the communication about
end-of-life care.

WQ: “Sometimes the decision maker who is ‘too close’ to the resident may make
decisions based on how THEY feel, not truly what the resident’s wishes are.”

HJ: “…if the family member has had conversations where the resident has expressed or
commented on what their end of life decisions are this can lessen the burden of the family
member when making the decisions.”

KO: “ Depends on how close that person is to the resident.”

ZA: “If a family does not have a good relationship with a resident it can make it difficult if
not impossible to talk about end-of-life options.”

PL: “A child will often times be unable to picture life without mom or dad therefore
wanting things done that the resident may not want.”

**Theme 4: Interdisciplinary Team Agreement**

Nurses articulated that the interdisciplinary team should have a unified position. The interdisciplinary team members should be on the same page when presenting end-of-life care options to the surrogate decision maker. If the interdisciplinary team is in agreement it is viewed as having a positive influence in the end-of-life discussions; whereas, if the team is not in agreement it has a negative effect on the discussion.

CR: “Religious beliefs of the IDT may interfere with the resident/surrogate’s wishes.”

HJ: “Physicians especially have the greatest influence as elders take the physician word/recommendations as ‘gospel’.”

CX: “…these folks inhibit my ability. We are not always on the same page.”

GF: “Important that the IDT has a fundamental agreement on facility approach to end of life.”

JA: “Interdisciplinary team members can inhibit communication if they are not on the same page with the same ideas.”

**Theme 5: Living Will as a Communication Roadmap**

Participants expressed that an advance directive or living will has a positive impact as it is used as a communication roadmap for the long-term care nurses when discussing end-of-life care options with surrogate decision makers at it has the resident’s wishes for treatment or non-treatment.

HJ: “Residents with an advanced directive or living will provides a start to the conversation with the surrogate as the resident has already provided a framework of end-
of-life wishes.”

UZ: “If no living will has been made or advanced directives discussed, it is more difficult to determine what should or should not be done.”

XI: “No advanced directives make communication more urgent.”

GF: “Very important due to you having a clear answer for what the resident’s wishes are.”

Two themes were generated from data obtained regarding research sub question 1d. The first category is peaceful environment, the second is the need to create emotional distance:

**Theme 6: Peaceful Environment**

An environment without distractions augments the end-of-life discussions between the long-term care nurse and surrogate decision maker according to study participants.

UZ: “Environment plays a key role in facilitating good communication.”

JA: “The room should be in a quiet part of the facility.”

HJ: “Facilitation of discussion is definitely in a private area where there is a comfortable home-like setting (i.e. quiet area) that is relaxed where there can be a 1:1 conversation without interruptions.”

CR: “Distractions are detrimental to communication.”

MY: “The fewer distractions the better.”

**Theme 7: The Need to Create Emotional Distance**

Participants voiced that end-of-life communication with surrogate decision makers can be challenging the closer the long-term care nurse is to the resident and their family members.

KO: “I shut down more with closer residents’ families since I am selfish with my relationship. It’s hard to give no biased statements to surrogates.”
As care givers we also become attached to residents, especially in LTC where some residents may consider the staff family. Remaining neutral and objective can be difficult.”

PL: “Sometimes we as nurses spend more time with a resident than their family. Having a professional relationship makes communicating a little easier.”

UZ: “As a professional, my relationship must be non-biased…do no harm.”

Although having strong trusting bonds was noted to positively influence end-of-life discussions, the long-term care nurse participants in this study voiced that they may get too close to the resident and this leads them to needing to create this emotional distance in order to objectively discuss end-of-life care options with the surrogate decision maker.

**Research Question 2**

The second research question to be addressed was what types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers.

Participants identified *written information* and *more education* as the top two types of support they seek or need to facilitate end-of-life discussions. See table 6 for complete list of the types of support desired by long-term care nurses.
TABLE 6. Frequency of Types of Support Desired by Long-Term Care Nurses

<table>
<thead>
<tr>
<th>Kinds of Support</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written Information</td>
<td>6</td>
</tr>
<tr>
<td>More Education</td>
<td>5</td>
</tr>
<tr>
<td>Other Options/Alternatives</td>
<td>3</td>
</tr>
<tr>
<td>Chaplains/Clergy</td>
<td>3</td>
</tr>
<tr>
<td>Physician Support/Open Mindedness</td>
<td>2</td>
</tr>
<tr>
<td>Colleague Support</td>
<td>2</td>
</tr>
<tr>
<td>Local In-Services</td>
<td>2</td>
</tr>
<tr>
<td>Resident Support System</td>
<td>2</td>
</tr>
<tr>
<td>Workshops</td>
<td>1</td>
</tr>
<tr>
<td>Social Workers</td>
<td>1</td>
</tr>
<tr>
<td>End-of-Life Specialist</td>
<td>1</td>
</tr>
</tbody>
</table>

Summary

This chapter provided both quantitative and qualitative analysis to answer the research questions of (1) What are long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers and (2) What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers.

Quantitative analysis included demographic characteristics data on study participants, ratings of nurses’ personal factors, characteristics of the end-of-life surrogate decision maker, contextual factors, and for the situational input of resident characteristics using the quantitative software program SPSS 24. In addition, the qualitative data was analyzed using the software program ATLAS.ti version 7.5.16 to guide the descriptions of the identified seven themes that
contribute to long-term care nurses’ experience of communicating with end-of-life surrogate decision makers.
CHAPTER 5: DISCUSSION

“I hear and I forget. I see and I remember. I do and I understand.” ~ Confucius

The overarching goal of this research study was to describe long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers, through the examination of the attributes of personal and contextual factors, surrogate decision maker characteristics and situational related inputs that influence or inhibit the communication process. Other goals were to contribute knowledge that may be used to influence quality of resident end-of-life care as well as nurses’ work satisfaction. The conceptual framework of the End-of-Life Transactional Communication Model in Long-Term Care was used to guide this study, but was revised given the results. The mixed methods convergent design methodology was used for collecting both quantitative and qualitative data simultaneously with the data being merged to answer the research questions. By using this design, the two main research questions and the sub questions were answered to achieve a fuller understanding of the long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers. The framework was modified based upon the convergence of quantitative and qualitative results.

Nurses’ Experiences Communicating with End-of-Life Surrogate Decision Makers

There has been limited research specific to long-term care nurses communicating with end-of-life surrogate decision makers. Long-term care nurses are in a pivotal position in augmenting the quality of life for residents and improving the death and dying experience for residents, their family members, and surrogate decision makers through communication about end-of-life care options.
Personal Factors of the Nurse

Findings from this research study elucidated that certain personal factors of a long-term care nurse are instrumental in their experiences discussing end-of-life care options with surrogate decision makers.

In previous studies, researchers have been split as to the amount of influence level of education and knowledge about end-of-life has in a nurse’s ability to engage in end-of-life care discussions. Mutto, Errazquin, Rabhansl, and Villar (2010) conducted a study that showed basic nursing education is inadequate in relation to end-of-life care. Results from this study showed that knowledge about end-of-life is very important and level of education is quite important to the majority of long-term care nurse respondents, and influences their ability to discuss end-of-life care options. These results support the findings from the study conducted by Dunn et al. (2005) that nurses with higher levels of education is positively associated with more death education training. Furthermore, in support of these results is a study about nurses’ experiences in caring for dying patients by Nguyen, Yates, and Osborne (2014) that showed there was a positive correlation for death education training and level of education.

Spiritual and Religious Beliefs

Spiritual and religious beliefs were rated as quite important to the majority of long-term care nurses in the current study. These results are parallel to the study on nurses’ attitudes and experiences with dying patients conducted by Cevik and Kav (2013) where 52.3% of the nurses stated they have strong religious beliefs and 45% stated that their religious belief influenced their attitudes toward caring for those who are dying; whereas, in a study involving nephrology nurses, Ho, Barbero, Hidalgo, and Camps (2010) reported that there was no statistical
significance in relation to religious influence.

Mohamed Ali and Ayoub (2010) reported that “greater experience in working with dying patients were associated with more positive attitudes toward death and caring for dying patients” (p. 19). Nurses in the current study rated previous experiences with death as quite important in their ability to communicate with residents, their family members, or surrogate decision makers, which supports the findings from other studies related to exposure to death and dying (Dunn et al., 2005; Mohamed Ali & Ayoub, 2010). This researcher has considerable personal and professional experience with death and dying and agree with other nurses who have stated that frequent exposure to death and dying enables better communication and the ability to connect with residents, their family members, or surrogate decision makers (Dunn et al., 2005; Seno, 2010; Sinclair, 2011). Participant (TT) cautioned nurses to “Be open minded to everyone’s decision, not just what you think is best” based on previous experiences and their “belief system.”

**Nurse Self-Confidence**

Nurse self-confidence is vital in providing quality care for dying residents and engaging in end-of-life discussions with surrogate decision makers as noted by the participants in this study who rated this factor as very important. Fry, MacGregor, Hyland, Payne, and Chenoweth (2015) showed that confidence in one’s abilities empowers nurses in caring for the elderly. Also, studies have shown that self-confidence directly reinforces “a nurse’s level of competency to carry out care efficiently…leads to better patient outcomes” (Chessner-Smyth & Long, 2012, p. 154). A literature review by Perry (2011), supports this current study’s findings that self-confidence is a crucial or a very important personal factor of the nurse in their practice setting. According to Coffey, McCarthy, Weathers, Friedman, Gallo, Ehrenfeld et al. (2016), nurses in
the United States felt confident and comfortable in caring for end-of-life patients and their family members.

**Nurses’ Perceptions of Characteristics of Surrogate Decision Makers**

According to the participants in this study, level of education was not an influential factor for surrogate decision makers; however, the nurse participants rated the surrogates’ **level of understanding** as very important in communicating about end-of-life care options for residents.

When engaging in conversations about palliative and end-of-life care, family members or surrogate decision makers expressed their desire for healthcare professionals to **speak in layman’s terms** to facilitate a clear understanding (Buckey & Molina, 2012; Iverson, Celious, Kennedy, Shehane, Eastman, Warren et al., 2014; Nelson, Puntillo, Pronovost, Walker, McAdam, Iiaoa et al., 2010). Medical jargon tends to inhibit the surrogate decision makers’ ability to understand end-of-life care options (Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010; Wood, Chaitin, & Arnold, 2016). Many participants mentioned how the level of understanding influenced communication about end-of-life care options. CX advised nurses to “Communicate with the surrogate…on their level of understanding.” Additionally, some researchers have pointed out that surrogate decision makers having a higher level of understanding about the resident’s wishes and frequent contact with nurses helps when communicating about the available end-of-life care options (Buckey & Molina, 2012; Majesko, Hong, Weissfeld, & White, 2012; Rodriguez, Navarrete, Schwaber, McKleroy, Clouse, Kerrigan et al., 2008; A. Torke et al., 2012; D. Wilson, 2011).

A surrogate decision maker’s **spiritual/religious beliefs** were rated as very important by the long-term care nurses who participated in this study. This finding supports previous research
that showed surrogate decision makers often turned to their faith, prayer, and belief in an afterlife to make end-of-life care options on behalf of the resident (Buckey & Molina, 2012; Steinberg, 2011; D. Wilson, 2011). Moreover, surrogates take into consideration the resident’s spiritual/religious beliefs when communicating with healthcare providers about end-of-life care options (E. A. Boyd et al., 2010).

Participants in this study rated a surrogate **decision maker’s confidence in the long-term care nurse** as very important just like they rated confidence in themselves as very important. Researchers have associated confidence with trust and trustworthiness in interactions between nurse-resident and nurse-surrogate decision makers (Adams, Anderson, Docherty, Tulsky, Steinhauer, & Bailey, 2014; Dine & Gastmans, 2012; Epstein & Wolfe, 2016; Sellman, 2007). Arnold and Boggs (2016) classified the following as critical elements of trust: (1) good communication, (2) respect, (3) honesty, (4) commitment, and (5) knowledge. A surrogate decision maker’s trust or confidence in the long-term care nurse is necessary in communicating about end-of-life care options for a resident and creates the perception of shared decision making (Belcher, 2009; Epstein & Wolfe, 2016). Sister Simone Roach’s 5 C’s of caring are highly applicable for long-term care nurses in communicating with surrogate decision makers about end-of-life care options for residents who are dying.

The 5 C’s are commitment, conscience, competence, compassion, and confidence (Roach, 1992). As a former long-term care nurse, this investigator has found that these qualities to be essential in building trust and gaining a surrogate decision maker’s confidence. **Commitment** to be being an advocate on behalf of the resident and surrogate decision maker. Provide quality end-of-life care through the concept of **Conscience** by focusing on being
empathetic and putting one’s self in the shoes of the surrogate decision maker. Competence through the demonstration of skills learned as a nurse. Showing Compassion by means of providing kind and considerate treatment always. Confidence can be shown by consistently acting in a competent and compassionate manner even in difficult situations such as communicating with surrogate decision makers about end-of-life care options. Through using these qualities, this investigator has gained the confidence of residents and surrogate decision makers, which greatly helped in facilitating end-of-life care discussions.

**Contextual Factors**

In contrast to prior studies that suggest the contextual factors of the current CMS payment system and OBRA’s emphasize on rehabilitation versus custodial care being influential in providing end-of-life care to residents in the long-term care setting (Hodgson & Lehning, 2008; Martz & Gerding, 2011; Marx, 2007; Reb, 2003; Stevenson & Bramson, 2009; Swagerty, 2010), the long-term care nurses in this study rated these two factors as not important. One plausible explanation for this is that CMS has revised the MDS 3.0 standards to include quality of life for residents. Quality of life is multi-dimensional and includes physical, social, psychological, and spiritual dimensions. Nevertheless, these revised standards are non-specific to end-of-life care.

With respect to the contextual factors of hospice services/providers contracted by the long-term care facility and staff views of hospice being in the facility, participants rated these as very important in communicating with surrogate decision makers about end-of-life care options for residents. Prior findings in other research studies that found long-term care administrators and staff “do not always perceive hospice as important to improve the quality of
end-of-life care” (Hanson, Sengupta, & Slubicki, 2005, p. 1208). Furthermore, Hanson et al. (2005) suggest that the long-term care facility’s preferences, not the resident’s or surrogate decision maker’s preferences, determine access to a hospice provider. Long-term care nurse CX wrote that nurses should have the freedom to “make referrals to all local hospices” for surrogate decision makers to choose from for end-of-life care. Usually long-term care staff believe they are the “experts” in caring for dying residents although studies have reported that long-term staff lack knowledge of appropriate palliative care (Stillman, Strumpf, Capezuti, & Tuch, 2005). This researcher’s professional experiences as a long-term care and hospice nurse are parallel to the findings in the study conducted by Lau, Masin-Peters, Berdes, and Ong (2010) that long-term care staff are guarded and find hospice providers to be intrusive and “stepping on toes” (p. 306). Since the long-term care staff most likely have been caring for the resident for an extended period, they believe they know what is best for the resident. There is an air of professional mistrust toward hospice, which causes lack of cooperation and confusion in providing quality end-of-life care for residents, their family members, or surrogate decision makers (Hanson et al., 2005; Lau et al., 2010). In regards to contextual factor, WQ wrote that long-term care nurses should “Work with your staff on not being judgmental…we as professionals cannot put our feelings or opinions on top of all the other stress they [surrogate decision makers] are experiencing.”

**Situational Related Inputs**

The situational related input of **timing** pointed to resident characteristics that included the **stage of illness, cognition, pain, and anxiety** were major contributory situational related inputs shared by long-term care nurses in this study with the timing of the end-of-life discussion with
surrogate decision makers. When a resident’s condition (e.g., medical diagnosis, cognition, increased pain, and anxiety) worsens and the prognosis is poor there is a greater need to communicate about end-of-life care options with the surrogate to provide the resident with the care they desire.

The findings in this study support the study conducted by Welch, Miller, Martin, and Nanda (2008) where nursing home staff’s recognition of terminal decline was influential in discussing end-of-life care options and making referrals to hospice providers. In addition, residents’ family members or surrogate decision makers emphasized the importance of long-term care nursing staff being able to anticipate “illness trajectories and…palliation needs” as being influential (Fosse, Schaufel, Ruths, & Malterud, 2014, p. 5). Knowing the “stages of disease process” was emphasized by study participant ZA, which supports the findings from the aforementioned studies.

The importance of an environment that is therapeutic without distractions is conducive when discussing end-of-life care options with surrogate decision makers. Waller, Dewar, Masterson, and Finn (2008), in a review of eight end-of-life care sites, found that a quiet, uncrowded room that was home-like was emphasized by participants. Environments where there was a lack of seating, rooms were semi-private versus private, and loud playing TVs or radios caused undue stress to residents, their family members or surrogate decision makers (Hirakawa, Kuzuya, & Uemura, 2009; Kayser-Jones, Schell, Lyons, Kris, Chan, & Beard, 2003). The results from this study were comparable to these prior studies as noted by participants who reported having an environment that is not “busy, loud or chaotic” facilitates good communication. These results were not surprising since environment has been mentioned by residents, long-term care
staff, and surrogate decision makers to this researcher in her capacity as a long-term care and hospice nurse.

An unexpected finding in this study was that the situational related input of interpersonal space was not viewed as the physical distance between the long-term care nurse, the resident, resident’s family members, and the surrogate when discussing end-of-life care options for the resident, but rather the **emotional space** between them. Participants voiced that in the long-term care setting they become very close to the residents and their family members and at times are considered as “family” versus the professional. As noted in the literature review, long-term care staff often have similar reactions to that of family members when a resident’s status declines (van Riesenbeck et al., 2015). In a study conducted by Sheppard (2015), registered nurses mentioned that they would call to “check on my patient” on their day off (p. 58). Heaslip and Board (2012), mentioned that the participant’s in their study “shut off” their emotions as a defensive mechanism to protect themselves. In the current study, participant KO wrote about being too close to residents and residents’ family members and “shutting down.” Participant’s in a study conducted by Yoder (2010) stated, “‘I try to ignore the situation’ and, ‘I detached myself…[and went on] autopilot.’” (p. 194). Researchers have expressed nurses detaching or shutting down as “emotional distancing,” “avoidance,” “depersonalization,” and “differentiation of self” (Fischer, Mitsche, Endler, Mesenholl-Strehler, Lothaller, & Roth, 2013; Lahav, Stein, & Solomon, 2016; Michaelsen, 2012) These statements give the impression that there are times when nurses may need to take a step back and reassess their personal and professional relationships with residents, patients, family members, and surrogate decision makers. This is summarized nicely by Harris (2014), “boundaries assure that professionals recognize and respect the emotional and physical
Support Desired by Long-Term Care Nurses

Most participants identified and sought out additional education in facilitating end-of-life care options with surrogate decision makers. This finding corresponds with several studies that have reported the increased need of palliative and end-of-life care education in nursing programs at all levels (Hirakawa et al., 2009; Raudonis, Kyba, & Kinsey, 2002; Whittaker, Kernohan, Hasson, Howard, & McLaughlin, 2006). In studies conducted by Cevik and Kav (2013) and Mutto et al. (2010) a lack of formal education inhibited nurses’ ability to engage in discussions with surrogate decision makers and inhibited the quality of end-of-life care provided to residents. However, the participants in this study did not limit education to themselves. They seek educational materials such as pamphlets, booklets, take home information for surrogate decision makers. This finding appears to be novel due to a paucity of literature referring to educational materials for surrogate decision makers. Through professional experiences as a hospice nurse, this researcher utilized end-of-life educational materials for residents, families, surrogate decision makers, and other professionals written by Barbara Karnes, RN who is an end-of-life nurse educator (Karnes, 1986).

Long-term care nurses, in this study, voiced wanting more support from physicians, social workers, clergy, and their colleagues. These findings align with earlier studies where nurses mentioned wanting interdisciplinary team support and coordinated communication (Iverson et al., 2014; Wood et al., 2016). Participant XI wrote that having the “interdisciplinary team on the same page” would be beneficial in communicating with end-of-life surrogate decision makers.
Implications for the Conceptual Framework: Bringing Together Quantitative and Qualitative Results

The EOL Transactional Communication Model in LTC presented in chapter 1 was renamed to the Conceptual Model of Factors that Promote End-of-Life (EOL) Discussion between the Long-Term Care (LTC) Nurse and EOL Surrogate Decision Maker to reflect the findings of the study. Additionally, the primary categories were clarified to be succinct and mirror the factors as voiced by the long-term care nurses who participated in this study. Figure 3 is a model of the revised conceptual framework that represents the voices of long-term care nurses. As is characteristic of a conceptual framework, the concepts are clear but somewhat broad and the relationships among them are not yet specified. However, the model depicts the direction of important influences of the factors and characteristics on the EOL Discussion.
FIGURE 3. Conceptual Model of Factors that Promote End-of-Life (EOL) Discussion Between the Long-Term Care (LTC) Nurse and EOL Surrogate Decision Maker.

The key findings of the study have implications for the conceptual framework by offering factors that promote end-of-life discussions between the long-term care nurse and the end-of-life surrogate decision maker. Based on the study findings, it was apparent that the original conceptual framework needed to be clarified to reflect the voice of the long-term care nurse as being instrumental.

The updated conceptual model is comprised of the long-term care nurses’ and the end-of-life surrogate decision maker’s characteristics based on the quantitative importance ratings results; whereas, in the original conceptual model these did not have specific characteristics listed. The long-term care cultural factors and the interpersonal factors in the updated conceptual model is comprised of the additional factors voiced by the participants and the themes
inductively derived from the content analysis in this study.

In the original conceptual model, the long-term culture and advanced care planning were broadly classified under contextual factors. In the updated conceptual model, these factors are concise and consistent with the study findings of interdisciplinary team agreement and living will. Also, in the updated conceptual model, the heading of interpersonal factors with the corresponding findings were added to reflect the voice of the long-term care nurse participants.

The theme of having strong trusting relationships between the nurse and surrogate family member reinforced the positive correlation between the levels of long-term nurses’ self-confidence in their LTC role and the surrogate decision maker’s confidence in the LTC nurse. Furthermore, the theme of having strong trusting relationships between the nurse and surrogate family member reinforced the quantitative finding of “very important” for the end-of-life surrogate decision maker’s confidence in the long-term care nurse.

The qualitative findings of themes regarding the institutional staff’s previous experiences and knowledge base on end-of-life care and death and dying along with the theme for interdisciplinary team agreement supported the quantitative finding of the importance ratings for staff views about hospice being in the facility as “very important.”

**Study Limitations and Strengths**

As with any study, limitations must be acknowledged. One limitation in this study was employing the social media network of Facebook as the recruitment strategy to obtain a diverse sample of participants nationwide. The study sample did contain three males and two Hispanic participants though females and Caucasian/White participants were overrepresented (Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010). Thus, the application of results beyond the dominant
ethnic group is not viable. This research suggests broadening sampling methods supportive of more gender and ethnically diverse samples (Buckey & Molina, 2012).

Since all responses were completed online by self-report, participants may have inflated or minimized their responses. According to Peer and Gamliel (2011), bias can be either “response style” or “response set.” In “response style” participants may distort their responses in one way or another regardless of the content being inquired about. “Response set” is the conscious or conscious longing to respond to the content in a way that portrays the participant in a certain way. Response bias, if any, could have been decreased by a randomly selected and greater number of participants. Another type of bias is acquiescence bias and this may have influenced participants’ responses. Acquiescence bias refers to participants’ tendency to agree with statements in a survey that require them to agree or disagree with a question (Javeline, 1999). Questions that requested participants to agree or disagree asked the participant to explain why they agreed or disagreed. Response rates for internet-based qualitative research range between 18.3% and 84.6%, and this study had a response rate of 88% (Im & Chee, 2013), indicating a strength of the study in terms of response rates.

Implications for Practice and Education

The conceptual framework provided in this study could be beneficial in guiding long-term care nurses to reflect upon their practices related to end-of-life care communication with surrogate decision makers. This study begins to address gaps in the literature about personal and contextual factors as well as situational related inputs that influence or inhibit long-term care nurses’ ability to communicate with end-of-life surrogate decision makers. In addition, results suggest that long-term care administrators should offer supplementary end-of-life education and
communication training for nurses. Also, to create support systems with a network of individuals or groups who can provide nurses the emotional support they seek in order to provide quality end-of-life care to residents, their family members and surrogate decision makers.

Although there have been significant efforts made over the past 50 years in educating healthcare providers and the public about palliative and hospice care and death and dying, there is an implication for nursing programs, of all levels, to focus more on end-of-life care in the curriculum (Gillan, Van der Riet, & Jeong, 2014; Giovanni, 2012). Nurse educators are in a pivotal position to equip nursing students with skills necessary to providing outstanding quality end-of-life care to residents, their family members, and surrogate decision makers (Benner, Sutphen, Leonard, & Day, 2010; Hamilton, 2010).

Incorporating educational modules from the End-of-Life Nursing Education Consortium (ELNEC) into nursing programs is an example of the education that may be provided because it addresses communication and factors that influence communication regarding end of life decisions. ELNEC’s sixth module is designated to communication because communication is the basis for outstanding end-of-life care. Furthermore, using ELNEC’s sixth module would be beneficial in meeting the supportive needs that participant’s in this study mentioned (ELNEC, 2016).

Another educational approach includes experiential learning to supplement traditional lecturing as it encourages nursing students to reflect on and learn from the hands-on experience (Gillan, Van der Riet, et al., 2014; Vaillancourt, 2009). With the growth of nursing programs, there has been a shortage of clinical learning sites so simulation has become a widely accepted valuable educational tool (Cato, 2012; Gillan, Jeong, & van der Riet, 2014). Simulation
resembles the clinical practice setting as closely as possible (Cato, 2012) and is known “for its positive effects on knowledge acquisition, communication skills” (Gillan, Jeong, et al., 2014, p. 766) and self-confidence. Nurse educators can design end-of-life simulation scenarios as they offer a solution for the lack of death and dying opportunities nursing students come across in their allotted clinical timeframe (Cato, 2012; Gillan, Parmenter, Van der Riet, & Jeong, 2013; Walter, 2010).

Implications for Future Research

This study provided original insights into elements that facilitate end-of-life communication between nurses and surrogate decision makers in the long-term care setting. Additionally, this study has contributed to the understanding of self-reported experiences of long-term care nurses in communicating with end-of-life surrogate decision makers. Given that many of the long-term care nurse participants were open to sharing their experiences, one recommendation is to use a phenomenological approach with in-depth interviews and observations for future research to describe the lived experience of long-term care nurses communicating with end-of-life surrogate decision makers. Also, the phenomenological approach may enlighten researchers about the unexpected finding of interpersonal space being viewed as the emotional space between the long-term care nurse and surrogate decision maker versus the physical space.

A second recommendation for future research is to conduct a study to determine if there is a difference in the facilitators for the long-term care end-of-life surrogate decision maker as compared to the long-term care nurses.
Conclusions

As the number of the older adult population living in long-term care facilities continue to increase, the demand for nurses to develop expertise in caring for dying residents and communicating with them, their family members, and surrogate decision makers will increase.

This is the first study that has identified individual and organizational factors influential in long-term care nurses’ ability in communicating with end-of-life surrogate decision makers. Also, this study has contributed to a better understanding of long-term care nurses’ experiences in communicating with end-of-life surrogate decision makers. Understanding long-term care nurses’ experiences and providing the support they seek and desire may strengthen their capacity to communicate about death and dying and their delivery of quality end-of-life care to residents.
APPENDIX A

IRB APPROVAL
Date: June 02, 2016
Principal Investigator: Diane Marie Walter
Protocol Number: 1606616749
Protocol Title: Long-Term Care Nurses Experiences in Communicating with End-of-Life Surrogate Decision Makers: A Mixed Methods Study

Level of Review: Exempt
Determination: Approved

Documents Reviewed Concurrently:
Data Collection Tools: Walter_Qualtrics Survey.docx
HSPP Forms/Correspondence: Diane Walter-fl07.doc
HSPP Forms/Correspondence: Diane Walter-2016-01 Feb 16_0-1.doc
HSPP Forms/Correspondence: Signature page.pdf
HSPP Forms/Correspondence: Walter_appendix_F.docx
Informed Consent PHI Forms: Walter_Disclosure Statement Form LTC Study.docx
Informed Consent PHI Forms: Walter_Disclosure Statement Form LTC Study.pdf
Other Approvals and Authorizations: Walter_AADNS-permission.pdf
Recruitment Material: Walter_Recruitment Posting LTC Study.docx

This submission meets the criteria for exemption under 45 CFR 46.101(b). This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidelines of the IRB.
- Exempt projects do not have a continuing review requirement.
- Amendments to exempt projects that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination. See the Guidance on Exempt Research information on changes that affect the determination of exemption. Please contact the HSPP to consult on whether the proposed changes need further review.
- You should report any unanticipated problems involving risks to the participants or others to the IRB.
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented, the approved consent(s) are attached to the approval notification from the HSPP Office.
APPENDIX B:

DISCLOSURE STATEMENT FORM
Appendix B

Disclosure Statement Form

Introduction

This study has been approved by the University of Arizona Human Subjects Board, according to state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

The purpose of this study is to describe long-term care nurses' experiences in communicating with end-of-life surrogate decision makers. It is designed to reflect the voice of long-term care nurses regarding their experiences, feelings and beliefs surrounding end-of-life care decision making.

Procedures

You will be asked to complete questions that are designed to answer the research questions:
1. What are long-term care nurses' experiences in communicating with end-of-life surrogate decision makers?
2. What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers?

This questionnaire will be conducted with an online Qualtrics-created survey. The survey begins with some demographic questions.

Risks/Discomforts

While this study poses no physical risks, questions on the survey may bring up memories of stressful or difficult interactions regarding end-of-life discussions. If this occurs, there will be a list of websites you may use to contact a professional, or you may contact your primary care provider.

Benefits

There are no direct or immediate benefits to you for participating in the study. However, you will be contributing to the understanding of long-term care nurses' experiences about communicating with end-of-life surrogate decision makers.

Confidentiality

You will not be personally identified in any reports or publications that may result from this study. All data obtained from participants will be kept confidential and kept in an encrypted digital file and stored in a fireproof locked cabinet. Other than the primary investigator and dissertation committee members no one else will have access to data. The data collected will be

Protocol 1606616749 Approved by Univ. of Arizona IRB on 1-Jun-2016
stored in the HIPPA-compliant, Qualtrics-secure database until it has been deleted by the primary investigator.

**Compensation**

There is no monetary compensation for participating in this study.

**Participation**

Participation in this research study is completely voluntary. By responding to the survey, you are indicating your willingness to participate in the study. You have the right to withdraw at anytime or refuse to participate entirely without any penalty. If you desire to withdraw, please close your internet browser.

**Questions about the Research**

If you have questions regarding this study, you may contact Diane Walter, MSN, RN, DNS-CT, at 402-300-1150 (call or text), or mmange192@email.arizona.edu

**Questions about your Rights as a Research Participant**

If you have questions you do not feel comfortable asking the researcher, you may contact Human Subjects Protection Program at 520-626-6721 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.
APPENDIX C:

RECRUITMENT POSTING
Long-Term Care Nursing Research Study

You are invited to participate!
Looking for volunteers for LTC nursing research study.

Participants will be asked to complete a survey to share experiences of communicating with end-of-life (EOL) surrogate decision makers.

Eligibility:
In order to participate in this study you must be:
- Be a licensed practical/vocational nurse (LPN/LVN) or a registered nurse (RN)
- Able to read/speak English
- Have at least 1 year LTC nursing experience
- Reside in the United States

Why participate?
- Share your experiences of communicating with EOL surrogate decision makers
Participants will provide valuable insight on EOL communication from the LTC nurse perspective

What would I have to do to participate?
- Take a survey with questions concerning your experiences in talking with end-of-life surrogate decision makers, demographics (such as age, education, years of experience)
- The survey is estimated to take 30 minutes
- You may be contacted up to 2 times by email throughout the research process, with the second time used to validate or clarify responses
- The survey is confidential
- You may withdraw from participation at any time

Interested? Need more information?
- Contact: Diane Walter, MSN, RN, DNS-CT
  - Cell: (402) 300-1150
  - Email: mmangel924@email.arizona.edu

This study has been approved by the University of Arizona Human Subjects Board, according to state and federal regulations and University policies designed to protect the rights and welfare of participants in research.
APPENDIX D:

QUALTRICS SURVEY
Long-Term Care Nurses’ Experiences in Communicating with End-of-Life Surrogate Decision Makers

LTC Nurses’ Experiences

Q1.1 Are you a licensed practical/vocational (LPN/LVN) or registered nurse (RN)?
- Yes (1)
- No (2)

Answer If Yes Is Selected

Q1.2 Are you able to read/speak English?
- Yes (1)
- No (2)

Answer If Are you able to read/speak English? Yes Is Selected

Q1.3 Do you have at least 1 year of experience working in long-term care (LTC)?
- Yes (1)
- No (2)

Answer If Do you have at least 1 year of experience working in long-term care (LTC)? Yes Is Selected

Q1.4 What type of long-term care facility do you work in?
- Skilled Nursing Facility (Nursing Home) (1)
- Assisted Living Facility (2)

Answer If What type of long-term care facility do you work in? Skilled Nursing Facility (Nursing Home) Is Selected

Q1.5 Do you reside in the United States?
- Yes (1)
- No (2)

Answer If Do you reside in the United States? Yes Is Selected

Q2.1 Disclosure Statement Form

Introduction
This study has been approved by the University of Arizona Human Subjects Board, according to state and federal regulations and University policies designed to protect the rights and welfare of participants in research. The purpose of this study is to describe long-term care nurses' experiences in communicating with end-of-life surrogate decision makers. It is designed to
reflect the voice of long-term care nurses regarding their experiences, feelings and beliefs surrounding end-of-life care decision making.

Procedures
You will be asked to complete questions that are designed to answer the research questions: 1. What are long-term care nurses' experiences in communicating with end-of-life surrogate decision makers? 2. What types of support do long-term care nurses identify that they seek or need in regards to communicating with end-of-life surrogate decision makers? This questionnaire will be conducted with an online Qualtrics-created survey. The survey begins with some demographic questions.

Risks/Discomforts
While this study poses no physical risks, questions on the survey may bring up memories of stressful or difficult interactions regarding end-of-life discussions. If this occurs, there will be a list of websites you may use to contact a professional, or you may contact your primary care provider.

Benefits
There are no direct or immediate benefits to you for participating in the study. However, you will be contributing to the understanding of long-term care nurses' experiences about communicating with end-of-life surrogate decision makers.

Confidentiality
You will not be personally identified in any reports or publications that may result from this study. Written narratives will be identified by pseudonyms. All data sources will be kept in an encrypted digital file and stored in a fireproof locked cabinet at the researcher’s home. Any files that may have identifying information will be kept separate from participant responses and kept in a secure location. Other than the primary investigator and dissertation committee members no one else will have access to data. The data collected will be stored in the HIPPA-compliant, Qualtrics-secure database until it has been deleted by the primary investigator.

Compensation
There is no monetary compensation for participating in this study.

Participation
Participation in this research study is completely voluntary. By responding to the survey, you are indicating your willingness to participate in the study. You have the right to withdraw at anytime or refuse to participate entirely without any penalty. If you desire to withdraw, please close your internet browser.

Questions about the Research
If you have questions regarding this study, you may contact Diane Walter, MSN, RN, DNS-CT, at 402-300-1150 (call or text), or mmangel924@email.arizona.edu.
Questions about your Rights as a Research Participant
If you have questions you do not feel comfortable asking the researcher, you may contact Human Subjects Protection Program at 520-626-6721 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.

Q3.1 What is your age in years?

Q3.2 What is your gender?
- Male (1)
- Female (2)
- Other (3)

Q3.3 How would you classify your ethnicity?
- Arab (1)
- Asian/Pacific Islander (2)
- Black (3)
- Caucasian/White (4)
- Hispanic (5)
- Indigenous or Aboriginal (6)

Q3.4 What, if any, religion do you identify with? Please respond below.

Q3.5 What is the highest level of education completed and in what field? (fill in the line)
  - Vocational/technical training (LPN/LVN) (1)
  - Associates degree (2)
  - Diploma (3)
  - Bachelor's degree (4)
  - Master's degree (5)
  - Doctoral degree (6)

Q3.6 If you have any certifications, please list them here.

Q3.7 Employment Status
- Full time (1)
- Part time (2)
- PRN (as needed) (3)

Q3.8 Years of experience working in long-term care?

Q3.9 If you have special training/education in end-of-life care, please briefly describe it. For example, did you receive training at your institution? Through your nursing program? Through
End-of-Life Nursing Education Consortium (ELNEC)? Please leave blank if you have not had special training.

Q3.10 In the past 12 months, approximately how many times have you engaged in end-of-life discussions with surrogate decision makers?

Q3.11 Number of years in any other professional work experience (fill in the line)

Hospital (1)
Clinic (2)
Hospice (3)
Home Health (4)
Other (Describe) (5)

Q4.1 Of the following list of factors concerning you, please rate how important they are in influencing your ability to communicate with surrogate decision makers about end-of-life care?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Somewhat important</th>
<th>Quite important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-confidence in my role as a long-term care nurse (1)</td>
<td>Self-confidence in my role as a long-term care nurse (1)</td>
<td>Self-confidence in my role as a long-term care nurse (1)</td>
<td>Self-confidence in my role as a long-term care nurse (1)</td>
</tr>
<tr>
<td>Knowledge about end-of-life (2)</td>
<td>Knowledge about end-of-life (2)</td>
<td>Knowledge about end-of-life (2)</td>
<td>Knowledge about end-of-life (2)</td>
</tr>
<tr>
<td>My level of education (3)</td>
<td>My level of education (3)</td>
<td>My level of education (3)</td>
<td>My level of education (3)</td>
</tr>
<tr>
<td>My previous experiences with death and dying (4)</td>
<td>My previous experiences with death and dying (4)</td>
<td>My previous experiences with death and dying (4)</td>
<td>My previous experiences with death and dying (4)</td>
</tr>
<tr>
<td>My spiritual or religious beliefs about death and dying (5)</td>
<td>My spiritual or religious beliefs about death and dying (5)</td>
<td>My spiritual or religious beliefs about death and dying (5)</td>
<td>My spiritual or religious beliefs about death and dying (5)</td>
</tr>
</tbody>
</table>

Q4.2 If there are factors concerning you that you believe influence your ability that were not listed above, please list here.

Q4.3 Of the following list of factors about the surrogate, please rate how important they are in influencing your ability to communicate with end-of-life care surrogate decision makers?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Somewhat important</th>
<th>Quite important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrogate's confidence in the long-term care nurse</td>
<td>Surrogate's confidence in the long-term care nurse</td>
<td>Surrogate's confidence in the long-term care nurse</td>
<td>Surrogate's confidence in the long-term care nurse</td>
</tr>
</tbody>
</table>
Q4.4 If there other factors about the surrogate not listed above that you believe influence your ability that was not listed above, please list them.

Q5.1 Of the following list of factors regarding the institution and staff, please rate how important they are in influencing your ability to communicate with end-of-life care surrogate decision makers?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Somewhat important</th>
<th>Quite important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ Current structure of the Center for Medicare &amp; Medicaid Services (CMS) payment system (1)</td>
<td>_____ Current structure of the Center for Medicare &amp; Medicaid Services (CMS) payment system (1)</td>
<td>_____ Current structure of the Center for Medicare &amp; Medicaid Services (CMS) payment system (1)</td>
<td>_____ Current structure of the Center for Medicare &amp; Medicaid Services (CMS) payment system (1)</td>
</tr>
<tr>
<td>_____ The Medicare Hospice Benefit (MHB) (2)</td>
<td>_____ The Medicare Hospice Benefit (MHB) (2)</td>
<td>_____ The Medicare Hospice Benefit (MHB) (2)</td>
<td>_____ The Medicare Hospice Benefit (MHB) (2)</td>
</tr>
<tr>
<td>_____ Hospice services contracted by facility (3)</td>
<td>_____ Hospice services contracted by facility (3)</td>
<td>_____ Hospice services contracted by facility (3)</td>
<td>_____ Hospice services contracted by facility (3)</td>
</tr>
<tr>
<td>_____ No contracted hospice services (4)</td>
<td>_____ No contracted hospice services (4)</td>
<td>_____ No contracted hospice services (4)</td>
<td>_____ No contracted hospice services (4)</td>
</tr>
<tr>
<td>_____ The Omnibus</td>
<td>_____ The Omnibus</td>
<td>_____ The Omnibus</td>
<td>_____ The Omnibus</td>
</tr>
</tbody>
</table>
Q5.2 If there other factors regarding the institution and staff not listed above that you believe influence your ability to communicate with end-of-life care surrogate decision makers, please list them here.

Q5.3 How does a resident's status of having (or not having) an advance directive or living will in place influence or inhibit your ability to communicate with the end-of-life care surrogate decision maker?

Q5.4 Please explain why you agree or disagree that the way or reason by which someone became a resident's end-of-life care surrogate decision maker influences the surrogate decision maker's ability to discuss end-of-life options.

Q5.5 How does healthcare interdisciplinary team members influence or inhibit your ability to communicate with the end-of-life care surrogate decision maker?

Q5.6 How does the family members' relationship with the resident influence or inhibit your ability to communicate with the end-of-life care surrogate decision maker?

Q5.7 How does your relationship with the resident influence or inhibit your ability to communicate with the end-of-life care surrogate decision maker?

Q5.8 How does your relationship with the resident's family members influence or inhibit your ability to communicate with the end-of-life care surrogate decision maker?

Q6.1 What do you find facilitates or inhibits the discussion when communicating with end-of-life care surrogate decision makers? (for example physical environment, room location, furniture, distractions, TV or radio)

Q6.2 Please explain, if applicable, any characteristics of the resident that may influence the timing of the end-of-life conversation with surrogate decision makers (for example, the resident's age, stage of illness, certain behaviors, etc.).

Q7.1 What kinds of support would you like to see to help you in communicating with end-of-life surrogate decision makers?
Q7.2 What recommendations do you have for other nurses/future nurses working in this setting which might allow them to continue working in long-term care over long periods of time?

Q8.1 Please share any additional information you would like about end-of-life care in the long-term care setting and/or surrogate decision making.

Q8.2 Mental Health Care Resources: http://www.mentalhealthamerica.net/find-affiliate
https://findtreatment.samhsa.gov/
REFERENCES


Holloway, I., & Wheeler, S. (2010). Qualitative Research in Nursing and Healthcare


