

FAMILY CAREGIVER ROLE STRAIN
AND SATISFACTION IN MAKING LIFE-SUSTAINING TREATMENT
DECISIONS FOR ELDERLY ILL RELATIVES: INSTRUMENT DEVELOPMENT

By

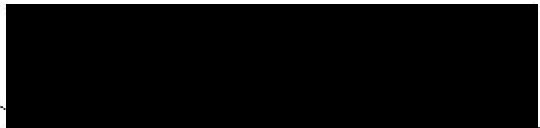
Lissi Hansen

A Dissertation

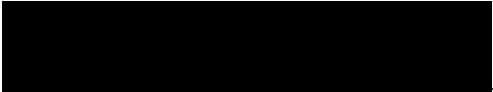
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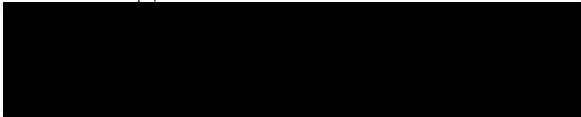
Patricia G. Archbold, RN, DNSc, FAAN, Elnora E. Thomson Distinguished Professor,
Department of Population Based Nursing, School of Nursing, Research Advisor



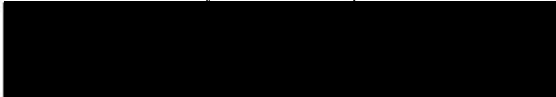
Barbara J. Stewart, PhD, Professor, Department of Population Based Nursing, School of
Nursing, Committee Member



Una Beth Westfall, RN, PhD, Professor, Department of Population Based Nursing,
School of Nursing, Committee Member



Linda Ganzini, MD, Director of Geriatric Psychiatry, PVAMC, Associate Professor of
Psychiatry, OHSU, Committee Member



Beverly Hoeffler, RN, DNSc, FAAN, Associate Dean for Academic Affairs, School of
Nursing

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ABSTRACT

TITLE: Family Caregiver Role Strain and Satisfaction in Making Life-Sustaining
Treatment Decisions for Elderly Ill Relatives: Instrument Development

AUTHOR: Lissi Hansen

APPROVED:



Patricia G. Archbold, RN, DNSc, FAAN, Elnora E. Thomson
Distinguished Professor (Department of Population-Based Nursing),
School of Nursing, Research Advisor

This exploratory-descriptive study was designed to lay the foundation for developing measures of family caregiver role strain and satisfaction in making life sustaining treatment (LST) decisions for elderly relatives in a variety of settings. Specific aims were to: (1) refine the conceptualization of family caregiver role strain and satisfaction in making LST decisions, within the context of ongoing family care, (2) describe factors associated with family caregiver role strain and satisfaction in making LST decisions, and (3) generate items for measures of family caregiver role strain and satisfaction in making LST decisions, based on the refined conceptualization and words of caregivers. Previous research has not focused on LST decision-making by family caregivers within the context of ongoing family care. This study addressed this gap in the literature, and using role theory, applied a new theoretical perspective to the current LST decision-making literature.

Semi-structured interviews were conducted with 17 family caregivers after the death of 16 relatives. Content analysis was the method of analysis. Refinement of the conceptualization of family caregiver role strain and satisfaction added a new perspective, the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives and its temporal sequence, which expands on understanding of the experiences

of caregivers who make LST decisions. Role strain in the context of LST decision-making by family caregivers complements the existing literature on role strain in family care. To more accurately reflect the findings, “satisfaction” was changed to “ease.” Because “ease” does not fully capture the terms used by participants to describe the non-negative aspects of making LST decisions, this concept needs further theoretical development. Six categories of data were derived: (1) caregiver, (2) ill relative, (3) family relations, (4) health care provider, (5) health care system, and (6) responses. Various antecedent factors and subcategories emerged from the data that may be associated with LST decision-making by caregivers. The findings also resulted in draft items for measures of family caregiver role strain and ease in making LST decisions. The conceptual framework can be used to guide theory, research, and practice related to selected areas of family caregiving and end-of-life care.

TABLE OF CONTENT

ACKNOWLEDGEMENT OF FINANCIAL SUPPORT.....	iii
ACKNOWLEDGEMENT.....	iv
ABSTRACT.....	vi
TABLE OF CONTENT.....	viii
LIST OF FIGURES.....	xiii
LIST OF TABLES.....	xiv
CHAPTER 1.....	1
Introduction.....	1
Statement of the Problem and Significance to Health Care	
Professionals.....	1
Aims.....	3
CHAPTER 2.....	5
Review of the Literature.....	5
Role Theory.....	5
Role Strain.....	5
Satisfaction.....	6
Premises of the Study.....	6
Definitions of Concepts and Variables.....	8
Conceptualization of Role Strain and Satisfaction.....	8
Definition of Variables.....	8
Organizing Framework.....	10
Role Strain in Family Care.....	11

Satisfaction in Family Care.....	12
Role Strain and Satisfaction in Making LST Decisions.....	13
Studies Focusing on Hypothetical Decision-Making	
Situations.....	13
Studies Focusing on Actual Decision-Making Situations....	13
Indicators of Strain from Making LST Decisions.....	21
Emotional Burden.....	21
Burden.....	22
Strain Related to Acceptance of Responsibility of the	
Surrogate Role.....	22
Strain Due to Lack of Information.....	23
Strain from Lack of Mutual Treatment Goals between	
Family Members and Health Care Providers.....	24
Guilt and Regrets about Decisions.....	25
Indicators of Satisfaction from Making LST Decisions.....	27
Satisfaction with Care-Related Decision-Making.....	27
Comfort with Decisions Based on Actual and Hypothetical	
Situations.....	28
Antecedent Factors that may affect Responses in Making LST	
Decisions.....	29
Family Member Factors.....	29
Knowing the elderly relative's wishes.....	29
Relationship Factors.....	30

Spouse versus non-spouse.....	30
Mutuality.....	30
Elderly Relative Factor.....	31
Age.....	31
Cognitive impairment.....	31
Summary.....	32
CHAPTER 3.....	34
Method.....	34
Design.....	34
Sample.....	34
Inclusion Criteria.....	35
Procedure.....	36
Sample Access.....	36
Recruitment Procedure.....	36
Sample Size and Characteristic.....	38
Family Caregivers.....	38
Deceased Elderly Ill Relatives.....	41
Instrument.....	44
Pilot Interviews.....	44
Qualitative Interviews.....	45
Data Collection.....	45
Data Management.....	46
Protection of Human Subjects.....	47

Analysis.....	48
Reliability and Validity.....	51
CHAPTER 4.....	53
Results.....	53
Caregiver.....	58
Ill Relative.....	76
Family Relations.....	92
Health Care Provider.....	102
Health Care System.....	116
CHAPTER 5.....	119
Discussion and Conclusions.....	119
LST Decision-Making Literature Related to the Caregiver.....	121
Prior Experience.....	121
Role Expectations and Responsibility.....	123
Understanding of Ill Relative's Immediate Situation.....	123
Readiness for Death.....	124
Decision-Making.....	124
LSTs.....	125
Responses.....	125
LST Decision-Making Literature Related to Ill Relatives.....	126
Advance Directives.....	126
Health Decline Trajectory.....	126
Medical Diagnosis.....	127

Overall Health Problems.....	128
Dying Process.....	129
LST Decision-Making Literature Related to Family Relations.....	130
Caregiver and Ill Relative.....	130
Caregiver and Other Family Members.....	131
LST Decision-Making Literature Related to Health Care	
Providers.....	131
Health Care Provider Behavior in Relation to	
Communication and Information.....	132
Health Care Provider Behavior in Relation to Interaction	
with the Caregiver and Ill Relative.....	133
Advance Directives and Medical Treatment.....	133
LST Decision-Making Literature Related to Health Care System...	135
Item Generation, Retention, and Reduction.....	135
Ethnic Variation.....	136
Response Format.....	137
Limitations of the Study.....	137
Implications for Nursing Research.....	138
Implications for the Practice of Nursing and Other Disciplines.....	139
Summary.....	140
REFERENCES.....	142
LIST OF APPENDICES.....	157

TABLE OF FIGURES

Figure 1 - Preliminary Organizing Framework: Family Caregiver Role Strain and Satisfaction in Making Life-Sustaining Decisions.....	10
Figure 2 - Refined Conceptual Framework: Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.....	56
Figure 3 - Caregiver Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.....	59
Figure 4 - Ill Relative Category in the Family Caregiving Process in Making LST Decisions for Him or Her.....	78
Figure 5 - Family Relations Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.....	94
Figure 6 - Health Care Provider Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.....	103
Figure 7 - Health Care System Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.....	117

LIST OF TABLES

Table 1 -	Characteristics of Family Caregivers.....	39
Table 2 -	Characteristics of Deceased Ill Relatives.....	42
Table 3 -	Concepts, Definitions, and Data Bits.....	54
Table 4 -	Caregiver Category: Concepts, Concept Definitions, Potential Indicators in the Data Set, and Draft Items.....	61
Table 5 -	Ill Relative Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.....	79
Table 6 -	Family Relations Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.....	95
Table 7 -	Health Care Provider Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.....	104
Table 8 -	Health Care System Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.....	118

CHAPTER 1

Introduction

Statement of the Problem and Significance to Health Care Professionals

This study was designed to lay the foundation for developing closed-ended self-report measures of family caregiver role strain and satisfaction in making life-sustaining treatment (LST) decisions for elderly ill relatives in a variety of settings. The long-term goal was to lead to improved understanding of the experiences of families who participate in such decisions and enable evaluation of approaches to improve end-of-life care.

In the past two decades, there has been a great deal of research on the experiences of family caregivers for elders. However, the research has focused primarily on family care in the home for elders with chronic illnesses such as Alzheimer's Disease (AD) (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991), Parkinson's Disease (Carter et al., 1998), cancer (Given & Given, 1996; Schumacher, 1996), and stroke (Grant, 1996; Schulz, Tompkins, & Rau, 1988). Though most studies have looked at in-home caregiving, a few researchers have followed family caregivers into long-term care facilities (Maas, Buckwalter, & Kelly, 1991; Maas, Buckwalter, Kelly, & Stolley, 1991; Tickle & Hull, 1995), and hospitals (Collier & Schirm, 1992; Li, 1996).

While considerable effort has been devoted to understanding the impact on family caregivers of family care for ill elders, caregiver researchers have not systematically explored the effects on caregivers of end-of-life decision-making. There is growing interest in end-of-life decision-making, including its interrelated processes, but the phenomenon has thus far been viewed as a discrete event, rather than an aspect of

ongoing caregiving by families. The number of families who will be involved in decision-making about LST for elderly ill relatives can be projected to increase markedly in the next five decades. According to the Census Bureau's projections, the elderly population (persons 65 years of age and older) will more than double by the year 2050, to 80 million (U. S. Department of Commerce Economics and Statistics Administration, 1995). The number of elders who experience multiple chronic illnesses, cognitive impairment, disability and dependence will also increase (U. S. Department of Commerce Economics and Statistics Administration, 1995), as will advances in LST technology.

Making decisions to withhold or withdraw LST can be difficult and painful for families. Qualitative studies suggest that health care providers in acute care settings can ease the decision-making process by providing information to families and supporting the decisions they make (Jacob, 1998; Norton & Talerico, 2000; Swigart, Lidz, Butterworth, Arnold, 1996; Tilden, Tolle, Garland, & Nelson, 1995). Little is known, however, about such decisions and their effects on family members when ill relatives are in less acute settings, such as nursing homes or home health (Bradley, Peiris, & Wetle, 1998; Forbes, Bern-Klug, & Gessert, 2000; Kayser-Jones, 1995; T. Mills, personal communication, November 18, 2000; Tolle, Tilden, Rosenfeld, & Hickman, 2000; Wilson & Daley, 1999). Further, systematic evaluation of the impact on families of providing information and support to them is not possible without valid and reliable measures of families' responses to decision-making about LST. The lack of such measures has limited research on such important topics as variations in family responses to participating in making LST decisions, predictors of caregiver role strain and satisfaction in family caregivers involved in decisions about LST, the relationship of role strain and satisfaction to health

outcomes for family caregivers, appropriate ways to target interventions to decrease family caregiver role strain and increase satisfaction with LST decisions, the effectiveness of interventions used by health care professionals in relation to LST decisions, and the impact of LST decisions by family caregivers on the quality of care for elderly ill relatives at the end of life.

Aims

The purpose of this research was to provide a sound basis for developing measures of family caregiver role strain and satisfaction that will be useful in evaluating approaches to improve end-of-life care. The specific aims of the study were:

- Aim 1. To refine the conceptualization of family caregiver role strain and satisfaction in making life-sustaining treatment decisions, within the context of ongoing family care.
- Aim 2. To describe factors associated with family caregiver role strain and satisfaction in making life-sustaining treatment decisions.
- Aim 3. To generate items for measures of family caregiver role strain and satisfaction in making life-sustaining treatment decisions, based on the refined conceptualization and words of caregivers.

In order to achieve the specific aims of the study, an exploratory-descriptive design was proposed. See Appendix A for a short summary of and rationale for modifications in the proposed study method made during operationalization.

The following chapter, Chapter 2, includes the review of the literature and the preliminary organizing framework of the study. Chapter 3 describes the research design and methods. Chapter 4, the results section, includes the conceptual framework

developed from qualitative interview data and an explication of categories of family caregiver role strain and satisfaction in making LST decisions for elderly ill relatives. Chapter 5 includes interpretations of the results and a discussion of implications of findings.

CHAPTER 2

Review of the Literature

Development of measures of family caregiver role strain and satisfaction in making LST decisions draws on two bodies of literature -- strain and satisfaction in family care and decision-making about LSTs. This literature suggests indicators of strain and satisfaction experienced by family members in making LST decisions for ill relatives, as well as antecedent factors that may affect family members' responses to making such decisions.

Role Theory

Role theory is a social psychological and sociological theory that exists in a variety of forms. According to some, it is basically identical to symbolic interactionism, but according to others role theory is a subtheory within symbolic interactionism (Burr, Hill, Nye, & Reiss, 1979). Symbolic interactionism is an approach to "the study of human group life and human conduct" (Blumer, 1969, p.1). The theoretical components of this study was derived from the work of Burr and colleagues (1979), who summarized, evaluated, and built on the perspectives of others to describe the relevance of symbolic interactionism to family processes. They suggest that "the best way to understand humans is to deal with the mentalistic meanings and values that occur in the minds of people, because that is the most direct cause of their behavior" (1979, p. 49).

Role Strain

Burr and colleagues (1979) viewed role strain and satisfaction as relevant to understanding family processes. Role strain is described in the context of a theory of role strain as introduced by Goode (1960). He pointed out that institutions are made up of role

relationships, and social behavior and social structure are approached through role strain. He defined role strain as “felt difficulty in fulfilling role obligations” (Goode, 1960, p. 483). Individuals use role bargains to reduce their role strain; these bargains are based on individual, familial, and social expectations, including culture. The choices an individual makes among role behaviors to reduce strain determine “the allocations of role performance to all institutions of the society” (Goode, 1960, p. 483). Goode’s theory focuses on behaviors of individuals in relation to institutional imperatives, interactions between individuals, and elements in individuals’ choices. An important component is that a person can stand in relation to him or herself.

Satisfaction

Burr and colleagues (1979) presented an interactionist theory of satisfaction, according to which the learned meanings, values, and sentiments attached to things create the responses to them. Burr and colleagues defined satisfaction as “an individual’s affective response varying in the amount of gratification with something” (1979, p. 68). They suggested that satisfaction may be influenced by factors other than the congruence of expectations and rewards, as proposed by others. For example, the degree of satisfaction a person feels might be influenced by this person’s comparison of his or her experience to that of others with whom he or she has a reference relationship (Burr et al., 1979, p. 68).

Premises of the Study

In this study, role theory was conceptualized using the Blumer version of symbolic interactionism (1969), which views meanings “as social products, as creations

that are formed in and through the defining activities of people as they interact” (Blumer, 1969, p. 5). The three main premises of this study were set forth by Blumer (1969):

1. “Human beings act toward things on the basis of the meanings that the things have for them” (p. 2). Such things include everything that the human being may note in his or her world such as physical objects, other human beings, institutions, guiding ideals, activities of others, and situations the individual encounters in his/her daily life.
2. “The meaning of such things is derived from, or arises out of, the social interaction one has with one’s fellows” and the interaction one has with oneself (p. 2).
3. “These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters” (p. 2). The meanings the person forms when interpreting the world around him or her are vehicles for guiding and forming action.

Other premises of the study are those of Burr and colleagues (1979):

1. “Humans are reflective, and their introspection gradually creates a definition of self.” (p. 47).
2. “The self has several different parts,” such as the physical and social self (p. 47).
3. “The human is actor as well as reactor” (p. 48). Therefore, an investigator should see the world from the point of view of the participants in the study.
4. “The human mind is indelible” (p. 48). The mind integrates and continuously modifies old and newly acquired meanings and values.
5. “Man ought to be studied on his own level” (p. 48).

Additional premises:

1. Family caregivers are able to reflect on their experiences of strain and satisfaction in making LST decisions for an elderly ill relative, and to discuss the meaning of these experiences to them.
2. Family caregivers' role strain and satisfaction in making LST decisions for an elderly ill relative can be identified and measured empirically (Weiss, 1995).

Definitions of Concepts and Variables

Conceptualization of Role Strain and Satisfaction

Role strain has been defined in a number of ways (Goode, 1960; Lefebvre & Sandford, 1985; Pearlin & Schooler, 1978; Ward, 1986). For the purpose of this study, role strain was initially defined as family caregivers' felt difficulty following LST decisions for elderly ill relatives. Satisfaction has also been defined in various ways (Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Orbell & Gillies, 1993). For the current study, satisfaction was initially defined as family caregivers' felt comfort following LST decisions for elderly ill relatives. This definition was derived from the work of Mezey, Kluger, Maislin, and Mittelman (1996) and the work of Burr and colleagues (1979). The definitions of role strain and satisfaction were refined over the course of the study.

Definition of Variables

"Family caregiver" was defined as a family member or a friend who was like family and was involved in making the decision to either withhold or withdraw LSTs for the ill elder as part of his or her caregiving role.

“Decision” was defined as the family caregiver’s act of making up his or her mind either to withhold or to withdraw LSTs for the elder.

“LSTs” were defined as therapies that may extend life, specifically, antibiotics, artificially administered fluids, artificially administered nutrition, cardiopulmonary resuscitation (CPR), chemotherapy, renal dialysis, hospitalization, intubation, surgery, transfer to the intensive care unit (ICU), and mechanical ventilation. These treatments were selected based on the literature, on their inclusion in advance directives and the Physician Orders for Life-Sustaining Treatment form (POLST), and on the investigator’s clinical experience. In the state of Oregon, the POLST form was developed to prevent unwanted transfers of nursing home residents to hospitals and unwanted implementation of intensive medical interventions and treatments (Tolle, Tilden, Nelson, & Dunn, 1998).

“Withholding of LST” was defined as “the considered decision not to institute a medically appropriate and possibly beneficial therapy,” in full anticipation that the relative would die “without initiation of the therapy in question” (Prendergast, 2000, p. 92).

“Withdrawal of LST” was defined as “the cessation and removal of any medical treatment with the explicit intent not to substitute an equivalent alternative treatment,” in full anticipation that the relative would die “as a result of the change of therapy” (Prendergast, 2000, p. 92).

“Advance directive” was defined as a verbal and/or written statement given by “an individual directing which forms of medical treatment the individual wishes to receive or forego, should he or she be in stated medical conditions (such as irreversible

unconsciousness, severe and irreversible dementia, or terminal illness) and lack decisionmaking capacity” (Hastings Center, 1987, p. 80).

Organizing Framework

The study was based on the preliminary organizing framework depicted in Figure

1.

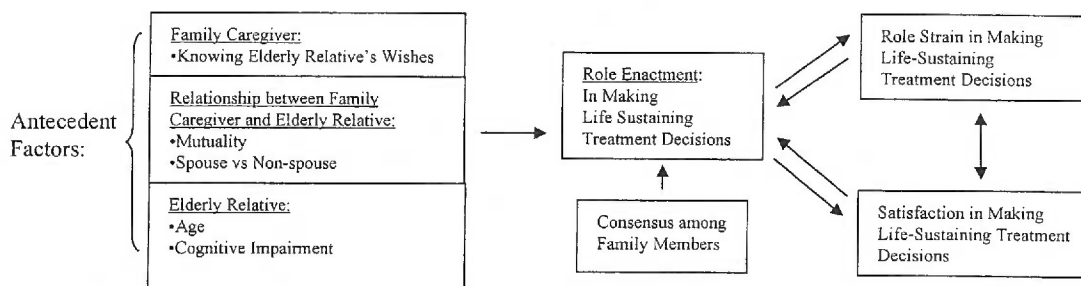


Figure 1. Preliminary Organizing Framework: Family Caregiver Role Strain and Satisfaction in Making Life-Sustaining Treatment Decisions

This framework was derived in part from the work of Burr and colleagues (1979) and the work of Archbold, Stewart, Greenlick, and Harvath (1986). It was also founded on the results of studies of family decision-making about LSTs for ill relatives at the end of life and three pilot interviews by the investigator. The framework included antecedent factors associated with role strain and rewards in other areas of family care. Involvement in LST decisions was conceptualized as one component of enactment of the family caregiving role within the ongoing context of family relations and family caregiving. Because LST decisions are made in context and over various lengths of time, role strain and satisfaction may vary. Therefore, the investigator explored the role strain and satisfaction perceived by the family caregiver after the death of the elderly ill relative.

Role Strain in Family Care

Much of the literature on the experience of family caregivers for elders has focused on role strain or burden (Archbold, Stewart, Harvath & Lucas, 1986; Given & Given, 1991; Given & Given, 1996). Family caregiver role strain is a multi-dimensional concept that includes the impact of caregiving on the family caregiver's emotional, physical, and financial status, his or her work and social life, and mortality (Given & Given, 1991; Given & Given, 1996; Schulz & Beach, 1999). Often, caregiver role strain has been studied in relation to elders' level of impairment and the number of direct care activities required, though indirect care activities such as planning, organizing, monitoring, and supervising care may also be demanding for family caregivers and produce stress (Bowers, 1987; Given & Given, 1991).

Several measures index various aspects of family caregiver strain (Appendix B). These measures range from single-item to 100-item measures and include single or multiple components of strain. Several measure strain in relation to direct care activities (Barber, 1993; Brooks, 1984; Cantor, 1982; Robinson, 1983). Most of the measures have been tested for reliability, but validity testing has been less frequently performed. Archbold and colleagues, who view role strain as central to an understanding of family care, developed one of the most comprehensive measures of caregiver strain, including nine dimensions of strain (Archbold et al., 1986) (Appendix B). Role strain in making LST decisions is a dimension of strain in family care that has not been explored. An extensive literature review, using databases such as HaPI (Health and Psychosocial Instruments), Medline, AgeLine, and CINAHL and references included in each reviewed

research report produced no measure for family caregiver role strain and satisfaction in making LST decisions for elderly ill relatives.

Satisfaction in Family Care

During the past decade, research has increasingly focused on the positive aspects of caregiving, including gains, benefits, rewards, gratification, pleasure, uplifts, enjoyments, and satisfaction (Kramer, 1997). Satisfaction has been examined in regard to relationship quality and changes in relationship quality between the caregiver and care-receiver; marital history; the care-receiver's level of physical, psychological, and social functioning; the caregiver's social support, frequency, and quality of social and recreational activities; and the care-related decision-making process (George & Gwyther, 1986; Kinney & Stephens, 1989; Kramer, 1993; Motenko, 1989; Smerglia & Deimling, 1997; Walker, Shin, & Bird, 1990; Worcester & Quayhagen, 1983).

Measures that index various aspects of satisfaction with family caregiving range from single-item to 110-item measures (Campbell, Converse & Rodgers, 1976; George & Gwyther, 1986; Kinney & Stephens, 1987; Miller, 1989) (Appendix C). Just as with measures of strain, most of the measures of satisfaction have been tested for reliability but validity testing is less frequent.

Four questionnaires measure patients' and family members' satisfaction with level of medical care and their involvement in decisions regarding that care (Appendix D). Three of these questionnaires were developed by Guyatt and colleagues (1995) and one was developed by Baker and colleagues (2000). None, however, focus on LST decisions and family caregiver role strain and satisfaction in making such decisions for elderly ill relatives.

Role Strain and Satisfaction in Making LST Decisions

Studies Focusing on Hypothetical Decision-Making Situations

Most studies of surrogate decision-making about LSTs have used hypothetical situations (Cogen & colleagues, 1992; Diamond, Jernigan, Moseley, Messina, & McKeown, 1989; Hare, Pratt & Nelson, 1992; Ouslander, Tymchuk, & Rahbar, 1989; Seckler, Meier, Mulvihill, & Paris, 1991; Suhl, Simons, Reedy & Garrick, 1994; Terry et al., 1999; Tomlinson, Howe, Notman & Rossmiller, 1990; Uhlmann, Pearlman & Cain, 1988; Zweibel & Cassel, 1989). In these studies, family members were presented with case scenarios and asked to indicate their preference of treatments for ill relatives with a range of conditions such as cancer, stroke, chronic lung disease, and dementia (Gerety et al., 1993; Hare et al., 1992; Ouslander et al., 1989; Seckler et al., 1991; Suhl et al., 1994; Uhlman et al., 1988; Zweibel & Cassel, 1989). Each case included different LST options. The studies did not examine family members' responses to actual decisions. However, studies that focused on actual decision-making about LSTs, and on medical and personal care decisions from concrete case examples have provided some indicators of role strain and satisfaction by family members (Silberfeld, Grundstein-Amado, Stephens, & Deber, 1996).

Studies Focusing on Actual Decision-Making Situations

Several studies have focused on actual decision-making about LSTs or other medical treatments for incapacitated or critically ill patients in hospital settings (Baggs & Schmitt, 2000; Jacob, 1998; Jeffers, 1998; Sonnenblick, Friedlander & Steinberg, 1993; Swigart, 1994; Swigart et al., 1996; Tilden et al., 1995; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999; Tilden, Toll, Nelson & Fields, 2001). However, the studies differed in

methods and analyses, making comparisons challenging. The studies by Jacob (1998) and Swigart and colleagues (1996) used the grounded-theory method, but other studies have been atheoretical (Jeffers, 1998; Sonnenblick et al., 1993; Tilden et al., 1995; Tilden et al., 1999). Sample sizes in the studies ranged from 11 to 108 family members. Data were collected using semi-structured interviews, self-report questionnaires, and psychometric measures (Tilden, Toll, Nelson, & Fields, 2001).

The studies by Sonnenblick and colleagues (1993) and Swigart and colleagues (1996) were conducted during the actual LST decision-making process. In the study by Sonnenblick and colleagues (1993), the mean time from the interviews with the children until the death of their parents was 4 ± 1 days; Swigart and colleagues (1996) interviewed family members within 72 hours of the time a LST decision was made. The studies by Jacob (1998), Jeffers (1998), and Tilden and colleagues (1995, 1999, 2001) were conducted 1 week to 15 years after the LST decision was made, or 1 to 8 months after the death of the terminally ill family member.

Sonnenblick and colleagues (1993) interviewed 108 Israeli children (ages were categorized into two groups < 45 years ($\underline{M} = 38.0$) and ≥ 45 years ($\underline{M} = 56.0$)) of 48 terminally ill elderly patients (ages 62 to 104, $\underline{M} = 80.0$, $\underline{SD} = 1.3$ – surprisingly low $\underline{SD}$) regarding their attitudes toward LSTs for their parents. A majority of those interviewed requested the continuation of fluid, nutrition, and medication for their parents (78%, 66%, and 73%, respectively). Approximately 25%-29% requested initiation of resuscitation, mechanical ventilation, and renal dialysis. The degree of the children's religiosity and the frequency with which they had visited their parents were significant predictors of their request for LSTs. Requests for LSTs were more frequent among children who were

ultraorthodox or orthodox Jews than among those who were secular. Also, requests for LSTs were more frequent among children who visited their parents more than once a week. Because the study was conducted in Israel, it is not clear whether these findings are generalizable to the U.S. population. Also, the impact of the Holocaust on the Jewish population was not described in the report. It is possible that it might have influenced the children's request for LSTs for their terminally ill parents.

Three research groups -- Cooper-Kazaz, Friedlander, Steinberg, and Sonnenblick (1999) and Tilden and colleagues (1999, 2001) have examined the effect of passage of time on family members' responses to LST decisions. Cooper-Kazaz and colleagues (1999) did a 6-year follow up study of the sample from the study by Sonnenblick and colleagues (1993). Fifty-one of the original 108 children participated in the later study. The researchers found that the attitudes of the children regarding the LST decisions that they had made for their terminally ill parents remained unchanged. In the study by Tilden and colleagues (1999), 30 family members were interviewed at 1 and 6 months after the death of their ill relatives. At 6 months after their relatives' death, family members reflected on "the need for corroborating evidence that they had made the right decision" (Tilden et al., 1999, p. 426). In a later study, Tilden and colleagues (2001) examined levels of family stress associated with decisions to withdraw LST at 1 to 2 months after a relative's death (T1), and 6 months later (T2). Seventy-four family members participated at T1 and 64 at T2. The mean family stress scores were high at both times. Although these groups all examined the effect of passage of time on family members' responses to LST decisions, they focused on different aspects (attitudes toward LST decisions,

certainty of the decision, stress associated with LST decisions) and on different time periods (1 to 2 months, 6 months, and 6 years after the death of the relatives).

Swigart and colleagues (1996) conducted their study during family members' actual decision-making process. They interviewed 30 family members (ages 34 to 74, $M = 50.0$) from 16 families with a critically ill member. The ages of patients ranged from 29 to 83 years ($M = 60.0$). Five additional families refused to participate, indicating that they were too stressed to talk. For 10 of the 16 critically ill family members, removal of supportive drug therapy or mechanical ventilation was recommended by physicians. Three families did not follow the physicians' recommendations. For six critically ill members, decisions were related to CPR. Ten of the critically ill members died in the ICU; six improved and were transferred out of the unit.

The researchers found that families' willingness to forego life support involved three interrelated processes: (a) understanding and reframing the critical illness of the patient, (b) reviewing and revising the perceived life story of the patient, and (c) maintaining family roles and relationships. Most of the families believed that they had done all that they could for the patient, that the patient did not want to continue living on life support, and that foregoing life support would not ruin important family relationships. However, a few families' attempts to forego life support for a critically ill family member were filled with conflict and an extended end-of-life period.

Jeffers (1998) and Jacob (1998) focused on family members' experiences with LST and other medical treatment decisions. Jeffers (1998) interviewed 11 family members, ages 58 –72 years, 14 months to 15 years after they had made treatment decisions for an incapacitated relative. Using an interpretive phenomenologic research

method, Jeffers identified four main themes that described family members' experiences in treatment decision-making: (a) contextualizing the decision, (b) actualizing agency, (c) reviewing and resolving, and (d) transcending. Contextualizing the decision referred to making the decision within the context of the relative's present, past, and future health. Actualizing agency referred to the experience and family members' feelings as they consented to or refused treatment for their relative. Reviewing and resolving referred to family members' reflections on their experiences with health care providers. Transcending referred to family members' strength gained from their faith, support of others, and use of the decision-making experience to help others.

It was unclear from Jeffers' report whether the decisions were to withhold or withdraw medical treatments and whether the decisions were related to LSTs. Three of the decisions were listed as "other treatment decision types," one was listed as consent to surgery, and another as consent to radiation and diagnostics. All but one family member experienced the death of their relative after the decision, but it is unclear whether the decision resulted in the death or some other event led to it.

Jacob (1998) interviewed 17 family members 1 week to 5 years after their involvement in limiting LST for a relative in the ICU. These family members (ages 18 to 71, $M = 57.3$) were relatives of a total of 15 ICU patients, who were between 16 and 85 years old ($M = 59.9$). Fourteen of the 15 patients were cognitively unable to make decisions. The 1 patient who was capable of participating in her own decisions refused to do so and a daughter took on the decision-making role. For 10 of the 15 patients, mechanical ventilation was either withheld or withdrawn. Decisions were made not to resuscitate 4 patients. The decision to consent to a gastrectomy was made for 1 patient.

Jacob used the grounded-theory method to describe these experiences of the family members who participated in these LST decisions.

When family members were asked how they felt about their decision, they talked about “looking back” and “going on.” They tried to make sense of the positive and negative aspects of their experience, integrate these into their lives, and continue living. Family members who felt that they had worked in harmony with health care professionals during the decision-making process were going on with their lives in a positive way. It was not clear how family members who had experienced disharmony in their interactions with health care providers or other problems during the decision-making process viewed their lives after the death of their relatives.

In a 1995 study, Tilden and colleagues examined the physician and nurse behaviors that family members found supportive and those they found to increase the burden of making LST decisions. The researchers interviewed 32 family members of 12 decisionally incapacitated ICU patients after the family members had participated in decisions to withdraw LSTs. The ages of family members ranged from 24 to 82 years; the ages of patients ranged from 41 to 69 years ($M = 50.4$, $SD = 14.9$). Eleven patients had mechanical ventilation withdrawn, 3 had intravenous fluid and medication withdrawn, and 1 had renal dialysis withdrawn. Family members found that these health care provider behaviors increased the burden of their decision: “postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the burden of decision-making on one person, withdrawing from the family, and defining death as a failure” (Tilden et al., 1995, p. 633). Behaviors of physicians and nurses that family members found helpful included these: “encouraging advanced planning, timely

communication, clarification of families' roles, facilitating family consensus, and accommodating families' grief" (Tilden et al., 1995, p. 633).

In the study by Tilden and colleagues (1999) cited earlier, the researchers explored the processes involved in hospital-based decision-making by 30 family members of 18 deceased ill relatives. The ages of the deceased relatives ranged from 34 to 78 years ($M = 59.0$, $SD = 14.0$). They were all decisionally-incapacitated, and they all spent time in an ICU. Their deaths followed the withdrawal of LSTs such as mechanical ventilation and renal dialysis and occurred within minutes to days after the withdrawal. Families move through four phases in a fairly linear sequence: (1) recognition of futility, (2) coming to terms, (3) shouldering the surrogate role, and (4) facing the question.

Six months after the LST decision, the main theme was family members' quest for certainty. To increase their certainty, they assessed sources of information and combined pieces of information in relation to the decision they had made. Their need to corroborate evidence for the decision was termed "seeking a triangulation of certainty" (Tilden et al., 1999, p. 437).

In a later study, Tilden and colleagues (2001) examined three aspects of family decision-making to withdraw LSTs for 51 deceased patients: (a) levels of family stress associated with the decisions at 1 to 2 months after patient death (T1) and 6 months later (T2); (b) factors that affected stress, and (c) reasoning used by families and clinicians in reaching the decision. The ages of the deceased relatives ranged from 30 to 90 years ($M = 60.0$, $SD = 16.9$). For 60%, the decision had been to remove mechanical ventilation. Other treatments that were withdrawn included intravenous fluids, feeding tubes, medications, and renal dialysis. Seventy-four family members participated at T1 and 64

at T2. Their ages ranged from 20 to 81 years ($M = 48.7$). Data were collected from 45 clinicians (age 25 to 57 years, $M = 37.5$) at approximately 2 months after the death of the patients.

Three items were used to measure family and clinician reasoning about the LST decision: (a) patient quality-of-life, (b) patient preference, and (c) prolongation of patient life. Family stress was measured using the Horowitz Impact of Events Scale (IES) and the Mental/Emotional State Scale of the Rand 36-Item Health Survey 1.0. The IES is a 15-item scale that consists of two subscales: (1) Avoidance (scale range = 0 - 40) and (2) Intrusion (scale range = 0 - 35). High scores indicate high stress. The Mental/Emotional State Scale is a 5-item measure of emotional state in the past month. Score range from 0 to 100, and low scores indicate a more negative emotional state.

On the three items used to measure reasoning about the LST decision, family members and clinicians rated patient quality of life and preference about the same. However, in a significant number of cases, family members rated prolongation of patient life higher than clinicians did. When family members and clinicians were asked to choose the most important factor, both groups chose patient preference.

Compared to other stressed groups, the family stress scores measured on the two scales were high at both T1 (Intrusion: $M = 15.9$, $SD = 9.1$; Avoidance: $M = 11.8$, $SD = 8.9$) and T2 (Intrusion: $M = 10.8$, $SD = 8.7$; Avoidance: $M = 8.5$, $SD = 8.5$). Although the scores were lower at T2, they still exceeded the stress levels of groups experiencing events such as ferry and construction disasters. At both T1 and T2, family emotional state scores (T1, emotional state: $M = 60.1$, $SD = 21.9$; T2, $M = 66.5$, $SD = 19.9$) were more negative than those found in other stressful situations such as surviving cancer. At T1,

factors that affected stress were the ethnicity of the patient, advance directives, and family commute distance. When the deceased patient was a member of an ethnic minority or did not have an advance directive (either verbal or in writing), family stress scores were significantly higher and emotional state scores were significantly lower. Longer commute distances by family members to the hospital was also associated with significantly higher stress scores. At T2, however, these factors were not significant.

Indicators of Strain from Making LST Decisions

Six indicators of strain from making LST decisions have been described in the literature: (a) emotional burden, (b) burden, (c) strain related to acceptance of the responsibility of the surrogate role, (d) strain due to lack of information, (e) strain from lack of mutual treatment goals of family members and health care providers, and (f) guilt and regrets about decisions.

Emotional Burden

In Jacob's study (1998), most of the family members interviewed had experienced the emotional burden of responsibility for the decision, but none wished that they had not been involved in the decision. In the study by Silberfeld and colleagues (1996), emotional burden was a consequence of surrogate decision-making by family members who were asked about medical and personal care decisions for a relative. To explore how choices should be made by surrogate decision-makers, the researchers compared views of 34 physicians, 36 family members of patients with AD, and 35 family members of patients with schizophrenia. The mean age of the family members was 57.2 years ($SD = 11.5$); the mean age of physicians was 41.0 years ($SD = 8.0$). Respondents were asked to classify medical and personal care decisions using concrete case examples, some based on recent

experiences. A greater proportion of physicians (88%) than family members (63%) believed they had sufficient information to make a surrogate decision. Many more family members than physicians experienced emotional burden (82% vs. 29%) and lack of support (31% vs. 3%) in making such decisions. A larger percentage of family members of patients with schizophrenia felt serious strain in making surrogate decisions than did family members of patients with AD (41% versus 24%). The reasons for this difference were not clear, though Silberfeld and colleagues did mention that far fewer family members of patients with schizophrenia than of patients with AD believed they had sufficient information to make a decision, and family members of patients with schizophrenia had more inter-family disputes than family members of patients with AD. The researchers concluded that family members want to make decisions when they have adequate information and support. The authors also suggested that lack of support may be one aspect of the strain of decision-making.

Burden

The burden of making life-sustaining and other treatment decisions has been described by Jeffers (1998) and by Tilden and colleagues (1995). Jeffers noted that family members who had made treatment decisions for incapacitated relatives felt there was “no other person within their experiences who shared the full burden and responsibility of decision-making” (1998, p. 362).

Strain Related to Acceptance of the Responsibility of the Surrogate Role

The studies by Jeffers (1998) and Tilden and colleagues (1999, 2001) found that the hardest thing for most family members to do was accept the responsibility of the surrogate decision-maker’s role. To describe their difficulties, family members used

terms such as “difficult,” “intense,” “painful,” “overwhelming,” “devastating,” “traumatic,” and “exhausting” (Tilden et al., 1999, p. 435; Tilden et al., 2001, p. 110).

Strain Due to Lack of Information

The importance of information provided by health care providers was described in the study by Tilden and colleagues, cited earlier; families spoke of “the need for more information,” and said they were “starving for information” (1995, p. 638). Family members wanted to be prepared and therefore wanted accurate information about the patient’s prognosis as soon as possible.

A need for information about the prognosis of the patient was also found by Hanson, Danis, and Garrett (1997), who 2 months after the death of a relative interviewed by phone 461 family members regarding their perceptions of the care their relatives had received. The relatives died from chronic diseases such as chronic lung disease, cancer, congestive heart failure, and stroke; their average age at death was 79.4 years ($SD = 8.3$). Forty-four percent of the family members suggested that physicians should improve their communication with family members. They wanted information that was honest, compassionate, and timely, and more information on the patient’s prognosis. They also wanted physicians to treat the whole person, instead of just aspects of the dying person, and to use less medical jargon.

Norton and Talerico (2000) have suggested behaviors of health care providers that can help the process of decision-making at the end of patients’ lives. Using the grounded theory method, the researchers interviewed 20 participants, of whom 10 were nurses, 5 physicians, and 5 family members of patients who either had a life threatening illness or had died 6 months to 2 years earlier. The researchers found that family members had

experienced difficulties in obtaining the information they needed to make end-of-life decisions, and suggested specific communication and assessment strategies to be used by health care providers to facilitate such decision-making. Communication strategies recommended included “being clear, avoiding euphemisms, spelling out the goals and expectations of treatment, using words such as “death” and “dying,” and being specific when using such words as “hope” and “better.” Assessment strategies recommended included assessing patients’ physical conditions and end-of-life wishes, patients’ and family members’ understanding of the disease and prognosis, and their expectations and goals” (Norton & Talerico, 2000, p. 6). The current study built on work done by Tilden and colleagues (1995), Hanson and colleagues (1997), and Norton and Talerico (2000), to lay the foundation for developing measures of family caregiver role strain and satisfaction that can be used to evaluate information provided by health care providers, as well as their communication and assessment strategies.

Strain from Lack of Mutual Treatment Goals of Family Members and Health Care Providers

In Jacob’s study (1998), family members discussed the need to arrive at a judgment about the patient’s condition and work with health care providers to ensure that family members’ decisions about LSTs are enacted. Family members found the decision-making situation troubling when the patient was treated by health care providers who did not attend to family treatment goals. These researchers concluded that health care providers can “best support family members by helping the members arrive at a judgment about the patient’s condition and treatment desires and by connecting with the family members to ensure that treatment goals are mutual” (1998, p. 30). They also concluded

that long-term acceptance of the experience and the decision depends greatly on the interactions between the family members who make the decision and health care providers.

Guilt and Regrets about Decisions

Mayer and Kossoff (1999) retrospectively analyzed the clinical course of 105 patients who died in a neurological intensive care unit or shortly after transfer to another unit. Seventy-four patients died of cardiac death, and 31 of brain death. Of the 74 patients who died of cardiac death, 32 (mean age 69.1 years, $SD = 15.0$) had mechanical ventilation withdrawn. Of the 42 patients (mean age 67.7 years, $SD = 14.4$) who did not have mechanical ventilation withdrawn, 15 had other, unspecified treatments withheld or withdrawn. Of the 31 patients who died of brain death, 3 had treatments withheld or withdrawn, and 13 were “Do Not Resuscitate” (DNR). Thirty surrogate decision-makers of the deceased patients who had mechanical ventilation withdrawn were surveyed 49 to 719 days after their relatives’ death, and 24 returned the survey. One question asked respondents to rate on a 4-point scale (very comfortable, comfortable, uncomfortable, and very guilty) their level of comfort or guilt with the decision to withdraw life support. Two respondents felt very guilty, 3 were uncomfortable, 10 were comfortable, and 9 were very comfortable. Because the researchers did not contact 20 of the surrogate decision-makers of withdrawing treatment, they may have underestimated the number of surrogate decision-makers who were uncomfortable with the decision to withdraw life support. Furthermore, the researchers measured two concepts (level of comfort or guilt) in one item, which might have weakened the findings from this particular item.

Studies have not specifically explored whether family members have regrets about LST decisions, though in the study by Tilden and colleagues, regrets were addressed by one study participant, who said: "That's why basically I have no regrets. I was carrying out her wishes" (1999, p. 437). There is some question about possible feelings experienced by family members who make LST decisions for a relative who has not expressed his or her wishes regarding end-of-life care, and by family members who do not follow the wishes of the relative. Some family members have reported guilt because they did not make the decision soon enough to terminate LSTs for their relative. They felt that they had prolonged their relative's suffering. Also, in the study by Jeffers (1998), when family members considered what might have happened had they made different decisions, some expressed feelings of guilt or regret regarding their decisions. In the study by Jacob (1998), a woman who did not know her husband's wishes found it a tremendous burden to have to make a LST decision. Another participant expressed profound guilt at withholding LST from her husband. She wished that she had transferred him to another facility. Recently, Mitchell, Berkowitz, Lawson, and Lipsitz (2000) surveyed surrogate decision makers (family members and/or guardians) (≥ 54 years) of 94 patients (≥ 65 years) who had been on tube-feeding for at least 2 months and had been unable to make their own health care decisions at the time of tube placement. The survey asked about the health status of the patient, advance directives, communication with health care providers, perceived goals of tube-feeding, and the decision-making process. Seventy-one of the 94 decision-makers were in favor of tube feeding at the time of the decision, and retrospectively, 58 continued to be in favor of tube-feeding, but 57 felt that the tube-feeding decision had not been an easy one, and 51 felt that they had not made the

best decision (the numbers may not add up, but they were the ones reported). Although these findings suggest that some decision-makers regretted the decision to have the patient tube-fed, the authors did not address this specifically, nor did they examine the responses of decision-makers who had elected not to place feeding tubes.

Indicators of Satisfaction from Making LST Decisions

Two indicators of satisfaction from making LST decisions have been described in the literature: (a) satisfaction with care-related decision-making, and (b) comfort with decisions based on actual and hypothetical situations.

Satisfaction with Care-Related Decision-Making

Smerglia and Deimling (1997) examined the impact of caregiver type (adult child versus spouse), care-receiver impairment, and family adaptability, cohesion, and conflict on satisfaction with care-related decision-making and caregiver well-being. Of the 244 caregivers who participated in the study, 169 were adult child caregivers and the remaining 75 were spouses. In addition to being interviewed, participants answered questions about family structure and environment, the caregiving context and network, satisfaction with caregiving decisions, and caregiver well-being. Three predictors -- being a spouse caregiver, having less family adaptability, and feeling less satisfaction with decision-making -- were significant predictors of higher caregiver depression. Caregivers who reported more satisfaction with care-related decision-making reported better health, but this was not statistically significant, suggesting that satisfaction with care-related decision-making is not directly linked to health.

Comfort with Decisions Based on Actual and Hypothetical Situations

As stated earlier, when Mayer and Kossoff (1999) asked surrogate decision-makers of deceased patients to rate on a 4-point scale (very comfortable, comfortable, uncomfortable, and very guilty) their comfort or guilt with the decision to withdraw life support, 9 respondents were very comfortable, 10 were comfortable, 3 were uncomfortable, and 2 felt very guilty about their decision. Using hypothetical situations, Mezey and colleagues (1996) examined anticipated decisions about LSTs in 50 spouses of patients with a minimum of Stage 4 AD. The spouses participated in open-ended interviews and completed instruments that measured “decisions to consent to or forego four treatments (resuscitation, breathing machine, feeding tube, and antibiotics) under the condition of critical illness and irreversible coma, patient’s quality of life, and spouse standard of decision-making” (Mezey et al., 1996, p. 145). Spouses were significantly more likely to forego treatments for coma (66%) than for critical illness (10%). Under the condition of critical illness, spouses who consented to treatment were more comfortable with the decision than were spouses who did not. This was true for all four treatments and the differences were significant for CPR and antibiotics ($p = .001$).

Using hypothetical scenarios to examine medical treatment preferences including LSTs, Emanuel, Barry, Stoeckle, Ettelson, and Emanuel (1991) found that 77% ($n = 312$) of the 405 outpatients surveyed and 86% ($n = 88$) of the 102 members of the general public surveyed felt that making decisions for themselves would be easier than making decisions for incompetent, ill relatives.

Antecedent Factors that may affect Responses in Making LST Decisions

Three categories of factors were found that focused on the time preceding LST decision-making: (a) family member factors, (b) relationship factors, and (c) elderly relative factors.

Family Member Factors

Knowing the elderly relative's wishes. Although physicians' knowledge of their patients' LST preferences might be lacking (SUPPORT Principal Investigators, 1995), family members' knowledge of their relative's wishes regarding LSTs has been found important in making actual and hypothetical LST decisions for relatives (Jacob's, 1998; Mayer & Kossoff, 1999; Reckling, 1997; Teno, Stevens, Spornak, & Lynn, 1998; Tilden et al., 1999; Tilden et al., 2001). In a study of the satisfaction, understanding, and feelings of family members who signed actual DNR orders for a relative, 70 family members were surveyed 2 months after their ill relative's death, and 22 surveys were returned (Loscalzo, Cooper, Arena, & Llovera, 1996). The majority of the deceased relatives had had terminal cancer. Patients' wishes, comfort, and quality of life were the major factors in family members' decisions. Less important factors were reported to be strain on the patient's family and the wishes of other family members.

Karel and Gatz (1996) examined the importance attributed to the following factors when considering a hypothetical LST decision for oneself or a parent: (a) mental capacity, (b) pain, (c) type of treatment, (d) time left to live, (e) doctor's recommendation, (f) opinion of family, (g) age, (h) burden of care, (i) financial strain, and (j) knowing what the individual would have wanted. The authors used data collected from 1,205 persons who represented three generations, from a total of 291 families; they

ranged in age from 24 to 93. In approximately 267 parent-child dyad pairs (n was not specified), 88% of the children (n = approximately 235) felt that knowing their parents' wishes was extremely important in considering LST decisions for them.

Relationship Factors

Spouse versus non-spouse. Reust and Mattingly (1996) conducted 13 semi-structured interviews with 22 patients and 17 family members to study family involvement in medical decision-making. Patients were recruited from a community-based family practice residency program. The researchers found that when a parent was incapacitated and decisions about nursing home placement or a living will had to be made by adult children, decision-making was usually troubling. In contrast, when a spouse had to make a decision for an incapacitated patient, the decision-making was most often described as supportive of the patient: the spouse "just knew" what the patient would have wanted (1996, p. 43). The spouse would take over and make decisions by using substituted judgment and expert knowledge of the patient.

Mutuality. Mutuality is defined as the positive quality of a care receiver/caregiver relationship. In a study including 78 primary caregiver/care receivers dyads, Archbold, Stewart, Greenlick, and Harvath (1990) found that greater mutuality was associated with lower levels of caregiver role strain for six of nine aspects of role strain measured (strain from feelings of being manipulated, global strain, mismatched expectations, increased tension, role conflict, and direct care), both at 6 weeks and 9 months after care receivers had been discharged from a hospital. It may be that family caregivers who have a positive relationship with their elderly relative experience less role strain in making LST

decisions. However, no measures of family caregiver role strain in making LST decisions have been found.

Elderly Relative Factors

Age. Hamel and colleagues (1999), who investigated the effect of age on decisions by health care providers to withhold LSTs among 9,105 hospitalized adult patients, found that after adjusting for differences in their prognoses and preferences, older age was associated with higher rates of decisions to withhold ventilator support, surgery, and dialysis. The same findings were common among patients with dementia. However, the authors did not examine how age and cognitive impairment of patients might have been associated with LST decisions by family members.

In the study by Karel and Gatz (1996) described earlier, the researchers found a great deal of variability in whether age was an important factor in considering LST decisions. Among 1,205 subjects ranging in age from 24 to 93, 20.2% felt that age was not important, whereas 30.6% felt that it was extremely important. Although age seemed more important for older people than middle-aged and younger people, there was a great deal of variability in the importance contributed to age among all three groups. Clearly, there is a need to better understand how the age of elderly relatives may be associated with decisions made by family members regarding LSTs.

Cognitive impairment. Studies of the importance of relatives' medical conditions in family members' care decisions are inconclusive. While elders' physical functioning has not been found to be a significant predictor of caregivers' satisfaction with decision-making (Smerglia & Deimling, 1997), Silberfeld and colleagues (1997) found that a greater portion of family members of younger patients with schizophrenia were

dissatisfied with their medical and personal care decisions than family members of elderly patients with AD.

Using hypothetical situations, Zweibel and Cassel (1989) examined the most commonly considered criteria for decision-making at end-of-life (survival potential, pain, cost, patient's cognitive status, patient's age, and patient's ability for independent living). Lack of mental acuity and being a burden on the family were the most important criteria for elders and family members who functioned as surrogate decision-makers. Ninety percent of the 55 elders and 90% of the 107 family members who participated in the study would consider lack of mental acuity when making decisions about LST options. Pain was an important factor for many of the respondents of both groups, but the patient's age was not important for either group. Survival potential appeared to be a relatively more important factor for family members than for patients.

In the study by Mezey and colleagues (1996) described earlier, spouses were more likely to decide to forego all LSTs in the face of critical illness when patients had Stage 7 AD than when patients had Stages 4 to 6 AD. When considering a LST decision for a parent, Karel and Gatz (1996) found that family members ($n = 185$) who were caregivers rated the parent's mental capacity, age, and time left to live less important than did non-caregivers.

Summary

While some research has focused on the effects on family members of making LST decisions for ill relatives, research is lacking on LST decision-making by family caregivers within the context of ongoing family relations and family caregiving. Some indicators of family caregiver role strain and satisfaction and antecedent factors that may

affect responses in making LST decisions have been documented. However, no existing measure was found that measures family caregiver role strain and satisfaction in making LST decisions for elderly ill relatives. The reported study has addressed this gap in the literature.

CHAPTER 3

Method

Design

This exploratory-descriptive study was designed to (1) refine the conceptualization of family caregiver role strain and satisfaction in making life-sustaining treatment decisions, within the context of ongoing family care, (2) describe factors associated with family caregiver role strain and satisfaction in making life-sustaining treatment decisions, and (3) generate items for measures of family caregiver role strain and satisfaction in making life-sustaining treatment decisions, based on the refined conceptualization and words of caregivers.

Semi-structured interviews were conducted with family caregivers to obtain descriptions of their role strain and satisfaction in making LST decisions for elderly ill relatives in a variety of settings. The interview guide was reviewed by five regional experts in gerontology, gerontological and family care nursing, and decision-making at the end-of-life and pilot tested with three family caregivers (Appendix E). Data obtained from the qualitative interviews were analyzed using content analysis.

Sample

Purposive sampling strategy was used to assure that the sample would include family caregivers with a broad range of experiences in making LST decisions, and there would be participation by both male and female caregivers and by caregivers from minority groups. Family caregivers of relatives who had died from a range of primary diagnoses, including heart disease, cancer, chronic obstructive pulmonary disease and dementia, and in a variety of settings such as homes, nursing homes, assisted living

facilities, and hospitals were included in the study. Family caregivers of persons with dementia were included because of the frequency with which such family caregivers function as surrogate decision-makers. According to Nunnally and Bernstein (1994), when constructing measures it is essential that the domain of content includes “both the material to be tested on and the population for whom the material is to be suitable” (1994, p. 295). The inclusion of family caregivers of elderly relatives who had died of various diseases and in different settings was designed to enhance the applicability of new measures of family caregiver role strain and satisfaction in making LST decisions across a wide range of situations.

Inclusion Criteria

Family caregivers were included if they (a) had participated in deciding to either withhold or withdraw LSTs for relatives 65 years of age and older who had died 2 to 6 months earlier; (b) read and spoke English; (c) were adult (21 years of age or older); and (d) were representative of the population in the greater Portland Metropolitan area by gender, race and ethnic origin.

All interviews except for two, were conducted 2 to 6 months (59 to 183 days, mean 104 days) after the death of the elderly relative. Two caregivers were interviewed more than 6 months (209 and 239 days) after the relative’s death. The delay in interviewing occurred because of rescheduling by the caregivers and the investigator’s decision not to conduct interviews of a sensitive nature close to holidays such as Thanksgiving. The time frame of 2 to 6 months after the death was selected based on a recommendation by Dr. Rosenfeld (personal communication, 1999) and on the literature (Cowles, 1988; Foley and Brock, 1990; Tilden et al., 1995). Cowles (1988) suggested

that interviews be conducted 1 month after the death of a relative, Foley and Brock (1990) suggested initiating interviews 3 months after the death of a relative, to minimize respondent burden and recall error. Tilden and colleagues (1995) contacted and recruited families to be interviewed 2 to 6 months after the death of eligible patients. Because the topic of the study was very sensitive, children and adolescents were excluded as participants.

Procedure

Sample Access

After Institutional Review Board (IRB) approval was obtained, health care providers from Oregon Health & Science University (OHSU), Legacy Health System, Portland, Oregon, and the Veterans' Affairs Medical Center (VA) helped recruit participants into the study (Appendix F). Four physicians, three nursing managers, one nurse practitioner (NP), one chaplain, and one faculty member from the OHSU School of Nursing identified potential family caregivers meeting the criteria to participate. Some of these health care providers cared for elders in health care settings such as homes, nursing homes, assisted living facilities, and hospitals; others interacted more with family caregivers of elders.

Recruitment Procedure

In the initial step in recruiting family caregivers, the investigator met with nursing managers, NPs, and physicians to present the study, and ask for their help. Each of the health care providers received a short description of the study (Appendix G). The health care providers identified all of the family caregivers who they knew had participated in making LST decisions for a deceased elderly relative during the past 6 months. Data on

the type of LST decisions made, the health care providers' perception of the family caregivers' experiences in making such decisions, and the characteristics of the deceased relative were obtained from the providers. Based on these data and discussions that followed with the health care providers, a list was made of the family caregivers to contact. The list was prioritized based on family caregivers' experiences, including type of LST decision, gender, minority group membership, and characteristics of the deceased relative.

The nursing managers ($n = 3$), NP ($n = 1$), and physicians ($n = 4$) then contacted the family caregivers by telephone, briefly explained the study, and invited the caregivers to participate. Family caregivers who had participated in making LST decisions were contacted at least 2 months after the death of their elderly relative. If family caregivers agreed to participate in the study, the nursing managers, the NP, and the physicians gave their names to the investigator.

To obtain a sample of 17 family caregivers, the health care providers identified 23 caregivers. Three could not be reached by telephone, 1 was lost to follow-up contact, 1 caregiver declined participation for unknown reasons, and 1, who said that she would like very much to participate in the study, was not allowed by a family member to do so, because the family member was afraid that the caregiver would be upset when talking about the deceased relative.

The investigator then telephoned the 18 family caregivers to further explain the study and invite questions about it. None of the family caregivers contacted by the investigator declined to participate. However, one family caregiver contacted by the investigator had had a very difficult time with the LST decision she had made for an

elderly relative, and wanted time to think about whether she had the emotional strength to participate in the study. After thinking about it, the family caregiver set up a time for the interview, but on the day of the interview, she canceled the appointment due to unrelated reasons. A few days later the investigator tried to contact the caregiver by telephone. When she was unsuccessful in reaching the potential participant with two phone calls, she elected not to try to re-establish contact with this family caregiver.

Sample Size and Characteristics

Family Caregivers

The sample consisted of 17 family caregivers. Nine were Caucasian women and 6 were Caucasian men. Two African-American caregivers participated: 1 man and 1 woman (Table 1). As noted earlier, purposive sampling strategy was used to assure participation by both male and female caregivers and by caregivers from minority groups. Because men generally have higher death rates than women at every age (U. S. Department of Commerce Economics and Statistics Administration, 1995) and 73% of all caregivers are women (National Alliance for Caregiving and American Association of Retired Persons, 1997), the sample was expected to include more women than men. The demographic characteristics of the family caregivers are presented in Table 1. To protect the confidentiality of the caregivers, demographics of individual caregivers or their deceased relative are not given.

Table 1

Characteristics of Family Caregivers

<u>Characteristic</u>	<u>Family Caregivers (N=17)</u>
Age (years)	
Range	26 - 85
Mean (<u>SD</u>)	59.2 (14.7)
Marital status	
Married	8
Widowed	6
Single	2
Divorced	1
Education	
High school	5
Some college	5
College	3
Master's degree or higher	4
Employment	
Retired	7
Employed outside the home	9
Employed inside the home	1

(table continues)

Table 1

Characteristics of Family Caregivers

<u>Characteristic</u>	<u>Family Caregivers (N=17)</u>
Relationship to deceased relative	
Adult child	8
Spouse/friend	8
Grandchild	1
Religion	
Presbyterian	3
Baptist	2
Catholic	2
Christian	2
Church of Christ	2
Protestant	2
Lutheran	1
Metaphysics	1
No religion	1
Not disclosed	1

Note. SD = standard deviation; N = number of participants.

Five husbands and two wives had participated in making LST decisions for their spouses. One person had participated in making such decisions for a friend. Five daughters had participated in making LST decisions for four mothers and one father. Three sons had participated in making such decisions for two mothers and one father.

One of the sons stated that his mother had been the main decision-maker and decided not to have specific LSTs. One granddaughter had made the LST decision for her grandmother. One granddaughter and her grandfather participated in the same interview about their deceased relative. (The interview was scheduled with the grandfather, but during the interview the granddaughter was asked by her grandfather to join the conversation because of her participation in and recollection of the LST decision-making for their relative. Both of them read and signed the consent form.)

Except for one family caregiver who elected not to disclose religious affiliation and one who was not affiliated with any religion, the sample reported various religious affiliations, 14 of them associated with the general Christian religion.

Deceased Elderly Ill Relatives

The deceased relatives had had various diagnoses such as emphysema, renal failure, dementia, cancer, stroke, coronary artery disease (CAD), congestive heart failure (CHF), and myocardial infarction (MI). The demographic characteristics of the deceased elderly relatives are presented in Table 2.

Table 2

Characteristics of Deceased Ill Relatives

<u>Characteristic</u>	<u>Deceased Ill Relatives (N = 16)</u>	
Age		
Range	67 – 92	
Mean (<u>SD</u>)	81.4 (9.0)	
Gender		
Female	12	
Male	4	
Ethnicity		
Caucasian	14	
African American	1	
American Indian	1	
Advance Directives		
Written	11	
Verbal	4	
None	1	
Living arrangement		
House	7	
Apartment	4	
Assisted living	2	
Retirement home	1	
Nursing home	1	
Alzheimer unit	1	(<u>table continues</u>)

Table 2

Characteristics of Deceased Ill Relatives

<u>Characteristic</u>	<u>Deceased Ill Relatives (N = 16)</u>
LST decision: withheld ^a	9
CPR	4
Hospitalization	2
Chemotherapy	1
Renal dialysis	1
Surgery	1
Food & fluids	1
ICU admission	1
LST decision: withdrawn ^b	8
Mechanical ventilation	6
Medication	3
Feeding tube	1
Fluids	1

Note. SD = standard deviation; N = number of participants. a. The frequencies add up to more than 9 because some deceased ill relatives had more than one LST withheld. b. The frequencies add up to more than 8 because some deceased ill relatives had more than one LST withdrawn.

Fifteen of the 16 deceased relatives had had advance directives. Six had written advance directives, and 4 had a power of attorney for health care; 4 had stated their wishes verbally but not in writing, and one had a living will. Eight of the deceased relatives had LSTs withheld, 7 had treatments withdrawn, and 1 had treatments both withheld and withdrawn. Medications withdrawn included: (a) cardiac medications n = 1,

(b) vaso-pressors $n = 1$, and (c) antibiotics $n = 1$. The approximate time from the “final” decision to withhold or withdraw LST treatments until the death of the elderly relative ranged from seconds to 92 days. Six of the elderly relatives died within seconds to minutes after implementation of the LST decision, three within hours, six within days to approximately 3 weeks, and one after 3 months. Prior to death, four of the 16 elderly relatives had hospice involved in their care, from 2 to 21 days.

Of the 16 elderly ill relatives, 9 had died in the hospital setting (ICU $n = 6$, Medical unit $n = 2$, Step down unit $n = 1$), 3 had died in assisted living facilities, 1 in a retirement home, 1 in a vacation house, 1 in an Alzheimer’s unit, and 1 in a hospice facility. Prior to death, 7 of the elderly relatives had lived in houses, 1 alone, and 6 with other family members. One had lived alone in an apartment. The others had lived in assisted living facilities, in retirement and nursing homes, and in an Alzheimer’s unit.

Instrument

Pilot Interviews

The interview guide was pretested with three family members of elderly ill relatives (70 years and older) who had died following LST decisions. The purpose of the pilot interviews was to assess the clarity and comprehensibility of the questions, and to establish the approximate length of the interview. The three family members were all middle aged; two were daughters who had participated in making LST decisions for their mothers, and one was a nephew who had participated in making such decisions for an aunt. Two of the elderly relatives had suffered from AD, the third from cardiac disease. The interviewees did not find the questions ambiguous and were able to respond to them with a free flowing dialogue. The pilot testing of the interview guide supported its clarity

and comprehensiveness and no changes needed to be made. The average length of the interview was approximately 1 hour (range of interviews was 22 to 77 minutes).

Qualitative Interviews

In the interviews, the investigator included demographic questions in order to describe the study sample more completely. Because of the eagerness of the first interviewee to describe her experiences in making LST decisions, in subsequent interviews the investigator gave the demographic questions in writing at the end of the interview (Appendix E).

Data Collection

The interviews were scheduled to last approximately 1 hour in order to prevent respondent fatigue (Cowles, 1988; Flesch, 1975b). They ranged in time from 36 to 128 minutes (min.) ($M = 68.8$, $SD = 29.0$). The few longer interviews (3 interviews: > 75 min.; 5 interviews: > 60 and ≤ 75 min.; 8 interviews: ≤ 60 min.) were not limited because of the expressed desire by the family caregiver to continue.

During the interviews, the investigator observed whether family caregivers hesitated to answer certain questions or seemed anxious or disturbed by certain questions. Observations were carefully mentioned to the caregivers. Most seemed “inspired” to speak about their experiences, and often began to tell about their deceased ill relative before the investigator could start the tape recorder.

After the interviews, family caregivers were provided with the investigator’s telephone number and encouraged to call if they had additional feelings and thoughts they would like to discuss. None of the participants contacted the investigator after the interview. The investigator made memos of the interviews and her interactions with the

family caregivers to help her recollect non-verbal communications during the interviews and the context in which they occurred.

The interviews were conducted at a site and time chosen by the caregivers, to promote their convenience and comfort in participating in the study. All but three of the interviews were conducted at caregivers' homes. One interview was conducted in a quiet corner of a hospital corridor, and two interviews were conducted in the caregivers' offices. Prior to the interview, the study was explained and a consent form was signed (Appendix H). All interviews were tape-recorded.

Data Management

Recorded interviews were transcribed using Microsoft Word Version 97. After transcription, they were verified for accuracy and completeness by the investigator. The software program, Non-numerical Unstructured Data Indexing Searching and Theorizing (QRS NUD*IST 4) was used to facilitate handling of the data. QRS NUD*IST 4 is organized in two interlocked subsystems: the Document System and the Index System. Verified transcripts were organized and stored in the Document System. The investigator wrote and stored memos of the interviews in this system. The Index system is made up of nodes. These notes contained coded data bits and were moved into categories and subcategories that emerged from the data and were constructed by the investigator. As data analysis proceeded, the index system was used to reorganize and reduce data by shifting and emerging nodes.

Protection of Human Subject

Approvals for the study were obtained from IRBs of three major health care institutions.

All study participants were free to decline answering any questions at any point in the interview, to stop the interview at any point, and to withdraw from the study at any point. All information obtained from the participants was kept strictly confidential. Confidentiality was protected by (a) assigning each participant a code number and only the code number appeared on the typed transcripts, (b) coding responses from the interviews, and (c) by storing them and transcripts of the interviews in a computer with a restricted password. Names of persons and places mentioned during the interviews were erased and changed to other non-related names. Tapes of the interviews, printed copies of interviews for committee members and participants of the gerontological seminar, and notes from the interviews were placed in a locked safe. After the transcription of the tapes, the interviews on the tapes were erased.

The potential risk to family caregivers during the interviews involved psychological discomfort from remembering and speaking about the events, experiences, and feelings in making LST decisions for elderly ill relatives. The investigator is an expert clinician and knows how to assess behavioral symptoms in people and used clinical judgement to intervene when necessary. One of the family caregivers who became especially upset during the interview agreed to a break when one was recommended by the investigator. If appropriate during the interview, the investigator reminded the family caregivers that they were free not to answer any questions. If the investigator had noticed increased anxiety or distress from family caregivers, she would

have provided them with a list of telephone numbers of public mental health providers and encouraged them to contact and speak with one of them. None of the participants requested or was provided with a list of telephone numbers of public mental health providers.

Analysis

Transcribed interviews were analyzed using content analysis (Krippendorff, 1980; Markoff, Shapiro, & Weitman, 1974; Waltz, Strickland, & Lenz, 1984), because (a) it is the method of choice in the initial stages of instrument development, (b) it can be applied to recorded data, (c) it can provide a combined deductive-inductive approach to data, (d) it is systematic and provides relative objectivity by incorporating rules into the analysis, and (e) it allows actual words and phrases from individuals to be used to minimize loss of the richness of their meaning. Also, content analysis is appropriate for drawing scientific conclusions (Waltz et al., 1984). Content analysis has been defined in the literature in several ways (Berelson, 1954; Krippendorff, 1980; Markoff et al., 1974; Waltz et al., 1984). For the current study, content analysis was defined as a methodical measurement involving “the systematic and objective reduction or simplification of recorded language to a set of categories ... that represent the presence, frequency, intensity, or nature of selected characteristics” (Markoff et al., 1974, p. 5; Waltz et al., 1984, p. 299).

Since some potential indicators and antecedent factors of family caregiver role strain and satisfaction in making LST decisions have been documented and were included in the preliminary organizing framework, they were looked upon as deductively derived. Indicators and antecedent factors of family caregiver role strain and satisfaction from the sample data were interpreted as inductively derived. According to Waltz and colleagues

(1984) and Imle (1997), a combination of the two strategies may be used and is appropriate with an exploratory-descriptive research design. Indicators of family caregiver role strain and satisfaction reported in the literature (e.g., lack of information) were included as tentative categories for the content analysis.

Content analysis consisted of two interrelated processes: (a) specifying characteristics of the content to be analyzed and (b) “applying explicit rules for identifying, coding, and recording the characteristics (Waltz et al., 1984, p. 299). Three explicit rules were applied by the investigator. After the transcripts were verified, each was read to gain a sense of the whole (Mertens, 1997). Next, each interview was read again and major categories such as advance directives, health care providers, and decision-making were identified, based on the first rule of data coding and questions suggested by Glaser (1978) and by Waltz and colleagues (1984). Each interview was then read and coded, line by line, to achieve a complete and thorough coverage of the data. The investigator did all coding of the data to minimize the risk of missing an important category or subcategory and a feeling by the investigator that something might have been left out (Glaser, 1978). The unit of analysis was words and phrases spoken by study participants. Codes were written next to the lines. If the investigator was uncertain of a code, she left out the line and wrote in the margin that the line had not been coded. Lines without codes and areas of data for which the investigator questioned the codes were marked with colored stickers. The investigator discussed lines not coded and areas of uncertainty with two of her dissertation committee members. Lines not coded were coded and codes determined based on these discussions. Before coding each line electronically and entering it into QRS NUD*IST 4, selected segments of four interviews were also

coded by one of the dissertation committee members to ensure interrater reliability in the coding. Once full agreement on the coding scheme was reached, the investigator electronically coded each line, and codes were verified and entered into subcategories or potential indicators. As the investigator worked through each interview, codes from each of them were compared with others from the same study participant and other participants to clarify relationships. Categories and subcategories that emerged from the data were compared to the categories and subcategories found in the literature. Because of this, the content of the interview data was read and processed several times.

Initially, 25 categories and 255 subcategories were created from the interview data. Each code included the words and phrases used by study participants to describe it, which minimized the loss of meaning (Markoff et al., 1974; Waltz et al., 1984). Since some of the codes were unrelated to family caregiver role strain and satisfaction in making LST decisions for an elderly relative, they were deleted as such, but saved for potential later analysis. Many subcategories were combined into one, since they covered only one concept; e.g., “family being supportive” and “family not being supportive” were combined to “family support.” Other codes had only one non-important coded data bit defining them, and were therefore deleted. Others were moved under other subcategories; e.g., “being there” was moved to “family relations.” Initially, the investigator wrote definitions for 25 categories and 97 subcategories. Definitions defining subcategories of a larger category named “Health Care Provider” and their data bits were analyzed by participants attending the gerontological seminar, to ensure they agreed with the investigator on the initial analysis. Based on discussions with committee members, the number of categories and subcategories was reduced. During this process, definitions

were refined and modified to capture the meaning of the evolving categories and subcategories.

The categories were reduced from 25 to 6 (caregiver, ill relative, family relations, health care provider, health care system, and responses) as it became evident that several subcategories could be included under fewer, more broadly defined categories. The inductive approach and the data analysis discussions with the dissertation committee members prevented premature closure of the analysis. As recommended by Waltz and colleagues (1984), created categories were mutually exclusive. Draft items for measures of family caregiver role strain and satisfaction in making life-sustaining treatment decisions were then generated from each of the identified categories.

Reliability and Validity

Threats to reliability and validity of the data obtained during the interviews were addressed using the methods suggested by Waltz and colleagues (1984) and LeCompte and Goetz (1982). Reliability of the data was enhanced by having the investigator serve as the sole interviewer. To enhance the validity of the data, the investigator observed whether participants hesitated to answer certain questions or seemed anxious or disturbed by certain questions and wrote notes about participants' responses immediately after the interviews. Participant behaviors and inconsistencies in responses were noted by the investigator and carefully called to the participants' attention.

Threats to reliability of the content analysis were addressed using the recommendations of Garvin, Kennedy, and Cissna (1988), who emphasized that both unitizing and interpretive reliability are important. Unitizing reliability, defined as "consistency in assessing what is to be coded" (Garvin et al., 1988, p. 52; Waltz et al.,

1984), was enhanced by using interviews that were tape-recorded and transcribed. The transcriptions were coded line-by-line and the identified units (words and phrases) were examined repeatedly. To ensure reliability in the coding scheme, segments of four interviews were coded independently by one of the dissertation committee members. The segments were chosen because they contained particular data that could be interpreted and coded in more than one way. The committee member's coding was compared to that of the investigator. Full agreement on the coding scheme was reached through discussions between her and the investigator. Interpretive reliability was defined as "consistency in assigning units to categories" (Garvin et al., 1988; Waltz et al., 1984, p. 307). To ensure interrater reliability of the content analysis, two doctoral students with experience in qualitative data analysis coded the bodies of two interviews using revised definitions of subcategories. Coding decisions were compared. Before discussing the coding with the students, inter-rater agreement on the codes was calculated to be 92.2%. Full agreement on the definitions and their codes was reached between the students and the investigator.

To enhance the thoroughness and reliability of the content analysis as it proceeded, the analysis was a collaborative effort between the committee members and the investigator. The number of categories and number of subcategories were reduced and definitions were modified and revised. During this iterative data reduction, the results of the study emerged. These will be presented in Chapter 4.

CHAPTER 4

Results

The goal of this study was to lay the foundation for developing data-based measures for LST decisions made by family caregivers for elderly ill relatives. To develop such measures, an encompassing framework for LST decisions was needed. Therefore, the study refined the conceptualization of family caregiver role strain and satisfaction in making LST decisions, within the context of ongoing family care; described factors associated with family caregiver role strain and satisfaction in making LST decisions; and generated items for measures of family caregiver role strain and satisfaction in making LST decisions, based on the refined conceptualization and words of caregivers.

The initial and refined definitions of the concepts of family caregiver role strain and satisfaction are given in Table 3. The initial definition of satisfaction was derived from the work of Mezey and colleagues (1996) and the work of Burr and colleagues (1979). Based on the data collected here on predictors of “satisfaction” used by family caregivers, the term satisfaction was changed to “ease.” Caregivers described how they felt at the time of the decision-making (e.g., “Well, the decision itself was easy”), as well as how they were feeling about the decisions 6 to 8 months after the decision-making (e.g., “I’m pretty much at peace with the decisions”).

Table 3

Concepts, Definitions, and Data Bits

Concept Name	Initial Definition	Definition as Refined Through Analysis	Data Bits
Family Caregiver Role Strain	Felt difficulty following LST decisions for elderly relatives.	Felt difficulty in making LST decisions for elderly relatives.	1. "So it was, it was tough." 2. "Oh, I think it was really difficult." 3. "I think it's a very hard decision." 4. "So you know it, again making the decision the first time was much more difficult." 5. "What, making the decision? It wasn't too bad."
Satisfaction	Felt comfort following LST decisions for elderly relatives.		
Ease		Feeling of being without discomfort in making LST decisions for elderly relatives.	1. "Well, the decision itself was easy." 2. "I'm pretty much at peace with the decisions." 3. "And I don't question she's at peace with the decision." 4. "I feel comfortable with what I did." 5. "It's not that it [the decision] was easy, but it was not difficult."

As the data analysis proceeded, the framework for the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives was developed, and six categories of concepts, definitions, and data bits from study participants were derived from the data. Categories were: (a) Caregiver (I), (b) Ill Relative (II), (c) Family Relations (III), (d) Health Care Provider (HCP) (IV), (e) Health Care System (V), and (f) Responses (E),

these are presented in Figure 2. Except for the category, "Health Care System," all were extensively represented in the data. Subcategories derived from the data are listed alphabetically under each category.

Categories and Subcategories that may be associated with Caregiver Role Strain and Ease in Making LST Decisions

...gives the following order that may be associated with Caregiver Role Strain and Ease in Making LST Decisions										
Temporal Sequence	A. Antecedent Factors				C. Post LST Decision-Making and Prior to Death		D. Post LST Decision-Making and Post Death		E. Responses	
Category	Historical Factors		Immediate Factors							
Subcategories	I. Caregiver		II. Caregiver				I. Caregiver		1. Caregiver	
	1. Prior Experience		1. Prior Experience				1. Death Unexpected		1. Decision-Making	
	2. Role Expectations and Responsibility		2. Readiness for Death						2. Process	
			3. Role Expectations and Responsibility							
			4. Understanding of Ill Relative's Immediate Situation							
Category	II. III Relative		III. III Relative		III. III Relative					
Subcategories	1. Advance Directives		1. Advance Directives		1. Health Decline Trajectory					
	2. Health Decline Trajectory		2. Health Decline Trajectory		2. LSTs guided by advance directives					
			3. Last Illness							
			4. Medical Dispositions							
			5. Overall Health Problems							
Category	III. Family Relations		III. Family Relations		III. Family Relations				III. Family Relations	
Subcategory	1. CG ~ III Relative		1. CG ~ III Relative		1. CG ~ Other FM				1. CG -> FM	
	2. CG ~ Other FM		2. CG ~ Other FM						2. CG & Other FM	
									3. FM -> CG	
Category	IV. HCP		IV. HCP		IV. HCP				IV. HCP	
Subcategory	1. Knowing		1. HCP Behavior		1. Advance Directives		1. HCP Behavior		1. Information	
					2. HCP Behavior				2. Medical Treatment	
Category	V. Health Care System		V. Health Care System		V. Health Care System					
Subcategory	1. Type of setting		1. Type of setting		1. Type of setting		1. Type of setting			
Time	Role Strain and Ease									
	Years to months to days to hours				Hours to minutes				Second to weeks	
									Seconds to years after death	

Figure 2. Refined Conceptual Framework: Family Caregiving Process in Making LST Decisions for Elderly III Relatives. CG = caregiver; FM = family member; HCP = health care provider.

Role strain and ease in making LST decisions for elderly ill relatives may be experienced by family caregivers before, at the time of, and after such decisions have been made. The process occurs over time and in context. This study found four elements in the temporal sequence of the Family Caregiving Process: antecedent factors (A), conceptualized role enactment: in making LST decisions (B), post LST decision-making and prior to death (C), and post LST decision-making and post death (D). The Family Caregiving Process is influenced by both long-term (historical) and immediate antecedent factors, which include aspects of ongoing caregiving by family members. Antecedent factors influence the context in which LST decisions are made (the contextualized role enactment of making LST decisions). Then there is the time after LST decisions are made: the time prior to the death of the relative and the time after the death. Responses (E) are family caregivers' reactions to the process itself, the LST decision-making, other family members, and health care providers.

The main focus of the analysis here was on the caregiver's experiences, though data analysis was also performed on the ill relative, family relations, health care provider, health care system, and responses. Because the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives occurs in a temporal sequence, antecedent factors are presented first. The contextualized role enactment in making LST decisions is then presented, followed by a discussion of the time after the contextualized role enactment. Finally, responses are described. Because the interview data were obtained from family caregivers 2 to 8 months after the death of their relatives, all findings are based on the meanings their experiences had for them at that point in the process.

Items for the proposed measures of family caregiver role strain and ease in making LST decisions were generated and retained based on (1) the number of participants who discussed a concept, (2) completeness in the description of a concept, and (3) the investigators clinical expertise which included a judgment of the importance of an item. Redundant items were deleted.

During the item generation process, characteristics of the study participants were considered, including their ages, ability to read, and ability to think abstractly. The intent was to develop measures that are simple to administer and require no special training by participants.

Caregiver

The category “Caregiver” and its subcategories are presented in the conceptual framework in Figure 2. A detailed version of the “Caregiver” category is presented in Figure 3. Subcategories are listed alphabetically. Potential indicators listed below subcategories are components of the concept that may be associated with family caregiver role strain and ease in making LST decisions. Potential indicators are listed according to the number of study participants who mentioned them, or in alphabetical order. Concepts, concept definitions, potential indicators in the data set, and draft items for measures of family caregiver role strain and ease in making LST decisions are listed in Table 4.

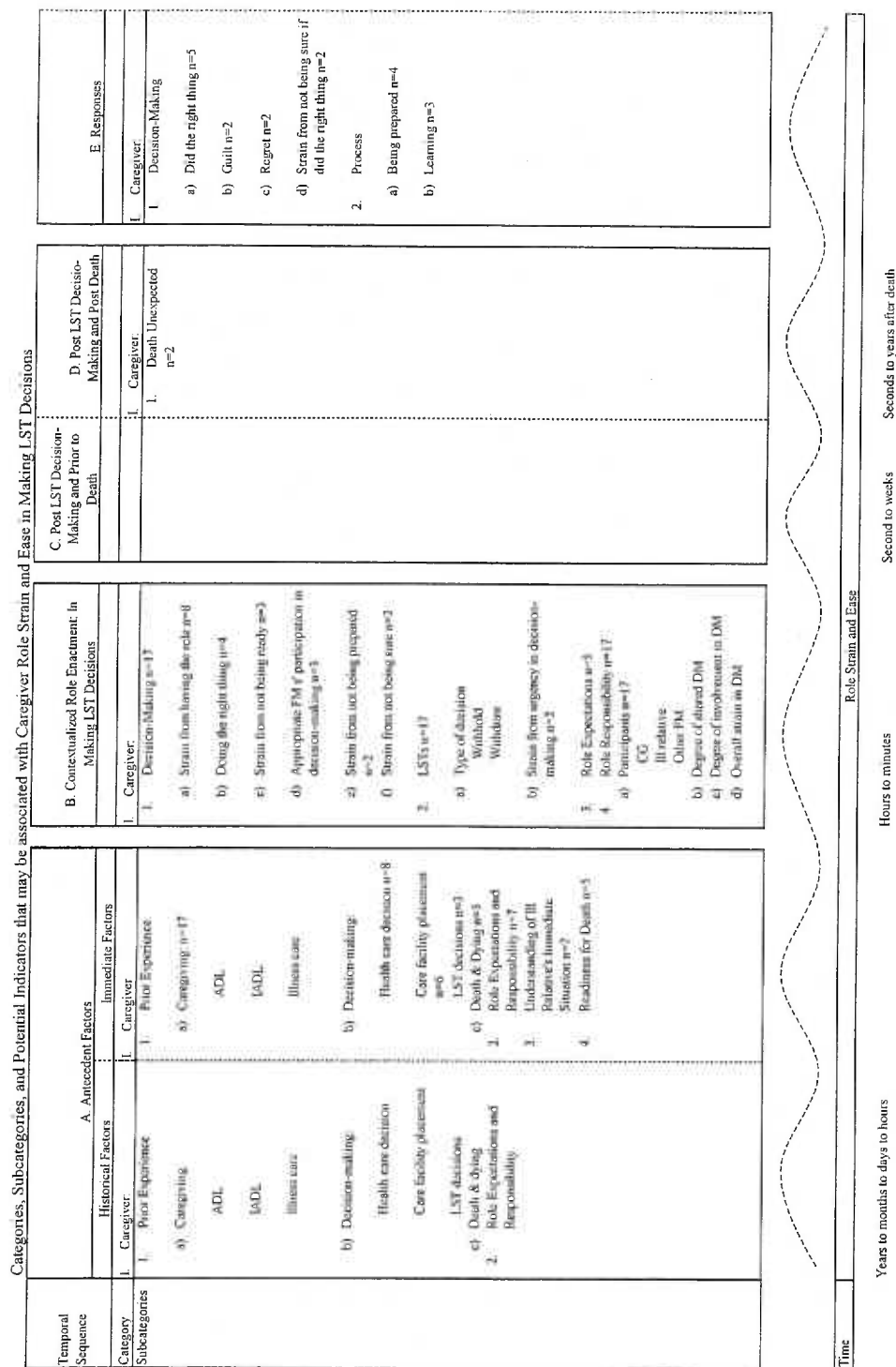


Figure 3. Caregiver Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives. CG = caregiver; FM = family member; n = the number of caregivers who addressed the concept

In Figure 3, under antecedent factors (A), both historical and immediate, two subcategories are listed: (1) prior experiences and (2) role expectations and responsibility. Participant data supported the inclusion of these two subcategories under both factors since family members have been caregivers for different lengths of time and have performed various caregiving activities such as activities of daily living (ADLs) and instrumental activities of daily living (IADLs) prior to the end-of life period (see Table 4).

Table 4

Caregiver Category: Concepts, Concept Definitions, Potential Indicators in the Data Set, and Draft Items.

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
A. Antecedent Factors			
1. Prior Experiences	Past practices by CG that may have made it easier or harder for him/her to make LST decisions for his/her ill relative.		
a) Caregiving: ADL		“Um, but at the same time, uh you know, staying over there and getting up with him [father] during the middle of the night and helping him walk to the bathroom and all that sort of stuff was not that bad” (3, 478-481).	Prior to your latest LST decision-making, did you do the following: 1. Did you do day-to-day personal care activities, such as bathing, dressing or feeding, for your ill relative?
IADL		“And she [mother] would, well like one time, I had to do something and I didn’t, wasn’t able to go to the doctor with her, but this is the only time I didn’t go to the doctor with her” (10, 770-773).	2. Did you do things like housekeeping, driving or banking for your ill relative?

Note. (n, n) In the parenthesis, the first n is the code number assigned to the study participant. The second n is the unit number assigned to the lines of the interview text.

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
Illness care		"I was there, I took care of her [mother] for 6 months before she passed" (10, 25-26).	3. Did you provide care to your relative (e.g., help with medications) because he or she was ill during the last one or two years of his or her life?
b) Decision-making: Health care decisions		"And you really don't realize you know, sorting through your stuff all the trips to the hospital. All the decisions. At one point I told my husband, I said, "You know, my God, this stuff is creepy. You know, you do it at a time and you think about it, God, I did this, oh I forgot that. You just do it because you have to get them [parents] from point A to point B. But it's an amazing emotional constant pull" (8, 1343-1350).	4. Did you make health care decisions for your ill relative during the last one or two years of his/her life?
Care facility placement		"And totally, very honestly that was so much harder than anything else that had happened. I cried so much over putting them [parents] in separate apartments [care facility]. It was just terrible. Nothing else has been anywhere close" (2, 63-66).	5. Did you make the decision for your ill relative to move into a care facility?
LST decisions		"So you know it again; making the decision [LST decision] the first	6. Have you participated in making LST decisions before?

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
c) Death & dying		time was much more difficult. With the idea, "Boy, we pull the plug on him [father]. I know he can't ask for aspirin. I know he can't ask for anything" (8, 335-337). "But she [wife] was not making any sounds but the blue lips and uh slowing of activity. Didn't seem right to me, and so I thought to myself, I wonder if she, is she choking? (6, 429-433).	7. Have you ever been in the presence of a dying person?
		"My father died in 1997 and I had much different feelings, reactions, so when my mother died recently, I was much more prepared for what was going to be asked of me" (8, 5-7).	8. Have you gone through the experience of having a person close to you die?
2. Role Expectations and Responsibility	CG's belief about who should be obligated for making LST decisions for an ill relative prior to the time such decisions need to be made.	"And I knew that I had to make the decision" (8, 483). "You know, and I've been family for all these years, but um, again, I kind if had to sit down with my husband and say, "You guys have	Prior to my ill relative's last illness that led to his/her death, 1. I believed it was my responsibility to help make LST decisions for him/her. 2. I believed it was other family members' responsibility, not mine, to help make LST decisions for our ill relative.

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
		to step up and make these decisions. Not me" (1, 409-412).	
		"And I'm trying to deal with those and it's reached a point where it's kind of like, and believe me, there's six of us kids. So it should have been spread out equally" (1, 597-599).	3. I believed that family members should share in LST decisions for ill relatives.
		"And I really didn't like the idea that my father was quite comfortable with that somehow I was going to choose when he died" (3, 326-328).	4. I believed it was my ill relative's responsibility to have made LST decisions in advance for him or herself.
		"I didn't think she was passing" (10, 29-30).	5. I thought my ill relative should have made his or her own LST decisions in advance.
3. Understanding of the Ill Relative's Immediate Situation	CG's perception of the severity of the relative's present illness.	"Um, but right until the end, even though we all, we all knew he was dying ..." (3, 264 - 265).	Right up until health care providers talked about LST options with me, I didn't realize he/she was dying.
4. Readiness for Death	CG's emotional preparedness for the death of the ill relative.	"And still was a hard time, but I think everybody, everybody was ready for my mom's passing ..." (5, 291-293). "Oh God, I don't want to think about this. I'm not ready" (8, 1235).	Before LST options were talked about by HCPs, to what extent were you ready for the death of your ill relative?

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
B. Contextualized Role Enactment: Making LST Decisions			
1. Decision-Making			
a) Strain from having the role	The difficulty for the CG in making LST decisions for his/her ill relative.	"He [son] said, "You [father] didn't want to be responsible for her [mother's] death" (6, 512-513). "It wasn't fair to put it on my daughter. So, you know, somebody had to step in to the gulch" (1, 625-626). "She [daughter-in-law] wrestled with whether that [the decision] was the right thing to do or not" (9, 393-394). "But you just, you just hate that, and you hate to be the one that is on, you know" (19, 1370 -1371). "I felt like I was doing the right thing" (11, 236). "I just knew it was OK. It was the right thing to do" (13, 217).	How hard was it because you did not want to feel responsible for somebody else's death? How hard was it to step up and make the decisions? How much of a struggle was it for you to make LST decisions for your ill relative? To what extent did you hate to be the one who had to make LST decisions for your relative? At the time you made LST decisions for your ill relative, how sure were you that you were doing the right thing? At the time the HCPs asked you to make LST decisions for your ill relative, was it hard because
b) Doing the right thing	Degree of CG certainty about doing the right thing for one's ill relative regarding LST.		
c) Strain from not being ready	The CG's felt difficulty due to not being emotionally prepared to		

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
d) Appropriate FMs' participation in decision-making	The CG's opinion of whether the right family members were involved when LST decisions were made for their ill relative.	"She [daughter] just wouldn't face that [the decision]" (13, 340). "She [daughter] didn't want her father to die, but she knew that he would not want to live the way he was" (13, 347-348). "And I didn't want to hear it or I you know, I didn't believe them or something" (10, 926-927).	1. You couldn't face the decisions? 2. You weren't ready for your ill relative to die? If yes, how upsetting was that to you? 3. You weren't ready to make such decisions? At the time LST decisions were made for your ill relative, 1. Was there someone who you thought should have participated who did not? 2. Do you think that somebody else should have participated in the decision-making instead of you? 3. Were there persons who you wished could have participated in the decision-making, but did not? If so, who were these people:

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
e) Strain from not being prepared	The CG's felt difficulty in making LST decisions for his/her ill relative because of not feeling ready.	"There'll always be grieving, but those types of decisions are hard to make at a time when they come unprepared or you haven't talked about them" (1, 519-521). "Why, you know, why at some point hadn't I thought about how this [decision-making] was going to happen" (8, 1163-1165).	At the time LST decisions were made for your ill relative, how hard was it because 1. You had not talked them over with your ill relative ahead of time? 2. You felt unprepared to make such decisions? 3. You had not thought about the making of such decisions ahead of time?
f) Strain from not being sure	The CG's felt difficulty about the uncertainty of not doing the right thing for his/her ill relative regarding LST.	"I had, when I look back on it [the decision], I had a problem, it's like taking a pet in for euthanasia" (8, 562-563).	At the time you made LST decisions for your ill relative, how hard was it because you were unsure about doing the right thing?
2. LSTs	The making of actual and final decisions to withhold and/or withdraw treatments for an ill relative.	"I told them 'No' when they [nurses] suggested the feeding tube" (4, 335). "But when they want to take him off fluids, you know, that it's, I felt like I was really pulling the plug. And that was a tougher decision, and I didn't want a tube down his stomach to feed him" (8, 321-324).	See Appendix I
a) Type of decision			
Withhold			
Withdraw			

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
b) Strain from urgency in decision-making	Degree to which LST decisions had to be made quickly and the degree to which that made it harder for the CG to make such decisions.	"No, I didn't talk to anybody. It [the decision] was too fast" (11, 220)	At the time LST decisions were made for your ill relative, how hard was it because 1. You had to make the decisions quickly? 2. You had to make the decisions faster than you wanted to? 3. You had to make the decisions before being able to consult with other family members?
3. Role Expectations	Degree to which the CG felt obligated to make LST decisions for his/her ill relative.	"I didn't necessarily feel that it was my responsibility" (1, 361-362). "And that one decision was the hardest one, was that being responsible for somebody else's decision that they, I wish they could make" (8, 981-983). "I really felt it was Peter's [husband's] dad's responsibility, and tried to get him involved" (1, 364-365). "I didn't want to be the person to say, 'I give up on you'" (15, 802-803).	To what extent did you feel that it was your place to make LST decisions for your ill relative? To what extent did you feel that it was your responsibility to make LST decisions for your ill relative? To what extent did you feel that other family members should have taken more responsibility when making LST decisions for your ill relative? To what extent did you not want to be the one to make LST decisions for your ill relative?

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
4. Role Responsibility	Enactment of the decision-making role.		Who participated in making LST decisions for your ill relative. Circle all that apply.
a) Participants	CG's interpretation of who the participants were when LST decisions were made for the ill relative.	"And of course the decisions were all mine ...I am responsible for it" (6, 653 - 654). "And so, the decision was really and like I say, it was hers, it was not ours" (9, 268- 269). "And my sister came down from Seattle and we decided that it was time to choose. And, we decided to do it" (10, 391 - 393). "I think we all decided, we all decided" (5, 208).	1. You. 2. Your ill relative. 3. One or more family members. 4. Others: _____ Please specify _____ 5. Altogether, how many persons participated in making LST decisions for your ill relative (do not include health care providers in your estimate)? _____ persons.
b) Degree of shared decision-making	Degree to which LST decisions were made collaboratively.	"It was a decision I had to make on my own" (11, 222). "And since I don't have any siblings, I was pretty sure that she [mother] would agree with me" (2 273). "You know, for some reason, I didn't feel that she [mother] was in the loop, but for some reason, it	To what degree was LST decision-making for your ill relative shared by others? (if applicable, include other family members, but not health care providers)? (Circle your answer) 1. I made the decisions alone. 2. I was the primary decision-maker, but one or more other persons were involved. 3. I shared the decision-making equally with other persons. 4. I was involved in making the

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
c) Degree of involvement in decision-making	CG's degree of participation when LST decisions were made for his/her ill relative.	wasn't, I didn't feel like I shared the responsibility that much" (8, 601-603). "And my husband and I talked about the decisions. I talked to my daughter the afternoon that we were actually making decisions" (2, 76-78).	decisions, but was not the primary decision-maker. 5. I had little involvement in making the decisions. How much were you involved in making LST decisions for your ill relative?
d) Overall strain in decision-making	CG's overall level of felt difficulty in making LST decisions for his/her ill relative.	"So it was, it was tough" (1, 451). "I think it's a very hard decision" (8, 212).	Overall for you, how hard was it to be involved in making LST decisions for your ill relative?
D. Post LST Decision-Making and Post Death			
1. Death Unexpected	Whether or not the CG anticipated that his/her ill relative was not going to survive this last illness.	"It [the death] was totally unexpected" (11, 284).	Was the death of your ill relative unexpected? At the time you made the LST decisions had you expected your ill relative to survive longer than he or she did? No, I expected him or her to die relatively quick. Yes, I thought he or she would live at least a week or two. Yes, I thought he or she would live at

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
E. Response			
1. Decision-Making	Degree of CG certainty that he/she did the right thing for his/her ill relative regarding LST.	"Later I thought, I've made the right decision" (2, 161).	Now that some time has passed since you made LST decisions for your ill relative, how sure are you that you did the right thing?
a) Did the right thing			
b) Guilt	Feeling responsible for ill relative not receiving the best LST decisions.	"These feelings of guilt" (8, 283).	How much guilt have you felt due to the LST decisions you made?
c) Regret	Feeling remorse for ill relative not receiving the best LST decisions.	"I am torn after the life-sustaining treatment decision(s) that I made for my relative" (10, 722).	How much regret have you felt due to the LST decisions you made?
d) Strain from not being sure about doing the right thing	Degree of CG felt difficulty resulting from the uncertainty that he/she did the right thing for his/her ill relative regarding LST.	I should have pushed them to get Dad into the hospital sooner. But it didn't happen, so by the time he got in there, his chemistry was pretty screwed up" (8, 284-287).	Now that some time has passed since you made LST decisions for your ill relative, how hard is it because you are unsure whether you did the right thing?
2. Process			
a) Being prepared	CG will reflect or has reflected, discussed, and communicated preferences regarding his/her own wishes for end-of-life care.	"The more prepared I am, the better it is to handle" (1, 798).	Because you made LST decisions for your ill relative, how prepared did that make you to decide on LSTs for yourself?

Concept Name	Concept Definition	Potential Indicators in the Data Set	Draft Items
b) Learning		"I'm a little better educated about these kinds of things than I was 2 years ago" (7, 552-523).	How much have you learned from making LST decisions for your ill relative? (please describe).

All 17 participants in the study discussed their role as caregivers; seven talked about role expectations and responsibility, seven about “understanding the ill relative’s immediate situation” (understanding, $n = 5$, not understanding, $n = 2$) and five about “readiness for death” (ready, $n = 2$, not ready, $n = 3$).

When family caregivers participated in making LST decisions for elderly relatives, four subcategories were associated with the decision-making: (1) decision-making, (2) LSTs, (3) role expectations, and (4) role responsibility.

Six potential indicators are listed under the subcategory “decision-making:” (a) strain from having the role ($n = 8$), (b) doing the right thing ($n = 4$), (c) strain from not being ready ($n = 3$), (d) appropriate family members’ participation in decision-making ($n = 3$), (e) strain from not being prepared ($n = 2$), and (f) strain from not being sure ($n = 2$). Five family caregivers talked about “doing the right thing” after they had made the LST decisions for a relative. “Doing the right thing” might be associated with less role strain and a greater feeling of ease, both at the time LST decisions are made and later.

Potential indicators of the subcategory “LSTs” included: (a) type of decision (see Table 2, page 43) and (b) strain from urgency in decision-making. Withholding LST might be more acceptable than withdrawing treatment (Reckling, 1997) and perhaps therefore, associated with less family caregiver role strain. Both withholding and withdrawing treatments and strain from urgency in decision-making ($n = 2$) were included in this study (see Appendix I). Although role strain or ease in relation to “urgency” was not mentioned by these family caregivers, its possible that higher urgency may be associated with more role strain.

The following two quotes illustrate the broad time frame over which LST decisions may be made.

And, and so I was always kind of constantly re-evaluating it and saying OK, given where she [mother] is today, is this the right decision. You know, this is what I want to do (01, 181-183).

No, it was too fast. It was a decision I had to make on my own (11, 222).

Five family caregivers addressed the subcategory “role expectations.” They felt obligated to and ended up making LST decisions, although they said it was not “their place” to do so, either because they did not want to or because they felt other family members should have been more involved.

The following quotation illustrates the difficulty family caregivers experienced when other family members were not as involved as they were expected to be.

Do you want somebody there for love and care for you. And if you do, then you should show some of that towards your own family at this point in time in their lives. And, and they didn't [son and daughter-law]. I mean even after Grandma died, it took them three days to come down here. And I was like floored. And it was kind of like, “Wow.” I did everything [all decision-making including funeral arrangements], right down to it. They did nothing. They showed up and so you know, I'm still struggling with that a bit (1, 578-585).

Role responsibility (n = 17) included four potential indicators: (a) participants, (b) degree of involvement in decision-making, (c) degree of shared decision-making, and (d) overall strain in decision-making. The participants in the decision-making on LSTs for elderly relatives, their degree of involvement in it, and the degree to which the participants shared the decision-making might have been associated with role strain and ease. For instance, being the only one who made LST decisions for a relative might be perceived by a family caregiver as being more or less difficult.

The following quotation from a family caregiver who made the LST decisions alone illustrates this:

But people are just, they roll their eyes at me, and they go. You don't have anybody to dicker with And I think see, and that I think, I can't even imagine the emotions and the shit that you'd have to go through when you've got siblings. That's a "born again Christian" that's going to keep them [your parents] alive forever, and somebody's into Buddhism or whatever and let's you know, they can't even decide on what decisions to make and whether they're [your parents] going to be cremated or not (8, 1179-1190).

All study participants talked about being involved or sharing the LST decision-making for an elderly relative. Two items on shared decision-making (I was involved in making the decisions, but was not the primary decision-maker and I had little involvement in making the decisions) were included as possible items. They were not in the data, since these family caregivers had been the main decision-makers for their relatives.

The degree to which death was expected was described extensively by eight participants. Six talked about their knowledge of their elderly relative's expected death (e.g., "We knew she didn't have much time left" [5, 18]) but two participants found the death of their relatives unexpected. It is possible that caregivers who expect the death of their relatives will experience less role strain if LST decisions have to be made than caregivers who do not expect their relatives to die. Unexpectedness and urgency were experienced by the same two participants.

Several of the participants described six responses to the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives depicted in Figure 3. Four of these responses were related to the actual LST decisions, and two were related to the process. The four responses related to the decisions were: (a) did the right thing ($n = 5$), (b) guilt ($n = 2$), (c) regret ($n = 2$), and (d) strain from not being sure if the caregiver had done the right thing ($n = 2$). The following quotations illustrate these responses:

I have no second thoughts about whether it was the right thing to do or not. Not at all (9, 444-446).

And then we'd, we'd decide, OK, we decided this and we're, we're having this guilt with dad (03, 99).

And I feel terrible because I probably could have said "no" [to the decision] (10, 722).

I don't know if there is anything I would change (7, 388)

[After the LST decision was made for relative] what we were led to believe was going to happen didn't or we would have gone a different direction [different decision] and figured out something (2, 202-204).

The two responses related to the process were: being prepared (n = 4) and learning (n =

3). The following quotations illustrate these:

Being prepared:

Well, the main thing now that's I'm a total believer in preparation (12, 758).
Because you know we're all older. And this time we wouldn't go in and let the doctor make the decisions. We would go in we're all Internet savvy. We would do our homework. And we all promised each other that we would not let that happen to any of us. We're going to go in with our decisions made and gonna put our foot down, and then sue us if you feel like it (03, 988-994).

Learning:

I can honestly say that we learned a lot (1,259).

I've just learned so much about what impact it can have (8, 1364).

I have learned immensely from the whole process (1, 877).

Though family caregivers might feel guilt about the LST decisions they made for their relatives, they might at the same time learn from the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives, thus role strain and feeling of ease are not mutually exclusive concepts. The influences of the deceased relatives, family relations, and health care providers on family caregiver role strain and feeling of ease in making LST decisions for relatives are described below.

Ill Relative

The category "Ill Relative" and its subcategories are presented in the conceptual framework in Figure 2. A detailed version of the "Ill Relative" category is presented in

Figure 4. Subcategories are listed alphabetically. Potential indicators listed below subcategories are components of the concept that may be associated with family caregiver role strain and ease in making LST decisions. Potential indicators are listed according to the number of study participants who mentioned them, or in alphabetical order. Concepts, concept definitions, potential indicators in the data set, and draft items for measures of family caregiver role strain and ease in making LST decisions are listed in Table 5.

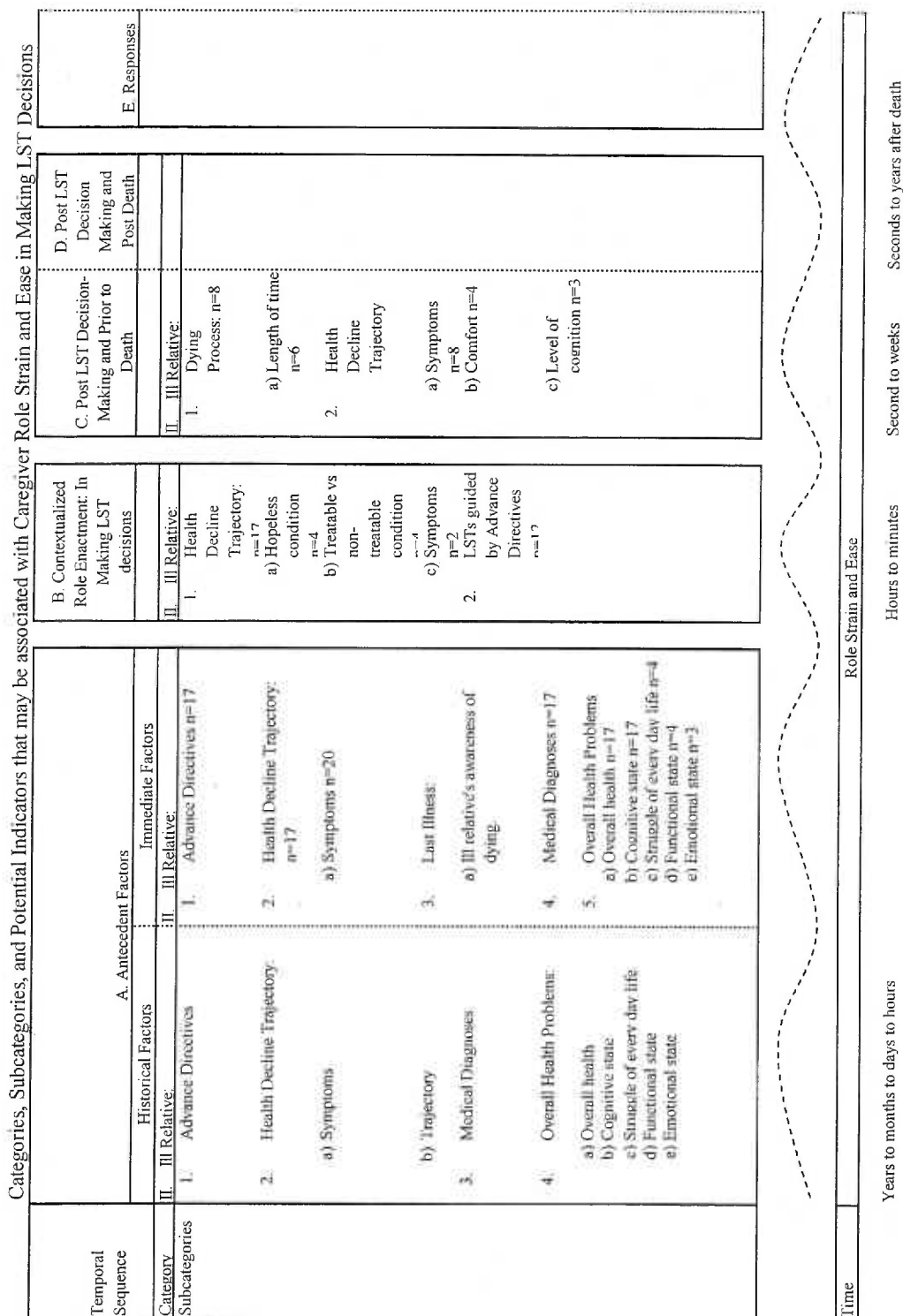


Figure 4. III Relative Category in the Family Caregiving Process in Making LST Decisions for Him or Her. n = the number of caregivers who addressed the concept.

Table 5

III Relative Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
A. Antecedent Factors			
1. Advance Directives	CG's knowledge of the deceased relative's wishes regarding LST.	"But I never heard her [grandmother] say that she wanted life support or she didn't" (15, 683). "So we knew what her [mother's] wishes were. She made it clear" (5, 215-216). "Advance directives on health. We double-checked into all that once we had the Power of Attorney" (1, 198-199).	Did you know your relative's wishes regarding life-sustaining treatments? If yes, how clear were you on your ill relative's wishes? If clear, how did you become clear? 1. My ill relative had written down his/her wishes. 2. My ill relative had discussed his/her wishes with me. 3. My ill relative had both written down his/her wishes and discussed them with me. 4. My ill relative had appointed a Power of Attorney for Health

Note. (n, n) In the parenthesis, the first n is the code number assigned to the study participant. The second n is the unit number assigned to the lines of the interview text.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
2. Health Decline Trajectory			
a) Symptoms	The kind of symptoms that the ill relative experienced at three points in time (during the last year of life, when the LST decisions were made, and from the time these decisions were made until his/her death), and the extent to which the presence of such symptoms made it easier for the CG to make or have made the LST decisions.	“He had been having the abdominal discomfort since about April. Maybe sooner than that, but by then he was complaining, definitely telling me that it was hurting. Um, and it just got worse and worse. And it definitely had gotten worse the last week there. That wasn’t what killed him, but that was the hardest thing to deal with” (2, 302-308).	During the last year before your ill relative’s death: Did you believe he/she experienced: 1. Pain 2. Other discomforts such as nausea 3. Anxiety 4. Suffering 5. Struggling 6. Loss of consciousness 7. Shortness of breath 8. Fatigue
b) Trajectory	(See Appendix J)	“And she started probably declining a couple of years ago” (1, 123-124). “He gradually deteriorated over the months” (2, 34).	(See Appendix J)
3. Last Illness	Course of relative’s last illness.	“It [the last illness] was the last month. So everything kind of moved pretty quickly” (14, 64-65). “She [wife] was having trouble, like she was having a stroke” (15, 227-228).	How would you describe your ill relative’s last illness that led to his/her death: 1. It was sudden (came on suddenly) 2. It was acute with rapid decline 3. It was unexpected 4. It was more serious than expected

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
a) Ill relative's awareness of dying	The CG's belief that his/her relative was dying and the extent to which this interpretation made it easier or harder to make the LST decisions for the ill relative.	"She [mother] knew and I believe that she did know she was dying" (10, 1931).	5. It was prolonged I believe that my relative knew that she/he was dying.
4. Medical Diagnoses (See Appendix K)			
5. Overall Health Problems	Course and severity of pre-death health problems and the extent to which this course made it easier or harder to make the LST decisions for a ill relative.	"And he [husband] was always in quite good health" (13, 39-41) "Well grandmother has been fairly healthy except for the last few years" (1, 94-95). "Her medicine, her body kept changing I guess and the medicine kept not working, you know. But we'd have to rush her to the hospital in an ambulance. And then we'd adjust her medicine and, and then she would be all right for a week or so, and then it would happen again" (11, 67-71).	Before your ill relative's last illness, how would you rate his/her overall health? During the past year how many times was your ill relative hospitalized? 1. None 2. 1 time 3. 2 times 4. 3 times 5. 4 times 6. More than 4 times
a) Overall health			
b) Cognitive state	Ability to comprehend and communicate.	"Her [mother] mind was wonderful. She remembered everything from way back to yesterday" (11, 52-54).	One year before your ill relative died, how would you rate: His or her ability to remember what

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		"The dementia was really accelerating" (7, 154).	was said? His or her ability to understand what was said? His or her ability to communicate in words? One month before your ill relative died, how would you rate: His or her ability to remember what was said? His or her ability to understand what was said? His or her ability to communicate in words?
c) Struggle of every day life	Length and amount of battle from pre-death health problems.	"Life was beginning to be a struggle for her [mother]" (5, 266-267). "And she [wife] struggled for I guess 8, 10 years" (9, 18-19).	How much was everyday life a struggle for your ill relative because of his/her overall health condition? For how long had everyday life been a struggle for your ill relative? 1. During the last month of his/her life. 2. During the last 2 to 6 months of his/her life. 3. During the last 7 to 12 months of his/her life. 4. During the last 2 to 3 years of his/her life. 5. During the last 4 to 5 years of

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
			his/her life. 6. More than the last 5 years of his/her life.
d) Functional state	Ability to do ADL.	“She was alert, but bedridden at that point” (8, 414-418).	One year before your ill relative died, how would you rate: His or her ability to do daily living activities like bathing, dressing, eating? His or her ability to do daily living activities like getting in and out of bed or chairs, using the toilet? One month before your ill relative died, how would you rate: His or her ability to do daily living activities like bathing, dressing, eating? His or her ability to do daily living activities like getting in and out of bed or chairs, using the toilet?
e) Emotional state	Level of happiness with everyday life.	“He was also talking to me about committing suicide” (3, 200-201).	His or her happiness with everyday life?

B. Contextualized Role Enactment

1. Health Decline Trajectory	The state the ill relative was in and the degree to	“I knew there was nothing they [HCP] were going to do that would make her	At the time LST decisions were made for my ill relative, I believed his/her
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Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
a) Hopeless condition	which this made it harder for the CG to make LST decisions.	become any better" (4, 372-373). "There was no hope for resuscitation." (12, 355-356).	condition to be hopeless – very hopeful. To what extent did that make it harder for you to make the LST decisions for him/her?
b) Treatable versus non-treatable condition	Extent to which the ill relative's condition appeared remediable and his/her death preventable	"But I guess it's, it's easier to think of somebody dying of an accident, you know, that's more fate-ish. Than something that you know is curable. It's really hard to see your parents die of pneumonia" (8, 1006). "They were saying that she had leukemia, but they said, you know, she could have lived years with that" (10, 966-967). "You know, but then if they were more [on top of things], maybe she would have bounced back" (11, 349-350).	At the time LST decisions were made for your ill relative, to what extent did you believe that your ill relative's health condition could have been treated? To what extent did that make it harder to make LST decisions for him/her?
c) Symptoms		"Um, well like I said the hard part was having him being in pain" (2, 600).	At the time LST decisions were made for your ill relative, did you believe he/she experienced: 1. Pain? 2. Other discomforts such as nausea? 3. Anxiety? 4. Suffering? 5. Struggling? 6. Loss of consciousness? 7. Shortness of breath?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
2. LST guided by Advance Directives	CG's ability to make LST decisions for his/her relative as guided by advanced directives, and whether or not the decisions reflected the ill relative's wishes.	"I think that also helped me make decisions at the end, because they were very proactive" (8, 103). "I am doing what I think he [father] wants done" (2, 614). "Well it was hard because we knew that her being on the machine because she had told us take it out" (11, 407-408). "The hard part was saying 'Yes, use the paddles,' because I knew that I was going against what she wanted" (11, 236).	8. Fatigue? At the time you made LST decisions for your ill relative, how easy was it because you were clear about his/her wishes? At the time you made LST decisions for your ill relative, how hard was it because you were not clear about his/her wishes? To what extent did you make LST decisions based on what you believed that your ill relative would have wanted? At the time you were ready to make LST decisions for your ill relative, did the HCP not want to do so? If true, how hard was that for you? At the time LST decisions were made for your ill relative, did you do what he/she wanted? If not, how hard was that for you? Does that make it difficult in any way for you to live with the LST decisions made for your ill relative? If so, in what ways? (please describe)

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
C. Post LST Decision-Making and Prior to Death			
1. Dying Process	Description of course of dying from the time the LST decisions was made for the ill relative until his/her death.	"I had felt it was a gift to me that her death was as quiet as it was" (6, 615-616). "It was a relief when she quit breathing" (5, 296). "It's just hard to watch the body struggling" (5, 313). "So she was peaceful and, and gradually at the end she just kind of zoned out" (4, 432-434). "And I was in that sense, I was really happy for him that he did not last very long. That he didn't suffer a great deal and that, that the actual end of his life when he was really not very coherent and really didn't understand what was going on and was kind of panicked and all of that really only lasted a few days" (3, 214-219).	The next set of questions focuses on your perception of your ill relative's death (at the end). 1. How quiet was his/her death? 2. How much of a struggle was his/her death? 3. How peaceful was his/her death? 4. How much did he/she suffer at the end? 5. How anxious was he/she at the end? 6. How panicky was he/she at the end?
a) Length of Time	Time period from the LST decisions until the ill	"He [father] had been struggling with this for a week, and they [health care	Approximately how much time passed from LST decisions were made for

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
	relative's death.	providers] had said they didn't know when he was gonna go. Sometimes it takes two to three weeks which is you know, I think that's real agonizing. But I could tell that he was fighting it. You know, he just, he didn't, he wasn't ready to check out." (8, 352-357).	your ill relative until his/her death? (Circle your answer) 1. Minutes 2. A few hours 3. A day 4. A couple of days 5. A week 6. A couple of weeks 7. Several weeks
			When you think about the length of time it took from LST decisions were made for your ill relative until his/her death, which would you say? 1. It went much more quickly than expected 2. It went a little quicker than expected 3. It went as expected 4. It took a while longer than expected 5. It took a great deal longer than expected
2. Health Decline Trajectory		"We kept saying, "Where is it?" "Well it [pain medication] will be here shortly." And then it just wasn't and you know then it was really, that was hard, really hard to have him in pain" (2, 219-222).	Between the time the LST decisions were made for your ill relative and his/her death, did you believe he/she experienced: 1. Pain 2. Other discomforts such as nausea
a) Symptoms			

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
			3. Anxiety 4. Suffering 5. Struggling 6. Loss of consciousness 7. Shortness of breath 8. Fatigue
b) Comfort	Ill relative's degree of well-being, and whether that influenced how the CG felt about the LST decisions.	"The morphine, it took a lot of hours to get it there, and that really bothered me. They were trying, they were giving him suppositories and various things to try to make him more comfortable" (2, 205-208).	From the time the LST decisions were made for your ill relative until his/her death, how comfortable was he/she? Did your ill relative's level of comfort make you question the LST decisions you had made? If yes, in what ways? (please describe)
c) Level of cognition	Ill relative's ability to comprehend and the extent to which this influenced how the CG felt about the LST decisions.	"I knew that some understanding was still going on even though he couldn't communicate (2, 438-439). "So we kind of, all of us resigned ourselves, he wasn't very conscious then, so that was helpful" (12, 549-550). "He was coherent, we could talk to him (2, 111).	From the time the LST decisions were made for your ill relative until his/her death, 1. How much could he/she communicate in words? 2. How much could he/she communicate in other ways such as by squeezing your hand? 3. How much did he/she understand what was going on? 4. How alert was he/she? 5. Overall, to what extent did his/her level of awareness make you feel that you had made the right decisions or the wrong decisions?

In Figure 4, under antecedent factors (A), four subcategories are listed: (1) advance directives, (2) health decline trajectory, (3) medical diagnoses, and (4) overall health problems. Potential indicators from participant data supported the inclusion of these four subcategories. These subcategories are listed under both historical and immediate factors because elderly relatives may have experienced different illnesses and suffered from those over various lengths of time. All 17 study participants were asked by the investigator if their deceased elderly relative had had an advance directive. Fifteen of the 16 deceased relatives had had advance directives. Six had had written advance directives, 4 had had a power of attorney for health care, 4 had stated their wishes only verbally, and 1 had had a living will. All 17 participants described the decline of their relative's health. Six of the 16 relatives had experienced a gradual decline with an acute event, 6 had experienced an acute event, and 4 had experienced a more gradual decline. Of the "symptoms" listed under "health decline trajectory," pain was mentioned by 8 of the participants, 5 mentioned loss of consciousness, and 5 struggling; 1 mentioned the word "suffering" and 1 mentioned "labored breathing." Discomforts such as nausea, anxiety, shortness of breath, and fatigue are included here for completeness of symptoms, though these were not in the data.

The main medical diagnoses of the deceased elderly relatives were obtained from health care providers by the investigator. However, the measures of family caregiver role strain and ease will include "medical diagnoses" (Appendix K). The participants described medical diagnoses as they discussed the LST decisions that were made. "Overall health problems" were described by all 17 participants, including five potential indicators that might be associated with family caregiver role strain and ease in making

LST decisions for relatives. These indicators are: (a) overall health ($n = 17$), (b) cognitive state ($n = 17$), (c) struggle of everyday life ($n = 4$), (d) functional state ($n = 4$), and (e) emotional state ($n = 3$). The following quotations illustrate the role that medical diagnoses, struggle of everyday life, pain, and cognitive state might play in making LST decisions.

Uh hmm. And that, he [father] didn't, he wasn't like he had cancer and had incredible pain you know. He was uh, he was very weary of life and congestive heart failure and uh, and emphysema made him, made everything a struggle for him. But it wasn't like he was in acute pain either. I think if, if he was, you know he had pancreatic cancer or something like that, I think I might have felt very differently about that" (3, 250-258).

She [wife] knew that she couldn't have the ventilator pulled – he would die. But his mind was still good. And that's an entirely different situation (13, 862-863).

All 17 participants discussed their relative's last illness (immediate antecedent factor) and 5 discussed the ill relative's awareness of dying (awareness of dying, $n = 3$, unsure about awareness, $n = 2$).

Under contextualized role enactment (B), when family caregivers actually participated in making LST decisions for elderly relatives, two subcategories might be associated with the LST decision-making and therefore, with family caregiver role strain and ease. These subcategories were: (1) "health decline trajectory" and (2) "LSTs guided by Advance Directives." "LSTs guided by advance directives" included the caregiver's ability to make LST decisions for his or her relative using the advance directive. Family caregivers of 12 of the 16 relatives described what their relatives wanted or did not want in regard to LSTs. Two of the caregivers did not follow their relative's wishes.

"Hopeless condition," "treatable versus non-treatable condition," and "symptoms" were included as potential indicators of the "health decline trajectory." Four participants said their relative had had no hope for resuscitation, four felt that their relative's current

health condition might have been treatable, and two talked about the pain their relative had experienced. The following quotation illustrates the question about a treatable condition:

I wanted um you know, a real heavy shot of you know, I've seen it twice in my parents is when they have been you know, with pneumonia or whatever, they get a dose of what fluids, get a good dose of uh antibiotics, and then a good dose of whatever, excuse me, they put through the IV. And you know they, they get their shot in their arm. And I kind of wanted that one more "shot in the arm" to see if it was gonna happen. But it wasn't suggested, and everybody said, "I don't think it's going to make the difference at this point" (8, 324-333).

Under "post LST decision-making and prior to death" (C), two subcategories might be associated with LST decision-making and therefore, family caregiver role strain and ease. These subcategories were: (1) dying process and (2) health decline trajectory. Eight participants discussed the dying process and six discussed the length of time it took from when the decisions were made to the death of their relative. If the dying process lasts longer and is more of a struggle for the dying ill relative than anticipated by the caregiver, the caregiver may question the LST decisions that were made and experience more role strain and less ease about having made such decisions. During the interview, the investigator asked participants about the length of time it took from when the LST decisions were made until the death of their ill relative. The approximate time from the "final" decisions to withhold or withdraw LSTs until the death of the relative ranged from seconds to 92 days. Six of the relatives died within seconds to minutes after the implementation of the LST decisions, 3 within hours, 6 within days to approximately 3 weeks, and 1 after 3 months.

Potential indicators of the "health decline trajectory" were: (a) symptoms, (b) comfort, and (c) level of cognition. In particular, pain and comfort were important for

caregivers after they made the LST decisions up until the death of their elderly relative. Five participants discussed pain and four discussed comfort. The relative's level of cognition was mentioned by three participants. Having relatives in pain and discomfort might increase caregivers' role strain and perhaps reduce their feeling of ease in relation to the LST decisions they made. The following quotations illustrate concern about pain:

He [the physician] ordered some heavier medication and that was the only thing that I would say was really kind of awkward was that we had trouble getting him there as fast as I thought was important (2, 187-191).
 We kept saying, 'Where is it?' 'Well it [pain medication] will be here shortly.'
 And then it just wasn't and you know then it was really, that was hard, really hard to have him in pain (2, 219-222).
 And we were very fortunate I felt in that I never felt like she was in any real pain (7, 256-157).

Figure 4 depicts the "Ill Relative;" therefore, subcategories and potential indicators related to relatives after their deaths are not listed, although role strain and ease felt by caregivers in making LST decisions might continue after the death of their relatives.

The findings in relation to the "Ill Relative" were based on descriptions by family caregivers of their experiences in making LST decisions. The meanings arose out of the interaction the caregivers had with their ill relatives, and were modified through an interpretive process by the caregivers. Since caregivers also interacted with other family members and health care providers in relation to the LST decision-making, the meanings of these interactions shaped and guided their activities as well.

Family Relations

The category "Family Relations" and its subcategories are presented in the conceptual framework in Figure 2. A detailed version of the "Family Relations" category is presented in Figure 5. "Family Relations" represent the various connections between

the family caregiver and his or her relative and other family members. Subcategories are listed alphabetically. Potential indicators listed below subcategories are components of the concept that may be associated with family caregiver role strain and ease in making LST decisions. Potential indicators are listed according to the number of study participants who mentioned them, or in alphabetical order. Concepts, concept definitions, potential indicators in the data set, and draft items for measures of family caregiver role strain and ease are listed in Table 6.

Categories, Subcategories, and Potential Indicators that may be associated with Caregiver Role Strain and Ease in Making LST Decisions

Temporal Sequence	Antecedent Factors				D. Post LST Decision-Making and Post Death	E. Responses
Category	Historical Factors		Immediate Factors			
	III. Family Relations:		III. Family Relations:			
Subcategories	I. CG & III Relative a) Knowing the person n=17 b) Closeness Emotional n=4 Physical n=4 c) Being part of the relative's life Spending time together n=3 Being there n=2 2. CG & Other FM a) Relationships n=17		I. CG & III Relative a) Being part of the relative's life Spending time together Being there b) Closeness Emotional Physical CG & Other FM a) Relationships		I. CG & III Relative a) Being there n=7 b) Unfinished business n=5 c) Saying good-bye.	I. CG -> FM a) FM not being there: n=4 Anger Pulling back Selfprotection Struggle 2. CG & Other FM a) Growing closer n=3 FM -> CG a) Decision-making Anger n=2
Time	Role Strain and Ease				Role Strain and Ease	
	Years to months to days to hours		Hours to minutes		Second to weeks	
					Seconds to years after death	

Time

Role Strain and Ease

Years to months to days to hours

Hours to minutes

Second to weeks

Seconds to years after death

Figure 5. Family Relations Category in the Family Caregiving Process in Making LST Decisions for Elderly III Relatives. CG = caregiver; FM = family member; n = the number of caregivers who addressed the concept.

Table 6

Family Relations Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
A. Antecedent Factors			
1. CG & Ill Relative			
a) Knowing the person	CG's depth of familiarity with relatives' values, character and life course.	"Like I knew my parents and their medical history. And while it's not my natural expertise, I've had to become their advocate and I had to become good at knowing, judging what's going on with them" (2, 901-905). "She was just that type of person" (9, 51). "As she got older, she got crankier and she liked that in herself" (11, 12-13).	How well did you know your ill relative?
b) Closeness: Emotional	Being close.	"Not that they [mother and brother] didn't have a good relationship, we were just closer – had always been" (7, 94-95).	The last year of your ill relative's life, how close (emotionally) were you to him/her?
Physical	Living near by.	"And then last year we looked at another assisted living facility because it was new, it was here close" (1, 118-119).	The last year of your ill relative's life, 1. You lived the closest of the family members to him/her? 2. One or more family members lived

Note. (n, n) In the parenthesis, the first n is the code number assigned to the study participant. The second n is the unit number assigned to the lines of the interview text.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
c) Being part of the relative's life:	Involvement with the relative prior to his/her death.		closest to him/her?
Spending time	Being together.	"I was with her [mother] within six months before she passed, we watched TV and we had some long talks. I mean you know, it was the best time that I had with my mom" (10, 532-536). "We were the ones that were there on a day-to-day basis (1, 210-211).	During the last year of your ill relative's life, to what extent were you able to spend quality time with him/her? During the last year of your ill relative's life, to what extent were you able to be there for him/her?
Being there	Being physically and/or emotionally available.		
2. CG & Other FM	Interactions between the CG and other FM.	"And then she [sister] would come back, like I said, we didn't have a relationship, but if we were sitting together or whatever, and I would try to talk to her some, it was always negative coming back" (10, 1472-1475).	Before your ill relative's last illness, did you not see eye to eye with one or more of your FM? During your ill relative's last illness, did you not see eye to eye with one or more of your FM?
a) Relationships			
B. Contextualized Role Enactment			
1. CG & FM			
a) Agreement among FM	FMs coming to a mutual arrangement regarding the LST decisions for their ill relative.	"He [son] knew what the decision was. And he told me that he didn't like it"	At the time you made LST decisions for your ill relative, were one or more family members not in agreement with you?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		(11, 369-370). "I guess it was satisfying because we, we really were all in agreement" (7, 312-313).	If yes, how difficult was that for you?
b) Other FM being there	FM being emotional and physical available.	"And he definitely supported all the decisions, he was there for me if nothing else" (1, 540-541).	At the time you made LST decisions for your ill relative, how much were other FMs there for you? (Circle your answer)
c) Support from other FM in decision-making	Other FM standing behind CG in making LST decisions for their ill relative.	"She just came in a couple of hours, and we're not close and in fact, we don't see eye-to-eye on nothing. And so she was of no support for me whatsoever" (10, 639-641).	At the time you made LST decisions for your ill relative, how much did other FMs support your decisions? (Circle your answer) Did other FM s' support make you feel more ease with your LST decisions? If yes, how much easier was the decision because of the support from other FMs?
C. Post LST			
Decision-Making and Prior to Death			
1. CG & Ill Relative			
a) Being there	Being physical and/or emotional available.	"And I just wanted to be with her those last few days. I'm glad I was" (5, 324-325). "I wasn't there when she actually	After you had made LST decisions for your ill relative, were you able to be (stay) with him/her? If no, how hard was that for you?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
b) Unfinished business	Having left something undone with the ill relative.	stopped breathing" (15, 411-412). "I should have stayed at the hospital longer" (13, 406). "I don't feel that that she [wife] and I left anything undone" (9, 708).	Do you think that somebody else should have been there, but was not? If yes, how hard was that for you? Was there something that was left undone between your ill relative and you? If yes, how difficult is that for you?
c) Saying "good-bye"	Getting closure on the CG's relationship with the ill relative.	"I got to tell her [mother] 'Good-bye'" (11, 116). When it was over, I told him [father] it was OK to go now" (3, 564-565).	After you had made LST decisions for your ill relative, were you able to tell him/her "Good-bye"? If not, how difficult was that for you?
E. Responses			
1. CG → FM			
a) FM not being there:	FM being emotional and physical available.		Were one or more FMs not there for you when you had to make LST decisions for your ill relative? Where there FMs who you thought would be there for you at the time you had to make LST decisions for your ill relative, but who were not there?
Anger		"I don't have a lot to say to them at this point in time. I haven't been able to voice what my feelings are toward them" (1, 599-600). "It's just that you know emotionally, I	

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		just wasn't ready to deal with them and say, you know, this what you have done, because I think they have hurt their son too. He's been very hurt by this" (1, 705-708).	
Pulling back		"Right know, I'm probably at a point where I'm pulling back from both my family and my husbands family. My family is my husband and my children, and that's it" (1, 590-593).	
Self protection		"I'm divorced from family right now. It was just a too big of a load for me to deal with" (1, 661-662).	
Struggle		"So that, that was the struggle that came out of this" (1, 532).	
2. CG & Other FM a) Growing closer		"I think it brought the family closer together."	
3. FM → CG a) Decision-making: Anger		"My sister actually has been kind of angry with me at times" (10, 1028).	

In Figure 5, under antecedent factors (A), two subcategories are listed: (1) CG & ill relative and (2) CG & other FM. These subcategories are listed under both historical and immediate factors because family caregivers' connections with their relative and other family members might change over time, but also more immediately, because of changes in the health status of the ill relative. Potential indicators of the "CG & ill relative" are: (a) knowing the person (n = 17), (b) closeness (n = 8), and (c) being part of the relative's life (n = 5). "Knowing the person" is listed only as a historical antecedent factor since "knowing" develops over time.

Under contextualized role enactment (B), one subcategory, "CG & other FM," is listed, with three potential indicators listed below it: (a) agreement among FM (agreement, n = 6, not in agreement, n = 3), (b) other FM being there (being there, n = 4, not being there, n = 3), and (c) support from other FM (support, n = 5, lack of support, n = 2). "Agreement among family members" was the most frequently mentioned finding in this subcategory; most participants addressed this aspect. Being in agreement and not being in agreement are illustrated by the following quotations:

So we were totally in agreement. And if she [mother] had felt really different about it, I [daughter] would have honored her opinion and her wishes. So it was really easy because we were together [regarding the LST decision for her father] (2, 269-272).

She [one sister] was pretty appalled by the decision I made [for our mother] (01, 575).

Under "post LST decision-making and prior to death" (C), one subcategory was found: "CG & ill relative," and three potential indicators related to the relative before the death were of importance to caregivers: (a) being there (being there, n = 6; not being there, n = 1), (b) unfinished business (finished business, n = 3, unfinished business, n =

2), and (c) saying good-bye (saying good-bye, $n = 3$, not saying good-bye, $n = 2$).

“Giving permission to die” was a component of saying good-bye.

Responses by family caregivers and other family members were in three subcategories: (1) CG → (responses toward) FM, (2) CG & other FM, and (3) FM → (responses toward) CG. Four participants commented on family members not being present and “there” for them during the process and at the time of decision-making. The words most frequently used by the participants to describe their reactions toward these family members were: (1) anger, (2) pulling back, and (3) struggle. “Self-protection” was chosen to describe a participant who “had built a shell” around herself for protection from family:

The following quotations illustrate ways in which family members were not there:

I have for about a couple of months been nursing a pretty good anger against my brother. Because he wasn't there. And he could have been (3, 283-285).

I'm not saying I'm not compassionate. I'm too emotional. I get too involved. And I don't know that I could pull myself back enough to protect myself. And boy we have to do that though. I'm kind of that mode (1, 944-947).

I'm struggling a bit in dealing with his parents [her in-laws who weren't there when LST decisions had to be made for a grandmother] (1, 596)

I have this little shell built around me right now, you know. And, and that's OK because I think that comes from you know, you have to heal yourself in different ways. And that's pretty much where I am at. I know that some of my family doesn't quite understand that, but they will (1, 951-955).

Three participants described how they and other family members had grown closer because of the process of making the LST decisions.

The family growing closer is illustrated by the following quotation:

And that we've gotten to know each other. We've kind of drifted apart as adults. And we have become a unit again, We've become closer (3, 734-735).

Two family members were angry with study participants because of the LST decisions they had made for their ill relatives. One family member felt that a participant had killed their relative:

No, um my younger sister told my brother at the funeral that she feels that I killed my mother (10, 1433-1434).

Health Care Provider

The category “Health Care Provider” and its subcategories are presented in the conceptual framework in Figure 2. A detailed version of the “Health Care Provider” category is presented in Figure 6. Subcategories are listed alphabetically. Potential indicators listed below subcategories are components of the concept that may be associated with family caregiver role strain and ease in making LST decisions. Potential indicators are listed according to the number of study participants who mentioned them, or in alphabetical order. Concepts, concept definitions, potential indicators in the data set, and draft items for measures of family caregiver role strain and ease are listed in Table 7.

Categories, Subcategories, and Potential Indicators that may be associated with Caregiver Role Strain and Ease in Making LST Decisions									
Temporal Sequence	A. Antecedent Factors				B. Contextualized Role Enactment: In Making LST decisions		C. Post LST Decision-Making and Prior to Death		E. Responses
	Historical Factors		Immediate Factors		IV. HCP		IV. HCP		
Category	IV. HCP		IV. HCP		IV. HCP		IV. HCP		IV. HCP
Subcategories	1. Knowing n=4		1. HCP Behavior		1. Advance Directives 2. HCP Behavior		1. HCP Behavior		1. Information n=8 a) Proactive b) Strain due to emotional reaction 2. Medical Treatment n=8 a) Lack of treatment b) Satisfaction
			a) In relation to communication and information: Providing information n=10 Straight forward n=8 Availability n=4 Helpful n=4 b) In relation to interactions with CGs: Respect n=8 Consistency n=6 Working with n=6 c) In relation to medical background Down play n=4 Treatment aggressiveness n=3				a) Cared for CG n=4 b) Cared for ill relative n=6		
Time									
Years to months to days to hours			Role Strain and Ease				Seconds to years after death		

Table 7

Health Care Provider Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
A. Antecedent			
Factors			
1. Knowing	HCPs' depth of knowledge of the deceased relative.	"They [parents] had the same doctor through all this, he knew that she didn't want any life giving" (8, 485-486). "And it was, you know a doctor I'd never seen before or knew her [mother]" (11, 308).	Before LST decisions were made for your ill relative, To what extent did the HCPs know him/her? To what extent did that make it easier for you to make LST decisions for him/her when the time came?
1. HCP Behavior	Actions of HCPs prior to LST decision-making.		Before LST decisions were made for my ill relative,
a) In relation to communication and information:		"And he got right back to me and was very caring. And gave me information that I didn't know that I needed" (2, 893-894).	1. HCPs gave me information that I didn't know that I needed. 2. HCPs were very caring.

Note. (n, n) In the parenthesis, the first n is the code number assigned to the study participant. The second n is the unit number assigned to the lines of the interview text.

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
Providing information		“And they do an excellent job. And the doctors do inform the family what is going on. And what they are going to do next. And the nurses are very good about explaining what they are going to do next” (13,329-333). “Very helpful and gave me good inputs that helped, helped in the decision-making process” (7, 533-534). “He [HCP] was willing to give me the information that I needed” (8, 1143). “But we didn’t realize they were putting it (endotracheal tube) in when they did, because we just went in and it was in there” (14, 108-109). “The HCPs weren’t communicating to me what they were doing to my relative” (14, 328). “There was no feedback at all from nobody” (14,190). “We really wanted some answers and nobody was giving them to us. We weren’t getting any answers. We didn’t know what to do” (14, 155).	1. HCPs informed me about what was going on. 2. HCPs informed me about what they were going to do next. 3. HCPs gave me input that later helped in the decision-making process. 4. HCPs were willing to give me the information I needed. 5. To what extent were you provided timely information about LSTs for your ill relative? 6. To what extent did HCPs keep you informed about your ill relative’s condition so you could make informed LST decisions? 7. To what degree did you want answers regarding LST for your ill relative, but nobody was giving them to you?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		“But that does make it very, very difficult when there’s times when you need to reach somebody, can’t reach somebody, can’t get an answer at that point in time” (1, 524-528).	8. To what degree were HCPs available when you needed them?
Straight forward		“She, we want her off [mechanical ventilation]. That’s it. And I want you to tell me straight. And because I, I didn’t play games” (14, 566-567). “The cardiologist was very “up front,” just talked to us” (9, 230).	To what extent were HCPs straight forward with you in providing you information?
Availability		“She was always there to answer any questions that I had and you know, help us along” (1, 879). “I got no communication with this one doctor – 7 day period” (14, 152). “Um Mom’s surgeon came and went the first day and never saw him again. And literally until the day they decided they were going to take the breathing machine away and never saw him again” (14, 161-164).	1. To what degree were HCPs available to give information when you needed it? 2. To what degree was your ill relative’s primary HCP available to talk to you? 3. To what extent was it difficult to make LST decisions for your ill relative because of lack of contact with the HCPs who were treating him/her?
Helpful		“She [HCP] was just very, very helpful. She wasn’t condescending” (9, 462).	1. HCPs answered a lot of questions.
b) In relation to interactions with			

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
CGs: Respect		"I really appreciated that like from the first time I talked to Dr. G., he said, 'You're the daughter with no end, you're on the scene. I want you to be comfortable with this and feel free to call back'" (2, 906-910).	1. To what degree did you feel that HCPs respected you?
Consistency		"I always dealt with different people, different doctors and different nurses" (3, 383).	1 To what degree did you have to deal with many different HCPs before you made LST decisions?
Working with		"HCP were good at working with us" (1, 227). "HCP were not clear sighted in dealing with me" (14, 462). "When HCP were working with me, the human touch wasn't there" (14, 143).	1. How well did HCPs work with you? 2. To what degree were HCPs clear sighted in dealing with you? 3. To what degree did one or more HCPs lack the human touch when working with you?
c) In relation to medical background: Downplay		And of course the whole time I was concerned because we have strict deals that there's not to be any you know respirator or anything, and they kept assuring me" (13, 104-107).	1. To what extent did HCPs assure you that LST were needed?
		"I was concerned about the treatment my relative was getting because there was not to be anything, respirator" (13, 122-123).	1. To what extent were you concerned with the LST your ill relative was getting?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
Treatment aggressiveness		"HCP continued to treat my relative despite his/her living will" (14, 315).	HCP continued to treat my relative despite his/her living will.
B. Contextualized Role Enactment			
1. Advance Directives	HCPs' attitude toward the use of advance directives to guide LST decisions for relatives.	"Again I said, 'Look, I said, you said 24 hours, there's no response. I cannot see any value in keeping her hooked up for another 48.' But then, I have no idea what his, what his intent, I can't read his mind, but that didn't set well with me" (9, 192-195). "It just seemed to me that he was trying to force us to do something that wasn't correct" (9, 233-235).	When LST decisions were made for your ill relative, 1. One or more HCPs did not agree with your request regarding LSTs for him/her. 2. One or more HCPs questioned your LST decisions for him/her. 3. You had to convince health care providers to follow your ill relative's wishes? 4. One or more HCPs questioned his/her advance directive. 5. You were opposed to the way HCPs managed LSTs for your ill relative? 6. One or more HCPs did not follow his/her wishes regarding such treatments.
2. HCP Behavior	LST possibilities described by HCP.	"She [physician] was not directive. And she was giving us alternatives, but not telling us what to do" (3, 366-367). "I thought he was pretty masterful at kind of holding back until the right time, and then started something that	When you made LST decisions for your ill relative, how clear were the HCPs in describing LST options available for your ill relative?
a) In relation to communicating LST options: Clarify			

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		was really a summation of what we had been talking about in a way that made it clear for both of us" (3, 374-377).	
		"I had not dealt with this before so I didn't know what questions to ask" (2, 895).	
b) In relation to interactions with CGs:	Actions of HCPs in relation to LST decision-making.		
Support			When you made LST decisions for your ill relative, 1. One or more HCPs were not supportive. 2. One or more HCPs were not helpful.
Helpful		"There were two doctors that really, really helped me. You know, they were there for me" (10, 434-435).	If true, to what extent did that make the decisions harder? If false, to what extent did that make the decisions easier?
C. Post LST			
Decision-Making and Prior to Death			
1. HCP Behavior	The degree of care provided to CG and to his/her ill relative after LST decisions had been made.		After LST decisions were made for your ill relative, to what extent did the HCPs check to see how you were doing? After LST decisions were made for
a) Cared for CG		"Just being sure that I was OK. She laid her hand on my shoulder. Make sure that I'm, and she checked with me over	

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		the next couple of days to see if I was OK" (2, 638-340).	your ill relative, to what extent were HCPs accessible to you?
		"But she took the time to come back. And she made sure that I knew that she was on duty 24-7 (2, 650-651).	After LST decisions were made for your ill relative, how much care did he/she receive from HCPs?
b) Cared for ill relative		"And they just anytime I asked for anything they were right there and many other times they were coming and checking" (2, 246-247).	After LST decisions were made for your ill relative, to what extent were the HCPs right there for him/her?
			After LST decisions were made for your ill relative, to what extent did HCPs check his/her condition?
E. Responses			
1. Information			
a) Proactive		"I just, nobody talked about the process [of making decisions] and I think that just have to be a proactive thing" (8, 1169-1170).	To what extent would the end have been easier had you been getting the information you needed?
		"Getting information in the end would have made things easier" (15, 655-657).	
b) Strain due to emotional reaction		"So I need some answers. I don't want to play any more games. I just want some answers. Don't think that that's unrealistic to find out what's going on." And she just got snottier and snottier,	Were there times when you expressed anger to the HCP? To what degree was the LST decision-making the worst experience of your life?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
		real just up in my face. And I said, "OK, I want to talk to a doctor. I don't care who it is. I want to know what's going on, I want to know if that machine needs to come off, because I know that she doesn't want it on." 'What does your Mom normally have?' 'I don't know. But her husband is in there, and he doesn't want her on that machine. And I know that she doesn't want to be on that machine. So give me the paperwork. We'll fill it out. I don't have a problem with that.' 'Well, we'll have to talk to the doctor.' "My point! So I left. I just left her standing there, because I couldn't talk to her any more. I was shaking. It's not my way to do that. You know, I felt bad. I apologized to everybody. Just, you know, I broke down. The nurses on almost every shift, every nurse, everyday knew where we were, but they just never got out there. But once that we had our explosion, they were on it. And I didn't think that was right. I still don't think that what I did was right. I still feel bad that I lost my temper. But we just didn't get anywhere. I mean, I just, you know, telling them nicely that to please let us	To what degree was the LST decision-making the most difficult experience of your life? To what degree was the LST decision-making the most upsetting experience of your life? To what degree was the LST decision-making the most upsetting experience you have ever had? To what degree was the LST decision-making the most difficult time in your life?

Concept Name	Concept Definition	Potential Indicators in Data Set	Draft Items
2. Medical Treatment		know what was going on and we were right outside, and you know, it just didn't work, you know" (14, 237-266).	
a) Lack of treatment		"Didn't think it was a big deal, but had everybody really been on top of things, how long would she have lasted?" (8, 507-508).	To what extent did one or more HCPs not think that it was a big deal that your relative did not get treatment earlier? Did your ill relative get medical care in a timely manner? If HCPs had been on top of things, my relative might have lived longer.
b) Satisfaction		"I'm glad that HCP did what they did to help her" (16, 389).	How satisfied were you with the medical treatment your ill relative received?

In Figure 6, under antecedent factors (A), the subcategory “knowing the person” (n = 4) is listed as a historical factor, since time is a factor in getting to know someone else.

The quotation below illustrates “knowing the person:”

And in fact, one time I wasn't there. And I was gone for a couple of days and they got his sodium out of balance. He went in the hospital, and they just about killed him. You know, and you know, I understand. It was a mistake, and it was a mistake by honest, good people. But I really felt like, I often wonder what in the world would an old person do without a son or a daughter or someone to be there to advocate for them and to understand what was going on and, and not let them do whatever they were going to do. Which very often was frankly contraindicated by all of the experience we had had. The other thing was that Dr. Black really knew my father. But when he went in the hospital, she was out of the picture. There was somebody else completely different and, and they just started changing his medication, you know, doing stuff like that, which very often kind of fouled him up. And I think that what led us to the, the advance directive about you know amputation and all of that was six months ago when he was in the hospital (3, 416-440).

Under antecedent factors (A), the subcategory “HCP behavior” is listed under immediate factors. The potential indicators of “HCP behavior” are: (a) in relation to communication and information, (b) in relation to interactions with CGs, and (c) in relation to medical background. These take place before and often close to the time LST decisions have to be made. Potential indicators of “communication and information” are: (1) providing information (n = 10), (2) straight forward (straight forward, n = 5, not straight forward, n = 3), (3) availability (n = 4), and (4) helpful (helpful, n = 3, not helpful, n = 1). Potential indicators of “interactions with CGs” are: (1) respect (respect, n = 4, not respect, n = 4), (2) consistency (consistency, n = 4, no-consistency, n = 2), and (3) working with (working with, n = 4, working without, n = 2). Potential indicators of “medical background” are: (1) down play (n = 4) and (2) treatment aggressiveness (n = 3).

Under the contextualized role enactment (B), two subcategories are listed: (1) “advance directives” and (2) “HCP behavior. Advance directives are listed here because they guide health care providers when LST decisions are made. In three situations, health care providers did not follow the wishes of the relatives at the point when the caregivers thought that providers should have done so. “HCP behavior” has two potential indicators that might be associated with family caregiver role strain and ease in making LST decisions: (a) in relation to communicating LST options (clarity, $n = 6$) and (b) in relation to interactions with CGs (support, $n = 5$, helpful, $n = 2$).

These quotations illustrate “communicating LST options:”

And he [physician] laid it out for me. He said, ‘There’s three things we can do. We can either just leave her on the IVs and the antibiotics. I don’t think it’s going to do her much good, but we can do it. We can take her down to the intensive care. We can do a bunch of stuff to her, but will she come out, I don’t know. Will she, will it sustain her? Maybe. Or we can take off everything.’ And um, you know, he was very good at laying it out (8, 490-497).

In contrast to the above, this quotation shows lack of communication:

And that’s what was wrong with Mom. We made the decision [LST decision] up front, but then we couldn’t move things [with HCP] (03, 907-908).

Because of prior experience with LST options, one caregiver and her siblings knew what option they wanted for their mother, but were unable to have it implemented by health care providers. This caregiver described several times how physicians in particular “stonewalled” her and her siblings.

“HCP behavior in relation to interactions with CGs” was important for participants when LST decisions were made and was also an antecedent factor. The following quotation illustrates health care provider support at the time of LST decision-making:

You're the daughter with no end; you're on the scene. I [physician] want you to be comfortable with this and feel free to call me. I'm on call tonight. Um, but as far as I see it, we can leave him comfortable ... if he is not better tomorrow But, if you have any reservations about that, get him into emergency and I'll support that 100% (2, 908-914).

After LST decisions had been made (post LST decision-making and prior to death, C), 10 participants noted that health care providers were there for them ($n = 4$) and their dying ill relative ($n = 6$). These two potential indicators of "HCP behavior" were coded as "cared for." Caregivers who felt that they and their ill relative were cared for by health care providers might have felt less role strain and a higher feeling of ease from having made LST decisions for relatives. This is illustrated by the following quotation:

She [nurse] had been around us a lot of times and it appeared to her that that's the way it's gonna be. Um, she is very gentle. Certainly not forceful about it. Just being sure that I was doing OK. She laid a hand on my shoulder. Make sure that I'm, and she checked with me a lot of time over the next couple of days to see that it was OK and other people were very supportive. Nobody else had anything to do with the decision except the RN. She came back that night, later at night to make sure that the medication was up, and done the way they were supposed to and everything. I don't know, she had a social activity, she brought a niece or somebody with her that was, that she was doing something with. But she took the time to come back. And she made sure that she knew she was on duty uh 24-7 (2, 636-650).

Based on participants' interactions with health care providers during the Family Caregiving Process in Making LST Decisions for Ill Relatives, two subcategories of responses emerged from the data in relation to: (1) "information ($n = 8$) and (2) "medical treatment ($n = 8$). The participants' experiences might have led to them to feel more or less role strain and/or ease in making such decisions. Three caregivers described how they wanted health care providers to be more proactive and prepare caregivers for the process they might have to go through when decisions had to be made for relatives.

I would prefer it if the physician was a little bit more proactive and say, "These, this is a decision you're going to have to make, whether you like it or not, is this

decision you might have to make.” And I think, I think physicians and everybody are a little too intimidated by the process and the fact that, that’s not fair, they are not supposed to be talking about death to people (8, 1143-1151).

For one family, not being able to obtain information from health care providers so they could make the right LST decision for their ill relative was extremely difficult (see Table 8). At the time of the interview, the family continued to express emotional strain resulting from their experiences with health care providers. In relation to medical treatment, some participants (n = 3) said that their relatives had gotten the best treatment (satisfaction), whereas others (n = 5) said that their relatives had not gotten appropriate or timely treatment. Caregivers blamed health care providers for this (see Table 8). The following quotation illustrates lack of treatment by health care providers:

Yeah, I mean, I don’t feel that they did, everything that they could to save her. And then by the time they did do everything, it was too late. Because I mean you think about her when she was talking about her head problems. I mean why wouldn’t you look into that? (15, 919-923).

Health Care System

“Health Care System” was not well defined (Figure 7). Because of its possible implications for family caregivers’ feeling strain and/or ease in making LST decisions for ill relatives, the category was kept as a part of the framework.

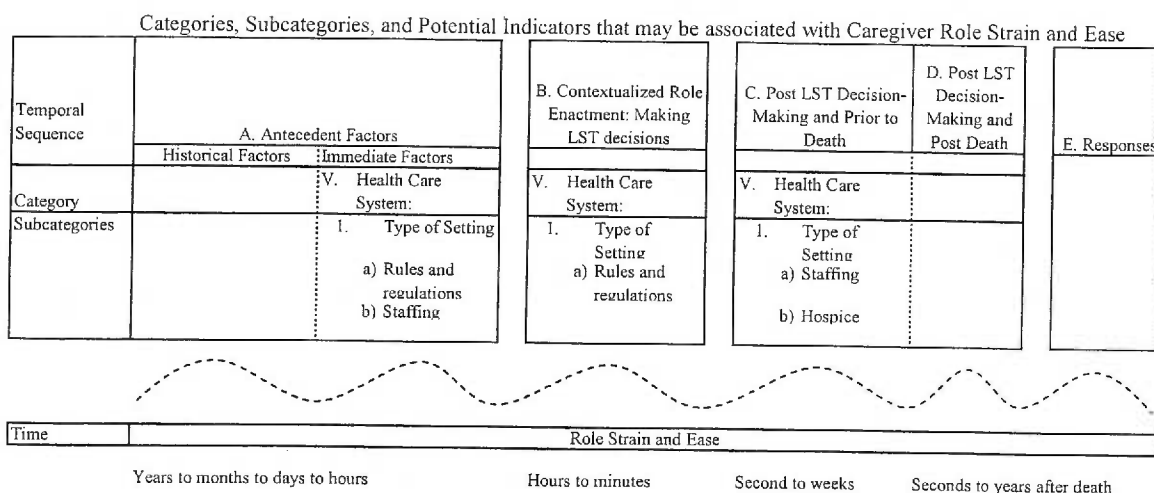


Figure 7. Health Care System Category in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives.

This category might be further explored in future research (see Table 8). Its possible implications are illustrated by the following quotation. A family caregiver removed the relative's feeding tube so she could stay in the Alzheimer's unit. For her, change was worse than not having a feeding tube and, at the same time, the health care providers "had their way," as the caregiver put it.

Well for one thing she couldn't stay where she was. And to me, that was one big thing that did I allow them to put the stomach tube back in to uh give her medication and so forth. That they would have to move her back to the hospital or the move to uh nursing site. Because they couldn't keep her in the Alzheimer's Unit. Well, one of the worst things for her at this point was change.

Several caregivers complemented the work of hospice ($n = 4$) and others talked about understaffing ($n = 3$), but staffing's and hospice's role in LST decision-making in relation to family caregivers were not described in any detail.

Table 8

Health Care System Category: Concepts, Concept Definitions, Potential Indicators in Data Set, and Draft Items.

Concept Name	Concept Definition	Potential Indicators of Participant Data	Draft Items
B. Contextualized Role Enactment			
1. Type of setting a) Rules and regulations	Health care facility.	“Everything was always so cut and dried. You can only do this. We can only do this. And that makes it harder to deal with the system” (1, 952-952). They wouldn’t take her [wife] in the Alzheimer’s, with the tube” (4, 268).	At the time you made LST decisions for your ill relative, did the type of setting your ill relative was in influence your LST decisions? If yes, please describe.
C. Post LST Decision-Making and Prior to Death			
1. Type of setting a) Hospice	Health care facility.	“Hospice made the transition to dying very comfortable for him/her” (5, 572-573). “Hospice made the end easier” (5, 302)	Did your ill relative receive hospice care? If yes, for how long? Did hospice make your ill relative’s dying easier? If yes, in what ways? Did hospice influence your LST decisions for your ill relative? If yes, in what ways?

Note. (n, n) In the parenthesis, the first n is the code number assigned to the study participants. The second n is the unit number assigned to the lines of the interview text.

CHAPTER 5

Discussion and Conclusions

This study has produced a data-based conceptual framework and draft items for measures of family caregiver role strain and ease in making LST decisions for elderly ill relatives in a variety of health care settings. Based on refinements of the conceptualization of family caregiver role strain and satisfaction, the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives was developed to expand understanding of the experiences of family caregivers who participate in such decisions. The findings place LST decision-making within the context of ongoing family care.

Role theory within the symbolic interactionist view was used to frame this study. Initially, role strain was defined as “family caregivers’ felt difficulty following LST decisions for elderly relatives.” This definition of role strain was revised to: “family caregivers’ felt difficulty in making LST decisions for elderly relatives,” to encompass the possible strain felt by caregivers during the trajectory of the Family Caregiving Process in making such decisions.

Initially, “satisfaction” was defined as “family caregivers’ felt comfort following LSTs decisions for elderly relatives.” As a part of role theory, the work done by Burr and colleagues (1979), and satisfaction in family care, “satisfaction” was chosen by the investigator to capture family caregivers’ felt comfort from making such decisions. However, the word “satisfaction” was not used by any of the 17 participants in the study, either spontaneously or with prompting. Neutral or more positive aspects of making LST decisions by family caregivers were reflected in statements such as “The decision itself was easy,” “I’m pretty much at peace with the decision,” and “I feel comfortable with

what I did.” Therefore, to more accurately reflect the findings from the study, the term “satisfaction” was changed to “ease,” defined as “family caregivers’ feeling of being without discomfort in making LST decisions for elderly relatives.”

Clearly, the term “ease” does not fully capture the concept described by participants, nor does it reflect the trajectory of the Family Caregiving Process in making such decisions. The concept of “ease” needs further clarification, and this will be part of the investigator’s postdoctoral studies. For example, one participant said, “It’s not that it [the LST decision] was easy, but it wasn’t difficult,” suggesting that this participant felt some level of discomfort at the time the decision was made. In contrast, other participants used “at peace” to describe how they felt about the LST decision 6 to 8 months after it had been made. Most family caregivers who felt at peace with the LST decision they had made had gone through a cognitive and reflective transition at the conclusion of which they experienced the feeling of being at peace. Some family caregivers who were not at peace with the LST decision experienced guilt or regrets; others experienced uncertainty about the decision. Such uncertainty has also been reported elsewhere. In the study by Tilden and colleagues (1999), 6 months after the decision to withdraw life-extending treatments, the main theme expressed by participants was a “quest for certainty” (1999, p. 437). They were attempting to combine many pieces of information to increase their certainty about the decisions made.

Role strain and satisfaction were the components of role theory used for this study. Role strain adds a new theoretical perspective to the LST decision-making literature, which has been primarily atheoretical. Also, role strain of family caregivers in the context of LST decision-making complements the existing literature on role strain in

family care. “Ease” is a new conceptual component in the LST and caregiving literature that needs further development and testing.

The Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives and its temporal sequence provides a detailed picture of LST decision-making. This conceptual framework can be used to guide theory, research, and practice related to family caregiving and end-of-life care. Some antecedent factors associated with the process of making LST decisions for relatives occurred at different time points for participants in this study. These family caregivers’ role strain and ease in making LST decisions might be more or less influenced by the potential indicators derived from the data and experienced at various points over the trajectory of the process.

LST Decision-Making Literature Related to the Caregiver

The literature to date on the experiences of family members making LST decisions has primarily viewed decision-making as a discrete event, rather than an aspect of ongoing caregiving by families. The findings of this study were based on the experiences of making LST decisions reported by family caregivers. From the data analysis, four time periods in the Family Caregiving Process emerged at which LST decision-making might be associated with caregiver role strain and ease: (a) antecedent factors, (b) contextualized role enactment: in making LST decisions, (c) post LST decision-making and prior to death, and (d) post LST decision-making and post death.

Prior Experiences

In this study, “prior experiences” were listed under antecedent factors. Thus caregiving activities and the functional status of the care recipient have been included as part of the measures of family caregiver role strain and ease in making LST decisions for

elderly ill relatives (See Figure 3, antecedent factors, A). Bonner and colleagues (1999) suggest that the length of time that family members have functioned as caregivers may be associated with LST choices. Using hypothetical situations, these researchers explored African-American caregivers' preferences for LSTs for relatives with dementia or stroke. The researchers found that trust in the health care system influenced LST choices made by the caregivers.

Placing an elderly relative in a long-term care facility is a very difficult life experience for some family caregivers (Forbes, Bern-Klug, & Gessert, 2000; Penrod & Dellasega, 1998) – according to findings from the current study, harder for some than making LST decisions. Forbes and colleagues (2000) conducted focus groups with 28 family members of nursing home residents with moderate to severe dementia. The researchers examined family members' decision-making related to resuscitation, hospitalization, and use of antibiotics for the residents. Some of the family members found it difficult to discuss end-of-life decisions and dying of their relatives due to the burden and guilt they carried as a result of the nursing home placement. Little has been reported, however, about family caregivers who first make care facility placement decisions for a relative and who at a later point make LST decisions for the same relative. If care facility placement decisions are indeed more difficult for family caregivers than making LST decisions, knowing that may be useful in preparing the family of care facility residents who find it difficult to discuss comfort care and end-of-life decisions. Knowledge gained in this area may help health care providers better understand the experiences of caregivers when they make care facility placement decisions for elderly relatives and educate and prepare these caregivers for the road ahead, which may include

LST decisions. Such decisions may not be as difficult as imagined, especially with advanced planning that includes end-of-life care.

Role Expectations and Responsibility

Role expectations and responsibility were included as antecedent factors and under contextualized role enactment: making LST decisions. The inclusion of these subcategories in measures of family caregiver role strain and ease in making LST decisions for elderly relatives is supported by the literature. Jeffers (1998) and Tilden and colleagues (1999, 2001) found that when making LST decisions for relatives, the hardest thing for most family members to do was accept the surrogate decision-maker's role. In most families, the independent decision-making role provoked anxiety and was avoided (Tilden et al., 1995). Reckling (1997) has described the roles that family members and health care providers adopt during the discussion and implementation of a decision to withhold or withdraw treatment from relatives of the family members. These roles are: strong advocate, moderate advocate, neutral participant, moderate resister, and strong resister. Reckling (1997), however, did not explore family caregivers' role strain and feeling of ease in making such LST decisions for relatives.

Understanding of Ill Relative's Immediate Situation

"Understanding of ill relative's immediate situation" is considered here an immediate antecedent factor. The importance of understanding the immediate situation was also described by Swigart and colleagues (1996), who found that in order for family members to decide to forego life support, they needed to first conduct work in three interrelated areas: "(1) understanding and reframing the critical illness, (2) reviewing and revising the perceived life story of the patient, and (3) maintaining family roles and

relationships” (Swigart et al., 1996, p. 485). The work of “understanding and reframing the critical illness” involves gathering information and coming to a physiological understanding of the illness, its treatments and mechanisms of deterioration (Swigart et al., 1996).

Readiness for Death

Wilson and Daley, who interviewed 11 family members who had lost a relative, within 4 weeks of the death, described “family perspectives on death and dying in long-term care settings” (1999, p. 19). The major themes that emerged from their study were: “caring behaviors of staff, participating in the dying process, and providing spiritual support” (Wilson & Daley, 1999, p. 19). One family member said that her mother was ready to die, that “she just didn’t want to be here anymore” (Wilson & Daley, 1999, p. 23). Whether or not the daughter was ready for the death of her mother was not indicated by the researchers. The influence of family caregivers’ readiness for the death of their ill relative on LST decision-making has not been systematically evaluated. In the current study, five participants noted whether or not they were ready for the death of their ill relative. Based on the comments of these participants, it is likely that family members who are ready for the death of their ill relative experience less role strain than family caregivers who are not ready when making LST decisions.

Decision-Making

Some studies have found that aspects of “not being prepared” were related to how prepared families felt for the surrogate decision-making role. Some families felt more prepared because of their experiences with prior events such as a previous death in the family or other relatives’ chronic medical conditions (Tilden et al., 1999).

LSTs

Generally, withholding LST treatment may be more acceptable than withdrawing treatment but on the other hand, Reckling (1997) notes that because implemented LSTs provide ill persons with a trial of therapy, withdrawing such treatments could be viewed as more acceptable than withholding them. However, research has not explored this question systematically. Since both aspects of LST decisions are included in the measures of family caregiver role strain and ease in making such decisions, these conflicting views can be explored in future research.

Responses

Four responses to LST decision-making and two responses related to the Family Caregiving Process were found in the current study. The four responses related to the decision were: (a) did the right thing, (b) guilt, (c) regret, and (d) strain from not being sure if the caregiver had done the right thing. These responses have also been described in the literature (Jacob, 1998; Jeffers, 1998; Mayer & Kossoff, 1999; Tilden et al., 1999; 2001). More positive responses to LST decision-making for ill relatives have been reported less frequently. In the study by Tilden and colleagues, several participants described the decision-making as an honorable duty “that left them enriched” (1999, p. 435). Positive responses identified by participants in the current study were “being prepared” and “learning.” More research is needed to explore other responses, as well as negative responses experienced by family caregivers during the Family Caregiving Process. What exactly do family caregivers learn? How do they use what they have learned? Can health care providers influence family caregivers’ learning? If so, in what ways and at what points during the Family Caregiving Process?

LST Decision-Making Literature Related to the Ill Relative

Advance Directives

Family members' knowledge of their relatives' wishes regarding LSTs has been found important in making actual and hypothetical LST decisions for relatives (Jacob's, 1998; Mayer & Sharon, 1999; Reckling, 1997; Teno et al., 1998; Tilden et al., 1999; Tilden et al., 2001; Swartz & Perry, 1993). This finding was supported by the current study. Fifteen of the 16 deceased relatives had had advance directives. Six had had written advance directives, 4 had had a power of attorney for health care, 4 had stated their wishes verbally, and 1 had had a living will. Because family caregivers knew their ill relatives' wishes, they were better able to follow them and therefore some of the caregivers felt more relieved. Only 20% of adult Americans have completed advance directives (Perrin, 1997), but in the current study the number of elderly relatives ($n = 11$) who had written advance directives, was much higher (68.8%). Because the percentage who had an advance directive was so much higher than the general population, the results of this study may reflect the fact that the State of Oregon is in the forefront of end-of-life care. Thus the experiences of the participants in this study may have differed from the experiences of most family caregivers, whose relatives do not have advance directives. To address this question, further testing of the items is planned for a location other than Oregon.

Health Decline Trajectory

Based on the finding that LST decision-making may differ for family caregivers whose relatives had suffered long-term chronic illnesses, the "health decline trajectory" has been included in the measures of family caregiver role strain and ease in making LST

decisions for relatives. Among the symptoms listed under “health decline trajectory,” pain, loss of consciousness, and struggling were addressed by most family caregivers. Pain, in particular, has been found an important factor in LST decisions (Karel & Gatz, 1996), and pain control is considered a component of a good death (Lynn et al., 1997; Steinhauser et al., 2000, 2000). Other symptoms such as nausea, anxiety, shortness of breath, and fatigue have been included in the measures of family caregiver role strain and ease in making LST decisions because of their prevalence at the end of life (Lynn et al., 1997; Kaye, 1999).

Forbes and colleagues (2000) described decision-making by family members in regard to resuscitation, hospitalization, and use of antibiotics for relatives who were nursing home residents. They found that death had two faces. Death was unacceptable to family members if the resident had a treatable condition such as pneumonia. Death was acceptable if: “(a) it was caused by an acute event, (b) the physician had declared the resident terminally ill, (c) it was caused by circumstances beyond the family’s control, (d) it occurred in a manner one could live with, (e) it was considered God’s will, or (f) it occurred when there was no hope” (Forbes et al., 2000, p. 254). In the current study, the hopelessness of the relative’s condition was addressed, as well as the extent to which the relative’s condition was treatable. Some family caregivers experienced what was unacceptable to family members in the study by Forbes and colleagues (2000), and they questioned whether or not their ill relative could have survived with treatment.

Medical Diagnoses

Medical diagnoses have been included in the measures of family caregiver role strain and ease in making LST decisions for relatives for descriptive purposes. Little

research has explored differences in LST decision-making between family caregivers whose relative had specific long-term chronic illnesses and family caregivers whose relative was healthy before the last illness (Swigart, 1996). Studies using hypothetical scenarios to explore LST decision-making (Bonner et al., 1999; Karel & Gatz, 1996; Mezey et al., 1996) and studies exploring actual LST decision-making (Loscalzo et al., 1996; Mayer & Kossoff, 1999; Keenan et al., 1997; Reckling, 1994; Smedira et al., 1990; Tilden et al., 1999, 2001) have investigated factors associated with withdrawing LSTs, but the importance of these factors has varied. In the study by Mayer and Kossoff (1999), the most important factors in making the decision to withdraw LSTs were poor expected quality of life, poor prognosis, the patient's known wishes, and the patient's current level of suffering. In other studies, the patient's own wishes were rated as most important (Tilden et al., 1999, 2001). In the current study, the relative's wishes, his or her "health decline trajectory," and "overall health problems" were factors in LST decision-making.

Overall Health Problems

Research investigating family caregivers' ratings of the importance of the relative's cognitive, functional, and emotional state when considering actual LST decisions is lacking. However, using hypothetical situations, Mezey and colleagues (1996) examined anticipated decisions about LSTs among 50 spouses of patients with a minimum of Stage 4 AD. Spouses were significantly more likely to forego all four treatments (resuscitation, breathing machine, feeding tube, and antibiotics) for coma (66%) than for critical illness (10%). Karel and Gatz (1996) examined the importance attributed by an intergenerational community sample to the following factors in considering a hypothetical LST decision for oneself or a parent: (a) mental capacity, (b)

pain, (c) type of treatment, (d) time left to live, (e) doctor's recommendation, (f) opinion of family, (g) age, (h) burden of care, (i) financial strain, and (j) knowing what the individual would have wanted. Caregivers rated the age of a parent, his or her mental capacity, and time left to live less important in LST decision-making than non-caregivers did. The oldest participants rated financial strain and burden of care on the family more important than the younger generation did in LST decision-making for oneself. Being a burden to family was explored from care receivers' point of view, not their caregivers (Karel & Gatz, 1996). In the current study, a few family caregivers described the concerns expressed by their ill relatives, who did not want to become a burden to their family.

Dying Process

The findings of the current study support the inclusion of the "dying process" in measures of family caregiver role strain and ease in making LST decisions for elderly relatives. Eight participants discussed the dying process and six commented on the length of time from decisions until the death of their relative. Berns and Colvin (1998) elicited stories from family members, friends, and/or significant others of 416 patients who had died in hospitals, nursing homes, home health, and hospice in order to identify the experiences participants recalled regarding the death of the patients. The data analyses led to six propositions; one was: "Families will remember details of the events surrounding the death and will describe their loved one's death as either peaceful and comfortable or as painful and struggling" (Berns & Colvin, 1998, p. 585). Wilson and Daley (1999) explored the responses of 11 family members who had experienced the death of a relative in a long-term care facility. The researchers found that the length of

time for the dying process of their relative played a role in how the family members coped with the loss. Neither Berns and Colvin (1998) nor Wilson and Daley (1999), however, investigated how family members who made LST decisions for their relative were affected by the decisions in the context of the dying process.

LST Decision-Making Literature Related to Family Relations

Caregiver and Ill Relative

With respect to the relationship between the caregiver and the ill relative, “knowing the person” was addressed by all 17 participants. The importance of this factor has been well documented (Tilden et al., 1999, 2000). Tilden and colleagues (2001) described “knowing the patient” as one factor families used in arriving at a LST decision for their hospitalized relative. Swigart and colleagues (1996) found that lack of closeness between family members and ill relatives made the decision-making more difficult since family members had little information on which to base a decision.

In the current study, family caregivers valued the fact that they had been part of their relatives’ lives. Most caregivers had followed the wishes of their relatives regarding LSTs because they “knew the person.” This finding is in contrast to the findings of Sonnenblick and colleagues (1993). They reported that requests for LSTs were more frequent among children who visited their parents more than once a week, than among those who visited less than once a week. Of the 108 children who participated in the study, 56 knew their parents’ wishes regarding LSTs, but only 26 requested that their parents’ wishes be followed. The researchers conducted their study in Israel, however, and their findings may not be generalizable to the U.S. population.

Berns and Colvin (1998) found that “being present or absent at the death of their loved one was a significant memory for survivors.” However, only 3 out of 68 family members or close friends who were not present for the death mentioned feelings of guilt. In the current study, 7 of the 17 participants discussed being there for the dying of their ill relative.

Caregiver and Other Family Members

Research is limited on prior family roles and relationships and the experiences of family caregivers in making LST decisions for a relative, although “the Daughter from California Syndrome” is well known among health care providers (Molley, Clarnett, Braun, Eisemann, & Sneiderman, 1991). Conflicts among family members at the time and after LST decision-making for relatives have been documented (Tilden et al., 1995; Norton & Talerico, 2000), though responses to family conflicts such as anger have been documented to a lesser degree.

The importance of family support has been reported by Swigart and colleagues (1996), who found that support by other family members for the decision-maker and their permission for him or her to make decisions made it easier to let the person go.

LST Decision-Making Literature Related to Health Care Providers

The findings of the current study on the behavior of health care providers and advance directives are consistent with other research in these areas. Potential indicators that were most important to participants were: (a) health care provider behavior in relation to their way of communicating with them, as well as the information the health care providers provided them, and (b) the way health care providers interacted with them and their ill relative.

Health Care Provider Behavior in Relation to Communication and Information

In the current study, 10 participants commented on the information provided to them by health care providers and ways in which the information was provided. Some health care providers were thought to have done an excellent job; others did not provide the information the family needed or communicate at all. The importance of information to families and strategies to deliver such information have been documented. Norton and Talerico (2000), for example, suggest specific communication strategies to be used by health care providers to facilitate end-of-life decision-making. These strategies include: "Being clear, avoiding euphemisms, spelling out the goals and expectations of treatment, using words such as "death" and "dying," and being specific when using such words as "hope" and "better" (Norton & Talerico, 2000, p. 6). The importance of the information provided by health care providers is clearly described by Tilden and colleagues, in whose study families spoke of "the need for more information," and said they were "starving for information" (1995, p. 638). Hanson and colleagues (1997) interviewed by phone 461 family members 2 months after the death of a relative and asked their perceptions of the care their relatives had received at the end of life. Family members said they had wanted information that was honest, compassionate, and timely, and more information on the relative's prognosis. They also wanted physicians to treat the whole person, instead of just aspects of the dying person, and to use less medical jargon. Family members wanted to be prepared and therefore wanted accurate information about prognosis as soon as possible.

Health Care Provider Behavior in Relation to Interactions with the Caregiver and Ill Relative

The current study's most important finding in relation to health care providers' interactions with family caregivers was that caregivers wanted to be respected by the health care providers, and have their knowledge of their ill relative validated. The participants also wanted the same health care providers to be "working with" them. Similarly, Jacobs (1998) reported the need of family members to arrive at a judgment about the patient's condition and "work with" health care providers to have family members' decisions about LSTs enacted. Tilden and colleagues (1995) described behaviors of health care providers that increased family members' burden as well as behaviors that family members found helpful when making LST decisions. Behaviors that increased burden were "postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the burden of decision-making on one person, withdrawing from the family, and defining death as a failure" (Tilden et al., 1995, p. 633). Helpful behaviors were "encouraging advanced planning, timely communication, clarification of families' roles, facilitating family consensus, and accommodating families' grief" (Tilden et al., 1995, p. 633).

Advance Directives and Medical Treatment

In the current study, health care providers did not follow the advance directives of three ill relatives at the point when family caregivers thought they should have done so. Family members of one of the three still felt tremendous strain because of this at the time of the interview. Jacob (1998) also reported that family members found decision-making troubling when the patient was treated by health care providers who did not subscribe to

the mutuality of treatment goals. She also concluded that in the long term, acceptance of the experience and the decisions depends greatly on the interactions between the family members who make the decisions and health care providers.

In the current study, 16 of 17 family caregivers knew of their ill relatives' wishes, and several of them had discussed these with health care providers. However, as noted by Hanson and colleagues (1997), discussions about advance directives do not always take place. In their study, in 23% ($n = 106$) of deaths ($n = 461$), family members did not believe that they or their deceased relative had participated in LST option discussions with health care providers. Yet 41% ($n = 189$) of the deceased relatives had had a living will. The absence of discussion was not affected by whether or not the relative had a living will.

The current study did not explore whether or not there were differences in family caregivers' judgment of treatment by health care providers in different settings. Hanson and colleagues (1997), who did examine comments by family members regarding health care settings, found that comments were more positive about hospital care at the end-of-life than about care in nursing homes. Negative comments about hospital care included concerns about treatment delays. Negative comments about nursing home care included poor judgement about diagnosis and treatment, and lack of attention to dying residents. Tolle and colleagues (2000), who investigated care of the dying across a range of settings, conducted telephone interviews with 475 family members 2 to 5 months after the death of a relative to "identify barriers of optimal care of a population-based representative sample of decedents across a full range of settings in which death occurred" (2000, p. 310). From factor analysis of the data, three short scales were

derived: (a) Barriers to Receiving Preferences for Amount of Life-Sustaining Treatment (5 items), (b) Support from Clinicians (5 items), and (c) Management of Pain (4 items). In general, family members were satisfied with the care provided to their dying relative. Family members also rated their satisfaction with support they received from health care providers fairly high. Nearly all (97%) of the family members believed that their relatives' preferences about LSTs had been respected. Among these family members, the researchers found no differences in Barriers to Receiving Preferences for Amount of Life-Sustaining Treatment across settings (Tolle et al., 2000, p. 314).

LST Decision-Making Literature Related to the Health Care System

Several authors have reported how the behaviors of health care providers influence family members' experiences when they make LST decisions for relatives (Jacob, 1998; Tilden et al., 1995). Less is known about the health care system's influence on family caregivers' experiences in making LST decisions. However, the importance role of hospice in end-of-life care and LST decision-making has been documented extensively (Hanson et al., 1997).

Item Generation, Retention, and Reduction

Initial items for measures of family caregiver role strain and ease in making LST decisions were generated from the following categories: (a) caregiver, (b) ill relative, (c) family relations, (d) health care provider, (e) health care system, and (f) responses. Because the primary focus of the content analysis was on the caregiver, items generated for this category are more complete than for the other categories. Items still need to be generated for the "responses" category. Other items that need to be generated include items that (a) clearly reflect how angry and upset some family caregivers were with

health care providers, and (b) the extent to which health care providers clearly explained to family caregivers how poorly their ill relative was doing prior to the time LST decisions were made.

To generate, retain, and reduce items for each category for measures of family caregiver role strain and ease in making LST decisions for elderly ill relatives, suggestions listed by Ebel (1963) and Waltz and colleagues (1991) were followed. These suggestions were: (a) express items as clearly and simply as possible, (b) choose words that have precise meanings and avoid complex and awkward word arrangements, and (c) adapt the level of difficulty of the items to the level of the study participants (Ebel, 1963; Waltz et al., 1991). Words in items were chosen that reflected the current use of the language, e.g., “dying” was used in items instead of “passing.” For the proposed measures of family caregiver role strain and ease in making LST decisions, items were generated and retained based on (a) the number of participants who discussed a concept, (b) completeness in the description of a concept, and (c) the investigator’s clinical expertise which included a judgment of the importance of an item. Redundant items were deleted.

Ethnic Variation

Because the study sample lacked much ethnic variation, further testing of the items is needed if the measures of family caregiver role strain and ease in making LST decisions are to be used with different ethnic groups. This may pose a challenge since the degree of assimilation of different ethnic groups into mainstream American culture varies, and many ethnic groups have other values and beliefs about dying and end-of-life care. For example, advance directives may reflect a “middle-class” approach to health

care, not patients and families who represent ethnic minority, immigrants, or refugee populations (Lynn & Teno, 1993).

Response Format

The measures of family caregiver role strain and ease in making LST decisions for elderly relatives will use a multi-item self-report format. This format is a useful way to obtain sensitive information that is difficult to gather by other means (Polit and Hungler, 1995). Although response formats have not been decided upon yet, they will doubtless include options such as alternate-choice (“yes-no,” “true-false”) and scaled responses (Likert-like scales, semantic differential scales) (Appendix L). The format and response range will be selected based on refinement of the conceptual framework: Family Caregiving Process in Making LST, and definitions of the key concepts to be measured. The range of responses will be from 2 to 7 rating points.

Limitations of the Study

This study has several limitations. The first is the small sample (17 participants) which limits the generalizability of the study findings. Further, the findings were derived from participants’ recall of the LST decision-making experience. Nevertheless, the information on experiences recalled by participants is valuable because these experiences were real to them. The participants were spouses, children, and a grandchild of elderly ill relatives, not parents of young or adult children for whom LST decisions had to be made; therefore, the findings may not be generalizable to these parents. Furthermore, 15 of the 16 participants had had an advance directive.

A second limitation is related to the health care providers who helped in the recruitment of participants and the settings from which participants were recruited. These

settings were all research-oriented. Some of the health care providers in these settings were interested in participants' experiences in making LST decisions. One health care provider, for example, specialized in geriatrics, referred 3 of the 17 participants. However, nurse managers who had not been involved in the direct care of the elderly relatives recruited other participants. A few of these participants had had very negative and emotionally difficult experiences in making LST decisions.

A third limitation comes from the unique aspects of end-of-life care in Oregon, which may have led to greater awareness of the use of advance directives and choices at the end of life.

Implications for Nursing Research

This is the first study to use role theory in the context of LST decision-making by family caregivers. The data on role strain in the context of LST decision-making by family caregivers complement the existing literature on role strain in family care. Ease is a new conceptual component in the LST and caregiving literature, and more data need to be collected from family caregivers to better understand the trajectory and potential nuances of "ease" in the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives. Further testing of the conceptual framework derived from this analysis should include data from caregivers of diverse ethnic minority groups and age groups.

To develop psychometrically sound measures of family caregiver role strain and ease in making LST decisions for elderly relatives, the draft items generated here need to be tested. Such testing needs to include readability and ease of completion for family caregivers as well as evidence of reliability and construct validity of the measures. When these have been accomplished, the investigator will examine topics such as: (a) variations

in family responses resulting from participating in making LST decisions, (b) predictors of caregiver role strain and ease in family caregivers involved in decisions about LSTs, (c) the relationship of role strain and ease to health outcomes for family caregivers, (d) ways to target interventions to decrease family caregiver role strain and increase ease with LST decisions, (e) the effectiveness of interventions used by health care professionals in relation to LST decisions, and (f) the impact of LST decisions by family caregivers on the quality of care for elderly ill relatives at the end of life.

Implications for the Practice of Nursing and Other Disciplines

The conceptual framework presented here can be used to help health care providers in a variety of health care settings better understand caregivers' experiences in making LST decisions for elderly relatives. The framework can be used by health care providers (a) during the time when antecedent factors exist, (b) when LST decisions have to be made, (c) after the decisions have been made and before the death of the relative, and (d) after the death of the relative. The framework will alert providers to potential indicators of role strain and ease that may have preceded and might follow the caregivers' current place along the trajectory of the Family Caregiving Process. Then health care providers will better understand where caregivers have been and where they may be going. Findings from the literature suggest that when family caregivers consider LST decisions for relatives, they consider their relative's past, present, and future condition (Jeffers, 1998). Findings from the current study support the view that LST decision-making is not an isolated experience, and health care providers should consider the past, current, and future condition of caregivers who may have to make or have made LST decisions for elderly ill relatives.

In addition to providing a better understanding of caregivers' experiences in making LST decisions for elderly relatives, the framework also provides potential indicators of role strain and ease related to elderly relatives, family relations, and health care providers. These can help health care providers be more alert to their way of interacting with others and their way of practicing their discipline. Further, the items suggested here provide sample language to be used by practicing health care providers when talking to families about the often difficult topic of LST decision-making and death.

Summary

This report presents findings from the content analysis of data from an exploratory-descriptive study. Semi-structured interviews were conducted by the investigator with 17 family caregivers to obtain descriptions of their role strain and satisfaction in making LST decisions for elderly ill relatives in a variety of settings. Role strain and satisfaction are components of role theory that were incorporated into the study. Refinement of the conceptualization of family caregiver role strain and satisfaction added a new perspective, termed the Family Caregiving Process in Making LST Decisions for Elderly Ill Relatives and its temporal sequence, which can expand understanding of the experiences of family caregivers who participate in such decisions. Role strain provides a new theoretical perspective to the LST decision-making literature, which has been primarily atheoretical. Furthermore, role strain in the context of LST decision-making by family caregivers complements the existing literature on role strain in family care.

Because the term “satisfaction” was not used by any of the participants in this study, it was deleted from the organizing framework and instead, “ease” was included as a new conceptual component of LST decision-making and caregiving. Since the concept does not fully capture the spectrum of terms used by participants to describe the neutral to positive aspects of making LST decisions, it needs further theoretical development and testing.

Six categories of data were derived from the study: (a) caregiver (b) ill relative, (c) family relations, (d) health care provider, (e) health care system, and (f) responses. Various antecedent factors and subcategories that emerged from the data may be associated with LST decision-making by family caregivers. The findings of this study also led to the generation of preliminary draft items for measures of family caregiver role strain and ease in making LST decisions for elderly ill relatives. The study lays the foundation for developing such closed-ended self-report measures. The conceptual framework can be used to guide research, practice and theory development related to selected areas of family caregiving and end-of-life care.

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LIST OF APPENDICES

- A Summary of and Rationale for Modifications in the Research Method
- B Summary of Measures of Strain used in Studies of Families
- C Summary of Measures of Satisfaction used in Studies of Families
- D Measures of Family Satisfaction with Decision-Making and Care
- E Interview Guide and Demographic Question Sheet
- F Letters of Support
- G Short Description of Study
- H Consent Forms
- I Life-Sustaining Treatments
- J Health Decline Trajectory
- K Medical Diagnoses
- L Examples of Response Formats

Appendix A

Summary of and Rationale for Modifications in the Research Method

	Proposed	Actual Implementation	Explanation of Modification
Aims	Aim 1. To refine the conceptualization of family caregiver role strain and satisfaction following life-sustaining treatment decisions and to obtain suggestions for item wording. Aim 2. To obtain evidence for content validity of the new measures of family caregiver role strain and satisfaction following life-sustaining treatment decisions. Aim 3. To pre-test the new measures of family caregiver role strain and satisfaction following life-sustaining treatment decisions.	Aim 1, (and not Aim 2 and 3) was required by the investigator in partial fulfillment of her doctoral study. Based on the content analysis of the interview data, the wording of Aim 1 changed to: "To refine the conceptualization of family caregiver role strain and satisfaction in making life-sustaining treatment decisions, within the context of ongoing family care." Furthermore, 2 new aims were added: 1. To describe factors associated with family caregiver role strain and satisfaction in making life sustaining treatment decisions. 2. To generate items for measures of family caregiver role strain and satisfaction in making life sustaining treatment decisions, based on the refined conceptualization and words of caregivers.	Since the investigator interviewed 17 study participants and not 8 to 10 as originally proposed (see below), the fulfillment of Aim 1 and the two new aims were the requirement for her dissertation work. The original aims, Aim 2 and 3 will become parts of the investigator's post-doctoral studies.
Methods	Exploratory-descriptive.	Proceeded as proposed.	
Design	The sample of family caregivers of elderly ill relatives who have died under the care of primary care providers affiliated with Oregon	The sample of family caregivers of elderly ill relatives who had died were obtained from health care providers affiliated with OHSU,	Because the investigator was informed by a faculty member at the OHSU's School of Nursing that she knew of
Setting			

	Health Sciences University (OHSU) and Legacy Health System in Oregon will be obtained.	Legacy Health System, and the Department of the Veterans Affairs Medical Center (VA) in Portland, Oregon.	family caregivers' affiliated with the VA who might be potentially appropriate study participants, the investigator sought and obtained Institutional Review Board approval from this site in addition to the other two.
Sample	Purposive sampling will be used to identify family caregivers of ill relatives who died from a range of primary diagnoses such as heart disease, cancer, chronic obstructive pulmonary disease or dementia.	Proceeded as proposed.	
Sample criteria	Family caregivers will (1) have participated in decision-making about life-sustaining treatments (LSTs) (either to withhold or withdraw treatments) for elderly relatives 65 years and older who died 2 to 6 months earlier; (2) read and speak English; (3) be adult (21 years of age or older); and (4) be representative of the population in the greater Portland Metropolitan area by gender, race, and ethnic origin.	Proceeded as proposed.	One exception to the sample criteria was a family caregiver who believed that her ill relative was dead prior to the withdrawing of the ventilator. According to the health care provider, that was not the case. The caregiver and the health care providers had been in agreement regarding the withdrawing of the ventilator.
Sample size	About 8 to 10 caregivers who have participated in decisions about LSTs for elderly ill relatives will	The sample size was increased to 16 to 18 family caregivers.	The rationale for the increase in sample size was to assure that the sample would include

	be interviewed.			family caregivers with a broad range of experiences in making LST decisions.
Instrument	Semi-structured qualitative interviews will be conducted with family caregivers.	Interview questions regarding the demographics of study participants were changed from questions asked by the investigator in the beginning of the interview to a list of questions to be answered in writing by the participants at the end of the interview.		The rationale for this change after the first interview was due to the eagerness of the participant to describe her experiences with LST decision-making for her elderly relative. Asking her the questions in the beginning of the interview felt more like an interruption than an initiation to get the interview started.
Procedure	The interview will be limited to approximately 1 hour in order to prevent fatigue.	The interview ranged in time from 36 to 128 minutes ($\underline{M} = 68.8$, $SD = 29.0$).		The rationale for not limiting the few longer interviews to approximately 1 hour was due to an expressed desire by the study participants to continue and finish the interviews.
Analysis plan	Recorded interviews will be transcribed and analyzed using content analysis	Proceeded as proposed.		
Draft of measures	Items for a draft of measures of family caregiver role strain and satisfaction will be generated from analysis of the qualitative data, literature review, the investigator's clinical experience, and discussions with the dissertation committee.	Proceeded as proposed.		

Appendix B

Summary of Measures of Strain used in Studies of Families

Summary of Measures of Strain used in Studies of Families.

Concept	Measure	Description	Sample	Reliability	Validity
Cantor, 1983 Strain (not defined).	The measure was developed to learn more about the degree of emotional, physical, and financial strain experienced by caregivers caring for elders.	A 3-point measure of strain.	Total N = 111 caregivers. N = 37 spouses, N = 40 children, N = 21 other relatives, N = 13 friends and neighbors.	None reported.	None reported.
Concept Robinson, 1983 Strain was defined as "those enduring problems that have the potential for arousing threat, a meaning that establishes strain and stressor as interchangeable concepts" (p. 344).	Measure The Caregiver Strain Index. The index measures family member's strain in providing various degree of care to older patients at home.	Description The index is a 13-item, ordinal measure.	Sample Sample consisted of spouses, family, friends, and neighbors, aged 22 to 83. N = 81.	Reliability Cronbach's alpha was .86.	Validity Evidence of construct validity was obtained for each of the three areas: ex-patient characteristics; subjective perceptions of the care-taking relationship by caregivers, and emotional health of caregivers.
Concept Brooks, 1984	Measure The Strain Scale.	Description 7-point scale, a 1-	Sample 55 relatives of 46	Reliability None reported.	Validity None reported.

Subjective burden was described as stress felt by the person caring for the patient, resulting from the presence of objective burden.	The scale is a measure strain of subjective burden.	item measure. Range: no strain to moderate and severe strain.	males who had experienced severe head injuries.	(Brooks, 1984; Schultz, Smyrnios, Carrafa & Schultz, 1994).	(Brooks, 1984; Schultz, Smyrnios, Carrafa & Schultz, 1994).
Concept Archbold, Stewart, Harvath, & Lucas, 1986; Archbold, Stewart, Greenlick, & Harvath, 1990 Caregiver role strain was defined as "the felt difficulty in fulfilling the caregiver role for a family member or friend" (Archbold, Stewart, Harvath, & Lucas, 1986, p. 7)	Measure The Family Caregiving Inventory. The inventory contains measures of caregiving concepts including 9 dimensions of strain (Archbold, Stewart, Harvath, & Lucas, 1986)	Description The inventory contains 10 scales measuring strain from: 1. direct care (51 items), 2. lack of resources (5 items), 3. worry (11 items) 4. role conflict (11 items), 5. economic burden (4 items), 6. mismatched expectations (5 items), 7. increased tension (4 items),	Sample Pretest: N = 50 caregiver dyads, aged 33 to 87. Longitudinal study: N = 103 caregivers of elders discharged from the hospital Caregivers ranged in age from 21 to 82 years. Care receivers ranged in age from 65 to 93 years. Longitudinal study: N = 78 dyads (primary caregiver and care receiver). Caregivers ranged in age from 21 to 82 years. Care receiver	Reliability Cronbach alphas ranged from .57 to .98. All but one alpha were .75 or greater.	Validity 16 expert in areas of gerontology, family caregiving, and methodology evaluated the measure for content validity. Evidence for construct validity has been established by testing hypothesized relationships of strain with other variables (Archbold et al., 1990) and by demonstrating increased levels of strain across stages of Parkinson's disease (Carter et al., 1998).

		8. feelings of being manipulated (4 items), 9. frustration due to communication problems, 10. global strain (4 items).	ranged in age from 65 to 93 years. Parkinson's study: N = 380 spouses. Mean age of spouse caregivers: 63 years.		
Concept Deimling & Bass, 1986 Caregiver-elder relationship strain (not defined).	Measure The Relationship Strain Scale. The scale measures aspects of the caregiver-elder relationship, such as feeling of strain and resentment toward the elder by the caregiver.	Description The scale is an 8-item measure.	Sample N = 586. Spouse and daughter caregivers. Mean age of spouse caregivers: 72.8 years. Mean age of daughter caregivers: 53.7 years.	Reliability Cronbach's alpha was .88.	Validity None reported.
Concept McCubbin, Patterson & Wilson, 1987 Family strain (not defined). The authors described the effects of prior strains on family	Measure The Family Strain Index. The index is one of seven indices in the Family Index of Regenerativity and Adaptation --	Description The index is a 10-item measure.	Sample N = 1000 families (non-military).	Reliability Internal reliability index: .69.	Validity Validity coefficient: .87.

systems.	General and was designed to measure life events and changes that can make "a family vulnerable to the impact of a subsequent stressor or change" (McCubbin, 1987, p. 291).				
Concept	Measure	Description	Sample	Reliability	Validity
Sheehan & Nuttall, 1988 Personal strain was defined as "the extent of physical, social, and financial disruption experienced in the life of caregivers as a result of caregiving responsibilities" (p. 94)	The Personal Strain Scale. The scale assessed the degree to which the caregiver felt that his/her responsibilities were affecting: 1. job performance 2. financial matters 3. social activities 4. recreational activities 5. relationship with others.	The scale is a 6-item measure.	N = 98 family caregivers providing care to a frail or impaired elderly relative..	None reported.	None reported.
Concept	Measure	Description	Sample	Reliability	Validity
Barber, 1993	The Relationship	The scale is a 6-	N = 109 spouses of	Cronbach's alpha	None reported.

Relationship strain (not defined).	Strain Scale. The scale measures strain in her or his relationship with others due to caregiving.	item version of the Relationship Strain Scale constructed by Deimling and Bass (1986). It uses a 4-point response format.	persons with Alzheimer's disease.	was .81.	
Concept Lengacher, 1993 Role strain was defined as "a subjective experience that can be described as a tension, a driving force, anxiety, and/or frustration that a woman may experience due to multiple demands she puts upon herself or demands put upon her by others" (p. 72).	Measure The Lengacher Role Strain Inventory. The purpose of the inventory is to assess the characteristics of role strain in women who have multiple roles.	Description The inventory is a 5-point, 100-item Likert-type scale.	Sample N = 327 female students in three different colleges.	Reliability Cronbach's alphas for three female nursing student groups were .93, .94, and .95. For non-nursing groups the Cronbach alphas were .95 and .97.	Validity 6 experts evaluated items for content validity. Evidence of construct validity was revealed using the contrasted-group approach. Significant differences were found between the nursing and non-nursing groups.
Concept England & Roberts, 1996 Parent caregiver strain is defined as	Measure The Parent Caregiver Strain Questionnaire. The questionnaire	Description The questionnaire is a 40-item measure. The questionnaire is divided into three	Sample N = 283 adult children responsible for the care of dependent parents.	Reliability Cronbach's alpha was .88.	Validity Factor analysis provided evidence for construct validity. Five

“a sensory-perceptual reaction to the circumstances of parent care” (p. 501).	measures degree of exhaustion, emotional arousal, and goal discrepancy distress.	parts: 1. exhaustion scale (a 5-point scale) 2. emotional arousal scale 3. goal discrepancy scale			factors were identified. They explained 59% of the total variance in caregiver strain. Coefficient alphas for the five factors ranged from .74 to .93.
Concept Lengacher, 1997 Role strain is defined as “a subjective experience which can be described as a tension, a driving force (which could be viewed as a positive or negative force) anxiety and/or frustration that a woman experiences because of the multiple demands she puts on herself or that are put upon her by others, due to the fact that she is	Measure The Women’s Role Strain Inventory. The inventory was developed to measure characteristics of role strain in women who have multiple roles.	Description The inventory is a 44-item, 5-point Likert type scale. It has three subscales: 1. role distress 2. role enhancement 3. role support	Sample N = 445 female nurses in three major hospitals and health science centers. Mean age was 37.9 years. 82% worked full time, 18% worked part-time.	Reliability Cronbach alpha for the total scale was .93. Alphas for the subscales ranged from .80 to .89. Test-retest correlation for the total scale was .79. Correlations for the subscales ranged from .66 to .91.	Validity Three experts evaluated content validity. Factor analysis was performed and supported construct validity.

employed, a spouse, a caregiver, and a mother (p. 143).					
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Appendix C

Summary of Measures of Satisfaction used in Studies of Families

Summary of Measures of Satisfaction used in Studies of Families.

Concept	Measure	Description	Sample	Reliability	Validity
Campbell, Converse & Rodgers, 1976; Walker, Shin & Bird, 1990 Satisfaction (not defined by Walker, Shin & Bird, 1990). "Satisfaction with a domain of life as expressed by an individual is seen as dependent on his evaluations or assessments of various attributes of that domain" (Campbell, Converse & Rodgers, 1976, p. 10)	The Semantic Differential Scale, Life Satisfaction, and Happiness. Satisfaction with the caregiving role was measured by a scale consisting of "10 semantical differential pairs: enjoyable, miserable; hopeful, discouraging; full, empty; friendly, lonely; interesting, boring; worthwhile, useless; rewarding, disappointing; brings out the best in me, doesn't give me much chance; easy, hard; and free, tied down" (Walker, Shin & Bird, 1990, p. 148-149).	Response choices for each pair of items range from 1 (positive) to 7 (negative).	N = 133 elderly mother-adult daughter pairs (Walker, Shin & Bird, 1990).	None reported.	None reported.

Concept	Measure	Description	Sample	Reliability	Validity
Worcester & Quayhagen, 1983 Satisfaction (not defined)	Caregiver Satisfaction. The scale measure the caregiver's satisfaction in the caregiving role.	A global rating scale with responses from 1 to 5. Five indicates the greatest satisfaction.	N = 48; 19 current caregivers and 29 past caregivers.	None reported.	None reported.
Concept George & Gwyther, 1986; Kramer, 1993b Satisfaction (not defined)	Measure Satisfaction with Social Involvement. The scale measures caregiver satisfaction with the frequency and quality of social/recreational activities.	Description The scale is a 7-item measure. The scores range from 0 = not at all satisfied to 4 = extremely satisfied (Kramer, 1993b).	Sample N = 510 family caregivers.	Reliability Cronbach's alpha was .79.	Validity None reported.
Concept "Hassles refer to the minor irritations, and uplifts the small satisfactions, that occur in a designated week of caregiving" (Kinney & Stephens, 1987, p. 42). Hassles were	Measure Caregiving Hassles and Uplifts Scale. The original scale consists of 110 events that typically occur in caregiving. These events are divided into 4 categories: 1. care recipients' limitations in	Description "Each item can be appraised as an hassles, an uplift, or both or neither for the past week of caregiving" (Kinney & Stephens, 1989, p. 403). Each item is rated on a 4-point intensity scale ranging from not at	Sample N = 60 caregivers to family members experiencing Alzheimer's disease.	Reliability Test-retest reliability for respondents' total Hassles scores at a 1-day interval = .85; for respondents' total Uplifts score at 1-day interval = .89. Reliability of Hassles subscales range from .73 to	Validity Based on weak magnitude of associations, the Caregiving Hassles and Uplifts scale was revised to the 45-item Caregiving hassles Scale (Kinney & Stephens, 1987).

defined as "minor events that are appraised by an individual as threatening to his or her well-being" Uplifts were hypothesized to "buffer an individual from the consequences of these hassles" (Kinney & Stephens, 1989, p. 402)	DAL (12 items), 2. care recipients' cognitive status (20 items), 3. care recipients' behavior (53 items), 4. practical/logistical aspects of caregiving (25 items).	all to a great deal.		.91. Reliability of Uplifts subscales range from .71 to .90.	
Concept Sheehan & Nuttall, 1988 Satisfaction (not defined)	Measure Caregiving Satisfaction. Satisfactions associated with caregiving were measured to determine caregivers' positive perception of their caregiving experience.	Description The scale is a 5-item measure. "The items assessed the degree to which caregivers reported feeling appreciated, saw caregiving as providing the opportunity to repay the elder, felt increased confidence as a result of caregiving, perceived	Sample N = 98 family caregivers who provided care to a frail or impaired elderly relative.	Reliability None reported.	Validity None reported.

		caregiving responsibilities based upon a sense of enjoyment rather than duty, and enjoyed the elder's personality" (p. 94).			
Concept	Measure	Description	Sample	Reliability	Validity
Motenko, 1989 Satisfaction, gratification, and enjoyment (not defined)	Satisfaction, Gratification, and Enjoyment. Specific aspects of caregiving were measured by three dichotomous indicators.	"Is there anything that is satisfying to you about these changes (or lack of changes) in the people that you are close to since your husband got sick?" "In general, is there any aspect of your marriage relationship that is gratifying or enjoyable now?" "Although caring for your husband is difficult is anything enjoyable about your husband being home?" (p. 168)	N = 50 wives who were caring for husbands with dementia.	None reported.	None reported.

Concept	Measure	Description	Sample	Reliability	Validity
Miller, 1989 Satisfaction (not defined)	Satisfaction in the Caregiving Role. Satisfaction in the caregiving role was measured by one item based on magnitude scaling technique.	"How many points would you give to show how good it makes you feel to help (your parent?) The better it makes you feel, the bigger the number" (p. 280). Scale values ranged from 0 to 3,000,000.	N = 571 son and daughter caregivers.	Reliability of magnitude scaling variables was discussed in general; not specific to satisfaction.	Validity of magnitude scaling variables was discussed in general; not specific to satisfaction.
Concept Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman & Rovine, 1991 Satisfaction was viewed as one dimension of caregiving appraisals and defined as "benefits accruing to the caregiver through his or her own efforts" (Lawton, Kleban, Moss,	Measure Caregiving Satisfaction Scale. The scale measures positive aspects of caregiving.	Description 5-item scale. E. g. "I really enjoy being with ____."	Sample N = 632 for respite sample. N = for nursing home applicant sample. Samples for older people with demented illnesses (Lawton, Kleban, Moss, Rovine & Glicksman, 1989). N = 285 spouse caregivers and N = 244 adult child caregivers of elders suffering from Alzheimer's disease	Reliability Cronbach's alpha was .67 for respite sample and .68 for nursing home applicant sample; retest reliability was .76 (Lawton, Kleban, Moss, Rovine & Glicksman, 1989). Cronbach's alpha was .71 (Lawton, Moss, Kleban, Glicksman & Rovine, 1991).	Validity Validity correlations for respite sample: .13 to .54. Validity correlations for nursing home applicant sample: .09 to .55. Correlations were derived from: burden ratings, quality of relationship, negative affect, positive affect, emotional burden, and relationship with impaired

Rovine & Glicksman, 1989, p. 64). Caregiving satisfaction was defined as "subjectively perceived gains from desirable aspects of, or positive affective returns from caregiving (Lawton, Moss, Kleban, Glicksman & Rovine, 1991, p. P182)			(Lawton, Moss, Kleban, Glicksman & Rovine, 1991).		person.
Concept	Measure	Description	Sample	Reliability	Validity
Caregiver satisfactions were defined as "perceptions on the part of the caregiver that certain aspects of the caregiving provided are beneficial to the caregiver and his/her family" (Strawbridge, 1991, p. 19)	The Caregiving Satisfaction Scale The scale measures long-term caregiving satisfaction.	The scale is a 15-item measure. Responses are coded on a 4-point response set from 1 = strongly disagree to 4 = strongly agree. Higher scores indicate a higher level of satisfaction.	A total of 100 adult child caregivers caring for elderly parents or parents in-in-law.	Cronbach's alpha was .86.	None reported

Concept	Measure	Description	Sample	Reliability	Validity
Orbell, Hopkins, & Gillies, 1993; Orbell and Gillies, 1993 Satisfaction (not defined). Satisfaction defined in Orbell and Gillies, 1993, p. 279: satisfaction is "extent to which carers derived a sense of enhanced self-worth"	Care Work Satisfaction Scale. The scale measures positive dimension of care appraisals.	The scale is a 6-item measure. Each item is scored on a 7-point scale (strongly agree to strongly disagree).	N = 108 adult caregivers, ages ranged from 18 to 76 years.	Cronbach's alpha was .92.	None reported.

Appendix D

Measures of Family Satisfaction with Decision-Making and Care

Measures of Family Satisfaction with Decision-Making and Care.

Concept	Measure	Description	Sample	Reliability	Validity
Guyatt, Mitchell, Molloy, Capretta, Horsman & Griffith, 1995 Satisfaction (not defined)	Patient and Relative Satisfaction Indexes. 3 questionnaires: - the Patient Satisfaction Index (P-SI) with 23 items (7 items related to decision-making), - the Relative of Competent Patient Satisfaction Index (RES SI) with 34 items (4 items related to decision-making), and - the Relative of Incompetent Patient Satisfaction Index (RIP-SI) with 29 items (7 items related to	The items are scored on a 7-point scale; 7 indicates the highest level of satisfaction and 1 indicates the lowest level of satisfaction.	N = 102 patients. N = 153 of whom 75 were relatives of competent patients and 78 were relatives of incompetent patients.	Cronbach's alpha coefficients were: .94 for P-SI, .92 for REC-SI, and .94 for PIP-SI. Test-retest coefficients were: .86 for P-SI, .90 for REC-SI, and .94 for PIP-SI.	Observed correlations: global satisfaction with health care and participation in decisions ranged from .59 to .68 (predicted correlations: .50 to .70), frequency with which decisions were not considered ranged from .65 to .75 (predicted correlations: .30 to .50), likelihood of wanting to do things differently ranged from .59 to .72 (predicted correlations: .30 to .50), and health care worker rating of patient and relative satisfaction ranged from .18 to .22 (predicted

Concept	decision-making).				correlations: .40 to .60.
Baker & colleagues, 2000 Satisfaction (not defined)	Measure of satisfaction with patient's medical care: - Two items measure satisfaction with patient comfort. - Six items measure satisfaction with communication (4 items) and decision-making (2 items).	Description The Comfort Score ranged from 0 to 2. The Communication (and decision-making) Score ranged from 0 to 6.	Sample N = 767 family members and other respondents for seriously ill hospitalized adults who died.	Reliability Cronbach's alpha coefficients was .80 for the Communication Score and .71 for the Comfort Score	Validity The Comfort Score was inversely associated with the degree of patient pain (Kruskal-Wallis test, $p < .004$). The Communication Score was positively associated with the extent to which family members reported patient preferences for care were followed (Kruskal-Wallis test, $p < .0001$).

Appendix E

Interview Guide and Demographic Question Sheet

Interview Guide

Questions for Family Caregivers Who Participated in Making Decisions about Limiting or Withdrawing Life-Sustaining Treatments for an Elderly Relative

Study Title: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development.

Instructions: Dr. ? gave me your name as someone who had made decisions about life-sustaining treatments for a relative. With the exception of a few questions about you, all the questions I will ask you relate to the circumstances surrounding the time when you had to make (that/those) decisions. All your responses are confidential and will be used to better understand the way (that/those) decisions influenced the way you were feeling at that time and the way you may be feeling now. You may choose not to answer any particular question. The interview will be audiotaped and take approximately 1 hour of your time. There are no right or wrong answers. Sharing your experiences can be a way for me to better understand what the experience was like for you.

Interview Questions:

1. What were the circumstances under which decisions about life-sustaining treatments were made? (Help the interviewee put him or herself back in the situation)

I wonder if you could tell me a bit about your relative's situation at the time you were faced with the decision about life-sustaining treatment for him (or her)?

- ☐ What was your relative's health status? (medical condition)
- ☐ Did you and your relative think or talk about these kinds of decisions before the situation occurred? (advanced planning)
- ☐ If so, tell me when that came about?

2. What decisions were made?

Tell me about the decision (decisions) you had to make regarding the use of life-sustaining treatments?

- ☐ What factors did you consider in making this decision (these decisions)?
- ☐ What actions did you take?
- ☐ From my clinical experience in the Intensive Care Unit, I know that making such decision (decisions) for a relative can be extremely hard for some family members, but not as difficult for others. What was it like for you?
- ☐ Was anything particularly hard at the time of your decision?
- ☐ Was anything particular satisfying at the time of your decision?
- ☐ Since the time of your decision until now are there other things that happened that made living with the decision (decisions) harder for you?
- ☐ Since the time of your decision until now are there other things that happened that made living with the decision (decisions) more satisfying for you?

- ☐ How are you feeling now that some time has passed?
- 3. How were the nurses, doctors and other health care professionals interacting with you at the time you made the decision?
 - ☐ Did their way of interacting with you influence your decision (decisions)?
 - ☐ If so, in what way/ways?
 - ☐ What did they say or do that was helpful/unhelpful for you when the decision (decisions) was made?
 - ☐ What is the most important thing you would teach health care professionals about the decision (decisions) that you participated in making?
- 4. How did your other family members deal with the decision (decisions) about life-sustaining treatment for your relative?
 - ☐ How did their way of dealing with the decision (decisions) influence the way you were feeling?
 - ☐ What changed for you and your family members as a result of making the decision?
- 5. If you could change how things went in that situation, what would you like to change? What would you keep the same?
- 6. If you had to face a similar situation in the future, would you think or feel any differently?
- 7. Is there any thing you would like to ask me or to tell me before we end this interview?
 - ☐ Is there anything I should have asked that I did not?

Conclusion:

Thank you so much for volunteering your time and sharing the experiences you had regarding decision-making with me. Your responses will contribute to the development of an instrument to be used by clinicians and researchers to improve the care and support of family caregivers who will have to make similar decisions for a relative.

Demographic Questions

The following questions are optional. Please write in your answers to the questions.

1. In what year and month were you born? _____
2. Are you married? _____
3. What is the highest grade in school that you completed? _____
4. What is your occupation? _____
5. What is your religious affiliation? _____
6. What is your ethnic background? _____

Appendix F

Letters of Support



OREGON HEALTH
SCIENCES UNIVERSITY
DEPARTMENT OF NEUROLOGY
3181 S.W. SAM JACKSON PARK RD.
MAIL CODE L226
PORTLAND, OR 97201-3098
TEL 503-494-7772
FAX 503-494-7242

July 8, 1999

Lissi Hansen, RN, MS
15708 SE Evergreen Hwy.
Vancouver, WA 98683

Dear Lissi Hansen,

I enjoyed reviewing the draft of your National Research Service Award Proposal, "Measures of Family Role Strain and Satisfaction from Decision-Making about Life-Sustaining Treatment for Elderly Relatives." The area you have chosen for your project has significant empirical and clinical implications for demented patients and their families, as limited knowledge exists about life-sustaining treatment decisions by family members of demented patients.

The Alzheimer Disease Center has a database of over 700 patients diagnosed with Alzheimer's disease or other dementias. We will be pleased to work with you in obtaining participants for the study. Center staff will assist you in making the initial contacts with potential research participants when you are ready to begin your data collection.

I wish you the best of luck in obtaining funds to support you for this important study.

Sincerely,

A handwritten signature in cursive script that reads "Linda Boise".

Linda Boise, PhD., Director
Education and Information Core
Alzheimer Disease Center



Legacy Portland Hospitals
Legacy Emanuel Hospital & Health Center
Legacy Good Samaritan Hospital & Medical Center
1015 N.W. 22nd Avenue
Portland, Oregon 97210
(503) 229-7711

July 1, 1999

NIH

Dear Sir or Madam:

Ms. Lissi Hansen proposes to develop a needed instrument to assess strain and satisfaction of family members involved in decision making about life-sustaining treatments for their loved ones. Such a tool would be of great help for both research and clinical care as we strive to improve end-of-life care for our patients.

Our Legacy Clinic is privileged to be asked to participate by Ms. Hansen in this important project. The primary care providers at our site will be pleased to help facilitate identifying family members who may be willing to participate. We hope to use this information also for our own quality improvement purposes.

Again, we strongly endorse the project and hope that adequate funding support is made available.

Sincerely,

Patrick M. Dunn, M.D.
Acting Site Director
N.W. Clinic Site
Legacy Health System

PMD/mkh

*Legacy Emanuel Hospital & Health Center, a Lutheran-affiliated Center of Caring & Excellence.
Legacy Good Samaritan Hospital & Medical Center, affiliated with the Episcopal Diocese of Oregon.*

Legacy Health System includes Emanuel Hospital & Health Center, Good Samaritan Hospital & Medical Center, Meridian Park Hospital, Mount Hood Medical Center, Visiting Nurse Association, Ambulatory Care Clinics and CareMark/Managed HealthCare Northwest PPO.

Appendix G

Short Description of Study

To:

Regarding: A request for help from you in the recruitment of 16 to 18 study participants (family caregivers including widows, widowers, daughters, and sons) for my dissertation.

The goal of the study is: to develop closed-ended self-report measures of family caregiver role strain and satisfaction following life-sustaining treatment (LST) decisions for elderly relatives in a variety of health care settings.

Specific aims of the study are: (1) to refine the conceptualization of family caregiver role strain and satisfaction following LST decisions and obtain suggestions for item wording, (2) to obtain evidence for content validity of the instruments of family caregiver role strain and satisfaction following LST decisions, and (3) to pretest the new instruments of family caregiver role strain and satisfaction following LST decisions.

Descriptive studies of families' experiences of making LST decisions suggest that health care providers can ease the decision-making process and its consequences by providing information and support to families. However, no existing instrument was found that measures the role strain and satisfaction experienced by caregivers making decisions about LSTs for elderly relatives and no studies have been conducted evaluating strategies to provide information and support to these caregivers.

Criteria for the study participants: They will (1) have participated in decision-making about LSTs (either withholding or withdrawing treatments) for elderly relatives 65 years and older who died 2 to 6 months earlier; (2) read and speak English; (3) be adult (21 years of age or older); and (4) be representative of the population in the greater Portland Metropolitan area by gender, race and ethnic origin.

LSTs are defined as: (1) antibiotics, (2) artificially administered fluids, (3) artificially administered nutrition, (4) cardiopulmonary resuscitation (CPR), (5) chemotherapy, (6) renal dialysis, (7) hospitalization, (8) intubation, (9) surgery, (10) transfer to the intensive care unit (ICU), and (11) ventilation.

Recruitment process: I really would appreciate your help in the recruitment process of study participants. I would like you to identify family caregivers who participated in making LST decisions for a deceased elderly relative during the past 6 months. It is important to think about all the caregivers you have been in contact with in order to include in the study caregivers who have had a range of experiences regarding LST decisions -- both positive and negative. It would be most helpful if you would briefly discuss potential participants with me. Based on our discussion, we will determine whom of the caregivers to be contacted. I would like for you to briefly explain the study and invite the caregivers to participate. If the caregivers agree to talk to me and perhaps to participate in the study, I will contact them. I will set up an interview with the interested caregivers and obtain consent. The interview will be on one occasion and will take approximately 1 hour.

Thank you so much for your time and help.

Sincerely,

Lissi Hansen

Lissi Hansen

hansenl@ohsu.edu

(503) 617-9163

Appendix H

Consent Forms

IRB# _____
Approved:

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form

TITLE: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development.

PRINCIPAL INVESTIGATOR: Lissi Hansen, RN, MS, (503) 494-3840
Ph.D. Student
School of Nursing, Oregon Health Sciences University

CO-INVESTIGATOR: Patricia G. Archbold, RN, DNSc, FAAN, (503) 494-3840
Elnora E. Thomson Distinguished Professor
School of Nursing, Oregon Health Sciences University

PURPOSE:

You have been invited to participate in this research study because you have had the experience of participating in making decisions about life-sustaining treatments for a relative. The purpose of this study is to learn from your experience about circumstances that may influence the way you are feeling now and the way you felt at the time when you participated in making and implementing that or those decisions. The information that you provide will be used to develop questionnaires to measure strain and satisfaction experienced with such decisions. Strain may be the difficulty you felt when you participated in making and implementing such a decision or decisions. Satisfaction may be the comfort you felt when you participated in making and implementing such a decision or decisions.

PROCEDURES:

You will be interviewed on one occasion by the principal investigator at a time and place convenient for you. The interview will be audiotaped. The informal interview will be based on a list of semi-structured, open-ended questions related to your experience of the circumstances that may influence the way you are feeling now and were feeling at the time when you participated in making decisions about life-sustaining-treatments for a relative. The interview will take approximately 1 hour.

RISKS AND DISCOMFORTS:

Some of these semi-structured, open-ended questions may seem personal and deal with private or sensitive issues. These questions may cause you to become emotionally upset. If it is determined that you may benefit from counseling, an appropriate referral will be

made.

You may chose not to answer any question at any point in the interview. You may chose to stop the interview at any point. You may call the principal investigator regarding thoughts and feelings that you would like to discuss. The principal investigator will provide you with a list of telephone numbers of mental health counselors if you should choose to contact one.

BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit family members in the future.

ALTERNATIVES:

You may choose not to participate in this study.

CONFIDENTIALITY:

Neither your name nor your identity will be used for publication or publicity purposes. The interview will be audiotaped and transcribed, however your name will not be used in the transcription in order to maintain confidentiality. The audiotapes, transcribed data, and notes will be kept in a locked file cabinet only accessible to the principal investigator. The audiotapes will be erased immediately after transcription. According to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS:

There will be no costs to you for participating in this study.

LIABILITY:

The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self insured for liability claims. If you suffer any injury from this research project, compensation would be offered to you only if you establish that the injury occurred through the fault of the University, its officers or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please all the Medical Services Director at (503) 494-6020.

PARTICIPATION:

We encourage you to ask any questions that occur to you about this research project and your part in it. Lissi Hansen, RN, MS or Patricia G. Archbold, RN, DNSc, FAAN, (503) 494-3840, have offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. Your participation is voluntary. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences University. Your signature below indicates that you have read the foregoing and agree to participate in Phase 1 of this study. You will receive a copy of this consent form.

Participant's Signature	Date
-------------------------	------

Witness's Signature	Date
---------------------	------

Investigator's Signature	Date
--------------------------	------

LEGACY HEALTH SYSTEM
Consent Form

TITLE: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development

PRINCIPAL INVESTIGATOR: Lissi Hansen, RN, MS, (503) 617-9163
Ph.D. student,
School of Nursing, Oregon Health Sciences
University

CO-INVESTIGATOR: Patricia G. Archbold, RN, DNSc, FAAN, (503)
494-3840
Elnora E. Thomson Distinguished Professor,
School of Nursing, Oregon Health Sciences
University

PURPOSE:

You have been invited to participate in this research study because you have had the experience of participating in making decisions about life-sustaining treatment for a relative. The purpose of this study is to learn from your experience about circumstances that may influence the way you are feeling now and the way you felt at the time when you participated in making and implementing that or those decisions. The information that you provide will be used to develop questionnaires to measure responses in relation to the strain and satisfaction experienced with such decisions in order to improve health care at end-of-life. A total of approximately 16 to 18 research subjects will be participating from Legacy Health Systems and Oregon Health Sciences University.

PROCEDURES:

You will be interviewed on one occasion by the principal investigator at a time and place convenient for you. The interview will be audiotaped. The informal interview will be based on a list of semi-structured, open-ended questions related to your experience of the circumstances that may influence the way you are feeling now and were feeling at the time when you participated in making decisions about life-sustaining-treatments for a relative. The interview will take approximately 1 hour.

RISKS AND DISCOMFORTS:

You may find some of the questions uncomfortable, and they may bring up memories that may or may not be upsetting to you. You may chose not to answer any question at any point in the interview. You may chose to stop the interview at any point. You may call the principal investigator regarding thoughts and feelings that you would like to discuss.

The principal investigator will provide you with a list of telephone numbers of mental health counselors if you should choose to contact one.

BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit family members in the future.

ALTERNATIVES:

You may choose not to participate in this study.

CONFIDENTIALITY:

Neither your name nor your identity will be used for publication or publicity purposes. The interview will be audiotaped and transcribed, however your name will not be used in the transcription in order to maintain confidentiality and anonymity. The audiotapes, transcribed data, and notes will be kept in a locked file cabinet only accessible to the principal investigator. The audiotapes will be erased immediately after transcription. According to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS:

There will be no costs to you for participating in this study.

RESEARCH RELATED INJURY:

Legacy Health System is composed of non-profit hospitals that are dedicated to providing medical treatment for injury or illness. Should you suffer any injury as a result of this research project, emergency treatment will be available. However, compensation for emergency treatment will be available from the hospital only if you establish that the injury occurred through the fault of the hospital, its physicians, officers or employees. Further information regarding this policy, or questions concerning your rights as a research subject may be obtained from the Office of Research Administration at (503) 413-2474.

QUESTIONS OR PROBLEMS:

If you have any questions about this study please contact the principal investigator, Lissi Hansen at (503) 617-9163 or co-investigator, Patricia G. Archbold at (503) 494-3840. If you believe you have suffered a research related injury contact the principal investigator Lissi Hansen at (503) 617-9163 or co-investigator, Patricia G. Archbold at (503) 494-3840.

VOLUNTARY PARTICIPATION:

Your participation is voluntary. You are free to refuse to participate or to withdraw from participation at any time and it will in no way affect your relationship with, or treatment at Legacy Health Systems. The principal investigator may terminate your participation.

You will receive a copy of this consent form.

CONSENT:

I have read the information about this research study and voluntarily agree to participate in the study. The risk and benefits have been explained to me. The principal investigator has offered to answer all of my questions. My signature below indicates that I agree to participate in Phase 1 of this study.

Participant's Signature

Date

Investigator's Signature

Date

Witness's Signature

Date

**VA/OHSU Research Consent Form**

Subject Name:

Date:

Title of Study: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development.

Principal Investigator: Lissi Hansen, RN, MS, Ph.D. Student, OHSU VAMC: 648 Portland, OR

Description of Research By Investigator:PURPOSE:

You have been invited to participate in this research study because you have had the experience of participating in making decisions about life-sustaining treatments for a relative. The purpose of this study is to learn from your experience about circumstances that may influence the way you are feeling now and the way you felt at the time when you participated in making and implementing that or those decisions. The information that you provide will be used to develop questionnaires to measure strain and satisfaction experienced with such decisions. Strain may be the difficulty you felt when you participated in making and implementing such a decision or decisions. Satisfaction may be the comfort you felt when you participated in making and implementing such a decision or decisions.

PROCEDURES:

You will be interviewed on one occasion by the principal investigator at a time and place convenient for you. The interview will be audiotaped. The informal interview will be based on a list of semi-structured, open-ended questions related to your experience of the circumstances that may influence the way you are feeling now and were feeling at the time when you participated in making decisions about life-sustaining-treatments for a relative. The interview will take approximately 1 hour.

RISKS AND DISCOMFORTS:

Some of these semi-structured, open-ended questions may seem personal and deal with private or sensitive issues. These questions may cause you to become emotionally upset. If it is determined that you may benefit from counseling, an appropriate referral will be made.

You may chose not to answer any question at any point in the interview. You may chose to stop the interview at any point. You may call the principal investigator regarding thoughts and feelings that you would like to discuss. The principal investigator will provide you with a list of telephone numbers of mental health counselors if you should choose to contact one.

Subject's Identification (I.D. plate or give Name - first, last, middle)



VA/OHSU Research Consent Form

Continuation Page 2 of 3

Subject Name:

Date:

Title of Study: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development.

Principal Investigator: Lissi Hansen, RN, MS, Ph.D. Student, OHSU

VAMC: 648 Portland, OR

Description of Research By Investigator:BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit family members in the future.

ALTERNATIVES:

You may choose not to participate in this study.

CONFIDENTIALITY:

Neither your name nor your identity will be used for publication or publicity purposes. The interview will be audiotaped and transcribed, however your name will not be used in the transcription in order to maintain confidentiality. The audiotapes, transcribed data, and notes will be kept in a locked file cabinet only accessible to the principal investigator. The audiotapes will be erased immediately after transcription. According to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS:

There will be no costs to you for participating in this study.

LIABILITY:

Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care and treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 1151. For all study participants, compensation damages resulting from the negligence of federal government employees may be available in accordance with the provisions of the Federal Tort Claims Act. For additional information concerning claims for damages, you may contact VA Regional Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

Any patient participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairman, Institutional Review Board, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service, (503) 273-5122.

Your signature below indicates that you understand that the Department of Veterans Affairs Medical Center, your investigators, and the sponsors of this research bear no responsibility for any costs you may incur at other hospitals, clinics, or care institutions related to this study or to any of your medical conditions.



VA/OHSU Research Consent Form

Continuation Page 3 of 3

Subject Name:

Date:

Title of Study: Family Caregiver Role Strain and Satisfaction following Life-Sustaining Treatment Decisions for Elderly Relatives: Instrument Development.

Principal Investigator: Lissi Hansen, RN, MS, Ph.D. Student, OHSU VAMC: 648 Portland, OR

RESEARCH SUBJECT'S RIGHTS:

I have read or have had read to me all of the above.

Lissi Hansen has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of VA or other benefits to which I am entitled.

The results of this study may be published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Lissi Hansen at (503) 617-9163 during the day and Lissi Hansen at (503) 617-9163 after hours. If any medical problems occur in connection with this study, the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a copy of this consent form.

Signature of Subject_____
Date_____
Time_____
Signature of Witness_____
Signature of Investigator or Investigator Representative

Investigator Initials _____ (if investigator did not sign above)

*Initial of patient or representative acknowledging receiving a copy of this informed consent: _____

Appendix I

Life-Sustaining Treatments

Life-Sustaining Treatments:

Type of final LST Decisions	What type of LST decisions did you make? Check all that apply:	If you left some of the treatments in place, check the ones that were left in place:	If you had treatments removed, check the ones that were removed:	If you decided not to start treatments, check the ones:
1. Antibiotics				
2. Breathing tube				
3. Cardiopulmonary resuscitation (CPR)				
4. Chemotherapy				
5. Feeding tube				
6. Fluids				
7. Hospitalization				
8. Renal dialysis				
9. Surgery				
10. Transfer to an intensive care unit				
11. Ventilator/Respirator				

Appendix J

Health Decline Trajectory

Health Decline Trajectory: Degree of Health Decline.

Introduction: Please, choose the trajectory that best describe your deceased relative's health the last couple of years of his/her life.

- | | |
|---|---|
|  |  |
| 1. Prolonged steady decline | 2. Gradual decline |
|  |  |
| 3. Fairly healthy with rapid decline | 4. Fairly healthy with sudden/acute decline |
|  |  |
| 5. Gradual decline with ups and downs | 6. Ups and downs with fairly rapid decline |
|  | |
| 7. Ups and downs with sudden/acute decline | |

Appendix K

Medical Diagnoses

Medical Diagnoses:

What main medical diagnoses had your ill relative received?

Please circle all that apply.

1. Heart Disease (e.g. congestive heart disease) No Yes If yes, in about what year did this diagnosis occur

199__ or 200__

2. Lung Disease (e.g. emphysema)

3. Cancer

4. Stroke

5. Kidney Disease

6. Liver Disease

7. Diabetes

8. Alzheimer's Disease or other dementia

9. Parkinson's Disease or other movement disorder

10. Mental illness (e.g. depression)

11. Other

12. Other

What was your ill relative's last illness? (the illness that influenced you to make LST decisions)

Please list all if more than 1:

Appendix L

Examples of Response Formats

Examples of Response Formats

1. Participants in making LST decisions.

Family members refer to other members of the family who you considered as participants when LST decisions were being made for your ill relative. Ill relative refers to your deceased family member.

	Who participated in making LST decisions for your ill relative. Circle all that apply.		
1	You.	Yes	No
2	Your ill relative.	Yes	No
3	One or more family members.	Yes	No
4	Others: _____ Please specify		
5	Altogether how many persons participated in making LST decisions for your ill relative (do not include health care providers in your estimate)? _____ persons		

2. Overall strain in making LST decisions.

Overall for you, how hard was it to be involved in making LST decisions for your ill relative?	
Very hard	4
Pretty hard	3
Some what hard	2
Not too hard	1
Not at all hard	0

3. Strain from urgency in making LST decisions.

If yes, circle how hard it was for you to make such decisions.

	At the time LST decisions were made for your ill relative, how hard was it because	yes	no	Very hard 5	Pretty hard 4	Some what hard 3	Not too hard 2	Not at all hard 1
1	You had to make the decisions quickly?							
2	You had to make the decisions faster than you wanted to?							