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Amyotrophic Lateral Sclerosis Patients' Sociological Resilience, Self-Determination, and Decision-Making for Life-Sustaining Treatments

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Walden University
2020

Abstract

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by

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MSW, University of Hawaii at Manoa, 2009

BSW, Brigham Young University Hawaii, 2007

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

People with amyotrophic lateral sclerosis (ALS) suffer from a rare, progressive, untreatable, and fatal neuromuscular disease. Their decision-making for life-sustaining treatments may not be fully self-deterministic. While researchers have examined resilience and self-determination in people with mental health problems and chronic illness, none have researched these variables in ALS patients from a socioecological framework. The purpose of this study was to explore the relationships between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. A cross-sectional concurrent mixed-methods design was used, with online surveys completed by 197 people with ALS who were solicited through the National ALS Registry. Qualitative content and thematic analysis revealed that people with ALS' perceived burdens, disease progression, functional abilities, profound loss, quality of life, adaptability, resources, relationships, and environmental and supernatural forces contributed to their decision-making for life-sustaining treatments. Quantitative data were analyzed using binary logistic regressions, showing no significant relationships between socioecological resilience, self-determination, and decisions for life-sustaining treatments. Significant relationships were found between covariates (i.e., age, gender, military veteran status, and disease progression) and decisions for life-sustaining treatments. The positive social change implications include establishing an ecological decision-making model to improve social work services and empower decision-making. The findings also provide empirical rationales for increased socioeconomic resources to support people with ALS' decisions for life-sustaining treatments.

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Dedication

I dedicate this study to the thousands of people with amyotrophic lateral sclerosis who die quietly and obscurely from respiratory failure and starvation. You have inspired me to press forward and complete this project. I also dedicate this study to the medical providers, allied health professionals, researchers, and policymakers who devote their careers to finding a cure for and providing care and services to people with this disease. Finally, I dedicate this study to the many families who have cared for and lost loved ones. Our fight gives me hope. May we run the marathon until we find a cure. No white flags!

Acknowledgments

I express my heartfelt gratitude to the many people and organizations that supported me on this incredible dissertation journey. Dr. Sean Hogan, who served as chair and methodology expert, thanks for your unyielding support, mentorship, and guidance. Your dedication and urgency matched my own and enabled me to complete this study in short order and with the utmost quality. Dr. Debbie Rice, thanks for your poignant and critical feedback as a committee member and content expert. I thank my entire committee for giving your time, attention, and consideration, which means so much to me and thousands of others affected by ALS. I give heartfelt appreciation to Dr. Donna McArthur and Dr. Jay Kenney, who served as peer reviewers to ensure that my qualitative interpretations reflected the participants' responses. Shoshanna Van Tress, thanks for your editorial advice along the way.

To my loving wife, Courtney, thanks for supporting me throughout this journey. I would not have started, let alone finished this study, if not for your unwavering love and dedication to our family, notwithstanding my terminal illness. To my children Lucy, William, Hallee, Ivy, Jameson, and Ace, I hope my commitment to this study instills a passion for life and worthy ambition in you. To my parents, brothers, extended family, friends, and mentors far and wide, who are too many to list, thanks for your love, encouragement, and support. To the Pat Tillman Foundation, your financial support, mentorship, and community enrichment have enabled my success immeasurably. Finally, I extend profound gratitude to the people with ALS who participated in this study and shared their thoughts and feelings. This project was a community effort!

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(https://wwwn.cdc.gov/ALS/ALSClinicalResearch/aspx)

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Chapter 1: Introduction to the Study

People with amyotrophic lateral sclerosis (ALS) suffer from a rare, progressive, untreatable, and fatal neuromuscular disease; approximately five of every 100,000 people in the United States have ALS at any given time (Mehta et al., 2018). Due to unexplained motor neuron death in the brain and spinal cord, people with ALS slowly lose the ability to move, speak, swallow, and eventually breathe on their own; most people with ALS die of respiratory failure within 5 years of diagnosis (Jeffery & Fish, 2018; Mehta et al., 2018). Ceriana et al. (2017) approximated that only 16% of people with ALS receive tracheostomies to prolong their lives, and only 38% of those procedures are planned, suggesting that many people with ALS might not exercise full self-determination for life-sustaining treatments. I conducted this study to understand the socioecological factors that contribute to this disparity within the ALS population.

I explored how people with ALS' socioecological resilience and self-determination related to their decision-making for life-sustaining treatments, a topic which, until this study, scholars had not examined. Understanding this relationship could promote positive social change within the ALS and social work research communities. The study's findings could inform social workers' interactions and interventions with people with ALS surrounding life-sustaining treatments. Finally, this study's findings could provide empirical evidence for expanding socioeconomic and health care resources, which, until this point, has been ignored in research and policy development. Such resources could empower people with ALS' decision-making for life-sustaining treatments.

In this chapter, I outline the study's background, problem, and purpose. Next, I present the study's research questions (RQs) and hypotheses and the conceptual framework and describe the nature of the study. I provide an overview of the research design, participants, instrumentation, procedures, and data analysis plans. Then, I define key terms and discuss the study's assumptions, scope and delimitations, limitations, and significance. The chapter ends with a summary of key points.

Background of the Study

Resiliency in children and adults has garnered the increasing attention of researchers in recent decades. Resilience research took root when Werner and Smith (1982), Garmezy (1991), and Rutter (1987) conducted landmark studies focusing primarily on children that laid the groundwork for establishing resilience theory and its defining characteristics. Resilience research with various contexts and populations has increased dramatically over the past several decades, including with children and adolescents, education, organizations, and more recently, with adults (Hall & Theron, 2016; Kuntz et al., 2016; Liebenberg & Moore, 2016). Social research efforts related to people with ALS have been sparse, and studies related to resilience and people with ALS have been rare. However, in 2008, Congress passed the ALS Registry Act, which funded the National ALS Registry, commonly referred to as the ALS Registry (Mehta et al., 2018). Since its inception, the ALS Registry has collected, maintained, and analyzed data about people with ALS (Mehta et al., 2018), and researchers have conducted studies with people with ALS at higher frequencies and with more urgency.

Since the United States Congress funded the ALS Registry, researchers have explored the prevalence of and the biological risk factors associated with being diagnosed with ALS (Bryan et al., 2016; Kaye et al., 2017; Mehta et al., 2018). While the overwhelming majority of the research related to ALS has been biomedically focused on finding a cure for the disease, researchers have done a modest number of social research studies with people with ALS. For example, Cornwell (2016) and Lerum et al. (2017) conducted studies about physicians' perspectives on resilience-related issues that medical teams should consider when providing care to people with ALS. Cui et al. (2015), Jalilianhasanpour et al. (2018), and Stephens et al. (2016) explored how mental health symptoms are related to the resilience of people with ALS and people with other neurological diseases. While these studies were not focused on decision-making, they did involve the resilience of people with ALS.

Other scholars have researched phenomena indirectly related to people with ALS' resilience and self-determination for life-sustaining treatments. Anderson et al. (2019), Delaney (2018), Hwang et al. (2017), Kavanaugh et al. (2017), Li et al. (2018), and Sandstedt et al. (2018) conducted studies on resilience and experiences with caregivers of people with ALS and people with other diseases. For some people, spirituality can be a determining factor. Fombuena et al. (2016), Gitterman and Knight (2016), Jeffery and Fish (2018), Jones et al. (2018), and Roger and Hatala (2018) examined how spirituality can help people with ALS and other chronic illnesses and disabilities. Others have investigated resilience in health care. Terrill et al. (2016) examined how resilience can act as a buffer to secondary health problems for people with chronic disabilities and diseases,

and Ushikubo (2014) examined people with ALS' perceptions of, and preferences for, dying at home versus dying in nursing homes. Finally, Ceriana et al. (2017), Connolly et al. (2015), Francoeur et al. (2016), Fried et al. (2002), Houben et al. (2017), Levi et al. (2017), Schwartz et al. (2004), and Young et al. (1994) explored the preferences for life-sustaining treatments at the end of life for people with ALS and others populations. While these studies' findings were not directly related to the present study's objectives, they informed the literature gap I addressed.

There is scant research on the variables of this study; several recent researchers have explored people with ALS' resilience (Jakobsson Larsson et al., 2016; Marconi et al., 2016; Pagnini et al., 2011; Parkin Kullmann et al., 2018) and decision-making for life-sustaining treatments (Levi et al., 2017; Sonenberg & Sepulveda-Pacsi, 2018). I could not find any studies involving people with ALS' self-determination. None of the studies that I found examined the relationship between resilience, self-determination, and decision-making for life-sustaining treatments. Moreover, researchers have not done studies on people with ALS that have approached those variables from a socioecological framework or with a mixed research methodology. Further research on this relationship using a mixed-methods approach was needed to understand the phenomenon more completely and empower people with ALS' voices. Because I could not find any singular studies that focused on people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments, I used those variables as the basis for conducting this study.

Problem Statement

While anyone can be diagnosed with ALS, researchers have identified various potential risk factors, including military service, age, cigarette smoking, alcohol consumption, exposure to toxic or hazardous substances, head trauma, and having a familial genetic mutation passed on to offspring (Jeffery & Fish, 2018; Mehta et al., 2018). ALS is a heterogeneous disease at the onset of symptoms; however, the result is almost always homogeneous, consisting of death either from starvation, respiratory failure, pneumonia, or other respiratory complications (Mehta et al., 2018). Along with physical disability, people with ALS often lose employment, relationships, and the ability to care and advocate for themselves; they often cannot afford life-sustaining medical treatments financially or exhaust all resources to obtain them (Anderson et al., 2019; Santaniello, 2018). The hardships that people with ALS face are particularly apparent as they begin to experience respiratory decline and are faced with end-of-life decisions for tracheotomies and percutaneous endoscopic gastrostomies (PEGs), which the majority of people with ALS decline (Ceriana et al., 2017). Because people with ALS experience progressive paralysis and loss of functioning (Cornwell, 2016), they could be an ideal population for conceptualizing resilience, self-determination, and decision-making in ways commensurate with their adversity.

Werner and Smith (1982), Werner (1993, 1997), Garmezy (1974, 1985, 1991), and Rutter (1987) conducted studies on resilience, primarily concerning children, which resulted in the emergence and establishment of resilience theory and its defining characteristics. In various contexts, resilience research has increased dramatically over

the past several decades, including with children, adolescents, education, organizations, and the workplace (Hall & Theron, 2016; Kuntz et al., 2016; Liebenberg & Moore, 2016). Despite the burgeoning of resilience research in these areas, less research has been done to understand the socioecological resilience of adult populations, particularly adults who have been exposed to prolonged and ongoing adversity (Liebenberg & Moore, 2016), such as people with ALS. Whereas the majority of resilience research has been done on children and adolescents, some recent resilience research has been done in the health care setting with older adults (Clarke et al., 2018; Mager, 2018), adult abuse survivors (Liebenberg & Moore, 2016), adults with neurological conditions (Cui et al., 2015; Jalilianhasanpour et al., 2018; Stephens et al., 2016), and adult caregivers (Anderson et al., 2019; Delaney, 2018; Ewen et al., 2015; Hwang et al., 2017). According to Liebenberg and Moore (2016), however, researchers have approached the vast majority of adult resilience studies statically and narrowly and without a socioecological perspective. While an increasing number of researchers have conducted resilience studies with various populations, it is clear that few of these studies have been done with people with ALS.

While numerous researchers from various disciplines have conducted studies on self-determination, some of which have focused on the health care setting (Bernard et al., 2014; Martin et al., 2017; Miller, 2016; Osei-Frimpong, 2017; Perlman et al., 2018), fewer have involved resilience (see Perlman et al., 2017, 2018; Trigueros et al., 2019), and none have examined socioecological resilience. Whereas all of the studies involving resilience and self-determination were related to mental health or physical activity, I

could not find any studies where the researchers explored these variables with people with ALS from a socioecological framework. Therefore, the research problem that I addressed with this study was the knowledge gap related to people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. I helped fill this gap by examining how people with ALS' experiences with, and their attitudes about, socioecological resilience and self-determination were related to their decision-making for life-sustaining treatments, such as tracheotomies and PEGs.

Purpose of the Study

The purpose of this mixed-methods study was to explore the relationships between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. I wanted to increase knowledge related to the health care decision-making of people with ALS. I examined how people with ALS' experiences with, and attitudes about, socioecological resilience and self-determination were related to their decision-making for life-sustaining treatments. For the quantitative component of the study, people with ALS' attitudes about socioecological resilience and self-determination were the independent variables, and people with ALS' decision-making for life-sustaining treatments was the dependent variable. Additionally, I used age, gender, military veteran status, and disease progression (i.e., negative symptoms) as variables to control if they were related to people with ALS' decision-making for life-sustaining treatments. To complement the quantitative data, I used structured qualitative open-ended questions to collect data about people with ALS' experiences with socioecological resilience, self-determination, and decision-making for life-sustaining

treatments. The qualitative data were collected and analyzed for triangulation, convergence, and divergence (see Schoonenboom & Johnson, 2017). I used these methods to address the research gap surrounding people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments and to add to the existing body of knowledge concerning the variables.

Research Questions

RQ1- Qualitative: How do socioecological resilience and self-determination contribute to people with ALS' decision-making for life-sustaining treatments?

RQ2- Quantitative: What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments?

$H_0$2: There is no relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

$H_1$2: There is a positive relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

RQ3- Quantitative: What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments?

$H_0$3: There is no relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

$H_1$3: There is a positive relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

Theoretical Framework

I approached this study with two guiding frameworks. A socioecological framework informed the resilience variable, and self-determination theory (SDT) informed the self-determination variable.

Socioecological Resilience

Early resilience researchers focused their efforts on understanding children's intrinsic traits and characteristics, self-esteem, protective and risk factors, and processes related to positive adaptation to adversity (Liebenberg & Moore, 2016; Richardson, 2002). However, according to Liebenberg and Moore (2016), researchers such as Bonanno and Diminich (2013), Masten (2014), and Wright et al. (2013) have approached resilience research from a socioecological framework rather than from the stance of traditional resilience theory. More recent findings have clarified that researchers should approach resilience as a dynamic and iterative process rather than merely a static state, outcome, or diagnostic end state (Liebenberg & Moore, 2016). Equally important is the understanding that resilience involves the ecological interactions between a person's environment, contexts, positive adaptation, and resources (Liebenberg & Moore, 2016; Masten, 2014). Conceptualizing resilience from a socioecological perspective enabled me to measure people with ALS' resilience holistically and answer the RQs meaningfully and with increased clarity.

Self-Determination Theory

SDT aims to understand the motivational factors for the choices made by humans. According to Perlman et al. (2018), SDT posits that autonomy (the state of being the

originator of one's behaviors), competence (feeling effective in one's decisions), and relatedness (feeling understood and cared for by others) are the three psychological needs that influence people's motivations for self-determination. While the three psychological needs hold respective constructs, definitions, and utilities, their synergistic and interactive nature gives the overall determining effect (Perlman et al., 2018). Another critical component of SDT is internalization, which involves people shifting their attitudes about accepting positive behaviors from doing so out of obligation or pressure to buying into and maintaining the change after experiencing its benefits (Ng et al., 2012). Additionally, SDT recognizes the interplay between the intrinsic and extrinsic motivational factors contributing to people's self-determination (Osei-Frimpong, 2017). Finally, according to Ng et al. (2012), Osei-Frimpong (2017), and Perlman et al. (2018), some researchers have applied SDT to health care and mental health settings and have posited that encouraging patients' autonomy and meeting their basic needs contributes to healthy self-determination when dealing with a chronic illness. As such, the basic psychological needs encapsulated in SDT contained the essential features to measure people with ALS' self-determination in this study.

Rationale for Framework

As suggested by Liebenberg and Moore (2016), I operationalized, measured, and interpreted resilience socioecologically, emphasizing the interactions between the individual, relational, communal, environmental, and adaptive factors that contribute to resilience. In concert with socioecological resilience, SDT was an appropriate framework to inform and operationalize the self-determination component of this study because it

has been linked with resilience (Perlman et al., 2018); therefore, I used SDT to measure and interpret the participants' autonomy, competence, and relatedness. Because the socioecological resilience conceptual framework and SDT aligned with the research purpose and RQs, my study's findings added to the existing body of knowledge concerning the interplay between socioecological resilience, self-determination, and decision-making and yielded meaningful findings toward social change.

Nature of the Study

I employed a cross-sectionall mixed-methods research (MMR) design where QUAL + QUANT were equally emphasized. I collected and analyzed the quantitative survey data and open-ended qualitative responses concurrently to ascertain the relationships and explore the phenomenon (see Schoonenboom & Johnson, 2017) surrounding people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. For the qualitative analysis, I performed content and thematic (i.e., codification, categorization, and thematization) analysis, and for the quantitative analysis, I performed descriptive analysis and binary logistic regression tests. I also conducted a bivariate correlation test to examine the relationship between socioecological resilience and self-determination.

Mixed-Methods Research Framework

After gaining traction in the 1970s and 1980s, MMR evolved into a robust yet complicated approach to research with a wide array of applications and perspectives (Ivankova & Plano-Clark, 2018). Ivankova and Plano-Clark (2018) cited the three most understood and used conceptualizations for MMR (see Creswell, 2008; Greene, 2008;

Tashakkori & Teddlie, 2010). Greene (2008) called for four domains to operationalize MMR, including the researcher's philosophical and theoretical underpinnings; a justification for using their methods to answer RQs; methodological procedures for data collection, analysis, interpretation, and practical guidelines thereof; and the sociopolitical commitments and rationales for pursuing a study. However, after deriving 30 topics from almost 300 journal articles, Creswell (2008) argued in favor of using five domains as a map, some of which overlapped with Greene's (2008) domains, including philosophical and theoretical considerations, mixed-methods techniques, the nature of mixed-methods, how MMR is applied, and how MMR is politicized. Creswell intended the map to be the beginning of a scholarly conversation to enable established and emerging scholars to understand and apply MMR across disciplines (Creswell, 2008). Tashakkori and Teddlie (2010) presented three domains, including conceptual, methods, and methodology, and contemporary applications, along with the numerous challenges and controversies related to the conceptualization, quality and trustworthiness, terminology, design typologies, and utilization of MMR. While these interpretations improved MMR's overall theoretical conceptualization, they neither achieved a universally agreed-upon operationalization for MMR nor provided mixed-methods researchers with connected pedagogical instructions on how to practically conduct an MMR study across disciplines (Ivankova & Plano Clark, 2018).

This study's methodology followed Ivankova and Plano Clark's (2018) socioecological framework to conceptualize the MMR process. According to Ivankova and Plano Clark, the socioecological model for MMR integrates the researcher's adaptive

and contextual influences, research content, and domains to create an iterative study. The five overlapping domains include the major decisions made when constructing and implementing an MMR design, the MMR definitions and rationales for the methodology, the logic for the methods and procedures, how the design intersects with the related frameworks, and an assessment of the design's quality. Additionally, the socioecological MMR model involves three layers of interactive contextual factors, including personal, interpersonal, and societal contexts (Ivankova & Plano Clark, 2018). These contextual factors influenced how I made MMR decisions. By coupling my MMR design with a socioecological methodological approach, my interpretation of the findings aligned with the research purpose, questions, and framework.

Two qualities set Ivankova and Plano Clark's (2018) model apart from the others. First, the socioecological MMR model drew from a single theoretical foundation, Bronfenbrenner's (1979) socioecological perspective (Ivankova & Plano Clark, 2018). Second, the socioecological MMR model provided a flexible and practical framework to shape my project according to three critical criteria: (a) the personal, interpersonal, and social contexts related to my study; (b) the MMR content, including the definitions, rationales, logic, and actions taken to ensure quality and trustworthiness; and (c) the MMR processes, including my research purpose and questions, methods, and inferences (see Ivankova & Plano Clark, 2018). Because this study drew from socioecological principles to frame the variables, it was logical to approach the methods using an MMR framework with socioecological underpinnings.

Definitions

In this section, I define the study's pertinent central concepts and constructs to operationalize the variables and enhance understanding:

Caregiver(s) of a person with ALS: Someone who is an informal (unpaid) caregiver of a people with ALS, such as a spouse, child, parent, family member, or friend (Anderson et al., 2019; Galvin et al., 2016).

Life-sustaining treatments: Medical treatments, either planned or unplanned, that prolong one's life for an undetermined amount of time (Schwartz et al., 2004; Young et al., 1994).

Percutaneous endoscopic gastrostomy (PEG): An invasive medical procedure by which a tube is passed into a patient's stomach to provide a means of feeding when oral intake is not adequate (Perseguer et al., 2019).

Person(s) with ALS: Someone diagnosed with definite or probable ALS by a specialized ALS neurologist (Ludolph et al., 2015).

Self-determination: The dynamic interplay between one's extrinsic and intrinsic motivations realized by the synergistic fulfillment of basic psychological needs, including autonomy, competence, and relatedness (Gagné et al., 2018; Perlman et al., 2018), thereby enabling self-regulated choices.

Socioecological resilience: In addition to the interplay between risk and protective factors, socioecological resilience is the dynamic and evolving process of systemically exchanging individual strengths, resources, relationships, and environmental conditions

to negotiate, positively adapt to, and rebound from significant and overwhelming adversity (Liebenberg & Moore, 2016).

Tracheostomy: An invasive medical procedure that creates an opening in the neck to place a tube into a person's windpipe for mechanical ventilation as a life-sustaining measure (Patton, 2019).

Assumptions

Assumptions are thoughts, ideas, or perspectives that one believes but cannot prove with certainty (Ellis & Levy, 2009). Researchers base their assumptions on the phenomenon they are investigating, along with their philosophical, epistemological, and ontological orientations (Ellis & Levy, 2009). I made several assumptions for this study. First, a fundamental philosophical assumption that I made was that all the participants, regardless of their demographics and ability levels, could live resiliently in unique ways. Second, I assumed that most people with ALS, even in their vulnerable circumstances, were capable of making autonomous decisions, except those with diminished decision-making capacity due to advanced frontotemporal dementia (see Maiser & Tiryaki, 2017). Third, as a mixed-methods researcher with a pluralistic epistemological and ontological approach to knowledge, I assumed that combining research methods would lead to a more comprehensive and understanding of the phenomenon, more so than quantitative and qualitative methods by themselves (see Lincoln & Guba, 1985). Fourth, when analyzing and interpreting the data, I assumed that the participants' responses were honest, sincere, and complete to the best of their abilities (see Ellis & Levy, 2009). Finally, I assumed that the participants generally perceived that they were experiencing

significant and overwhelming adversity due to being diagnosed with ALS. In clarifying my assumptions, as described previously, I give context and reference points for the consumers and stakeholders to consider while evaluating this study's meaningfulness.

Scope and Delimitations

According to Ellis and Levy (2009), delimitations clarify what researchers will and will not be doing and how the results might or might not be applicable. My primary focus in doing this study was to examine how people with ALS' socioecological resilience and self-determination were related to their decision-making for life-sustaining treatments using qualitative and quantitative forms of inquiry. Anyone diagnosed with ALS who was 18 years or older, documented with the ALS Registry, and without diminished decision-making capacity due to frontotemporal dementia was eligible to participate in the study. I used the ALS Registry's sampling frame to select the participants randomly because it is currently the most representative ALS sampling frame in the United States (Kaye et al., 2017).

Consequently, I generalized my quantitative findings across the overall ALS population; however, I limited my generalizations for several reasons. First, because this study recruited only people with ALS over the age of 18, the results were not representative of rare juvenile ALS cases (Kumar et al., 2016). Second, people with ALS of minority descents were not adequately represented because the ALS Registry likely does not fully capture their prevalence rates (see Kaye et al., 2017). I also limited my quantitative generalizations across other contexts and patient populations because the sampling frame was limited to people with ALS. Nevertheless, the research design and

variables for this study were original and innovative and could initiate a broader scholarly discussion about people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments.

Regarding this study's theoretical delimitations, I drew from a socioecological perspective (Liebenberg & Moore, 2016) to conceptualize resilience rather than merely using a traditional resilience construct. Whereas resilience theory has historically explored risk and protective factors, my RQs called for a broader ecological approach to examine and identify the systemic interactions, processes, and mechanisms for resilience, self-determination, and decision-making for life-sustaining treatments (Jefferies et al., 2018; Liebenberg & Moore, 2016; Liu et al., 2017). While resilience theory recognizes the major constructs and characteristics of risk and resilience, it does not account for individuals' dynamic and systemic exchanges between contexts, environments, and resources (Liebenberg & Moore, 2016). Hence, a traditional resilience framework would not have sufficiently aligned with the research purpose or the methodological approach to answer the RQs for this study adequately.

Limitations

While this study yielded meaningful findings for positive social change, I expected that it would have some limitations, challenges, and barriers. First, some people with ALS could have been considered vulnerable due to the terminal and debilitating nature of the disease; therefore, to prevent coercion, I informed the participants fully, obtained explicit consent, and emphasized that participation was strictly voluntary. Second, I encouraged the participants to use accessibility accommodations, such as

caregiver assistance, to ensure they could accurately communicate their responses. Third, because the ALS population is somewhat small and frequently changes due to death, I expected it to be challenging to obtain a robust probability sample amenable to inferences and generalizations. Another potential limitation of this study dealt with researcher bias. While my positionality could have strengthened my observations and interpretations as a researcher with ALS, it also could have created bias and negatively impacted the results, if not adequately controlled. To mitigate researcher bias, I implemented an anonymous survey data collection method, instead of conducting in-person interviews. I also maintained a thorough audit trail of the data analysis procedures and solicited objective peer reviewers to assess my analyses and interpretations for researcher bias (Lincoln & Guba, 1985; Onwuegbuzie & Leech, 2005). While this study had limitations, the benefits and findings justified the means.

Significance

I examined the research gap associated with people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments, and the findings have critical social change implications. The results give an evidence-based advocacy rationale to increase funding and resources, such as caregiver reimbursements, that would enhance people with ALS' quality of life and empower their self-determination for life-sustaining treatments. This study also yielded an ecological decision-making model, which will inform how ALS social workers approach their treatment plans and discussions with people with ALS concerning life-sustaining treatments. Also, because I am a person with ALS, these findings could inspire others

with ALS to be engaged in resilience-minded and strength-based social change efforts. The presentations and publications of this study's results could inform and encourage ALS clinics to adopt interventions that foster people with ALS' resilience, autonomy, competence, and relatedness (see Perlman et al., 2018). Such interventions would empower people with ALS' decision-making and help them to cope with the disease more resiliently. Finally, this study's results could bridge the literature gap for and add perspective to the existing literature surrounding socioecological resilience, self-determination, and decision-making for life-sustaining treatments.

Summary

In this chapter, I described this study's research topic and outlined the study's background, including the relevant literature surrounding socioecological resilience, self-determination, and decision-making for life-sustaining treatments. I also stated the problem, purpose, and RQs and described the theoretical framework on which I based the study. Additionally, I clarified the nature of the study, its major definitions, assumptions, scope and delimitations, and its limitations. Finally, I discussed the potential significance and social change impact that this study's findings could have on people with ALS, multidisciplinary clinic social workers, and the scholarly discussion involving socioecological resilience, self-determination, and decision-making for life-sustaining treatments.

In the next chapter, I conduct a thorough literature review, including a discussion about the literature review strategy, the literature concerning the theoretical foundation

and theoretical framework, and an exhaustive review of the key variables and concepts of the study.

Chapter 2: Literature Review

The research problem that I addressed in this study concerned the literature gap involving people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. The results inform how scholar-practitioners and policymakers can improve services, enhance resources, and empower people with ALS' decision-making for life-sustaining treatments. Before this study, some researchers had investigated resilience on adult populations (Anderson et al., 2019; Clarke et al., 2018; Cui et al., 2015; Delaney, 2018; Ewen et al., 2015; Hwang et al., 2017; Jalilianhasanpour et al., 2018; Liebenberg & Moore, 2016; Mager, 2018; Stephens et al., 2016), and others had addressed self-determination (Bernard et al., 2014; Martin et al., 2017; Miller, 2016; Osei-Frimpong, 2017; Perlman et al., 2017, 2018; Trigueros et al., 2019). However, studies had not examined the linkage between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments.

In this chapter, I describe my literature search strategy and review the literature related to the theoretical and conceptual foundations, constructs, methodology, and methods. I review the quantitative and qualitative components, key concepts, controversial aspects, and what remains understudied within previous research, including the strengths and weaknesses of how researchers have approached the study phenomenon. Finally, I summarize the major themes and gaps from the literature. The literature review revealed that many of the studies' findings, as they related to this study's variables, used qualitative methodologies and did not use socioecological frameworks.

Literature Search Strategy

I searched for various articles about ALS, resilience, self-determination, decision-making, and life-sustaining treatments. The keywords and combinations I searched in the Walden University Library and other institutions' databases were *resilience* (307,358 results), *resilience theory* (4,321 results), *socioecological resilience* (183 results), *self-determination* (105,728 results), *self-determination theory* (24,851 results), *amyotrophic lateral sclerosis* (80,351 results), *ALS*, *Lou Gehrig's disease* (25,811 results), *motor neuron disease* (24,839 results), *life-sustaining treatments* (8,420 results), *caregiver* (393,899 results), *resilience with amyotrophic lateral sclerosis* (73 results), *resilience with ALS* (338 results), *resilience with motor neuron disease* (15 results), *self-determination with amyotrophic lateral sclerosis* (28 results), *self-determination with ALS* (180 results), and *self-determination with motor neuron disease* (6 results), *decision-making with amyotrophic lateral sclerosis* (705 results), *decision-making with ALS* (2,008 results), and *decision-making with motor neuron disease* (229 results). I searched the keywords in Walden's EBSCO Thoreau multi-database search tool and in PsychINFO, Social Work Abstracts, SocINDEX with Full Text, SAGE Journals, Google Scholar, and ERIC. I began my search by including the years between 2015 and 2020, and then when searching for seminal articles, I broadened my search to all years up until 2020. I stopped searching for articles once I reached saturation and was not identifying new ones.

Theoretical Foundation

I used two frameworks as foundational rationales for this study: socioecological resilience to inform resilience and SDT to inform self-determination. By approaching this

study with a socioecological MMR approach, I was able to operationalize and align the variables' theoretical constructs with the methodology, which permitted me to answer the RQs holistically and meaningfully.

Socioecological Resilience

Researchers such as Garmezy (1974, 1985, 1991), Garmezy and Nuechterlein (1972), Rutter (1987), Werner (1989, 1993, 1997) and Werner and Smith (1982) began to take an interest in resilience when their research findings showed that some children appeared to respond, adapt, and have better outcomes than others when experiencing significant adversity. These early resilience researchers focused primarily on the biological and micro level protective factors, such as the attributes and close relationships that contributed to the resilience of children. For example, Garmezy and Nuechterlein (1972) found that children who were more successful at overcoming adversity had healthy social interactions with their peers, high self-esteem, cognition without impulsivity, inclinations for learning and achievement, and a parent or a parental figure with defined roles and awareness of their individuality.

Werner's (1989, 1993) findings solidified resilience theory more concretely. In a longitudinal birth cohort study conducted in Hawaii, Werner (1993) found that one third of the participants born into high-risk circumstances (n = 72) matured in similar ways compared with those who were not born into high-risk environments. More specifically, Werner (1993) identified five protective factors, characteristics, and resources that contributed to the resilience of the high-risk participants, including positive temperament, values and skills that enabled them to leverage their abilities, parental and caregiver

competencies that fostered nurturing environments and positive self-esteem, trustworthy surrogate figures, and opportunities that enabled them to transition successfully throughout their stages of development and significant life events. Werner's findings corroborated Rutter's (1987) admonition to instill protective factors in vulnerable youth that promote self-esteem and confidence, provide opportunities, and mitigate the risk and likelihood of compounded problems in the future. These seminal findings encapsulated the beginnings of resilience theory and laid the foundation for socioecological aspects of resilience to manifest in the future.

There has been a proliferation of resilience research in the social science field since the 1970s, with the research eventually bifurcating into two primary operationalizations (Liu et al., 2017). One definition asserts that resilience is an inherent trait, or a combination of traits, that contribute to one's ability to adapt positively to adversity (Liu et al., 2017). The other definition postulates resilience as a dynamic process whereby protective mechanisms enable positive outcomes amidst risk factors and adverse opposition. Liu et al. (2017) outlined various theoretical approaches to which scholars have recently ascribed. For example, some scholars have argued that enduring trials can have a compounding and protective effect against future adversity and that resilience is a by-product of having endured other trials (Liu et al., 2017). However, this approach has not been fully supported by research as resilience scores differ between people who experience similar types and degrees of adversity (Seery & Quinton, 2016). Researchers have also asserted that resilience is a coping capacity premised upon the notion that resilient people return to a healthy homeostatic state after recovering from a

trial (Liu et al., 2017). Critics of this approach have pointed out that there are varying ways to define and measure healthy functioning and are skeptical about the practicalities involved with people bouncing back and functioning as they did before their trials (Liu et al., 2017). Still, other scholars have conceptualized resilience as a continuum of protective factors, such as self-mastery, self-regulation, self-efficacy, interpersonal skills, and social support, that protect against risk factors and vulnerabilities (Prince-Embury et al., 2017). Given the wide variance of perspectives and approaches to researching resilience, scholars have agreed neither on a singular definition nor a unifying and comprehensive framework that accounts for all of the concepts involved. Researchers should therefore continue to investigate resilience and develop a comprehensive definition that applies all of the mechanisms involved.

While resilience researchers have traditionally used a theoretical framework that accounts for the exchange between protective and risk factors, researchers have begun to conceptualize resilience using Bronfenbrenner's biopsychosocial ecological systems perspective as an underpinning framework (Liebenberg & Moore, 2016; Ungar, 2015, 2018; Ungar et al., 2013). According to Ungar et al. (2013), conceptualizing resilience from a socioecological perspective is poised to impact the resilience field in similar ways that Bronfenbrenner's biopsychosocial ecological systems framework shaped the scholarly understanding of human development. In the semblance of the biopsychosocial ecological systems perspective, socioecological resilience accounts for the interactions and exchanges within and between micro-systems, mezzo-systems, exo-systems, macro-systems, and chrono-systems (Ungar, 2018; Ungar et al., 2013). By approaching

resilience from this perspective, researchers and clinicians can identify systems-based factors that enhance or diminish people's resilience.

Micro-Systemic Interactions

The micro-systemic interactions of socioecological resilience include the activities, roles, and relationships with which one interacts in personal and tangible settings, such as family members and immediate social circles at places of worship, school, and employment (Ungar, 2018; Ungar et al., 2013). The micro-system also involves an individual's biology, psyche, personality, and cohesion with family, loved ones, and peers (Ungar, 2018; Ungar et al., 2013). For example, according to Ungar et al. (2007, 2013), people are more likely to have greater resilience if they maintain healthy micro-systemic interactions and experiences with people and constructs outside the family, such as places of worship and other social circles where they feel acceptance and belonging. In the early formation of traditional resilience theory, scholars considered micro-systems to be the primary indicator for adaptive coping and resilience; however, other scholars have challenged this notion with socioecological resilience by acknowledging that other systems are at play (Liebenberg & Moore, 2016). Given the progressive and ongoing adversity that people with ALS experience, including limb and speech paralysis, without adaptive resources for high-tech augmentative and alternative communication and life-sustaining treatments, people with ALS might be challenged in their micro-systemic interactions, and subsequently, their resilience overall.

Mezzo-Systemic Interactions

The mezzo-systemic features of socioecological resilience involve interactions within microsystems (Ungar, 2018; Ungar et al., 2013). For example, when a person with ALS' family interacts with their places of worship, or when a person with ALS' caregiver interacts with the multidisciplinary clinic providers, they engage the mezzo-system. Ungar et al. (2013) described mezzo-systemic resilience as a triangular and interactional process whereby entities within a person's micro-system exchange resources and energy that mitigate someone's exposure to risk factors and promote resilience.

Exo-Systemic Interactions

The exo-systemic features of socioecological resilience relate to the connective, yet distal, interactions that enhance the micro- and mezzo-systemic interactions and subsequently impact someone's well-being (Ungar, 2018; Ungar et al., 2013). Some examples of exo-systemic exchanges that could benefit people with ALS include caregiver support groups that help the caregivers of people with ALS or assistive technology that enables people with ALS to communicate and interact with society in adaptive ways. Exo-systemic interactions might help remove barriers to care, magnify the impact that caregivers have on people with ALS, and enhance people with ALS' ability to live more purposefully and independently.

Macro-Systemic Interactions

The macro-systemic interactions of socioecological resilience involve the philosophical, ethnocultural, socioeconomic, and political forces that exchange resources and energy with the micro-, mezzo-, exo-, and chrono-systems, often indirectly and from

a distance (Ungar, 2018; Ungar et al., 2013). Again, using people with ALS as an example, macro-systemic features of resilience are the laws and policies that influence the care, quality of life, cultural influences, and norms unique to the ALS community. These macro-systemic interactions affect the ALS community broadly and individually.

Chrono-Systemic Interactions

The chrono-systemic interactions of socioecological resilience speak to the ebbing and flowing nature of resilience; that is, people's resilience is not a linear process and entails high and low periods linked by time, events, and experiences (Liebenberg & Moore, 2016; Ungar et al., 2013). In that regard, researchers should consider conducting longitudinal studies that account for human development, events, and experiences (Ungar et al., 2013). For people with ALS, the primary chrono-systemic interactions involve the timing, events, and experiences surrounding their disease progression, medical care, relationships, loss of functioning, decision-making, and their death and dying process.

Overarching Principles for Socioecological Resilience

Ungar (2018) and Ungar et al. (2013) outlined three principles that distinguished socioecological resilience from other approaches: equifinality, differential impact, and cultural moderation. The first principle, *equifinality*, means that there are varying ways by which people are resilient. According to Ungar et al. (2013), increasing and enhancing one's mezzo- and macro-level interactions would likely increase their resilience more than merely increasing their micro-level interactions. However, it should be noted that each person is unique and will respond differently to systemic interactions; hence, the second principle is *differential impact*. Differential impact, from a socioecological

resilience framework, implies that interventions and resilience factors will affect people differently across time and contexts. Because people's perceptions and reactions to circumstances and resources will differ from one another, some people might not identify with or benefit from a particular resource or intervention, whereas others might benefit significantly from it. Therefore, resources, resilience factors, and strength-based interventions are contextual, and the degrees of impact will vary widely. The third principle, *cultural moderation*, espouses socioecological resilience to the understanding that minority cultures should be involved in defining resilience and that emic and etic approaches should be balanced (Ungar et al., 2013). These principles established ethics for the socioecological resilience perspective, which, to its credit, increased its potential for conceptualizing complex phenomena with vulnerable populations, like people with ALS.

Other Aspects of Socioecological Resilience

In a study that explored socioecological resilience cross-culturally, Ungar et al. (2007) concluded that the youth who considered themselves resilient, and whose communities considered them to be resilient, navigated and resolved seven "tensions" simultaneously, according to their strengths and resources (p. 294). The first tension, access to material resources, included resources concerning daily sustenance basic needs such as money, education, medical care, food, clothing, and shelter. The second tension dealt with relationships such as significant others, peers, family members, and people in the community. The third tension, identity, involved awareness of a sense of purpose, aspirations, strengths, weaknesses, personal values, and beliefs. The fourth tension was

power and control, including self-care and changing their environment to access resources. The fifth tension had to do with one's adherence to and observance of cultural practices, values, and beliefs. The sixth tension was social justice, including fulfilling a meaningful role in the community and social justice. Finally, the last tension, cohesion, was the degree to which one balanced their personal interests with contributing to the greater good or something greater than themselves (Ungar et al., 2007). It is important to note that Ungar et al. (2007) concluded that the seven tensions were interrelated as a dynamic state within a web of systemic exchanges between individuals, families, communities, cultures, and contexts. Moreover, while each of these tensions carries unique characteristics, there is also an interplay between people's cultural, contextual, and personal strengths; each person reconciles them in inimitable ways according to their respective ecological systems (Ungar et al., 2007).

While scholars have yet to agree on the operationalization of resilience, there are common themes that researchers have frequently cited. For example, most scholars recognize that resilience involves, in some capacity, a continuum of fluctuating strengths or resources that interact with and reconcile risks, adaptive coping after significant stress or adversity, the ability to adjust after biopsychosocial disruptions, favorable outcomes, learning, and development across the lifespan (Liebenberg & Moore, 2016). Because none of these themes would contradict a socioecological approach to resilience, socioecological resilience appears to be the most replete approach to date. Scholars should consider approaching resilience studies from a socioecological perspective in the future. Notably, the strengths that set socioecological resilience apart from traditional

resilience theory are its assertions that resilience ebbs and flows, is systems-based, and deliberately values culture and context (Liebenberg & Moore, 2016; Ungar et al., 2013). To exploit these strengths in my study, I used socioecological resilience as a guiding resilience framework.

Self-Determination Theory

Researchers' interests in understanding human motivation and self-determination took root in the late 1950s and began to form theoretical connections in the early 1970s. White (1959), for example, published an article asserting that competence and autonomy were the foundation for intrinsic motivations. After White's (1959) work, much of the research about motivation revolved around intrinsic and extrinsic motivation. Whereas intrinsic motivation refers to people's innate motivation for learning, exploration, enjoyment, and mastery for self-fulfillment, extrinsic motivation is present when people complete tasks expecting an external reward when complying with a set of rules and regulations (Ryan & Deci, 2000). Deci (1971) conducted an experimental study and found that external rewards, such as money, tended to decrease intrinsic motivation, whereas verbal reinforcement and positive feedback increased intrinsic motivation. Subsequently, more researchers added to the body of knowledge surrounding intrinsic and extrinsic motivation, particularly Deci and Ryan (1985, 1991), who eventually conceptualized their work into SDT (Deci & Ryan, 2000; Ryan & Deci, 2000; Ryan et al., 1997).

SDT attempts to explain the choices that people make based on their intrinsic motivations as opposed to extrinsic motivations and posits that people must satisfy three

psychological needs, including autonomy, competence, and relatedness, to make self-regulated decisions (Deci & Ryan, 2000; Perlman et al., 2018). According to Perlman et al. (2018), autonomy refers to an individual's desire to be the decision-making agent in congruence with their inner self. Competence refers to an individual's desire to control their outcomes and aptitudes. Relatedness is the extent to which the individual interacts with and cares for others (Perlman et al., 2018). Additionally, within SDT exist six sub-theories, also referred to as mini theories, that explain various aspects of motivation.

Cognitive Evaluation Theory

Cognitive evaluation theory posits that external events affect intrinsic motivation. Events that foster greater competence cause an increase in intrinsic motivation, and events that reduce competence result in less intrinsic motivation (Deci & Ryan, 1985; Gagné et al., 2018; Riley, 2016). Cognitive evaluation theory also asserts that external events that initiate or regulate behavior affect intrinsic motivation in three ways, including information, control, and amotivation (Deci & Ryan, 1985; Riley, 2016). For example, according to Deci and Ryan (1985) and Riley (2016), information can increase perceived competence, which increases intrinsic motivation. One's degree of control can increase or decrease their perceived success or failure, which would either increase or decrease their intrinsic motivation. Finally, amotivation can cause perceived incompetence, which would result in a reduction of intrinsic motivation (Deci & Ryan, 1985; Riley, 2016).

Organismic Integration Theory

The next sub-theory, organismic integration theory, is the process of integrating and internalizing an extrinsic motivation into one that is intrinsic (Deci & Ryan, 1985, 2000; Gagné et al., 2018; Kleinert et al., 2017). This process involves people's psychological shift from completing tasks for external rewards or external regulation into an innate fulfillment of doing a task after experiencing the benefits (Gagné et al., 2018; Riley, 2016; Ryan & Deci, 2000). Organismic integration theory posits that people can transition their behavioral motivations from a sense of obligation (extrinsic motivation) to an innate and genuine desire (intrinsic motivation).

Causality Orientations Theory

Deci and Ryan (1985) developed the third SDT sub-theory, causality orientations theory, which explains how people orient themselves within their environments according to the degree to which they meet the basic needs of SDT (autonomy, competence, and relatedness). This sub-theory posits three orientations, which are autonomy, control, and impersonal, or amotivational. The autonomy orientation occurs when a person meets all three basic needs of SDT and behave in a way that values the environmental context (Gagné et al., 2018). The control orientation occurs when a person only meets the competence and relatedness needs and focuses on the rewards, gains, and approval of the environmental context. Finally, the impersonal or amotivational orientation occurs when a person fails to meet all three needs; this orientation is associated with poor functioning and incompetence (Gagné et al., 2018).

Basic Psychological Need Theory

The fourth SDT sub-theory, basic psychological need theory, posits that people's overall well-being and ability to function rests upon the fulfillment of SDT's basic needs (autonomy, competence, and relatedness) (Ryan & Deci, 2000; Van den Broeck et al., 2016). Basic psychological need theory asserts that if a person does not meet any of the basic needs, they will likely experience diminished well-being and will not function optimally (Ryan & Deci, 2000).

Goal Content Theory

Goal content theory, SDT's fifth sub-theory, distinguishes extrinsically motivated goals from intrinsically motivated goals in terms of how they affect people's well-being and motivation (Deci & Ryan, 2000; Gagné et al., 2018; Zhang et al., 2018). For example, whereas Deci and Ryan (2000) associated extrinsic goals with people's temporal status such as financial wealth, popularity, or accumulation of possessions, intrinsic goals tend to be related to relationships, community, personal growth, and learning (see Gagné et al., 2018; Zhang et al., 2018).

Relationships Motivation Theory

The sixth sub-theory is relationships motivation theory and postulates that people's well-being is dependent on their relationships with other people (Deci & Ryan, 2014; Gagné et al., 2018; Ryan & Deci, 2000). Relationships motivation theory emphasizes the critical roles that the give-and-take exchanges in relationships play, where each party's autonomy, competence, and relatedness are valued (Deci & Ryan, 2014).

I used SDT's sub-theory, Basic Psychological Need Theory, as a framework to operationalize this study's second independent variable, people with ALS' self-determination. As such, I examined people with ALS' autonomy, competence, and relatedness quantitatively and qualitatively to understand the relationship between their self-determination and decision-making for life-sustaining treatments. While I expected that my findings would add to the literature surrounding people with ALS' decision-making for life-sustaining treatments, my findings also added to the broader understanding of SDT. Furthermore, researchers have not examined this phenomenon with people with ALS or terminal illnesses.

Literature Review

To fully appreciate the context of people with ALS' adversity, it is crucial to understand people with ALS' biopsychosocial factors. Therefore, I begin the literature review by discussing the historical context, ethical considerations, prevalence and epidemiology, and the biopsychosocial issues involved with ALS. Then, I discuss the previous approaches and methods that apply to people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments.

Historical Context of ALS

Sir Charles Bell, an Edinburgh surgeon (Turner & Swash, 2015), first discovered the clinical features of ALS in the mid-19th century. In 1862, Charles Radcliffe and Lockhart Clarke further classified the disease as a nerve-based disease consisting of paralysis and muscular atrophy (Turner & Swash, 2015). In 1874, Jean-Martin Charcot, a French neurologist, bridged the knowledge gap between patient symptoms and

neurological presentations and officially named the disease amyotrophic lateral sclerosis (Turner & Swash, 2015). However, in the decades since that time, neurologists and clinical researchers have been mystified and challenged to solve the puzzle to the disease's pathogenesis, etiology, and epidemiology. Over time, neurologists gradually improved the diagnostic procedures and attempted to understand ALS pathology, but, because ALS has not been well understood and was virtually unknown to the public (Turner & Swash, 2015), it was not until 1990 that researchers developed a uniform diagnostic procedure (Geevasinga et al., 2019).

In 1939, the famous New York Yankee baseball player, Lou Gehrig, was diagnosed with ALS and delivered his famous farewell speech at Yankee Stadium (Smith, 2015), bringing the disease out of obscurity. Later, the disease would become informally known in the United States as Lou Gehrig's disease. In 1963, Stephen Hawking, a 21-year-old doctoral student, was diagnosed and became a public face for ALS as he completed his doctorate, made groundbreaking scientific discoveries, and taught cosmology and physics (Smith, 2015). As the longest recorded ALS survivor, Hawking contributed a lifetime of scientific publications, inspirational documentaries, and television show appearances, which sparked an awareness movement for the ALS community.

Within the last decade, other well-known people with ALS have established non-profit organizations to raise funds for ALS medical research and patient services. Steve Gleason, a retired New Orleans Saints football player who was diagnosed with ALS in 2011, started a non-profit organization, the Team Gleason Foundation (Moustafa, 2018).

The Gleason Foundation has granted people with ALS with end of life adventure trips, speech and eye gaze equipment, and has advocated for law reform to leverage biotechnology and assistive technology in people with ALS' favor (Moustafa, 2018). Hope Loves Company is a non-profit organization that teams with Young Men's Christian Association (YMCA) camps throughout the country to provide healing experiences and emotional support to children who have parents or grandparents with ALS (O'Donnell-Ames, 2008). In 2014, the ALS Ice Bucket Challenge (IBC), a groundbreaking social media fundraising phenomenon, significantly increased ALS public awareness and raised over $115 million within eight weeks for the ALS Association and over $220 million globally for ALS medical research (Sohn, 2017). Since the IBC, hundreds of people have established fundraising efforts and non-profit organizations geared toward funding research for an ALS cure.

While medical research efforts have increased dramatically since the IBC, social researchers have not followed the same trajectory to inform social welfare and clinical interventions for people with ALS. Many organizations, including the ALS Association, a nationwide ALS helping organization, was established in the United States in 1985 (Stephens et al., 2015; Ward & Edmondson, 2015), have attempted to expand their resources and diversify their clinical research and investment portfolios. Nevertheless, given the history of ALS being an untreatable and incurable disease that kills tens of thousands of people throughout the world every year, many people with ALS, ALS advocates, and allies are growing impatient for clinical progress (Traynor, 2018). Given that it is unknown when researchers will find a cure, increased financial emphasis in

social research is needed to guide social programs that help people with ALS and their families adaptively cope with the emotional and mental health challenges associated with this disease.

Political Trends

Historically, the ALS population has not garnered significant political attention; however, since the IBC, there have been some critical political developments that directly impacted people with ALS. In 2017, for example, within one year of submitting the new drug application, the Food and Drug Administration (FDA) cooperated with Mitsubishi Tanabe Pharma Corporation to expedite the approval and distribution of Radicava (Cruz, 2018). Through this unprecedented collaboration, Radicava became the first FDA approved ALS treatment since Riluzole's approval in 1995 (Cruz, 2018). Like Riluzole, Radicava is neither a cure nor a treatment for slowing the progression of the disease; however, preliminary studies showed that the drug helps some people with ALS conduct their activities of daily living (ADLs) for a longer period (Cruz, 2018). Laws and policies related to medical research and drug development, such as access to investigational drugs, insurance coverage, and expedited FDA approval, are gaining traction as controversial issues in the political and advocacy arenas affect people with ALS.

Since the IBC, the ALS Association has developed robust programs for medical research, advocacy, and public awareness; however, groups of people with ALS and ALS advocates have called for a more aggressive approach in supporting patients' rights to use experimental and alternative therapies. Some people with ALS and ALS advocates have vigorously promoted one such treatment, NurOwn, a stem cell therapy that a company

named Brainstorm developed, hoping to gain FDA approval after finishing their phase three clinical trial (Traynor, 2018). However, since President Trump signed the Right-to-Try legislation into law, many medical professionals and policymakers question the law's applicability and effectiveness, and Brainstorm has denied people with ALS access to NurOwn under the law (Traynor, 2018). Still, people with ALS and ALS advocates continue to push for NurOwn's approval, and other experimental therapies such as regulatory T cells, also known as Tregs, and CuATSM, a delivery system for copper across the blood-brain barrier. This push to approve these therapies before completing the phase three studies has been made primarily under the recently passed Right-to-Try Law (Traynor, 2018). Currently, lawmakers, drug developers, physicians, and other stakeholders are negotiating how to implement the law; however, many professionals, including the FDA, have reservations about the law because experimental drugs are not tested thoroughly for safety (Lynch et al., 2018). Despite the exponential increase in the number of investors funding clinical studies for a cure, people with ALS continue to die from their disease. They will continue to need socioeconomic and mental health services to enable them to live with ALS and die with as much dignity as possible.

Finally, the Steve Gleason Act of 2015 was another recent political development for people with ALS. This law permanently removed the Medicare cap for speech and eye gaze technology, which gave people with ALS the ability to communicate and thrive to the greatest extent possible (Moustafa, 2018). Likely sparked by the IBC, the general population and lawmakers have become more aware of people with ALS' circumstances;

however, the ongoing and polarizing psychosocial needs that people with ALS experience are still largely unaddressed.

Prevalence of ALS

ALS is a progressive neurodegenerative disease brought on by upper and lower motor neuron death. Upper motor neuron death causes increased muscle tone, spasticity, and brisk reflexes, and lower motor neuron death causes muscle weakness, atrophy, and paralysis (Mehta et al., 2018; Walhout et al., 2018). While there is some understanding of the bio cellular and genetic antagonists contributing to ALS, researchers understand neither its etiology nor its pathogenesis well (Mehta et al., 2018; Oskarsson et al., 2018). However, it is clear that approximately 5-10% of the incidents are familial (when a parent passes a gene mutation on to their children), and 90-95% are sporadic random occurrences (Müller et al., 2018). The majority of familial cases are autosomal dominant, meaning there is a 50% chance that the parents will pass their gene mutation on to their offspring (Müller et al., 2018). While researchers have discovered numerous familial gene mutations, they remain perplexed about what and how exactly the triggers promulgate genetic mutations, particularly in sporadic forms of ALS (Mehta et al., 2018). ALS is a complex and obscure disease and will likely require a great deal of time and persistence to develop treatments and preventative protocols. Additionally, because sporadic ALS inflicts the overwhelming majority of people with ALS (Mehta et al., 2018), researchers have a massive void to fill to understand ALS from epidemiological and prevalence perspectives.

Researchers have been attempting to understand the prevalence of ALS in the United States for decades. It was not until researchers established the National Registry of Veterans (Kasarkis et al., 2004), which paved the way for the ALS Registry (Bryan et al., 2016; Horton et al., 2016; Kaye et al., 2017; Mehta et al., 2018), that they were able to surveil and approximate its prevalence. Since establishing the ALS Registry, researchers have estimated that there are approximately five cases of ALS for every 100,000 people, with the highest rates being White males older than 60 years of age from the Midwestern and Northeastern parts of the United States (Mehta et al., 2018). In other studies, researchers have attempted to ascertain the prevalence in obscure populations, such as the Western Himalayas (Sondhi et al., 2018), to examine potential risk factors in a highly rural farming community, and in Liguria, a Northwest region of Italy (Bandettini et al., 2013). Kaye et al. (2017) conducted a comparative analysis study between the ALS Registry and the Metropolitan Surveillance Program to evaluate the ALS Registry's completeness and accuracy. They found the ALS Registry to be mostly accurate, except that it is likely missing minority cases of African Americans and Hispanics (Kaye et al., 2017). While the registry appears to estimate ALS prevalence in the United States more accurately than before, the researchers affiliated with the ALS Registry recognized that they must troubleshoot its processes and potentially perform outreach procedures to estimate the minority cases better in the future (Mehta et al., 2018).

Military Veterans and ALS

ALS appears to be nondiscriminatory; however, demographics, such as age and gender, show higher incident rates than the overall population (Mehta et al., 2018). In the

United States, military service is also a risk factor that causes a disproportionate number of ALS cases. In an unprecedented landmark study, Haley (2003) found that veterans were being diagnosed with ALS at alarming and increasing rates, particularly among those who served in the Persian Gulf. Weisskopf et al. (2005) conducted another landmark study which found that veterans of all military branches were nearly twice as likely to die from ALS than the overall population. Policymakers at Veterans Affairs (VA) eventually regarded Weisskopf et al.'s (2005) and Haley's (2003) findings as supportive evidence to change federal policy. In 2009, the VA ruled ALS a presumed service-connected disability and granted veterans with ALS (veterans with ALS) 100% disability and compensation entitlements (Kniffen, 2009). Since being granted access to disability, compensation, and health care entitlements, veterans with ALS have likely received considerably better care and more financial resources than the overall ALS population in the United States. While veterans with ALS' compensation and entitlements are warranted, given their propensity for contracting the disease, their non-veteran counterparts are likely overburdened with caregiver costs, medical bills, and financial debt. Given this discrepancy, research should be done to understand the biopsychosocial burdens that non-veteran people with ALS experience compared to veterans with ALS. In my search of the literature, I could not find any such comparative studies.

Other Risk-Factors for ALS

While epidemiological researchers have not definitively or comprehensively ascertained the risk factors besides military service, ethnicity, gender, and age, according

to Mehta et al. (2018) and Oskarsson et al. (2015), who cited numerous epidemiological studies, there are some patterns that researchers have investigated with interest. For example, some epidemiologists have examined how being exposed to occupational substances such as pesticides, electromagnetic fields, heavy metals, formaldehyde, and vehicle exhaust could be potential triggers. Others have investigated various occupations such as veterinarians, medical professionals, elite athletes, construction workers, hairdressers, and barbers. Still, others have explored the possibility of toxins from dietary and nutritional habits, infectious agents, smoking cigarettes, and drinking alcohol. While researchers have found clues about potential risk factors, many of the studies lacked the sample sizes, statistical power, and representation to generalize with statistical significance (Mehta et al., 2018; Oskarsson et al., 2015). Epidemiologists and other researchers must find ways to increase the sample sizes and improve their findings' generalizability to identify the risk factors with significance. Perhaps equally important to the future of understanding ALS epidemiologically is correlating risk factors with genetic biomarkers (Oskarsson et al., 2015) to understand which environmental factors trigger corresponding genotypes. Making these connections could help researchers and clinicians target treatments more precisely and educate the public on prevention measures in the future.

Social Work with People with ALS

Currently, social workers most frequently treat people with ALS in multidisciplinary environments as part of a synchronous medical treatment team, including a neurologist, pulmonologist, nurse, pharmacist, palliative psychologist,

physical therapist, occupational therapist, dietician, speech pathologist, and when desired, a chaplain (Jeffery & Fish, 2018; Soriani & Desnuelle, 2017). In most cases, interdisciplinary teams begin palliative care immediately after diagnosis and transition people with ALS into hospice care once their respiratory decline is considered terminal (Jeffery & Fish, 2018; Soriani & Desnuelle, 2017). ALS multidisciplinary social workers provide mental health treatment, grief and dying counseling, bereavement counseling, advocacy, crisis intervention, advance care planning, and connect people with ALS and their families to community resources (Geronimo et al., 2017). ALS multidisciplinary social workers also assist people with ALS in adjusting to the progressive loss of function and play a central role in giving them access to care and services (Geronimo et al., 2017). Finally, social workers also have the daunting task of maintaining the client-worker relationship throughout the family's ALS journey and helping families after their loved one with ALS dies.

Providing ongoing care can be challenging considering the prolonged and substantial burden that ALS has on patients and caregivers (Anderson et al., 2019; Foley et al., 2016; Hollowood, 2018), including processing and understanding the meaning of being diagnosed with ALS, how it affects families, and how to navigate the health care system (Cipolletta & Amicucci, 2015). The burden that ALS places upon patients and families could even impact people with ALS' ability to make end of life decisions related to hospice or palliative care (Bentley & O'Connor, 2016). Social workers play a critical role in helping people with ALS and their families deal with the daily struggles associated with the disease and helping them to overcome care obstacles. While ALS

multidisciplinary clinics attempt to provide people with ALS with the most comprehensive care possible, I could not find any articles that examined or evaluated the multidisciplinary care model currently in use. Researchers should address this literature gap to inform the biopsychosocial interventions that treat people with ALS' needs. Additionally, researchers should investigate the barriers to care, cultural, financial, or otherwise, which may deter people with ALS from utilizing home hospice, palliative care, and life-sustaining treatments.

Social workers and their multidisciplinary team colleagues who treat people with ALS must be aware of the potential clinical issues that could derail people with ALS' resilience. Due to the complex nature of ALS, the psychosocial issues related to treating people with ALS and their families abound. Cornwell (2016) identified numerous issues involved with caring for people with ALS, including family dynamics, problems between spouses and partners, denial during the early phases of the disease, employment and financial troubles, withdrawal and isolation, caregiver burden, prolonged and progressive grief, and discovering a sense of meaning in their ALS experience. According to Cui et al. (2015) and Stephens et al. (2016), people with ALS tend to experience high rates of depression, anxiety, and co-occurring mental health problems, such as frontotemporal dementia (FTD). Additionally, at the onset and symptomology of the disease, many people with ALS experience a significant degree of anxiety, particularly as they wait 12 months or longer to be diagnosed (Cornwell, 2016). Maiser and Tiryaki (2017) found that people with ALS tend to experience a great deal of anxiety and depression while waiting for a diagnosis and in the early stages of the disease, which may increase their propensity

for suicide ideation and physician-assisted suicide. Moreover, Turner et al. (2016) found statistically significant relationships between people's histories with anxiety, depression, schizophrenia, and bipolar disorder and were subsequently diagnosed with ALS. Hence, given the progressive nature of ALS, more research should be done to understand how people with ALS' mental health conditions before and after diagnosis potentially contribute to their resilience, self-determination, decision-making for life-sustaining treatments, and physician-assisted suicide.

Still, despite the many risk factors previously mentioned, some protective factors might help some people with ALS live more resiliently. Whereas Stephens et al. (2016) found that depression was positively correlated with pain and could be mitigated by self-efficacy, Cui et al. (2015) concluded that higher education levels, shorter disease progressions, and lower ALS Functional Rating Scores (ALSFRS) could preserve cognitive function. Hence, while people with ALS commonly experience overwhelming adversity, social workers who treat them must be keenly aware of the protective factors that could mitigate or reduce mental health complications.

Biopsychosocial Issues

Some researchers have conducted recent studies that yielded findings relevant to people with ALS' biopsychosocial needs. Kukulka et al. (2019), for example, did a mixed-methods study with people with ALS (n = 14), caregivers of people with ALS (n = 16), and providers (n = 12) of varying disciplines, including chaplains, doctors, nutritionists, social workers, and speech-language pathologists. The primary biopsychosocial issues found from the interviews included the need for additional

caregiving help, better education about ALS, and more resources that promote independence, such as transportation to appointments (Kukulka et al., 2019). O'Brien and Clark (2015) searched online for spiritual and religious narratives written by people with ALS in the United States, Europe, Canada, and Australia. They found that people with ALS' religious faith and spirituality can be a buffer against despair and help make sense of their lives, deaths, and experiences with ALS (O'Brien & Clark, 2015). O'Brien and Clark's (2015) findings were later supported by Roger and Hatala (2018), who found that spirituality can be a source of purpose and meaning when facing a chronic illness. However, they also found that religion and spirituality can be detrimental and have an opposite effect for some (O'Brien & Clark, 2015; Roger & Hatala, 2018). Fombuena et al. (2016) found that resilience was a better predictive variable for spirituality than age, gender, concerns about pain, discomfort symptoms, social support networks, and inadequate symptomatic control in people with advanced illnesses. Research should be done to understand the relationship between people with ALS' resilience and their biopsychosocial and spiritual functioning.

Caregiving

Many families affected by ALS rely on varying types of caregiving; however, informal caregivers, such as family members, carry much of the load. For example, whereas spouses, children, siblings, and parents of people with ALS act as primary caregivers, young children, friends, and extended family members often take on secondary caregiver roles (Kavanaugh et al., 2017; Sandstedt et al., 2018). When available and affordable, informal caregivers contract with agencies for respite care,

resulting in better familial caregiving overall (Nakai et al., 2017; Ushikubo & Suzuki, 2015). Some people with ALS receive their care from long-term nursing homes, which can also be a valuable caregiving resource. However, long-term care is not typically preferred (Domínguez-Berjón et al., 2016) and might be disproportionately represented by people with ALS who are unmarried, male, and ethnic minorities (Goutman et al., 2014). Caregivers play a central role in the treatment and well-being of people with ALS; therefore, researchers should make ongoing efforts to understand the complexities involved.

Social researchers have emphasized investigating the caregiving aspects of ALS, which has brought new knowledge to providers working with people with ALS and their families. Anderson et al. (2019), for example, conducted semi-structured interviews with 15 caregivers of people with ALS in Australia and found three overarching thematic caregiving issues. First, they discovered that people with ALS and their caregivers experienced a profound and progressive sense of physical and emotional loss. Second, caregivers felt lost in a labyrinth associated with the uncertainties of care options, resources, progression, and the perpetual lifestyle changes that accompany ALS. The third theme from Anderson et al.'s study was how caregivers of people with ALS found hope, resilience, and meaning in their ALS journeys. Many caregivers expressed how they tried to maintain hope and resilience by seeking positive experiences and fundraising for medical research to cure ALS. Others discussed how it was important to see their loved ones with ALS as the same person they were before being diagnosed, despite their physical limitations (Anderson et al., 2019). In another qualitative study, Galvin et al.

(2016) found four caregiving themes, including psychosocial and emotional well-being, limitations and restrictions, relationships, and everyday practicalities of caring for people with ALS. In Galvin et al.'s study, the caregivers reported psychosocial and emotional issues such as anger, worry, stress, fear, frustration, uncertainty, and unresolvable suffering. In the same study, caregivers also felt limited and constrained in their freedom, responsibilities, and use of time, and by the relentless nature of the disease. Concerning their relationships, caregivers experienced role reversals, identity confusion, and changes in how they communicated and interacted with their loved ones with ALS. Finally, the practicalities associated with caregiving, such as bathing, hygiene, mobility, managing the bio- and assistive technology, and peripheral aspects related to the disease, can be burdensome to caregivers (Galvin et al., 2016). While these researchers identified important caregiving themes, they also demonstrated that more research must be done to understand how to support caregivers of people with ALS in their roles and tasks.

Another facet of caregiving entails the dyadic aspect of the relationship between the ALS patient and their family/caregiver. Garcia et al. (2017) conducted a longitudinal quantitative study to understand this dyadic relationship better. They found that ALS patients' and caregivers' experiences, psychological health, and quality of life could be shared, meaning, one person's experiences can affect the others (Garcia et al., 2017). In the future, researchers should explore the dyadic relationship between ALS patients and their caregivers to gain a better understanding and develop interventions accordingly.

Caregiving and Resilience. Scant research has explored the relationship between informal caregiving and resilience with people with ALS and their caregivers. Some

researchers have suggested that caregiver resilience is best understood by examining the caregiver's perceived burdens in concert with their care demands (see Ewen et al., 2015); however, that correlation might be incomplete. In their study on caregivers of patients with terminal cancer, Hwang et al. (2017) found that the absence of familial support could contribute to caregivers' waning resilience. Additionally, Delaney (2018) conducted a study that evaluated the benefits of a mindfulness self-compassion training program on nurses' compassion fatigue and resilience. While Delaney's study did not involve informal caregivers, it demonstrated that training could reduce compassion fatigue and maintain resilience (Delaney, 2018). Similar research should be done with caregivers of people with ALS to understand what factors and interventions, such as mindfulness self-compassion training, could reduce compassion fatigue and foster resilience to withstand the burdens associated with providing care.

Hospice and Palliative Care

Hospice and palliative care are critical services for people with ALS and their family members; however, based on recent research, the medical profession must expand their infrastructure to accommodate patients' needs at the end of life. According to Lupu et al. (2018), to keep up with and adequately treat the growing population of patients needing palliative and hospice care, more than twice the current number of palliative and hospice medical specialists will need to be trained every year until the year 2040. The need for adequate hospice and palliative care for people with ALS is brought into a clearer context when considering the vast majority of people with ALS require comfort care, artificial nutrition, ventilatory support, and other medical treatments to die with

dignity (Tiirola et al., 2015). Understanding best practices about hospice and palliative care, including advanced care planning and decision-making, must remain a high priority when providing end of life care for people with ALS.

Resilience and People with ALS

To my knowledge, researchers have not examined the relationship between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. However, some researchers have approached the phenomenon indirectly, some of which used quantitative methods, and two of which used qualitative methods. I could not find any resilience articles involving people with ALS that used an MMR design. Pagnini et al. (2011) conducted a quantitative study that examined the relationships between people with ALS' resilience, quality of life, and psychological well-being. Pagnini et al. administered three instruments, including the McGill Quality of Life Questionnaire, the Hospital Anxiety and Depression Scale (HADS), and the Resilience Scale for Adults, to 25 participants diagnosed with definite or probable ALS. Pagnini et al. found that people with ALS scored below what would be expected of the overall population for various data points of the Resilience Scale for Adults, including social resources, social competence, future planning, structured style, and the total resilience score. Additionally, Pagnini et al. (2011) concluded that suffering from ALS tends to reduce people with ALS' resilience and contributes to social withdrawal.

While not explicitly operationalized as a resilience study, Jakobsson Larsson et al. (2016) conducted a longitudinal study to evaluate how 36 people with ALS' coping strategies changed from early to later disease stages. This study also examined the

relationships between the people with ALS' coping strategies, emotional well-being, and physical functioning from early to late disease stages. The participants completed the Motor Neuron Disease Coping Scale, which was designed and validated for the study, the HADS, and the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALS FRS-R) within 3 months of being diagnosed and every 6 months for 2 years. The participants were assigned to groups (1-5) as they continued to complete the instruments every six months; however, due to attrition, the groups became smaller as the study progressed. Jakobsson Larsson et al. performed descriptive and inferential statistical analyses, including correlations between coping strategies, ALSFRS-R scores, and anxiety and depression using Spearman's rho. Jakobsson Larsson et al. reported their participants' coping strategies, physical function, emotional distress, and medical treatment. The coping strategies included support, positive action, independence, positive thinking, philosophy, alternative therapies, and spiritual beliefs, all of which did not vary from early to late stages of the disease. For physical function, ALSFRS-R scores were lower in the first two of the five groups, indicating that most of the participants' physical decline was faster in the first 6-9 months of the study; 21 of the 36 participants died during the study. The mean scores for the HADS were low, but several participants scored above the clinical cutoffs for each of the subscales in the earlier groups; however, none of the participants scored above the clinical cutoffs in groups 4 or 5. For medical treatments, the participants with depression, anxiety, pseudobulbar affect (uncontrollable weeping or laughing), and other mental health problems were treated with antidepressants, anxiolytics, and other medications. Finally, the researchers found

statistically significant correlations between coping strategies, anxiety, and depression. Physical disabilities and well-being were also correlated with coping strategies and disease progression (Jakobsson Larsson et al., 2016).

Parkin Kullmann et al. (2018) conducted an international online study investigating whether psychological stress due to premorbid occupational stress, resilience, and anxiety was a pathological indicator for ALS. Parkin Kullmann et al.'s case-control study included cases with participants diagnosed with ALS (n = 400) and a control group of participants not diagnosed with ALS (n = 450). The participants completed a multi-lingual web-based survey that included the Modified Social Readjustment Rating Scale, the Connor-Davidson-Resilience Scale (CD-RS), and the Modified Geriatric Anxiety Index. Parkin Kullmann et al. performed Mann-Whitney U tests to compare the case and control groups and found that there were no differences in the occupational stress and anxiety scores between groups and that the people with ALS tended to have higher resilience scores than the controls (Parkin Kullmann et al., 2018), which appeared to contradict Jakobsson Larsson et al.'s (2016) findings.

Marconi et al. (2016) conducted a qualitative study that involved administering an 8-week mindfulness training and then 44 semi-structured interviews to explore people with ALS' (n = 26) and caregivers of people with ALS' (n = 18) experiences with the training and its impact on their perceived discomfort and physical limitations. The researchers applied a grounded theory approach and organized the results according to two major themes: resources and limitations. In their analysis, Marconi et al. identified eight domains that summarized how the mindfulness training was a resource, including

improvement and well-being, relaxation, emotional self-regulation, acceptance, consciousness, breathing issues, sleep, and relationships. Concerning the limitations and challenges involved with the intervention, the participants overwhelmingly reported that the following deterred them from using the intervention: a) the transportation to the sessions was arduous, b) the interventions increased their caregivers' burdens, and c) it was difficult for them to replicate the mindfulness exercises at home (Marconi et al., 2016).

Finally, McCabe and O'Connor (2012) conducted a qualitative study that explored why some people with progressive neurological diseases such as Huntington's disease, ALS, multiple sclerosis, and Parkinson's disease seemed to respond more resiliently than others. Based on participants' scores from a previous quantitative study, McCabe and O'Connor purposefully selected 30 participants and placed them in two resilience groups, "low level of adjustment" and "high level of adjustment" (p. 18). Then, McCabe and O'Connor (2012) conducted structured interviews with the participants, the data of which were analyzed thematically and comparatively between the groups.

Five themes emerged in McCabe and O'Connor's (2012) analysis, including coping, activities and work, financial pressures, quality of life, and social support. Whereas the participants belonging to the high adjustment group did not use support groups frequently and regarded a positive attitude as an important coping mechanism, the low adjustment group tended to depend on support groups and did not use a positive attitude for coping. Concerning activities and work, the high adjustment group intentionally engaged in social activities to cope and were less inclined to maintain

employment, whereas the low adjustment group worked more, participated less in social activities, and exhibited patterns of wanting to escape the demands of their disease (McCabe & O'Connor, 2012). While both groups endorsed experiencing financial stress, they differed in how they approached coping with it. The high adjustment group found coping in budgeting and prioritizing their spending, and the low adjustment group relied on employment, family assistance, and charitable donations to cope. Finally, the groups shared similar ways of coping concerning the quality of life and social support themes (McCabe & O'Connor, 2012).

While all of these researchers did studies that approached resilience differently, each study involved people with ALS' and caregivers' resilience; however, none of them approached resilience from a socioecological perspective or with an MMR design. Moreover, the quantitative studies (Jakobsson Larsson et al., 2016; Pagnini et al., 2011) involved resilience measures that might not be appropriate for vulnerable adult populations. According to Liebenberg and Moore (2016), the Adult Resilience Measure-Revised (ARM-R) is better suited for vulnerable adults who experience significant adversity, such as people with ALS; hence, replicating Parkin Kullmann et al.'s (2018) research design using the ARM-R could yield more meaningful and significant findings.

Resilience and Self-Determination

I could not find many studies that involved both resilience and self-determination constructs, and none of those found involved people with ALS. Ng et al. (2012) did a study that explored the self-determination of people with chronic health conditions. They performed a systematic meta-analysis to calculate the effect sizes between the indices of

mental and physical health, autonomy of health care climates, psychological need satisfaction, and self-regulation in health care promotion. They found SDT to be a viable framework for conceptualizing people's motivation for their health-related behaviors (Ng et al., 2012). In contrast, Perlman et al. (2017) collected primary data using the CD-RS (Campbell-Sills & Stein, 2007) and the Basic Psychological Need Satisfaction Scale (Deci et al., 2001) from 159 participants with mental health diagnoses. Their study found that resilience could be related to the self-determination of people with mental health problems (Perlman et al., 2017). In another study, Perlman et al. (2018) examined a model for understanding the correlation between the motivational constructs related to self-determination and the resilience of people with mental health conditions. They recruited 106 participants to complete the Basic Psychological Need Satisfaction Scale, the CD-RS, and the Self-Determination Scale (SDS) and performed Cronbach's alpha, Pearson correlations, and goodness-of-fit analyses (chi-square, comparative fit index, standardized root mean residual, root mean square error of approximation). As with Perlman et al.'s (2017) earlier study, Perlman et al. (2018) found that resilience, self-determination, and psychological needs were statistically significantly related and that clinicians should consider these concepts when providing treatment to people with mental health problems.

Decision-Making With ALS

Conceptualizing ALS decision-making is complex and involves numerous considerations, including the philosophies surrounding mechanical ventilation (Ando et al., 2014; Stewart, 2014; Webster & Shirley, 2014; Young et al., 1994), artificial nutrition

(Stavroulakis et al., 2014), the ethical implications of beneficence, non-maleficence, professional-patient relationships, respecting patients' autonomy (Armon, 2018), quality of life issues involved with hospice, palliative care, and end of life care (Connolly et al., 2015; Kiernan, 2015; Linse et al., 2018; Stasolla et al., 2013), advance care planning (Levi et al., 2017; Sonenberg & Sepulveda-Pacsi, 2018), and Medicare payments (Sonenberg & Sepulveda-Pacsi, 2018). Hence, people with ALS' decision-making is multifaceted and multilayered and must be treated accordingly.

Philosophies and Ethics

The perspectives about decision-making vary widely across disciplines and stakeholders, including scholars, ethicists, policymakers, administrators, physicians, allied health professionals, patients, and families (Armon, 2018; Connolly et al., 2015; Levi et al., 2017; Young et al., 1994). However, scholar-practitioners are the gatekeepers charged with balancing the ethics of decision-making in ways that do not exploit their patients under the auspices of patient autonomy (Armon, 2018). Armon (2018) described how researchers and clinicians should define beneficence, non-maleficence, professional-patient relationships, and respective patients' autonomy in hierarchal order when treating people with ALS. According to Armon, beneficence is the first factor and refers to the effect size and duration that a treatment positively helps people with ALS. Next, concerning maleficence, if the burden outweighs the effect size and duration, the therapy is likely not worth the investment and could do more harm than good. Next, researchers and clinicians must develop productive relationships with their patients and respect that people with ALS are a vulnerable population, given their loss of control, communication,

and terminal status. Therefore, professionals must carefully consider their patients' well-being when they ask people with ALS to participate in clinical trials and therapies and ensure the science and methods incur minimal risk. Finally, once beneficence, maleficence, and the professional-patient relationship are established and maintained, researchers and clinicians must inform, disclose, and educate people with ALS thoroughly and accurately about the risks and potential benefits of treatments (Armon, 2018).

Given the complex and progressive nature of ALS, clinicians who treat people with ALS will likely encounter ethical dilemmas. According to Santaniello (2018), clinicians should be particularly mindful of ethical dilemmas when prescribing medications, alternative therapies, palliative care, and end of life treatments. Seitzer et al. (2016) conducted an exhaustive systematic review of 56 sources and identified 103 ethical issues, which the authors grouped into six broad categories, that clinicians should consider. The first category, diagnosis and prognosis, dealt with issues surrounding early diagnoses, diagnostic errors, respecting patients' self-determination for disclosure, discussing prognostic information appropriately, and communicating prognostic timelines to people with ALS. The second ethical category, medical indication, dealt with the diagnostic measures and approaches to therapy, particularly patients' self-determination for genetic testing and facilitating an environment where medical and mental health therapies are flexible, dynamic, and inclusive to patients' wishes. The third ethical category, decision-making capacity, included the timing of sharing medical updates, the patient-provider relationship, assessing for decision-making capacity, advance care

planning about life-sustaining treatments, and surrogate decision-making. End of life decision-making was the fourth category and included issues surrounding the discontinuation of life-saving measures, physician-assisted suicide, palliative sedation, and other general concerns about death and dying. The fifth category involved the ethics related to care processes and evaluation, such as ongoing treatment assessment obligations, empowering patients psychosocially and spiritually, and being aware of caregivers' needs. Finally, the last category, social and context, included ethical issues related to caring for people with ALS' next of kin, family finances, cultural considerations about end of life decisions, and the social implications of genetic testing (Seitzer et al., 2016). There are many ethical considerations that clinicians must consider in their daily interactions and approaches to helping people with ALS and their families.

As drugs, therapies, and interventions increasingly become available to treat people with ALS, clinicians and researchers must regularly evaluate the relevant ethics associated with these developments and protect their patients' decision-making, as much as possible, without causing unnecessary harm. While experimental drugs and therapies can have clinical benefits, without adequate testing and good ethical judgment, they can cause pain, harmful side effects, and unnecessary burden to the people who try them (Feustel et al., 2020; Lynch et al., 2018). Consequently, physicians and clinical researchers must use caution when administering experimental therapies to people with ALS and must do so with the patient's immediate well-being in mind.

Physician-assisted suicide (PAS) and euthanasia are also ethical issues that physicians must consider when working with people with ALS. PAS occurs when a

physician supplies a lethal drug to a patient to self-administer and kill themselves. Euthanasia is a medical procedure whereby a physician administers a lethal drug to a patient who wishes to end their life. As people with ALS react to their diagnoses and disease progression, they might contemplate PAS or euthanasia. While numerous states within the United States have legalized PAS and euthanasia, scholars, policymakers, and patients have debated these practices at length (Andriessen et al., 2019). Some scholars, ethicists, and physicians, such as Sutherland (2016), a retired family physician with ALS, have argued that PAS and euthanasia grant people who are experiencing extraordinary suffering with a dignified death. However, others maintain that the procedures embolden a slippery slope and contradict the ethical obligation not to harm patients (Andriessen et al., 2019). As the ethical debates surrounding experimental treatments, PAS, and euthanasia persist, ALS multidisciplinary social workers must be available to support people with ALS' decision-making within the legal parameters of their clinical jurisdictions.

Philosophies and ethics are particularly important when considering that ventilatory support and PEGs are currently the only effective treatment available to prolong people with ALS' lives once they suffer respiratory failure. Faull et al. (2014) conducted a mixed-methods study to understand the ethical issues of withdrawing noninvasive and invasive ventilatory support. Faull et al. distributed an online survey to 993 palliative care physicians in Europe, which asked three questions (scaled 0-10) to rate their views on the practical, emotional, and ethical challenges of withdrawing ventilatory support from their patients. Respondents also provided open-ended responses

that were codified, categorized, and thematically analyzed (Faull et al., 2014). The Association for Palliative Medicine of Great Britain and Ireland used Faull et al.'s (2014) data to publish their guidance, which prescribes the timing, standards, and processes that physicians should follow to withdraw ventilatory support as carefully and humanely as possible (Faull & Oliver, 2016). This study brought about crucial guidance for British and Irish hospice physicians to follow while weaning patients off of ventilatory support; however, it did not specifically collect data about people with ALS.

In another study, Stavroulakis et al. (2014) conducted 18 semi-structured interviews to conceptualize the people with ALS' perceptions about the optimal timing for having a PEG inserted for supplemental nutrition. Stavroulakis et al. (2014) used NVivo 10 software to perform concurrent codification and multiple iterations of thematic analysis until they reached data saturation. Stavroulakis et al. (2014) concluded that despite physicians' advice for early PEG insertion, people with ALS' individual and unique psychosocial factors might contribute to delayed decision-making and hesitation for PEG insertion. Therefore, ALS multidisciplinary clinics must be keenly aware of the psychosocial factors that could become barriers to people with ALS' decision-making (Stavroulakis et al., 2014).

Quality of Life and End of Life Care

Empowering people with ALS' decision-making throughout the palliative and hospice care process at the end of life is imperative to enable them to maintain the best quality of life possible and to die with dignity. In their recent literature review of end of life decision-making, Connolly et al. (2015) concluded that people with ALS should

typically begin palliative care immediately after being diagnosed and then transition to hospice care at a time of their choosing. However, historically, most doctors approached end of life discussions from a biomedical standpoint with little or no focus on psychosocial needs (Connolly et al., 2015). From the outset, ALS multidisciplinary clinics must make effective use of the palliative social workers and psychologists to address the psychosocial aspects of care and decision-making by discussing options, helping patients complete advance directives, and removing barriers that prevent people with ALS from doing so. As Connolly et al. (2015) and Kiernan (2015) discussed, because ALS is a heterogeneous disease with limited predictability, most interventions and requests for durable medical equipment are ad-hoc, reactive, and delayed, which makes it problematic to keep up with patients' increasing and persistent needs. Herein lies the conundrum of the intersection between palliative care and delayed Medicare payments and reimbursements. Despite clinicians' best efforts, the chasm between clinical practice and health care policy limits their ability to empower their patients' decision-making and maintain their quality of life, especially early in the disease. In response, medical social workers involved in policy must advocate that Medicare establishes exceptions to policy and procedures to process palliative care claims expeditiously.

Communication

A challenge sometimes overlooked when providing palliative care to people with ALS involves acquiring high-tech augmentative and alternative communication devices, such as computer devices with eye gaze capabilities, before they need it (Linse et al.,

2018). A person's voice is a central component of who they are and their ability to communicate their needs. ALS multidisciplinary clinics must remove the barriers that prevent people with ALS early access to assistive speech devices. Early access to these devices improves people with ALS' quality of life and enables them to communicate their end of life decisions. According to Linse et al. (2018), research has shown that eye gaze computer devices help people with ALS regain communication, retain their familial and social circles more abundantly, reduce caregiver burden, and increase autonomy and decision-making. However, in some cases, people with ALS become too demoralized, discouraged, or afflicted by frontotemporal dementia to get the full benefits of assistive speech technology (Linse et al., 2018).

There are also challenges and limitations with accessing and using assistive speech technology, especially for those with oculomotor dysfunctions, tracheostomies, or quadriplegia. Linse et al. also observed that some people with ALS refuse to use eye gaze technology because they have a hard time letting go of their natural voice and accepting a synthesized version. Others might experience difficulty adapting to the technology due to age, education level, or computer literacy. Finally, Linse et al. also reported that environmental concerns, such as paying for, upkeeping, and repairing the devices, deter people with ALS from using them (Linse et al., 2018). Eye gaze technology can give people with ALS increased autonomy and empowered decision-making; however, more research is needed to determine how to bridge the accessibility and education gaps to maximize their impact.

Advance Care Planning

Advance care planning is another vital component of people with ALS' decision-making that warrants discussion. In my search of the literature, I found two studies that discussed advance care planning of people with ALS (see Levi et al., 2017; Sonenberg & Sepulveda-Pacsi, 2018) and another that examined the social work roles involved with advance care planning (see Francoeur et al., 2016). According to Sonenberg and Sepulveda-Pacsi (2018), advance care planning entails providing patients and their families with information and education about the life-sustaining treatments available to them and empowering their autonomy throughout their decision-making process. Levi et al.'s (2017) study examined the extent to which the communication between people with ALS and their ALS physicians surrounding life-sustaining treatments improved after using a computer-based advance care planning decision aid. Levi et al. concluded that the aid significantly increased the agreeability of preferences between the people with ALS and physicians who participated in the study. Another key finding from this study was that after using the advance care planning aid, the physicians felt more confident that their decisions were in congruence with their patients' preferences. Finally, the data indicated that only half of the people with ALS had completed an advance directive or had heard at least a fair amount about advance directives before their involvement in the study (Levi et al., 2017).

Many people with ALS do not fully understand the life-sustaining treatment options available to them or know how to make their wishes known on an advance directive (Levi et al., 2017). However, recent changes to Medicare might incentivize the

completion of advance directives because physicians and other practitioners, such as social workers, can now be reimbursed for initial and subsequent advance care counseling appointments (Sonenberg & Sepulveda-Pacsi, 2018). ALS multidisciplinary social workers are uniquely qualified and positioned to collaborate with other team members to ensure people with ALS have the information to understand their options for life-sustaining treatments and opportunities to complete advance directives (Francoeur et al., 2016). Future research on advance care planning should examine the extent to which Medicare reform has impacted people with ALS' decision-making for life-sustaining treatments and their quality of life at the end of life.

Summary and Conclusions

ALS multidisciplinary social workers play a critical role in helping people with ALS and their families live more resiliently at the end of life. Wang et al. (2017) discussed three primary social work responsibilities when assisting people in making their end of life decisions. First, social workers help people with ALS and their families to address the psychosocial and spiritual problems that manifest as they pass through the death and dying process. Second, social workers educate people with ALS about and help them make health care decisions, particularly those that pertain to life-sustaining treatments. Third, social workers serve as a resource to support the family members' grief during and after the death and dying process (Wang et al., 2017). However, when considering ALS's progressive and debilitating nature, including communication deficits, engaging people with ALS and their families in patient-centered shared decision-making models is of paramount concern and is under-researched (Pagnini et al., 2016).

In their qualitative findings of a patient-centered shared decision model for multidisciplinary clinics, Hogden et al. (2015) identified six themes that ALS multidisciplinary clinical teams should consider when implementing a shared decision-making model. First, a vital element of the decision-making process includes helping people with ALS and their caregivers to accept and adapt to their diagnoses and prognoses. Acceptance and adaptation to life with ALS may help people with ALS and their caregivers become amenable to introspective decision-making. Second, the multidisciplinary team must respect and support their ALS patients' and caregivers' autonomy, including their beliefs, values, and philosophical views. Third, timing and planning are critical to people with ALS' outlook and willingness to engage in services. The neurologist must try to expedite the diagnostic process while simultaneously giving their patients sufficient time and space to process their diagnoses and prognoses. Fourth, ALS multidisciplinary teams should provide their patients and family members evidence-based information about drugs, therapies, and investigational options so they can make informed decisions in their care. Fifth, multidisciplinary teams must provide their patients with sufficient time and attention during appointments to ask and receive answers to questions and facilitate an environment wherein they can make the best decisions possible. Finally, because people with ALS are vulnerable to high anxiety and depression levels, multidisciplinary clinics should provide the promptest services and communication possible (Hogden et al., 2015). In addition to adhering to a patient-centered shared decision model, ALS multidisciplinary clinics can empower people with ALS' decisions by implementing accessible advance care planning aids that educate and

generate life-sustaining treatment preferences into actionable medical plans (Levi et al., 2017).

ALS decision-making is a complex process interwoven by layers of factors between the people with ALS, their family/caregivers, and multidisciplinary teams. Researchers in the field should emphasize understanding how to implement patient-centered shared decision-making care models. My literature search identified studies concerning people with ALS' use of tracheostomies (Faull & Oliver, 2016; Faull, Rowe Haynes, & Oliver, 2014), PEGs (Stavroulakis et al., 2014), and their general decision-making (Hogden et al., 2015). I also found studies where the researchers investigated the self-determination and autonomous motivation of people with chronic illnesses (Ng et al., 2012) and the linkage between people's resilience, self-determination, and mental health problems (Perlman et al., 2017, 2018). Additionally, I found studies in which the researchers investigated the resilience of adult child-abuse survivors from a socioecological perspective (Liebenberg & Moore, 2016) and people with spinal cord injuries (Catalano et al., 2011; Jones et al., 2018; Monden et al., 2014). While it appears that researchers have not investigated people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments in a single study, some have conducted studies that investigated aspects of my study's phenomenon indirectly.

Most of the current literature involving resilience, self-determination, and decision-making for life-sustaining treatments has been compartmentalized, has seldom established statistically significant relationships, and has not been related to people with ALS. Moreover, while Perlman et al. (2017) and Perlman et al. (2018) examined the

relationship between resilience and self-determination, they did not measure resilience from a socioecological framework. Liebenberg and Moore (2016) recommended that researchers conduct resilience studies from a socioecological framework on vulnerable adult populations who have experienced prolonged adversity. Therefore, because people with ALS experience progressive and constant adversity (Cornwell, 2016), I conducted a mixed-methods study to examine this phenomenon.

In the next chapter, I explain my study's mixed-methods design, including my role as the researcher and the methods and methodology related to selecting and recruiting the population, instrumentation, data collection, and analysis. I also discuss the threats to validity, how I assessed for trustworthiness, and ethical procedures and considerations.

Chapter 3: Research Method

My purpose in conducting this study was to examine the relationship between people with ALS' experiences with, and their attitudes about, socioecological resilience, self-determination, and decision-making for life-sustaining treatments. In this chapter, I describe the setting in which I conducted the study, outline the research design and my rationale for it, and discuss my role as the researcher. I also discuss the methodology, including the participant selection logic, the procedures for recruiting participants and collecting the data, the quantitative and qualitative instruments, and the data analysis plan. Finally, I discuss the validity threats and my strategies for maintaining trustworthiness.

Setting

Because many people with ALS rely on augmented devices for communication (Linse et al., 2018), I used SurveyMonkey (http://www.surveymonkey.com/), an accessible online survey platform, to enable participants of all ability levels and stages of disease progression to complete the data collection instruments. While using an online survey method significantly normalized the study's setting, other factors could have influenced the participants' responses. For example, while all the participants used a computer or smartphone to respond, some responded in a hospital bed or nursing home, or while seated in a motorized wheelchair or in less adaptive settings in their homes, depending on each participant's level of functioning and needs. Similarly, whereas some people with ALS needed help from their caregivers to respond, others responded without a caregiver's assistance.

Furthermore, people with ALS who resided in nursing homes and without an informal caregiver may have felt less comfortable asking the nursing staff to help them respond. These factors could have affected the accuracy and completeness of the responses, particularly regarding the qualitative questions that request open-ended answers. To capture the participants' environments, I included an item in the survey that asked about the settings and conditions in which the participants responded. Additionally, I encouraged the participants to request assistance from caregivers and to take frequent breaks, if necessary, to help them respond accurately and thoroughly.

Research Design and Rationale

I examined three RQs, one of which was qualitative and the others quantitative. The qualitative RQ was: How do socioecological resilience and self-determination contribute to people with ALS' decision-making for life-sustaining treatments? The quantitative RQs were: What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments? What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments? The central concept that I examined was the relationship, attitudes, and experiences surrounding people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. I used a cross-sectional QUAL + QUANT MMR design to collect and analyze the data concurrently, descriptively, inferentially, and thematically.

MMR is an emerging and expanding methodology in terms of its scope and ability to make sense of complex and obscure phenomena (Ivankova & Plano Clark,

2018). While philosophical and epistemological differences still exist amongst purist researchers (those who identify with only one methodology and not another), some scholars have called for pluralistic pedagogical frameworks that explore and confirm the phenomena being studied (Onwuegbuzie & Leech, 2005; Onwuegbuzie & Teddlie, 2003). In that regard, Onwuegbuzie and Teddlie (2003) introduced an MMR model where exploratory methods include descriptive statistics, exploratory factor analysis, and thematic analysis. Confirmatory methods are comprised of inferential statistical analysis and confirmatory thematic analysis (when findings and theories are examined over time and across populations). Onwuegbuzie and Leech (2005) termed this type of MMR as *pragmatic research*, implying that effective MMR requires researchers to remove ontological barriers and approach complex research problems from multiple perspectives.

MMR is particularly amenable when a researcher examines a phenomenon manifested in obscure and vulnerable populations, such as ALS. Combining quantitative and qualitative data collection methods empowers members of vulnerable populations while simultaneously enabling the researcher to compare, contrast, and integrate the participants' voices with the quantitative data (Gelo et al., 2008; Liebenberg & Moore, 2016). Therefore, my primary rationales for using MMR for this study were empowerment, triangulation, complementarity, and methodological efficiency (Creswell & Plano Clark, 2011; Gelo et al., 2008; Liebenberg & Moore, 2016; Lincoln & Guba, 1985; Plano Clark & Ivankova, 2016). Triangulation enabled me to compare the quantitative and qualitative results for convergence and divergence, and complementarity added strength to each of the methodologies and offset their weaknesses (Onwuegbuzie

& Leech, 2005). This study's design also allowed me to gather and interpret the data comprehensively, which added to the existing literature, both qualitatively and quantitatively (Gelo et al., 2008; Onwuegbuzie & Leech, 2005). Finally, conducting a concurrent single sample survey design, rather than a sequential one, maximized time and efficiency (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016), which was critical given my positionality as a person with ALS.

Role of the Researcher

I discuss my researcher role with Ivankova and Plano Clark's (2018) socioecological MMR conceptual framework in mind. That is, how my personal, interpersonal, and social contexts influenced how I operationalized the research content domains and executed the research process. My pluralistic ontological research orientation and affinity for both inductive and deductive approaches of scientific inquiry was a personal context that meshed well with an MMR approach. Being a researcher with ALS is another personal context that I carefully reconciled throughout the research process. I also hold to the philosophy that resilience phenomena between dynamic processes, inherent traits, and social ecology need not be mutually exclusive, as some scholars have posited (Liebenberg & Moore, 2016). Finally, my positionality and previous experiences as a child abuse survivor, disabled Army veteran, and child welfare worker, and my agreement with current research that spirituality can be a protective factor for resilience and coping, are also crucial to my personal context (see Fombuena et al., 2016; Kukulka et al., 2019; Liebenberg & Moore, 2016; O'Brien & Clark, 2015; Roger & Hatala, 2018). I managed these personal contexts for bias by describing the

procedures, participants, and responses in thick detail; by incorporating peer debriefing; and by maintaining a detailed and complete audit trail (see Lincoln & Guba, 1985; Onwuegbuzie & Leech, 2005).

My interpersonal contexts for this study included the ethical considerations unique to quantitative, qualitative, and mixed-methods research; ethics related to informed consent, confidentiality, and professional conduct; the institutional review board (IRB) process; editorial requirements and guidelines; and the dynamics between my committee members and me (Ferguson & Clark, 2018; Plano Clark & Ivankova, 2016). Another paramount interpersonal context that I guarded carefully was the interactions and ethics involved with researching a vulnerable ALS population (Plano Clark & Ivankova, 2016). Given my positionality as a researcher with ALS, who also provides clinical social work services to others with ALS, I deliberately collected the data using an online survey to mitigate researcher bias, dual relationships, and power differentials.

My social contexts involved the institutional and societal constructs that influenced my study throughout the design planning and implementation (Ivankova & Plano Clark, 2018; Plano Clark & Ivankova, 2016). For example, the content I was exposed to while completing research courses, my faculty interactions and feedback, and my university's IRB parameters affected the RQs and design that I implemented (Ivankova & Plano Clark, 2018; Plano Clark & Ivankova, 2016). My interactions and experiences with the ALS community's cultural norms, and those of the broader society, challenged and influenced how I interpreted the data (Ivankova & Plano Clark, 2018;

Plano Clark & Ivankova, 2016). Finally, knowing that my colleagues in the MMR, resilience, social and behavioral sciences, and ALS research professional circles will be consuming and critiquing the final product influenced how I approached the research process (Ivankova & Plano Clark, 2018; Plano Clark & Ivankova, 2016). Moreover, because my study involved people with ALS who had terminal illnesses, I had an ethical responsibility to approach this study in a manner that dignified the ALS population and to report the findings as expeditiously and transparently as possible.

Methodology

In this section, I describe and justify the procedures I used to select the participants and determine the sample size and data saturation. I also discuss the qualitative and quantitative instruments; the procedures for recruitment, participation, and data collection; and outline the data analysis plan I followed.

Participation Selection Logic

Population and Criterion

According to Mehta et al. (2018), in 2015, the ALS Registry identified 16,583 people living with definite ALS in the United States; however, that number is likely missing minority cases (Kaye et al., 2017). While anyone is susceptible to ALS, the ALS Registry has consistently found that most people with ALS in the United States are White, over 60 years old, and are male more often than female (Bryan et al., 2016; Mehta et al., 2018). The population that I examined in this study included people with ALS who were registered with the ALS Registry because the ALS Registry offered the most replete and accurate representation of the ALS population available.

Eligibility to participate in this study was people who were 18 years or older, diagnosed with ALS, documented in the ALS Registry, and without diminished decision-making capacity due to frontotemporal dementia. According to Ludolph et al. (2015), less common motor neuron diseases, such as progressive bulbar ALS, flail arm syndrome, flail leg syndrome, progressive muscular atrophy, and primary lateral sclerosis, often pathologically progress to meet the diagnostic criteria for ALS. However, people with these motor neuron diseases do not have the same life-determining decisions for life-sustaining treatments as people with ALS. Therefore, because a physician must have told registrants with the Registry that they have met the diagnostic criteria for ALS, people diagnosed with these spectrum-related motor neuron diseases were not eligible to participate.

Sample Size Calculation

Sample sizes and data saturation are key determinants for producing valid and ethical quantitative and qualitative research findings (Faber & Fonseca, 2014; Fusch & Ness, 2015). The sample size for this study was equal for the qualitative and quantitative methods (see Onwuegbuzie & Collins, 2007). Using G*Power 3.1 software (see Faul et al., 2007), I selected a one-tailed z test logistic regression model with two probabilities, error of probability (.05), power (.80), R^2 (.271), a normal x-distribution, and calculated a minimum sample size of 99 participants. However, to maximize generalizability, I aimed to sample at least 200 participants.

Sample Size and Data Saturation. When conducting an MMR study, it can be complicated and challenging to balance a sample size while ensuring that data saturation

is met. In qualitative research, data saturation refers to collecting data until the researcher is not gaining new information from their participants in order to attain a representative sample (Teddlie & Yu, 2007). According to Teddlie and Yu (2007), the process of managing a sample size with data saturation sometimes involves a degree of compromise based on the study's sampling priorities. For example, if the sampling priority leans toward the quantitative methods, attaining a sufficient sample size for quantitative analysis would take precedence overachieving qualitative data saturation. Likewise, the reverse is true if the researcher prioritizes qualitative sampling over the quantitative (Teddlie & Yu, 2007). I placed equal emphasis on the quantitative and qualitative sampling methods; however, to establish statistically significant correlations, I needed to sample at least 99 participants. Therefore, I attempted to recruit as many participants as possible to maximize the quantitative results' generalizability.

The literature surrounding optimal sample sizes and attaining data saturation is conflicted and ambiguous. According to Mason's (2010) content analysis of qualitative studies, the researchers conducted a mean of 31 interviews to reach data saturation. However, because I collected the data using structured open-ended survey questions, it was unclear how many participants would be needed to reach saturation. Nonetheless, I followed Fusch and Ness's (2015) recommendations and assessed for whether or not the information was sufficient for the study to be replicated, if new information was being gathered, and if new codes or themes were generated (see Guest et al., 2006; O'Reilly & Parker, 2013; Walker, 2012). However, it should be noted that during my analysis, I continued to identify new information and established new codes and categories until I

exhausted the entire sample. Consequently, I did not reach data saturation, as Fusch and Ness (2015) defined, until I analyzed the entire data set.

Because researchers have not traditionally been consistent or transparent when applying data saturation as a basis for their sample sizes, I also followed Malterud et al.'s (2016) method for conceptualizing sample sizes, which they termed as *information power*. In that regard, I considered five additional factors, including the broadness of the study's aim, the density of the study's sample specificity, the level of the study's theoretical involvement, the extent of clear and robust communication between the researcher and the participants, and the depth of their data analysis plan (Malterud et al., 2016). While my study aimed to answer three specific RQs, the findings associated with answering those questions are broad and extensive. While the sample for this study was distinct, their responses were diverse. Additionally, the online survey significantly hampered my ability to connect and interact with the participants. While this study's theoretical framework was sound and well defined, the phenomenon had never been examined with the ALS population. Finally, the qualitative data analysis plan for this study was robust and extensive.

After reconciling the data saturation and information power criteria with the data, I concluded that all viable cases were needed to conceptualize the data and draw trustworthy conclusions. Furthermore, having a larger sample size added depth to the data analysis and enabled me to quantify the codes and themes in meaningful ways. The final sample consisted of 197 people with ALS.

Sampling Strategy

Because no other researchers, to my knowledge, had done studies that examined these variables with people with ALS previously, I recruited a sample as demographically representative of the overall ALS population as possible. Recruiting a representative sample enhanced the generalizability of the findings (Martínez-Mesa et al., 2016; Pickering, 2017) and established a baseline understanding of the variables. To do this, I employed what Onwuegbuzie and Collins (2007) referred to as a "concurrent, identical sampling design" (p. 293), where the qualitative and quantitative data are collected at the same time and from the same population. In line with that design, I used a simple random sampling strategy; that is, I gained access to a robust sampling frame of people with ALS to select participants randomly.

Simple Random Sampling. Simple random sampling is a common and well-known quantitative sampling strategy where each participant, or case, from an accessible population has an equal and independent opportunity of being included in the sample without affecting the probability of others being selected (Martínez-Mesa et al., 2016; Teddlie & Yu, 2007). While researchers can perform a simple random selection by flipping a coin or drawing numbers from a hat, researchers often use an algorithm from a computer-based program (Liu et al., 2017) or Microsoft Excel to randomize numbered cases within a sampling frame (Mélard, 2014). For this study, the ALS Registry performed the simple random sampling procedure using technology unique to the ALS Registry data set.

Procedures for Recruitment, Participation, and Data Collection

After my university's IRB conditionally approved the proposal, I applied for access to the ALS Registry's sampling frame. I submitted two forms, including the National Amyotrophic Lateral Sclerosis Research Application Form and the Part A-Research Notification Form, which the ALS Registry processed and approved within 3 weeks. I began recruiting once the IRB granted final approval. The IRB approval number was 05-13-20-0985288.

Recruitment Procedures

I implemented an effective recruitment strategy to ensure I had a sufficient number of participants to conduct the inferential statistical analyses. Once the ALS Registry approved my study, and we negotiated a letter of agreement, the ALS Registry took a random sample of and emailed the recruitment letter to 11,961 potential participants from a sampling frame containing a total of 16,583 people with ALS. The recruitment letter included the purpose of the study, a weblink to the survey, a statement of how long the survey would be available, an estimation of how long it would take to participate, and information about how the participants could contact a crisis counselor using the Crisis Text Line. I did not provide any incentives or compensation to the participants.

The National ALS Registry. In 2008, the United States Congress funded the ALS Registry, and, in 2010, the ALS Registry began collecting and maintaining prevalence and epidemiological data related to people with ALS (Mehta et al., 2018). The ALS Registry collaborates with and helps researchers recruit participants by notifying

people with ALS of their studies, supplying biorepository samples, and granting researchers access to the prevalence and risk factor data collected previously (Mehta et al., 2018). I had no personal or professional conflicts with the ALS Registry that would compromise this study's integrity.

Participation

The sample consisted of adults aged 18 or older who had been diagnosed with ALS and had self-registered with the ALS Registry. After receiving the recruitment email, the participants could immediately click the weblink from their smartphone, computer, or high-tech augmentative and alternative communication devices to begin the survey. I embedded the informed consent at the beginning of the survey, and the participants were not permitted to proceed with the survey until they acknowledged that they had read and understood the informed consent and agreed to participate. After agreeing to the informed consent, the survey began with the instructions followed by the demographic items. While everyone who the ALS Registry randomly selected to participate presumably had an eligible diagnosis, a demographic item on the survey asked them to confirm their ALS diagnoses to ensure they met the inclusion criteria.

The sample had one month from the date of receiving the email notification to respond. Once the participation window closed, I asked the ALS Registry to update the website and close the recruitment. Once the participants reached the end of the survey, before submitting their responses, they were given information about how they could contact a crisis counselor using the Crisis Text Line listed in the recruitment letter, if necessary. The Crisis Text Line is a helping agency open 24-hours a day, seven days a

week, that provides crisis counseling to people in need. I utilized this agency because it was free and accessible, even for the participants who used high-tech augmentative and alternative communication devices synchronized with their cellular phones for text communication.

Instrumentation

I included 10 open-ended qualitative items related to people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. I also implemented two quantitative instruments, one to measure the participants' socioecological resilience and the other to measure their self-determination, to examine the relationship between these variables and their decision-making for life-sustaining treatments. Because I could not find any validated or compatible instruments that measured people with ALS' choices for life-sustaining treatments, I asked yes and no questions to ascertain their decision-making for tracheostomies and PEGs. Finally, I asked the participants to answer a series of demographic items, which added descriptive data and additional control variables for the quantitative inferential analysis.

Qualitative Components

I implemented a structured qualitative protocol (see Appendix A) to complement and give context to the quantitative data regarding the participants' attitudes about socioecological resilience, self-determination, and decision-making for life-sustaining treatments. According to Ravitch and Carl (2016), while there are some disadvantages to using a structured online survey platform to collect qualitative data, such as missing contextual data gained only from face-to-face interactions and marginalizing people

without internet resources or education, there are certainly benefits as well. For example, survey research is typically efficient at collecting and analyzing a large amount of data from participants across geographical distances. Also, the participants can remain anonymous, and the researcher often has greater reliability and validity in their results (Ravitch & Carl, 2016).

Implementing a survey-based open-ended qualitative protocol enabled me to collect a large amount of data, bridged the accessibility gap, and allowed the participants to respond fully. I had other rationales for collecting the qualitative data using an online survey instead of conducting face-to-face interviews, including (1) communication challenges given the way the disease progresses, (2) people with ALS' preferences to communicate and do tasks without being pressured by a face-to-face setting, (3) provide the ability for the participants to take breaks, (4) greater expedience that enabled me to complete the study in quick order, and (5) the time sensitiveness given the mortality issues of the study population.

While developing the qualitative protocol, I considered constructs from the socioecological resilience framework (Jefferies et al., 2018; Liebenberg & Moore, 2016; Ungar et al., 2013), self-determination theory (Deci & Ryan, 2000; Perlman et al., 2018), and my own experiences as a person with ALS living with a tracheostomy. After my university's IRB approved the study's proposal to collect the data, I conducted an informal pilot test of the qualitative protocol with three family members and friends to assess the qualitative questions' appropriateness and comprehensiveness.

Four of the qualitative protocol questions asked the participants about their self-identified strengths, their perceived challenges about the present and the future, how their ability to withstand and bounce back from trials had changed since being diagnosed with ALS, and how their caregivers and loved ones had impacted their ability to live with ALS. I asked these questions to gain a contextual understanding of the participants' socioecological resilience processes and mechanisms (Jefferies et al., 2018; Liebenberg & Moore, 2016). The questions that asked about how the participants' ability to withstand and bounce back from trials had changed yielded data about their chrono-systemic experiences with socioecological resilience (Ungar et al., 2013).

The remaining eight questions asked about the participants' thoughts about having or getting tracheostomies and PEGs. The participants only answered four of the last eight questions depending on if they had a tracheostomy and PEG or not. The participants who did not have tracheostomies and PEGs answered what would motivate or prevent them from getting the treatments. The participants who already had tracheostomies and PEGs answered with what motivated them to get the procedures. These questions yielded rich data concerning the participants' raw thoughts about tracheostomies and PEGs. They also identified the factors that influenced their decision-making for tracheostomies and PEGs. For example, according to cognitive evaluation theory, a sub-theory of SDT, people's experiences can instigate or exacerbate negative self-perceptions of competence, thereby decreasing intrinsic motivation and self-determination (Deci & Ryan, 1985; Gagné et al., 2018; Riley, 2016).

Quantitative Components

I used two quantitative instruments to examine the relationship between independent and dependent variables: the ARM-R (see Appendix B) and the Basic Psychological Need Satisfaction Scale (BPNSS) (See Appendix C). Both instruments were available to download, without restrictions, after registering with the instruments' owners.

Adult Resilience Measure-Revised. The first instrument, the ARM-R (Jefferies et al., 2018), measured the independent variable socioecological resilience. The ARM-R was adapted from the Child and Youth Resilience Measure-Revised and has been widely used and validated, including the subscales (Jefferies et al., 2018; Liebenberg & Moore, 2016). There are four versions of the ARM-R, which account for varying levels of functioning, intelligence, and abilities; however, each version includes 17-Likert-scale items. Two of the versions are formatted according to a 5-point Likert-scale and differ slightly to accommodate different levels of reading comprehension and abilities. Similarly, the other two versions of the ARM-R adhere to a 3-point Likert-scale and should be administered based on the participants' reading comprehension and abilities. For this study, I used the 3-point Likert-scale "simple" version of the instrument to accommodate for mild cognitive disorder often seen in people with ALS (Nagashima et al., 2019) and to mitigate survey fatigue (O'Reilly-Shah, 2017).

Jefferies et al. (2018) found the ARM-R to be reliable and consistent, with a moderately high Cronbach's alpha for personal resilience (α = .82), relational resilience (α = .82), and overall resilience (α = .82). In the same study, Jefferies et al. performed

exploratory factor analysis and found the subscales had good fit statistics (RMSEA = .059, RMSR = .55). They also performed a Rausch model validation and found that the subscales met the criteria for multidimensionality, showed good fit statistics and targeting properties, were without bias and problematic local dependency, and successfully differentiated between the participants' resilience levels (Jefferies et al., 2018).

In another study, Liebenberg and Moore (2016) assessed the ARM-R for validity and reliability with the commonly used Warwick Edinburgh Mental Well-Being Scale (WEMWBS) on adult institutional childhood abuse survivors. In their study, they found that the ARM-R was strongly correlated with the WEMWBS (r = .816) and had a strong Cronbach's alpha (α = .967), which supported the instrument's internal reliability. Liebenberg and Moore recommended that the instrument be used with vulnerable adult populations who experience prolonged adversity, such as people with ALS. In conjunction with the International Resilience Project, numerous scholars assessed the ARM-R for content and face validity across 14 communities and 11 countries and concluded it to be contextually sensitive (Liebenberg & Moore, 2016). Moreover, the instrument is useful because it can be scored for respondents' overall resilience and two subscales, personal and relational resilience (Liebenberg & Moore, 2016). The ARM-R aligned well with my study's theoretical framework, research problem, purpose statement, and the corresponding RQ, and was particularly malleable in its ability to measure people with ALS' resilience, given their significant adversity as a vulnerable population.

Basic Psychological Need Satisfaction Scale. Deci and Ryan (2000) developed the BPNSS as an instrument to accompany SDT and measure the degree to which people's basic needs, including autonomy, competence, and relatedness, are satisfied in order to make intrinsically motivated and self-regulated choices that improve well-being. The BPNSS measured the other independent variable, self-determination, for this study. According to SDT, people who have their basic needs met are more likely to be healthier, more productive, and more autonomous in their decision-making (Deci & Ryan, 2000; Perlman et al., 2018). The instrument consists of 21-7-point Likert-scale items and measures the overall basic need satisfaction and its subscales, including autonomy, competence, and relatedness.

Gagné (2003) adapted an instrument that Ilardi et al. (1993) used to measure need satisfaction in the workplace into the General Need Satisfaction Scale, now referred to as the BPNSS. Psychometric analysis of the instrument showed internal validity for autonomy (α = .69), relatedness (α = .86), and competence (α = .71) and showed moderate correlations (r = .51, r = .61, r = .66). After averaging the subscales into an index of general need satisfaction, the composite Cronbach's alpha was .89 (Gagné, 2003). The BPNSS aligned well with SDT and enabled me to examine the relationship between self-determination and decision-making for life-sustaining treatments.

Decision-Making for Life-Sustaining Treatments. Because I could not find any validated or compatible instruments that measured decision-making, I implemented yes and no questions and integrated them with the demographic items (see Appendix D). These items asked about people with ALS' decisions for life-sustaining treatments. These

items inquired about whether the participants already had or were planning to get life-sustaining treatments to prolong their lives. They also discerned they had heard about and completed an advance directive to document their life-sustaining treatment preferences.

Demographic Items. My survey's demographic items (see Appendix D) asked about the setting and conditions in which the participants responded. These items also collected information about the participants' age, gender, ethnicity, marital status, socioeconomic status, the year they were diagnosed, levels of functioning, military veteran status, health insurance status, and bankruptcy status.

Data Analysis Plan

Given that this was a mixed-methods study, I performed various qualitative, quantitative, and mixed-methods analyses. I mixed the qualitative and quantitative data using a joint display table (see Guetterman et al., 2015); that is, I performed the quantitative and qualitative analyses separately and then displayed the points of convergence and the mixed conclusions in a table.

Qualitative Analysis

I exported the qualitative survey data into Microsoft Excel spreadsheets in several batches and imported them into the NVivo project file. I previewed the data to get a sense of the codes that emerged before conducting any coding sequences (Ravitch & Carl, 2016). Coding, categorizing, and thematizing the data was a recursive and iterative process that spanned three coding sequences. Content analysis was also done to quantify the codes and comment frequencies (See Morgan, 1993; Newman et al., 2013; Sandelowski et al., 2009). As I coded the data, I maintained a memo folder embedded in

the NVivo software to notate my observations and interpretations of the data, which was necessary for conceptualizing the findings. I produced a word count frequency table and a word cloud to visualize the participants' most-used 30 words to complement the results.

Quantitative Analysis

Using Statistical Package for the Social Sciences (SPSS), I performed both descriptive and inferential statistical analysis. The quantitative RQs and accompanying hypotheses I answered by conducting this study were

What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments?

$H_0$2: There is no relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

$H_1$2: There is a positive relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments?

$H_0$3: There is no relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

$H_1$3: There is a positive relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

I previewed the data several times for errors, and then sanitized (i.e., cleaned) and edited them accordingly (see Van den Broeck et al., 2005). When I examined the data, I found missing cases across numerous variables, including date of birth, gender, ethnicity,

marital status, annual income, the status of having a tracheostomy, the status of having a feeding tube, knowledge about advance directives, the status of completing advance directives, military veteran status, the degree to which ALS compromised their financial stability, medical bankruptcy, items from the ARMR, and items from the BPNSS. As a result, there were a total of 62 cases with missing values. To address the missing annual income data points (n = 15), I performed mean substitution (Kang, 2013) and inserted the sample's mean annual income ($107,840). I used the "select cases" function in SPSS and added the "NMISS(Variable) < 1" formula in the "If condition is satisfied" option to exclude the remaining cases with missing values across all required variables. Performing this function resulted in excluding 47 cases from the statistical analyses.

In preparation for the inferential analyses, I scored the ARMR and the BPNSS independent variables. Various items in the BPNSS needed to be reverse scored. As such, I recoded those items into new variables and changed their values accordingly. To make the 12 states of disease progression items amenable for data analysis, I totaled each participant's number of negative symptoms into a single continuous control variable. Finally, I combined the yes, no, and undecided responses for the participants' decisions for tracheostomies and PEGs into two single dichotomized variables, plan or have tracheostomy (yes/no) and plan or have PEG (yes/no).

After all of the data were cleaned and prepared, I performed descriptive analyses, including the frequencies, percentages, measures of central tendency (mean, median, and mode), and measures of dispersion for all relevant data points. I performed four binary logistic regression tests to examine the relationships between people with ALS' scores on

the ARMR, BPNSS, and their decisions for tracheostomies and PEGs (i.e., yes and no responses), controlling for age, gender, military veteran status, and their state of progression (i.e., negative symptoms).

Threats to Validity

In quantitative research, validity refers to the extent to which an instrument accurately measures a phenomenon and is generalizable across contexts (Patino & Ferreira, 2018). Two types of validity concerned the present study, external and internal validity. External validity reflects the generalizability of the findings across other contexts, and internal validity refers to the extent to which the results are truthful to the sampled population (Patino & Ferreira, 2018).

External Validity

Given that the present study adhered to a cross-sectional design, the most likely threats to external validity included testing reactivity (Mitchum et al., 2016) and the specificity of the variables (Haynes & O'Brien, 2000). Regarding testing reactivity, commonly referred to as the Hawthorne Effect (Paradis & Sutkin, 2017), I expected that some participants would inflate or deflate their answers due to knowing someone would be evaluating their responses. To mitigate the testing reactivity threat, I reassured the participants in the informed consent that their answers were confidential and encouraged them to answer as truthfully as possible. The specificity of the variables refers to the extent to which the researcher operationalizes and defines the variables (Burkholder et al., 2016; Haynes & O'Brien, 2000). I asked yes and no questions to collect the data because I could not find validated instruments that measured decision-making for life-

sustaining treatments. In doing so, I clearly distinguished the independent variables from the dependent variables and defined the variables accordingly.

Internal Validity

Internal validity refers to the extent to which the findings measure what the researcher intends and are truthful to the measured population (Patino & Ferreira, 2018). I did not adapt the instruments for this study, thereby maintaining their validity and reliability. This study was also not susceptible to threats of history, maturation, attrition, or repeated exposure to the instruments because I only sampled the participants' attitudes once at a single point in time. To some extent, however, some of the participants could have experienced testing fatigue.

Selection bias is another common threat to internal validity. According to Sarstedt et al. (2018), while researchers should attempt to select from a sampling frame that resembles the overall population as much as possible, it is impossible to know for certain if sampling bias inadvertently occurs because we cannot know everything about a population. Such is the case with the ALS population; indeed, while the ALS Registry has attempted to know as much as possible about the ALS population as a whole, it is likely that there are missing cases, particularly for minorities and low-income people with ALS (Kaye et al., 2017). However, despite its potential limitations, the ALS Registry likely maintains the most current and accurate prevalence data on people with ALS in the world (Mehta et al., 2018). For that reason, I randomly selected from the ALS Registry's sampling frame to minimize selection bias. Moreover, recruiting from the ALS Registry's

sampling frame enabled me to randomly select the sample, which significantly enhanced the study's rigor and generalizability.

Issues of Trustworthiness

Trustworthiness for qualitative research entails four principles, namely credibility, transferability, dependability, and confirmability (Amankwaa, 2016; Korstjens & Moser, 2018; Lincoln & Guba, 1985; Ravitch & Carl, 2016; Shenton, 2004). Credibility refers to the extent to which the findings reflect the participants' realities and experiences (Amankwaa, 2106). Transferability is the degree to which the findings relate to other contexts (Amankwaa, 2106). Dependability is the consistency by which the researcher's findings reflect the data (Amankwaa, 2106). Confirmability is the extent to which the findings reflect the participants' views and experiences rather than the researcher's bias (Amankwaa, 2106).

My plan for mitigating and assessing for the threats against trustworthiness involved strategies for each criterion. I planned to minimize the credibility threats by randomly sampling the participants, being transparent about my role with the participants, and having peers review the findings and provide critical feedback (Amankwaa, 2016; Shenton, 2004). To mitigate the transferability threats, I planned to write thick descriptions of the phenomenon and the setting in which the participants responded (Amankwaa, 2016; Shenton, 2004). Concerning dependability, I planned to triangulate qualitative and quantitative research methods and describe the methodology in sufficient detail that other researchers could replicate the study (Shenton, 2004). Finally, to minimize the confirmability threats, I planned to triangulate research methods and use

concept maps to confirm the audit trail (Shenton, 2004). Given the anonymous nature of my data collection methods, I did not conduct member checks or cultural immersion procedures.

Ethical Procedures

Randomly selecting the participants enabled me to make inferences and predictions about the relationships between the variables. Hence, it was critical to gain access to a robust sampling frame in an ethical manner. After I obtained conditional approval from the IRB, I applied with the ALS Registry to access their sampling frame. Once I negotiated a researcher agreement with ALS Registry to randomly select and notify the sample, I applied for final approval with the IRB. After the IRB granted the final approval, the ALS Registry emailed the recruitment letter to the sample and invited them to complete the survey. The recruitment letter (see Appendix E) contained a link to the survey, the study's implications, the Crisis Text Line's contact information, and an email address at which they could contact me with questions. After clicking on the survey link, the participants were immediately taken to the informed consent. The informed consent included information about my role as the researcher, background about the study, the procedures, voluntary nature, risks and benefits, payment, and privacy surrounding their participation. The participants were not permitted to proceed with the survey until they acknowledged that they were informed and agreed to participate.

Mainly due to the sampling strategy, I did not involve my place of employment in this study. I did not have any conflicts of interest or power differentials, and, to maintain anonymity, I did not provide any incentives or compensation to the participants. Instead,

in the recruitment letter, I invited the participants to email me to request a copy of the study's results as a token of appreciation.

Treatment of Human Subjects

While the IRB did not require additional approvals and determined that I did not target people with ALS as a vulnerable population, some participants might have had limitations in their ability to voice concerns and advocate for themselves. My positionality as a researcher with ALS may have acted as a buffer to minimize harm because I have personal experiences with the vulnerabilities and challenges that many people with ALS face. On the other hand, I also needed to establish boundaries to maintain objectivity in collecting and analyzing the data. To address this concern, I recused myself from having direct contact with the participants during the data collection process by using an online survey rather than having direct contact with the participants. As a result, I had little to no contact with the participants while the data were collected. However, a handful of participants contacted me with questions using the email address provided on the recruitment letter.

Another ethical consideration for this study concerned the participants' rights to refuse to complete the survey (Hammer, 2017). Because the participants completed the survey electronically, I communicated in the recruitment letter and informed consent that the participants had the right not to answer any or all of the questions. This aspect of the study's ethics was particularly salient because many of the participants had speech or other communication limitations that could have made it difficult for them to refuse or communicate discomfort as they responded to the items on the instruments. In the survey

instructions, I encouraged the participants to use communication strategies, such as mouthing communication, blinking, head nodding, head shaking, and high-tech augmentative and alternative communication devices. Finally, the informed consent and instructions displayed the contact information for a nationwide crisis text line to address any emotional or mental health problems resulting from their participation.

Another ethical consideration related to the electronic nature of the participants' involvement was not having face-to-face contact with the participants to refer them to clinical services. Because the study asked the participants to respond to items related to decision-making for life-sustaining treatments, some participants could have experienced adverse emotional and mental health problems during and after completing the survey. To mitigate the participants' adverse reactions resulting from their participation and to ensure they understood the risks and rights with their involvement, I included a clear description of the study's instruments and the nature of the questions in the informed consent.

Treatment of the Data

Researchers must assure participants that their responses and private information are safeguarded, protected, and properly maintained and discarded. I did not collect any personally identifiable information. However, I am nonetheless responsible for maintaining and discarding the study's raw data within 5 years of collecting the data (Creswell & Creswell, 2018). Consequently, I stored the data on an encrypted hard drive and, as stated in the agreement with the ALS Registry, will share the data with the ALS Registry, as necessary. With the accompanying confidentiality agreements, I shared the

raw non-identifiable data with two colleagues for peer debriefing and, as needed, with my dissertation committee for transparency and feedback. In addition to protecting the participants' personal and identifiable information, researchers must also be fully transparent in their procedures, data collection methods, data analysis, and findings (Hammer, 2017). In that regard, I was accountable to the university, the participants, and my colleagues for being truthful and transparent in the methods and disseminating the findings with sufficient detail that other researchers could judge the study's quality, rigor, and scholarship (Creswell & Creswell, 2018; Hammer, 2017).

Summary

In this chapter, I described how the settings in which the participants responded could have affected the results. I outlined the research design and my rationale for it. I discussed my role as the researcher, including how my personal, interpersonal, and social contexts influenced my biases and interpretations of the findings. I also discussed the methodology, including how I selected the participants, the quantitative and qualitative instruments I used, the procedures I followed to recruit and collect the data, and my data analysis plan. I clarified the threats to validity and my strategies for maintaining trustworthiness. Finally, I discussed the ethical procedures and how I treated the participants and the data.

In the next chapter, I review the research purpose and questions and discuss aspects of the research setting that could have influenced the data and my interpretations. I also discuss the participants' demographics, data collection procedures, and how I

analyzed the data. Finally, I report the qualitative and quantitative findings and examine the trustworthiness of the results.

Chapter 4: Results

The purpose of this study was to examine how people with ALS' socioecological resilience and self-determination are related to decision-making for life-sustaining treatments. I carried out this study to initiate a scholarly discussion about how social workers and multidisciplinary teams can improve the interactions they have with, and the interventions they implement for, people with ALS surrounding decision-making for life-sustaining treatments. I posed one qualitative and two quantitative RQs:

RQ1- Qualitative: How do socioecological resilience and self-determination contribute to people with ALS' decision-making for life-sustaining treatments?

RQ2- Quantitative: What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments?

$H_0$2: There is no relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

$H_1$2: There is a positive relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

RQ3- Quantitative: What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments?

$H_0$3: There is no relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

$H_1$3: There is a positive relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

In this chapter, I review how the research setting and the conditions in which the participants responded could have affected the results. I discuss the participants' demographics, the procedures that I implemented during data collection and analysis, and the qualitative and quantitative findings. Finally, I discuss the strategies that I applied to maintain the trustworthiness of the qualitative data.

Research Setting

I employed an online survey data collection method for several reasons. It would have been counter-productive to conduct face-to-face interviews because many people with ALS require adaptive ways to communicate and might have found it difficult to communicate in a face-to-face environment. Consequently, the online survey format enabled the participants to complete the survey in adaptive and inclusive settings flexible to their unique needs. The internet survey also accommodated participants' physical limitations and afforded them the opportunity to take breaks, which may have empowered them to respond fully. Additionally, administering an online survey permitted me to collect the data anonymously while simultaneously mitigating researcher bias.

Table 1 shows the descriptive statistics (i.e., frequencies and percentages) according to the setting and conditions in which the participants responded to the survey. The participants selected one or more items, indicating if they were in a wheelchair or a bed; were using a high tech augmentative speech or eye gaze device, smartphone, or computer; were residing in a family home or a nursing home; and if they needed caregiver assistance to complete the survey.

Table 1

*Participant Settings and Conditions (*N = *197)*

Setting of survey	Frequency	Percent
Setting		
Wheelchair	56	28.4
In bed	10	5.1
Home residence	135	68.5
Nursing home	2	1.0
Condition		
Assistive speech or eye gaze device	26	13.2
Smartphone	49	24.9
Computer	115	58.4
Needed caregiver assistance	14	7.1

Demographics

The mean, median, and mode ages of the participants were 62.47, 64, and 60, respectively (*SD* = 9.74). Table 2 shows the descriptive statistics of the other primary demographic variables used for the quantitative statistical analysis. The age, ethnicity, and gender demographics for the participants followed similar trends of previous studies. As with studies done by Bryan et al. (2016), Kaye et al. (2017), and Mehta et al. (2018), the most prevalent demographic was composed of White men between 55 and 75 years of age; racial minorities (Black or African American, Hispanic or Latino, and Asian or Asian Americans) cumulatively made up 4% of the participants. Just over half of the sample had incomes below $100,000, and the mode income bracket (*n* = 61) was between $100,000 and $149,999. While only one of the participants indicated that they had filed for bankruptcy because of financial constraints related to ALS, 86 (43.7%) participants strongly agreed (on a 5-point Likert scale ranging from *strongly disagree* to *strongly*

agree) that their financial stability had been compromised since being diagnosed with ALS.

Table 2

*Descriptive Statistics of Demographic Variables (*N = *197)*

Variable	Frequency	Percent
Gender		
Female	88	44.7
Male	109	55.3
Ethnicity		
White or Caucasian	189	95.9
Black or African American	4	2.0
Hispanic or Latino	2	1.0
Asian or Asian American	2	1.0
Marital status		
Married, or marriage-like relationship	161	81.7
Single, never married	12	6.1
Widowed	5	2.5
Separated	1	0.5
Divorced	18	9.1
Annual family income		
Less than $34,999	25	12.7
$35,000-$49,999	18	9.1
$50,000-$74,999	29	14.7
$75,000-$99,999	30	15.2
$100,000-$149,999	61	31.0
$150,000-$199,999	21	10.7
$200,000-$499,999	8	4.1
$500,000-$1,000,000	5	2.5

Most (79.2%) of the participants had at least one child; 20.2% had none. The majority of participants with children had between one and three (n = 127, 64.5%) with the mode being two (n = 68, 34.5%). The year in which the participants were diagnosed ranged between the years 2001 (n = 1) and 2020 (n = 16), the mode being 2019 (n = 55). Twenty-eight participants indicated that they were military veterans. Whereas most participants indicated that they had a Medicare insurance plan (n = 144, 73.1%), 107

(54.3%) stated that they had private insurance. Sixty-eight participants (34.5%) indicated that they had both Medicare and private insurance plans. Three of the 28 veterans (10.7%) did not indicate that they were cared for by VA or Tricare, which shows a potential gap in care and service connection benefits to which the veteran participants were entitled. Eleven (5.6%) of the participants were Medicaid recipients, and another 22 (11.2%) stated they had other or no insurance. Finally, while 182 (92.4%) of the participants indicated that they knew what an advance directive was, only 126 (64.4%) had completed one.

The participants were asked to identify their progression status by selecting all of the applicable options. Table 3 shows the frequencies and percentages of the participants' status of progression. The data showed a wide range of disease progression (i.e., negative symptoms) and abilities.

Table 3

*Status of Progression (*N = *197)*

Variable	Frequency	Percent
Walk on own power	113	57.4
Wheelchair for mobility	88	44.7
Uses hands for tasks and self-care	116	58.9
Breathes without ventilator support	158	80.2
Ventilator support while sleeping	81	41.1
Ventilator support during day	28	14.2
Speaks with natural voice	152	77.2
Speech device to speak	40	20.3
Uses eye gaze	26	13.2
Can eat by mouth	171	86.8
Feeding tube	41	20.8
Caregiver for all ADLs	53	26.9

Note. Ventilator support represents using either invasive or noninvasive machines.

Data Collection

I obtained IRB approval before collecting and analyzing the data. I collected the quantitative and qualitative data concurrently using an anonymous internet survey from a single population. I collected the data during the novel coronavirus (COVID-19) pandemic; employing the online survey enabled me to collect the data as described in the proposal. The ALS Registry randomly sampled 11,961 people with ALS from their sampling frame, which, according to the ALS Registry, consisted of approximately 16,583 people with ALS who were self-registered in the ALS Registry (see Mehta et al., 2018). However, an unknown number of the sample were deceased when the ALS Registry emailed the recruitment letter. The sample had access to the survey for 31 calendar days. A total of 277 participants clicked the link to initiate the survey, and 244 reached the end of the survey and submitted responses, resulting in an 88% completion rate. The participants averaged 23 minutes to complete the survey; however, some participants took breaks and submitted their responses several days after beginning. Among the 244 study respondents who submitted the survey, 47 surveys were incomplete; consequently, 197 cases were viable for data analysis.

All data were automatically recorded and maintained in my password protected SurveyMonkey account. Every 3-5 days, I imported the data into password-protected SPSS and NVivo project files, which were electronically located on an external hard drive. For compatibility purposes, I exported the qualitative data into Microsoft Excel files and imported them into NVivo.

Data Analysis

Qualitative Coding Process

I maintained a memo in NVivo, which served as an audit trail to account for my actions and observations (see Amankwaa, 2016). I carried out three recursive manual coding sequences, all of which used NVivo to perform content analysis and calculate code and comment frequencies. The first of the manual coding sequences was deductive. I used the 12 qualitative items that the participants answered as themes to maintain continuity across the participants' responses and ensure that the findings answered the qualitative RQ and aligned with the study's conceptual framework (see Saldaña, 2016). The second coding sequence was deductive and inductive and involved constructing concept maps for each theme, enabling me to seamlessly visualize, mouse click, and organize the codes and categories in systematic and analytical ways (see Kinchin et al., 2010). To keep the respondents' answers conjoined to the 12 qualitative items and the codes and categories that I established, I did not analyze the codes and categories across the 12 themes during the first two coding sequences.

During the third coding sequence, which was independent of the previous sequences, I compared and contrasted the codes and categories across the 12 qualitative items for commonalities, patterns, and broader themes. This process was inductive and involved calculating the number of comments and codes that applied to each theme. By performing the third coding sequence independently from the first two sequences, I established two sets of findings. One set of findings branched from the 12 qualitative items that the participants answered (this involved both deductive and inductive analysis),

and the second set of findings involved comparing and contrasting the concept maps' codes inductively to develop transcendent themes.

Results

In this section, I present the findings in order of the RQs. I answer the qualitative RQ in two ways: first, I answer according to the content analysis of the codes and categories that I derived from the 12 open-ended items to which the participants responded in the survey; and second, I present the results from the inductive thematic content analysis across the codes and categories. I include the concept map visualizations in this section because they were central components for conceptualizing the results. Next, I answer the quantitative RQs by reporting the findings from the binary logistic regression tests.

Qualitative Content Analysis Findings

The first RQ was: How do socioecological resilience and self-determination contribute to people with ALS' decision-making for life-sustaining treatments? To answer this RQ, I asked the participants to respond to 8 of 12 possible structured open-ended questions, depending on their status of having or not having life-sustaining treatments when completing the survey. Each study participant responded to 2 of 4 qualitative tracheostomy questions (1-4) and 2 of 4 qualitative feeding tube questions (5-8); there were 4 qualitative questions common to all respondents (9-12). The qualitative survey items were:

1. What are your thoughts about having a tracheostomy?
2. What motivated you to get a tracheostomy?

3. What are your thoughts about getting a tracheostomy?
4. What would motivate or prevent you from getting a tracheostomy?
5. What are your thoughts about having a feeding tube?
6. What motivated you to get a feeding tube?
7. What are your thoughts about getting a feeding tube?
8. What would motivate or prevent you from getting a feeding tube?
9. What resources do you have that give you strength?
10. What are the greatest challenges that you now face or that you think you will face since being diagnosed with ALS?
11. How has your ability to withstand and bounce back from trials changed since being diagnosed with ALS?
12. In what ways do your caregivers and loved ones impact your ability to live with ALS?

The results contained in the following sections include the participants' comments verbatim from the data. As such, the grammar and spelling have not been corrected.

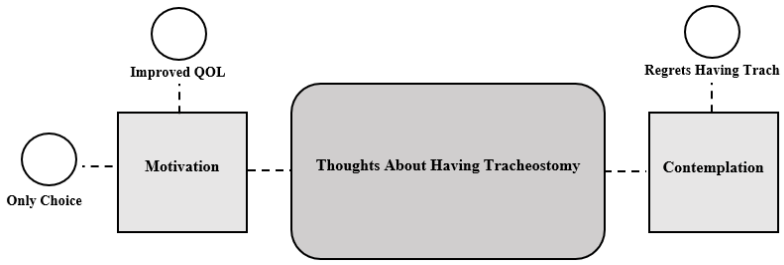
Content Analysis for Qualitative Item 1

Three participants responded to the first qualitative item, which asked the participants who had a tracheostomy to share their thoughts about having one. While the number of answers to this item was limited, I observed two categories (see Figure 1). I named the first category, motivation, to which I assigned the codes improved QOL and only choice. Concerning the improved QOL code, the participant stated, "I can talk," which I interpreted to mean that getting a tracheostomy had helped them to maintain their

ability to speak. Another participant said, “For me, it was the only decision. I have children,” which was the rationale for the second code named, only choice. I called the second category, contemplation, to which I assigned the code, regrets having trach, because the participant stated, “I sometimes regret my decision, especially since my other abilities have deteriorated.”

Figure 1

Concept Map of Qualitative Item 1



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

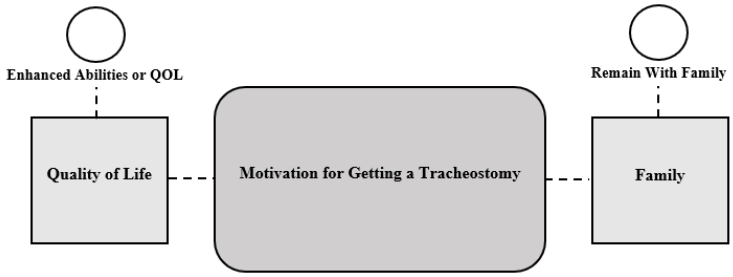
Content Analysis for Qualitative Item 2

As with the first item, 3 participants responded to the second item, which asked the participants with a tracheostomy to discuss what motivated them to get one. I assigned 3 comments across 2 categories, including quality of life and family (see Figure 2). I assigned one comment to the code enhanced abilities or QOL because a respondent stated, “to talk.” I assigned 2 comments to the code named remain with family, which I linked to the family category. The comments for those codes were “wanted to spend more time with family” and “I have 3 children. Before I was given a correct diagnosis, I had 2

of them while having bulbar onset ALS and exhibiting symptoms. I need to be here for them."

Figure 2

Concept Map of Qualitative Item 2



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Content Analysis for Qualitative Item 3

The third item asked those who did not have a tracheostomy to share what they thought about getting one. I assigned 269 comments across 5 categories and 28 codes. Table 4 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 3 displays how the categories and codes are linked.

Table 4

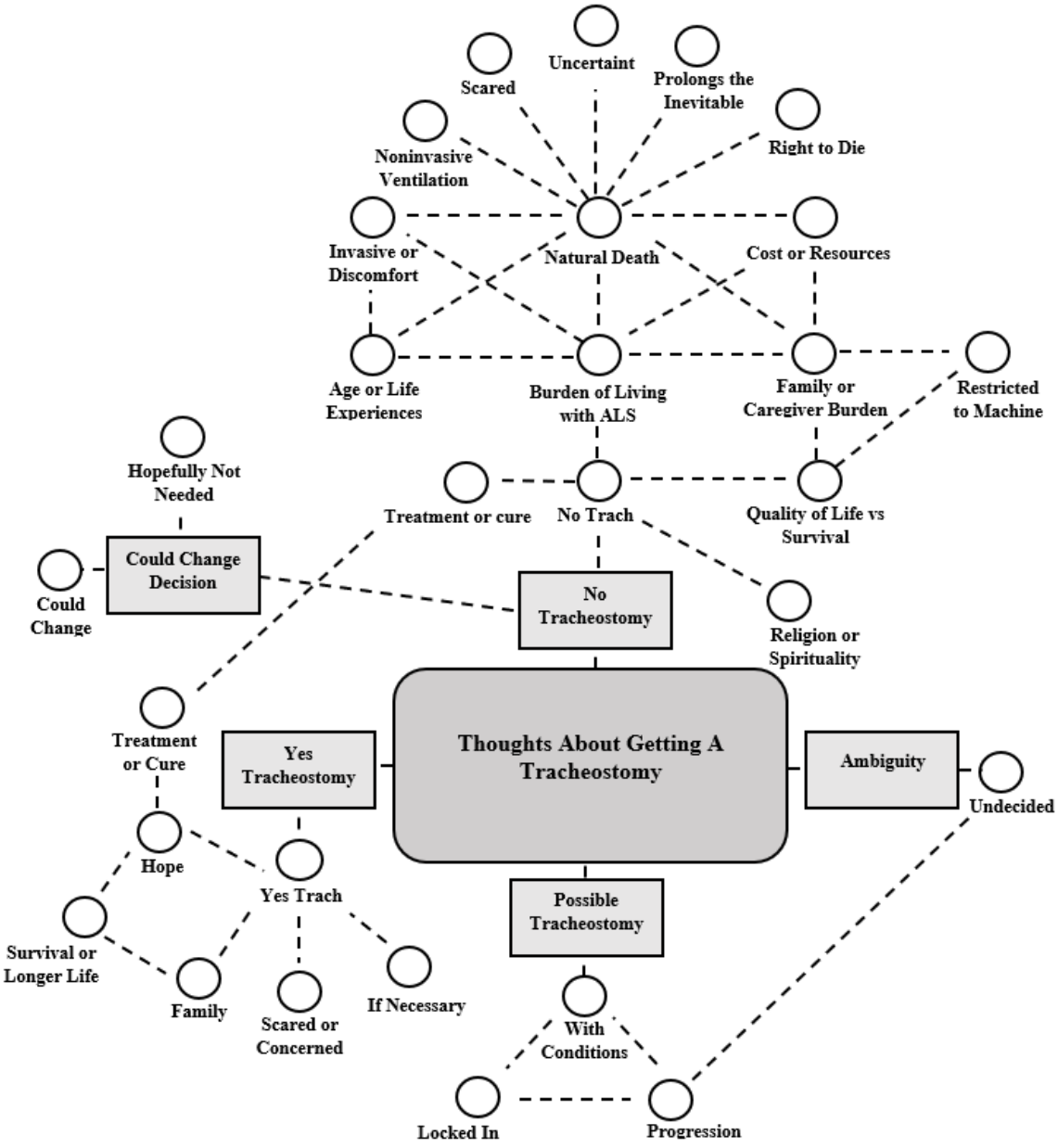
Categories and Codes for Item 3

Category	Codes
No tracheostomy (167 comments)	Age or life experiences, burden of living with ALS, cost or resources, family or caregiver burden, invasive or discomfort, natural death, treatment or cure, noninvasive ventilation, no trach, prolongs the inevitable, quality of life vs survival, religion or spirituality, restricted to machine, right to die, scared, uncertainty.
Could change decision (11 comments)	Could change, hopefully not needed.
Yes tracheostomy (40 comments)	Treatment or cure, family, hope, if necessary, survival or longer life, scared or concerned.
Possible tracheostomy (35 comments)	Locked in, progression, with conditions.
Ambiguity (16 comments)	Undecided.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 3

Concept Map of Qualitative Item 3



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for No Tracheostomy and Could Change Categories.

Table 5 shows the content analysis results for the 178 comments that I assigned across 18 codes.

Table 5

Codes and Comments for No Tracheostomy and Could Change Decision Categories

Code	Sample of participant responses
Age or life experiences (7 comments)	"I have had a great life." "Having no spouse or dependent children, I think at the point I would need a tracheostomy I would be at a point where I would no longer to be contributing and become a total consumer with an extremely limited future. I think at this point it would be time to go to hospice." "I've seen too many that regret doing this." "I am an older person and have had a full life. When my quality of life declines that far I do not wish to burden my family with the extra care required to have a trach." "Not interested in prolonging life due to my age."
Burden of living with ALS (14 comments)	"Don't want to be dependent on someone else for ventilator management, suctioning, etc." "Requires too much support." "May add way too many years of dependency to your life." "Right now I feel like I would be miserable and my family would be miserable taking care of me." "I don not wish to experience any hell-on-earth scenarios." "The amount of care necessary does not make it a good choice for me."
Cost or resources (7 comments)	"In my location 24 day treak caregivers are not reliable." "I would like to get a tracheostomy but the cost of care afterwards is too high!" "Without any insurance coverage for care." "The cost and difficulties in providing 24/7 care to me make it undesirable." "I would consider it but I don't have the home support to care for me."

Could change decision (9 comments)	“Being "alive" is not the same thing as "living." That sounds trite, I realize, but, it's my belief, at this time...that may change when I can't breathe!”
	“It’s not a quality of life I want to experience. However, when the day comes that I actually have to make that decision, I may change my mind.”
	“At this time I have no breathing issues. If that changes I may consider a tracheostomy.”
	“I might consider it when it becomes necessary depending on my health status at the time and my quality of life after getting it.”
	“I'm not at the point where i need one. When i get to that point I may change my mind.”
Family or caregiver burden (22 comments)	“The amount of time involved in maintaining it safely would be too much for my caregivers.”
	“My understanding is a tracheostomy would require 24 hour care. I do not want to put this burden on my family.”
	“I'm certainly not against folks who have adequate support getting tracheostomies. My wife would not be prepared to support me at that level, so I would not burden her with the additional care.”
	“Right now I feel like I would be miserable and my family would be miserable taking care of me.”
Hopefully not needed (2 comments)	“Hopefully will not need.”
	“Hope I won't need one.”
Invasive or discomfort (17 comments)	“Do not want a trach. I feel its too invasive for my way of life.”
	“Waste of time. Makes agony only last longer.”
	"I don’t want to extend my life if I am always in pain or extremely crippled.
	“Too restrictive and not needed if in frozen state.”
	“Suffering enough.”
Natural death (12 comments)	“I can’t do it. I want to go out naturally.”
	“I don't want to extend my life by the use of artificial devices.”
	“By the time it will be needed I will be ready to leave.”
	“At that point I would consider myself near dead. And would consider death the better option.”
Noninvasive ventilation (2 comments)	“I will use trilogy; have decided not to have invasive trac to extend the last years of living with this disease.”
	“Convinced by the pulmunologist that noninvasive vpap machine is just as effective but less demanding for the caregiver.”

No trach (28 comments)	“Don’t want a trach.” “No Chance.” “I don’t want one.” “DON'T WANT ONE.” “No.” “No heroic measures.”
Prolongs the inevitable (4 comments)	“Don't want add time to my life.” “Do not wish to prolong life with Als.” “I feel that if it's necessary, it's the end anyway.” “Do not want to prolong life.”
Quality of life vs survival (27 comments)	“Do not want to live my life like that.” “I prefer quality of life, I.e., ability to have free dome of movement and do all I can for as long as I can, over longevity.” “No quality of life and too much maintenance.” “I have decided not to get a tracheostomy should it become needed. I believe it would put too much burden on those caring for me and would decrease my quality of life to an unacceptable level.” “Do not agree that it provides a good quality of life.”
Religion or spirituality (3 comments)	“Not God's will.” “Not needed, heaven is waiting.” “Pray God will take me home before that is a question.”
Restricted to machine (12 comments)	“I feel that at my current age of 64, and still being in relatively good condition, I do not see myself being hooked up to a breathing machine to extend my life further. I also understand that approximately 95% of ALS patients choose the same.” “Don’t want a machine to keep me alive.” “Once on a ventilator, it is difficult to discontinue use and I wouldn't want prolonged time on an invasive ventilator.” “I don't want to be connected to a machine to sustain my life. Especially if I'm not able to do anything.”
Right to die (5 comments)	“I will use the right to die before getting it.” “I will not get a trach. It is stated in my living will and my family is aware of my wishes.” “I plan to get hospiced or go to Vermont for a mercy killing instead.” “I’ve no intention of getting one. I specify it in my living will.” “Specified in my DNR.”

Scared (2 comments)	"Scarry." "I'm claustrophobic. I want the disease to run it's course."
Treatment or cure (3 comments)	"As related to the use with ALS, with the current no cure possibility, in evaluating my personal deterioration rate, I don't at this time want to prolong my life in that state." "No need to prolong if no cure." "I don't want to prolong my life because I have no hope of returning to my pre-als functioning."
Uncertainty (2 comments)	"Uncertainty on extra work for caregiver vs quality of life and life extended by unknown amount of time." "I just don't know what to expect in the future."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Yes Tracheostomy Category. Table 6 shows the content analysis results for the 40 comments that I assigned across 6 codes.

Table 6

Codes and Comments for Yes Tracheostomy Category

Code	Sample of participant responses
Family (5 comments)	"I feel that this will allow me to live longer and be with my family." "I'll do anything to have more time with my family." "While nervous about getting a trach and the burden it will place on my family, I have a strong desire to live and see my sons's lives unfold." "It's a way to prolong my life. It will give me more time with family."
If necessary (9 comments)	"If necessary to breath and survive I will get one." "If I need it I will get one. I'm not to thrilled about it. As a respiratory therapist I know what is involved." "Great tool when needed." "Only if required." "IF REQUIRED IN FUTURE, I AM OKAY WITH THAT... MY ALS IS IN LOWER REGION (LEGS)."

	"Would get one if suggested by MD and if I feel comfortable at the time needed."
Scared or concerned (9 comments)	"I have concerns with additional workload for my caretaker (wife)." "It's life prolonging but another scary step in the ALS process." "Scared and I don't know when is the right time. I'm hoping that my Neurologist will start these conversations with me 4-6 months in advance. This should not be a last minute conversation." "Scared, hopefully will not have to but willing to depending on how long it would extend life." "It's scary but I want to live!"
Survival or longer life (12 comments)	"I feel that this will allow me to live longer and be with my family." "I'm trying to attempt to live as long as possible. If this helps me do that, then let's do it." "If necessary to breath and survive I will get one." "Life > death I understand life can and will get really hard, but I believe living is better than dying." "I want to live! Whatever I have to do to live, no matter how difficult, I will do it."
Treatment or cure (2 comments)	"If there is no cure or life-sustaining treatment on the horizon at the point in time." "The cure for ALS is certain and will come soon. I want to live to see my grand children be what they want to be."
Yes trach (3 comments)	"Hope it will help." "It's not so bad." "I was just diagnosed and have no insurmountable problems. I am generally in favor of what're I may need down the road. But they should be a "not sure" answer."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Possible and Ambiguity Categories. Table 7 shows the content analysis results for the 51 comments that I assigned across 4 codes.

Table 7

Codes and Comments for Possible and Ambiguity Categories

Code	Sample of participant responses
Locked in (3 comments)	"If I'm trapped in or soon to be trapped in a body I can't control, I don't want to prolong my life. To me that is not quality but merely quantity." "Not being able to talk or eat is not how I want to live." "getting locked in."
Progression (11 comments)	"I don't know if I will get one or not. My als is bulbar, meaning my voice and ability to swallow are the first things to go. If I am still healthy enough then yes I may get one but that decision still has to be made." "My respiratory function is still normal. I will consider a tracheostomy when and if it becomes needed." "I might consider it when it becomes necessary depending on my health status at the time and my quality of life after getting it." "If I cannot talk, my life is over." "As long as I am basically healthy otherwise and able to communicate in some way with loved ones, I am unwilling to just give up and die."
Undecided (16 comments)	"Have not decided yet." "I am unsure, whether I will agree to a trach." "Don't know." "I haven't thought about it." "Somewhat on the fence." "I don't know if I will get one or not."

With conditions (21 comments)	"Only in emergency." "If there is no cure or life-sustaining treatment on the horizon at the point in time that I need to make the tracheostomy decision, I believe I will *not* do it." "If I am still healthy enough then yes I may get one but that decision still has to be made." "If I was still a viable person, I might get one. If not, I would rather not." "If I can still move my arms when the time comes, I would get a tracheostomy." "I feel I can still contribute and make the world a better place, so I would try it. I would discontinue if I was too much of a burden on family or if quality of life not good." "Do not want to have one unless I am mobile and be a contributing member of society." "I would consider it but I don't have the home support to care for me."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 4

The fourth item asked those who did not have a tracheostomy to share what would motivate or prevent them from getting one. I assigned 259 comments and organized them into 5 categories and 34 codes. Table 8 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 4 displays how the categories and codes are linked.

Table 8

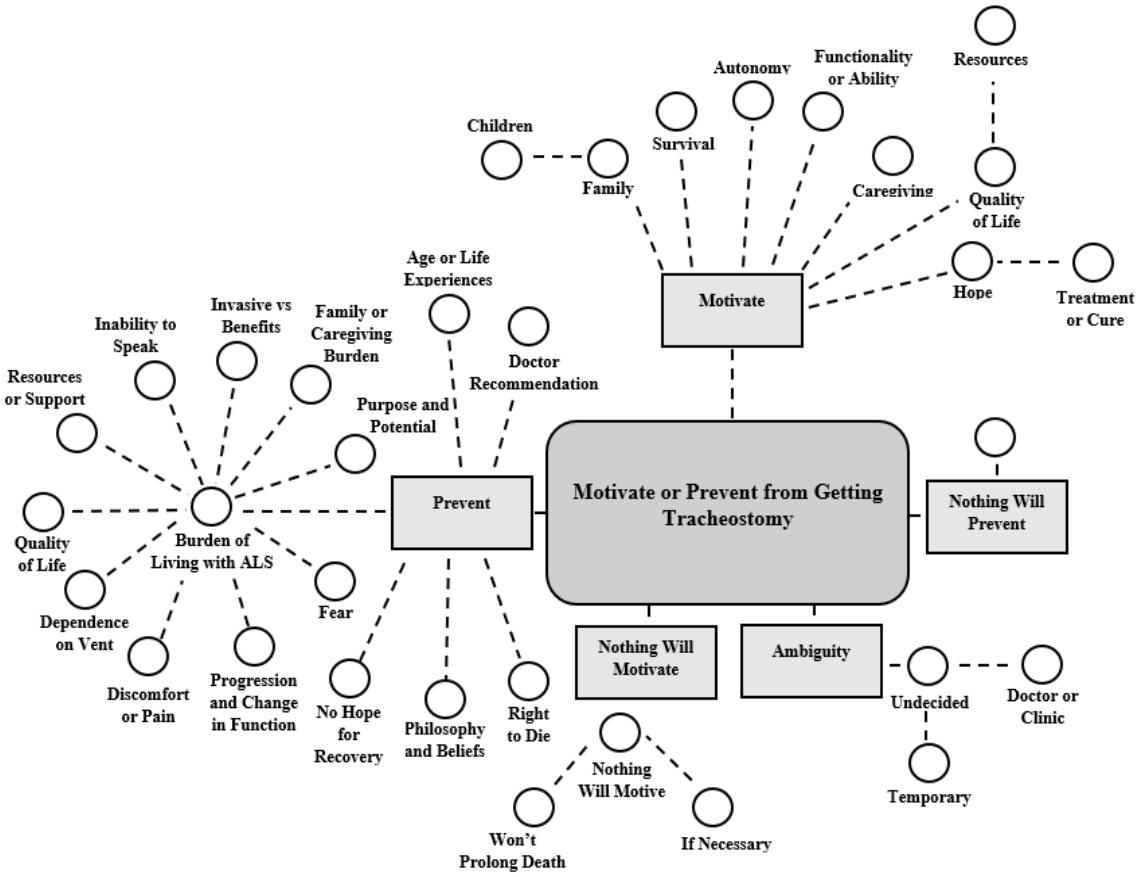
Categories and Codes for Item 4

Category	Codes
Prevent (134 comments)	Age or life experiences, burden of living with ALS, dependence on vent or others, discomfort or pain, doctor recommendation, family or caregiver burden, fear, inability to speak, invasive vs benefit, legal right to die, no hope for recovery, philosophy or beliefs, progression and change in functioning, purpose and potential, quality of life, resources or support.
Nothing will motivate (37 comments)	Caregiver or family burden, nothing will motivate, won't prolong death.
Motivate (68 comments)	Autonomy, caregiving, children, family, functionality or ability, hope, need, quality of life, resources, survival, treatment or cure.
Nothing will prevent (3 comments)	Nothing will prevent.
Ambiguity (17 comments)	Doctor or clinic, temporary, undecided.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 4

Concept Map of Qualitative Item 4



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Prevent Category. Table 9 shows the content analysis results for the 134 comments that I assigned across 16 codes.

Table 9

Codes and Comments for Prevent Category

Code	Sample of participant responses
Age or life experiences (6 comments)	"I am not waiting for a specific life event before dieing... I have had a great life." "If my wife was no longer living, I would not get a trach." "I work in health care. Know what is like and the complication that are associated." "I have lived an incredibly active life as a marathoner and producer traveling the world." "My age."
Burden of living with ALS (7 comments)	"If I wanted to be done with all the drugs and my family's ok with my not getting one." "This battle is bad enough as in" "Wanting to be done with this disease would prevent me from getting one." "Restrictions." "The appearance to others."
Dependence on vent or others (7 comments)	"I understand a trach is something that may extend my life, and make it easier to breath. But I have no interest in being dependent on it to keep me alive." "To me is life support that I do not want to rely on." "I just don't see myself being hooked up to a machine 24/7." "24/7 care." "Dependent on others."
Discomfort or pain (7 comments)	"Discomfort." "Extended suffering." "Prolong a life that is going to end. Why make me and others suffer when it can be over quickly." "Unknown comfort level."
Doctor recommendation (1 comment)	"Not much. Only have my doctors felt strongly against it, like there's a high chance I would die during the surgery."

Family or caregiver burden (28 comments)	“In my location 24 day treak caregivers are not reliable.” “Its a burden I don't want top place on wife and family.” “The financial and emotional/physical (day to day) burden it would place on my family.” “At this time nothing would change my mind about a tracheostomy. I use a non-invasive ventilator and do not wish to put any more burden on my caregiver. Also, I am not willing to decrease my quality of life just to add a little more time to my life.”
Fear (7 comments)	“I fear it would leave me stuck at home and essentially alone.” “Fear." “My own fear of having one.” “Fear and wanting to be done with this disease would prevent me from getting one.”
Invasive vs benefit (6 comments)	“Too invasive.” “Don't want to live with a pipe in my throat.” “Limited mobility.” “Unable to survive the op.”
Inability to speak (2 comments)	“Not being able to talk would prevent me.” “Inability to talk.”
Legal right to die (5 comments)	“I have an advanced directive that I do not want a tracheotomy.” “DNR.” “California End of Life Option Act.” “Living will might not let me, not sure.”
No hope for recovery (3 comments)	“If there is no hope of recovery I don't want to get a tracheostomy.”
Philosophy or beliefs (3 comments)	“Also religious belief. I am not opposed to healthcare or medication but at some point I might believe it would be better to be with the Lord in heaven then leaving.” “Lifestyle choice for me.”
Progression and change in functioning (17 comments)	“No tracheostomy: If I could not move any part of my body, nor hold my head up.” “How bad I was physically.” “If condition worsens and to what degree.” “If I was locked in, I would not get a trach.”

	"A mental impairment and/or overall health bad enough that communication and quality of life are miserable."
Purpose and potential (3 comments)	"I don't want to be kept alive just to be "kept alive." "Being out of control." "Lack of meaning."
Quality of life (18 comments)	"Quality of life." "Don't see it as a way to continue with quality of life." "Quality of life would be negatively impacted." "What prevents me from getting a trach is that my quality of life would be deteriorating and I would not wish to endure that life." "I am not willing to decrease my quality of life just to add a little more time to my life."
Resources or support (14 comments)	"Lake of physical support in-house." "Cost." "The cost of care afterwards prevents me from getting one!" "The level of care would be great, although I could afford any associated cost." "Financial burden."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Nothing Will Motivate Category. Table 10 shows the content analysis results for the 37 comments that I assigned across 3 codes.

Table 10

Codes and Comments for Nothing Will Motivate Category

Code	Sample of participant responses
Caregiver or family burden (2 comments)	"Honestly, I don't want to do much to extend life. Its a burden I don't want top place on wife and family." "At this time nothing would change my mind about a tracheostomy. I use a non-invasive ventilator and do not wish to put any more burden on my caregiver."
Nothing will motivate	"Not interested." "Nothing would motivate me to get one."

(26 comments)	"Nothing." "Life is not worth living if I cannot breath on my own." "Nothing will change my mind."
Won't prolong death (9 comments)	"I understand a trach is something that may extend my life, and make it easier to breath. But I have no interest in being dependent on it to keep me alive." "Not worth prolonging life." "Why prolong the disease?"

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Motivate Category. Table 11 shows the content analysis results for the 68 comments that I assigned across 10 codes.

Table 11

Codes and Comments for Motivate Category

Code	Sample of participant responses
Autonomy (3 comments)	"Ability to feel I have significant control over my own life." "I know in Japan they do tracheostomy at an early stage of disease progression. I would research that if I was to consider tracheostomy." "If I feel as though it would help me."
Caregiving (5 comments)	"I would consider it if it didn't require constant monitoring and caregivers." "Additional care from someone else." "To have healthcare coverage to provide daily care required."
Children (5 comments)	"2 sons under 3 years old. I'm motivated." "If I were younger and had small children." "If my son was younger, maybe." "My sons." "Grandkids, I want to see them as long as I can."
Family (7 comments)	"Stay with family and friends longer." "Continuing to be with my family would motivate me."

	"If I were younger and with young family, I would consider getting one." "If my family/caregivers feel comfortable assisting me with it..." "I know that I will be having long discussions with my family and my physician." "My husband might want to change my mind but he understands that I don't want to live in that condition."
Functionality or ability (14 comments)	"If I am functional in other ways, I might agree to a trach." "The only way I would consider it, was if I was still able to breathe on my own and care for it myself." "If my cognitive function was still normal, it would motivate me to get a tracheostomy so that I could continue to have a meaningful life." "Ability to move arms, hold up head with no support." "The ability to communicate will be a major factor in my decision." "If I am still able to function ad be somewhat productive I'll do it." "What would motivate me is if I could still function and live a somewhat good life with it. If other part of my body still worked and I was mentally in a good place, I might reconsider."
Need (4 comments)	"Need would motivate me," "Need."
Quality of life (10 comments)	"Better info on quality of life with tracheostomy and some idea of how long it would extend life." "If my quality of live is still good." "It will depend on my assessment of my quality of life and my assessment of my burden to my family." "I need the following to make life worth living: ability to communicate with others, ability to consume media, ability to feel I have significant control over my own life. If I need a tracheostomy and feel I will continue to have these things, I would consider having it done."
Resources (2 comments)	"Summer weather." "To have healthcare coverage to provide daily care required."
Survival (10 comments)	"Prolong life." "Being alive." "Live longer." "Continuing to be with my family would motivate me."

Treatment or cure (8 comments)	“A near-term cure/life-sustaining treatment would motivate me *to* get a tracheostomy.” "Prolong life until hopefully a cure is found.” “A cure, or at least a therapy that would stop the progression.” “If I could recover from the illness and remove the machine I would do it.”

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants’ responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Nothing Will Prevent Category. There were 3 comments which stated, “n/a” and “no value added.” Because these participants indicated in the demographic question that they wanted a tracheostomy, I interpreted their responses to communicate that nothing would prevent them from getting one. Hence, I assigned them to this category.

Codes and Comments for Ambiguity Category. Table 12 shows the content analysis results for the 17 comments that I assigned across 3 codes.

Table 12

Codes and Comments for Ambiguity Category

Code	Sample of participant responses
Doctor or clinic (1 comment)	"I will rely on the recommendation of my ALS medical team."
Temporary (4 comments)	"Would only consider it if was for temporary mgmt.of an acute, reversible condition." "Would only get one for the time it took me to starve myself to death." "I did think about getting a trach if I came down with COVID, but it isn't something I would once my respiration is bad from ALS." "If an invasive ventilator is projected to be temporary, I might agree to it."
Undecided (12 comments)	"Not sure. Maybe if the end was very close and it would not give me more than a few weeks." "It is difficult to make a decision today because I still breathe well on my own." "Not sure, one day at a time." "DON'T KNOW." "Don't know enough about it."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 5

The fifth item asked those who had a PEG to share their thoughts about having one. I assigned 98 comments and organized them into 4 sentiment categories and 18 codes. Table 13 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 5 displays how the categories and codes are linked.

Table 13

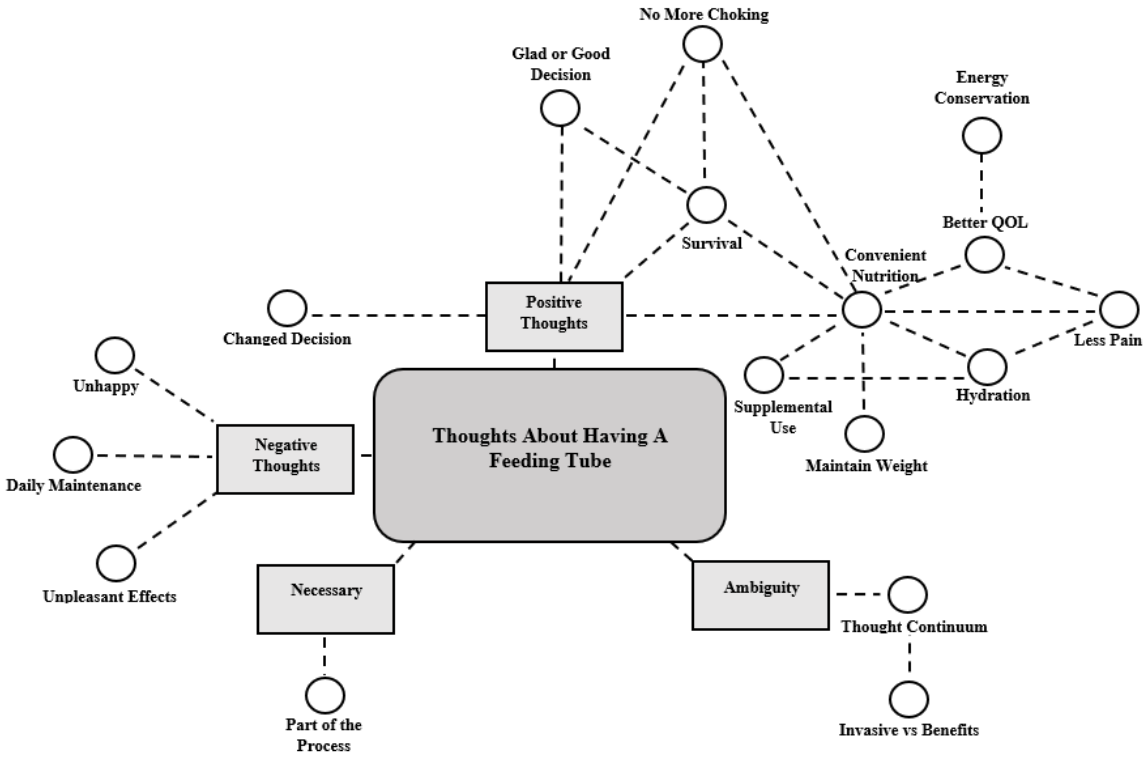
Categories and Codes for Item 5

Category	Codes
Negative thoughts (6 comments)	Daily maintenance, unhappy, unpleasant effects.
Positive thoughts (76 comments)	Changed decision, convenient nutrition, better QOL, energy conservation, less pain, hydration, maintain weight, supplemental use, glad or good decision, no more choking, survival.
Ambiguity (10 comments)	Thought continuum, invasive vs benefits, undecided about use.
Necessary (6 comments)	Part of the process.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 5

Concept Map of Qualitative Item 5



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Negative Thoughts Category. There were 6 negative comments about having a feeding tube. I assigned 2 of the comments to the unhappy code, 2 to the unpleasant effects code, and 2 to the daily maintenance code. The participants that I assigned to the unhappy code stated, “if I had it to do over again, I would NOT get a feeding tube,” and “I don’t like it. I need it mostly for water because it is hard for me to swallow.” For the unpleasant effects code, the participants said, “extended my suffering” and “I don't like it because I end up burping the food up right

after and it tastes nasty." Finally, the comments that reflected negatively about the daily maintenance were "daily maintenance is a hassle," and "it is a lot of maintenance and I have already had it exchanged recently."

Codes and Comments for Positive Thoughts Category. Table 14 shows the content analysis results for the 76 comments that I assigned across 11 codes.

Table 14

Codes and Comments *for Positive Thoughts Category*

Code	Sample of participant responses
Better QOL (12 comments)	"I have had a PEG tube for 2.5 years. It's contributed to better health, better quality of life." "I feel well, manage the feedings on my own and I am definitely healthier with the tube." "It gives me freedom to live a quality life since losing my swallowing ability. I am still very active and it does not interfere with my life at all." "Due to weigh issues early in my diagnosis it became a wise chose to have feeding tube put in. My quality of life has been inhanced because of better nutrition in spite of progression of ALS." "Simple. Much easier than eating. Saves energy. Improves QOL."
Changed decision (1 comment)	"I originally did not want one. However I am glad I got it."
Convenient nutrition (9 comments)	"The feeding tube is a convenient way of getting nutrition and hydration." "The tube is great,when i have trouble swallowing it works. It works for foodor medicine that tastes bad." "I got one early as suggested by my doctor. It allowed me to get use to it and when it became difficult for me to get the calories I needed by normal oral eating." "Makes life so much easier."
Energy conservation (3 comments)	"Much easier than eating. Saves energy." "Able to eat when I'm too tired." "I was able to supplement through my tube shortening it was taking me to eat and not get so tired."

Glad or good decision (14 comments)	“Glad I got one.” “My nuerologist and wife pushed me. I'm glad they did.” “I think it's the best decision I've made. It gives me freedom to live a quality life since losing my swallowing ability. I am still very active and it does not interfere with my life at all.” “If I did not have a feeding tube, I would have choked to death three years ago. Having the tube stopped my weight loss, removed 95% of the anxiety that existed in my daily life. Best decision I made.”
Hydration (2 comments)	“I can not swallow liquids. It helps me stay hydrated and less pain.” “I don’t like it. I need it mostly for water because it is hard for me to swallow.”
Less pain (2 comments)	“Less pain.” “I believe feeding tube will be helpful in latter stages of the disease progression to minimize pain.”
Maintain weight (6 comments)	“It’s a necessary evil. I still have a quality life but eating is now difficult and I’m losing weight too quickly.” “Due to weigh issues early in my diagnosis it became a wise chose to have feeding tube put in. My quality of life has been inhanced because of better nutrition in spite of progression of ALS.” “I was rapidly losing weight.”
No more choking (3 comments)	“Life sustaining. No choking but I miss real food.” “If I did not have a feeding tube, I would have choked to death three years ago.” “I am not choking on medications.”
Supplemental use (14 comments)	“I still eat normally and use the tube to supplement my meals.” “I have only used it during a couple stretches of time when I was recovering from acute illnesses (pneumonia; bacterial lung infection) when my oral imtake was insufficient to meet nutritional needs & maintain weight.” “The tube is great,when i have trouble swallowing it works.” “It allows me to get adequate nutrition when I'm feeling too tired to eat normal food.” “I still have quality of life and decided to supplement nutrition.”

Survival (10 comments)	"My swallowing is so difficult, that I would not survive without one." "I have bulbar onset and cannot eat by mouth, so the feeding tube absolutely saved my life." "Life sustaining. No choking but I miss real food." "It can become necessary in order to sustain life. Unless you like the idea of very slowly dying from starvation and dehydration." "Vital to keep living."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Ambiguity Category. Table 15 shows the content analysis results for the 10 comments that I assigned across 2 codes.

Table 15

Codes and Comments for Ambiguity Category

Code	Sample of participant responses
Invasive vs benefits (2 comments)	"It's fine a lot of hassle." "It's less invasive and burdensome than a tracheotomy. I've had one for 9 years."
Thought continuum (8 comments)	"Although its invasive, I'm not tied to a machine 24/7." "Annoying at first, but I've gained 12-15ilbs in the last year after losing 20-25lbs since onset." "I have mixed feelings. I like it because it allows me to get adequate nutrition when I'm feeling too tired to eat normal food but at the same time I don't like it." "Life sustaining. No choking but I miss real food." "It is life sustaining but it was a very sad day when I decided to not take anymore food by mouth." "The feeding tube will not be used to prolong my life, only provide comfort and strength while I'm still able to enjoy life." "I was not excited to get it by any means to get a feeding tube; however, my breathing numbers had declined enough that we feared waiting until I really needed it would run the risk of being inoperable due to weakened breathing."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Categories for Necessary Category. I assigned 1 code, part of the process, to the necessary category, which consisted of 6 comments. These comments recognized the feeding tube as a necessary step in the process of having ALS. Examples of these comments were, "necessary," "it can become necessary in order to sustain life," "it's just part of the process. A no-brainer," and "it's a necessary evil. I still have a quality

life but eating is now difficult and I'm losing weight too quickly."

Content Analysis for Qualitative Item 6

The sixth item asked those who had a PEG about what motivated them to get one. I assigned 79 comments and organized them into 5 categories and 15 codes. Table 16 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 6 displays how the categories and codes are linked.

Table 16

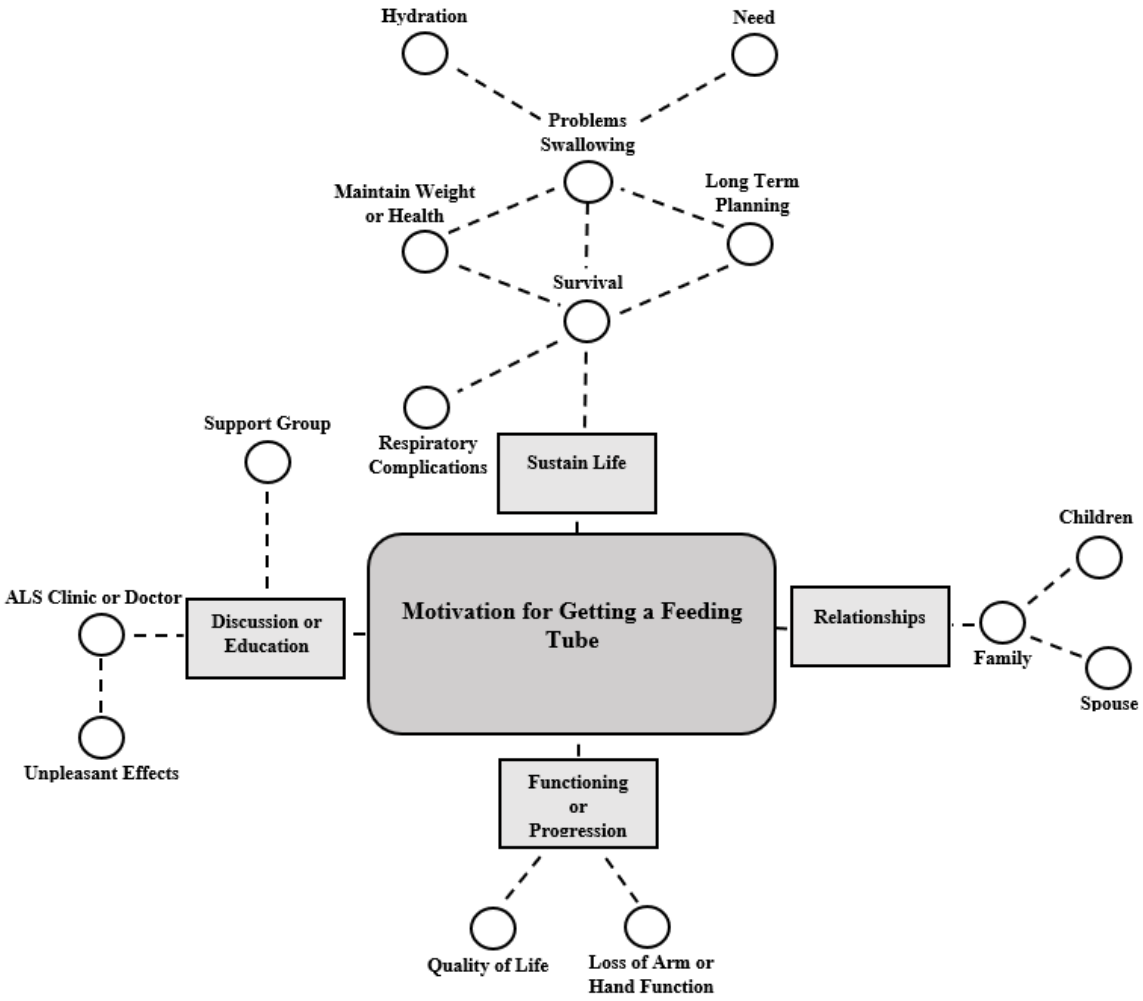
Categories and Codes for Item 6

Category	Codes
Sustain life (47 comments)	Hydration, long term planning, maintain weight or health, need, problems swallowing or eating, respiratory complications, survival.
Discussion or education (23 comments)	ALS clinic or doctor, support group, told not to wait.
Relationships (5 comments)	Children, family, spouse
Functioning or progression (4 comments)	Quality of life, loss of hand or arm function

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 6

Concept Map of Qualitative Item 6



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Sustain Life Category. Table 17 shows the content analysis results for the 47 comments that I assigned across 7 codes.

Table 17

Codes and Comments for Sustain Life Category

Code	Sample of participant responses
Hydration (3 comments)	"Drinking enough to stay hydrated was becoming a concern. I was told not to wait until my ALS had progressed to the point that the surgery would be a much larger deal." "I want to stay hydrated and receive nourishment." "The realization that I would need it later and I was dehydrated."
Long term planning (7 comments)	"I got it as soon as I could to prevent potential problems later." "Preparing for future." "Proactive got the tube before i needed it." "Year before needed would have been dangerous to have surgery now." "The realization that I would need it later and I was dehydrated."
Maintain weight or health (10 comments)	"Weight loss." "The excessive weight loss that was impacting energy level." "The need for calories and nourishment." "Inability to get adequate calories orally and the high risk of aspiration. Each meal was taking an hour of being fed by my caregiver." "I was losing weight."
Need (2 comments)	"I was in fairly good physical shape, could still eat, talk, etc. I knew that I would need it at some point." "I was not excited to get it by any means to get a feeding tube; however, my breathing numbers had declined enough that we feared waiting until I really needed it would run the risk of being inoperable due to weakened breathing."
Problems swallowing or eating (15 comments)	"Swallowing problems." "Can't swallow well...bulbar onset ALS." "I was getting too tired to eat sometimes." "Eating was impossible." "Really using lots of energy to eat. Also choking a lot."

Respiratory complications (7 comments)	"The impact of the ALSto my lungs suggested feeding tube earlier than later. The feeding tube was put in without benefit of anesthesia bc of lung weakness." "Decreased breathing capacity procedure done preemptively." "Breathing at 53%."
Survival (3 comments)	"Longer survival." "Don't want to starve to death."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Discussion or Education Category. Table 18 shows the content analysis results for the 23 comments that I assigned across 3 codes.

Table 18

Codes and Comments *for Discussion or Education Category*

Code	Sample of participant responses
ALS clinic or doctor (17 comments)	"Originally, because it was recommended by neurologist & ALS Multidisciplinary team as a prophylactic measure while my respiratory status was not too compromised." "ALS Clinic." "My nuerologist and wife pushed me." "An inspirational pep talk from my pulmonologist!" "My Dr. pushed for me to get it. He assured me that and I quote, Death by asphyxiation was a less horrible way to die than death by starvation." "Doctor." "Doctor recommendation when lung function decreased." "Recommend by Dr when first diagnosed."
Support group (3 comments)	"ALS support Group." "ALS meeting discussion about taking medications when you can no longer swallow." "I watched a video on feeding tubes provided by my ALS chapter."
Told not to wait (3 comments)	"All the medical diet people recommended that I needed it now!"

	"Drinking enough to stay hydrated was becoming a concern. I was told not to wait until my ALS had progressed to the point that the surgery would be a much larger deal." "My doctor suggested that I get it sooner the better. I was a little scared. But I'm sure glad I did."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Relationships Category. Table 19 shows the content analysis results for the 5 comments that I assigned across 3 codes.

Table 19

Codes and Comments *for Relationships Category*

Code	Sample of participant responses
Children (1 comment)	"My daughters."
Family (1 comment)	"Also, being able to have more time with family."
Spouse (3 comments)	"I love my wife, who wanted me to have it. "My wife." "Also giving me more time with my husband." "Wife."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Comments for Codes in Functioning or Progression Category. For the final category, functioning or progression, I assigned 3 comments to the code quality of life and 1 comment to the code loss of hand or arm function. The comments associated with th**e** quality of life category included: "I was still very active physically, but could no

longer chew for bolus feeding," "To enhance my ability to continue to provide a certain level of quality of life," and "I'm still able to move around with my wheelchair and enjoy activities. The feeding tube provides me the ability to continue to do those things for now." The comment for the loss of hand or arm function code was "Arm weakness."

Content Analysis for Qualitative Item 7

The seventh item asked the participants without a PEG to share their thoughts about getting one. I assigned 201 comments and organized them into 3 categories and 29 codes. Table 20 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 7 displays how the categories and codes are linked.

Table 20

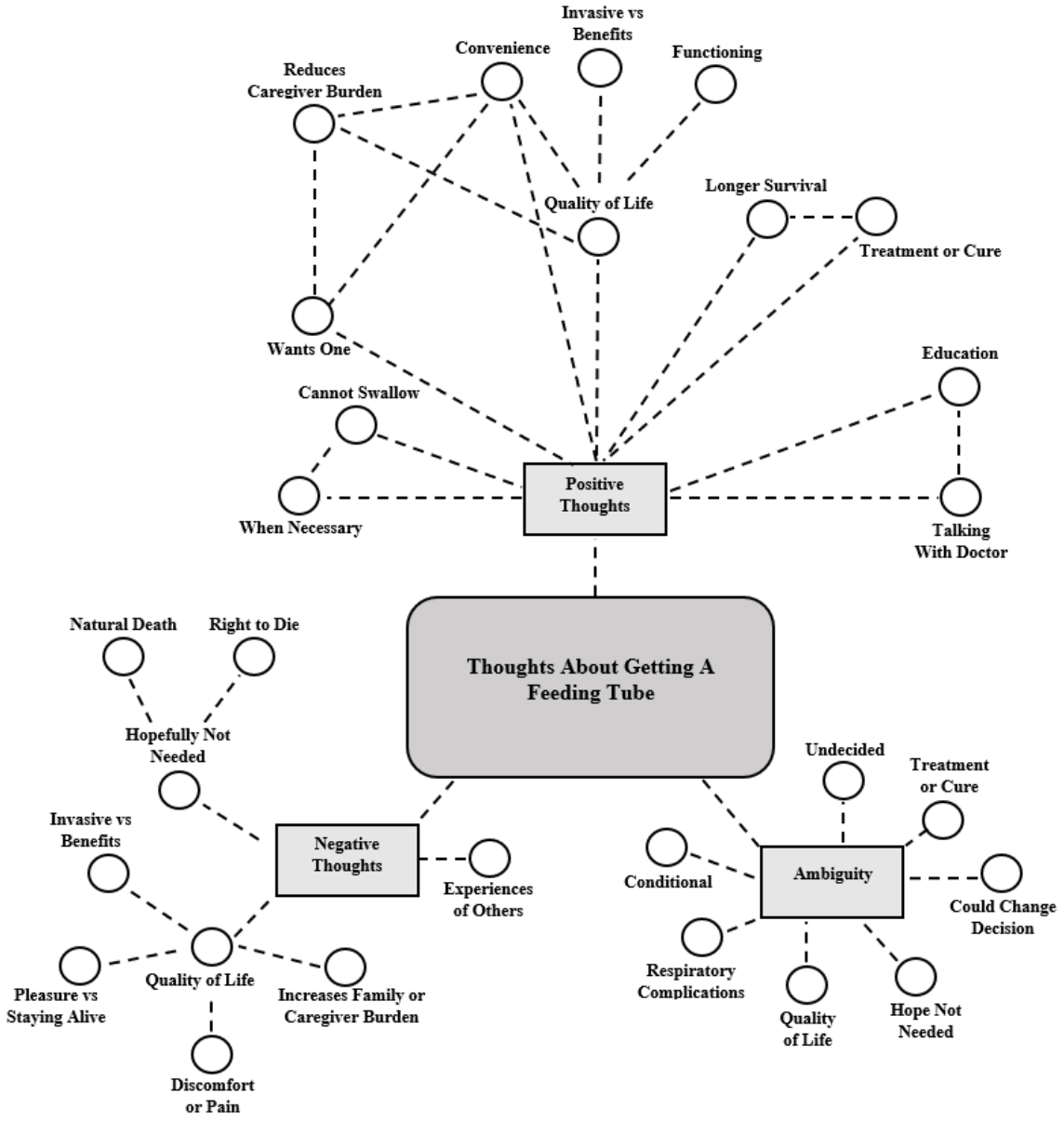
Categories and Codes for Item 7

Category	Codes
Positive thoughts (84 comments)	Convenience, education, functioning, treatment or cure, invasive vs benefits, loss of swallowing function, longer survival, quality of life, reduces caregiver burden, scared, talking with doctor, wants one, when necessary.
Negative thoughts (72 comments)	Discomfort or pain, doesn't want one, experiences of others, increases family or caregiver burden, invasive vs benefits, natural death, pleasure vs staying alive, quality of life, right to die.
Ambiguity (45 comments)	Conditional, could change decision, hope not needed, quality of life, respiratory complications, treatment or cure, undecided.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 7

Concept Map of Qualitative Item 7



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Positive Thoughts Category. Table 21 shows the content analysis results for the 84 comments that I assigned across 13 codes.

Table 21

Codes and Comments for Positive Thoughts Category

Code	Sample of participant responses
Cannot swallow (6 comments)	"Not being able to swallow enough calories to provide sufficient nutrition." "I don't need a feeding tube at this time. When I begin having problems swallowing, I would consider getting a feeding tube." "When I no longer can swallow." "Eating is challenging now. If I continue to lose weight, I will get one to get proper nutrition and fluids."
Convenience (9 comments)	"Makes it easy to get some food." "I'm getting one to make my care easier, to improve hydration, to make taking meds easier." "Understanding the sever choking and vomiting that ALS brings about when eating and drinking for some and appears will happen to me while I still have some mobility, at this time I plan to use the feeding tube to avoid that for myself and my family." "Eating is challenging now. If I continue to lose weight, I will get one to get proper nutrition and fluids."
Education (3 comments)	"I would be open to the idea - would like to learn more about it before making a decision." "I'VE HEARD IT'S NOT A BIG DEAL." "Not that intrusive, per users."
Functioning (5 comments)	"If I can still move my arms, use my hands, and hold my head up, I would get a feeding tube to continue with the energy to enjoy life." "If I am still largely functional it could be worth doing." "Similar to my thoughts on the tracheostomy, I would want more independence and more use of my arms."
Invasive vs benefits (8 comments)	"There are many reasons to get a feeding tube that don't make it an excessive procedure." "This is not as invasive. And improves life for my caregiver." "Feeding tubs for ALS patients have an overwhelmingly beneficial impact."

	"Could be a good thing if needed and not too much trouble." "seems simple and can be kept private."
Longer survival (3 comments)	"It will allow me more time with my family." "I think it is a great option to sustain life and get nutrition to survive." "Not pleased but don't feel it will be necessary in the near future."
Quality of life (8 comments)	"It will make taking meds easier. No more getting choked on pills." "It suck to contemplate, but it will allow me to live longer with a better quality of life." "If I am totally dependent on someone else and miserable and can't do anything I might decide not to get one. But if my quality of life is still good I would get one." "I feel I can be more productive with a feeding tube and it would not necessarily interfere with my "routine" life." "I think I might be willing to get a feeding tube if I feel my quality of life has not declined to a point that I feel I am more of a burden than an asset to my family."
Reduces caregiver burden (3 comments)	"This is not as invasive. And improves life for my caregiver." "I'm getting one to make my care easier, to improve hydration, to make taking meds easier." "Appreciate that I can still eat (via mouth) and use it for supplemental calories or for pills. Doesn't create huge responsibility/pressure for my spouse."
Scared (2 comments)	"It sucks." "Not as scared as a trach. Preliminary conversations initiated by my doctor, a good 4-6 months in advance, will be critical. Hopefully ALSFRS-R scores will flag this."
Talking with doctor (2 comments)	"I'm having trouble swallowing right now, but I am still ambulatory. The doctor is supposed to call me today to give education on this topic. I think I've already decided to go ahead with it." "Radiologic placement of the tube seems to be highly successful."
Treatment or cure (2 comments)	"Treatment for illness is moving too slow to consider Hanging On." "A cure."
Wants one	"I'd get one."

(18 comments)	"A good option." "Reasonable." "Is not too invasive and would help." "When first DX'd, everything sounds overwhelming, but a feeding tube does not sound daunting."
When necessary (15 comments)	"If it's necessary and will prolong life, then I want to get one." "I would get one if and when necessary." "Again, if my condition declines to the point that a feeding tube is needed, I will most likely agree to have one." "I hate the idea, but it may be necessary, since I've lost 53 pounds so far, and often find it difficult to swallow food, liquids, and pills."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Negative Thoughts Category. Table 22 shows the content analysis results for the 72 comments that I assigned across 9 codes.

Table 22

Codes and Comments for Negative Thoughts Category

Code	Sample of participant responses
Discomfort or pain (3 comments)	"Again, prolonged misery." "Because eating has been possible, not interested in the complications associated with feeding tubes."
Doesn't want one (19 comments)	"Not too fond of the idea." "I refuse to live that way." "Not interested in it." "Not interested in getting one." "I do not want to extend my life through the use of a feeding tube."
Experiences of others (3 comments)	"My father and sister had one and I do not want to prolong my life in that state." "Seen others have bad experiences." "The people that I've seen who resort to them die a short time later."

Increases family or caregiver burden (4 comments)	"I had one and they are a lot of trouble to keep clean and for your care giver." "Don't want family to suffer any longer." "The life altering procedure will dictate lifestyle for more than than just me."
Invasive vs benefits (8 comments)	"I'm hoping it's not necessary for me, because it seems quite invasive." "It is an unpleasant procedure and according to my research, it does not increase your lifespan." "IT IS TOO INVASIVE OF A PROCEDURE."
Natural death (7 comments)	"I am also not afraid to die as I know God will take care of me." "Why prolong the disease?" "I think for me that it's time to let go."
Pleasure vs staying alive (7 comments)	"I don't smoke or drink or do drugs...I really enjoy eating as my only vice...so, if I can't, I feel my life will be very limited." "I enjoy food....one of the joys of life." "I really enjoy eating, and always have. A feeding tube on a temporary basis would be doable for me. On a permanent basis, I would not want to live that way. I suppose that I feel this way in part due to my age and understanding that meaningful treatments/a cure are still years away." "I own several high end restaurants and food and the dining experience is my greatest joy."
Quality of life (15 comments)	"Don't want e tend in that condition." "Not interested in prolonging my life with no quality." "Similar to my thoughts about the trach, I don't want to prolong my life via artificial means. To me, quality of life is more important than quantity of life." "It would prolong a worsening quality of life." "I don't want it if it's only to keep me alive longer and doesn't help my quality of life."
Right to die (5 comments)	"Don't want one. Will use the right to die." "Would rather die." "It will prolong death which would not be a quality of life." "That procedure is beyond the time I wish to live."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Ambiguity Category. Table 23 shows the content analysis results for the 45 comments that I assigned across 7 codes.

Table 23

Codes and Comments for Ambiguity Category

Code	Sample of participant responses
Conditional (17 comments)	"I will get one as long as my breathing is ok and the tube isn't too uncomfortable." "If I can still move my arms, use my hands, and hold my head up, I would get a feeding tube to continue with the energy to enjoy life." "If it's a mickey" "A feeding tube on a temporary basis would be doable for me." "If there is no hope of recovery I don't want the feeding tube." "I think I might be willing to get a feeding tube if I feel my quality of life has not declined to a point that I feel I am more of a burden than an asset to my family."
Could change decision (6 comments)	"At this time, I do not like the idea of being artificially fed. My thoughts may change if I get to the point when I have to make this decision." "Not too fond of the idea, but that might change if I become incapable of eating and I am still a viable person." "I say yes to the survey but when the time comes it might be a different decision." "I am once again torn on this decision. It depends on how my health is at the time I need to decide."
Hope not needed (1 comment)	"I'm hoping it's not necessary for me, because it seems quite invasive."
Quality of life (3 comments)	"I hope I don't need to, but I will if my quality of life is still pretty good." "Still up in the air whether i will get one. quality of life will determine what i do." "Undecided at this time. a question for quality of life." "I don't think I want a feeding tube. It is invasive and I don't think it would be worth it."
Respiratory complications	"I have a difficult decision. I can still swallow solid food with no problem but my fvc is down to 26. At the clinic facility which i go

(2 comments)	to a radiologist inserts the tube. My pulmonologist didn't recommend i get the tube at my last visit 9 days ago. We will revisit this issue at the clinic in September." "I don't need one yet, but I am being encouraged to get one before my breathing gets worse."
Treatment or cure (2 comments)	"If there is no cure or life-sustaining treatment on the horizon at the point in time that I need to make the feeding tube decision, I believe I will *not* do it." "If there is no hope of recovery I don't want the feeding tube."
Undecided (14 comments)	"Uncertain at this time." "Not sure that I will get one or not." "Actually ambivalent. Haven't thought much about it." "I would be open to the idea - would like to learn more about it before making a decision."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 8

The eighth item asked the participants without a PEG to share what would motivate or prevent them from getting one. I assigned 159 comments and organized them into 5 categories and 25 codes. Table 24 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 8 displays how the categories and codes are linked.

Table 24

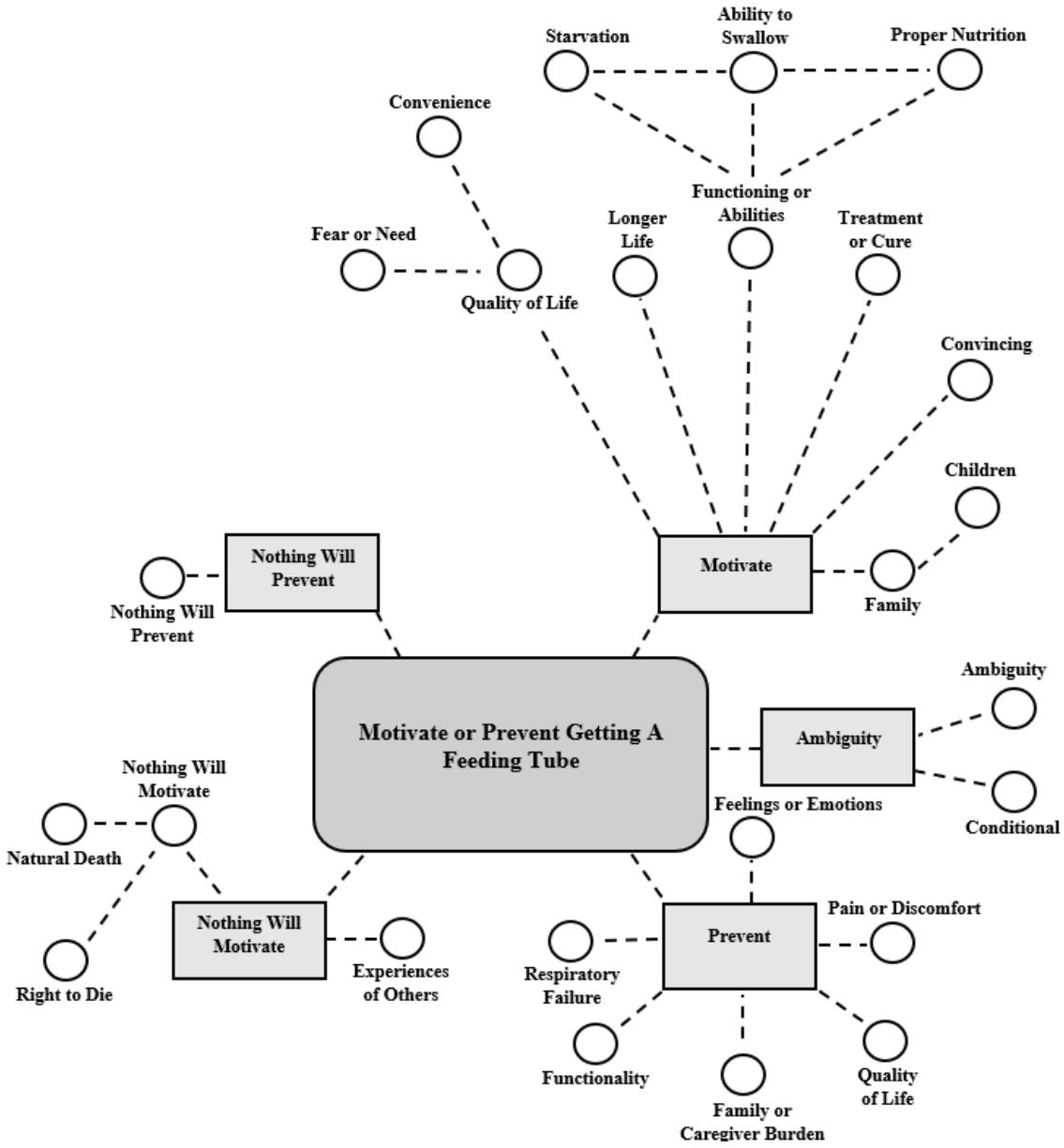
Categories and Codes for Item 8

Category	Codes
Motivate (62 comments)	Ability to swallow, children, convenience, convincing, family, fear or need, longer life, functioning or abilities, treatment or cure, quality of life, proper nutrition, starvation.
Nothing will prevent (11 comments)	Nothing will prevent.
Prevent (39 comments)	Family or caregiver burden, feelings or emotions, finances or cost, functionality, pain or discomfort, quality of life, respiratory failure.
Nothing will motivate (36 comments)	Natural death, nothing will motivate, right to die.
Ambiguity (11 comments)	Ambivalent, conditional.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 8

Concept Map of Qualitative Item 8



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Motivate Category. Table 25 shows the content analysis results for the 62 comments that I assigned across 12 codes.

Table 25

Codes and Comments for Motivate Category

Code	Sample of participant responses
Ability to swallow (6 comments)	"Not being able to swallow enough calories to provide sufficient nutrition." "I will be motivated to get a feeding tube when it appears I cannot consume enough calories o keep my weight up." "I would be motivated if I was having trouble choking or in fear of aspirating." "Choking would certainly accelerate this decision." "Will get it when needed for calories or difficulty with choking to avoid aspiration."
Children (3 comments)	"If I had small children." "If my son was younger, maybe." "If my children begged me to reconsider."
Convenience (3 comments)	"Ease of use." "Taking pills would be easier." "To stay hydrated and nourished."
Convincing (1 comment)	"Good reports from others that had one."
Family (3 comments)	"Family." "Stay longer with family and friends." "Wanting to be with family would motivate me."
Fear or need (6 comments)	"Fear." "Need." "That decision will come when confronted with the need." "My own fear." "Will get it when needed for calories or difficulty with choking to avoid aspiration."
Functionality or abilities (11 comments)	"Normal cognitive function would motivate me to get one." "Being able to maintain the tube myself is the greatest attraction."

	"If I were still able to function physically and cognitively to have an acceptable quality of life that would include being physically active and independent." "The status of my abilities at the time the decision has to be made." "My breathing would have to improve because I am currently using a CPAP machine frequently throughout the day. I would also have to gain some use of my arms."
Longer life (5 comments)	"I like living." "Life-sustaining." "It would motivate me to sustain my feeding/life."
Proper nutrition (3 comments)	"Not being able to swallow enough calories to provide sufficient nutrition." "I will be motivated to get a feeding tube when it appears I cannot consume enough calories o keep my weight up." "I have alsways had trouble maintaining my weight. This would be a helpful prolongation of my life."
Quality of life (12 comments)	"I would get one if needed and I still had good quality of life left." "I'm scheduled to get one in a few weeks. I'm motivated by anecdotal info. I hear that it Can basically be ignored until it's needed, makes caregiving simpler when it is needed, and improves your general condition re nutrition and hydration for better quality of life." "It would depend on my prognosis at the time and whether is would add to my life and what quality of life I would have." "Motivation would to be take as good of care of myself as possible to improve my life." "Sustaining a productive life is a motivating factor."
Starvation (2 comments)	"Not starving." "If I can not longer eat orally and am becoming malnourished I would agree."
Treatment or cure (7 comments)	"Clear leadership,well defined roadmap for intervention and mindset change by those in charge to develop effective treatment." "A cure." "A cure or life-sustaining treatment on the horizon at the point in time that I need to make the feeding tube decision will motivate me to choose a feeding tube." "If there is hope that progress can be made to keep me alive with new treatments."

	"If I can recover and remove the feeding tube I would do it."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Nothing Will Prevent Category. I assigned 11 comments to the nothing will prevent code because they exhibited certainty about getting a PEG. These comments were decisive and did not offer other rationales or ambiguity in their decision-making. Examples of these comments included, "Nothing," "I will get a tube. As of now I can't think of anything to prevent me from getting one," "Do no [*sic*] see it as a big negative impact on the quality of my life," "Nothing would prevent me," and "I AM ALL FOR IT."

Codes and Categories for Prevent Category. Table 26 shows the content analysis results for the 39 comments that I assigned across 7 codes.

Table 26

Codes and Comments for Prevent Category

Code	Sample of participant responses
Family or caregiver burden (3 comments)	"Financial and day to day burden it would place on my family." "Burden on my spouse. Also religious belief. I am not opposed to healthcare or medication but at some point I might believe it would be better to be with the Lord in heaven then leaving." "Being a burden."
Feelings or emotions (3 comments)	"Fear and wanting to be done with this disease would prevent me from getting one." "Personal feelings." "But right now the idea of a feeding tube is foreign to me and makes me queasy, Even though I know it might help prolong my life."
Finances or cost	"Financia.l"

(2 comments)	"Cost."
Functionality (6 comments)	"If it wouldn't help me I wouldn't get it." "The ability to communicate." "My physical condition." "COVID-19."
Pain or discomfort (2 comments)	"Discomfort." "If I had no ability to move any part of my body, I would not get a feeding tube. I would prefer to decrease my body requirements so I do not suffer."
Quality of life (20 comments)	"I don't see where I'd get ANY enjoyment from having one...it would just be a way to keep my body alive." "Challenges in having a "normal life" with a feeding tube in place." "Quality of life." "Deteriorating quality of life." "Sustaining a vegetative, inactive carcass is not."
Respiratory failure (3 comments)	"If my breathing was severely compromised, I would not get a tube." "Reduced breathing capacity could serve to preven." "If I known how my disease would progress I would have gotten one. It is too late now."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Nothing Will Motivate Category. Table 27 shows the content analysis results for the 36 comments that I assigned across 3 codes.

Table 27

Codes and Comments for Nothing Will Motivate Category

Code	Sample of participant responses
Natural death (9 comments)	"No surgery or permanent appliance is wanted." "I do not want to prolong life with Als." "I do not feel that extraordinary measures should be taken to keep me alive at this point, unless they were temporary." "Desire a natural death." "Prevent me from dieing from a useless life."
Nothing will motivate (25 comments)	"Don't want to live like that." "Why bother." "Nothing would affect my decision." "Far to invasive." "Don't want to eat mush through a straw." "Nothing."
Right to die (2 comments)	"California End of Life Option Act." "DNR."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Ambiguity Category. Table 28 shows the content analysis results for the 11 comments that I assigned across 2 codes.

Table 28

Codes and Comments for Ambiguity Category

Code	Sample of participant responses
Ambivalent (7 comments)	"I already have a port for radicava and that is providing some discomfort. I don't want any more pain than I have to have, but this choking is driving me crazy." "Unsure" "I don't know." "Not determined yet."
Conditional (4 comments)	"If I am completely paralyzed with no productive future, I would probably pass. If I can still function it may be worth doing." "If my quality of life is fairly decent, I will use it. When I am very disabled, I will sto[p using it." "All depends where I am at end of life." "Otherwise a lifestyle choice."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 9

The ninth item asked the participants to share the resources that gave them strength. I assigned 515 comments and organized them into 5 categories and 38 codes. Table 29 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 9 displays how the categories and codes are linked.

Table 29

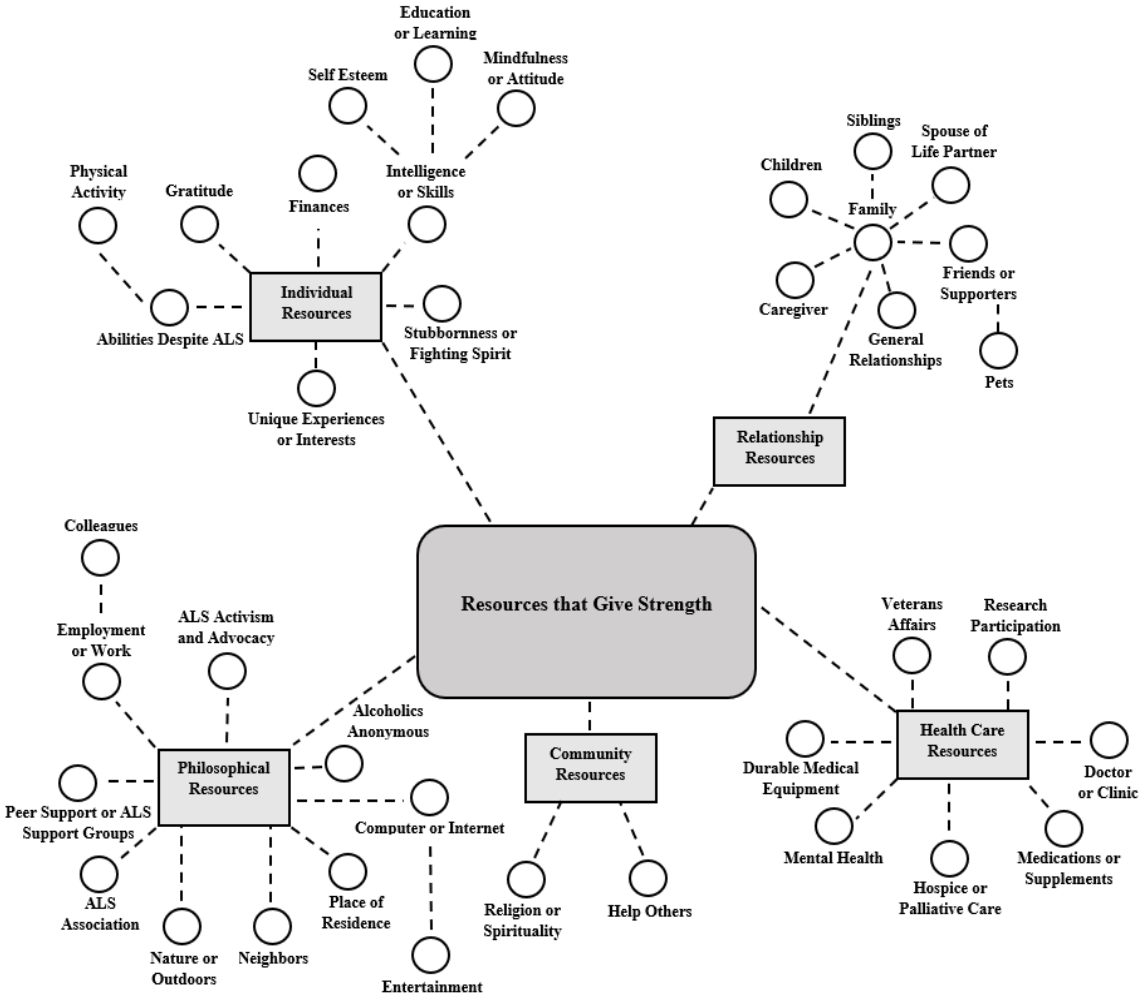
Categories and Codes for Item 9

Category	Codes
Individual resources (74 comments)	Abilities despite ALS, education or learning, finances, gratitude, intelligence or skills, mindfulness or attitude, physical activity, self-esteem, stubbornness or fighting spirit, unique experiences or interests.
Relationship resources (236 comments)	Caregiver, children, family, friends or supporters, general relationships, pets, siblings, spouse or life partner.
Health care resources (46 comments)	Durable medical equipment, doctor or clinic, hospice or palliative care, medications or supplements, mental health, research participation, Veterans Affairs.
Philosophical resources (90 comments)	Help others, religion or spirituality.
Community resources (69 comments)	Alcoholics anonymous, ALS activism or advocacy, ALS Association, colleagues, computer or internet, entertainment, employment or work, peer support or ALS support group, place of residence, nature or outdoors, neighbors.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 9

Concept Map of Qualitative Item 9



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Comments for Codes in Individual Resources Category. Table 30 shows the content analysis results for the 74 comments that I assigned across 10 codes.

Table 30

Codes and Comments for Individual Resources Category

Code	Sample of participant responses
Abilities despite ALS (3 comments)	"I am still able to walk around town and interact with people, and that's quite important to me." "I still drive but not far. So this is awesome." "My talents."
Education and learning (8 comments)	"Higher education." "My greatest resource is my education as a registered nurse. I feel that training has provided great insight to guide the development of my care plan. It has also helped me find creative solutions to problems I experience as my disease progresses." "My passion for learning and research." "My educational background and interest in learning, especially new things." "I also frequently research possible solutions for what I want to accomplish using the internet."
Finances (18 comments)	"Financial resources." "My savings account, my retirement account (to take care of my spouse after I am gone)." "Sufficient income to not feel financially vulnerable." "Enough $$$."
Gratitude (1 comment)	"Gratefulness for a long life -- have outlived the age of my parents."
Intelligence or skills (9 comments)	"Intelligence, judgment." "Knowledge developed as an RN." "My mind/ attitude." "A broad knowledge of life based skills." "Confidence, ability to find information, think, and decide." "Mental acuity."
Mindfulness or attitude (12 comments)	"My mind/ attitude." "Emotional strength." "The ability to laugh in the face of ominous reality."

	"Me, myself, and I." "My own inner peace with life." "Meditation."
Physical activity (6 comments)	"Stretches, rubber band exercises." "Exercise." "Physical theray." "I'm not a natural runner, but have trained for and completed 20 marathons on all 7 continents."
Self-esteem (3 comments)	"Strong moral & ethical background." "STRONG SELF CONCEPT." "My strong personality."
Stubbornness or fighting spirit (9 comments)	"Stubbornness." "My strong personality." "My twin brother and I were born three months early. We were baptized and given last rites when we were born because the doctors did not think we would survive, weighing less than two pounds each. I think I've been a fighter ever since." "My own inner strength to combat/overcome any challenges that I encounter." "My natural inner strength and determination."
Unique experiences or interests (5 comments)	"Life experience." "Past positive life-experiences...advocacy for nature conservation, recreating in wild nature..." "Past experiences." "Past sports background and experiences." "Experience."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Relationship Resources Category. Table 31 shows the content analysis results for the 236 comments that I assigned across 8 codes.

Table 31

Codes and Comments for Relationship Resources Category

Code	Sample of participant responses
Caregiver (8 comments)	"Family and caregivers." "Caregivers." "My caregiver." "My church and people that care for me." "I have a fantastic family and group of caregivers that take care of me." "Excellent caregivers." "I have good caregivers."
Children (18 comments)	"Wife and kids." "Children." "My two sons are also very supporting. My younger son is an adult with high function autism (Aspergers). I try to model the perseverance and tenacity he has shown in his 29 years. He serves as an inspiration to me. My older son who is 33 is a rock. He helps out with household tasks that I can no longer do. He and his wife visit regularly for family meals. I am a lucky man!" "Children, grandchildren." "Adult children." "I have always put my children first in my life. They continue to sustain me."
Family (102 comments)	"My family." "Family." "Family and caregivers." "Connections to the church family and my children." "My family also gives me strength." "Loved ones." "Caring family."
Friends or supporters (60 comments)	"Friends." "Friendships." "Good supportive friends." "Emails with friends." "I have Great friends and a great partner."

	"Close friends." "Have many good friends in the woodturning community who give me moral support."
General relationships (3 comments)	"Being around people living life with honesty and integrity." "Being around people who live knowing how fragile life is." "Relationships."
Pets (3 comments)	"Pets." "My dog."
Siblings (1 comment)	"I have a very funny brother who corespondents with me."
Spouse or Life partner (41 comments)	"My wife being the most important part." "Wife." "Highly dependent on wife." "My husband." "My wife has been with me every step of the way as my primary caregiver. She helps me to navigate through the medical issues/community, day to day challenges (meals, ambulation, mobility, toileting)." "Spouse." "Partner." "A partner willing to stay on this journey with me." "Only resource is my husband." "My husband and I have been married for 37 years and despite some ups and downs in our years together, we have managed to be supportive of each other, especially now in our old age." "Loving partner." "My loving wife."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Health Care Resources Category. Table 32 shows the content analysis results for the 46 comments that I assigned across 7 codes.

Table 32

Codes and Comments for Health Care Resources Category

Code	Sample of participant responses
Doctor or clinic (23 comments)	"My doctors." "I attend an ALS Clinic, locally. I feel that is important to my well-being, as I see ALL the disciplines that are important to my health...at once...to keep me "on-track" and alert me of any issues with my condition." "Health care providers." "There are also some members of my clinic who give me strength." "Doctors and nurses." "Mayo clinic." "The group of doctors that provide my health care." "My ALS Clinic team at the VA is fantastic and supportive as is my local Infusion Nurse. I feel I can always reach out to them or several folks in my turners club for help or just someone to talk too." "PT/therapists, MD/ALS team."
Durable medical equipment (7 comments)	"Walker, lift chair and elevated toilet are enablers." "My scooter; my mechanized wheelchair; my hand controlled ramp van; my diaphragm pacer; my trilogy; roll in shower and roll in shower chair; my Tobi Dynavox." "My bi-pap really helps." "Access to assistive technology." "I do wear an AFO on left leg and have a rollator and walking stick when needed for longer walks." "I also have all the machines i need."
Hospice or palliative care (3 comments)	"I also have a Kaiser palliative home care nurse to help." "I just graduated out of hospice care which also provided many resources." "I get good medical attention from Hospice personnel."
Medications or supplements (2 comments)	"Steroids, supplements, HGH." "Vitiams."

Mental health (3 comments)	"Counselor." "Monthly meetings with my therapist." "Comfort that end of life does not affect mental capacity."
Research participation (1 comment)	"Medical research studies."
Veterans Affairs (7 comments)	"Support from the VA." "The VA." "VA." "The V.A. has provided additional benefits that will help me through the next steps of this disease." "The VA home care team has been wonderful. I receive infusions 10 days a month (for the last 2 years) and the 3 RNs in the hospital are excellent as well as having become good friends." "The fact that I'm a Veteran and have the backing from the VA gives me enormous strength."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Philosophical Resources Category. Table 33 shows the content analysis results for the 90 comments that I assigned across 2 codes.

Table 33

Codes and Comments for Philosophical Resources Category

Code	Sample of participant responses
Help others (3 comments)	"HELP THOSE NEWLY DIAGNOSED." "Helping others." "I have no religious beliefs; never have, never will. I do have strong moral and ethics based on study of both western and eastern philosophers."
Religion or spirituality (87 comments)	"My spiritual faith gives me strength. I know that God will take care of me no matter what happens. As such, I am not afraid of death. I look at ALS as an opportunity to continue to strive to be a better person....to learn more about myself and to help others. I believe God put this challenge in front of me for a reason. It may

	not be clear to me that that is just yet, but I believe there is a reason." "Spirituality." "My relationship with Jesus Christ and other believers, prayer, sermons." "My faith gives me the most strength. God doesn't give me more than I can handle." "Religious meditation and readings." "Bible." "My pastor." "Faith that God is in control." "I am not a religious person, but I do believe in "our better angels" and choose the glass half full approach to life."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Community Resources Category. Table 34 shows the content analysis results for the 69 comments that I assigned across 11 codes.

Table 34

Codes and Comments for Community Resources Category

Code	Sample of participant responses
Alcoholics anonymous (2 comments)	"Al Anon." "I am 19 years sober and a member of AA. The people and program really help guide me through ALS."
ALS activism and advocacy (3 comments)	"ALS community and activism." "Although I can't cure my disease, I am fully engaged in research studies and advocacy." "ADVOCATE FOR ALS."
ALS Association (13 comments)	"ALS Association." "The ALS Association, here, hosts "virtual conferences" (even BEFORE the quarantine!) to allow those without driving or time capabilities to attend." "ALS.org." "The local ALS foundation." "My ALSA case worker."

Colleagues (3 comments)	"Connection with former work colleagues." "The people work at organizations I volunteer with." "My coworkers."
Computer or internet (11 comments)	"Internet." "Computer." "Computer, I can sit at computer and look out window to palm trees, beautiful skies." "The ability to use the internet to research issues." "I am lucky enough to have an eye gaze computer that gives me access to the outside world." "Technology." "Social media."
Employment or work (4 comments)	"My job." "Working." "Disability friendly employer."
Entertainment (4 comments)	"Netflix, Amazon." "I escape reality with novels or fiction video shows." "Rock-n-roll music." "Sometimes liquor."
Place of residence (7 comments)	"My home." "My neighborhood community- lots of diversity and freedom of self-expression." "Private home in a community wihich is supportive." "Have been lucky enough to not live in a nursing home."
Nature or outdoors (2 comments)	"The outdoors." "I live in a beautiful spot with trees and flowers. I spend a lot of time outside in my outside living room."
Neighbors (4 comments)	"Neighbors." "My neighbors." "My community involvement on boards and committees."
Peer support or ALS support groups (16 comments)	"ALS support groups." "Access to similarly situated people online helps as well." "ALS association support group." "The ALS community." "Also podcasts and blogs written or recorded by other ALS patients."

“ALS groups, Rare Disease Groups.”

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants’ responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 10

The tenth item asked the participants to share about the greatest challenges that they faced since being diagnosed with ALS. I assigned 401 comments and organized them into 3 categories and 47 codes. Table 35 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 10 displays how the categories and codes are linked.

Table 35

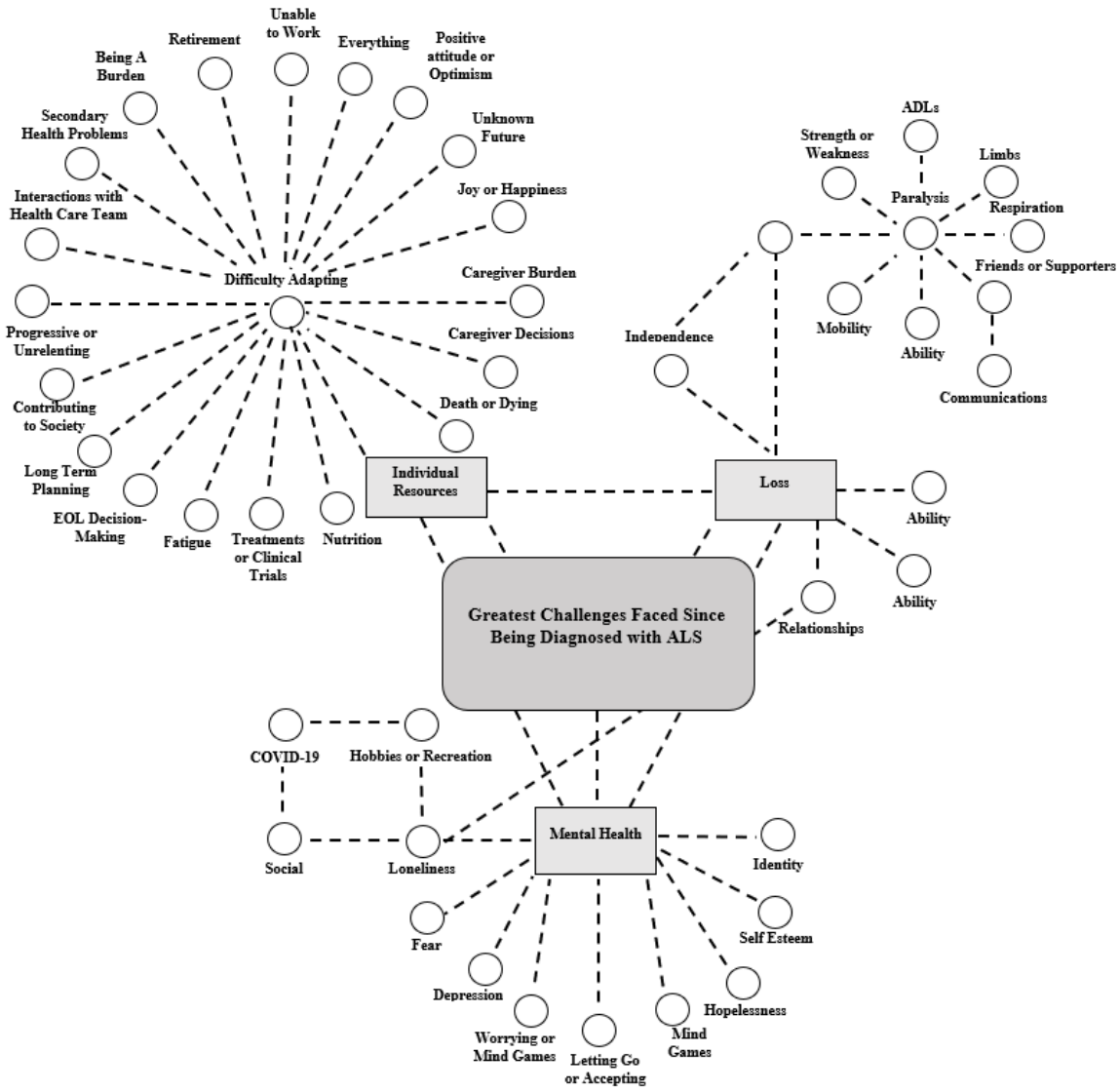
Categories and Codes for Item 10

Category	Codes
Adapting (102 comments)	Being a burden, caregiver burden, caregiver decisions, contributing to society, difficulty adapting, death and dying, EOL decision-making, everything, fatigue, interactions with health care team, joy or happiness, long term planning, nutrition, positive attitude or optimism, progressive or unrelenting, retirement, secondary health problems, treatments or clinical trials, unable to work, unknown future.
Loss (250 comments)	Ability, ADLs, communication, financial, independence, limbs, loss of control, loss of functioning, mobility, paralysis, relationships, respiration, speech or swallowing, strength or weakness.
Mental health (49 comments)	COVID-19, depression, fear, guilt, hobbies or recreation, hopelessness, identity, letting go or accepting, loneliness, mind games, self-esteem, social, worrying or anxiety.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 10

Concept Map for Qualitative Item 10



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Adapting Category. Table 36 shows the content analysis results for the 102 comments that I assigned across 20 codes.

Table 36

Codes and Comments for Adapting Category

Code	Sample of participant responses
Being a burden (6 comments)	"I certainly much concerned about being a burden to my sister, my caregiver." "When I am a burden to my family and unable to work or care for myself." "I don't want to be a burden to my family." "Being a burden." "The greatest challenges now are humbling myself to accept and ask for help." "My ALSA case worker."
Caregiver burden (8 comments)	"Workload increase for my wife and family." "My husband is strong enough to transfer me, but if he gets hurt or sick I have no way of managing." "Not having enough caregiver support- my husband does so much now. The more I progress, the harder it will be for him (he's only one person)." "Sustainable Daily/Nightly care." "I am terrified of losing the use of my arms and hands,which are getting weaker..without hands there's so many things I will not be able to do. I do not want to be a dead body with a brain. I don't want to hurt him."
Caregiver decisions (4 comments)	"At what point should I hire caregivers to give my family a rest. Having strangers come into the home to help with personal care is not something I look forward to. A necessary evil." "Learning that at some point I will have to submit to others for my care. I love my wife dearly and know she will treat me well. So it's not so much that I don't think I will be taking care of, it's more that I will have to be taken care of." "Needing to move into a continuing care situation since I will not be able to live in my own home without assistance. Since I live alone, I feel that a continuing care facility setting would be the safest plan."

Contributing to society (3 comments)	"Not being able to care for myself and others in a physical sense." "THE ABILITY TO HELP OTHERS IN A MEANINGFUL WAY." "Not being able to help my family."
Death and dying (6 comments)	"Dying." "Dying awake and struggling." "Death." "Fear of leaving my family." "The way to die." "Dying early and missing watching kids I love grow up not being here to support/help my partner."
Difficulty adapting (10 comments)	"My initial reaction to getting help is to tough it out and not give in to the disease. I know that is not realistic given the progressive nature of ALS. The nature of this disease can be wearing, i.e. it seems to chip away at me little by little." "I have always been on my own raising my kids. It's hard to have to lean on them. I feel a sense of resentment from my kids." "Moving from a supporter to having to be supported is a major challenge. I'm still fairly young, so the loss of the things I was looking forward to is also a major challenge." "My wife has to balance taking care of me and everything else in our lives due to the fact that I am not ready for an unknown person to come into our home and help. That will be a challenge that I must overcome. I have learned to live in the present, enjoying each and every day. That will change, I know, but I am not ready to think about my last days on earth." "The ALS community." "When to call it a day. I refuse to become helpless." "Living in today, staying positive, giving up control." "To live with this disease, emotionally and physically."
EOL decision-making (4 comments)	"End of life decision making." "Facing end-of-life decisions." "Planing before I die. That is what you should be doing." "Ultimately, the biggest challenges will be the decisions whether to accept or not a tracheotomy or feeding tube."
Everything (2 comments)	"Everything!"
Fatigue (2 comments)	"Fatigue." "Loss of energy."

Interactions with health care team (2 comments)	"Communication and support by health providers and others that I have interacted since diagnosis. Examples include failure to return phone calls (3 people), failure to respond to information requests after webinar (2) and most importantly providing false or misleading information (4)." "I have been excluded from trial due to vital capacity and health provider disrespect for Right to Try Act."
Joy or happiness (2 comments)	"My greatest challenge is to be joyful." "My life is like being on a dimmer switch." "I live in a beautiful spot with trees and flowers. I spend a lot of time outside in my outside living room."
Long term planning (3 comments)	"Realizing that I will need to go to a "facility" far more quickly than if the family support system were there." "Also I love living in this little park model But a wheel chair will not fit in here. So my medication is to what I can to stay mobile as long as I can. I did look into assisted living in my area. That might be option down road." "Needing to move into a continuing care situation since I will not be able to live in my own home without assistance. Since I live alone, I feel that a continuing care facility setting would be the safest plan."
Nutrition (1 comment)	"Have lost 15# and afraid a feeding tube will be necessary in my future."
Positive attitude or optimism (8 comments)	"I am worried when I am more immobile with disease will change me. I want to continue to be the same person and not turn into someone who is angry and miserable. I think it will be a challenge to stay positive." "THE DESIRE TO BE OPTIMISTIC ALL OF THE TIME." "Keeping a good attitude about life in general." "Staying active enough so I can maintain a positive attitude." "Being satisfied with what I am able to do." "The greatest challenge is facing my limitations. Over and over again.pushing to find purpose in the struggle."
Progressive or unrelenting (21 comments)	"Always going downhill. Never gets better. Cannot speak clearly. "Swallowing getting worse." "Walking around is current greatest challenge. It will get worse." "Progression of the disease- when I am a burden to my family and unable to work or care for myself."

	"Constant, slow decline in abilities. What I can do keeps changing." "My mobility slowly being taken away." "Trying to be prepared for next phase of lost abilities." "I hate seeing my body deteriorate little by little."
Retirement (2 comments)	"Early retirement." "Pre-mature retirement."
Secondary health problems (6 comments)	"Chronic diarrhea." "Sleeping at night." "I was always challenged with incontinence and bowel problems." "Added diagnosis of Pulminary fibrosis." "Recovering from brain bleed while losing more of my muscles."
Treatments or clinical trials (3 comments)	"Can't get treatment or help I need or get into a clinical trial." "Not having access to experimental therapies that show potential to slow disease progression." "Mental anguish knowing there's no cure."
Unable to work (4 comments)	"I can no longer work." "Working." "I farm and my lake of mobility is causing me great difficulties in day to day operations of our family farm." "Unable to work."
Unknown future (5 comments)	"Living to see my grand children grow to a reasonable age." "Not knowing what to expect next." "As far as future I try not to think of it." "I currently live on 6 acres with horse, dogs and cats. I constantly wonder/worry about the viability of continued residence when my physical abilities start to really deteriorate." "Dealing with the an known, what next in the disease progression."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Loss Category. Table 37 shows the content analysis results for the 250 comments that I assigned across 14 codes.

Table 37

Codes and Comments for Loss Category

Code	Sample of participant responses
Ability (12 comments)	"The grief of losing abilities - will eventually lose ability to walk completely, take care of self, etc." "I was very active before my ALS progressed to a point that I am less mobile. Currently, taking a shower is a big challenge for me even with the shower chair and the extended hose attachment. It takes a lot of energy and wears me out. Also writing is now very difficult as I have lost most of the use of my dominant hand." "Physical abilities to do what I have done in the past." "Watching my abilities disappear." "I can't turn over in bed."
ADLs (21 comments)	"Where to begin? So there's no cooking, cleaning, laundry, driving, etc. Writing is also a challenge as is sorting papers." "Daily activities." "Lose of ability to move; not being able to care for myself." "The ability not to be able to dress my self." "Inability to clean myself after toileting." "Frustration with decreasing ability to perform basic tasks."
Communication (4 comments)	"Interacting with people who think that ALS is a mental disability." "Communicating effectively." "Speaking with family and friends is difficult." "Not pleased but don't feel it will be necessary in the near future."
Financial (7 comments)	"Thinking about the physical and monetary challenges that I will face take up my time." "My biggest challenge is financial. I live alone and have to pay out of pocket for caregivers. The cost is $10,000 a month so my savings is disappearing quickly." "Financial burden." "Not enough money." "Financial constraints."

	"My greatest challenge up to this time was positioning my family financially to keep them from going bankrupt. I believe I have done that but it is still a concern."
Independence (62 comments)	"Loss of independence." "I am more dependant on others now." "Being totally dependent on others will everything." "Not being self sufficient." "Losing the ability to take care of myself. I am very very independent and cannot imagine not being able to take care of myself and not being able to do the physical things I enjoy."
Limbs (14 comments)	"Loosing the use of legs then arms." "The loss of the use of my hands and legs." "I always thought losing use of my legs would be my greatest hurdle but not any longer. As the lose of use of my arms increase, that is and will be my biggest challenge." "Can't use hands." "Loss of hand strength has required caretaker for all daily living activities."
Loss of control (7 comments)	"Loss of control." "Giving up control." "Loss of control over my life." "The greatest challenge is facing my limitations. Over and over again."
Loss of functioning (8 comments)	"Loss of my physical self." "Recent rather significant decline." "Hands motor skills, balance becoming bad." "Losing use of my body...speech, hands, breathing. For me speech is the hardest blow." "Declining muscle strength in my hands, arms, legs and the diminished mobility and independence this will bring."
Mobility (46 comments)	"Losing the ability to walk." "Mobility." "As I progress, losing mobility will be devasting." "Having to walk with braces and a walker." "Movement and flexibility." "I can not walk." "I can't walk well. It is hard and tiring. Risk of fall has increased greatly lately. I know I will be wheelchair bound soon. This will be a challenge. I am very very independent and cannot imagine not

	being able to take care of myself and not being able to do the physical things I enjoy."
Paralysis (2 comments)	"Become paralyzed." "I am incapable of movement."
Respiration (11 comments)	"Losing the ability to breathe." "The ability to breathe & move." "Breathing." "As of the last year, my breathing has gotten much worse, and I have totally lost the use of my arms. I am currently using my CPAP machine to sleep and for a few hours during the day and evening before bed."
Speech or swallowing (39 comments)	"Lack of voice." "My speaking and my balance are SEVERELY limited!" "Loss of verbal communication." "Slurred speech, choking." "Cannot speak clearly. Swallowing getting worse." "Loss of my normal voice." "I understand breathing and eating with be difficult, eventually lead me to the end."
Strength or weakness (7 comments)	"Lack of strength." "Muscle weakness and atrophy." "I am getting weaker, and just going up stairs is difficult." "Loss of strength and dexterity. I used to be very athletic, and now I can't properly throw a ball." "Complete loss of leg strength will be a challenge."
Relationships (10 comments)	"Divorce." "The ability to...talk with my wife, family or fellow workers and friends." "I have always been on my own raising my kids. It's hard to have to lean on them. I feel a sense of resentment from my kids." "My husband. Not sure he is in it for long haul." "NOT BEING TREATED AS FAMILY MEMBER IN MY OWN HOME."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Mental Health Category. Table 38 shows the content analysis results for the 49 comments that I assigned across 13 codes.

Table 38

Codes and Comments for Mental Health Category

Code	Sample of participant responses
COVID-19 (4 comments)	"Prior to Covid-19, I had several people pitching in to care for me. Since the coved I have not had that help to relieve so more guilt on my part. It was easier being a burden a lot of people than just one." "Will need a hoyer lift or similar, but no home assessment people are available during this pandemic. My husband is strong enough to transfer me, but if he gets hurt or sick I have no way of managing." "The recent pandemic is also an obvious concern in just remaining healthy."
Depression (3 comments)	"Depression because I can't do what I want or need." "Depression."
Fear (5 comments)	"Fear of being unable to move or communicate my need to move." "Fear of leaving my family." "Have lost 15# and afraid a feeding tube will be necessary in my future." "I am terrified of losing the use of my arms and hands,which are getting weaker without hands there's so many things I will not be able to do."
Guilt (2 comments)	"Oh boy,that is a big question to ponder! The greatest challenges now are humbling myself to accept and ask for help, and forgiving myself for not being able to clean or prepare meals, Thinking about the physical and monetary challenges that I will face take up my time. I certainly much concerned about being a burden to my sister, my caregiver. Prior to Covid-19, I had several people pitching in to care for me. Since the coved I have not had that help to relieve so more guilt on my part. It was easier being a burden a lot of people than just one." "When I am a burden to my family and unable to work or care for myself."
Hobbies or recreation	"I love to write and sew and losing these crafts will be devastating."

(5 comments)	“Continued decreasing ability to do what I have always done. Gardening, digging soil, pulling weeds. Photography, with lighting setup. Sewing, with pillow cushions to cover.”
	“Loss of strength and ability to do favored activities.”
	“Doing home projects, can't do any sports, mobility.”
Hopelessness	“Hopelessness.”
(3 comments)	“Mental anguish knowing there's no cure.”
	“Loss of my body while aware that it is happening.”
Identity	“Not be able to enjoy things that has brought me enjoyment.”
(4 comments)	“Giving up a very active like style and watching myself decline.”
	“Not be able to enjoy things that has brought me enjoyment.”
	“I want to continue to be the same person and not turn into someone who is angry and miserable. I think it will be a challenge to stay positive.”
Letting go or accepting	“Letting go of lifes great offerings good and bad, my spouse, my friends.”
(4 comments)	“I have learned to live in the present, enjoying each and every day. That will change, I know, but I am not ready to think about my last days on earth.”
	“The grief of losing abilities - will eventually lose ability to walk completely, take care of self, etc.”
	“Acceptance that I will die no matter what care I receive!”
Loneliness	“Having others truely understand the struggles of ALS.”
(3 comments)	“I live alone and because I am answering this during the COVID-19 pandemic, I have no one else coming into my home. My husband died in December 2019, and I miss him.”
	“Living alone and dealing with this shit alone.”
Mind games	“Then there's the mental aspect. I am extremely self reliant. As my
(12 comments)	body changes I figure I'll have a few challenges dealing with my inability to handle my own affairs. I'm preparing for that now by stopping and thinking about the situation before I react to it.”
	“Sometimes think that I am in capable of thinking for myself.”
	“Mentally losing one thing after another.”
	“Losing independence but not knowing the timeline that it will occur.”
	“Knowing what i can no longer do.”
	“Mental anguish knowing there's no cure.”

	"The sense that I am headed downhill, out of control like snow ball gaining momentum-all the while being unable to do anything for myself."
Self-esteem (1 comment)	"Embarrassment."
Social (1 comment)	"Shopping and interacting in public is challenging, especially since I have a hard time managing my saliva and can't speak. I am often treated as deaf or like I'm stupid."
Worrying or anxiety (2 comments)	"This is very stressful." "Worry about my family."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Content Analysis for Qualitative Item 11

Item 11 asked the participants to share about how their ability to bounce back from trials had changed since being diagnosed with ALS. I assigned 266 comments and organized them into 4 categories and 29 codes. Table 39 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 11 displays how the categories and codes are linked.

Table 39

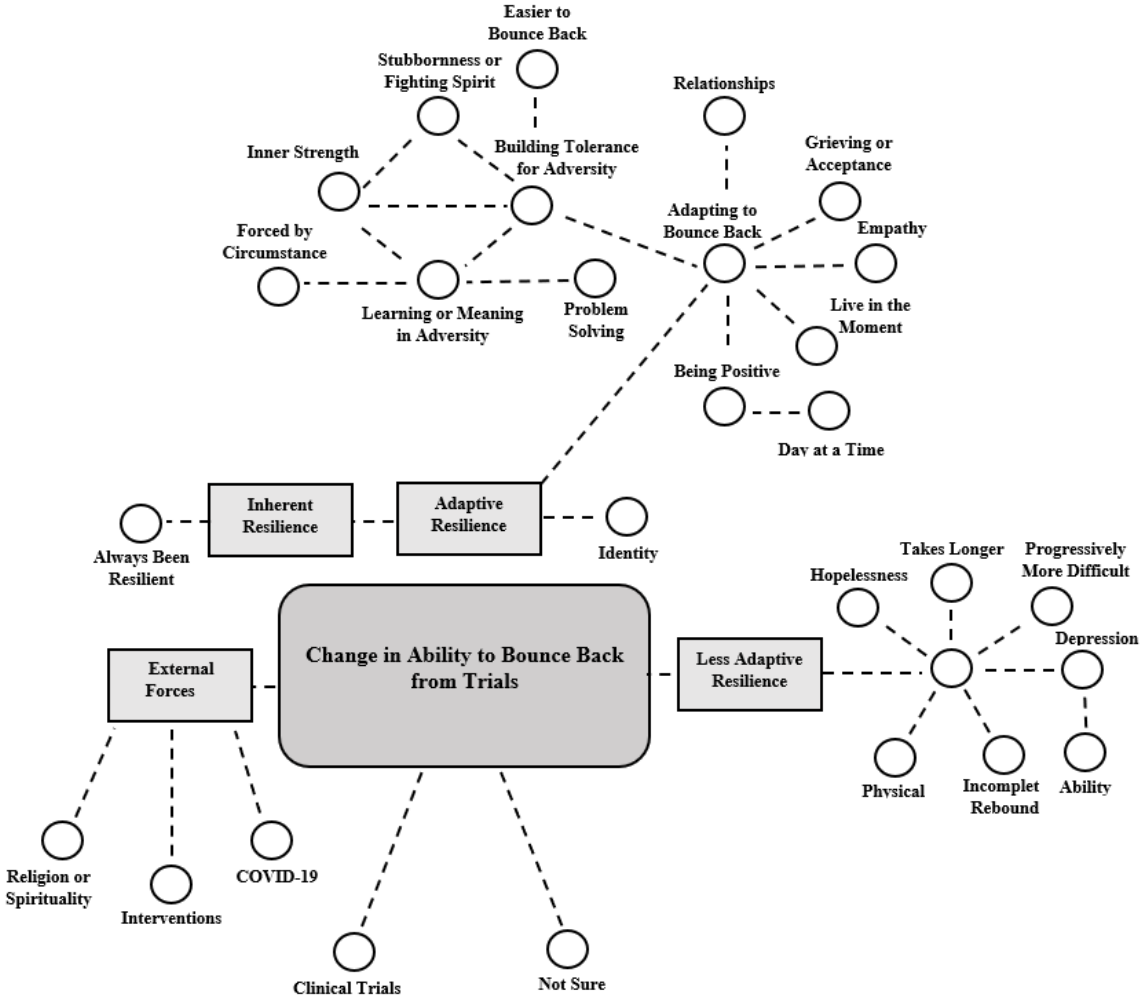
Categories and Codes for Item 11

Category	Codes
Adaptive resilience (164 comments)	Adapting to bounce back, being positive, day at a time, building tolerance for resilience, empathy, easier to bounce back, forced by circumstances, grieving or acceptance, inner strength, learning or meaning in resilience, live in the moment, no change, problem solving, relationships, stubbornness or fighting spirit.
Inherent resilience (7 comments)	Always been resilient.
Less adaptive resilience (72 comments)	Depression, family resources, harder to bounce back, hopelessness, incomplete rebound, mindfulness, physical, progressively more difficult, takes longer.
External forces (11 comments)	COVID-19, interventions, religion or spirituality.
(12 comments)	Clinical trials, not sure.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 11

Concept Map for Qualitative Item 11



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Adaptive Resilience Category. Table 40 shows the content analysis results for the 164 comments that I assigned across 15 codes.

Table 40

Codes and Comments for Adaptive Resilience Category

Code	Sample of participant responses
Adapting to bounce back (19 comments)	"It's not easy to rely on others for everything but I'm doing ok with it now most days." "Pretty good. I adapt to the situation." "Physically weak. Emotionally strong." "It has increased. I have learned to adapt to challenges on a daily basis. Adaptation is something I have grown accustomed to and am now good at." "Rough at first, but it is part of the disease." "I just readjust to a new normal when needed." "I would say as time has gone on above average." "I think I handle things better now."
Being positive (13 comments)	"I feel I'm more able to cope with the changes around me now. Its hard to explain, but I have a "nothing can bother me" attitude. It's a comforting feeling." "I try to remain very positive, at times that can be difficult." "I've always believed that you can't control WHAT happens to you...only HOW YOU REACT TO IT....so, I have good days and bad days, but, attempt to keep that attitude!" "I think I have done very well in keeping a positive attitude."
Building tolerance for adversity (15 comments)	"My sister died from ALS. I know what to expect, and have accepted my inability to perform tasks at my previous level." "I don't sweat the small things as much. I feel if i can handle this I can handle about anything. I don't see many things that are worse than ALS." "I have no 'trials' outside of having ALS. I no longer worry about anything or consider any event or circumstance I have to confront as a trial. Outside of ALS, everything is small stuff." "Yes i was having panic attacks frequently and now I am not." "Had cancer twice so this is just another bump in the road. Strongly believe in laughter." "I AM PRETTY STRONG. HAD A LIFETIME OF CHALLENGES TO PREPARE ME."

	"With every test or trial I gain confidence in my ability to overcome. I'm like a snowball gaining size and speed downhill. Just about unstoppable."
Day at a time (4 comments)	"Not at all... live a day at a time." "I take one day at a time and make adjustments as needed whether "I can do the task or have to ask for help." "I have learned to adapt to challenges on a daily basis."
Empathy (2 comments)	"It has grown, become more empathetic." "My pastor suggested an activity for the church, which has given me purpose, and helped others."
Easier to bounce back (16 comments)	"Improved." "I think it has made me stronger and a source of encouragement to others." "Seem less anxious." "It's shown me that I'm very resilient, and I have a great ability to compensate." "I think I handle things better now."
Forced by circumstances (2 comments)	"Because of extensive spine surgery, my biggest "trial" has been pain and trying to find a solution that will give me maximum independence while I still have it. For the most part I have been able to adjust to the pain but I am observing deterioration which frightens me. Despite this I push myself to "function" at my current maximum level consistently." "I am forced into being more patient."
Grieving or acceptance (7 comments)	"So far, I morn losses and learn to accept the new ability limitations. Of course, some losses take more time to accept." "I would say I've learned to accept losses, trials, bad news, etc with less frustration and emotion, to just accept and move on." "Starting to have a sense of "being tired" of this continual downslope of new adjustments I usually grieve for a day or so with each new loss and then adapt/problem solve." "I've learned to accept things more readily Thani did before."
Inner strength (6 comments)	"I have gotten stronger." "An ALS DX definitely was a game changer. I went through a period of depression but one day I just said to myself to get it together, and so I harnessed my inner strength and started becoming more active." "I amaze myself at how resilient I am."

	"Not changed maybe even more determined." "I think I handle things better now." "I have good days and great days and I only allow myself bad moments and then time to move on after acknowledging the feelings.
Learning or meaning in adversity (10 comments)	"I am a stronger person since my diagnosis. An ALS diagnosis gave me a different perspective on life." "The diagnosis provided a lot of clarity and more short term look at the future which is many ways good." "I have learned to focus on gratitude for what I can still do and not on what I can't. Also value family time and relationships and learning to not sweat the small stuff." "Last of the trials. Learning how to accept help from others. Learning how to live, when you can not change your situation or the impact on others." "I look at my life as limited, so have backed out of some things. But keeping some which are important to me. I have had to go to one handed typing, which was hard at first, but I have adapted." "I believe that we almost have to learn to do so more now than in our lives before ALS." "I've learned to accept things more readily Thani did before."
Live in the moment (2 comments)	"Positively, grab the moment and do what I want to do. Seriously work on the bucket list." "I have a strong will to live and so I face the challenges and try to make the most of each day that I can spend with my family."
No change (40 comments)	"Not at all." "My ability to bounce back mentally hasn't changed.much at all." "No change." "Still positive." "I'm the same, mentally." "It hasn't changed. I have had to journey with Type 1 diabetes for 42 years prior to ALS." "I don't think it has changed. It's just that the trials are different now. I am determined to do as much as I can."
Problem solving (6 comments)	"Early on I was able to figure out ways around problems and obstacles, now I just have to accept it." "Starting to have a sense of "being tired" of this continual downslope of new adjustments I usually grieve for a day or so with each new loss and then adapt/problem solve."

Relationships (7 comments)	"My family helps me to deal with those that I cannot avoid." "Also value family time and relationships and learning to not sweat the small stuff." "My emotional buffer is small,er, But, my family does everything so I'm often stress free." "Willing to accept help from others to do some of the things that I used to take for granted to do." "Encourage from spouse." "Pretty good. Lots of support from family and friends."
Stubbornness or fighting spirit (15 comments)	"I fight even more now." "I am stoic about this." "I fight for my family." "Although I am not quite as resilient under stress as I once was, I continue to fight through times of challenge and uncertainty. Mind over matter." "I continue to be stubborn." "I'm very strong minded." "I don't think it has changed. It's just that the trials are different now. I am determined to do as much as I can."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Inherent Resilience Category. I assigned 7 comments to the always been resilient code of the inherent resilience category. One of the comments in this code stated, "I have always been strong and independent. It's not easy to rely on others for everything but I'm doing ok with it now most days." For this participant, resilience involved relying on others. In contrast, another participant relied on their individual strengths and their ability to problem solve, stating:

> Have remained the same as it has my whole life. Retired from the Army after 22 years and worked in management positions for the next 25 years. Learned to pull yourself up by your boots -- solve the problem and move on.

Similarly, another participant said, “I have always had a positive attitude toward my situation with ALS. It is what it is so deal with it in a positive way. Don't drag others down with you.”

Codes and Comments in Less Adaptive Resilience Category. Table 41 shows the content analysis results for the 72 comments that I assigned across 8 codes.

Table 41

Codes and Comments for Less Adaptive Resilience Category

Code	Sample of participant responses
Depression (6 comments)	“Depression.” “Depressed due to everyday becoming weaker from ALS.” “Difficult emotionally.” “Not motivated, sometimes depressed.” “I've become more depressed and angry.”
Harder to bounce back (12 comments)	“Everything is harder.” “I definitely have less ability to put up with people, particularly family, that annoy me. I am less able to put up with folks than I used to be.” “More difficult.” “Worsen.” “Deteriorated considerably.” “ALS diagnosis was BIG trial.” “It has declined considerably.”
Hopelessness (9 comments)	“ALS has been my only trial I have failed at.” “I give up easier, I don't want to try to do anything.” “What bounce back? ALS never sleeps.” “Sometimes impossible.” “I have less resilience, sometimes feeling hopeless.” “No hope of improvement.” “Bounce back? To what? There is no reprieve. Most of the time I am not upset but we all know what the outcome is. It never goes away. It truly isLSTD. Lon,slow,torturous death.”
Incomplete rebound (9 comments)	“I'm less able to bounce back to 100%.” “I rebound but not all the way back. So every challenge leaves me at increased deficit.”

	“Although I am not quite as resilient under stress as I once was.” “Can’t bounce back. Can only move forward.” “Diminished, but not a lot.” “Decreasing independence, also bringing decreasing ability to bounce back from trials.”
Mindfulness (6 comments)	“MORE EMOTIONAL.” “Difficult / I get stuck in my own mind about change.” “My ability to cope are compromised sometimes, and given the nature of our society, my confidence in adequate quality of life in the future wanes.” “I struggle sometimes not feeling selfish.” “The challenges are getting harder and more serious and anxiety is much higher.”
Physical (14 comments)	“Some adverse situations like being paralyzed cannot be reversed.” “Phy.sically, I get more fatigued and occasionally it takes me longer to recover.” “Physically weak. Emotionally strong.” “I have become slower physically and that affects my attitude towards difficulties sometimes.” “Much weaker than before, tired all the time.” “The continued physical deterioration (despite efforts to remain as active as possible) is frustrating.” “I have had a few respiratory issues that have quickly accelerated and put me in the hospital. Each time this has happened it has taken longer to get back to close to where I was before.” “It takes longer to recuperate from physical activity.”
Progressively more difficult (11 comments)	“Becomes harder as times goes on.” “It takes a toll. This disease chips way pieces of you every day.” “Things are very bad and getting worse. I wish I didn't have ALS, and wish there was a cure already!” “It has lessened as time passes.” “My ability to "bounce back" has definitely taken an extreme hit since my ALS diagnosis. With the realization that ALS is a progressive and degenerative disease, there is no "bouncing back" which is a very stark and difficult realization.”

Takes longer (5 comments)	"IT TAKES ME LONGER TO BOUNCE BACK." "Occasionally it takes me longer to recover." "Frustrations mount more frequently and resolution is slower, but I resolve them." "Longer to bounce back." "Slower and sometimes impossible."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for External Forces Category. Table 42 shows the content analysis results for the 11 comments that I assigned across 3 codes.

Table 42

Codes and Comments for External Forces Category

Code	Sample of participant responses
COVID-19 (6 comments)	"I had a period of feeling useless, especially since the COVID-19 pandemic struck. I am a PA and have cared for patients for 40 years, and desperately wanted to return to work, but knew that I couldn't." "Covid-19 has really taken its toll on my physical strength, not being able to go to the gym." "Every day is a gift, but now with covid 18, riots, friends, family can't visit and I just feel like it's getting harder with getting up." "My ability to accept delayed gratification because realistically, if I can't do something now, I'll probably not have the ability in the future. Covis 19 has been a bummer." "Since Covid Stay at Home in place, have had to miss many trips and events, but understand it's for the best to stay away from people and I'm dealing very well with it."
Interventions (2 comments)	"It has help me to have a mental health counselor to whom I speak once a week." "Have hired additional in home assistance."
Religion or spirituality (3 comments)	"My pastor suggested an activity for the church, which has given me purpose, and helped others." "My faith is a solid foundation where I can always find solace and encouragement."

“Great, a positive mental attitude and my faith in God.”

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants’ responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Comments for Uncategorized Codes. I identified two outlier codes, which I named clinical trials and not sure. I did not assign these codes to categories. I assigned 9 comments to the clinical trials code because they referred to how the participants bounced back from taking part in clinical trials instead of bouncing back from adversity and hardships. The 3 comments that I assigned to the not sure code were ambiguous or simply stated, “not Sure.” One of the participants who commented ambiguously stated, “So far not bad, but I am early in this adventure. Was diagnosed about 2 1/2 months ago.” The other ambiguous statement was, “I honestly don't think it has changed. That said I'm not sure if or how it will change down the road as the disease progresses.”

Content Analysis for Qualitative Item 12

Item 12 asked the participants to share about how their caregivers impacted their ability to live with ALS. I assigned 330 comments and organized them into 3 categories and 36 codes. Table 43 shows the overall content analysis for this item, showing the number of comments, categories, and codes, respectively. Figure 43 displays how the categories and codes are linked.

Table 43

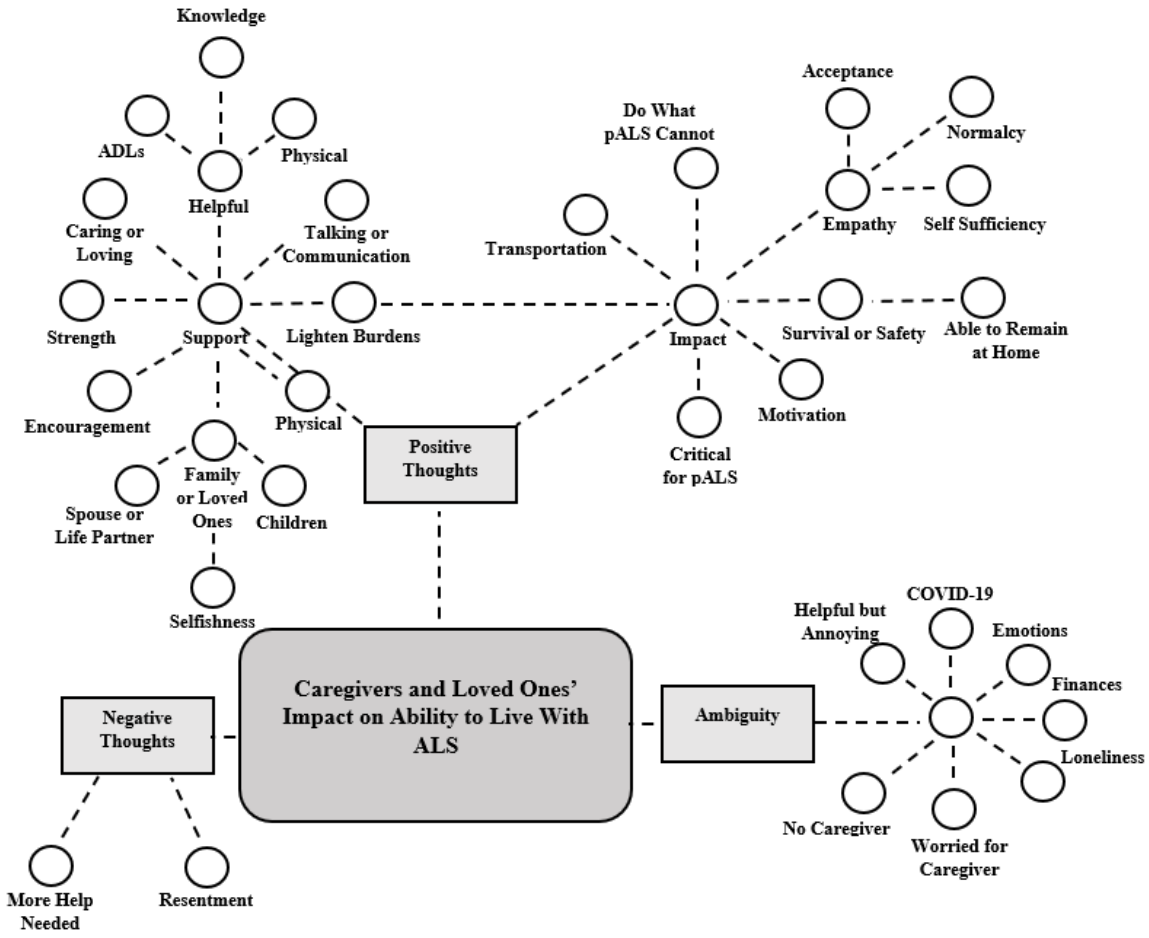
Categories and Codes for Item 12

Category	Codes
Positive thoughts (297 comments)	Acceptance, ADLs, caring or loving, children, critical for people with ALS, do what people with ALS cannot, empathy, encouragement, family or loved ones, helpful, humor, impact, knowledge, lighten burdens, motivation, normalcy, physical, remain at home, selflessness, self-sufficiency, strength, support, survival or safety, spouse or life partner, talking or communication, transportation.
Negative thoughts (6 comments)	Independence, more help needed, resentment.
Ambiguity (27 comments)	COVID-19, emotional, finances, helpful but annoying, loneliness, loss, mixed responses, worried for caregiver.

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Figure 12

Concept Map for Qualitative Item 12



Note. The theme, categories, and codes are depicted by the rounded rectangle, squares, and circles, respectively. The dashed lines linking the codes and categories denote connections and are not to be interpreted as causal relationships.

Codes and Comments for Positive Thoughts Category. Table 44 shows the content analysis results for the 297 comments that I assigned across 25 codes.

Table 44

Codes and Comments for Positive Thoughts Category

Code	Sample of participant responses
Acceptance (2 comments)	"Acceptance." "Express non-judgmental support."
ADLs (10 comments)	"Assistance with activities of daily living." "Paid caregivers help with daily essentials." "Personal care." "Prepare meals, wash cloths, clean living space & bathroom, take me to doctors apts., etc." "Without them, I can not bathe."
Caring or loving (29 comments)	"Very caring." "They are so supportive and loving." "They provide the best care possible." "Bath me, cook, and care about me." "My wife dresses me, feeds me, helps me into my wheelchair, helps me into bed, and use the portable toilet. She helps talk about situation and tells me she loves me." "My wife is my caregiver now and I know she loves me!" "Help me to feel loved and important."
Children (8 comments)	"My sons and their wives have been supportive and caring." "My adult kids who live 3000 miles away keep me going." "After getting over the initial shock of the diagnosis my children are very supportive and have accepted the realities of ALS." "children and caregivers have made it possible to stay in my own home." "MY SON BRINGS JOY." "My son shops for me, and does chores at my home that are difficult for me."
Critical for people with ALS (3 comments)	"They're critical to prolong my life." "If it weren't for them my life would be very different. I'd have given up right away." "Both are critical to my survival."

Do what people with ALS cannot (2 comments)	"They provide care and support in ways that I am no longer able to." "Help with things I can no longer do."
Empathy (4 comments)	"THEY ARE SO VERY HELPFUL AND UNDERSTANDING." "My wife shows great love and comfort; she is patient with my difficulties." "Understanding, unconditional love and willingness to make every effort to comfort me."
Encouragement (18 comments)	"Encouragement." "They support me and encourage me." "My wife encourages me, reminds me gently of things I should do." "In everyway -- seeing that they need and want me, have prevented me from ever getting down about this." "Cares for all my needs. Provides emotional support." "My loved ones give me encouragement." "My wife is my caregiver, she does a excellent job, always encouraging, keeps me mentally strong." "They encourage me when I am feeling tired or low."
Family or loved ones (25 comments)	"I have tremendous support from my direct, and indirect family. Not only for me but for my wife also." "My family has been extremely supportive and does what is necessary." "Initially when I began to need assistance at home I had an extensive network of friends, family and neighbors helping me. This allowed me to delay hiring caregivers for over a year." "My family and friends are extremely supportive and loving and that keeps me going." "OUTSTANDING SUPPORT FROM LOVE ONES AND CARE GIVERS."
Helpful (34 comments)	"Tremendous help." "They are the wind beneath my wings and support me and help me be what I can be with my physical disabilities from ALS." "Family support and love is helpful and gives me reason to live." "Lends a helpful hand through out the day." "They love me intensely and are always getting things for me they think might be of help to me. They are always eager to help in any capacity and like to make me happy." "We talk while she is helping me and she likes doing many of thing I like to do."

Humor (3 comments)	"Humor." "We laugh often, seldom cry, and stay busy." "They keep me comfortable and make me laugh all the time."
Knowledge (3 comments)	"My husband is learning how much care and safety measures I need." "Very up to date on what is available and always looking for clinical trials, diets, and physical therapy to help me." "They make it possible, by researching solutions for continuing a good quality of life."
Lighten burdens (7 comments)	"They provide support, caring and help when needed. make life easier. Help with big things." "They help in anyway they can, make things easier for me when they can." "They make it as easy as they possibly can." "Help ease the burden." "They absolutely increase the quality of my life. Their effort allows me to be comfortable and enjoy."
Motivation (4 comments)	"They bring positivity, they are a sounding board, they are my motivation." "Hope and optimism." "My wife and a few friends make my world bigger and are there for me and that is a source of energy." "There always upbeat and friendly whenever around me but also just let me vent or talk through things if something arises."
Normalcy (2 comments)	"Encouragement & treating me as 'normal.' "They also treat me as normal as possible."
Physical (10 comments)	"They are a huge help. Physically and mentally." "Hands-on physical contact." "They assist me with the things I cannot do."
Remain at home (2 comments)	"I am able to live at home." "Children and caregivers have made it possible to stay in my own home."
Selflessness (3 comments)	"They put me first. They keep me comfortable." "They are my lifelines. I would not be able to live without their self less support." "My spouse is a super person. Not once has she complained and is always ready and willing to do whatever it takes to get the job done. She is strongest person I have ever known."

Self-sufficiency (9 comments)	"I used to help clean the house, wash dishes, get groceries. No i cannot do most of those. I can do simple things as far as meals. I can still shower and toilet myself." "They complete tasks for me that I can mo longer do, help me when needed, and let me do what I can independently." "Very helpful. Sometimes too much help. I like to do things I can still do. Sometimes they baby me." "I'm pretty much self sufficient at the present time I get help with some every day things that are more difficult to do. Stairs are not very easy." "My partner lives 25 miles from me. He will come and drop meds off and water help where I need. Before the Virus he would come 3 times a week and stay over to help me. But I general help myself." "They let me continue to try to stay as active as possible, as long as I am being safe." "My family has been very supportive of me and my disease. I have a small group of friends who are also very supportive. I am fortunate that I am still reasonably self-sufficient just needing help with some heavy work around the house."
Spouse or life partner (35 comments)	"My husband is quite eager & willing to get supplies or devices etc. that might make things easier for me." "Highly dependent on wife." "I have an extremely supportive spouse and parents, and that certainly makes me feel supported in making decisions and living with this crappy disease." "My husband is my primary caregiver. All our children live elsewhere. He makes it possible for me to stay at home since I can't cook, bathe or dress myself." "My wife is my primary caregiver. As i progressively can do fewer things she does them for me. She is wonderful." "My wife waits on me hand and foot." "Without my husband I have no idea how I would manage."
Strength (4 comments)	"They give me strength and hope." "ENABLE ME TO BE MY BEST SELF." "I can't do this without them."
Support (45 comments)	"Supportive." "They are VERY supportive my limitations." "Great support."

	"Unconditional love and support- they let me express when I am scared or sad and my family stands by me in support and allows me to make the best decisions." "Stand by me." "I feel supported by them, which makes it easier to cope with the challenges." "They allow me to make my own decisions and are ALWAYS here for me!" "They are always here for me when I need them. I know I have a lot of support. Therefore I'm not worried about getting help as this disease progresses." "They bring me flowers,food, books emails. They don't like to talk about how I will die or the many indignity s I endure. They bring their pets to visit."
Survival or safety (23 comments)	"Help me stay alive." "I would not be able to survive without my loved ones." "without them, I can not bathe. I need them after I fall, i cant get up." "Without them, I cease to exist." "They are my lifelines. I would not be able to live without their self less support." "Want to keep me safe."
Talking or communication (8 comments)	"Having someone to talk about it with." "Talking and always asking if I'm okay or need help." "Help me and listen." "They bring positivity, they are a sounding board, they are my motivation." "Constant communication."
Transportation (4 comments)	"Transportation." "Again blessed with an outstanding support group. They call, visit, take me out, allow me to vent physical frustrations." "I am less able to do chores and such (like driving) so I am becoming increasingly dependent on others." "Bought a ramp van."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Negative Thoughts Category. Table 45 shows the content analysis results for the 6 comments that I assigned across 3 codes.

Table 45

Codes and Comments for Negative Thoughts Category

Code	Sample of participant responses
Independence (1 comment)	"My husband is always treating my like a child in not wanting me to do things. He is afraid I will hurt myself."
More help needed (2 comments)	"Negligible impact." "Needing more support for everyday tasks."
Resentment (3 comments)	"I hate needing help." "I have to rely on them." "MY HUSBAND IS A CONSTANT COMPLAINING."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Codes and Comments for Ambiguity Thoughts Category. Table 46 shows the content analysis results for the 27 comments that I assigned across 8 codes.

Table 46

Codes and Comments for Ambiguity Thoughts Category

Code	Sample of participant responses
COVID-19 (3 comments)	"With COVID19, my wife's care has been even more critical." "Folks are very interested in how I am doing. I see friends despite covid and it helps keep me grounded." "My partner lives 25 miles from me. He will come and drop meds off and water help where I need. Before the Virus he would come 3 times a week and stay over to help me. But I general help myself."
Emotions (4 comments)	"Emotional." "My mood is affected by their mood. They do everything for me. If I am down they can brighten my day and they can also bring me down if I am in a good mood."

	"You have to understand their frustration as well as your own and then learn to be OK with it. Put their frustrations first." "They don't like to talk about how I will die or the many indignity s I endure."
Finances (2 comments)	"In order to hire a full-time care provider or even part time to give him a break that would take so much of the income that we couldn't afford to live. But yet my husband is so positive with me. I think when he gets down or in a negative position, mostly when he's tired and weary, it affects me to the point where I close off, I've even seen myself not asking for anything to eat for 24 hours at a time and just get really quiet." "Initially when I began to need assistance at home I had an extensive network of friends, family and neighbors helping me. This allowed me to delay hiring caregivers for over a year."
Helpful but annoying (2 comments)	"They're critical to prolong my life. They annoy me. I hate needing help." "Very helpful. Sometimes too much help. I like to do things I can still do. Sometimes they baby me."
Loneliness (3 comments)	"Communication is still the biggest challenge, even with family. I often feel alone and miss relaxing conversation. I have so much in my head that isn't spoken I often feel overwhelmed and need complete silence to process. I think family has a hard time understand this because they haven't experienced experience it." "Some of my family are very supportive and helpful some have started avoiding me now that I am getting farther along. That make it very lonely and sad." "If I didn't have my wonderful husband, I really don't know what I would do. I don't know how I would be able to live alone even at this stage that I am in."
Mixed responses (7 comments)	"Very helpful. Sometimes too much help. I like to do things I can still do. Sometimes they baby me." "My wife supports me so much. However I worry about her ability to continue - eg lifting and physical support." "They are hands off as much as posible." "Like anything, I think they have the ability to make it easier or much harder." "They care about me, but want to keep me safe so they don't have to worry. "Geographical distance."

No caregiver (2 comments)	"I live by myself, far from family. Do not need caregivers yet." "I don't have a regular caregiver yet, already I have two friends that help out."
Worried for caregiver (4 comments)	"My husband tries to stay as positive as possible, but he normally is an introvert and more towards the negative personality. He works really hard on that with me. He tries to encourage. It breaks my heart to see the pain he's and when he's helping me." "I don't want their lives to be impacted by my limitations." "I'm unsure if my wife fully comprehends the full impact the disease will have down the road. She four years older and isn't in the best of health herself. Time will tell."

Note. The comments shown indicate the number of instances that a portion or the entirety of the participants' responses aligned with a given category and are not to be interpreted as the sample size of a given category.

Qualitative Thematic Content Analysis Findings Across Qualitative Items

I performed a word frequency query in NVivo, which populated the 30 most used words from the participants' comments; the comments aligned well with the codes and themes (see Table 47). Figure 13 displays a word cloud visualization of the word frequencies, where the most used words are shown in the larger and darker font.

Table 47

30 Most Used Words

Word	Frequency	Word	Frequency
Life	387	Ability	92
Family	318	Getting	90
Want	207	Much	90
Care	169	Also	89
Help	151	Feeding	87
Time	151	Things	85
Quality	143	Loss	71
Friends	132	Good	70
Able	132	Think	69
Still	118	Just	68
Support	108	Burden	67
Wife	108	Know	65
Tube	103	Feel	64
Live	99	Needed	63
Need	93	Faith	62

Figure 13

Word Cloud of 30 Most Used Words

I observed numerous codes and categories that repeatedly manifested across the 12 qualitative items, which, when analyzed collectively, provided further understanding about how people with ALS' socioecological resilience and self-determination contributed to their decision-making for life-sustaining treatments. I observed 7 transcendent themes across the qualitative items. Table 48 lists the themes and the keywords involved, the total comment frequencies, and the qualitative survey items they represented.

Table 48

Thematic Content Analysis Across 12 Qualitative Items

Theme	Keyword from codes/categories	Comment frequencies	Qualitative items observed
1. Individual, communal, health care, philosophical, and relational resources are critical to supporting people with ALS' decision-making.	Abilities despite ALS, alcoholics anonymous, ALS activism or advocacy, ALS Association, caregiver, children, clinical trials, colleagues, computer or internet, contributing to society, cure or treatment, doctor or clinic, durable medical equipment, education or learning, entertainment, employment or work, family, finances, friends or supporters, general relationships, help others, hospice or palliative care, intelligence or skills, medications or supplements, mental health, mindfulness or attitude, nature or outdoors, neighbors, peer support or ALS support group, pets, physical activity, place of residence, religion or spirituality, resources, self-esteem, siblings, spouse or life partner, stubbornness or fighting spirit, unique experiences or interests, Veterans Affairs.	931	2, 3, 4, 8, 9, 10, 11, 12
2. For many people with ALS, decisions for life-sustaining treatments are not merely yes or no decisions at single points in time. Instead, these decisions are chrono-processes influenced by tensions related to perceived burden,	Age or life experiences, burden, convenient nutrition, cost or resources, EOL decision-making, cure or treatment, could change decision, conditional or ambiguity, fear or scared, functioning or ability, independence, invasive or discomfort, long term planning, loss of functioning, no hope for recovery, progression, progressive or unrelenting, purpose and	846	1, 2, 3, 4, 5, 6, 7, 8, 10, 12

functioning, quality of life, loss, and disease progression at the time of making the decision and after the procedure.	potential, quality of life, regrets having trach, resources, survival or longer life, undecided, unknown future, with conditions, worried for caregiver, won't prolong death.		
3. People with ALS who can adapt to their situations and environments seem to be more willing to consider getting life-sustaining treatments.	Adapting to bounce back, changed decision, children, convenience, convincing, discussion or education, enhanced abilities or QOL, remain with family, could change, cure or treatment, family, functionality or ability, glad or good decision, hopefully not needed, if necessary, inherent resilience, invasive vs benefits, need, nothing will prevent, quality of life, scared or concerned, supplemental use, survival or longer life, wants one, yes trach.	769	2, 3, 4, 5, 6, 7, 8, 9, 11, 12
4. People with ALS who are less able to adapt to their situations and environments seem to be less willing to consider getting life-sustaining treatments.	Age or life experiences, burden, cost or resources, cure or treatment, dependence on vent or others, difficulty adapting, discomfort or pain, doctor recommendation, depression, family resources, fear, finances or cost, functionality, harder to bounce back, hopelessness, inability to speak, incomplete rebound, invasive, mindfulness, more help needed, natural death, none, nothing will motivate, no trach, philosophy or beliefs, pleasure vs staying alive, physical, progression and change in functioning, progressively more difficult, purpose and potential, quality of life, resentment, resources or support, restricted to machine, right to die, scared, takes longer, won't prolong death.	567	3, 4, 7, 8, 9, 10, 11, 12

5. Relationships and connections are critical for people with ALS' resilience, self-determination, and ability to die with dignity.	ALS Association, caregiver, children, family, colleagues, friends, health care providers, neighbors, pets, spouse/ partner, support group, Veterans Affairs.	674	2, 3, 4, 6, 8, 9, 10, 12
6. The COVID-19 pandemic, the availability of a treatment/cure, and religious beliefs are environmental and supernatural forces that impact people with ALS' resilience and decisions.	COVID-19, cure or treatment, religion or spirituality.	136	3, 4, 7, 8, 9, 10, 11, 12
7. To gain a sense of control over their disease and circumstances, some people with ALS act resiliently and exercise their self-determination by choosing to die when and how they wish without life-sustaining treatments.	Hopelessness, loss of control, natural death, mind games, progressively more difficult, prolong death, right to die.	96	3, 4, 7, 8, 10, 11

Quantitative Findings

I performed binary logistic regressions to assess the predictive relationships between the independent variables (socioecological resilience and self-determination) and the dependent variables (plan for tracheostomy and plan for feeding tube), controlling for disease progression (i.e., the number of negative symptoms), age, gender, and military veteran status. Each dependent variable had two outcome categories (yes and no).

Before performing the models, I assessed for 5 assumptions (see Petrucci, 2009; Tabachnick & Fidell, 2019) to determine if bivariate regression was an appropriate data analysis test, including:

1. Confirming the presence of nominal-level dependent variables and at least one independent variable at the continuous, ordinal, or nominal level
2. Confirming the independence of observations
3. Confirming there were no outliers that could skew the findings
4. Confirming that there was no multicollinearity between the independent variables
5. Confirming the linearity between the independent variables and the log odds.

I confirmed the first 3 assumptions by visually inspecting and evaluating the data after importing them into SPSS and when assigning the variables to perform the tests. I confirmed the fourth assumption by performing a variance inflation factor (VIF) test on the independent variables. While the VIF test yielded a coefficient below .80 ($r = .727$, $p < .001$), the VIF statistic was 1.00, indicating that there were no multicollinearity symptoms. Additionally, all of the standard error statistics for the significant findings were below 2.00, indicating that the independent variables were not highly related (see

Petrucci, 2009). To confirm the linearity between the independent variables and the log odds, I interpreted the log odds ratios with statistical significance at $p < .05$.

The ARMR consisted of 17 scaled items, and the BPNSS consisted of 21 scaled items; both instruments showed strong psychometric reliability yielding Cronbach's alpha of .82 and .88, respectively. For the ARMR, the participants' mean, median, and mode scores were 47.5, 49.0, and 50.0, respectively (*SD* = 3.80). The minimum score was 31.0, and the maximum was 51.0 out of the highest possible score of 51.0. For the BPNSS, the participants' mean, median, and mode scores were 5.1, 5.2, and 4.8, respectively (*SD* = .649). The minimum score was 3.1, and the maximum was 6.2 out of the highest possible score of 7.0.

Statistical Significance of Predictions for Research Question 2

The first quantitative RQ and hypotheses were

What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments?

H_0: There is no relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

H_1: There is a positive relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

I performed 2 binary logistic regression tests to determine the relationship between socioecological resilience and decision-making for life-sustaining treatments, controlling for the relevant demographic variables and the number of negative symptoms in the participants' disease progression for tracheostomies and PEGs, respectively (see

Table 49). The results indicated that the null hypothesis could not be rejected and that there was not a significant relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments. The participants' age, gender, military veteran status, and disease progression (i.e., negative symptoms) were significant predictors for choosing whether or not to get a tracheostomy or PEG. Military veteran status (not being a military veteran) and age were *negatively* significant predictors of choosing to get a tracheostomy and PEG, thereby decreasing the odds of choosing to get the procedures. Being female was a *positively* significant predictor for choosing to get a PEG, thereby increasing the odds of choosing to get PEGs. The negative symptoms (i.e., disease progression) variable was a *positively* significant predictor of choosing to get a PEG. With every 1 unit increase in negative symptoms, the odds of choosing to get a PEG increased.

Table 49

*Logistic Regressions of Predictors (Resilience) of Treatments (*N = *197)*

Variable	B	SE	Wald	Sig.	Exp(B)	95% C.I. for Exp(B)
			Tracheostomy			
ARMR	.097	.056	2.952	.086	1.102	[.986, 1.230]
Age	-.074	.019	14.660	< .001	.929	[.894, .965]
Gender	-.329	.395	.694	.405	.720	[.332, 1.561]
Military vet. status	-1.469	.479	9.398	.002	.230	[.090, .589]
Negative symptoms	.133	.093	2.058	.151	1.142	[.952, 1.370]
Overall model evaluation						
Omnibus tests of model coefficients				< .001		
Hosmer and Lemeshow				.801		
			PEG			
ARMR	-.023	.048	.232	.630	.977	[.889, 1.074]
Age	-.042	.019	4.850	.028	.959	[.924, .995]
Gender	1.248	.355	12.347	< .001	3.483	[1.737, .6.988]
Military vet. status	-1.599	.538	8.828	.003	.202	[.070, .580]
Negative symptoms	.510	.116	19.375	< .001	1.665	[1.327, 2.090]
Overall model evaluation						
Omnibus tests of model coefficients				< .001		
Hosmer and Lemeshow				.805		

Statistical Significance of Predictions for Research Question 3

The second quantitative RQ and hypotheses were

What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments?

H_0: There is no relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

H_1: There is a positive relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

I performed 2 binary logistic regression tests for the BPNSS to determine the relationship between self-determination and decision-making for life-sustaining treatments, controlling for the relevant demographic variables and the number of negative symptoms in the participants' disease progression for tracheostomies and PEGs, respectively. Table 50 shows the models' regressions of associations. The results indicated that the null hypothesis could not be rejected and that there was not a significant relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments. As with the first model, the participants' age, gender, military veteran status, and the number of negative symptoms in their disease progression were significant predictors for choosing whether or not to get a tracheostomy or PEG. Military veteran status (not being a military veteran) and age were *negatively* significant predictors of choosing to get a tracheostomy and PEG, thereby decreasing the odds of choosing to get the procedures. For every 1 unit increase in these variables, the odds of choosing to get a tracheostomy and PEG decreased. Again, being female was a *positively* significant predictor for choosing to get a PEG, thereby increasing the odds of choosing to get PEGs. The negative symptoms of disease progression variable was a *positively* significant predictor of choosing to get a PEG. With every 1 unit increase in negative symptoms, the odds of choosing to get a PEG increased.

Table 50

*Logistic Regressions of Predictors (Self-Determination) of Treatments (*N = *197)*

Variable	B	SE	Wald	Sig.	Exp(B)	95% C.I. for Exp(B)
			Tracheostomy			
BPNSS	.422	.312	1.822	.177	1.524	[.826, 2.812]
Age	-.077	.020	15.099	< .001	.926	[.891, .963]
Gender	-.361	.393	.843	.359	.697	[.323, 1.506]
Military vet. status	-1.463	.475	9.501	.002	.231	[.091, .587]
Negative symptoms	.114	.091	1.574	.210	1.121	[.938, 1.341]
Overall model evaluation						
Omnibus tests of model coefficients				< .000		
Hosmer and Lemeshow				.601		
			PEG			
BPNSS	.115	.272	.177	.674	1.122	[.658, 1.913]
Age	-.043	.019	4.952	.026	.958	[.923, .995]
Gender	1.228	.355	11.986	< .001	3.415	[1.704, 6.844]
Military vet. status	-1.586	.538	8.688	.003	.205	[.071, .588]
Negative symptoms	.517	.115	20.055	< .001	1.677	[1.337, 2.103]
Overall model evaluation						
Omnibus tests of model coefficients				< .001		
Hosmer and Lemeshow				.779		

Other Findings

Another finding unrelated to the RQs concerned the relationship between the independent variables—socioecological resilience and self-determination. Bivariate correlation test results showed a strong positive relationship between the participants' socioecological resilience ($M = 47.48$, $SD = 3.80$) and self-determination ($M = 5.10$, $SD = .649$), $r = .715$, $p < .001$.

Evidence of Trustworthiness

I implemented various strategies to mitigate threats against trustworthiness and maximize the study's credibility, confirmability, transferability, and dependability, as Amankwaa (2016) and Shenton (2004) recommended. To maintain the study's credibility, I sampled the participants randomly and had two peer researchers review the findings for errors and bias, and to provide critical feedback. I was also transparent in the informed consent about my role, biases, and assumptions, and the study's limitations. For dependability, I triangulated qualitative and quantitative research methods and described the methodology such that other researchers could replicate the study. To ensure transferability, I triangulated the data collection techniques and provided sufficient detail in the manuscript to enable other researchers to replicate the design. Finally, to minimize the confirmability threats, I triangulated research methods and used concept maps to confirm the audit trail (see Amankwaa, 2016; Shenton, 2004).

Summary

This study yielded meaningful and significant findings to answer the qualitative and quantitative RQs. Qualitative content analysis and thematic content analysis revealed that the participants' disease progression, functional abilities, profound loss, quality of life, age, resources, relationships, time, environmental and supernatural forces, and attempts to maintain control contributed to their decision-making for life-sustaining treatments. Additionally, for many people with ALS, decisions for life-sustaining treatments are not singular or momentary; instead, they are ongoing decisions that can change as they progress through the disease, navigate tension points, and have new

experiences. Furthermore, while many people with ALS are willing to answer yes or no about getting life-sustaining treatments, they also have thresholds for which conditions and circumstances are or are not acceptable to get life-sustaining treatments.

Binary logistic regression analysis showed that neither the ARMR nor the BPNSS was a significant predictor of people with ALS' decision-making for tracheostomies or PEGs. However, age, gender, military veteran status, and the disease progression (i.e., negative symptoms) were significant predictors for choosing whether or not to get life-sustaining treatments.

In the next chapter, I interpret the findings by comparing them with the existing literature on decision-making for life-sustaining treatments and in the context of socioecological resilience and self-determination theory. I also discuss the study's limitations, make recommendations for future research, and elaborate on the implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

I conducted this study to examine the relationship between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments. This study initiates a scholarly discussion about how social workers at ALS multidisciplinary clinics can interact and intervene more effectively with people with ALS as the latter make decisions regarding life-sustaining treatments. These findings may also contribute new insights about resiliency in people with ALS. Because people with ALS experience progressive, persistent, and overwhelming adversity (Cornwell, 2016), they could be an ideal population from which to gain new knowledge about resilience and self-determination.

I implemented a mixed-methods QUAL + QUANT research design and collected and analyzed the data concurrently. I performed qualitative content analysis and binary logistic regression analyses to ascertain the results. The qualitative findings showed that widespread and interconnected psychosocial factors influenced people with ALS' decisions for life-sustaining treatments. These results indicated that people with ALS' decisions for life-sustaining treatments are not always linear. Many people's decisions can change over time as their circumstances and environments evolve with their perceived burden, functioning, quality of life, loss, and disease progression. The binary logistic regression analyses revealed that the null hypotheses could not be rejected and that socioecological resilience and self-determination were not positively related to people with ALS' decision-making for life-sustaining treatments. However, there were statistically significant relationships in covariates, including age, gender, military service,

and disease progression (i.e., negative symptoms). The combined qualitative and quantitative results demonstrated that people with ALS' decision-making for life-sustaining treatments is complex and ecologically systemic and warrants an evidence-based and process-oriented approach.

Interpretation of the Findings

In this section, I interpret the findings and compare them with the literature surrounding decision-making for life-sustaining treatments and the broader theoretical constructs of resilience and self-determination. First, I interpret the qualitative findings from the 12 qualitative survey items. Next, I interpret the quantitative findings. Then, I compare and contrast the qualitative and quantitative findings using a joint display table (see Guetterman et al., 2015).

Interpretation of Qualitative Findings

Research Question 1

How do socioecological resilience and self-determination contribute to people with ALS' decision-making for life-sustaining treatments?

Theme 1: Individual, Communal, Health Care, Philosophical, and Relational Resources Are Critical to Supporting people with ALS' Decision-Making. The participants made a total of 921 comments that referenced their resources. Whereas two participants stated that they did not have any resources that gave them strength, the remaining participants identified at least one resource. Many participants identified more than one resource and, collectively, identified a broad array of resources that gave them strength. The participants' most central and foundational resources were relationships

with their families, loved ones, and caregivers. Those relationship resources were coupled with spiritual ones involving God, faith, and church membership in many cases. Many participants regarded a sense of self as a strengthening resource, including their abilities, attitudes, life experiences, finances, intelligence, mindfulness, self-esteem, and skills. Others cited their doctors, clinics, hospice programs, medical equipment, counseling, and VA. Finally, some participants identified community resources that supported them, such as ALS support groups, the ALS Association, their places of residence, neighborhoods, technology, and their online communities. Table 51 lists the resources that the participants identified according to their respective ecological systems.

Table 51

Resources of Strength

Ecological system	Resource
Micro/mezzo systems	Abilities despite ALS, education or learning, finances, gratitude, help others, intelligence or skills, mindfulness or attitude, physical activity, self-esteem, stubbornness or fighting spirit, unique experiences or interests, caregiver, children, colleagues, family, friends or supporters, general relationships, neighbors, pets, siblings, spouse or life partner.
Exo system	Alcoholics anonymous, clinical trials/ research, computer or internet, durable medical equipment, doctor or clinic, employment, entertainment, hospice/ palliative care, medications or supplements, mental health, nature/outdoors, peer support, ALS support group, Veterans Affairs.
Macro system	ALS activism or advocacy, ALS Association, contributing to society, place of residence.
Chrono system	Cure or treatment, religion or spirituality.

The participants identified resources that represented each of the ecological systems. In my literature search, I did not find any articles that reported findings of people with ALS' resources; therefore, I could not compare these findings to others. However, these findings are consistent with the socioecological perspective, emphasizing how ecological resources systemically contribute to people with ALS' resilience (see Liebenberg & Moore, 2016; Ungar, 2018; Ungar et al., 2013).

Theme 2: Several Factors Influence people with ALS' Decisions for Life-Sustaining Treatments. For many people with ALS, decisions for life-sustaining treatments are not merely yes or no decisions at single points in time. Instead, these decisions are chrono-dependent processes influenced by tensions related to perceived burden, functioning, quality of life, loss, and disease progression at the time of making the decision and after the procedure. As discussed in Chapter 2, chrono-systemic interactions are woven into socioecological resilience, given its ties to Bronfenbrenner's biopsychosocial ecological systems perspective (Liebenberg & Moore, 2016; Ungar, 2015, 2018; Ungar et al., 2013). However, in my literature search, studies that applied the construct of time to decision-making were elusive and scant. Nonetheless, Ceriana et al. (2017) observed that the people with ALS in their sample who had a planned tracheostomy versus an unplanned one experienced more time between getting diagnosed and being tracheostomized. Ceriana et al. concluded that the people who had planned tracheostomies had more time to discuss and decide about getting a tracheostomy. Similarly, Hogden et al. (2015) found that some people with ALS felt that the time between diagnosis and needing a tracheostomy combined with being overwhelmed with

their disease progression and making many decisions simultaneously impacted their decision-making. They also found that people with ALS tended to have a "wait and see" approach to their decision-making (Hogden et al., 2015, p. 1777).

This study adds to Ceriana et al.'s (2017) and Hogden et al.'s (2015) assertions that time contributes to people with ALS' decision-making. I sampled people with ALS who were and were not tracheostomized, and my findings showed that people with ALS' decision-making does not stop after getting a tracheostomy. On the contrary, tracheostomized people with ALS must decide each day if they want to continue to live indefinitely. An evidentiary comment from one of the present study's tracheostomized participants gave context to a phenomenon I term *indefinite decision-making*, stating, "I sometimes regret my decision, especially since my other abilities have to [*sic*] deteriorated." This participant's comment suggests that some people with ALS might experience regret and internal conflict about having a tracheostomy. Consequently, people with ALS who have life-sustaining treatments must decide whether or not to continue to live in their progressed state with tracheostomies and PEGs. The chrono-systemic implication of decision-making is particularly salient when considering that people with ALS who are severely advanced in their progression might not be as communicative or able to have regular contact with their ALS clinics to discuss changing their decisions.

Factors such as perceived burden, functioning, quality of life, loss, and disease progression should also be considered in the decision-making process. Hogden et al. (2015) discussed briefly how three of those factors (disease progression, loss, and

functioning) contributed to their decision-making model; however, they did not focus on these factors in their study. For example, while Hogden et al. mentioned that fast progression rates impacted decision-making, they did not use it as a control variable (given the study's qualitative methodology) or address it in the context of decisions specifically for life-sustaining treatments. Similarly, while they acknowledged that people with ALS experience loss, they did not discuss *how* people with ALS' losses are connected to decision-making factors. Finally, while their study mentioned people with ALS' functioning in the context of the Amyotrophic Lateral Sclerosis Functional Rating Score-Revised, it did not attempt to associate functioning with decision-making (Hogden et al., 2015). It appears that the present study is the first to yield data that increases understanding about how perceived burden, functioning, quality of life, loss, and disease progression contribute to people with ALS' decision-making for life-sustaining treatments.

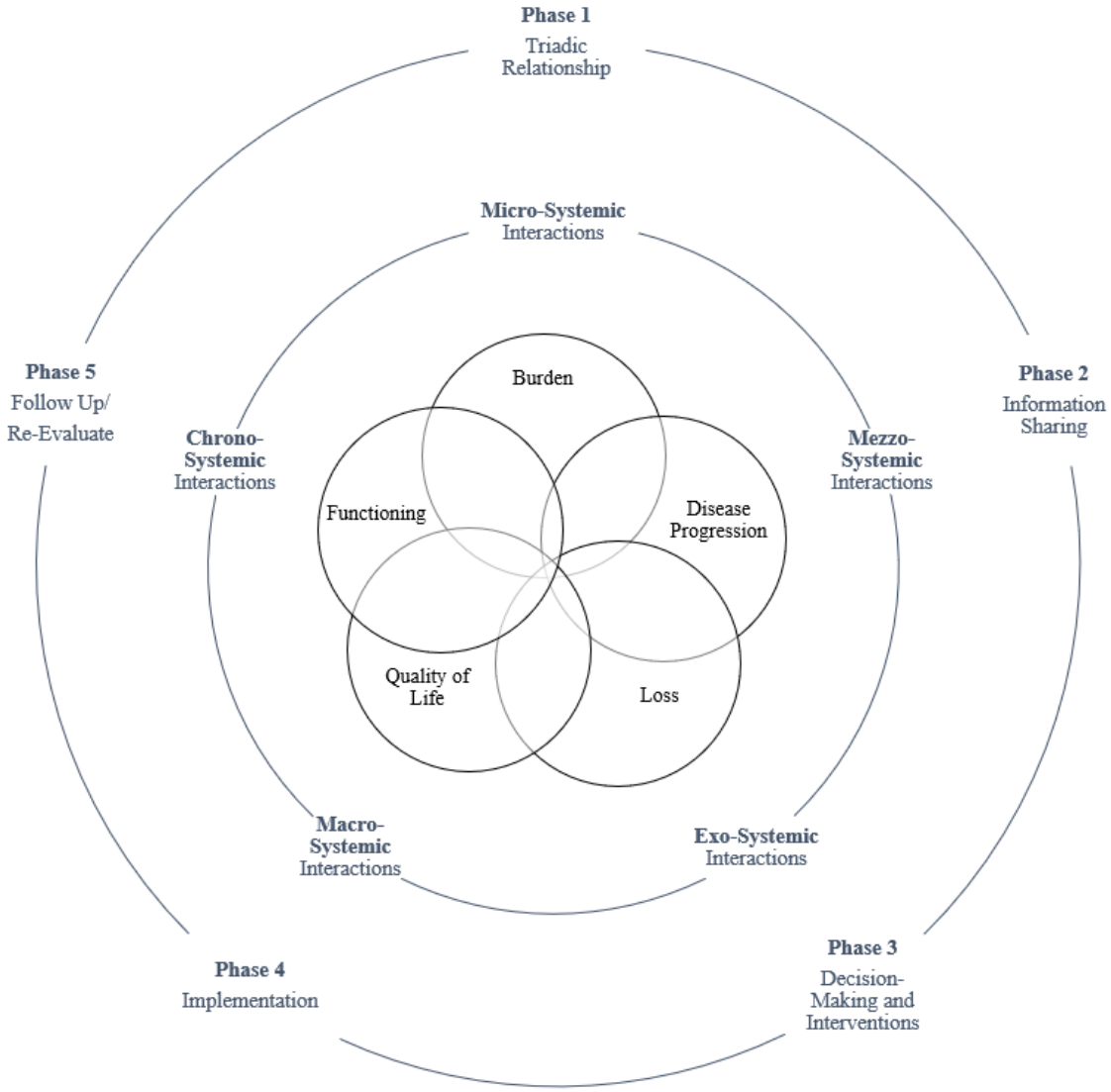
The data showed that people with ALS' perceived burden, functioning, quality of life, loss, and disease progression were tightly interwoven tension points in the decision-making process and indicated that these tensions can sway decisions in favor of or against life-sustaining treatments. Indeed, because these tensions seemed to be motivating factors throughout the decision-making process, there could be other triggers at play (not yet identified) that intersect with and cause people with ALS to choose for or against tracheostomies and PEGs. Rather than merely discussing the options available and having people with ALS answer yes or no for life-sustaining treatments, ALS multidisciplinary clinics must identify how these tensions affect their patients' decision-making. Hence,

people with ALS' decision-making for life-sustaining treatments is a fluid and multidimensional process that must be visited and revisited throughout the disease experience.

Figure 14 displays an *ecological decision-making model* that I propose ALS multidisciplinary social workers follow as they help their patients navigate the decision-making process. The model is comprised of the five decision-making tensions, five socioecological systemic interactions, and a process involving five phases to empower people with ALS' decision-making.

Figure 14

Ecological Decision-Making Model



The five primary decision-making tensions (see the Venn diagram at the center of Figure 14) are tightly woven with each other and represent the conditions that prevented or motivated this study's participants to get PEGs and tracheostomies. Amidst these tensions, the participants had unique thresholds of conditions and circumstances that they

would or would not be willing to accept when deciding about life-sustaining treatments. In addition to the five decision-making tensions, my ecological decision-making model entails five recursive phases (see the outer layer of Figure 14) that ALS social workers should consider implementing. The first phase is establishing a *triadic relationship* between the provider, the patient, and the family/caregivers. Building a productive relationship entails developing trust, compassion, and effective communication to foster an environment wherein the patient can make the best decisions for them (Hogden et al., 2015). The second phase, *information sharing*, involves sharing accurate facts and information surrounding life-sustaining treatments, including ideal timing, expectations, and potential outcomes, in a neutral manner for the person with ALS to consider. The third phase, *decision-making and interventions*, is the period during which the patient and family/caregiver make an initial decision about whether or not to get a PEG and tracheostomy. During this phase, the social worker must also determine whether or not specific conditions (i.e., perceived burden, functioning, quality of life, loss, and disease progression) or ambivalence would motivate or demotivate the person with ALS to get a PEG or tracheostomy. Social workers should consider performing motivational interviewing to help people with ALS who are ambivalent to become fully decided and remove barriers to empower their decisions. The fourth phase is *implementation*, which consists of helping the person with ALS follow through with their decisions to get life-sustaining treatments. The final phase is to *follow-up* with the patient on an ongoing basis to ensure they have not changed their decisions over time. This phase also includes

providing follow-up care to help the patient work through the residual fear, trauma, and emotional stress involved with their decisions.

Each phase in the ecological decision-making model is recursive, and people with ALS might repeat phases based on their experiences and disease progression. For example, some people might change their minds about getting life-sustaining treatments if their respiratory system progresses more quickly than their limb involvement. In contrast, other people with ALS might be less willing to get life-sustaining treatments if they feel that living with a tracheostomy would increase the burden on them and their families/caregivers. Additionally, building rapport and establishing productive relationships with ALS patients requires time and persistent effort. Therefore, ALS social workers must work consistently to improve and maximize relationships with their patients and family/caregivers. Regarding the information sharing phase, ALS social workers must be prepared and willing to share information with their patients on more than one occasion because each person will process and retain information differently. As Hogden et al. (2015) observed, ALS social workers must also be prepared to refer their clients to support groups and other reliable sources of information, such as the ALS Association, to ensure they are educated from a diverse array of sources independent from their ALS clinic.

As depicted in Figure 14, to fully support and empower people with ALS' decision-making, ALS social workers must help their patients navigate the decision-making process while simultaneously engaging the ecological systemic interactions (see the middle layer of Figure 14). Ecological systemic interactions play a critical role in

executing this ecological decision-making model. ALS multidisciplinary social workers must consider the micro, mezzo, exo, macro, and chrono-systemic interactions as they help people with ALS navigate the primary tensions in their decision-making. They must also consider these systemic interactions when applying the ecological decision-making phases to ensure their patients' strengths and resources are used and that all of the potential obstacles are addressed holistically.

This ecological decision-making model is consistent with much of Hogden et al.'s (2015) model, which proposed four cyclical decision-making stages. The first stage is the *engagement process* and entails the patient, caregiver, and health care providers establishing a collaborative relationship for each decision. The second stage, *option information*, is when the provider shares with the patient and caregiver the options available, the ideal timing, and the potential outcomes. The third phase, *option deliberation*, is when the patient, family, and/or caregiver deliberate and make decisions based on the information and discussions they have had with their health care professional. Finally, the fourth stage, *decision implementation*, is when the patient and the health care team implement the decision and carry out the intervention or plan (Hogden et al., 2015).

Hogden et al.'s (2015) decision-making model posited concepts similar to my model, such as establishing a triadic relationship, sharing information, and periods for decision-making and implementation. However, my ecological model differs from Hogden et al.'s in that it accounts for the five tensions that impact people with ALS' decision-making, the interplay of ecological systemic interactions, interventions that

clinical social workers can provide during the decision-making phase, and the process of following up with ALS patients on an ongoing basis to ensure their decisions are up to date.

Theme 3: People with ALS who can adapt to their situations and environments seem to be more willing to consider getting life-sustaining treatments. Adaptability is a central factor often incorporated into resilience frameworks, albeit with different applications. As it relates to socioecological resilience, adaptation is the ability for ecological systems to interact dynamically to facilitate coping and growth (Liebenberg & Moore, 2016; Ungar, 2015). For the present study, the data showed that the participants who were adaptable to their circumstances and environments seemed more amenable to, or at least open to the idea, of having life-sustaining treatments than those who were less adaptive. These participants' adaptability might have acted as a protective factor for their resilience (see Liu et al., 2017). Table 51 shows the adaptive resilience factors, which were generally positive, that I observed in relation to their corresponding interactive systems. While the participants' comments represented all of the ecological systems, the participants' comments were skewed toward the micro and mezzo systemic interactions, implying that the participants' perceptions of resilience were micro and mezzo centric. While the participants' comments tended to favor the micro-systemic interactions, from a birds-eye perspective, these results supported and corroborated other researchers' findings that resilience is an ecological process rather than merely an innate ability to overcome adversity (see Masten, 2014; Ungar, 2015, 2018; Ungar et al., 2013).

Table 52

Codes as Protective Factors that Contributed to Adaptive Resilience

Ecological system	Code
Micro/mezzo systems	Adapt, adapting to bounce back, attitude, being positive, building tolerance for adversity, caring or loving, changed decision, could change decision, day at a time, easier to bounce back, empathy, encouragement, grieving or acceptance, inner strength, learning or meaning in resilience, lighten burdens, live in the moment, no change, nothing will prevent, part of the process, positivity, problem solving, relationships, self-esteem, stubbornness or fighting spirit, talking or communication, thought continuum.
Exo system	ADLs, ALS clinic or doctor, physical resources.
Macro system	Forced by circumstances, hope.
Chrono system	Conditional, when necessary.

While the data supported an ecological systems approach to resilience, there were also micro systemic protective factors, such as building tolerance for adversity, bouncing back more easily, being stubborn, and having a fighting spirit that influenced the participants' adaptability. These codes were in congruence with traditional resilience theory, which emphasized how people's unique capacity and innate characteristics enable them to overcome adversity (see Garmezy, 1974, 1985, 1991; Garmezy & Nuechterlein, 1972; Liu et al., 2017; Rutter, 1987; Werner, 1989, 1993, 1997). More specifically, some of the participants from this study felt that overcoming adversity earlier in life made them more resilient and better able to withstand the adversity they expected to face as they progressed in their diseases. This finding is consistent with Rutter (2012), who elaborated

on the results from behavioral and neuroendocrinological studies showing that positively coping with periods of stress can increase one's ability to withstand future stressors.

Theme 4: People with ALS who are less able to adapt to their situations and environments seem to be less willing to consider getting life-sustaining treatments. Some participants were less adaptive in their resilience than others, which appeared to contribute to them being less inclined to choose to get life-sustaining treatments. Hogden et al. (2015) found that people with ALS' ability to accept and adapt to their circumstances was an essential element of the decision-making process. Hogden et al.'s (2015) finding was consistent with this study in that grieving and acceptance contributed to the participants' ability to adapt. However, just as adaptation contributed to resilience and choosing to get life-sustaining treatments, less adaptive systemic interactions appeared to contribute to some participants electing not to get life-sustaining treatments. Table 52 shows the codes of the risk factors that were generally negative and contributed to being less adaptive and unwilling to get life-sustaining treatments. The coding frequency for the negative exo- and chrono-systemic interactions of those who were less adaptive was higher than the positive exo- and chrono-systemic interactions of the adaptive protective factors. This contrast demonstrates the importance that exo- and chrono-systemic interactions have on people's ability to adapt, as Masten (2014), Ungar (2015, 2018), and Ungar et al. (2013) discussed. People with ALS who experience gaps in, or who have negative experiences with their exo- and chrono-systemic interactions, might experience more difficulty adapting and living with ALS than those who have robust and positive exo- and chrono-systemic interactions.

Table 53

Codes of Risk Factors that Contributed to Less Adaptive Resilience

Ecological system	Code
Micro/mezzo Systems	Age or life experiences, being a burden, death and dying, difficulty adapting, discomfort or pain, depression, EOL decision-making, everything, family/caregiver burden, family resources, fatigue, fear, finances or cost, functionality, harder to bounce back, hopelessness, incomplete rebound, invasive vs benefit, joy or happiness, long term planning, mindfulness, more help needed, natural death, none, nothing will motivate, no trach, nutrition, philosophical or beliefs, pleasure vs staying alive, physical, positive attitude or optimism, purpose and potential, resentment, resources or support, retirement, right to die, scared, takes longer, secondary health problems.
Exo system	Dependence on vent or others, doctor recommendation, interactions with health care team, restricted to machine, treatments or clinical trials.
Macro system	Contributing to society.
Chrono system	Progression or change in functioning, progressive or unrelenting, progressively more difficult, quality of life, unknown future, won't prolong death.

Theme 5: Relationships and connections are critical for people with ALS' resilience, self-determination, and ability to die with dignity. The findings showed that the relationships that participants had with other people were vital protective factors that enabled them to live more resiliently and die with dignity. In particular, relationships with family, spouses/partners, children, friends, health care providers, and supporting organizations such as the ALS Association, support groups, and VA were central indicators in how they coped with the day to day challenges they faced. This finding was

consistent with Hogden et al. (2015), who found that the triadic relationship between people with ALS, caregivers, and health care teams must be built on trust and partnership toward a decision. However, the present study adds to Hogden et al.'s (2015) findings in that the data showed that relationships beyond the family and ALS health care providers, such as friendships, neighbors, the ALS Association, support groups, other people with ALS, and VA, also impacted the participants' psychosocial well-being indelibly.

The socioecological perspective on resilience and self-determination theory (SDT) support this study's findings that relationships impact the participants' coping and decision-making. Ungar et al. (2007) conducted a qualitative study of adolescents spanning 11 countries and found family and peer relationships to be 1 of 7 interactive ecological "tensions" that facilitated resilience (p. 351). Similarly, in their study on adult child abuse survivors, Liebenberg and Moore (2016) observed that family and social/community relationships and a sense of belonging were critical micro and mezzo systemic interactions for fostering resilience in vulnerable adult populations. Likewise, SDT posits that the social environment, including positive and negative interactions and relationships, influence the degree to which people achieve the autonomy, competence, and relatedness needed for healthy motivation and well-being (Rocchi et al., 2017). In the backdrop of these theoretical underpinnings, the findings suggest that socioecological resilience and self-determination function adjacently and complementary to one another. The bivariate correlation test results between the independent variables supported this qualitative finding. Both my qualitative and quantitative findings support Perlman et al.'s (2018) study, which found that self-determination and resilience were related, and

Perlman et al.'s (2017) study, which found SDT's relatedness was a predictor for resilience. More research should be done to understand how the relationship between SDT and socioecological resilience contributes to people with ALS' decision-making.

Theme 6. The COVID-19 pandemic, the availability of a treatment/cure, and religious beliefs are environmental and supernatural forces that impacted people with ALS' resilience. The novel coronavirus (COVID-19) pandemic is an example of an environmental force that accentuated the participants' adversity and decreased their ability to cope with their challenges. Table 53 shows the 13 comments that the participants expressed across 4 response categories and spanned across 3 of the qualitative items.

Table 54

Comments Expressing How COVID-19 Affected Participants' Coping

Category	Sample of participant responses
COVID-19 robbed them of their time left alive to do meaningful activities	"I had a period of feeling useless, especially since the COVID-19 pandemic struck. I am a PA and have cared for patients for 40 years, and desperately wanted to return to work, but knew that I couldn't. My pastor suggested an activity for the church, which has given me purpose, and helped others." "Covid-19 has really taken its toll on my physical strength, not being able to go to the gym." "Knowing that my condition will only deteriorate, with no chance of improvement, has done 2 things. Positively, grab the moment and do what I want to do. Seriously work on the bucket list. Negatively, it has affected my ability to accept delayed gratification because realistically, if I can't do something now, I'll probably not have the ability in the future. Covis 19 has been a bummer." "Since Covid Stay at Home in place, have had to miss many trips and events, but understand it's for the best to stay away from people and I'm dealing very well with it." "With COVID19, my wife's care has been even more critical."
COVID-19 affected their family and social support	"I live alone and because I am answering this during the COVID-19 pandemic, I have no one else coming into my home. My husband died in December 2019, and I miss him." "Every day is a gift, but now with covid 18, riots, friends, family can't visit and I just feel like it's getting harder with getting up." "Folks are very interested in how I am doing. I see friends despite covid and it helps keep me grounded." "My friends and family would do more if not for COVID-19. Always asking what I need."
COVID-19 made it more challenging for them to get care and services/ resources	"Prior to Covid-19, I had several people pitching in to care for me. Since the coved I have not had that help to relieve so more guilt on my part. It was easier being a burden a lot of people than just one." "Will need a hoyer lift or similar, but no home assessment people are available during this pandemic. My husband is strong enough to transfer me, but if he gets hurt or sick I have no way of managing."

	"My partner lives 25 miles from me. He will come and drop meds off and water help where I need. Before the Virus he would come 3 times a week and stay over to help me. But I general help myself."
COVID-19 increased their anxiety about death and dying	"The recent pandemic is also an obvious concern in just remaining healthy." "Good at first, but now hoping for the Wuhan Virus."

Ungar et al. (2013) asserted that while other researchers, such as Rutter (2006) and Masten (2005), recognized that people's environmental interactions affect coping, they overemphasized interventions involving innate characteristics and underemphasized resource-oriented interventions to cope with adversity. As a whole, the data from this study support Ungar et al.'s (2013) assertions. However, the findings from this theme demonstrate that in some cases, such as with people with ALS (who have an untreatable and fatal disease) dealing with uncontrollable forces, such as COVID-19 that propel them into social isolation, people must rely more on their unique and innate attributes than on their resources, which are limited, to cope. Consequently, social workers must help their extremely vulnerable clients with ALS, who might be isolated from environmental resources, to recognize and utilize their unique and innate strengths while simultaneously leveraging environmental resources (to the extent possible) in creative and adaptive ways.

A pivotal uncontrollable environmental force that impacted some participants' decision-making was whether an effective treatment/cure existed, or if they felt researchers would discover one soon. The participants made 38 comments across 6 items that contained the words treatment or cure. Table 54 shows examples of the participants' statements that indicated how their decisions were motivated by treatments or cures.

Whereas some of the comments stated that they would not get life-sustaining treatments because researchers would not discover a treatment or cure soon, others were more optimistic and indicated that they would get life-sustaining treatments because they felt researchers were on the cusp of finding a cure. Still, others took a pragmatic approach and indicated that they would get life-sustaining treatments only if there were promising options for a treatment/cure that would reverse their disease progression.

Consequently, here again, people with ALS' decision-making is often not merely a yes/no decision. Instead, many participants based their choices on their circumstances across time. This finding appears to be new and not previously researched. I could not find any studies in which researchers investigated how the potential for a treatment or cure impacted people with ALS' decision-making.

Table 55

Comments Expressing How Decision-Making Was Motivated by Treatments/Cures

Category	Sample of participant responses
A cure not discovered soon	"As related to the use with ALS, with the current no cure possibility, in evaluating my personal deterioration rate, I don't at this time want to prolong my life in that state." "No need to prolong if no cure." "If there is no cure or life-sustaining treatment on the horizon at the point in time that I need to make the feeding tube decision, I believe I will *not* do it." "Clear leadership, well defined roadmap for intervention and mindset change by those in charge to develop effective treatment." "Mental anguish knowing there's no cure."
A cure discovered soon	"Motivation-prolong life until hopefully a cure is found." "The cure for ALS is certain and will come soon. I want to live to see my grandchildren be what they want to be." "If a cure was around the corner." "A cure."

	"A cure or life-sustaining treatment on the horizon at the point in time that I need to make the feeding tube decision will motivate me to choose a feeding tube." "Same as with the trach. A better technological or medical option may stop me from getting a feeding tube." "If there is hope that progress can be made to keep me alive with new treatments." "Not having access to experimental therapies that show potential to slow disease progression."
Reversing the symptoms/ progression	"Also, if ALS wasn't terminal." "A cure or a drug that helps to reverse the effects of the disease." "If I could recover from the illness and remove the machine I would do it." "I don't want to prolong my life because I have no hope of returning to my pre-als functioning." "If there is no hope of recovery I don't want the feeding tube." "If there is hope I could later be removed from it."

Finally, the participants made 97 comments attributing God, faith, the Bible, and their church communities as resources that gave them strength. This finding was consistent with Ungar et al.'s (2007) research on adolescents, which found that spirituality was a critical resilience factor in several areas, including identity, cohesion, and social justice. Additionally, Liebenberg and Moore's (2016) qualitative findings showed that spirituality played a role in helping adult child abuse survivors to find meaning in their traumatic events. While Bronfenbrenner (1979) characterized spirituality and religion as a micro-systemic interaction, the present study's findings supported spirituality as a supernatural energy force that provided strength toward resilience (see Richardson, 2002). In their systematic review, Koenig (2012) found that spirituality and religion helped people cope with internal/ biological adversity (genetic predisposition to mental disorders) and external adversity (environmental influences). Koenig (2012) also

found that people with devout spiritual beliefs and religious observance could cope with adversity and adapt to health problems better than those without spiritual beliefs. In connection with others, my findings suggest that spirituality and religious observance could be a supernatural force in people's lives, rather than merely an ecological interaction, that promotes resilience and vitality.

Theme 7. To gain a sense of control over their disease and circumstances, some people with ALS live resiliently and exercise their self-determination by choosing to die when and how they wish. There was evidence in the data that suggested that in their state of hopelessness and prolonged suffering, some participants sought to regain control over their circumstances by choosing not to get tracheostomies and PEGs. In their widespread international qualitative study of adolescents, Ungar et al. (2007) found that the participants used the limited resources at their disposal to care for themselves and others. Similarly, I observed that some of the participants decided to use their right to die, or their power to die naturally, find peace, and end the suffering happening to them and their loved ones. In that context, participants who decided not to have life-sustaining treatments were living resiliently in meaningful and triumphant ways, rather than prolonging their deaths. This finding is also consistent with Liebenberg and Moore's (2016) observation that researchers and clinicians must not approach resilience merely as a static outcome (in this case, living longer). Instead, this phenomenon should be understood as the dynamic leveraging of assets available to a person's unique ecological systemic interactions, particularly when their resources are limited.

Interpretation of Quantitative Findings

Research Questions 2 and 3

The quantitative RQs and their accompanying hypotheses were

What is the relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments?

$H_0$2: There is no relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

$H_1$2: There is a positive relationship between people with ALS' socioecological resilience and their decision-making for life-sustaining treatments.

What is the relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments?

$H_0$3: There is no relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

$H_1$3: There is a positive relationship between people with ALS' self-determination and their decision-making for life-sustaining treatments.

Interpretation of Primary Findings

To my knowledge, no other researchers have done studies that attempted to test the relationships between resilience, self-determination, and decision-making for life-sustaining treatments of people with ALS or any other population. The relationships between people with ALS' socioecological resilience, self-determination, and decision-making for life-sustaining treatments were not statistically significant. Instead, I found age, gender, military veteran status, and disease progression (i.e., negative symptoms) to

be significant predictors of their decision-making. The significant relationships were consistent across the measures and the type of life-sustaining treatment. For example, I found that age and military veteran status were significant predictors for tracheostomies and PEGs across all four models. I also found gender and disease progression (i.e., negative symptoms) to be significant predictors for PEGs for both measures. As such, the discussion that follows is relevant to both of the quantitative RQs.

Age was a significant predictor across all models, which showed that the participants were less likely to choose to get a tracheostomy and PEG for every increased year in age. This finding was consistent with Ducos et al.'s (2017) clinical observation study, which found that older ICU patients were more likely to limit or withdraw from life-sustaining treatments than younger patients. The two most cited rationales for the participants in Ducos et al.'s study to refrain from life-sustaining treatments were the severity of their illnesses and being advanced in age. Those rationales were similar to the participants' explanations in this study who were between 55-77 years old, many of whom cited their advanced age, experiences, and disease progression as rationales for their decision-making. Ducos et al.'s (2017) and this study's findings contradict those of Ting et al. (2017), however, which found that patients under the age of 65 were less likely to use extracorporeal membrane oxygenation than those over the age of 65.

The participants' military veteran status was also a significant predictor across all of the models and showed that being a military veteran increased the odds of choosing to get tracheostomies and PEGs. This finding may support Ungar et al.'s (2013) assertion that having access to and utilizing resources can facilitate adaptive coping and resilience

because military veterans have access to health care and financial entitlements that their non-veteran counterparts do not. Researchers should do more studies to ascertain this finding's causality, which could clarify which resource-oriented interventions would empower people with ALS' resilience and decision-making.

While the sample in this study consisted of over 10% more men than women, the frequency distributions for tracheostomies and PEGs by gender were mixed. For example, 29 men and 16 women indicated that they had or wanted to get a tracheostomy. Conversely, 63 women and 55 men indicated that they wanted to get or had a PEG, which was consistent with the binary regression tests that significantly showed that females were more likely to choose to get PEGs than males. The PEG results contradicted Ting et al.'s (2017) findings where male patients were more likely to get extracorporeal membrane oxygenation treatments than females. Ting et al. indicated that the differences between men's and women's outlooks on life and well-being could account for the gender disparities of end of life decision-making. Researchers should conduct more studies to understand the role that gender plays in people with ALS' decisions for life-sustaining treatments.

The disease progression (i.e., negative symptoms) variable was a significant predictor for PEGs. This finding is consistent with the second theme of the qualitative results, which found that the participants' disease progression was a factor in people with ALS' decision-making. While Hogden et al. (2015) acknowledged in their qualitative study that people with ALS' disease progression contributed to the participants' decision-making, the methodology did not permit them to establish a significant relationship. This

study's mixed methodology enabled me to make qualitative observations about and confirm a statistically significant predictive relationship between people with ALS' disease progression and their decision-making for life-sustaining treatments. However, more research should be done to understand why this finding applied to PEGs and not tracheostomies. Understanding this dichotomy is particularly crucial, given this study's qualitative findings supported disease progression being a factor for people with ALS' decision-making for both treatments.

Other Quantitative Findings

The strong positive relationship between the Basic Psychological Needs Satisfaction Scale and the Adult Resilience Measure-Revised (ARM-R) warrants some discussion. Perlman et al. (2017, 2018) conducted studies that examined the relationship between mental health patients' self-determination and resilience. While these researchers used the Connor-Davidson-Resilience Scale (CD-RS) to measure resilience, like this study, they found positive correlations between the participants' basic psychological needs and resilience (Perlman et al., 2017, 2018). This positive relationship implies that satisfying people with ALS' basic psychological needs could increase their resilience and ability to cope with the adversity that ALS brings. Miller and Gramzow (2016) conducted a study that used motivational interviewing interventions to support participants' basic psychological needs and to resolve their ambivalence about and increase their motivation to do physical activity. Similarly, experimental research should be done to determine if motivational interviewing can help people with ALS to resolve

their ambivalence about and increase their motivation to get, or not to get, life-sustaining treatments.

Finally, there was a tangential finding related to how the participants scored on the ARM-R compared to other studies. The participants' mean, median, and mode scores for the ARM-R were 47.5, 49.0, and 50.0, respectively. These data differed from Pagnini et al. (2011), which used the Resilience Scale for Adults and found that the resilience scores decreased with increased suffering. While this study had ARM-R scores as low as 31.0, only 14.1% of the participants had scores below 45.0; hence, the participants' resilience scores were remarkably high, despite many of the participants being quite progressed in the disease. Having high resilience scores despite the participants' overwhelming adversity was consistent with Parkin Kullmann et al.'s (2018) case-control study, which found that people with ALS who completed the CD-RS had higher resilience scores than the control group. It should also be noted that when answering the qualitative items, the participants were able to identify many resources that strengthened them in their adversity. This finding supports Ungar et al.'s (2013) assertion that the utility of resources contributes to adaptive and ecologically systemic resilience.

Joint Display of the Data

Table 54 shows the joint table display of the qualitative and quantitative findings that intersected, along with their respective mixed conclusions. I observed age, military service, and disease progression as biopsychosocial factors present across the qualitative and quantitative methodologies and impacted the participants' decision-making. Many of the participants who indicated in the demographic questions that they were not planning

to have tracheostomies and PEGs also provided conditions in their qualitative responses that would motivate them to get such treatments. The contrast between the qualitative and quantitative items indicated that many people with ALS' decisions were ambiguous and could change based on motivations and conditions, such as burden, disease progression, quality of life, loss, and functioning. Moreover, if provided additional resources to reduce family and caregiver burden, some people with ALS who otherwise would not, might be willing to consider getting life-sustaining treatments.

Table 56

Joint Display Table of Qualitative and Quantitative Findings

MMR conclusion	Qualitative finding	Quantitative finding
1. Older people with ALS who have had more life experiences are less likely to get tracheostomies.	Older age and life experiences were deterrents for choosing to get life-sustaining treatments.	Each year increased in age decreased the odds of people with ALS choosing to get a tracheostomy.
2. Military veterans with ALS have resources that non-veteran people with ALS do not, making them more likely to choose to get life-sustaining treatments.	Military veterans acknowledged the VA as a critical resource for health care and financial support.	Military veterans with ALS were more likely to choose to get tracheostomies and PEGs than people with ALS who were not military veterans.
3. The state of disease progression contributes to whether or not people with ALS choose to get/ maintain life-sustaining treatments.	Disease progression contributes people with ALS' continuum of decision-making about whether or not to get/ maintain life-sustaining treatments.	Each increase in negative symptoms of disease progression increased the odds of people with ALS choosing to get PEGs.
4. For many people, tracheostomies are not merely yes or no decisions. Some people with ALS who answer no also have specific conditions under which they might be willing to get a tracheostomy.	One hundred and forty comments communicated ambiguity about having/ getting a tracheostomy, or specific conditions that would motivate them to get one.	One hundred fifty-two (77.2%) people with ALS indicated they would not get a tracheostomy, and 45 (22.8%) indicated they would or already had one.
5. For many people, PEGs are not merely yes or no decisions. Some who answer no also have specific conditions under which they might be willing to get a PEG.	One hundred and forty-five comments expressed ambiguity about having/ getting a PEG, or specific conditions that would motivate them to get one.	Seventy-nine (40.1%) people with ALS indicated they would not get a PEG, and 118 (59.9%) indicated they would or already had one.

Limitations of the Study

While this study yielded significant and meaningful results, it also had limitations. The response rate was 1.2% (197 participants from a sampling frame of 16,583 people with ALS; therefore, the results might not be fully generalizable to the overall ALS population. Because only three participants were tracheostomized, their voices and attitudes likely did not represent the overall population of tracheostomized people with ALS. Also, while the descriptive statistics followed the trends of other recent studies (Bryan et al., 2016; Kaye et al., 2017; Mehta et al., 2018), racial minorities with ALS were likely underrepresented; therefore, the findings might not be fully generalizable to minority people with ALS. This disparity could have also contributed to selection bias, given the rate of high scores on the ARM-R. However, it should be noted that racial minorities' underrepresentation is not unique to studies involving ALS. A broad epidemiological strategy must be implemented to better ascertain racial minorities' health-related studies (Mehta et al., 2018; Ward et al., 2019). The findings regarding military veterans should also be generalized with caution because I did not over sample veterans. The sample size was also limited, particularly for people with ALS who did not have PEGs, which could have limited the regression tests' statistical significance. Another limitation was that I could not ask follow-up questions for clarification because the qualitative protocol was structured and administered online. Also related to the online survey, the participants' physical limitations working with technology and testing fatigue could have contributed to some of the missing quantitative data values. Finally, the results were limited to a single point in time, given its cross-sectional design.

Recommendations

The findings brought to light the need to explore various aspects of people with ALS' decision-making in future research. This study's research design should be replicated with a larger sample size while over sampling for people with ALS who are racial minorities, military veterans, below 55 years of age, and who have tracheostomies. When compared and contrasted with these findings, such a study would result in greater generalizability across the entire ALS population. Additionally, implementing this research design in a longitudinal framework spanning the time of diagnosis until after getting life-sustaining treatments would allow for cause and effect generalizations over time. Researchers should do follow up studies to validate indefinite decision-making and the five tensions involved.

Researchers should also consider employing an experimental design to evaluate and validate an accessible, intuitive, and interactive online decision-making web-application (seamlessly integrated with hospitals' data management systems) whereby people with ALS can establish and update their decision-making preferences at any point in time. While Levi et al.'s (2017) study examined if the Make Your Wishes Known computer-based decision-making aid helped people with ALS construct advance directives, the aid did not account for the decision-making tensions identified in this study. Developing and validating a decision-making application for research and clinical settings would enable researchers to understand people with ALS' decision-making more accurately and with statistical significance, keep hospitals informed of people with ALS'

decisions in real time, and empower people with ALS' decisions across the decision-making tensions and threshold.

Finally, there were theoretical implications of this study. The data yielded a new construct involving the five tensions that contribute to a threshold continuum of decision-making, which might have broader applications to SDT and the chrono-systemic aspects of the socioecological resilience perspective. More research should be done to understand how the five tensions and threshold continuum fit into the theoretical frameworks of self-determination and socioecological resilience. My findings also suggest that people with limited resources who become powerless in their environments, such as people with ALS, must rely more upon individual strengths and attributes than their resources to cope and adapt in their prolonged adversity. Researchers should examine how the dynamic interplay between innate characteristics and adults' coping capacities that sustain prolonged and progressive adversity fits the socioecological resilience perspective.

Implications

This study's findings have several implications for positive social change. The findings suggested that people with ALS who are military veterans could be more likely to choose to get life-sustaining treatments. That finding might be due, at least in part, to military veterans having more socioeconomic and health care resources than people with ALS who are not military veterans. Hence, these findings give an empirical rationale for increasing health care and financial resources for people with ALS who are not veterans. Increased financial resources, such as caregiver reimbursements, could decrease family and caregiver burden. Moreover, additional resources would empower people with ALS'

decision-making by enabling them to get life-sustaining treatments without being thrust into poverty. Providing more resources would also enhance people with ALS' socioecological resilience and fulfilling their basic psychological needs (i.e., autonomy, competence, and relatedness).

This study's qualitative and quantitative results yielded the ecological decision-making model, which establishes a process by which ALS multidisciplinary social workers and clinic teams can navigate the decision-making process with their patients better. The decision-making process for life-sustaining treatments should start soon after the patient is diagnosed and must be approached ecologically across time rather than merely sharing information and obtaining a yes or no answer. ALS multidisciplinary social workers must empower and advocate for people with ALS to be able to change their decisions at any time before or after getting the procedures. ALS social workers must advocate that their multidisciplinary teams establish a productive triadic decision-making relationship between ALS clinic providers, the people with ALS, and their families/caregivers. Moreover, ALS social workers must empower people with ALS' decisions in the context of the five decision-making tensions (i.e., burden, functioning, quality of life, loss, and disease progression) across time, both before and after the procedures are performed. Many participants stated that they would base their decision-making for life-sustaining treatments on their ALS physicians' recommendations, which demonstrates the power and influence that ALS providers can have on people with ALS. As such, ALS providers must be mindful of potential power differentials and encourage the triadic decision-making relationship toward a shared decision-making process.

This study also had parallels with Leach and Patall's (2016) study on need supporting advising with undecided students, albeit with different populations. In their study, Leach and Patall sought to examine the relationship between need supporting advising and meeting college students' psychological need satisfaction (i.e., autonomy, competence, and relatedness) to maximize their decisions when declaring a major to study. Similarly, given the strong positive correlation that was found between the participants' basic psychological needs and socioecological resilience, while respecting people with ALS' autonomy and decisions, ALS multidisciplinary social workers should consider employing motivational interviewing interventions with people who are undecided or who might be willing to get tracheostomies and PEGs if specific conditions are met. In those cases, social workers must also help people with ALS and their families remove the psychosocial and socioeconomic barriers that could prevent them from attaining the conditions under which people with ALS might be willing to get life-sustaining procedures.

Conclusion

This study was a community effort between me, the researcher, and the participants, which allowed hundreds of people with ALS to share their thoughts and perceptions about resilience, self-determination, and decision-making for life-sustaining treatments. Before undertaking this project, researchers had neither examined people with ALS' decision-making for life-sustaining treatments thoroughly, nor had they researched people with ALS' decision-making for life-sustaining treatments using socioecological resilience and self-determination as independent variables. Indeed, this study captured

people with ALS's experiences and perceptions from all stages of progression and levels of functioning. Furthermore, the quantitative methodology significantly predicted that covariates such as age, gender, military veteran status, and disease progression (i.e., negative symptoms) were related to people with ALS' decision-making. The findings filled gaps in the literature and brought additional literature gaps to light, which should be investigated in the future. Finally, this study yielded empirical rationales for positive social change to reduce people with ALS' burden, enhance their quality of life, improve their discussions and interactions with ALS multidisciplinary health care providers, and empower their decisions for life-sustaining treatments.

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Appendix A: Qualitative Protocol

The following are open-ended questions that will ask about your thoughts, feelings, and experiences related to resilience and decision-making for life-sustaining treatments, such as tracheostomies and feeding tubes. For questions 67-71, only answer only the ones that apply to you.

Answering these questions will give the researcher a more complete understanding of your views and experiences about resilience, self-determination, and life-sustaining treatments. Please consider answering the following questions truthfully and in detail; however, as with the previous sections of this survey, you are not required to answer any or all of these questions.

1. What resources do you have that give you strength?
2. What are the greatest challenges that you now face or that you think you will face since being diagnosed with ALS?
3. How has your ability to withstand and bounce back from trials changed since being diagnosed with ALS?
4. In what ways do your caregivers and loved ones impact your ability to live with ALS?

Appendix B: Adult Resilience Measure-Revised (ARM-R)

The next 17 items are from the Adult Resilience Measure-Revised (Jefferies et al., 2018) and will ask about your resilience. Your responses are voluntary and completely anonymous and confidential. Please answer how you feel about each item at the present time as truthfully as possible.

To what extent do the following statements apply to you? There are no right or wrong answers. Use the following scale to respond:

1	2	3
No	Sometimes	Yes

5. I get along with people around me
6. Getting and improving qualifications or skills is important to me
7. I know how to behave in different social situations (such as at work, home, or other public places)
8. My family is supportive towards me
9. My family knows a lot about me (for example, who my friends are, what I like to do)
10. If I am hungry, I can usually get enough food to eat
11. People like to spend time with me
12. I talk to my family/partner about how I feel (for example, when I am sad or concerned)
13. I feel supported by my friends
14. I feel that I belong in my community

15. My family/partner stands by me when times are hard (for example, when I am ill or in trouble)
16. My friends care about me when times are hard (for example, when I am ill or in trouble)
17. I am treated fairly in my community
18. I have opportunities to show others that I can act responsibly
19. I feel secure when I am with my family/partner
20. I have opportunities to apply my abilities in life (like using skills, working at a job, or caring for others)
21. I like my family's/partner's culture and the way my family celebrates things (like holidays or learning about my culture)

Scoring the ARM-R

The items in the ARM-R were all positively worded and equally weighted; therefore, scoring involved simply summing the responses together. The minimum and maximum scores possible were 17 and 51, respectively.

From "The CYRM-R: A Rasch-validated revision of the Child and Youth Resilience Measure," by J. P. Jefferies, L. McGarrigle, and M. Ungar, 2018, *Journal of Evidence Informed Social Work, 16*(1-2), p. 70-92 (https://doi.org/10.1080/23761407.2018.1548403). Copyright 2019 by the Resilience Research Centre, Dalhousie University.

Appendix C: Basic Psychological Need Satisfaction Scale (BPNSS)

The next 21 items are from the Basic Psychological Need Satisfaction Scale (Deci & Ryan, 2000; Gagné, 2003) and will ask questions about your autonomy, competence, and relatedness, which, according to self-determination theory, must be satisfied to make self-regulated decisions. Your responses are voluntary and completely anonymous and confidential. Please answer how you feel about each item at the present time as truthfully as possible.

Feelings I Have

Please read each of the following items carefully, thinking about how it relates to your life, and then indicate how true it is for you. Use the following scale to respond:

1	2	3	4	5	6	7
Not at all True			Somewhat True			Very True

22. I feel like I am free to decide for myself how to live my life.
23. I really like the people I interact with.
24. Often, I do not feel very competent.
25. I feel pressured in my life.
26. People I know tell me I am good at what I do.
27. I get along with people I come into contact with.
28. I pretty much keep to myself and don't have a lot of social contacts.
29. I generally feel free to express my ideas and opinions.
30. I consider the people I regularly interact with to be my friends.
31. I have been able to learn interesting new skills recently.

32. In my daily life, I frequently have to do what I am told.
33. People in my life care about me.
34. Most days I feel a sense of accomplishment from what I do.
35. People I interact with on a daily basis tend to take my feelings into consideration.
36. In my life I do not get much of a chance to show how capable I am.
37. There are not many people that I am close to.
38. I feel like I can pretty much be myself in my daily situations.
39. The people I interact with regularly do not seem to like me much.
40. I often do not feel very capable.
41. There is not much opportunity for me to decide for myself how to do things in my daily life.

People are generally pretty friendly towards me.

Scoring Information.

Form three subscale scores, one for the degree to which the person experiences the satisfaction of each of the three needs. To do that, you must first reverse score all items that are worded in a negative way (i.e., the items shown below with (R) following the items number). To reverse score an item, simply subtract the item response from 8. Thus, for example, a 2 would be converted to a 6. Once you have reverse scored the items, simply average the items on the relevant subscale. They are:

Autonomy:1, 4(R), 8, 11(R), 14, 17, 20(R)

Competence: 3(R), 5, 10, 13, 15(R), 19(R)

Relatedness: 2, 6, 7(R), 9, 12, 16(R), 18(R), 21

From “The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior,” by E. L. Deci and R. M. Ryan, 2000, *Psychological Inquiry*, *11*(4), 227-268 (https://doi.org/10.1207/S15327965PLI1104_01). Copyright 2000 by the Center for Self-Determination Theory.

Appendix D: Demographic Items

Please complete the following demographic information. Please note that your information is anonymous and confidential. If you do not feel comfortable answering a question, please skip it and move on to the next question. While your responses are voluntary, this information will greatly enhance the researcher's findings.

42. **Age:** What is your date of birth? Please use the format MM/DD/YYYY _____

43. **Gender:** With which gender do you most identify?

    Male _____

    Female _____

    Other (please specify) _____

44. **Ethnicity:** With which ethnicity do you primarily identify?

    White or Caucasian _____

    Black or African American _____

    Hispanic or Latino _____

    Asian or Asian American _____

    American Indian or Alaska Native _____

    Native Hawaiian or Pacific Islander _____

    Other (please specify) _____

45. **Marital Status:** What is your current marital status?

    Single, never married _____

    Married or marriage-like relationship _____

    Widowed _____

Separated _____

Divorced _____

46. **Children:** How many children do you have? _____

47. **Income:** In the past 12 months, what was your total household income before taxes?

Please answer in this format $10000.00 _____

48. **Health Status:** Have you been diagnosed with ALS?

Yes _____

No _____

49. **Health Status:** In what year were you diagnosed with ALS? _____

50. **Health Status:** At the time of completing this survey, do you have a tracheostomy?

Yes _____ ***(If Yes, skip to Questions 12 and 13)***

No _____ ***(If No, skip to Questions 11, 14, and 15)***

51. **Health Status:** Are you planning to get a tracheostomy to prolong your life?

Yes _____

No _____

52. What are your thoughts about having a tracheostomy?

53. What motivated you to get a tracheostomy?

54. What are your thoughts about getting a tracheostomy?

55. What would motivate or prevent you from getting a tracheostomy?

56. **Health Status:** At the time of completing this survey, do you have a feeding tube?

Yes _____ ***(If Yes, skip to Questions 18 and 19)***

No _____ ***(If No, skip to Questions 17, 20 and 21)***

57. **Health Status:** Are you planning to get a feeding tube to prolong your life?

    Yes _____

    No _____

58. What are your thoughts about having a feeding tube?

59. What motivated you to get a feeding tube?

60. What are your thoughts about getting a tracheostomy?

61. What would motive or prevent you from getting a tracheostomy?

62. **Health Status:** Do you know what an advance directive is?

    Yes _____

    No _____ ***(If No, skip to Question 18)***

63. **Health Status:** Have you completed an advance directive to document your choices regarding a tracheostomy or feeding tube?

    Yes _____

    No _____

64. **State of Progression:** Please indicate your current level of functioning. ***Select all that apply.***

    I can walk on my own power, even for short distances _____

    I rely on a wheelchair for mobility _____

    I can use my hands for everyday tasks and self-care _____

    I can breathe on my own without the `need for ventilatory support _____

    I rely on the use of invasive or non-invasive ventilation when I sleep _____

    I rely on the use of invasive or non-invasive ventilation during the day _____

I can use my natural voice to speak so others can understand _____

I rely on a speech-generating device to speak to others _____

I rely on eye gaze technology for all communication and personal tasks _____

I can eat by mouth _____

I rely on a feeding tube for supplemental nutrition or hydration _____

I rely on a caregiver to do all of my activities for daily living _____

65. **Setting:** Please indicate the setting you are in while completing this survey. ***Select all that apply*.**

Wheelchair _____

Bed _____

Assistive speech/ eye gaze device _____

Smartphone _____

Desktop or laptop computer _____

A caregiver is helping me _____

Home of residence _____

Nursing home or community living center _____

66. **Military Service:** Are you a United States military veteran?

Yes _____

No _____

67. **Health Insurance:** What type of health insurance do you have? ***Select all that apply.***

Medicare _____

Medicaid _____

Private Insurance _____

Veterans Affairs/ TRICARE _____

Other or none (please specify) _____

68. **Financial Burden:** On a scale from 1 to 5, with 1 being Strongly Disagree and 5 being Strongly Agree, how much do you agree with the following statement: Since being diagnosed with ALS, my family's financial stability has been compromised.

1	2	3	4	5
Strongly Disagree		Neither Agree nor Disagree		Strongly Agree

69. **Financial Burden:** Have you or your family had to file for medical bankruptcy due to financial constraints from ALS?

Yes _____

No _____

*Note, the first item on the survey will be from the informed consent and will read as, "If you feel you understand the study well enough to make a decision about it, please indicate your consent by clicking "Yes" to participate in the survey." For this reason, the demographic items start with number 2.

Appendix E: Recruitment Letter

Hello, my name is Jeremy Van Tress. I am a student at Walden University. I am also a person living with ALS. I am doing this study to understand more about the decisions for life-sustaining treatments of people with ALS. This study is also required to complete my doctoral program.

To take part, you must be at least 18 years old. You must be diagnosed with ALS and registered with the National ALS Registry. You must also be able to make your own decisions.

The survey is voluntary and anonymous. You can use a smartphone, laptop/desktop computer, tablet, or a speech assisting device connected to the internet to complete the survey. Please click this weblink https://www.surveymonkey.com/r/FKK3GMH to take part.

The survey will take about *30 minutes*, depending on your abilities. People who use eye gaze technology might need more time. I encourage you to take breaks as needed. You are not required to answer any of the items. Your responses will strengthen the study and could help others with ALS in the future. You have 1 month from receiving this invitation to respond, or until 250 people complete the survey, whichever comes first.

Some people who complete the survey may experience anxiety or depression after participating in this study. If you need help or feel anxious or depressed after responding, you can contact the following agency 24 hours a day 7 days a week:

The Crisis Text Line: Using your mobile device, text 741741 for assistance. You can learn more about the Crisis Text Line by visiting https://www.crisistextline.org/.

The results of this study will be reported and shared with ALS researchers, ALS health care providers, and people with ALS. You may email me at the email address listed below with questions or to request a copy of the results. Thank you for taking part in this study and all the best.

Sincerely,

Jeremy J. Van Tress, MSW, CSWA
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Principal Investigator
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