

Learning How Older People Form Sense of Coherence through an Interpretation of Their
Experiences of Decline and Serious Illness during a 30-Day Readmission:

An Interpretive Description

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I declare that this thesis is my own work and has not been submitted for the award of a higher
degree elsewhere.

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Abstract

Learning How Older People Form Sense of Coherence through an Interpretation of Their Experiences of Decline and Serious Illness during a 30-Day Readmission:

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Background: Older people with multiple comorbidities and frailty are frequently and repeatedly readmitted to acute care hospitals within 30 days of their previous discharge from the hospital. This phenomenon takes a toll upon their physical reserves and emotional stamina. These losses become serial at this time of life. As one ages there are experiences of serial losses of friends, family, other social support and physical independence. Such serial losses have been conceptualized by Antonovsky's "General Resistance Resources" and may also affect how one views the world as predictable and manageable, a so-called "Sense of Coherence". Understanding this Sense of Coherence in these patients may help prevent negative changes and help design appropriate interventions.

Literature Review: A systematically constructed literature review using an integrative design was conducted to understand the characteristics of older adults who are readmitted to the hospital within 30 days of their last discharge. PubMed, Embase and CINAHL were searched for peer reviewed published studies investigating 30-day readmissions of people aged 65+. Found studies (n=24) primarily used quantitative cohort designs (n=23). Frailty, co-morbid conditions, and polypharmacy were common. The single qualitative study (n=3 interviews) identified that lack of communication between healthcare providers may be a concern. Further qualitative enquiry is needed to explore this phenomenon in more depth.

Empirical Study: The purpose of the empirical study was to examine how 30-day readmissions, physical decline and serial losses may affect older people's Sense of Coherence. Using an Interpretive Description design, a purposive sample of people aged 65+ at the time of a current 30-day readmission to an academic U.S. hospital was recruited. Data were collected using semi-structured interviews. Directed Content Analysis was used to evaluate and interpret the data, using concepts from Sense of Coherence as *a priori* codes, supplemented by inductive coding.

Two new concepts were identified: Incomprehensibility and Devolving Sense of Coherence. These are new contributions to the theory of Salutogenesis and the construct of Sense of Coherence.

Sense of Coherence near the end-of-life differs greatly from Sense of Coherence for those who are healthy or living with mild illness. Participants who have Comprehensibility as a result of forthright communication appear to have better manageability than those with Incomprehensibility and poor communication regarding their disease processes and prognoses. When participants suffer serial losses with Incomprehensibility it may result in a Devolving Sense of Coherence at the end-of-life.

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Chapter 1. Introduction

1.1 Background and Overview

My recent observations as a palliative care nurse practitioner in an acute care hospital sparked an interest in the area of study for this thesis. There I observed very sick older people coming into the hospital with frailty and chronic progressive diseases. These patients frequently received what I perceived to be overtreatment, sometimes referred to as overdiagnosis (Armstrong, 2018; Jenniskens et al., 2017). Overtreatment are “instances in which the diagnosis is correct according to current standards but the diagnosis and associated treatment has a low probability of benefitting the patient, and may instead be harmful” (Armstrong, 2018). This overtreatment would often result in further physical decline. This decline results in the patient becoming more deconditioned than when first admitted to the hospital. These same individuals were then often readmitted to the hospital within a very short period of time. It was apparent that further exploration of this phenomenon was needed to learn the effect on patients from the patient perspective, and potentially find ways to avoid the phenomenon of frequent readmissions to the hospital. This thesis endeavours to help further understanding of this problem.

Early in my career during my first year as a hospice nurse, I went to admit a patient who lived in a skilled nursing facility in the long-term care unit. This was a 96-year-old woman with advanced dementia. She was non-ambulatory, incontinent, with severe lower and upper limb contractures, and had a parenteral feeding tube in her abdomen. She had tested positive for resistant strains of Staph Aureus in her urine and E.coli at her feeding tube site. Over the course of the previous three months the patient had two hospitalizations which included a three-week Intensive Care Unit stay whilst being treated for Methicillin-Resistant Staph Aureus Pneumonia. She was returned to her

facility and returned to the Intensive Care Unit less than a month later with Vancomycin Resistant Enterococci sepsis. She returned to her facility and the next day whilst receiving incontinence care during positioning an attendant heard and felt a snap in her hip. The staff sent her to the emergency department where it was determined she had suffered a hip fracture. The emergency doctor refused to admit her and sent her back to the hospital with a referral to hospice.

At that time, I conducted a goals of care discussion with the husband who agreed it was time to stop artificial nutrition and hydration. When I told the nurse in charge, she frantically blocked the door and loudly told me that I was murdering the patient. After some amount of discussion through tear blurred eyes, she said “I guess the best thing would have been to never start the tube feeds”

I once had a patient with end stage renal disease who was frail and had congestive heart failure and had refused haemodialysis. She requested to go home with hospice. A young and zealous nephrologist convinced her that she would benefit from the dialysis. When asked “What do you think you accomplished by changing her mind?”, his response was “I saved her life”. So, we find ourselves in an environment of overtreatment which oftentimes is accompanied suffering (Armstrong, 2018; Druml & Druml, 2019; Hoffman, 2017; Jenniskens et al., 2017). I have no idea how the patient fared after the start of haemodialysis, but we do know the average life expectancy after the start of dialysis in this population averages 2.5 years. We also know that such patients report a significant decrease in quality of life and functional status (Ifudu et al., 1994; Wong et al., 2012)

This thesis arose from this, and similar experiences, as I witnessed the result of overtreatment of very sick older patients who receive procedures and treatment that are unlikely to make them physically whole and will probably decrease their quality of life (Casarett et al., 2020; Hoffman,

2017). These same patients were discharged only to return with a subsequent infection or other complications within days to weeks.

As an inpatient palliative care provider, I perceived resistance from other providers and nurses regarding the de-escalation of care for such patients. There seemed to be a failure to reflect upon the meaning of this furthered weakness, and so, the cycle repeated. This is a phenomenon that Hillman dubbed “The Western Medicine Conveyor Belt” (Hillman et al., 2015). Often regardless of the patient’s advanced illness or frailty they are provided the care based on the “standard of care” without considering the risks and benefits to the seriously ill or frail patient.

In addition, I was greatly influenced by the writings of Eric Cassell. He has written many insightful books and articles regarding the relationships between providers and the very sick (Cassell, 1976, 2004; Cassell, 2005; Cassell, 2009; Cassell et al., 2001). These writings include the power structure of such relationships. Also, he muses regarding the differences in communication abilities of the very sick. His work has formed my practice and ideas that led to this thesis (Cassell, 1985; Cassell, 2005; Cassell, 2009; Cassell, 2012, 2016; Cassell et al., 2001).

Many of these patients are suffering, vulnerable, and lack insight regarding their circumstances (He et al., 2016). Frequent hospital admissions take a toll upon the patients’ physical reserves (Timmer, 2014). Also, these admissions affect the patients' ability to manage and cope with their circumstances. There is variability in how these sick and older patients respond to serious illness in regard to a loss of function, symptoms, frequent encounters with the medical system, and changes in how they engage with the world based on the amount of social support received, socio-economic status, level of anxiety, depression, and countless other factors.

The seriously ill older population often require frequent hospitalizations prior to the realization of the healthcare team or the patient and family realizing the need for palliative care. Frequent hospitalizations are referred to as 30-day readmissions in the United States (Centers for Medicare and Medicaid Services, 2012, 2016). This thesis focuses upon 30-day readmissions and their effects on the older and seriously ill. It is important to note that frequent readmissions of the seriously ill older population is an international problem. However, this thesis and study are decidedly U.S. centric as the healthcare financing and punitive policy for 30-day readmissions are largely unique to the U.S. (He et al., 2016; Mather et al., 2015).

These patients consent to such treatment because they are often unaware they have other choices (Thorsteinsdottir et al., 2013). These choices are consideration of accepting these treatments in total, or to partially accept certain parts of the recommendations from the healthcare team. The patient may choose comfort care, which is to live with their condition and accept only treatment that will improve their comfort and quality of life, and to allow a natural death (Chen & Younger, 2008; Keleman & Groninger, 2018).

There are contributing factors as to why the conveyor belt phenomenon occurs. The least cynical of these is that providers believe they are behaving benevolently (Fried et al., 2003; Jeffs et al., 2014). One such factor includes an asymmetry of power within the patient provider relationship (Cassell, 2005; Ploug & Holm, 2015), and consent is often obtained without any exploration of the patient's values and wishes for their lives (Chavez et al., 2018; Dilworth et al., 2012). Overtreatment will be discussed further in this chapter.

This chapter includes a review of the history of 30-day readmissions, and the associated economics, prevalence, policy and the systemic and demographic issues affecting 30-day

readmissions. In addition, a brief review of palliative care and hospice in the United States is presented. This is for the purposes of describing how palliative care and hospice is different than many other models internationally. It will also discuss the theory and methodology chosen for this thesis.

1.2 Prevalence, Economics and Policy of 30-Day Readmissions

The policies regarding 30-day readmissions to the hospital and the prevalence of these readmissions are discussed in this section. The chapter includes a presentation of how economic and healthcare policy influence systemic issues regarding 30-day readmissions of older adults. Whilst the phenomenon of frequent and early readmissions has been occurring within the older population for decades and intensive efforts to decrease this phenomenon have been mildly successful, the likelihood of these numbers increasing in the United States are good. This will be further examined.

The prevalence of thirty-day readmissions for older people has decreased over the last two decades. The Readmission Reduction Program incited many interventions, and healthcare delivery changes in an attempt to avoid penalties. In the year 2013, the rate of older adults who were discharged from an acute care hospital were readmitted to an acute care hospital within 30 days in the United States for this population was 16%. Five years later, in 2019 this number decreased to 15% annually (Arias-Casais et al., 2019). These are many of the very sickest patients in the U.S. Whilst at first glance this seems to be an improvement, it is known that older adults with multiple comorbidities have the greatest number of frequent readmissions which drives more than half of all health care costs in the United States and these costs continue to grow (Meier, 2015).

In the United States this population of older adults is expected to be larger than the population of children by 2030 (Vincent & Velkoff, 2010). Between the years 2010 and 2050 there is an anticipation of a growth of 42 percent in the U.S. (Vincent & Velkoff, 2010). A population of those over 65 years was 310 million in 2010, to a prediction of 439 million worldwide by 2030 (Vincent & Velkoff, 2010). With the anticipation of a population of people over the age of 65 years reaching 61 million in the U.S. by the year 2030, the U.S. health care system must address the problem of 30-day readmissions (Knickman, 2002). These are important data, as the driving force of U.S. policy are frequently financial concerns. Left unchecked, the number of these 30-day readmissions will grow in proportion with the increase of the ageing population. The United States ageing population increase is consistent with predictions regarding the world population. The number of older people is expected to increase by 60% over the next 10 years (He et al., 2016). Understanding how we can better care for and manage this onslaught of an ageing population is necessary to meet the populations needs in a sustainable manner.

This study will focus on the experiences of serious illness of older people during a 30-day readmission in the United States. The healthcare system in the United States has a unique and convoluted payment system with penalties, benefits and access that differs from most of the world. In 2010, as part of the passage of the Affordable Care Act, the Centre for Medicare and Medicaid Services began to study the ramifications (McIlvennan et al., 2015). Understanding how we can better care for and manage the anticipated onslaught of an ageing population is necessary to meet this groups needs in a sustainable manner.

In addition to these systemic issues, there are other contributing factors to 30-day readmissions which are beyond the control of the patients. These issues include insurance, utilization of services, as well as disease burden, frailty, socioeconomic class and ethnicity (Enguidanos et al., 2012;

Whitney, 2016). This information is important as the U.S. Medical System relies upon fiscal outcomes to determine policy.

The social and demographic issues regarding 30-day readmissions are intricate. The policies which affect healthcare access and resources are controlled by many separate bureaucratic institutions, such as health care settings, third-party payers (private insurance companies), the Centre for Medicare and Medicaid Service regulations, housing authorities, and other resources.

As an example, the type of insurance an older person has provides insight as to the amount of access the participant has to healthcare. Those with dual coverage have Medicare, which is the “socialized” medical insurance for older and disabled Americans, as well as Medicaid, which is a "safety-net" healthcare insurance provided to low-income individuals. Medicare insurance requires co-payments from individuals for their health services, whilst Medicaid does not require such co-payments. Medicare-advantage is a managed care program which older patients may choose to decrease or eliminate their co-payments for their regular visits than if they have “fee-for-service” Medicare.

There is a great deal of literature on the underutilization and lack of access to palliative care (Enguidanos et al., 2012). Also, there is evidence of inadequate prognostication and communication, which is an area of speciality of palliative care (Chang et al., 2014; Enguidanos et al., 2012; Hancock et al., 2007). There is also evidence of positive outcomes for patients who receive palliative care who have a serious illness which includes a reduction in 30-day readmissions (Gagne-Henderson et al., 2017). The following section further discusses palliative care in the United States.

1.3 Palliative Care in the United States

In 1981, the Medicare Hospice Benefit was written and passed by the U.S. Congress and signed into law (Conner, 2007). This allowed Medicare beneficiaries to elect hospice services in exchange for their hospitalization benefits. Hospice is an active choice and must be elected by the patient or the family if the patient does not have capacity. This means that beneficiaries must agree not to return to the hospital. Hospice is not provided in the hospital as hospice is paid for by the hospital benefit. Some hospices lease beds from hospitals so as not to have to precariously move the imminently dying. Most hospice care in the U.S. is provided in the patients' homes.

In 2018 only 53.8% of all eligible individuals elected the hospice benefit (National Hospice and Palliative Care Organization, 2020). Many people continued to spend the end of their lives in the hospital setting. We know that approximately 80% of Americans would prefer to die at home (Stanford, 2020), yet only 30.7% achieve this goal (Cross & Warraich, 2019). Other sites of death include skilled nursing facilities (20.8%), hospice facilities (8.3%), and hospitals (29.8%). In the U.S. there is an axiom that "hospice is a program, not a place". There are very few hospice facilities and most hospice is delivered in the patient's home or nursing facility. The term palliative care entered the U.S. medical lexicon as a response to the need for alternatives to hospice (Meghani, 2003). Hospice is intended only for patients in the last 6 months of their lives as attested to by two physicians (Centers for Medicare and Medicaid Services, 2008). Palliative care may be received at any time during the trajectory of an illness (Center to Advance Palliative Care, 2011). Inpatient hospital-based palliative care programs were established with the recognition that few patients were opting for hospice and that patients were dying with overtreatment and a high symptom burden in the hospital (Center to Advance Palliative Care, 2011; Meghani, 2003). Many of these patients were those who received aggressive, overtreatment until their deaths (Armstrong, 2018;

Druml & Druml, 2019; Handforth et al., 2014; Hoffman, 2017; Ifudu et al., 1994; Jenniskens et al., 2017; Thorsteinsdottir et al., 2013).

An additional benefit to those who are referred for hospice is that they are mandated to receive access to a full interdisciplinary team as well as access to a 13-month bereavement programme (Centers for Medicare and Medicaid Services, 2008). Frequently, patients do not die in their preferred place is due to the lack of planning and end-of-life discussions (Agar et al., 2008). These additional benefits are not typically available through palliative care whilst they are mandated in the hospice regulations (Centers for Medicare and Medicaid Services, 2008).

1.4 Overtreatment at End of Life

Overtreatment is considered treatments and interventions that have little to no benefit to the patient. It is also associated with treatment which are performed upon the patient to which the patient is not fully informed (Noah & Feignson, 2017). Amongst the lack of information include values, quality of life and goals of the patient. If fully informed consent is achieved it may be learnt the patient would not choose such interventions for themselves (Armstrong, 2018; Druml & Druml, 2019; Hoffman, 2017). Overtreatment is closely associated with what is known as overuse of medical services (Brownlee et al., 2014). As well as treatments and interventions, the concept of overuse of medical services also includes polypharmacy and hospitalizations. It is important to clarify that patients often receive overtreatment with full consent which is their right. More work regarding the offering of such treatment to patients needs to be done on the bio-ethical level as well as the more utilitarian aspect of wasted resources.

These circumstances are manifested to the greatest extent in Intensive Care Units, where most patients are sedated and placed on artificial life. These are the very sickest patients in the hospital

(Cassell, 2005; Druml & Druml, 2019; Hoffman, 2017). In addition, it is known that being very ill in and of itself impairs the ability to communicate (Cassell et al., 2001). In turn, this inability to communicate leaves surrogate decision makers to make choices without the patient's involvement or consent (Verceles & Bhatti, 2018). It is known that surrogate decision makers frequently do not understand the wishes of the patient and this may create a greater risk of overtreatment (Perkins, 2007; Whitlatch et al., 2009).

1.5 Access and Payment for Palliative Care

There is greater access to non-hospice palliative care during the time the patient is in the hospital. As of 2019 in-patient palliative care is currently available at 72% of all U.S. hospitals (Morrison, 2013). There are increasing numbers of outpatient services available in the form of ambulatory care clinics at large academic centres and large non-profit medical centres (Meier & Beresford, 2008; Rabow et al., 2013). The remaining gap in care for the palliative specialty in the United States are those services which are delivered in the community in the home of the patient (Kamal et al., 2013). Currently, Medicare will pay for visiting nursing services in the home for patients requiring skilled nursing needs who are not hospice patients. If the patient continues to elect aggressive treatment and does not have a skilled nursing need and does not choose hospice, they lose their home nurse. Medicare does not provide specialized home palliative care other than for those who elect to forego curative measures and choose the hospice benefit. There is no specialized palliative care routinely available to patients in their home (Kamal et al., 2013).

With the recognition of the millions of homebound patients who would benefit from palliative care there are efforts to increase access to palliative care in the home (Landers, 2016; Leff et al., 2015). Currently, there are estimates that four million Americans are homebound and unable to leave their

place of residence to seek primary or palliative care (Leff et al., 2015). There have been some efforts to provide palliative care to nursing home residents (Lima & Miller, 2018; Stone et al., 2019). This is likely because of the ease of seeing more than one patient at a time in a facility. Whether in their own homes or in nursing homes, access to palliative care remains a challenge in the U.S. for these patients.

1.6 Significance of the Research

There is a paucity of evidence describing the experiences of older adults facing 30-day readmissions which will be discussed further in Chapter 2. Understanding the perspective of older adults' experiences of 30-day readmissions may lead to better interventions to improve outcomes. There is a need for qualitative inquiry regarding this phenomenon. Asking older adults what they have experienced, feel and need regarding 30-day readmissions will prove valuable, not only in the possible prevention of 30-day readmissions but also in the prevention of the emotional, physical and psychological costs this population currently endures. The next section will discuss the adaptation of the theoretical framework of the thesis.

1.7 Theoretical Framework and Methodology

The thesis is focused upon how factors related to 30-day readmissions may affect one's Sense of Coherence as they experience a loss of function, independence and other General Resistance Resources (Antonovsky, 1979, 1987).

As such, Antonovsky's construct of Sense of Coherence is the theoretical framework for this thesis (Antonovsky, 1979, 1987). This study will seek to learn about how older people form their Sense of Coherence in the presence of serious illness and increasing debility. This is accomplished

through listening to experiences during a 30-day readmission and their lives outside of the hospital. From the perspective of palliative care, the primary approach to understanding circumstances is achieved by qualitative interviewing and listening to patients' perceptions and experiences. This is the theoretical thread which binds this thesis together. The results of this thesis may inform clinicians of how they might better help older people gain an understanding of what is happening to them and to intervene in a manner that will help prevent the phenomenon of 30-day readmissions and form a healthy Sense of Coherence.

As a palliative care nurse, it is difficult to disregard prior knowledge from the perspective of the discipline of palliative care nursing. The selected methodology of Interpretive Description encourages the use of prior knowledge from one's discipline. In her methodology, Thorne describes nursing as an integration of the social sciences and the biomedical sciences (Thorne, 2008, 2016). Palliative Nursing's *raison d'être* is the "amelioration of human distress, the accommodation of frailty, to counter personal vulnerabilities, and to make meaningful sense of the indignities which are caused by the failures of our bodies and minds" (Thorne, 2008, 2016). These palliative nursing goals support the use of Sense of Coherence as the theoretical framework of this thesis.

How these frameworks, methodologies, and concepts relate to this study and one another will be more fully developed in Chapter 3, as it addresses the methodology and the theoretical framework. The framework, Sense of Coherence, was chosen to explore the participants' strengths and needs through their own words to help learn more about the experiences of those encountering 30-day readmissions.

Asking older adults what they have experienced, feel and need regarding 30-day readmissions may prove valuable. Valuable, not only in the possible prevention of 30-day readmissions, but also in helping this population avoid the emotional, physical and psychological perspectives distress of serious illness by understanding how they form their Sense of Coherence. Without the inclusion of their voices, effective interventions that are patient centred cannot be effectively accomplished. This thesis will address the lack of qualitative data regarding older Americans experiencing 30-day readmissions.

This study does not seek to provide an intervention, rather it will lead to evidence and insight of why these readmissions occur. This is accomplished by learning more about the experiences of the older population with serious illness as they are interviewed during a 30-day readmission and seeks to learn of the ways the participants form their Sense of Coherence.

Chapter 2. Literature Review

2.1 Introduction

The literature review is presented in this chapter. This review is the result of a search to capture a comprehensive and diverse range of studies examining 30-day readmissions in older adults. The purpose of this review was to learn as much about this subject that was available about older adults and 30-day readmissions. The intent was to learn the characteristics of such patients, why they were being readmitted, what led to the readmission and how they coped with being readmitted to the hospital within 30-days of their last discharge. This information was sought to inform the empirical study of this thesis.

The first section includes a description of the problem and the review questions. An explanation of the integrative review approach and how it was employed is presented in the second section. The third section will be a presentation of the results. An interpretation of the findings follows in the fourth section. A discussion of the strengths, limitations, and implications of the review for the empirical study concludes the chapter.

2.2 Problem Identification and the Review Questions

The purpose of problem identification is to present an issue that requires investigation (Whittemore, 2005; Whittemore & Knafel, 2005). This section shows the problems explored in this review and the questions posed.

The Centre for Medicare and Medicaid Services defines a 30-day readmission as an unplanned admission for any reason to any acute care hospital within 30 days of discharge (Centers for Medicare and Medicaid Services, 2016). As described in the first chapter, older people readmitted

to the hospital often results in further physical decline and suffering (Drumml & Drumml, 2019; He et al., 2016; Ifudu et al., 1994; Timmer, 2014; Wong et al., 2012). This phenomenon is known as “Hospital Associated Deconditioning” (Falvey & Stevens-Lapsley, 2015; Kortebein, 2009). It has been established that the cost of readmission of this older population is overwhelming the healthcare system and is unsustainable (Meier, 2015). The study of the factors associated with 30-day readmissions may lead to understanding and prevention of this phenomenon.

As described above thirty-day readmissions have been recognized to be of concern and a problem to health care system stakeholders and the patients which the system serves. One of the purposes of this review is to understand overarching themes related to 30-day readmissions of older persons in order enter the research field with a comprehensive knowledge of the issue. Another purpose of the review is to validate and assure that the thesis study is grounded upon existing knowledge of the phenomenon and that the thesis study sample is appropriate.

The question for this literature review is "What factors contribute to readmission to a hospital within 30 days of discharge for people who are over 65"? This question informs the thesis study by identifying the reasons for 30-day readmissions and shedding light upon the characteristics of who these patients are, and their needs to prevent further readmissions. This question aims to reveal the continued unmet needs of this population and justifies further investigation. In addition, this question may give insight as to how the health care system may intervene earlier with palliative care or other interventions to better serve this population.

2.3 The Integrative Review

The Integrative Review method was chosen as it allows consideration of data using varying research methods, as well as an interpretive analysis of the findings (Whittemore & Knafl, 2005).

The use of diverse forms of knowledge is important to not just interpret quantitative data in the review but to also include the qualitative experiences of the person affected by the 30-day readmission. Without this diverse knowledge it is not possible to fully understand the significance of this phenomenon, not just to the health care systems' stakeholders, but equally important, to the patient experiencing the 30-day readmission.

This review design was informed by the work of Cooper (1984) and Whitemore and Knafl (2005) regarding the integrative review. There are five stages in the creation of an integrative review. The process for the integrative review involves a problem formulation stage, a literature search stage, a data evaluation stage, a data analysis stage, and a presentation stage. The first of these is problem identification, which is described in the previous section of this chapter. The remaining steps of the integrative review will be explained further as the chapter progresses (Whitemore, 2005; Whitemore & Knafl, 2005).

2.3.1 Literature Search

The second stage in the integrative review is the literature search stage (Cooper, 1984; Whitemore, 2005; Whitemore & Knafl, 2005). The literature search began with the development of a search strategy which included the following components:

- Determine the type of literature to include
- Determine inclusion/exclusion criteria
- Determine search keywords, terms, and MeSH terms
- Determine databases to be searched
- Review collected articles and apply criteria

A search for all peer-reviewed journal articles related to 30-day hospital readmissions of adults over the age of 65 was conducted. The decision to limit data to peer-reviewed journals was made to ensure that only primary evidence applicable to the association and causality of readmissions were captured. While grey literature was considered, it was ultimately excluded as there is the possibility of political and social agendas that may influence the data presented therein.

This search included research for the years of 2010 to the present. This range was chosen as 2010 was the first year the U.S. Centre for Medicare and Medicaid Services began piloting and developing the Hospital Readmission Reduction Program (Centers for Medicare and Medicaid Services, 2016).

2.3.2 Inclusion/Exclusion Criteria

The inclusion and exclusion criteria for the literature review are presented in Table 2.1. Specific diseases were excluded as they may be planned admissions for surgery, or unforeseen accidents occurring within 30 days of the last discharge. Also, the review purpose was to examine non-disease specific reasons for 30-day readmissions and sought broader data.

The age of 65 and older was decided upon as this is the age that older people become eligible for the Medicare benefit in the U.S.A. The relevance of 30-day readmissions in the U.S.A. becomes most concerning for this population as patients over the age of 65 years have a 1.5 odds ratio of being readmitted to the hospital (Berry et al., 2018). Also, the Healthy People 2020 report published by the Centre of Disease Control uses this age to identify define older people (Office of Disease Prevention and Health Promotion, 2020). Also, 65 years is the age used to describe older people in the report by The Common Wealth Fund describing the high cost of care in the U.S.A., and the International Report describing world trends in aging (Hayes, 2016; He et al., 2016). The

United Nations uses the age of 65 years to report on aging trends internationally (United Nations, 2020). The decision to use this age for the literature review was made as there is evidence that this is an accepted classification of old age, and it is relevant to the empirical study population.

Table 2.1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Research from peer-reviewed journals	Research regarding readmission due to specific disease or procedure (i.e., All hip Surgeries, All Congestive Heart Failure patients) as they relate to 30-day readmissions.
All research designs	Evaluation or validation of interventions or tools related to 30-day readmissions
Research regarding people 65 years and older with a 30-day readmission	Abstracts for conferences
English language articles	Abstracts for presentations
Reports dated 2010 to present	Studies that include all ages not disaggregated for 65 years or older.
	Articles recommending or evaluating policy
	Reports
	Systematic Reviews

2.3.2.1 Databases. The databases searched were PubMed, CINAHL, EMBASE. PubMed was chosen as it is the most extensive database and would result in the most considerable number of articles. CINAHL was searched to retrieve a higher number of nursing and allied health perspectives, creating a more interdisciplinary perspective. EMBASE was chosen to ensure that articles regarding high-risk drug exposure and polypharmacy articles would be included.

A list of medical subject headings (MeSH), subject terms, and keywords were established and documented for each database searched (Appendices 1, 2). PubMed and CINAHL were searched using variations of the MeSH terms for "older adults, debility" using OR and the second MeSH term and variances on "30-day readmissions" (Appendix 1). As EMBASE and Cochrane do not accommodate MeSH subject terms the search consisted of keywords such as geriatrics, older, frailty, 30-day readmissions (Appendix 2). Terms and keywords were chosen for the breadth of their applicability to all types of data.

The PRISMA Diagram (Figure 2.1) was used to record the process of the pursuit of relevant literature to illustrate decisions during the search (Moher et al., 2009; Whitemore, 2005). The search resulted in a total of 2581 articles after duplicates were removed. Once the inclusion and exclusion criteria were applied, 24 items remained for inclusion in the review.

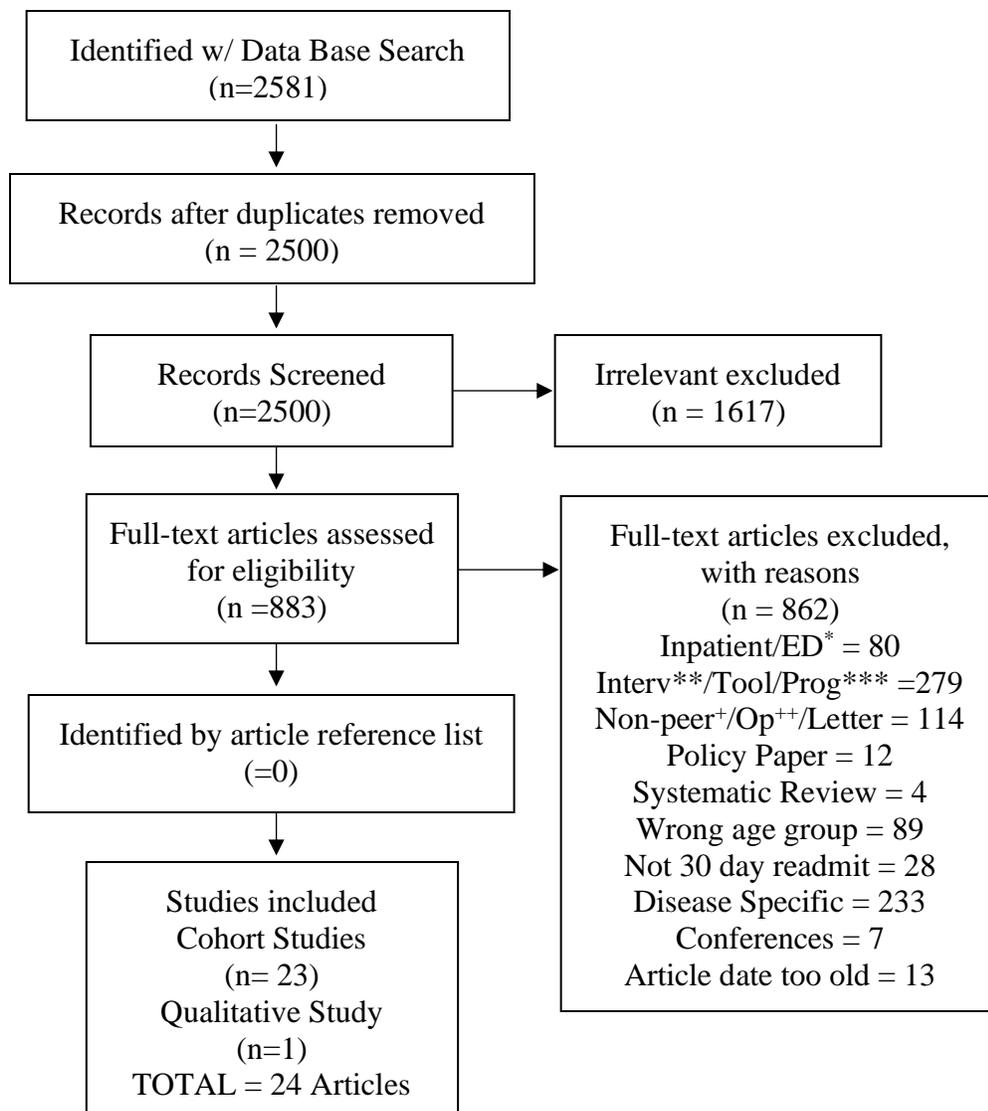


Figure 2.1. PRISMA.

(*Emergency Department, **Intervention, ***Program, +Non-Peer-Reviewed ++Opinion Piece)

2.4 Data Evaluation

After the literature search was completed, there was an evaluation of the quality of the data. The Critical Appraisal Skills Program (CASP) checklists are used, as they have been piloted and provide assessments for diverse types of studies (CASP, 1993; Young & Soloman, 2009) (Appendix 3). Each of the included quantitative studies are Cohort studies of one type or another.

The Cohort CASP checklist facilitates the task of determining if each article includes the minimal expectations that are included in a quality study or review. The three categories in the checklists include 1) Are the results valid? 2) What are the results? 3) Are the results useful locally? The one included qualitative study was judged using the Qualitative CASP checklist (Appendix 3). The overarching questions in the qualitative checklist coincide with the cohort list items: 1) Are the results valid? 2) What are the results? 3) Are the results useful locally? Using the CASP checklist all articles appeared of high quality and were included.

In addition, the articles were scrutinized using the criteria set out by Whitemore adapted from Lohr and Carey (1999) and West et al. (2002). This extra layer of evaluation was to confirm the previous method of evaluation and were selected as these criteria are suggested in the existing literature regarding the integrative review method (Whitemore, 2005) (Table 2.2). Neither the CASP nor Whitemore criteria called for numerical scoring. In the final analysis, when using these tools and criteria the decision for inclusion is left to the reviewer.

The analysis of this scrutiny is displayed in a side-by-side two-column table (Appendix 4). All articles evaluated through these processes met the preponderance of the criteria of the Whitemore and CASP standards of quality and were included in this review.

The next section will be a description of the data analysis using the integrative review.

Table 2.2*Integrative Review Quality Criteria*

Study Construct	Example
Sample	Inclusion and exclusion criteria well defined and appropriate Health, demographic, socioeconomic status, and other confounding characteristics considered Sample size justification
Study Protocol	Study procedures systematic and well specified
Measurement	Choice of outcomes appropriate Data collection specified and systematic Measures demonstrate adequate reliability and validity
Threats to Validity	Confounders and bias carefully considered and controlled
Statistical Analysis	Statistics appropriate and well described Levels of significance or confidence intervals, or both, reported Intention-to-treat analysis for longitudinal data
Discussion	Conclusions supported by results with possible biases and limitations considered
Intervention	Detailed information about treatment, setting, and interventionist provided Efforts undertaken to ensure treatment integrity Blinding (of patients, investigators, data collectors, and care providers) as appropriate Randomization of subjects to treatment and control group Evidence of study group comparability at baseline provided

Note. Adopted by Whittmore (2005) from Lohr and Carey (1999) and West et al. (2002).

2.5 Data Analysis

Data analysis was conducted using the integrative approach (Cooper, 1984; Whitemore, 2005; Whitemore & Knafl, 2005). The integrative approach includes ordering the data through data reduction, and an unbiased interpretation and synthesis of the data (Whitemore, 2005; Whitemore & Knafl, 2005). The process of data reduction will be presented in this section.

2.5.1 Data Reduction

The purpose of data reduction in the integrative review is to process the collected data from the multiple methods presented in the articles into a meaningful classification system and framework (Whitemore, 2005; Whitemore & Knafl, 2005). Data reduction began with data extraction using a coding form (Cooper, 1984). A form was developed for data extraction (Appendix 5) (Cooper, 1984; Taveres de Souza et al., 2010). The review resulted in two types of research methods. The papers included various Cohort studies and a Qualitative study. A commonality between all coding forms includes data for references, methodology, country of origin/setting, and sample size. Results for each article were documented in the coding forms (Cooper, 1984). Data were extracted and coded with constant comparison (Whitemore, 2005; Whitemore & Knafl, 2005) to reveal the overarching factors reported in the included studies (Table 2.3).

The data reduction resulted in the following factors and subgroups:

Table 2.3*Data Display*

Factor 1 Sociodemographic	Factor 2 Systemic	Factor 3 Physiological	Factor 4 Pharmacological
Gender	The utilisation of Health Resources	Disease Process	Number of Prescriptions
Age	Length of Stay	Frailty Characteristics	High-Risk Drug Exposure
Living Conditions	Discharge Location	Comorbidity/ Complexity	
Ethnicity	Insurance Coverage	Nutritional Status	
Socioeconomics		Mental Illness	
Marital Status			

The data resulting from the analysis has been placed into a table by the author, the four themes, and their subgroups along with results (Appendix 6). This table was created to help clarify the data for the reader and the researcher.

The interpretation and synthesis will be shown in the next section.

2.6 Presentation of the Results

The synthesis of the data will now be presented. The review found 24 articles. The articles two methodologies which included varying quantitative cohort designs and one qualitative study.

These studies represent knowledge obtained from Australia, France, Italy, New Zealand, Norway, Spain, and the U.S.A. Seventeen of the 24 articles originated from the U.S.A.

There were no notable differences in the findings from international studies when compared to U.S. studies in the review. The exceptions are the study concerning New Zealand (Robinson & Kerse, 2012) and Australia (Islam et al., 2014). This is addressed in the Socioeconomic section of this section and later interpreted in the interpretation section (2.7).

Two of the included articles studied samples from the U.S. Veteran Administration population. One of the two studies closely resembled the other articles' results. The only obvious difference from other samples being the sociodemographic category of gender. This factor and other differences were carefully controlled in the design and analysis of the study (Pugh et al., 2014).

The other veteran study did not control for gender differences. The sample did adequately represent ethnic diversity which is similar to the population in the U.S. Also, there is difficulty in generalizability as it is the only article considering alcohol use and adopts a Veteran's Administration specific tool for measuring alcohol use. This article met the greater part of both the CASP and Whittemore criteria. Also, the findings of the article are valuable as it considers the use of alcohol in this specific population in relation to 30-day readmissions. This is an important area deserving more attention (Chavez, 2016).

It is important to note that all studies were analysed to determine statistical significance. Those where analyses found not to have statistical significance are reported as such. All studies' data were reported regardless if analyses found statistical significance to protect against bias and strengthen the review. This is indicated in the narrative of the results section and the All-Data Table (Appendix 6).

2.6.1 Sociodemographic Factors

Sociodemographic factors play an essential role in who may be at risk for 30-day readmissions. A description of these factors is in the following sub-sections. The interpretation section will include an exploration of these findings.

2.6.1.1 Gender. Women are readmitted more frequently within 30 days of discharge with a range of 52% to 68% (Berges et al., 2015; Fisher, 2016b; Fisher et al., 2013; Goldenheim et al., 2014; Islam et al., 2014; Morandi et al., 2013; Navarro et al., 2012; Sattler et al., 2015; Traissac et al., 2011). Two articles included in the review identified males as having a higher number of 30-day readmissions (Chavez, 2016; Pugh et al., 2014). One study taking place in Israel had males being readmitted more frequently at a rate of 61% (Tonkikh, 2016)

2.6.1.2 Age. Being over the age of 65 is an indicator of early readmission when compared to other age groups (Barnett et al., 2015). The data show the mean age for patients being readmitted to the hospital within 30-days is 77.3 years with a range of mean ages between 74.5 – 80 years (Goldenheim et al., 2014; Hain et al., 2012; Pugh et al., 2014; Robinson et al., 2012).

2.6.1.3 Ethnicity. Ten articles addressed the topic of ethnicity. Prevalence of 30-day readmissions was reported to be between 60.9% - 84.2% for Caucasians. Two articles found that patients of African descent were less likely to be readmitted with a prevalence of 40.9% - 47.4% (Goldenheim et al., 2014; Whitney, 2016).

When looking at the relative risk of a population of U.S. Veterans it was found that using those who are Caucasian as a reference, Hispanics have a risk ratio of .93 and African descent a risk ratio of .90 (Pugh et al., 2014). Recall the definition of relative risk: the ratio of the probability of

the exposed group over the probability of the non-exposed group. Here the exposed group is membership of a minority group over the non-exposed group. The non-exposed group is the Caucasian group. Therefore, with a risk ratio below one, Hispanic and African American veterans are consequently less likely to be readmitted than Caucasian veterans. Conversely, the New Zealand research found that the indigenous group has a risk ratio of 1.79 when compared to Caucasians who have a risk ratio of 1.0 (Robinson & Kerse, 2012).

2.6.1.4 Socioeconomics. It was found that Australians who had more economic advantages and living in a skilled nursing facility were more likely to be readmitted at 38.9% compared to those who were disadvantaged at 9.8% (Islam et al., 2014). The opposite was true of those living at home (Islam et al., 2014). This may be explained partially by other sociodemographic and systemic realities to be examined in the interpretation section of this chapter.

Robinson and Kerse (2012) report that indigenous people (Maori) were more likely to be, both disadvantaged and to be readmitted within 30 days in New Zealand. Those who were disadvantaged had a 1.15 risk ratio for a 30-day readmission than others (Robinson & Kerse, 2012).

2.6.1.5 Living Situation. "Living situation" describes where and with whom the participant lives. Marital status is included in this subgroup. More than half of people who are readmitted to the hospital within 30 days are unmarried at 59% (Berges et al., 2015; Fisher, 2016a). This data does not inform us of how many are widowed, divorced, or never married, nor if being unmarried is associated with readmissions.

Regarding the living situation, the majority of people being readmitted within 30 days live with friends or family (71.1%) (Fisher, 2016b). Those who live alone are the next largest group at 27.7 – 34% (Fisher, 2016b; Islam et al., 2014). Living alone is not a risk factor for readmission (Traissac

et al., 2011). It is reported that those living in skilled nursing facilities for long-term care are readmitted at a rate of 24.4% (Islam et al., 2014). A study that followed patients living at home with private caregivers (511) found that 105 of the group were readmitted to the hospital; a rate of 21% (Fisher, 2016b). Early readmissions in this group may be explained by a myriad of factors including, but not conclusively, greater health literacy, better insurance (Navarro et al., 2012) and entitlement and advocacy by the family for the economically advantaged patient (Islam et al., 2014).

2.6.1.6 Experiences. For this review, experiences denote the psychosocial aspects and the emotional state of the patient. As there was only one qualitative article, there is minimal data regarding the experiences of patients with a 30-day readmission.

The qualitative themes of "Being Left Out", "Feeling Let Down", and "Being Cared For" were identified in the research (Dilworth et al., 2012). Patient's described "being left out" as it pertains to not being heard, being disregarded, being dismissed, and excluded from decision making. "Feeling let-down" was described as disappointment with the healthcare system, such as poor planning during transitions, gaps in care, and long waits for follow-up appointments. Whilst in the hospital descriptions of "being cared for" were mixed. There were descriptions of loss of autonomy, medication errors, and length of stays which were longer than initially anticipated. However; these feelings of disappointment were contrasted by feelings of gratitude for the good care received by nurses and the quality of the food (Dilworth et al., 2012).

2.6.2 Systemic Factors

Systemic factors include issues beyond the control of the patient. The subgroups include the utilisation of health services, length of stay, discharge location, and insurance coverage. These are

factors that are almost solely controlled by the healthcare system. These results are presented in the following sub-sections.

2.6.2.1 Utilization. Utilisation refers to the exposure the individual has to the health system, within the hospital, and in community settings. Such exposures would include services received by the individual; the number of primary care visits one has before a 30-day readmission and the number of hospitalisations or emergency department visits of the individual prior to a 30-day readmission.

Findings show that patients who have two to four visits with a primary care provider within the first 30 days of discharge were admitted more frequently (50%) than those with fewer or more visits (Pugh et al., 2014). In addition, it was found that patients who were on home hospice and contacted their primary care provider within the first week had a RR of 2.4 for a 30-day readmission (Goldenheim et al., 2014).

Those patients who had two or more visits to the emergency department experienced 30-day readmission 40.7% of the time (Sattler et al., 2015). It was also learned that patients who had 2.2 hospitalisations the prior year were at the greatest risk for a 30-day readmission (Tonkikh, 2016). Also, patients who were exposed to palliative care during their last hospitalisation were readmitted only 10% of the time (Enguidanos et al., 2012). This indicates that inpatient palliative care may reduce the incidence of 30-day readmissions (Gagne-Henderson et al., 2017). It may also be indicative of better inclusion in planning and more skilled communication to prevent the patient from "Feeling Left Out" (Dilworth et al., 2012).

2.6.2.2 Length of Stay. A long length of stay is a predictor of a 30-day readmission. The mean length of stay for the 30-day readmitted patient's last hospital admission was 6.7 days (Navarro et al., 2012). Regardless if a patient was discharged from an acute hospital or skilled nursing facility,

those who had a length of stay 6-9 days have the highest number of 30-day readmissions (Islam et al., 2014; Navarro et al., 2012). Similarly, patients with a length of stay of greater than six days have an OR of 1.9, which implies a probability of 65.5% (Traissac et al., 2011). Those with a prior hospitalisation length of stay of greater than 13 days had a hazard ratio of 2.67 which implies they have 2.67 times the chance of being readmitted within 30-days (Morandi et al., 2013). Without adequate time for recovery when admitted to a short-term rehabilitation facility patients discharged from rehabilitation with a LOS of fewer than 9.5 days are readmitted to the hospital at a rate of 69% (Fisher, 2016b).

2.6.2.3 Discharge Location. Those discharged to a skilled nursing facility have the highest risk of a 30-day readmission (25% - 41%) when compared to those sent home with visiting nurses (Hain et al., 2012; Navarro et al., 2012). Those sent home from the hospital with visiting nursing services were readmitted between 28 to 34% of the time (Hain et al., 2012; Navarro et al., 2012). Those sent home without services were readmitted 25% to 39% of the time (Hain et al., 2012; Navarro et al., 2012).

2.6.2.4 Insurance. The data regarding insurance coverage is of interest only to several U.S.A. studies. There were diverging results for this sub-group. There may be explanations for these differences which will be presented in the interpretation section. All patients in the U.S.A had Medicare insurance. Goldenheim et al. (2014) showed that of the 30-day readmission population, 21.1% had Medicare only, while 78.9% had Medicare and Medicaid (dual coverage). The sample for the Goldenheim et al. (2014) study were all home hospice patients, which will be addressed in the interpretation section. Contrary to these findings, Navarro et al. (2012) found that 70.8% of 30-day readmission patients had Medicare alone. Dual coverage patients experienced 30-day

readmissions at a prevalence of 26% (Navarro et al., 2012). Similarly, Whitney (2016) established that patients who have dual coverage have a decreased risk for a 30-day readmission.

2.6.3 Physiological Factors

Physiological factors include disease diagnosis, frailty syndrome diagnosis, the number of comorbidities, nutritional status, and mental illness. These findings are presented in the following sub-sections.

2.6.3.1 Disease. The data were examined to determine the three most common primary diagnoses associated with 30-day readmissions. Data were collected from 16 of the included articles which addressed this sub-group theme (Albrecht et al., 2014; Fisher, 2016a; Fisher et al., 2013; Goldenheim et al., 2014; Hain et al., 2012; Islam et al., 2014; Morandi et al., 2013; Navarro et al., 2012; Robinson & Kerse, 2012; Sattler et al., 2015; Tonkikh, 2016; Whitney, 2016; Yoo et al., 2015). Two articles found that malignancy was the most common factor leading to readmission (41.9% - 63.2%) but, both of these study samples were patients on home hospice service (Goldenheim et al., 2014; Whitney, 2016). These two articles were not used in the data synthesis as malignancy is overrepresented in the hospice population in the United States, with Cancer representing 30.1% of all admissions with Circulatory/Heart Disease following with 17.6% (National Hospice and Palliative Care Organization, 2015).

The data indicate that congestive heart failure (CHF), including all other cardiac conditions, is the most common disease process associated with 30-day readmissions (Albrecht et al., 2014; Fisher, 2016a; Fisher et al., 2013; Hain et al., 2012; Islam et al., 2014; Robinson & Kerse, 2012; Sattler et al., 2015; Whitney, 2016). The median rate of readmissions for cardiac patients is 35%.

Respiratory conditions, including COPD, were found to be the second most common condition for which patients were readmitted with 30-days (Fisher, 2016a; Hain et al., 2012; Islam et al., 2014; Morandi et al., 2013; Navarro et al., 2012; Robinson & Kerse, 2012; Sattler et al., 2015; Tonkikh, 2016; Whitney, 2016). Respiratory conditions account for between 6% and 39.5% of 30-day readmissions (the median percentage is 17.8%). As many of the data were reported as "all respiratory conditions", it is difficult to determine if pneumonia or other infectious processes were included in the diagnoses. The third most commonly reported condition related to 30-day readmissions is renal disease with a range of 24.3% - 58.8% (Sattler et al., 2015; Tonkikh, 2016; Whitney, 2016).

2.6.3.2 Frailty. Half of the research included in this review found that frailty characteristics were more significant than disease processes as they related to 30 – day readmissions (Albrecht et al., 2014; Fisher, 2016a, 2016b; Fisher et al., 2013; Islam et al., 2014; Morandi et al., 2013; Navarro et al., 2012; Pugh et al., 2014; Tonkikh, 2016; Traissac et al., 2011). A reduction in the ability to perform activities of daily living resulted in the largest number of patient's being readmitted 31.0% - 61.54%. Dehydration is an associated condition which accounts for a high number of 30-day readmission of older adults (32%) (Navarro et al., 2012). Navarro only examined participants with frailty, which may have put the sample at a higher risk for readmission. Fall syndrome is also found to have an association with readmissions that range from 25% - 32% (Albrecht et al., 2014; Islam et al., 2014; Traissac et al., 2011). A decrease in mobility resulted in a readmission rate of 16.7% - 26% (Fisher, 2016a; Fisher et al., 2013; Islam et al., 2014), as well as a decrease in activities of daily living (Albrecht et al., 2014; Morandi et al., 2013; Tonkikh, 2016; Traissac et al., 2011).

2.6.3.3 Comorbidity Factors. Comorbidity is associated with an increased risk for readmission (Albrecht et al., 2014; Fisher, 2016b; Fisher et al., 2013; Islam et al., 2014; Navarro et al., 2012; Pugh et al., 2014; Sattler et al., 2015; Traissac et al., 2011). Of those readmitted within 30 days of discharge, 69% had one or more comorbidities (Fisher, 2016b). The average number of comorbidities of those with a 30-day readmission is four comorbidities. Patients with six to ten comorbidities were most frequently readmitted (29%) of all those with comorbidities (Fisher, 2016b).

2.6.3.4 Nutrition. Malnutrition or risk for malnutrition increases the incidence of readmission (Robinson, 2015; Tonkikh, 2016). Those diagnosed as being malnourished are readmitted at a rate of 14.4% compared to a similar population of older adults without malnutrition, who were readmitted at 4% (Robinson, 2015). Serum albumin levels were lower for those readmitted (Tonkikh, 2016).

2.6.3.5 Mental Illness. Depression was the most common mental health issue found in this population. In one study where 19% of the patients were readmitted within 30 days, and where the prevalence of depressive symptoms was also 19% (n=750, age>65) they found depressive symptoms were not significantly associated with hospital readmission (Albrecht et al., 2014). However, the study also concluded that depressive symptoms were related to other poor outcomes and maybe under-diagnosed during hospitalisation of older adults (Albrecht et al., 2014). Another study showed that those with depressive symptoms had an OR of 1.66 of being readmitted within 30 days, but in the end, confirmed that the readmission rate was not statistically significantly higher (Berges et al., 2015). Readmitted patients have depression between 8.4% - 15% of the time (Albrecht et al., 2014; Berges et al., 2015; Navarro et al., 2012; Whitney, 2016). Any mental illness

places older patients at risk for a readmission with an OR of 0.92, which implies a probability of 48% (Pugh et al., 2014).

2.6.4 Pharmaceutical Factors

2.6.4.1 Polypharmacy and High-Risk Medication Exposure. The two pharmaceutical factors are 1) the number of prescriptions and 2) the risk of readmission and the association of exposure to high-risk medications with readmissions. These factors are described in this section. Patients who have a greater number of prescriptions have an increased risk of a 30- day readmission. Those patients with seven or more prescriptions are readmitted at 59.3% while those with twelve or more prescriptions are readmitted 51.5% of the time (Pugh et al., 2014; Sattler et al., 2015). These findings seem to imply more prescriptions lead to a reduction in the probability of readmission. This is likely explained by the ordinary variability seen in these studies. Also, of note, there was an association between exposure to certain high-risk medications and readmissions (Pavon et al., 2014) (Appendix 6).

2.6.5 What is Missing: The Qualitative Data

What is missing in the data is the voice of the patient. Interestingly, there are so many policies and interventions that have been developed without the inclusion of the patients' perceptions (see PRISMA excluded articles). Without the patient's voice, the determination of what is needed to prevent 30-day readmissions is only uninformed guesswork, and patient-centred care will elude our efforts. There was only one qualitative study that met the inclusion criteria. This qualitative study was conducted in Australia in 2012. They studied the experiences of older adults who were in the hospital after being readmitted shortly after their last discharge. The sample included three

interviews asking older people affected by this phenomenon of an early hospital readmission to share their experiences (Dilworth et al., 2012).

The authors concluded that the causes of the readmissions were potentially preventable (Dilworth et al., 2012). They identified gaps in planning for appropriate resources after discharge. The authors implied the need for further qualitative studies to find the voice of the patient to include shared development of a plan of care and shared decision making (Dilworth et al., 2012). The empirical study of this thesis will be a start in furthering qualitative knowledge regarding older adults with a 30-day readmission.

2.7 Interpretation

This interpretation will include topics that warrant further consideration. The first part of the interpretation will explore the explanations for why some of the factors influence 30-day readmissions and how they may be interrelated. The second part of this interpretation is an examination of the single qualitative study found during the literature search.

This review provides the common characteristics, or factors, within this population. Unfortunately, it is unsuccessful in clearly describing how these factors may be interrelated as none of the included articles examined relationships between the factors. Without interpretation, this quantitative data does not explain why the phenomenon of 30-day readmissions occurs.

2.7.1 Sociodemographics

2.7.1.1 Gender. The findings within the included studies in this review show that women patients are at a higher proportion than men for 30-day readmissions. The additional frequency of readmission found for females was significantly higher in studies with smaller samples (<1000)

compared to those with larger samples (>1000). Women comprise 55% of the world's population, this number rises in the older population as the life expectancy for women is higher (He et al., 2016). The studies in the larger samples were closer to the world population figure. A factor putting some older females at higher risk of readmission may be related to inadequate availability of primary caregivers in the home (Schulz & Eden, 2016). With the cultural and economic changes regarding women in the workplace, there may be fewer caregivers available to provide the full-time care provided in earlier generations who are female. This is essential in the prevention of re-hospitalisations for this group as well as their male counterparts (Schulz & Eden, 2016). Women have historically been caregivers and have longer life expectancies than men which may be an explanation for this difference in readmission proportion. Older women may be caring for their male counterparts, protecting them from a greater number of readmissions.

Two of the articles contradicted the results regarding gender. These articles were limited to samples, including U.S. veterans. The U.S. military currently has an active force which is 84.5% male (National Center for Veteran Analysis and Statistics, 2017). This would explain the discrepancy from the other studies as the populations were skewed towards male participants.

2.7.1.2 Living Situation. The data regarding marital status in the literature review shed little light upon marital status across the older population. The United States Census Bureau released two reports in 2016. One report was *An Ageing World: 2015 International Population Reports*, surprisingly, there were no data regarding global marital status (He et al., 2016). The other is *Ageing in the United States* (Mather et al., 2015). These reports found that in older people in the United States women are widowed at 34%, and their male counterparts are widowed at 12%. The report shows that women are divorced at a rate of 13% and men at 11%. Those with intact marriages are women at 48% and men at a rate of 72%.

The same report also found that 96% of people age 65 and older live in their private dwellings. The percentage of those living in institutions increases with age. The number of women age 80 – 89 no longer living in their homes and living in facilities increases to 7%. This number increases to 19% for those women aged 90-99 (Mather et al., 2015).

2.7.1.3 Ethnicity, Socioeconomics, and Systemic Interrelated Factors. Ethnicity and Systemic Factors are interrelated. Those from minority groups tend to be of a lower socioeconomic status than those who are Caucasian (Assistant Secretary for Planning and Evaluation, 2015; National Centre for Social and Economic Modelling, 2013). In the United States, this results in a higher number of people of African descent having better access to health insurance (dual coverage). When looking at readmission and ethnicity, it would be essential to state that, in general, people of African descent are reluctant to utilise hospice services in the United States for cultural, spiritual, and historical reasons (Yancu et al., 2010). Mistrust of the healthcare system may account for higher 30-day readmissions rates for people of African descent from hospice other groups.

Others, who are more affluent or middle class, have Medicare only insurance alone. Some in these two groups also have a privately paid supplement insurance (Atherly, 2002). The CMS will pay a skilled nursing facility fully for the first 20 days (Centers for Medicare and Medicaid Services, 2015). A skilled nursing facility stay is partially paid for up to 100 days before the full burden of cost is placed upon the patient and family (Centers for Medicare and Medicaid Services, 2015). Skilled nursing facility cost is extremely burdensome for the average family. Such costs can be between \$90,000 and \$100,000 annually (Levine, 2020). To re-establish coverage for a skilled nursing facility, a patient must return to the hospital and have a length of stay of at least three days, after which they may return to the skilled nursing facility for an additional 100 days (Centers for

Medicare and Medicaid Services, 2015). This may explain why people who have Medicare insurance coverage alone are readmitted to an acute care hospital more frequently.

Patients who live in skilled nursing facilities for long term care are frailer and have increased ADL deficits than those who are sent to their homes which puts them at risk for readmission (Cohn et al., 2018; Fisher, 2016a, 2016b; Fisher et al., 2013; Pearl et al., 2017). Another reason older adults who live in skilled nursing facilities are at higher risk for a 30-day readmission may be due to understaffing in these facilities (Maas, 2008). Those in poverty who are readmitted from their home are unlikely to have resources to pay for private duty healthcare workers compared to their more affluent counterparts (Landers, 2016) which may partially explain their readmission rate. Privately funded caregivers would afford one on one care in the home, but Medicare Insurance will only pay for skilled nursing (Landers, 2016), which is the more expensive option (Chappel et al., 2004).

Furthermore, for those in a country with a fee-for-service system, as is Australia and the United States, those who are on the verge of being impoverished must pay for part of their care and part or all of their medications (Madden, 2008). With these patients having so many prescriptions and having fewer monetary resources, this interferes with the ability to purchase their medications, which may lead to cost-related nonadherence and readmissions (Madden, 2008; Sattler et al., 2014).

2.7.2 Physiological Factors

The articles showing malignancy as the most common reason for readmission may be explained as people with chronic illnesses are underrepresented in the hospice population. At the same time, those with Cancer are overrepresented (National Hospice and Palliative Care Organization, 2015).

The studies finding malignancy as the most common readmission diagnosis were samples of hospice patients.

2.8 Importance of Data

What the physiological and pharmacological themes have shown is that the patients who are readmitted are the very sick and frail. Also, many of the readmitted population have multiple chronic comorbidities. At this time, there is little we can change regarding medical interventions, other than assuring routine advanced disease management. The review did not provide data that could be applied in a clinical setting, rather only provided commonalities within the population.

The thematic area where we can make a difference in 30-day readmissions for older adults is through systemic change. This would require a more in-depth study and more knowledge of the inter-relation of systemic issues, followed by a societal willingness to make a policy change.

The most salient issue revealed by the literature review is the glaring gap in the knowledge base of what the patients understand and think about their situation. With only one study addressing qualitative issues for this group, there must be further research following this literature review with a focus on learning more from the patient regarding the experiences of 30-day readmissions. Although the one study only included three interviews, it provided insight into the need to include the patients' voices in order to determine the needs of older people with early readmissions.

2.8.1 United States Compared to International Data

Whilst the physiological data gathered in this review are congruent and virtually identical, the same cannot be said of the systemic and sociodemographic data. All of the physiological data, regardless of country, points to fragility, chronic disease and comorbidity are associated with 30-

day readmissions. The types of diseases with which patients were diagnosed were the same irrespective of their geographic location.

The sociodemographic data were dissimilar in some countries when compared to the United States. For instance, in Australia, the poor and in New Zealand the indigenous poor were less likely to be readmitted than their counterparts in the U.S. (Islam et al., 2014; Robinson & Kerse, 2012). For those in Australia, the study offered an explanation that the financially affluent in that country feel more entitled to services and are more demanding about receiving services (Islam et al., 2014). Regarding the indigenous poor in New Zealand it is surmised that poor health and lack of access to resources accounts for the high rate of readmission (Robinson & Kerse, 2012). In the U.S. this can possibly be explained by looking at the relationship between the ample insurance coverage to which the poor have access in the U.S. if one is over 65. In the U.S., this dual coverage of having Medicare insurance and Medicaid insurance allows patients to remain in place, whilst those with Medicare alone must be readmitted to an acute hospital for three days every 120 days to restart the skilled nursing facility benefit (Centers for Medicare and Medicaid Services, 2015, 2017b).

The international studies varied only slightly from the U.S. studies in the area of socioeconomic and systemic issues. However, the review did show the similarities of this population in developed countries as far as frailty, comorbidities and pharmaceutical issues are concerned.

2.9 Discussion

The studies all had similar findings regarding the factors related to 30-day readmissions. The socioeconomic results were similar, except for the study in New Zealand (Robinson & Kerse, 2012) which is discussed later. These similarities may indicate a high likelihood for

generalizability for the findings of this literature review and its usefulness in the forthcoming research.

2.9.1 Comparison of U.S. to International Results

The studies not conducted in the U.S. included in this review varied only slightly from those studies from the U.S. These differences are in the area of socioeconomic and systemic issues. The differences lay in the variances of government payment schemes. However, the review did show similarities in European countries and the United States. This assures that the results of this literature review will help with the identification of a homogeneous sample for the thesis study. The homogeneity of the review results may help with the generalizability of the thesis results regarding the participants' experiences.

2.9.2 Strengths

This review has provided a great amount of knowledge about the physical, socio-economic, systematic and pharmacological characteristics of older people who have 30-day readmissions. This information is important for understanding characteristics that can alert clinicians to the risks for this population.

Finally, the search was appropriate for the review. The review contributed to the thesis by providing an understanding of the factors that the sample possesses almost universally. This provided the knowledge and expectations as the researcher entered the field. It also guided how, and which questions would help to gather the data required from participants to answer the thesis research question.

2.9.3 Limitations

The review fails to describe how these factors may be interrelated. Quantitative data alone cannot explain why the phenomenon of 30-day readmissions occurs. The body of knowledge requires more qualitative data to help our understanding of 30-day readmissions.

The greatest weakness of the qualitative study is its sample size. The study included only three participants. In defence of the small sample, the author references Holloway and Wheeler (2002). Holloway and Wheeler (2002) state that when critiquing a study, one must take into consideration the researcher's resources and time.

Initially, this review intended to find all information regarding older people and 30-day readmission. The search terms were very broad to avoid omitting any study design. In a re-examination of the process, it was thought it might have been advantageous to include the word "experience" in the MeSH term search. The MeSH database was then searched for the heading "experience". No such heading exists as a unique term. The MeSH database was used to ensure a systematic and repeatable search to achieve the greatest number of results (U.S. National Library of Medicine, 2020).

EMBASE and Cochrane do not use MeSH terminology, so the word experience potentially could have been used; however, using any other keywords not included in the MeSH search was thought to change the search into a non-systematic review lacking discipline and rigour.

Since the keywords and MeSH terms were very broad, it was thought this would produce all available data. In retrospect of the finished thesis study, it may be that a review which included different keywords would have garnered more qualitative data. This a limitation of this review.

Still, the review aimed to obtain all data regarding older people experiencing 30-day readmissions, which remains important to the thesis.

2.10 Conclusion

The subjects of the review are the sickest and frailest patients in the population. This review characterizes the thesis study sample and validates the selection of the thesis study participants. In this case, it may be that many of these 30-day readmissions are unavoidable; however, the systemic and demographic factors appear to be interrelated and are as important as the physiological factors. While complicated, and challenging to address, systemic issue changes may be the only way to successfully impact the number of patients being readmitted to an acute care hospital within 30-days of discharge.

There is strong evidence of an important gap in the literature. This gap is the lack of qualitative data regarding 30-day readmissions for the older population. Quantitative data gives us a great deal of understanding, but it is incomplete. Further qualitative query is needed to enhance knowledge of 30-day readmissions in older people. The study for this thesis contributes to this endeavour. There is an absence of the patient voice, experience, understanding of their life circumstances, and coping mechanisms concerning 30-day readmissions. This will be addressed in the empirical research, from the theoretical perspective of Sense of Coherence (Antonovsky, 1987). Such data may contribute to how clinicians can assist this population in confronting their challenges and improving their outlooks and hopes for the future. This is the endeavour of this thesis.

Chapter 3. Theoretical Underpinnings

3.1 Introduction

Included in this chapter are the descriptions of the paradigmatic, philosophical, theoretical, methodological, and the theoretical framework which formed this thesis. Included in the overview of Interpretive Description will be the relationship between knowledge and nursing, the goals of palliative care nursing, the acquisition of knowledge, adequate knowledge, credibility and trustworthiness. The fourth section will include a discussion of the theoretical framework, Sense of Coherence, and how this construct has influenced the epistemological and ontological basis of this study. Finally, there is a presentation of the relationship between the theoretical framework and Interpretive description, and why the two are synergistic as the scaffolding for this study.

3.2 Underpinnings

3.2.1 Paradigmatic and Philosophical Underpinnings

This thesis is written from the paradigmatic perspectives of Qualitative Research as the research paradigm. The epistemological positioning of the thesis is Constructivist. Post-Positivism and Naturalism are the ontological postures of the thesis. These will be described more fully throughout this chapter.

3.2.2 Qualitative Research as a Paradigm

Qualitative research is more than a method to obtain knowledge. In the not too distant past, qualitative research was a great departure from the only existing research paradigm of quantitative research. Qualitative research is a world view of the nature of knowledge and reality. Rather than

relying on “hard” numbers and facts, the qualitative paradigm relies on the common experience of the individual (Legard et al., 2003; Morse, 2016). The qualitative paradigm recognizes the expert to be the person who experiences an examined phenomenon (Coyle & Tickoo, 2007). This research has been approached from this perspective.

3.2.3 Epistemological Perspective

The epistemological positioning for this study is based on Constructivism, Interpretivism and Objective Hermeneutics (Andrews, 2012; Porter & Robinson, 2011; Schwandt, 2011; Woolfolk, 1992). This positioning claims that reality is constructed by each individual through cognitive processes which are continually evolving and are an interpretation derived by the researcher (Twosmey-Fosnot, 2005; Woolfolk, 1992). More importantly, is the idea that knowledge and truth is in constant change with each new experience. This stance acknowledges that a definitive truth is unattainable (Woolfolk, 1992). This knowledge is directly related to the ontological positioning of this thesis as perception and interpretation of knowledge is dependent on the individuality of the subject (Clark, 1998; Montero, 2002; Rockmore, 1997).

3.2.4 Ontological Perspective

The ontological positioning for this thesis is Post-positivism and Naturalism. The Post-Positivist recognizes the importance of the inclusion of varying methods of research when searching for knowledge and that qualitative knowledge brings new and more complete understanding. This also comes with the understanding that all methods fall short of perfection (Clark, 1998; Thorne, 2016).

Post-positivism aims toward understanding within a given context rather than a factual knowing (Fox, 2008).

The naturalist understands that reality is multi-factorial. A naturalist accepts that reality is reliant upon contextualization and must be examined wholistically (Lincoln & Guba, 1985; Schwandt, 2011). This understanding, within a given context, lends itself to fit within the constructivist paradigm. Heidegger professes that being in the world cannot be separated from our past experiences, history, or culture (Nelhaus, 1998). For the researcher, as one cannot separate oneself from their being, it is impossible to completely discard previous experience and knowledge. This experience and knowledge could be personal or professional. The ontological positioning will be further illustrated in this chapter whilst discussing the theoretical framework and methodology.

3.2.5 Theoretical Perspectives

The theoretical perspectives given consideration throughout the writing of the thesis are Salutogenesis and Interpretive Description. Salutogenesis is a theory of what well-being “looks like”. In the writing of this thesis two constructs were adopted from Antonovsky’s theory of Salutogenesis: Sense of Coherence, and General Resistant Resources. Sense of Coherence is utilised as the theoretical framework, whilst the construct of General Resistance Resources helps to identify the elements present or not present to older people as they develop their Sense of Coherence. These constructs will be more fully discussed in the theoretical framework section.

Interpretive Description (Thorne, 2008, 2016) is the chosen methodology for the development and design of this thesis. Interpretive Description is a new qualitative methodology. Interpretive Description entered the qualitative research arena as a new methodology in 2008 (Thorne, 2008). It could be argued that Interpretive Description is a theory unto itself. A theory must be constituted of four properties:

- definitions of concepts used by the theorist.
- identifies a domain to which it applies
- Proposes a set of relationships with variables
- makes specific testable claims

Interpretive Description fits these criteria. (Wacker, 1998). All methodologies meet these criteria. This is what separates a methodology from a method. This will be further described in the next section. Interpretive Description will be more fully explained in section 3.3 of this chapter.

3.2.6 Theory, Methodology or Method

3.2.6.1 Paradigm. Qualitative research is an all-encompassing paradigm unto itself. Within this paradigm there is an hierarchy (Figure 3.1).

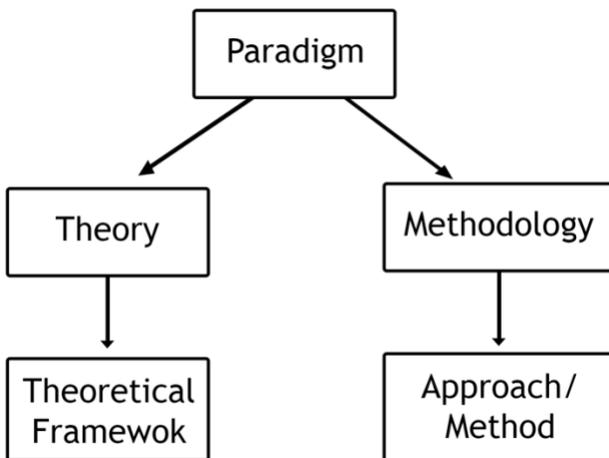


Figure 3.1. Paradigm hierarchy.

3.2.6.2 Theory. Theory is a set ideas and interrelated concepts and constructs which the theorist explains and defines. With these defined constructs and ideas the theorist makes assertions

regarding the implications of the theory related to certain human experiences (Collins & Stockton, 2018; Kerlinger & Lee, 2000; Kivunja, 2018). Theory displays the values and beliefs that inspire the research (Collins & Stockton, 2018). A theory is a philosophical epistemological stance.

3.2.6.3 Methodology. Theory of method, and methodology are terms which are used interchangeably (Collins & Stockton, 2018). This differs from theory in that methodology is a manner in which we obtain and understand knowledge (epistemology). A methodology is the incorporation of a philosophy of how a study should be conducted (Lessem & Schieffer, 2011; Silverman, 2010). This philosophy helps the researcher to understand the choices that need to be made throughout the research endeavour as the research study is designed (Collins & Stockton, 2018). The implementation of methodology must be evident from the beginning to the end of the research (Collins & Stockton, 2018).

3.2.6.4 Method/Approach. A method, or approach, is a choice of how one treats each step turn during the research (Lessem & Schieffer, 2011; Thorne, 2016). This differs from a methodology as a method or approach is the techniques chosen for conducting the research (Lessem & Schieffer, 2011; Silverman, 2010). An example of a method or approach is Framework Analysis which is a method of analysing data (Gale et al., 2013).

As an illustration of how one method was used in this thesis, semi-structured interviews were the approach applied for the data collection of the study (Galletta, 2007; Siedman, 2013). Semi-structured interviews allow for directed questioning yet allows for a narrative flow based upon the participant's experience. The approach used for analysis was Directed Content Analysis (Assarroudi et al., 2018; Hsieh & Shannon, 2005; Mayring, 2000). Directed Content Analysis is

an analytical approach in which a priori codes may be considered. All of the approaches used in this thesis will be described in Chapter 4.

3.3 Interpretive Description

Interpretive Description is a methodology situated within a full explanation of its ontological, epistemological and theoretical girding. This is similar to other traditional methodologies such as Ethnography, Interpretive Phenomenology Analysis, Narrative Research, Grounded Theory and others (Creswell & Poth, 2018; Mills, 2014).

Some qualitative researchers do not believe that Interpretive Description is a new methodology. Rather, they argue, Interpretive Description is a type of Grounded Theory (Berterö, 2015). Thorne does not claim that Interpretive Description is a new methodology. Interpretive Description names and provides theory to what is already occurring in the realm of qualitative study (Thorne, 2008, 2016).

Interpretive Description lends an organizing logic and theory to what has been occurring in research as more clinical scientists in the domain of health found a need to depart from conventional qualitative research traditions to answer their discipline specific questions, by producing purposeful description which is applicable to the clinical arena. Sally Thorne lent an auditable logic and theory which coincides with this “moving away” from the more traditional methodologies of Ethnography, Phenomenology and Grounded Theory (Thorne, 2008, 2016).

Sally Thorne laid claim to the dilemma of method slurring and has attempted to assuage critics of borrowing approaches from varying methodologies by developing a complete methodology which is a theory of qualitative research. Interpretive Description provides an explanation of and a

rationalization for this “slurring” by lending a name to an auditable logic which provides validity to a study. This is what Thorne refers to as “departure and diversification” (Thorne, 2016).

Some may ask where the boundaries of Interpretive Description lie. It could be argued that there are no boundaries as long as the researcher can provide evidence within an auditable logic which is philosophically Constructivist and Naturalistic (Thorne, 2016). The auditable logic provides rigour and a cogent choice of methods in the construction of a study which departs from conventional methodologies. Interpretive Description lends the qualitative paradigm a flexible method in a way that Ethnography, Grounded Theory, Phenomenology and other qualitative methods do not provide. Interpretive Description breaks away from the rigidity of these traditional methodologies, or as Sandelowski says, the “tyranny of method” (Sandelowski, 2000). This flexibility is beneficial to the discipline conducting the research in order that the design is conducive to the specific needs of the clinician.

By adopting the Interpretive Description paradigm, the knowledge produced by the logic design will come closer to probable answers to the research question. In addition, the knowledge gained meets the purposes of the question being asked from the ontological and epistemological position of the discipline. Interpretive Description endorses that knowledge and methodologies are imperfect, so researchers are limited to work within these confines. Researchers, therefore; rely on probable truths (Thorne, 2008). Whilst objective and subjective realities are polarized concepts it is necessary for the applied science of nursing to bestride both forms of reality by drawing from factual material and social construct (Thorne, 2016).

3.3.1 Flexibility

As mentioned in the previous section, the flexibility allowed by Interpretive Description is its greatest strength. It may also be argued that it is also its greatest limitation. This is due to the potential of scepticism of other scientists not comfortable with this flexibility. Interpretive Description counters this argument with the call for a strong auditable logic. Interpretive Description allows the flexibility within an auditable logic so that specific approach choices can be made which target the aims and purposes of the research (Thorne, 2016). The flexibility allowed by Interpretive Description is the very characteristic of the methodology that may be the strongest point of criticism as discussed in the next section.

Whilst this lack of comfort with the flexibility of Interpretive Description may linger, it is important to recognize the need to name and describe the way clinicians are performing qualitative research when they do not rely on conventional methodologies. The traditionally accepted methodologies do not provide the ability to use varying means of developing knowledge (Thorne, 2016). For instance, most qualitative methodologies have been only inductive. In the methodologies of Grounded Theory, Phenomenology, and Ethnography all analysis is inductive (Creswell & Poth, 2018; Glaser & Strauss, 1965; Morse, 2016; Sandelowski & Barosso, 2007; Smith et al., 2009). The inductive approach does not allow for the use of data from previous qualitative research or theories as foreknowledge, or a priori themes. Interpretive Description does allow for deductive approaches in the presence of rigour within the auditable logic (Thorne, personal communication, 2007). This allows the use of approaches which incorporate deductive a priori themes such as Framework Analysis or Directed Content Analysis (Hsieh & Shannon, 2005; Mayring, 2000; Srivastava & Thomson, 2009), both of which are acceptable by the Interpretive Description methodology.

The next section reviews existing critiques of the methodology. It will include some of the challenges encountered by researchers selecting Interpretive Description to design a study.

3.3.2 Critique of Interpretive Description

The first criticism noted by Hunt (2009) is the lack of specificity of the methodology. This criticism includes a perceived lack of guidance from a procedural and protocol standpoint (Hunt, 2009). His criticism is related to the use of Interpretive Description as a student. Whilst it is true that one cannot locate a full procedural prescription, the whole purpose of Interpretive Description is that each design utilizing an auditable logic is unique and dependent upon the needs of each study. Each study employs varying approaches within the auditable logic. This may prove to be disconcerting to some researchers, even those from a naturalistic inquiry tradition. The study using Interpretive Description as a methodology is bound by two elements. The study must have an auditable design, and the research must be reproducible. This is the standard of rigour for this methodology.

In addition, as a student, few academic researchers are familiar with the methodology. This lack of familiarity leads to uneasiness and sometimes confusion for the student and supervisor (Hunt, 2009). Employment of Interpretive Description may prove risky for the novice researcher who is dependent upon those very supervisors and mentors who lack the familiarity with the methodology.

Whilst the aforementioned critique notes novelty as a drawback, some criticize that the methodology is not new. It has been said that Interpretive Description is “old wine in a new bottle”(Bertero, 2015). Bertero claims that Interpretive Description is a type of Grounded Theory. This is not the case, especially in that Interpretive Description grants the flexibility to use deductive

approaches if it helps to answer the research question. Interpretive Description is a unique methodology.

These criticisms may be assuaged as Interpretive Description becomes more widely employed and the qualitative culture becomes more familiar with the methodology. With the increased use of the methodology, there will be further critiques of its limitations, guidance with the procedure, and familiarity with the terminology within Interpretive Description. The use of Interpretive Description in the current literature is discussed in the next section.

3.3.3 Use of Interpretive Description in the Literature

The articles included in this overview of Interpretive Description use in the literature was unsystematic. One of the articles combined Interpretive Description with Appreciative Inquiry (Bettle et al., 2018). The article describes the design as using Appreciative Inquiry as its theoretical framework and Interpretive Description for data collection, analysis and to ensure rigour (Bettle et al., 2018). This approach of combining two methodologies is encouraged by Interpretive Description as long as it fits the need of the researcher to answer the research question (Baker et al., 1992).

Some articles were found using Interpretive Description only as an approach to analysis (Chan et al., 2017; Håkanson et al., 2012; Karageorge et al., 2018; Mejdahl, Schougaard, Hjollund, Riiskjær, & Lomborg, 2018; Mejdahl, Schougaard, Hjollund, Riiskjær, Thorne, et al., 2018; Strachan et al., 2018; Utley, 2017). These variances in the use of Interpretive Description may be due to Thorne's allowance for flexibility. It may also be related to the continued struggle for rigour and uniformity in a qualitative design.

It was evident that Interpretive Description was the underpinning methodology used in some studies (Burnett & Corlett, 2017; Damilola et al., 2018; Freeman et al., 2018; Karageorge et al., 2018; Lasiuk et al., 2013; Miciak et al., 2018; Nkulu Kalengayi et al., 2012). Each described a constructivist orientation and had an evident auditable logic. In addition, these articles described the importance of their disciplinary orientation and the need to have usable information for the clinician within the findings. Ontologically, Interpretive Description is situated from a decidedly disciplinary perspective, which is one of the distinctive characteristics of the methodology (Thorne, 2014). The use of data derived from these studies will be discussed in the section describing transferability. These studies are similar to the empirical study of this thesis as they all adapted Interpretive Description as a full Methodology. The use of all aspects of Interpretive Description was present in the mentioned articles as well as this empirical study.

3.3.4 The Disciplinary Question

Interpretive Description encourages the consideration of the researcher's disciplinary frame of reference during the investigation. Over time, clinician-researchers began to realise that social researchers sought out the essence of experience. The need for answers to the clinicians' questions were different. There was a realisation by nurses for the need for more pragmatic knowledge which could lead to application in the clinical setting (Thorne, 2016). Nurses had been attempting to make existing methodologies fit their more clinically based research questions. Often these methods were ill-fitting to their purposes. Clinicians needed a methodology which would allow new qualitative knowledge to be applied to clinical problems which are complex and multifaceted (Thorne, 2008, 2016).

Each discipline has developed its own unique knowledge base. Each discipline has distinct needs to build and write curricula and scholarly projects. There may be overlap and value of the work between disciplines, but there is an intentionality of these efforts within each discipline (Thorne, 2016).

Thorne (2008) realized that current methodologies required a recasting to conform with the theory of any clinical discipline. In her writings, she uses nursing as an example of how a discipline, in and of itself, is theory. She argues that nursing theory is the lens from which a nurse views the world (ontology) and knowledge (epistemology). As nursing uses applied science and naturalistic inquiry, its goal is to further apply both types of knowledge to improve the care and outcomes of the population served.

3.3.5 Interpretive Description Analysis

The goal of Interpretive Analysis (Thorne, 2016) is to develop new constructions of the collected data to answer the pragmatic aspects of the research question for future clinical application. In this case, it is applied to determine the clinical and personal ramifications of those experiencing 30-day readmissions. This approach borrows from other analytic methodologies to process the data, but in the end, it is unique as it does not simply report the data, but rather uses interpretive authority to prescribe meaning to the data (Thorne, 2016). Interpretive authority requires the researcher to build-in systems to assure that claims made from the data are subjective truths, rather than simple bias. This obligates the researcher to support claims with direct evidence from the data. Thorne (2016) describes an analysis process which thoroughly deconstructs that which seems obvious and to reconstruct these into new ways of interpretation of the text to reveal the new meanings of these reconstructions.

3.3.6 Palliative Care and Goals of Palliative Care Nursing

Palliative care is a philosophy that guides the support and existential healing of patients with serious, and often, life limiting illnesses. The term healing differs from cure (Egnew, 2005). The meaning of healing will be discussed further in this section. Palliative Care is an interdisciplinary practice which includes nurses, physicians, social workers, and chaplains as the core team members (National Consensus Project for Quality Palliative Care, 2018).

The nature of “being” is multi-dimensional. Palliative care’s ontological positioning is that of “integration” of the self (Cassell, 1976) and is based on life experience (Antonovsky, 1979). Integration refers to the physiological, mental and spiritual aspects of the self (Cassell, 1976, 2004, 2009). Nursing is an integration of the social sciences and the biomedical sciences (Thorne, 2008). This positioning is what drives the methodological direction which nurses take in research. As described by Thorne (2008), Nursing’s *raison d’etre* is the “amelioration of human distress, the accommodation of frailty, to counter the personal vulnerabilities of illness and sickness, and to make meaningful sense of the indignities which are caused by the failures of our bodies and minds” (Thorne, 2008). Sally Thorne agrees that these goals are the goals of palliative care nursing (personal communication, December 7, 2018). This thesis is written from the perspective of palliative care nursing and corresponds to these core values and goals. Palliative care nursing aligns with the chosen theoretical framework in that palliative care nursing attempts to increase Sense of Coherence which will be further addressed in the discussion chapter (Chapter 6).

Nursing concerns itself with the sick rather than the pursuit of disease and cure. There is a difference between illness and being sick (Antonovsky, 1987; Cassell, 1976, 2009; Kleinman et al., 1978). This difference is that a person has an illness, which is a biological disruption to one’s

physiology, whereas; when a person is sick there is an embodied feeling of un-wellness which includes symptoms and a level of fear, dependence and loss of self (Cassell, 1976). This episode of sickness may include an element of danger to life (Cassell, 1976). The mounting symptoms of sickness threaten the integration of the individual, creating an increasingly smaller world (Cassell, 1976, 2009).

The disciplinary orientation of nursing includes physiology, spirituality, humanity, psychology, medical science, the observation of patterns in care and behaviour, establishing standardized practice and hands-on care; in other words, whole-person care. Nursing is integrated and holistic. It is the meshing of science, humanity and art. Thus, it is based upon the interplay between the subjective and objective (Thorne, 2016). Interpretive Description allows the clinician to *be* their own discipline, in the ontological sense, while utilizing newly discovered empirical evidence, both quantitative and qualitative, through structure and logical design.

3.3.7 Acquiring Knowledge

Phenomenology, ethnography and grounded theory are methods which call for the researcher to acknowledge their positioning, but to enter the field attempting to disregard this positioning (Creswell, 2007; Madden, 2017). This is not effective in forming further usable knowledge in a clinical discipline. For applied health disciplines, knowledge is built on the foundation of earlier scientific discovery. Interpretive Description understands that the discipline has an acquired base of knowledge which is built upon with further inquiry (Thorne, 2008, 2016). The methodology of Interpretive Description allows for the flexibility required for the analysis.

Interpretive Description is theoretically agnostic but acknowledges that elements of theory are often applied to the methodology to answer the question being asked. The first element in

“identifying the theoretical fore structure is the researcher acknowledging their own “theoretical allegiance” (Thorne, 2016). This framework allows for the contextualization of a phenomenon based on the individual’s unique history, experiences and circumstance.

Thorne (2008) argues that one must clarify to oneself the basic tenets of the “burning question” of the discipline. Nursing is a very complex endeavour. As earlier described, Thorne (2008, 2016) beautifully illustrates the purpose of palliative care nursing. The question is how to accomplish these purposes. Interpretive Description requires the researcher to explore the relationship with the ideas the researcher holds and how the researcher is positioned within these ideas (Thorne, 2016). The researcher must identify their “complex selves” within the discipline and within the concerns and experiences which have led them to the topic of the study (Thorne, 2016). This topic was decided upon after many years of witnessing elderly patients with multiple co-morbidities receiving very aggressive treatment and enduring suffering from the treatment only to be discharged from the hospital and return with the same problem, weaker, with a lower baseline of function and with, what the researcher perceived to be, a further decrease of Sense of Coherence (Antonovsky, 1979; Greyson et al., 2015; Hoyer et al., 2014). By allowing these individuals to explain their experiences their stories may shed light upon this and other issues concerning the population of these older patients.

3.3.8 Adequate Knowledge

The relationship between knowledge and qualitative research consists of both ontological and epistemological standings. These are garnered from the disciplinary perspective of the researcher and knowledge-seeking from a qualitative perspective. As there are multiple possible answers garnered from interviews relying upon reporting from individuals with differing illnesses, cultures,

life experiences, and biases; an absolute truth or knowledge is not possible. Although imperfect, we must work with probable truths (Thorne, 2016).

Interpretive Description is not a complete transformation from earlier qualitative approaches. Thorne acknowledges that this results in “tension between theoretical integrity and utility” of results (Thorne, 2016). Each researcher needs to explore their approach and develop a rigorous and defensible logic design. This is not methodological eclecticism, rather an approach that goes beyond description to the interpretation of questions asked by clinicians. It allows for careful dissection of what is known, and examination of what may be learned and applied from freshly collected data. In light of Interpretive Description’s novelty, Thorne (2016) discusses the importance of credibility. This is presented in the next section.

3.3.9 Enhancing Credibility and Trustworthiness

Interpretive Description has developed a set of evaluation standards. Table 3.1 describes how the four evaluation criteria are used to produce credible, high-quality research using this methodology (Thorne, 2016). A more specific explanation of how these criteria were applied will be examined in Chapter 6 when discussing the strengths and limitations of the study.

Table 3.1*Credibility and Trustworthiness Criteria*

Criteria	Description
Epistemological Integrity	Epistemological Integrity is accomplished by maintaining a consistent approach to reasoning and assumptions within the study. An element of validity and quality is reached through the adherence to the methods and theoretical framework chosen to be used in the design and analysis of the study.
Representative Credibility	To claim representative credibility, it is necessary to show an alliance between the observed experience and the theoretical conclusions within the sample and the approaches undertaken in the study. The sample should also illustrate diversity.
Analytic Logic	This is achieved through a constant and coherent line of reasoning within the interpretations and claims produced by the study.
Interpretive Authority	To achieve interpretive authority there must be an adequate amount of information regarding the data. This information includes the reflexivity as well as reactivity occurring during the research process.

3.3.10 Knowledge Integration and Transferability

The findings as a result of the use of Interpretive Description are purposeful. There is no claim that the knowledge produced by other methodologies is inferior. However, knowledge for its own sake is not enough for the clinician-researcher. The ends of new knowledge must be purposeful to answer clinical and/or theoretical questions. Interpretive Description holds that the applicability of new knowledge is its' transferability (Thorne, 2016; Thorne et al., 2004). Within the methodology of Interpretive Description, this is referred to as "knowledge integration" and "knowledge transfer" (Thorne, 2016). Knowledge transfer is the expectation of Interpretive

Description research to affect policy or clinical intervention. Knowledge integration and transfer is an indication of the validity of the work.

The literature review in this thesis shows there have been many interventions and hospital policies implemented without adequate knowledge of the patient's experience. The majority of these interventions involved discharge planning, patient education and follow-up phone calls to the patient after discharge (Dedhia et al., 2009; Luke et al., 2011; Naylor et al., 1994; Steeman et al., 2006). This indicates practice without being informed by the population they are targeting with these interventions.

The knowledge accumulated in this study may also be integrated to contribute to the theory used in this thesis. The next section describes the knowledge integration of data found through the employ of Interpretive Description for pragmatic use.

3.3.10.1 The Use of Outcomes. One of Thorne's claims regarding Interpretive Description as a methodology is the ability to use findings to affect policy and practice. This is of great importance to argue for the use of Interpretive Description. Without proof of this, the result is knowledge as a means to no end or research as an intellectual exercise.

The transferability of knowledge derived from Interpretive Description is evident in research that exists in the literature. Several researchers were contacted to determine the transfer of knowledge using their findings. Some described their outcomes being used in clinician education. One author had findings used for continued education for health care professionals. In addition outcomes were used to improve guidelines for cross-cultural encounters (Nkulu Kalengayi et al., 2012). A researcher in the UK reports that her findings have resulted in Masters and BSc modules at the university and on an Infection Prevention and Control unit at an academic hospital (Burnett &

Corlett, 2017). Another researcher has plans for an intervention aimed at patients to improve their ability and willingness to share with clinicians their experiences with Asthma (Damilola et al., 2018). Unfortunately, there has been no funding for the intervention. The integration of knowledge gained from Interpretive Description research is useful and pragmatic. With a future breadth of adoption of the methodology the ability to integrate this new knowledge will become more evident.

There is a great amount of diversity in the disciplines using this methodology and the topics being studied. Some of these disciplines include Health Administration, Nursing, Psychology, Pharmacy and Medicine. Notably, many of these studies were concerned with palliative care. This thesis will contribute to the growing utilization of this methodology.

3.4 Theoretical Framework

In 1979, Aaron Antonovsky, a sociologist and anthropologist whose work was focused on public health research, created the “Salutogenic Model” (Antonovsky, 1979). Salutogenesis is the acknowledgement that with better public health practices and the discovery of antibiotics Western medicine can largely contain diseases caused by microorganisms and environmental toxins. It also acknowledges that whilst of great import to learn how to prevent and moderate chronic illness, death cannot be thwarted (Antonovsky, 1979). Antonovsky (1979) argues that his theory of Salutogenesis acknowledges that the most important direction for social science and medicine is to learn how to make our lives better. Finally, and probably most important to this research is Antonovsky’s belief that health is more than the absence of disease (Antonovsky, 1979, 1987). Antonovsky understands Salutogenesis as a state that begins at birth and is dependent upon life experience, socio-cultural aspects, and the historical context into which one is born. He claims that the socio-cultural aspects and historical context of the individual lead to the development of

General Resistance Resources (Antonovsky, 1979). General Resistance Resources include the Major Psychosocial General Resistance Resources and the Genetic and Constitutional General Resistance Resources. Major Psychosocial General Resistance Resources include material resources, knowledge/intelligence, ego identity, coping strategies, social supports, commitment, cultural stability, magic, religion/philosophy/art, and preventive health orientation. Each Individual has varying General Resistance Resources. The strength of one's Sense of Coherence is dependent on the level and how one is able to engage and use their General Resistance Resources (Figure 3.2).

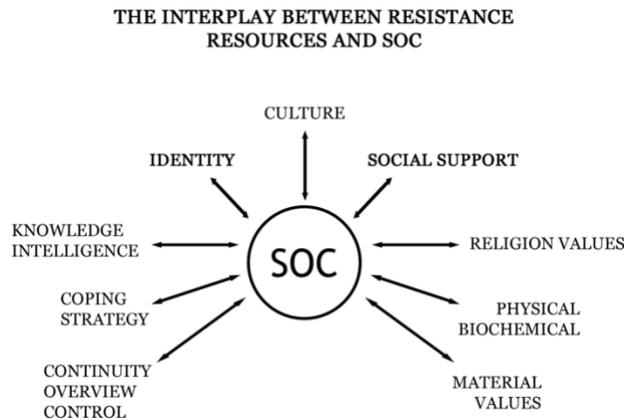


Figure 3.2. The interplay between Resistance Resources (Mittelmark, Bull, & Bouwman, 2017; Mittelmark, Bull, Daniel, et al., 2017).

In “Unravelling the Mystery of Health” (Antonovsky, 1987) there was greater attention paid to and written of Sense of Coherence. Sense of Coherence is composed of three concepts: Comprehensibility, Manageability and Meaningfulness (please see glossary). These three concepts will be key in this research as they will be used as a priori codes during the analysis, which is one reason why Interpretive Description is the best choice for this design.

Sense of Coherence is the theoretical framework for this thesis. Its concepts will be used as a priori codes for the research. Sense of Coherence will be discussed further in the Results and Discussion chapters of this thesis.

3.4.1 Expansion of Sense of Coherence

Since Antonovsky's death in 1994, his work continues to be significant to healthcare and social researchers. The construct, "Salutogenesis" has become a well-known term among researchers and many public health professionals as a new and holistic way to approach health. The acceptance of the word Salutogenesis into the Merriam-Webster dictionary in 2019 speaks to how important Antonovsky's work has become (Merriam-Webster, 2019).

There are numerous studies regarding General Resistance Resources. Another construct within Antonovsky's theory is Specific Resistance Resources, but little attention was paid, or research conducted regarding this concept until later (Antonovsky, 1979, 1987; Mittelmark, Bull, Daniel, et al., 2017). Specific Resistance Resources are related to societal and political activities which promote the health and well-being of people (i.e., public health, education, housing) (Mittelmark, Bull, Daniel, et al., 2017).

Prior to his death the World Health Organization held a conference and called for a new way to promote health on a societal level by diverging from the disease-wellness continuum and cited Salutogenesis as an approach to a new way of thinking when developing policy and interventions (Kickbusch, 2003). Since that time there have been many emerging thoughts about Salutogenesis and Sense of Coherence. The overarching themes of these emerging ideas are 1) How does a strong Sense of Coherence come to be for the individual, 2) Is it possible for a major change in one's Sense of Coherence to occur after early adulthood, and 3) Can one speak of a collective Sense of

Coherence (Mittelmark, Bull, & Bouwman, 2017). The empirical study of this thesis will be a contribution to the expansion of Sense of Coherence as it relates to changes occurring in the seriously ill older population. Examples of how these emerging themes are being addressed is presented in this section.

3.4.1.1 Researching the Development of Sense of Coherence. An example of how the development of a strong Sense of Coherence occurs has been studied (Slootjes & Shaharso, 2017). This was a study of female immigrants from Middle Eastern and North African countries into the Netherlands. Data were drawn from interviews with the participants and traits of a weak and a strong Sense of Coherence were compared and examined. These results are convincing and congruent with the theory. This study is evidence of how a strong Sense of Coherence is formed in comparison to a weaker Sense of Coherence. It is also evidence that Sense of Coherence is dynamic dependent upon changes in one's General Resistance Resources.

Antonovsky wrote of a trait he called "general personality orientation". This orientation includes the characteristics of such things as an individual's locus of control, hardiness, and self-efficacy (Antonovsky, 1991). Antonovsky proposes that general personality orientation contributes to one's Sense of Coherence. The Slootjes and Shaharso (2017) study is provocative and begs for further research in this area. The empirical study of this thesis will extend this work, albeit in a different manner and approach.

3.4.1.2 Researching Change in Sense of Coherence. Another area of examination is testing the variability of Sense of Coherence over a lifetime. This emerging theme is the area of study within this thesis. This will be addressed later in the results chapter of this thesis.

There is a study examining constancy Sense of Coherence in older people (Nilsson et al., 2010). Amongst the findings is the claim that Sense of Coherence improves as one becomes older. The results of this study challenge Antonovsky's assumption that Sense of Coherence is mostly stable throughout a lifetime.

There are other studies that are just the beginning of research in this area (Hakanen et al., 2007; Lovheim et al., 2013; Smith et al., 2003). Further research is needed to determine if Sense of Coherence is, in fact, more a developmental construct, or if it remains a constant through the lifespan. If it is found that Sense of Coherence is a developmental construct it would be clinically significant. Such a finding would be evidence to build clinical interventions to affect and improve the strength of one's Sense of Coherence at the end-of-life. Whilst there have been interventions developed and published regarding Sense of Coherence in the health care literature, especially in the area of health promotion (Heggdal & Lovaas, 2018; Super et al., 2016; Wainwright et al., 2007), there is a need for such research and interventions at the end-of-life.

3.5 Summary

This chapter includes an overview of the paradigmatic hierarchy of research, methodology, theory and method. Also, included is a description of the epistemological and ontological premise for this thesis. It described how the discipline of palliative care nursing is compatible and can be integrated with the selected methodology, and the theoretical framework for this study. There was a discussion of Interpretive Description and how it encourages a more discipline-driven means to deriving new knowledge and applying it in the clinical setting. In addition, Interpretive Description provides the clinician with the freedom to design their own auditable logic using elements of other approaches, designs and philosophy that are better tailored to the purposes of the study.

There was a discussion of Antonovsky's theory and how it has been used in the thesis as the theoretical framework. There was discussion of the future of potential research of the theory. In the following chapter, a description of the study's auditable logic will be provided.

The theoretical framework of Sense of Coherence is an appropriate choice of this thesis as it is directly related to the subject being studied. It is adaptable with the premises of Interpretive Description. Both, Interpretive Description and Sense of Coherence are deeply compatible with the values and world view leading to this study. These are the threads which bind this thesis together.

Chapter 4. The Auditable Logic Design

4.1 Introduction

This chapter will provide an overview of the auditable logic design with a description of the study purpose, objectives, research question, sample, recruitment procedures, representative credibility, data collection, data analysis processes, ethical issues and the institutional research approval. These will be described using the methodological approach of Interpretive Description.

4.2 Purpose of the Research

There is an absence of qualitative study in the area of older people and 30-day readmissions. In addition, there is a lack of qualitative knowledge regarding Sense of Coherence of older people as they experience serial loss during progressing disease and 30-day readmissions. This study aims to provide further knowledge in these two areas.

4.3 Research Question

The question being asked of this research is “Do the experiences of older adults with a 30-day readmission affect the construction of their Sense of Coherence?” The concepts of Sense of Coherence consist of Comprehensibility, Manageability and Meaningfulness. This question will be explored considering all three concepts of Sense of Coherence (Antonovsky, 1979, 1987) as *a priori* codes. The answer to this is highly complex and multidimensional. It requires an approach that recognizes the interplay of a patient’s physiological, spiritual, socio-demographic and psychosocial dimensions to achieve a holistic interpretation of the patients understanding of the Comprehensibility, Manageability and Meaningfulness of their experiences, or their Sense of Coherence (Antonovsky, 1979, 1987). It is also a complex question that requires a methodology

which allows the researcher flexibility displayed through the use of an auditable and logical integrity (Thorne, 2008, 2016). The integrity and the credibility is assured by the auditable logic design of the study (Thorne, 2016).

4.4 Objectives

Interpretive Description suggests that objectives flow from the research question and the disciplinary perspective of the researcher. According to Thorne (2016), a qualitative social research approach helps to inform our understanding of the societal influences on the forming of our responses as human beings.

The objectives of this study are:

1. To allow the participant to describe the course and trajectory of their illness, and how their illness has affected their readmission(s) to the hospital, their quality of life, their relationships and their Comprehensibility of what has happened.
2. To allow the participant to identify the information shared with, and resources provided to them upon their last discharge which helped with the Manageability of their condition outside of the hospital.
3. To elicit the participants to engage in describing past hospital admissions, any changes in functional status and present 30-day readmissions.
4. To allow the participant to share the Meaningfulness of these experiences and how they may affect their future.
5. To interpret the findings of the effects of the experiences of older adults with serious illness on their Sense of Coherence from the interview data collected during a 30-day readmission to the hospital.

4.5 Sample

Purposive sampling was adopted and is described below (Table 4.1).

Table 4.1

Process of Purposive Sampling

Process Title	Definition
Sample Universe	Indicates the characteristics that all participants will have in common in the sample. This is accomplished through inclusion and exclusion criteria.
Sample Size	Deciding on the size of the sample considering epistemological and practical purposes.
Sampling Strategy	The chosen strategy model (i.e., Random, Convenience, Stratified or Quota)
Sample Sourcing	The process approach to recruitment: advertisement, incentives, control for bias, and ethical concerns regarding consent.

Source: Robinson (2014), Silverman (2010), and Thorne (2016).

4.5.1 The Sample Universe

The Sample Universe allows the researcher to identify only participants that have had the experience in question. Table 4.2 describes the inclusion and exclusion criteria for the study to assure the sample contained only appropriate individuals.

These criteria were chosen with the intent of identifying patients who had a 30-day readmission. We know from the literature review such participants are likely to have frailty and comorbidities (Mor et al., 2010).

Table 4.2*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
65 years of age or older	Admitted on Observational Status*
Readmitted to the hospital within 30 days of their last hospital discharge	Planned readmissions for interventions
English speaking	
Possesses capacity as described in Human Research Protection Program Policy 340 (Appendix 7)	

Note. * This refers to a person who returns to the hospital and is kept in the hospital for observation, rather than a formal readmission.

4.5.2 Sample Size

There is little qualitative data in the literature and that which does exist has much smaller samples regarding the issue in question (Dilworth et al., 2012). The goal was to enrol between 15 and 30 participants. This sample number was deemed to be adequate to determine patterns and to begin understanding the experiences of this population. This rationale is in accordance with Thorne's guidance regarding sample size (Thorne, 2016). Thorne advises that the choice of sample size requires sound reasoning and explanation. This study will begin to contribute to a better understanding of the experiences of 30-day readmissions in the context of Sense of Coherence for this sample.

4.5.3 Strategy for Recruiting the Sample

This section serves to explain the process of recruitment for the study. It will cover the recruitment design, the use of non-researcher recruiters, and the consent process. The process of recruitment

is illustrated in Figure 4.1. This strategy utilizes purposive and convenience sampling to meet the needs of the study. Purposive sampling was achieved with the use of the inclusion/exclusion criteria. Convenience sampling refers to non-randomization during recruitment. The hospital's Joint Data Analytics Team generated a daily report identifying all older adults admitted to the hospital. The report was screened to determine those who had an unplanned 30-day readmission from those who had planned readmissions for chemotherapy, surgery or other procedures.

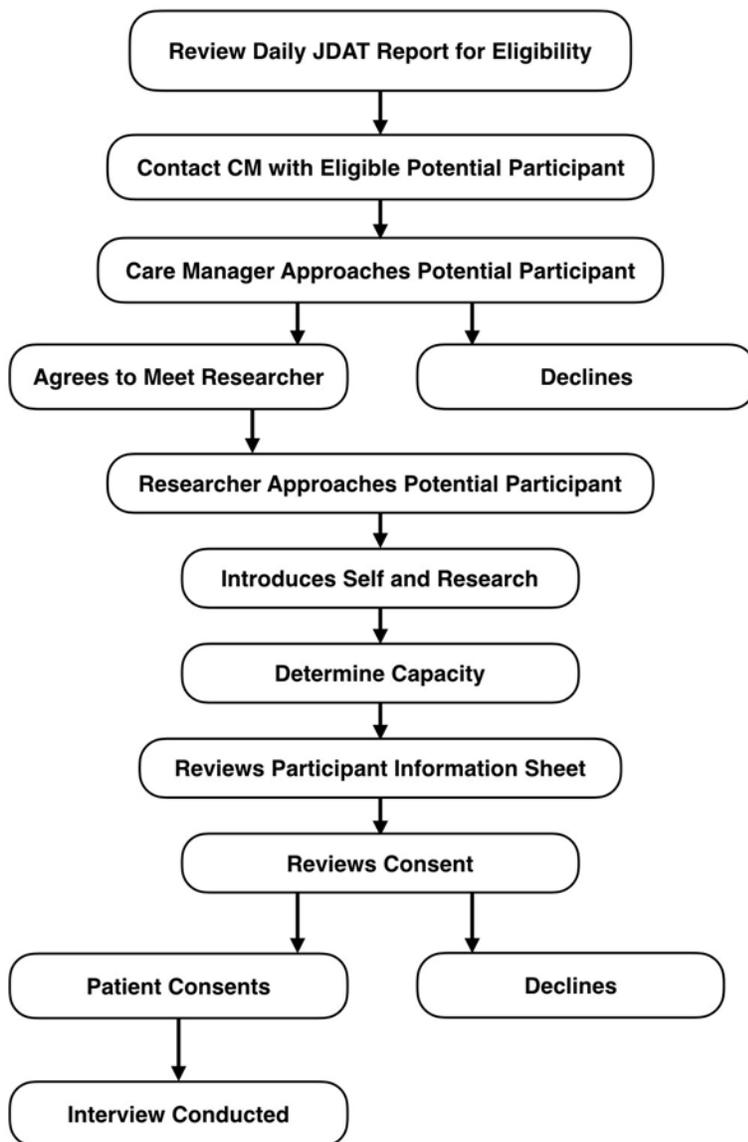


Figure 4.1. Recruitment process using Joint Data Analytics Team Report (JDAT).

The hospital case managers were willing and agreed to approach those patients identified in the Joint Data Analytics report. There was variability in the numbers approached due to time constraints and other issues which will be discussed in the findings chapter. The case managers introduced the topic and asked the patient if they were willing to hear more about the research. If the answer was “yes”, the case manager notified the researcher, and the researcher would attempt to contact the patient and determine their willingness to participate. There was inconsistency in the recruiter providing the Patient Information Sheet (Appendix 8). For this reason, all participants received the Patient Information Sheet when approached by the researcher for consent.

4.5.4 Sample Sourcing – Non-Researcher Recruiter

Non-researcher recruiters were utilized in this study. The purpose of this was to ensure that patients did not feel pressured to participate. The study enlisted the help of a group of registered nurse case managers. The Case Managers had already been interacting with the potential participant therapeutically and there was an expected level of familiarity. It was anticipated that this familiarity would elicit a level of comfort rather than having a stranger approaching. The case managers had no interest in the study, other than the recruitment of potential participants.

4.5.5 Consent

When the potential participant expressed they would like to learn more about the study, the care manager notified the researcher. The researcher approached the potential participant, introduced and briefly described the research. If the potential participant expressed interest their capacity was determined (Appendix 7). The participant information sheet was then reviewed (Appendix 8). The consent form which includes consent to research, the Health Information Portability and Accountability Act release <https://www.cdc.gov/phlp/publications/topic/hipaa.html> (Appendix 9)

were given to the potential participant. After the explanation was provided to the potential participant time was allowed for thoughtful agreement or disagreement to participate. If a potential participant asked to have time to consider they were approached again after each 24-hour period. If the patient had not affirmed consent for participation within 72 hours they were not approached again.

4.6 Data Collection

This section describes the activities surrounding the data collection. The data collection is consistent with Interpretive Description. Data collected included demographic data, interviews and field notes (memos and reflective journal). A description of preliminary thinking and modification from the initial plan for data collection has been included.

4.6.1 Semi-structured Interviews

Data was collected using an adaptation of Siedman's in-depth semi-structured interviews (Siedman, 2013). This approach to interviewing was selected as it is used to explore complex problems within the human experience. This method echoes the epistemological and ontological positioning of Sense of Coherence, the theoretical framework of the study (Antonovsky, 1979, 1987). This will be explained in this section.

The overarching assumption of in-depth interviewing is that the approach allows participants to share the meaning of how an experience has affected their lives. This is associated with the definition of Sense of Coherence. Antonovsky argues that the three concepts of Sense of Coherence are intertwined with how the participants experience their lives and how those experiences contribute to their global orientation (Antonovsky, 1987).

There was an expectation that many of the participants may be debilitated and fatigue very easily. Therefore, shorter interviews were conducted whilst continuing to broach all three overarching topics suggested by Seidman. The length of interviews should not be constrained by the researcher's parameters, rather the length should be guided by the abilities, and reflect the needs of the participants (Legard et al., 2003). An interview guide was developed (Appendix 10).

Seidman describes the purpose of each interview segment to have a distinct focus. Each interview segment is related to a concept within the theoretical framework. The interviewer helped the participant focus on these areas:

1. Focused Life History (Comprehensibility) – The theme allowed the participant to tell the story of their health and life. This allowed the observation of the participants understanding of their circumstances. The participant was invited to reconstruct the history of their failing health and their understanding or Comprehensibility of their prognosis, the trajectory of their illness, previous encounters with the health care system and the events leading to this hospitalization.
2. The Details of the Experience (Manageability) – The second theme concentrated on the details of the time after their last discharge including resources, care, met needs, unmet needs, symptom management, care access and emotions experienced. The participants were asked to describe their experience in the home or skilled nursing facility with a focus upon their expectations, perceived needs, resources, and quality of communication upon the last discharge, access to caregiving and health services, and functional status. They were asked to share how their needs were met through resources or independently. This line of discussion illuminated the ability of the patient to manage (Manageability) after the last discharge.

3. Reflection on Meaning (Meaningfulness) – The third theme examined the intellectual and emotional connections between the participants' illness experience and their lives. This final interview segment explored the older person's sense of meaningfulness of their past, current and future experiences and expectations. There were also questions about their expectations, goals and wishes for the future, and what brings meaning to their lives in the context of their diminishing health.

The interviews used the three focused *a priori* areas of Comprehensibility, Manageability and Meaningfulness as instructed in Directed Content Analysis when using previous theory (Hsieh & Shannon, 2005). The interviews began with open-ended questions, moving towards more directed questioning as described in the interview guide (Appendix 10). These interviews covered all of the above-mentioned themes but were less rigid and were more conversational than the focuses appear.

4.6.2 Demographic Data

After the consent process and interviews were completed, data were collected from the Electronic Medical Record, and the participant. A *pro forma* was developed for this purpose (Appendix 11). The data on these forms included the randomized interview code, ethnicity, gender, living situation, place of residence (urban or suburban), utilization of the healthcare system, the number of comorbidities and prescriptions taken by the participant, as well as the participants' insurance status. This information served to draw comparisons between this population and the data in the literature review. It also lends insight into the sample's diversity. An aggregated table of selected data information is found in Chapter 5 (Table 5.1).

4.7 Sorting, Organization of the Data and Data Analysis

The three steps to the Interpretive Description analysis of the data include: 1) Sorting and Organizing, 2) Making Sense of Pattern, 3) Writing the Interpretive Description (Thorne, 2016). This process is consistent with all analysis using Interpretive Description (Thorne, 2016). However, the flexibility of Interpretive Description allows for varying approaches to achieve this process. A personal communication with Sally Thorne (2017) resulted in the agreement of the appropriateness of choosing Directed Content Analysis as it fits the purpose of the study in answering the research question.

The next sections will review the three steps of Interpretive Description analysis. This is a pragmatic way to organize and sort the data to begin the analysis, through the use of Cognitive Processing (Thorne, 2016).

4.7.1 Sorting and Organizing the Data

The first step in the analysis of the data when using an Interpretive Description approach is sorting and organization of the data. The decision was made to conduct the initial coding and analysis following a directed content approach as discussed by Thorne (2016) and described by Hsieh and Shannon (2005). The Directed Content Analysis method was chosen as it recognizes the potential for existing theory to direct a research question (Hsieh & Shannon, 2005) using deductive tactics with *a priori* codes. The goal of Directed Content Analysis is to contribute to a conceptual expansion of a theoretical framework. In addition, Directed Content Analysis provided a practical and orderly manner in the construction and management of the data.

Analysis was deductive, iterative and began at the time of the interview. The interviewer listened with intent to understand and follow up with questions to fill in gaps of understanding of the participant's experience. Once the interview was completed the recording was listened to and notes on inflexion and emotion were recorded. This is part of the interpretive process. An illustration of this process is provided in Appendix 12.

The recordings were sent to a professional transcriber through an encrypted and secure server belonging to Yale University. Once the transcripts had been transcribed, they were uploaded as documents into Atlas.ti. Once this was accomplished, initial deductive coding ensued.

Cognitive processing was used during the analysis. Thorne (2016) adapted Cognitive Processing for Interpretive Description analysis from Morse (1994). This includes four steps to help develop the supposition required to write the Interpretive Description. The first step is to comprehend the data and the research milieu. The second step is synthesizing the data to illustrate patterns within the interviews and determine what the important findings are that should be included in the results. The third step is theorizing. This is the process of developing “best guesses” of what the data means in consideration of other existing theory. The final step is analysis. Included in this analysis was re-contextualizing, which is the process of bringing the data back from the theoretical to a more pragmatic conclusion and interpretation.

The Directed Content Analysis approach is also referred to as “deductive category application” (Hsieh & Shannon, 2005; Mayring, 2000) (Figure 4.2). It allows for the ordered assignment of passages of extracted text to a well-defined conceptual category. As newly defined categorical concepts arise through interpretation, they are added to the existing theoretical coding framework. The final defined categorical concepts and coding tree arise after all coding has been completed.

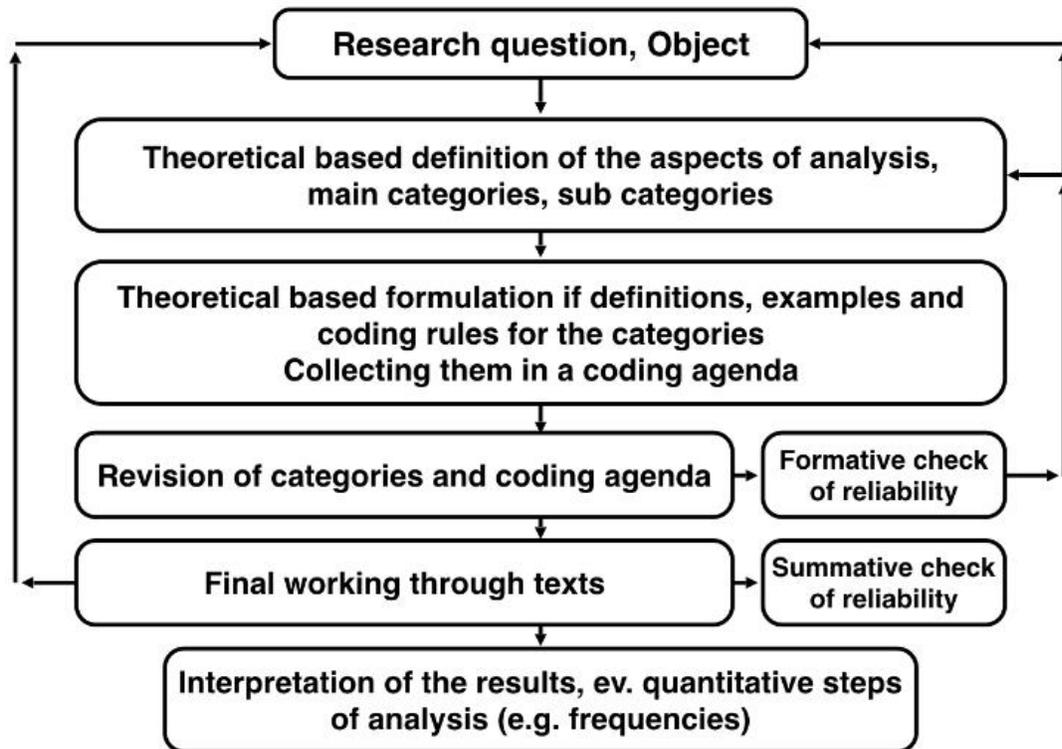


Figure 4.2. Step model of deductive category application (Mayring, 2000).

After the initial analysis, the process moves beyond sorting and organization, which is part of the scaffolding of the study through Directed Content Analysis. To further the depth and meaning of the interviews there is an interpretation of the themes, patterns, commonalities and also interpretation of the individual variability within the human response (Thorne et al., 2004). This is accomplished through a critical examination of the documents and listening and relistening to the interviews to achieve an “interpretive explanation” of the data.

4.7.2 A Priori Codes from Sense of Coherence, Overarching Themes, Sub-Themes, and Associated Codes

The analysis of the interviews used the *a priori* codes of Comprehensibility, Manageability and Meaningfulness which led to subsequent Sub-Themes, Associated Themes and a Unique Theme. This analytical process is presented in this section, Figure 4.2, and Figures 5.2, 5.3, and 5.4).

The *a priori* codes were used as category headings. The codes associated with the Sense of Coherence *a priori codes* are included in a table along with any subsequent Sub-Themes and Associated Codes and will be more fully discussed in Chapter 5 (Figure 5.2). In addition, the table includes the frequency of each code identified and associated with each of the *a priori* codes, as is part of the method of Direct Content Analysis (Aveyard et al., 2016; Hsieh & Shannon, 2005; Mayring, 2000).

Deductive coding began at the first interview. The cognitive process begins at the first encounter with the first participant. The first cycle of coding was to obtain sub-themes associated with each *a priori* code. The process of interpretation formally began during the sub-themes identification.

The next step in the process was to begin identifying the sub-themes and how they were associated with each of the overarching themes. Subsequent coding for associated codes was accomplished inductively. This iterative process enhances the understanding of the implications of data (Thorne, 2016). The assigning of associations and relationships from the data using iterative reasoning and considerations of the overarching themes continued throughout the analysis. During this process, research notes were documented in Atlas.ti. These notes and memos transcended the organization of the data to the beginning of understanding the relationships and associations between the overarching themes, sub-themes and associated codes.

During this process it was found that in addition to the *a priori codes*, another code/concept was identified which is associated with Sense of Coherence specifically to this population. This code was closely related to Comprehensibility and of great importance in this study. Comprehensibility and the newly identified concept became the overarching themes for the study (Figures 5.2 and 5.3)

There was great reliance upon the reflective journal which was kept throughout the process (Thorne, 2008, 2016). The “journal” was written by hand in a notebook as well as notes kept in Atlas.ti during coding and analysis. The notebook portion of the journal was to recall thoughts, questions and the process of decision making throughout the analytic process so that query of the data was conducted in a structured and meaningful way. The contents of this journal served as a reference during the writing of this thesis and was an important part of the data analysis.

The sub-themes were identified, and the deductive process continued using the sub-themes as the “new” *a priori codes*. This step in the process was used to determine associated codes. The product of this endeavour is illustrated in flow charts (Figures 5.2 and 5.3).

It was during this process that there was recognition of a unique phenomenon which was seemed unique from the other themes. This theme/phenomenon was recognized during the iterative process of relistening to the recordings for inflexion, rereading the transcripts, rereading memos in Atlas.ti and referring to the reflective journals. This new theme/phenomenon was separated from the overarching themes and sub-themes as a unique theme (Figure 5.4). Further presentation and explanation of how this sub-theme was determined is found in Chapter 5.

4.7.3 Writing the Findings and Interpretive Description

The entire process of this analysis is iterative and concurrent, which will lead to continuous Interpretive Analysis occurring with the collection and the sorting and organizing of the data (Thorne, 2016), and then written in the discussion of the study's implications (Chapter 6, section 6.6). This process allows for the spontaneous process of analysis to begin and the development of ideas to be brought forth in subsequent interviews. It also allows for an early start of the process of comparing possible codes and patterns (Thorne, 2016). It was at this point that the newly discovered categorical concepts were considered in the context of the theoretical framework.

Using the notes and journal as a foundation, overarching conceptual claims were established based upon the data analysis and data integration (Thorne, 2016). An explanation of these claims as well as illustrative tables of the socio-demographic data and coding data and examples of the coded themes will be described in the results (Chapter 5).

The Interpretive Descriptive approach is to describe the findings and the meaning of the research. It will be shown that there is a distinction between subjective bias and what may qualify as probable truth (Thorne, 2016). In addition, there is a distinction between interpretation and description. As mentioned earlier, these processes are elements of interpretive authority. In addition, measures will be taken to assure trustworthiness. These measures were discussed in Chapter 3. The integrity of the auditability of the design lends to the credibility and trustworthiness of this approach.

4.8 Ethics and Institutional Approval

There are four ethical issues addressed in this study. This section will reflect upon the protection of this vulnerable population, risk reduction in the interview process, assuring capacity and protection of confidentiality. This section will also explain the ethics approval process.

4.8.1 Vulnerable Population Risk and Minimizing Risk

Society considers the population of this study to be a vulnerable population (Schroeder-Butterfill & Marianti, 2006). The conditions of frailty, end-stage disease and comorbidities make this a vulnerable population and puts them at risk. These conditions may affect the stamina of the participants to endure long, in-depth interviews due to fatigue. Safeguards were taken to protect participants. The following sections address those safeguards.

4.8.2 Interview/Risk and Minimizing Risk

Some participants were asked about experiences that may have been uncomfortable for them to recall and discuss. The participants were to be asked if they were able to continue if he or she showed signs of hesitance or fatigue. None of the participants asked to stop the interviews or showed any distress.

In addition, this protocol presented minimal risks to the subjects and Unanticipated Problems Involving Risks to Subjects or Others (UPIRSOs), including adverse events, were not anticipated. This protocol is specific to the institution where this study was conducted. Any Reportable Events, which are events that are serious or life-threatening and unanticipated (or anticipated but occurring with a greater frequency than expected and possibly, probably, or definitely related) or Unanticipated Problems Involving Risks to Subjects or Others that would cause temporary or

permanent interruption of study activities would have been reported immediately. Fortunately, no such events occurred, and this was not necessary.

4.8.3 Capacity

Potential participants who met the criteria for the study were approached by the primary investigator and determined to have capacity before discussing the study details. They were assessed for capacity in conformity with HRPP Policy 340 (Appendix 7). A brief conversation ensued with each potential participant to determine if the patient was able to do the following:

- Ability to communicate a reasoned choice regarding participation;
- Ability to understand relevant information about the study, including consequences of participation for the participant's own situation (such as health condition) and consequences of the alternatives to participation.
- Ability to comprehend the nature of the situation and its likely consequences; and
- Ability to manipulate information rationally.

Once capacity was determined the consent form was explained and the participant then chose to consent or refused to be included in the study. All but two interviews took place at the same time the consent was signed. The two participants who were interviewed on a different day were re-evaluated to determine capacity.

4.8.4 Confidentiality

The identity of the participant was coded to protect privacy. Identifiers, such as names, medical record numbers or addresses were not documented in compliance with the Health Insurance Portability and Accountability Act (HIPAA) procedures.

An encrypted audio recorder was used to collect interviews. These digital recordings were erased from the recorder once they were transcribed. Interview recordings and transcriptions are stored on a password-protected laptop with encrypted software.

All data (recordings, transcripts and consent forms) have been stored in the Atlas.ti are to remain stored for two years and maybe revisited for secondary analysis. The participant was notified of this in the consent procedure. After storing the data for 10 years as required by the University of Lancaster, all data will be destroyed. To ensure patient privacy interviews were conducted in a private space.

4.9 Representative Credibility

Representative Credibility is the term used within Interpretive Description to describe the trustworthiness within sample selection. It calls for the assurance of diversity within the sample and maintains that all participants have a shared experience. Also, an auditable logic with regards to the selection of the sample is maintained as illustrated in this chapter and in the Results Chapter (Chapter 5).

The researcher sought to recruit adults aged 65 years and older who were readmitted within 30 days of their last acute hospital discharge in the setting of a two-campus urban academic medical centre in New England, U.S.A. This institution was selected after a Joint Data Analytics Team (JDAT) report revealed this hospital had the highest numbers of patients meeting the study criteria (16%) within this large system of five hospitals.

4.10 Institutional Research Approval

To conduct this research institutional approval was required by the sponsoring institution and the institution where the research was conducted. The following is a description of the process of ethics approval from both campuses.

4.10.1 Yale University Institutional Review Board

As the study was being conducted at Yale University their Institutional Review Board (IRB) needed to approve the study. The protocol application Form 100 FR 28 (Appendix 13) was submitted to the Yale IRB and the study was approved to begin collecting data on September 23, 2016, and to be completed on September 22, 2017. The Yale IRB approval letter was received on September 23, 2016, and provided the Human Subjects Protocol number 1608018304 (Appendix 14).

4.10.2 Lancaster University FMREC

Upon approval from the Yale IRB, a second approval was required from the Lancaster University Faculty of Medical Research Ethics Committee. The Yale Protocol (Appendix 13) and Letter of Approval (Appendix 14) were submitted. The FHMREC Letter of Approval (Appendix 15) was received on October 17, 2016.

4.11 Summary

This chapter has outlined the design and processes undertaken to achieve a credible and high-quality study. By following these steps, the reader can see an auditable trail of the design and

methods. This will become more evident as the results of the research will be displayed in the next chapter.

Chapter 5. Findings

5.1 Introduction

The analytical process using Interpretive Description and the construct of Sense of Coherence is presented here. The results reported within this chapter provide evidence of how participants form their Sense of Coherence. It is important to understand that these results regarding Sense of Coherence are specific to a defined population (older people) within a specific context (in the presence of serious illness or near the end of life in a healthcare setting whilst being readmitted to the hospital within 30-days of the last discharge). The first section of this chapter is a description of the recruitment and characteristics of the research sample.

This is followed by a presentation of the data and an interpretation of the results from the study in the interview findings section. The findings regarding the overarching theme of Comprehensibility, along with the Sub-themes of Directed Communication Comprehensibility and Intuitive Comprehensibility, as well as the related associated codes for each Sub-theme will be presented along with interpretation. In addition, the theme of Incomprehensibility and the related subthemes of Intuitive Incomprehensibility, Directed Communication Incomprehensibility along with the associated codes will be presented along with an interpretation. Incomprehensibility is a new concept related to Sense of Coherence. These topics will be presented in this section.

An explanation and interpretation of a Devolving Sense of Coherence will be presented. Devolving Sense of Coherence is a new finding within the study which makes a new contribution to Antonovsky's theory. Devolving Sense of Coherence and Incomprehensibility are specific to this study of Sense of Coherence as one ages and is near the final phase of life.

Finally, an interpretation is offered of how Comprehensibility and Incomprehensibility affect the other *a priori* concepts. There will be a sub-section regarding Manageability and Comprehensibility. There will also be a sub-section regarding Manageability and Incomprehensibility. This is followed by a brief discussion of Meaningfulness and the two Overarching Themes.

5.2 Participants

A total of 44 patients were approached to discuss the research. Consent was obtained from 28 participants, there was attrition of three participants (Figure 5.1). The mean duration of the interview is 26 minutes (range 9 – 46 minutes).

The sociodemographic characteristics and pertinent data for the sample are described in Table 5.1. The participant geographic and ethnicity characteristics of this study closely align with the general population of the older population of the hospital and the surrounding service area. This was confirmed using the U.S. Census data for 2018 (U.S. Census Bureau, 2018).

5.2.1 Physical Characteristics

The results regarding comorbidities are contained in Table 5.2. Eleven of the participants had a diagnosis of “frailty” documented in their medical records. All but two participants had a history of falls, decreased functional status, weakness, multiple co-morbidities and frequent hospitalisations documented in their records. It is known that frequent hospitalizations are linked to progressive frailty (Oakland & Farber, 2014).

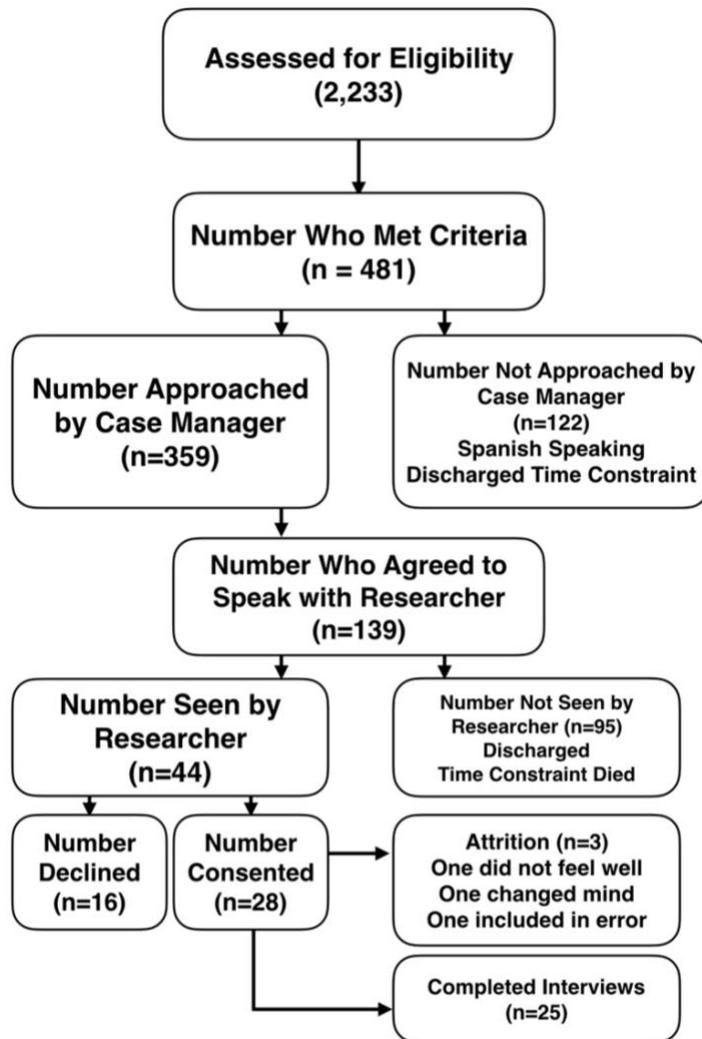


Figure 5.1. Results of recruitment for interviews.

5.2.2 Pharmacological Factors

Polypharmacy was found in all but one participant in the sample. Polypharmacy is an associated factor within this study sample as the mean number of prescriptions is 13.52 and the range of prescriptions was 4 - 24 (Table 5.2). For this study, polypharmacy is defined as the prescription of five or more medications to an individual (Viktil et al., 2006).

Table 5.1*Demographic Characteristics of Sample*

Characteristics	Result			
	(N) Percentage	Mean	Median	Range
Age		75.3	75	65-95
Gender				
Female	(13) 52%			
Male	(12) 48%			
Ethnicity				
Caucasian	(19) 76%			
African Descent	(4) 16%			
Asian	(1) 4%			
Latino/Hispanic	(1) 4%			
Insurance Coverage				
Medicare Only	(7) 28%			
Medicaid Only	(1) 4%			
Dual Coverage*	(4) 16%			
Medicare Advantage	(5) 20%			
Medicare w/Private Supplemental Insurance	(8) 32%			
Physical Characteristics				
Frailty Documented in Chart	(11) 44%			
Number of Comorbidities				
Pharmacological Factors		3.08	3	2-5
No. of Prescriptions		13.52	13	4-24

Note. *Dual Coverage is indicative of low socioeconomic status and provides the greatest access to healthcare in the United States.

Table 5.2*Results of Deductive Analysis with Code Frequency*

Overarching Theme	Comprehensibility		Incomprehensibility	
Sub-Themes	Directed Communication Comprehensibility	Intuitive Comprehensibility	Directed Communication Incomprehensibility	Intuitive Incomprehensibility
Associated Codes	Continuity of Message (13)	Acceptance (13)	Big Picture Conversation: Unclear (24)	Avoidance (2)
	Big Picture Conversation (9)	Getting Weaker/Sicker (87)	Low Health Literacy (5)	Denial (39)
	Intellect/Education (7)	Insight (8)	Not Understanding the Limitations of Medicine (32)	Lack of Insight (2)

5.3 Study Findings

A presentation of the findings is found in this section. This will include definitions of the Overarching Themes, Sub-Themes, and Associated Codes for the study findings as well as the New Unique Theme discovered in the analysis. This will be followed by a further interpretive description along with interview abstracts to act as evidence.

5.3.1 Overarching Themes, Sub-Themes, Associated Codes and New Unique Theme

The Overarching Themes are Comprehensibility and Incomprehensibility. This section is a presentation of each Overarching Theme with their corresponding Sub-Themes, and Associated Codes. In addition, a Unique Theme and definition is offered as a finding. Also, the definition of

each is included. These definitions come from the interpretation of the findings. Figures 5.2 through 5.4 illustrate the relationships of each Overarching Theme and Unique Theme with Sense of Coherence, as well as any Sub-Themes or Associated Codes.

In Figure 5.2 there is an illustration of the relationships mentioned above. The associated codes are at the top of the figure and are contributing factors to whether the participant achieved Comprehensibility through events or General Resistance Resources. Directed Communication Comprehensibility was achieved either due to or a combination of Message Continuity, a Big Picture Conversation, or Innate Intellect/Education. Intuitive Comprehensibility was achieved either due to or a combination of Acceptance, Getting Sicker/Weaker, experiencing Treatment Failure or personal Insight. Having Directed Communication or Intuitive Comprehensibility leads to greater Comprehensibility of one’s circumstances related to their health and prognoses. This Comprehensibility leads to better Manageability. The figure shows that there was no relationship between Comprehensibility and Meaningfulness. Comprehensibility led to an increase in Sense of Coherence.

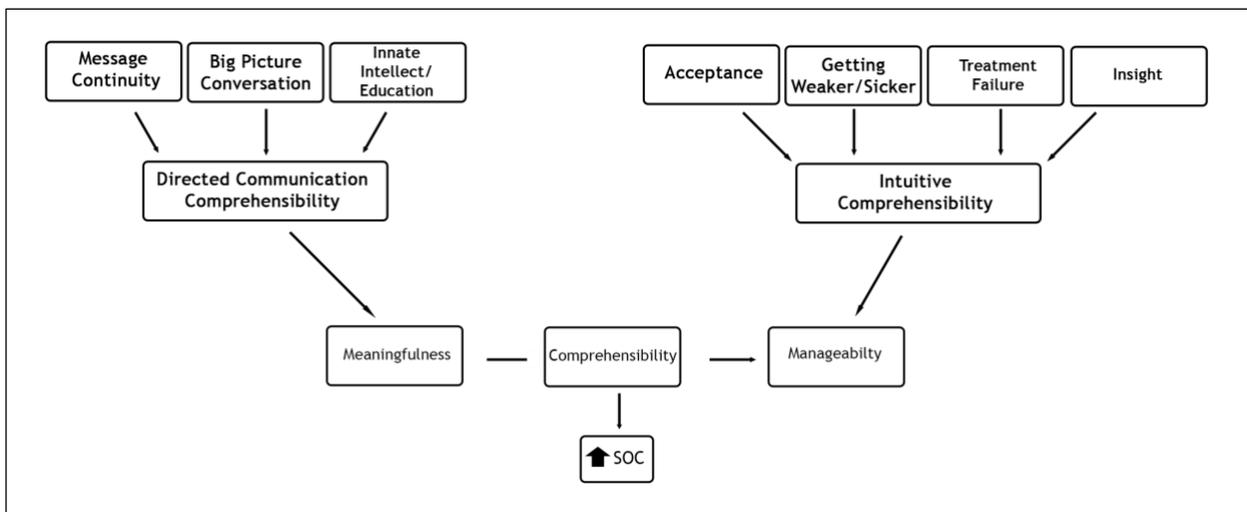


Figure 5.2. Comprehensibility.

In Figure 5.3 there is an illustration of the relationships which lead to Incomprehensibility. The associated codes are at the top of the figure and are contributing factors to whether the participant achieved Incomprehensibility through events or a lack of General Resistance Resources. Directed Communication Incomprehensibility came to be either due to or a combination of an Unclear Big Picture Conversation, Low Health Literacy, or Not Understanding the Limitations of Medicine. Intuitive Incomprehensibility came to be due to or a combination of Avoidance, Denial, or a Lack of Insight. Having Directed Communication Incomprehensibility or Intuitive Incomprehensibility leads to overall Incomprehensibility of one's circumstances related to their health and prognoses. This Incomprehensibility leads to poorer Manageability. The figure shows that there was no relationship between Incomprehensibility and Meaningfulness. Incomprehensibility led to a decrease in Sense of Coherence.

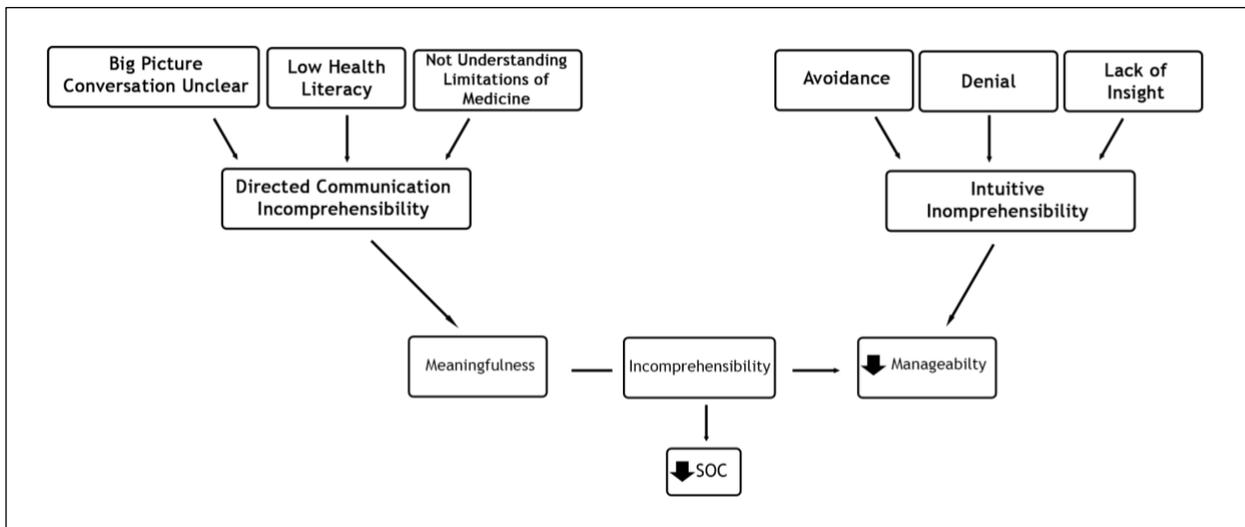


Figure 5.3. Incomprehensibility.

Figure 5.4 is an illustration of a Devolving Sense of Coherence. The figure shows that there was no discernable evidence of the patients having any level of Meaningfulness or Manageability. It was not possible to recognize any level of Sense of Coherence.

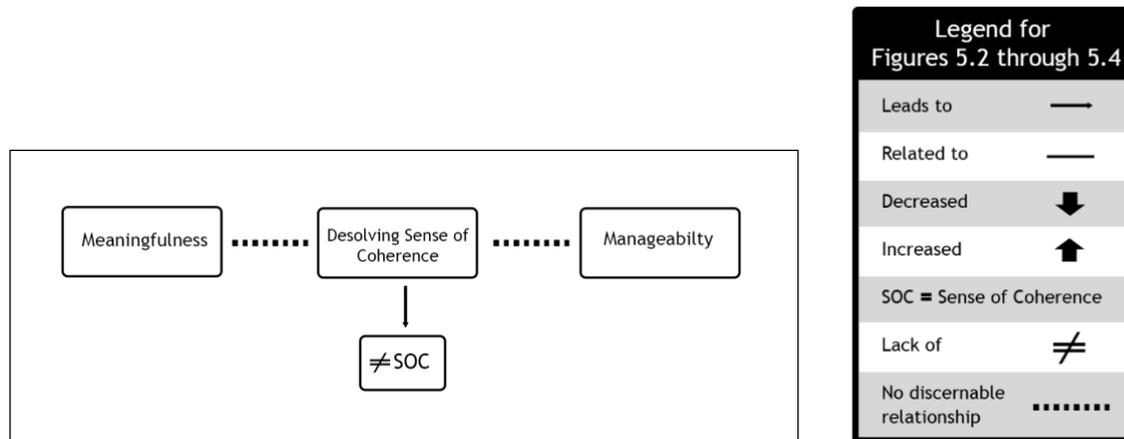


Figure 5.4. Devolving sense of coherence.

The following is a definition of Comprehensibility and its Sub-Themes and Associated Codes.

Comprehensibility -- For this study in an expansion of Antonovsky’s original thoughts and definition, Comprehensibility is considered in the environment of older people facing multiple losses, declining health and nearing death. It is specific to the understanding of their prognosis and how it affects their Manageability and Meaningfulness. Comprehensibility is an overarching theme within this study’s findings.

- **Directed Communication Comprehensibility-** Directed Communication is a Sub-Theme of Comprehensibility. It is the delivery of purposeful and directed modes of communication. Directed modes of communication are conversations with providers during a hospital visit or office visit which are truthful and clear using direct language. It can also be written instruction or evidence. When effective prognostic communication occurs, it leads to Directed Communication Comprehensibility. Directed Communication is a sub-theme of Comprehensibility.

The following are the Associated Codes of Directed Communication Comprehensibility.

- **Continuity in Message** – This refers to the consistency of the message being delivered. It refers to good communication between the healthcare team so that all members are delivering the same message. Continuity in Message is a code within the sub-theme of Directed Communication Comprehensibility.
- **Big Picture Conversation** -- A big picture conversation includes a discussion of expectations from a disease trajectory and where the participant is upon that trajectory along with information about the prognosis. This conversation also may include a discussion of the risks and benefits of certain treatments as well as goals for their treatment. Big Picture Conversation is a code within the sub-theme of Directed Communication Comprehensibility.
- **Innate Intellect/Education** – This is related to Antonovsky’s General Resistance Resources (1979). It refers to the individual’s innate intelligence or level of health literacy which may support Comprehensibility. Intellect/Education is a code within the sub-theme of Directed Communication Comprehensibility.
- **Intuitive Comprehensibility** – Intuitive Comprehensibility is a Sub-Theme of Comprehensibility. This refers to the achievement of Comprehensibility regarding prognosis and ramifications without the benefit of adequate communication. These participants rely upon intuition to achieve Comprehensibility related to the following associated codes. Intuitive Comprehensibility is a sub-theme of Comprehensibility.

The following are the Associated Codes of Intuitive Comprehensibility

- **Acceptance** -- Part of acceptance is the receipt of stimuli and relating the stimuli to the task of understanding and assimilation. Achieving acceptance of decline in the very sick older population may provide a sense of relief and an ability to put

aside the worries of finding answers to perhaps the unanswerable. Acceptance is a code within the sub-theme of Intuitive Comprehensibility.

- **Getting Weaker/Sicker** -- The ability to perceive physical changes, such as the decline in one's function and weakness, lead some participants to understand that their health is waning and will not return. Getting Weaker/Sicker is a code within the sub-theme of Intuitive Comprehensibility.
- **Treatment Failure** – Experiencing treatments that fail to improve health or cure is a powerful means of achieving Intuitive Comprehensibility. Participants who observe their treatment failures can associate the return or progression of their disease with the reality of their condition. Treatment Failure is a code within the sub-theme of Intuitive Comprehensibility.
- **Insight** – This refers to understanding one's prognosis and circumstances through past experiences of watching others in failing health and self-awareness. Insight is a code within the sub-theme of Intuitive Comprehensibility.

The following is a definition of Incomprehensibility and its Sub-Themes and Associated Codes.

- **Incomprehensibility** – This is a state in which the individual lacks understanding of their prognosis and the ramifications of the prognosis on their circumstances in the environment of serious illness and declining health. Incomprehensibility is a new concept and an overarching theme within this study's findings.
 - **Directed Communication Incomprehensibility** – Directed Communication Incomprehensibility is a Sub-Theme of Incomprehensibility. This refers to Incomprehensibility which is related to the lack of effective Directed

Communication. Directed Communication Incomprehensibility is a sub-theme of Incomprehensibility.

The following are the Associated Codes of Directed Communication Incomprehensibility

- **Big Picture Conversation: Unclear** – This code is defined as a participant who did not understand the Big Picture Conversation or those participants where it was unclear if a Big Picture Conversation took place. Big Picture Conversation: Unclear is a code within the sub-theme of Directed Communication Incomprehensibility.
- **Low Health Literacy** – This refers to the lack of General Resistant Resources in the area of understanding health information. Low Health Literacy is a code within the sub-theme of Directed Communication Incomprehensibility.
- **Not Understanding the Limitations of Medicine** – Participants with this code either do not understand the limitations of Western Medicine, or they have unrealistic expectations for their conditions. Not Understanding the Limitations of Medicine is a code within the sub-theme of Directed Communication Incomprehensibility.
- **Intuitive Incomprehensibility** – Intuitive Incomprehensibility is a Sub-Theme of Incomprehensibility. Perception varies from one participant to the next. Some participants are resistant or unable to address and understand their circumstances, or simply perceive matters inaccurately. These perceptions and resistance often result in Intuitive Incomprehensibility. Intuitive Incomprehensibility is a sub-theme of Incomprehensibility.

The following are the Associated Codes of Intuitive Incomprehensibility

- **Avoidance** -- A code related to Incomprehensibility which includes the avoidance of discussing issues related to one's mortality or dying. Avoidance is a code within the sub-theme of Intuitive Incomprehensibility.
- **Denial** -- Another component of Incomprehensibility is denial. In some cases, denial can be a defence mechanism that protects the individual from engaging with anxiety-provoking stimuli (Cramer, 1998). Denial in the presence of Incomprehensibility and serious illness is a temporary defence mechanism. The realities of disease progression make facing these stimuli inevitable. When one is in a state of denial one rejects the information that they have a serious or terminal illness. The state of Denial may hinder the individual from a state of acceptance and be a barrier to planning and reconciliation at the end of life. Denial is a code within the sub-theme of Intuitive Incomprehensibility.
- **Lack of Insight** – This refers to a lack of awareness of self and lack of recognition of evident decline and serious illness. This results in an inability to grasp the peril of their circumstances and begets a state of Incomprehensibility. Lack of Insight is a code within the sub-theme of Intuitive Incomprehensibility.

The following is a description of the finding of a Unique Theme which emerged during the study.

- **Devolving Sense of Coherence** – The Unique Theme of Devolving Sense of Coherence describes an aspect of Sense of Coherence observed at the end-of-life among some of the participants. A Devolving Sense of Coherence is a state in which, over a relatively short period of time, the participant may have lost or had a decline in many of their General Resistance Resources (Antonovsky, 1979). Antonovsky describes General Resistance

Resources as a multitude of personal characteristics which determine individual response to crisis (Antonovsky, 1979). As people age and near death it is natural that the number of losses is serial and increase with time (Brown & Lowis, 2003; Erikson & Erikson, 1998; Hoyer et al., 2014). It is suspected that Incomprehensibility may contribute to a Devolving Sense of Coherence. Devolving Sense of Coherence is a unique and separate Unique Theme of the study and is nescient in its understanding.

5.3.2 Findings from Interview Content Analysis

This section includes an interpretation of the findings which are presented along with Interview abstracts. The abstracts are offered as support for the interpretations. The evidence suggests that Sense of Coherence may be unique at the end of life and justifies distinct consideration. In addition, consideration of the Overarching theme, Incomprehensibility, should be considered as a new concept of Sense of Coherence at the end-of-life. An interpretation is offered of how Comprehensibility and Incomprehensibility affect the other *a priori* concepts.

5.3.3 Comprehensibility and Incomprehensibility

Participants were found to fall somewhere between the theme of Comprehensibility or Incomprehensibility. As a result of Interpretive Authority, and through deductive analysis, this study finds that Comprehensibility or Incomprehensibility is limited to the participants understanding of their prognosis and the ramifications of their circumstances. This is not an “all or nothing” categorization. Some participants were nearing understanding; however, for varying reasons which will be described, could not or would not completely understand their prognosis and the ramifications of their conditions.

These Overarching Themes led to the identification of Sub-Themes. It is important to know that the Sub-themes and Associated Codes which follow have subtle differences and are associated with communication and knowledge. The Associated Codes included in the results have a strong association with either Comprehensibility or Incomprehensibility and are categorized under the Sub-Themes. This section will show the relationships of the Associated Codes to the Sub-Themes and provide interpretation of the findings, along with excerpts from the interviews to illustrate some of the evidence from the interviews. Figures 5.2 and 5.3 illustrate the relationships between the Overarching Themes, Sub-Themes and the Associated Codes. A full list of all codes is provided (Appendix 16).

Next is a description of the Sub-Themes and Associated Codes of the Overarching Theme of Comprehensibility. This will be followed by an explanation of the Sub-Themes and Associated Codes of Incomprehensibility.

5.3.4 Sub-Themes and Associated Codes of the Overarching Theme of Comprehensibility

There are two sub-themes of Comprehensibility. They are Directed Communication Comprehensibility and Intuitive Comprehensibility. This section provides a definition and description of these two Sub-Themes. These Sub-Themes represent two different ways that the participants obtained Comprehensibility. In addition, the Associated Codes for each Sub-Theme will be presented.

5.3.4.1 Directed Communication Comprehensibility and Associated Codes. Directed communication is achieved through several codes related to the information received. For this sample, these codes include Continuity in Message, Big Picture Conversation, and

Intellect/Education. The following is an extract demonstrating Directed Communication Comprehensibility.

Interviewer: So, can you tell me, um, what you were here for the last time that you came.

Nelson: Blood pressure was low.

Interviewer: Did they tell you why that was the case?

Nelson: Nope. They said it might have been from dialysis...and they say I might have come in, uh, dialysis and, uh, took too much fluid off.

Interviewer: So, has anybody talked to you about an infection or anything like that?

Nelson: Yeah, that's all they're talking about is trying to find an infection.

Whilst it was a slow process, it is evident that this participant has had an effective Big Picture Conversation with at least one of his providers.

5.3.4.1.1 Continuity in Message. Receiving consistency in the messaging of information is important for the participant to gain knowledge from the healthcare team to make logical decisions. This is a very important element of achieving Directed Communication Comprehensibility. Continuity in messages minimizes mixed messaging and confusion for the participant. All members of the team must be able to deliver a message that is accurate and constant.

Researcher: What do you feel, how do you feel about the communication? Not necessarily just at Hospital X, but at Jersey, too, with the system? How do you feel about the . . .

Olivia: I thought it was aw--, I did not like the communication in Jersey at all. I think it's much better here. When I was up on Floor X it was great. I saw all kinds of people every day, and, um, you know, everybody had, you know, their own, put in their two cents worth, but everybody's told me what... everybody seemed to be pretty much on the same page and,

you know, there weren't a lot of, if any, discrepancies, and, um, you know, I got very clear written information when I left.

Other participants also described the importance of accuracy and the continuity of the message. Consistency in messaging is paramount to Comprehensibility. Without consistent messaging from the team the participant's decision making is likely to be based on disordered and incorrect information. The meaning and accuracy of the message may be lost. Other aspects of continuity will be discussed in the next chapter.

5.3.4.1.2 Big Picture Conversation. Whilst the Big Picture Conversation is the foundation of Directed Communication Comprehensibility, it may be undermined if there is a lack of continuity in the message.

Edward: And unfortunately, I get these, between the congestive heart failure and these, you know, somebody along the line, a doctor somewhere, I give you a list of doctors I see, you won't believe it, said to me, you know, I'm in frail health. And I know I'm in frail health. I have been for a long time. So that makes me more susceptible, I think, to picking up things.

Researcher: Because of your frailty?

Edward: Yeah.

Another participant shares a very direct and fruitful conversation discussing decisions regarding planning for her care when she goes into cardiac arrest or respiratory arrest. The participant was able to reiterate the conversation she had with her physician and the decisions she made for herself in the doctor's office in the absence of a crisis.

Receiving information from providers leads to an ability for cognitive organization and processing and allows the participant to understand his vulnerability. Understanding one's vulnerability allows for other processing, such as the ability to plan for the future which leads to Manageability. It also allows for one to evaluate their values and what brings meaning in their lives which strengthens Meaningfulness.

5.3.4.1.3 *Intellect/Education.* It is evident from the findings that patient education is very important to the attainment of Comprehensibility. Straight forward information and facts allow the participants to obtain Directed Communication Comprehensibility. This requires a previous level of education or innate intelligence. This innate intelligence and education are part of General Resistance Resources (Antonovsky, 1979). These General Resistance Resources vary from one individual to the next and are required to process the information into an understanding of the implications of their circumstances and achieve Comprehensibility. This will be further explained in light of clinician responsibility in the discussion chapter (Chapter 6).

Ursula: Really the more communication that we had was here, you know. That they really explain to you really clear what is going on. What I have, what I have to do and all that. There was things that I didn't even know. The doctor here is explaining to me a lot of thing really clearly.

Researcher: Do you think that makes a difference?

Ursula: Yeah. It makes a lot of difference.

Researcher: How does that make a difference?

Ursula: Communication the doctor and patient is, it make a lot of difference because you expect that the doctor tell you really what's going on without no holding back. You know, and that's what happen, you know.

Researcher: When, when, before you got here, did coming here and hearing all this information, do you think that you have a better understanding of your illness? Do you feel like you, how, how has that changed?

Ursula: Yeah, yeah. I got, yeah, I got more knowledge of things that's going on.

This extract illustrates how patient education regarding the disease and how one is to care for themselves makes a difference in Comprehensibility. It differs from the Big Picture Conversation as the information did not include prognosis, rather it contains educational information regarding her illness and how to care for herself. In other instances, with participants, it was evident that those with higher educational levels were better prepared to understand the information of their circumstances. An instance of this is from a participant who is a nurse practitioner. This participant could easily understand the message being relayed to her from her providers. Whilst it should be a given that medical jargon should not be used with laypeople, unfortunately this is not always the case (Dunlay & Strand, 2016).

Comprehensibility related to directed communication requires candid and thorough communication between the participant and the healthcare system, as well as continuity in the message from the healthcare members within the system.

5.3.4.2 Intuitive Comprehensibility and Associated Codes. Intuitive Comprehensibility refers to a type of understanding that occurs with or without effective Directed Communication. The participants who have Intuitive Comprehensibility can perceive the precarity of their circumstances without requiring formal and direct verbal communication from a provider or written information for understanding from the healthcare system or other sources. Rather, these

individuals use intuition effectively to observe and organize stimuli to come to terms with their circumstances. This leads to adequate problem solving which may lead to Comprehensibility.

Barbara: Well I've been sick since last April, you know with the pneumonia, I never really recovered from that, uh, I...I...I went to PT I uh went to the gym. I'm a gym person, and I thought I was doing very well and then I started getting tired again. All I wanted to do is rest. I couldn't wait to get into my favourite chair and fall asleep. And my husband started worrying about me, so we went to the doctor and he said "It's unusual for you to feel this way" so he said "I suggest you go to the hospital, get a complete work-up", and that's what I did, called 911 went in and here I am, and then I went home thinking my husband could take care of me, and it was just too much, uh, he didn't say it (Voice goes up) by I knew it.

The codes which lead to the sub-theme of Intuitive Comprehensibility are Acceptance, Getting Weaker/Sicker and Insight. The codes associated with Intuitive Comprehensibility within this group of participants include Acceptance, Getting Weaker/Sicker, Treatment Failure, and Insight. It is important to know that these codes may be interrelated. For some participants, there may be multiple factors which lead to Intuitive Comprehensibility. Each code will be described in this sub-section.

5.3.4.2.1 Acceptance. For some participants Intuitive Comprehensibility is obtainable.

Laura: I accepted [it] really graciously. I was very proud of myself because we had travelled. Once we got our kids through college, once we got the house fairly well paid off, we traveled extensively, and I would tell anyone, don't wait till you're 70 because you might get a big surprise like I did.

This participant was referring to accepting her failing health and poor prognosis graciously. Acceptance of the inability to do the things one was once able to do in the past makes room for peace and enjoying the life they have now. Acceptance of one's mortality allows one to enter into the work of life review.

Part of the benefit of performing a life review is to come to a place of knowing and feeling one's life is well-lived and complete (Erikson & Erikson, 1998). By obtaining Intuitive Comprehensibility through acceptance, the individual can enter into life review, which also may contribute to Meaningfulness. Also, with acceptance, there may be the ability to begin to make plans for the future and complete unfinished business before the end of life. This can contribute to Manageability and Meaningfulness.

Hannah: My husband died 22 years ago, June 20. He was born on Dec 20 and died on June 20, 74 years after. Good guy. Pianist. Had 2 Diplomas. I loved it at night, summer night, he was sitting and playing and I in my nightgown going down my driveway...I had a long driveway...and the music come, just everybody are young at that time...you don't think forward what is going to happen.

The processing of stimuli which leads to acceptance of one's limitations and illness and a life well lived contributes to Intuitive Comprehensibility.

5.3.4.2.2 Getting Weaker/Sicker. Another factor of perception is the use of one's physical senses to become aware of one's decline.

Matthew: If I can get out of the hospital. I spent an awful lot of the holidays since, since uh, 2015, Christmas and New Year's, and uh, well, I've spent every holiday, at least one

of the holidays every year in the hospital, Easter, Thanksgiving, Mother's Day, Father's Day, you know all of that stuff. I've been in the hospital. But when I'm out, uh, I have, uh, it's not bad, so, you know. Am I doing everything I want to do? No. Uh, am I doing everything I can do? Yeah.

This participant described how he is no longer able to directly engage in activities he found important in the past due to becoming weaker but has since learned new ways to enjoy these activities. This is partially due to his ability to adjust and accept his physical changes. To reach acceptance one accurately perceives and confronts the changes and challenges of a serious illness. This too is part of Intuitive Comprehensibility.

5.3.4.2.3 Treatment Failure. For the following participant, the absence of direct communication in the environment of mixed messaging for the participant hampers her Comprehensibility.

Zelda: And I talked to Dr.X last week about stopping the meds for a while, the chemo for a while. At first, he was resistant to it, and I said, well, I am extremely tired, I need to get back on my feet, I need to rest because I've been sleeping all the time.

Interviewer: So, are you now off of the chemotherapy?

Zelda: Yes. For almost a week now.

Interviewer: What did he, what was his resistance to it? You said the doctor was resistant. Did he say why?

Zelda: Because I think because he found a new one. Because yesterday he came in with another trial paper to read and it's like, 'are you kidding me?' It's draining. He's not the type to give up, so.

When a provider continues to offer treatment in the presence of advancing disease it is a barrier to the patient being able to fully understand their prognosis. This same participant said that she did think she was nearing the end of her life and that she had recently discussed what she would want if her heart stopped with her niece. Using commonsense and association, coupled with the knowledge of the limitations of Western medicine allows some participants to accept their circumstances to attain a level of Intuitive Comprehensibility. This patient died during this hospitalization.

5.3.4.2.4 Insight. The following excerpt demonstrates how insight contributes to Intuitive Comprehensibility.

Hannah: I keep telling myself, my children, it can happen any time, any day.

Researcher: so, you know that then?

Hannah: Of course, I realize and I think mother died the way, heart...

Researcher: Did your doctor ever tell you that you could go at any time?

Hannah: No.

Researcher: He never said that to you?

Hannah: No, never...that's what I realized

This participant has the insight to understand her mortality despite the vague and ineffective communication received from her providers. At one point during the interview, this participant thought that her physician was complimenting her that she had a large heart. She has determined a poor prognosis for herself based on prior experiences with her mother, which she describes in another part of the interview. She believes her mother died of the same condition and recalls seeing similar symptoms.

Another participant describes an ability to recognize when she is not doing well and is becoming dehydrated due to the change of taste in her food. The ability to recall past experiences increases insight and the capability to make associations with current stimuli. This leads some participants to Intuitive Comprehensibility...

5.3.5 Sub-Themes and Associated Codes of the Overarching Theme of Incomprehensibility

5.3.5.1 Directed Communication Incomprehensibility. The other Sub-Theme related to Incomprehensibility is Directed Communication Incomprehensibility. When Directed Communication is absent or inadequate it leads to Directed Communication Incomprehensibility. It must also be acknowledged that individuals may not receive communication messages effectively due to the stress of hearing bad news, medical jargon, and the use of euphemistic language.

Ike: I started shaking all over in the middle of the night. I couldn't stop.

Interviewer: You couldn't stop? You started shaking in the middle of the night and you couldn't stop? ...And now I came back and I go downstairs and got over there and I just stood and shook again.

Interviewer: Huh. What did they say was the problem?

Ike: They don't know.

This participant's medical record reflected that he had syncope and dehydration. The participant has a long history of heart disease which included a myocardial infarction. This participant has likely been exposed to information regarding his diagnosis, but it is likely the Big Picture Conversation was unclear.

Directed Communication Incomprehensibility occurs in the absence of a “Big Picture Conversation”. Rather, these participants have the factor “Big Picture Conversation: Unclear” in common. This means that the participant does not have a big picture understanding of the reality of their circumstances. Other elements associated with these interviews include: “Low Health Literacy” and “Not Understanding the Limitations of Medicine”. The following is an example of having Big Picture Conversation-Unclear.

5.3.5.1.1 Big Picture Conversation: Unclear.

Researcher: do you feel like the doctors and nurses are telling you everything you need to know?

Frank: To be honest with you, I don't think they know.

Researcher: okay

Frank: I mean, they don't give me any increase of medicine, you know, I mean, I'm just here.

In actuality, the team knows the patient's health problems. What is unclear is if he ever received an explanation or he did not understand the explanation. The quote “They don't know” or “They can't figure it out” occurred repeatedly within those with Directed Communication Incomprehensibility. The factor “Big Picture Conversation: Unclear” is common to each participant who has Directed Communication-related Incomprehensibility. This is true regardless of if the participant has the other factors associated with Incomprehensibility.

5.3.5.1.2 Low Health Literacy. The factor of low health literacy is associated with some participants with Directed Communication Incomprehensibility. Even with health education, we

cannot be certain if the participants' intellectual abilities are adequate to receive, process or retain the information.

Researcher: Why were you taking muscle relaxers?

Frank: pain in my neck. I stopped taking one and um, that morning I two or three o'clock in the morning they told me I got up, the last I remember, I got up and I called my son, and the next thing I know I was in the hospital, and they said I had been in a coma for a couple of weeks, and um, they traced it back to this muscle relaxer. Evidently, it was the type of deal when you don't stop taking it all of a sudden, but nobody had said anything. Well that was the beginning of it, and I have been going downhill ever since

Researcher: After that, you had some other problems, didn't you?

Frank: No

Researcher: what about your lungs?

Frank: That was all tied into that.

The participant is unable to differentiate his chronic illness of Chronic Obstructive Pulmonary Disease from complications of his abruptly stopping a muscle relaxer. This leads him to misunderstand his condition. Those with low health literacy also have Incomprehensibility related to Directed Communication Incomprehensibility. Another participant shared that she does not know how to get better and is incapable of recognizing when her condition is worsening to seek timely assistance. Those participants with low health literacy may have Incomprehensibility.

5.3.5.1.3 Not Understanding the Limitations of Medicine. Another code that was associated with Incomprehensibility is Not Understanding the Limitations of Medicine. This is not a common phenomenon. Advances in technology and the mechanization of the human body have blurred the

line for realistic expectations from patients and society. A gentleman with multi-system failure and sepsis questions the competency of the healthcare team.

Aaron: You know, you know...that's what I can't figure out...here I am at Hospital X, and they can't figure out what I got going and it's because it's a combination of things. You know the liver, the ah, what's that thing called? Alcohol-related?

Researcher: Cirrhosis.

Aaron: Cirrhosis, that's right. Kidney. So there trying to weigh everything all at the same time.

This participant is in multi-system failure and cannot appreciate that there are some things which medicine cannot remedy, regardless of how prestigious the doctors or hospital. Another participant described a notable height change due to age and osteoporosis. She describes being frightened by it and believes that the doctors will be able to reverse this natural course of the ageing process. These factors are evidence of the sub-theme “Not Understanding the Limitations of Medicine” which support the theme of Incomprehensibility.

An analysis of the factors of Incomprehensibility have driven an interpretation that the sub-themes of “Intuitive Incomprehensibility” and “Directed Communication Incomprehensibility” lead to the theme of Incomprehensibility

5.3.6 Intuitive Incomprehensibility

As intuitive factors vary from one subject to the next based upon life experience and personality, or as Antonovsky describes, General Resistance Resources (Antonovsky, 1979, 1987). Some participants are recalcitrant or unable to address and understand their circumstances, or simply

perceive matters differently from the healthcare culture. This leads to the sub-theme of Intuitive Incomprehensibility with the overarching Theme of Incomprehensibility within this sample.

Interviewer: Okay. So when you left the hospital, did you feel as strong?

Grace: Yes! Really good! Really good! But what really gettin' to me the medicine they givin' me in the hospital – good. And the medicine don't get not a . . .

Interviewer: And you're not getting what you need to keep you that way.

Grace: That's right, like in the hospital.

Rather than recognizing her own behaviour as relating to her exacerbations, she identifies the need for the stronger intravenous diuretics to be available at home. Later when asked about her non-adherence to fluid restrictions she admitted that this may be the case. This could be described as selective Incomprehensibility.

5.3.6.1 Avoidance. Culturally, Westerners tend to avoid the topic of death and our own mortality (Becker, 1973; Lonetto & Templer, 1986; Robben, 2018). This extract is evidence of avoidance in this exchange with a participant during his interview.

Researcher: What does this all mean to you?

Quincy: It means (chuckles) I don't know, I just try to do the best I can. Do you know what I mean?

Researcher: Does it make you think about your own mortality?

Quincy: No, not really.

Researcher: Not really?

Quincy: No.

Researcher: OK.

Quincy: No, it doesn't, no.

After relaying information about a terminal illness, the participant was adamant that he has not thought about his own mortality, which indicates an unwillingness to face his circumstances and a lack of insight. This patient had several comorbidities, frailty, dysphagia and has been in the hospital 18 times in the past 12 months. Another participant shares that whilst his mortality occasionally comes to mind, he avoids thinking about it to preserve a positive attitude. Avoidance prevents planning and self-reflection which are important to the development of Sense of Coherence and Comprehensibility and the developmental life task of life review (Haber, 2006).

Many of this sample welcomed the discussion as would be expected as people grow older, sicker and near the end of life. In Erikson's Human Developmental Stage of older adulthood, the developmental task is ego integrity vs. despair. A part of this process is life review which includes a discussion of one's experiences with death and mortality (Haber, 2006).

5.3.6.2 Denial. This is evident during an interview with a participant who has been diagnosed with hepatic cirrhosis, renal failure, sepsis and gallstones which he earlier explained in his interview. He concentrates upon the least lethal of his conditions.

Aaron: Well there were a lot of things in play when I came here because I thought it was strictly a, um, gallbladder issue and they found all sorts of different problems with the liver, kidneys a "bacriol" that goes through my blood

Interviewer: a what? A bacteria in your blood?

Aaron: A bacteria, yeah. It goes through my blood, and they're working on all of it. As of today, all of the vitals, as of this morning all of my vital signs are perfect, including my

liver, including my kidneys, everything except for...they're still trying to figure out that last piece of the puzzle to be able to complete the process.

Interviewer: And what piece of the puzzle is that?

Aaron: The gallbladder.

Another participant describes months of deterioration, falling, shaking and frequent hospitalizations and nursing home admissions. He currently has no resources in his home to help with his ability to manage, cope and accept much-needed help and resources. When asked if he would benefit from extra help in his home he became angry and stated he did not need help. This shows a lack of understanding of his circumstances.

5.3.6.3 Lack of Insight. This participant who is in multi-system failure describes continuing to return to work but refused to recognize his limitations. On two occasions his employer was forced to tell the participant to go home. On the second occasion, he was told not to come back, but that if he were to get well he could return.

Aaron: So, I was home for a week, and then my regular...I went to work on Monday and uh, they called my wife and said "Come pick your husband up, he's not driving home" 'cause they could see I was sick and didn't have the enthusiasm or voice that I had going in there. So, they did that and I and went back Tuesday and they said we have to put you on a leave of absence for medical until your better and come back. Whenever you're ready to come back you've got a job.

This patient cannot read between the lines of what his providers tell him or how he is feeling. He is unable to gauge his abilities through his physical senses. Everyone around this patient can

recognize that he is seriously ill, but the patient does not have the insight to recognize his circumstances. This participant died during his hospital admission.

Similarly, another participant has many co-morbidities. He is been experiencing increased hospitalizations and increased debility. He is unable to recognize that his co-morbidities are interrelated.

5.4 The Relationships Between Themes

The evidence shows that Comprehensibility and Incomprehensibility affect Manageability and Meaningfulness. There was an attempt to find connections between Manageability and Meaningfulness, however; no such relationship was evident in this sample. When studying the relationships between Incomprehensibility and Comprehensibility with the *a priori* theme of Meaningfulness there were differences in the tenor of the meaningfulness found by the participant. Comprehensibility and Incomprehensibility may affect the other two concepts. The following sections will describe these relationships.

5.4.1 Manageability, Meaningfulness and the Overarching Themes

The analysis found that there were differences in Manageability dependent upon the Comprehensibility or Incomprehensibility of the participant. These relationships are illustrated in Figure 5.5. The main difference is that those with Incomprehensibility have less awareness of their reduced level of Manageability. Whilst those with Comprehensibility are better able to identify and access resources. There were no obvious associations between Meaningfulness to the Overarching Themes.

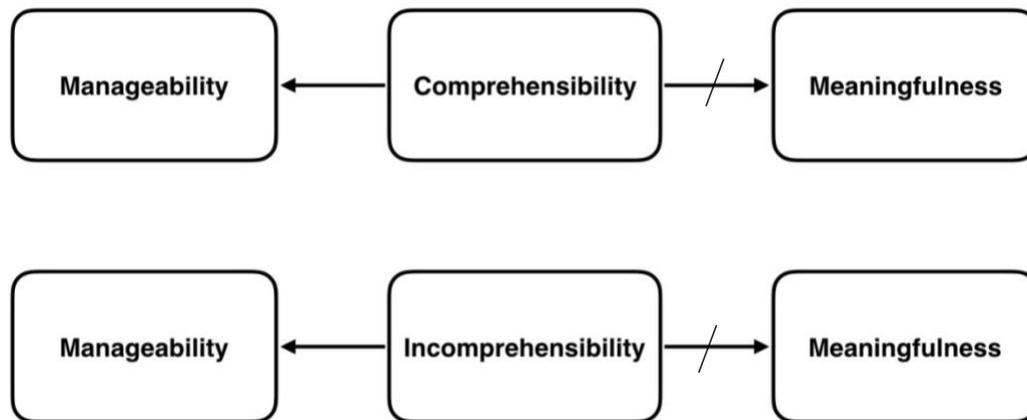


Figure 5.5. Relationships between overarching themes with Manageability and Meaningfulness.

5.4.2 Associated Codes for Manageability and Comprehensibility

There is evidence that some participants with Comprehensibility were managing better at home, despite their level of functionality, and had acquired more resources for support for themselves than some of those with Incomprehensibility. Some completely dependent patients were able to find Manageability through external sources. The codes associated with Manageability and Comprehensibility are Being Cared For, Resources, Lack of Resources and Caring for Others.

5.4.2.1 Being Cared for with Comprehensibility.

Edward: My wife, we have been married 59 years, she has been absolutely positively unbelievable. She has been there for me every minute, 24/7. She cooks, she cleans, she does bills, banking, chequebooks, she does the grocery shopping, the cooking. She takes care of all my pills and she knows everything, what they are. I don't...she does so much, it's just incredible.

Other participants similarly were being cared for by family members who help improve their lives by providing care for them and for the things that bring meaning to their lives.

5.4.2.2 Resources. Some with Comprehensibility who live alone are able to acquire needed resources that allow them to maintain independence in their own homes. This is true despite having a great deal of debility and a lack of functionality.

Researcher: So how do you handle your, your incontinence at home?

Karen: I use Pull-ups when I go out, that's for sure, but I've been doing really good with doing different kind of exercises that I do. And it's been helping me so I go from my, usually, I have a chair similar to this, but it's electric.

Researcher: And do you stay in that most of the day?

Karen: I use that most of the day. And then, um, I have a hospital bed. My bathroom has plenty of bars all around wherever I need them. And, um, everything is set. We set everything up

Researcher: And you have help at home?

Karen: Yeah. I got a aid that comes in, like I say, 5 days a week, Tuesday to Saturday. She helps me wash. You know. Get to the areas that I can't get into. You know because I get very upset about not being clean....And so, she helps me with that and then one day a week I have a nurse.

Other participants with Comprehensibility speak of the help they receive at home from food delivery services, home nurses and home physical therapy.

5.4.2.3 Lack of Resources. It is important to note that even in cases when participants have Comprehensibility some, due to lack of resources or not being cared for, did not fare as well. For those with greater functional debility, their choices were limited by finances and insurance.

Valerie: And so that time I went to Skilled Nursing B. Skilled nursing A didn't want me back. I think because it was within the 30 days probably.

And I can't remember how long I was at Skilled nursing B, maybe, oh, because I was running out of insurance because I have a total of 100 days counting Medicare and what my primary covers. Um, and so I was running out of insurance. I'd left when I ran out and ...

Researcher: Where did you go?

Valerie: Home.

Some participants are living with others who are also in need of resources and care. This makes Manageability difficult to obtain, as they are also caregivers in the presence of their own vulnerability.

5.4.2.4 Caring for Others.

Sal: And I was pretty sick. So, they shot me back in here to the same department, to ah, with the same group. I had left a day or two too early. I didn't fulfil the total program. I wanted to get home. My wife was ill. She had two strokes. It's a long story. I had to get home. And it didn't work out, I had to come right back.

There were other participants who expressed similar circumstances in which they were caring for others when they are sick and require help themselves.

5.4.3 Manageability and Incomprehensibility

Those participants with Incomprehensibility were unable to manage well without external sources. The one code linked with increasing Manageability for those with Incomprehensibility is Being Cared For.

5.4.3.1 Being Cared for with Incomprehensibility. Whilst this participant has Incomprehensibility, he has a strong advocate in his wife who not only advocates and watches out for him but also provides all of his physical care at home.

Aaron: Yeah, my wife knows all that.

Researcher: ok, so you didn't know what was going on, but your wife did?

Aaron: She knows everything...She talks to the doctor (clears throat) on my behalf, and the nurses. She knows all the lingo, all the antibiotics, all the medications, all that. So, she's...

Researcher: And I did watch her with the nurse looking at all of your laboratory work.

Another participant spoke of his daughter coming to the hospital and taking over all of his care and demanding things for his care when he was unable to do this for himself.

5.4.4 The Theme of Meaningfulness

Whether a patient has Comprehensibility or Incomprehensibility did not affect the ability to find Meaningfulness in their lives and experiences. However, there was a difference in the tone and depth of the meaningfulness for those who have Comprehensibility compared to those with Incomprehensibility.

When analyzing the coding of participants who are identified with the concept of Meaningfulness the related codes included Family/Love/Relationships, Spirituality, Life Review and Hopes/Goals. This was true despite their level of Comprehensibility or Incomprehensibility.

5.5 The Overarching Theme of Devolving Sense of Coherence

Within this sample, two individuals died within 48 hours of their interviews. Their words were less important than the tone and desperation of their words. They were very emotional and seemed to have a sudden and unspoken awareness of their impending death. The interviews illustrating a Devolving Sense of Coherence displayed a sense of loss of self, autonomy, and power that may not be possible to obtain or regain. This led to further examination of Antonovsky's theory of Salutogenesis and Sense of Coherence at the end-of-life. Offered are two extracts from the reflection notes and extracts from the interviews as evidence of a Devolving Sense of Coherence.

Journal Extract from Interview with Barbara:

The participant was eager to speak. She did most of the talking without questions. When a question was asked she answered it quickly following it up with much-added detail, which was not related to the question. She seemed desperate to get her words out. She spoke about God punishing her, time flying by and her apathy about the things she used to care about, and being "petrified" about her illness. She worries about being a burden to her husband as she can no longer do for herself. She mentioned how he once said, "you're killing me". This is of concern as he is her sole caregiver. The interview ended quickly as she needed to go for a procedure. I returned to continue the interview yesterday, but she was too ill to speak. She died last night.

Interview Extract with Barbara:

Barbara: Um, then there's three of us that hanged together since high school. We're like friends for 60 yrs, and um the one we rely on all the time had a major, major heart attack. They think she was going to make it. So, that kinda really blew me away, and uh, hmph. (Pause) After that, I uh, (pause) I said what's there to live for, we are only living to die, you know? We go to Pompano Beach, and you see all these old people just about, walking on a walker, and I wasn't like that. I was very rambunctious, and I would say "This is God's waiting room" you know, and I got more and more depressed. It got to a point when I didn't like Florida

Journal Extract from Interview with Peter:

This gentleman was hypervigilant and hypersensitive. I accidentally brushed against his hand and he yelled out. He was agitated. At the beginning of the interview he seemed reticent, but as it progressed his words and emotions seemed to gush forth in tone and tenor. He had so many crises and changes in these last three months as his health has greatly deteriorated and he is overwhelmed. It is difficult to imagine how anyone going through these changes could be anything but overwhelmed. He has been living in CT for three months and has been in the hospital for as many times. He moved across the country, sold his house, and just lost his son during these three months. These last three months have been very chaotic. His son died during this hospitalization.

Addendum: This patient died in the hospital. I can't imagine the grief his wife must be feeling as she buries her son and husband in such a short period of time.

Interview Extract with Peter:

*Peter: But anyway, when I was coming home they released me from the hospital, but before that happened on Thursday morning of that week my son from, ah, West--, Southport came into the hospital at 9:00, 9:30 in the morning and said to me, 'I got bad news'. He said, 'Rick, (sobbing) Rick died'...(sobbing) The first time I went into the hospital . . . The first time I went into the hospital he was also taken to the hospital and I didn't know it. He was upstairs and I was downstairs at Yale-New Haven. He had severe pains in his stomach. 1: And they had to do an emergency operation. They discovered his can--, cancer (sobbing).
Researcher: I'm so sorry.*

Peter: (sobbing) The second time I went in the hospital, my son showed up again to tell me he died (sobbing). And here I am now back in the hospital and they're still working to find out what's really, really wrong. There's a problem with my kidneys. There's this fluid situation. I'm diabetic. I have a million things wrong with me. I'm taking medication, there must be 30 different medications a day, 30 a day, and they're attempting to make some...

A person with a Devolving Sense of coherence exhibited an inability to establish coping, reconciliation, retention of dignity, and may not be able to resolve death anxiety for lack of time. All of these elements are required to develop Manageability or Meaningfulness and a strong Sense of Coherence. Devolving Sense of Coherence occurs at a time when the patient is near death and overwhelmed with symptoms, lack of time and personal loss to regain or develop a Sense of Coherence. This Unique Theme will require further exploration and study. Devolving Sense of Coherence will be discussed further in the next chapter.

5.6 Summary

In summary, the results of this study are the identification of a new Overarching Theme derived from Sense of Coherence known as Incomprehensibility. The results also find that there is some association between Manageability with the themes of Comprehensibility and Incomprehensibility. The results show both those with Comprehensibility and Incomprehensibility are able to obtain Meaningfulness. Also, there was a presentation of the New Unique Theme of Devolving Sense of Coherence. The next chapter will include further discussion and interpretation of these findings.

Chapter 6. Discussion

6.1 Introduction and Important Findings

The results of this study include an expansion of the concept Comprehensibility and two new concepts as they are related to Antonovsky's construct of Sense of Coherence at the later stages of life. One of the new concepts has been labelled Incomprehensibility. The other new concept is a state of Sense of Coherence which is specific to the participant who is nearing death which is called Devolving Sense of Coherence. These conclusions are the most important findings within the study. This section provides a summary and discussion of these findings. In addition, this chapter includes a comparison of the findings with existing knowledge, implications of the study, the study's strengths and limitations, and concludes with a summary of the thesis.

6.1.1 Comprehensibility and Incomprehensibility at the End of Life

It is important to discuss what is meant by the two overarching themes of Comprehensibility and Incomprehensibility. They are not meant to indicate that one who has Comprehensibility or Incomprehensibility understands or does not understand all matters concerning their condition. Rather patients may or may not have a great deal of understanding regarding the pathology of their disease process. They may or may not have a good understanding of the mechanisms of the pharmacotherapy and the medication schedule. In this study, the focus is upon whether one has Comprehensibility or Incomprehensibility explicitly regarding their understanding of where they lay on the trajectory of their disease, their prognosis, and the ramifications of this information upon their future. In other words, do they understand they are nearing the end of their lives? Whether the participant has Comprehensibility or Incomprehensibility is multi-factorial and dependent upon what Antonovsky refers to as General Resistance Resources. These resources will be further

described and discussed later in the chapter. The only claim being made in this thesis is that Comprehensibility or Incomprehensibility may affect how older, very sick individuals form their Sense of Coherence.

6.1.2 Devolving Sense of Coherence at the End-of-Life

As mentioned, Antonovsky describes Sense of Coherence, as a mostly fixed state during one's life time with periods of dynamism; however, as people age and near death it is natural that the number of experienced losses become serial and increase with time (Antonovsky, 1979, 1987; Brown & Lewis, 2003; Erikson & Erikson, 1998). Antonovsky offers an analogy of an individual's Sense of Coherence being much like a tightrope walker. He describes how certain events occur that shake one's Sense of Coherence but, by using our General Resistance Resources the tight ropewalker can regain his balance. Antonovsky states that this may happen many times over the course of one's life until eventually the individual cannot regain his balance and falls to his own destruction, which I take to mean "dies" (Antonovsky, 1979, 1987). It is this final phase of life when one "falls to his own destruction" which Antonovsky has failed to consider in his theory (Antonovsky, 1993). A Devolving Sense of Coherence is possibly this final phase in an environment of serial loss of General Resistance Resources and Incomprehensibility of the circumstances surrounding one's disease and/or prognosis.

6.2 Existing Literature Regarding Sense of Coherence and End-of-Life

There were no articles found specifically addressing Sense of Coherence or Salutogenesis at end of life. There were many articles which examined Sense of Coherence of caregivers of chronically or terminally ill patients (Alpuente et al., 2018; Ekwall et al., 2007; Potier et al., 2016; Pretorius et al., 2009; Wennerberg et al., 2012). Another study examined Sense of Coherence of nurses

caring for the dying (Hall-Lord et al., 2018). There are a few articles which looked at Sense of Coherence near the end of life, but all subjects were cancer patients and many were experiencing untimely deaths (Friedrichsen & Strang, 2001; Winger et al., 2016). The lack of evidence in the area of Sense of Coherence in the older population at the end of life provides a great deal of opportunity for further study.

6.2.1 Antonovsky, Sense of Coherence and Growing Old

During a lecture, at the University of California, Berkeley, Antonovsky spoke to a group of Gerontologists where he acknowledged that he believed the theory of Salutogenesis is applicable to the ageing person. In addition, he acknowledged that there is a great deal to learn, and he does not have the answers to all of the questions regarding ageing. It is evident from the transcript of this talk that Antonovsky had become aware that there was much more to study, think and write about regarding this phase of life (Antonovsky, 1993). It is unfortunate that he died just one year after this talk before he could make further contributions to the end-of-life knowledge base.

Antonovsky agreed that ageing is a phase of human development, echoing Erickson's Theory of Human Development. Specifically he referred to this phase as holding the possibility of older people to continue developing "social-psychological factors" as they age (Antonovsky, 1993). This claim undermines what he had said in his original work, that being, Sense of Coherence is mostly fixed by the age of 30 years (Antonovsky, 1987).

Antonovsky's overarching theme in *Health, Stress, and Coping* (1979) and his subsequent work *Unravelling the Mystery of Health* (1987) is Salutogenesis. In his work, Antonovsky seeks to understand the cause of health rather than the cause of disease (Lindstrom & Erickson, 2006). Antonovsky sees Sense of Coherence as a mostly stable state maintained throughout the lifetime,

with times of dynamism. He does not investigate how Sense of Coherence changes during the unique life stage of growing old, experiencing loss of independence, the loss of the ability to drive, declining functional status, cognitive decline, worsening health, and also isolation and loneliness as a result of family and friends dying and the facing of their own mortality (Antonovsky, 1979; Brown & Lewis, 2003; Erikson & Erikson, 1998; Holland & Rabbitt, 1992; Hoyer et al., 2014; Hubbard et al., 2014; Pinguart & Sorenson, 2000; Wang et al., 2020; Wang, 2016). The subject of these losses are what Antonovsky describes as General Resistance Resources (Antonovsky, 1979, 1987). These losses most frequently continue to mount as one nears death unless one dies suddenly (Brown & Lewis, 2003; Erikson & Erikson, 1998). At this late stage of life, General Resistance Resources may never be regained. This begs the question of how one gains Sense of Coherence as one dies. Interventions resulting from this study's findings may decrease Incomprehensibility and move the patient towards Comprehensibility. This holds potential for a stronger Sense of Coherence and a more healthful dying process for some. This would require further interventional study.

Whether the participant has Comprehensibility or Incomprehensibility is determined by how one receives, perceives and processes stimuli and is reliant upon the participants' life experiences, personality, perception and intelligence/knowledge, social support, also known as General Resistance Resources (Antonovsky, 1979, 1987; National Academies of Sciences Engineering and Medicine, 2016; Schulz & Eden, 2016). As everyone has a unique set of these resources this thesis cannot claim a complete understanding of all factors affecting the themes of Comprehensibility or Incomprehensibility.

6.3 Implications and Recommendations

Implications and recommendations for this thesis are in several areas. These areas include implications for future research, biomedical hospital and legislative policy, educational policy, and clinical interventions.

6.3.1 An Extended Interpretation of Sense of Coherence and Devolving Sense of Coherence at the End-of-Life

This study asserts that Sense of Coherence, and Salutogenesis at end-of-life may be a unique life phase worthy of examination independent of other life phases. Dying and end-of-life is unique from every other phase of life. Whilst Antonovsky examined Sense of Coherence throughout the life span and what creates “health”, the theory of Salutogenesis, the framework of Sense of Coherence and the findings of this study point to the need for further examination of Sense of Coherence at the end-of-life. How might an individual avoid a Devolving Sense of Coherence and have a “healthy” death? Further study in this area may lead to findings which help answer this question and understand how to promote a “healthy” Sense of Coherence at the end-of-life and a “healthy” death. This study will be a contribution to the “good death” “healthy death” knowledge base.

6.3.2 Incomprehensibility and Comprehensibility

A “Big Picture Conversation” intervention should be studied to determine if patients move toward Comprehensibility using “Directed Communication”. Tools will need to be developed for evaluation and reassessment of Incomprehensibility and Comprehensibility. These tools will need

to be developed to identify the type of Incomprehensibility or Comprehensibility the patient has and to determine if changes occur with intervention.

6.3.3 Bioethical Implications

The discovery of Incomprehensibility implies an ethical obligation for providers who engage in discussions with older, very sick patients. The provider owes their charge a “Big Picture Conversation” (Hancock et al., 2007; Huang et al., 2015; Numico et al., 2009). This conversation should be direct and exclude euphemisms. At the end of the conversation the patient should be evaluated for Comprehensibility. Without a “Big Picture Conversation” intervention the provider has contributed to the patient’s Incomprehensibility and is derelict in their duty to the patient. This is an area which deserves further exploration in the future regarding duty and bioethics.

6.3.4 Policy

Currently, in the United States legislature there is debate regarding two bills in the house and senate named Palliative Care and Hospice Education and Training (H.R. 647 and S.2080). These bills would grant nursing, medical, social work and chaplaincy schools \$15,000,000 annually from 2020 to 2040 for Palliative Training Centers. The results of this study serve as additional evidence of the need to increase such funding through these bills and to promote the development of end-of-life communication skills within all specialties in generalist palliative care.

These results also serve as evidence of a need to create policy which increases access to palliative care. The results point to potential to decrease 30-day readmissions which is an incentive to increase access to palliative services. In addition, the evidence of this study could be used in conjunction with other mounting evidence to support educational policy and mandates for formal

education in Medical Schools, and Nursing Education. Hospital policies could also be bolstered by these results. New policy could be accomplished through the Joint Commission of Hospital Accreditation by mandating expert communication education for end-of-life communication earlier in a terminal or chronic diagnosis with mandatory palliative consultations for patients meeting predetermined criteria. Currently, in the United States, the National Comprehensive Cancer Network has set out guidelines which network members must meet to be a member (National Comprehensive Cancer Network, 2019). These guidelines require palliative care be integrated as a component of usual and comprehensive cancer treatment. Similar guidelines could be developed for geriatric patients.

6.4 Clinical Practice and Academic Curriculum

6.4.1 Increased Resources for EOL Communication by Skilled Clinicians

There is a gap in knowledge regarding the results of clear communication in discussions regarding prognosis and life-limiting illnesses. This study provides evidence of the need to provide hospital clinicians with the tools to be forthright and unequivocal in their communication. Patients and families come to professionals for their knowledge and experience. Often the clinician fears they will dash patient hope. Our job is not to provide hope, rather it is to help to reframe hope and empower patients with the knowledge of their circumstances and all of their available options. These findings can provide evidence of the need and the request for further resources to educate hospital clinicians properly.

6.4.2 Interventions to Move from Incomprehensibility to Comprehensibility

Educational modules could be implemented with primary care and hospitalist providers. The providers would be equipped with appropriate language to use with patients when having a “Big Picture Conversation”, absent of euphemisms. This type of communication is “Directed Communication”. Further, a method for evaluation of the patients understanding considering Comprehensibility could be included. Comprehensibility would be evaluated then reassessed at the next patient visit in the primary setting.

6.4.3 Palliative Nursing and Sense of Coherence—A New Model for Nursing

During the research there was a glimmer of the potential for a new Palliative Care Nursing Model. This model is nascent and will require further thought, study and testing. By amalgamating the goals of palliative nursing, the domains of palliative care and the framework of Sense of Coherence there may be potential to guide nurses to care for their patients at the end of life to insure their best Sense of Coherence under the circumstances.

6.5 Strengths and Limitations

6.5.1 Limitations

A limitation of the study is the size of the sample recruited. The number of participants recruited for this study was small. This limits the ability to generalize these findings beyond this small sample. However, this sample size is considered an acceptable size for an Interpretive Description study.

Another limitation is that the study would have benefitted from a longitudinal course. Identification of these participants earlier in the trajectory of the illnesses would have shown changes to their Sense of Coherence over time. However, this presents an opportunity for further study.

6.5.2 Strengths

This study has begun to fill a gap in the literature in two ways. Up until now there has been no further work exploring Salutogenesis in the very old nearing death. This study begins to do this through identifying further concepts related to Sense of Coherence. The new concept of Incomprehensibility furthers investigation of Sense of Coherence and contributes knowledge in end-of-life care for the old and very sick who are nearing death.

In addition, the new theme of Devolving Sense of Coherence contributes a new area of investigation as it relates to Salutogenesis. Devolving Sense of Coherence occurs in the environment of serial loss as very sick older people face their own mortality. This occurs without the time or opportunity to ever regain one's Sense of Coherence and implies we are studying the time which Antovsky refers to as "falling to one's destruction". This area will require a great deal of research to further knowledge.

6.6 Reflexivity and Interpretive Description

This section will include some of the reflexivity which occurred regarding and during the iterative analysis and interpretation. The hope is to show that reflexivity is a part of the iterative and interpretive process. Throughout the entire time working on this study and thesis, interpretation and reflexivity occurred. Thorne sees reflexivity as a means to bolster validity through reflexive

accounting. Reflexivity allows one to recall the thought processes during analysis which lead to conclusions. Interpretive Description acknowledges that the clinical researcher approaches research from the origin of one's discipline (Thorne, 2008, 2016). As such, this thesis, study and reflexivity are decidedly viewed through the prism of the discipline of palliative care nursing.

It is known that the researcher brings a part of themselves into the field in qualitative research, so it is with the clinician researcher bringing their disciplinary selves into the field. Thoughtful reflexivity increases the credibility of the work (Dodgson, 2019). Interpretive Description acknowledges that all researchers have prior knowledge. Rather than viewing this knowledge as bias it may enhance the credibility of the research product. This is especially true as the goal of Interpretive Description is to produce pragmatic findings that can be applied in the clinical arena.

Upon beginning this study there was an expectation the findings would reveal how 30-day readmissions affect the participants Sense of Coherence. By sampling those older adults who have a 30-day readmission the population recruited were those who are the very ill and sick older adults. Much was learned about what it is like to be older with serious illness and facing one's own mortality and forming Sense of Coherence.

Reflexivity reveals a self-awareness that this may have been a subconscious intent. After many years of experience working with the very old and very sick it is evident that patients who have frequent readmissions to the hospital are usually the very sickest of patients. This has been true in my own clinical experience. The actual purpose of the study evolved over an iterative analytic process, interpretation and self-reflection which continued through the entire study and the writing of this thesis.

6.6.1 Overtreatment and Crossing the River Styx – An Observation

Intervention is imperative to help the patient move from Incomprehensibility into Comprehensibility, especially in light of overtreatment. We now find ourselves in an era of regular overtreatment of the old, sick and frail (Wong et al., 2012). We all, clinicians and patients alike, need to recognize when it is appropriate to stop overtreatment and allow a natural death. The practice of overtreatment produces devastating societal and personal effects along with evidence that patient's whose wishes are to forego aggressive treatment are frequently not followed (Pasman et al., 2013; Wong et al., 2012). Death was once a communal and familial event, most commonly occurring at home (Blauner, 1966; Toolis, 2017). Modern dying has confounded death and dying awareness with technologies such as Cardiac Pulmonary Resuscitation and Mechanical Ventilation, Continuous Renal Replacement Therapy and other forms of artificial life support. In addition, the advent of antibiotic therapies has separated the old man from what was once known as his friend, that being pneumonia or other infections (Blauner, 1966). Infections were once the most common way that people died naturally. Whilst these discoveries have proven wonderful in decreasing mortality, especially in the young and otherwise healthy, it results in overtreatment for the aged. Now, the majority of deaths for the older population occur in the hospital after long bouts of frailty and multiple chronic conditions (Field, 1996), This predisposes the old to a long and prolonged dying process (Blauner, 1966; Field, 1996).

We know that conversations with a palliative care provider can reduce 30-day readmissions and increase the number of patients admitted to hospice (Gagne-Henderson et al., 2017). There can be an analogy drawn between these conversations and the Greek myth of Karon, who delivers the newly dead across the River Styx. This myth tells the only way one enters the afterlife is if

someone places a gold coin beneath the tongue of the dead for passage. If there is no coin their souls are left to wander the banks of the river for eternity.

These “Big Picture” conversations are much like the gold coins in the myth. The conversation provides the Comprehensibility required to have a strong Sense of Coherence and move forward through the dying process in peace. On the other hand, the patient with Incomprehensibility finds themselves wandering the riverbank aimlessly and faltering without the proper preparation to recognize what the future holds. Through twenty-seven years of clinical experience with the dying many patients I have cared for patients appeared to be dying with a “Devolving Sense of Coherence”. Without Comprehensibility these patients had less than peaceful deaths. Palliative sedation was required for four patients in my care, and all of them received sedation for existential reasons and were in a state of Incomprehensibility. Prior to conducting this study, these four patients were never seen in light of Incomprehensibility, rather they were described as having existential crisis. This study suggests that their may be possible interventions that may lead to increased Comprehensibility.

A contribution to the knowledge base is the finding that in Antonovsky’s original work end-of-life was not considered as a unique aspect of Salutogenesis and Sense of Coherence. This study asserts that Sense of Coherence, Salutogenesis and end-of-life may very well be a phase of life worthy of examination independent of other phases of life. Dying and end-of-life care is unique from every other phase of life. Birth and dying are the only two unifying events which all of humanity share. They are periods of the utter unknown to those in the midst of the experience. There is potential to learn more about Sense of Coherence during the dying process.

6.7 Summary

This study has provided a contribution to the Theory of Salutogenesis and the Model of Sense of Coherence. That being the new concept of Incomprehensibility. Further investigation of the concepts of Incomprehensibility and Comprehensibility are imperative. Further work will strengthen the finding and the importance of considering Sense of Coherence at the end-of-life for older patients as a unique aspect of Salutogenesis and “healthy dying”.

The new concept, “Devolving Sense of Coherence” is a new concept within Antonovsky’s construct of Sense of Coherence. This is very different from the rest of Antonovsky’s theory. The contribution of Devolving Sense of Coherence opens a new area of growth and inquiry regarding Sense of Coherence at the end-of-life for all age groups. Further study is required to determine the importance of Devolving Sense of Coherence to the theory.

There are other indications for further development and research of a new palliative nursing model by amalgamating the Goals of Palliative Nursing, Domains of Palliative Care and Sense of Coherence. In addition, there is work to research and develop a new theory for a “Devolving Sense of Coherence” at end-of-life specific to the older and very sick population.

The study also shows the need to further understand end-of-life communication and the need for education of clinicians. This will require educational interventions that go beyond the theoretical and provide hands on mentoring and real-life experiences. This is needed in the clinical environment and in formal educational curricula.

The needs of this population are great. This study is a small contribution to the base of knowledge on this topic. There is hope that we will learn more about how clinicians may contribute to making

these difficult times more bearable for the old and dying who live in a society of death anxiety and unrealistic expectations of Western Medicine. Also, this must happen concurrently with the acknowledgement that our clinician colleagues are also of the same culture. There is much to do to improve these conditions, especially with the growing ageing population.

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Appendix 1: PubMed and CINAHL MeSH Terms

MeSH Headings in PubMed for Frail Older People Used as Subject Headings in CINAHL	MeSH Heading in PubMed for Readmission Used as Subject Headings in CINAHL
All combined with OR*	All combined with OR*
Elderly, Frail	Patient Readmissions
Frail Elders	Readmission, Patient
Elder, Frail	Readmissions, Patient
Elders, Frail	Hospital Readmissions
Frail Elder	Readmissions, Hospital
Functionally-Impaired Elderly	Hospital Readmission
Elderly, Functionally-Impaired	Readmission, Hospital
Functionally Impaired Elderly	
Frail Older Adults	
Adult, Frail Older	
Adults, Frail Older	
Frail Older Adult	
Older Adult, Frail	
Older Adults, Frail	

Note. *The headings in each column were combined with AND as part of a Boolean search.

Appendix 2: EMBASE Keywords

Keywords** for Frail Elderly in EMBASE	Keywords** for Readmission in EMBASE
All combined with OR*	All combined with OR*
Geriatric	30 Day Readmission
Older patients	Hospital Readmission
Elderly Patients	Early Readmission
Frail Elderly	Unplanned Readmission
	Homebound Elderly
	Frequent Hospitalisations

Note. *The headings in each column were combined with AND as part of a Boolean search. ** EMBASE does not accommodate MeSH terms.

Appendix 3: CASP Checklist

1. Did the study address a clearly focused issue?

Yes ___ No ___ Can't Tell ___

2. Was the cohort recruited in an acceptable way?

Yes ___ No ___ Can't Tell ___

3. Was the exposure accurately measured to minimise bias?

Yes ___ No ___ Can't Tell ___

4. Was the outcome accurately measured to minimise bias?

Yes ___ No ___ Can't Tell ___

5. (a) Have the authors identified all important confounding factors?

Yes ___ No ___ Can't Tell ___

(List those you might be important or the author missed)

(b) Have they taken into account of the confounding factors in the design and/or analysis?

(List)

6. (a) Was the follow up of subjects complete enough?

Yes ___ No ___ Can't Tell ___

7. What are the results of this study?

8. How precise are the results?

9. Do you believe the results?

Yes ___ No ___ Can't Tell ___

10. Can the results be applied to the local population?

Yes ___ No ___ Can't Tell ___

11. Do the results of this study fit with other available evidence?

Yes ___ No ___ Can't Tell ___

12. What are the implications of this study for practice?

Appendix 4: CASP/Whittemore Quality Table

Citation and Country	Whittemore Criteria	CASP Scores
<p>Albrecht, J. S., et al. (2014). Depressive symptoms and hospital readmission in older adults. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socio-economic status and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate: YES Data collection specified and systematic: YES Measures demonstrate adequate reliability and validity: YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described: YES Levels of significance or confidence intervals, or both, reported: YES Intention-to-treat analysis for longitudinal data: NO</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered: YES:</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? Yes Can the results be applied to the local population? Yes, as a consideration of depressive symptoms as a risk factor regardless of location. Do the results of this study fit with other available evidence? Found that Depressive SX were slightly less significant than other studies. What are the implications of this study for practice? Yes. Important for clinicians to be aware of depression as a risk factor for readmission.</p>

Berges, I. M., et al. (2015). Associations between depressive symptoms and 30-day hospital readmissions among older adults. U.S.A.	Sample	Cohort
	Inclusion and exclusion criteria well defined and appropriate:	Did the study address a clearly focused issue?
	YES	YES
	Health, demographic, socioecostatus and confounding characteristics considered:	Was the cohort recruited in an acceptable way?
	YES	YES
	Sample size justification:	Was the exposure accurately measured to minimise bias?
	NO	YES
	Protocol	Was the outcome accurately measured to minimise bias?
	Study procedures systematic and well specified:	YES
	YES	Have the authors identified all important confounding factors?
	Measurement	YES
	Choice of outcomes appropriate:	Have they taken account of the confounding factors in the design and/or analysis?
	YES	YES
	Data collection specified and systematic:	Was the follow up of subjects complete enough/long enough?
YES	YES	
Measures demonstrate adequate reliability and validity:	What are the results of this study?	
YES	See All Data Table	
Validity	How precise are the results?	
Confounders and bias carefully considered and controlled?	Very Precise.	
NO	Do you believe the results?	
Statistics	YES	
Statistics appropriate and well described:	Can the results be applied to the local population?	
YES	YES	
Levels of significance or confidence intervals, or both, reported:	Do the results of this study fit with other available evidence?	
YES	YES	
Intention-to-treat analysis for longitudinal data:	What are the implications of this study for practice?	
NO	Recognition and planned intervention to decrease risk of readmission	
Discussion		
Conclusions supported by results with possible biases and limitations considered:		
YES		

<p>Bogaisky, M., & Dezieck, L. (2015). Early hospital readmission of nursing home residents and community-dwelling elderly adults discharged from the geriatrics service of an urban teaching hospital: patterns and risk factors.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? NO</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? NO Have they taken account of the confounding factors in the design and/or analysis? NO Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Precise considering the measurement of all readmits based upon discharge location. Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Recognition of risk of skilled nursing facility patients for readmission and development of interventions.</p>
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<p>Chavez, L. J. (2016). Unhealthy alcohol use in older adults: Association with readmissions and emergency department use in the 30 days after hospital discharge. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: NO</p> <p>Protocol Study procedures systematic and well specified: UNCLEAR</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? N/A What are the results of this study? See All Data Table How precise are the results? Very Do you believe the results? YES Can the results be applied to the local population? NO, measurement tool is specific to veteran's and the results were mixed. Do the results of this study fit with other available evidence? Unclear: other data investigate alcohol hepatitis and/or cirrhosis and 30-day readmissions rather than ETOH use. What are the implications of this study for practice? NONE</p>
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<p>Dilworth, S., et al. (2012). Feeling let down: An exploratory study of the experiences of older people who were readmitted to hospital following a recent discharge.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: NO Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described N/A QUALITATIVE Levels of significance or confidence intervals, or both, reported N/A Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Qualitative Was there a clear statement of the aims of the research? YES Is a qualitative methodology appropriate? YES Was the research design appropriate to address the aims of the research? YES Was the recruitment strategy appropriate to the aims of the research? YES Was the data collected in a way that addressed the research issue? YES Has the relationship between researcher and participants been adequately considered? YES Have ethical issues been taken into consideration? YES Was the data analysis sufficiently rigorous? YES Is there a clear statement of findings? YES How valuable is the research? This study is valuable as it is the beginning of exploration of this topic. It takes into consideration the patient, and is the only article found with this goal in mind.</p>
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<p>Enguidanos, S., et al. (2012). 30-day readmissions among seriously ill older adults. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: NO</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? These results may encourage development of home based palliative care to avoid readmissions.</p>
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<p>Fisher, S. R., et al. (2013). Mobility after hospital discharge as a marker for 30-day readmission. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Recognition of lack of mobility on the risk for readmission and intervention for rehabilitation/ Physical therapy to decrease such risk.</p>
	<p>Protocol Study procedures systematic and well specified: YES</p>	
	<p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p>	
	<p>Validity Confounders and bias carefully considered and controlled? YES</p>	
	<p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p>	
	<p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	

<p>Fisher, S. R. (2016b). Predictors of 30-day readmission following inpatient rehabilitation for patients at high risk for hospital readmission.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? NO, but acknowledged as a limitation of the study. Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? “Discrimination between patients who are and who are not likely to be readmitted to an acute care hospital within 30 days of rehabilitation discharge”.</p>
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<p>Fisher, S. R. (2016a). Inpatient walking activity to predict readmission in older adults. U.S.A.</p>	<p>Sample</p> <p>Inclusion and exclusion criteria well defined and appropriate: YES</p> <p>Health, demographic, socioecostatus and confounding characteristics considered: YES</p> <p>Sample size justification: YES</p> <p>Protocol</p> <p>Study procedures systematic and well specified: YES</p> <p>Measurement</p> <p>Choice of outcomes appropriate YES</p> <p>Data collection specified and systematic YES</p> <p>Measures demonstrate adequate reliability and validity YES</p> <p>Validity</p> <p>Confounders and bias carefully considered and controlled? YES</p> <p>Statistics</p> <p>Statistics appropriate and well described YES</p> <p>Levels of significance or confidence intervals, or both, reported YES</p> <p>Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion</p> <p>Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort</p> <p>Did the study address a clearly focused issue? YES</p> <p>Was the cohort recruited in an acceptable way? YES</p> <p>Was the exposure accurately measured to minimise bias? YES</p> <p>Was the outcome accurately measured to minimise bias? YES</p> <p>Have the authors identified all important confounding factors? YES</p> <p>Have they taken account of the confounding factors in the design and/or analysis? YES</p> <p>Was the follow up of subjects complete enough/long enough? YES</p> <p>What are the results of this study? See All Data Table</p> <p>How precise are the results? Very Precise</p> <p>Do you believe the results? YES</p> <p>Can the results be applied to the local population? YES</p> <p>Do the results of this study fit with other available evidence? YES</p> <p>What are the implications of this study for practice? The predictive property of walking and ADLs on 30-day readmissions.</p>
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<p>Goldenheim, A., et al. (2014). Rehospitalization of older adults discharged to home hospice care. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? YES Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Recognition of the importance of inpatient palliative care consultations as well as appropriate hospice referrals in decreasing 30-day readmissions.</p>
	<p>Protocol Study procedures systematic and well specified: YES</p>	
	<p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p>	
	<p>Validity Confounders and bias carefully considered and controlled? YES</p>	
	<p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p>	
	<p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	

<p>Hain, D. J., et al. (2012). Characteristics of older adults re-hospitalized within 7 and 30 days of discharge: implications for nursing practice. U.S.A.</p>	<p>Sample</p> <p>Inclusion and exclusion criteria well defined and appropriate: YES</p> <p>Health, demographic, socioecostatus and confounding characteristics considered: NO</p> <p>Sample size justification: YES</p>	<p>Cohort</p> <p>Did the study address a clearly focused issue? YES</p> <p>Was the cohort recruited in an acceptable way? YES</p> <p>Was the exposure accurately measured to minimise bias? YES</p> <p>Was the outcome accurately measured to minimise bias? YES</p> <p>Have the authors identified all important confounding factors? YES</p> <p>Have they taken account of the confounding factors in the design and/or analysis? YES</p> <p>Was the follow up of subjects complete enough/long enough? YES</p> <p>What are the results of this study? See All Data Table</p> <p>How precise are the results? Precise</p> <p>Do you believe the results? YES</p> <p>Can the results be applied to the local population? YES</p> <p>Do the results of this study fit with other available evidence?</p> <p>What are the implications of this study for practice? Recognition of the risk and vulnerability for patients discharged to skilled nursing facilities for 30-day readmissions.</p>
	<p>Protocol</p> <p>Study procedures systematic and well specified: YES</p>	
	<p>Measurement</p> <p>Choice of outcomes appropriate YES</p>	
	<p>Data collection specified and systematic YES</p>	
	<p>Measures demonstrate adequate reliability and validity YES</p>	
	<p>Validity</p> <p>Confounders and bias carefully considered and controlled? YES</p>	
	<p>Statistics</p> <p>Statistics appropriate and well described YES</p>	
	<p>Levels of significance or confidence intervals, or both, reported YES</p>	
	<p>Intention-to-treat analysis for longitudinal data NO</p>	
	<p>Discussion</p> <p>Conclusions supported by results with possible biases and limitations considered YES</p>	

<p>Islam, T., et al. (2014). Factors associated with transfers from healthcare facilities among readmitted older adults with chronic illness. Australia</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: NO Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? NO</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? No, 28 days. Preferrably for the purposes of the thesis study the readmission date would be 30-days. Study was included as this was deemed close enough to the 30-day criteria. What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? NO. Cultural and economic differences between the local population and the study population. Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Recognition of the effects of economic differences and power structures in 30-day readmissions. Also, again, skilled nursing associated with 30-day readmission risk.</p>
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<p>Morandi, A., et al. (2013). Predictors of rehospitalization among elderly patients admitted to a rehabilitation hospital: The role of polypharmacy, functional status, and length of stay. Italy</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES-except that there was a lower incidence of delirium at discharge than previous studies What are the implications of this study for practice? This study provides insight to multiple risk factors related to 30-day readmissions and illustrates the importance of the involvement of specialist geriatricians.</p>
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<p>Navarro, A. E., et al. (2012). Identifying risk of hospital readmission among Medicare aged patients: an approach using routinely collected data. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? NO, this study showed a lower incidence of readmission. What are the implications of this study for practice? The study implies that good follow-up coordination, discharge planning, and community palliative care may decrease the incidence of 30-day readmissions</p>
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<p>Pugh, J. A., et al. (2014). Influence of frailty-related diagnoses, high-risk prescribing in elderly adults, and primary care use on readmissions in fewer than 30 days for veterans aged 65 and older.</p> <p>U.S.A.</p>	<p>Sample</p> <p>Inclusion and exclusion criteria well defined and appropriate: YES</p> <p>Health, demographic, socioecostatus and confounding characteristics considered: YES</p> <p>Sample size justification: YES</p>	<p>Cohort</p> <p>Did the study address a clearly focused issue? YES</p> <p>Was the cohort recruited in an acceptable way? YES</p> <p>Was the exposure accurately measured to minimise bias? YES</p> <p>Was the outcome accurately measured to minimise bias? YES</p> <p>Have the authors identified all important confounding factors? YES</p> <p>Have they taken account of the confounding factors in the design and/or analysis? YES</p> <p>Was the follow up of subjects complete enough/long enough? YES</p> <p>What are the results of this study? See All Data Table</p> <p>How precise are the results? Very Precise</p> <p>Do you believe the results? YES</p> <p>Can the results be applied to the local population? YES</p> <p>Do the results of this study fit with other available evidence? YES</p> <p>What are the implications of this study for practice? More efficient targeting of transitions of care to prevent 30-day readmissions.</p>
	<p>Protocol</p> <p>Study procedures systematic and well specified: YES</p>	
	<p>Measurement</p> <p>Choice of outcomes appropriate YES</p> <p>Data collection specified and systematic YES</p> <p>Measures demonstrate adequate reliability and validity</p>	
	<p>Validity</p> <p>Confounders and bias carefully considered and controlled? YES</p>	
	<p>Statistics</p> <p>Statistics appropriate and well described YES</p> <p>Levels of significance or confidence intervals, or both, reported YES</p> <p>Intention-to-treat analysis for longitudinal data YES</p>	
	<p>Discussion</p> <p>Conclusions supported by results with possible biases and limitations considered YES</p>	

<p>Robinson, R. R. (2015). Low serum albumin and total lymphocyte count as predictors of 30-day hospital readmission in patients 65 years of age or older. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? N/A Have they taken account of the confounding factors in the design and/or analysis? N/A Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? Non-available What are the implications of this study for practice? Clinician recognition of low PEM upon 30-day readmissions, and the need for further investigation.</p>
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<p>Robinson, T., & Kerse, N. (2012). Medical readmissions amongst older New Zealanders: A descriptive analysis. New Zealand</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? No, differing ethnicity/cultural issues and differing systemic reimbursement make it difficult to apply the finding locally. Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Alerts the healthcare system that race and socioeconomic status have an impact upon readmission rates.</p>
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<p>Sattler, E. L., et al. (2015). Factors associated with inpatient hospital (re)admissions in Medicare beneficiaries in need of food assistance. U.S.A.</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioeconomic status and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Management Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered NO</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? Have they taken account of the confounding factors in the design and/or analysis? Was the follow up of subjects complete enough/long enough? What are the results of this study? See All Data Table How precise are the results? Very precise Do you believe the results? YES Can the results be applied to the local population? YES, those who are of the same socioeconomic status Do the results of this study fit with other available evidence? Non-available What are the implications of this study for practice? Recognition that for impoverished older adults, in-home food delivery and other home services may decrease 30-day readmissions.</p>
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<p>Tonkikh, O. (2016). Functional status before and during acute hospitalization and readmission risk identification. Israel</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity YES</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data YES</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered YES</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? Frailty is a risk factor for early readmissions and intervention may decrease risk.</p>
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<p>Traissac, T., et al. (2011). The short mean length of stay of post-emergency geriatric units is associated with the rate of early readmission in frail elderly. France</p>	<p>Sample Inclusion and exclusion criteria well defined and appropriate: YES Health, demographic, socioecostatus and confounding characteristics considered: YES Sample size justification: YES</p> <p>Protocol Study procedures systematic and well specified: YES</p> <p>Measurement Choice of outcomes appropriate YES Data collection specified and systematic YES Measures demonstrate adequate reliability and validity</p> <p>Validity Confounders and bias carefully considered and controlled? YES</p> <p>Statistics Statistics appropriate and well described YES Levels of significance or confidence intervals, or both, reported YES Intention-to-treat analysis for longitudinal data NO</p> <p>Discussion Conclusions supported by results with possible biases and limitations considered NO LIMITATION DISCUSSED</p>	<p>Cohort Did the study address a clearly focused issue? YES Was the cohort recruited in an acceptable way? YES Was the exposure accurately measured to minimise bias? YES Was the outcome accurately measured to minimise bias? YES Have the authors identified all important confounding factors? YES Have they taken account of the confounding factors in the design and/or analysis? YES Was the follow up of subjects complete enough/long enough? YES What are the results of this study? See All Data Table How precise are the results? Very Precise Do you believe the results? YES Can the results be applied to the local population? YES Do the results of this study fit with other available evidence? YES What are the implications of this study for practice? This study suggests that older patients with delirium should be considered for specialized units. Readmission risk is multi-factorial and requires more study.</p>
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Whitney, P. P. (2016). Relationship between insurance and 30-day readmission rates in patients 65 years and older discharged from an acute care hospital with hospice services. U.S.A.	Sample	Cohort
	Inclusion and exclusion criteria well defined and appropriate:	Did the study address a clearly focused issue?
	YES	YES
	Health, demographic, socioecostatus and confounding characteristics considered:	Was the cohort recruited in an acceptable way?
	YES	YES
	Sample size justification:	Was the exposure accurately measured to minimise bias?
		YES
	Protocol	Was the outcome accurately measured to minimise bias?
	Study procedures systematic and well specified:	YES
	YES	Have the authors identified all important confounding factors?
	Measurement	YES
	Choice of outcomes appropriate	Have they taken account of the confounding factors in the design and/or analysis?
	YES	YES
	Data collection specified and systematic	Was the follow up of subjects complete enough/long enough?
YES	YES	
Measures demonstrate adequate reliability and validity	What are the results of this study?	
YES	See All Data Table	
Validity	How precise are the results?	
Confounders and bias carefully considered and controlled?	Very Precise	
YES	Do you believe the results?	
Statistics	YES	
Statistics appropriate and well described	Can the results be applied to the local population?	
YES	YES	
Levels of significance or confidence intervals, or both, reported	Do the results of this study fit with other available evidence?	
YES	Non-available	
Intention-to-treat analysis for longitudinal data	What are the implications of this study for practice?	
YES	Awareness that dual coverage (Medicaid/Medicare) allows patients greater access to resources, therefore possibly contributing to lower readmission rates.	
Discussion		
Conclusions supported by results with possible biases and limitations considered		
YES		

* Indicates a frailty characteristic outside of studies focusing upon 30-day readmissions and

Appendix 5: Data Extraction Form

Data Extraction Form Cohort

30-Day Readmissions and the Elderly

Reference:

Year:

Database:

CASP Score:

Study Design:

Country/Location:

Setting/source of data:

Objective:

Sample Size:

Characteristics/Demographics

Ages

Gender

Ethnicity

Disease

Primary

Co-morbidities

Charlson

Functional Status

of Meds

Readmission Location

Home with care

Home without Care

Skilled Nursing Facility

Home Hospice

Follow-up Times

FINDINGS:

Comments

Useful Articles from Reference List:

Appendix 6: Literature Review All Data Table

Citation and Country	Method	Setting or Source of Data	Objectives and Study Results	Data Collection	Sample Size	Factors with Subgroups			
Albrecht, J. S., et al. (2014). Depressive symptoms and hospital readmission in older adults. U.S.A.	Prospective Cohort Design	Home-Dwelling Patients discharged from tertiary hospital	Quantify the risk of 30-day unplanned 30-day readmissions of patients 65 years and older Result: Depression alone was not associated with an increase in 30-day readmissions.	Enrolled within 72 hours followed by telephone first month of discharge between July 1, 2011 and August 9, 2012	716	Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
						Gender Not Reported	Utilization Not Reported	Disease Process w/Depression Cardiac 19% Cancer 14%	Number of Prescriptions Not Reported
						Age Not Reported	LOS Not Reported	Frailty Traits: Falls ≥2 = 25% <i>p</i> < 0.001 ADL deficit ≥1 = 31% <i>p</i> < 0.001	High Risk Medication Exposure Not Reported
						Ethnicity Not Reported	Discharge Location Not Reported	Comorbidity Charlson Comorbidity Index Score Readmitted 2.5(3.5) <i>p</i> = 0.001 Not readmitted 2.0 (2.0) <i>p</i> = 0.001	
						Socioeconomics Not Reported	Insurance Not Reported	Mental Illness Positive association of depressive symptoms and 30-day readmissions	

						Living Situation				
						Not Reported				
						Sociodemographic	Systemic	Physiological	Pharmacological	
						Subgroups				
Berges, I. M., et al. (2015). Associations between depressive symptoms and 30-day hospital readmissions among older adults. U.S.A.	Prospective Cohort Design	20 bed ACE Unit (Geriatric Unit)	Identify association between depression and 30-day readmissions of older patients over age 65	Face two-face interviews, chart abstractions	789	Gender	Utilization	Disease Process	Number of Prescriptions	
						Female 66%	Not Reported	Not Reported	Not Reported	
						Age	LOS	Frailty	High Risk Medication Exposure	
						76.9 (6.53)	Not Reported	Not Reported	Not Reported	
						Ethnicity	Discharge Location	Comorbidity		
Caucasian 79%	Not Reported	Not Reported								
						Socioeconomics	Insurance	Mental Illness		
						Not Reported	Not Reported	Readmitted with high level of depressions symptoms 15%		
						Living Situation				
						Married 59%				
						Sociodemographic	Systemic	Physiological	Pharmacological	
						Subgroups				
Bjorvatn, A. (2013). Hospital readmission among elderly patients. Norway	Retro-spective Cohort Study	Public Hospitals 1999-2006	Relationship between Length of Stay and 30-day readmissions	Registered data	Approximately 1M	Gender	Utilization	Physiological		Pharmacological
						Female 52%	Not Reported	Top 4 DRGs		Not reported
						Male 48%		1) Lymphoma		
								2) Malignancy male reproduction organ		
								3) Malignancy Hepatic/Pancreatic		
		4) COPD								
		5) Pulmonary Edema								
						Age	LOS			
						76.5 (mean)	7.34 days (mean)			

Bogaisky, M., & Dezieck, L. (2015). Early hospital readmission of nursing home residents and community-dwelling elderly adults discharged from the geriatrics service of an urban teaching hospital: Patterns and risk factors. U.S.A

Retro-spective Cohort Study

Large Urban Hospital

Compare rates and risk factors for early readmission of older adults living in the community or living in nursing homes.

Chart Review 1038

Results:
Nursing home residents at greater risk for 30-day readmission than community dwelling participants.

Statistically CKD, COPD and Pressure Ulcers were associated with higher risk for re-admission

Ethnicity
Not Reported

Discharge Location
Not Reported

Socioeconomics
Systemic

Insurance
Not Reported

Living Situation
Not Reported

Sociodemographic	Systemic	Physiological	Pharmacological
Subgroups			
Gender	Utilization	DX	Number of Prescriptions
Nurse Home	Not Reported	Diabetes	Not Reported
Female 73%		Nurs Home 45%	Exposure to high risk medications
Community		Comm 38%	Not Reported
Female 63%		CHF	
		Nrs Home 35%	
		Comm 25%	
		Dementia	
		Nrs Home 57%	
		Comm 37%	
		COPD	
		Nrs home 19%	
		Comm 22%	
		CKD	
		Nrs Home 23%	
		Comm 28%	
		Dialysis	
		Nrs Home 10%	
		Comm 2%	
Age (mean)	LOS	Frailty	
Nrs Home	Not Reported	Not reported	
81.6			
Comm			
83.6			
Ethnicity	Discharge Location	Comorbidity	
Not Reported	Not Reported	Not Reported	

Cabre, M., et al. (2014). Oropharyngeal dysphagia is a risk factor for readmission for pneumonia in the very elderly persons: observational prospective study. Spain	Observational Prospective Study	Data collection from clinical databases and electronic clinical notes. All discharged patients from Geriatric unit June 2002-Dec 2009	To determine whether oropharyngeal dysphagia is a risk factor for readmission for pneumonia in elderly persons discharged from an acute geriatric unit. Result: Dysphagia is significant in increasing prevalence and risk for readmission with aspiration pneumonia.	Data extraction from clinical databases and electronic clinical notes of patients discharged from Geriatric unit June 2002-Dec 2009.	2,359	Socioeconomics Not Reported	Insurance Not Reported	Mental Illness Not Reported	
						Living Situation On 1 st admission 625 (60%) Nursing Home 413 (40%) Community			
						Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
						Gender Female 52%	Utilization Not Reported	Disease Process Readmits with dysphagia CHF 47.5% Dementia 73.8% Cerebrovascular 62.9% Renal 53.6%	Number of Prescriptions Not Reported
						Age 85.7 (6.3)	LOS Not Reported	Frailty Dysphagia 47.52% <i>p</i> =0.001	High Risk Medication Exposure Benzodiazepines 51.6% Antipsychotic 69.5% Antidepressant 54.5% <i>P</i> <0.001
						Ethnicity Not Reported	Discharge Location Not Reported	Comorbidity Not Reported	
						Socioeconomics Not Reported	Insurance Not Reported	Mental Illness Not Reported	

					Living Situation				
					Not Reported				
					Sociodemographic	Systemic	Physiological	Pharmacological	
					Subgroups				
Chavez, L. J. (2016). Unhealthy alcohol use in older adults: Association with readmissions and emergency department use in the 30 days after hospital discharge. U.S.A.	Retrospective Cohort	Community Dwelling Veterans	Determine the risk of 30-day readmission by Alcohol use. Result: High risk drinking is modestly related to 30-day readmissions	Data Extraction of managed care records. Alcohol Use Disorder Identification Test (AUDIT-C) scores and data on readmissions were collected.	579,330	Gender Male 98.1% Note: U.S. military veterans	Utilization Not Reported	Disease Process Identified using Alcohol Disorder Identification Test: Readmits High Risk Drinking 15.4% Moderate Risk Drinking 12.2% Low Risk Drinking 12.2% Non-Drinking 14.6%	Number of Prescriptions Not Reported
					Age 77.4 (7.4)	LOS Not Reported	Frailty Not Reported	High Risk Medication Exposure Not Reported	
					Ethnicity Caucasian 84.2% Non- Caucasian 15.8%	Discharge Location Not Reported	Comorbidity Not Reported		
					Socioeconomics Not Reported	Insurance Not Reported	Mental Illness Not Reported		
					Living Situation Not Reported				

Dilworth, S. et al. (2012). Feeling let down: An exploratory study of the experiences of older people who were readmitted to hospital following a recent discharge. Australia	Qualitative Design: Interviews	In-depth Interviews	Experiences of older patients during an early readmission	Inductive Approach	3	Thematic Findings			
						Theme One:	Theme Two:	Theme Three:	
						Being Let Down- “expresses the participants’ experience of not being given information, being given mixed messages and feeling unheard and disregarded.”	Being Cared For- “describes both the care required in context of the hospital admission and additional care required at home.”	Feeling Let Down- “describes the experience of falling through the gaps in service provision and being disappointed by services and staff.”	
Enguidanos, S., et al. (2012). 30-day readmissions among seriously ill older adults. U.S.A.	Retrospective Cohort	Patients who received inpatient palliative care	Investigate factors associated with 30 day readmits for patients with In-patient Palliative Consultation (IPC). Results: Patients receiving IPC were readmitted at a lower proportion of 10%.	Data Extraction from electronic medical record including demographic information, primary diagnosis, probability of death (Heckman scores), patient disposition after discharge.	408	Sociodemographic Systemic Physiological Pharmacological			
						Subgroups			
						Gender	Utilization	Disease Process	Number of Prescriptions
						Not Reported	Readmits in relation to receiving inpatient palliative care consultation Readmits 10% No readmits 90%	Not Reported	Not Reported
						Age	LOS	Frailty	High Risk Medication Exposure
						Not Reported	Not Reported	Not Reported	Not Reported
						Ethnicity	Discharge Location	Comorbidity	
						Not Reported	Not Reported	Not Reported	
						Socioeconomics	Insurance	Mental Illness	
						Not Reported	Not Reported	Not Reported	
						Living Situation			
						Not Reported			

Fisher, S. R., et al. (2013). Mobility after hospital discharge as a marker for 30-day readmission. U.S.A.	Prospective Cohort Study	Patients discharged to home	Determine how the number of steps after discharge affected the risk of readmission.	Measurement of number of steps taken first week after discharge via accelerometry	111	Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
			Results: Patients who ambulate a greater number of steps after discharge were readmitted at a lower rate of 2.5%. This was independent of ADL performance. Those who walked 297 steps a day were least likely to be readmitted			Gender Female 63.9%	Utilization Not Reported	Disease Process Cardiac 41% Infections 13% GI 13% Endocrine 15% Other 18%	Number of Prescriptions
						Age Not Reported	LOS Not Reported	Frailty Not Reported	High Risk Medication Exposure Not Reported
						Ethnicity Not Reported	Discharge Location Home	Comorbidity Those with comorbidity odds ratio for readmission OR (95% CI) <i>p value</i> 1.24 (0.31-4.97) <i>p</i> =0.05	
						Socioeconomics Not Reported	Insurance Not Reported	Mental Illness Not Reported	
						Living Situation Not Reported			
Fisher, S. R. (2016b). Predictors of 30-day readmission following inpatient rehabilitation for patients at high risk for hospital readmission.	Observational Cohort Study	Acute Hospital U.S.A.	Identify factors which may aid clinicians to predict 30-day readmissions.		2,498	Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
			Results: Patients with low functional status and rehabilitation LOS were greatest predictors of 30-day readmissions.			Gender 4th quartile (highest risk) Female 50%	Utilization Readmission by Risk Quartile 1 st (lowest risk) 9.4% 2 nd 16.1% 3 rd 22.7% 4 th (highest risk) 33.8%	Disease Process	Number of Prescriptions

<p>Using the Center for Medicare & Medicaid Services (CMS) 30-day Readmission Risk Standardization Model the highest risk quartile records were isolated. Regression tree analysis used to create a stratification of risk factors for readmission</p>	<p>Age 4th quartile (highest risk) 75.6 (11)</p>	<p>LOS Prior Acute Hospitalization LOS by CMS Risk Quartile 1st (lowest risk) Readmitted 9.4% 2nd Readmitted 16.1% 3rd Readmitted 22.7% 4th (highest risk) Readmitted 33.8%</p>	<p>Frailty 4th quartile patients had the lowest cognitive and motor scores (ADLs) on the Functional Independence Measure. Cognitive Scores 23.1 (6.6) Motor Function Scores 33.9 (10.4)</p>	<p>High Risk Medication Exposure Not Reported</p>
	<p>Ethnicity 4th quartile (highest risk) Caucasian (Non-Hispanic) 80.6% African Descent (Non-Hispanic) 12.3% Hispanic 5.1% Other 2%</p>	<p>Discharge Location Not Reported</p>	<p>Comorbidity 69% ≥ 1</p>	
	<p>Socioeconomics Not Reported</p>	<p>Insurance Medicare and/or Medicaid</p>	<p>Mental Illness Not Reported</p>	

Fisher, S. R. (2016a). Inpatient walking activity to predict readmission in older adults. U.S.A.	Prospective, observational clinical cohort study	Acute Hospital	Determine if number of steps taken in the hospital influence readmissions. Results: Ambulation ability was a greater predictor of 30-day readmission than ADL deficits.	Measurement via accelerometry of number of steps taken while admitted in acute care hospital.	164	Living Situation																																							
						4th quartile (highest risk) Lived with Family/Friends 71.1% Lived alone 27.7% Paid caregiver/other 1.2%																																							
<table border="1"> <thead> <tr> <th>Sociodemographic</th> <th>Systemic</th> <th>Physiological</th> <th>Pharmacological</th> </tr> </thead> <tbody> <tr> <td colspan="4" style="text-align: center;">Subgroups</td> </tr> <tr> <td>Gender</td> <td>Utilization</td> <td>Disease Process</td> <td>Number of Prescriptions</td> </tr> <tr> <td>Female 70.7%</td> <td>Not Reported</td> <td>Cardiovascular Readmission 50.0%</td> <td>Not Reported</td> </tr> <tr> <td></td> <td></td> <td>Pulmonary Readmission 26.92%</td> <td></td> </tr> <tr> <td></td> <td></td> <td>Gastrointestinal Readmission 03.85%</td> <td></td> </tr> <tr> <td></td> <td></td> <td>Infection Readmission 3.85%</td> <td></td> </tr> <tr> <td></td> <td></td> <td>Endocrine Readmission 15.39%</td> <td></td> </tr> <tr> <td>Age</td> <td>LOS</td> <td>Frailty</td> <td>High Risk Medication Exposure</td> </tr> <tr> <td>76.2 (7.00)</td> <td>Not Readmitted 4.99 (4.13) Readmitted 6.46 (4.96)</td> <td>Measures of ambulation and readmission Readmissions Avg Steps 323 26% p=<0.1</td> <td>Not Reported</td> </tr> </tbody> </table>						Sociodemographic	Systemic	Physiological	Pharmacological	Subgroups				Gender	Utilization	Disease Process	Number of Prescriptions	Female 70.7%	Not Reported	Cardiovascular Readmission 50.0%	Not Reported			Pulmonary Readmission 26.92%				Gastrointestinal Readmission 03.85%				Infection Readmission 3.85%				Endocrine Readmission 15.39%		Age	LOS	Frailty	High Risk Medication Exposure	76.2 (7.00)	Not Readmitted 4.99 (4.13) Readmitted 6.46 (4.96)	Measures of ambulation and readmission Readmissions Avg Steps 323 26% p=<0.1	Not Reported
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Goldenheim, A., et al. (2014). Re-hospitalization of older adults discharged to home hospice care. U.S.A.	Secondary Analysis of Previous Study	Identify factors associated with 30-day readmission of older adults newly discharged to hospice. Results: Factors related to advanced care planning and goals of care are related to readmission.	Secondary data from study looking at 30-day readmits of patients 65 year or older with PCPs d/c from hospital Feb. 1, 2005-Jan. 31, 2010 from urban academic centre.	206	Ethnicity	Discharge Location	Comorbidity	
					Caucasian 69.5%	Discharged home with or without support 87%	Not Reported	
					Socioeconomics	Insurance	Mental Illness	
					Not Reported	Not Reported	Not Reported	
					Living Situation			
					Not Reported			
					Sociodemographic	Systemic	Physiological	Pharmacological
					Subgroups			
					Gender	Utilization	Disease Process	Number of Prescriptions
					Female 73.7	Patients/families who called PCP 1 or more times first week after d/c had 2.4x greater risk of readmission within 30 days of discharge and hospice admission (HR 2.35, CI0.9)	Readmitted from hospice Cancer 63.2% CHF 10.5% COPD 10.5% Dementia 10.5% Other 8.5%	Not reported
					Age	LOS	Frailty	High Risk Medication Exposure
					No readmit 81.0 (8.3) Readmit 77.1 (8.0)	No readmission 8.7 (6.2) Readmission 7.8 (7.4)	Not reported	Not reported
					Ethnicity	Discharge Location	Comorbidity	
					Caucasian 26.3% African Descent 47.4% Hispanic 15.8% Other 10.5%	All discharged home on hospice	Not reported	

					Socioeconomics	Insurance	Mental Illness	
					Not reported	Hospital Readmissions from Hospice Medicare alone Readmission 21.1% (4) Medicare & Medicaid (Dual) Readmission 78.9% (15)	Not reported	
					Living Situation			
					Not reported			
					Sociodemographic	Systemic	Physiological	Pharmacological
					Subgroups			
					Gender	Utilization	Disease Process	Number of Prescriptions
					Not readmitted	Not Reported	All Cardiac disorders	Not Reported
					Males		34%	
					45%		CHF	
					Females		10%	
					55%		All Infectious Disease	
					Readmitted		21%	
					Males		All Respiratory Disorders	
					45%		6%	
					Females		COPD	
					Readmit		3%	
					55%		All Malignant Disorders 6%	
							Patients with malignancy more likely to be readmitted within 7 days	

Hain, D. J., et al. (2012). Characteristics of older adults re-hospitalized within 7 and 30 days of discharge: Implications for nursing practice. Age 75 and over. U.S.A.

CMS eligible data from a community Hospital June 1, 2007 – May 31, 2008

Examine re-hospitalization rates and re-hospitalization by diagnosis

Results:
CHF was the most frequent cause of readmission.

Infectious disease was the second highest cause of readmission.

Data on Re-hospitalized Medicare fee for service patients

6,809

					Age	LOS	Frailty	High Risk Medication Exposure
					No readmit 83 (5.7)	Not Reported	Not Reported	Not Reported
					Readmit 84 (5.5)			
					Ethnicity	Discharge Location	Comorbidity	
					Not Reported	Readmissions Home self-care 25%	Not Reported	
						Home w/home care 34%		
						Skilled Nursing Fac. 41%		
					Socioeconomics	Insurance	Mental Illness	
					Not Reported	All participants had Medicare Insurance	Not Reported	
					Living Situation			
					Not Reported			
					Sociodemographic	Systemic	Physiological	Pharmacological
							Subgroups	
					Gender	Utilization	Disease Process	Number of Prescriptions
					Female 57%	Not Reported	CHF 31 (29%) COPD 26 (24%)	Not Reported

adults with chronic illness. Australia	public health services in Melbourne, Australia	Age Not Reported	LOS Mean LOS by day prior to readmission by discharge location	Frailty Incontinent 17% OR 7.18 CI1.19-43.3 Impaired Skin 18% OR 18.06, CI 1.84-176.16 Ltd. Mobility 17% OR, CI unavailable Falls 32% OR, CI unavailable Disoriented 17% OR, CI not available *all characteristics of Frailty	High Risk Medication Exposure Not Reported
	Results: Please see sub-group results.		Length of Stay % (N) Home 1 day 5.9% 2 – 5 days 31.4% 6 – 9 days 47.1% 10 – 19 days 7.8% 20 - 28 days 7.8% Healthcare Facility 1 day 3.6% 2 – 5 days 30.9% 6 – 9 days 32.7% 10 – 19 days 23.6% 20 – 28 days 9.1%		
		Ethnicity Not Reported	Discharge Location Not Reported	Comorbidity Number of Diagnoses 1-5 Dx 10% 6-10 Dx 29% 11-15 Dx 14% 16+ Dx 7%	

					Socioeconomics	Insurance	Mental Illness	
					Most advantaged	Not Reported	Not Reported	
					Home			
					9.8%(5)			
					Facility			
					30.9% (17)			
					Least Advantaged			
					Home			
					45.1% (23)			
					Facility			
					21.8% (34)			
					Living Situation			
					Advantage			
					Lives alone			
					Home			
					34% (17)			
					Facility			
					24.4% (11)			
					Lives with caregiver/family			
					Home			
					66%(33)			
					Facility			
					75.6			
					Sociodemographic	Systemic	Physiological	Pharmacological
					Subgroups			
					Gender	Utilization	Disease Process	Number of Prescriptions
Morandi, A., et al. (2013). Predictors of re-hospitalization among elderly patients admitted to a rehabilitation hospital: the role of polypharmacy, functional status,	Older patients admitted to in-hospital rehab facility	Determine rate of readmission and risk factors for unplanned readmission for the elderly from a rehabilitation facility.	Data collected from administrative data bases at the facility.	6,383	Female 71%	Not Reported	Orthopaedic 44% Neurologic 16% Respiratory 17% Cardiologic 10%	5 (2)

and length of stay. Italy		Results: Predictors of readmission included polypharmacy, functional status, and long hospital LOS.				Age 80 (6) LOS LOS in Acute Care Hospital HR (CI) P value 7-13 days 1.74 (0.93 3.25) p=0.80 >13 days 2.67 (1.39-5.10) p=0.003 Longer LOS increases risk for readmission Ethnicity Not Reported Socioeconomics Not Reported Living Situation Not Reported	Frailty Delirium 18% Gait Disturbance 9% Comorbidity Not Reported Mental Illness Not Reported	High Risk Medication Exposure Not Reported
Navarro, A. E., et al. (2012). Identifying risk of hospital readmission among Medicare aged patients: an approach using routinely collected data. U.S.A.	636 bed non-profit USC Medical Centre (Lower-socio-economic area) Patients 65 and over	Determine risk associated with hospital readmission using. Results: Frequency of readmissions increased for those discharged home without care and skilled nursing facilities, and diagnosed with	Data collection from electronic medical records of older patients discharged in the year 2007	8298	Sociodemographic Gender Female 56.6 Age 78.8 (8.3)	Systemic Utilization Not Reported LOS 6.7 (6.1)	Physiological Disease Process Respiratory 9.1% CHF 3.55% Frailty Fluid/Elect (dehydration) 32.8%	Pharmacological Subgroups Number of Prescriptions Not Reported High Risk Medication Exposure Not Reported

respiratory disease or CHF.	<p>Ethnicity</p> <p>Caucasian 60.9%</p> <p>Hispanic 14%</p> <p>AA 15.8%</p> <p>Other 9.3%</p>	<p>Discharge Location</p> <p>Home with care 28.1%</p> <p>Home without Care 39.1%</p> <p>Skilled Nursing Facility 32.8%</p>	<p>Comorbidity</p> <p>Those readmitted averaged 1.7 Comorbid Conditions</p> <p>Readmissions with Comorbidity by Reason for hospitalization</p> <p>Dehydration 32.8%</p> <p>CHF 24.3%</p> <p>DM 24.3</p>
	<p>Socioeconomics</p> <p>Not Reported</p>	<p>Insurance</p> <p>Readmissions from hospice by Insurance</p> <p>Medicare 70.8%</p> <p>Medicaid 26%</p> <p>Other Insurances 26.6%</p>	<p>Mental Illness</p> <p>Depression 13%</p>
	<p>Living Situation</p> <p>Married 43.5 (383)</p> <p>Single 12.7% (112)</p> <p>Widowed 32.7% (288)</p> <p>Divorced/Separated 11.0% (97)</p>		

Pavon, J. M., et al. (2014). Identifying risk of readmission in hospitalized elderly adults through inpatient medication exposure. U.S.A.	Retrospective Observational Study	Tertiary and Quaternary Care Academic Health System	To Examine association between inpatient medication exposure and risk of readmission	Data from Electronic Health Records	4,627	Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
						Gender	Utilization	Not reported	Top 5 drug classes
						Female 57%	Medicare/ Medicaid 73%		1) Anticoagulants
						Male 43%	Private/managed care 27%		2) Opiates
									3) Anticholinergics
									4) Benzodiazepines
									5) Anticonvulsants
						Age	LOS		
						74	5 days		
						Ethnicity	Discharge Location		
						Caucasian 58%	Not Reported		
						Socioeconomics	Insurance		
						Not Reported	Not Reported		
						Living Situation			
						Not Reported			
Pugh, J. A., et al. (2014). Influence of frailty-related diagnoses, high-risk prescribing in elderly adults, and primary care use on readmissions in fewer than 30 days for veterans aged 65 and older. U.S.A	Veteran's Facilities			Merged electronic medical records of inpatient, outpatient, and pharmacy facilities for patient's meeting criteria between October 1, 2004 and September 1, 2006.	134,829	Sociodemographic	Systemic	Physiological	Pharmacological
						Subgroups			
						Gender	Utilization	Disease Process	Number of Prescriptions
						OR (CI) p value	No. of Primary Care visits and percentage of readmissions	Not reported	
						Male			0-5
						1.06			14.2%
						(0.95 – 1.18) <.001	0-1 – 38.4%		6-8
							2-4 – 50.2%		15.9%
							≥ 5 – 10.9%		9-11
									18.4%
									≥12 51.5%

Study 4 variables Effect upon veterans ≥ 65 years	Age OR (CI) p value 75 – 84 years 1.01 (0.98 – 1.04) .46 85+ years 1.02 (0.97 – 1.08) .35	LOS 5 (6.3)	Frailty Frailty Related DX 38.4% Frailty DX/Characteristics include: Coagulopathy Involuntary weight loss Fluid/electrolyte Imbalance Anemia Falls/fx	High Risk Medication Exposure HRME exposure was not helpful in identifying risk for readmission
Results: Amount of use of primary care does not increase risk of readmission. Frailty diagnosis does increase risk of readmission High risk medication is not associated to readmissions	Ethnicity OR (CI) p Value Reference Caucasian African Descent 0.90 (0.86 – 0.94) <.001 Hispanic 0.93 (0.86 – 1.01) 0.8 Other 1.05 (0.93 – 1.19) .41 Missing Data 0.81 (0.74 – 0.89) <.001	Discharge Location Not reported	Comorbidity Number of Comorbidities 5.5 (5.9)	
	Socioeconomics Not reported	Insurance Not reported	Mental Illness All Mental Illness OR (CI) P 0.92 (0.89 – 0.96) $p < .001$	
	Living Situation Not reported			

Robinson, R. R. (2015). Low serum albumin and total lymphocyte count as predictors of 30-day hospital readmission in patients 65 years of age or older. U.S.A.	507 bed Community Medical Centre	Determine if Protein Energy Malnutrition (PEM) is a risk for 30-day readmissions for older adults. Results: PEM is related to increase in frequency of readmission	1683	Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Those with PEM and Readmit Female 55.9%	Not reported	Not reported	Not reported
				Age	LOS	Frailty	High Risk Medication Exposure
				79 (8.42)	Not reported	Nutritional Status Readmits w/ Protein Energy Malnutrition (PEM) N=219 Readmits: W/PEM 14.5% W/O PEM 4% All Patients with PEM 58% PEM is associated with 30-day readmission	Not reported
				Ethnicity	Discharge Location	Comorbidity	
				Not reported	Not reported	Not reported	
				Socioeconomics	Insurance	Mental Illness	
				Not reported	Not reported	Not reported	
				Living Situation			
				Not reported			
Robinson, T., & Ngaire, K. (2012). Medical readmissions amongst older New Zealanders: A descriptive analysis. New Zealand	Government funded hospitals	To better understand medical readmission in older people in New Zealand to determine if interventions might be worthwhile. Results:	217,323	Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Risk Ratio RR (CI) P value Male RR 1.161 p<0.001 Female RR 1	Not reported	Cardio 23.8% Respiratory 17.8% GI 7.4%	Not reported

<p>Indigenous people were more likely to be readmitted. Those readmitted had more costly and complex illness, and had poorer outcomes.</p>	<p>Age Age \geq 65 as a Risk Factor RR(CI) P value Risk Ratio 1.026 (1.016-1.036) p=<0.001</p>	<p>LOS 4.9 days</p>	<p>Frailty Not reported</p>	<p>High Risk Medication Exposure Not reported</p>
	<p>Ethnicity Caucasian RR = 1 Maori (indigenous people) 1.179 (1.115-1.246) P=<0.001</p>	<p>Discharge Location Not reported</p>	<p>Comorbidity Not reported</p>	
	<p>Socioeconomics Poverty RR = 1.152 (1.104-1.203) p=<0.001</p>	<p>Insurance Not reported</p>	<p>Mental Illness Not reported</p>	
	<p>Living Situation Not reported</p>			

Sattler, E. L., et al. (2015). Factors associated with inpatient hospital (re)admissions in Medicare beneficiaries in need of food assistance. U.S.A.	State of Georgia	Examine unique factors associated with inpatient admissions and readmissions of older Medicare beneficiaries in need of food assistance.	892	Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Female 68.5%	ED Visits prior to readmission None = 34.6% 1 visit= 24.7% 2+ visit =40.7%	All Statistically Significant <.001 Readmitted by disease process: CHF 54.9% Diabetes 53.1% Chronic Kidney DX 46.3% COPD 39.5% Dementia 26.5%	All p values <.001 0-2 6.2% 3-6 34.6% 7+ 59.3%
		Results: Those in need of food assistance were readmitted more frequently than those not requiring assistance.		Age	LOS	Frailty	High Risk Medication Exposure
				74.5 (8.3)	Not reported	Not reported	
				Ethnicity	Discharge Location	Comorbidity	
				African Descent 27.2%	All patients reside in their homes	Fair-poor self-reported health readmissions 83.3% $p = \leq .05$	
				Socioeconomics	Insurance	Mental Illness	
				Household Income < \$20,000 78.4% Food Assistance Recipient 20% Food insecurity not significant for readmission risk	Not reported	Not reported	
				Living Situation			
				Not reported			

Tonkikh, O. (2016). Functional status before and during acute hospitalization and readmission risk identification. Israel	27 Hospitals	Determine if functional status upon admission to the hospital or decline during hospital stay affects risk of 30-day readmission.	559	Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
		Results: Patients having a higher decline in ADLs during hospitalization had greater odds of readmission.		Gender Male 61.2%	Utilization No. Hospitalizations the year before 2.20 (2.2)	Disease Process % (N=) P value CHF 45.9% (39) 0.001 Chronic Kidney DX 58.8% (50) >.001 COPD 18.8% (16) 0.56 DM 43.5% (37) 0.84	Number of Prescriptions Not reported
				Age 79.7 (6.6)	LOS 6.7 (5.1)	Frailty ADL decline while hospitalized OR = 1.32 (CI 1.02-1.72) p=0.034 Nutritional Status Albumin M 3.0 (0.5) High Risk Malnutrition 51.8%	High Risk Medication Exposure Not reported
				Ethnicity Not reported	Discharge Location All discharged home 22.4% readmitted	Comorbidity Not reported	
				Socioeconomics Not reported	Insurance Not reported	Mental Illness Not reported	
				Living Situation Not reported			

				Sociodemographic	Systemic	Physiological	Pharmacological
Traissac, T., et al. (2011). The short mean length of stay of post-emergency geriatric units is associated with the rate of early readmission in frail elderly. France	7 bed Geriatric Unit Academic Hospital	Evaluate risk factors for early re-hospitalisation of frail older patients in a short stay geriatric unit Results: Readmission was associated with Delirium, LOS >6 days and home discharge	476				
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Female 68%	Not reported	Not reported	Not reported
				Age	LOS	Frailty	High Risk Medication Exposure
				87.3 (5.8)	OR 1.9 CI 1.1-3.5 P=0.02 For LOS >6 days	Fall Syndrome 30.9% Delirium % 61.8%	Not reported
				Ethnicity	Discharge Location	Comorbidity	
				Not reported	All home 14.3% readmitted	4.3 (1.8)	
				Socioeconomics	Insurance	Mental Illness	
				Not reported	Not reported	Not reported	
				Living Situation			
				Not reported			
Yoo, J. W., et al. (2015). Hospital readmission of skilled nursing facility residents: A systematic review. U.S.A.	Experimental			Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Age	LOS	Frailty	High Risk Medication Exposure
				Ethnicity	Discharge Location	Comorbidity	
				Socioeconomics	Insurance	Mental Illness	
				Living Situation			

Whitney, P. P. (2016). Relationship between insurance and 30-day readmission rates in patients 65 years and older discharged from an acute care hospital with hospice services. U.S.A.	3 acute care hospitals	Determine if dual eligible (Medicare and Medicaid) differ from those older adults with only one government insurance in rates of readmission. Results: Patients with dual coverage had significantly lower odds of readmission than those who did not have dual coverage.	2,755	Sociodemographic	Systemic	Physiological	Pharmacological
				Subgroups			
				Gender	Utilization	Disease Process	Number of Prescriptions
				Female 57.8%	Not reported	CHF 35.1% Pulmonary Disease 33.1% Dementia 3.7% Diabetes 5.1% Malignancy 41.9% Renal Disease 24.3%	Not reported
				Age	LOS	Frailty	High Risk Medication Exposure
				77.8 (8.8)	9.3 (8)	Not reported	Not reported
				Ethnicity	Discharge Location	Comorbidity	
				Caucasian 19.6% African Descent 40.9% Hispanic 33.8%	Home with Hospice N=1255 Skilled facility with hospice N=1500	Not reported	

Socioeconomics	Insurance	Mental Illness
	Dual Coverage (Medicaid/Medicai d)	Depression 8.4%
	Compared to Medicare Only	
	Lower risk for dual covered patients for readmission than Medicaid or Medicare alone.	
	Dual Coverage RR 0.86 SD 0.11 P = 0.244	
Living Situation		
Not reported		

Appendix 7: Capacity

Yale University Institutional Review Boards

IRB Policy 340 Participation of Individuals with Impaired Consent Capacity

Responsible Office	Office of Research Administration	Effective Date January 8, 2009
Responsible Official	Institutional Review Board Executive Chair	Last Revision 11Dec2017

Policy Sections2

 340.1 IRB Considerations2

 340.2 Investigator Obligations3

 340.3 Surrogate or Legally Authorized Representative4

 340.4 Additional Safeguards4

Scope

This policy defines the heightened safeguards that all researchers must employ in order for a Yale Institutional Review Board (IRB) to approve the participation of adult individuals with impaired consent capacity in biomedical, behavioral, and social science research.

Policy Statement

IRBs and investigators must operate according to the principles that individuals with impaired consent capacity who are recruited for or enrolled in research studies must be treated in a manner commensurate with their special status. Research involving these individuals should employ additional safeguards as appropriate to the study and the participant population in order to protect their rights and welfare.

Reason for the Policy

It is important, necessary, and in keeping with the Belmont principles of beneficence and justice to include individuals with impaired consent capacity as participants in research projects. A number of conditions associated with decisional impairment, such as stroke and Alzheimer’s disease, afflict ever-increasing numbers of individuals in society and impose growing burdens on those individuals, their families, and society. Scientifically and ethically appropriate research involving these individuals is critical to illuminate the underlying disease mechanisms that lead to these conditions and to identify promising treatments. To be most useful and free of bias, that research must include individuals with severe and chronic forms of these disorders as well as those exhibiting minimal impairment. Engaging individuals in research who cannot consent for themselves or whose decision-making capacity may be compromised or may fluctuate over time may result in their inability to protect their own self-interests. Therefore, additional safeguards must be implemented, as required in 45 CFR §46.111(b) and 21 CFR §56.111(b) and described herein (see Procedure 340 PR.1 Assessment of Capacity to Consent for additional

information).

Definitions

Assent

An individual's affirmative agreement to participate in research. This should be sought in addition to the consent of a legally authorized representative or surrogate when the individual is sufficiently cognitively capable of understanding the nature of his or her participation in a research study. Mere failure to object should not, absent affirmative agreement, be construed as assent.

Impaired Consent Capacity

A compromised capacity to understand information related to the research and to make a reasoned decision about initial or continuing participation in research that may preclude the individual from providing legally effective consent. Such impairment or compromised capacity may be temporary, permanent, or may fluctuate. Examples of individuals who may have impaired consent capacity include women in active labor, individuals who have suffered a stroke or other acute and severe illness, individuals under the influence of drugs or alcohol, individuals experiencing considerable pain, individuals under extreme emotional distress (e.g., learning of a newly diagnosed life threatening or terminal illness for self or loved one, anticipating imminent major surgery), and individuals suffering from cognitive disorders or mental disorders. Impaired consent capacity as defined in this policy is distinct from legal incompetence.

Legal Incompetence

A designation of status that has been adjudicated in a court proceeding, and often referring to an inability to manage one or more significant areas of life such as business or monetary affairs. Although an individual may be designated as legally incompetent, he or she does not automatically have impaired consent capacity in terms of consenting to research. Similarly, an individual may be legally competent, but still have impaired consent capacity in terms of providing consent to participate in a research study.

Legally Authorized Representative (LAR)

An individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research. An LAR is authorized through a legal process and has documentation of that designation.

Research Advance Directive

A document used to indicate willingness to continue to participate in a research study or in future studies. In filling out an advance directive, the participant, who at the time is capable of consenting, provides consent to document his/her willingness to continue to participate in the research study in the future or in other future studies during which it is likely that the participant will not be capable of providing consent. An advance directive may also be used to allow the participant to name an individual that the participant would like to act as his/her surrogate to provide permission for the participant's continuation in a current study or enrollment in a future study, in addition to the participant's assent. (See Research Advance Directive template at <http://www.yale.edu/hrpp/forms-templates/biomedical.html>) Advance directives, with surrogate appointments should be considered in studies which investigate subjects over time and involve the potential for a decline in capacity to give ongoing consent to participate or in those studies in which alteration of consciousness is likely to occur during the course of the study.

Surrogate Permission

Permission for an individual to participate in research given by an appropriate surrogate (e.g., next of kin – spouse, parent, child, sibling) when an individual is assessed as not capable of providing fully informed and legally effective consent.

Therapeutic Misconception

An individual's belief that research studies are intended to benefit the participants who enroll in them and that the individual is being asked to participate in a research trial as part of his or her clinical care even after adequate and repeated information and explanations about the risks and benefits of the study have been provided.

Policy Sections

340.1 IRB Considerations

IRBs reviewing projects involving adult participants with impaired consent capacity must include one or more members or consultants who are familiar with the conditions that may affect the prospective participant's capacity to provide consent and with the concerns of the population being studied. IRBs should consider whether it is necessary to consult with or to have in attendance a special representative familiar with the disorder and capable of addressing concerns specific to the subject population (45 CFR §46.107(a); 21 CFR §56.107(a)).

The IRB will approve research projects which propose to include individuals with impaired consent capacity only after consideration of safeguards in addition to the requirements for approval described in the IRB Review Policy. (See [340 CH. 1, Impaired Consent Capacity Checklist](#))

Appropriateness of Inclusion

Individuals who have been found to have impaired consent capacity may be enrolled in research **only when** the IRB finds that their participation in the study is justified, there is a sufficient plan for obtaining and continually assessing assent, and appropriate additional safeguards are in place to protect them, such as, where appropriate and feasible, provisions for surrogate permission or an advance directive.

Furthermore, the IRB must find that their participation in research:

- Presents no more than minimal risk; or
- Presents greater than minimal risk, provided that IRB finds that:
 - The risks are justified given the potential benefits of the research either to the participants or to the development of generalizable knowledge to benefit the participants' class of individuals.

Justification for Inclusion

Whenever possible, research should be designed to include only those individuals who are capable of consenting for themselves. In some studies, however, where benefit is likely, it is more ethical and in line with the Belmont principles to include individuals with impaired consent capacity. In other studies, even those without potential (or likely) benefit to participants, the only way to answer the scientific aim may be to include such individuals in the research.

Investigators proposing research targeting adult individuals with impaired consent capacity as participants must provide IRBs with a thorough justification for their proposed research design, including how capacity will be assessed, plans to include surrogate permission, plans for assessing subject assent (where appropriate) and a description of the procedures that are designed to minimize risks and discomfort to participants. IRBs must consider whether the protocol includes a reasonable rationale for inclusion of individuals with impaired consent capacity as a target population.

Risk:Benefit Assessment

A research study specifically designed to include individuals with impaired consent capacity must have as its goal either to study treatment designed to directly benefit the individual, or the development of important generalizable knowledge regarding the disease or condition of the targeted population that includes a substantial portion of individuals with the same impaired capacity as the subjects. The IRB's deliberations shall include consideration of the nature and degree of anticipated impairment of the targeted study populations, the risk level of the proposed study, and the potential for direct benefit to the study participants.

340.2 Investigator Obligations Requisite Expertise

The investigator must ensure that the individual who is responsible for determining whether a potential participant has the capacity to consent has the appropriate expertise necessary to determine and monitor the participant's capacity initially and on an ongoing basis. The determination is made by individual observation of and interaction with the potential participant. The determination may be made by an investigator or by another professional who has appropriate expertise. It may also include opinions from one or more caregivers.

Assessment of Capacity to Provide Consent

Research studies designed to involve individuals with impaired consent capacity must include a means to assess a potential participant's capacity to provide consent and the criteria for identifying individuals who are impaired. At a minimum, this assessment must include a method to evaluate the potential participant's ability to understand the relevant study information, e.g., the nature of the research and its likely consequences, to process information about the research rationally, and to communicate a choice clearly as to whether or not he/she wishes to participate.

1. For research contemplating enrolling participants who are not able to provide informed consent at the outset of the study, and where an advance directive is not possible due to their condition, permission from a surrogate for their participation must be approved by the IRB (see Policy 200, Informed Consent for Human Research).
2. Assent must be sought when the individual is sufficiently cognitively capable of understanding the nature of his or her participation in a research study and capable of communicating. Where assent is required, mere failure to object may not, absent affirmative agreement, be construed as assent.

340.3 Surrogate or Legally Authorized Representative

Absent a participant-designated or state-specified legally authorized representative (LAR) for research decision-making, investigators may engage and IRBs may approve as surrogates individuals who are specified in state statutes as LARs for medical decision-making or, in the absence of such statutes, individuals who would normally provide consent for medical care under prevailing, commonly accepted clinical practices. Participant assent also must be obtained whenever possible.

The IRB shall consult with Institutional legal counsel regarding the categories of surrogates eligible to serve as LARs in different situations.

The IRB shall adhere to Connecticut state statutes that explicitly prohibit court-appointed guardians of mentally retarded individuals from giving permission for their wards to participate in research unless certain stringent terms and conditions are met (CGS § 45a-677(e)).

340.4 Additional Safeguards

The IRB may require additional safeguards depending on the protocol and the level of potential risk to

the participants involved. Such safeguards may include the use of an independent monitor and/or assessor; special informational or educational techniques; or the use of waiting periods to afford participants and their surrogates more time to decide about participation.

Related Information

[340 PR.1 Assessment of Capacity to Consent](#)

[340 CH 1 Points to Consider: Studies Involving Participants with Impaired Capacity to Consent](#)

Federal Regulations: 45 CFR §46.111(b); 21 CFR §56.111(b); 45 CFR §46.107(a); 21CFR §56.107(a)

Connecticut State Statutes: CGS §45a-677(e)

Contacts

Subject	Contact	Phone
Research Studies involving Individuals with Impaired Consent Capacity	Human Investigation Committee or Human Subjects Committee	(203) 785-4688 ysmhic@yale.edu human.subjects@yale.edu
Surrogate or Legally Authorized Representative	Office of the General Counsel	(203) 432-4949

Roles and Responsibilities**Human Research Protection Program**

The Human Research Protection Program (HRPP) is responsible for oversight of human research protection through ongoing education, monitoring and evaluation of all parties involved in the conduct of human research.

Human Investigation Committee (HIC)

HIC I, HIC II, HIC III and HIC IV serve as the four Institutional Review Boards or IRBs for biomedical human research conducted at Yale University.

Human Subjects Committee (HSC)

The HSC serves as the Institutional Review Board for social, behavioral and educational human research at Yale University.

Office of the General Counsel (OGC)

The OGC serves as legal advisor to the Yale community.

Revision History

1/8/2009, 9/26/2012

Appendix 8: Participant Information Sheet

Yale SCHOOL OF MEDICINE



200 FR 9 (2016-1)

Title: Making Sense of 30-Day Readmissions: Experiences of Older Adults

Principal Investigator: Rebecca Gagne Henderson APRN ACHPN

Funding Source: Privately Funded PhD Thesis

Introduction

You are being asked to join a research study. The following information will explain the purpose of the study, what you will be asked to do, and the potential risks and benefits. You should ask questions before deciding whether you wish to participate, or at any time during the course of the study.

Purpose

You are being asked to participate because you are age 65 or over and are in the hospital after being readmitted within 30-days of your last discharge from the hospital. We are trying to learn more about the experiences and views of patients before, during and after they have been re-hospitalized.

This study is a partial requirement for the researcher's completion of a PhD degree from Lancaster University, UK.

Procedures

If you choose to participate in the study, you will be asked to consent to the study by signing the consent form. You will be asked to participate in an approximate 60-minute interview that will be audio recorded. After signing the consent form the researcher will make an appointment with you for the interview. This will be at your convenience and after you have had the time to think about whether you wish to participate in the interview or

not.

After the interview is completed your involvement in the study will be complete.

Possible Benefits

This research is not designed to benefit you directly. However, knowledge gained from the results may help us to better understand why older patients are readmitted to the hospital. It is also hoped that this research helps us to understand how to prevent readmissions.

Possible Risks

Your part in this research study consists solely of participating in the interview. This study does not require you to have procedures or treatments. Therefore, being in this study does not involve any physical risks to you. However, there is a slight risk regarding the confidentiality of your participation in this study. This could happen due to break-in to the physical office, or a computer security breach. Should information about you become known to persons outside this study you will be notified. The researchers are required to keep your study information confidential, however, so the risk of breach of confidentiality is very low.

Another low risk is the discomfort or distress you may experience if you recall difficult memories regarding your illness. Should this occur you will be given time to compose yourself, if you wish the interview will be stopped. You may also become tired during the interview. Should this happen you may ask to stop the interview. The researcher will also “check-in” with you to make sure you are feeling well.

Privacy / Confidentiality

To protect your confidentiality, your name and other identifying information will not be recorded on any study documents. You will be assigned a study number and the code linking your number with your name will be stored in a separate locked file cabinet. We will only collect information that is needed for research. Only the researchers involved in this study and those responsible for research oversight will have access to the information you provide. Examples of information that we are legally required to disclose include abuse of a child or older person, or certain reportable diseases. The interview will be conducted in the privacy of your hospital room.

Voluntary Participation

Participation in this study is completely voluntary. You are free to decline to participate, to end participation at any time for any reason, or to refuse to answer any individual question at any time. Once the interview is complete you maintain the right to withdraw from the study in 24 hours. Refusing to participate will involve no penalty or loss of benefits to which you are otherwise entitled (such as your health care outside the study, the payment for your health care, and your health care benefits). By providing verbal consent, you have not given up any of your legal rights.

Questions

You have heard the above description of the research study. You have been told of the risks and benefits involved and, at this point, all of your questions regarding the study have been answered.

If you have any further questions about this study, you may contact the investigator, Rebecca Gagne Henderson APRN, ACHPN at Rebecca.gagnehenderson@ynhh.org or 203-867-8262. If you would like to talk with someone other than the researchers to discuss problems, concerns, and questions you may have concerning this research, or to discuss your rights as a research subject, you may contact the Yale Human Investigation Committee at (203) 785-4688 or the University of Lancaster Research Ethics Committee by emailing Diane Hopkins at d.hopkins@lancaster.ac.uk.

have access to the information you provide. Examples of information that we are legally required to disclose include abuse of a child or older person, or certain reportable diseases. The interview will be conducted in the privacy of your hospital room.

Voluntary Participation

Participation in this study is completely voluntary. You are free to decline to participate, to end participation at any time for any reason, or to refuse to answer any individual question at any time. Once the interview is complete you maintain the right to withdraw from the study in 24 hours. Refusing to participate will involve no penalty or loss of benefits to which you are otherwise entitled (such as your health care outside the study, the payment for your health care, and your health care benefits). By providing verbal consent, you have not given up any of your legal rights.

Questions

You have heard the above description of the research study. You have been told of the risks and benefits involved and, at this point, all of your questions regarding the study have been answered.

If you have any further questions about this study, you may contact the investigator, Rebecca Gagne Henderson APRN, ACHPN at Rebecca.gagnehenderson@ynhh.org or 203-867-8262. If you would like to talk with someone other than the researchers to discuss problems, concerns, and questions you may have concerning this research, or to discuss your rights as a research subject, you may contact the Yale Human Investigation Committee at (203) 785-4688 or the University of Lancaster Research Ethics Committee by emailing Diane Hopkins at d.hopkins@lancaster.ac.uk.

Appendix 9: Consent Form



Making Sense of 30-Day

Readmissions: The

Experiences of Older

Adults

Researcher: Rebecca Gagne Henderson APRN, ACHPN

Purpose:

You are invited to participate in a research study designed to examine the experiences of older adults who are readmitted to the hospital within 30-days of prior discharge. Through the sharing of your experiences we hope to determine causes, identify potential interventions for prevention and understanding of the needs of those facing these events.

Procedures:

Participation in this study will involve an approximate 60-minute audiotaped interview.

Risks and Benefits:

Although this study will not benefit you personally, we hope that our results will add to the knowledge about how the health care system may better serve older adults.

You may experience some negative emotions by recalling your experiences. There are no physical risks associated with this study. Every effort will be made to keep your information confidential; however, this cannot be 100% guaranteed.

You may also become tired during the interview. If this is the case the interview will be stopped. If you are willing the interview could be continued at a later time.

Confidentiality:

All of your responses will be anonymous. Only the researchers involved in this study and those responsible for research oversight, such as representatives of the Yale University Human Research Protection Program, Yale University Human Subjects Committee and the research supervisors at Lancaster University, UK and Yale Medical School will have access to any information that could identify you. Your responses will be numbered and the code linking your number with your name will be stored in a separate locked file cabinet. In addition, the interview will be recorded using an encrypted recorder. Please note, however, that unlike information you provide to your doctor or lawyer, the researchers can be compelled by a court to disclose this information, that is if the data would have any value in court proceedings. When we publish any results from this study we will do so in a way that does not identify you unless we get your specific permission

to do so. We may also share the data with other researchers so that they can check the accuracy of our conclusions but will only do so if we are confident that your confidentiality is protected. Except as permitted by law, your health information will not be released in an identifiable form outside of the Yale University research team, and the collaborating research institution. Note, however, that your records may be reviewed by those responsible for the proper conduct of research such as the Yale University Human Research Protection Program, Yale University Human Subjects Committee or representatives of the U.S. Department of Health and Human Services.

Information may be re- disclosed if the recipients are not required by law to protect the privacy of the information. At the conclusions of this study, any identifying information related to your research participation will be destroyed, rendering the data anonymous. You will be asked to complete a separate HIPAA Research Authorization form 5032 (RAF).

Voluntary Participation:

Your participation in this study is voluntary. You are free to decline to participate, or to refuse to answer any individual question. You may withdraw from the study within 24 hours after the completion of the interview. Your identifying information will be removed within the first 24 hours after the interview. Thereafter, we will be unable to identify the interview as your own, as it will be anonymized .

Refusing to participate will involve no penalty or loss of benefits to which you are otherwise entitled or affect your relationship with Yale New Haven Hospital.

Your participation in this study is extremely valuable for our research, and we hope that participating will prove to be an educational experience for you.

Questions:

If you have any questions about this study, you may contact the researcher, Rebecca Gagne Henderson at at 203-867-8262, Rebecca.Gagnehenderson@ynhh.org

If you would like to talk with someone other than the researchers to discuss problems, concerns, and questions you may have concerning this research, or to discuss your rights as a research subject, you may contact the Yale Human Subjects Committee at (203) 785-4688 or the University of Lancaster Research Ethics Committee by emailing Diane Hopkins at d.hopkins@lancaster.ac.uk.

If, after you have signed this form you have any questions about your privacy rights, please contact the Yale Privacy Officer at 203-432-5919.

If you would like to talk with someone other than the researchers to discuss problems or concerns, to discuss situations in the event that a member of the research team is not available, or to discuss your rights as a research participant, you may contact the Yale University Human Subjects Committee, 203-785-4688, human.subjects@yale.edu. Additional information is available at <http://www.yale.edu/hrpp/participants/index.html>

Agreement to Participate:

I have read the above information, have had the opportunity to have any questions about this study answered and agree to participate in this study.

By checking this box I agree to have my interview audiotaped

(printed name)

(date)

(signature)

Appendix 10: Interview Guide

Each interview is anticipated to last 30 minutes. The maximum duration will be 40 minutes' dependent upon the participants' ability to continue and if there is more to discuss.

Interview 1: Comprehensibility

Objective: To allow the participant the opportunity to contextualize the history and experience of their failing health and the 30-day readmission.

Please tell me about the history of the illness prior this rehospitalization after your illness was diagnosed.

How has this illness affected your quality of life?

How has your condition affected your relationships?

Was this event expected.

Where has the patient resided, who the primary care giver has been.

Has anyone every asked you what your goals are regarding health care decisions?

Interview 2: Manageability

Objective: To assist the patient in describing the experience of the days after discharge leading to the rehospitalization.

Please tell me how you managed day to day after your last discharge.

Please tell me about your emotions after the discharge

When you left the hospital what were the instructions at discharge, who gave instructions?

How were the listening skills of the clinicians in the hospital?

What resources were available to you to help you manage the circumstances after discharge? (home health, PT, meals on wheels, etc)

Interview 3: Meaningfulness

Objective: To facilitate the participants' reflection of past and present experiences (interview one and two) and to explore their expectations for the future.

Please share with me what you think of the overall experiences regarding your illness up to this time.

What do you understand about what your physicians and nurses have told you about your illness and prognosis this hospitalization?

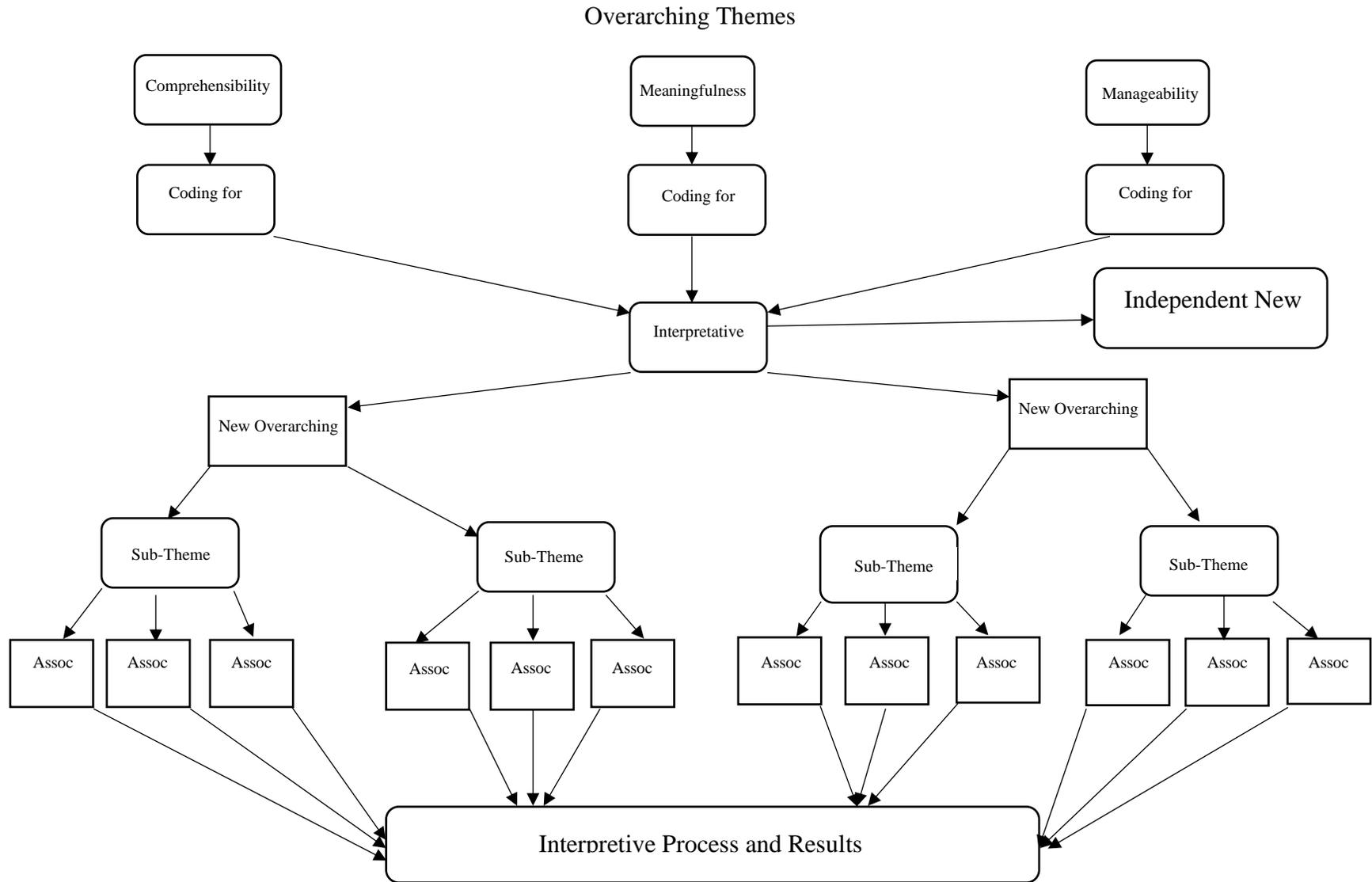
What do you think this means for you in the future?

Tell me about the quality of experiences regarding communication with your physician and nurses during this stay.

Appendix 11: Pro Forma

CODE # 1-10					
AGE					
ETHNICITY					
PLACE OF RESIDENCE					
Home Alone	Home PCG	Home Family	Home Family and PCG	Skilled Nursing	Assisted Living
UTILIZATION					
Hospitalization /12 months	# 30 day readmits 12 months	Adm/Date date of last discharge and new admit date	# Emergency visits in 12 months	Number of Comorbid Illnesses	Number of home prescriptions

Appendix 12: Analytic Process



Appendix 13: Yale IRB Protocol Application

 <p align="center"> YALE UNIVERSITY IRBs Application for Full or Expedited IRB Review of a Study Involving Human Participants in Social or Behavioral Science or Educational Research </p> <p align="center">100 FR 28 (2015-1)</p>

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Title of Research Project: Making Sense of 30-Day Readmissions: Experiences of Older Adults			
Principal Investigator: Rebecca Gagne Henderson APRN, ACHPN	Yale Academic Appointment: Yale School of Medicine, Palliative and End of Life Care Education, Faculty Yale School of Medicine, Program for Bioethics, Affiliated Faculty Yale School of Nursing, Complimentary Clinical Instructor		
Department: NEMG Palliative Care			
Campus Address: 1450 Chapel St. New Haven, CT 06511			
Campus Phone:	203-867-8262		E-mail: Rebecca.gagnehenderson@ynhh.org
Protocol Correspondent Name & Address (if different than PI):			
Campus Phone:		E-mail:	

Faculty Advisor: Jennifer Kapo, MD	Yale Academic Appointment: Associate Professor, Internal Medicine		
Campus Address: 333 Cedar St., LMP 1072, New Haven, CT 06510			
Campus Phone: 203 785 6977			E-mail: Jennifer.kapo@yale.edu

Investigator Interests:

Does the principal investigator, or do any research personnel who are responsible for the design, conduct or reporting of this project or any of their family members (spouse or dependent child) have an incentive or interest, financial or otherwise, that may affect the protection of the human participants involved in this project, the scientific objectivity of the research or its integrity? Note: The Principal Investigator (Project Director), upon consideration of the individual's role and degree of independence in carrying out the work, will determine who is responsible for the design, conduct, or reporting of the research.

See Disclosures and Management of Personal Interests in Human Research
<http://www.yale.edu/hrpp/policies/index.html#COI>

Yes No

Do you or does anyone on the research team who is determined by you to be responsible for the design, conduct or reporting of this research have any patent (sole right to make, use or sell an invention) or copyright (exclusive rights to an original work) interests related to this research protocol?

Yes No

If yes to either question above, list names of the investigator or responsible person: N/A

The Yale University Principal Investigator, all Yale University co-investigators, and all Yale University individuals who are responsible for the design, conduct or reporting of research must have a current financial disclosure form on file with the University's Conflict of Interest Office. Yale New Haven Hospital personnel who are listed as co-investigators on a protocol with a Yale University Principal Investigator must also have a current financial disclosure form on file with the University's Conflict of Interest Office. If this has not been done, the individual(s) should follow this link to the COI Office Website to complete the form: <http://www.yale.edu/coi/>

NOTE: The requirement for maintaining a current disclosure form on file with the University's Conflict of Interest Office extends primarily to Yale University and Yale-New Haven Hospital personnel. **Whether or not they are required to maintain a disclosure form with the University's Conflict of Interest Office, all investigators and individuals deemed otherwise responsible by the PI who are listed on the protocol are required to disclose to the PI any interests that are specific to this protocol.**

SECTION II: GENERAL INFORMATION

1. **Probable Duration of Project:**

Data Collection, follow-up and analysis is expected to be completed by December 31, 2019.

2. **Study location:**

Yale New Haven Hospital, SRC, 1450 Chapel Street, New Haven, CT 06511
Yale New Haven Hospital, YSC, 20 York Street, New Haven, CT 06510

3. **Help us categorize your research!** Are you using any of the following?

- Class Project
- Participant Observation
- Interviews
- Surveys
- Focus groups (study is not anonymous)
- Research in K-12 schools (submit a School Agreement form for the study)
- Deception (submit a Debriefing sheet)
- Audiotaping, videotaping or photography of individuals (study is not anonymous)
- Public viewing of videotapes or photographs
- Yale Psychology Pool (study does not qualify for exemption)
- International research sites (attach the International Checklist)
- Online (web-based) activities
- Social networks

SECTION III: FUNDING, RESEARCH TEAM AND TRAINING

Funding Source:

Self funded PhD thesis and research.

PI of grant (if applicable)	Title of Grant (if applicable)	Name of Funding Source (i.e. Dept name or Fellowship)	Funding type	Funding Mechanism
N/A			<input type="checkbox"/> Yale fellowship <input type="checkbox"/> Yale department <input type="checkbox"/> No funding (student projects, etc.) <input type="checkbox"/> Federal <input type="checkbox"/> State <input type="checkbox"/> Non Profit <input type="checkbox"/> Industry <input type="checkbox"/> Other For Profit <input type="checkbox"/> Other	<input type="checkbox"/> Grant: Yale Inst. # <input type="checkbox"/> Contract# <input type="checkbox"/> Contract Pending <input type="checkbox"/> Investigator/ Department Initiated <input type="checkbox"/> Sponsor Initiated <input type="checkbox"/> Other, Specify:

Research Team: List all members of the research team. Indicate under the affiliation column whether the investigators or study personnel are part of the Yale faculty or staff, or part of the faculty or staff from a collaborating institution, or are not formally affiliated with any institution.

ALL members of the research team MUST complete Human Subject Protection Training (HSPT) and Health Insurance Portability and Accountability Act (HIPAA) training (if applicable) before they may be listed on the protocol.

See NOTE below.

	Name	Affiliation: Yale/Other Institution (Identify)	Net ID
Principal Investigator	Rebecca Gagne Henderson, APRN, ACHPN	Yale School of Medicine, Palliative and End of Life Care Education, Faculty Yale School of Medicine, Program for Bioethics, Affiliated Faculty Yale School of Nursing, Clinical Instructor YNHH, SRC Palliative Manager Doctorate Student at Lancaster University, Observatory of End of Life Care	Rg493
Yale Faculty Advisor	Jennifer Kapo MD	Associate Professor, Internal Medicine, Chief Palliative Medicine, YNHH	Jmk94
Lancaster Faculty Advisor	Katherine Frogatt, PhD	Lecturer	n/a
Lancaster Faculty Advisor	Catherine Walshe, PhD	Lecturer	n/a

NOTE: The HSC will remove from the protocol any personnel who have not completed required training. A request to change study personnel will need to be submitted when training is completed.

SECTION IV: RESEARCH PLAN

1. Statement of Purpose:

Purpose

To explore the experiences of how older patients, make sense and meaning of being readmitted to an acute care hospital within 30-days of discharge from their last hospitalization.

Aims:

1. To assist the participants to express comprehensibility by describing the course and trajectory of their illness, and how their illness has affected the readmissions to the hospital, quality of life and relationships.
2. To identify the information shared with and resources provided to participants upon their last discharge to help the manageability of their condition outside of the hospital.
3. To elicit the participants' descriptions of the past hospital admission and present 30-day readmission, and to share the meaning of these experiences and how they may affect the future.

Research Question:

How do older adults describe meaningfulness, comprehensibility and manageability during the period of time leading to a 30-Day acute hospital readmission?

What are potential explanations for 30-day readmissions for participants.

2. Background:**Prevalence and Economics**

Over the past ten years there has been increasing attention paid to early re-hospitalizations for some patients that are high utilizers of medical resources. In 2010, as part of the Affordable Care Act (ACA) the Center for Medicare and Medicaid Services (CMS) began to study the ramifications of early readmissions upon payers. In 2012, CMS initiated the Rehospitalization Reduction Program (HRRP) (Centers for Medicare and Medicaid Services, 2016). This program penalizes hospitals up to 3% of their total annual CMS reimbursements for a pre-prescribed percentage level of patients readmitted within 30 days of discharge from an acute care hospital which is deemed unacceptable to CMS. Also, for any CMS benefitted patient readmitted within 30-days of discharge there is no reimbursement for that hospital stay.

Older adults, aged 65 and older, comprise over 12% of these 30-day readmissions. These are the sickest patients and we know that this population drives more than half of all health care costs in the United States (Meier, 2015). The risk for an early readmission increases with age. With the anticipation of a population of aging baby boomers over the age of 65 years reaching 61 million by the year 2030 it is necessary the health care system address the problem of early readmissions (Knickman, 2002).

The prevalence of 30-day readmissions for elderly people has increased over the last two decades. In the year 2000 in the U.S.A. the 30-day readmission rate for this population was 18.2%. Just six years later, in 2006, this number increased to 23.5% (Yoo et al., 2015).

The personal cost to older adults and their loved ones is immeasurable in terms of loss of quality time with family, inconvenience and suffering.

Demographics and Systemic Issues

There is an intermingling of systemic issues contributing to 30-day readmissions related to insurance, access and utilization of services, as well as disease burden, socioeconomic class and ethnicity.

Advanced age is an indicator for early readmission (Bjorvatn, 2013). There is a levelling off of this increased rate by the age of 75 years (Bjorvatn, 2013; Garcia-Perez et al., 2011; Robinson & Kerse, 2012). It is difficult to determine why this may be the case, as the available data are quantitative. These data only measure the risk of 30-day readmission, but fail to reveal why this is the case.

Being female has been found to be a determining factor in placing an individual at risk for readmission (Goldenheim et al., 2014; Navarro et al., 2012). In a study of readmissions of home hospice patients, it was found that 74.6% were female (Goldenheim et al., 2014).

Increased utilization of healthcare services may put this population at risk for a readmission. One study found that patients seeing a geriatrician had an odds ratio of 1.01 of being readmitted (Pugh et al., 2014). It was also found that patients newly admitted to

hospice had a 2.35 hazard ratio of being readmitted should they be in contact by phone with a primary provider (Goldenheim et al., 2014).

Another significant systematic factor is the location of the patient after discharge from the hospital (Bjorvatn, 2013; Bogaisky & Dezieck, 2015; Hain et al., 2012; Islam et al., 2014; Navarro et al., 2012). Patients who were residents of a SNF in Denmark were at a 41% higher risk for a 30-day readmission than patients living at home (Bogaisky & Dezieck, 2015). These findings are similar to those found in the U.S.A where one study had the exact same result of 41% (Hain et al., 2012). Another study found the rate of readmissions at 32.8% for SNF patients (Navarro et al., 2012).

Navarro et al. (2012) found that readmission from home was higher at 39.1%.

A greater number of results from the literature found long length of stays (LOS) to be a risk factor for a readmission (Garcia-Perez et al., 2011; Islam et al., 2014; Morandi et al., 2013; Pavon et al., 2014; Yoo et al., 2015).

Disease Processes, Comorbidities and Frailty Characteristics

The literature shows a great deal of consensus regarding illnesses that are analogous with 30-day readmissions. Overall, the most common diagnoses related to early readmissions are congestive heart disease (CHF) and other cardiac issues (Albrecht et al., 2014; Cabre et al., 2014; Fisher et al., 2013; Yoo et al., 2015) followed by Chronic Obstructive Pulmonary Disease (COPD) and respiratory disease (Bjorvatn, 2013; Navarro et al., 2012; Yoo et al., 2015).

Pugh et al. (2014) examined the risk of frailty indicators. Pugh et al. (2014) concluded the best way to identify patients at risk of 30-day readmissions was frailty related diagnosis or markers. The study found 38.4% of older adults who had a 30-day were admitted with a diagnosis associated with frailty.

Most of these patients have symptoms and conditions that could be better managed in their own homes or residences (Meier, 2015).

Gaps in Knowledge

There is a paucity of evidence regarding the populations experiences regarding 30-day readmissions. Understanding the perspective of older adults experience of 30-day readmissions may lead to better interventions and policy to improve outcomes. In addition, quantitative data found in the literature cannot measure nor describe the amount of stress and suffering readmissions cause the older adult and their family.

There are many articles on the characteristics of this population and many evaluations of interventions. These interventions have been developed, implemented and evaluated without any qualitative data reflecting the patients perceived needs. Asking older adults what they have experienced, feel and need regarding 30-day readmissions may prove valuable.

Theoretical Framework

A priori theoretical concepts will be used to guide the study. How these concepts relate to this study will be explained further in the methodology section. This will allow the gathering data which will be useful to answer the research question. This theory was chosen

to explore the participants' strengths and needs through their own words to help prevent 30-day readmissions.

Antonovsky (1979) created the Salutogenic Model and defines salutogenesis as an individual's persistent feeling that the world is predictable and that things will turn out as best as possible in consideration of the circumstances. Antonovsky acknowledges that health is only one part of well-being which includes the ability to cope, adapt, be creative and feel productive within a society.

These abilities have not been assessed in previous studies regarding the 30-day readmissions of older adults, but may shed light on the needs not yet identified to help this population.

The salutogenic model includes several concepts which require explanation. The pertinent concepts to the model are: salutogenesis, sense of coherence (SOC), meaningfulness, comprehensibility and manageability. Of these, three concepts will serve as the theoretical framework for the study and interview structure.

- ï Comprehensibility – the extent to which one perceives the stimuli that confront deriving from the internal and external environments, as making cognitive sense, as information that is ordered, consistent, structured, and clear, rather than as noise—chaotic, disordered, random, accidental, and inexplicable (Antonovsky, 1979)

- ï Manageability—the extent to which one perceives that resources that are at one’s disposal are adequate to meet the demand posed by the stimuli that bombard one. (Antonovsky, 1987)

- ï Meaningfulness—the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement, and are challenges that are “welcome” rather than burdens that one would much rather do without. This does not mean that someone with a high sense of meaningfulness is happy about the death of a loved one, the need to undergo a serious operation, or being fired, but rather that when these unhappy experiences are imposed on such a person, he or she will willingly take up the challenge, will be determined to seek meaning in it, and will do his or her best to overcome it with dignity (Antonovsky, 1979).

These concepts and construct will guide the exploration of how older adults make sense of 30-day readmissions through the interview.

Research Plan:

Methodology

Interpretive Description will be used to study older adults’ self-described experiences of their health decline, the period of time between their last discharge and the current hospitalization (Thorne, 1997, 2008; Thorne et al., 2004). The decision to use interpretive description is based upon the method’s flexibility in approach. This method allows the researcher to design a study which will best answer the question being asked in a manner which will further knowledge leading towards pragmatic solutions. Interpretive description

refers to a “logic design”, which is the use of varying methods for each step of the study design. It allows the use of “logic derived from the disciplinary orientation” of the researcher to explore the issue and discipline while designing the study. Thorne (2008) acknowledges clinical disciplines ask questions which are unique to their practice and require pragmatic and practical answers to clinical problems. This allows the researcher to enter into questioning and analysis of the data that will increase insight and possibly generate ways to apply the newly gained evidence to improve conditions for the participant through practice (Thorne, 2008; Thorne et al., 2004). The phenomenon being examined in this research is highly complex. This is why an approach allowing the “interplay” of a patient’s physiological, socio-demographic and psychosocial aspects is necessary to achieve a holistic interpretation of the patients understanding of the manageability, comprehensibility and meaning of the experience.

Most importantly the interpretive description approach to analysis and description of findings is meant to answer questions regarding phenomenon that will allow the development of solutions to problems which are clinically based.

Participant Population: The population to be examined will be older adults aged 65 years and older who are readmitted within 30 days of their last acute hospital discharge to Yale New Haven Hospital’s (YNHH) Saint Raphael (SRC) and York Street (YSC) campuses. These two campuses were selected after a Joint Data Analytics Team (JDAT) report revealed the two campuses had the highest and comparable numbers of patients meeting the study criteria for the health system (16 – 16.3%).

3. **Describe how access to the population will be gained in this study:**

Purposeful sampling will be adopted using the criteria. The researcher will use a daily report prepared by the hospital's JDAT. The JDAT report will identify all older adults readmitted to the hospital who meet inclusion criteria. Due to time constraints not all patients will be recruited, as the researcher will not be available on all days. The JDAT daily report will include the following identifying data: Age >65 years, patient name, MRN, bed location, 30-day readmission this hospital stay. The potential participants identified who meet criteria and included will be approached by a social worker or nurse familiar with the study. Should the potential participant express interest in learning more about the study the researcher will introduce themselves to the participant to determine participant capacity (Appendix 1), review the participant information sheet (Appendix 2), and the consent form (Appendix 3). After the patient is given time to read the information sheet and consider participation, and should the potential participant agree they will sign the consent form (Appendix 3), which includes consent for audiotaping the interview and HIPAA release to become a participant in the study and an appointment will be made to begin the interview.

4. **Participant classification:** Check off all classifications of participants that will be specifically recruited for enrollment in the research project. Will participants who may require additional safeguards or other considerations be enrolled in the study? If so, identify the population of participants requiring special safeguards and provide a justification for their involvement.

Children Healthy Non-English Speaking Prisoners

Economically disadvantaged

Decisionally Impaired Employees Pregnant women

Yale Students

X Other vulnerable population: Many of the participants will be severely debilitated and potentially near the end of life.

Psychology Pool

NOTE: Is this research proposal designed to enroll children who are wards of the state as potential participants? Yes X No (If yes, see [HRPP Policy 310.4](#) for further requirements)

5. Inclusion/Exclusion Criteria:

Inclusion Criteria

- i ≥ 65 years of age
- i Readmitted to the hospital within 30 days of their last hospital discharge
- i English speaking
- i Possesses capacity as described in HRPP Policy 340 (Appendix 1)

Exclusion Criteria

- i Observational Status – Patient's who return to the hospital may be kept in the hospital for observation rather than a formal admission.

SECTION V: RECRUITMENT/CONSENT AND ASSENT PROCEDURES

1. Recruitment Procedures:

Are you collecting any information about the individuals prior to their signing a consent form? Yes No

The location in the hospital and name of the potential participant will be collected from EPIC. If the patient assents from the study their name and location in the hospital will be disposed of in compliance with HIPAA regulations.

2. Indicate recruitment methods below. Attach copies of any recruitment materials that will be used.

- Flyers
- Internet/Web Postings
- Radio
- Posters
- Mass E-mail Solicitation
- Telephone
- Letter
- Departmental/Center Website
- Television
- Newspaper
- Through local NGO or other local contact
- Social Media (Facebook, Twitter)
- Classroom recruitment
- Table set-up / in-person recruitment of public
- Snowball sampling
- Other (describe): Screening

3. Targeted Enrollment: Give the number of participants:

- a. Targeted for enrollment at Yale for this protocol: a minimum of 15 interviews and a maximum of 25 interviews.
- b. If this is a multi-site study, give the total number of participants targeted across all sites NA_

4. How was this estimate derived?

The members of this population will all have experienced a 30-day readmission. Due to the intricacy of the event it is anticipated there will be a great deal of rich data collected requiring intense analysis. The goal is to complete a minimum of interviewing 15 participants with a maximum of 30 interviews. It is expected that this sample will be adequate to determine patterns and begin understanding the experiences of this population. It is acknowledged that this qualitative study could not capture all aspects of the phenomenon of a 30-day readmission, nor will it lend itself to generalization beyond the population in this hospital's catchment area (Siedman, 2013; Silverman, 2010). It is a starting point of learning the aspects of 30-day readmissions yet to be discovered.

5. Consent Personnel:

Rebecca Gagne Henderson APRN, ACHPN, PI

6. Process of Consent/Assent (*NOTE: When a study includes minors, parent provide permission [not consent] for the child's participation, and the child provides assent for participation*)

After IRB approval a daily JDAT report will be used to screen newly admitted patients to determine if they meet the age and readmission status criteria using purposeful sampling (Siedman, 2013; Silverman, 2010). Should the potential participant meet these criteria a social worker or nurse familiar with the study will approach the patient. If the potential participant expresses interest the PI will determine capacity (Appendix 1), provide the study information sheet (Appendix 2) and describe the study. The potential participant will be given time to consider committing to the study. This time period will vary by participant. Should the individual agree to participate a consent form for participation in the study and to be audiotaped (Appendix 3) and a HIPPA release (Appendix 4) will be signed by the participant and PI. The first interview will be scheduled should the participant agree.

The participant will be able to withdraw from the study until the time of coding and anonymizing the interview. This will occur within 24 hours of the interview.

- 7. Evaluation of Participant(s) Capacity to Provide Informed Consent/Assent:** Indicate how the personnel obtaining consent will assess the potential participant's ability and capacity to consent to the research being proposed, if applicable

The PI will assess for participant capacity in conformity with HRPP Policy 340 (Appendix 1). As the research is of minimal risk the PI will briefly converse with the potential participant by determining the following:

- ï Ability to communicate a reasoned choice regarding participation;
- ï Ability to understand relevant information about the study, including consequences of participation for the participant's own situation (such as health condition) and consequences of the alternatives to participation;
- ï Ability to comprehend the nature of the situation and its likely consequences; and
- ï Ability to manipulate information rationally.

8. Documentation of Consent/Assent: Specify the documents or verbal scripts that will be used during the consent/assent process. Copies of all documents should be appended to the protocol, in the same format that they will be given or spoken to participants.

Please find the capacity policy (Appendix 1), patient information sheet (Appendix 2), consent form/audiotaping/HIPAA release (Appendix 3), Pro forma (Appendix 4) and Interview guide (Appendix 5) attached to the protocol as appendices.

9. Non-English Speaking Participants:

The study is limited to English speaking participants. The PI only speaks English and as the study is a self-funded PhD thesis there are no resources to provide interpreters.

10. Are any of the study procedures likely to yield information subject to mandatory reporting requirements?

There is the potential that the study may encounter revelation of elder abuse. Should this be the case the PI will report the circumstance and make a referral to the hospital MSW as

well as notifying the IRB of the incident. In addition, any revelation of any reportable incident will be reported.

11. Consent/Consent Waiver: In certain circumstances, the IRB may grant a waiver of documentation of consent, or a full waiver of consent, depending on the study. If you will request either a waiver of consent, or a waiver of signed consent for this study, complete the appropriate section below.

I plan to obtain signed consent

I plan to obtain verbal or online consent

I plan to obtain signed consent for part of the study, and verbal or online consent for another part of the study.

I do not plan on obtaining consent due to the nature of the study (explain):

SECTION VI: PROTECTION OF RESEARCH PARTICIPANTS

Confidentiality & Security of Data:

1. What participant information will you be collecting?

In addition to the below mentioned information the participant will be asked to share details of their personal lives in an interview. Also, please the attached pro forma (Appendix 4).

The data referenced in item 2 will be secured until the data has been collected. The identity of the participant will be coded to protect privacy. Once data is collected the identifiers will be disposed of in compliance with HIPAA regulations.

Audio tapes will be stored in a locked file cabinet in a locked office. Interview transcriptions will be stored on a password protected laptop with encrypted software.

2. Will any of the following identifiers be collected?

Names

All geographic subdivisions smaller than a State, including: street address, city, county, precinct, zip codes

Telephone numbers

Fax numbers

E-mail addresses

Social Security numbers

Medical record numbers

Health plan beneficiary numbers

Account numbers

All elements of dates (except year) for dates related to an individual, including: birth date, admission date, discharge date, date of death, all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older

Certificate/license numbers

Vehicle identifiers and serial numbers, including license plate numbers

- Device identifiers and serial numbers
- Web Universal Resource Locators (URLs)
- Internet Protocol (IP) address numbers
- Biometric identifiers, including finger and voiceprints
- Full face photographic images and any comparable images
- Any other unique identifying numbers, characteristics, or codes

These identifiers will be used for screening and will be disposed of after the interview is coded on the pro forma (Appendix 6)

Other potentially identifying information to be collected:

- X Audiotapes
- Videotapes
- Faces (focus groups, photographs or other way that an individual would be physically recognized)
- Potential for identification from the bulk of the information, even if direct identifiers are not collected (deductive disclosure).

3. If applicable, what methods and procedures will be used to safeguard the confidentiality and security of the identifiable study data and the storage media indicated above during and after the participant's participation in the study?

Do all portable devices contain encryption software? X Yes No

4. How will the research data be collected, recorded and stored?

Audio recordings will be stored in a locked cabinet in a locked office.

5. How will the digital data be stored?

CD DVD Flash Drive Portable Hard Drive

Secured Server Laptop Computer Desktop Computer

Audiotaping Videotaping Handwritten notes

Other: The data will also be backed up by the Lancaster University server.

6. If applicable, how will transfer of data to Yale be completed? What will be done with the data when the research is completed? Are there plans to destroy the identifiable data or the link to personal identifiers? If yes, describe how, by whom and when identifiers will be destroyed. If no, describe how the data and/or identifiers will be secured.

No. Interview data (audiotapes, transcripts) will be destroyed by the PI 10 years after the study is complete in compliance with HIPAA procedures. The data will be maintained for 10 years as required by the UK and Lancaster University protocol.

7. Will a Certificate of [Confidentiality](#) be needed? (*See also the NIH Certificate of Confidentiality Kiosk, <http://grants.nih.gov/grants/policy/coc/index.htm>*)

No

SECTION VII: POTENTIAL RISKS AND BENEFITS

1. **Risks:** Describe the reasonably foreseeable risks, including risks to participant privacy, discomforts, or inconveniences associated with participants participating in the research.
Note: All studies have the potential for risk, if not physical, there may be psychological, reputational, or financial risks or risks to breach of confidentiality.

Participants will be asked to recall experiences that may be emotionally painful, such as loss of function, grief or loss of independence. Also, participants may be comprised of members of a vulnerable populations of older frail adults who may be at risk of fatigue during interviewing.

Minimizing Risks: Describe the manner in which the above-mentioned risks will be minimized.

The population described for this study are likely vulnerable due to conditions of frailty, potential end stage disease and comorbidities. These conditions may affect the stamina of the participants to endure long, in-depth interviews due to fatigue. Steps will be taken to protect participants. The interviews will be approximately 60 minutes in duration. The researcher will ask the participant if they are able to continue should the participant shows signs of fatigue. If the participant feels tired the interview will be postponed and continued at a later time.

In addition to fatigue the participant will be asked about experiences which may be uncomfortable for the patient to recall. The researcher is a skilled interviewer who is able to discern when patients have discomfort with a topic. The researcher will stop the

interview should the participant become upset and will ask frequently during the interview about the participant's comfort level. If the participant says they feel upset, they will be reminded that they may discontinue at anytime.

In addition, this protocol presents minimal risks to the subjects and Unanticipated Problems Involving Risks to Subjects or Others (UPIRSOs), including adverse events, are not anticipated. In the unlikely event that such occur, Reportable Events (which are events that are serious or life-threatening and unanticipated (or anticipated but occurring with a greater frequency than expected) and possibly, probably, or definitely related) or Unanticipated Problems Involving Risks to Subjects or Others that may require a temporary or permanent interruption of study activities will be reported immediately (if possible), followed by a written report within 5 calendar days of the Principal Investigator becoming aware of the event to the IRB (using the appropriate forms from the website) and any appropriate funding and regulatory agencies. The investigator will apprise fellow investigators and study personnel of all UPIRSOs and adverse events that occur during the conduct of this research project. The PI will notify Yale and Lancaster faculty, the IRB and the by email. The protocol's research monitors, which are comprised of the Yale and Lancaster University faculty and Yale's Data and Safety Monitoring Committee (DSMC) will be informed of any adverse event in which the participant becomes agitated or distraught resulting in withdrawal from the study, requiring medication or counseling within 5 days of the event becoming known to the principal investigator.

Potential reportable events may include a participant becoming violent, or agitated to the point of requiring medication.

2. Data and Safety Monitoring Plan: *All studies require the inclusion of a Data and Safety Monitoring Plan (DSMP) with an explicit statement of overall risks (e.g., minimal, greater than minimal/moderate, or high), a means to address attribution and grading of adverse events and a description of procedures for monitoring the ongoing progress of the research and reporting adverse events. The Data and Safety Monitoring Plan should describe how the principal investigator intends to provide ongoing supervision and evaluation of the activities of the study including whether appropriate progress is being made. It should document the procedures and means to protect the welfare and safety of subjects and protect the integrity of the data.*

The plan must include provisions for data review and performance of safety reviews, at a specified frequency, as well as the plan for reporting to the HSC and/or other internal or external organizations. When participating in a multi-site study, the Yale principal investigator must indicate how safety reports and/or reporting of serious adverse events from other sites will be provided to the Yale HSC.

Include an appropriate Data and Safety Monitoring Plan (DSMP) based on the investigator's risk assessment stated below. (Note: the HSC will make the final determination of the risk to subjects.).

- a. What is your assessment of the overall risk level for subjects participating in this study?

Minimal Risk:

- ï participant may become fatigued easily

- i participant may recall frightening, sad or traumatic events
- b. If children are involved, what is your assessment of the overall risk level for the children participating in this study?

N/A
- c. **Copy, paste, and then tailor an appropriate Data and Safety Monitoring Plan from <http://www.yale.edu/hrpp/forms-templates/biomedical.html> for**

Minimal Risk DSMP

The principal investigator is responsible for monitoring the data, assuring protocol compliance, and conducting the safety reviews at the specified frequency of once quarterly. The review will be conducted by the PI under the supervision of the Yale faculty and Lancaster University faculty.

During the review process the principal investigator will evaluate whether the study should continue unchanged, require modification/amendment, or close to enrollment.

The principal investigator, the Institutional Review Board (IRB) or the International Observatory of End of Life Care at Lancaster University and the Safety Monitoring Committee (DSMC)] have the authority to stop or suspend the study or require modifications.

This protocol presents minimal risks to the subjects and Unanticipated Problems Involving Risks to Subjects or Others (UPIRSOs), including adverse events, are not anticipated. In the unlikely event that such events occur, Reportable Events (which are events that are serious or life-threatening and unanticipated (or anticipated but occurring with a greater frequency than expected)

and possibly, probably, or definitely related) or Unanticipated Problems Involving Risks to Subjects or Others that may require a temporary or permanent interruption of study activities will be reported immediately (if possible), followed by a written report within 5 calendar days of the Principal Investigator becoming aware of the event to the IRB (using the appropriate forms from the website) and any appropriate funding and regulatory agencies. The investigator will apprise fellow investigators and study personnel of all UPIRSOs and adverse events that occur during the conduct of this research project. The PI will notify Yale and Lancaster faculty, the IRB and the DSMC by email. The protocol's research monitors, which are comprised of the Yale and Lancaster University faculty and DSMC will be informed of any adverse event in which the participant becomes agitated or distraught resulting in withdrawal from the study, requiring medication or counseling within 5 days of the event becoming known to the principal investigator.

a. For multi-site studies for which the Yale PI serves as the lead investigator: N/A

1. **Potential Benefits:** Identify any benefits that may be reasonably expected to result from the research, either to the participant(s) or to society at large. (*Payment of participants is not considered a benefit in this context of the risk benefit assessment.*)

Better understanding of this populations experiences, thoughts and perceptions regarding causes of 30-day readmissions may result in better interventions and greater support for this population.

This may lead to better patient outcomes and higher quality of life for this population.

SECTION VIII: RESEARCH ALTERNATIVES AND ECONOMIC

1. **Alternatives:** What other alternatives, if any, are available to the study participants outside of the research?

N/A

2. **Payments for Participation (Economic Considerations):** Describe any payments that will be made to participants, if any, the amount and timing of payments and the conditions for receiving this compensation (if applicable). If you plan to hold a drawing, be sure to include the following on any consent or recruitment materials mentioning the lottery: 1) the value of the prize; 2) the sponsor of the prize (this cannot be a federal funding source); 3) the odds of winning; 4) that there are no restrictions to winning.

N/A

3. **Costs for Participation (Economic Considerations):** Clearly describe the participant's costs associated with participation in the research, if any, and the interventions or procedures of the study that will be provided at no cost to participants.

N/A

SECTION IX: PRINCIPAL INVESTIGATOR AGREEMENT

As the **principal investigator** of this research project, I certify that:

- The information provided in this application is complete and accurate.
- I assume full responsibility for the protection of human participants and the proper conduct of the research.
- Subject safety will be of paramount concern, and every effort will be made to protect participants' rights and welfare.
- The research will be performed according to ethical principles and in compliance with all federal, State and local laws, as well as institutional regulations and policies regarding the protection of human participants.
- All members of the research team will be kept apprised of research goals.
- I will obtain approval for this research study and any subsequent revisions prior to my initiating the study or any change and I will obtain continuing approval of this study prior to the expiration date of any approval period or submit a request to close the study prior to its expiration..
- I will report to the HSC any unanticipated problems involving risk to participants.
- I am in compliance with the requirements set by the University and qualify to serve as the principal investigator of this project or I have a faculty advisor.
- I will identify a qualified successor should I cease my role as principal investigator and facilitate a smooth transfer of investigator responsibilities, if applicable

PI Name (PRINT)

Date

Signature

SECTION X: FACULTY ADVISOR AGREEMENT

As the **faculty advisor** of this research project, I certify that:

- The information provided in this application is complete and accurate.
- This project has scientific value and merit and that the student or trainee investigator has the necessary resources to complete the project and achieve the aims.
- I will train the student investigator in matters of appropriate research compliance, protection of human subjects and proper conduct of research.
- The research will be performed according to ethical principles and in compliance with all federal, state and local laws, as well as institutional regulations and policies regarding the protection of human subjects.
- The student investigator will obtain approval for this research study and any subsequent revisions prior to initiating the study or revision and will obtain continuing approval prior to the expiration of any approval period.
- The student investigator will report to the HIC any serious injuries and/or other unanticipated problems involving risk to participants.
- I am in compliance with the requirements set forth by the [University](#) and qualify to serve as the faculty advisor of this project.
- I assume all of the roles and responsibilities of a Principal Investigator even though the student may be called a PI.

Jennifer Kapo MD

Advisor Name (PRINT)

Date

Signature

Katherine Froggatt, Phd

Advisor Name (PRINT)

Date

Signature

Catherine Walshe, PhD

Advisor Name (PRINT)

Date

Signature

For School of Medicine Applications only:A

SECTION XI: DEPARTMENT CHAIR'S ASSURANCE STATEMENT

Do you know of any real or apparent institutional conflict of interest (e.g., Yale ownership of a sponsoring company, patents, licensure) associated with this research project?

Yes (provide a description of that interest in a separate letter addressed to the HIC.)

No

As Chair, do you have any real or apparent protocol-specific conflict of interest between yourself and the sponsor of the research project, or its competitor or any interest in any intervention and/or method tested in the project that might compromise this research project?

Yes (provide a description of that interest in a separate letter addressed to the HIC)

No

I assure the HIC that the principal investigator and all members of the research team are qualified by education, training, licensure and/or experience to assume participation in the conduct of this research trial. I also assure that the principal investigator has departmental support and sufficient resources to conduct this trial appropriately.

Chair Name (PRINT) and Signature

Date

Department

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Appendices

Appendix 1: **Assessment of Capacity to Consent**

Appendix 2: **Participant and Information Sheet**

Appendix 3: **Consent for Participation in a Research Project/Audiotaping/HIPAA**

Appendix 4: **Demographic Pro Forma**

Appendix 5: **Interview Guide**

Appendix 14: Yale Letter of Approval

Yale University *Institutional Review Board* *Telephone: 203-785-4688*
150 Munson St 3rd Floor *Fax: 203-785-2847*
P.O. Box 208327
New Haven CT, 06520-8327 *<http://www.yale.edu/hrpp>*

To: Rebecca Gagne Henderson
From: **Yale University Institutional Review Board**
Date: 09/23/2016
HIC/HSC Protocol#: 1608018304
Study Title: Making Sense of 30-Day Readmissions: Experiences of Older Adults
Submission Type: **Response to Revisions Requested for Initial Protocol Approval**
IRB Action **Expedited Approval**
Approval Date: 09/23/2016
Expiration Date: 09/22/2017

The IRB has reviewed your response to the specific minor revisions requested of you via expedited review for the above mentioned amendment.

The IRB has determined that these revisions satisfy the request and therefore approves this research protocol. This review meets approval criteria set forth in 45 CFR 46.111. The approval of this protocol is considered valid through the Expiration Date noted above.

Review Comments:

- The HSC has determined that this protocol presents minimal risk to subjects.
- The Committee finds that informed consent can be waived for this study for recruitment purposes only per federal regulation 45 CFR 46.116(d). This part of the regulations states that 1) this research involves no more than minimal risk to the subjects, 2) the waiver or alteration will not adversely affect the rights and welfare of the subjects, 3) the research could not practicably be carried out without the waiver and 4) whenever appropriate the subjects will be provided with additional pertinent information after participation.
- A HIPAA waiver has been approved via expedited IRB review for [access to and] use of PHI listed in the enclosed application for recruitment purposes only. The IRB finds that the use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals, based on (1) an adequate plan to protect the identifiers from improper use and disclosure; (2) an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law; and (3) adequate written assurances that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of protected health information would be permitted by this subpart; The IRB also finds that the research could not practicably be conducted without the waiver or alteration; and the research could not practicably be conducted without access to and use of the protected health information. HIPAA regulations require that accounting logs be maintained when researchers access

patient records under a waiver of authorization including those approved for recruitment purposes. You are thereby reminded of your obligation to create the log. For further information on maintaining logs and on the accounting of disclosures, please see hipaa.yale.edu.

- Please be advised that Yale-New Haven Hospital and Yale Medical Group have implemented a new reporting request process. Requests for medical records should be made through JDAT as described at <http://medicine.yale.edu/ycci/oncore/availableservices/datarequests/datarequests.aspx>. YNHH and Yale University consider it a violation of patient privacy for research personnel to review medical records of patients who have opted out of research use of their records. All record review requests should therefore be through JDAT.
- The HSC acknowledges that IRB approval is being sought at University of Lancaster. The PI is reminded to submit a copy of the IRB approval to the Yale HSC once received.
- The HSC acknowledges receipt of and approves the following documents: HSC protocol application, informed consent form, HIPAA Research Authorization Form and information sheet.
- The HSC acknowledges receipt and review of the following documents: Demographic Pro Forma, interview guide, research proposal, scanned signature pages (2) and training certificates for PI (7).

Amendments: If you wish to change any aspect of this study, such as the study procedures or processes, the informed consent document(s), recruitment activities, or wish to add or remove investigators or key study personnel, you must communicate your requested changes to the IRB using the appropriate form located at <http://www.yale.edu/hrpp>. Any changes must be approved by the IRB prior to implementation.

Request for Reapproval: It is the investigator's responsibility to obtain reapproval of ongoing research prior to the Expiration Date. Please submit the request for reapproval form at least two months prior to the expiration date to allow for reapproval processing and review.

*Should the research activities no longer involve human participants and you are only conducting data analysis of de-identified data (with no link to identifiers), IRB approval is no longer required. However, the IRB does require notification via submission of a closure form.

Request to Close: When the study procedures and the data analysis of identifiable data are fully complete, the Request to Close form must be completed and sent to the IRB requesting that the study be closed. Investigators should attach a copy of the study findings. Abstracts or publications satisfy this findings requirement.

Adverse Events/UPIRSOs: Serious, unanticipated, and related adverse events, and unanticipated problems involving risk to subjects or others must be reported generally within 5 days of the PI becoming aware of the event (see Policy 710: Reporting Unanticipated Problems Involving Risks to Subjects or Others, including Adverse Events).

Please keep this memo with your copy of the approved protocol documents.

Appendix 15: FHMREC Letter of Approval



Applicant: Rebecca Gagne Henderson

Supervisor: Catherine Walshe

Department: Health Research

FHMREC Reference: FHMREC16

17 October 2016

Dear Rebecca

Re: Making Sense of 30-Day Readmissions: Experiences of Older Adults

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

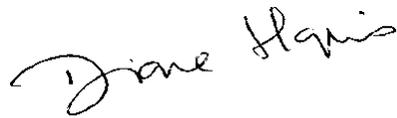
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins". The signature is written in a cursive style with a large initial 'D'.

Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 16: Full List of Codes

ATLAS.ti Report

Older Adults and 30 day readmissions

Codes

Report created by Joseph Henderson on Jan 19, 2020

○ **30-day readmission**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

○ **acceptance**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **Active Life Style**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

○ **activities of daily living**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

○ **acute illness**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **adding resources**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **adequate resources**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **adherence**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **adjusting**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **ADL**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

- **advocate**

Created: 3/12/18 by Joseph Henderson, **Modified:** 3/12/18 by Joseph Henderson

- **after discharge**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **after life**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **alone sometimes**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **ama**

Created: 9/13/18 by Joseph Henderson, **Modified:** 9/13/18 by Joseph Henderson

- **ambulance**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **ambulation**

Created: 5/25/17 by Joseph Henderson, **Modified:** 5/25/17 by Joseph Henderson

- **amputation**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **anger**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **anguish**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **anticipatory loss**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **artificial life support**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **assisted living**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **attitude**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **avoidable**

Created: 3/27/18 by Joseph Henderson, **Modified:** 3/27/18 by Joseph Henderson

- **avoidance**

Created: 1/30/18 by Joseph Henderson, **Modified:** 5/24/19 by Joseph Henderson

- **bad choices**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **baseline change**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **bed ridden**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **Being Cared for/Support**

Created: 4/20/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

○ **bereavement**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

○ **better care**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **big picture comprehension**

Created: 5/20/19 by Joseph Henderson, **Modified:** 5/20/19 by Joseph Henderson

○ **Big Picture Conversation, unclear**

Created: 2/4/19 by Joseph Henderson, **Modified:** 2/4/19 by Joseph Henderson

○ **Blame/Guilt**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

○ **blessed**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **bravado**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

○ **Burden to others**

Created: 11/29/17 by Joseph Henderson, **Modified:** 11/29/17 by Joseph Henderson

○ **Burdent to me**

Created: 11/29/17 by Joseph Henderson, **Modified:** 11/29/17 by Joseph Henderson

○ **can't remember**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **caregiver illness**

Created: 8/16/18 by Joseph Henderson, **Modified:** 8/16/18 by Joseph Henderson

- **Caregiving**

Created: 5/25/17 by Joseph Henderson, **Modified:** 5/25/17 by Joseph Henderson

- **Caring/supporting others**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **changing provider**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **Changing Treatments**

Created: 5/13/17 by Joseph Henderson, **Modified:** 5/13/17 by Joseph Henderson

- **choices**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **clinical relationship/trust**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **CNA**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **code status**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **comfort**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **Communication in health care system**

Created: 4/23/17 by Joseph Henderson, **Modified:** 8/2/18 by Joseph Henderson

- **communication with nurses - inadequate.**

Created: 3/24/18 by Joseph Henderson, **Modified:** 3/24/18 by Joseph Henderson

- **communication with provider - inadequate**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **comp vs incomp**

Created: 9/13/18 by Joseph Henderson, **Modified:** 9/13/18 by Joseph Henderson

- **companionship**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **Comprehensibility**

Created: 4/20/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

Comment:

8-1-18 I had coded any thing regarding the patient's understanding of their circumstances as comprehensibility. After analyzing for awhile began to notice that this code needed to be divided into Comprehensibility and Incomprehensibility.

While some may describe their functionality they have little to no insight of what this means in the big picture.

- **Comprehensibility vs incomprehensibility**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Condition Changes/Set Back**

Created: 5/13/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

Comment:

Researcher could have listened more, allowed patient to expand upon "that's enough for me"

- **confusion/delerium**

Created: 11/29/17 by Joseph Henderson, **Modified:** 11/29/17 by Joseph Henderson

- **conservatorship**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **continuity in message**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

○ **continuity of care**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

○ **control**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **coping**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

Comment:

One day at a time

○ **Coping Mechanisms**

Created: 1/4/19 by Joseph Henderson, **Modified:** 1/4/19 by Joseph Henderson

○ **crisis**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **culture**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **Death/Dying**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

○ **decline**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

○ **dehydration**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **Denial**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **Dependence**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **Depression/Apathy**

Created: 5/11/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **Destiny**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **diagnosed**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **diet restrictions**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **dignity**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **disappointment**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **discomfort**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **disoriented**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **distrust of health care**

Created: 3/20/18 by Joseph Henderson, **Modified:** 3/20/18 by Joseph Henderson

- **dizzy**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **Doing what I can**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **don't wait**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **Driving**

Created: 5/25/17 by Joseph Henderson, **Modified:** 5/25/17 by Joseph Henderson

- **dual coverage**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **dysphagia**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **education/knowledge**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **effect on lifestyle**

Created: 3/20/18 by Joseph Henderson, **Modified:** 3/20/18 by Joseph Henderson

Comment:

Health decline has not affected lifestyle

- **emergent**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **emotional**

Created: 8/16/18 by Joseph Henderson, **Modified:** 8/16/18 by Joseph Henderson

- **empathy**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **EMR Dictates Care**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **Encounter w/Healthcare Transitions**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **Encounter w/Healthcare Transitions - good**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **endurance**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **ESRD**

Created: 3/27/18 by Joseph Henderson, **Modified:** 3/27/18 by Joseph Henderson

- **expectations**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

- **experience**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

- **falls**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **family not near**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **family strife**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **Fatigue/weakness**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **Fear**

Created: 5/11/17 by Joseph Henderson, **Modified:** 5/11/17 by Joseph Henderson

- **feeling alone**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **feeling sick**

Created: 3/12/18 by Joseph Henderson, **Modified:** 3/12/18 by Joseph Henderson

- **felt good**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **fever**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **fight the disease/illness**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Financial Security**

Created: 4/20/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

- **First hospitalization**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

- **forgetting**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

- **fracture**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

- **Frailty**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **frequent flyer**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **frequent hospitalizations**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

- **frequent infections**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **frequent intervention**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **frequent surgeries**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **friendly**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **friends**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **frustration**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **Functionality**

Created: 5/24/17 by Joseph Henderson, **Modified:** 5/24/17 by Joseph Henderson

- **Functionality returning**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **fungal infection**

Created: 3/29/18 by Joseph Henderson, **Modified:** 3/29/18 by Joseph Henderson

- **Future**

Created: 5/25/17 by Joseph Henderson, **Modified:** 5/25/17 by Joseph Henderson

- **get to you**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **Getting along**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **Getting Better**

Created: 5/13/17 by Joseph Henderson, **Modified:** 5/13/17 by Joseph Henderson

- **Getting Old**

Created: 5/11/17 by Joseph Henderson, **Modified:** 5/11/17 by Joseph Henderson

- **Getting Sick/Weaker**

Created: 5/16/17 by Joseph Henderson, **Modified:** 1/19/20 by Joseph Henderson

- **Goals**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **God/Fate/Luck**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **Going Home**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **good doctors/medicine**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **good life**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **Grateful**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **grief**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **grooming**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **happier dead**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **hard/difficult**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **healing**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **healthcare literacy**

Created: 3/23/18 by Joseph Henderson, **Modified:** 3/23/18 by Joseph Henderson

- **helping others**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **home alone**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **Home Services**

Created: 5/13/17 by Joseph Henderson, **Modified:** 5/13/17 by Joseph Henderson

- **homeostasis, no**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **Hope**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **hospitalizations in one year**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

Comment:

5 x in 6 mos

- **house calls**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **humor**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **hygiene**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **ICU**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **important**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

- **in the moment/no life review**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **inability to participate in usual activities**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **inadequate resources**

Created: 9/21/18 by Joseph Henderson, **Modified:** 9/21/18 by Joseph Henderson

- **Incomprehensibility**

Created: 1/30/18 by Joseph Henderson, **Modified:** 8/2/18 by Joseph Henderson

Comment:

it is true that patient has HIV, but this is under control, and she is likely to die from her ESRD and CHF.

- **Independence**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **Independence vs. Dependence**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **ineffective coping**

Created: 3/23/18 by Joseph Henderson, **Modified:** 3/23/18 by Joseph Henderson

- **infection**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **injury**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **incomprehensibility**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

- **insight**

Created: 8/20/18 by Joseph Henderson, **Modified:** 8/20/18 by Joseph Henderson

- **Insurance**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **Intellectualization**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

○ **irreverent**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **Joy/Pleasure**

Created: 5/13/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

○ **keep your boots on**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

○ **kelly**

Created: 2/26/19 by Joseph Henderson, **Modified:** 2/26/19 by Joseph Henderson

○ **lack of communication**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **lack of improvement**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **lack of indepenence**

Created: 1/2/19 by Joseph Henderson, **Modified:** 1/2/19 by Joseph Henderson

○ **lack of Independence**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **lack of insight**

Created: 3/23/18 by Joseph Henderson, **Modified:** 3/23/18 by Joseph Henderson

○ **lack of trust**

Created: 3/22/18 by Joseph Henderson, **Modified:** 3/22/18 by Joseph Henderson

○ **Length of Hospital Stay**

Created: 5/24/17 by Joseph Henderson, **Modified:** 5/24/17 by Joseph Henderson

○ **Length of Illness**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

○ **length of rehab stay**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **Length of time at home**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

○ **letting go**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **life fleeting**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

○ **life review**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **life threatening**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

○ **likeable**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

● **Limitations of Medicine**

Created: 4/23/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

○ **lives with family**

Created: 3/24/18 by Joseph Henderson, **Modified:** 3/24/18 by Joseph Henderson

○ **living**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **living alone**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

- **living will**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

- **living with family**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **long term care**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

- **longevity of marriage**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Loss**

Created: 5/11/17 by Joseph Henderson, **Modified:** 8/3/18 by Joseph Henderson

- **loss of appetite**

Created: 11/27/17 by Joseph Henderson, **Modified:** 11/27/17 by Joseph Henderson

- **loss of interest**

Created: 3/12/18 by Joseph Henderson, **Modified:** 3/12/18 by Joseph Henderson

- **loss track of time**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **love/relations**

Created: 11/30/17 by Joseph Henderson, **Modified:** 11/30/17 by Joseph Henderson

- **love/relations/family**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **Low Health Literacy**

Created: 5/26/19 by Joseph Henderson, **Modified:** 5/26/19 by Joseph Henderson

● **Manageability**

Created: 5/13/17 by Joseph Henderson, **Modified:** 8/2/18 by Joseph Henderson

Comment:

Manageability undertermined by unknown.

Fear r/t unknown and

but wife caring and advocating

○ **many appointments with provider**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **marriage/life partner**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **medical history**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

○ **medical van**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **medicare**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **medication affordability**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

○ **Medication Management**

Created: 11/27/17 by Joseph Henderson, **Modified:** 11/27/17 by Joseph Henderson

○ **medication side effect**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **meeting needs**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **memories**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **misdiagnosed**

Created: 3/20/18 by Joseph Henderson, **Modified:** 3/20/18 by Joseph Henderson

- **mistakes perceived**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **more energy**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **mortality**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **most of my life**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **moving**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **multiple hospitalizations**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **my time**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **nausea**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **neuro**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

○ **never considered mortality**

Created: 9/20/18 by Joseph Henderson, **Modified:** 9/20/18 by Joseph Henderson

○ **no changing treatment**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **no control**

Created: 9/21/18 by Joseph Henderson, **Modified:** 9/21/18 by Joseph Henderson

○ **no family**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **no interest**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

○ **no reconciliation/no forgiveness**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **no rehospitalization**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

○ **No support**

Created: 1/30/18 by Joseph Henderson, **Modified:** 7/13/19 by Joseph Henderson

○ **non-adherence**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **not able to do what I did before**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

○ **not an option**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

○ **not elective**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

○ **Not getting better**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

○ **not home bound**

Created: 9/13/18 by Joseph Henderson, **Modified:** 9/13/18 by Joseph Henderson

○ **not manageing**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **not managing**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **not understanding Limitations**

Created: 5/26/19 by Joseph Henderson, **Modified:** 5/26/19 by Joseph Henderson

○ **not working**

Created: 3/12/18 by Joseph Henderson, **Modified:** 3/12/18 by Joseph Henderson

○ **not worried/anxious**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **nursing assistant**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **nursing care**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

○ **Nursing Home/Rehab**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

○ **nutrition**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

○ **obligation to others**

Created: 3/19/18 by Joseph Henderson, **Modified:** 3/19/18 by Joseph Henderson

○ **oblivious in youth**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

○ **oxygen dependent**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **past**

Created: 2/2/18 by Joseph Henderson, **Modified:** 2/2/18 by Joseph Henderson

○ **patient centered care**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

○ **peace**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

○ **pets**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **pharmacist**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **physical therapist**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **placating?**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

○ **Place of death**

Created: 3/31/18 by Joseph Henderson, **Modified:** 3/31/18 by Joseph Henderson

○ **plan of care**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **planning**

Created: 3/31/18 by Joseph Henderson, **Modified:** 3/31/18 by Joseph Henderson

○ **Pneumonia**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

○ **polypharmacy**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **potential crisis**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **powerless**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

○ **prayer**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **prepared**

Created: 9/21/18 by Joseph Henderson, **Modified:** 9/21/18 by Joseph Henderson

○ **prevention of rehospitalization**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Pride**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **priorities**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **Privacy**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **private pay**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **procedure**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **procedure side effect**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **procedures**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **prognosis**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **progression of disease**

Created: 3/20/18 by Joseph Henderson, **Modified:** 3/20/18 by Joseph Henderson

- **Projected incomprehensibility**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **provider**

Created: 10/1/18 by Joseph Henderson, **Modified:** 1/5/19 by Joseph Henderson

○ **quality of life**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **readmissions**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **ready**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

○ **ready or not**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **recovering from depression**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **recovering from surgery**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

○ **recurrence infection**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **recurrence of ischemic colitis**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

○ **refusing resources**

Created: 9/17/18 by Joseph Henderson, **Modified:** 9/17/18 by Joseph Henderson

○ **regrets**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

○ **rehospitalization**

Created: 5/25/17 by Joseph Henderson, **Modified:** 5/25/17 by Joseph Henderson

- **rejecting resources**

Created: 3/17/18 by Joseph Henderson, **Modified:** 3/17/18 by Joseph Henderson

- **religion/faith**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **remission/cure**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **resolving grief**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **Resources**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **retirement**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **return within days**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **risks and benefits**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **ritual**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **role change**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **sadness**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **sale home**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **same diagnosis**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **self care**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **senior living**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **sepsis**

Created: 3/29/18 by Joseph Henderson, **Modified:** 3/29/18 by Joseph Henderson

- **seriously ill**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **sexuality**

Created: 9/13/18 by Joseph Henderson, **Modified:** 9/13/18 by Joseph Henderson

- **shakey**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **shame/embarassed**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

- **signs of exacerbation**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Snow Bird**

Created: 2/18/18 by Joseph Henderson, **Modified:** 2/18/18 by Joseph Henderson

- **so drugged**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **social worker**

Created: 3/31/18 by Joseph Henderson, **Modified:** 3/31/18 by Joseph Henderson

- **societal changes**

Created: 2/20/18 by Joseph Henderson, **Modified:** 2/20/18 by Joseph Henderson

- **something to live for**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **specialist**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **spirituality**

Created: 1/30/18 by Joseph Henderson, **Modified:** 5/29/19 by Joseph Henderson

Comment:

Fear without understanding Meaningfulness

no forgiveness - no comprehensibility = not understanding the urgency for reconciliation

Merged comment from Meaning on 9/5/18, 11:16 AM

Patient is unable to make meaning due to incomprehensibility. While he is able to articulate each problem individually, he is unable to discern the severity of his prognosis. He has yet to have someone with knowledge and experience illustrate the big picture meaning of his situation.

- **spirituality/God**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **Status Quo**

Created: 12/3/17 by Joseph Henderson, **Modified:** 12/3/17 by Joseph Henderson

- **staying home**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

- **stop eating**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **stopping treatment**

Created: 3/29/18 by Joseph Henderson, **Modified:** 3/29/18 by Joseph Henderson

- **suicide**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

- **surgery**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **susceptible**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **sx**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **Symptoms**

Created: 5/12/17 by Joseph Henderson, **Modified:** 5/12/17 by Joseph Henderson

- **System inadequacies**

Created: 4/23/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

- **telling her story**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **testing/diagnosing**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

- **tired**

Created: 3/14/18 by Joseph Henderson, **Modified:** 3/14/18 by Joseph Henderson

- **too sick**

Created: 2/7/18 by Joseph Henderson, **Modified:** 2/7/18 by Joseph Henderson

- **tradition**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **treatment**

Created: 12/13/16 by Joseph Henderson, **Modified:** 1/2/19 by Joseph Henderson

Comment:

Health issues which complicate wellness. Insight that even in the incomprehensibility that outcomes may have been better if earlier attention at time of dx

- **treatment failure**

Created: 11/29/17 by Joseph Henderson, **Modified:** 11/29/17 by Joseph Henderson

- **treatment successful**

Created: 3/28/18 by Joseph Henderson, **Modified:** 3/28/18 by Joseph Henderson

- **treatments**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **trial/experimental**

Created: 3/29/18 by Joseph Henderson, **Modified:** 3/29/18 by Joseph Henderson

- **trials**

Created: 3/29/18 by Joseph Henderson, **Modified:** 3/29/18 by Joseph Henderson

- **turn for the worse**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

- **unavoidable**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

- **unaware**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

- **unexpected**

Created: 11/30/17 by Joseph Henderson, **Modified:** 11/30/17 by Joseph Henderson

- **Unknown**

Created: 5/15/17 by Joseph Henderson, **Modified:** 5/15/17 by Joseph Henderson

- **unmanageable**

Created: 8/16/18 by Joseph Henderson, **Modified:** 8/16/18 by Joseph Henderson

- **unsure**

Created: 2/6/18 by Joseph Henderson, **Modified:** 2/6/18 by Joseph Henderson

- **urgency**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **Usefulness/Work**

Created: 4/20/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

- **vague communication**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

- **value of health care**

Created: 2/4/18 by Joseph Henderson, **Modified:** 2/4/18 by Joseph Henderson

- **Very ill**

Created: 4/20/17 by Joseph Henderson, **Modified:** 4/23/17 by Joseph Henderson

○ **veteran**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **visiting nurse**

Created: 2/5/18 by Joseph Henderson, **Modified:** 2/5/18 by Joseph Henderson

○ **vulnerable**

Created: 3/5/18 by Joseph Henderson, **Modified:** 3/5/18 by Joseph Henderson

○ **waiting for death**

Created: 3/12/18 by Joseph Henderson, **Modified:** 3/12/18 by Joseph Henderson

○ **wake up call**

Created: 8/16/18 by Joseph Henderson, **Modified:** 8/16/18 by Joseph Henderson

○ **weight loss**

Created: 3/6/18 by Joseph Henderson, **Modified:** 3/6/18 by Joseph Henderson

○ **Wheelchair**

Created: 9/20/18 by Joseph Henderson, **Modified:** 9/20/18 by Joseph Henderson

○ **will power**

Created: 1/31/18 by Joseph Henderson, **Modified:** 1/31/18 by Joseph Henderson

○ **Wish**

Created: 5/16/17 by Joseph Henderson, **Modified:** 5/16/17 by Joseph Henderson

○ **wonders of medicine**

Created: 2/3/18 by Joseph Henderson, **Modified:** 2/3/18 by Joseph Henderson

○ **worry**

Created: 1/30/18 by Joseph Henderson, **Modified:** 1/30/18 by Joseph Henderson

Glossary

The definitions of terminology used in this thesis are presented in this glossary. The following are definitions of healthcare policy about early readmissions followed by definitions of concepts found within the theoretical framework of this thesis:

1. **30-Day Readmission** – A readmission to any acute care hospital within 30 days of discharge from an acute care hospital.
2. **Affordable Care Act (ACA)** –Health reform act passed by the 111th Congress and signed into law by President Barack Obama in March 2010. Provisions included expanding coverage to health insurance through mandated purchase, implementation of measures to improve quality and decrease the cost of healthcare and to eliminate denial of health coverage due to "pre-existing conditions" (Healthcare.gov, 2018).
3. **Centre for Medicare and Medicaid Service (CMS)** – Medicare is the U.S. government healthcare benefit for people over the age of 65, and the disabled, or those who have End Stage Renal Disease. The benefit was established in 1964 and is funded through payroll taxes and federal funding. Medicaid was added to this benefit in 1965 for those who live at 133% of the poverty level (Centers for Medicare and Medicaid Services, 2017a).
4. **Frailty Syndrome** - the presence of three of the five following phenotype criteria demonstrating compromised energetics which according to Fried et al include: low grip strength, low energy, slowed walking speed, low physical activity, and/or unintentional weight loss (Fried et al., 2001). It is important to know that there are other concepts and definitions which describe frailty as a phenomenon. This definition was chosen as it is the working definition for the phenomenon at the hospital at which the study was conducted.

5. **Older Adult** – An Adult aged 65 years or older. There is no definitive age which qualifies one as an older adult. Some articles say 60 years or older and others define it at 65 years or older (Harvey et al., 2013). Sixty-five was chosen as it is the age at which Americans are eligible for Medicare Insurance (Centers for Medicare and Medicaid Services, 2017a). There will be further discussion of this choice in the following chapter.
6. **Rehospitalization Reduction Program (HRRP)** - The Affordable Care Act (ACA) established the Hospital Readmission Reduction Program (HRRP) in 2012. Under this program, hospitals are financially penalized if they have higher than expected risk-standardized 30-day readmission rates for acute myocardial infarction, heart failure, and pneumonia. It has since expanded the number of conditions which are penalized for a 30-day readmission. A hospital can be denied reimbursement for a 30-day readmission as well as a loss of up to 3% of annual reimbursement for exceeding a predetermined limit of readmission events (McIlvennan et al., 2015).

This thesis will adopt Antonovsky’s construct of Sense of Coherence as the theoretical framework and its concepts of Comprehensibility, Manageability, and Meaningfulness from his Theory of Salutogenesis (Antonovsky, 1979, 1987). The definitions of the construct and concepts within this framework are defined below:

1. **Salutogenesis** – Antonovsky describes Salutogenesis as holistic well-being. He rejects the concept of health being the “absence of disease” and sees this concept as a description of the relationship between health, stress and coping (Antonovsky, 1979).
2. **Sense of Coherence** – Antonovsky defines Sense of Coherence as the global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments

in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement (Antonovsky, 1987).

3. **Comprehensibility** – the extent to which one perceives the stimuli that confront deriving from the internal and external environments, as making cognitive sense, as information that is ordered, consistent, structured, and clear, rather than as noise—chaotic, disordered, random, accidental, and inexplicable (Antonovsky, 1979).
4. **Manageability** – the extent to which one perceives that resources that are at one’s disposal are adequate to meet the demand posed by the stimuli that are encountered (Antonovsky, 1987).
5. **Meaningfulness** – the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement and are welcomed challenges, rather than burdens that one would much rather do without (Antonovsky, 1979).
6. **General Resistance Resources** – Antonovky defines General Resistance Resources as all social supports, genetic disposition and experiential events which impact the way an individual responds to a crisis (Antonovsky, 1979).