

QUALITATIVE ANALYSIS OF OLDER ADULTS' EXPERIENCES WITH SEPSIS

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DEDICATION

This dissertation is dedicated to family. To my parents, Walter and Myra Neal, who set a guiding example that education and persistent work are valuable personal resources. My mother set an example as a Rehabilitation Clinical Nurse Specialist—insisting a graduate degree was essential in nursing. Dad sent me solving puzzles at an early age. Our dinner conversations about the complexities in peoples’ lives within their work in health care and the ministry taught me to listen to peoples’ stories with compassion. To my husband, Dave, who graciously waited for this to be finished—thanks for keeping the technology going. To my three daughters, Sara, Emily, & Diana—your mere presence exceeds any expectations I may have had in my life, including this dissertation. I am extremely proud to be your mother and am amazed at the young women you are becoming. It is the people I have met and the conversations I have had that have propelled me forward, creating the joy in this journey.

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Rebecca D. Hancock

QUALITATIVE ANALYSIS OF OLDER ADULTS' EXPERIENCES WITH SEPSIS

Atypical symptoms, multiple co-morbidities and a lack of public awareness make it difficult for older adults to know when to seek help for sepsis. Diagnosis delays contribute to older adults' higher sepsis mortality rates. This research describes patients' and caregivers' experiences with the symptom appraisal process, self-management strategies, provider-nurse-patient interactions, and barriers when seeking sepsis care. Convenience and purposive stratified sampling were utilized on two data sources. A nurse-patient and nurse-family caregivers were interviewed. Online stories by older adult patient survivors or family members from the Faces of Sepsis™ Sepsis Alliance website were analyzed. Emergent themes were identified using qualitative descriptive methods. Listlessness and fatigue were most bothersome symptoms for the nurse-family caregivers. Fever, pain and low blood pressure were most common complaints, followed by breathing difficulty, mental status changes and weakness. Patients expressed "excruciating pain" with abdominal and soft tissue sources of infection, and with post-operative sepsis. Concern was expressed that self-management strategies and medications create barriers by masking typical sepsis signs. Health care providers' interpersonal interactions, lack of awareness of sepsis symptoms and guidelines, complacency towards older adults, and denial by patients were barriers. Further barriers were staff inexperience, delays, care omissions, and tension between health care providers, patients and caregivers—with emerging advocacy by patients and family. In conclusion, providers should assess previous self-management strategies when evaluating symptoms. At primary care visits or hospital discharge, older patients with risk factors

need anticipatory guidance for sepsis symptoms and possible emergent infections-- specifically patients with pre-existing risk factors such as urinary tract infections, pneumonia, or operative events. Public and professional education are needed to overcome a lack of urgency and understanding of symptoms for diagnosis, treatment and guideline adherence for inpatients and outpatient clinics. Further research on subjective sepsis symptoms may improve patient-clinician communications when evaluating sepsis in older adults.

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LIST OF ABBREVIATIONS

CG: Caregiver

ED: Emergency Department

EMS: Emergency Medical Services

FoS: Faces of Sepsis™

Chapter One

In the United States, sepsis is the most expensive diagnosis for older adults, with 1.1 million cases costing \$20.3 billion annually (Torio & Andrews, 2013), or an estimated \$20,000 per admission (Sutton & Friedman, 2013). Sepsis was the most common inpatient discharge in 2015 (Castellucci, 2017). Repeated sepsis admissions within one year increased from 11.5% in 2005 to 16% in 2010 and 23% in 2015-2017 in the U.S. (Reddy, Blonsky, & Bauer, 2018; Sutton & Friedman, 2013). In-hospital mortality for adults is 29% for sepsis (Stevenson, Rubenstein, Radin, Wiener, & Walkey, 2014), 46% for severe sepsis (Dellinger et al., 2013). and 56% for septic shock (Kumar et al., 2006). Sepsis is defined as the presence of a probable or documented infection with systemic manifestations of infection. It is an overwhelming and life-threatening response to infection that can lead to tissue damage, organ failure, and death (Sepsis Alliance, *Definition of Sepsis*, 2016). Sepsis can progress to severe sepsis, which is defined as sepsis plus sepsis-induced organ dysfunction or tissue hypoperfusion (Dellinger et al., 2013). Sepsis kills 258,000 Americans annually. For each hour delay in effective antibiotic therapy, mortality rates increase by 7.6% for septic shock patients (Kumar et al., 2006).

“Failure to rescue” is the inadequate or delayed response to clinical deterioration in hospitalized patients (Subbe & Welch, 2013). Hospital acquired sepsis has been deemed a “failure to rescue” event if the hospitalized patient dies due to inadequate or untimely responses to decline from sepsis (Isaac, Zaslavsky, Cleary, & Landon, 2010). Sepsis Alliance was founded in 2007 to raise awareness about sepsis for the public and health care providers. More than 700 sepsis survivors and family members of sepsis

patients have shared their stories on the Faces of Sepsis section of the Sepsis Alliance website (“Sepsis Alliance: Faces of Sepsis,” 2017). The high mortality rates, high costs, negative outcomes, and lack of awareness associated with sepsis make improvements in the continuum of care imperative.

The purpose of this research study is to describe the experiences of older adult patients and their caregivers (CGs) during the pre-acute phase of sepsis. The pre-acute phase begins with the time of the first symptom and ends at the time of sepsis diagnosis. The research addresses the significance of sepsis in older adults, diagnosis, theoretical influences (including the biopsychosocial aspects of older adults with sepsis), risk factors, guidelines, role of emergency medical services (EMS), and influences of public knowledge. Qualitative descriptive methods of analysis are utilized on two different samples to identify signs and symptoms, self-management strategies, interactions, and barriers during the development of sepsis symptoms. The analysis yielded three research reports to better understand the needs of older adults with sepsis.

Background

Diagnosis. Sepsis is classified in two categories: sepsis and septic shock. Sepsis is the presence of infection (probable or documented) with systemic vascular manifestations of infection (Dellinger, et al., 2013). Septic shock includes hypotension not reversed with fluid resuscitation (Dellinger, et al., 2013). Sepsis-induced hypotension is infection-induced hypotension, with elevated lactate or oliguria (Dellinger, et al., 2013). Along with a suspected or confirmed infection, sepsis is diagnosed by the presence of fever, heart rate greater than 90 beats per minute, tachypnea, altered mental status, significant edema or positive fluid balance over 20 ml/kg over 24 hours or

hyperglycemia (Dellinger, et al., 2013). Seven specific laboratory values indicate organ dysfunction and tissue perfusion variables include hyperlactatemia and decreased capillary refill or mottling. Each of the signs and symptoms may manifest differently in the older adult and be clouded by the complex concomitant conditions of the patient (e.g. heart failure, cognitive impairment, diabetes, pulmonary disease) (Dellinger, et al., 2013).

The Systemic Inflammatory Response Syndrome or Modified Early Warning System assessments are recommended to screen for sepsis (Dellinger, et al., 2013). Consistent use of screening tools with changes in symptoms leads to earlier and more accurate diagnoses of sepsis. Early identification of sepsis may reduce progression to severe sepsis and septic shock, resulting in improved outcomes.

In three studies on sepsis patients, 41 subjective symptoms experienced prior to diagnosis were identified (Clarke, Bird, Kakuchi, Littlewood, & van Hamel Parsons, 2015; Martin, 2012; Younger & McClelland, 2014) While these symptoms are helpful, it is unknown how often the older adults with “atypical” symptoms experience them (see Table 1).

Table 1

Pre-Hospital Symptoms of Sepsis

Pre-Hospital Symptoms of Sepsis	
Physical	Behavioral
Clamminess	“Completely gaga”
Feeling cold	Irritable
Feeling hot	“Odd”
Hot and cold flushes	Personality change
Rigors	
Shivery	
Sweatiness	
Rhinitis	
Cough	
Breathlessness	
Sore throat	
Abdominal pain	
Indigestion	
Loss of appetite	
Nausea	
Vomiting	
Backache	
Confusion	
Dizziness	
Excessive sleepiness	
Faintness	
Headache	
Poor concentration	
Shuffling gait	
Fatigue	
Weakness	
Floppiness	
Generalized achiness	
Hypotension	
Inability to get up	
Pallor	
Urinary incontinence	
Tachycardia	
Feeling unwell	
Breathing problems	
Abdominal problems	
Falls	

In a study of neutropenic patients with known high incidence of sepsis, time from first symptoms to diagnosis ranged from almost instantaneous to days (Clarke et al., 2015). Less than half the patients had fever or shivers, and their CGs often noted altered behavior. Categories of physical symptoms included “classically infective,” respiratory, abdominal, neurological, and others. Behavioral symptoms ranged from “completely gaga” to irritable. The most common symptom for seeking care was fever, yet some were reluctant to “bother” medical staff with symptoms. The mean delay in presentation was 11 hours, and 37% of patients took more than 12 hours to present to the ED after symptom onset. Logistical problems in the pathway to first medical contact included not being taken more seriously by non-specialist medical staff, misattribution of symptoms, poor communication between provider and patient, wishing the fever would pass, and denial/fear of hospitals. The path to the hospital for neutropenic patients, like older adults at higher risk of sepsis, may have modifiable opportunities. As an opportunity for further research, the extensive list of pre-hospital signs and symptoms of infection in this study may have implications for pre-hospital assessment of sepsis signs and symptoms in older adults. In addition, in higher-risk populations like older adults and neutropenic patients, patients and CGs may experience similar barriers to care.

Guidelines. The Surviving Sepsis Campaign International Guidelines for Management of Severe Sepsis and Septic Shock represent an evidence-based approach to treating the hospitalized patient with sepsis (Dellinger et al., 2013; Rhodes et al., 2017). The guidelines provide measurable signs and symptoms at the time of diagnosis to mark the severity of the sepsis and to minimize progression of sepsis to septic shock. Diagnosis using the Systemic Inflammatory Response Syndrome (SIRS) assessment is

recommended. Blood cultures, lactate assessment, fluid resuscitation, vasopressors, immunotherapy, antibiotics, crystalloids, and ventilation with measurable resuscitation targets should be initiated within 3 to 6 hours depending on symptoms (Dellinger et al., 2013). Adherence to the guidelines has been shown to reduce hospital mortality from sepsis by 50% (Doerfler et al., 2015). Because of the high cost and mortality associated with sepsis and the clarifications in diagnostic criteria within the 2004, 2008, 2012, and 2016 editions of the guidelines, research opportunities still exist for the older adult population. In a study specifically of fluid administration, patients with a higher proportion of fluids within the first three hours had a significantly decreased mortality (Lee et al., 2014). Other factors associated with guidelines compliance were hyperthermia, care from nurses with three or more years of experience, and care from senior residents or board-certified emergency physicians (Kang et al., 2012). In an observational prospective study with a historical control group, older adults who were treated per the sepsis guidelines had an absolute risk reduction in 28-day mortality of 16% (El Solh, Akinnusi, Alsawalha, & Pineda, 2008), but this study included drotrecogin alfa (Xigris), a medication for severe sepsis and septic shock that was removed from the market in October 2011 after failing to demonstrate efficacy (Gauer, 2013; Savel & Munro, 2012). Unfortunately, pharmaceutical promotional activities and financial backing of the investigators who wrote the guidelines raised concerns about the Surviving Sepsis Campaign despite demonstrated mortality reductions when using the guidelines (Eichacker, Natanson, & Danner, 2006). While 6 of the 36 pages in the 2012 guidelines are dedicated to pediatric patients, no specific guidelines are present for older adults.

Emergency Medical Services. In a literature review of the pre-hospital chain of care, researchers noted the sepsis prognosis worsened for each hour of delay until the start of antibiotics but found no rationale that pre-hospital treatment by EMS improved the prognosis (Herlitz et al., 2012). Delay of care from the onset of symptoms until the start of treatment can be classified into patient delay or systems delay (Herlitz et al., 2012). Only 54% of patients admitted for severe sepsis are transported by paramedics, and emergency services for transportation are more frequent for sepsis (3.3 per 100 transports) than for myocardial infarction (2.3 per 100 transports) or stroke (2.2 per 100 transports) (Seymour et al., 2012). Research that evaluated the quantity and quality of calls for EMS categorized prehospital sepsis care processes by EMS. In a study of more than 400,000 EMS encounters, between 40% and 60% of patients transported for severe sepsis were admitted to the hospital and 19.6% died in the hospital. On-site care exceeded 45 minutes, and transport time averaged 12.6 minutes (Seymour et al., 2012). When EMS arrived on the scene, presenting hypotension was noted in 21% of cases while SIRS criteria for heart rate was met in 58% of cases and respiratory rate in 50% of cases. But more hypotension, depression, and hypoxemia were prevalent for cases diagnosed on admission compared with cases diagnosed later in the hospital stay. Severe sepsis cases were more likely to result in an in-hospital death than myocardial infarction or stroke cases (Seymour et al., 2012).

Some EMS staff called information prior to ED arrival so staff could prepare for the patient. Researchers identified 29 sepsis-related phone calls to the ED, 15 subcategories, and 3 main categories of information (“deterioration,” “physical signs and symptoms,” and “difficulties establishing satisfactory contact with patient”) (Bohm,

Kurland, Bartholdson, & Castrèn, 2015). Most calls to EMS were from nursing homes (52%) or relatives (34%), with other calls coming from police (3%), geriatricians (3%), home care services (3%), and the Swedish medical care hotline (3%)—never from the patient. Sudden deterioration often was associated with anxiety on the part of the caller and included the patient's falling and collapsing. Physical signs and symptoms included breathing difficulties, nausea and vomiting, pain, pallor, other measurable signs of illness (vital signs by professionals), confusion, drowsiness, unconsciousness, and not answering. Reported symptoms varied between lay and professional callers (Bohm et al., 2015).

Like EMS staff, nursing assistants provide care for older adults and develop a keen eye for changes in a patient's condition in the pre-hospital phase at long-term care facilities. Twenty-one nursing assistants in focus groups said they made decisions when a resident felt unwell based on 1) recognition and formulation, 2) strategies for gathering and evaluating information, 3) influences of personal experiences, and 4) preconceptions and external support systems from peers (Sund-Levander & Tingström, 2013). Within a model of nursing assistants' clinical decision-making process, specific causes of inaction were identified: fear of not being believed, attitudes to treatment, feeling powerless, and fear of unnecessary alarm. The nursing assistants' choice of action was described as stand up for yourself, hand over, wait and see, or give up (as an advocate for the patient). Much like laypersons await feedback from health care providers to validate their concerns, feedback from other nursing staff was an important criterion in whether to act on observations of patient deterioration for nursing assistants (Sund-Levander & Tingström, 2013).

Influential Theoretical Frameworks and Concepts

Help-Seeking Theoretical Model. Deciding to seek help is a complex process that often has no experiential precedent. Help-seeking is defined as “a problem focused, planned behavior, involving interpersonal interaction with a selected health-care professional” (Cornally & McCarthy, 2011, p. 280). Symptom appraisal and help-seeking are associated with self-efficacy (Bandura, 1986; Cornally & McCarthy, 2011). Deciding to act is influenced by social cognitive factors with only moderate effects from knowledge and awareness (Bandura, 1986; Cornally & McCarthy, 2011) . In sepsis, the patient’s or CG’s help-seeking is influenced by symptom appraisal, interactions with others, self-management strategies, and perceived barriers.

Facilitators and Barriers to Help-Seeking for Patient – CG Dyads. Because research has not been conducted on the facilitators and barriers in the sepsis diagnostic process, only speculative factors exist. Key events from the pre-diagnosis period may be a series of transitions in a trajectory that result in a defining event such as a diagnosis (Carter-Harris, 2015). There may be similarities in diagnostic trajectories, despite individual differences. The transition from feeling healthy or “normal” to ill, with the transition to believing a situation is acute may be its defining attributes. Detecting facilitators and barriers as key events, or defining attributes, in the trajectory can contribute to the sepsis literature for older adults. Key event mapping identifies the key events that alter a trajectory towards a diagnosis and may be an applicable research method of retrospective analysis (Carter-Harris, 2015) . It would be helpful for a CG to understand the seriousness of symptoms, and that may be affected by agency or linked lives.

Life Course Perspective. The life course consists of a complex set of interlocking trajectories, or pathways, over the life span that are marked by sequences of events, transitions, and exposures across several biologically- and socially-defined life stages (or phases) that impact the development of individual lives. There are four principals of the life course perspective: 1) lives unfold over time and to understand the present, one must understand the past; 2) the focus is on the intersection of history and personal biography or the way historical conditions shape life course trajectories to provide individually unique opportunities and constraints upon human actors; 3) it pays attention to human agency—or to the consequences of individual decisions; and 4) it focuses on linked lives—or on ways an individual’s life course is intertwined with those of others (George, 2011).

In addition, the life course perspective focuses on heterogeneity of cohorts, individuals, and the myriad pathways that can lead to the same or different outcomes. Effects over generations create an individual or generational cumulative advantage or disadvantage. One can analyze the effects of CG identity by considering social interactions of CGs and their entourages to understand the caregiving trajectory in disease diagnosis (Carpentier, 2012). While each of the four principles informs this research, the principals of human agency and linked lives are most relevant for understanding the help-seeking behavior in the context of caregiving and sepsis.

Agency. Agency is the subjective sense of control and includes self-efficacy, mastery, personal control, and planned competency (Hitlin & Kwon, 2016). Agency can act as a cause, effect, mediator and moderator over the life course and may provide structural advantages while interacting with linked lives to influence outcomes

(Shanahan, Mortimer, & Johnson, 2016). There is a temporality to agency while it is a part of social engagement, history, and future planning. This sense of control declines around age 60 in the United States. Optimism within agency can buffer the effects of various life stressors (Hitlin & Kwon, 2016). A belief or expectation that a patient should have improved health may elicit an action or decision by the dyad. Agency by the CG or patient may create a sense of urgency and clear decision-making to seek early treatment for sepsis, or at least a recognition that a medical assessment is necessary. Therefore, the trajectory toward a sepsis diagnosis.

Linked lives. The interrelated relationships of CGs' and patients' linked lives impact caregiving decisions such as help-seeking. The caregiving decisions create behavioral patterns that affect health outcomes. Some suggest those behavioral patterns are linked to educational levels of the linked lives (Kirkpatrick Johnson, Staff, Schulenberg, & Patrick, 2003). In a sepsis case study, the social interactions by children of the dyad did not trigger a visit to health care providers. The linked lives did not benefit the trajectory of care. If the linked lives include a family member with a medical background, the time to diagnosis might be shortened. The trajectory of an Alzheimer's diagnosis, although longer, may mirror the trajectory of an older adult with sepsis with the linked lives that affect the process. Linked lives are an important consideration for caregiving during the development of sepsis symptoms. The linked lives of the dyad affect decision-making whether the dyad is one unit or two, as decision-making entities seeking health care. Also, communications within the dyad will affect the trajectory of illness.

Caregiving and diagnosis within the Alzheimer's population has similar considerations to the older adult sepsis population due to the age, co-morbid conditions, concomitant medications, and CG-patient linked lives. The empirical evidence of the life course perspective was studied in the pathway to a diagnosis of Alzheimer's (Carpentier, Bernard, Grenier, & Guberman, 2010). Lengths of time to reach a diagnosis varied from 10 months to 31 months. Patient-family relationships with gentle negotiations and a support network that lowered tensions and mitigated differences resulted in the most complex and longest trajectories to diagnosis. Application of the diagnostic process and linked lives within the sepsis caregiving scenario may reveal a CG trying to maintain social continuity, assuming this illness is transient and minimizing the symptoms. The more actors there are in the scenario, the longer it may take to obtain a diagnosis because of the depth of social support. However, if any linked lives in the CGs' social context have experienced sepsis, this could affect the decision-making. If health care-seeking behavior was immediate and phone calls to primary care providers were answered or visits scheduled quickly, those linked lives may positively affect health outcomes. For example, one linked life that may alter the trajectory in a diagnosis of disease would be a nurse in the family. Different linked lives may impact health behaviors and outcomes.

Educational effects. Education may alter an individual's health and lifestyle by impacting economic, social, psychological, and interpersonal resources. Specifically, obtaining a college degree may affect health due to the related better employment, higher earnings, greater social support, enhanced cognitive resources, and increased self-direction (agency) (Kirkpatrick Johnson et al., 2003). Changes in family structure or economic circumstances or the emergence of new health threats may alter the effects of

education. Linked lives for those with higher educational levels may affect the trajectory of sepsis diagnosis. For example, the presence of educated medical personnel in a social structure such as family or friends may alter the trajectory because of knowledge shared or timeliness of decisions. The cumulative inequality or disadvantage of linked lives in the context of lower educational levels may lengthen the time to diagnosis due to less access to health care, altered social support networks, or lower perceptions of self-efficacy/agency. The effects of education on agency could certainly affect health outcomes related to sepsis for the dyad.

Educational needs of the linked lives may be substantial also. For example, if the health care providers in the linked lives are not knowledgeable about the need for timely treatment of sepsis and the associated symptoms, they may advise the dyad to disregard the symptoms because they may seem flu-like in nature whereas a more knowledgeable health care provider may recognize an infection or sepsis as the underlying cause. This disregard of potential sepsis might delay diagnosis and increase the risk of mortality. If a patient and CG visit a wound clinic to treat an infection and the health care provider does not identify sepsis symptoms, the time to treatment may have similar delays.

Gender, race, and religious effects. Gender may affect the caregiving decisions for an acute illness such as sepsis. In a meta-analysis of 30 studies, researchers found that female CGs are at greater risk for psychiatric morbidity than male CGs (Yee & Schulz, 2000). However, male CGs are three times more likely than female CGs to develop dementia (Wennberg, Dye, Streetman-Loy, & Pham, 2015). Women are more likely to experience a psychological burden from caregiving, but men may be less likely to express such burden. Men approach caregiving as a job more so than women and feel

proud of the job. While men feel more obligated in the caregiving role, it is assumed that women will be the primary CGs. White CGs report higher levels of depression and burden than African American CGs. Religion, prayer, and faith, which are known coping mechanisms for caregiving, show greater advantage for African Americans. Religious involvement has been associated with better health, improved psychological well-being, increased social support, and greater levels of self-esteem and self-efficacy (Wennberg, Dye, Streetman-Loy, & Pham, 2015). In the life course perspective, the caregiving role may be a developmental stage within the life course. In the case of a patient with sepsis, linked lives related to gender, race, and religion may have effects on coping and time to diagnosis.

Life course principles may provide a framework to analyze decision-making when seeking care for sepsis. Facilitators and barriers affect the trajectory. Religious involvement may affect agency and care-seeking behavior, thus affecting the duration of time before treatment is sought. The gender of the CG and the communications between the patient and the CG may have a positive or negative impact. Because no research has been completed on help-seeking behaviors for sepsis, there are many unknowns. Interviews with patients and CGs may provide clues to the effects of education, access to quality care, communication, culture, religion, and historical experiences on the decision to seek treatment for sepsis.

Application to Sepsis Caregiving

Because symptoms of infection are atypical in the older adult, it is more difficult for patients and CGs to know when to seek or initiate treatment (Girard, Opal, & Ely, 2005). There is no clear understanding of the patient's experience prior to hospitalization

for older adults who experience atypical signs and symptoms of sepsis and may depend on a CG to guide sepsis care. While the patient's perspective and the CG's perspective are both important, help-seeking behavior for older adults may most often be influenced by the CG's decisions. Little is known about the factors affecting how and when CGs and older adults with symptoms of sepsis seek care at an emergency department (ED).

During the trajectory between first symptom and diagnosis in the ED, help-seeking behaviors can be analyzed using the life course perspective. The principles of the life course perspective can be applied to this unique trajectory. By understanding which principles of the life course perspective affect the trajectory toward diagnosis, one may be able to influence the trajectory. The primary principles of the life course perspective provide an overarching framework. Advice from linked lives may affect the time to diagnosis. Dismissal by a health care provider as a non-emergent situation or not communicating clear guidelines to re-assess for escalating symptoms may be a barrier in the linked lives scenario. The advice may also affect agency of the CG by denying his or her perspective on the seriousness of symptoms or severity of current condition compared to normal. Facilitators and barriers within the linked lives need to be assessed for sepsis.

There may be a typical temporal sequence of supports, barriers, and decision points that are instrumental in moving the patient closer to a diagnosis. Those supports and barriers need to be assessed especially for the CG's decision-making process because the CG for an older adult may be the more influential decision-maker in the dyad, assuming the CG is the most cognitively intact of the two. The goal is to determine interventions to shorten the duration from first symptom to diagnosis.

Delving into the experience of the CG for older adults is important because older adults often experience delirium or confusion in the course of sepsis symptomatology. This may be the only sepsis symptom. From this perspective, the CG has the more accurate perspective on the key events.

Life course agency suggests subjective beliefs influence later trajectories and life course outcomes (Hitlin & Kwon, 2016). The characteristics of the CG and the subjective beliefs influence decision-making. Teasing out the decisions and actions of the CG may provide substance for the antecedent beliefs—if an interview is carefully guided in this direction. Not only must actions and decisions be assessed, but also the historical experiences that may guide the process.

The implications for the life course perspective are evident for a CG of an older adult developing sepsis. Caregiving for an older adult may be a unique life course perspective within a specific social, cultural, and organizational context. The perceived successes or failures of caregiving and related mortality of the patient may be a transition that alters the trajectory of life for the patient and the CG. No studies have been done on the decisions by family CGs during the development of sepsis symptoms. At the micro-level, agency and the feelings of self-efficacy may affect the speed with which CGs make decisions to seek care for sepsis symptoms. Linked lives and the educational level, gender, race, and religious involvement of CGs may be factors, but no studies have considered sepsis caregiving. At the macro-level, social contexts, historical perspectives related to previous illnesses, the desire to maintain normality in the caregiving role, and organizational structure also affect caregiving help-seeking behaviors.

There are implications for research, education, and clinical practice related to caregiving for an older adult developing sepsis. Because Alzheimer's disease is more prevalent in older adults, some parallels might be evident in the caregiving decision for older adults with Alzheimer's or sepsis. Qualitative research into the trajectories and pathways that lead to a diagnosis that results in survival or death is needed. As suggested in the Alzheimer's population, qualitative analysis of the benefits to the CG of an early diagnosis, such as reduced physical limitations after a hospitalization, reduced costs, and improved outcomes, may create educational opportunities and other interventions for CGs (Wackerbarth & Johnson, 2002).

Because sepsis symptoms in the older adult are often atypical, the CG and patient may not clearly know when to call for help. More qualitative research on the observations of the CG of a sepsis patient may be needed. In clinical practice, the role of the CG can be recognized as an informant of the temporality of changes in baseline conditions that may be sepsis symptoms, such as cognitive changes. Each concept within the life course perspective is likely to have facilitators and barriers in the trajectory to a sepsis diagnosis. Only by listening to the voice of the key players—CGs or patients—will we understand the key transitions.

The life course necessarily complicates the usual biological quantitative approach to health care problem-solving by combining biopsychosocial facets of life. Because sepsis can progress into septic shock very quickly, research into the specific differences in patients' subjective symptoms at different stages of the disease may benefit CGs. Applying the life course perspective to the case study, multiple life course perspectives are needed to analyze the temporal transitions and trajectories of the illness and effects of

caregiving decisions and associated contextual factors. CGs who have experienced repeat occurrences of sepsis in their loved one may provide new knowledge of the benefits of specific linked lives, advantages of accumulated knowledge, and effects on CGs and patients. Adjustments to the social structure of CGs may change the relationship of linked lives, agency, and the constraints within a social and organizational structure. The goal of research, education, and clinical practice is to study the facets of caregiving as a developmental stage using the life course perspective and to provide insights to reduce time to diagnosis for the older adult with sepsis. Education for CGs and patients may be the conclusion, but organizational effects that affect linked lives and agency cannot be excluded. Communication patterns and historical experiences within the dyad may affect agency. Qualitative narratives of the evolution of a sepsis diagnosis for an older adult are needed for further study. Questions are needed that assess the life course principles, possibly using a process like key event mapping but applying it to shorter trajectories (Carter-Harris, 2015). The questions would include life course concepts to understand the sequence of observations, decisions, facilitators, and barriers of the CG during this often-tumultuous journey. While the help-seeking and life course perspectives are valuable, the social cognitive influences cannot be easily separated in the decision-making process (Bandura, 1986).

Risk Factors and Symptoms Associated with Sepsis

Major risk factors for septic shock are diabetes, immunosuppressive therapy, elective surgery, chronic renal failure, and alcohol abuse (Kumar et al., 2006).

Researchers cite the importance of assessing functional status as a risk factor for pneumonia, a precursor to sepsis (Torres et al., 2004). Non-modifiable risk factors for

sepsis include age, gender, and ethnicity. There is an increased incidence in infants and older persons, males compared with females, and blacks compared with whites (Englert & Ross, 2015). Source infections can be identified in only 78% of septic shock cases (Kumar et al., 2006). Sources of sepsis specifically for older adults are urinary tract (44%), respiratory (33%) intraabdominal (16%), and skin or soft tissue (7%) infections (El Solh et al., 2008). This contrasts with work by Kumar in patients of all ages, where 22% of sources of infection were unknown (Kumar et al., 2006). The atypical symptoms of older adults have not been clearly quantified thus far in the literature. However, factors associated with early progression to shock include older age, female sex, hyperthermia, anemia, comorbid lung disease, and vascular access infection (Glickman, et al., 2010). In one version of the sepsis guidelines, it is noted that more research is needed for care of the older adult (Dellinger et al., 2013), yet little has been done.

In a study of more than 10 million adult discharges from 1979 to 2002, age was independent predictor of mortality (Martin, 2012). Older adults die earlier during the hospitalization and are more frequently discharged to non-acute facilities for care (54% for younger adults vs. 76% for older adults). The researchers found age to be a major factor in both the risk for and subsequent outcome of sepsis (Martin, 2012).

With aging comes an altered temperature response to infections. Bloodstream infections are a precursor to sepsis. Researchers studied 230 patients with four different pathogens, assessing longitudinal tympanic membrane temperatures. They recommended a basal body temperature increase of 1 degree Celsius is significant given the blunted maximum temperature reached by those over age 75 (Lu, Chen, Chang, Yen, & Dai, 2013). Age, as a risk factor, has associated altered symptoms in the response to sepsis in

older adults. While “fever” may be absent, there may still be an important increase in basal body temperature.

In a study of help-seeking experiences for sepsis, qualitative interviews were done to understand pre-hospital behaviors in neutropenic sepsis patients (Clarke et al., 2015). Researchers used grounded theory methods to identify potentially modifiable factors that delayed patients’ presentation to the hospital. The neutropenic population is known to have an expected incidence of sepsis in over 70% of post-cytotoxic therapy patients. Unlike the multinational survey by Rubulotta et al. (2009), most patients in this sample clearly understood the incidence, potential severity, and outcomes of neutropenic sepsis (Clarke et al., 2015). Onset times from first symptoms ranged from days to almost instantaneous. Fewer than half the patients had fever or shivers. Caregivers often noted altered behavior. The most common symptom for seeking care was fever, yet some were reluctant to “bother” medical staff with symptoms. The mean delay in presentation was 11 hours, and 37% of patients took over 12 hours to present to the ED after symptom onset. The pathway to first medical contact included logistical problems such as not being taken more seriously by non-specialist medical staff, misattribution of symptoms, poor communication between provider and patient, wishing the fever would pass, and denial/fear of hospitals (Clarke et al., 2015). The path to the hospital for neutropenic patients, like older adults at higher risk of sepsis, may have modifiable opportunities. As an opportunity for further research, the extensive list of pre-hospital signs and symptoms of infection in this study may have implications for pre-hospital assessment of sepsis signs and symptoms in older adults. In higher-risk populations like older adults and neutropenic patients, perhaps patients and CGs experience similar barriers to care.

Older Adults

Older adults with sepsis have higher prevalence and mortality than younger patients. Sixty-six percent of patients admitted with sepsis are over the age of 65 (Sutton & Friedman, 2013), and the average age of the patient with sepsis is 67 years old (Stevenson, Rubenstein, Radin, Wiener, & Walkey, 2014). Sepsis is the tenth-leading cause of death for older adults (Torio & Andrews, 2013). A primary sign of infection is fever, yet fever is often absent in older adults (Girard et al., 2005; Norman, 2000). Functional deterioration, delirium, anorexia, malaise, urinary incontinence, falls, or weakness may be the only symptom of sepsis in the older adult (Girard et al., 2005; Nasa, Juneja, & Singh, 2012; Wester, Dunlop, Melby, Dahle, & Wyller, 2013). Increased age is a risk factor for early organ failure with sepsis, although delayed diagnosis and treatment may contribute to this sepsis complication in the older adult (Englert & Ross, 2015). Despite this knowledge of risk factors in older adults, it is unclear what geriatric-specific symptoms should be considered in the pre-hospital assessment. The interactions among emergency medical personnel, the patient, the CG, and other health providers are an integral part of a timely diagnosis and optimal time to treatment from home to the ED.

Public Awareness and Knowledge

Three studies focused on the education of the public, CGs, and patients. Patients and CGs have identified a general lack of awareness of the diagnosis, its severity, and insufficient follow-up to acute care in a qualitative review of CGs' experiences with severe sepsis patients. And despite the known long-term effects of sepsis, the CGs identified a lack of appropriate health care providers and services following discharge (Gallop et al., 2015). Using an Actor-Partners Interdependence Model, researchers

analyzed requests for advice from the German Sepsis Aid's National Helpline. In a 2009 survey of 6,021 laypeople in the United States, Italy, France, Spain, and the United Kingdom, 88% of respondents had not heard of sepsis (Rubulotta et al., 2009). The percentage of people who had heard of sepsis ranged from 53% in Germany to 4% in France (19% of respondents in the United States had heard of it). In Italy, Spain, the United Kingdom, France and the United States, of people recognizing the term sepsis, 58% did not know it was a leading cause of death (Rubulotta et al., 2009). The majority had heard about sepsis from the media. Researchers surmised that education in the community is needed to raise public awareness of symptoms (Rubulotta et al., 2009). The goal would be to increase awareness of sepsis symptoms, decrease mortality, and improve outcomes (Rubulotta et al., 2009). In addition, improving public awareness of the seriousness and frequency of sepsis may generate funding for research using political and philanthropic tactics (Rubulotta et al., 2009). Improved awareness may also educate sepsis patients and CGs on the need for early intervention. Education to reduce time to treatment may yield a parallel trajectory as that for acute myocardial infarction and stroke care.

Problem

Sepsis in older adults has not been sufficiently addressed in the literature to understand the development of sepsis in the older body. Symptoms are known to be atypical, but no studies have specifically quantified or identified their atypical nature. Communication between the patient, CG, and health care professional can be inhibited by cognitive deficits. The need to appraise signs and symptoms amid multiple pre-existing conditions and concomitant medications can be challenging. Older adults have higher

mortality rates and hospital readmission rates—but what are the factors that affect these rates? By understanding the subjective experience of older adults and their CGs, the most salient issues may emerge. Because little is known about this experience, qualitative descriptive methods of data analysis can be used to analyze the experiences of patients and CGs encountering sepsis signs and symptoms.

Gaps in Literature

Because time to treatment is critical for sepsis, screening is essential. Timeliness of care is as important as for acute myocardial infarction or stroke. In a systematic review of pre-hospital sepsis care, emergency services for transportation are more frequent for sepsis than for myocardial infarction and stroke (Seymour et al., 2012). Health care providers, CGs, and patients do not have clear recommendations of when to seek care for different sepsis symptoms. The hospitalization period has been studied intensely, but within the sepsis guidelines, it is noted that more research on the effects of guidelines-based care of geriatric patients is needed (Dellinger et al., 2013). The post-hospitalization time period has been studied somewhat (Gallop et al., 2015). No published studies have focused on the experiences of older adults or CGs seeking care, barriers to accessing care, and most troublesome symptoms associated with a severe infection. No theoretical model describes the interpersonal dance of symptom recognition, symptom self-management, and health care-seeking behaviors that precede a trip to the ED for sepsis care.

A recent systematic review focused on the pre-hospital management and identification of sepsis by EMS (Lane, Ichelson, Drennan, & Scales, 2016). The researchers found no randomized controlled trials and 16 cohort studies. While various

assessments are used in the pre-hospital setting, studies are lacking for diagnosis accuracy and relevant signs and symptoms. The principle assessment by EMS included criteria for Systemic Inflammatory Response Syndrome (Lane et al., 2016). More efficient and evidence-based care in the pre-hospital phase would reduce the time to transport and improve compliance with the sepsis guidelines. Neither of these reviews highlighted specific needs of older adults. The literature highlights the need for standardization of pre-hospital care by EMS as well as education for patients and CGs.

Qualitative Methods

Little is known about the pre-hospitalization experience of the older adult with sepsis. Qualitative research methods are needed to study the older adult population with sepsis because the patient and CG experiences are poorly understood. This complex trajectory can only be explored by talking with or understanding the experience in the words of the patient and the CG (Creswell, 2013). We need to empower the voice of the patients, so we can improve the communications between providers and patients during the rapid onset of sepsis symptoms. With this understanding of older adult symptoms, barriers, and interactions with others, we can provide better anticipatory guidance to older adults at increased risk of sepsis.

Specific Aims of the Dissertation

These qualitative studies explored narratives to understand how and why older adults with sepsis and their CGs seek care in the ED. Nurses were interviewed for one sample, and online posts from patients and CGs were obtained for the second dataset. Nurses were chosen because they have clear expectations and methods of navigating the health care continuum. The nurse seeks condition-specific patient information to

determine a plan of action. From nurses' descriptions of therapeutic and diagnostic clues, a framework for seeking sepsis care can emerge (Greenhalgh & Hurwitz, 1999) The patient and CG online posts revealed subjective experiences that have not previously been described. Specifically, the dissertation described:

1. Signs and symptoms that older adults with sepsis and their CGs consider bothersome enough to seek care;
2. Self-management strategies that are attempted before care is sought in the ED;
3. Interactions between older adults, their CGs, and health care providers from the time of symptom identification at home to when emergency care is sought; and
4. Barriers encountered by older adults with sepsis and their CGs in seeking care in the ED.

The samples captured different means of communicating about sepsis: verbal narratives from nurses and written stories from patients and CGs. The same aims and methods were applied to the two different samples (interview transcripts and online posts). With the interviews, more depth was obtained in each scenario. The expert nurses and semi-structured interviews demonstrated a trajectory of care from symptom onset to diagnosis. The nurses' experiences provided a possible framework for the data analysis in the online posts. In the posts, the depth and breadth of descriptions varied more because no questions were used to guide the content. Methods offered qualitative analysis of appraised signs and symptoms, self-management, interactions, and barriers for older adults with sepsis. From multiple views, one can identify the "typical" in perceived "atypical" signs and symptoms of sepsis in older adults, help-seeking behaviors, self-management strategies, and associated opportunities to reduce time to treatment. The

interactions from linked lives permeate the two sets of data. Understanding the patients' and CGs' experiences highlights opportunities for improvements in sepsis care processes for older adults.

Chapter Two

Help-Seeking in Sepsis Care for Older Adults:

Qualitative Analysis of Nurse Narratives

Sepsis is a systemic inflammatory response to infection associated with organ failure and high mortality rates (Sepsis Alliance, 2016). Sepsis is the most expensive diagnosis for older adults in the United States, with 1.1 million cases costing \$20.3 billion annually (Torio & Moore, 2016) or an estimated \$20,000 per admission (Sutton & Friedman, 2013). Since October 2015, compliance with sepsis guidelines is an expected core outcome measure for acute care hospitals (Rhodes et al., 2017). The guidelines require blood cultures, fluid replacement therapy, and antibiotics to be initiated within three hours of sepsis onset. In Germany, goal-directed guidelines for older adults resulted in a 7.1-day shorter length of stay, and a 5.2% lower risk of mortality (Heppner et al., 2012). Prior to the implementation of the mandated guidelines, in-hospital mortality for adults was 29% for sepsis (Stevenson et al., 2014), 46% for severe sepsis (Dellinger et al., 2013), and 56% for septic shock (Kumar et al., 2006). The guidelines resulted in a decreased mortality rate of 21% in 2016 for Medicare patients receiving early goal directed care and 30% for those not receiving the same care for severe sepsis and septic shock (Uppal & Dickerson, 2017). Barriers to implementing sepsis guidelines can be categorized into five domains: (1) intervention, (2) outer setting, (3) process, (4) inner setting, and (5) individuals, with most falling into the latter two categories (Weiss, 2017). Delay of care from the onset of symptoms until the start of treatment can be classified into patient delay or systems delay (Herlitz et al., 2012). For each hour delay in effective antibiotic therapy, mortality rates increase by 7.6% for septic shock patients (Kumar et al.,

2006). Older adults are known to have atypical symptoms of sepsis making diagnosis more difficult. Rapid diagnosis and treatment are needed to prevent death, especially in older adults. However, little is known about the decision-making when older adults or their caregivers (CGs) seek care at an Emergency Department (ED) for sepsis.

Older Adults

Older adults, and specifically nursing home residents, have a higher incidence of severe sepsis and associated co-morbidities. Nursing home residents had higher ICU admissions, hospital lengths of stay, and in-hospital mortality compared to non-nursing home residents (Ginde, Moss, Shapiro, & Schwartz, 2013). Delayed diagnosis and treatment may contribute to early organ failure as a sepsis complication in the older adult (Englert & Ross, 2015). Older adults die earlier during hospitalization and are more frequently discharged to non-acute facilities for care (76% of older adult sepsis patients vs. 54% of younger sepsis patients) (Martin, 2012). An estimated 75% of Medicare beneficiaries who survive sepsis have functional disability at discharge and 17% have moderate to severe cognitive impairment (Sutton & Friedman, 2013).

High mortality rates, costs, negative outcomes, and lack of awareness make further understanding of and adherence to sepsis care guidelines imperative. Through an analysis of nurses' narratives of sepsis experiences, the goal of this study is to describe the processes and barriers for older adults when seeking care for sepsis.

Purpose

This qualitative study explored narratives of three nurses to understand how and why older adults with sepsis and their CGs seek care in the ED. We chose nurses because nurses have clear expectations and methods for navigating the health care

continuum. The nurse seeks condition specific patient information to determine a plan of action. From nurses' descriptions of therapeutic and diagnostic clues, a framework for seeking sepsis care can emerge (Greenhalgh & Hurwitz, 1999). Specifically, this study describes:

1. Signs and symptoms that older adults with sepsis and their CGs consider bothersome enough to seek care;
2. Self-management strategies that are attempted before care is sought in the ER;
3. Interactions between older adults, their CGs, and health care providers from the time symptoms are identified at home to when emergency care is sought; and
4. Barriers encountered by older adults with sepsis and their CGs when seeking care in the ED.

Review of Literature

Although research has found older adults experience worse outcomes from delayed diagnosis and treatment complications, early goal-directed therapy can improve outcomes for these patients. Amidst complex co-morbidities and atypical symptoms, sepsis diagnoses are challenging especially in older adults. Despite the mandated sepsis care guidelines, it is still difficult to diagnose and educate across the continuum of care. More research is needed on care of the older adult using the sepsis guidelines (Dellinger et al., 2013).

Prevalence. Older adults have higher sepsis prevalence and mortality rates than younger patients. The incidence of hospitalizations with a primary or secondary diagnosis of sepsis increased 32% from 2005 to 2010 (Sutton & Friedman, 2013). Sixty-six percent of patients admitted with sepsis are over the age of 65 (Sutton & Friedman,

2013) and the average age of the patient with sepsis is 67 (Stevenson et al., 2014). Sepsis is the tenth-leading cause of death for older adults (Gorina, Hoyert, Lentzner, & Goulding, 2006; Torio & Moore, 2016) and the third-leading cause of death in the U.S.(Sepsis Alliance, 2016). Older patients are 13 times more likely to develop sepsis than younger patients and have a twofold greater risk of death (Rubulotta et al., 2009). There is no clear understanding of the patient's experience prior to hospitalization, especially for older adults who experience atypical signs and symptoms.

Despite statistics citing worse outcomes from delayed diagnosis and treatment complications, early goal directed therapy can improve outcomes for older adults. Amidst complex co-morbidities and atypical symptoms, sepsis diagnoses are challenging especially in older adults. Despite a mandate for sepsis care guidelines, it is still challenging to diagnose and educate across the continuum of care. It is noted that more research is needed for care of the older adult in the sepsis guidelines (Dellinger et al., 2013).

Symptoms. Symptoms of infection are atypical in the older adult and fever is often absent(Girard et al., 2005). Functional deterioration, delirium, anorexia, malaise, urinary incontinence, falls, or weakness may be the only symptoms (Girard et al., 2005; Nasa et al., 2012; Wester et al., 2013). Therefore, it is more difficult for older patients and their CG's to know when to seek or initiate treatment(Girard et al., 2005). In the 2012 sepsis guidelines, 6 of the 40 pages are dedicated specifically to pediatric patients' special recommendations, with a relative absence of recommendations for treating older adults (Dellinger et al., 2013; Rhodes et al., 2015).

In a study of 230 patients with four different pathogens, investigators found a tympanic membrane basal body temperature increase of one degree Celsius or 1.8 degrees Fahrenheit is significant given the blunted maximum temperature reached by those over age 75 (Lu et al., 2013). This contrasts usual approaches to infection that necessitate a temperature of 101.5 degrees to warrant treatment, which is 2.9 degrees Fahrenheit above “normal.” While “fever” may be absent, there may still be an important increase in basal body temperature. The atypical symptoms of older adults have not been clearly quantified thus far in the literature.

Risk Factors. Various studies emphasize greater risk and worse outcomes of sepsis in older adults. Major risk factors for septic shock are diabetes, immunosuppressive therapy, elective surgery, chronic renal failure, and alcohol abuse (Kumar et al., 2006). Sepsis sources for older adults are urinary tract (44%), pulmonary (33%) intraabdominal (16%), and skin or soft tissue (7%) (El Solh et al., 2008). Sepsis diagnosis is complicated when 22% of infectious sources are suspected without a clear pathogen or source (Kumar et al., 2006). Non-modifiable risk factors for sepsis include age, gender, and ethnicity. There is an increased incidence in infants and older persons, males compared with females, and blacks compared with whites (Englert & Ross, 2015). Researchers found age to be a major factor in both the risk for and subsequent outcome for sepsis (Martin, 2012). The incidence of recent injuries, surgeries, inserted lines, or hospitalizations as possible risk factors have not been quantified.

Barriers. Barriers to care are cited in literature. Previous research noted a lack of understanding of the diagnosis and severity by discharged patients and CGs (Gallop et al., 2015). In a study of neutropenic patients with sepsis, “attempts to obtain treatment

were sometimes thwarted by non-specialists' failure to recognize (symptoms)...and several were discharged without treatment...and some patients denied their symptoms to avoid hospitalization" (Clarke et al., 2015, p. 2687). Even among pre-hospital care providers, inconsistencies exist in screening tools and care diagnostic processes for sepsis (Fitzpatrick, McKenna, Rooney, Beckett, & Pringle, 2014; Roebuck, 2015).

Public Awareness and Knowledge. Patients and CGs have identified a general lack of awareness of the diagnosis, its severity, and insufficient follow-up to acute care. Despite the known long-term effects of sepsis, CGs identified a lack of appropriate health care providers and services following discharge (Gallop et al., 2015). In 2009, 19% of Americans had heard of sepsis (Rubulotta et al., 2009). In 2016, 55% of Americans had heard of sepsis, but 74% incorrectly identified or were unsure of key symptoms (Sepsis Alliance, 2016). Most heard about sepsis from the media. Rubulotta et al suggest that improving public education and awareness of the seriousness and frequency of sepsis may decrease mortality, improve outcomes, and generate funding for research using political and philanthropic tactics (Rubulotta et al., 2009). Education to reduce time to treatment may yield a parallel improvement in symptom identification like acute myocardial infarction and stroke care. Sepsis Alliance developed the acronym SEPSIS to alert patients to symptoms: Shivering, fever, or very cold; Extrême pain or general discomfort ("worst ever"); Pale or discolored skin; Sleepy, difficult to rouse, confused; "I feel like I might die"; and Short of breath (Sepsis Alliance, 2016).

Theoretical Framework

Decision-making is complicated in a patient's first case of sepsis because there are no experiential precedents for the help-seeking behaviors. Help-seeking can be

defined as “a problem focused, planned behavior, involving interpersonal interaction with a selected health-care professional” and is contrasted with help-negation (Cornally & McCarthy, 2011, p. 280). In help-negation, help-seeking may not resolve the problem and a person may seek alternative sources of help or alter help-seeking appraisal and behaviors (Cornally & McCarthy, 2011). The decision to seek help is a complex process extending beyond knowledge and awareness or problem recognition and definition. The decision to act is largely influenced by social cognitive factors (Bandura, 1986), so enhancing knowledge and awareness only have moderate effects on help-seeking behaviors (Cornally & McCarthy, 2011). Buried in the help-seeking process is perceived self-efficacy, defined as “people’s judgments of their capabilities to organize and execute courses of action required to attain designated types of performances...with the judgments of what one can do with whatever skills one possesses” (Bandura, 1986, p. 391). Antecedents to help-seeking include symptom presence, cause, significance, severity, consequence, duration, type and frequency (Cornally & McCarthy, 2011). Processing of the symptoms include appraisal, perception, and evaluation or interpretation (Bandura, 1986; Cornally & McCarthy, 2011). Following the decision to act, there is a social-cognitive selection of source of help with consideration of the type, source and amount of help needed (Cornally & McCarthy, 2011). This includes appraisal through recognition of symptoms and evaluation of symptoms. Unique attributes in older adults and nurse-patients and nurse-caregivers are the perceived self-efficacy of the nurse, and the atypical symptoms of sepsis in older adults. Both factors are antecedents and affect symptom identification and require unique judgment skills of the nurse. The help-seeking concept is useful for understanding this process; however, it does not

address the importance of interpersonal relationships or prior knowledge. For example, help-seeking is often conceptualized as an individual behavior, but this process occurs within the context of social networks. Caregivers may act as a patient advocate and influence the help-seeking, possibly encouraging earlier intervention.

Self-management of symptoms by patients and CGs is integral to the help-seeking processes yet is not clearly represented in the model. Patients and CGs may attempt to manage an illness prior to seeking help from health care providers. While self-management is not specifically included in help-seeking, it is integral to self-efficacy decision making as described by Bandura (Bandura, 1986). Self-management strategies precede help-seeking and may be more apparent when a nurse is a primary actor in the scenario. The interplay of self-management and the help-seeking process can change the trajectory of illness. Experienced barriers can also change the trajectory of illness. This study seeks to highlight the impact of barriers and self-management on the help-seeking process for sepsis.

Nurses Informants

Using case study methodology, nurse-patients and nurse-caregivers were interviewed to understand the barriers to seeking care for sepsis in the help-seeking process. One of the main barriers to seeking care among older adults is the lack of knowledge about sepsis symptomology and the disease course (Gallop et al., 2015; “Sepsis Alliance: Symptoms,” 2016). However, nurses advocating for themselves or another patient would ideally have specialized education and knowledge. Interviewing nurses who sought care for sepsis enables us to investigate barriers to treatment in the “best” conditions (i.e., among those who are highly trained and knowledgeable). More

specifically, the narrative approach emphasizes the transformative interconnections of actions and social actors, which highlight the complexity within the help-seeking process (Carpentier, 2012). When people share stories, common themes, sequences of events, behaviors and meanings become evident (Draucker & Martsolf, 2010). It is prudent to analyze the sepsis experience through narratives from the participating actors. Nurses sharing stories or “bearing witness” about care is a form of moral agency that is ethically supported with specific nursing knowledge, bringing value to the nurse-patient relationship (Naef, 2006). From this inductive process, needs and interventions can be addressed that are client-centered (Carpentier, 2012).

Methods

The study met criteria for Institutional Review Board “exempt” status. The principal investigator (PI) completed semi-structured interviews with participants, and they received a copy of the questions prior to their interviews. Audio recordings and de-identified transcripts were stored in a secure database and locked cabinets and protected health information was redacted from transcripts. The PI took notes during the interview about questions that may require further explanation (Charmaz, 2014). Instructions at the beginning of the interview gave participants the option of stopping at any time if they became uncomfortable.

Qualitative descriptive and grounded theory methods of data analysis were used for the study. The goal was to identify and articulate common meanings and behaviors within the psychosocial process (Charmaz, 2014). Using a scientific, systematic approach to objective and comparative analyses of experiences, the human experience is described within a specific phenomenon (Charmaz, 2014). This constructivist approach

includes “learning about the experience within embedded, hidden networks, situations, and relationships, and making visible hierarchies of power, communication and opportunity” (Creswell, 2013, p. 87). At the center of this inductive process is the patient/CG experience. The Constant Comparative Method allowed adjustments to the codes, interview tool, and sample between surveys (Glaser & Strauss, 1967). Qualitative descriptive methods are valuable when little is known about a phenomenon and basic knowledge of the phenomenon is necessary (Sandelowski, 2000b). No previous studies have explored the experiences the sepsis help-seeking behaviors of older adults. Nurses’ narratives are a unique methodological approach to data collection when using qualitative analysis to understand help-seeking behaviors in sepsis. Little is known about the sepsis experiences of older patients and CG’s, so a qualitative descriptive approach is justified.

Data Analysis. Sentences were coded to identify common themes for a parsimonious picture of experiences from the interviews. Initial coding identified gerunds (Charmaz, 2014), with a focus on actions, thoughts and feelings addressing the specific aims. Thorough review of the initial coding allowed emergent themes to be identified. Focused coding summarized the most significant or frequent codes. Axial coding created major themed categories and subcategories (Charmaz, 2014; Glaser & Strauss, 1967). Thematic statements that include synthesis, process, and outcomes were sought (Sandelowski & Leeman, 2012).

Sample. A convenience sample of two family nurse CGs and one nurse-patient volunteered to be interviewed by the PI. All interviewees were white females, employed full time in nursing with a bachelor’s, master’s and doctoral degree. The interviews lasted 19, 30, and 44 minutes in length. Individual interviews were conducted in a

private setting. The time since the sepsis diagnosis was 7 months, 18 years, and 6 weeks respectively. The three interviewees each had a minimum of 30 years' experience as a nurse and all were employed in nursing at the time of the event. Events occurred at medium or large EDs in a large midwestern city in the United States. The first two events occurred before the Centers for Medicare and Medicaid Services began tracking sepsis guidelines compliance in acute care hospitals in 2015.

Results

Case 1. The first interview was with Jane, a wife-nurse, caring for her husband with osteomyelitis. Both were employed full time. The nurse worked in a hospital. The wife-nurse also consulted their daughter, who was a medical professional as well. The patient had been attending an outpatient wound clinic twice a week. The wife-nurse performed daily dressing changes for 16 months and the skin ulcers were the source of the sepsis. Sepsis symptoms evolved over two weeks, culminating in a near unresponsive episode at work and a call to emergency medical services. The patient was hospitalized for seven days and discharged to a skilled nursing facility for 10 weeks of antibiotic therapy before returning to work. The husband's pressure ulcers related to long-term wheel chair use were the source of infection.

Case 2. The second interview was Betsy, a daughter-nurse, caring for her father with late-stage Parkinson's disease. The daughter was employed full time at a university, and the father was retired from full-time military duty. While the patient was immobile and had difficulty communicating, he participated in physical therapy, listened to music, played computer games and had a "good quality of life". The daughter drove her father to the ED after sepsis symptoms evolved over a four-hour period. He survived the

hospitalization and lived another six months in his home with hospice services. An indwelling urinary catheter was the source of the sepsis.

Case 3. The third interview was Theresa, a nurse who had a surgical procedure requiring two post-operative drains that were still in place at the time of sepsis diagnosis. Her husband drove her to the ED 23 days after surgery and 17 hours after the onset of symptoms. She was initially discharged from the ED but was admitted to the hospital emergently after her surgeon’s office called her the following day as a routine procedure. Aspiration pneumonia was the source of her sepsis.

Appraisal: Piecing Together Signs and Symptoms. The nurses sorted through early atypical symptoms and continued to observe, knowing each patient had a source of possible infection present (wound, urinary catheter, surgical drain). Stated risk factors, signs and symptoms are noted in Table 2.

Table 2

Sepsis Symptoms and Risk Factors

Sepsis Symptoms Observed and Experienced by Nurses		
Case Study 1: Jane	Case Study 2: Betsy	Case Study 3: Theresa
Caregiver Observations	Caregiver Observations	Patient Experiences
<ol style="list-style-type: none"> 1. Shaking cold 2. Decreased urine output 3. Listlessness 4. Confusion 5. † Hard to arouse 6. Fatigue 7. † Excessive sleep 8. Weakness 9. Dehydration 10. Decreased appetite 11. Really tired 12. “not feeling good” 13. Scared 	<ol style="list-style-type: none"> 1. Not feeling well 2. Fever 3. Sweaty 4. Decreased energy 5. Decreased Parkinsonian movements 6. Decreased appetite 7. † Lethargy 8. Eyes “wouldn’t light up” 9. “Just not himself” 	<ol style="list-style-type: none"> 1. Surgical site drainage 2. Back pain with inspiration 3. Nausea 4. Feeling of generalized discomfort 5. Feeling really bad 6. Unable to get out of bed 7. † Fever

14. Almost passed out	10. History of aspiration pneumonia	8. Headache “like the top of my head coming off” 9. Low blood pressure 10. Vomiting 11. Heart rate 100
Risk Factors		
<ul style="list-style-type: none"> • Age 53 • Male • Pressure Ulcers • Osteomyelitis • Wound vac drain 	<ul style="list-style-type: none"> • Age 79 • Male • Parkinson’s Disease • Urinary Catheter 	<ul style="list-style-type: none"> • Age 66 • 3 weeks post-operative surgery • Persistent drainage & wound vac drain at surgical site • History aspiration pneumonia • Sleep apnea • Asthma

† Symptom triggering help-seeking in ED

While the nurses synthesized the evidence, their angst in the decision-making process and symptom appraisal was evident in the quotes and tone of the interviews (see Table 3).

Table 3

Themes and Example Narratives

Themes and Example Narratives	
Theme-Description	Example
Appraisal-- piecing together signs and symptoms of sepsis	<ul style="list-style-type: none"> • felt cold all the time...wanted to be under a blanket • the urine output and listlessness were a red flag to me • didn't run a fever and was not complaining of any pain at all • when (his favorite) movie came on and he didn't really want to watch it and slept, I knew • got confused and hard to arouse but insisted on going to work the next day • had that catheter quite a while...he was just not feeling well • energy was less, appetite was less. Just didn't seem to be doing as well • could tell there wasn't something not right...fever and sweaty • having a lot of drainage, but nothing showed infection. • I started feeling generalized discomfort, wouldn't call it pain.... I got to feeling really bad and couldn't get out of bed • ran a fever 101 to 102 • was so nauseated and had this headache that was unusual ...like the top of my head was coming off... my blood pressure was low, 100/70 • back would hurt when I took a deep breath in my thorax area • Fever and sweaty and I needed to take him in for that
Self- Management Strategies-- using interventions when reacting to the time- sensitive decline in function	<ul style="list-style-type: none"> • increased fluids and took (heavy doses of) ibuprofen for pain that had probably been masking the temperature. • threw up and took Zofran • thought my ibuprofen's just not working too good for my osteoarthritis • I knew he needed to be on IV antibiotics and he refused to go the hospital • He thought that the (oral) antibiotics that they gave him would be all that he needed • got sicker, but I was trying to think, "If I lie real still and drink plenty of fluids and take the ibuprofen, I'll get to feeling better" • My husband said, "well do you want me to take you to urgent care?" I said, "no" ...all my specialists are at the hospital so "I think I need to go to the ER
Patient- Caregiver-	<ul style="list-style-type: none"> • no one communicates with you and tells you, "this is what we think you may have...We are going to do this to see if we

<p>Health Care Provider Interactions--vacillating locus of control</p>	<p>can make a diagnosis...I was so sick I didn't look up on the computer to see what my own lab values and everything were. I figured they would tell me</p> <ul style="list-style-type: none"> • I had to request that and almost demand wound cultures and then I had to almost demand they put him on antibiotics • I was appalled with that "pneumonia is Parkinson's friend" because I wasn't going to buy that...we don't have to have him die of sepsis or be in that much pain and suffering • Quite frankly, he saved my life, because with my blood pressure going down even more, it could have been a bad scene if I hadn't gotten adequate care, but he did a fabulous job.
<p>Barriers-identifying conflicts in help-seeking and self-management strategies</p>	<ul style="list-style-type: none"> • Somebody said to me, "pneumonia is Parkinson's friend." • I was angry because I knew he shouldn't go to work and he refused (to go to the ED) • Our daughter, a medical person was trying to explain to him that he needed to go, and he kept refusing, underlying he was scared • They (outpatient clinic) didn't seem concerned. It was my speaking to them. They didn't even do the wound cultures on their own.... • had a wound vac on and they weren't concerned that maybe it wasn't getting where it needed to be and getting the drainage out of there • They did the appropriate screening, but they didn't do anything with the data. They didn't make any kind of diagnosis. They did blood cultures, and then they sent me home.... when I was in the ER my blood pressure was 60 over 40, 80 over 60 • I learned a very valuable lesson, the fact that I could have died, and it would have been really a lot my fault, ... I will never let it happen again that I don't know what the plan of care is, what are the results of my lab test, and just to tell me they're normal isn't going to fly anymore • She listens to your lung sounds here and here, through the ACE bandages ... If she would have bothered to look at my chart, you might want to focus more on the lungs and all in the lower sections

Symptoms evolved over two weeks, four hours, and 17 hours, respectively, in the three scenarios. Over two weeks, Jane observed an early progressive disengagement in usual activities such as dinners out and television shows, and symptoms of cold chills,

decreased appetite, fatigue, excessive sleep, weakness, and finally dehydration, decreased urine output, confusion, difficulty arousing, and unconsciousness. Over four hours, Betsy observed general malaise, decreased energy, decreased Parkinsonian movements, decreased appetite, fever, and sweatiness. The nurse-patient experienced increased breathing pain, fever, hypotension, nausea, vomiting, headache, and malaise. Typical in older adults, each patient had complicating, underlying pre-existing illnesses that made sorting through symptoms more challenging. They also had major risk factors for infection that they articulated as concerning. Two of the three participants discussed the symptoms with a health care professional prior to hospital admission—one with the wound care clinic and another with the ED. Each nurse also had a strong sense of self-efficacy that they could decipher the cause of the illness and seek treatment appropriately, although they were not positive that sepsis was the diagnosis.

Self-Management Strategies: Reacting to the Time Sensitive Decline in Function. The nurses re-assessed progress following several self-management processes. Specific self-management strategies included self-medication with anti-nausea, fever or pain medication; wound vacuum maintenance; ingesting fluids; recommended interventions with health care providers in outpatient clinics and the ED; and information seeking. Each of the nurses knew emergency care was needed and acted as facilitators in help-seeking behaviors. Some self-management strategies were successful in treating symptoms, but some help-seeking strategies were thwarted by either the patient or health care providers. The use of pain medication may have masked fever. However, with support of a nurse, each sepsis patient survived the sepsis experience, despite the sub-optimal trajectory of care.

Vacillating Locus of Control: Patient-Caregiver-Health Care Provider

Interactions and Conflicts. The interviewees mentioned specific interactions with others when seeking care, sometimes taking the lead and accepting guidance at other times. Jane coordinated care with wound care nurses, physicians, and her daughter—all medical professionals. Her husband’s supervisor called her when he had a syncopal episode at work. Betsy engaged with only the ED staff prior to diagnosis. Theresa discussed her condition with her husband, ED personnel (a physician’s assistant), and the nurse practitioner and medical assistant at her surgeon’s office. Each interviewee described a situation when they began to proceed beyond “help-seeking” to direct care; for example, Jane requested wound cultures and antibiotics prior to the hospitalization.

The nurses’ frustration was apparent:

“I had somebody say to me, “pneumonia is Parkinson’s friend.”” I was appalled with that because I wasn’t going to buy that...We don’t have to have him die of sepsis or be in that much pain and suffering.”

“No one communicates with you and tells you, “This is what we think you may have.... We are going to do this to see if we can make a diagnosis....I was so sick I didn’t look up on the computer to see what my own lab values and everything were. I figured they would tell me.”

When frustrated and conflicted with processes of care, the nurses seemed to assume control and become more authoritarian in actions and statements, especially the nurse CGs. The nurse-patient seemed unable to synthesize her symptoms enough to direct care but retrospectively wished she had. While ill, she was unable to enact a “patient advocate” stance on her own behalf.

Barriers: Identifying Conflicts in Help-Seeking and Self-Management

Strategies. The nurses had deviations from expected care in an outpatient clinic, ED,

and inpatient unit. The sources of the sepsis were among the four most prevalent sources. Despite the recommendation of two family members who were health care providers, Betsy's husband refused to go to the ED. Theresa was discharged from the ED after receiving two liters of fluids but was admitted the following day for sepsis. The interviewees had specific expectations of care that required negotiation:

“Like I said, they [the outpatient clinic] didn't seem concerned. It was my speaking to them--they didn't even do the wound cultures on their own. I had to request that and almost demand that. I had to almost demand they put him on antibiotics because they weren't concerned that it had E coli in it.... He had a wound vac on at that point, too, and they weren't concerned that maybe it wasn't totally getting where it needed to be and getting the drainage out.”

Untreated sepsis has been identified as a “failure to rescue” event (Schmid, Hoffman, Happ, Wolf, & DeVita, 2007), implying that failure to recognize and treatment sepsis is negligent.

“They did all the appropriate screening, but they didn't do anything with the data that they got. They didn't make any kind of diagnosis. They did blood cultures, and then they sent me home.... When I was in the ER my blood pressure was 60 over 40, 80 over 60”

“I really learned a very valuable lesson, and not only the fact that I could have died, and it would have been a lot my fault, because I'm just thinking, ‘Well, I just don't feel real well....I will never let it happen again that I don't know what the plan of care is, what are the results of my lab test, and just to tell me they're normal isn't going to let it fly anymore.’”

Each nurse was in an advocate role but experienced barriers in the diagnostic or treatment process: a patient refusing to seek care, staff nurses' perception that dying of pneumonia was acceptable, discharge from the ED without a diagnosis, the outpatient clinic not meeting the expectations of the nurse-CG. Anger was evident in the tone of the two nurse-caregivers as an outcome of the appraisal processes. Like previous research,

most barriers were from individuals (Weiss, 2017). But this study focused on the pre-acute phase and unlike previous research, significant barriers are present outside the hospital (Weiss, 2017). Appreciation and regained trust was evident in one quote:

“Quite frankly, he saved my life, because with my blood pressure going down even more and my respirations continuing to go up and everything, it could have been a bad scene if I hadn't gotten adequate care, but he did really a fabulous job.”

Discussion

As nurses pieced together the symptoms, they encountered resistance from a patient, delays from ED staff and an outpatient clinic, and a suggestion that it is acceptable to die from sepsis in the face of Parkinson's disease. In contrast to the current sepsis guidelines that require treatment within three hours of diagnosis (Rhodes et al., 2017), the nurses encountered a lack of urgency in sepsis diagnosis and treatment. The lack of urgency, underlying beliefs, and perhaps education were barriers to care from medical personnel. Like previous qualitative studies, there was a failure to recognize symptoms, one patient one discharged without adequate treatment, and patients denied symptoms to avoid hospitalization (Clarke et al., 2015; Gallop et al., 2015).

Primary symptoms of concern to the nurses were fever and lethargy. This only somewhat supports the theory of atypical biological responses in older adults (Girard et al., 2005). While fever is considered atypical in older adults, it was present in two of the older patients. Relative temperature changes may still be a determining factor of “fever” that needs to be quantified as indicated by previous research (Lu et al., 2013). Theresa believed her fever was masked by the ibuprofen she used for associated arthritis pain. She also noted her blood pressure was low despite missing her anti-hypertensive medication due to nausea. All symptoms in the SEPSIS acronym except pallor and

shortness of breath, or four of the six primary items in the sepsis symptoms, were present in the scenarios, and therefore the acronym would be a useful educational tool for patients. The historical experiences and educational backgrounds of the nurses gave them an advantage over lay persons when synthesizing the myriad symptoms. Possible infection from existing risk factors (wound, urinary catheter, and drains) warrants anticipatory guidance for patients.

Nursing Implications

Specific implications for practice exist. Like emergency treatment for stroke and myocardial infarction, rapid assessment and treatment saves lives. Implementation of time sensitive sepsis diagnostic and treatment guidelines are essential across the continuum of care, including outpatient clinics. Conversations about treatment options, including palliative care in the face of serious disabilities need to occur instead of allowing a patient to die from an infection against the wishes of the patient or CG—a serious “failure to rescue” tragedy. Patients and CGs need to be educated so both understand sepsis, especially when risk factors are present. If patients have self-medicated for pain, providers must consider this when assessing for fever and the possible masking of fever due to acetaminophen or ibuprofen use. Similarly, patients should be asked when the last dose of anti-hypertensives or beta blockers was taken when assessing aberrant blood pressure or heart rate.

Limitations

The strength of this study lies in the power of the very experienced nurses’ narratives for patients with complex medical histories. The nurses highlighted antecedents in the help-seeking process that affected the trajectory of care. Despite the

barriers, all three patients survived the hospitalization. More information from chart reviews and other characters in the scenario may have yielded additional lenses through which to analyze the cases. Understanding the internal processing and decision making of this knowledgeable sample who had a story to tell provides insights into opportunities for process improvements. Despite the small sample, these nurse narratives provide a valuable key to identifying opportunities for improvement in sepsis care.

Conclusion

Qualitative analysis from the nurse's perspective can provide key insights to sepsis care for older adults. In clinical practice, outpatient clinics need to know of sepsis symptoms and treatment guidelines. The perceived complacency around time sensitive sepsis treatment must be addressed as previously done for cardiac and stroke care. Sepsis symptoms in older adults need further research, so a common language and understanding is clearly shared among providers and patients. Previous self-management strategies for symptoms such as fever or pain must be considered when screening for sepsis. Associated risk factors and prevention education need further study in a larger sample of older adults but must include recent surgeries, indwelling medical devices, or recent infections. Further study of pre-hospital management, education for associated risk factors and public / provider education could reduce delays and improve outcomes. Further research to improve the trajectory of care for older adults with sepsis is warranted.

Relevance to Clinical Practice. Expert clinicians such as the three nurses included in this study should be adept at navigating the health care system, especially when navigating a diagnosis of sepsis. However, despite their level of understanding, the

nurses encountered barriers. In practice, the lack of urgency towards possible sepsis in outpatient clinics may be addressed with further education about current sepsis diagnostic criteria and guidelines. Detailed questioning about self-medication and current medications can identify the possible masking of heart rate or temperature elevations. Anticipatory education must be provided to older adults following hospital procedures or infections that put them at risk of sepsis. The education must provide symptoms of new or worsening infections and expected actions. Further specificity in older adults' subjective sepsis symptoms may improve patient-clinician communications when evaluating for possible sepsis.

Chapter Three

Older Adult Sepsis Signs and Symptoms in Faces of Sepsis™

Sepsis is a life-threatening condition that arises when the body's response to infection injures its own tissues (Singer et al., 2016). Patients rapidly decline from sepsis to septic shock if timely treatment is not initiated (Dellinger et al., 2013). Each hour delay in effective antibiotic therapy increases mortality by 7.6% for septic shock patients (Kumar et al., 2006). Treatment delays also increase cost by extending the length of stay for intensive care and inpatient hospitalizations. Sepsis is the most expensive diagnosis for older adults in the United States, with 1.1 million cases costing \$20.3 billion annually (Torio & Andrews, 2013). More recent research estimate the cost at \$32,000 per admission (Arefian et al., 2017). In 2013, septicemia was the most expensive condition billed to Medicare with a cost of \$14.5 million for 838,000 hospitalizations, accounting for 6.9% of all Medicare hospitalizations (Torio & Moore, 2016).

In 2016, 55% of Americans had heard of sepsis yet 74% incorrectly identified or were unsure of key symptoms (Sepsis Alliance, 2016). Due to altered immune system responses, co-morbid conditions, and medications, symptoms of infection are often atypical in older adults, delaying diagnosis and treatment of sepsis (Englert & Ross, 2015; Nasa et al., 2012). A primary sign of infection is fever, yet fever is often absent in older adults (Girard, Opal, & Ely, 2005). The Centers for Medicare and Medicaid Services began measuring hospitals' adherence to standardized sepsis treatment guidelines in October 2015 to reduce sepsis mortality and time from symptom onset to treatment (Centers for Medicare and Medicaid Services, 2018). The guidelines recommend lactate levels, blood cultures, fluid resuscitation, and antibiotic initiation

within three hours of sepsis diagnosis. Medicare patients who are treated for severe sepsis and septic shock with the sepsis guidelines have a 79% in-hospital survival rate compared with a 68% survival rate for those who are not treated with the guidelines (Uppal & Dickerson, 2017). Before the guidelines were implemented, patients treated for septic shock had a 44% in hospital survival rate (Kumar et al., 2006) .

This study, analyzed social media stories about older adults' experiences with a sepsis diagnosis featured on the website of Sepsis Alliance, which aims to “save lives and reduce suffering by raising awareness of sepsis as a medical emergency” (“Sepsis Alliance: Faces of Sepsis,” 2017). On the Faces of Sepsis™ (FoS) section of the website, patients and caregivers post stories about their experiences with sepsis. Analysis of the content of these stories may provide insights to improve time to treatment, defined as the time from symptom onset to initiation of blood cultures, antibiotics, and fluid resuscitation within standardized sepsis protocols. By understanding the lived experiences of patients and caregivers, as described by them, it may be possible to improve patient-clinician assessments and communications about symptomatology. Better knowledge about the patient experience may lead to the development of interventions to reduce time to treatment, raise awareness, and reduce suffering for older adults.

To help patients remember the symptoms of sepsis, Sepsis Alliance (2016) developed the acronym SEPSIS: Shivering, fever, or very cold; Extreme pain or general discomfort (“worst ever”); Pale or discolored skin; Sleepy, difficult to rouse, confused; “I feel like I might die”; and Short of breath. Primary systemic inflammatory response syndrome clinical criteria include fever, heart rate of more than 90 beats per minute,

respiratory rate of more than 20 breaths per minute, and abnormal white cell counts in the presence of a new or worsened infection (Dellinger et al., 2013). Geriatric-specific sepsis symptoms include mental status changes, falls, delirium, anorexia, malaise, urinary incontinence, weakness, functional decline, withdrawal, and agitation (Englert & Ross, 2015; Nasa et al., 2012). Little is known about how older adults and their caregivers review signs and symptoms when seeking care for sepsis.

Purpose

This study explores the human experience of developing and either surviving or dying from sepsis. The purpose is to identify the most common signs and symptoms that older adults with sepsis and their caregivers experience prior to seeking medical care. This qualitative descriptive study analyzes older adults' and their caregivers' online narratives of their experiences with a new sepsis diagnosis.

Help Seeking Theoretical Model

Deciding to seek help is a complex process that often has no experiential precedent for patients' first sepsis experience. Help-seeking is defined as ““a problem focused, planned behavior, involving interpersonal interaction with a selected health-care professional” (Cornally & McCarthy, 2011, p. 280). Symptom appraisal is an antecedent to help-seeking. Deciding to act is influenced by social cognitive factors with only moderate effects from knowledge and awareness (Bandura, 1986; Cornally & McCarthy, 2011). There is a gap in the literature in identifying older adults' signs and symptoms of sepsis. The older adult is known to have atypical symptoms of sepsis, but can the symptoms of sepsis can be better identified, leading to better awareness and decreased time to treatment?

Review of Literature

Two qualitative studies identified a number of reasons for delays in sepsis treatment, including lack of awareness and knowledge of severe sepsis among patients; patient denial of symptoms to avoid hospitalization; hospital experiences; thwarted attempts to recognize sepsis; and inadequate discharge education about sepsis (Clarke et al., 2015; Gallop et al., 2015). Three studies of adult patients identified 34 sepsis symptoms, but these studies were not specific to older adults (Clarke et al., 2015; Martin, 2012; Younger, P. McClelland, 2014). Even though symptoms are believed to be atypical in older adults, no studies have specifically studied symptoms in this population. Improved knowledge about the symptoms and experiences of older adults is needed.

Methods

The study qualified for Institutional Review Board “exempt” status. Qualitative descriptive data analysis methods were applied (Sandelowski, 2000a, 2010). A constructivist approach was chosen to classify signs and symptoms into themes. Applied goals of qualitative methods are to identify hidden networks, situations, relationships, communications and opportunities in textual data (Charmaz, 2014; Creswell, 2013). For this study, events were identified and classified in the sepsis experience that led to seeking of care.

Sample. Sepsis Alliance allows patients and caregivers to post about their experiences with sepsis on the Faces of Sepsis (FoS) section of its website (Sepsis Alliance, 2017). The FoS section was launched in 2011 and includes more than 700 posts from people of all ages. This study used selective sampling to identify the 25 most

recent posts that met the inclusion criteria. The site's medical director selected the stories using the following criteria: (a) posted after October 2015; (b) featuring older adults identified by stated age or contextual clues; and (c) featuring patients residing at home prior to sepsis diagnosis. The October 2015 date was purposefully chosen to identify stories posted after the sepsis guidelines were implemented in acute care hospitals. All participants signed a consent agreement granting Sepsis Alliance and its affiliates permission to use, publish, or distribute the story without restriction (personal information would not be shared). The original submissions were used for the study, not the edited postings. The submission form asked for the patient's name, a photo, the name and relation of the submitter (if not the patient), and story type ("Survivor" or "Tribute") but offered no advice for content beyond "Story."

The stories were classified as survivor (48%) or tribute (52%). They featured predominantly female patients (68%). Narrators also were predominantly female (80%); many stories were narrated by children of patients (48%) or self-narrated (32%) (see Table 4). An average patient age of 65.2 years old was determined from 11 of the posts. The patient's age could not be determined in the remaining 14 posts, but the text and/or pictures implied the patient was an older adult. Line-by-line coding resulted in 494 unique lines of data. Of those lines, 311 (63%) were about the pre-sepsis diagnosis phase. Post-diagnosis signs and symptoms were excluded from analysis to meet the primary purpose of this study. The posts averaged 510 words in length (range: 152–2007) and occurred in 2016 and 2017. Some posts identified locations, including Italy, England, and the United States.

Table 4

Sample Demographics

Sample Demographics (n=25)				
		Total	Male	Female
Est. Average age	65.2 years			
Patients			8 (32%)	17 (68%)
Narrators			4 (20%)	21 (80%)
Relationship to patient				
Children		12 (48%)	4 (33%)	8 (64%)
Self		8 (32%)	4 (50%)	4 (50%)
Granddaughters		2 (8%)		
Wife		2 (8%)		
Niece		1 (4%)		
Survivors		12 (48%)	9 (75%)	3 (25%)
Victims		13 (52%)	5 (38%)	8 (62%)
% Post-operative		9 (36%)		
Survived		5 (56%)		
Died		4 (44%)		

Data Analysis. Textual data were reduced to line items and then coded and simplified as gerunds for data analysis (Charmaz, 2014). Gerunds were classified into signs and symptoms or other themes for data analysis. Lines of data, gerunds, themes, and aims were categorized in Excel to ease sorting and review within contexts. Frequencies of themes were counted, categorized, and reduced to relevant study aims or residual (Creswell, 2013). Demographic data were abstracted from the posts. An advisory panel reviewed themes and classified aims for agreed categorization. Constant, iterative comparisons of the micro and macro level of sorted data were used to identify overall themes and study aims. A combination of qualitative and quantitative data analysis, or quantizing (Sandelowski, 2000a), was used to compare frequencies of cited events and aims in an overall qualitative approach to data analysis. Qualitative

descriptive methods were chosen because little is known about the sepsis experience in older adults who experience atypical symptoms. Signs and symptoms from the texts were analyzed.

Results

Pre-diagnosis signs and symptoms constituted 159 of the 494 data lines (32%) from the 25 posts. Signs and symptoms included 108 descriptions by family caregivers (67%) and 51 descriptions by patients (32%). Narrators reported an average of five signs or symptoms per person (range: 0–16) for both the observed and experienced events (see Table 5). Sixteen different sources of infection were described, and five patients stated no source of infection (see Table 6).

Table 5

Number of Sepsis Signs and Symptoms per Patient

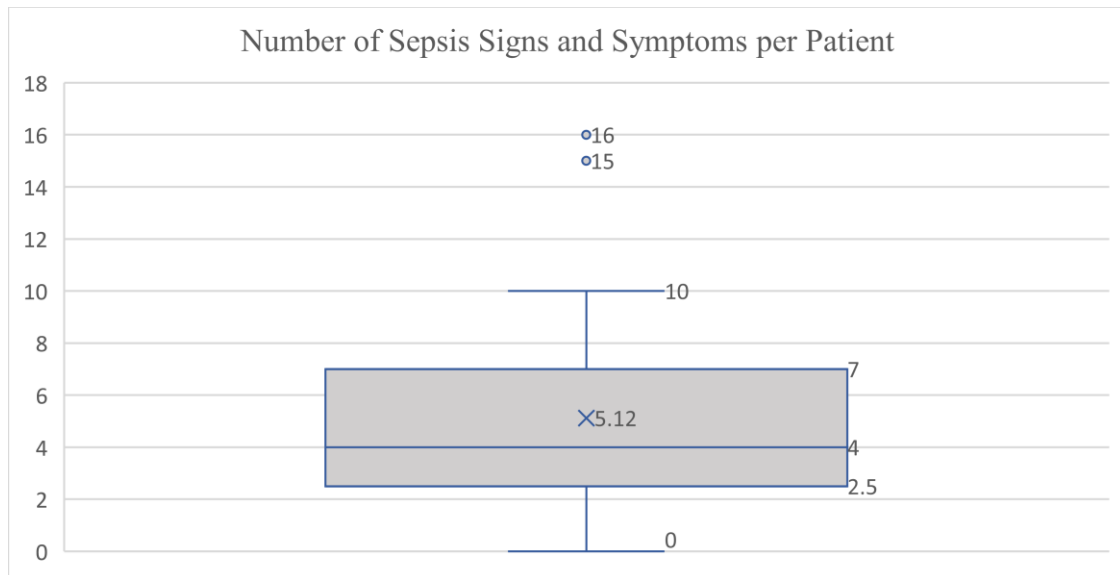


Table 6

Sources of Sepsis Infection

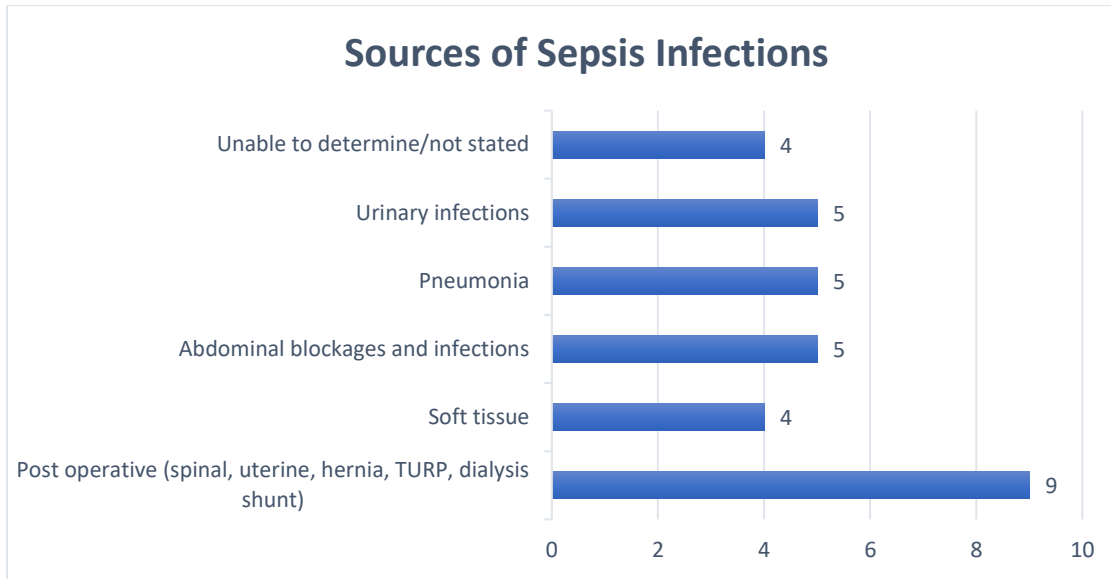
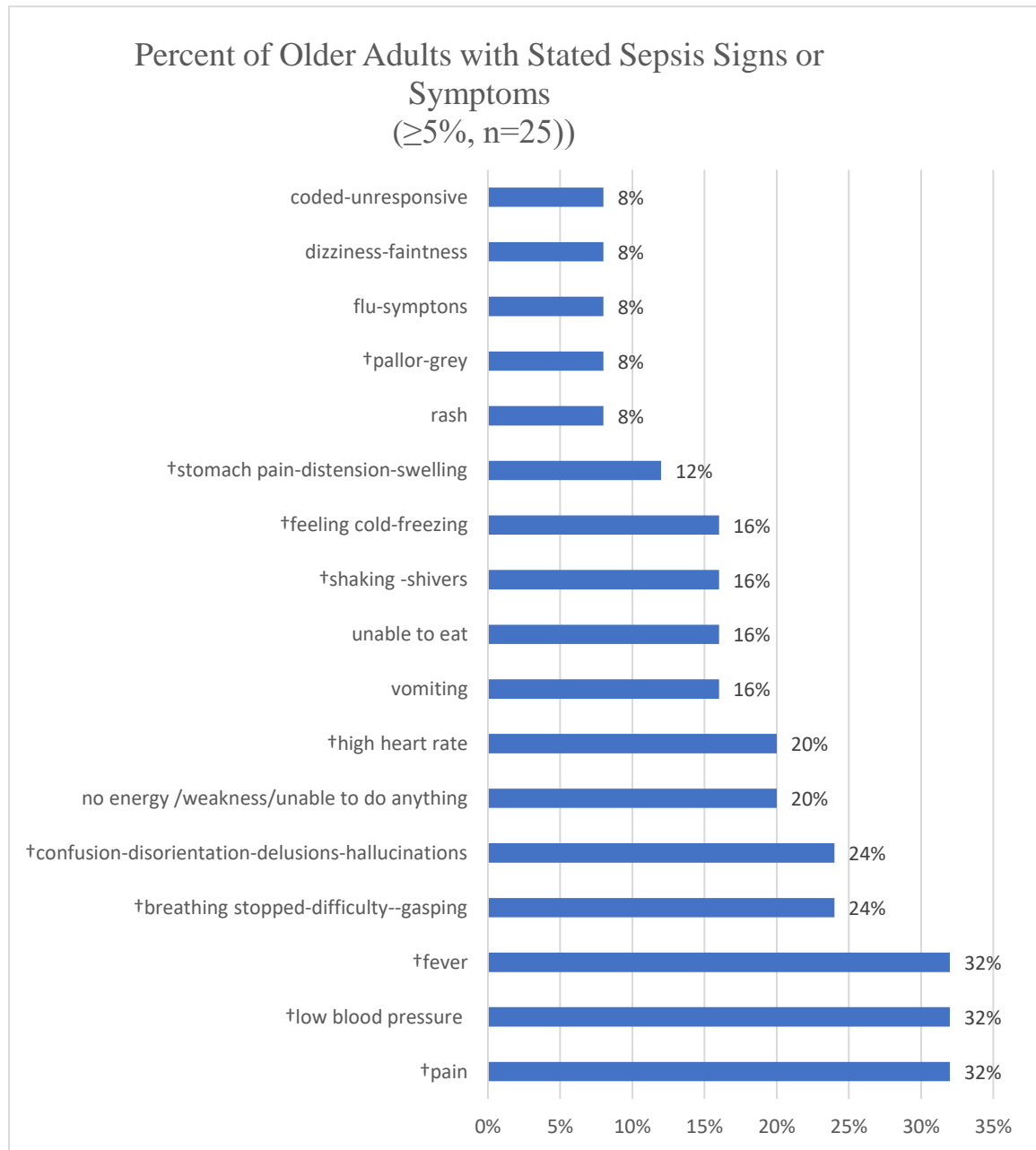


Table 7

Percent of Older Adults with Stated Sepsis Signs or Symptoms



† typical signs, symptoms or sepsis precursors

The most common complaints were fever, pain, and low blood pressure (see Table 7). Patients described pain as “crippling,” “extreme,” “great,” and “excruciating.”

Caregivers described pain as “agonizing” and “severe.” Pain was identified in soft tissue, abdominal, or post-surgical sources but not in pneumonia or urinary tract infections. Changes in cognition such as “confusion/disorientation/hallucinations/delusions” were described for 25% of patients by five caregivers, and one patient described herself as “disoriented.” Further signs and symptoms for patients included “breathing stopped/difficulty/gasping” (24%), weakness (20%), high heart rate (20%), shaking/shivers (16%), and feeling cold/freezing (16%).

Twenty-one patients (84%) had clear stated antecedent events including surgeries, soft tissue infections, urinary tract infections, bowel blockages, cholecystitis, and pneumonia. Two patients had post-surgical wounds with excessive drainage. Four patients (16%) who did not have stated sources of infection died. Five patients (20%) did not have any “typical” sepsis symptoms. Of those five, 80% were post-operative sepsis events. Residual signs and symptoms that were experienced once are listed in Table 8. Six patients had errors of commission or omission in their care during the symptom appraisal process, including missed sepsis diagnoses or pain sources; equipment malfunction; protocol and surgery delays; and inaccurate diagnoses, such as atrial fibrillation instead of cholecystitis.

Table 8

Sepsis Signs and Symptoms in <5% of Patients

Sepsis Signs and Symptoms in <5% of Patients	
Observed	Experienced
Hard to arouse	Organs swelling
Anemia	Internal hemorrhaging
Low potassium	Bug Bites
Agony	Feeling alone
Dehydration	Feeling scared
Falling	Feeling body shutting down
Weight loss	Slurring words
Distressed	Emotional
Couldn't feel legs	Felt like dying
Restless	
Cough	
No Bowel Movement	
Felt worried	

Participants concluded their posts with both disgust and gratitude: “Screw you sepsis!” or “I owe my life to these two hospitals and pray for them and the ICU nurses.” One patient stated, “I collect sepsis stories and educate many people I come in contact with . . . and the sepsis experience has been priceless to my family.”

Discussion

The narrators of the posts were predominantly female, medical patients, sepsis victims’ children sharing stories about their parents. Patients and caregivers viewed the symptoms as a litany of events with no true triggering event indicating the need to seek help. The symptoms were not described in a chronological or escalating order but as a composite of seemingly unrelated complaints, alluding to great difficulty interpreting the events by patients and caregivers. Signs and symptoms were the most prevalent theme in

the posts and reflected a continuous ruminating, even following recovery or death. When seeking information about symptoms, subjects used Google, reviewed patient records, called emergency medical services, and called a doctor. One inpatient nurse and one surgery office nurse were contacted to assist with symptom appraisal. As in previous studies, there was a consistent lack of information given to patients and family, which was summarized as follows: “If we had only known the signs of sepsis,” “Wish more people were aware of sepsis,” “No one explained sepsis” (Gallop et al., 2015).

Similar to previous studies, this study found 16% of cases with unstated or unknown sources of sepsis (Kumar et al., 2006). All patients with unstated sources died. This suggests those with unstated sources of infection have greater mortality risk, so more in-depth assessment of history and pain sources is warranted. Most symptoms were consistent with those included in the Sepsis Alliance SEPSIS acronym. Subjects also were aware of symptoms such as low blood pressure, high heart rate, vomiting, lack of energy, and historical pneumonia and urinary tract infection diagnoses. Patients described pain in more extreme terms, while caregivers described mental status changes in more extreme terms.

Of utmost concern is the number of post-operative events and the lack of forewarning of the possibility of infection or symptoms of sepsis. Patients experienced excruciating pain, a principle symptom of infection. Continued post-operative, acute, or worsened pain and drainage should be carefully assessed by clinicians and reported by family. Like previous studies, this study suggests recommended better discharge education following infections such as sepsis or operative events (Gallop et al., 2015). The unknown variable in these scenarios is length of time from symptom onset to

initiation of treatment. Much time was spent in the symptom appraisal process before patients or caregivers contacted emergency medical services. If social cognitive factors influence help-seeking more than knowledge (Cornally & McCarthy, 2011), it is advisable to quickly seek counsel from medical professionals when assessing symptoms of sepsis. Over half of the post-operative patients were at home at the time of sepsis symptom onset, again suggesting the need for anticipatory guidance for new or worsening infection symptoms and the possibility of sepsis. It is likely that patients with atypical symptoms were simply unaware they had the sepsis symptoms since 74% of people are unaware of sepsis symptoms (Sepsis Alliance, 2016). Fever was not stated by 68% of the patients in this study, greater than the 13% of afebrile patients in a previous study of older adults with bacteremia (Girard et al., 2005; Gleckman, R. Hilbert, 1982).

The patients in this study had a 48% survival rate, which is lower than the 68% rate for Medicare patients in early 2017. Grief and anger were evident in the posts, perhaps prompting a need to submit the story, especially in cases when the patient died. Previous research found only 54% of patients admitted for severe sepsis are transported by paramedics (Seymour et al., 2012). In this study, paramedics diagnosed sepsis in only 25% of cases. While transitions in care are known to be dangerous for older adults (Ham, R. Sloane, P. Warshaw, G. Potter, J. & Flaherty, 2014), increased use of emergency medical services may alert the ED to the sepsis and improve the mortality rate for older adults. Other delays and omissions occurred at hospitals:

“At the second hospital, they started antibiotics twelve hours after she presented to the emergency room. . . . She never received any of the care described in the surviving sepsis guidelines.”

worsened infectious symptoms. Patients and caregivers should be advised to contact a health care professional instead of independently ruminating through the appraisal process with potentially 16 different signs and symptoms, delaying treatment. Help-seeking is enhanced by social cognitive factors (Cornally & McCarthy, 2011), so seeking counsel of clinicians more quickly should hasten the diagnosis. Weakness, vomiting, and loss of appetite were atypical symptoms the patients experienced and may be additional warning signs of sepsis. Severe pain and mental status changes in older adults should seriously be considered symptoms of possible sepsis. Expected cautionary sepsis education may focus on older adults with a recent history of pneumonia, urinary tract infection, surgery, or abdominal pain.

Education on sepsis screening and the timely implementation of the sepsis treatment guidelines needs to be provided to emergency department staff as well as staff at inpatient, outpatient clinic, wound care, and post-operative clinics. It is imperative clinicians follow the standard sepsis guidelines with an expectation of antibiotics within three hours of sepsis diagnosis. Sepsis patients should be given the same time and attention as stroke or myocardial infarction patients in emergency departments and inpatient units. Contacting emergency medicine services for transport may shorten time to treatment by alerting the ED prior to arrival of a sepsis patient.

Pre-existing concomitant medications and illnesses that may mask or alter symptoms in older adults must be considered. Only 32% of older adults in this study had a fever. Medications such as beta blockers and pain relievers that may mask fever or increased heart rates must be reviewed. However, previous recommendations to base fever on older adults with blunted fever responses to one degree from basal body

temperature may be justified instead of a standard concern for a temperature over 101.5°F (Lu et al., 2013). Further research to identify delays in the symptom appraisal process in a larger sample of older adults or through interviews may provide additional insights to reduce time to treatment for sepsis.

Chapter Four

Help-Seeking by Older Adults in Faces of Sepsis™

Sepsis is a life-threatening condition that arises when the body's response to infection injures its own tissues (Singer et al., 2016). Patients rapidly decline from sepsis to septic shock if timely treatment is not initiated (Dellinger et al., 2013). Sepsis is the most expensive diagnosis for older adults in the United States, with 1.1 million cases costing \$20.3 billion annually (Torio & Andrews, 2013). Sepsis costs an estimated \$20,000 per admission (Sutton & Friedman, 2013). Each hour delay in effective antibiotic therapy increases mortality by 7.6% for septic shock patients (Kumar et al., 2006). Paramedics transport only 54% of patients admitted for severe sepsis (Seymour et al., 2012). In October 2015, the Centers for Medicare and Medicaid Services began measuring hospital compliance with sepsis bundles, which were established to reduce sepsis mortality by implementing standardized sepsis care and reducing time from symptom onset to treatment ("Centers for Medicare & Medicaid Services: Measures," 2018). Delays can occur when symptom terminology differs in patient and clinical descriptions. Delays may be categorized into five domains: (1) intervention, (2) outer setting, (3) process, (4) inner setting, and (5) individuals (patients) or systems (Herlitz et al., 2012; Weiss, 2017). Understanding the patient's subjective experience may improve the clinician's understanding of precipitating sepsis signs and symptoms.

This study analyzes stories about older adults' experiences with a sepsis diagnosis featured on the website of Sepsis Alliance, which aims to "save lives and reduce suffering by raising awareness of sepsis as a medical emergency" (Sepsis Alliance, 2016). On the Faces of Sepsis™ (FoS) section of the website, patients and caregivers

post stories about their experiences with sepsis. Analysis of the content of these stories may provide insights to improve time to treatment, which is defined as the time from symptom onset to initiation of antibiotics and fluid resuscitation. By understanding how patients and caregivers describe the sepsis experience, we can better summarize the felt symptoms and signs, improve symptom assessment for older adults, and guide education for patients, families, caregivers, and clinicians. Ultimately, we can develop patient-centered interventions that will reduce time to treatment, raise awareness, and decrease suffering. To help patients remember the symptoms of sepsis, Sepsis Alliance (2016) developed the acronym SEPSIS: Shivering, fever, or very cold; Extrême pain or general discomfort (“worst ever”); Pale or discolored skin; Sleepy, difficult to rouse, confused; “I feel like I might die”; and Short of breath. Little is known about when older adults or their caregivers seek care for sepsis.

Study Aims

This qualitative descriptive study explored online narratives written by older adults and their caregivers about their experiences with a new sepsis diagnosis. The specific aims of the study include the following:

1. Describe the self-management strategies patients and their caregivers attempt before seeking care in the emergency department (ED).
2. Describe interactions among older adults, their caregivers, and health care providers from the time symptoms are identified at home to when emergency care is sought.
3. Describe the barriers encountered by older adults with sepsis and their caregivers in seeking care in the ED.

Experiences that were classified outside these aims were analyzed for emergent themes.

Review of Literature

In 2016, 55% of Americans had heard of sepsis yet 74% incorrectly identified or were unsure of key symptoms (Sepsis Alliance, 2016). Symptoms of infection are thought to be atypical in the older adult. For example, a primary sign of infection is fever, yet fever is often absent in older adults (Girard et al., 2005). Medicare patients who are treated for severe sepsis and septic shock with the sepsis bundle have a 79% in-hospital survival rate compared with a 68% survival rate for those who do not get the bundled care (Uppal & Dickerson, 2017). Before the sepsis bundle was implemented, patients treated for septic shock had a 44% in-hospital survival rate (Kumar et al., 2006).

Transitions can be intra- or inter-facility but are known to be dangerous, especially for older adults with multiple co-morbidities (Ham, R. Sloane, P. Warshaw, G. Potter, J. & Flaherty, 2014). One barrier during transitions is that older adults are passive in interactions with providers and try not to be perceived as complainers or burdensome to caregivers (Ham, R. Sloane, P. Warshaw, G. Potter, J. & Flaherty, 2014). It is important to understand patients' health histories to recognize changes in condition and function.

Help-Seeking Theoretical Model

Deciding to seek help is a complex process that often has no experiential precedent. Help-seeking is defined as “a problem focused, planned behavior, involving interpersonal interaction with a selected health-care professional” (Cornally & McCarthy, 2011, p. 280). Symptom appraisal is an antecedent to help-seeking, which is associated

with self-efficacy (Cornally & McCarthy, 2011). Deciding to act is influenced by social cognitive factors with only moderate effects from knowledge and awareness (Bandura, 1986; Cornally & McCarthy, 2011). With sepsis, the patient's or caregiver's help-seeking is influenced by symptom appraisal, interactions with others, self-management strategies, and perceived barriers.

Methods

This study qualified for Institutional Review Board "exempt" status. Qualitative descriptive data collection and analysis methods were applied (Sandelowski, 2000b, 2010). A constructivist approach was chosen to identify hidden networks, situations, relationships, communications, and opportunities in textual data to identify and classify events in the sepsis experience (Charmaz, 2014; Creswell, 2013).

Sample. Sepsis Alliance allows patients and caregivers to post about their experiences with sepsis on the Faces of Sepsis (FoS) section of its website ("Sepsis Alliance: Faces of Sepsis," 2017). The FoS section includes more than 700 posts from people of all ages. This study used stratified purposeful sampling to identify the 25 most recent posts that met the inclusion criteria. The site's medical director selected the stories using the following criteria: a) posted after October 2015 (when the Centers for Medicare and Medicaid Services implemented the sepsis bundle); b) featuring older adults as patients as identified by stated age or contextual clues; and c) featuring patients residing at home prior to sepsis diagnosis. All participants signed a consent agreement granting Sepsis Alliance and its affiliates permission to use, publish, or distribute the story without restriction (personal information would not be shared). The original submissions were used for the study. The submission form asked for the patient's name, a photo, the name

and relation of the submitter (if not the patient), and story type (“Survivor” or “Tribute”) but offered no advice for content beyond “Story.”

The patients consisted of 12 survivors (48%) and 13 victims (52%) and 8 males (32%) and 17 females (68%). Eight (32%) of the stories were written by the patient, while 12 (48%) were written by a patient’s child; two (8%) by a patient’s grandchild; two (8%) by a patient’s wife; and one (4%) by a patient’s niece or nephew (4%) (see Table 9).

Table 9

Sample Demographics

Sample Demographics (n=25)				
		Total	Male	Female
Est. average age	65.2 years			
Patients		25	8 (32%)	17 (68%)
Narrators		25	4 (20%)	21 (80%)
Relationship to patient				
Children		12 (48%)	4 (33%)	8 (64%)
Self		8 (32%)	4 (50%)	4 (50%)
Granddaughters		2 (8%)		
Wife		2 (8%)		
Niece		1 (4%)		
Survivors		12 (48%)	9 (52%)	3 (38%)
Victims		13 (52%)	5 (63%)	8 (47%)
% Post-operative				
Survived		5 (56%)		
Died		4 (44%)		

Specific ages were stated in 11 posts, with an average of 65.2 years. The patient’s age could not be determined in the remaining 14 posts, but the text and/or pictures implied the patient was an older adult. Line-by-line coding resulted in 494 unique lines of data. Of those lines, 311 (63%) were about the pre-sepsis diagnosis phase and were retained for data analysis. The 183 lines (37%) about the post-diagnosis stage were excluded

from analysis because they did not pertain to the primary purpose of this study. The posts averaged 510 words (range: 152–2007) and occurred in 2016 and 2017. Identified locations of the events included Italy, England, and the United States.

Data Analysis. The stories were reviewed within the specific aims and for emergent themes. Textual data were reduced to line items and coded as gerunds of thoughts, actions, and feelings (Charmaz, 2014) (Charmaz, 2014). The gerunds were then classified into themes and aligned with aims or residual categories. Lines of data, gerunds, and themes were categorized in Excel to ease sorting and review within contexts. Frequencies of themes were counted, categorized, and reduced to relevant study aims or residual (Creswell, 2013). Demographic data were abstracted from the posts. An advisory panel reviewed themes and classified aims for agreed categorization. Constant, iterative comparisons of the micro and macro level of sorted data were used to identify overall themes and study aims. A combination of qualitative and quantitative data analysis, or quantittizing (Sandelowski, 2000a). was used to compare frequencies of cited themes and aims in an overall qualitative approach to data analysis. Qualitative descriptive methods were chosen because little is known about the sepsis experience in older adults who experience atypical symptoms

Data lines were classified by the study aims into signs and symptoms, self-management strategies, interactions, barriers, and residual. Data lines for the post-diagnostic timeframe or referring to signs and symptoms or residual classifications were omitted from analysis. Pre-sepsis diagnosis data lines and data lines referring to self-management strategies, interactions, or barriers were retained for analysis.

Results

The 494 data codes were further classified into the primary study aims: signs and symptoms (n = 239, 48%), self-management (n = 33, 7%), interactions (n = 34, 7%), barriers (n = 63, 13%), and residual (n = 125, 25%). Signs and symptoms were reserved for later data analysis. Residual data codes were reserved for data analysis for emergent themes. Study aims were analyzed from 143 data lines.

Implementing Self-Management Strategies. Specific quotes are in Table 10. Three themes of self-management were identified: (1) information-seeking, (2) medical care-seeking, and (3) medicating. In 15 of the 25 posts (60%), self-management strategies were identified prior to the sepsis diagnosis. Both patients and caregivers employed the self-management strategies.

Table 10

Exemplary Quotes

Theme	Exemplary Quotes
Implementing Self-Management Strategies	
Information seeking.	When I Googled “septicemia, I blanched. It sounded terrible.
	When he arrived (home) via medical transport I looked at his release papers. It took me a while to find the “septicemia in the paperwork.
	Why didn’t anyone at the hospital or any of his doctors tell us that he had or could have sepsis? By the time I had hunted for his diagnosis on the paperwork sent home, he probably had the beginnings of what would become sepsis. There were no checklists for us—nothing that would have ever led us to believe that this infection would kill him.
Medical care seeking and medicating.	Treated the pain with the usual antacids and Tylenol and tried to go back to sleep
	My brother and I decided almost immediately to bring her home via air ambulance. It took us 4 days to arrange a flight and, with difficulty, obtain discharge from the Italian hospital. Mom and I flew home on a tiny Lear jet ambulance, stopping every 4 hours to refuel.
	Paramedics who attended to her knew instinctively what the problem was and admitted her to the hospital
Seeking Interactions	
	My mother called me up and said he wasn’t doing well but I thought she was probable being dramatic. I finally got to visit him at the rehab center. I could see my mother was not being dramatic.
Overcoming Barriers	
Hospital services	This time it was decided NOT to send her to the original hospital who dismissed her sickness and discharged her even after we begged them not to.
	Attended a wound clinic at my hospital but sent home with some soft packing for wound but still in extreme pain in joints. (Five days later) I was unable to eat or move comfortably
Delays	says he would not do surgery till the following day in the morning. Once again, we waited all day, then sometime about 6-7 they send my mom back to her room and told her no surgery that day again, but then about 10:00pm they come back to take my mom into surgery
	With my mother answering those questions correctly and then saying that she didn’t want to go the ER, the EMS allowed her to stay home. Even though she had all the hallmark symptoms of sepsis: fever, difficulty breathing, low blood pressure, fast heart rate, and mental confusion, they allowed her to stay home.

Inexperience, omissions & errors	Entering his room, every light in his room was on. I could see his IV had slipped from his arm and was dripping on the floor; his bed was soaked with blood from an open vein. His urinary bag was empty but there was no intake or output charted. My husband’s heart rate was 140, temp 103 and the new nurse that walked in greeted me with a smile. “He’s doing fine!” she said brightly.... I wanted to scream and yell and slap that young nurse but instead I picked up the phone and called a Rapid Response.
	Our mom was 64 and in generally good health...She had multiple signs of sepsis and even though protocol was in place and an alert was given, the doctor ignored it and missed our chance.... After 4 days of trying everything, our lovely mom passed away.
Gratitude	I realize how fortunate I have been after reading about so many losses and what other survivor's experienced. Thank all of you for sharing. I hope I can help someone through recuperation.
	We are truly Blessed that she is still alive and will take whatever struggles GOD gives us and we thank GOD every day for Blessing us with our beautiful mother and grandmother

Information seeking for advocacy. Information-seeking came from four sources:

(1) reviewing discharge paperwork, (2) “Googling” septicemia, (3) using personal medical knowledge to guide sepsis diagnosis and care, and (4) contacting health care providers or family members with questions. In one post, the narrator was a wife and a nurse. To self-manage, she asked for six items. Because staff were unsuccessful at inserting a nasogastric tube, the wife asked for topical lidocaine gel and bed repositioning to manage the insertion. She also requested a blood pressure assessment and an explanation for finding her husband with an IV line hanging and dripping blood while he was tachycardic and febrile and had no urine output. She requested blood sampling for heart failure assessment, and a Rapid Response call for suspected sepsis.

Medical care seeking and medicating. Medical care-seeking occurred during 15 different hospital admissions for 12 patients (48%). One patient (27%) and 11 caregivers (73%) requested care. Multiple other hospital, rehabilitation, or long-term care

transitions during the post-diagnosis phase were cited. The total number of transitions between home, EDs, hospitals, rehab facilities, and extended care facilities averaged 3.3 (range: 1–7) per post. Paramedics made the initial sepsis diagnosis for two patients. Only one caregiver discussed self-medicating for severe abdominal pain associated with the sepsis. Patients and caregivers self-managed by calling emergency services, a doctor’s office, and family members for information. Some transitions were also perceived as barriers to care.

Seeking Interpersonal Interactions. The narrators sought interactions from the doctors, health care professionals, the patient, or other family members during the pre-sepsis diagnosis phase in 14 (56%) of the posts. The health care professionals included nurses, doctors, and paramedics. Interactions involved confirmation of symptoms, sharing concerns of the possibility of sepsis, advising emergency care, and explaining gravity of symptoms. Nine of the 10 (89%) interactions with health care professionals were in person and one was via telephone. When an interaction between the narrator and the patient occurred, often it was to visually confirm symptoms and the need for a higher level of care or to contrast current and prior symptoms.

“I had been awake for nearly 24 hours and I craved a shower and a nap. Four hours later he called me. ‘I’m in trouble!’ he said. ‘I need you to come back.’ There was an odd sound to his voice, but I didn’t question his concerns and I flew back to the hospital.”

“He was sitting on the sofa talking to me when I left for work and 5 hours later he was this ill.”

One sister consulted with her brother prior to transporting their mother home from outside the United States. One male was experiencing post-surgical fatigue and flu-like symptoms, and his wife consulted with their daughter.

Overcoming Barriers. Of the pre-diagnostic aims of this study, the most frequently cited line item was barriers. Barriers were classified into hospital services, delays, education, inexperienced staff, errors, and omissions. Sixteen of the 25 posts (64%) had barriers identified in the pre-sepsis diagnosis phase.

Hospital services. Hospitals either were not able to care for the patient or provided inadequate care. Some patients were quickly transferred to a different hospital where the family expected the appropriate level of care for sepsis, at the request of both the family and the hospital staff. One patient had a persistent wound after hip surgery for two months. Five days after being assessed in a wound clinic, the patient was unable to eat or move and was sent to the ED by the nurse from the surgery office and diagnosed with septic shock. Eight of the 25 patients (32%) were readmitted to the hospital. One family member stated, “Once she got to a rehab facility, it all went downhill from there.”

Delays. Delays in care, including surgeries, hospital admissions, and sepsis diagnoses, were noted for six of the patients (24%). Delays in surgery were noted for four of the patients (16%). Despite being tended to by paramedics, one patient refused to go the hospital when experiencing sepsis symptoms one month after a partial colectomy for diverticulitis. Less than 24 hours later, the patient “couldn’t feel her legs” and was scared and confused. She asked to be taken to the ED, but the narrator complained of a surgery delay to repair the leaking fused colon. Four other posts described delays in hospital admissions despite apparent sepsis symptoms. Two patients were assessed by

physicians in the ED and sent home. Two patients did not receive elements of the sepsis bundles such as fluids, cultures, or lactate levels.

“At the second hospital they started antibiotics, 12 hours after she presented to the emergency room at the first hospital. She never received any of the care described in the Surviving Sepsis Guidelines—no fluid boluses, blood cultures, or lactate levels. . . . Because my mother was more than 70 years old, she was not being treated aggressively. She did not meet the admission criteria for ICU because of her age and diagnosis. . . . My brother and I decided to immediately bring her home via air ambulance.” (The event occurred outside the U.S.)

Educational deficits of patients and family members were identified in the posts.

Four family members were completely unaware of sepsis and were quoted as saying,

“What is sepsis?” and “We had never heard about sepsis!”

“My entire family struggles every day with ‘what if’s’—had we only known the signs of sepsis, this would have had a very different outcome. Every chance we get we will tell her story [and] educate people on the signs of sepsis.”

“What I still don’t understand is: Why didn’t anyone at the hospital or any of his doctors tell us that he had or could develop sepsis?”

The niece of one 66-year-old patient, who experienced delays in care, stated:

“We can send people to another planet, but we can’t fix something that seems so simple. . . . I miss her terribly. Screw you, sepsis.”

Clinical staff also had educational deficits. Clinical staff’s inability to recognize sepsis symptoms resulted in delays in diagnosis even in hospital-onset sepsis and delays in hospital admissions from the ED. One young nurse did not recognize sepsis in the post-operative patient. In other incidents, sepsis was misdiagnosed or minimized as a

rheumatoid arthritis flare-up of pain, atrial fibrillation, a non-septic surgical wound, an oral gum infection, a foot infection, and sciatica.

Inexperience, omissions, and errors. Inexperienced staff, omissions, and errors plagued seven of the patients (28%). One wife, who was also a nurse, overcame the inexperience of staff and anticipated errors by claiming to be a “guard dog,” sitting by her husband’s bedside for 60 days to intercept and prevent 15 medical errors. Signs and symptoms of sepsis were not identified in a timely manner, causing fatal delays in treatment. One caregiver expressed grief for not getting a second opinion and encouraged others to advocate “when ‘something just doesn’t feel right’ with your body or medically.”

“Our mom was 64 and in generally good health. . . . She had multiple signs of sepsis, and even though [a] protocol was in place and an alert was given, the doctor ignored it and missed our chance. . . . After 4 days of trying everything, our lovely mom passed away.”

Emergent Themes. Additional themes emerged. When discussing the pre-hospital experience, posts often focused on grief, gratitude, transitions in care, precipitating events, medical procedures, and historical quality of life (see Table 10). Eight of the patients were re-admitted to the hospital either following a surgical procedure or after enduring sepsis.

Grief. The patients and caregivers expressed grief over not knowing the sepsis was severe enough to cause death. They also lamented not getting enough timely information to prepare themselves for death or post-hospitalization conditions (Gallup, 2015). Grief was especially evident in posts when there were unanswered questions, such as no definitive source of infection, and the patient died.

Gratitude. Despite barriers in navigating the health care system, narrators expressed gratitude to God, four doctors, five nurses, and the Sepsis Alliance website during the post-diagnosis phase (see Table 10). They were grateful for education, diagnoses, hospital care, home care, and therapists.

“I realize how fortunate I have been after reading about so many losses and what other survivors experienced. Thank all of you for sharing. I hope I can help someone through recuperation.”

Quality of Life. As narrators sifted through medications, considered co-morbid conditions, and progressed through the symptom appraisal process, they often described the patient’s pre-hospital quality of life, including the patient’s interests, activity level, and characteristics. The review not only accentuated the change in conditions, but also allowed the narrator to therapeutically reminisce about the patient.

Transitions. When patients transitioned to different levels of care such as an intensive care unit or hospital, caregivers recognized and described intense treatments, personal turmoil and grave concern. Transitions to the hospital were most often initiated by caregivers while many inner hospital transfers were initiated by clinicians. Seventy-six transitions were described.

Discussion

This is the first study to provide qualitative analysis of the sepsis experience of older adults. By allowing patients and caregivers to share their suffering, barriers, and self-management strategies, Sepsis Alliance accomplishes its mission to raise awareness and reduce suffering from sepsis through catharsis and education. One daughter stated, “I share this story in hopes that people realize the importance of getting a second opinion when ‘something just doesn’t feel right’ with your body or medically.” While grief is

evident in this social media, the media use may influence or mediate the nature of grief itself (Andrew, 2014). The grieving process is aided by this cathartic writing,

Caregivers emerged as advocates from the observer role. Tension between health care providers, patients, and caregivers was evident in the texts, with emerging advocacy to overcome barriers when possible. Barriers were cited more frequently than self-management strategies or interactions. The emergent themes showed a range of emotions and means of coping with the experience.

Limitations. This study provided a perception of care through the lens of patients and caregivers, who wrote passionately about care for older adults with sepsis. Detailed medical conditions and co-morbid conditions that affected symptom appraisal and perceptions were not corroborated by medical chart reviews. Despite the limited perceptions for data analysis, understanding the patient experience is an important element to bridge the gap between clinical assessments of signs and the patient's description of symptoms.

Conclusion. This descriptive analysis of sepsis care for older adults provides many opportunities for improvements in care that can save lives. Listening to patient and caregiver concerns can help identify potential barriers. As partners in care, patients and caregivers should be encouraged to speak up when they have concerns about care, including delays. Older adults often have engaged caregivers as partners in their care, and these caregivers should be perceived as a valuable resource instead of an adversary. The study identified two opportunities for education: (1) sepsis awareness for the general public, and (2) adherence to sepsis screening and treatment guidelines for clinicians,

including those at outpatient wound care clinics. Patients and caregivers should consult emergency medical services to assist with symptom appraisal as appropriate.

The narrators discussed multiple transitions in care, which are known to be dangerous. Consistent transition communications between clinicians and with patients and families will prevent errors. Understanding the older adult's function and quality of life prior to sepsis may highlight the gravity of symptoms and be the impetus for action. Finally, older adults and their caregivers need anticipatory guidance about the risk and symptoms of infection, especially following operative procedures, pneumonia, urinary tract infections, and wound care and with abdominal pain.

Chapter Five

Summary

The purpose of this research was to describe the experiences of older adults and their CGs when sepsis symptoms are developing. The goal was to understand, from the perspective of patients and CGs, the experienced signs and symptoms, self-management strategies, interactions with others, and barriers when seeking help for sepsis signs and symptoms. Older adults are known to have atypical symptoms of infection. The underlying question was: How can the public, patients, and health care clinicians navigate the course from symptom onset to treatment in the most expedient manner?

Since the research was completed, more concerning statistics about sepsis survival have emerged. Each year, approximately 14 million patients with sepsis survive to hospital discharge. Only 47% of Medicare patients who were hospitalized for severe sepsis and septic shock in the first quarter of 2017 received treatment according to the sepsis guidelines (Uppal & Dickerson, 2017). There is an 8% better mortality rate for Medicare patients with severe sepsis and septic shock who receive the care guidelines compared to those who do not (31% vs. 23%) (Uppal & Dickerson, 2017). In a study of post-hospitalization experiences, half the patients recovered, and one-third died the subsequent year. Of those who survived hospitalization, 20% were re-hospitalized within 30 days and 40% were re-hospitalized within 90 days (Prescott & Angus, 2018; Reddy et al., 2018). Sepsis is the most common discharge diagnosis for Medicare patients who are re-hospitalized within 30 days.

Because of multiple chronic conditions and altered immune responses, older adults are at greater risk of death and post-sepsis impairments (Nasa et al., 2012).

Patients experience persistent functional and cognitive limitations and mental health problems, including anxiety, depression, post-traumatic stress disorder, and exacerbations of chronic illnesses (Prescott & Angus, 2018). Improving time to treatment with effective sepsis guidelines, including antibiotics and fluid replacement therapy, can reduce mortality and impairments resulting from sepsis, especially for older adults (Kumar et al., 2006). The opportunity to treat patients before sepsis has progressed to severe sepsis or septic shock requires earlier arrival at the ED. No published studies have focused specifically on the experiences of the older adult or their CGs when they are at home, deciding whether to seek medical care for sepsis. This research specifically focused on help-seeking experiences for sepsis by older adult patients and their CGs.

Using qualitative descriptive methods of analysis, two samples were studied. The first sample included nurse-caregivers and a nurse-patient hospitalized for sepsis. The second sample included older adult patients and CGs featured on the Faces of Sepsis (FoS) section of the Sepsis Alliance website.

The first aim of the research was to describe the experienced sepsis signs and symptoms for older adults. The nurse-caregivers and nurse-patient appraised symptoms for as little as four hours and as long as two weeks before receiving emergency medical care in the three interviews, encountering barriers along the way. In both samples, the CGs noticed mental status changes as severe as hallucinations and delusions as well as functional deteriorations including disinterest in usual activities, weakness, listlessness, and fatigue. The patients described cold shivers and excruciating pain, especially when the source of sepsis was an abdominal or soft tissue infection or when the sepsis occurred post-operatively. Most sepsis symptoms aligned with the SEPSIS symptoms acronym

(Sepsis Alliance, *Definition of Sepsis*, 2016) except for confusion and being unable to eat. The sources of infection aligned with previously published findings such as urinary tract infections, pneumonia, and abdominal problems, but in 33% of interviews and 36% of stories, they were post-operative events. Those patients without an identified source of sepsis died. The average number of described symptoms was 5 (range: 0–16). Descriptions of concomitant diseases and medications clouded the symptom appraisal process for patients and CGs. Conscious sorting of new or pre-existing symptoms and their possible association with infections in the patient was evident in the stories. Complaints of fever, low blood pressure, and pain were present in 32% of the FoS patients, followed by breathing difficulties and confusion in 24% and tachycardia and weakness in 20%.

The second aim of the research was to describe self-management strategies employed before seeking emergency care for sepsis. Self-management strategies were categorized as information-seeking, medical care-seeking, and medicating. Computer searches, application of personal knowledge to appraise symptoms, and contacting health care providers or family to discuss symptoms were documented. The patients and CGs in the study requested specific medical care such as cultures, blood test results, blood pressure readings, transports to a different hospital, care level or continent, and calling a Rapid Response team while at the hospital. The patients self-managed with pain medications. Self-management strategies often transitioned to advocacy by or for the patient.

The third aim of the research was to describe interactions among older adult patients, their CGs, and health care providers from the time symptoms are identified at

home to when emergency care is sought in the ED. Interactions were mostly face-to-face rather than through telehealth technology. Tension was evident in personal interactions in both the interviews and the stories. The nurses primarily sought ED care early, and those three patients survived sepsis hospitalizations. The purpose of the interactions was to confirm symptoms, share concerns of the possibility of sepsis or worsening infection symptoms, and suggest interventions. CGs described discussions with patients or a need to visually confirm symptoms.

The final aim of the research was to assess barriers to sepsis care. Compared to the previous aims, barriers were the most frequently cited concern. In the three interviews, the informants discussed barriers to care such as a patient refusing emergency care, emergency care providers sending a patient home only to be hospitalized the following morning, complacency toward getting cultures in an outpatient would clinic, and a possible “failure to rescue” suggestion by a nurse that “pneumonia is a Parkinson’s patient’s friend.” The barriers were classified as hospital services, surgery delays, education of patients and staff, inexperienced staff, patients or hospital personnel denying the severity of symptoms, errors, and omissions. When confronting barriers and trying to advocate for the patient, CGs, at times, did not believe their concerns were taken seriously, resulting in requested transports to another hospital or continuously sitting at the patient’s bedside to monitor care.

Other themes emerged from the data, including grief, gratitude, discussions of historical quality of life, multiple care level transitions, and descriptions of medical procedures and precipitating events. Within the emergent themes, the discussions

seemed cathartic and allowed progression in the grieving process. Anger and frustration were evident as CGs became vocal advocates for patients.

Strengths

This is the first study to describe and classify sepsis signs and symptoms, self-management strategies, interpersonal interactions, and barriers during the pre-hospitalization phase for older adults. It also is the first study to focus on the pre-acute phase of sepsis in older adults, who are known to have atypical symptoms of sepsis. Qualitative research methods were used to understand the experience of sepsis by older adult patients and their CGs. Qualitative analysis of a subset of the FoS posts and nurse interviews are novel approaches to understand the sepsis experience of older adults and subsequently suggest interventions to improve care. Because the FoS posts included both victims and survivors, the experiences of those who died from sepsis and those who survived were able to be analyzed. Descriptions of the sepsis process are necessary before theoretical models can be accurately applied to the sepsis experience.

Limitations

The interviews allowed more in-depth questioning than the stories, but the stories were specifically what the patients and family members wanted to share. Understanding the context of care from health care providers' perspective and the medical documentation in the scenarios would be beneficial to further analyze the symptom onset to diagnosis trajectory. This study focused only on the pre-hospital phase of sepsis for patients living at home and sepsis that develops from long term care environments represents another data source to potentially improve care for the older adult with sepsis. Finally, this study was retrospective in design. Interviews of patients, caregivers, and

clinicians closer to the time of diagnosis may yield additional insights for older adults with sepsis.

Future Research

The studies have implications for further research. More analysis of sepsis stories with a focus on the time following the diagnosis of sepsis to death or recovery is needed to identify interventions to improve outcomes. Research on decision-making by EMS clinicians affecting compliance with sepsis guidelines may improve hospital care processes. The existing data within FoS stories includes pediatric patients, who also have atypical symptoms. Similar research is needed in the pediatric population to understand symptom evolution, self-management strategies, parent and child perceived experiences, and barriers to care. Interviews with patients, CGs, and hospital clinicians immediately following diagnosis or hospitalization is needed. Research to improve time to treatment, hospital care processes, discharge education, and post-hospital care is needed to improve sepsis outcomes.

Conclusion

The data suggest several interventions to reduce barriers in care. Patients who had no source of infection cited in the stories died. Earlier access to EMS or primary care providers, who can relate the health history to current symptoms, may improve treatment by identifying the source of infection. Engaging CGs as partners and quickly addressing their concerns may reduce hospital delays and errors. The study also has implications for education. Patients who experience pneumonia, urinary tract infections, or operative events or have risk factors such as remaining surgical drains, urinary catheters, or skin ulcerations need anticipatory guidance about symptoms of new or worsening infections

and the need for quick emergency care. This may occur in a primary care office or at the time of hospital discharge. In clinical practice, outpatient wound, and post-operative clinics should ask questions about new or worsening infections to consider the possibility of sepsis in vulnerable older adults. Older adults' medications for pain may mask fever, and cardiac medications may prevent a normal sign of infection, tachycardia. Masking of symptoms due to medications and dismissal of infections as normal post-operative symptoms or related to pre-existing conditions are concerns for older adults that can delay treatment. Lastly, older adults and CGs need to know what sepsis is and the possible outcomes so they can mentally prepare. The stories included anger about care and omissions and phrases such as "If we had only known the signs of sepsis" or "I wish more people were aware of sepsis" or "No one explained sepsis." Improved public awareness about sepsis symptoms may prompt earlier identification of sepsis before it progresses to severe sepsis or septic shock. These recommendations can reduce time to treatment and improve outcomes for older adults with sepsis.

Chapter Six

Appendix A

Institutional Review Board Exempt Status

Pre-Hospital Sepsis Care for the Older Adult: Using Qualitative Descriptive Methods to Understand Decision-Making When Seeking Emergency Care

Request an Action	show
Data Validation	show
Print	show
Summary & History	hide
Summary & History	
hide Summary	
Summary	
Sequence 1/1:	
Protocol Number: 1708946799	Initial Submission Date: 08/27/2017
Initial Approval Date: 09/13/2017	Expiration Date: Generated on Approval
Last Approval Date: Generated on Renewal Approval	Type: Exempt
PI: Buelow, Janice M	Status: Exempt
Title: Pre-Hospital Sepsis Care for the Older Adult: Using Qualitative Description Methods to Understand Decision Making When Seeking Emergency Care	
Personnel:	
Name Role Affiliation Unit(s)	
1 Buelow, Janice M Principal Investigator IU IN-NURS : NURSING	
2 Hancock, Rebecca Diane Co-PI Student/Fellow/Resident IU IU-UNIV : UNIVERSITY LEVEL	
Attachments:	
File Name Attachment Type Description Last Updated Last Updated By Action	
Hancock Sepsis Interviews 20170827.docx Protocol: Other Semi-structured interview guides for patient or caregiver. 08/27/2017 09:23 PM redhanc view	
Funding Source:	
Funding Type Funding Number Sponsor Name Sponsor Type Prime Sponsor Name Prime Sponsor Type	
1 Unfunded	
Participant Types:	
Description Count	
1 Total 10	
Organization:	
Organization ID Organization Type Contact FWA Number	
1 900011 Indiana University Performing Organization Talbott, John : 980 Indiana Avenue, Room 2232, Indianapolis, IN 46202-2915 FWA0003544	
Additional Information:	
FDA IND or IDE #: IU or Investigator held IND/IDE? Y/N: Reference ID2:	
Summary/Keywords:	
show Submission Details	

Protocol 1708946799 Exempt

irb@iu.edu <irb@iu.edu>

Wed, Sep 13, 2017 at 12:30 PM

To: jbuelow@iu.edu, redhanc@iupui.edu

The IRB protocol number 1708946799, Principal Investigator Buelow, Janice M has had the action "Protocol Exempt" performed on it.
The action was executed by Cook, Heather L.. Additional information and further actions can be accessed through the Quali Coeus system.

Appendix B

Institutional Review Board Exempt Status

Online Blogs of the Sepsis Experience:

A Qualitative Descriptive Analysis of Victims' & Survivors'

Secure | <https://apps.iu.edu/kc-prd/protocolMedusa.do#topOfForm>

Request an Action [show](#)

Data Validation [show](#)

Print [show](#)

Summary & History [hide](#)

Summary & History

Summary

Sequence 1/1:

Protocol Number:	1708947195	Initial Submission Date:	08/27/2017
Initial Approval Date:	09/14/2017	Expiration Date:	Generated on Approval
Last Approval Date:	Generated on Renewal Approval	Type:	Exempt
PI:	Buelow, Janice M	Status:	Exempt

Title: Online Blogs of the Sepsis Experience: A Qualitative Descriptive Analysis of Victims' & Survivors' Experiences

Personnel:

Name	Role	Affiliation	Unit(s)
1 Buelow, Janice M	Principal Investigator	IU	IN-NURS : NURSING
2 Hancock, Rebecca Diane	Co-PI Student/Fellow/Resident	IU	IU-UNIV : UNIVERSITY LEVEL

Attachments:

File Name	Attachment Type	Description	Last Updated	Last Updated By	Action
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Funding Source:

Funding Type	Funding Number	Sponsor Name	Sponsor Type	Prime Sponsor Name	Prime Sponsor Type
1 Unfunded					

Participant Types:

Description	Count
1 Total	50

Organization:

Organization ID	Organization Type	Contact	FWA Number
1 90001: Indiana University	Performing Organization	Talbot, John : 980 Indiana Avenue, Room 2232, Indianapolis, IN 46202-2915	FWA0003544

Additional Information:

FDA IND or IDE #:

2/11/2018

Indiana University Mail - Protocol 1708947195 Exempt



Rebecca Hancock <redhanc@umail.iu.edu>

Protocol 1708947195 Exempt

irb@iu.edu <irb@iu.edu>
To: jbuelow@iu.edu, redhanc@iupui.edu

Thu, Sep 14, 2017 at 9:09 AM

The IRB protocol number 1708947195, Principal Investigator Buelow, Janice M has had the action "Protocol Exempt" performed on it.
The action was executed by Cook, Heather L.. Additional information and further actions can be accessed through the Quali Coeus system.

Chapter Seven

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CURRICULUM VITAE

Rebecca D. Hancock

EDUCATION

Doctor of Philosophy, Indiana University School of Nursing,
Earned at Indiana University Purdue University at Indianapolis 2018

Master of Science in Nursing-Clinical Nurse Specialist Track, Geriatric Focus
Indiana University, Indianapolis, Indiana, 1991

Bachelor of Science in Nursing
DePauw University, Greencastle, Indiana, 1984

PROFESSIONAL EXPERIENCE

Indiana Hospital Association, Patient Safety & Quality Advisor 2017-Present

- Data and Program Management for Hospital Improvement and Innovation Network for Health Research and Educational Trust CMS Grant
- Regional Patient Safety Coalition liaison

Franciscan Health-Indianapolis

Quality Data Analyst 2012-2016

- Manage & report hospital quality dashboards for 240+ departments, 3 hospitals
- Data analysis in Excel and site-specific databases for CMS Core Measures & Hospital Acquired Conditions, Partnership for Patients Grant Management,
- Quantros, EPIC EMR, Business Intelligence System, Care Discovery, Partnership for Patients database reporting
- Excel, Word, Publisher & PowerPoint proficient; Lean 6 Sigma Yellow Belt
- Guest speaker to educate other departments on quality measurement and improvement strategies

Nurse Educator, Nursing Orientation Skills Lab 2011-2012

Indiana University School of Nursing 2010-2014

Research Assistant

- NIH Research Study—Telephone Assessment and Skill-Building (TASK II): a program for family caregivers of stroke survivors—Nurse Intervener

Hancock, Inc., President 1998-2011

Clinical Research Nurse Specialist –Independent Research Consulting

- Self-employed Geriatric Clinical Research Nurse--Alzheimer's Disease, psychosis, pain clinical trials—patient assessment, education, protocol consulting & data management

- Trial coordination for Johnson & Johnson, Myriad, Eli Lilly, Danone, Bristol Myers-Squibb, Janssen, Forest, Uromed, Abbott Pharmaceuticals, Covance

IU Health – Methodist Hospital

Clinical Outcomes Specialist, Quality Department	1996-1998
Geriatric Clinical Research Nurse	1988-1996
Patient Care Manager, Coronary Care	1986-1988
Staff Nurse, Coronary Care	1984-1986

Indiana State Department of Health, Grant Research Monitor 1995-1997

PROFESSIONAL ORGANIZATIONS AND ACTIVITIES

Association of Clinical Research Professionals Certified	1991-Present
Sigma Theta Tau, International Honor Society of Nursing	1984-Present
Methodist Hospital of Indiana Research Review Committee	1994-1998
DePauw University Alumni Steering Committee Co-Chair	1992-1994
Governor’s Indiana State Task Force for Alzheimer’s Disease	1990-1992
DePauw University School of Nursing, Adjunct Faculty	1986-1989

LICENSES & CERTIFICATIONS

ACRP Certified Clinical Research Coordinator	1993-Present
Registered Nurse	1984-Present
Basic Life Support	1983-Present

PUBLICATIONS

Hancock, R., Bender, P., Dayhoff, N., Nyhius, A. Factors Associated with Nursing Interventions to Reduce Urinary Incontinence in Hospitalized Older Adults. *Urologic Nursing*. September 1996. 16(3):79-85.

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Manuscript reviewer and contributor for Medication Administration chapter in: Miller, Anne & Norton, Barbara. *Skills for Professional Nursing Practice*. Appleton Century-Crofts. 1986.

ABSTRACT & POSTER PRESENTATIONS

Rappaport, S.A., Nakra, R., **Hancock R.D.**, Gajderowicz, S.J., Woods, J.R. Efficacy and Quality of Life for Hypnotic Medication in Geriatric Patients (Abstract, Poster Presentation, 1990 American Geriatrics Society Annual Meeting)

Hancock, R., Bender, P, Dayhoff, N. Factors Associated with the Use of Nursing Interventions to Reduce Urinary Incontinence in Hospitalized Older Adults. The National Multi-Specialty Nursing Conference on Urinary Incontinence, paper presentation, Phoenix, January 1994.

Hancock, R., Bender, P, Efficacy of a Nurse Managed Urinary Continence Clinic, poster presentation, Clinical Nurse Specialist and Cost Effectiveness Conference, Indiana University, September 1992.

PRESENTATIONS

Franciscan Health Barbara Cunningham Research Day

- Sprague, A., Heckman, S., **Hancock, R.**, White, J., Baker, K., & Roberson, S. (2015). Surviving Sepsis Campaign Collaborative on the Center for Geriatric Medicine. Saint Francis Nursing Practice Showcase. Indianapolis, IN.
- **Hancock, R.** (2014). Partnership for Patients: Reducing Hospital Acquired Conditions 2012-2014. Saint Francis Nursing Practice Showcase. Indianapolis, IN.
- **Hancock, R.** Partnership for Patients: Reducing Hospital Acquired Conditions 2012-2014, Saint Francis Nursing Practice Showcase, St. Francis Hospital, Nov 2014

Medical Research

- Medical Research for the Older Adult, Older Adult Service and Information System, July 1990, 1992, 1993.

Urinary Incontinence

- Uromed Urethral Occlusion Device, American College of Sports Medicine Foundation, American Association of Women's Health, Obstetric and Neonatal Nursing, American Medical Women's Association, 1995
- Uromed Investigation Panel- Training and Clinical Perspectives, American Urological Association, Las Vegas, April 1995.
- Uromed Device Training Lead, Sweden, November 1995.

Alzheimer's Disease

- Coordinator and co-presenter for development of 4-week Alzheimer's Caregivers' Workshop. Methodist Hospital, Department of Geriatric Medicine, 1992.

RESEARCH

Principal Investigator

- Qualitative Analysis of Older Adults' Experiences with Sepsis, 2017-2018
- Development of a Complexity Rating Tool to Assess the Relative Difficulty of Coordinating Clinical Trial Protocols, 1992-1996

- Comparison of Venipuncture and Arterial Catheter APTT's in Heparinized Patients, 1991.
- Nurses' Beliefs, Attitudes and Knowledge about Urinary Incontinence in the Hospitalized Older Adult, 1992-95.

Co-Investigator

Alzheimer's Disease

- MPC 7869 (R-flurbiprofen) in the Treatment of Outpatients with Mild Alzheimer's Disease, 2005-2009
- Memantine in the Treatment of Alzheimer's Disease in Nursing Home Patients 2004-2006
- Abilify in the treatment of Psychosis in Nursing Home Patients with Alzheimer's Dementia, 2002-2003
- Depakote in the Treatment of Agitation in Nursing Home Patients with Dementia, 2001.
- Risperdal versus placebo in the treatment of nursing home patients with dementia with psychosis, 2000-2003.
- Olanzapine versus Conventional Anti-Psychotics and the Incidence of Tardive Dyskinesia, Nursing Home Study, 1999-2002
- Olanzapine versus placebo versus another atypical antipsychotic in the treatment of Psychosis in Alzheimer's Dementia, 1999-2002
- Olanzapine for Patients with Psychosis Associated with Moderate to Severe Alzheimer's Disease, 1994-1995.
- Xanomeline in Mild-Moderate Alzheimer's Disease, 1991-1995
- Tacrine Treatment IND, 1992-1994
- Oxiracetam in the Treatment of Patients with Cognitive Impairment Associated with Dementia of the Alzheimer's Type, 1990-1991

Urinary Incontinence

- Duloxetine HCI vs Placebo in Patients with Symptoms of Urinary Incontinence and Frequency, May-August 1996
- Uromed Urethral Occlusion Device Study, 1993-1998
- Terodiline for the Treatment of Urge Incontinence in Elderly Outpatients, 1990-1992
- Evaluation of Ditropan SR on the Quality of Life and Economic Impact in Elderly Patients Suffering with Urinary Incontinence, 1989-1990

Cardiovascular

- Dobutamine Stress Telemedicine Echocardiography in the Emergency Department, 1995-1996
- Effects of Antihypertensive Therapy on the Quality of Life in Elderly Females: A Comparative Study of Diltiazem SR, Enalapril, and Atenolol, 1988-1989

- Clinical Evaluation of the Usage and Acceptability of Two Abbott Temporary Cardiac Pacing catheters and Compatible Temporary Cardiac Pacing Lead, October-November 1988

Stroke Caregivers

- Telephone assessment and Skill Building (TASK II)-NIH funded study through IU School of Nursing: Telephone intervention program for stroke caregivers during acute post-hospitalization period, 2010-2014

Depression

- Fluoxetine in Geriatric Patients with Depression 1998-1999
- Fluoxetine / Placebo Trial in Geriatric Patients with Major Depressive Disorder, 1990-1993

Other

- Hill-Rom Critical Care Beds and Time-Motion Study, May-June 1991