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Delays in help-seeking among patients with bloodstream infection (BSI) impact the timeliness of appropriate treatment and contribute to poor outcomes. The purpose of this study was to identify psychosocial factors influencing help-seeking delays among patients with BSI using the Common-Sense Model of Self-Regulation. A qualitative descriptive study using in-depth, semi-structured interviews with 10 former patients diagnosed with BSI was conducted to identify factors influencing patient pre-hospital delay. Three main themes were identified in the qualitative analysis: Gathering Threads for a Tapestry, Weaving the Threads into a Tapestry for a Garment, and Being Clothed and in Their Right Mind. Four men and six women hospitalized at a university medical center with BSI were enrolled and completed all study components. An inability to recognize symptoms of BSI resulted in delayed help-seeking. Participants had difficulty recognizing their experienced symptoms as being related to BSI if they lacked experience with infection or could not differentiate them from symptoms of other chronic comorbid conditions. When reacting to symptoms of BSI, participants searched for their meaning to develop an action plan. Help-seeking is a coping strategy used by all participants, and they all delayed seeking care. Participants encountered facilitators and barriers to help-seeking. Patient-reported outcomes of BSI on their quality of life (QOL) varied widely, from none to major impact. Problems of symptom recognition and lack of awareness for BSI contributed to help-seeking delays in patients with BSI. Many patients with BSI reported enduring impacts on QOL.

A QUALITATIVE STUDY EXPLORING PRE-HOSPITAL PATIENT DELAYS IN SEEKING CARE FOR SYMPTOMS OF SEPSIS

by

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In loving memory of

my father Johnny A. Ruffin, and my mother Pauline W. Ruffin

In honor of

my children Ingrid J. Ruffin, Yaphett J. Ruffin, and Olivia J. Ruffin

APPROVAL PAGE

This dissertation, written by FELICIA RUFFIN, has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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"The race is not given to the swift nor the battle to the strong but to those who endure to the end." (Anonymous)

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CHAPTER I

INTRODUCTION

Pre-hospital patient delay is a common problem among many patients when they experience symptoms of a bloodstream infection that puts them at risk for developing sepsis (Aboud et al., 2017b; Bogale et al., 2017; Launay et al., 2014). The pre-hospital patient delay has been described as the time from the onset of symptoms to the patient's arrival at the hospital where a qualified healthcare professional can diagnose and begin treatment (Clarke et al., 2015). During the pre-hospital phase, patients interact with healthcare providers and others to engage in help-seeking behavior. According to Cornally and McCarthy (2011), help-seeking behavior is a decision-making process that leads to problem-focused, planned action to address a challenging problem. The authors' definition of help-seeking behavior implies that the pre-hospital phase in the help-seeking decision-making process has several components that may include others (i.e., community health workers or caregivers).

Additionally, health care providers (e.g., Emergency Medical Services (EMS) or general practitioners) may be contacted or encountered before admission to the hospital for diagnosis and treatment for symptoms of infection or sepsis. Understanding help-seeking behavior is a means by which to explore and understand the pre-hospital patient delay. Delayed help-seeking behavior impacts the timeliness of appropriate treatment and contributes to high morbidity and mortality rates in patients diagnosed with sepsis (Cornally & McCarthy, 2011; Liu et al., 2017).

The pre-hospital patient delay has been examined in the research literature to determine the interval of delay times and the factors associated with delays in help-seeking. A recent research study in which the authors examined the pre-hospital experiences of patients with neutropenic sepsis showed that the delay in presentation to the hospital ranged from 0 to 68 hours (Clarke et al., 2015). Another study revealed that delays in seeking treatment outside the home were associated with 81% of deaths, where participants delayed seeking treatment by 1 to 2.5 days after recognizing the acute illnesses such as bacterial sepsis and acute lower respiratory tract illness (Bogale et al., 2017). Finally, a study of adult patients who presented to the Emergency Department (ED) for symptoms of infection revealed that the median pre-hospital patient delay time was three days before presenting to the ED (Latten et al., 2019). Although people wait for hours and sometimes days to seek health care for symptoms of an acute illness, researchers know little about why patients delay seeking care when they experience symptoms of sepsis. Delays in seeking care is a barrier to presentation to the hospital where a diagnosis can be made, and antibiotic and other supportive therapies can begin (Clarke et al., 2015). Based on this, a qualitative descriptive study was conducted to describe the sources of information, the illness perceptions, and the experiences of patients diagnosed with sepsis. Furthermore, this study sought to identify factors in the pre-hospital phase that serve as facilitators and barriers to arrival at the hospital when symptoms of infection or sepsis occur.

Delays in the detection and treatment of bacteremia and sepsis are common. Examination of delays in the pre-hospital phase could lead to better patient outcomes when evaluating and treating patients with bacteremia. Bacteremia, also known as bloodstream infection, is the first phase leading to sepsis. Early patient recognition of symptoms can reduce delay times to arrive at the hospital where effective treatment can begin, possibly decreasing morbidity and mortality caused by sepsis (Andersson et al., 2018). Sepsis is a systemic inflammatory response to bacteremia. Bacteremia and sepsis are global problems that affect people of all ages and genders and all socioeconomic, cultural, and racial categories (Baghdadi et al., 2018; Charlet et al., 2017; Launay et al., 2014; Nguyen et al., 2013).

A broad range of individuals is at risk for bacterial infection and sepsis. However, people with compromised immune systems and people with chronic diseases (e.g., diabetes mellitus, acquired immune deficiency syndrome, cancer, and kidney and liver disease) are at higher risk for infection (van Hal et al., 2012). Furthermore, the very young and the elderly are at higher risk for infection (Aboud et al., 2017). Bacteremia is a type of infection associated with high morbidity and mortality rates, ranking among the top seven causes of death in Europe and North America (Nielsen, 2015). Mortality rates vary in some reports between 13% to 30% in Europe and North America, or as high as 80% in some locations such as Bangladesh, Malaysia, and Sri Lanka (Axelsson et al., 2016; Esposito et al., 2017; Schultz et al., 2017). According to Nielsen (2015), the incidence of bacteremia has risen for decades, and the short-term prognosis has seen minimal improvements.

As noted, sepsis and septic shock are complications of bacteremia (Andersson et al., 2018). While bacteremia is the presence of microbes in the bloodstream, sepsis is a potentially life-threatening systemic illness that occurs when microbes release chemicals into the bloodstream (Aboud et al., 2017). Sepsis is an immune response that can rapidly lead to tissue damage, multiple organ failure, and death (Aboud et al., 2017; Minasyan, 2017). The nature of sepsis makes it challenging to define, and therefore, it remains one of the most poorly understood medical conditions (Minasyan, 2017).

Sepsis ranks eleventh as a significant cause of death in the United States, affecting over 1.5 million Americans each year, killing approximately 250,000 (Arefian et al., 2017; Lester et al., 2018; *NVSS - Mortality Tables - Leading Causes of Death - LCWK9*, 2019). Furthermore, sepsis is an established global health threat, with over 35 million cases annually (Arefian et al., 2017). A recent study conducted to evaluate the association between timing of administration of antibiotics and mortality among patients with sepsis found that each hour of delay in antibiotic therapy increases mortality by 9% (Liu et al., 2017). Therefore, timely and quality sepsis care depends on effective preventive interventions and early recognition and treatment (Guery & Calandra, 2019).

The cost of sepsis is difficult to estimate (Arefian et al., 2017). A review of the literature revealed that studies that examine the cost of sepsis estimate hospital cost only or Intensive Care Unit (ICU) cost alone, but few studies consider the indirect cost of sepsis (Arefian et al., 2017). The cost of the care and treatment of sepsis ranges from $16,324 to 51,022 or more per hospitalization, depending on the severity of the illness (Paoli et al., 2018). Nevertheless, sepsis care comes at an enormous cost to patients and the health systems that care for them. The over 54 million sepsis cases worldwide carry an annual cost estimated to be over $20 billion, making sepsis the most expensive condition to treat in United States hospitals (Arefian et al., 2017). Delays in help-seeking contribute to the problem because patients at risk for sepsis who delay arriving at the hospital may be more severely ill when presenting, increasing care costs (Baghdadi et al., 2018). Improvements in early detection of sepsis by patients and providers may have the effect of reducing the severity of the disease and the cost of care in the United States (Paoli et al., 2018).

Nurses can collaborate with other health care workers to take an active role in research that examines the processes involved in symptom reporting and delays in help-seeking (Houghton, 2019). The factors that contribute to pre-hospital patient delay must be understood to improve patient outcomes of sepsis (Andersson et al., 2018; Clarke et al., 2015). Therefore, more studies are needed to explore the psychosocial factors that contribute to delays in help-seeking when patients experience symptoms of infection. This study addressed the growing problem of delays in help-seeking among patients who become septic by applying the Common-sense Model of Self-regulation to explore the psychological and social factors contributing to delays in help-seeking (Leventhal et al., 2016).

Qualitative methods enable the recording and analysis of patients' pre-hospital experiences with bacterial infections and sepsis. In-depth interviews provided information that enables examining patients' experiences in the pre-hospital phase, patients' presenting characteristics, and exploring factors associated with possible delays in help-seeking (Gallop et al., 2015). Content analysis of in-depth interviews allows for the elaboration of illness beliefs and can aid in the discovery of the cognitive, affective, and other factors that may lead to delays in response to the symptoms experienced. New knowledge can inform the development of interventions designed to reduce delays in seeking care from appropriate healthcare providers when patients experience symptoms of infection**.** The development of effective interventions may be guided by a better understanding of the processes that affect behaviors when symptoms occur. Interventionists have used the CSM-SR as the theoretical foundation in successful interventional programs (Benyamini & Karademas, 2019).

Background and Significance

Sepsis is well known as one of the most common reasons for hospitalizations in the United States (US) and is a leading cause of death in non-cardiac intensive care units (Baghdadi et al., 2018). Despite the accessibility of antibiotics, morbidity and mortality from sepsis remain high worldwide (Aboud et al., 2017; Baghdadi et al., 2018; Bogale et al., 2017). The high incidence rates in sepsis may be due to more chronic illnesses in the aging population, the use of more invasive devices and procedures, and immunosuppressive drugs (Lehman & Thiessen, 2015). Additionally, patients are undergoing more organ transplants (Lund et al., 2017). Finally, antibiotics resistance is increasing, and there is a growing awareness and tracking of sepsis (Weiner et al., 2016).

Rhee et al. (2017) have pointed out that accurately measuring the incidence and trends in sepsis is difficult because there are differences in clinical awareness, and over the years, coding practices have changed. In the past, clinical documentation and coding of patient comorbidities were based on the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes. ICD-9-CM coding has evolved into the ICD-10-CM coding in recent years, which provides more specific data and updated knowledge about sepsis. ICD-10-CM defines sepsis as an infection coupled with two or more systemic inflammatory response syndrome (SIRS) criteria, considering the patients' overall clinical condition (Roat, 2013). Roat (2013) surmises that, unfortunately, changes in the coding system have not resolved the challenges associated with the definition of sepsis. Therefore, changes in the definition of sepsis and the heterogeneous nature of the sepsis definition, and how providers report incidence and mortality rates have impacted sepsis knowledge and management (Rhee et al., 2017). Even though reporting of the incidence and sepsis outcomes vary in the literature, providers have linked early goal-directed therapy to better outcomes (Axelsson et al., 2016; Rhee et al., 2017).

Statement of the Problem

Sepsis is a life-threatening condition where every minute counts, and delayed help-seeking can result in dire consequences that can be mitigated by early recognition and treatment. Data are sparse concerning the experiences of patients before they reach the hospital. Furthermore, there is a paucity of research examining the suspicion and treatment of infection in the pre-hospital setting (Andersson et al., 2018).

Although delays in help-seeking have implications for all healthcare providers, nurses can be at the forefront of research designed to understand the process of symptom recognition and reporting (Walters, 2018). Furthermore, nurses can impact change in patient delays in seeking help promptly by developing interventions and measuring the effectiveness of the interventions using various research methodologies (Walters, 2018). Interventions designed by nurses can reduce patient pre-hospital delays in seeking care for symptoms of infection. Effective interventions will ultimately lead to a decrease in mortality and morbidity rates, as well as a reduction in the cost of sepsis (Walters, 2018). Therefore, an understanding of the factors that influence decision-making around care-seeking is needed to develop effective interventions.

Purpose of the Study

The purposes of this current inquiry are to identify patients' sources of information, to explore the perceptions and experiences of patients diagnosed with sepsis, and to explore facilitators or barriers to seeking care for symptoms of suspected sepsis. This qualitative descriptive study design involved a semi-structured interview with patients admitted to a hospital for the treatment of sepsis. Nurses can use the knowledge gained through this study regarding the help-seeking behaviors of patients diagnosed with sepsis to design and test interventions that could improve outcomes among patients with sepsis.

Five notable studies examined the care-seeking process to make connections between variables associated with pre-hospital patient delay (Aboud et al., 2017; Baghdadi et al., 2018; Bogale et al., 2017; Charlet et al., 2017; Clarke et al., 2015). In the present research, applying a theoretical framework can provide a framework for understanding patients' perceptions of their illness experiences and help identify psychosocial factors and variables that contribute to delays in help-seeking in the pre-hospital phase. Understanding a patient's illness perceptions enables identifying pre-hospital factors that prevent patients from engaging in efficient and effective decision-making to mitigate delays in care-seeking. Patients who recognize their symptoms as severe and associated with infection are more likely to seek help early rather than later (Clarke et al., 2015).

Conceptual Framework

The Common-Sense Model of Self-regulation (CSM-SR) is among many health behavior theories that researchers can use to explore why some adults with bacteremia or sepsis seek care early by presenting at the hospital and others do not. In research and practice, the CSM-SR can be used to discover the factors associated with the pre-hospital patient delay from the patient's perspective. As shown in Figure 1, the CSM-SR is a conceptual model used to investigate the cognitive, affective, and behavioral processes that a person may undergo in self-management of illness threats (Diefenbach & Leventhal, 1996; Leventhal et al., 2016).

According to Diefenbach and Leventhal (1996), the CSM-SR operates under the assumption that the individual is a problem-solver who engages in a multilevel process to formulate perceptions of illness to derive meaning from the symptoms experienced and to devise action plans to cope with illness. The authors present a model that illustrates the importance of symptom interpretation as an integral part of understanding the processes involved in self-regulation. This theoretical framework further explains how signs and symptoms stimulate the activation of prototypes, which represent an individual's history (Benyamini & Karademas, 2019; Leventhal et al., 2016). The authors described prototypes as the functioning self, past experiences with illness, treatments, or other life experiences that come together to make up memory structures. In the proposed framework, the authors posit individuals use prototypes to derive meaning from cognitive and affective processes to identify and label the illness in the stimulus-response cycle. Furthermore, the authors postulate that the meaning that the individual attributes to the symptoms determine the strategies they employ to cope with the symptoms of the illness.

Figure 1

The Common-Sense Model of Self-Regulation

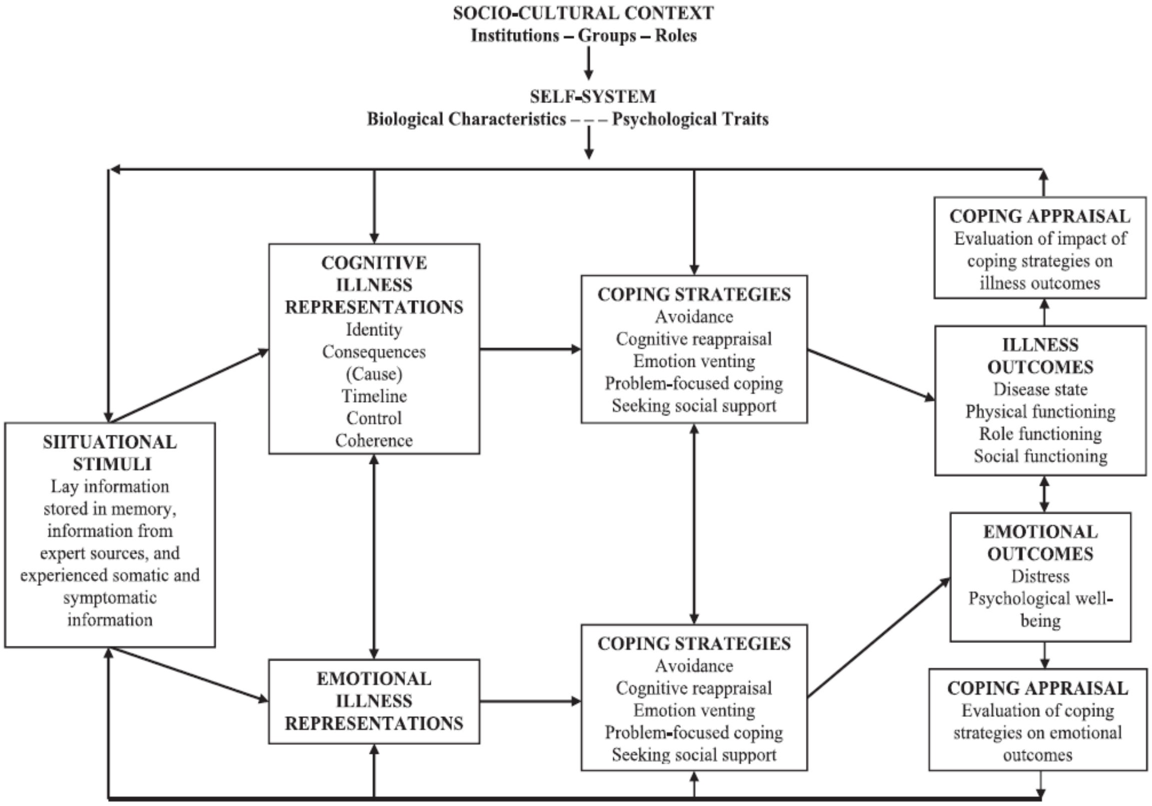

Figure 1. Schematic representation of common-sense model of illness representations based on Leventhal et al.'s (1992) illustration. The coping strategy and illness outcome categories are based on the classification procedure used in the present study developed by Hagger and Orbell (2003).

Note. Source: Hagger and Orbell (2003).

According to the CSM-SR, the illness perceptions that are generated by the prototypes during the symptom experience consist of five dimensions: identity, timeline, cause, controllability, and consequences (Diefenbach & Leventhal, 1996; Leventhal et al., 2016). Leventhal et al. described the dimensions of the model as follows. The model describes identity as a representation of the person's ideas about the physical representation of the illness and the assigned label or name given based on the perceptions of associated symptoms or conditions, e.g., cancer, heart disease, or flu. Furthermore, the authors described the timeline dimension as the perceived and measured rates of onset, duration, and decline. Accordingly, the timeline dimension is the individual perception of how long they feel the illness will last and represents the individual's attempts to connect the stimulus to a timeframe, i.e., acute, chronic, or cyclical (Leventhal et al., 2016). The third dimension the authors identified is the causal dimension, which represents the things the person feels contributed to the illness, e.g., environmental toxins cause cancer, stress causes heart attacks, or germs cause infections.

Additionally, the causal dimension is the individual's attempts to define what they suspect is the cause of the somatic sensations (Leventhal et al., 2016). The fourth dimension described by the authors is the controllability of the illness, which explains the meaning the individual assigns to the symptoms in response to treatments, either self-treatment or treatment prescribed by a health care professional. Finally, the consequence attribute represents the experienced and anticipated physical, cognitive, emotional, or social disruptions that the individual can imagine or project (Leventhal et al., 2016). Leventhal's model includes action plans and coping strategies. According to Diefenbach and Leventhal (1996), the model processes include physical and psychological outcome appraisal and an evaluation of whether the action plans and coping strategies are achieving the desired outcome.

The CSM-SR has previously been used to investigate delays in help-seeking for symptoms of acute coronary syndromes, which are also known for their atypical presentation (Davis et al., 2013). Therefore, Leventhal's (2016) CSM-SR may also be successfully applied in identifying psychosocial factors that influence delays in help-seeking behavior in sepsis. Understanding these factors could inform the development of interventions that enhance patients' ability to recognize the signs and symptoms of infection and seek care without delay. Therefore, in this study, the CSM-SR was used to guide the research questions, the interview guide, and the data analysis (Leventhal et al., 2016).

Research Questions

The research questions that were answered in this study are:

1. What sources of information do patients use to guide their decisions to seek help?
2. What are the illness perceptions and experiences of patients diagnosed with sepsis who delayed seeking care >24 hours from the onset of symptoms?
3. What barriers and facilitators are encountered in the help-seeking process for patients with sepsis who delayed seeking care for >24 hours from the onset of symptoms?

Assumptions

The CSM-SR holds the assumption that the individual is a problem-solver who engages in a multilevel process to formulate representations of health threats and create and implement action plans to cope with an illness. In this process, symptom interpretation is a major component for understanding the processes involved in self-regulation. According to the CSM-SR, individuals engage in appraisal processes, which includes the appraisal of symptoms, but mainly the appraisal of the cognitive and emotional outcomes of coping strategies (Leventhal et al., 2016).

Also, the following assumptions are relevant to this study.

1. Illness perceptions are multidimensional, individualistic psychosocial factors that help govern emotional and cognitive reactions to the symptoms of infection.
2. Individuals search for the meaning of their symptoms to identify or label the disease or condition.
3. Social and cultural contexts impact an individual’s ability to recognize, interpret, and act on symptoms.
4. Adult patients encounter barriers and facilitators when seeking treatment for symptoms of infection.

The researcher for this study assumes that patients diagnosed with sepsis often delay seeking care for their symptoms and are willing to discuss their thoughts, feelings, and experiences about help-seeking decisions and behaviors. Additionally, given the theoretical framework, it is assumed that patients are influenced by various factors that guide their decision to seek help.

Conclusion

Many patients diagnosed with bacteremia and sepsis encounter barriers to early arrival at the hospital when they experience symptoms of an infection. The often-atypical presentation and the growing incidence of chronic illnesses such as diabetes mellitus, acquired immune deficiency syndrome, cancer, and kidney and liver disease may contribute to patients' inability to associate symptoms with an infection. The direct cost of sepsis causes undue financial hardship on patients and healthcare systems. The indirect cost of sepsis creates impairments for patients physically, cognitively, and emotionally. The Centers for Disease Control and Prevention (CDC) has charged health care providers to develop patient-provider partnerships to improve health outcomes for all citizens by managing patients diagnosed with sepsis (CDC, 2019). Developing interventions to mitigate delays in help-seeking in patients with sepsis begins with an in-depth understanding of patients' perceptions and beliefs about sepsis and factors that affect how quickly they arrive at the hospital.

By applying the CSM-SR, healthcare providers, and nurses, in particular, can come to understand the psychological and social factors that are associated with pre-hospital patient delays. In this way, nurses and other healthcare providers can be empowered to provide educational interventions that could reduce delays in help-seeking, improve self-management, and improve physical and psychological outcomes (Walters, 2018). In summary, studies have shown that adverse outcomes result from delays in help-seeking, and positive outcomes are possible with early diagnosis and treatment of sepsis. The more patients understand the symptoms of infection and the need to seek care early, the less likely they are to delay seeking care. Finally, by educating patients about the dangers of sepsis, nurses and other health care providers can impact the lives of millions of people who are at the highest risk of infection (Walters, 2018).

CHAPTER II

REVIEW OF RELEVANT LITERATURE

Recent studies have found a correlation between delays in help-seeking and poor outcomes of bacterial sepsis (Aboud et al., 2017; Clarke et al., 2015). A review of the literature that examined delays in treatment for sepsis revealed gaps in knowledge regarding the perspectives of patients, bystanders, dispatchers, and Emergency Medical Services (EMS) staff (Herlitz et al., 2012). Launay et al. (2014) found that one of the most frequent examples of substandard care involved delays in seeking medical care (20%). This review is an overview of what researchers know about pre-hospital patient delays in help-seeking among patients diagnosed with sepsis, including facilitators and barriers to timely help-seeking. Included is a review of the Common-Sense Model of Self-regulation (CSM-SR), the theoretical framework for the study, and its use in patients with sepsis. This model conceptualizes the illness perception dimensions, namely identity, timeline, cause, control, and consequences, as well as coping strategies and illness outcomes (Leventhal et al., 2016).

Pre-hospital Patient Delays in Help-Seeking

Patient delay is a maladaptive behavior that is a challenge for medical professionals and patients who engage in delayed help-seeking (Cacioppo et al., 1989). Pre-hospital patient delays in help-seeking begin with the onset of symptoms and continue until the patient comes in contact with a qualified health care provider who can diagnose and treat the sepsis (Herlitz et al., 2012). Specifically, the pre-hospital delay has been defined as "the time of symptom onset until the time of hospital arrival" (Davis, 2015, p. 1). Clarke et al. (2015) found that 37% of the patients in their study delayed seeking treatment when experiencing symptoms of neutropenic sepsis (NS). Furthermore, a wide range of factors contributed to the pre-hospital patient delay (Clarke et al., 2015). These studies have provided evidence that factors associated with pre-hospital delay must be understood to improve patient outcomes of sepsis.

The time interval that patients spend during the help-seeking and decision-making processes are the foci in studies that seek to illuminate the need for early recognition and treatment of sepsis (Makic & Bridges, 2018). Delays in help-seeking correlate strongly with an individual’s ability to recognize the seriousness of the symptoms (Rorat & Jurek, 2015). However, recognition of sepsis in adult patients and particularly elderly patients over the age of 65 can be challenging due to the often atypical or subtle presentation of the symptoms (Englert & Ross, 2015).

Studies That Address Delays in Help-Seeking for Symptoms of Sepsis

Studies that explore delays in help-seeking and factors associated with delays are sparse. Herlitz et al. (2012) conducted a literature search that sparked research interest to understand the association between delays in help-seeking and sepsis outcomes, emphasizing the pre-hospital phase. This review of the literature uncovered several gaps in the research related to the care and treatment of patients with sepsis. Interestingly, it was discovered that studies addressing the patients’ perspective were nonexistent at the time of the literature review. Like Herlitz et al., Aboud et al. (2017) and Clarke et al.

(2015) shared the idea that there is a correlation between delays in help-seeking and poor outcomes of bacterial sepsis. Clarke et al. (2015) conducted a qualitative study to examine the pre-hospital experiences of patients in England with NS. The researchers identified early presenting features and explored factors delaying patients' arrival at the hospital when they experienced symptoms of sepsis, including inconsistent information about symptoms, doctors' inability to associate mild symptoms as being associated with NS, and patients' psychological responses to symptoms.

The study by Clarke et al. (2015) is unique in that it contributes to the paucity of data regarding patients' experiences before they arrive at the hospital with symptoms of sepsis. The significant finding was that the mean delay time was over 12 hours for 37% of patients, with a range of 0-68 hours. The reliance on qualitative data obtained solely from interviews means this study does not provide much concrete, quantitative data. However, the thorough content analysis of interview data and a participant pool made up of patients and caregivers makes the study results valuable. The study advances our understanding of delays in help-seeking and how facilitators and barriers influence pre-hospital patient delay.

The relevant qualitative findings of the study by Clark et al. (2015) were that patients understood the potentially life-threatening nature of NS. Patients' sources of information were not only doctors and nurses but also other patients, friends, relatives, and personal experiences. Patients reported a broad range of physical and behavioral symptoms that varied from classical (i.e., fever) to atypical (i.e., feeling unwell). The onset of symptoms ranged from insidious to abrupt. Some patients reported not wanting to bother staff with calls, and sometimes when they contacted staff, staff misattributed symptoms. The trajectory of care sometimes included a call or visit to the hematology unit, EMS, or a general practitioner. This study contributes to our understanding of barriers and facilitators by identifying barriers to help-seeking and suggesting strategies to mitigate delays fostered by inconsistent patient education, poor attitudes towards patients and caregivers, challenging logistics, and ineffective patient-provider communication. To reduce delays in help-seeking, the authors suggested soliciting patient and caregiver input to redesign patient education material that is clear and consistent, asking others' opinions about the patients' state and addressing psychological barriers early, reconfiguring staff to reduce wait times, and improving communication between providers using patient-held records of patients' illness, treatments, and complications.

Given the paucity of studies of delays in help-seeking among adults, this review includes studies involving adults, neonates, and children as long as the study focus concerns help-seeking for an acute illness or bacterial sepsis. Aboud et al. (2017) sought to determine the impact of an intervention designed to improve the quality of care for children with suspected sepsis to reduce delays in the care-seeking process. The intervention involved delivering messages to facilitate timely care by educating mothers about the risk of sepsis, the availability of a call center for advice, affordable emergency transportation, and upgraded hospital care.

Aboud et al. (2017) used a cluster non-randomized trial with a case-control design to identify where in the care-seeking process delays occur. The investigation is unique because it used two rounds of cross-sectional surveys, at baseline and end line, in a preand post-interventional approach to the problem of delays in help-seeking. The investigators found that several factors contribute to delays in care-seeking among parents of young children in Bangladesh. The most significant finding was that families who received the intervention had shorter delay times. Mothers informed others before seeking care and sometimes sought care from an informal practitioner. The results of this study confirmed that delays in help-seeking are a serious problem. The findings demonstrated the importance of community-based interventions to encourage the timely utilization of available health services by mothers of young children. This finding applies to the care and treatment of individuals with symptoms of sepsis regardless of cultural background or age category.

A limitation of the study by Aboud et al. (2017) is that random assignment was not employed, which may have led to contamination of the control group. The researchers based the crude measure of delays on the mothers' report of the number of days between the symptoms onset and the decision to seek care. This time interval included the hours or minutes taken to reach a qualified provider to receive care. Therefore, this study has a limitation of possible recall bias. As Herlitz et al. (2012) pointed out, it is difficult to know the exact onset of symptoms.

Charlet and colleagues (2017) conducted a mixed methods study to explore the aspects of pre-hospital delay, which they termed as Delay 1 and Delay 2 based on the Three Delays Model (Thaddeus & Maine, 1994). Although the model put forth by Thaddeus and Maine involved a delay in the decision to seek care (Delay 1), the delay in reaching appropriate care (Delay 2), and delay in receiving care (Delay 3), this study focused on Delay 1 and Delay 2. Charlet et al. (2017) adapted the Three Delays Model by splitting Delay 1 into two steps: recognizing the illness and decision-making. The study, which involved cases of newborn and maternal illness and death, synthesized data from seven studies carried out in Ethiopia, India, Indonesia, Nigeria, Tanzania, Uganda, and Nepal. This cross-cultural approach to patient delays in help-seeking allowed the researchers to examine the processes involved in identifying an illness (Delay 1), making decisions (Delay 1), and seeking care (Delay 2). The significant finding was that during Delay 1, regardless of cultural background, individuals, family members, and caregivers identified a range of signs and symptoms indicative of the severity of the disease.

Charlet et al.'s (2017) study showed that cultural and psychosocial factors influenced the decision to seek care outside the home. In this investigation, patients' coping strategies employed during Delay 1 included doing nothing, using home remedies, or seeking care from spiritual healers or skilled healthcare providers. The perceived cause of the illness was a factor that determined whether they sought medical attention or called a spiritual leader, and sometimes it was both. The investigation involved the collection of qualitative and quantitative data from a diverse group of participants. This study provided evidence to support our understanding of the factors associated with patient delay and coping strategies utilized by patients, regardless of cultural background. Although this investigation did not specifically address the acute phase of sepsis, the study included other acute illnesses. Furthermore, it is useful in understanding help-seeking in the acute phase of illness because the population studied included cases of maternal and newborn illness and death.

In a similar investigation that incorporated qualitative and quantitative data, Bogale et al. (2017) investigated types of delay and factors associated with a delay in help-seeking for decedent newborns in Ethiopia. The study used social and verbal autopsy information, and, like Charlet et al. (2017), the investigators use the Three Delay Model to classify the type of delay that may have contributed to the infants' deaths (Thaddeus & Maine, 1994). Social and verbal autopsies are interview techniques used to gather information about the causes of death from caregivers of decedents (Bogale et al., 2017). The results of the study revealed that 51% of the deaths occurred within the first 24 hours. Bacterial sepsis was the principal cause of death in many cases. Recognition of illness and initiation of appropriate treatment typically occurred within one day, but 81% of the deaths resulted from delays in seeking treatment. The researchers completed 37 social autopsies, and the deaths of 30 of the infants were attributed to Delay 1 (i.e., delay in treatment-seeking outside the home). An important conclusion of the study is that minimizing delays at home and improving health facilities can reduce mortality. Given the small sample size and the cultural diversity in Ethiopia, the results of this study are not generalizable. Furthermore, a limitation of the study is that recall and social desirability bias may have affected the responses to interview questions. Similar to Aboud et al.'s (2017) investigation, this study demonstrated the role that delays at home play in the outcomes and emphasizes community-based interventions.

Researchers may view organ dysfunction on admission as a clinical indicator of delays in help-seeking. For example, Baghdadi et al. (2018) conducted a study to investigate whether a lack of insurance is predictive of organ dysfunction on admission in patients with community-acquired sepsis. The investigation included a sample of adult patients experiencing symptoms of sepsis. Of the total sample with organ dysfunction on admission, 47% were women, and 54% were Non-Hispanic White. Ten percent of patients with organ dysfunction on admission did not have insurance. The researchers measured organ dysfunction as the number of subcategories of organ dysfunction. The subcategories in the study included cardiovascular, respiratory, renal, hepatic, hematologic, and neurologic. The researchers also studied the impact of the lack of insurance on mortality rates in sepsis. This study contributes to our understanding that the causes of organ dysfunction may be related to factors such as underlying health status, help-seeking behaviors, or quality of care.

Baghdadi et al. (2018) found a correlation between a lack of insurance and death due to sepsis in cases of community-onset sepsis. Overall, organ dysfunction on admission explained the relationship between lack of insurance and in-hospital mortality. The authors postulated that delays in seeking medical care might cause poor survival in patients with organ dysfunction on admission. Additionally, patients may have had underlying health status or did not receive quality care. Although these mortality differences are difficult to explain, cited research indicated that patients without insurance might delay seeking care for serious diseases (Kumar et al., 2014).

In Baghdadi et al.’s (2018) study, the reliance on quantitative data obtained solely from discharge data means this study provides detailed data related to the severity of the patients’ illness at admission and throughout the hospitalization. Furthermore, the data provided a large, diverse participant pool making this study valuable in furthering our understanding of the factors that contribute to death due to sepsis that may have been influenced by delays in seeking care. However, this study involved a sample of patients that may not be representative of patients with sepsis because they excluded patients over the age of 65, who represent the majority of patients with sepsis. Changes in diagnostic coding may have affected sample selection, and there may have been errors in coding organ dysfunction.

Overall, this review shows that studies of delayed help-seeking in patients diagnosed with sepsis used various methods and designs. When so much is unknown about pre-hospital patient delays in help-seeking for symptoms of sepsis, qualitative methods are well suited to capture the cognitive and emotional aspects that are filtered through the patients' experiences in this area. When we ask questions in qualitative research about perceptions of illness, we are capturing a cognitive and emotional picture that the patients have and considering the role of their experiences. For example, we seek to learn what patients thought when they experienced symptoms of infection and how they incorporate knowledge gained from healthcare professionals, family members, friends, and their own experiences. The interviews can include probes that address the new experience with the infection and explore how patients use their previous encounters with infection, or lack thereof, to decide when to seek care and from whom. The patients' experiences with an infection help us understand the mental and emotional framework that people start from when they experience symptoms of infection.

Defining and Diagnosing Sepsis

Esposito et al. (2017) and Makic and Bridges (2018) define sepsis and septic shock as clinical syndromes characterized by an overwhelming and life-threatening immune response to an infection. This definition is in keeping with the initial definition of sepsis proposed by the American College of Chest Physicians (ACCP) and the Society of Critical Care Medicine (SCCM). In 1991, severe sepsis was defined as sepsis with organ dysfunction, hypoperfusion, and hypotension. Furthermore, the definition of septic shock included persistent hypotension unresponsive to the administration of fluid resuscitation (Esposito et al., 2017; Makic & Bridges, 2018). The signs and symptoms of sepsis-induced hypotension include elevated lactate, oliguria, and acute mental status changes (Esposito et al., 2017). Sepsis diagnostic criteria included hypo- or hyperthermia, tachycardia, tachypnea, and high or low white blood count (Esposito et al., 2017; Makic & Bridges, 2018).

Recently, the European Society of Intensive Care Medicine (ESICM) and Society of Critical Care Medicine (SCCM) revised the definitions to eliminate the term severe sepsis and to eliminate the concept of systemic inflammatory response syndrome (SIRS) (Lester et al., 2018; Makic & Bridges, 2018). Since 2016, clinicians have defined organ dysfunction by clinical criteria indicative of organ failure. Clinicians operationalize organ failure using the Sequential Organ Failure Assessment (SOFA) score (Makic & Bridges, 2018). Therefore, health professionals have defined sepsis as organ dysfunction caused by an infection. The evolution of the definition of sepsis has contributed to the problems related to the recognition and treatment of sepsis because clinical experts continue to struggle with the parameters to define sepsis and organ failure. A controversial view of sepsis recognition presents a challenge for clinicians in educating patients on what signs and symptoms to respond to seek help promptly.

Past definitions of sepsis required the use of lab values and complicated clinical features such as mean arterial pressure (MAP), Glasgow Coma Scale (GCS), and urinary output (Lester et al., 2018). Healthcare workers perform these procedures at healthcare facilities. In a more patient-centered description of sepsis symptoms, the letters in the word sepsis are used to describe the signs and symptoms of sepsis (Herrera, 2017). The "S" stands for shivering, fever, or cold. "E" stands for extreme pain or general discomfort. "P" stands for pale or discolored skin. "S" stands for sleepy, difficult to awake, or confused. "I" stands for "I feel like I might die." "S" stands for shortness of breath. Wattanapaiboon et al. (2020) recently conducted a study in which they evaluated patients presenting symptoms with sepsis to the symptoms in a mnemonic. Of note, the symptoms in their mnemonic differed from those proposed by Herrera (2017). One of the most significant findings was that 15% of the patients in their study had symptoms that were not in the mnemonic they used. They concluded that using the mnemonic could lead to misdiagnosis in some cases. Therefore, sepsis symptoms need to be clarified, and the mnemonic may need to be revised. If individuals in the community can accurately recognize the severe symptoms of sepsis, they may seek care early at a medical facility by contacting EMS or presenting to the hospital for evaluation of their symptoms.

Risks Factors for Sepsis and Delays in Help-Seeking

Englert and Ross (2015) classified risk factors for sepsis as non-modifiable and modifiable. Non-modifiable risk factors encompass age, gender, and race. Researchers compare infants to older persons, males to females, and African-Americans to Whites in studies of sepsis outcomes. Modifiable risk factors for sepsis are disease-specific, including chronic conditions, i.e., heart disease, cancer, and respiratory diseases, as well as polypharmacy associated with chronic conditions. Other modifiable risk factors include recurrent hospitalizations and procedures for chronic conditions, compromised immunity brought on by changes in the structure and function of the immune system (e.g., atrophy of the thymus leading to a decline in the number of T-cells and depressed T-cell response to new pathogens).

Age and Sepsis

According to U.S. Census reports in 2016, Americans over the age of 65 made up 15.24% of the U.S. population (U.S. Census Bureau, n.d.). Healthcare spending is highest in this age group because the elderly may be managing multiple chronic conditions, and 50% of the intensive care unit (ICU) admissions involve elderly patients (Englert & Ross, 2015). Moreover, sepsis ranks highest among older adults, and age is a predictor of mortality from sepsis. Englert and Ross reviewed the literature that examined sepsis in older adults, including prevalence, atypical presentation, and considerations for sepsis management in the elderly. Throughout the literature, studies found age to be a risk for sepsis and a predictor of mortality, particularly in the intensive care unit. Patients over the age of 65 are 13 times more likely to develop sepsis and have a two-fold risk of death due to sepsis (Englert & Ross, 2015). The authors concluded that age is a risk factor for early organ failure in patients with sepsis who may have experienced delays in diagnosis and treatment.

Wester and colleagues (2013) investigated age-related differences in the clinical presentation and the course of sepsis. According to the authors, sepsis increases with age due to comorbid conditions, suppressed immune response, and institutionalization. For older adults, the atypical clinical presentation complicates the diagnostic process. It may lead to delays in help-seeking, resulting in delays in diagnosis and treatment. Older adults may present with unspecific deterioration, such as an inability to perform daily tasks and age-related biological changes. The study involved record reviews of patients with bloodstream infections stratified by bacteria type and age category, e.g., < 65 vs. 65-84, and ≥ 85 years old. The outcomes were organ failure within one day and in-hospital mortality. The researchers found that the higher age groups experienced atypical symptoms, a decline in general health, and high in-hospital mortality. Classic symptoms were protective of early organ failure. Fever was protective of in-hospital mortality. So along with age, the risk factors for in-hospital mortality in this population were >1 comorbid illness, leukopenia, and the number of failing organs.

Sociodemographic Differences in Sepsis Incidence, Care, and Outcomes

Racial disparities are associated with differences in disease incidence and outcomes (Barnato et al., 2008). The literature features conflicting results regarding racial differences in sepsis incidence, care, and outcomes (Barnato et al., 2008; Moore et al., 2015). Chaudhary et al. (2018) conducted a retrospective analysis of discharge data to identify the proportion of patients with sepsis in each racial category, i.e., Black versus White, then stratified the patients by age. The investigation involved comparing characteristics of Black versus White race, age, gender, insurance, admission type, the risk for mortality, and sepsis type.

In the study conducted by Chaudhary et al. (2018), sepsis was categorized as community-acquired sepsis (CAS), hospital-acquired sepsis (HAS), and healthcare-associated sepsis (HCAS). The categorization was based on whether the concurrent presence of serious infection and organ dysfunction were present on admission (CAS) or not (HAS). HCAS was classified based on whether the patient was in a nursing home, on dialysis, or admitted to the hospital in the 30 days before admission to the hospital for sepsis. Community-acquired sepsis and healthcare-associated sepsis were more common in African-Americans than in Whites. Hospital-acquired sepsis was less common in African-Americans. Older African-Americans sepsis rate was higher than Whites, but mortality was lower for African-Americans than Whites. African-Americans with CAS and HCAS may have delayed seeking care given their higher prevalence of severe infection and organ dysfunction on admission (Chaudhary et al., 2018).

The data for the study by Chaudhary et al. (2018) were derived from geographically diverse hospitals and are considered a representative sample. Evolving sepsis documentation and coding practices may have affected the results. More research is needed to ascertain the factors influencing racial differences in sepsis outcomes. This study involved a retrospective analysis. However, chart review is the gold standard for accurately assessing sepsis subtypes (e.g., community-acquired, healthcare-associated, and hospital-acquired). This investigation did not identify neighborhood factors, such as income, poverty, education, and housing characteristics, that may have confounded the association between race, sepsis incidence, sepsis care, and outcomes (Galiatsatos et al., 2019). The researchers found that sepsis incidence was higher among people living in areas with higher poverty rates, where African-Americans and Hispanics were more likely to live (Chaudhary et al., 2018). Finally, this study examined the short-term (30-day) outcomes but not long-term post-discharge outcomes.

Barnato et al. (2008) conducted a retrospective population-based cohort study using hospital discharge and U.S. census data from 68 hospitals to explore the effects of poverty, urbanicity, and region of residence on sepsis incidence, case-mix, and treating hospital on ICU case fatality. Case fatality was 24.6%, but mortality was slightly higher in those admitted to the ICU (29.9%). In this study, predictors of higher incidence rates of sepsis included age, race, male sex, poverty, and urbanicity. Barnato et al. (2008) showed that sepsis incidence rose with age and was more common in men. African-Americans had double the rate of sepsis compared to Whites, and age was lower in African-Americans and Hispanics compared to Whites. Overall, mortality for African-Americans was higher than for Whites due to both greater incidence and higher case fatality.

A limitation of this study by Barnato et al. (2008) is the use of hospital data sets, which are imperfect data sources for generating rates of disease within hospitalized patients. The use of the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes identifying infection and acute organ dysfunction may be insensitive. Furthermore, coding may have been subject to change over time. Incorrect coding may result in misclassification of sepsis types that may affect case fatality estimates.

Barriers and Facilitators to Help-seeking Among the Poor

When patients experience barriers to care, it can alter the trajectory of an illness like sepsis. Caring for patients with sepsis is most successful if patients do not delay seeking care for acute illness, putting themselves at risk of experiencing a fatal outcome. A more direct trajectory to care-seeking among patients in low-income areas can lessen the financial burden of an acute illness. Herdman et al. (2016) conducted a study to determine if poverty is related to pre-hospital patient delay in participants with acute febrile illness. Like other studies, the authors defined pre-hospital patient delay as the time from symptom onset to arrival at the hospital. Herdman et al. used a multi-dimensional poverty index based on the participants' socioeconomic status to classify participants as poor or nonpoor. Fifty-one percent of acutely ill adults and children in this study were classified as poor.

In Herdman et al.'s (2016) study, data collection involved face-to-face interview-assisted surveys by which they collected sociodemographic data, symptom information, and information about causes of delay and sources of help. Other data collected during the interview were the mode of transportation and the direct and indirect cost of the illness. Herdman et al. found that the pre-hospital patient delay was 22 hours longer for the poor than the nonpoor. This difference was more pronounced in adults than in children. Both the poor and the nonpoor often relied on informal medical advice before presenting at a hospital. However, the poor were less likely to have contacted a qualified doctor. For the poor, delays in decision-making were related to a lack of money. Due to more significant delays, the poor experienced worse outcomes. Herdman et al. concluded that poverty is associated with longer pre-hospital delays.

Herdman et al. (2016) offered several recommendations to facilitate a reduction in delays in help-seeking in poor people. The investigators suggested improving access to quality care close to home, which will reduce cost and delay time for patients. In addition to educating patients about their rights to free medications and services, Herdman et al. recommended more education for providers in the immediate management of acute febrile illness. The authors recommended providing education to informal providers about recognizing warning signs of sepsis that should prompt informal providers to refer patients to qualified doctors or hospitals. Additionally, to reduce delays in help-seeking, Herdman et al. recommended providing tools for health care providers to aid in diagnosis and treatment. To lessen some of the financial burdens that the poor face, health systems can promote insurance options for the poor (e.g., credit vouchers). This investigation emphasizes the importance of long-term social changes to address the effects of poverty on the help-seeking process, such as improvements in living standards, education, and management of chronic health. Finally, addressing psychosocial factors will also have a positive impact on pre-hospital management.

A limitation of this study by Herdman et al. (2016) is selection bias because random selection was not employed. This study did not capture cases of non-hospitalized individuals. These patients may have sought care elsewhere, or the barriers to care may have been overwhelming, causing the underrepresentation of patients most affected by poverty. Another limitation of this study is misclassification bias, where patients may have been classified as poor when they were nonpoor. This investigation addressed the relationship between poverty and illness and provided a greater understanding of care-seeking behavior and the impediments imposed by poverty.

Public Awareness as a Barrier to Help-Seeking in Patients with Sepsis

Four recent studies focused on the public awareness of sepsis among physicians, caregivers (CGs), and patients. Gallop et al. (2015) conducted a study to determine the impact of sepsis on patients and CGs. Awareness and knowledge varied among patients and CGs. Some patients and CGs were unaware that they had a diagnosis of sepsis (Gallop et al., 2015). Furthermore, the study showed that some people with a vague awareness that the term ‘sepsis’ had been used did not seek additional information. Also, for others, all they knew was that sepsis could be fatal.

A study that sought to identify adverse events and risk factors in patients who developed sepsis in Poland showed that most medical errors occurred despite known adverse effects of sepsis because of the physicians’ inability to recognize, diagnose, and treat the infection (Rorak & Jurek, 2015). The study further revealed that patients and families become anxious during the help-seeking process. According to the authors, in the health systems in Poland, lack of knowledge about symptoms, diagnosis and treatment, and ignoring the dangers of sepsis are significant causes of adverse events in sepsis cases. The researchers concluded that increasing knowledge and creating algorithms for all health care workers might improve the safety of patients with sepsis.

In a 2015 survey of laypeople in Sweden, 80% of respondents had not heard of sepsis (Mellhammer et al., 2015). The researchers found that two of 10 people had heard of sepsis, compared to 9 of 10 people who had heard of other diseases such as stroke. When asked a question about the causes of sepsis, 18% could not answer the question. Sixty-two percent thought sepsis was blood poisoning due to bacterial or other infections. Blood poisoning is a term that people in Sweden use instead of sepsis. The term blood poisoning, which is associated with dirty objects or wounds, is misleading in understanding when to seek care. This study also revealed that healthcare workers might not use the word sepsis when informing patients and relatives about sepsis because in Sweden, 'sepsis' is considered a foreign term. The researchers concluded that targeting the lack of awareness of sepsis might improve the outcome for patients with sepsis resulting in a reduction in the pre-hospital delay that is a barrier to early diagnosis and treatment.

Huang et al. (2019) recently conducted a study that described participants' perceptions of their experiences following hospitalization for sepsis. The study revealed that sepsis survivors suffer from many systemic health problems, including physical and psychological effects. The participants reported eating problems, body pain, tiredness, and myriad other physical problems. Some of the psychological changes that the participants reported included anxiety, depression, fatigue, and memory loss. Additionally, the authors found that survivors were dissatisfied with sepsis-related care, especially related to education, both in the hospital and after discharge. According to the authors, participants who reported poor baseline knowledge of sepsis also reported that the healthcare system did not provide education about sepsis after the sepsis episode, i.e., they did not explain sepsis or what to expect after sepsis. The researchers concluded that there is a need to raise international awareness of sepsis in the lay public. Raising awareness will mitigate the lack of public knowledge by delivering messages that change the way sepsis survivors and others respond to symptoms of sepsis. Raising awareness may also serve to motivate individuals to seek medical help in a timelier manner when symptoms occur, which may lead to better outcomes.

Although there are many barriers to seeking health care, the lack of awareness is seen as an area to target to improve the management of sepsis. The public needs to understand that a local infection can progress to sepsis. Poor public awareness of sepsis may affect people's ability to respond to sepsis and septic shock promptly, which may lead to improper management of sepsis (Mellhammer et al., 2015). The patient pre-hospital delay has become a target to enable early intervention and behavior change. The recent research infers that a facilitator to early help-seeking is education in the community that raises public awareness, increases knowledge of sepsis symptoms, reduces mortality, and improves outcomes. By promoting awareness, health care professionals may also teach patients with sepsis and their CGs about the need for early intervention and the benefits of reducing the time to help-seeking for treatment of the infection.

Additional Barriers and Facilitators to Help-Seeking

Several researchers have proposed many reasons to explain why patients delay seeking help for bacterial infections and sepsis symptoms. One of the main reasons is an unawareness of the danger signs and risk of sepsis (Aboud et al., 2017b; Clarke et al., 2015). Some patients have concerns about lack of financial means or insurance, lack of transportation to the hospital, and perceived poor quality of care that they may receive at the hospital (Aboud et al., 2017; Baghdadi et al., 2018; Bogale et al., 2017; Charlet et al., 2017; Herdman et al., 2016). Still, others delay seeking care at the hospital because they include family members in decision-making or seek care from informal practitioners rather than qualified healthcare providers (Aboud et al., 2017; Clarke et al., 2015; Herdman et al., 2016). Often, friends, family members, and informal care providers are the preferred sources of help over health care professionals (Aboud et al., 2017; Clarke et al., 2015).

In a qualitative study of help-seeking in patients with NS, Clarke et al. (2015) identified several barriers to care-seeking, including inconsistencies in the information patients sometimes received relative to the urgency of the symptoms. This study showed that sometimes the doctor may be unable to associate mild symptoms as being associated with NS and dismissed patients without treatment. Furthermore, the researchers found that patients sometimes denied their symptoms and delayed seeking help because they wanted to avoid hospitalization. Clarke et al. also found that patients’ emotional reactions to the illness (e.g., fear or anxiety) resulted in delays in help-seeking. Finally, they found that social factors such as competing priorities of work or caring responsibilities are barriers to early help-seeking. Removing potential barriers will enable the patient to identify appropriate professional help to access and seek advice from qualified sources.

Conversely, researchers have proposed facilitators to include community intervention that emphasizes the danger signs of sepsis and the risk of sepsis (Aboud et al., 2017; Charlet et al., 2017). Additionally, the availability of call centers that organize reliable and affordable transportation to a health facility where the patients can receive quality care with medications for sepsis and someone is available to help navigate the hospital can facilitate the help-seeking process (Aboud et al., 2017; Herdman et al., 2016). Herdman et al. (2016) identified several possible facilitators of help-seeking. These included providing information to patients and informal providers about recognizing the warning signs of sepsis to prompt referral to a qualified doctor or hospital. According to Herdman et al., to address the cost associated with the treatment of the illness, more education is needed for patients about their rights to free medication and services, as well as insurance options for the poor. Herdman et al. (2016) and Clarke et al. (2015) found that providers need more knowledge about the immediate management of acute febrile illness and sepsis, which will provide them the competence to advise and care for the patients.

Additionally, long-term social change can address the effects of poverty on the help-seeking process related to living standards, education, and management of chronic health (Herdman et al., 2016). Herdman et al. (2016) maintained that individual psychological and social factors such as contextualized messages that reinforce the threat of sepsis and the need for skilled care could facilitate the multi-step help-seeking process. The process begins when the patient becomes aware of the severe illness and the need for professional help.

To better understand the impact of pre-hospital patient delay, more studies are needed to describe the events that occur at each stage in the illness process. This understanding will enable researchers to develop interventions based on the barriers and facilitators contributing to speedy or slow decision-making in each stage. An individual’s experience of symptoms and their active efforts to cope with disease and disease threats are directly linked to delays in seeking care.

Perceptions of Illness

Perceptions of illness are concerned with how patients cognitively assemble information they obtain from personal experience with illness, the symptom experience, laypeople, and expert knowledge from health care professionals. The interplay between cognitive and affective processes in decision-making influences coping strategies and the speed at which help is sought (Hagger et al., 2017). Patients assemble and use information that concurs with and shapes their beliefs about the threat of infection when they experience symptoms of infection (Leventhal et al., 2016). For example, a woman with a headache and a rapid heart rate may view these symptoms as a normal part of menopause if she is in the perimenopausal stage. However, symptoms like confusion or loss of consciousness may be considered to be severe signs and symptoms. The lack of specificity in the symptom experience leaves room for misinterpretation of symptoms (Englert & Ross, 2015).

According to Leventhal et al. (2016), patients who misinterpret symptoms may engage in ineffective self-management. These authors have described illness perceptions or representations as a way of thinking about illness. According to the authors, illness perceptions are crucial elements for understanding how a patient with symptoms of infection interprets and manages health problems. Furthermore, they discuss how illness perceptions guide coping strategies, as well as cognitive and emotional outcomes. Symptom onset is critical to help-seeking, and patients who misinterpret their symptoms may delay seeking help (Leventhal et al., 2016). Symptoms that deviate from normal functioning influence the type and gravity of the explanation individuals consider (Leventhal et al., 2016). The first appearance of symptoms may seem mild with infections, and the patient may not associate the mild symptoms with a serious disease (Wester et al., 2013). However, as symptoms become severe, patients tend to associate them with serious illnesses. Reappraisal occurs as symptoms worsen.

Diefenbach and Leventhal (1996) discuss how patients engaging in appraisal and reappraisal of their symptom experience try to come up with explanations to assign meaning to their symptoms. According to the authors, illness perceptions inform the patients' ongoing management of the symptoms during the appraisal process. Patients may manage symptoms through self-medication, which may even mean consuming over-the-counter medications or someone else's medications, including antibiotics. The patient may also choose to monitor their symptoms for a while, hoping that they are self-limiting. Sometimes patients judge symptoms as not significant. Sometimes delays occur when patients take time to inform others and defer to their advice, rather than directly seeking help from a qualified health care professional in the hospital (Aboud et al., 2017). According to Clarke et al. (2015), patients at risk for neutropenic sepsis might not distinguish symptoms of neutropenic sepsis from side effects of chemotherapy and other drugs used to manage the condition. The side effects might mask the presenting features of sepsis (Clarke et al., 2015). However, if a patient mismanages their symptoms, and the patient delays seeking care, they may have worse outcomes.

The Common-Sense Model of Self-Regulation

According to the Common-Sense Model of Self-Regulation (CSM-SR), when an individual is engaging in a multilevel process, he or she is involved in the formulation of perceptions of health threats, as well as the formation and execution of action plans to restore health (Leventhal et al., 2016). Leventhal et al. (2016) summarized the CSM-SR as follows by describing how bodily sensations or dysfunction serve as stimuli. The theoretical framework reinforces the role of actual symptom experience as a critical motivation for behavior. According to the authors, the stimuli lead to the activation of prototypes or memories about the individual's usual way of living, past experiences with illness, treatments, or life events. This accumulation of memories engenders a perception of illness. Illness perceptions are personal beliefs about illness identity, timeline, cause, control, and consequences. Based on the representations generated, the individual will develop ideas about how to treat the symptoms or execute action plans. The CSM-SR entails widely used concepts that aid in understanding and promoting self-management of acute and chronic diseases.

First, the term prototype is used when a person experiencing symptoms remembers something from their past that can be compared to the new bodily sensation or symptom. Patients use prototypes of illness to derive the meaning of cognitive and affective processes as they try to identify or label the illness (Leventhal et al., 2016).

According to the CSM-SR, a person’s prototypes may be improved by their own experiences with disease and treatment or messages from health professionals, family members, friends, mass media, and personal observations (Leventhal et al., 2016). The onset of symptoms is the most common reason for the activation of prototypes and representations. Cognitively, external and internal stimuli serve to incite illness perceptions, where an individual makes comparisons to past experiences with illness. A person who is feeling good may conclude that they are healthy, but, on the other hand, the patient may associate specific symptoms with an illness (McAndrew et al., 2014). The final stages of information processing close the feedback loop by evaluating coping strategies where anticipated outcomes are compared to the outcomes of physical and psychological states (Diefenbach & Leventhal, 1996).

Principles Underlying the Common-Sense Model

The Common-Sense Model of Self-Regulation (CSM-SR) highlights the processes and mechanisms of self-management employed by an individual. Fundamental to the model is the belief that the individual is a problem-solver (Diefenbach & Leventhal, 1996). By explaining this model, we can comprehend the transitional processes involved in the initiation and maintenance of behaviors used to manage health threats (Leventhal et al., 2016). This model describes the interactive nature of the variables significant in health behaviors when confronted with illness threats (Leventhal et al., 2016). Furthermore, the CSM-SR provides a framework to identify factors that influence help-seeking behavior and health outcomes (Leventhal et al., 2016).

Coping Strategies

Researchers can apply the CSM-SR to psychosocial studies involving patients experiencing symptoms of sepsis because the symptoms serve as stimuli that elicit cognitive representations and emotional reactions, whereby patients derive meaning that fosters coping strategies and appraisal of outcomes. Coping may involve self-monitoring, self-medicating, using home remedies, or contacting a medical professional for help to cope with symptoms. As the patient interprets the symptoms experienced, they make coping decisions iteratively. In parallel with the cognitive processes, symptomatic stimuli arouse emotional responses (Hagger et al., 2017). For example, the person may feel fearful that they have a life-threatening disease like sepsis. This emotional response might lead to coping actions to reduce the fear response and illness perceptions (Hagger et al., 2017). As the person thinks about controlling or curing the illness, they may attempt to diagnose and treat the illness. So, the threat of illness acts as a stimulus that results in simultaneous cognitive activities and emotional reactions that bring about the performance and appraisal of coping actions (Hagger et al., 2017). The CSM-SR domains operate based on the individuals' expectations according to their schemata and what happens when facing a health threat (Benyamini & Karademas, 2019).

According to CSM-SR, coping is a behavioral response to a health threat. Coping strategies may serve to gain more information about the symptoms to apprise a working diagnosis. Over time, CSM-SR plots the self-regulatory process that involves evaluating whether the strategies lead to goal achievement. The appraisal of the outcomes leads to revised representations and behaviors in coping with the health threat (Benyamini &

Karademas, 2019). If coping strategies are unsuccessful, the individual will change coping procedures or alter the cognitive and emotional representations. Within the appraisal and help-seeking intervals, the dynamic nature of symptom perceptions, interpretation, and self-management is an iterative process. When patients experience symptoms of sepsis, the physical and cognitive dysfunction motivate care-seeking. Whether a symptom experience in patients with sepsis leads to care-seeking depends on symptom properties in one or more of the identity, timeline, cause, control, or consequences domains of the illness representation (Leventhal et al., 2016). For example, differences in the timeline and the speed and ease with which care seekers label their symptoms as being associated with sepsis will impact how quickly they seek help and the outcome of the illness (Leventhal et al., 2016). Failure and delay in responding to symptoms occur in response to chronic conditions and acute conditions like sepsis (Leventhal et al., 2016). The CSM-SR is a useful theoretical approach in studies designed to measure and describe the time intervals and events that led to the diagnosis and treatment of diseases.

The Common-Sense Model of Self-regulation Applied to Delays in Help-Seeking

Help-seeking behavior is a psychosocial decision-making process for determining whether to seek help and the timing of the decision-making (Cornally & McCarthy, 2011). In the case of an ill person, help-seeking for symptoms involves symptom perception, interpretation, and appraisal, as well as motivation and ability to visit a healthcare professional (Cornally & McCarthy, 2011). Involving family members and other external care may contribute to delays in help-seeking (Aboud et al., 2017;

Axelsson et al., 2016). Symptom onset is essential for care-seeking, especially when their emergence becomes intensified, has a long duration, and the patient receives social input from physicians, relatives, or friends (Leventhal et al., 2016). In the study by Aboud et al. (2017), patients who sought care from informal practitioners, or took the time to inform others, experienced more prolonged delays. Fear and anxiety are important psychological factors associated with patient delay (Leventhal et al., 2016).

Patient delay is a maladaptive behavior that is a challenge for medical professionals and the patient who engage in delayed help-seeking (Cacioppo et al., 1989). To address the problem of patient pre-hospital delay, the research community must seek to understand the processes underlying patient decision-making. During the process of pre-hospital delay, mental representations of symptoms are individualized and help govern emotional and behavioral reactions to symptoms (Diefenbach & Leventhal, 1996). Therefore, the call for understanding delays in help-seeking remains an essential issue for nurses and other healthcare professionals.

The CSM-SR is a theoretical framework that scientists may find useful in explaining delays in the decision-making process in patients with sepsis (Leventhal et al., 2016). The domains of the CSM-SR can be used to understand how patients acquire new information, process information, and react to the threat that infections pose on an individual level. The CSM-SR is a patient behavior model that can explain why patients may delay seeking professional help when experiencing symptoms of bacterial infections. No literature was found that applies the CSM-SR as a framework for use with patients with bacterial infections or sepsis. More research is needed to identify sources of information, clarify illness perceptions, and identify the barriers and facilitators to early help-seeking in patients experiencing symptoms of bacterial infections. The application of the CSM-SR can increase understanding of what patients believe, feel, and think when they experience symptoms of infection. Components of the CSM-SR have been tested in several studies that sought to understand the process of delay in care-seeking for symptoms of acute diseases (Davis, 2015). Recently, several researchers have sought to expand the use of the model to understand thinking processes by focusing on nonverbal aspects of interpretation and the interaction between cognitive and emotional reactions (Broadbent et al., 2019; McAndrew et al., 2019; Orbell & Alison Phillips, 2019).

Summary

This literature review provided a descriptive overview of what is known about the care and treatment of patients experiencing symptoms of sepsis and delays in help-seeking. Although the research focused on adults hospitalized for treatment of sepsis, studies that include subjects below the age of 18 years provide valuable input to understand the phenomenon of pre-hospital patient delay. The CSM-SR is a theoretical framework used to examine patient factors that influence the decision to seek help at the onset of symptoms. The CSM-SR contains elements that were used to capture the themes in this qualitative study. The model comprises cognitive and affective variables that are known to influence behavior.

Furthermore, it is evident that few studies in the United States have explored the presenting features and factors associated with delayed help-seeking, and none were found that applied the CSM-SR. Therefore, more research is needed to examine psychological and social variables influencing the decision to seek care early. Understanding the decision-making processes that lead to delays in help-seeking can facilitate improvements in understanding the importance of early diagnosis and treatment and improving health outcomes. This research is unique because it uses a theoretical framework to describe what patients hospitalized with sepsis know, think, and feel that influenced their decision to seek care. Furthermore, this research contributes to our understanding of delay times and the barriers and facilitators affecting help-seeking at the onset of symptoms.

CHAPTER III

METHODOLOGY

The purposes of this current inquiry were to identify patients' sources of information about sepsis, to explore the perceptions and experiences of patients diagnosed with sepsis, and to explore facilitators or barriers to seeking care for symptoms of suspected sepsis. Despite increasing recognition of the benefits of early goal-directed therapy, there remains a considerable delay between symptom onset and the start of antibiotic treatment (Guery & Calandra, 2019). Many patients miss the therapeutic window because they delay seeking help for their symptoms. To date, a paucity of research exists exploring the perceptions of patients who delayed seeking care for symptoms of sepsis, and few studies have been found that qualitatively describe the phenomenon of delays in help-seeking as it relates to patients diagnosed with bloodstream infection and sepsis (Clarke et al., 2015). This chapter describes the methodology of the research and the rationales for the methodological decisions. This chapter includes the research design, setting, description of the sample, and data collection and data analysis procedures. Finally, this chapter discusses steps taken to improve the trustworthiness of the data and the potential limitations of the study.

Research Questions

The research questions answered in this study are:

1. What sources of information do patients use to guide their decisions to seek help?
2. What are the illness perceptions and experiences of patients diagnosed with sepsis who delayed seeking care >24 hours from the onset of symptoms?
3. What barriers and facilitators are encountered in the help-seeking process for patients with sepsis who delayed seeking care for >24 hours from the onset of symptoms?

Research Design

Qualitative Approach and the Theoretical Foundation

This study used a qualitative descriptive design to guide the research and the Common-Sense Model of Self-regulation (CSM-SR) to guide the research questions, the interview guide, and data analysis. Chapters I and II provided a detailed discussion of the CSM-SR. Figure 1 illustrated the design of the CSM-SR, a parallel processing model in which the onset of symptoms elicits cognitive and emotional responses that influence decision-making processes to address a health threat (Hagger & Orbell, 2003). The CSM-SR was used to situate the deductive and inductive analysis into context. The researcher used semi-structured interviews and a researcher-designed data collection form to collect descriptive data.

Since the pre-hospital experience of patients with bacteremia and sepsis is poorly understood, a qualitative description can serve as a structure to identify patients' perceptions of and experiences with sepsis, as well as barriers and facilitators to seeking care in a timely manner. The goal of qualitative descriptive studies is to summarize events in everyday terms, so the complexities of sepsis can be understood by dialoguing with patients and understanding the experiences from their perspective (Sandelowski, 2000). Qualitative methods produce rich data that are informative for understanding patients' experiences during events involving illnesses (i.e., sepsis; Sandelowski, 2000). Semi-structured interviews allow participants to discuss their illness beliefs while simultaneously eliciting cognitive and emotional reactions to sepsis. The qualitative descriptive method is the best because it offers flexibility in the approaches that can be taken and allows the researcher to produce knowledge that is novel (Sandelowski, 2010)

The qualitative descriptive method was chosen instead of ethnography, phenomenology, and grounded theory study designs because it is better suited to achieve the study's aims, which was to describe patients' perceptions and experiences without interpreting the phenomenon (Sandelowski, 2000). The empowerment of patients can result in improvements in decision-making during the symptoms experience. Armed with knowledge about the adults' illness perceptions and experiences, the facilitators and barriers, and the role that others play in seeking help, healthcare providers will be equipped to provide education to adults at risk for infection. Qualitative content analysis was conducted to explore patients' beliefs about sepsis by analyzing and summarizing the transcribed verbal data (Sandelowski, 2000). This qualitative analysis involves separating data elements according to an *a priori* framework and a system derived from the data to organize the data (Sandelowski, 2000).

The CSM-SR provides a framework to understand how patients' perceptions of illness influence help-seeking behavior. Individuals respond to a specific illness experience based on what they believe and know. The current study examined how patients diagnosed with sepsis view their illness. Not only do illness perceptions influence the timeliness of patients' help-seeking behavior, but also the choice of coping strategies. Understanding how patients perceive their illness is integral to understanding the patients' decision to seek treatment at the hospital. Therefore, the dimensions of the CSM-SR were used in directed content analysis to capture the themes based on the broader topical areas from the interview guide. Furthermore, new emerging themes generated from the data were coded and categorized (Sandelowski, 2000).

Sample and Sampling Methods

The sample in this study was derived from former patients in the southeastern United States hospitalized for the treatment of non-healthcare-associated community-acquired (NHCA) and healthcare-associated community-acquired (HCA) bloodstream infections and sepsis. Adult patients enrolled in the Bloodstream Infections Registry (BSIR) at a university medical center were approached about this study. The BSIR is an ongoing prospective cohort study that enrolls patients with a culture-confirmed diagnosis of bacteremia. Consecutive patients with bacteremia caused by *Staphylococcus aureus* (SAB) or Gram-negative rod bacteria (GNB) are eligible for enrollment into the BSIR if they are >18 years of age, are hospitalized, have not been previously enrolled into the BSIR, have signs or symptoms of infection, and provided written informed consent. Patients consenting for the BSIR who also agreed to be contacted for future studies were contacted by the student researcher and introduced to this study either at the time of enrollment in the BSIR while admitted to the hospital or via a telephone call after discharge. Patients enrolled in the BSIR who agreed to be contacted regarding future research studies were consecutively screened and approached by the student researcher regarding their interest in this qualitative study, starting with the most recently enrolled dating back within 6 months of the diagnosis. Interested participants were enrolled in this study via an additional written informed consent process and documentation. Permission to access this patient population was achieved by obtaining a letter of support from the Principal Investigator for the BSIR and an existing Data Use Agreement (DUA) fully executed between the university medical center and UNCG officials.

For those participants who met the inclusion criteria, a one-on-one interview was scheduled, and data were collected in a private and confidential place via telephone or video conferencing, depending upon the participants' preferences. Convenience sampling using the snowballing technique was used for participant recruitment. Braun and Clarke (2013) described convenience sampling as the least rigorous sampling method, where the sample is selected because the researcher can gain access to the participants. Participants who enrolled in the BSIR were approached about this qualitative study while they are hospitalized, or they were contacted via telephone or WebEx no more than 6 months following bloodstream infection diagnosis to undergo the consent process. If the patient agreed to participate, the student researcher arranged a convenient day and time to complete the qualitative interview. This allowed the student researcher to contact participants previously enrolled in the BSIR if they agreed to be contacted for future studies; this time was used to address issues concerning recall bias (Stephanie, 2016). During the interview, the investigator reconfirmed eligibility and administered a 6-item screener to identify participants with cognitive impairment (see Appendix A). If the participant had two or more errors on the cognitive screener, he or she was no longer eligible to complete the interview (King et al., 2020). The researcher presented potential participants with a screening question to determine if the patient delayed seeking care >24 hours from the onset of symptoms. Also, to reconfirm eligibility, the investigator reviewed the enrollment criteria with each participant's BSIR information for potential conditions that may have affected the participant's ability to complete the qualitative interview.

Braun and Clark (2013) suggested that the sample size is determined when data saturation is reached, meaning the researcher is no longer acquiring any new information from the participants' data. Small qualitative interview studies typically consist of 6-10 participants, while medium projects consist of 10-20 interviews, but this number varies (Braun & Clark, 2013). For example, in a qualitative descriptive study using patients with neutropenic sepsis in an examination of pre-hospital delays, the sample size consisted of 22 cancer patients and 10 caregivers (Clarke et al., 2015).

Given the typical sample sizes in qualitative studies, the student researcher had planned to enroll 10-20 participants previously admitted to a hospital to treat a bloodstream infection or sepsis in the previous 6 months before enrollment in this qualitative study. According to Stephanie (2016), regardless of the time frame, a certain amount of recall bias is inevitable and varies among cases because memories of past events are generally not reported completely and accurately. It is impossible to avoid recall bias, but it can be minimized by choosing patients with a new diagnosis and by verifying information with a medical record if it is available (Stephanie, 2016). The researcher excluded the following patients: non-English-speaking patients and patients with mental status changes or preexisting cognitive disorders. The mental status and cognitive exclusion criteria were planned to ensure that those recruited would be able to engage in the interview and produce credible information. Furthermore, participants were asked a screening question to determine if they remembered the specifics of the events surrounding the episode with bloodstream infection and sepsis.

Subject Selection

Inclusion Criteria:

- Age 18 years or older.
- Hemodynamically stable.
- Delayed seeking care >24 hours from the onset of symptoms.
- Had been diagnosed with sepsis within the past 6 months.

Exclusion Criteria:

- Non-English speaking.
- One or more errors in the cognitive screener. See Appendix A.
- Diagnosed with a hospital-acquired infection.

All participants were recruited from a university medical center in the southeastern U.S. Using the snowballing technique, participants who enrolled via the BSIR were asked at the end of the interview if they knew other individuals who met the criteria and if they were willing to give the study information and the researcher’s contact information to other potential participants. Institutional Review Board (IRB) approval was obtained from a university medical center in the southeastern U.S. and The University of North Carolina at Greensboro (UNCG). Once IRB approval was granted, participants were recruited through the BSIR at the university medical center, and data collected from participants were used under a Waiver of Authorization and Consent. Informed consent was obtained from all participants. All information was kept confidential to protect the privacy of participants' information. Study IDs were assigned and used during the data collection process to ensure that data were not linked to any specific participant. Privacy and confidentiality were protected by the aggregation of data and masking of organizations. A confidentiality agreement was put in place with the transcription service that transcribed the interview data. Participants who consented to participation in this research project agreed to engage in a one-time interview in person, by video conferencing, or by phone, administered at a convenient time for the individual participants. Additionally, the participants were asked to use follow-up calls to clarify responses and ask additional questions. The interview transcripts were de-identified for analysis.

Participants in this study were incentivized with a $25 check. This incentive provided partial compensation for the time and inconveniences that participating in the research may have caused. Twenty-five dollars is reasonable compensation, avoided the undue influence of the participants in the study, and avoided introducing bias by overcompensating the participants (Robinson, 2014).

Data Collection Procedures

Semi-Structured Interviews

Data collection included semi-structured, 30- to 60-minute interviews conducted in-person, via video conference, or phone, depending upon participant preference. The interviews were audio-recorded for transcription. Guided by the CSM-SR, the interview guide began with an open-ended question based on the illness perception domains of the model, then followed up with probing questions. The student researcher used an adapted interview guide to direct the discussion (Davis, 2017; King et al., 2019). See Appendix B for the adapted interview guide. During the interviews, participants discussed their beliefs and experiences regarding sepsis. Participants were interviewed to develop a broader understanding of the impact of what happens in the pre-hospital phase when patients experience symptoms of infection. The study researcher's clinical experience, literature related to patient decision-making and help-seeking for symptoms of infection, the CSM-SR, and discussions with professionals who treat adults with bacterial infectious diseases were employed to develop the interview guide. A convenient date, time, and place was chosen to conduct the in-person, video conference, or telephone interviews with the participants. Although questions were asked initially about "sepsis," the interviewer then adapted the questions to refer to the terminology used by the participants, for example, their type of infection (e.g., pneumonia and blood poisoning; Mellhammar et al., 2015). The interviewer redirected the discussion back to the main points as needed. If a participant had difficulty with recall, the interviewer helped the participant to think back to key events by providing context for the behavior using time periods based on personal, local, culturally specific, or widely known relevant events to which the participants could relate, such as seasons, holidays, or personal events (Carter-Harris, 2015). The researcher took field notes during the interviews. Beginning with the first interview, data collection was an iterative process whereby data analysis began with the first interview and continued until all interviews had been conducted and analyzed. Transcriptions of the audio recordings (excluding names) were verified for accuracy by the researcher.

Demographic and Clinical Characteristic Questionnaires

The student researcher used a researcher-designed data collection form to collect sociodemographic information such as age, race, gender, highest level of education completed, annual household income, and health insurance status. See Appendix C for the adapted demographic characteristic data collection form (Davis, 2017).

Data Management

Digital Recording and Digital Data

A digital recorder was used to record interviews saved on a password-protected computer on a secured network drive at the university medical center. The digital recordings were transcribed verbatim by a transcription service provider, and the investigator kept interview transcripts and field notes in the secured digital file. Only aggregated data were reported and retained. Encrypted digital data were managed on a password-protected and firewalled laptop computer and/or on secure network drives. The laptop had encryption software installed. All digital data were stored on a secure network drive accessed on a password-protected device.

Written Data

Paper files were kept behind double locks (i.e., locked filing cabinets and locked doors). Record retention was to continue 3-6 years after completing the study in keeping with respective institutional policies. After that time, the student researcher will destroy research information and information identifying the participants.

Data Analysis

Audio-recorded interviews transcribed verbatim were qualitatively analyzed using directed content analysis (Sandelowski, 2010). The researcher verified the transcripts compared to the audio recordings to ensure that they were accurate. Two levels of coding were used. Following confirmation of verbatim transcription, data were analyzed using the deductive and inductive category application for open coding of themes (Sandelowski, 2010). First, the identified codes based on the CSM-SR were used in the qualitative software, NVivo 12, to organize the codes. Second-level coding used new terms not used in the CSM-SR. An audit trail and audit processes were used to increase the trustworthiness of the findings (Sandelowski, 2010). The audit trail consisted of field notes and memos. Field notes were captured in a research journal and provided an opportunity for the researcher to be reflective and to document her thoughts. Memos were captured in the NVivo 12 program and consisted of the researcher's reflection on the codes and the information being coded, including what was done, why, and how.

The thematic analysis used deductive and inductive coding to identify, analyze, and report patterns across the dataset (Sandelowski, 2010). The researcher used a qualitative analysis software, NVivo 12, to code aspects that formed the basis of repeated patterns. Immediately following the acquisition of interview data, directed content analysis commenced using predetermined codes that matched the dimensions of the CSM-SR. Directed content analysis was used to capture the themes based on the broader topical areas from the interview guide. As themes emerged, they were categorized based on a preexisting framework (i.e., the CSM-SR). Any text not categorized with predetermined codes was given a new code or category or was coded as a sub-category of one of the existing codes (Sandelowski, 2010). The content analysis enables the extrapolation of the contextual meaning of the text (Sandelowski, 2000). Data collection and analysis continued until thematic saturation was achieved with the sample (i.e., no new dimensions emerge from the data; Braun & Clarke, 2013).

To ensure the credibility of the research data, the principal investigator for this study maintained an audit trail of coding and analytic decisions. The researcher provided the audit trail to an expert in qualitative research to verify data codes and themes. The researcher maintained a research journal that included field notes captured immediately following each interview. The field notes were used to document the research process and provide details about what was done, how it was done, and why things were done (Braun & Clarke, 2013). Field notes reflected the researcher's thoughts and feelings about key areas of interest throughout the research process.

Additionally, recording field notes provided an opportunity to explore the participants' thoughts, feelings, and non-verbal expressions. By offering additional insights into the data, writing field notes is a way to achieve emersion in the data leading to an in-depth understanding of the participants' experiences while making the participants’ accounts comprehensible. The archival record of field notes is a component of data collection and analysis, and they can be used in various ways (e.g., adding non-verbal content noted in the interview, presenting emotions of the participants and the researcher, or presenting questions or concerns raised during the interview). The researcher’s critical reflections recorded in the field notes provided context for the research study. The researcher read the field notes and analyzed them in NVivo 12 to identify codes and themes and compare the codes and themes in the field notes to the existing codes and themes (Phillippi & Lauderdale, 2018).

Chapter Summary

This qualitative descriptive study design fills a key literature gap by describing the perceptions and pre-hospital experiences of patients diagnosed with sepsis. The results of this study aids in understanding patients’ decision-making processes regarding when to seek care and from whom. The study used qualitative description as a study design to ensure that contextual factors could be explored through the perceptions and beliefs of patients with sepsis who engaged in help-seeking behavior. The Common-Sense Model of Self-Regulation was used to situate the deductive and inductive analysis into context and served as a guide for the research questions, the interview guide, and the data analysis. Semi-structured interviews and researcher-designed data collection forms were used for data collection. Ethical standards to protect human subjects were upheld throughout the study. The trustworthiness or dependability of data collection methods and analyses were addressed using audit trails and confirmation of coding and analysis by an experienced qualitative researcher. Since qualitative research is crucial in developing interventions, this research precipitates an understanding from the participants' perspective in a way that allows for developing interventions designed to mitigate patient pre-hospital delays (Sandelowski & Leeman, 2012).

CHAPTER IV

RESULTS

A qualitative descriptive design was used to explore the sources of information, illness perceptions, and the facilitators and barriers to help-seeking among patients diagnosed with bloodstream infection and sepsis. The Common-Sense Model of Self-Regulation (CSM-SR) was used as the theoretical framework to guide the research questions, the interview guide, and data analysis. This chapter will present the data analysis from semi-structured interviews that were subject to content analysis. The sections that follow demonstrate the application of the CSM-SR related to the study findings, followed by a chapter summary.

Sociodemographic and Clinical Characteristics of the Sample

Former patients who had been hospitalized for the treatment of bloodstream infection and who had been enrolled in the Bloodstream Infections Registry were contacted by phone and consented to participate in this qualitative study. The researcher interviewed 10 participants by phone, and audio recordings were then transcribed verbatim by a professional transcriptionist. The average duration of the interviews was 64.6 minutes, and ranged from 43 to 113 minutes. Ten participants made up a convenience sample of English-speaking men and women with a recent bloodstream infection diagnosis history requiring hospitalization. Table 1 presents the demographic and clinical characteristics of the consented participants. The majority of the participants were female (*n*=6, 60%) and self-identified as White (*n*=5; 50%). The ages of participants ranged from 34 to 73 years old, with an average age of 57.9. Nearly three-fourths of the participants had some college education. Nine of the ten participants were unemployed, either retired or disabled. Most participants had an annual household income of $20,000 to $60,000 and had Medicare or private insurance, or both covered the cost of care. Device infections (*n*=4; 40%), skin and soft tissue infections (*n*=1; 10%), and gastrointestinal and genitourinary (GI/GU) infections (*n*=5; 50%) were reported in the sample. Five of the infections were caused by *Staphylococcus aureus* (*n*=5), and the others were caused by *Escherichia coli* (*n*=4) and *Klebsiella pneumoniae* (*n*=1). Fifty percent of the participants had a prior history of a bloodstream infection. One participant reported having a urinary tract infection (UTI) in the past.

Table 1

Sociodemographic and Clinical Characteristics of the Sample (N=10)

	Male	Female	Total
Age			
Average age in Years	62.8	54.7	57.9
Age Range in Years	55-73	34-65	34 -73
Race	4	6	10
Caucasian/White	1	4	5
African-American/Black	3	1	4
American Indian/White	0	1	1
Relationship Status			
Married	3	2	5
Separated/Divorce	1	3	4
Widowed	0	1	1
Educational Level			
Did not complete high school	1	1	2
High School graduate	1	0	1

	Male	Female	Total
Some college/Associates Degree	0	3	3
Bachelor’s degree	2	2	4
Employment Status			
Employed fulltime	0	1	1
Unemployed, disabled	2	4	6
Unemployed, retired	2	1	3
Annual Household Income			
<$20,000	1	0	1
$20,000 – 39,999	2	4	6
$40,000 – 59,999	0	1	1
>$60,000	1	1	2
Insurance Status			
Medicare and Private	2	0	2
Medicare	1	3	4
Private	0	2	2
Medicaid	1	1	2
Infection type			
Escherichia coli	2	2	4
Klebsiella pneumoniae	0	1	1
MSSA	0	2	2
MRSA	2	1	3
Previous Bloodstream Infection			
Yes	2	3	5
No	2	3	5
Approximate Time Between Discharge and Interview Date			
Less than one month	0	1	1
2 months	1	0	1
3 months	2	1	3
4 months	1	3	4
5 months	0	1	1

Delay Intervals from Symptom Onset to Arrival at the Hospital

All of the participants went through recognizing the symptoms, inferring illness, and coping with their symptoms. One of the inclusion criteria that bound this study group is that they all delayed seeking care for > 24 hours from the onset of symptoms. The study results showed that it was difficult to measure the amount of time taken to seek care at the hospital. However, participants provided estimates of delay based on the three-delay model (Safer et al., 1979). First, this study attempted to measure appraisal delay, which is the amount of time it took for the participant to realize they were ill. Second, illness delay was the amount of time between realizing they were ill to when they decided to seek medical care. Finally, the behavioral delay was the amount of time between the decision to seek care and arrival at the hospital. Few participants could provide precise times for the onset of symptoms, so the time intervals recalled were estimates. Appraisal delays ranged from hours to days to weeks to months. One participant had difficulty determining the amount of time due to multiple recent admissions. Illness delay ranged from hours to days to one week to seek medical care. The behavioral delay had the lowest amount of time and ranged from 5 minutes to over 2 days. The participant who delayed two days after she decided to seek help stated, “I’m gonna say about 54–56 hours for me to actually get from calling my doctor’s office to actually being in the emergency room.” This participant took more than two days once she decided to seek care at the hospital. The amount of time used for the behavioral delay was related to how close the participants lived to the hospital. Some participants lived in the surrounding areas, so it may have taken them 1–1.5 hours to arrive at the hospital because they chose to seek care at the university medical center rather than the closest hospital to their home.

Data Analysis

Ten transcripts and sociodemographic data comprised the data for analysis. The researcher qualitatively analyzed the data after verifying the accuracy of the transcripts against the audio recordings. NVivo 12 (QSR International-Melbourne) was used to organize and categorize the themes. First, a deductive coding framework based on the CSM-SR was used to classify and code the participant responses according to *a priori* coding categories. Second, the researcher used an inductive approach using open coding. The data analysis allowed for exploring similarities, differences, and interconnectedness across codes and participants by comparing themes across individual participants. The researcher reviewed the interviews and used *a priori* codes and emergent themes aligned with the study's aims. Since the study applied a theoretical model to explore patients' experiences with bloodstream infections using in-depth interviews, relatively thick, rich data was generated from each participant. Therefore, data collection was discontinued when saturation was reached, i.e., additional data failed to generate new information because all participants answered the same set of interview questions (Sandelowski, 1995). The researcher aggregated demographic data collected using a researcher-made data collection form. An expert qualitative researcher reviewed the codes and themes. Approximately 942 codes were identified. See Appendix D for sample codes and corresponding text. The codes were collapsed into eight categories. See Appendix E for codes placed under the broad categories.

The researcher identified three main themes in the qualitative analysis of participant experiences—gathering threads for a tapestry, weaving the threads into a tapestry for a garment, and being clothed and in their right mind. The themes with subthemes in this paper are summarized and described in the following sections. Participant quotes support the themes and subthemes.

Overview of Themes

Theme 1: Gathering Threads for a Tapestry

Theme 1 involves how people acquire and use information to help them understand or derive meaning from their symptoms. Gathered knowledge shapes the beliefs that influence their behavior. Just like one would gather threads to create a tapestry, the participants were gathering pieces of information. Some of the information came from their own bodies (i.e., symptom information), as well as pieces of information from talking with other people. Participants use acquired knowledge gained in symptom appraisal, which begins at symptom onset. Symptom appraisal is an iterative cognitive process that the patients engage in throughout the trajectory of care-seeking. Theme 1 has four subthemes. The subthemes are acquiring and utilizing knowledge from somatic sensations and symptom information, lay information stored in memory, expert knowledge acquired from healthcare professionals, and knowledge gained through reading books, magazines, journals, and internet searches.

Theme 2: Weaving the Threads into a Tapestry for a Garment

Theme 2 describes what patients believe about the symptoms and the illness that influences their decisions and actions. This theme demonstrates how patients use acquired knowledge from symptom information, lay information, expert knowledge, the knowledge gained through reading to formulate illness perceptions. Illness perceptions are the participants’ beliefs about the symptoms and the illness that influence help-seeking behavior. In reacting to the symptom experience, participants encountered facilitators and barriers to help-seeking. Theme 2 has four subthemes. They are (a) cognitive illness perceptions, (b) emotional illness perceptions, (c) coping strategies, and (d) facilitators and barriers to help-seeking.

Theme 3: Being Clothed and in Their Right Mind

Theme 3 explains the appraisal and re-appraisal process, in which patients assess the impact that the bloodstream infection has on their health and life and those close to them. This theme addresses the participants' physical and psychological states that are impacted by the experience of having an infection. Bloodstream infections and sepsis complications and their impact become an indelible part of the patient's life that continues throughout their life, hence the metaphor of being clothed. This theme has two subthemes. The subthemes are illness outcomes and emotional outcomes.

The research questions that were answered by the themes identified in this study are (a) What sources of information do patients use to guide their decisions to seek help? (b) What are the illness perceptions and experiences of patients diagnosed with sepsis who delayed seeking care >24 hours from the onset of symptoms? and (c) What barriers and facilitators are encountered in the help-seeking process for patients with sepsis who delayed seeking care for >24 hours from the onset of symptoms?

Theme 1: Gathering Threads for the Tapestry

Subtheme 1. Knowledge from Symptom Information

The first subtheme is gathering knowledge from symptom recognition. It occurred early and was one of the first things the participants did. Symptom recognition and interpretation begin when the patient first notices the symptoms. Participants used the knowledge and personal and vicarious experiences to make sense of the health threat when symptoms occurred. To do this, the participants drew on many sources to derive meaning from the symptoms. The symptom onset acts as a stimulus to motivate help-seeking behavior. Somatic and symptom information also served as sources of information for the participants in the help-seeking decision-making process.

Finally, the symptoms are a primary source of information for the participant to process as they try to make sense of the illness. When patients experience symptoms, they iteratively engage in the cognitive appraisal of the symptoms. They sometimes compared the new symptoms to an experience to try to derive meaning from the symptoms. Participants reported a variety of symptoms that they experienced in the pre-hospital phase. Some of the typical symptoms that participants experienced were fever, headaches, and localized pain and swelling. Some participants experienced symptoms related to the gastrointestinal system, such as abdominal pain, heartburn, nausea, vomiting, and diarrhea. Other symptoms included shortness of breath, fatigue, and confusion. At least three participants denied having a fever, but two participants mentioned feeling “warmth.” For example, when referring to her leg that was painful and swollen, one participant stated, “it keeps fever in it.”

Sometimes symptoms of infection start locally, as with the participant who developed an abscess on his finger. He stated,

> My hand would ache sometime really, really bad. I would get chills or whatever, and so I put my jacket and stuff on. As far as my hands, they just start aching, and they never stopped. And it went on to the point where, on my right hand, it started to swell.

This participant tried using home remedies, like soaks and over-the-counter pain medications, which often will clear up a single skin abscess. However, his boil resisted home treatment, and the infection moved into his bloodstream. He sought knowledge and care from a local urgent care facility. The participant used the knowledge he had for dealing with aches and pain in the past, but when the home remedies did not work, he presented to the healthcare facility and was instructed to report to the hospital.

Bloodstream infection is an acute illness, and sometimes when patients are managing chronic conditions, symptom interpretation can be complicated. The presence of chronic conditions may make it difficult for the patient to determine whether their symptoms are related to an infection. That was the case with a participant who has a history of congestive heart failure (CHF). Below, he described his symptom experience that led to his being hospitalized and being diagnosed with a bloodstream infection.

> I was getting short of breath … The only symptom I had that I then associated with it was I had some fatigue. And I felt tired sometimes. But I need to stress to you that I was not flooded with all kinds of symptoms that either scared, or frightened, or impacted me. It just didn’t happen.

Throughout the interview, this participant focused on the shortness of breath, which he initially did not associate with an infection. He later became aware that he was also fatigued, which is quite common among the elderly population. However, knowing that an exacerbation of a chronic condition like CHF could be a symptom of infection would have benefited this participant and others in a similar situation.

Altered mentation is a common infection symptom that the general public may or may not relate to an infection. In at least three cases, participants stated that there were periods in their illness in which they were confused or delirious, and they had to rely on a family member to inform them of the changes in their mental status. When a patient experiences changes in their mentation, they cannot process information in the usual ways. Once they receive treatment and their cognitive faculties return to baseline, i.e., alert and oriented times three to four, they can function as expected. Here is what one participant had to say about her cognitive ability when she contracted the infection:

> I became delirious. And it was really frightening afterward. When I realized it. When Doug, my husband, and my brother, Tony, told me. That I wasn't making any sense and that kind of thing. That was really frightening. But it wasn't a fever or anything like that.

In this situation, the participant's family members had to intervene on the patient's behalf because sometimes infections can leave one incapacitated and unable to make decisions for themselves.

Subtheme 2. Lay Information Stored in Memory

Lay information stored in memory includes previous knowledge from working as a medical professional and talking with other friends or relatives who have experience working in a medical profession, not necessarily as a nurse or doctor. The participants' personal history of having a bloodstream infection is also considered as lay information. Nearly all of the participants used lay information to make sense of the symptom experience and the illness.

One participant with a history of a previous bloodstream infection illustrated the use of lay information when she developed symptoms of infection. She contracted her first bloodstream infection while she was in the hospital for pacemaker placement. On that occasion, she developed a fever, and since she was already hospitalized, she was able to undergo treatment quickly. However, the participant was at home the second time she contracted a bloodstream infection and stated she "did not spike a fever." In the second encounter described in this study, she stated that "it started with diarrhea. And then I started getting pain in my neck." In the following passage, she draws on her experience as a medical coder and emergency department worker and her experience with bloodstream infection. The source of the infection was the leadless pacemaker. She stated,

> Well, I used to work in the medical field as a coder. So, I read lots of different charts, and I worked in an emergency room for a little while. So, I picked up some knowledge from both of those jobs … The first time I got it was in May of, not 2020, 2019. Yeah. Well, no. No, I think it was 2019. When they put my pacemaker in, I got it. The day after my pacemaker, I got sick. That was the one time I did have a fever.

The participant draws on past experiences of working in the medical environment and compares the symptoms from the first infection and the symptoms from the new infection.

Another participant had a similar experience, except she benefited from her husband, who worked in "medical IT." Her husband had to decide to seek care because the participant's mentation was altered by the infection, as her main symptom was delirium. The participant was first asked, “What did you know about bloodstream infections before you were diagnosed?” She stated, “Oh, well, I learned about MRSA five years ago when I developed it from surgery at [the university medical center]. But before that, I didn’t know anything about it.” The way the participant obtained health information, in general, was that she gets information from the “Internet” and “magazines.” She went on to say of her husband, “Because he works in medical IT. So, he had a lot of information about that.” In this example, this participant recalls her first encounter with MRSA (Methicillin-Resistant *Staphylococcus aureus*) bacteremia as a source of information to understand her most recent infection. Additionally, she obtained some information from her husband, who had worked in an operating room (OR) with the IT department. Sometimes, it is the patient’s own experiences, and other times it is knowledge from others.

Subtheme 3. Expert knowledge from Health Professionals

Participants not only rely on lay information to make decisions, but they also rely on knowledge from experts. Information from expert sources typically comes from nurses and doctors working directly with the patients either in clinics, home health agencies, or hospitals. The majority of the participants interviewed attested to receiving education from doctors and nurses, as did the following two participants. When one participant, who developed an infection from gastrointestinal (GI) translocation in cholecystitis, was asked what sources of information she used, she stated, “They’re really good. I mean the [the university medical center] doctors and nurses and everything. They explained everything so well, you know?” The participant expressed her satisfaction with the information she received from the doctors and nurses caring for her while she was in the hospital. This participant did not have a history of infection, so she did not have past experiences upon which to draw. Still, the doctors and nurses provided information about the infection symptoms and how her condition developed.

Another example of obtaining information from experts is a participant with a long medical history of leukemia and a kidney transplant. He stated,

> Well, I ask a lot of questions of my medical staff. If I have a question about anything, I ask my doctors; if something curious has happened or something is going on with me, I ask my doctors.

The participant had a history of bloodstream infections because he is a leukemia survivor and a transplant recipient, both risks for infection. Since he has matriculated in healthcare systems for several years, he has grown comfortable asking the medical staff questions. Patients are not always fortunate to have doctors and nurses so willing to share information. The following two participants did not report having received sufficient information from the nurses and doctors. For example, one participant offered the following information about his experience with the doctors and nurses that was quite different from other reports:

> And they didn’t explain to me how dangerous it was … They didn’t really tell me or explain to me what they were suspecting. The doctors were not real communicative about what it was.

This lack of patient education was reported by another participant who complained about worsening leg pain following surgery for bladder cancer. It seems that she had some challenges with comprehending what she might have been taught because, as she said, she was focused on the pain. In the interview, she stated that they "may have told me," but she stated that she was in so much pain that she might not have been paying any attention to what they were saying. When asked, "What did you *not* like about the care you received?" she said,

> Just that nobody's explaining to me what's really happening. That's what I don't like because I don't know what's going on. They may know, but I don't know what's going on. This wasn't happening until he went in and did this, and then all of a sudden this starts happening. My left leg don't swell, but just my right leg swells and it hurts all the time. All this is on the right side as to where they treated me for the cancer … I mean, why is it that nobody's checking to see if it had anything to do with my bladder when he went in and scraped it and all this had happened? Nobody's saying nothing about that. And even though I heard a couple times, "He's gonna come by and see you," I ain't seen him since I went back up there, the doctor. I would love to talk to him, too, but I still haven't had a chance to.

This quote shows that patients value the doctors' time, but they don't always get the information they desire from the people caring for them. It was evident that she had some knowledge about what was going on with her, but it was not sufficient for her to be satisfied with the care she received. Sometimes patients need to have things explained so they can understand, and the information must be provided when the patient can focus, not when they are dealing with severe pain. Since nurses and doctors have limited time to spend with patients, they can provide supplemental, written material to educate the patient about their condition, how to care for themselves, and how to make the right decisions regarding health matters. This is where the reading material and the Internet might be helpful.

Subtheme 4. Knowledge Gained Through the Internet and Reading Books, Magazines, and Journals

Subtheme 4 leads us to another way that participants gathered health information, which was by using the internet. Eight of the 10 participants reported using Google to learn about medical conditions, medications, and what symptoms might mean. Only three participants indicated that they read books, magazines, and journals to obtain medical information. When asked about the ways that he obtained health information in general, one participant said,

> I Google it. If I have symptoms or it's late, it gives a medical term, or I go to the internet and I look under those different websites to find out what to learn about medications, about symptoms, about you know. And I get alerts from WebMedical. And it comes in – They will bombard you with all kinds of medical issues.

This participant has learned to be an independent learner when it concerns matters related to health. Sometimes the elderly patients are not expected to use computers to manage their health, but it is a medium used across almost all participants.

When the participant treated for bladder cancer was asked about how she learned about illness and health, she indicated that reading is one way that she obtains health information. She said,

> A lot of it, I read about it. I got little medical journals that I buy at the stores and books that I'll pick up about medicine, and infections, and pain, and stuff like that. I learn a lot by how much I'm reading.

The participants had multiple ways to obtain the information to manage their health. Reading is an excellent way to accomplish this. The patient who experiences symptoms and cannot contact the doctor or nurse can access some reputable books and journals that can help them learn about possible infection symptoms that require immediate care.

These illustrative quotes provide an overview of how patients gather information to be employed in self-management when symptoms occur. Throughout a person's life, one engages in gathering information that will be used to understand and explain medical conditions and the potential consequences. Participants used various ways to learn and to know about infectious diseases. Sources of information varied among participants, and knowledge is developed before, during, and after an encounter with an infection. When the participants encountered the health threat, they use their somatic sensations and symptom information, lay information stored in memory, expert knowledge from health professionals, and knowledge acquired through reading books, magazines, journals, and the Internet to formulate illness perceptions. These different ways of knowing come together to enhance cognitive abilities that patients use to decide when to seek care.

Theme 2. Weaving the Threads into a Tapestry for a Garment

Delayed help-seeking is a complex behavior that was found among the participants in this inquiry. Weaving the threads into a tapestry for a garment means that participants cognitively assembled information they obtained from personal experiences with the illness, the symptom experience, lay information stored in memory, and expert knowledge from health care providers. What will ensue is a discussion of the interplay between the cognitive and affective processes in decision-making that influence the speed at which the participants sought help. Furthermore, this research explores coping strategies used by the participants in this study. Participants used the knowledge gained from different sources to construct their beliefs. Consistent with the CSM-SR, participants interacted with their sociocultural environments, past experiences, and conscious and implicit knowledge of what the symptoms and the disease mean (Hagger & Orbell, 2003). The four subthemes associated with Theme 2 are (a) cognitive illness perceptions, (b) emotional illness perceptions, (c) coping strategies, and (d) facilitators and barriers to help-seeking.

Subtheme 1. Cognitive Illness Perceptions

Participants' cognitive illness perceptions of bloodstream infections were based on the five dimensions of the CSM-SR: label/identity, timeline, cause, control/cure, and consequences (Diefenbach & Leventhal, 1996). These dimensions were described in Chapter 1 and were express by the participants in this study. The emotional representations of the bloodstream infection included emotional reactions to and concerns about the illness.

Label/Identity. Participants experienced a variety of symptoms before they were diagnosed with an infection. When they experienced the symptoms, participants attempted to label or to identify the illness. Participants expressed their ideas about the physical representations of the illness and gave a label based on associated symptoms' perceptions. Six of the participants in this study mislabel their symptoms. When experiencing the symptoms of bloodstream infection, one participant thought it was COVID-19. Another participant labeled the symptoms of the pain in his hand as arthritis.

A participant experiencing worsening shortness of breath thought it was congestive heart failure, and another participant with diarrhea thought it was something she ate. A participant who had symptoms that felt like heartburn thought it was her gallbladder. A participant who was experiencing leg pain thought she had a blood clot. One participant stated, “I did not know, but I know something was wrong.”

Only two participants correctly labeled the symptoms as being associated with an infection. The two participants who labeled the illness correctly as an infection had a history of bloodstream infection and knew how to interpret the symptoms. The time to decide to seek help, although somewhat delayed, was shortened by the fact that they had prior experience with bloodstream infections. One participant who mislabeled the illness said,

> I went in there because I felt I was having a congested heart. But it turned out that all I had was congestive fluid in my system. So, I went there because I didn’t know. It was like congested heart stuff … I think I said I had experienced congestive heart many times. So, I knew what it was. I contacted my cardiologist.

This participant mislabeled his symptoms as heart failure (HF) because he had been managing it chronically. So, when the main symptom that he experienced was shortness of breath, he automatically thought it was a flare-up of his CHF. This belief influenced his decision to delay seeking care at the hospital and seek care from his cardiologists rather than going to the emergency department or contacting an infectious disease doctor.

Timeline. Consistent with the CSM-SR domain of the perception of the bloodstream infection timeline, participants expressed uncertainty about how long the symptoms and the illness would last. Some thought the illness would last a short time, only to discover that it was a severe illness that involved a longer recovery time than they expected. Participants identified a variety of symptoms that they experienced before and after the bloodstream infection diagnosis. Some reported symptoms that continued even beyond the diagnosis and treatment of the infection (e.g., the participant who complained of leg pain). Even after discharge, some of the participants continued to interpret bodily changes, and some understood that these changes signaled the long-term effects of the bloodstream infection.

Cause. In general, participants were aware of the many causes of bloodstream infection. Although some participants admitted to not knowing what caused the bloodstream infection, others were aware that there might have been different factors that caused the infection. The participants classified the perceived causes of bloodstream infection as biology and genetics, healthcare-associated, environmental, caused by self-care deficits, and one participant stated that they did not know. The biological reasons included compromised immune system, side effects of medications and treatments, and hereditary/genetics. Participants believed that the infection was related to healthcare, such as the presence of a medical device, post-surgical infections, e.g., kidney transplant and bladder surgery. Others believed that the cause of the infection was contact with someone in the environment. Finally, one participant thought that the infection occurred because she practiced poor hygiene. For example, one participant stated,

> I’m going to believe what my doctors told me because I don’t know what caused it, and I have no speculation as to what caused it. And I was told by my doctors

> that it was basically introduced into my body, most likely, through my port-a-cath.

Another participant said,

> Because my diabetes, for one. I think, like the doctor explained to me, if I hadn't been diabetic, it probably wouldn't even bother me. But since I was diabetic and sugars were running high, my immune system was compromised a little bit, and I got sick.

Control/Cure. The perception of treatment and personal control of the bloodstream infection showed that, in general, participants believe that they did not have control over whether they got better or worse. Only two participants stated that they "have the power to control" the illness, and even one of them said, "Well, I do think I have the power to control it. It's just that I feel like I got a really bad draw with the original infection." However, in terms of treatment control, all participants relied on the professionals' expertise and the medications they prescribed (i.e., the antibiotics). One participant mentioned eating healthy, staying active, taking supplements, as well as taking the medications used to treat the infection, but stated, "I don't think anybody can control anything."

Consequences. The perceived consequences of the bloodstream infection that participants reported did not vary significantly. Participants reported anticipated, actual, and potential consequences of the bloodstream infection. Participants reported social and medical consequences, with the majority being medical consequences. When deciding to seek care, one participant expected to be admitted to the hospital and arrived at the emergency department (ED) prepared to stay. The actual social consequence that she reported was “a loss of freedom for one week.” This participant believed that an actual medical consequence is that she will be more susceptible to disease. Most participants reported actual medical consequences. One participant stated that things “wrapped up quite well,” but then reported that being in the hospital and being treated for the infection physically weakened him. Another participant experienced a loss of his transplanted kidney due to the infection, and he had to restart hemodialysis. One participant reported that his anticipated medical consequences were that he would go to the hospital, get treatment, and go home. Instead, the participant was admitted and spent almost a week in the hospital. Another participant anticipated that she would get cultures, stay in the hospital, and get treated. Over half of the participants reported imagined medical consequences, stating they could have died. One participant said she could have lost her limb. Yet another participant reported an imagined social consequence and considered how, if he had died, how his death would have affected his family. He said,

> They would check it out, drain it, send me back home. Give me some antibiotics. That’s what I thought. Never thought that I will be admitted. Well, the consequences were, they told me what was going on, gave me a plan to take care of it, and told me what I had to do for 30 days, that I would have to take those infusions twice a day. And that’s what I did … I might be dead. I mean, when you’re told that your bloodstream was infected, that means my whole system is compromised. So, I figured if I hadn’t of went, I might’ve fallen dead and wouldn’t knew why. Nobody would’ve knew why until they did a autopsy. It could have from a financial part. I could not have – Suppose I didn’t have hospital insurance. That would have been a major burden for somebody else to deal with, or me to deal with. The scariest part is, suppose it would have actually caused my death, and the effect it would have had on my family.

The participant talked about anticipated, actual, and imagined medical and social consequences of having a bloodstream infection.

Subtheme 2. Emotional Illness Perceptions

Participants experienced several fear-based reactions to having the bloodstream infection. No participants used the word *fear* to describe their feelings, but one participant said she was “panicked, worried, anxious, and upset” as she remembered having a previous infection. She was having these feelings because she did not want to be re-admitted to the hospital and remembered the last time it took her 3 months to recover. Another participant said that she was “horrified” because she, too, remembered the last time she was in the hospital with an infection.

Participants who reported being scared felt that way because, for one participant, the doctors found a blood clot in her lung. Another participant was feeling “frightened and scared” because they were wondering what was occurring. This participant stated that it was “a traumatizing time for the family.” This participant had concerns about the unknown and the effect of the illness on the family. One participant was “upset” because the pain in her leg affected her ability to walk, and she had difficulty with daily living activities, like going to the grocery store.

One participant was “hurt” about losing his transplanted kidney due to the infection, and he did not want to go back on hemodialysis. “Hurt” here refers to psychological distress or emotional pain that usually originates from nonphysical sources but may result from grief or loss. He was also worried because his being sick with the infection meant that he could not care for his wife, who was suffering from a sickness. He stated,

> It hurt me because I didn't wanna go back on dialysis, and it really hurt me at first, but I'm getting over – I'm still getting over it right now. It made me feel bad because the thought of losing my kidney, and they gave me time – five years on a donated kidney, and I had almost six years – it hurt me real bad, but I'm getting over it.

One participant said she was "aggravated" with the procedure used to treat the infection, i.e., the providers placed a drainage bag. She was also "upset" and "depressed" because it was Christmastime, and she could not be with her family. One participant was angry because the blood draws were painful, and he was getting bruised from the blood draws. While most participants express anger, frustration, and fear-based emotions, one participant who had a history of infections stated that he became "clinical." He meant that he did not react emotionally. Instead, he resorted to a non-emotional state in which he started to coordinate things with his wife to get to the hospital where the doctors could make a diagnosis and begin treatment. He was constantly monitoring his temperature and contacted the transplant coordinator for advice. Of note, this participant had a long medical history where he had amassed knowledge and experiences to draw on when this new infection developed. He said,

> Well, really, with the wife, it was just get here, get here get me to the hospital. So, it wasn't like a – like I said, I've become very clinical … So, when something pops up, I'm kind of like, okay, they'll take care of it, and they'll tell me what they're doing so I won't be wondering. So, I just don't worry about it, I lay there and watch TV.

This subtheme of emotional illness perceptions is reflected in the quote below:

> Little worry-ration, little frustration. What if? What's going on? There's more frustration and worry-ation, but the actual thing that really got me most is I knew I didn't do anything to hurt it … Shocked and amazed. Bewildered a little bit, ‘cause I was like, how, how did these happen? … I ain't gon' say scared, but I felt uncomfortable. I felt really uncomfortable ‘cause I didn't know exactly what was going to be next.

Subtheme 3. Coping Strategies

Throughout the experience, symptoms continued to serve as stimuli that elicited cognitive and emotional illness perceptions. Through these illness perceptions, patients derive meaning that they use to determine the coping strategies. Coping strategies are the behavioral responses to the threat of the illness. In this study, participants use a variety of coping strategies to address the health threat. Common coping strategies included avoidance, seeking social support, task-oriented/problem-focused coping, emotional coping, and seeking help from healthcare providers.

Avoidance. A coping mechanism used was avoidance, where participants avoided going to the hospital. As participants employed the coping strategies, they continued to exhibit emotional illness perceptions. One participant stated,

> I was a wreck emotionally because I didn't wanna go to the hospital. And that was the main thing that he said, you need to go to the hospital. And it was so horrible, the first time when I went, the thought of going again and having to go through the same things again, I was not happy at all. Not happy. Because I don't like being in the hospital. I like to stay home. And that's part of my problem is, I will stay home as long as I can, which doesn't always benefit me and I'm stubborn.

This participant may have been coping with fear, which manifested as avoidance. This coping strategy allowed her to minimize the unpleasantness of going to the hospital. She focused on the emotions she was experiencing instead of the danger of the illness. Leventhal (1970) described it as fear control. She seemed to have been ignoring the symptoms, which cause her to delay seeking care at the hospital. Her past experiences influenced her decision because she wanted to avoid something that she may have experienced the last time she was in the hospital, resulting in delayed help-seeking. Nevertheless, healthcare avoidance is a barrier to health behavior and a significant cause for delayed help-seeking.

Seeking social support. Participants also engaged in seeking social support. Participants relied on other people in their life that would step in and take care of the things. The participants solicited social support from husbands and wives, moms and dads, adult children, and friends. One elderly gentleman who lived alone had established a relationship with his sister whereby she checked on him regularly and helped him with responsibilities such as bill paying. So, when he started to have symptoms, he contacted her to let her know about his well-being. When the symptoms worsened to the point where he could not manage at home, he called her to provide transportation to the hospital. He said,

> Well, I had my sister there. And so, we have – I spent my life up to where she's gonna manage my will. And she was there supporting me. And I knew she would be there through the things … told my sister about it. And so, she started hovering a little closer. And we made a pact that we call each other every day and say, "How you doing?" You know, we just text each other a short text every day to make sure that everybody is hanging in. And so, I told her. And I trust her a lot.

> So, I knew that she said she would be available should I decide to go again to the hospital. And so, that's actually what happened.

Task-Oriented/Problem-Focused Coping. The most frequently used coping strategy was task-oriented/problem-focused coping. Problem-focused coping included things like self-monitoring, self-medicating, using home remedies, calling the doctor, making appointments, and taking prescribed medications. One participant said,

> Okay. Don't let them just check for COVID, either. My primary care doctor, that's what he thought I had. I tried to tell him it wasn't, I knew it wasn't COVID. So, don't automatically assume that it's COVID. Just because I don't have a fever, it's just indigestion or anything like that. Trying to think what else. And if someone says they're having pain in their left side – right side, to really check them really good. And don't just pass them off as it might be COVID. Everything's COVID now.

This participant engaged in cognitive reappraisal, even while interacting with the doctor. As the participant tries to discover what is causing the symptoms, she considers the list of symptoms and why they might be happening.

Emotion-Oriented Coping. At least two participants engage in emotion-oriented coping. Praying and meditating are two emotion-oriented strategies these participants employed. The two quotes below exemplify this strategy. One participant said,

> The only thing I could do was just talk to the doctors and find out if they could tell me what was going on, and pray and ask the Lord to take the pain away. It's still there, but that's all I could do.

The other participant said,

> With that happening, with all the other stuff going on, it’s like, “Okay, go find your quiet place, meditate, and really evaluate life itself,” because it can come and go in a nanosecond, or it could slowly sneak up on like it was doing me. Sometimes you have control, which you don’t. You think you got it, but most of the time you appreciate it because it’s not a given.

Having the infection revealed to the participant that life is “fragile.” He compared having the infection with other traumatic experiences like “gunshot, car wreck, or heart attack,” things he considered “major” events. He did not realize the seriousness of the appearance of the boil on his hand. He had been dealing with it for weeks with over-the-counter pain medication and home remedies. Then he arrived at the urgent care facility and was told to go to the ED, which may have contributed to the feeling that the infection had sneaked up on him. In a related passage, he metaphorically spoke and said, “You don’t know where it’s at, when it’s at, or which way it’s coming, but it knocks on your door, and it’s like, ‘Here I am.’”

In both of these passages, the participants do not explicitly state their emotions, but we know from reading other passages that both of these participants experienced a range of emotions. The participants described a variety of emotions and engaged in emotion-focused coping in response to the illness. The first participant said, “Oh, God. It was bad. All I could do was cry like a little child that was in pain that didn’t know where that pain was coming from.” The other participant stated, “I mean it hurt bad. Being a diabetic well, a lot of stuff go through your mind. Juggling all of these emotions that pop up.” The participants’ emotional reactions varied when they were thinking about how long they might be ill. The first participant said, “Angry and upset because I like to walk, and it’s something I can’t hardly do.”

Kristofferzon et al. (2018) described emotion-focused coping as emotional regulation in response to stressful situations. Using relaxation, meditation, prayer, and avoiding information are examples of emotion-focused coping. These are strategies used to escape from the situation. In this study, sometimes it was difficult, even for patients experiencing them, to name the emotions. Sometimes the patients were more descriptive about the emotions or tied it to some physical manifestation of the illness. The patient who said she was crying because she was in so much pain likely was experiencing not just physical pain but also psychological distress brought on by the pain. She reported that she did not know the source of the pain. The second participant talked about juggling the emotions, but he never really said what they were. One could surmise that he experienced a range of emotions that he may have had difficulty identifying or labeling.

Seeking help from healthcare providers. Eventually, all of the participants coped by seeking help from a healthcare provider. The two quotes below reflect participants’ coping in this manner. One participant reported:

> So, I went to Urgent Care. Felt weird because, I actually didn’t know what it was. So, I went, and then when they told me that they were going to admit me to the hospital, I said, “Admit me to the hospital?”

Another participant said,

> I called – and then I talked to the transplant coordinator less than 30 seconds after. And she said you need to go to the nearest ED because I told her where I lived. I

> said it’s five hours away; she said, naw, you need to go to the nearest ED and get evaluated there. And I said yes, ma’am, and then hung up.

Subtheme 4. Barriers and Facilitators to Help-seeking

Barriers to Help-Seeking. Researchers can understand pre-hospital patient delays by exploring the barriers to care-seeking. The barriers usually represented an unmet need that prevented the patient from seeking care sooner. Once they interpreted the symptoms as an illness that required medical attention, all of the participants encountered delays in the help-seeking process. The most common reasons cited for care-seeking delays were a need for transportation to the hospital, contacting others about the symptoms, and reporting to a local/outside hospital. Three of the participants cited a need for transportation as the reason for delays in help-seeking. Although no participants mentioned children or family member caring responsibilities as a cause for delayed help-seeking, three participants needed to find someone to care for their dogs before going to the hospital. Interestingly, two of these participants also needed transportation to the hospital. One participant was driven to the hospital by a family member, and another participant contacted the Emergency Medical Services (EMS).

One participant lived alone with her dog, and she did not have her own transportation. To seek care, she would need to get someone to take care of her dog. Furthermore, she would need someone to transport her to the hospital. In this case, personal responsibilities were a barrier to care-seeking. The participant reported,

> I needed somebody that could take care of my dog and I needed transportation to seek care. Because I don’t have any transportation. So, those were the two major

> things. Transportation and somebody to take care of the puppy dog. Well, he's not a puppy but, he's my puppy.

Another participant saw the time of day as a barrier. She said,

> The biggest challenge that I had was – Okay. So, first of all, the doctor's office not having to be open. Because when I spiked a fever – If they'd have been open Sunday morning, I'd have called them right – or Monday morning, I'd have called them right then. So, I had to wait for the doctor's office to be open. I had to wait for the proper referrals. I had to wait for all of the tests to be run. And I had to wait for all the results of all of the testing.

The participant said she contacted the primary doctor multiple times and used prescribed medication for a less severe condition, i.e., heartburn. She kept thinking she was getting better. Meanwhile, multiple attempts to contact the primary care doctor and thinking she would get better caused delays in seeking care at a hospital.

One of the participants was so ill that she needed her husband to realize something was wrong. She also had concerns about the financial cost of hospitalization when she was having issues with insurance coverage. Additionally, three participants presented to a local/outside hospital (OSH). Two of them reported that they did not receive quality care at the OSH. At the OSHs, these two participants experienced long wait times before being transferred to the university medical center. One participant waited for his wife to provide transportation because he did not want to call EMS.

Facilitators to Help-Seeking. The facilitators and the barriers were similar. The facilitators represented the presence of something that the participant needed to make seeking care easier. For example, one participant stated that her husband provided transportation. Another participant sought medical advice that made it easier for her to seek care at the hospital. She contacted the infectious disease doctor who cared for her when she had a previous infection, and he told her to go to the hospital.

One participant said it was easier for him to decide to go to the hospital when he "decided to face the situation and stop the denial." He lacked awareness of the symptoms of sepsis, and initially, he failed to perceive the severity of the illness. For this participant, facing reality was important for him to seek care. He knew something was wrong, and because of his self-reliance, he thought he could manage it at home. He based his home treatment on his knowledge of a chronic condition, i.e., the shortness of breath related to CHF. He needed to face reality because he was not correctly interpreting his symptoms, which caused him to delay seeking care at the hospital. Because his symptoms became progressively worse as he tried to manage at home, he decided to seek care when things became unmanageable for him. Once he interpreted the condition as serious, and even though he related the symptoms to his heart condition, he decided to seek care from the cardiologist, who instructed him to go to the hospital. The other facilitators to care-seeking were that he secured care for his dog, and his sister provided transportation to the hospital. For another participant, the facilitator was that she needed her husband to realize that she was sick and needed to go back to the hospital, and she saw proximity to the hospital as a facilitator. Having insurance was seen as a facilitator for most of the participants. Several participants received encouragement from family and friends.

In managing the illness, participants assembled and integrated information gathered to cognitively construct the beliefs that influenced their behaviors, and they reacted emotionally to the illness threat. These findings are consistent with the regulatory processes described in the CSM-SR. As participants discussed their thoughts and feelings about what happened in the pre-hospital phase, they revealed the psychological and social factors contributing to delays in help-seeking. Participants reflected on bodily sensations and symptom information, lay information stored in memory, the knowledge gained from health professionals, and knowledge gained through reading to help them make decisions to cope with the illness. In coping with the illness, the participants encountered barriers and facilitators that contributed to delays that may have prevented timely diagnosis and treatment.

Theme 3. Being Clothed and in Their Right Mind

Theme 3 explains how people evaluate the outcomes of coping strategies. This theme has two subthemes. They are illness outcomes and emotional outcomes. Evaluating the outcomes allows the participants to determine if the coping strategies are working to restore health and wellness. Illness outcomes determine the impact of the bloodstream infection on the disease state and physical functioning, role functioning, and social functioning. Emotional outcomes determine the impact of the bloodstream infection on the participants’ psychological well-being and the degree to which they are distressed. Analogously, the participants first gathered the threads, representing the pieces of information from various sources. Then they wove the threads into a tapestry, representing the past events, relationships, and encounters. The knowledge, thoughts, and feelings came together to form their cognitive and emotional perceptions of the illness. The illness perceptions were used to derive or make meaning of the symptom experience.

The illness perceptions informed their decisions about coping strategies, which include help-seeking. With this final theme, symbolically, the tapestry has been woven into pieces of cloth sewn together to make a garment that covers them. This means that the experience with the bloodstream infection has become an indelible part of their lives and has impacted their lives to varying degrees and sometimes with enduring effects.

Subtheme 1. Illness Outcomes

Throughout the experience with the bloodstream infection, participants engaged in appraisal and re-appraisal of the impact of the coping strategies on the illness outcome. Part of that evaluation might include re-appraisal of the presence of symptoms. Each participant employed coping strategies to resolve the symptoms and the illness. The coping appraisal is a cognitive process that occurs iteratively. It is part of the final stage of the CSM-SR and involves an evaluation of the impact of coping strategies on the illness outcomes (Diefenbach & Leventhal, 1996). In evaluating coping strategies, individuals compare the anticipated outcomes to the disease states' actual outcomes and psychological well-being.

Disease State. The following extract illustrates an evaluation of the disease state: "I believe I responded perfectly because the bloodstream infection is gone. It did cause some scarring in my lung. It caused them to have to remove my port-a-cath." This participant has a positive evaluation of the outcome based on the fact that the infection is gone. In medical terms, that means that the follow-up blood cultures are negative. However, she is aware that the lasting impact is that her lungs are scarred. Further, the port-a-cath was removed, which is a medical device necessary to treat her myelodysplastic syndrome (MDS).

All of the participants reported that the infection was gone. In their words, they “started to feel better right away,” “responded perfectly,” “felt physically fine,” or “doing much better.” Even though each one experienced clearance of the bacterial bloodstream infection, most of the patients reported some kind of residual effects of the infection. Two participants reported residual effects such as feeling “weaker” or feeling “more susceptible to disease.” One participant’s life was changed when he suffered the loss of his kidney. He reported that he could not return to work or care for his family as he had done before the infection. After the infection, one participant reported that she had trouble walking and had to use a wheelchair and a cane but stated that she can do pretty much everything now in terms of bathing and dressing. Whereas she had to have help around the clock when she first came home, she can now function without help. One participant who, after being discharged from the hospital, reported still having difficulty walking. She reported, “When I go in the grocery store, and I’ve got to try to hop on something to stay off that leg to keep the pain out of that leg.” She continues to have pain in the leg, which may be more related to her other health problems, i.e., cancer or a combination. However, these are the residual effects of the infection. Two participants reported that they were physically fine and reported no lasting residual effects of the bloodstream infection.

Physical and Role Functioning. The majority of the participants reported residual effects in their physical functioning, i.e., their ability to perform basic and contributory activities of daily living. This, in turn, affected their role functioning. The quotes below illustrate this change in physical and role functioning. One participant said:

> For one thing, I was working pretty good. I can’t do that anymore. My job that I had, I had to – I can’t go out and do that because I’d be sick when I get out of the house, and I can’t really take care of my wife like I was doing because I stay sick all the time. Then, I was playing with my grandkids every day. I don’t even play with them no more, so it’s affected me in a whole lot of different ways.

After the infection episode, the participant was unable to continue to work. He had to quit his job as a landscaper. He reports being unable to take care of his wife, who has health issues, and cannot play with his grandchildren as he did before the bloodstream infection. He can do small physical tasks but cannot do his job because, as he said, he would “stay so sick.” He now undergoes hemodialysis, and he cannot work because it takes over a day to recover from the treatment. For this participant, the infection has had significant residual effects on his physical and role functioning.

Another participant had a different experience. She reported,

> Oh, yeah. I’m back doing everything that I used to do. Now when I started back to work, I work in a big school, I was like oh, gosh, I had trouble walking the halls. But I got a little tired walking back and forth, but other than that, I was good.

Unlike the previous example, she had minimal residual effects, and she returned to baseline functioning, allowing her to return to work as a teaching assistant.

Social Functioning. All of the participants reported that there were no residual effects on their social functioning. Two participants reported that they had already made changes in social interactions due to COVID-19. Another participant’s family lived at a distance, and friends paid shortened visits because of COVID-19, leaving her feeling isolated. She pointed out that this “has nothing to do with the bloodstream infection.” One participant stated, “I don’t know because I’m not really a social person. I’m just a homebody person besides being with my family.”

Subtheme 2. Emotional Outcomes

The participants simultaneously perform the coping appraisal strategy for emotional outcomes. This second part of the final stage of the CSM-SR involves an evaluation of the impact of coping strategies on emotional outcomes (Diefenbach & Leventhal, 1996). In the evaluation of coping strategies, participants measure emotional outcomes based on distress versus psychological well-being.

Fifty percent of the participants were still experiencing some level of distress even after the infection was cleared and they were discharged. One participant stated that even though the bloodstream infection was gone, she “felt fragile” and “realized how precious life is.” Another participant managing multiple comorbidities said her emotions “are a mess,” but she said it was a combination of everything, not just the bloodstream infection. She stated that having the infection made it more apparent that “this is a step closer to dying.” One woman said that she was doing much better physically, but emotionally, she is “worried, scared, and anxious.” Finally, another participant reported feeling bad because her leg pain is ongoing.

In terms of those who experienced psychological well-being, one woman said she felt fine physically and had not been affected emotionally by the infection. However, she was grief-stricken because after she was discharged from the hospital, she lost her husband to suicide. She felt that if she had not had this infection, he would still be alive. One participant said that she was "juggling varied emotions" but "felt blessed and strong." Another participant said that he was "upset in the beginning," but now was "doing great." The transplant recipient participant reported that even though he was still suffering from the bloodstream infection's effects because he was more fatigued, he was not impacted emotionally. The following are two examples of how participant reflected on their emotional outcomes:

> I didn't get depressed, if that's what you're fishing for. I didn't get depressed. I didn't even get overly scared. I've accepted it. I went through it, it was a hard run, it stressed my sister and all that. But we got through it. And I'm grateful for that. And there's not gonna be an emotional hangover. And as far as I'm concerned, I'm glad to be alive and I'm glad to be recovering. And I am recovering. So, I'm happy. I'm alert. I feel great, really.

This participant had a very positive attitude towards a very challenging situation and is representative of psychological well-being. However, the participant who was reflecting in the quote below continues to experience emotional distress:

> It's kind of got to me. I ain't gonna lie. I got so much on my mind with my wife being sick, and then I'm sick and I can't take care of her now, so it affected me emotionally a whole lot. I cry all the time. I go out in the yard at night – every night – I don't miss a night, and I put wood on the ground and burn it, and I just sit out there and burn wood and think about everything that's going on, and I just cry sometimes. It's still got an emotional effect on me. I still sit around and cry and stuff because I was having a good life, and once I caught that and lost my kidney, it just brought me back down to where I was at from the beginning.

Participants who engaged in self-management employed a multiplicity of coping strategies to restore health. In the final phase of the model feedback loop, participants evaluated the effectiveness of the coping strategies. They evaluated the outcomes of the illness and the impact on functioning, but also, they evaluated the emotional states compared to the pre-diagnosis phase. Participants experienced a wide range of both illness outcomes and emotional outcomes. In all cases, participants experienced a clearance of the bloodstream infection as evidenced by negative blood cultures. However, the residual effects of the infection were reported to be minimally impactful to enduring. The evaluation or appraisal of symptoms and outcomes occurred before, during, and after diagnosis and treatment. The outcome appraisal helped to determine if changes in coping strategies were needed.

The Common-Sense Model of Self-Regulation and the Themes

The Common-Sense Model of Self-Regulation was the guiding framework for this study. The focus of the study was to understand the social and psychological factors that influence delays in help-seeking. The CSM-SR guided the research questions, the interview guide, and the data analysis. Chapter 1 outlined the constructs of the model. This model was selected to help add more rigor to the study. The intention is to use this framework's concepts because they coincide with and are useful for studying the phenomenon of prehospital patient delays in help-seeking. The model involves a multilevel process that contains four main phases or stages and concepts that can be used to explain the help-seeking decision-making process. The application of this theory will allow the designing of more interventions, which are beneficial for practice.

The model contains four main sections that contain the variables: stimuli (information), cognitive and emotional illness perceptions (personal beliefs), coping strategies (action plans), and illness and emotional coping appraisal (outcome appraisal). This study demonstrated how patients process information, formulate illness perceptions, determine coping strategies, and evaluate illness and emotional outcomes. The researcher designed the research questions and the interview questions to elicit responses from the participants that coincide with the model's variables. Therefore, the three main themes coincided with the model's variables. The subthemes coincided as well. The detrimental effects of patient pre-hospital delays in help-seeking for symptoms of infection are not well-known. The challenge for patients with symptoms of infection is knowing when to seek help. Understanding the delays in help-seeking behavior from the patients' perspective will help develop interventions designed to educate patients about when to seek help for their symptoms.

Researchers have used this model in various patient populations. However, no studies have used this model in patients with bloodstream infections and sepsis. Help-seeking behaviors among patients with sepsis are not well understood. The utilization of the model in this study provides evidence that it can be used with this patient population. The evidence includes describing the study variables, e.g., sources of information, illness perceptions, coping strategies, facilitators and barriers, and outcome appraisals.

Basing the interview guide on the model allowed the participants to self-report their experiences with bacterial bloodstream infections. The discussions allowed participants to talk about the sources of information they used to formulate their beliefs, informing their decisions and actions. Assessing sources of information coincides with Theme 1, which was gathering threads for a tapestry. In this study and the model, information sources serve as stimuli to motivate help-seeking behavior, informed illness perceptions, or personal beliefs about the illness. Theme 2, weaving the threads into a tapestry for a garment, encompassed a description of the illness perceptions, the coping strategies (behaviors), and the facilitators and barriers to help-seeking. The idea is that the participants engaged in an integration of knowledge that informed the entire experience. Theme 3, being clothed and in their right mind, coincides with the model's coping strategies' outcome appraisal. In the study, the participants discussed the impact of having a bloodstream infection. Participants described the illness outcomes and the emotional outcomes and evaluated the effectiveness of the coping strategies.

The study findings support the CSM-SR model concepts. First, the CSM-SR assumption is that the individual is a problem-solver (Diefenbach & Leventhal, 1996). Each participant engaged in problem-focused coping as they sought help for their symptoms. According to the model, individuals engage in the multilevel process to formulate illness perceptions to derive meaning from the symptoms experienced. Additionally, the model contains the behavioral component that devises action plans to cope with the illness or health threat (Diefenbach & Leventhal, 1996). Based on the findings, each of the participants experienced the onset of symptoms. In many cases, the participants were not sure what was going on. They each began and continued the process of symptom appraisal and interpretation. Participants often delayed seeking care because they had difficulty recognizing the symptoms as indicators of a serious condition, like an infection, or associated the symptoms with another condition. The participants continued to draw on past experiences and knowledge gained to make sense of the symptoms experienced. According to the model, symptom interpretation is an essential part of understanding the processes involved in self-regulation.

Under Theme 1, gathering the threads for a tapestry, participants reported various sources of information that they used in the first phase of the illness as they attempted to recognize the symptoms. The theoretical framework explains how signs and symptoms stimulate the activation of prototypes. According to the theory, prototypes are the functioning self, past experiences with illness, treatments, or other life experiences that come together to make up memory structures (Benyamini & Karademas, 2019; Leventhal et al., 2016). So, when the participants experienced the symptoms, they tried to use past knowledge and experiences to make sense of the symptoms and the illness.

Theme 2, weaving the threads in a tapestry for a garment, means that the individuals integrate and use the past knowledge and past experiences to derive meaning from the symptoms experienced. Accordingly, in the second stage of the framework, the authors posit individuals use prototypes to derive meaning from cognitive and affective processes to identify and label the illness in the stimulus-response cycle. The study found that the majority of the patients mislabeled their illness, but the fact is their attempts are consistent with the model. The mislabeling may have led to delays in help-seeking. Throughout the interviews, the participants reported their thoughts and feelings as they engage in self-regulatory decision-making. According to the CSM-SR, the meaning that the individual attributes to the symptoms determines the strategies they will employ to cope with the symptoms and the illness (Diefenbach & Leventhal, 1996). The participants' responses to the interview questions showed that they engage in various coping strategies to address the health threat. Assigning meaning and devising action plans to cope with the illness is consistent with the model processes.

Theme 2 continued to relate to the theory because the illness perceptions followed the same pattern as the model suggests. According to the CSM-SR, the illness perceptions consist of five dimensions: identity, timeline, cause, controllability, and consequences (Diefenbach & Leventhal, 1996; Leventhal et al., 2016). The interview questions assessed each of these dimensions, allowing the participants to share their beliefs about the illness's different aspects. The dimensions of the model were described in chapter 1. As alluded to previously, Leventhal's model includes action plans and coping strategies. Participants listed several self-management strategies that they used to cope. Theme 2 also addressed barriers and facilitators to help-seeking and self-management strategies. In the third phase of the CSM-SR, the model addresses the behavioral components, representing what the participants did to cope with the illness.

One of the first things that participants did was contact either a family member, i.e., a spouse or an adult sibling, or a primary care provider. Two participants stated that they did not contact anyone. One participant went to the hospital, and the other one said, "I didn't contact anybody. I didn't call my primary care or anybody because I knew if I called the primary care, he was just gonna tell me to take some Imodium." The second contact that participants made was most often with an outpatient care facility, a hospital, or a care coordinator. Outpatient care providers influenced the participants that most to seek care at the hospital. In at least one case, it was the family member who influenced the patient to seek care. One participant decided to seek care on his own due to worsening symptoms.

Besides contacting others, the other coping strategies that the participants used were taking prescribed and over-the-counter medications. Some of the participants used home remedies such as limb elevation, massage, and application of warmth. One participant used exercise and reduced his food intake. Another participant stated he drank water because he thought he might be hypovolemic. Rest was a strategy used by two participants. Half of the participants initially had an emotional reaction to the symptoms. The majority of the participants reported they decided to seek care at the hospital because of worsening symptoms. Only one participant who had a background in the medical profession used his experience to decide to seek care.

Under Theme 3, being clothed and in their right minds, participants were questioned to determine the impact of bloodstream infection on different areas of their lives. The final stage of the model processes includes physical and psychological outcome appraisal and evaluating whether the action plans and coping strategies achieved the desired outcome (Diefenbach & Leventhal, 1996). The model-based questions elicited responses that showed that the impact on participants' lives and those close to them were varied. Although the infection was cleared in all cases, the bloodstream infection often had consequences with enduring effects. The following quote is an example illness outcome appraisal from one participant who delayed seeking care for 5 days. She said, "Once they started the IV antibiotics right away, so once the IV antibiotics started, I started to feel better." She also stated,

> And I was able to get out and come home and I didn’t need anybody to take care of me. And I was just weak for a while. Which, I could handle that. I just move slowly. But I was good because I could get home to my dog and be happy. And that just made me feel much better. Just being back to where I wanted to be. The thought of it being another 3-month process, it was not a fun thought.

This participant had had a previous bloodstream infection but still delayed seeking care. She seemed to be more concerned about her memories of recovery from a previous infection than actually getting to the hospital in a timelier fashion. After discharge, her physical functioning was impacted, but her emotional outcome was happiness because she could reunite with her dog.

Research Questions Answered

Research Question 1

What sources of information do patients use to guide their decisions to seek help?

Question 1 focused on the sources of information the participants used in the help-seeking decision-making process. The interview questions were designed to gain an understanding of how participants acquire knowledge.

Study participants engaged in the process of symptom recognition and interpretation at symptom onset. Being aware of the symptoms was the first source of information. The participants reported having symptoms like abdominal pain, fever, chills, confusion, diarrhea, dysuria, localized pain, malaise, and weakness. Some participants described their symptoms using medical terms to describe their signs and symptoms, such as bradycardia, delirium, hematuria, hypotension, and hypoxia. Fever, which is a classic symptom of infection, was not always present.

Participants also accessed lay information stored in memory. Some participants had experience working in a medical profession or had family members working in a healthcare setting. So, participants used lay sources of information in the process of symptom recognition. They remembered things they learned to try to understand this new onset of symptoms. At least three of the participants had prior experience with bloodstream infections. They used that prior experience during the symptom appraisal. The following quote is from a participant who had a past medical history of infection.

> Well, I had had them before, so yes. … But that was the third one I've had. It did because I knew what happened if you didn't seek care because I had been through it already. And so, yes. So, that was one of the reasons why I did call Dr. Hondershock and that's one of the reasons why I did end up agreeing to go to the hospital. … Oh, I just didn't wanna get as bad as I had been.

The preceding quote is an excellent example of how past experiences can be integrated into an individual's knowledge base and inform decision-making. She knew to seek care because she had been through a prior episode of bloodstream infections. She knew to contact an infectious disease doctor. This same participant also had jobs in the past that gave her some lay knowledge of infections.

> Well, I used to work in the medical field as a coder. So, I read lots of different charts and I worked in an emergency room for a little while. So, I picked up some knowledge from both of those jobs. And you know how a little bit of knowledge can be dangerous? Well, it can be.

The participants had infections in the past, so she knew what to expect when she got to the hospital. She knew that once she got to the hospital, that blood cultures would be taken, and it would take a couple of days to get the results back. The participant knew from past experiences that if she did not go to the hospital, she would “have probably died.”

Participants reflected on healthcare providers’ knowledge in different healthcare settings like clinics, home health agencies, and hospitals. Although at least two participants reported that they were told about the infection primarily by the physician, some gained knowledge from the nurses. The amount of information shared by doctors and nurses varied per patient. Some participants reported receiving lots of information from doctors and nurses, while others reported not adequately receiving information. Only two participants used the word *sepsis* or *septic shock* to describe the illness and what they had learned from the healthcare providers.

The final way that the participant said that they gained knowledge was by using the internet. Eighty percent of the participants reported that they used the internet to learn about conditions, medications, symptoms, infection, and pain. Reading and the internet were ways that participants accessed information, particularly when they did not have access to healthcare professionals’ expert knowledge. They reported reading books, journals, and magazines to learn about health-related topics.

In the following extract, the participant who had extensive medical experience as an emergency medical technician and operating room worker and with a history of leukemia and a kidney transplant describes how he acquired knowledge.

> Well, I ask a lot of questions of my medical staff. If I have a question about anything, I ask my doctors; if something curious has happened or something is

> going on with me, I ask my doctors. I try to think ahead and say, okay, in the future, if this happens again, what do I do? That's one. I also tend to read a lot, so I have a little bit of a medical library in my spare room. So, if something is going on and has gone on, and there is something I have a question about, I look it up in my book.

He went on to say:

> I also go online, and I'll go on things like, say, for example, [the university medical center] has a whole array of websites about different things and a whole array of videos about things. So, I access those and watch those and read those, and like I said, I'm a bit of a nerd, so I'll also go onto the National Institute of Health website, and I'll look things up there, too.

While most of the participants did not have the extensive experience and knowledge of this participant, this participant serves as an excellent example of how individuals may learn about infections.

Since part of this research intended to determine what sources of information participants used in the decision-making processes regarding when to seek care, learning what sources of information they use was essential. It was information woven together to formulate perceptions or beliefs. The perceptions and beliefs informed decisions about the coping strategies. Coping strategies addressed the barriers that the participants had to overcome to seek help at a hospital. In summary, participants used bodily sensations and symptoms, lay information stored in memory, expert knowledge, reading on the internet, and books, journals, and magazines.

Research Question 2

What are the illness perceptions and experiences of patients diagnosed with sepsis who delayed seeking care >24 hours from the onset of symptoms?

Research Question 2 addressed the participant patients' perceptions of the illness, and their cognitive appraisal and personal understanding of bloodstream infection symptoms and their potential consequences. The questions corresponded to the five dimensions of the CSM-SR that represent patients' cognitive and emotional illness perceptions. The emotional illness perceptions were assessed. Following is a summary of Research Question 2 findings.

Participants reflected on their symptoms experienced as they tried to label the disease. Most of the participants initially mislabeled the disease, which led to inappropriate self-management and delays in seeking help at the hospital. Even the participants who knew they were having symptoms of an infection because of prior knowledge of bloodstream infections still delayed seeking care. In some cases, mislabeling resulted from chronic, co-morbid conditions masking the symptoms of infection, such as the case of the patient with a history of congestive heart failure, who experienced shortness of breath, and the patient with severe leg pain and a history of bladder cancer.

Participants expressed uncertainty about how long the symptoms or/and the illness would last, so the perceptions of timeline were varied. Participants' beliefs about the cause of the infection ranged from not knowing to attributing it to more than one cause. Two causes of the bloodstream infection reported were a compromised immune system and side effects of medications. Other participants attributed their infection to self-care deficits, i.e., poor hygiene practices, environmental contact with infected persons, or related to surgery or the presence of a medical device. Following are two examples of how participants described the cause of the infection:

> I think I was around someone that may have had it and by me having a cut or something on my finger, I'm not sure. But I was truly exposed, and I didn't know it.

Another participant stated,

> Well, I had a micro-pacemaker placed in May. May of, I think it was '19. And the day after I had that I was fine. And came back from an X-ray, because they wanted to check the placement of it because they were gonna discharge me. And when I got back up to the room, I started shaking and I said, something's wrong with me. I called the nurse and she checked me, and they did the blood cultures and that was the first time I had it. So, I know when they gave me the pacemaker, they gave me a side of staph infection. And nobody could tell me different because I never had any Staph. infections prior to that.

Overall, the participants faced uncertainty about how to manage and control the infection symptoms. Most of the participants said that they did not have control over the illness but believed that the care and treatment would cure it. However, in terms of treatment control, they believed the antibiotics could help cure the infection. They relied on the healthcare providers to prescribe and administer the antibiotics and other treatments and procedures to treat the infection. For example, there were statements such as:

> Well, it cured it. But like my doctor told me when I went back, he said it could happen again. It could come back just like the first time like it came back the second, and just you have to be vigilant. If you're going to work with your hands, put on gloves, be careful, take your time.

Another participant stated, “I don’t think it’s gonna cure it. Well, I think it’s gonna hold it off. I don’t think it’s gonna cure it. But if it can keep me out of the hospital, I’m all for it.” Participants described various coping behaviors that enhanced their personal control of the infection, such as external control through faith in God.

> I had two different emotions. One was, “Thank God that they found out what it was and that it could be reversed.” The second was like, “Okay, that’s a long time. I hope this works.” Those were the two biggest emotions that I had, and that was about it.

Participants reported medical and social consequences, with more focus on the medical consequences. Their expectations did not always line up with what happened. In some cases, participants got better but did not return to their baseline level of health. For example, one participant reported getting better but indicated that the bloodstream infection weakened him. One participant who lost his transplanted kidney returned to hemodialysis and continued to be debilitated due to having the infection. The participants reflected on the potential consequences of loss of limbs, or worse, loss of life. Participants were all aware of the potential and actual consequences. Below is an illustration of how participants integrate knowledge gained to formulate illness perceptions, devise action plans, and evaluate the outcome.

> Honestly, I thought they would just – they would figure it out, you know? I think they would have figured it out that it was my gall bladder, hopefully. And I figured I’d have surgery that night and take it out and go home. That was my thinking, you know? … Oh, I would have died. If I would have kept waiting, I had that blood infection and I had no idea. And as soon as I would have waited, I would’ve been a goner … Well, I hope it hasn’t damaged anything else. I don’t think my body can take any worse damage. I hope everything’s good now.

This participant's emotional illness perception can be seen in the following quotes about her emotional reaction to the bloodstream. She said,

> I don't think it affected me emotionally. The only time that I was aggravated or whatever, they had to put a drainage bag in to drain all that suction out. And I always get ill with that, because it was a pain in the butt to deal with.

Even though this participant stated that the illness did not affect her emotionally, she later stated,

> And then they found the blood clot. Now that really scared me, was the blood clot … I was depressed, really. No, I was upset and depressed and it was right around Christmas, you know. It wasn't a very good time. I was kinda upset a little bit. Because it was around Christmastime and I felt like crap and you know, my family does a big Christmas, but I couldn't be around them. I was upset, really. I even told my mom and dad not to put up no Christmas nothing. I didn't wanna do anything.

Overall, the participants' emotional illness perceptions were seen in a range of emotional reactions to the bloodstream infection. In most cases, fear was the underlying emotion. Participants said they were worried, anxious, and even horrified by the prospect of having another infection, particularly those who, for them, this was a second episode. What made them frightened or scared was the complications of the infection. For example, two patients developed blood clots, one in her leg and the other in her lungs. Two participants responded with grief; one due to the loss of an organ (kidney), and another lost her spouse due to suicide. For example, one participant reported that if she had not gone back to the hospital, her husband would not have taken his own life. One participant worried that she would lose her leg because of the blood clots. She remembered her mother had lost her legs due to blood clots. Sometimes participants were unhappy about having to be admitted to the hospital. Some participants experienced aggravation and anger because of the discomfort associated with the procedures used to diagnose and treat the infection. Occasionally, participants reported not experiencing emotions as most had. One participant responded to the bloodstream infection with acceptance. He said,

> I mean, I've accepted it. I went through it, it was a hard run, it stressed my sister and all that. But we got through it. And I'm grateful for that. And there's not gonna be any emotional hangover.

Coping Strategies

The decision-making of participants in this study was impacted by the psychological and social aspects of the illness. Therefore, patients employed coping strategies to control the stress precipitated by the situation. Coping strategies are cognitive, behavioral, and emotional skills a person uses to manage stressful circumstances (Folkman & Lazarus, 1985; Hajisabbagh et al., 2019). Endler and Parker (1990, 1994) described three dimensions of coping strategies, i.e., task-oriented, emotion-oriented, and avoidance-oriented. Task-oriented coping is a way that an individual reduces or eliminates stressors. The authors describe emotion-oriented coping as an effort to alter emotional responses to stressful situations to reduce unpleasant feelings. On the other hand, avoidance-oriented coping, also known as escape coping, involves avoidance mechanisms to manage stressful situations. Participants not only engaged in task-oriented, emotion-oriented, and avoidance coping, they also coped by seeking social support and seeking medical care from healthcare providers.

Most of the participants used task-oriented coping such as taking over-the-counter medications and prescribed medications. Some made follow-up appointments at clinics. One participant took Imodium for diarrhea because she believed it was caused by something she had eaten. One participant used walking as an exercise to ensure that she kept her energy up. During her previous experience with bloodstream infection, she got to the point where she could not move. She wanted to make sure that this did not happen again. This participant had to have physical therapy (PT) and worked hard, understanding that PT was necessary for a full recovery. All of the participants were prescribed and received antibiotics. One participant's report is a good illustration of task-oriented/problem-focused coping:

> I took my medications the way they were prescribed to me. I rested. I finished my full doses of medication. And I followed up with all of my appointments, like I was supposed to.

The participants coped another way through the use of emotion-oriented coping such as prayer, meditation, and even crying. Patients who employed emotion-oriented coping used a set of skills that allowed them to adapt to the situation. Emotional information can be used to improve cognitive resources. One participant coped this way:

> I cry all the time. I go out in the yard at night – every night – I don't miss a night, and I put wood on the ground and burn it, and I just sit out there and burn wood and think about everything that's going on, and I just cry sometimes.

Even though this participant admits to crying, one could see the burning of the wood as meditative.

Avoidance was a strategy used, particularly for participants who had been in the hospital previously with an infection. One participant described being in the hospital as horrible and associated being in the hospital with unhappiness or other negative emotions. She stated,

> I was resisting. I was resisting going to the hospital because I think it's a miserable experience to be in the hospital. So, I was doing everything I could to stay out of the hospital. And I was too … I'll say stubborn … I was too stubborn. I didn't surrender to the need soon enough.

Most participants coped with the infection by seeking social support. Several participants relied on the people in their lives to take care of things. One particular participant reported that her husband, mom, and daughter had been standing there for her throughout as she was dealing with myelodysplastic syndrome (MDS). She knew that with this episode with the bloodstream infection, they would continue to support her. One participant talked to his wife, and she encouraged him to go and get his hand checked out. Another participant contacted his sister about the symptoms early on, and he called her to take him to the hospital when he felt he could no longer manage the symptoms at home. His sister also assisted him with paying his bills while he was in the hospital. Further, while he was in the hospital, his friend was caring for his dog.

Also, in terms of social support, patients relied on friends to stay with them during the recovery period after discharge. One woman's husband took over paying the bills. A young female who lived with her parents said she knew they would take care of her finances while in the hospital. She also found support from her co-workers. One participant's wife was his caregiver, and he said, "she knows everything that is going on." When he became ill, his wife provided transportation to the hospital. For one of the participants, her two daughters took care of her when she became ill. She reported that she went to live with them while recovering instead of going to a rehabilitation center.

All participants engaged in help-seeking from a healthcare provider. They each realized something was wrong and eventually sought the expertise of the doctors. One participant reported that he went to an urgent care facility and was instructed to go to the hospital because they could not treat the patient's condition. One participant called a heart specialist because he thought the shortness of breath was related to congestive heart failure. The cardiologist told him to go to the emergency department (ED) if it worsened, which he did. One participant called the infectious disease (ID) doctor who cared for her during a previous hospitalization for an infection. The ID doctor told her to go to the hospital. One participant went to her primary care physician, and they did tests. She took medicines they prescribed for her, even though the medicine did not cure the infection. One participant called the transplant coordinator. The coordinator told him to go to the local ED because he lived 5 hours from the university medical center.

In summary, Research Question 2 addressed participants' cognitive appraisal of the symptoms, their understanding, and concerns about the bloodstream infection (BSI). Participants described the symptoms experienced. Participants described their cognitive and emotional illness perceptions. The appraisal of symptoms led to both mislabeling and correctly labeling the illness. Mislabeling the illness resulted in longer delays in help-seeking. The participants' beliefs were characterized by uncertainty about the timeline of the illness. The participants reported on what they considered to be the cause of their infection. Control over the illness was mainly limited to believing that the treatment would control or cure the bloodstream infection. The infection's consequences showed improvements for many of the participants. However, some reported on lasting impacts on their quality of life. Participants reported a range of emotional outcomes. Emotional distress was seen in only a few patients once the infection was treated and the infection resolved. The majority of the participants returned to a state of psychological well-being following the infection.

Participants used several cognitive, behavioral, and emotional coping strategies. Once the participants appraised their resources and identified the coping plan, they implemented the self-management strategies. The strategies most often involved a passive strategy such as a "wait and see" coupled with a home remedies approach or seeking medical help or other task-oriented active approaches. The strategies were directed at dealing with the problem's practicalities or dealing with emotions such as worry or fear. They used experiences and knowledge gained to think about ways to approach the condition. They carried out various coping strategies to engage in self-management of the symptoms. Some engaged in emotion-oriented coping and avoidance to manage the stressful situation that the BSI created. Seeking social support and seeking medical care from a healthcare provider were the most prominent coping strategies used. This study has identified factors that affected the decision to seek medical help. The results showed that until the symptoms worsened, many people preferred to manage the problem rather than seek treatment at the hospital. A complex set of behavioral strategies were identified, some of which contributed to delays in help-seeking.

Research Question 3

What barriers and facilitators are encountered in the help-seeking process for patients with sepsis who delayed seeking care for >24 hours from the onset of symptoms?

This question addressed the help-seeking behavioral responses to the symptoms experienced and the barriers and facilitators that may have affected the speed with which help was sought. Coping strategies emerged as a subtheme of Theme 2, weaving the threads into a tapestry for a garment. It is in the execution of the coping strategies that barriers and facilitators arose (see Table 2). These are barriers that the participants had to overcome to access the medical help they needed when they experienced the bloodstream infection and sepsis symptoms.

The researcher identified nine codes related to barriers and facilitators and organized them into three categories: symptoms recognition, psychosocial support, and healthcare systems logistics. The participants had similar experiences. The codes were facilitators when an element was present and a barrier when it represented an unmet need. The participants reported many reasons to explain why they delayed seeking help for symptoms of bloodstream infection.

Table 2

Facilitators and Barriers to Help-Seeking for Symptoms of Sepsis by Three Categories

Facilitators	Barriers
Symptom Recognition	
☐ Worsening symptoms ☐ Family member realizing the participant was ill ☐ Facing the reality about the symptom severity ☐ Knowing symptoms of infection because of past history of bloodstream infection	☐ Waiting for the symptoms to disappear ☐ Inability to recognize the symptoms as being associated with an infection ☐ Confusion about the symptoms while managing chronic conditions ☐ Lack of experience with bloodstream infection ☐ Healthcare providers misattributing the symptoms
Psychosocial Support	
☐ Family members encouraged person to seek care at the hospital ☐ Family member providing transportation to the hospital	☐ Family members were the first to be contacted when symptoms occurred and decided to delay seeking care ☐ Person seeking care from their primary providers or specialty physicians ☐ Worries about the cost of hospitalization ☐ Competing needs (e.g., work or pet care)
Healthcare Logistics	
☐ Knowing where to seek care ☐ Contacting outpatient providers, and advised to seek care at the hospital ☐ Proximity to the hospital ☐ Having healthcare insurance ☐ Contacting the Emergency Medical Services	☐ Healthcare avoidance ☐ Attending outpatient appointments before presenting to the hospital ☐ Distance from the hospital ☐ Seeking care at local hospitals ☐ Lack of transportation ☐ Long wait times at outside hospitals Perceived poor quality of care

Symptom Recognition

Throughout the interviews, a major barrier identified was participants' inability to recognize the symptoms associated with an infection. Because they did not think they had an infection, many did not seek medical care by going to the hospital. The help-seeking process began when the participants became aware of the severe illness and the need for professional help. In one instance, the participant needed her husband to realize something was wrong and that she needed to go to the hospital. Another participant undergoing treatment with chemotherapy for bladder cancer said she did not know because everything was happening all at the same time. Symptoms of co-morbid conditions can mask the symptoms of the infection. As another example, an elderly gentleman who had a history of congestive heart failure experienced worsening shortness of breath (SOB) tried to manage it at home. He did not recognize SOB as a symptom of infection. He did not seek help at the hospital until the cardiologist told him to go to the hospital. Here's what the participant said:

> I was resisting. I was resisting going to the hospital because I think it's a miserable experience to be in the hospital. So, I was doing everything I could to stay out of the hospital. And I was too … I'll say stubborn … I was too stubborn. I didn't surrender to the need soon enough. The biggest problem is getting to the hospital, getting to the emergency room. Everything else was easy as pie. Except, like I said, the piss-poor skills in drawing my blood for about a week, almost, in the VA.

This participant encountered intrinsic barriers where the patient made a personal choice to delay seeking care at the hospital because of a perceived bad experience he would have at the hospital. He tried to employ self-care remedies to manage at home. He expressed dissatisfaction with the blood-drawing experience. Additionally, the participant encountered an extrinsic barrier, which was the lack of transportation, and, as he said, his “biggest problem is getting to the hospital, getting to the emergency room.” He was able to overcome this barrier by contacting his sister, who supported him. This is a good example of how social support can be a facilitator for overcoming barriers.

Psychosocial Support

In terms of psychosocial support, some participants delayed seeking care at the hospital because they included family members in the decision-making or waited to be told by a family member to go to the hospital. Often friends, family members, and outpatient care providers were the initial sources of help rather than a clinic or the hospital. Seeking social support was most often seen as a facilitator. Several cases involved family members who encouraged the participant to seek help at the hospital. Participants reported facilitators to include either the participant or a family member realizing something was wrong. For example, one participant stated that her adult children told her, “You gotta go somewhere.” It was then that she decided to go to the hospital. Finally, this study found that because most participants were unemployed, i.e., retired or disabled, social factors such as competing priorities of work or caring responsibilities were not a barrier to early help-seeking overall. However, three participants had to find someone to care for their dogs before going to the hospital. Additionally, a common facilitator was the availability of a family member or a friend that provided reliable transportation to the hospital where the participants received quality care and treatment for sepsis. One participant called the ID doctor who cared for her when she had a previous infection, and he told her to go to the hospital.

Healthcare Systems Logistics

Healthcare system logistics included barriers and facilitators related to transportation, outpatient clinic logistics, finances, and insurance. One participant experienced difficulty getting an appointment at an outpatient clinic because of the time of day. In this case, her primary care provider was treating her for heartburn. She kept hoping she would get better. She reported that she continued to have symptoms over the weekend, and the doctor's office was not open. The participant waited for the office to open. She was waiting for referrals, and she waited for prior testing results. Another participant went to an urgent care facility and was told that they could not help him and that he needed to go to the ED. Two participants went to local hospitals and experienced long wait times. They spoke of the perceived poor quality of care they received at the local hospitals. One participant said it was a bad experience because it was difficult to "obtain the right kind of care." The other participant went to a local hospital, waited overnight without treatment, and transferred to the university medical center the next day. Another participant contacted his transplant coordinator, who instructed him to go to the local hospital where he spent a week being treated for septic shock. When he arrived at the university medical center, he was diagnosed with a bloodstream infection a day after being discharged from the local hospital. This participant waited for hours for his wife to transport him to the university medical center for further evaluation and treatment.

Other barriers to obtaining care at the hospital included transportation to the hospital and care of pets. Two participants voiced that they had no access to transportation or no one to care for their dogs during the hospitalization. One of them said that once he faced the situation and stopped the denial, his sister provided transportation to the university medical center. Another participant called an ambulance when she needed transportation to the hospital. Travel time to the hospital was seen as a barrier and a facilitator. One participant had a 5-hour drive to the university medical center, so he had spent the first few days of his illness at a local hospital. However, another participant stated that the proximity to the university medical center was a facilitator that made it easier for her to seek care. She lived 5 minutes from the university medical center.

Finances and issues with insurance were barriers to going to the hospital. Some participants had concerns about the cost of hospitalization or problems with insurance. One participant reported,

> I guess just financial. Just trying to be aware of how much it could cost. Well, yes. But that's because of my insurance, it was a big mess. Well, at first, my insurance was Signa through my husband's insurance and mine. And then it was okay, we're gonna pay for Cobra for a while. But that took a while for them to tell me about that. And it was just a mess for a while. But it's all right now.

The participants who had insurance saw that as a facilitator, but of course, not having insurance can be a barrier that may lead to delays in help-seeking if the participant is trying to figure out how they will pay for care at the hospital.

The results of this study showed that participants sometimes engage in a myriad of coping strategies to address their symptoms and delayed seeking help because some wanted to avoid hospitalization. Sometimes, the patients' emotional reactions to the illness, i.e., fear or anxiety, resulted in help-seeking delays. There were concerns about the discomforts and inconveniences associated with being in the hospital.

Coping Appraisals and Outcomes

Although no specific research question addressed coping appraisals and outcomes, Theme 3 emerged and focused on appraising coping strategies and illness and emotional outcomes. The cognitive and emotional processes described by the CSM-SR are iterative, and they are nonlinear. For example, even before the patients experience their first symptoms described in the first phase or stage, they had amassed knowledge and experiences that they combined and used to gather new knowledge. At the onset of symptoms, individuals begin the process of symptom appraisal. The appraisal process continues throughout the experience with the illness. Also, the processes of the integration of knowledge and experience is nonlinear. Individuals come with a set of perceptions described by cognitive and emotional illness perceptions of the model. Theme 2 of the study describes the perceptions of the patient who delayed seeking care. The integration of new knowledge may initiate changes in their perceptions and beliefs. The coping strategies were met with barriers and facilitators. The concepts within the CSM-SR related to coping strategies have associated barriers and facilitators in the trajectory to the hospital for diagnosis and treatment. Theme 3, clothed and in their right mind, described the appraisal process in full. It is an appraisal of symptoms commensurate with the first part of the model, an appraisal of the coping strategies, and an appraisal of physical and emotional outcomes in the model's last stage. In the application of the CSM-SR, one must remember that the processes occur in parallel. Therefore, the cognitive and emotional processes occur at each stage simultaneously.

To better understand the impact of pre-hospital patient delay, this study described the events in the pre-hospital stage. It assessed the outcome several weeks after discharge. This understanding will enable researchers to develop interventions based on participants' illness perceptions and the barriers and facilitators that contribute to slow or speedy decision-making and seeking help in each stage of the process. An individual's experience of symptoms and their active efforts to cope with disease threats are directly linked to delays in seeking care. Applying the theoretical model (CSM-SR) will add to our understanding of the participants' experiences before the hospitalization and provide some crucial details about the impact of the infection on the participants' lives. With this understanding of the symptoms, barriers, facilitators, and interactions with others, nurses can provide educational interventions to adults at risk of infection.

Chapter Summary

Pre-hospital patient delay for patients with symptoms of bloodstream infection and sepsis is an important health concern. A primary focus of this research was to identify the factors associated with pre-hospital patient delays in a presentation to the hospital for symptoms of infection. Estimates of delay for each participant showed that the longest delay occurred during the period of appraisal. Guided by the Common-Sense Model of Self-Regulation, this qualitative descriptive study explored the sources of information, perceptions and experiences, and the facilitators and barriers to help-seeking. The findings were supportive of the themes that emerged from the content analysis for each research question. There were similarities and differences in how participants described the experiences of being ill and their reaction to the illness.

Three themes were derived from the content analysis. The themes that emerged related to the help-seeking decision-making process included (a) gathering threads for a tapestry, (b) weaving the threads into a tapestry for a garment, and (c) being clothed and in their right mind. The researcher identified subthemes for each theme.

Theme 1 and the four subthemes described the participants' sources that they used to gather information. The study results showed that patients who delayed seeking care interpreted information from their bodies and outside sources. During the dialogue, participants discussed the symptoms they experienced in the pre-hospital phase. Additionally, the participants reported on prior knowledge and experiences that influenced the length of delayed help-seeking.

In Theme 2, with the four subthemes that emerged, participants described how information gathered influenced their beliefs, emotional reactions, and concerns about the illness. The choice of coping strategies was determined by how the participants processed information. During the decision-making process, the coping strategies participants employed were avoidance, seeking social support, task-oriented coping, emotion-oriented coping, and seeking medical help. Each of these coping strategies influences the speed at which help was sought. Personal responsibilities, the need for transportation, and interactions with outpatient healthcare providers were sources of delay for the participants.

Under Theme 3 and the two associated subthemes, participants described emotional and illness outcomes. The outcomes varied per patient. They reported the impact of the bloodstream infection on them physically, functionally, socially, and emotionally.

In answering the research questions, there were elements from all CSM-SR stages that influenced the decision-making process. Two factors were more prominent than others. The first one was from Theme 1, which was the ability to process information, and the other one was from Subtheme 2 of Theme 2 and was related to managing emotions. If there were a lack of sufficient knowledge or too many negative emotions, there was a delay in presenting to the hospital. Some sought care from urgent care or outpatient clinics, which further delayed presentation to the emergency department. Many participants reported that they did not know that they had an infection. Recognition of the symptoms as a serious condition by patients and providers was critical for the patients because it informed their decision to seek help at the hospital in a timelier fashion, which could improve outcomes. Several psychological and social factors caused delays in help-seeking. Participants made decisions to seek help based on the availability or lack of resources such as access to healthcare facilities, availability of financial resources, insurance, or transportation. Participants also based the decision to seek help on intrinsic barriers such as personal choices due to emotional responses, self-care remedies, or the desire to avoid the hospital.

The decision to ultimately seek care at the hospital was influenced by worsening symptoms and family, friends, or providers who encouraged the participant to seek help at the emergency department. These facilitators enabled participants to seek care once they overcame the psychological and social barriers that impeded the decision to seek care. Barriers had a negative impact and altered the trajectory of care for the participants. Creating appropriate interventions that address multiple and complex psychological and sociocultural factors for adults at risk for infection is one way to influence behavior change. Chapter 5 follows with a discussion of the findings that will be examined in the context of current literature.

CHAPTER V

DISCUSSION

The study's major aim was to identify sources of information, explore the perceptions and experiences, and identify the barriers and facilitators that influence help-seeking behaviors in participants who experienced symptoms of bacteremia and sepsis. The study employed qualitative research methods that applied the Common-Sense Model of Self-Regulation (CSM-SR). Data collection included a researcher-made demographic form and semi-structured interviews conducted over the telephone. The participants were ten men and women who had been hospitalized for the treatment of a bloodstream infection at a university medical center in the southeastern U.S. They were selected using convenience sampling. Direct content analysis was used to code and categorize the data.

In Chapter IV, exploration and description of the participants' experiences were provided by analyzing the semi-structured interviews. In this qualitative study, participants' experiences with bloodstream infections were explored, focusing on the participants' thought processes, emotional reactions, and coping strategies when experiencing a bloodstream infection. This chapter includes a discussion of the study findings and an examination in the context of relevant literature. Additionally, implications for nursing practice, study limitations, and recommendations for future research are presented.

Summary of the Findings

Sepsis is a life-threatening condition in which early recognition and treatment can impact health outcomes. Delayed help-seeking can result in significant morbidity and mortality. Pre-hospital delay is a barrier to early help-seeking that contributes to delayed diagnosis and treatment. This research fills a gap in the literature by providing insights into the participants' cognitive, affective, and behavioral responses to symptoms of bloodstream infection. The knowledge gained from this research will aid in developing interventions designed to address the cognitive, psychological, and social factors that interfere with participants seeking treatment early in the course of the illness.

Research Question 1

What sources of information do patients use to guide their decisions to seek help?

During the pre-hospital phase of their illness experience, participants used information from various sources to decide when to seek care at the hospital. Participants described knowledge from symptom information, lay information stored in memory, expert knowledge from healthcare professionals, and knowledge gained through the internet and reading books, magazines, and journals. These sources of information helped them to increase their knowledge, understanding, and interpretation of their symptoms. The participants in this study used gathered information in decision-making to seek medical treatment when the symptoms occurred. Participants coalesced information from these sources to formulate illness perceptions, i.e., beliefs about the symptoms and the illness. The participants used information gathered from a variety of sources to understand the condition and the potential consequences. This finding is supported by

Clarke et al. (2015), who found that participants in their study of neutropenic sepsis (NS) derived their understanding of NS from a broad range of sources. For example, the participants in their study had been routinely given a pamphlet before starting chemotherapy. Participants reported that they delayed contact with the medical staff because the wording in the pamphlet lacked clarity. Some participants experienced inconsistencies in what was in the pamphlet and what the doctors told them.

Although there was a coalescence of the sources of knowledge among these participants, participants initially relied on symptom information and lay information stored in memory from themselves and family members in developing their beliefs about what the symptoms meant. Some of the pre-hospital signs and symptoms of bloodstream infection reported were fever, feeling cold, shortness of breath, nausea, vomiting, confusion, fatigue, and weakness. Most participants acknowledged that they did not initially associate their symptoms with having an infection. Having such a broad range of symptoms made it difficult for the participants to recognize these symptoms of a bloodstream infection. The inability to recognize these symptoms associated with an infection negatively affected the participants' timeliness in seeking care.

Furthermore, symptoms experienced may have been similar to symptoms of chronic diseases that a person was managing at the time of the infection. For example, one participant attributed his symptoms to his chronic condition of heart failure. This confusing of symptoms in this study led the participant to delay seeking care because he thought the symptoms indicated a recurrence of his chronic condition. These findings are supported in a study by Clarke et al. (2015), who found that patients sometimes delayed seeking help due to difficulties distinguishing sepsis symptoms from the side effects of chemotherapy treatment. Symptoms similar to other diseases may have caused misunderstanding and made it difficult for participants to determine if they needed to seek help at the hospital for their symptoms. To mitigate this barrier to help-seeking, nurses can instruct patients with co-morbid conditions to report symptoms that represent an exacerbation. A key role of nurses is to care for patients with chronic conditions and educate them about disease self-management, which includes the risk of infection that certain comorbid conditions introduce.

The course of symptom development also influenced when participants sought care. The participants' symptom onset was most often insidious and worsened abruptly. When participants experienced worsening of symptoms, for example, a spike in a fever, increased pain and swelling, worsening shortness of breath, vomiting, or worsening symptoms coupled with previous experiences with bloodstream infection, this was a motivating factor for them to seek medical care. Concerning sepsis, few studies address how the type of symptom onset, i.e., insidious or abrupt, influences symptoms recognition and interpretation, informing decision-making regarding seeking medical care and can impact delays in help-seeking. However, research on symptom recognition in other conditions provides insight on this topic. For example, Davis (2017) examined factors influencing women's ability to recognize and accurately interpret symptoms of a suspected acute coronary syndrome (ACS). Davis concluded that women with abrupt ACS symptoms sought care sooner than women who experienced evolving symptoms that put them at risk for delayed presentation, diagnosis, and treatment. Sepsis is a condition known for its ability to mimic symptoms of other diseases, which may lead to confusion about appropriate actions. To prevent delays in seeking care, healthcare workers should provide education specifically addressing early recognition of symptoms of sepsis to all individuals at risk for developing a bloodstream infection.

Information processing is a mental process whereby participants retrieved information stored in their memory to engage in symptom appraisal to determine what the symptoms mean. For example, some participants either had a previous bloodstream infection or knew someone who had had a bloodstream infection, in which case they recalled their past experiences or those of others to help make sense of the new symptoms. Additionally, sometimes family members were knowledgeable about symptoms of sepsis and used their knowledge to encourage the participant to seek care at the hospital. In some cases, family members witnessed the signs and symptoms and deemed the individual as ill. The participants in this study had difficulty reporting the amount of time from the onset of symptoms to arrival at the hospital, but they provided good estimates. The time taken to appraise the symptoms resulted in the longest delay affecting symptom recognition and interpretation. Given that appraisal delay is the longest interval in help-seeking and decision-making, the amount of time participants or their family members used to appraise their symptoms influenced how long it took them to seek care at the hospital.

These findings add to our current knowledge about the role of family and friends in symptom recognition and its influence on help-seeking behavior. This study found that participants often listened to the advice of family members when they recognized the seriousness of symptoms and encouraged them to seek care at the hospital. Clarke et al. (2015) noted that interactions with friends and relatives and the patients' own experiences of previous neutropenic sepsis episodes served as sources of information that influence the decision to seek help. The findings from the current study and Clarke et al. support that relatives and friends play a pivotal role in the help-seeking decision-making process. The role of family and friends in promoting early care-seeking is important to consider when designing interventions. Community-based education regarding symptoms recognition in sepsis is needed, and this education should include family members, friends, or caregivers of individuals at risk for sepsis.

In this study, participants often treated the symptoms at home before contacting a doctor, further delaying help-seeking at the hospital; this is especially true for participants who had never had a bloodstream infection and did not know what to expect. For example, one participant initially had pain in his finger, but it subsequently progressed to swelling and erythema. He took Aleve and Tylenol for the pain, which did not relieve the pain. He also rubbed his hand with ointments and soaked them in hot water. After weeks had passed, his wife told him he needed to get his hand checked, so he went to the urgent care facility. The providers at the urgent care facility instructed him to go to the hospital. When he presented at the hospital, he was diagnosed with a bloodstream infection.

This participant and others experiencing symptoms of a bloodstream infection responded to the symptoms based on their knowledge and their understanding of the illness and the symptoms experienced. Sepsis symptoms may not have been in the participants' repertoire of knowledge and experiences. This finding is important because it demonstrates how participants who lack knowledge of infection may misattribute their symptoms and try to self-treat, causing further delay. In the example above, because the symptoms started locally on his hand, it was difficult for the participant to associate the symptoms with being ill. If he had experienced systemic symptoms, such as fever, chills, or malaise, he might have associated the symptoms with an infection. Since the symptoms started locally, he spent much time trying to determine if he had injured his hand. To intervene, healthcare providers can teach patients about the importance of wound management. Community education is important because many skin and soft tissue infections start in the community setting and often in individuals with no history of bloodstream infection.

In some cases, the difficulty with associating the symptoms with an infection may have been further complicated when the individual contacted the primary care provider to report the symptoms, and the provider attributed the symptoms to other conditions. Misdiagnosis leads to inappropriate treatment and further delayed help-seeking at the hospital while the individual is waiting to see if the treatment will work. When these kinds of misattributions are made, the individual may be hesitant to go to the doctor in the future or may not seek care from a medical professional early. Clarke et al. (2015) reported that medical staff’s misattribution of symptoms to non-neutropenic sepsis (NS) causes weakened the patients’ and caregivers’ faith in their expertise. Englert and Ross (2015) also found that misattribution of symptoms by patients and medical staff led to an increased delay in seeking help for infection symptoms. Participants in the current study valued the doctor’s opinions and sought care from primary providers. However, in some cases, there was a misattribution of the symptoms. The doctor told at least one participant that they did not know about the lesion on his hand and then instructed the participant to report to the hospital for further evaluation and treatment. The participants sometimes relied on the doctors in outpatient settings when they may have been better served by going to the emergency department.

Finally, individuals may lack the language to communicate to the doctors about their symptoms. The person may contact the doctor and use language familiar to them when describing their symptoms. When symptoms of infection were insidious, and participants had symptom confusion, it was more challenging to recognize and communicate symptoms accurately to providers, which further delayed appropriate treatment. Until there is language development for communicating about bloodstream infection and sepsis, it will continue to result in poor outcomes. Therefore, healthcare workers should initiate educational interventions that first underscore the prevention of infections, then the importance of early recognition and timely treatment seeking. Since many people have not heard of sepsis, and even those who have heard the word sepsis may think it is a rare disease, interventions should raise awareness of sepsis. Everyone must know the name of this deadly disease. The public needs to know that sepsis is not only common, but it is also a very lethal disease that can affect any body system. Healthcare providers need to teach patients and their family members or caregivers the symptoms of infection and what to do when they occur. In addition, healthcare providers should have a low threshold for suspecting sepsis when symptoms occur.

Once a common language for communicating about sepsis is established, lay information can be incorporated into the fabric of knowledge individuals acquire and use in symptom recognition and decision-making. Lay information is knowledge and experiences from self or others used in the decision-making process. The contribution of lay information to reducing delays in help-seeking is of utmost importance. Lay information enables patients to make decisions that impact their lives. Participants used lay information to understand, explain, and assign meaning to their symptoms experienced.

In this study, lay information is represented in subjective reports from the participants' perspectives. Fifty percent of participants in this study had a history of bloodstream infection and sepsis and others knew someone who had a history of bloodstream infection. Other participants had worked in the medical field. However, even though they had lay information, they still delayed seeking care at the hospital for greater than 24 hours from the onset of symptoms.

Lay information can inform actions to reduce delays in help-seeking. However, based on the findings in this study, lay information is often not enough to prevent delays. However, it can be used as a foundation to design and implement educational interventions to emphasize the importance of early symptom recognition and early help-seeking at the hospital. The participants may have lacked understanding of the illness. However, it is possible that the barriers they encountered superseded their knowledge. Therefore, healthcare providers cannot rely totally on lay information from the patients' history to help patients make appropriate decisions. Incorporating lay information can improve the quality of care by enabling individuals to engage in collaborative decision-making with healthcare providers. Once patients understand what sepsis is, providers can implement educational interventions to help them understand their risk for a bloodstream infection, what symptoms to report, and when they should seek care at the hospital. Practitioners need to identify and educate anyone at high risk for infection, such as those managing chronic conditions such as diabetes, peripheral vascular disease, or wounds. Additionally, educational interventions should be directed toward individuals with invasive lines such as port-a-caths, peripherally inserted central catheters (PICC), hemodialysis catheters, and those undergoing surgical procedures.

Delays in help-seeking are not just a question of a lack of knowledge. Lay information helps providers understand the meaning of behavior in the context of each person’s individual circumstances and coping behaviors. Placing value on and incorporating lay information into the educational process enables patients to work in partnership with health care professionals to reduce delays. In this study, participants used lay information to make decisions, but sometimes they lacked sufficient knowledge. Rubulotta et al. (2009) also found that the public lacks knowledge of sepsis that is important in recognizing symptoms in patients with sepsis. Huang et al. (2019) found that the participants in their study who were survivors of sepsis lacked baseline knowledge of sepsis and experienced dissatisfaction with post-sepsis education received at the hospital. Therefore, as Huang et al. concluded, more effort is needed to raise international awareness of sepsis in the lay public. The authors emphasized that raising awareness of sepsis is vital. However, few studies evaluate the current levels of education among survivors of sepsis.

Research Question 2

What are the illness perceptions and experiences of patients diagnosed with sepsis who delayed seeking care >24 hours from the onset of symptoms?

Participant illness perceptions of bloodstream infections were based on the CSM-SR dimensions, which included: label/identity, timeline, cause, control, and consequences (Leventhal et al., 2016). Additionally, they had emotional illness perceptions and concerns about the bloodstream infection. These illness perceptions were reflected in the decision-making process related to when to seek care, where to seek care, and who influenced the decision to seek care at the hospital. Below is a description of how the CSM-SR dimensions are reflected in the text.

Illness perceptions can be seen in how participants identified and responded to various symptoms that they experienced before and after the infection diagnosis. Labeling the illness was an essential part of the help-seeking decision-making process. Using symptom information and other information sources, all of the participants attempted to label the illness. Participants often misinterpreted the symptoms and mislabeled the illness. In this study, misinterpreting the symptoms and mislabeling the illness resulted in delays in help-seeking. For example, one participant mislabeled the illness, even though she had the classic symptom of a fever. This resulted in a two to three day delay in seeking treatment, first at her primary care physician’s office. She finally arrived in an emergency department, where she was diagnosed with a bloodstream infection. In a similar study, Clarke et al. (2015) found that patients and medical staff sometimes misattributed symptoms and did not treat them as serious symptoms. The researcher reported that when doctors misattributed symptoms to non-neutropenic sepsis (NS) causes, it weakened the patient's and caregiver's faith in their expertise.

The above example shows how participants used information to formulate their beliefs about the illness. Mislabeling symptoms can lead to significant delays. As with this participant, sometimes individuals do not know how to manage or control the illness, and visits to the primary provider contributed to delay time. The participant described various coping behaviors that she used to control the illness. Nurses can teach patients the signs and symptoms to look for that are emergency warning signs of infection. Patient education can include instructions to the patients and family members to immediately seek emergency medical care if they are at risk for a blood infection and develop a fever. Patients and family members should be instructed to call 911 or have a family or friends drive them to the hospital and call ahead to the local ED. Individuals should be taught to notify the ED staff that they are seeking care for someone who may have an infection. Patients with a suspected infection will receive timely and appropriate treatment at the hospital, and the development of sepsis may be prevented.

In this study, having a history of bloodstream infection enabled some participants to label their condition correctly, thereby decreasing the pre-hospital delay interval for those participants. Typically, participants who were knowledgeable of infection-specific symptoms, like a fever, knew the symptoms were serious, correctly labeled the condition, and sought care faster. Nurses and other healthcare professionals can teach patients and the public about the classic and atypical symptoms of infection and sepsis. Knowledge about the symptoms may have the effect of decreasing the amount of time used to label the condition and to seek help.

In this study, most of the misperceptions about the cause of the infection seemed to have occurred in the pre-hospital phase. Lack of knowledge and confusion about the cause of the symptoms and the infection may have contributed to help-seeking delays. The participants reported that they believed the cause of infection included immunocompetence, medication side effects, and hereditary/genetics. Other participants believed that the infection was caused by the presence of a medical device or surgical procedures. One participant reported that he thought that someone he knew had MRSA, and he believed he contracted it from contact with that person. The perceived caused determined when the participant sought help and from whom. Other studies in the literature found that the perceived cause of an illness was a factor that determined when participants sought medical attention or called a spiritual leader, and sometimes both (Aboud et al., 2017). The researchers also found that seeking help from others contributed to delays in help-seeking.

The perceived causes are useful to help identify the risk for infections. Knowledge of personal risk for infection will enable individuals to reduce the amount of time seeking care from a medical professional at the ED. For example, the patient who developed the boil on his hand may have sought help faster had he understood his infection risk related to diabetes and how it affects wound healing. Also, he may have sought care sooner if he knew that infections could start locally and spread to the bloodstream. By understanding what individuals perceive as the cause of infection, nurses can help people understand the risk factors for infection; through identifying any misunderstandings in their perceptions, nurses can make necessary corrections through education.

In many cases, self-medicating and self-caring resulted in an increased delay in seeking help. Before being diagnosed with a bloodstream infection, patients engaged in self-management of their symptoms and may have dismissed important cues that they had a bloodstream infection. Some participants in this study denied their symptoms or the seriousness of the symptoms to avoid going to the hospital. Denial often prevents individuals from thinking they need help, which leads to increased appraisal delay time and delayed time to the presentation at the hospital. This finding is supported by Clarke et al. (2015), who identified denial as a barrier to help-seeking.

The majority of the consequences that the participants reported were related to their medical condition. Some participants reported being weakened by the infection and feeling like they were more susceptible to disease. Furthermore, sepsis was associated with acute physiologic impairment and taxed patients' functional reserves, leading to increased morbidity. When reflecting on the consequences of the bloodstream infection, participants expressed that they now understand that sepsis is a serious condition that could have resulted in death. Huang et al. (2019) also found that the participants in their study experienced difficulty in their physical functioning as part of the post-sepsis syndrome. The participants reported that they suffered from a multitude of physiologic and physical challenges leading to decreased physical functioning, including their ability to perform daily living activities.

The study results show that some participants perceived that the bloodstream infection changed their lives by affecting their physical condition, job and functional roles, and emotional states. Participants reported having distressing memories of the infection's lasting impact. Although the participants believe that the bloodstream infection did not change them socially, some reported that the infection complications impacted their ability to meet routine obligations. In this study, participants reported how the infection influenced their social and cultural context and their need for social support. Gallop et al. (2015) also studied the perceived consequences of sepsis and found that patients experienced lasting cognitive impairment, functional disability, and weakness. In the study by Gallop et al., patients also suffered long-term emotional effects, such as panic and anxiety.

Participants in this study reported adverse emotional reactions to having the bloodstream infection, including anger, frustration, and fear-based emotions, and for most participants, managing the infection was stressful. They were concerned about future disability, loss of independence, and death. Some participants in this study with previous episodes recalled the last time they had a bloodstream infection and that the recovery was long and arduous. Participants in this study had memories of past hospitalizations for bloodstream infections that elicited panic and horror feelings at the prospect of being re-admitted to the hospital. These findings are consistent with Gallop et al. (2015), who also found that participants reported distressing flashbacks and panic attacks following admission to the ICU to treat sepsis. These findings are similar to those demonstrated by Huang et al. (2019), who found that sepsis survivors in their study reported varying degrees of anxiety, depression, fatigue, and sleep disturbance.

Participants reported fear and dislike of hospitals. It was evident in this study that patients who experience negative emotions in reaction to having a bloodstream infection are more likely to delay seeking help at symptom onset. The thoughts of disability, loss of independence, and the threat of death can intensify emotions and cause patients to delay seeking help. In a study by Clarke et al. (2015), when patients felt ill and not being taken seriously, it caused them to ignore their symptoms and handle the situation independently, leading to unnecessary delays. In the current study and the study by Clark et al., participants experienced fear and disliked hospitals. Nurses should encourage patients to identify and share their feelings regarding hospitalization. Teaching all healthcare workers how to communicate with and support patients will encourage patients to report their symptoms early. Nurses can reassure patients that following up on their symptoms is not a waste of time, and they should feel free to report symptoms and discuss their emotions to save their life.

In this study, coping strategies impacted participants’ decisions in the pre-hospital phase, mainly if they were unsuccessful at addressing the health threat or relieving distress. The participants’ coping strategies included avoidance, seeking social support, task-oriented/problem-focused coping, emotional coping, and seeking help from healthcare providers. In this study, some participants reported that they denied their symptoms to avoid going to the hospital or being re-admitted for bloodstream infection.

Avoidance was typically accompanied by emotional distress, particularly for participants who had prior experience with a bloodstream infection or had significant long-term impacts from having a bloodstream infection.

Task-oriented/problem-focused coping was the most commonly used strategy for participants in this study. This study's results showed that, in the pre-hospital phase, some participants contacted outpatient healthcare providers, self-medicated, or used home remedies. Part of the appraisal process is self-monitoring. The "wait and see" strategy was the most crucial factor affecting early or late decision to seek medical help. More than half of the participants in this study experienced a prolonged pre-hospital delay due to self-treatment. Taking pain and other medications at home can increase the risk of pre-hospital delay. Other studies support these findings regarding the use of coping strategies. For example, Charlet et al. (2017) reported that participants in their research also used home remedies. The authors found that the perceived cause of the illness (supernatural versus biological) determined the type of care the participants sought (spiritual/traditional versus formal/skilled). The study results showed that some participants contacted spiritual leaders for council and remedies before seeking formal care, leading to delays in seeking formal care. In some cases, the spiritual leaders encouraged the participants to seek formal medical care when the illness had become very serious.

In this study, some participants contacted their primary doctor, visited the urgent care facility, and one participant reported contacting a transplant care coordinator. These providers were instrumental in helping the participants decide to seek help, even in the context of delayed help-seeking. These findings add to the current literature that participants in their studies coped with infection by contacting primary care providers or general practitioners (Clarke et al., 2015; Gallop et al., 2015). Clarke et al. (2015) also reported that participants contacted the hematology unit to report symptoms of neutropenic sepsis. Latten et al. (2019) found 83% of their participants visited a general practitioner, and 23% of the participants in their study had used antibiotics before presenting to the ED. In the current study and others, making appointments was a way to cope with the illness (Clarke et al., 2015; Gallop et al., 2015). The use of outpatient providers indicates a need for community-based education that includes not just individuals at risk but also family, friends, and healthcare providers in outpatient settings who are likely to be contacted before the individual decides to seek care at the hospital.

Research Question 3

What barriers and facilitators are encountered in the help-seeking process for patients with sepsis who delayed seeking care for >24 hours from the onset of symptoms?

Participants encountered a range of barriers and facilitators to help-seeking as they coped with the symptoms of the bloodstream infection. Direct content analysis revealed three types of barriers and facilitators categorized as symptom recognition, psychosocial support, and healthcare logistics. One of the most prominent barriers encountered by the participants was the inability to recognize the symptoms as being associated with an infection. Most of the participants did not seek help until the symptoms worsened. In some cases, the symptoms were not recognized because the participants lacked any experience with infection or were managing other chronic conditions that made it difficult for them to determine the cause of the symptoms. This led to delays in help-seeking as they attempted to manage their condition at home. These findings agree with Clarke et al. (2015), who identified the difficulty in recognizing symptoms of sepsis as a barrier to help-seeking.

Nurses can make a difference by ensuring that a list of infection symptoms is made available and includes information about when it is necessary to contact the primary provider versus when it is necessary to go to the ED. Individuals armed with a list of classic and atypical symptoms can be more empowered to self-monitor their symptoms and make faster decisions about when to seek care at the hospital. Nurses can reinforce education by providing written materials at an appropriate literacy level.

In this study, eight out of 10 participants reported using the Internet to obtain health information. One participant reported that when symptoms occur, he uses Google to try to find some general idea of what it could be or to gain understanding. Other participants also reported that if there are medical things that they do not understand, they research it online on different websites, such as WebMD, the National Institutes of Health website, or medical center websites. Using the computer to obtain health information and mobile medical applications (apps) is increasing. No studies were found using apps for educating individuals about sepsis. However, Gibbs et al. (2017) conducted a study to examine apps' content and accuracy for individuals seeking information about sexually transmitted infections (STIs). The study demonstrated that it is possible to incorporate technology into patient education. The authors concluded that content, quality, and accuracy vary and cautioned users about potentially harmful information. Nevertheless, there is value in technology and using websites (e.g., Centers for Disease Control and Prevention (CDC)), apps, and videos to improve patient education about sepsis. Another barrier experienced by the participants in this study occurred when individuals with illness preferred to rely on themselves rather than seek professional help. This finding might be due to a lack of insight into the threat the illness poses. The failure to perceive the severity of the illness and the belief that they could handle the problem independently were barriers to seeking help. The participants sometimes delayed seeking care because they wanted to wait for the symptoms to disappear. In previous qualitative studies, the authors found a failure to recognize the symptoms, and patients attempted to avoid hospitalization (Clarke et al., 2015; Gallop et al., 2015; Rorat & Jurek, 2015). Consequently, the lack of urgency, underlying beliefs, and a lack of education were barriers to care-seeking at the hospital. Clarke et al. (2015) also found that a barrier to seeking timely care was due to a flawed understanding of the bloodstream infection and sepsis.

In the trajectory of care-seeking, participants relied on family, friends, and providers in the outpatient setting to provide psychosocial support. Several participants' family members were the first to be contacted when the symptoms occurred. Family members were instrumental in encouraging the participants to seek care at the hospital. Before arriving at the hospital, participants sought help from their primary providers or specialty physicians, who referred the participant to ED after evaluating the participant. Herdman et al. (2016) found that the most predominant cause for delay in decision-making was when participants sought medical treatment elsewhere. Delays occurred when there was a lack of awareness on the part of family members or primary care providers. Targeting lack of awareness may improve outcomes and reduce pre-hospital delays to early diagnosis and treatment. Nurses should encourage individuals to rely on their support system because psychosocial support was an essential facilitator among the participants in this study. Rorat and Jurek (2015) suggested that since the trajectory of care-seeking involves relatives and healthcare workers in outpatient facilities, a possible means of patient safety would be widespread knowledge in communities and the creation of algorithms for healthcare workers and patients

A full explanation of algorithms for providers and patients is beyond the scope of this paper. However, as indicated earlier, both patients and providers need knowledge of both classical and atypical symptoms of bloodstream infection and sepsis. Algorithms used in outpatient and inpatient settings will be different. Physicians should complete a thorough systematic assessment of the patient’s symptoms in the outpatient setting when patients present for care. The physician in outpatient settings should then refer the patient to the emergency department (ED) if they are unsure what is causing the symptoms, or if they suspect infection. Gauer et al. (2020) described a typical algorithm for suspected sepsis to guide immediate action in evaluation of the source of infection and the severity of the illness in the inpatient setting. The providers should rapidly implement blood cultures, lab tests, administration of antibiotics, fluid resuscitation, and other measures as needed. If needed, the patient may need to be transferred to an intensive care unit, followed by a de-escalation of care once the patient begins to stabilize.

In terms of algorithms for patients, healthcare providers should teach patients what to do if they become ill. The patients should be taught to monitor mild and severe symptoms, especially fever/chills, shortness of breath/difficulty breathing, confusion, difficulty staying awake, or persistent pain. Algorithms for patients provide guidance about when to seek medical attention for symptoms that are concerning and stress that they should not delay seeking care. Patients and their family members should be instructed to call 911 and call the ED to notify hospital staff that they are seeking care for someone who may have a bloodstream infection or sepsis. For example, in a publication by Schorr et al. (2018), the authors evaluated patient education material from the CDC that was found to be understandable and actionable. The material provided information about sepsis, as well as step-by-step instructions on what an individual should do if they suspect they have an infection. In this study, barriers and facilitators involved navigating the healthcare system logistics. These barriers and facilitators were related to the availability of transportation, healthcare providers, and insurance coverage. As participants spoke about the strategies they used to cope with the bloodstream infection, they revealed the facilitators and barriers they encountered in the help-seeking process. Some participants lacked transportation to the hospital. They overcame this barrier by contacting family members or the emergency medical services (EMS). Additionally, sometimes the distance from their home to the hospital was a barrier that caused delays in help-seeking. On the other hand, living near the hospital where help was sought facilitated help-seeking by reducing behavioral delay.

One important facilitator is that all of the participants knew where to seek care. However, two participants who sought care at local hospitals experienced long wait times at outside hospitals (OSHs). Additionally, perceived poor quality of care was also noted as a barrier in this study. Some participants reported that they accessed health care through outpatient appointments before presenting to the hospital, which contributed to delays in arrival at the hospital.

The participants in this study reported other barriers and facilitators to help-seeking that they experience in the decision-making process. This study identified that having health insurance influenced the decision to seek help but did not always shorten the delay time. All of the participants had some kind of health insurance coverage. One participant indicated that she was worried about the cost of hospitalization when she experienced the symptom onset because she was transitioning from one insurance to another. Although the participant reported having some challenges with insurance that she resolved, the lack of insurance was not a barrier for most participants in this study. Others participants expressed concerns about the financial impact of being hospitalized for the bloodstream infection. Herdman et al. (2016) found that adults they classified as poor experienced longer delays in help-seeking. Individuals classified as poor were less likely to contact a qualified doctor. They experienced delays related to a lack of money.

Other research studies have addressed the issue of a lack of insurance and help-seeking. Researchers have found a lack of insurance correlated with death due to sepsis in community-onset sepsis because individuals may delay seeking care for serious illness (Baghdadi et al., 2018; Bogale et al., 2017; Charlet et al., 2017; Herdman et al., 2016).

Baghdadi et al. (2018) found that the lack of insurance was a barrier to timely care. The authors surmised that patients who lack insurance might be affected by other poverty-related barriers such as lack of transportation and competing needs. Herdman et al. (2016) conducted a study in Bangladesh to investigate the relationship between poverty and pre-hospital delays for patients with acute febrile illnesses. These researchers attributed delays in decision-making and travel to a lack of money and concluded that multidimensional poverty is associated with increase pre-hospital delays. Kumar et al. (2014) suggested that patients who lack insurance might delay seeking care for serious diseases. Herdman et al. recommended addressing the consequences of poverty and streamlining access to adequate healthcare.

The findings regarding competing priorities were not prominent because most of the study participants were unemployed, retired, or disabled. However, a similar idea emerged, in which three participants who had to obtain care for their dogs delayed seeking care. These participants identified personal responsibilities that interfered with their ability to seek help at the hospital in a timelier fashion. Clarke et al. (2015) also found that social factors such as competing priorities, like work, are barriers to help-seeking.

These findings are consistent with barriers to access to care listed in Healthy People 2030 (HP2030; HP2030, n.d.). Accessing health care for the participants in this study was related to the availability of social support, providers, transportation, money, and insurance. Provider availability, inconsistencies in providers, and office or hospital wait times were barriers to accessing care for these participants. HP2030 focuses on improving health by helping people get timely, high-quality care. Interventions are needed to increase access to healthcare professionals and improve communication between patients and providers. HP2030 also focuses on increasing social and community support because people’s relationships and interactions with family, friends, and coworkers significantly impact their health. HP2030 focuses on helping people get the social support they need. This important resource can guide interventions to improve community support related to the prevention and management of sepsis.

Implication for Nursing Practice

Survival of sepsis and the subsequent prognosis is highly dependent on the time between the onset of symptoms and arrival at the hospital for medical interventions. This study investigated what infection knowledge and psychosocial factors may contribute to the patients’ time to decide to seek care at the hospital (patient delay). Nurses can impact delay time by designing educational interventions to fill in knowledge gaps, fit an individual’s illness perceptions, correct inaccurate beliefs, and consider which barriers and facilitators impact delay time.

Gaps in knowledge impact patients’ decision-making when symptoms occur. Patients need to know that bloodstream infection and the sepsis complication is a medical emergency that requires early diagnosis and treatment to avoid the untoward effects of the condition. In addition, educational interventions can be designed to help patients recognize the symptoms of infection. Since most of the delay occurs during initial appraisal, knowing the infection symptoms will empower the patient to make faster decisions to seek treatment. On the other hand, not realizing the urgency of symptoms may prolong delay. Research has shown that knowledge gaps exist for providers and patients regarding preventing sepsis (Clarke et al., 2015; Mellhammar et al., 2015; Rorat & Jurek, 2015). Therefore, education should be targeted towards patients and health care providers.

This research has highlighted knowledge about cognitive and emotional illness perceptions. Therefore, educational intervention can be designed in a way that fits an individual's illness perceptions. Incorporating illness perceptions is an individualized approach to knowledge acquisition. The speed at which a patient can label their symptoms as being associated with an infection affects how quickly they decide to seek help. Nurses can teach patients that infection symptoms can have an insidious or abrupt onset. The duration of symptoms is also necessary to note. Patients must understand that they need seek help within hours, not days. Nurses can help patients understand that the recovery time may vary and that delays in the start of treatment could result in a significant amount of debility. Nurses can help patients understand the causes of infection to assess their own risk for infection. Lack of knowledge and confusion about the cause of infection may lead to misperceptions among patients and can become a significant source of delay.

Nurses can help patients understand the role of internal and external control mechanisms to manage bloodstream infection and sepsis symptoms. While many things may be out of the patients' control, nurses can empower them to make decisions that allow them to have an active role in the illness outcome. This study's results demonstrated the physical, functional, and social consequences of having an infection.

Knowing this, nurses could educate patients about the infection’s potential outcomes and provide resources that aid the patients in dealing with the infection’s long-term consequences.

In terms of emotional illness perceptions, a nurse can address the emotional responses to infection symptoms that can lead to inadequate coping strategies. Emotions are significant factors in patient decision delay. An individualized approach could modify these emotional factors that can cause an individual to delay seeking help, particularly if they fear being in the hospital. Nurses should not hesitate to integrate psychological aspects into their communication with patients with bloodstream infections. Nurses should consider emotional illness perceptions as a critical factor in patient and public education.

The cognitive illness perceptions discussed, i.e., label, timeline, cause, control, and consequences, are the individual’s beliefs about the infection. The emotional illness perceptions are the emotional reactions to and the concerns about the illness. Nurses can develop educational interventions in such a way that they can correct inaccurate beliefs and address emotional reactions and concerns about the infection. Correcting erroneous beliefs will impact patients’ decision-making and their behaviors in response to the onset of symptoms, thereby reducing delay.

This study also showed that patients’ coping strategies to manage the infection are associated with particular facilitators and barriers. Consistent with other studies, not recognizing the seriousness of symptoms was a barrier (Clarke et al., 2015; Rorat & Jurek, 2015). However, the critical time was the point at which a decision to seek external care was made and acted upon (Clarke et al., 2015; Gallop et al., 2015). The patient's answers to questions concerning coping strategies provided additional insights into psychological processes. When nurses design educational interventions, they should mitigate the barriers' effects and encourage facilitators. For example, this study found that patients delayed seeking care because they needed transportation and had pet care responsibilities. Some contacted urgent care or primary care providers instead of going to the emergency department. Nurses can teach patients to rely on social support and seek advice from knowledgeable family, friends, physicians, and nurses. Nurses could encourage patients not to ignore or deny the severity of the symptoms because that can lead to help-seeking delays.

This study showed that patients who ask for medical help sooner had more knowledge about infections and sought more social support during the pre-hospital phase. In general, those who sought care sooner appear to have positive attitudes and thoughts about personal difficulties. They interpreted the symptoms more often as being associated with an infection. Therefore, future education campaigns should address knowledge of infection symptoms, risk, and coping strategies.

Limitations

When interpreting the results of this study, the following limitations should be acknowledged. Due to the qualitative method used in this study, the findings are not generalizable to patients in other settings. However, the knowledge gained may potentially inform future research. There may be potential for selection bias due to the strategies used in sampling. Former patients were recruited from a single site in the

United States. Therefore, participant experiences may depend on the treatment available and quality of care at the institution where participant recruitment took place. Regional or national differences in the contribution of knowledge of symptoms, coping strategies, or psychological factors on patient decision time may play a role and should be further investigated.

Another limitation of this study is that the length of time between the episode of sepsis and discharge from the hospital may have caused some variation in the experience reported, leading to recall bias. Due to the lack of awareness of sepsis and the many comorbidities experienced, it was difficult for some participants to specifically attribute their experience to sepsis. Additionally, social desirability is possible wherein some participants might have gotten cues to answer in a certain way or agree with questions to please the researcher. A further limitation is that all of the findings are based only on the patients' perspective. This study did not include the perspective of caregivers or healthcare providers. Finally, another potential limitation is the lack of interview data from patients who died due to sepsis or refused participation.

Finally, using a theoretical framework as the organizing framework for data analysis means that the researcher may not recognize other ways to organize the data (Sandelowski, 1995). As a result, the researcher may be influenced by the model, which increases the chance that the researcher may find data supporting the model. Since the directed approach emphasizes the model, the researcher may lose sight of contextual aspects of the phenomenon under study (Sandelowski, 2000). The student researcher used an audit trail of coding and analytic decisions and confirmation with a qualitative expert to counteract the potential for bias (Sandelowski, 2000).

Recommendations for Future Research

This study has implications for future research involving patients with a sepsis diagnosis due to bloodstream infection. The findings from this study and other recent research revealed that many patients have difficulty appraising their symptoms and knowing when to seek care. Therefore, there is a need to develop community-based education that teaches patients to know the signs and symptoms of infection and infection risk. Therefore, the first recommendation for future research from this study is to design and implement educational interventions that researchers can evaluate in research studies that involve larger sample sizes.

More research is needed to understand the cognitive illness perceptions of patients diagnosed with bloodstream infections and sepsis in different groups. Future research should be conducted to address cultural differences in how individuals cope with symptoms of infection. Additionally, future research could further evaluate the role of emotional factors in influencing the adequacy of coping strategies. In particular, patients should know which emotions and coping strategies may prevent them from obtaining efficient and effective treatment. This novel way of thinking about patient decision-making in bloodstream infection and sepsis may help reduce delay. So, further research could address the psychological barriers, such as fear, denial, and wishful thinking, which can delay patient arrival at the hospital. Patients’ ability to work through emotions is essential for making the best decisions and achieving success in health matters. Patients may become frustrated when they cannot recognize emotions or express them. Researchers can develop tools to help patients identify what they feel. These new tools will enable the patients to pay attention to how they feel and to communicate their feelings. Researchers can conduct in-depth studies on how cognitive and emotional illness perceptions impact delay time.

The long-term impact of sepsis is not fully understood. More studies are needed that investigate the ongoing impacts, needs, and burden of care among survivors of sepsis. This research would help to identify the needs and measures nurses can use to address long-term impacts. Future research identifying the barriers and facilitators and their impact at each stage of the help-seeking process may help design interventions to decrease delays. Building on the current study, future interventions and their evaluation in future studies can validate these findings in a larger cohort and consider caregivers' experiences to help address approaches to reduce delays in seeking care and reduce unnecessary morbidity and mortality.

Conclusion

Few studies in the United States have explored the factors affecting patients' decisions to seek medical assistance at the onset of infection symptoms. The recent research suggests that patients who delay seeking care are at risk for adverse outcomes. These patients are affected by what they know, think, and feel. It is essential to understand patients' sources of information, illness perceptions, coping strategies, and the barriers and facilitators to help-seeking. Additionally, it is vital to understand the decision-making processes they use when they experience symptoms of an infection.

Delays in help-seeking are associated with poor outcomes, and many factors influence help-seeking behaviors. It is imperative to understand the factors the contribute to delay in help-seeking. Understanding different aspects of decision-making for patients who survived sepsis will provide essential information to design more effective interventions. These interventions could empower patients to make better and faster decisions to reduce delays in seeking care.

This qualitative study goes beyond previous sepsis research to provide insights into patient experiences of onset, treatment, recovery, and lasting effects of this potentially critical illness. Experiences varied depending on the illness context in which the patients experienced sepsis. The worst-affected patients reported lasting patient impacts on mobility and other complications, limiting self-care and usual activities. Patients reported a loss of independence, as well as emotional, work, and financial impacts. The study also identified problems of lack of awareness of the diagnosis or understanding of sepsis by participants.

Beliefs about bloodstream infections and sepsis, uncertainty about symptoms, and wanting to maintain control emerged in this study as factors influencing decisions to seek professional help for symptoms of infection. As such, this current study supports others' work in demonstrating that a typical response of individuals to infection is to attribute these symptoms to a less threatening cause. A desire to maintain control is also a significant factor influencing help-seeking behavior.

This investigation highlights some of the factors involved in participants' health-seeking behavior at the onset of infection symptoms. It touches on the notion of an individual maintaining control over their lives, even during a serious medical emergency. It also reveals the phenomenon of misinterpreting the signs and symptoms of sepsis. Misinterpretations are related to perceptions of the risk and contribute to delayed help-seeking. More research is needed to explore perceptions of infection risk, increase knowledge of symptoms, and test interventions designed to reduce delays in seeking treatment.

REFERENCES

Aboud, F. E., Rahman, E., Kassam, R., Khan, J., Ali, N. A., & Taleb, F. (2017). Interrupting pathways to sepsis: Effectiveness of an intervention to reduce delays in timely care for sick children in rural Bangladesh. *Social Science & Medicine (1982)*, *177*, 269–277. https://doi.org/10.1016/j.socscimed.2017.01.032

Andersson, H., Axelsson, C., Larsson, A., Bremer, A., Gellerstedt, M., Bång, A., Herlitz, J., & Ljungström, L. (2018). The early chain of care in bacteraemia patients: Early suspicion, treatment and survival in prehospital emergency care. *The American Journal of Emergency Medicine*, *36*(12), 2211–2218. https://doi.org/10.1016/j.ajem.2018.04.004

Arefian, H., Heublein, S., Scherag, A., Brunkhorst, F. M., Younis, M. Z., Moerer, O., Fischer, D., & Hartmann, M. (2017). Hospital-related cost of sepsis: A systematic review. *Journal of Infection*, *74*(2), 107–117. https://doi.org/10.1016/j.jinf.2016.11.006

Axelsson, C., Herlitz, J., Karlsson, A., Sjoberg, H., Jimenez-Herrera, M., Bang, A., Jonsson, A., Bremer, A., Andersson, H., Gellerstedt, M., & Ljungstrom, L. (2016). The early chain of care in patients with bacteraemia with the emphasis on the prehospital setting. *Prehospital and Disaster Medicine, 31*(3), 272–277. https://doi.org/10.1017/S1049023X16000339

Baghdadi, J. D., Wong, M., Comulada, W. S., & Uslan, D. Z. (2018). Lack of insurance as a barrier to care in sepsis: A retrospective cohort study. *Journal of Critical Care*, *46*, 134–138. https://doi.org/10.1016/j.jcrc.2018.02.005

Barnato, A. E., Alexander, S. L., Linde-Zwirble, W. T., & Angus, D. C. (2008). Racial variation in the incidence, care, and outcomes of severe sepsis. *American Journal of Respiratory and Critical Care Medicine*, *177*(3), 279–284. https://doi.org/10.1164/rccm.200703-480OC

Benyamini, Y., & Karademas, E. C. (2019). Introduction to the special issue on the common sense model of self-regulation. *Health Psychology Review*, *13*(4), 373–377. https://doi.org/10.1080/17437199.2019.1644189

Bogale, T. N., Worku, A. G., Bikis, G. A., & Kebede, Z. T. (2017). Why gone too soon? Examining social determinants of neonatal deaths in northwest Ethiopia using the three delay model approach. *BMC Pediatrics*, *17*(1), 216. https://doi.org/10.1186/s12887-017-0967-9

Broadbent, E., Schoones, J. W., Tiemensma, J., & Kaptein, A. A. (2019). A systematic review of patients’ drawing of illness: Implications for research using the Common Sense Model. *Health Psychology Review*, *13*(4), 406–426. https://doi.org/10.1080/17437199.2018.1558088

Cacioppo, J. T., Andersen, B. L., Turnquist, D. C., & Tassinary, L. G. (1989). Psychophysiological comparison theory: On the experience, description, and assessment of signs and symptoms. *Patient Education and Counseling*, *13*(3), 257–270. https://doi.org/10.1016/0738-3991(89)90020-7

Carter-Harris, L. (2015). An introduction to key event mapping: A primer for nurse researchers. *Applied Nursing Research*, *28*(2), 83–85. https://doi.org/10.1016/j.apnr.2015.01.003

Centers for Disease Control and Prevention. (2019, May 13). *Mission, role and pledge.* https://www.cdc.gov/about/organization/mission.htm

Charlet, D., Moran, A. C., & Madhavan, S. (2017). Summary findings from a mixed methods study on identifying and responding to maternal and newborn illness in seven countries: Implications for programs. *Journal of Health, Population, and Nutrition*, *36*(Suppl 1), 48. https://doi.org/10.1186/s41043-017-0126-9

Chaudhary, N. S. M., Donnelly, J. P. M., & Wang, H. E. M. (2018). Racial differences in sepsis mortality at U.S. academic medical center-affiliated hospitals. *Critical Care Medicine, 46*(6), 878–883. https://doi.org/10.1097/CCM.0000000000003020

Clarke, R. T., Bird, S., Kakuchi, I., Littlewood, T. J., & van Hamel Parsons, V. (2015). The signs, symptoms and help-seeking experiences of neutropenic sepsis patients before they reach hospital: A qualitative study. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *23*(9), 2687–2694. https://doi.org/10.1007/s00520-015-2631-y

Cornally, N., & McCarthy, G. (2011). Help-seeking behaviour: A concept analysis. *International Journal of Nursing Practice*, *17*(3), 280–288. https://doi.org/10.1111/j.1440-172X.2011.01936.x

Davis, L. L. (2015). Determining time of symptom onset in patients with acute coronary syndromes: Agreement between medical record and interview data. *Dimensions of Critical Care Nursing: DCCN*, *34*(4), 222–231. https://doi.org/10.1097/DCC.0000000000000117

Davis, L. L. (2017). A qualitative study of symptom experiences of women with acute coronary syndrome. *The Journal of Cardiovascular Nursing*, *32*(5), 488–495. https://doi.org/10.1097/JCN.0000000000000381

Davis, L. L., Mishel, M., Moser, D. K., Esposito, N., Lynn, M. R., & Schwartz, T. A. (2013). Thoughts and behaviors of women with symptoms of acute coronary syndrome. *Heart & Lung: The Journal of Critical Care*, *42*(6), 428–435. https://doi.org/10.1016/j.hrtlng.2013.08.001

Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress & the Homeless*, *5*(1), 11–38. https://doi.org/10.1007/BF02090456

Endler, N. S., & Parker, J. D. (1990). Multidimensional assessment of coping: A critical evaluation. *Journal of Personality and Social Psychology*, *58*(5), 844–854. https://doi.org/10.1037/0022-3514.58.5.844

Endler, N. S., & Parker, J. D. A. (1994). Assessment of multidimensional coping: Task, emotion, and avoidance strategies. *Psychological Assessment*, *6*(1), 50–60. https://doi.org/10.1037/1040-3590.6.1.50

Englert, N. C., & Ross, C. (2015). The older adult experiencing sepsis. *Critical Care Nursing Quarterly*, *38*(2), 175–181. https://doi.org/10.1097/CNQ.0000000000000059

Esposito, S., De Simone, G., Boccia, G., De Caro, F., & Pagliano, P. (2017). Sepsis and septic shock: New definitions, new diagnostic and therapeutic approaches. *Journal of Global Antimicrobial Resistance*, *10*, 204–212. https://doi.org/10.1016/j.jgar.2017.06.013

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, *48*(1), 150–170. https://doi.org/10.1037//0022-3514.48.1.150

Galiatsatos, P., Follin, A., Uradu, N., Alghanim, F., Daniel, Y., Saria, S., Townsend, J., Sylvester, C., Chanmugam, A., & Chen, E. s. (2019). The association between neighborhood socioeconomic disadvantage and readmissions for patients hospitalized with sepsis. In *C94. The impact of social determinants in pulmonary and critical care* (Vol. 1–296, pp. A5569–A5569). American Thoracic Society. https://doi.org/10.1164/ajrccm-conference.2019.199.1_MeetingAbstracts.A5569

Gallop, K. H., Kerr, C. E. P., Nixon, A., Verdian, L., Barney, J. B., & Beale, R. J. (2015). A qualitative investigation of patients' and caregivers' experiences of severe sepsis. *Critical Care Medicine*, *43*(2), 296–307. https://doi.org/10.1097/CCM.0000000000000613

Gauer, R., Forbes, D., & Boyer, N. (2020). Sepsis: Diagnosis and management. *American Family Physician*, *101*(7), 409–418. https://www.aafp.org/afp/2020/0401/afp20200401p409.pdf

Gibbs, J., Gkatzidou, V., Tickle, L., Manning, S. R., Tilakkumar, T., Hone, K., Ashcroft, R. E., Sonnenberg, P., Sadiq, S. T., & Estcourt, C. S. (2017). 'Can you recommend any good STI apps?' A review of content, accuracy and comprehensiveness of current mobile medical applications for STIs and related genital infections. *Sexually Transmitted Infections*, *93*(4), 234–235. https://doi.org/10.1136/sextrans-2016-052690

Guery, B., & Calandra, T. (2019). Early antimicrobial therapy for sepsis: Does each hour really count? *Seminars in Respiratory and Critical Care Medicine*, *40*(4), 447–453. https://doi.org/10.1055/s-0039-1694970

Hajisabbagh, N., Fereidooni-Moghadam, M., & Etemadifar, M. (2019). Coping strategies and their relationship with emotional intelligence in patients with epilepsy referred to Isfahan Epilepsy Society in 2017. *Epilepsy & Behavior*, *92*, 200–205. https://doi.org/10.1016/j.yebeh.2018.12.032

Hagger, M. S., Koch, S., Chatzisarantis, N. L. D., & Orbell, S. (2017). The Common Sense Model of Self-Regulation: Meta-analysis and test of a process model. *Psychological Bulletin*, *143*(11), 1117–1154. https://doi.org/10.1037/bul0000118

Hagger MS, & Orbell S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, *18*(2), 141–184.

Healthy People 2030. (n.d.). *Social determinants of health.* U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Herdman, M. T., Maude, R. J., Chowdhury, M. S., Kingston, H. W. F., Jeeyapant, A., Samad, R., Karim, R., Dondorp, A. M., & Hossain, M. A. (2016). The relationship between poverty and healthcare seeking among patients hospitalized with acute febrile illnesses in Chittagong, Bangladesh. *PloS One*, *11*(4), e0152965. https://doi.org/10.1371/journal.pone.0152965

Herlitz, J., Bang, A., Wireklint-Sundstrom, B., Axelsson, C., Bremer, A., Hagiwara, M., Jonsson, A., Lundberg, L., Suserud, B.-O., & Ljungstrom, L. (2012). Suspicion and treatment of severe sepsis: An overview of the prehospital chain of care. *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine, 20*, 42. https://doi.org/10.1186/1757-7241-20-42

Herrera, C. (2017, February 14). Sepsis: What you need to know | BestMEDICINE News. *BestMedicine by Renown Health*. https://bestmedicinenews.org/health/sepsis-need-know-2/

Houghton, D. D. (2019). CE: Infection in acute care: Evidence for practice. *Journal of Nursing*, *119*(10), 24–32. https://doi.org/10.1097/01.NAJ.0000586160.03391.82

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Huang, C. Y., Daniels, R., Lembo, A., Hartog, C., O'Brien, J., Heymann, T., Reinhart, K., Nguyen, H. B., & Sepsis Survivors Engagement Project. (2019). Life after sepsis: An international survey of survivors to understand the post-sepsis syndrome. *International Journal for Quality in Health Care*, *31*(3), 191–198. https://doi.org/10.1093/intqhc/mzy137

King, H. A., Doernberg, S. B., Miller, J., Grover, K., Oakes, M., Ruffin, F., Gonzales, S., Rader, A., Neuss, M. J., Bosworth, H. B., Sund, Z., Drennan, C., Hill-Rorie, J. M., Shah, P., Winn, L., Fowler, V. G., & Holland, T. L. (2020). Patients' experiences with Staphylococcus aureus and gram-negative bacterial bloodstream infections: A qualitative descriptive study and concept elicitation phase to inform measurement of patient-reported quality of life. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*. https://doi.org/10.1093/cid/ciaa611

Kristofferzon, M. L., Engström, M., & Nilsson, A. (2018). Coping mediates the relationship between sense of coherence and mental quality of life in patients with chronic illness: A cross-sectional study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *27*(7), 1855–1863. https://doi.org/10.1007/s11136-018-1845-0

Kumar, G., Taneja, A., Majumdar, T., Jacobs, E. R., Whittle, J., & Nanchal, R. (2014). The association of lacking insurance with outcomes of severe sepsis: Retrospective analysis of an administrative database. *Critical Care Medicine*, *42*(3), 583–591. https://doi.org/10.1097/01.ccm.0000435667.15070.9c

Latten, G. H. P., Claassen, L., Jonk, M., Cals, J. W. L., Muris, J. W. M., & Stassen, P. M. (2019). Characteristics of the prehospital phase of adult emergency department patients with an infection: A prospective pilot study. *PloS One*, *14*(2), e0212181. https://doi.org/10.1371/journal.pone.0212181

Launay, E., Gras-Le Guen, C., Martinot, A., Assathiany, R., Martin, E., Blanchais, T., Deneux-Tharaux, C., Roze, J.-C., & Chalumeau, M. (2014). Why children with severe bacterial infection die: A population-based study of determinants and consequences of suboptimal care with a special emphasis on methodological issues. *PloS One*, *9*(9), e107286. https://doi.org/10.1371/journal.pone.0107286

Lehman, K. D., & Thiessen, K. (2015). Sepsis guidelines: Clinical practice implications. *The Nurse Practitioner*, *40*(6), 1–6. https://doi.org/10.1097/01.NPR.0000465120.42654.86

Lester, D., Hartjes, T., & Bennett, A. (2018). CE: A review of the revised sepsis care bundles. *The American Journal of Nursing*, *118*(8), 40–49. https://doi.org/10.1097/01.NAJ.0000544139.63510.b5

Leventhal, H. (1970). Findings and theory in the study of fear communications. *Advances in Experimental Social Psychology*, *5*, 119–186.

Leventhal, H., Phillips, L., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): A dynamic framework for understanding illness self-management. *Journal of Behavioral Medicine*, *39*(6), 935–946. https://doi.org/10.1007/s10865-016-9782-2

Liu, V. X., Fielding-Singh, V., Greene, J. D., Baker, J. M., Iwashyna, T. J., Bhattacharya, J., & Escobar, G. J. (2017). The timing of early antibiotics and hospital mortality in sepsis. *American Journal of Respiratory and Critical Care Medicine*, *196*(7), 856–863. https://doi.org/10.1164/rccm.201609-1848OC

Lund, L. H., Khush, K. K., Cherikh, W. S., Goldfarb, S., Kucheryavaya, A. Y., Levvey, B. J., Meiser, B., Rossano, J. W., Chambers, D. C., Yusen, R. D., & Stehlik, J. (2017). The Registry of the International Society for Heart and Lung Transplantation: Thirty-fourth Adult Heart Transplantation Report—2017; Focus Theme: Allograft ischemic time. *The Journal of Heart and Lung Transplantation*, *36*(10), 1037–1046. https://doi.org/10.1016/j.healun.2017.07.019

Makic, M. B. F., & Bridges, E. (2018). CE: Managing sepsis and septic shock: Current guidelines and definitions. *Journal of Nursing*, *118*(2), 34–39. https://doi.org/10.1097/01.NAJ.0000530223.33211.f5

McAndrew, L. M., Crede, M., Maestro, K., Slotkin, S., Kimber, J., & Phillips, L. A. (2019). Using the common-sense model to understand health outcomes for medically unexplained symptoms: A meta-analysis. *Health Psychology Review*, *13*(4), 427–446. https://doi.org/10.1080/17437199.2018.1521730

McAndrew, L. M., Mora, P. A., Quigley, K. S., Leventhal, E. A., & Leventhal, H. (2014). Using the common-sense model of self-regulation to understand the relationship between symptom reporting and trait negative affect. *International Journal of Behavioral Medicine*, *21*(6), 989–994. https://doi.org/10.1007/s12529-013-9372-4

Mellhammar, L., Christensson, B., & Linder, A. (2015). Public awareness of sepsis is low in Sweden. *Open Forum Infectious Diseases*, *2*(4), ofv161. https://doi.org/10.1093/ofid/ofv161

Minasyan, H. (2017). Sepsis and septic shock: Pathogenesis and treatment perspectives. *J Crit Care*, *40*, 229–242. https://doi.org/10.1016/j.jcrc.2017.04.015

Moore, J. X., Donnelly, J. P., Griffin, R., Safford, M. M., Howard, G., Baddley, J., & Wang, H. E. (2015). Black-white racial disparities in sepsis: A prospective analysis of the REasons for Geographic And Racial Differences in Stroke (REGARDS) cohort. *Critical Care (London, England)*, *19*, 279. https://doi.org/10.1186/s13054-015-0992-8

Nguyen, D. B., Lessa, F. C., Belflower, R., Mu, Y., Wise, M., Nadle, J., Bamberg, W. M., Petit, S., Ray, S. M., Harrison, L. H., Lynfield, R., Dumyati, G., Thompson, J., Schaffner, W., & Patel, P. R. (2013). Invasive methicillin-resistant staphylococcus aureus infections among patients on chronic dialysis in the United States, 2005–2011. *Clinical Infectious Diseases*, *57*(10), 1393–1400. https://doi.org/10.1093/cid/cit546

Nielsen, S. L. (2015). The incidence and prognosis of patients with bacteremia. *Danish Medical Journal*, *62*(7), B5128. https://pubmed.ncbi.nlm.nih.gov/26183054/

NVSS - Mortality Tables—Leading Causes of Death—LCWK9. (2019, March 4). https://www.cdc.gov/nchs/nvss/mortality/lcwk9.htm

Orbell, S., & Alison Phillips, L. (2019). Automatic processes and self-regulation of illness. *Health Psychology Review*, *13*(4), 378–405. https://doi.org/10.1080/17437199.2018.1503559

Paoli, C. J., Reynolds, M. A., Sinha, M., Gitlin, M., & Crouser, E. (2018). Epidemiology and costs of sepsis in the United States—An analysis based on timing of diagnosis and severity level. *Critical Care Medicine*, *46*(12), 1889–1897. https://doi.org/10.1097/CCM.0000000000003342

Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research*, *28*(3), 381–388. https://doi.org/10.1177/1049732317697102

Rhee, C., Dantes, R., Epstein, L., Murphy, D. J., Seymour, C. W., Iwashyna, T. J., Kadri, S. S., Angus, D. C., Danner, R. L., Fiore, A. E., Jernigan, J. A., Martin, G. S., Septimus, E., Warren, D. K., Karcz, A., Chan, C., Menchaca, J. T., Wang, R., Gruber, S., & Klompas, M. (2017). Incidence and trends of sepsis in US hospitals using clinical vs claims data, 2009-2014. *JAMA*, *318*(13), 1241–1249. https://doi.org/10.1001/jama.2017.13836

Roat, L. (2013). *Facing the sepsis conundrum in the world of ICD-10—ICD10monitor*. https://www.icd10monitor.com/facing-the-sepsis-conundrum-in-the-world-of-icd-10

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25–41. https://doi.org/10.1080/14780887.2013.801543

Rorat, M., & Jurek, T. (2015). Sepsis in Poland: Why do we die? *Medical Principles and Practice: International Journal of the Kuwait University, Health Science Centre, 24*(2), 159–164. https://doi.org/10.1159/000369463

Rubulotta, F. M., Ramsay, G., Parker, M. M., Dellinger, R. P., Levy, M. M., Poeze, M., Surviving Sepsis Campaign Steering Committee, European Society of Intensive Care Medicine, & Society of Critical Care Medicine. (2009). An international survey: Public awareness and perception of sepsis. *Critical Care Medicine*, *37*(1), 167–170. https://doi.org/10.1097/ccm.0b013e3181926883

Safer, M. A., Tharps, Q. J., Jackson, T. C., & Leventhal, H. (1979). Determinants of three stages of delay in seeking care at a medical clinic. *Medical Care*, *17*(1), 11–29.

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health, 18*(4), 371–375. https://doi.org/10.1002/nur.4770180411

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*(4), 334–340. https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, *33*(1), 77–84. https://doi.org/10.1002/nur.20362

Sandelowski, M., & Leeman, J. (2012). Writing usable qualitative health research findings. *Qualitative Health Research*, *22*(10), 1404–1413. https://doi.org/10.1177/1049732312450368

Schorr, C., Hunter, K., & Zuzelo, P. R. (2018). Understandability and actionability of the CDC'S printable sepsis patient education material. *American Journal of Critical*

Care: An Official Publication, *27*(5), 418–427. https://doi.org/10.4037/ajcc2018121

Schultz, M. J., Dunser, M. W., Dondorp, A. M., Adhikari, N. K. J., Iyer, S., Kwizera, A., Lubell, Y., Papali, A., Pisani, L., Riviello, B. D., Angus, D. C., Azevedo, L. C., Baker, T., Diaz, J. V., Festic, E., Haniffa, R., Jawa, R., Jacob, S. T., Kissoon, N., … Global Intensive Care Working Group of the European Society of Intensive Care Medicine. (2017). Current challenges in the management of sepsis in ICUs in resource-poor settings and suggestions for the future. *Intensive Care Medicine*, *43*(5), 612–624. https://doi.org/10.1007/s00134-017-4750-z

Stephanie. (2016, May 27). *Recall bias: Definition, examples, strategies to avoid it*. Statistics How To. https://www.statisticshowto.com/recall-bias/

Thaddeus, S., & Maine, D. (1994). Too far to walk: Maternal mortality in context. *Social Science & Medicine*, *38*(8), 1091–1110. https://doi.org/10.1016/0277-9536(94)90226-7

U.S. Census Bureau. (n.d.). *2017 National Population Projections Tables: Alternative Scenarios*. U.S. Census Bureau. https://www.census.gov/data/tables/2017/demo/popproj/2017-alternative-summary-tables.html

van Hal, S. J., Jensen, S. O., Vaska, V. L., Espedido, B. A., Paterson, D. L., & Gosbell, I. B. (2012). Predictors of mortality in staphylococcus aureus Bacteremia. *Clinical Microbiology Reviews*, *25*(2), 362–386. https://doi.org/10.1128/CMR.05022-11

Walters, E. (2018). Raising awareness for sepsis, sepsis screening, early recognition, and treatment in the emergency department. *Journal of Emergency Nursing*, *44*(3), 224–227. https://doi.org/10.1016/j.jen.2017.10.008

Wattanapaiboon, K., Banditlerdruk, S., & Vattanavanit, V. (2020). Presenting symptoms in sepsis: Is the mnemonic “SEPSIS” useful? *Infection and Drug Resistance, 2020*(13), 2199–2204. https://doi.org/10.2147/IDR.S263964

Weiner, L. M., Webb, A. K., Limbago, B., Dudeck, M. A., Patel, J., Kallen, A. J., Edwards, J. R., & Sievert, D. M. (2016). Antimicrobial-resistant pathogens associated with healthcare-associated infections: Summary of data reported to the National Healthcare Safety Network at the Centers for Disease Control and Prevention, 2011–2014. *Infection Control & Hospital Epidemiology*, *37*(11), 1288–1301. https://doi.org/10.1017/ice.2016.174

Wester, A. L., Dunlop, O., Melby, K. K., Dahle, U. R., & Wyller, T. B. (2013). Age-related differences in symptoms, diagnosis and prognosis of bacteremia. *BMC Infectious Diseases*, *13*, 346. https://doi.org/10.1186/1471-2334-13-346

APPENDIX A

6-ITEM COGNITIVE SCREENER

Interviewer: I would like to ask you some questions that ask you to use your memory. I am going to name three objects. Please wait until I say all three words, then repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. Please repeat these words for me: APPLE – TABLE – PENNY. (Interviewer may repeat words three times if necessary but repetition not scored).

Did the patient correctly repeat all three words?	Yes	No
	Incorrect	Correct
1. What year is this?	0	1
2. What month is this?	0	1
3. What is the day of the week?	0	1
What were the three objects I asked you to remember?		
4. Apple =	0	1
5. Table =	0	1
6. Penny =	0	1

Reference:

Callahan, C. M., Unverzagt, F. W., Hui, S. L., Perkins, A. J., & Hendrie, H. C. (2002). Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Medical Care*, *40*(9), 771–781. https://doi.org/10.1097/00005650-200209000-00007

APPENDIX B

SEMI-STRUCTURED INTERVIEW GUIDE (ADAPTED VERSION DATE: JANUARY 13, 2020)

	Topic	Interview Question
		I want to understand more about what happens when patients experience symptoms of an infection and what they do when symptoms occur—especially in terms of seeking care.
	Broad, open-ended question to start	Tell me the story about when you first thought you might be having symptoms of an infection. Tell me how you thought about managing the other things in your life.
		That was a good overview. I want to learn more about the beginning; what your thoughts and feeling were early on about what was happening to you. Let's talk about when you first started to have symptoms.
Participants label/identify symptoms	Definability of symptoms: • Onset of symptoms • What symptoms did the patient have? • Quality of symptoms • Number of symptoms	Tell me what symptoms were you having before you were diagnosed with the infection that made you know that you needed to seek care? What other symptoms were you having? Tell me more about how the symptoms came on and how long they lasted? Starting from when you first noticed the symptoms, describe how bad the symptoms were? From the beginning and during the time you were having these symptoms, what were your thoughts about the symptoms? At the time of your first symptoms, tell me more about what was going on in your life? What was your initial reaction to the symptoms; what did you do? When you first started to notice the symptoms, how did the symptoms affect you emotionally? What symptoms did you have after you were diagnosed with the infection? Initially, what did you think was causing the symptoms? Appraisal of symptoms: What did you do to figure out what was causing the symptoms? Physical representation of the illness: What did you think was going on with you or what did you think you had, when the symptoms occurred? (Labeling the disease)

Topic	Interview Question
	Patients typically try to do things that will make them feel better when they feel ill.
• Coping strategies (What did the patient do to get better, e.g., home remedies, waiting to feel better, resting, going to the doctor.)	Who did you contact about the symptoms first? Who else did you contact about the symptoms? Did anyone in particular help you when you were trying to figure out what was going on? Besides contacting people, what did you do to cope with the symptoms and to try to feel better? Tell me how contacting people and doing the things you did to make your symptoms better affect you emotionally? (What were your feelings?) What in your memory do you think may have helped you the most to decide to seek help for your symptoms?
	I want to know more about how long it took you to decide to seek care for your symptoms.
• Delays in Help-seeking	What was the date and time that you first noticed your symptoms? Appraisal delay: Beginning with your first sign or symptom, how long did it take for you to realize that you were ill? Illness delay: Once you realized that you were ill, how long did it take for you to decide to seek medical care? Behavioral delay: Once you decided to seek medical care, how long did it take to arrive at the hospital? How did you get to the hospital?
	I want to know more about your decision to seek care.
Decision about seeking care	When did you decided to go to the hospital, what made you decide to go to the hospital to seek care?) Follow-up re: not being sure about seeking care: So, it sounds like initially, you did not think about going to the hospital (try to use their words). How did you decide to go to the hospital? What influenced your decision to go into the hospital? Probe related to influence of others related to going to the hospital: Did others influence the decision to go to the hospital? How so? What are the consequences of going to the hospital? What did you think would happen if you went to the hospital? What do you think would have been the consequences of not going to the hospital?

	Topic	Interview Question
		Often patients use knowledge gained to make decisions about when to seek care.
	• Knowledge of infection	Prior knowledge: What did you know about bloodstream infections before you were diagnosed? Did prior knowledge or lack thereof have any effect on your decision to seek care?
		Now I want to talk about sources of health information that you may use.
	• Sources of information o Lay information in memory o Information from doctors and nurses o Somatic and symptom information	Tell me about the ways that you obtain health information in general. Before you got this infection, what did you understand to be the symptoms of infection? How did you find out you had bacteria in your blood, also called bloodstream infection or bacteremia? What specific word did the provider use when explaining to you that you had the bloodstream infection? Can you tell me anything else that you learned from patient education with doctors and nurses? So, how was the proposed treatment plan for your blood stream infection explained to you? So, what was the initial plan, and who explained it? Can you think of any ways that patient education might affect the actual care that you or other patients might receive? Can you think of any education that nurses or doctors might provide which would help reduce the amount of time taken to seek care when symptoms occur?
	• Reaction to having an infection	When did you find out that you had a bloodstream infection? What were your thoughts about having the bloodstream infection? So, thinking back to when you were first told that you had bacteria in your blood, how did you react emotionally when you were told about that?
		I want to talk more about your beliefs about the symptoms and the symptom course.
Perceptions of timeline	• Symptom course (onset and continuation/duration of symptoms) • Timing, frequency, location and intensity of symptoms	How did it come on? (get to onset and try to get to acuteness of the disruption) How long did you think the symptoms would last? How long did the symptoms last? Where in your body did you have symptoms? Did you know what was happening right away or did it take some time to figure things out?

	Topic	Interview Question
		What were your thoughts about how long it would take you to get better? How did you react emotionally when you were thinking about how long you might be ill?
Concerns about sepsis	• Thoughts about seriousness • Thoughts about susceptibility to sepsis	Follow-up re: being unsure or uncertain about what was going on (if that comes up; otherwise, probe): So, it sounds like you were not sure initially about what was happening, tell me more about that (*use their words*). What did your "gut" tell you was going on? Follow-up re: needing to figure out things (if that comes up): So, you felt that you needed to figure things out … tell me more about how you did that. Follow-up re: unpredictable (if that arises): So initially you did not know what was going to happen. Tell me about your concerns at that time. Tell me about whether you thought that the illness was a serious condition?
Emotional representations of sepsis	• Level of distress	How did it make you feel to know that you were ill? What was the emotional impact of your illness?
Views about sepsis	Situational influences related to symptoms: • First time event • Acuteness of disruption • Personal knowledge of sepsis symptoms	Was this the first time this happened, or had you had similar experiences in the past? Had you ever thought about what it would be like to have an infection or sepsis? Follow-up re: a similar situation in the past: So how was this similar to the previous experience? Was it different in any way? If so, how was it different? Follow-up re: prior expectations: Was your experience similar to what you expected?
		I am interested in what you considered may have been the cause of your illness. As people are different, so there is no correct answer to this question. We are interested in your views about factors that caused your illness rather than what others including your doctors and family may have suggested to you.
Perceptions of cause of sepsis	• Thoughts about causality (the things the person feels contributed to the illness, e.g., germs cause infection.	What do you think was the cause of this infection? Why do you think you got the infection?
		I am interested in knowing more about whether you think that you have the power to influence your illness.

	Topic	Interview Question
Perceptions of treatment and personal control	- Coping	What are your thoughts and feeling about whether you can determine if your illness gets better or worse? Once you realized something was wrong with your health, what did you do to manage your illness? What treatment did you receive for your blood stream infection while in the hospital? What treatment did you receive for your blood stream infection after you left the hospital? How have you responded to your blood stream infection and its treatment overall? Do you feel that the treatment that you are receiving will cure your illness?
		Now, I want to talk about things that may have made it difficult for you to seek care and things that made it easy for you to seek care.
Barriers		In your opinion, what were the biggest challenges or problems that you faced when you decided to seek care? Was it difficult for you to obtain care? What do you think are the major things that prevented you from seeking care sooner? How did your family responsibilities and obligations impact the amount of time it took you to seek care? What changes do you feel would minimize the impact of (barrier)?
Facilitators		What do you feel facilitated you going to the hospital for treatment? What helped you obtain care? What things made it easier for you to seek care and access health care? If you could change one thing about the care you received or are receiving, what would it be? What did you like about the care you received? What did you not like about the care you received?
		Moving on to some questions about how your blood stream infection and its treatment has impacted you in different areas of your life.
Perceptions about the consequences of sepsis	- Thoughts about anticipated outcomes	What do you think will be the consequences of your illness? Tell me whether you think your illness will have major consequences for your life? Tell me whether you think your illness have serious financial consequences? Explain whether you think your illness affect the way others see you?

Topic	Interview Question
	Explain whether you think your illness has or will cause difficulty for those close to you?
	How has your blood stream infection and its treatment impacted you physically (your body)?
	How about how has your blood stream infection and its treatment impacted you mentally? So, the way that you think.
	How has your blood stream infection and its treatment impacted you emotionally?
	How has your blood stream infection and its treatment impacted you functionally? So, what we mean by that is like your daily activities in life.
	How has your blood stream infection and its treatment impacted you socially? So, with your family, friends, relationships, if at all.
	In what areas of your life has your blood stream infection and its treatment impacted you the most out of physical, mental, emotional, functional, and social?
	In what areas of your life has your blood stream infection and its treatment impacted you the least out of physical, mental, emotional, functional, and social?
	What do you think would have been different in your life if you had not had this infection? (You are asking about the influence of the infection in their life.)
	Closure: Again, thank you so much for answering all these questions. It has been very helpful.
	Is there anything you want to add and is there anything you want to ask me?

APPENDIX C

SOCIODEMOGRAPHIC DATA COLLECTION FORM (ADAPTED VERSION, MARCH 6, 2020)

Participant Characteristics	
Age in years	**___ years**
Race	1. Caucasian 2. African-American 3. Other
Gender	1. Male 2. Female
Education	1. Did not complete high school 2. High School graduate 3. Some College/Associates degree 4. Bachelor’s degree 5. Master’s Degree 6. Ph.D./M.D.
Employment Status	1. Employed fulltime 2. Employed part-time 3. Unemployed, seeking employment 4. Unemployed, disabled 5. Unemployed, retired 6. Looking after home 7. Student
Annual Household Income	1. No data 2. < $20,000 3. $20,000 – 39,999 4. $40,000 – 59,999 5. > $60,000
Insurance Status	1. No data 2. Private 3. Medicaid 4. Medicare 5. Self-pay 6. Other
Relationship Status	1. Never married 2. Married 3. Partnership 4. Separated/Divorced 5. Widowed
Point of Entry to the Hospital	1. Home 2. Assisted Living 3. Nursing Facility

At the end of the interview, participants who enrolled via the BSIR were asked: Do you know other individuals who meet the criteria for this study? Are you willing to give the study information and the researcher’s contact information to other people who may qualify for this study? If the researcher has additional questions or needs to clarify some of the information provided during the interview, would it be OK for the researcher to give a follow-up call?

APPENDIX D

EXAMPLES OF SOME EXTRACTS OF DATA COLLATED FOR THREE CODES

Coping with the bloodstream infection	Causes of delay	Consequences of the bloodstream infection
I realized something was wrong with my health. I sought out the expertise of the doctors.	The time of morning that it was—the time of day that it was, getting an appointment, results of prior testing runs.	So, in my opinion, I feel like I'm going to be more susceptible to these types of diseases now.
I took my medications the way they were prescribed to me. I rested. I finished my full doses of medication. And I followed up with all of my appointments, like I was supposed to.	I was resisting. I was resisting going to the hospital because I think it's a miserable experience to be in the hospital. So, I was doing everything I could to stay out of the hospital. And I was too … I'll say stubborn … I was too stubborn. I didn't surrender to the need soon enough.	Well, I think everything is wrapping up quite well. Consequences is I'm weakened by the treatment and the hospital stay. So, I'm having to build back strength. And so, there are no negative consequences gonna happen as a result of me having to be treated.
So, it's a matter of just taking the medicine and seeing what happened.	No, there really wasn't anything. It was just my husband realizing what was wrong with me.	Well, I hope it hasn't damaged anything else. I don't think my body can take any worse damage. I hope everything's good now.
I went to the doctor. I went to the doctor to find out what was going on, and follow procedures, and the plan that they gave me.	Because the hospital that I went to in my hometown – they're known for being slow, and people have to wait for hours and hours, so that was the worst at that hospital, but once I got to [the university medical center], everything was fine.	For one thing, I was working pretty good. I can't do that anymore. My job that I had, I had to—I can't go out and do that because I'd be sick when I get out of the house, and I can't really take care of my wife like I was doing because I stay sick all the time. Then, I was playing with my grandkids every day. I don't even play with them no more, so it's affected me in a whole lot of different ways.

APPENDIX E

THEMES AND CODES

Categories and Codes	How many participants mentioned it	How many times it was mentioned across all interviews
Sources of Information	10	255
• **Somatic and symptom information**	10	96
• **Lay information stored in memory**	10	79
• **Information from expert sources**	10	57
• **Reading Books and the Internet**	7	11
Cognitive Illness Perceptions	10	167
• **Identity/Label**	10	40
• **Timeline**	10	33
• **Cause**	10	32
• **Control/Cure**	9	16
• **Consequences**	10	36
Emotional Illness Perceptions	10	56
• **Emotional reaction to the BSI**	10	56
Coping Strategies	10	135
• **Avoidance**	3	5
• **Task-oriented coping**	9	28
• **Emotion-oriented coping**	2	2
• **Cognitive reappraisal**	2	4
• **Seeking social support**	9	21
Barriers to Help-seeking	9	29
Facilitators to Help-seeking	10	110
Illness Outcomes	9	105
• **Disease state**	8	8
• **Physical functioning**	9	21
• **Role functioning**	9	18
• **Social functional**	7	7
Emotional Outcomes	8	17