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Baccalaureate Nurses’ Experiences and Understanding of Adults Living with Sickle Cell Disease

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BACCALAUREATE NURSES' EXPERIENCES AND UNDERSTANDING OF ADULTS LIVING WITH SICKLE CELL DISEASE

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy in Nursing Education

Ron and Kathy Assaf College of Nursing
Nova Southeastern University

Shelia A. Reid

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This dissertation, written by Shelia Reid under the direction of her Dissertation Committee, and approved by all its members, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF PHILOSOPHY IN NURSING EDUCATION

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Certification

We hereby certify that this dissertation, submitted by Shelia Reid, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the Doctor of Philosophy in Nursing Education degree.

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Abstract

Background: Sickle cell disease (SCD) is a chronic, genetic blood disorder with most treatment interventions geared toward the acute phase of the disease, which often leads to fragmented care. In Canada, the teaching of SCD occurs without a genetic competency, resulting in miscommunication, misunderstanding, and inadequate nursing care.

Purpose: This investigator examined baccalaureate nurses' experiences and understanding of working with adults living with SCD.

Methods: A semi-structured interview guide was used to explore baccalaureate nurses' experiences and understanding of working with young adults living with SCD.

Results: Lindseth and Norbergs' (2004) interpretation of Ricoeur's hermeneutic interpretative phenomenological approach was used to analyze, interpret, and report the research findings.

Conclusions: With the research findings, an in-depth understanding of baccalaureate nurses' experiences and understanding of working with this vulnerable population was provided. Baccalaureate nurses' experiences and understanding offered new insights to foster curricula change in nursing education.

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Chapter One

Problem and Domain of Inquiry

Sickle cell disease (SCD) is a genetic blood disorder that affects millions worldwide, which is often characterized by painful episodes (Lovett, Sule & Lopez, 2014). The number of people living with SCD in Canada is unknown. The Centers for Disease Control and Prevention (CDC, n. d.) estimates that SCD affects 100,000 African-Americans, and one in 365 African-Americans are born with SCD. Lovett et al. (2014) stated that emergency providers must be familiar with SCD since one in every 12 African-Americans carries the recessive trait. The most severe form of SCD occurs with the vast-occlusive crisis. It results in severe pain and frequent hospital emergency visits (Lovett et al., 2014). The repetitive nature of SCD pain, coupled with emotional upsets, often lead to miscommunication between health care providers and SCD patients (Hanie, Sackett, & Hartman, 2014).

Although nurses initiate the first contact with SCD clients in the emergency departments, the care of SCD clients remains fragmented. Nursing interventions focused on symptom management with little to no treatment intervention geared towards the psychosocial aspect of care. Many studies have reported inadequate attention in the emergency department, such as delayed wait time for pain medication and health care providers' negative attitudes toward patients living with SCD (Bergman & Diamond 2013; O'Connor et al., 2014). Therefore, examining baccalaureate nurses' experiences and understanding of working with adults living with SCD is congruent with the National

League for Nursing (2016) educational research priorities that advocate for the use of evidence-based research to transform nursing education and practice. This study utilized a hermeneutic phenomenological interpretative research design.

Problem Statement

Tanabe et al. (2013) and Valente et al. (2010) found inadequate training and a lack of understanding as significant barriers in treating patients living with SCD. These researchers exposed the gap between the nursing curricula and the practice environments. No researcher seeks to understand baccalaureate nurses' experiences of working with this vulnerable population. Therefore, a phenomenological study was used to provide an in-depth understanding of baccalaureate nurses' experiences and insights to foster curricular changes.

Purpose of the Study

The purpose of the study was to understand and interpret baccalaureate nurses' experiences of working with adults living with SCD.

Research Question

The research question that guided this study was What are baccalaureate nurses' experiences and understanding of working with adults living with SCD?

The Significance of the Study

Nursing Education

In nursing, knowledge, attitudes, skills, and understanding are associated with the baccalaureate nurses' experiences. This research shows an alternate way of knowing that experiences are subjective and are used for nurses to construct new knowledge based on their education and skills (Sharma, 2014). While Benner (1982) articulated that learning and readiness depend on prior experience. Glassberg et al. (2013) found that the educational preparation of nurses directs the quality of care provided to the patients. As a result, educational preparedness determines the mastery of the competencies needed to complete the nursing program. Therefore, this investigator examined baccalaureate nurses' experiences and understanding of working with SCD patients to know the level of the preparedness of baccalaureate nurses who provide care for this population. The results of the study may indicate that curricular changes may be needed.

Nursing Practice

The Institute of Medicine (IOM, 2010) calls for a radical transformation of nursing education to mitigate the challenges nurses face in the changing health care organizations. For example, in the United States (US), Jenkins and Calzone (2012) implemented a genetic/genomic framework that guided the development of the baccalaureate genomics competencies. However, in Canada, genetic disorders, such as sickle cell disease, are taught without a genetic framework, which showed the gap between the nursing curricula and the advancement of genomic medicine. It is critical that Canadian nursing standards start to reflect the advances made in genomic medicine to provide quality care for patients living with SCD. Further, examining baccalaureate nurses' experiences and understanding offered personal insights that could facilitate changes in the practice settings that include care based on genetic variations.

Nursing Research

The literature review showed extensive research studies that focused on SCD symptoms management (Coleman, Ellis-Caird, McGowan, & Benjamin, 2016), caregiver support (Wesley, Zhao, Carroll, & Porter, 2016), and health care professionals' attitudes toward patients with SCD (Matthie & Jenerette, 2015). To date, no researchers have sought to explore baccalaureate nurses' experiences and understanding of working with adults living with SCD, although baccalaureate nurses' SCD education determines the quality of care provided to this population. Therefore, this research was significant to provide a new understanding about how baccalaureate nurses' SCD education affects caring for this population and add new knowledge to nursing science.

Public Policy

Canada conducts SCD newborn screening at the provincial level without any national policy. Bombard et al. (2012) stated that the goal of the newborn screening program was to decrease mortality and morbidity risks with early detection and symptoms management. Furthermore, Ontario's newborn screening policy does not show the SCD carrier status to parents without a written request (Miller et al., 2010). Therefore, nurses might be unaware of the status of the patient SCD trait at initial contact, which may lead to inadequate care. This study was significant in providing insights into baccalaureate nurses' perspectives of working with adults living with SCD. By performing this study, nurses could advocate for new policies changes that might deliver comprehensive care with psychosocial interventions.

Philosophical Underpinnings

The investigator utilized a social constructivist philosophical worldview. The constructivist’s paradigm is used to acknowledge that there are multiple realities; knowledge is subjective and constructed from the interactions with others that shaped their experiences (Creswell, 2014). Polit and Beck (2017) explained that the constructivist’s method of inquiry developed as an alternative to the objective postpositivism paradigm. The writing of Kant and Weber influenced this method of investigation (Polit & Beck, 2017). The constructivist believes that the lived experiences occur with the social contexts, and as a result, interpretations of oral and written accounts provide the meaning of the phenomena (Berg 2004; Creswell, 2014; Polit & Beck, 2017).

The focus of qualitative research is on the meaning individuals assign to their experiences within a social context (Creswell, 2014). Therefore, data from qualitative research is used to assist nurses in understanding the phenomena that affect patients and generate theories (LoBiondo-Wood & Haber, 2014). LoBiondo-Wood and Haber (2014) argued that doing a qualitative study must extend beyond "little is known about a phenomenon" (p. 89) to understand how the nature of the phenomenon affects patients' lives. Consequently, examining baccalaureate nurses' experiences and understanding of working with SCD patients has provided new insight that may facilitate curricula changes in nursing education and practice.

There are different types of qualitative research method; however, this dissertation research was compatible with a hermeneutic phenomenology research method of inquiry. Streubert and Carpenter (2011) described hermeneutic phenomenology as a research method whose purpose is to explain or interpret a phenomenon as the lived experience. Consequently, the goal of the constructivist's perspective is to examine, analyze, and interpret the subjective meanings to explain the phenomenon (Ricoeur 1976). In doing so, the constructivist's philosophical perspective grounds the hermeneutic phenomenological research design that provided insights into baccalaureate nurses' experiences and understanding of adults living with SCD.

Research Tradition

Phenomenology emerged during the 20th century from the disciples of psychology and philosophy and was rooted in the works of Brentano and Stumpf (Banega, 2012; Brentano, 1995). Brentano (1995) stated that Brentano's descriptive psychology introduced the concept of intentionality, which attributed conscious thinking to phenomena. Stumpf, a student of Brentano, is credited with improving phenomenology methods that distinguish different kinds of connections between parts that give rise to different relationships (Banega, 2012). Husserl believed that phenomenology should use a rigorous scientific method to encounter human consciousness (Streubert & Carpenter, 2011).

Although there are different types of phenomenological methods, the investigator selected the technique based on the research question. For example, descriptive phenomenology describes the lived experience while hermeneutic phenomenology seeks to understand and interpret the meaning of the lived experience. Descriptive phenomenology emerged from Husserl's work, which was influenced by Brentano and Stumpf (Matua & Van Der Wal, 2015). As a result, Husserl introduced phenomenological reduction or bracketing, which returns the phenomenon to its first awareness or essence to reduce researcher bias (Streubert & Carpenter, 2011).

Hermeneutic Phenomenology

Heidegger transformed phenomenology from descriptive to discipline for understanding and interpreting human existence (Gadamer, 2006). He created interpretive or hermeneutic phenomenology, which was further developed by Gadamer and Ricoeur (Lindseth & Norberg, 2004). The focus of the hermeneutic philosophy is on uncovering meaning in phenomena described in the written text (Laverty, 2003). Gadamer (2006) argued that our history and culture shape our existence into the world, which determines how we interpret the world. Therefore, the researcher using the hermeneutical methodologies reflects on his or her preunderstandings and biases to understand and explain the meaning of life experiences. The experiences of the baccalaureate nurse were typically the interactions that occur in clinical settings. As a result, the hermeneutic design was pertinent to this investigation, which presented insights into baccalaureate nurses' experiences and understanding of adults living with SCD.

The purpose of this dissertation study was to understand and interpret baccalaureate nurses' experiences and understanding of working with adults living with SCD. By using a qualitative hermeneutic method, the researcher embraces his/her pre-assumptions and biases to become a co-participant in the research. The investigator acknowledged that social, cultural, and historical construct shape the worldview that determines our preferences (Gadamer, 2006). Consequently, a qualitative hermeneutic method provided the critical lens needed to read, analyze, interpret, and understand the written text within the hermeneutic circle. The context for the study was baccalaureate nurses' experiences and understanding of working with adults living with SCD. As a result, a semi-structured interview guide was suitable to collect the data to provide the context of the study.

Definition of Terms

The definition of terms presented the common language used to describe the concepts in the study. The following terms were conceptually defined as follows:

1. Baccalaureate nurses are nurses who have completed a four-year baccalaureate nursing program and have been working in a three-year post hospital orientation.
2. Understanding is the perceived meaning that baccalaureate nurses' assign to their experiences working with adults living with SCD.
3. Experience is the skills and knowledge gained from working in the clinical practice or life world in which the phenomenon occurs.
4. Practice environments are the hospital units, such as acute medicine, surgical, and emergency departments, which employed baccalaureate nurses.

Chapter Summary

Chapter one described the problem and purpose of the study explored in this qualitative investigation. This chapter also exposed the gap in the literature that exists regarding baccalaureate nurses' experiences and understanding of working with SCD clients. Chapter one explained the significance of the study to nursing education, practice, research, and public policy. This chapter described the research tradition with the significance of the dissertation study. Chapter one also defined the definitions of terms relevant to the investigation.

Chapter Two

Review of the Literature

In nursing, knowledge, attitudes, skills, and understanding are associated with baccalaureate nurses' experiences. The baccalaureate nurse experiences connect directly with the level of the educational preparedness. To date, no researchers have examined baccalaureate nurses' experiences and understanding of working with sickle cell disease patients. Therefore, the purpose of the literature review was to synthesize the literature to provide the context for this dissertation study (Boote & Beile, 2005; Creswell, 2014). This investigator focused on the meaning that baccalaureate nurses assign to their experiences regarding SCD, supporting the need for qualitative research (Berg, 2004; Creswell, 2014). A comprehensive literature review was used to explore health care professionals' knowledge and attitudes in working with SCD patients. Besides, the literature review showed a reflection of the personal investigator experiences that inspired this investigation.

The Literature Review Search Criteria

An electronic literature search was conducted in the Cumulative Index of Nursing and Allied Health (CINAHL), Medline, Academic Premier, the OVID journals, and other peer-reviewed publications from government databases and nursing journals. The search utilized keywords, such as baccalaureate nurses, health care professionals, knowledge, education, attitudes, genetic and genomics competencies, and sickle cell disorders. The inclusion criteria consisted of research studies and peer-reviewed articles written in

English and completed during the period from 2010 to 2018. According to Polit and Beck (2017), research studies are conducted using a systematic method of scientific inquiry designed to answer questions or solve problems that expand knowledge. Whereas, peer-reviewed/scholarly articles are evaluated by experts in their fields to objectively assess the quality of the manuscript to disseminate knowledge (Arant Kaspar & vanDuinkerten, 2013). The studies and scholarly articles selected matched the keywords or were closely related to the keywords. The review excluded earlier studies except for research articles that were critical to the investigation. The literature review also excluded studies that focused on pediatric management of SCD.

The Boolean string of baccalaureate nurses' education and SCD yielded 11 articles; only two articles met the inclusion criteria. Replacing baccalaureate nurses with nurses yielded 56 results; after removing duplicates, five studies met the inclusion criteria and substituting health care professionals for nurses generated 79 results with nine studies meeting the inclusion criteria. The search in Ovid journals and other nursing journals with Boolean strings of genomics and nursing education, genetics and nursing curricula produced another 10 articles, and four met the inclusion criteria for this investigation. The references of selected studies produced additional articles for the review. With the duplicates removed, the literature review consisted of 28 articles.

Historical Overview of Sickle Cell Disease

SCD is a group of blood disorders that include sickle cell anemia, thalassemia A, and thalassemia B (Ngo & Steinberg, 2014). The most severe form of the disease is called sickle cell anemia, which occurs when an individual receives the two recessive genes from both parents (Ngo & Steinberg, 2014). Sickle cell anemia manifests as early as 4 months as a vaso-occulsive crisis, which occurs when the hemoglobin transforms into a crescent shape, starving the body of oxygen (Ngo & Steinberg, 2014). Having a sickle cell trait means an individual has only one defective gene and is a carrier of SCD. The severe form of the disease, sickle cell anemia, often is accompanied by a painful crisis (Lebensburger et al., 2015).

The sickling of the blood leads to other complications, such as acute chest syndrome and stroke, which increase the risk of early mortality (Lebensburger et al., 2015). Clients living with SCD often visits the emergency department during a severe, painful crisis but are often stigmatized as drug users (Jenerette, Pierre-Louis, Matthie, & Girardeau, 2015). Therefore, stigmatization SCD patients' symptoms affect nurses' ability to assess and treat SCD accurately and become a barrier to adequate care.

Health Care Professionals Knowledge about SCD Patients

With the literature review, the investigator found no studies that examined baccalaureate nurses' experiences with clients living with SCD disease, which showed a gap in the literature. The literature has exposed the need to understand baccalaureate nurses' experiences in working with SCD clients to connect these understandings with the level of educational preparedness. Kayle et al. (2016) reported that the lack of formal education for health care professionals contributed to negative attitudes towards SCD patients.

Haywood et al. (2011) and Puri Singh et al. (2016) found that one-time educational interventions changed health care professionals' negative attitudes towards SCD patients. However, Puri Singh et al. (2016) stated that older nurses exhibited more negative attitudes toward SCD patients than younger nurses. Consequently, older nurses were more likely to label SCD clients' symptoms, such as moaning and crying, as inappropriate pain-seeking behavior (Puri Singh et al., 2016). Jenerette, Brewer, Silva, and Tanabe (2016) used an SCD educational conference to increase clinicians' knowledge about the disease. They demonstrated that educating health care professionals changed their negative attitudes and drug-seeking stereotypes about SCD patients (Jenerette et al., 2016). However, Hanik et al. (2014) found no significant change in health care professionals' attitudes post educational intervention. Understanding baccalaureate nurses' experiences may help to provide consistent SCD education in the baccalaureate nursing curricula.

Health Care Professionals Attitudes and Quality of Care

The relationship between health care professionals and SCD patients affects the quality of care that shapes disease management. Freiermuth et al. (2014) found that nurses who had a higher level of negative attitudes and frustration toward SCD patients were more likely to stigmatize these patients' pain symptoms as drug-seeking behaviors. Furthermore, Freiermuth, Silva, Cline, and Tanabe (2016) suggested that factors, such as lack of understanding of the disease process and inadequate emergency protocols, contributed to the frustrations and negative attitudes displayed by nurses.

Glassberg et al. (2013) and by Jenerette et al. (2016) reported that doctors and nurses' negative attitudes stigmatized SCD clients as drug users, which led to delays in waiting time for pain medication. However, Jenerette et al. (2015) found no differences between nurses' worksites and the negative perceptions of persons living with SCD. These researchers suggested that the negative stigmatization of SCD patients occurred regardless of nurses' worksites (Jenerette et al., 2015) and showed the need to integrate SCD cultural content in nursing curricula.

Haywood, Tanabe, Beech, and Lanzkron’s (2013) used a cross-section comparative analysis study to examine the impact of race and delayed emergency wait time for pain medication confirmed the patient’s data regarding the stigma associated with SCD. Glassberg et al. (2013) also reported that race affected the attitudes of health care professionals, and Black health care professionals were more positive towards SCD clients than White health care professionals. Other studies (Bergman & Diamond, 2013; Haywood et al., 2010; Haywood et al., 2014; O'Connor et al., 2014) showed that health care professionals’ perceptions and mistrust affected the quality of care. This mistrust resulted in SCD clients labeled as “difficult patient” or “sicklers,” that often led to inadequate care (Haywood et al., 2014; O’Connor et al., 2014). Consequently, stigmatization and labeling resulting from hostile interactions affected patient care. Educating nurses about SCD may allow them to advocate for better SCD pain management.

Adherence to SCD Guidelines

Yawn et al. (2014) argued that despite the development of SCD guidelines to provide efficient management of SCD, many physicians struggled with adherence to these guidelines. Lunyera, Jonassaint, Jonassaint, and Shah (2017) assessed primary care physician attitudes toward SCD guidelines and the co-management of care with SCD specialist. They found that only 66% of primary care physicians were aware of the new guidelines, and 67% reported infrequent communication with the SCD specialist (Lunyera et al., 2017).

Azonobi, Anderson, Byams, and Schulkin (2014) showed the discrepancy between gynecologists and obstetricians' SCD guidelines and the practice policies. They showed that 19% of reproductive specialists reported insufficient training for SCD screening, 28% reported inadequate training for SCD assessment, and 39% reported lack of training on SCD treatment management (Azonobi et al., 2014). These researchers found that reproductive specialists lacked knowledge about the current SCD guidelines, which eventually affected the quality of care provided in the clinical settings (Azonobi et al., 2014; Lunyera et al., 2017). Therefore, if some physicians were unaware of the current SCD guidelines, then an understanding of baccalaureate nurses' experiences may show knowledge deficiency in the SCD baccalaureate nursing curricula.

Genetics and Genomics in Nursing Curricula

Guttmacher and Collins (2002) described genetics as the "study of single genes and their effects" (para. 3). They defined genomics as the interactions of all the genes with the internal and external environments (Guttmacher & Collins, 2002). Consequently, genomics has a broader implication for nursing interventions based on external factors that influence variations in the patient's health illness behavior. Anderson, Alt-White, Schaa, Boyd, and Casper (2015) showed that nurses lacked genetic literacy, skills, and confidence to apply genomics in the practice setting. In the United States, the American Association of Colleges of Nursing (AACN, 2008) used the Essential V11 to emphasize health promotion and illness prevention, which include genetics and genomics guidelines in the baccalaureate nursing programs. In Canada, there are no genetics and genomics competencies that govern the teaching of inherited disease, such as SCD.

In fact, in other countries, SCD education for health care professionals was insufficient. The Picker Institute Europe (2016) conducted a survey that showed only 68% of adults reported that health care professionals had enough knowledge of SCD. Eboh (2017) advocated making SCD education mandatory in United Kingdom nursing curricula to provide enough training for nurses. Conversely, Tonkin and Skirton (2013) argued that a curriculum that used a genetic framework would allow nurses to recognize the SCD symptoms and provide adequate care.

Donnelly, Nersesian, Foronda, Jones, and Belcher (2017) found that nursing professors lacked the knowledge to teach genetics and genomics content. Munroe and Loerzel (2016) also found that nursing students required the knowledge needed to incorporate genomics into clinical settings. Although Jenkins and Calzone (2014) used faculty genomic champions to increase faculty members' genetics and genomics education, these studies showed the need to evaluate the nursing curriculum to provide more focused genetic training. While Jenkins and Calzone (2014) argued that the integration of a genomic and genetic competency in nursing education may help nurses translate genetic research into the practice setting, as a result, educating nurses might reduce the negative attitudes and stigmatization towards people living with SCD.

Researcher Experiences

In qualitative research, it is essential to reflect on personal experiences to prevent bias. Drew (2006) stated that phenomenological analysis described the essence of our experiences, which stimulates the interrogative mode in which the researcher regularly queries the facts and explanations to prevent researcher bias. This investigator has worked as a registered nurse in a busy emergency department for 19 years, which stimulated her curiosity about the fragmented care provided to SCD patients. Although SCD is a chronic disease, most of focus of the treatment interventions was on the acute stage of the disease with little or no nursing responses that addressed health prevention or promotion. During this time, she has witnessed nurses' skepticism about SCD patients requests for increased pain medications.

Jenerette and Leak (2012) attributed the lack of understanding of SCD pain etiology to the absence of objective correlates. They argued that cancer pain was well-documented; predictable; and not questioned with objective correlates, such as a tumor that compressed a nerve (Jenerette & Leak, 2012). However, the unpredictable nature of SCD pain pathophysiology without visible signs and symptoms often led to suspicion about the quality of the pain (Jenerette & Leak, 2012). Therefore, enough education is needed to assess and treat SCD patients properly.

This investigator was often puzzled about the difference in the treatment of SCD to that of other chronic illness, such as diabetes miletus. For example, diabetes treatment interventions extend beyond acute symptoms management to include health prevention and promotion strategies. In Ontario, diabetes miletus specialists and nurses are educated to provide health teaching strategies that support chronic disease management. However, the focus of SCD nurses' interventions was on acute symptoms management, which lacked prevention and promotion strategies. Cystic fibrosis is another chronic genetic disorder in which the focus of the treatment interventions are beyond the acute setting to include individualized care plans, which ensures health prevention strategies. As a result, baccalaureate nurses should be educated to provide quality care that includes the chronic management of SCD.

The investigator's personal experiences led to the reflection of her practice, assumptions, knowledge, and biases regarding SCD to formulate the research question for the investigation of this research study. Therefore, the investigator examined baccalaureate nurses' experiences and understanding identified gaps in the nursing curricula that might elicit changes in the teaching of SCD.

Chapter Summary

The review of the literature showed the gap in the literature because no researcher has investigated baccalaureate nurses' experiences and understanding of working with adults living with SCD. The outline of the search criteria for the research articles/studies selection process was created. The historical overview was used to explain the etiology of SCD while the comprehensive literature review was used to explore health care professionals' knowledge, attitudes, and adherence to SCD guidelines, which provided the context for this investigation. The integration of genetics and genomics into nursing education and identified the deficiencies in the nursing curricula was also examined. The investigator's clinical experiences were the motivation for doing this research, and it resulted from the questioning of the quality of care provided to adults living with SCD.

Chapter Three

Methods

The method of inquiry for this dissertation study was hermeneutic phenomenology. The phenomenology study had an emergent design. Qualitative researchers used emergent designs to reflect and make decisions on information that has already been learned, which was critical to deriving themes from the data to facilitate new understandings (Lincoln & Guba, 1985; Polit & Beck, 2017). Polit and Beck (2017) claimed that qualitative research with one data collection point reflects the cross-sectional study design. Therefore, this phenomenological hermeneutical study used an emergent, cross-sectional design to facilitate the one-time collection of data through semi-structured face-to-face interviews.

Streubert and Carpenter (2011) disclosed that the hermeneutic interpretative framework has reflected the works of Heidegger, Gadamer, and Ricoeur. Heidegger (1962) introduced the historical and social contexts to the understanding of the lived experience. Gadamer (2006) described hermeneutics as a guiding principle used to explain, interpret, and understand the meaning of an ambiguous phenomenon hidden in the written text. Then, Ricoeur (1976) further showed that the lived experience was expressed as language and transformed into writing. Therefore, the interpretation of the meaning of the lived experience occurs from the written text (Ricoeur, 1976).

Lindseth and Norberg (2004) claimed that researchers use the hermeneutic interpretative design to interpret the meaning of the lived experience while Heidegger

(1962) asserted that reality is related to the understanding and interpreting experiences. Therefore, knowledge is a characteristic of interpreting and analyzing phenomena that question the existence in the world. This research design was an appropriate method to examine baccalaureate nurses' experiences and understanding of working with young adults living with SCD. A semi-structured interview schedule with open-ended questions guided the interviews.

The Research Design

The research design was inspired by the works of Ricoeur (1976), which was later interpreted by Lindseth and Norberg (2004). This research design was compatible with the research question and has echoed an ontological and epistemological approach to nursing practice. For example, the practice environment or the lived world has influenced baccalaureate nurses' experiences, knowledge, and understandings. Lindseth and Norbergs (2004) interpreted Ricoeur's hermeneutical approach to examine the phenomenon of interest from the perspectives of the participants within the context of their lived experiences. They further stated that the essential meaning of the event expressed through actions, narratives, and reflection promotes transcription for further interpretation (Lindseth & Norberg, 2004). Their methodological approach guided this dissertation study.

Research Design Procedures

Lindseth and Norberg (2004) used this methodology to occur within the hermeneutic circle through an interpretative series of analytic steps. Ricoeur (1976) stated that the interpretation of text begins in the hermeneutic circle in which the debate moves forward and backward through three different phases as follows: (a) the naïve reading, (b) structural analysis, and (c) interpretation.

Naïve reading. Lindseth and Norberg (2004) explained naïve reading as the initial phase of the hermeneutic circle in which the text was read multiple times to grasp the meaning of the text. During this period, the researcher must remain open to the text by switching from a natural attitude to a phenomenological approach to gain a naïve understanding of the text. For example, a natural position provides consciousness of the phenomenon while phenomenological realization moves beyond recognition to examine the text to provide new insights into the phenomenon. However, a naïve understanding of the text was crucial to structural analysis in which validation or invalidation occurs (Lindseth & Norberg, 2004).

Structural analysis. The second phase of Lindseth and Norberg's (2004) methodology is the thematic, structural analysis. The text was broken down into themes to answer the researcher's questions or broken into units, which reflect specific themes or subthemes (Lindseth & Norberg, 2004). Throughout this process, several structural analyses occur in which themes and subthemes were validated or invalidated with the naïve readings to disclose various meaning. Analysis of the central themes and subthemes were conducted based on the research question, methodology, and the context of the study. The text was read with the themes and naïve reading in mind to gain a deeper understanding of the phenomenon (Lindseth & Norberg, 2004).

This design does not allow the researcher to bracket his/her preconceptions or theories during this thematic analytical process (Ricoeur, 1976). Therefore**,** the researcher embraced his/her pre-understanding through critical reflection to gain new insights into the phenomenon. This step was used for the researcher to recognize that pre-understanding is shaped by cultural, historical, and social factors that provide the lens for critical appraisal of the text (Lindseth & Norberg, 2004).

Interpretation. Lindseth and Norberg (2004) disclosed that phenomenological hermeneutics facilitate studies that examine people's realities and possibilities. As a result, pre-understanding promotes understanding, which was formed and revised during the interpretation of the text (Lindseth & Norberg, 2004). The interpretation was two-fold. First, the researcher interprets the text to gain a deeper understanding of the phenomenon within the hermeneutic circle (Lindseth & Norberg, 2004). Second, during this process, the text also influences the researcher because pre-understanding is used for the researcher to critically examine the data and gain insight into a new reality that facilitates a new understanding (Lindseth & Norberg, 2004). Although multiple interpretations occurred, the process continues until data saturation occurs or until no new themes emerged (Lindseth & Norberg, 2004).

Research Assumptions

Creswell (2014) argued that worldview shapes the research design. This investigator employed a constructivist paradigm, which influences the research design. Crotty (2013) explained three significant assumptions of the constructivist model that are congruent with qualitative research as the following:

1. Knowledge is subjective and constructed.
2. Human beings make sense of reality through interaction within a social context.

3. A qualitative researcher constructs knowledge from interaction with participants to gain an understanding of their world.

Although these assumptions guide qualitative studies, there are a few assumptions that were specific to this phenomenological hermeneutic dissertation research. They are as follows:

1. The participants reflected and accurately portrayed their lived experiences that occur within the practice setting.
2. There are multiple realities of the lived experiences (LoBiondo-Wood & Haber, (2014).
3. The investigator used open-ended interview questions to collect data.
4. The investigator's prior understanding of the phenomenon helped to gain new insights into the phenomenon.
5. The phenomenological perspective was expressed as language and was shaped by the culture that informs the experience (Munhall, 2007).
6. Data collection continued until saturation occurred.
7. The data were broken into themes and validated with the original text to maintain credibility.

Setting

The setting for the dissertation research was Toronto Public Libraries. The researcher conducted face-to-face, semi-structured interviews at the local libraries in the private reading rooms where there was a quiet, relaxing atmosphere. In some institutions, the staff may feel threaten to disclose their knowledge and experiences (Munhall, 2007), so consequently, a neutral setting was chosen to alleviate this challenge. The local libraries were a non-threatening environment away from the practice setting, which allowed the participants to reflect and provided detailed descriptions of the phenomena.

Sampling Plan

Sampling Strategy

The sampling strategy included purposive and snowballing methods to obtain an adequate sample size. The investigator collected a purposive sample of baccalaureate nurses working in acute medicine, surgery, and emergency departments. The investigator contacted the College of Nurses of Ontario for a mailing list of baccalaureate nurses, who met the study's inclusion criteria from which the researcher selected a purposive sample. The purposive sample was used for the investigator to select participants based on the inclusion criteria, research question, and knowledge about the phenomenon. Although the purposive sampling technique has faced criticism for lack of generalizability, this method was suitable for a qualitative research design that seeks information from participants who are experts on the topic (Polit & Beck, 2017).

The investigator also used the snowballing method to recruit new participants based on the recommendation of prior informants. Polit and Beck (2017) described snowballing as an appropriate referral method for a sample selected from rigorous inclusion criteria. These strategies also facilitated demographic variation from multiple sites (Polit & Beck, 2017).

Eligibility Criteria

Inclusion criteria. Participants were baccalaureate nurses with a maximum of 3 years post-orientation experience in acute medicine, surgical units, and emergency departments. The participants were English speakers.

Exclusion criteria. Excluded from the study were participants who had prior work experience as practical nurses, personal support workers, and caregivers to SCD patients. Baccalaureate nurses who had SCD or were carriers of SCD trait were also excluded.

Sample Size

Guest, Bunce, and Johnson (2006) stated that the qualitative research sample size is determined based on the research design. Guest et al. (2006) reported that a sample size of 12 is enough to provide data saturation in a homogenous purposive sample, which might be insufficient with a heterogeneous sample. Hennink, Kaiser, and Maroni (2017) investigated code saturation versus meaningful saturation and showed that a sample size of nine provided code saturation while a sample size of 14 to16 provided more in-depth significant saturation.

However, Peters, McInnes, and Halcomb (2015) investigated nursing students' perspectives of clinical placement found that a sample size of nine was enough to provide data saturation. These studies showed that there are no specific guidelines for determining a qualitative research sample. In this study, the investigator continued the interviews until the achievement of data saturation at which point three more interviews were performed to confirm saturation. A maximum sample size of 12 was used to facilitate this investigation.

Human Rights Protection

Streubert and Carpenter (2011) explained that human rights protection is a critical part of the qualitative research process, guaranteeing that participants are informed about any undue risks associated with the study. Ethical considerations included informed consent, approval from the internal review boards, and the steps taken to maintain privacy and confidentiality during the research process. The internal review guidelines of Nova Southeastern University (NSU, 2018.) specified that interview questions might lead to an invasion of privacy.

At the first meeting, the investigator explained the purpose of the study and the risks and benefits associated with the investigation. The respondents reviewed the interview guide for any questions that the participants might interpret as an intrusion of privacy. Before the start of the interview, the investigator explained to the informants that they could refrain from answering any question that made them feel uncomfortable.

To maintain anonymity and confidentiality, the investigator asked the participants to choose codenames. The codenames were used during the interviews and stored in a separate cabinet from the audio-taped, transcribed interviews in the investigator's home office. The investigator indicated that all interviews would remain confidential. The de-identified data were coded during the analysis and stored on a password-protected computer management system in the investigator's home office. The investigator reminded the participants that involvement in the study was voluntary, and they could withdraw at any time during the study. The investigator asked the volunteers to read and sign the inform consent form.

Risks and benefits of participation. The participants received an honorarium of a 40-dollar Cineplex gift card for participating in the study. The study findings may have had an indirect benefit to the participants by providing insights into baccalaureate nurses' experiences and understanding, which might influence changes in nursing curricula that lead to changes in the practice settings.

Even though there were minimal risks associated with qualitative research, Streubert and Carpenter (2011) indicated that the researcher must anticipate that semi-structured interviews may stir up emotions and to allow the participants time for emotional support with appropriate feedback. For example, if the participant became upset during the interview, the investigator stopped the interview, offered emotional support, and if necessary, re-scheduled the interview. Although some interviewees described feelings of hopelessness, all the participants completed the interviews.

Data storage. All interviews were audio-taped and transcribed by the investigator. Copied data were coded and stored in NVivo on a password-protected computer that was only accessed by the investigator. NVivo is a software that supports qualitative and mixed method research (QSR international, n.d.). Additional backup copies of the data were stored on a password-encrypted, protected USB flash drive that was kept in a locked cabinet in the investigator's home office during the study and will be kept for a maximum of 3 years. The investigator stored the consent forms and codename key in a separate locked cabinet. The investigator will delete and discard computer files, audiotapes, flash drives, along with all paper documents, which will be shredded and discarded at the end of 3 years.

Recruitment

Upon the approval from the Nova Southeastern University Institutional Review Board, letters were sent to the College of Nurses of Ontario requesting permission to recruit participants from their membership for this study. When authorization was given to conduct the investigation, the investigator sent out invitation letters to baccalaureate nurses who met the study criteria.

Data Collection

In qualitative research, the researcher is the data collection instrument (Creswell, 2014) for semi-structured interviews. A semi-structured, open-ended interview schedule guided the interview. The investigator developed the interview schedule under the guidance of the dissertation committee members who are experts in qualitative research (see Appendix C). Once contacted, the investigator scheduled the appointments for the date and time of the semi-structured interviews. At the initial meeting, the investigator presented an overview of the purpose of the study and answered any questions the participants had regarding the study. The investigator reminded the participants that participating in the study was voluntary, and they could withdraw at any time during the study. The participants were directed to read and sign the consent form. The participants were asked to complete the demographic data sheet before the semi-structured interviews.

The one-time, semi-structured interviews lasting no more than 90 minutes were used for the data collection. After the completion of the interviews, the investigator explained that within the next 2 weeks, the investigator would contact the participants for a follow-up telephone call to confirm whether the transcribed data reflected their original ideas or perspectives. Semi-structured interviews are less rigid with probes to elicit detailed information about the phenomena (Patton, 2015; Polit & Beck, 2017). Therefore, the researcher relies on the participants' subjective perspectives, which are compatible with the research design (Berg, 2004). The investigator also used a journal to capture the participants' interpersonal cues, such as a smile and facial grimace that support contextual understanding of the question.

Data Management and Organization

The semi-structured interviews were digitally recorded using a codename chosen by the participant and transcribed verbatim into a word document. The investigator saved a copy of the data from the NVivo external folder to a password-encrypted removable disk for safe keeping in the event of a technology glitch. After the completion of all the interviews, the investigator transferred the data from the NVivo external folder to the internal folder for coding to assists the analysis. The investigator also saved a copy of the data from the internal folders to a password-encrypted removable disk for safe keeping.

Data Analysis

In Lindseth and Norbergs' (2004) method, the text undergoes the naïve reading to grasp and understand the data. Therefore, data from the nurses' interviews were analyzed and coded by conducting a line-by-line analysis of the transcribed interview in NVivo. After several readings and constant comparisons within the hermeneutic circle, the investigator coded each interview as nodes, which allowed the investigator to derive the themes for the structural analysis and interpretation (Lindseth & Norberg, 2004). The demographic data were used to examine the differences between factors, such as age, race, gender, education, and baccalaureate nurses' experiences, which affected the study findings. SPSS software was used to facilitate the analysis of the demographic data that generate the comparative tables (see Appendix E).

Trustworthiness and Integrity

Beck (1993) argued that qualitative research often faces criticism for lack of rigor; however, Lincoln and Guba (1985) proposed a framework to maintain the trustworthiness in qualitative research. Trustworthiness refers to how the researcher managed and reported credible, dependable, transferable, and truthful findings that replicate in a similar situation (Lincoln & Guba, 1985). The four criteria used to maintain trustworthiness were creditability, dependability, confirmability, and transferability (Lincoln & Guba, 1985). Polit and Beck (2017) added authenticity as the fifth criterion to enhance rigor in a qualitative investigation.

Creditability

Creditability describes the portrayal of an accurate account of the phenomenon (Lincoln & Guba, 1985). To maintain creditability, the investigator used the following techniques:

1. During the interviews, the investigator used probes to clarify the meaning of obscure responses.
2. The investigator transcribed the audio-taped interviews verbatim to represent the participants' own words truthfully.
3. During the structural analysis, the participants' own words facilitated the derivation of themes.
4. The investigator conducted members check that validated the data with the participants (Polit & Beck, 2017).

Patton (2015) explained triangulation as a technique used to increase the validity of the research findings by comparing the participants' responses demonstrated everyday experiences from multiple perspectives. The investigator used the triangulation method to substantiate participants' responses from multiple worksites and five different hospitals.

Dependability

Dependability refers to the consistency of the data if replication of the study occurs within a similar context (Polit & Beck, 2017). The investigator maintained creditability, which begins with the research design. A thorough explanation of the research methodology from the sampling techniques to the data analysis, which was used for the replication of the research with a comparable sample within a similar context (Polit & Beck, 2017). However, the achievement of dependability depends on creditability, which warrants an accurate portrayal of the phenomenon (Polit & Beck, 2017) to provide an audit trail.

Confirmability

Confirmability signifies an accurate portrayal of the data, one that reflects the participants' responses (Polit & Beck, 2017). The investigator validated the themes and transcripts with the participants to maintain confirmability. The use of quotations using the participants own words supported confirmability (Lincoln & Guba, 1985). The investigator drew from the expertise of the dissertation committee members who appraised the study procedures to guarantee that the research method was transparent and provided an audit trail to increase confirmability.

Transferability

Transferability refers to how the study findings might have meaning outside the study (Jeanfreau & Jack, 2010). The investigator provided in-depth descriptions of the research data to facilitate data analysis, which also demonstrated the transferability of the study (Jeanfreau & Jack, 2010). The transparency of an audit trail shows transferability. Therefore, transferability begins with the audio-taped, semi-structured interviews to member checks, verbatim transcription, naive reading, structural analysis, coding, interpretation, and the findings. This step was used to replicate the study with a similar sample within a comparable context.

Authenticity

Authenticity indicates how the researcher accurately describes the multiple realities of the phenomenon, which allowed the readers to immerse in the vivid descriptions of the lived experiences (Polit and Beck, 2017). The investigator used members checks to validate the authenticity of the transcribed text. The investigator provided rich descriptions of the participants' experiences and understandings in working with adults living with SCD. The structural analysis presented quotations derived from themes to substantiate the authenticity of the study. Using the participants' own words presented the heighten sense of awareness (Polit & Beck, 2017), which allowed the readers to gain an in-depth understanding of the phenomenon.

Chapter Summary

Chapter three included the study method of inquiry with an overview of the historical development of hermeneutic phenomenology. A thorough explanation of Lindseth and Norberg's (2004) research design facilitated data analysis. In chapter three, there was an explanation of the sampling plan and an outline of the human rights protection strategies. The risks and benefits related to the study and highlighted the steps taken to protect the participants during the research data collection, analysis, and storage were clarified in chapter three.

Chapter Four

Interpretation of the Findings

Chapter four presents the description of the sample, the interview schedule, and the interpretation of the findings. The data described baccalaureate nurses' experiences and understanding of working with adults living with SCD. The data showed how these experiences and understandings generated insights that affected the quality of care provided to adults living with SCD. A one-time, semi-structured, open-ended interview was used to present the perceptions of each participants.

Description of the Sample

A purposive sample of 12 participants who met the inclusion criteria volunteered to participate in this study. The participants worked in five different hospitals in medical, surgical, and emergency departments. To maintain confidentiality, each participant used their pseudonyms to complete the demographic data sheet and during the semi-structured interviews. Table 1. displayed the characteristics of the participants.

Table 1.
Demographic Characteristics of Study Participants

Gender	Age Range	Experience	Ethnic/Racial Identity	Level of Education	Nursing Specialty
F	22-30	18 < 2yrs	Asian/Pacific Islander	University Degree	Surgery
M	22-30	2 < 3yrs	Latin/Hispanic	University Degree	Emergency
M	22-30	2 < 3yrs	Asian/Pacific Islander	University Degree	Emergency
F	22-30	2 < 3yrs	Caucasian	University Degree	Surgery
F	42-50	2 < 3yrs	African Canadian	University Degree	Medicine
F	32-40	2 < 3yrs	African Canadian	University Degree	Medicine
F	22-30	2 < 3yrs	African Canadian	University Degree	Medicine
F	22-30	2 < yrs	African Canadian	University Degree	Medicine
F	22-30	2 <3 yrs	Indian Canadian	University Degree	Medicine
M	22-30	1 < 18m	Asian Pacific/Islander	University Degree	Emergency
F	22-30	2 < 3yrs	Other	University Degree	Medicine
M	22-30	2 < 3yrs	Indian Canadian	University Degree	Emergency

The investigator used SPSS to analyze the sample and compare the descriptive statistics that generated frequency tables and found that 66.7% (*n* = 8) of the sample comprised female participants and 33.3% (*n* = 4) male participants (see Appendix E). Comparison between the participants' age range presented that 83.3% (*n* = 10) of the participants were between 22 and 30 while the remaining 16.7% (*n* = 2) were between 31 to 40 and 41 to 50.

Thirty three percent (*n* = 4) of the sample were African Canadian, 25% (*n* = 3) Asian/Pacific Islander, 16.7% (*n* = 2) Indian Canadian, 8.3% (*n* = 1) Caucasian, Latin/Hispanic, and the rest belonged to the category of Other (see Appendix E).

Fifty percent (*n* = 6) of the sample worked in medical units, 16.7% (*n* = 2) in surgical units, and 33.3% (*n* = 4) in emergency departments. The participants who worked in emergency departments were male nurses; 83% (*n* = 10) of the participants had more than 2 years of nursing experience while 16.7% (*n* = 2) less than 2 years of nursing experience (see Appendix E). All (*n* = 12) the participants of this study were baccalaureates of a four-year university nursing degree program.

The Interview Schedule

A semi-structured, open-ended interview schedule developed by the investigator guided the interviews of each participant. The interview (see Appendix C) comprised four primary questions to understand baccalaureate nurses' experiences of adults living with SCD. Although each interview began with the initial question, the researcher used probes, which guided the interviews based on the responses of the participants.

Interview Questions Analysis

Twelve semi-structured interviews generated themes and subthemes within the hermeneutic circle for interpretation. During the analysis, after constant, sequential comparisons, several nodes were created in NVivo. Further analysis within the hermeneutic circle produced four themes along with their subthemes, which made up the conceptual framework to interpret the findings (see Table 2).

Table 2

Conceptual Themes and Subtheme

Themes	Subthemes
Experiences with SCD	Worksites and pain management
	Lack of knowledge about treatment plan
	Building relationships
	Advocacy
Baccalaureate Nursing Curriculum	Inadequate pathophysiology SCD preparation
	Insufficient understanding of genetics/genomics and SCD
Nursing interventions	Positive factors
	Negative factors
Patient education	Lack of resources for SCD patient education
	Limited SCD knowledge about health promotion/discharge planning strategies
	Limited knowledge about SCD research

Theme One Experiences with Sickle Cell Disorders

Baccalaureate nurses' experiences were critical to the research question that sought to understand baccalaureate nurses' experiences and SCD. The participants of the study shared their experiences with sickle cell anemia, which varied depending on the participant's worksites. All the participants disclosed that their initial encounter with SCD patients involved symptom management regardless of the worksite. Julie recalled,

> My experiences working with those with sickle cell disease. I find that they require, I guess, a lot of attention in terms of pain management because unless you have sickle cell, you don't really know how painful it is. So, it's more like you are trying to keep them comfortable and trying to manage their pain in–or trying to give them pain medication in a timely manner.

Roger reiterated similar encounters, "Not often did I see them, but when I did, it was fairly severe and crisis." Panteleon confirmed similar experiences:

> Yeah, I have had a lot of experience, both as a primary nurse being in charge on a floor with multiple adult patients and being the first responder to go help patients in terms of pain management and like multiple complications arising out of their diseases.

As a result, the following subthemes emerged that were crucial to interpretation and understand these experiences: (a) worksites and pain management, (b) limited knowledge about the treatment plan, (c) building relationship, and (d) advocacy.

Worksites and pain management. The participants agreed that their experiences with SCD patients were associated with acute symptoms of management of sickle cell anemia regardless of the worksite. They found the treatment intervention to mostly focus on pain management, which formed their perspective to care for this population. The three main worksites were medical units, surgical units, and emergency departments. The two participants who worked in different medical units described their experiences with SCD. Sam stated,

> We have a quite a few on our floor; most of their experiences are quite the same. They come in with a lot of pain, and we give hydromorphone pretty much around the clock; you are always going in giving pain medication.

Kelly reiterated similar experiences, "My experiences are we always have these people in our units, each of them requiring I believe not so much care like physical care; the primary intervention involves pain management and symptom management." Nicole felt that although pain management is the primary focus of nursing intervention, some SCD patients may be abusing the system. She said,

> I guess majority of the patients come in on a medical unit. Some of them are generally in pain and others might kind of take abuse of the system in terms of abuse of pain meds and don’t want to leave.

The participants who worked in emergency and surgery also indicated that all their experiences involved acute pain and symptom management. Pantaleon said,

> These patients that are in sickle cell crises are still walking and talking. To the regular eye, it does not seem like they are in a sickle cell crisis. They usually look fine. However, from a subjective standpoint, they are in 10 out of 10 pain. We usually provide quite heavy pain medications, such as Dilaudid, at high dosages. I would say it doesn’t work all the time.

Monica recalled most of her experiences were with young adults, “most of them are young adults. The major complaint is pain, not so much oxygen issues; they usually don’t have any breathing issues, but pain.”

The participants’ experiences were limited to sickle cell anemia, which is often characterized by painful episodes. They also indicated misconceptions about giving increased dosages of pain medications. Lee disclosed,

> I would say that there are some physicians that would say that even with the amount of medications we are giving them, the pain is more subjective than objective than, actually, what’s going on with the patient. I find it hard because I think what I’ve learned about sickle cell is that their pain is real and even though it seems that nothing is going wrong or they are not in 10/10 pain that they are having a real pain that needs to be treated. It’s hard because there are some physicians, that I can think of that see it as

> more of a psychological pain rather than what they are actually experiencing.

Subsequently, there are often misunderstandings regarding SCD patients' pain medication that lead to indecision during their nursing care. Kathy expressed how she struggled with giving pain medications to an SCD patient.

> She came crying obviously in a lot of pain. She had pain, her dosage for Dilaudid q1 or 2hr IV. I was a bit nervous because I have not given so much pain meds. I was bit nervous about it for given too much pain. She had sickle cell disease her whole life, but it was not controlled. I was a bit nervous because I had not given so much pain medication. I was scared that given too much would hurt the patient.

The quality of care begins with how nurses perceive their patients; this perception forms the basis of the nursing assessment. Therefore, when nursing interventions only focus on acute symptom pain management without psychosocial interventions, very often, it leads to misconceptions and uncertainty when providing care to patients presenting with SCD.

Lack of knowledge about treatment plan. Nursing education and clinical settings present the knowledge that inform the nurses how to provide care for patients with SCD. Some of the participants expressed their frustration when caring for SCD patients. Kathy recalled, "Honestly, I didn't know much and when I worked with sickle cell disease patient; it was the hematologist who told me to focus on giving pain medication on time and to focus on pain management, oxygenation, and hydration." This statement is implying that the baccalaureate nurse was not prepared to work with a post-surgical SCD patient. Minnie stated that she was not prepared to work with SCD patients on a medical unit.

> There is a gap between what I am taught and what I have seen in the hospital because there is not a lot being taught in school and I have to pick it up as I go along based on caring of these patients and other nurses who care for these patients.

Kelly described the gaps in the curriculum.

> Usually, it is up to the nurses to gain more knowledge through the experience working with patients, like they touch on sickle cells, saying that it is genetic, and how to manage it through hydration, pain meds, and folic acid. But for the most part, they just touch on it a little bit in the nursing theory.

While, Monica acknowledged that some SCD patients are aware of their treatment plan and explained “We have worked with them on a medicine floor, and these patients know about their disorders; for example, they know their IV pump rates for medication.” Whereas, Lee stated the inadequacies in the discharge planning process, which leads to multiple admissions.

> The health risks that we always talk to these patients about is always the first signs of pain. You need to go back to whoever your health provider is. Often, when I talk to these patients, they will tell me well. My health care provider says when it gets bad and the pain medication is not working, then you go to the ER. I think there is a gap in that kind of process because we send them out and they don’t really get the follow-up they need, and

> they are just right back to us or, the follow-up that they have is just go back to the ER to get admitted to the medicine ward.

The participants exposed the need for comprehensive education with nursing including individualized care treatment plans that addressed both the acute and the chronic aspect of SCD.

Building relationships. The quality of the patient outcomes is affected by the nurse-client relationship. Building relationships is one of the core influential subthemes according to the experiences of baccalaureate nurses who worked with adults diagnosed with SCD. The participants explained that building a relationship is essential to providing compassionate nursing care. JoJo disclosed the following:

> For me, it's important for you to understand how it works because, that way, you will be a little bit more compassionate to an individual who is going through a crisis, right? Because once you understand what is happening in their body, you know you will try to help. You don't know because in school it is about pain seeking that you know, but understanding is very, very important because that will bring more compassion.

Subsequently, building relationship begins with communication that helps nurses understand their patient's point of view. Lee discussed how communicating with SCD helped validate patient experience,

> I remember sitting there with the patient, and this is my first or second time meeting this patient. I was putting an IV in for this patient. I was just talking to them and, I found out, and this was very early on in that shift,

> that the previous nurse didn’t talk to the patient. We talk about pain management, and we talk about pain assessments—you have to communicate to understand the patient. It didn’t seem like anyone talked to that patient or educated them. They didn’t take the time to, actually, talk to the patient. It wasn’t thorough. It didn’t seem like they really regarded the pain as real. The patient felt very neglected. Even though they attempted the IV, it didn’t feel, for the patient, as if they were receiving any care.

Although some nurses focus on getting the task done, communication is necessary to engage with the patient and build respect and trust. Roger agreed that the nurse-patient relationship can determine the quality of care. Roger stated,

> I think there is a big category with one kind of group of nurses that do want to have the best care and will approach these patients like I said before the pain medication is due and do assessments and things like that. There is another group that is, totally, the opposite. I think they have a big stigma and say, just put them out of the room, and they’ll ask for pain meds. They are the ones that really don’t interact with the patients a lot.

While, other participants agreed that therapeutic relationships are an integral part of providing comprehensive nursing care. Sam disclosed, “I usually try to form a relationship with them because they are usually younger patients and I get along with them. I can talk to them about stuff like music.” Harold used the therapeutic relationship to comfort their patient. Harold stated,

> Providing a good nurse-to-patient relationship, I think, that's great in itself. I think it's clear that the care they get sometimes isn't the best; so, talking through it is a positive to them. So, I think that therapeutic relationship is good; even with the pain, you can see a change in their pain level.

Overall, the participants realized that the nurse-patient relationship is crucial to their perspective of adults with SCD.

Advocacy. All participants believed that advocating for the patient is essential in improving pain and symptom management. Sam reported,

> Usually, I give the pain medication as ordered. I also advocated for my patient. I will call the doctor and tell him that the pain medication is not working so that they can come and re-assess them. I would help to advocate for laxative because they might be constipated because they are on hydromorphone. I will ask the doctor for the acute pain service team to come and assess them.

Lee used advocacy to reduce the waiting time in an emergency department.

> You try and get to them as quickly possible because they're obviously in pain. That is the crisis that's an emergency. So, I mean, it's advocating on their behalf, letting physicians know, getting quick verbal orders. Yeah, intervening as soon as possible in terms of inserting an IV, getting IV medications, and kind of ruling out the emergencies.

Kathy explained the importance of family advocacy for SCD patients.

> Family support is needed to advocate for patients with sickle cell because most of these patients are born with this sickle cell disease throughout their life. And for this particular patient, she was now a mother, and her husband were supportive. He knew a lot about the disease, much more than I did, and he advocated for her.

All the participants indicated that their work sites, knowledge about patient treatment plans, building relationships, and advocacy influenced their perception of their patients and their experiences of working with adults diagnosed with SCD.

Theme Two Baccalaureate Nursing Curriculum

All the participants shared how the nursing curriculum affected their understanding of SCD. The participants disclosed two essential subthemes that were critical to their understanding of SCD. The subthemes were educational preparation and understanding genetics.

Inadequate SCD pathophysiology preparation. The participants indicated that an inadequate SCD education can lead to a lack of understanding in clinical practice. They recalled incidents that supported the theme of education preparedness. Nicole stated, “I would say not in depth, a little bit, we did not spend a lot of time on sickle cell, not an entire lecture. We just had one or two slides or reading about it for curiosity.” While, Monica described her introduction to SCD lecture in the form of a question, “The teacher just asked, or a professor asked, what do you do when you have a patient that has sickle cell? How do you treat them? And it was oxygen and pain medication.” Yet Minnie reiterated that insufficient education affected her understanding of SCD.

> I wouldn’t say completely because from what I can remember, we didn’t really have in-depth lecture or anything on patients with sickle cell

> disease. And I think our physiology class may have talked about it briefly in one lecture, like the physiology class about how it comes about and the sickle cell shape of the red blood cells and what sickle cell disease means. And then, I think, we had another lecture in one of my other classes about, like, nursing management of patients with sickle cell. And, like, there's the consideration to look for and basically, there would be a nursing plan of how it would manage patients with sickle cells disease. But it wasn't very much in-depth.

Lee who worked in an emergency department, which is the initial point of contact for patients, repeated similar inadequacies in the SCD curriculum.

> In terms of, actually, courses or anything like that, no, there are no extra courses that we've taken. There are no specific in-services that we provide for sickle cell crises; we do have these small educations; however, there are no classes or anything like that in terms of pain management.

Kathy recounted, "My education was very theoretical explained what is sickle cell disease and what you do in a crisis with the focus on pain medication and hydration. It was very brief, and it was not taught thoroughly." All the participants agreed that they were deficiencies in the SCD curriculum. Panteleon indicated the following:

> I feel like our education from a nursing perspective is mainly geared towards that of the acute care. So, I think, it is obviously a population that is very stigmatized and pigeonholed to just the crisis situation; when practicing, there is probably a lot more.

Teaching SCD with a focus on acute care showed gaps in the curriculum, resulting in a misunderstanding. Nicole recalled, “I was never taught in college nursing school how to deal with sickle cell disease patients.” While, Lee indicated the deficit in the SCD curriculum,

> No, we were taught what sickle cell was and what sick cell crises are, but beyond that, no. There’s not much that school really provided. If anything, it’s more our own education to look more into those things. There are no specific programs to tell us the treatment and management of different things; however, I think, it’s very clear that everyone’s teaching is so vague.

Overwhelmed, the participants felt that the nursing curricula did not provide an in-depth understanding of this inherited SCD.

Insufficient understanding genetics/genomics. Guttmacher and Collin (2002) described genetics, which is the study of the genes and genomics as the interaction of genes between the internal and external environment. Most of the participants knew that SCD is an inherited blood disorder. However, they did not fully understand the significance of genomics when caring for patients diagnosed with SCD. Kelly stated, “I don’t know if we learned anything aside from the fact that there is genetic components, and it’s an inherited disease. But we didn’t go super in-depth in terms of the curriculum.” Julie described similar response, “They touch on sickle cells, saying that it’s genetic and how to manage it through hydration, pain meds, and folic acid. But for the most part, they just touch on it a little bit in the nursing theory.”

While, Kathy, acknowledged her education was not focused specific to SCD.

> My education did not speak about genomics. I remember that our intervention was not only geared to sickle cell disease; it was geared to any patient who had surgery or required pain medication. We were taught in school about sickle cell disease as an adaptive response to malaria. We were taught if you had the full-blown recessive genes, you are more likely to form clots.

The statement indicated a theory-practice gap because genomics affects how the SCD patient copes with pre-surgical and post-surgical interventions. The participants' responses continued to disclose a lack of knowledge in teaching SCD. Roger recounted, "We never talk about genomics." Nicole reported, "I can't remember anything about genomics and anything like that." Harold recalled the following:

> I didn't know thalassemia A and thalassemia B are what you call it, I guess, part of sickle cell disorders. But I know for sickle cell, I know if one strain has the trait, another strain has the trait, the chances or likely the child can end up with sickle cell

Roger disclosed, "I don't know; I can't tell you the difference between the trait and just anemia itself." Sam recounted, "My SCD education was very brief, and we did not go into the difference between sickle cell disorders our focus was on sickle cell anemia crisis with the focus on what it is and on pain." Julie also commented on the deficiencies in the nursing curriculum.

> There is a gap between what I am taught and what I have seen in the hospital because there is not a lot being taught in school, and I have to pick it up as I go along. Based on caring of these pts and other nurses who

care for these patients.

Although most of the participants knew that sickle cell anemia is an inherited disorder, some lacked the knowledge regarding the differences between the sickle cell anemia and the less severe form of the disease. Monica recounted,

> They try and go through the difference between sickle disease and sickle cell trait in school. But I think, the therapy, the alternative therapies are just generalized for everybody for pain; not so much for specific to sickle cell. And, then, when you get to hospital, you are not going to see that; you're just going to see the pain medication.

Kathy repeated similar perspectives as that of most participants.

> I do know that there's a defect in the hemoglobin and that changes the shape and people coming with severe sickle disease crisis. I did not know that thalassemia A and thalassemia B are a part of sickle cell disorders. I only learned that now that you mentioned it. We did not touch on that in school. I know that sickle cell trait means that you have the recessive gene and you're the carrier. I also know that when you have two of the recessive genes, that's when you are full-blown sickle cell anemia, can you come in with a crisis.

Panteleon was the only participant who knew about the less severe form of SCD. Panteleon recalled, "I know that there is kind of multiple kinds of sickle cell disorders, that it's not just sickle cell anemia, but my primary experience will be sickle cell anemia and sickle cell crisis." All the participants indicated deficiencies in the teaching of SCD in the nursing curricula.

Theme Three Nursing Interventions

Nursing interventions referred to nursing care provided to patients. The quality of nursing interventions determines the success of patients' outcomes. The participants discussed factors that produced positive outcomes for patients diagnosed with SCD. The participants of this study already confirmed that most of their nursing interventions focused on acute care. These factors affected their care, either positively or negatively.

Positive factors. The participants reported that the goal of their nursing intervention was to make the patients feel as comfortable as possible and identified the following five positive factors that enhance the quality of care: (a) timely pain response, (b) nurse-client relationship, (c) nurse expertise, and (d) supportive alternative care.

The response to pain was crucial to positive outcomes to both the nurse and the SCD patient. This subtheme was evidence based on the account of the participants. Julie indicated, "I try to manage their pain because when their pain is not well managed, they tend to start lash out; I guess like that is expected when patients are experiencing pain and the pain is not managed." The pain response become the primary focus to make the patient feel comfortable. Nicole commented, "Just really patient-centered care, managing the pain, the symptoms try to get the pain under control." Jojo explained that knowing the differences between age-related response to pain is significant when providing care to SCD patients. Jojo reported,

> With the younger patient, nurses tend to believe that they are sleeping; but they know how to deal with it; they know how to deal with the pain; the older adults tend to show more pain and to express the pain much more and

> more likely to get upset if the pain meds are not working or the pain medication is not there when they want it.

The participants indicated that the age-related responses to pain contributed to successful outcomes.

The nurse-client relationship is significant in determining the quality of care given to SCD patients. Kelly claimed that once the pain becomes tolerable, the next stage is to build a therapeutic relationship. “I give the medication on time and, then when they are more comfortable, I try to build a relationship with them.” Building a therapeutic relationship assists the nurse to advocate on behalf of the patient. Lee also reported, “Providing a good nurse-to-patient relationship, I think, that’s great in itself. I think it’s clear that the care they get sometimes isn’t the best, so talking and getting to know them help to advocate for them is a positive.”

Harold disclosed that learning of their history is a positive factor when caring for SCD patient.

> If it is in the system that they suffer from sickle cell, usually the nurses are fairly good to take them at their word, even though that shouldn’t be the case. But in reality, it is when people come in, there is a tendency to be jaded.

Other positive factors include nursing expertise and supportive care. Having a nurse who is an expert in a particular skill will facilitate faster care to a patient diagnosed with SCD. Lee reported,

> I think 90% of nurses that try to do IVs on these patients, 90% of them fail. Thank God, I am okay at IVs; so, usually, I am the one that goes in and puts

> the IVs in these patients, and it is a great feeling because the reality is they never get a good IV. Usually, it is 10 pokes–poke, poke. So, that's already a good feeling for me, getting a good IV in the hand.

Another positive factor found that enhance the quality of care for SCD patients was providing supportive care. Monica indicated, "I know sometimes repositioning helps if they are having pain. Maybe, for back pain, you may want to reposition them or go another therapy like provide cold compress to whatever body part is hurting." Kelly described alternative therapy used to provide comfort care. Kelly stated,

> Comfort care is something that I would provide for them. Now, sometimes, they are not hungry because of the pain. You might encourage them just to have sips if they are just not feeling well—sips of water. If they are in crisis, sometimes, they do need a lot of comfort and someone to check in on them.

Other participants indicated effective pain management techniques, such as frequent pain assessment and effective time management skills to increase the quality of care for SCD patients.

Sam reported, "I usually give the patient the pain medication as ordered. I would usually ask him where the pain is coming from before giving the pain medication, and I asked them are you sure you need more medication right now." Nicole stated "If they need it, they need it, and I give it. In terms of my workload, I have to manage my time more efficiently." The participants recognized nursing interventions that facilitate positive outcomes for SCD patients involve much more than managing acute pain symptoms.

Negative factors. Negative factors detract from the quality of care provided to patients presenting with SCD. The participants reported that nurses' attitudes and stigmas diminished the care to people presenting with SCD. Nursing attitudes can be negative or positive. Harold recalled, "I usually don't see any difference of treatments or attitudes; it is a chronic condition. They are usually triaged on a lower task level. I think it is because it is not a life-threatening disorder." However, in an emergency, to triage a patient in an SCD crisis in the acute phase of the illness becomes a negative factor. Triaging patient at a lower level increases the waiting time for pain medications and reduces the quality of care for the patient.

The nurse's perceptions of the patient response to pain may impact the quality of care. Sam reported,

> It is very depressing giving so much pain medication, and it is not even working and, sometimes, these patients are seen as drug seeking. On the other hand, we have this patient that nurses might say see that she doesn't look like she is in pain, but she is in pain, but she is always asking for pain medication, so often, all the time. It seems like it is a lot of work going back in and out of the room given pain medication every 30 minutes; they are always asking for pain meds when they are in the hospital.

When the patient behavior is seen as drug seeking that increases the nurse workload because of the time spent administering pain medications. Patient pain response can be labeled as drug seeking, which results in longer waiting time for pain medications. Julie reported,

> When they come with pain or in a crisis, there is, I remember, this one patient we had. She had sickle cell that ran in her family, and she was a frequent admit, and mostly, nurses would take a while to give her pain meds; it would take a while to give her the pain meds because they think, you know, she is drug-seeking; she is always calling for her pain meds and everything else.

These comments indicated that patients who are seen negatively in a crisis are often stigmatized as drug seekers and have to wait longer for pain medications.

Harold also indicated that the patient's pain behavior might be seen negatively. He stated, "I think that some of the stigma that are attached to the behavior because they have so much pain medication that they are taking is that they are becoming addicts, drug addicts." According to Panteleon, the patients who called frequently have to wait longer for pain medications. Panteleon reported,

> But I know the attitude towards them upstairs on the medicine floor is that "Oh, I don't want to have the sickle cell patient because they're very needy, or there's a lot to do for them versus having other patients." Because, again, oftentimes, they're given pain medication very frequently; they're calling you to the room for these pain medications.

The participants indicated other stigmas apart from drug-seeking associated with SCD patients. Some of the stigmas used to label the patients are "needy," "difficult," and "frequent flyer." Minnie indicated,

> There are stigmas that are attached to people calling for pain meds a lot. Not me, personally, but some nurses when a patient tends to call a lot, they

> tend to, I guess, answer them less not less frequently, but not in a timely manner because, you know, they think they are too, what's the word I am looking for? They are too needy.

The labels that portrayed SCD patients negatively changed the attitudes of some nurses. Julie reported,

> Most nurses try to label them as a problem patient; so, once the nurses, they tend to label a patient as a problem patient, and once a patient is labeled as a problem patient, it is not the just that nurse, but this is pass this on in report to another nurse. When all the nurses notice that or they hear that patient is a problem patient and their whole attitude changed before they even meet the patient.

Again, negative attitudes may reduce the quality of care for SCD patients. A patient who as multiple admissions for SCD crisis may be seen viewed negatively by the nurses. Nicole acknowledged this concern, "When the patient comes into the unit, some nurses will say all right, great she is just here seeking drugs, or some will say here is another frequent flyer." A frequent becomes a labelled used to negatively portray the SCD patient.

The participants suggested fear of respiratory depression as another reason for making the nurses feel the need to delay administering pain medications to SCD patients in a state of crisis. Monica suggested,

> I worry about safety. Well, that's one thing. See, you have to worry about safety. That's something you can't deny that narcotics can be; they can cause respiratory depression, right? That has to be a concern. Now, what

> those nurses may do is use that as an excuse not to give the patients the medication that frequently.

Sam echoed similar sentiments regarding the fear of administering excessive pain medication, “It is a lot of work and I don’t want to get them drowsy and I don’t want to cause an overdose. Sometimes, even when you get the pain medication, q 30 minutes, the pain medication is not working.”

However, there were participants who had not encounters any negative attitudes toward patients diagnosed with SCD. Roger disclosed,

> I haven’t found any negative attitudes. Sometimes, I think, nurses get a little bit afraid because they don’t see it as often. And the physicians do put in the orders that there is no stop on their pain control; that they keep going until the pain is kind of relieved. And sometimes, I find nurses do not follow through completely on those orders and try to be overly safe with their dosages. The nurses’ fear becomes a factor that decreases the quality of care.

Kathy also stated, “I have not seen a lot of sickle cell disease patient and in surgery. I have not seen any attitudes towards patient with sickle cell disease.” The participants in the emergency departments and medical units indicated that nurses’ perceptions can affect the quality of care provided to SCD patients. Only in the surgical units, the nurses’ perceptions of SCD pain did not negatively affect the care provided to this population.

Theme Four Patient Education

For most chronic disorders, such as asthma, diabetes, and cystic fibrosis, health teaching prevents exacerbation of acute episodes. SCD is also a chronic disorder, and the participants acknowledged health patient education as one of the significant themes during the interpretation of the data. From patient education, the following three subthemes emerged: (a) health promotion, (b) health care experience and people of color, and (c) SCD research.

Limited knowledge about health promotion strategies. Most of the participants indicated that health promotion strategies were scant or non-existent when providing care for SCD patients. Jojo said,

> To be honest with you, I would say no. There is not a lot of materials on our discharge regarding SCD. There is more on hypertension, diabetes and, maybe, chronic kidney disease. But there is not much literature that I have to support me in giving that proper health teaching to SCD patients. So, I'm sorry, no, I don't do a lot.

Harold had similar views regarding insufficient education to provide adequate health teaching to SCD patients,

> Listen, this is what I was taught in school, and I usually tell them to basically follow the medication regimen. I also will tell them to recognize the symptoms that are life-threatening, such as any kind of chest pain or shortness of breath. Usually, if they are being discharged from ER, the ER physician who do the health teaching and that is my experience where I work.

Monica continued to repeat that curriculum deficiencies are responsible for lack of knowledge regarding patient education and health promotion strategies for people presenting with SCD. Monica recalled,

> Yes, I think so; but the nursing school must play their part. Nurses must know that information to back that up I have never seen it (health teaching/genomics), and it was not taught in school. We don't have that information; so, in regard to that, I think that we are failing in terms of health teaching or health promotion when our patients are being discharged with sickle cell disorder.

Kathy disclosed, "The focus in a surgical unit would be on pain medication is general surgery—it's about pain management. There were no specific nursing intervention gears towards discharge planning the focus was on general surgery in the acute setting."
Sam also shared similar comments regarding patient education and SCD. Sam indicated,

> SCD wasn't the main topic in nursing education. I only learn about this disease on the job, not in school. I learn about sickle cell disease on the job; there no intervention that support health promotion There were no health teaching about health promotion for SCD in school.

These views resonated from most participants about SCD and patient education.

Although most of the participants had no formal education to provide health promotion strategies to SCD patients, some made use of general discharge teaching, which was applicable to SCD patients to provide health teaching. Kelly disclosed, "But the one thing I would tell them when they are being discharged is to stay hydrated, right, and to stay away from contact sport[s]."
Julie suggested patient education may help decrease the re-admission rate. She said,

> I think the thing is that if there is a lot of health teaching with sickle cell anemia, patients wouldn't need to be re-admitted so many times. Just like, you know, with diabetes. If the patients are not being taught properly, they'll be back in because of the side effects for the poor diabetes management. Like, you know, diabetic ulcers and uncontrolled blood sugar and things like that, and the same thing apply to sickle cell patients in order to decrease the rate of re-admission.

Sam used the general non-specific hospital guide to assist patients with SCD, "No, not in school, not really. I usually follow hospital policy regarding discharge planning or health teaching. I would give them their prescription, then follow-up appointment, the paperwork, and referral, if there is any." However, Lee indicated that he used lifestyle factors to conduct informal health teaching. Lee stated,

> Lifestyle factors in terms of avoiding stress, sleeping well, taking medication as needed, coming to emerge or seeing your family physician, whatever the case may be when you suspect that something is going on kind of in the early stages.

Overall, the participants recognized the gaps in the curriculum regarding patient education and health promotion strategies for SCD patients.

Lack of resources towards SCD patients' education. Three participants acknowledged the disparities in the health care system and the people of color. Panteleon stated,

> Not really, no health teaching. Not that I can think of any way off the top of my head. One thing I think that isn't really discussed really is that it's

> primarily a disease in population in terms of like people of color. And I think that's another thing that doesn't get discussed is how health care kind of differs for people of color and their experience in health care. I think that is something, that surprisingly in my experience and that, a lot of physicians are aware of, a lot of the physicians in my emergency department.

Sam stated that the deficiencies seen in the teaching of SCD were because SCD affects mostly African Canadian[s]. Sam reported,

> No, I don't think so; the reason why I don't know about health promotion. I don't think a lot of money or time is spent on this disease; to be honest, I am not surprised cause this disease I think affects mostly African Canadian[s], and it wasn't a focus in our nursing education; I am not shocked about it, I am sad.

Monica reported that the lack of patient education associated with SCD was because this disease mostly affects African Canadians. She disclosed, "Well, sickle cell disease is an African Canadian disease, so there is the genetic part of it, but they do not provide health teaching around genomics nothing about that." These participants reported that the teaching and treatment of SCD disease reflected the disparities in the health care for people of color.

Lack of knowledge about SCD research. In Canada, there is hardly any nursing research about SCD. In fact, Sam disclosed, "I know it is most prevalent in, of, African descent; I really don't know the statistics on SCD." Julie proposed the need for more research on SCD. "I guess research has to be done on sickle cell anemia, the trait, and the management just so they can better prepare us in nursing school for when we are in the real life.” The participants acknowledged that the nursing curriculum shaped their experiences and understanding of SCD. Therefore, adequate education was needed to facilitate comprehensive care to a chronic disease, including health promotion and prevention strategies.

Graphic Depiction

A graphic depiction of the four themes and subthemes central to baccalaureate nurses’ understanding and experiences with SCD is illustrated in Figure 1. Each of the core themes and subthemes are central to understanding SCD connects to educational preparedness in the baccalaureate curriculum.

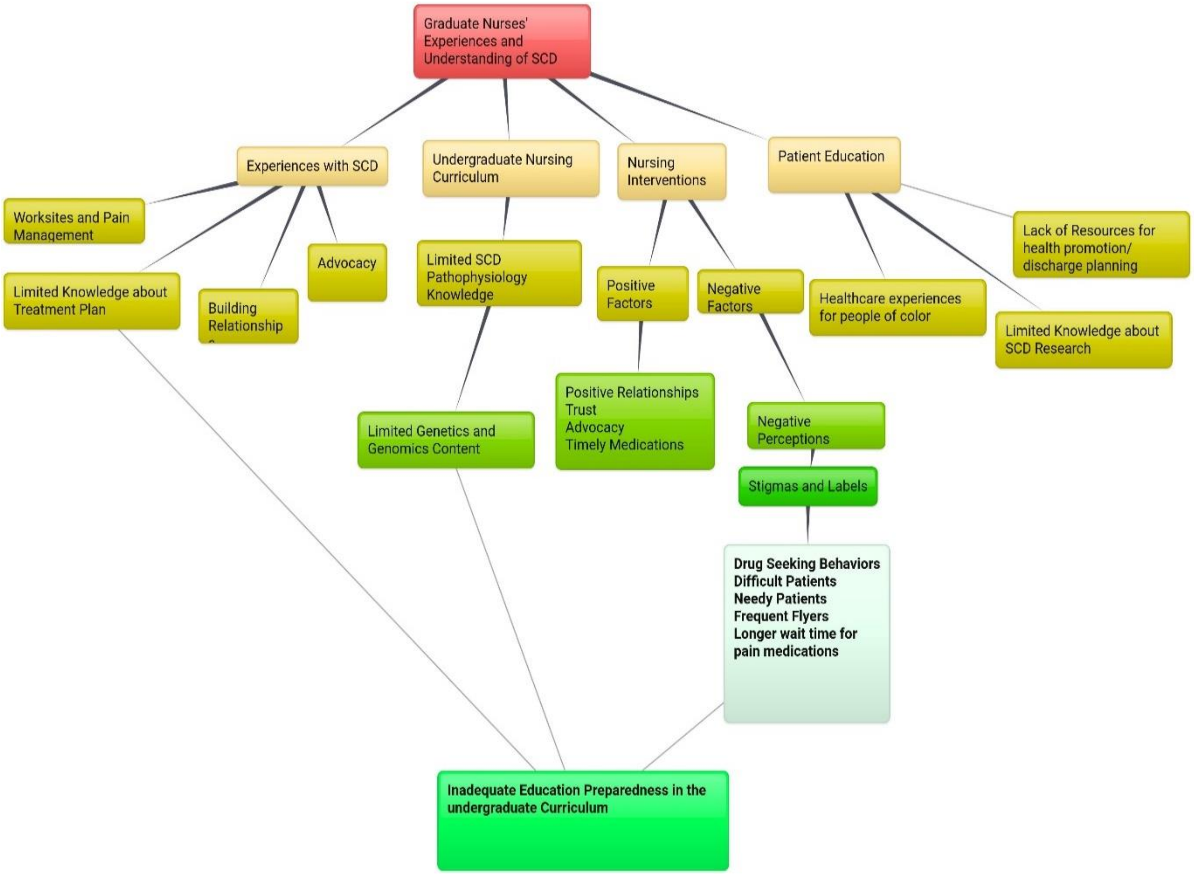

Figure 1. Themes and subthemes associated with educational preparedness in the baccalaureate curriculum. The figure represents graphic depiction of themes and subthemes associated with educational preparedness in the baccalaureate curriculum.

Chapter Summary

Chapter four presented an interpretation of the findings of baccalaureate nurses' experiences and understanding of working with adults living with SCD. Semi-structured, open-ended interviews were used for the 12 participants to describe their experiences and understanding of working with adults presenting with SCD. Lindseth and Norberg's (2004) qualitative hermeneutic design was used to facilitate the interpretation of the data. The four major themes identified were experiences with SCD: baccalaureate nursing curriculum, nursing interventions, and patient education. Most of the findings were associated baccalaureate nurses' perceptions, experiences, and understanding of SCD to the nursing curricular

Chapter Five

Discussion and Summary

The purpose of this research was to examine baccalaureate nurses' experiences and understanding of adults living with SCD. Chapter five presents a summary of the findings, the integration of the findings with previous research, and the implications of the findings as it relates to nursing education, nursing practice, nursing research, and public policy. Additionally, chapter five also describes the study's limitations. The findings from this research informed the practice setting and nursing education on the level of educational preparedness of baccalaureate nurses working with adults living with SCD.

The hermeneutical qualitative dissertation study presented baccalaureate nurses' experiences and understanding of SCD as congruent with the Lindseth and Norberg's (2004) design. This design was used for baccalaureate nurses to assign meanings to their experiences within the practice setting. The narrated accounts of the participants' real-life experiences in the practice settings generated four core themes along with their subthemes, which created the conceptual framework. The conceptual framework was used to facilitate the interpretation of the meaning baccalaureate nurses assign to their experiences and understanding of SCD. In nursing, knowledge, skills, and attitudes are associated with the baccalaureate nurses' experiences. As a result, most of the meaning baccalaureate nurses assigned to these experiences were connected to educational preparedness.

Summary of the Findings

The findings from this research contributed to the existing literature for the meaning that baccalaureate nurses assign to their experiences of working with adults living with SCD. Twelve semi-structured, open-ended interviews facilitated the interpretation of data that generated the four core themes critical to baccalaureate nurses' experiences and understanding of SCD. The core themes were experiences with SCD, baccalaureate nursing curriculum, nursing interventions, and patient education. These core findings were further established in the nursing curriculum.

The participants stated that their education shaped their experiences because their knowledge skills and attitudes formed their perceptions and guided their nursing interventions. All the participants recounted that their real-life experiences were related to their educational preparedness, which ground the knowledge and understanding needed to provide adequate care to adults living with SCD. The participants reported that inadequate educational preparedness influenced nursing interventions that determined the quality of care provided to adults living with SCD. For example, they stated that the lack of knowledge about the etiology of SCD and its genomic factors affected the quality of care provided for this population. Consequently, the participants reported that stigmatization of some SCD patients' pain response as drug-seeking behavior resulted in a longer wait time for pain medications.

Overall most of the participants reported that they did not provide comprehensive care to adults living with SCD mainly because their nursing interventions focused on the acute phase, which showed the inadequacies in the nursing curriculum. The participants cited that scant or non-existence patient education, which excludes health promotion strategies for a chronic disease, indicated a theory-practice gap. The participants also attributed the theory-practice gap to the inadequacies of their nursing education that failed to address the chronic phase of SCD. The findings presented were used for the participants to narrate their accounts about how these insufficiencies in the nursing curriculum affected their understanding of SCD. As a result, the participants reiterated that the nursing curriculum influenced nurses' perspectives that shaped their experiences and understanding of SCD. Ultimately, the participants' experiences and understandings determine the quality of care provided for this population.

Integration of the Findings with Previous Literature

The participants cited that their experiences and understanding of working with patients with SCD connected to the major themes and subthemes identified in the literature that guided the comparison of the findings to previous literature.

Experiences with SCD

The interpretation of the participants' experiences with SCD patients was guided by four themes and subthemes. In this dissertation study, the participants reported no difference between nurses' negative attitudes and SCD patients' pain response on medical units and emergency departments, which was consistent with the findings of Jenerette et al. (2015) who compared nurses' negative attitudes toward SCD patients by worksites. However, there was a difference between the dissertation results and Jenerette et al. (2015), which found no difference in negative attitudes between nurses' worksites, which included surgical units. However, the findings of the dissertation study found no negative attitudes toward SCD patients' pain responses on surgical units. But the dissertation study had a smaller sample size and only included the perspectives of only two surgical nurses. In addition, the findings of the dissertation study were found to support literature that showed the negative perceptions' of SCD patients' pain behavior led to longer wait times for pain medication (Haywood et al., 2014; O'Connor et al., 2104 & Glassberg et al. 2013).

Lack of Knowledge about Treatment Plan

All the participants in the dissertation study narrated accounts of negative attitudes due to insufficient education about treatment plans for SCD patients, which was consistent with the results of Kayle et al. (2016), which showed the lack of formal education for health care professionals working with SCD patients. Other researchers like Evensen et al. (2016), Puri Singh et al. (2016), and Haywood et al. (2011) confirmed the findings that inadequate SCD education for health care professionals increased negative attitudes toward this population. However, Matthie and Jenerette (2015) called for collaboration with SCD patients to develop individualized care plans to mitigate this problem.

Building Relationships

The participants cited that building relationships, advocacy for patients, and building trust were significant tools used to enhance the quality of care given to adults living with SCD. This result was consistent with the findings of Haywood et al. (2014) and Porter, Feinglass, Artz, and Tanabe (2012) who described trust and advocacy as significant elements of the therapeutic relationship used to improve pain management with SCD patients.

Baccalaureate Nursing Curriculum

The participants indicated that educational preparedness was crucial to their understanding of the disease. Although all the participants knew that SCD was an inherited disorder, the participants were unaware of the impact of the genetics/genomics factors on SCD management. These findings were consistent with Munroe and Loerzel (2016) who found that nurses were lacked the knowledge needed to integrate genomics in the practice settings. These deficiencies reported by the participants in the teaching of genetics/genomics content were consistent with results of Donnelly et al. (2017) who found that nursing professors also lacked the knowledge to teach genomics and genetics content. Additionally, Eboh, (2017) and Jenkins and Calzone (2014) also identified inadequate genetics/genomics content in the nursing curricula that supported the results of the dissertation study. Evensen et al. (2016) developed the Adult Sickle Cell Quality of Life Measure Information System Quality of Care Survey that showed the inadequate care being given to adults living with SCD was consistent with the findings of the dissertation study. Overall, the participants reported that the nursing interventions determined the quality of care given to SCD patients.

Nursing Inventions

The participants recounted that their nursing interventions were based on their perspectives, which were informed by their education and experiences.

Negative factors. Most of the participants' nursing interventions focused on acute pain symptoms management and SCD complications, which were consistent with the findings of multiple studies (Porter et al., 2012; Jenerette et al., 2015) with little no interventions focused on the chronic aspect of the disease. Other studies indicated how the negative attitudes of health care professionals affected the quality of care and became a barrier for effective pain management (Bergman & Diamond, 2013; Freiermuth et al., 2016), which were consistent with the findings of the dissertation study. Haywood et al. (2014), Jenerette et al. (2016), Jenerette et al. (2015), and O'Connor et al. (2014) indicated similar findings to the dissertation study in which the patients' pain response signaled drug-seeking behavior resulting in negative labels, stigmatization, and delayed wait time for pain management. Bergman and Diamond (2013) found that the negative labels such as "difficult patients" and "drug seeking" demoted mistrust. The dissertation study findings were congruent with the literature and showed that the negative perspectives led to mistrust, and stigmatization, and weakens the quality of care provided to SCD patients

Positive factors. The participants cited that positive relationships enhanced the quality of care provided to SCD patients. The participants used advocacy to build positive relationships that enhanced the care provided to SCD patients, which was consistent with Haywood et al. (2014) and Porter et al. (2012). The participants cited other positive factors, such as giving timely pain medication, which included disregarding of personal biases. This factor was consistent with a literature review in which nurses must provide appropriate pain medication without personal biases to enhance the quality of care provided to SCD patients (Matthie & Jenerette2015). Hanik et al. (2014) and Puri Singh et al. (2016) used educational interventions to increase knowledge and change health care professionals' perceptions about SCD, which was consistent with the findings of the dissertation study that showed nursing interventions linked to the nurses' perceptions on SCD. Therefore, the findings related to the formation of positive perspectives that build advocacy and trust (Haywood et al., 2015) were consistent with the findings of the dissertation study that used advocacy to build therapeutic relationships with SCD patients.

Patient Education

The participants indicated that the literature supported their insufficient knowledge to provide patient education and health promotion strategies for SCD. For example, Anderson et al. (2015) indicated that nurses lacked genetic literacy skills needed to translate genetics/genomics into practice. Consequently, the inadequacies reported in the curriculum became another barrier that prevented comprehensive care to the chronic phase of SCD.

The findings of the dissertation study showed that the lack of resources and insufficient care for SCD patients mirrored racial bias and health care disparities for people living with SCD was also supported in the literature. Haywood et al. (2013) reported that racial bias translates into longer wait time in emergency department for people of color. The findings of Haywood et al. (2013) were consistent with the dissertation study findings that the disparities in the health care experience of the SCD population that excluded health promotion strategies to a chronic disease. Ross and Lypson (2014) used artistic narrative to stimulate reflections in medical students about their biases and to help them acknowledge the physician bias towards pain management in SCD patients. This finding was consistent with the dissertation study that implied racial bias toward the pain response of SCD patients led to stigmatization. In addition, Haywood et al. (2014) supported the dissertation findings and showed that lack of patient education and health promotion of SCD reflected disparities in health care for patients living with SCD.

The literature for SCD health care professional research is abundant. However, the participants cited a lack of knowledge of SCD research, which was incongruent with the amount of literature available. However, In Canada, there is a dearth in the Canadian nursing literature regarding SCD. Overall, most of the dissertation findings were reinforced in nursing literature from different countries but predominately from the nursing literature from the United States that provided the context for this study

Implications of the Findings

Implications for Nursing Education

The findings of the dissertation study are crucial to nursing education because inadequate educational preparedness negatively affects nurses' perceptions, nursing interventions, and patient education. The participants stated that their perceptions, experiences, and understanding determined the quality of care provided for SCD patients. As a result, nurse educators can use the dissertation study to examine the SCD pathophysiology content to identify and clarify the misconceptions of SCD pain that promotes the negative response to the SCD patients' pain behavior.

The findings of the dissertation study showed that baccalaureate nurses lacked the knowledge to provide genetic/genomic competent care. In Canada, nursing professors must include a genetic/genomic framework that guide the teaching of any inherited disease. Additionally, nurse educators should integrate nursing genomics into nursing interventions for SCD patients to provide comprehensive care that includes patient education and health promotion. The findings of the dissertation study will also allow nursing professors to reflect about how SCD is taught in the nursing schools' curricula to identify the theory-practice gap, which determines the quality of care provided to SCD patients.

Implication for Nursing Practice

The findings of the dissertation study showed the inadequate care provided to SCD patients within the practice setting. Advanced practice nurses can utilize these findings to provide SCD educational workshops for baccalaureate nurses in different worksites. Advanced practice nurses can also work in collaboration with hematologist, staff nurses, and SCD patients to develop individualized care plans for SCD patients. The individualized care plans will assist baccalaureate nurses to provide adequate care for SCD patients and alleviate the theory-practice gap. The findings of the dissertation study demonstrated implicit biases toward the pain behavior of SCD. Therefore, the advanced practice nurses can also provide an educational workshop for nurses regarding the different pain coping strategies used by adults with SCD, which will mitigate the stigmatization of SCD patients.

Implications for Nursing Research

The findings of the dissertation study exposed the need for more nursing research that will address the inadequacies in the SCD nursing curriculum in Canada. For example, there is a need for a mixed study with a larger sample size that will address baccalaureate nurses' knowledge and understanding about SCD. The results of this dissertation study can also inspire other nurse researchers to examine the knowledge and understanding of SCD of experienced nurses and compare the findings with the with this study. Also, the findings indicate the need for SCD retrospective research to investigate SCD patients' expenditure per hospital visit. A cost analysis of multiple admissions may provide the evidence needed to introduce patients' education programs that focus on health promotion to decrease admission rates.

Implications for Public Policy

The participants of this study showed that there were unaware of any Canadian SCD statistics. The study findings can assist nurses to advocate for change policy changes that will implement the collection of SCD mortality and morbidity rates for nursing education, research, and health care subsidies. Moreover, although Ontario implements newborn screening for SCD, the carrier status is not disclosed without parents written consent for this information. The dissertation study showed the participants' knowledge deficit between sickle cell anemia and sickle trait. Therefore, there is a need for the implementation of a new screening program that informs parents of sickle carrier status without written consent. The sickle carrier status is essential medical information that SCD patients and nurses need to know when providing care for adults living with SCD.

Limitations

There were several limitations to this study that might relate to the research design and data collection method. The data collection method depended on the recall of past events due to which the participants might not give an accurate portrayal of the facts. The research design, which promoted that the investigator's pre-understanding was crucial to gain new insights during the analysis of the text, may have introduced researcher bias in this study. However, the investigator made every attempt to present the findings objectively using the participant's own words and member checks that validated the data. Another unforeseen limitation was due to cold weather, which slowed the data collection process. Although the data collection started in January, the cold weather led to several cancellations of scheduled face-to-face interviews. The investigator completed the data collection at the beginning of spring.

The study was conducted in a diverse geographical location, which might limit the transferability of the study to a population in which the phenomenon was less prevalent. The purposive sample also limits the generalizability of the study to only nurses who experience the phenomena. It is hoped that the accurate presentation of the study's findings and limitations will shed new light of baccalaureate nurses' experiences and understanding of working with adults living with SCD.

Chapter Summary

Chapter five discusses the implications of the findings for nursing education, nursing practice, nursing research, and public policy. This chapter shows how the findings of this dissertation study could allow nursing educators to implement curricular changes that will inform the practice setting. Additionally, it presents insights about how advanced practice nurse can utilize the study results to educate other nurses for the SCD patients' pain behaviors, and it also presents the study's limitations. Most importantly, the chapter also shows how the study's findings can invigorate new research ideas or motivate others to advocate for public policies that will enhance the quality of life for SCD patients.

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Appendix A

Institutional Review Board Approval

NOVA SOUTHEASTERN UNIVERSITY
Institutional Review Board

MEMORANDUM

To: **Shelia Reid**

From: **Vanessa A Johnson, Ph.D.,**

Center Representative, Institutional Review Board

Date: **November 21, 2018**

Re: **IRB #: 2018-604; Title, "BACCALAUREATE NURSES' EXPERIENCES ANDUNDERSTANDING of ADULTS LIVING WITH SICKLE CELL DISEASE"**

I have reviewed the above-referenced research protocol at the center level. Based on the information provided, I have determined that this study is exempt from further IRB review under **45 CFR 46.101(b) (Exempt 1: Educational research in educational settings)**. You may proceed with your study as described to the IRB. As principal investigator, you must adhere to the following requirements:

1) CONSENT: If recruitment procedures include consent forms, they must be obtained in such a manner that they are clearly understood by the subjects and the process affords subjects the opportunity to ask questions, obtain detailed answers from those directly involved in the research, and have sufficient time to consider their participation after they have been provided this information. The subjects must be given a copy of the signed consent document, and a copy must be placed in a secure file separate from de-identified participant information. Record of informed consent must be retained for a minimum of three years from the conclusion of the study.

2) ADVERSE EVENTS/UNANTICIPATED PROBLEMS: The principal investigator is required to notify the IRB chair and me (954-262-5369 and Vanessa A Johnson, Ph.D., respectively) of any adverse reactions or unanticipated events that may develop as a result of this study. Reactions or events may include, but are not limited to, injury, depression as a result of

participation in the study, life-threatening situation, death, or loss of confidentiality/anonymity of subject. Approval may be withdrawn if the problem is serious.

3) AMENDMENTS: Any changes in the study (e.g., procedures, number or types of subjects, consent forms, investigators, etc.) must be approved by the IRB prior to implementation. Please be advised that changes in a study may require further review depending on the nature of the change. Please contact me with any questions regarding amendments or changes to your study.

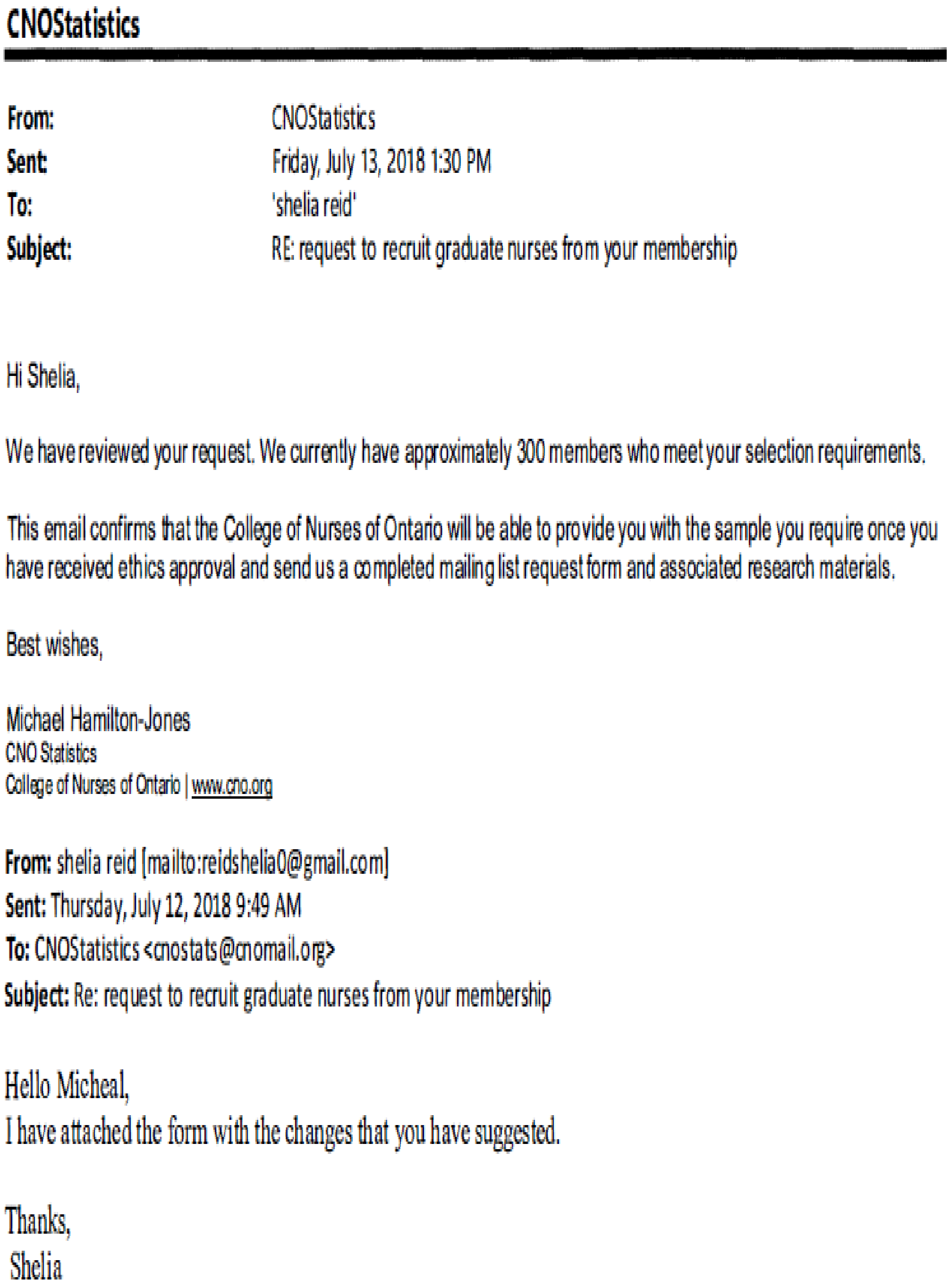
The NSU IRB is in compliance with the requirements for the protection of human subjects prescribed in Part 46 of Title 45 of the Code of Federal Regulations (45 CFR 46) revised June 18, 1991.

Cc: Marcia Derby-Davis

Vanessa A Johnson, Ph.D.

Appendix B

College of Nurses Approval to Recruit Email



CNOStatistics

From: CNOStatistics
Sent: Friday, July 13, 2018 1:30 PM
To: 'shelia reid'
Subject: RE: request to recruit graduate nurses from your membership

Hi Shelia,

We have reviewed your request. We currently have approximately 300 members who meet your selection requirements.

This email confirms that the College of Nurses of Ontario will be able to provide you with the sample you require once you have received ethics approval and send us a completed mailing list request form and associated research materials.

Best wishes,

Michael Hamilton-Jones
CNO Statistics
College of Nurses of Ontario | www.cno.org

From: shelia reid [mailto:reidshelia0@gmail.com]
Sent: Thursday, July 12, 2018 9:49 AM
To: CNOStatistics <cnostats@cnomail.org>
Subject: Re: request to recruit graduate nurses from your membership

Hello Micheal,
I have attached the form with the changes that you have suggested.

Thanks,
Shelia

Appendix C

Demographic Questions

Instructions: Please complete the information related to your experiences and understanding of working with sickle cell disease patients. Please check the box that corresponds to your answer. If you make an incorrect selection, please erase the answer with the pencil provided and check the correct response. The demographic questions will be completed before the start of the interview.

1. What is your gender? Male ☐ Female ☐ Other ☐

2. Select your age from the list below

   ☐ 22-30
   ☐ 31-40
   ☐ 41-50
   ☐ 50 or above

3. How long have you been an RN?

   ☐ 4 months up to 8 months
   ☐ 8 months but less than 1 year
   ☐ 1 year up to 18 months
   ☐ 18 months but less than 2 years
   ☐ 2 years but less than 3 years

4. What is your ethnic/racial identity?

   ☐ African Canadian
   ☐ Caucasian
   ☐ Native Canadian
   ☐ Latin/Hispanic
   ☐ Indian Canadian
   ☐ Asian/Pacific Islander
   ☐ Other

5. What is your highest level of education?
   ☐ College diploma
   ☐ University degree

6. Check the box that represents your nursing specialty.
   ☐ Medicine
   ☐ Surgical
   ☐ Emergency department
   ☐ Intensive Care Unit

Appendix D

Semi-Structured Topic Guide

Initial Interview Questions

Time of Interview:

Date of Interview:

Participant Number:

1. Describe to me about your experiences of working with adults living with sickle cell disease?
2. In your own words, tell me how your education has prepared you to work with patients living with sickle cell disease?
3. In a typical day, tell me about all the factors that have contributed to the care you provided to patients living with sickle cell disease?
4. Describe to me how your understanding of SCD has affected the care you provided for adults living with sickle cell disease?

Subsequent interview questions will be based on the initial responses and include additional probing questions to further explore how baccalaureate nurses' experiences and understanding affected the care provided to adults living with sickle cell disease.

Appendix E

Informed Consent

NSU Consent form to be in a Research Study Entitled
"*Baccalaureate Nurses' Experiences and Understanding with Adults Living with Sickle Cell Disease*"

.

Site Information
Toronto Public Libraries
Unfunded

What is this study about?
This is a research study that seeks to understand baccalaureate nurses' knowledge and experiences of working with adults living with sickle cell disease. The purpose of this study is to understand and interpret baccalaureate nurses' knowledge and experiences of working with adults living with sickle cell disease. To date, no research seeks to understand baccalaureate nurses' knowledge and experiences working with this vulnerable population. Therefore, this study might provide insights to foster curricula changes, which might lead to changes in the practice setting.

Why are you asking me to be in this research study?
You are being asked to be in this research study because you are a new baccalaureate nurse who speaks English and works in an emergency department, which is often visited by adults living with sickle cell disease. This study is expected to include a maximum of 15 people.

What will I be doing if I agree to be in this research study?
You can expect to sit for an audio-taped interview. This interview will last for 1 to 1½ hours. The interview will take place at your local community library at a mutually agreeable time. The investigator will ask you questions about your knowledge and experiences of working with adults living with sickle cell disease and record your responses. During the audio-taped interview, the investigator will take notes. Two weeks after the interview, the investigator will call you at a mutually agreeable time, to confirm that the transcribed interview themes represent your original perspectives/ideas. The investigator may terminate you from involvement in the study without your consent if it is determined that you are in danger or no longer meets the study criteria.

Are there possible risks and discomforts to me?
This research study involves minimal risk to you. To the best of my knowledge, the interview you will be doing has no more risk of harm than you would have in everyday life. If you had a negative experience, you might find some questions to be upsetting or stressful, if so, I can provide with material to help you deal with these feelings.

What happens if I do not want to be in this research?
You have the right to leave this research study at any time or refuse to be in it. If you chose to withdraw from the study before it is over, you will not get any penalty or lose services you have a right to receive. If you decide to leave the study, any information collected before the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as a part of the research. However, you may request that your data should not be used in the research study. All data collected will remain in the research records for a minimum of 36 months.

What if there is new information learned during the study that may affect my decision to remain in the study?
If significant new information relating to the study becomes available, which may relate to whether you want to remain in this study, I will provide you with this information. You may be asked to sign a new informed consent form if the information is given to you after you have joined the study.

Are there any benefits for taking part of this research study?
There are no direct benefits from being in this research study. However, I hope the information learned in this study might provide insights on the level of preparedness of baccalaureate nurses who provide care for this population.

Will I be paid or be given compensation for being in the study?
You will not be given any payment for taking part in the study. You will be compensated after the interview with a $ 40-dallor Cineplex gift card.

Will it cost me anything?
There no costs to you for being in this research study.

How will you keep my information private?
All information obtained in this study will be strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, and dissertation committee members may review research records. If the results of the study are published in a scientific journal, you will not be identified because only de-identified data will be used. All the study data will be kept for three years after the completion of the study. Questionnaires, transcripts, consent forms, codename key sheet, audio-recording, and researcher journal will be kept in locked cabinets in the researcher's home. After three years, all paper documents will be shredded. The computer files will be kept on a password encrypted computer and password encrypted flash drives. After three years, Eraser software will be used to permanently delete all computer files including files from the external flash drives. The audiotapes will also be destroyed three years after the completion of the study.

Will there be any Audio or Video Recording?
This research involves the audio recording of the semi-structured interview. There will be no video recording. This recording will be made available to the researcher, the

Institution Review Board and other representation of this institution. Because the audio-recording can be used to identify you, it is not possible to be sure that that the recording will always be confidential. However, the use of codenames will minimize this possibility. The researcher will transcribe the audio-taped interview to limit the number of people who are not connected to the research from listening to the audio recording. The recording will be kept, stored and destroyed as stated in the section above.

Whom can I contact if I have questions, concerns, comments, or complaints?
If you have questions now, please free to ask us. If you have more questions about the research, your rights or have a research-related injury, please contact:

Primary contact:
Shelia Reid MSN, BSN, RN. can be reached at (416) 244-1141 or (289) 259-6755

Research Participants Rights
For questions/concerns regarding your research rights, please contact:

Institutional Review Board
Nova Southeastern University
(954) 262-5369/ Toll Free: 1-866-499-0790
IRB@nova.edu

You may also visit the NSU IRB website at www.nova.edu/irb/information-for-research-participants for further information regarding your rights as a research participant.

Research Consent & Authorization Signature Section

Voluntary Participation- You are not required to participate in this study. In the event you do participate, you may leave the study at any time. If you leave this research before it is completed, there will be no penalty to you, and you will not lose any benefits to which you are entitled.

If you agree to participate in this research study, sign this section. You will be given a signed copy for your record. You do not waive any of your legal rights by signing this form.

SIGN THIS FORM ONLY IF THE STATEMENTS LISTED BELOW ARE TRUE:
- You have read the above information
- Your questions have been answered to your satisfaction about the research

Adult Signature Section

I have voluntarily decided to take part in this research study.

__________________________	_______________________	
Printed Name of Participant	Signature of Participant	Date
_______________________________	____________________________	
Printed Name of Person Obtaining Consent and Authorization	Signature of Person Obtaining Consent & Authorization	Date

Appendix F

Demographic Information

Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	male	4	33.3	33.3	33.3
	female	8	66.7	66.7	100.0
	Total	12	100.0	100.0	

Racial Identity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	African Canada	4	33.3	33.3	33.3
	Caucasian	1	8.3	8.3	41.7
	Latin/ Hispanic	1	8.3	8.3	50.0
	Indian Canadian	2	16.7	16.7	66.7
	Asian/Pacific Islander	3	25.0	25.0	91.7
	Other	1	8.3	8.3	100.0
	Total	12	100.0	100.0	

Nursing Speciality

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	medicine	6	50.0	50.0	50.0
	surgical	2	16.7	16.7	66.7
	emergency	4	33.3	33.3	100.0
	Total	12	100.0	100.0	