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USING LIVED EXPERIENCES OF ADULTS TO UNDERSTAND CHRONIC PAIN: SICKLE CELL DISEASE, AN EXEMPLAR

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ABSTRACT

Healthcare provision pertaining to painful, chronic conditions can best be optimized by developing positive healthcare provider (HCP)-patient relationships that minimize fragmented care. Nurses, with their holistic, humanistic approach provide a multidimensional focus that fosters individualized and effective outcomes for chronic events. The chronic pain phenotype is subjective, difficult to assess, define and effectively manage. Individuals with one such chronic syndrome, sickle cell disease (SCD), are living longer with pain that is poorly defined and inadequately managed. In addition to using quantitative assessment, clinicians and researchers must use substantive qualitative inquiry to understand the pain from the individual's perspective, define, and appropriately manage the pain. Combined quantitative and qualitative inquiry can help clinicians and researchers gain insights into pain experiences. This manuscript summarizes the importance of including a narrative (qualitative) inquiry, to offer a holistic, comprehensive and humanistic approach to understanding chronic pain from the individual's perspective and subsequently positively impacting care delivery. All nurses in the academy-educators, clinicians and researchers need to include a qualitative approach to care delivery, investigation and evaluation of the phenomenon pain, and intentionally demonstrate care. The experiences of individuals with chronic sickle cell disease (SCD) pain are used as an exemplar.

Keywords: Holism, Professionalism, Qualitative, Lived Experience, Ethics, Caring, Story, Beneficence, Sickle Cell Disease, Pain Assessment.

INTRODUCTION

Healthcare providers (HCP) who use the lived experiences of individuals with chronic pain to understand the individual's needs play an important role in improving HCP-patient relationships and healthcare outcomes. Clinicians and researchers are challenged to effectively manage chronic pain, with some providers doubting the veracity of the patient's complaints (Benjamin et al., 1999; Elander, Lusher, Bevan, & Telfer, 2003; Pack-Mabien, Labbe, Herbert, & Haynes, 2001). Often patients and HCP develop unhealthy professional relationships (Weissman & Haddox, 1989) and reciprocal distrust because of dissatisfaction in symptom management and care outcomes. Thus, such individuals or patients are at risk for disparate and fragmented care (Green et al., 2003; Green, 2005; McHugh & Thoms, 2001). For example, studies have shown that individuals with chronic pain are treated non-therapeutically and differently by healthcare providers,

and some of the differences are based on ethnicity, age and socioeconomic status (Haque & Telfair, 2000; van Ryn & Fu, 2003). In the absence of a therapeutic HCP-patient understanding, individuals will continue to receive improper care and will remain dissatisfied.

Nurses, as part of the HCP team, are well positioned to foster positive HCP-patient interaction and to use qualitative inquiry to promote patient satisfaction and good health outcomes. All levels of nurses can demonstrate caring attitudes to patients with chronic pain by using more qualitative inquiry and listening to bring out the individual's story. By soliciting the patient's stories of the lived experience, nurses can best capture the essence or nature of pain. The relative benefit of intentionally including the qualitative inquiry will be successful management outcomes.

The purpose of this manuscript is to awaken and focus nurse clinicians, educators and researchers on how, in addition to using other standard assessment mechanisms,

they can best assess, and manage chronic pain by using more qualitative inquiry. This updated focus can be accomplished when nurses are attentive to the benefits of qualitative inquiry especially for underserved populations. The author introduces ideas and strategies of how nurses can improve their skill sets and put this information into practice in clinical, educational and research settings.

The paradigm shift, beneficence, is based on a philosophical approach that is used to enhance therapeutic communication and to intentionally foster caring. To offer a practical case study approach, an exemplar with sickle cell disease (SCD) will be used. With SCD individuals have chronic, persistent pain and report perceived lack of HCP-patient therapeutic interaction. For the purpose of this discussion, terms that will be used interchangeably to suggest a narrative qualitative inquiry are: lived experience/phenomenology/tell your story /story/narrative inquiry.

Beneficence

In healthcare, the principles of beneficence dictate the clinician's ethical obligation to help relieve pain and suffering (Rosenblatt & Mekhail, 2005; Woods et al., 1997) and to prevent harm. Nurses are educated to use a holistic framework in practice (Adegbola, 2010), and should passionately champion a narrative inquiry to help patients to tell their stories in the clinical setting. Compassionate listening can be used both as an assessment technique as well as a modality for therapeutic intervention (Kazanowski, Perrin, Potter, & Sheehan, 2007). By listening compassionately, nurses give a "voice to often silent and suffering" (Quinlan-Colwell, 2009) individuals, demonstrate caring and help individuals relate their lived experiences (Adegbola, 2006; Adegbola, 2007; Adegbola, 2011b; Krupski et al., 2006).

The nurse's role is impactful because she/he helps to instigate and highlight the stories and lived experiences that need to be told by those who 'live' them. Nurses continually interact closely with patients, and often observe and experience the suffering of those receiving care (Kazanowski et al., 2007). Stories told capture and enhance the emotive element and give a voice to lived experiences that are often lost in obtuse clinical records or sterile

research designs. By recognizing the inter-relatedness of all dimensions of personhood, nurses can include these dimensions into care, by using a biopsychosociospiritual (BPSS) framework. By promoting the atmosphere and time for the patient to relate personal experiences, the practitioner will present the stage to increase quality of life and health outcomes for the individual (Adegbola, 2006; Adegbola, 2007; Adegbola, 2011b; Krupski et al., 2006).

Why Use A Narrative Qualitative Inquiry in Pain?

The narrative, qualitative inquiry of the lived experience gives healthcare providers direction in the assessment and management of chronic pain. Qualitative inquiry is often used when studying or evaluating a topic or phenomena that seek to explain human behavior and subjective nuances. The very essence of holistic nursing is to care for and heal the whole person. The most important aspects of pain management are the assessment and diagnosis of pain intensity (Niscola, Sorrentino, Scaramucci, de Fabritiis, & Cianciulli, 2009).

Assessment methodology that entertains subjective experiences contributes (Niscola et al., 2009) significantly to understanding the complex underpinnings of the pain phenotype and gives insight into enablers and barriers to pain management strategies (Mitchell & MacDonald, 2009). Thus, narrative qualitative inquiry provides a platform for information sharing in a cathartic way and peels away the layers of emotive events that form the bulb of a lifetime of chronic pain. This dialogue also provides comfort, gives a culturally relevant perspective and enables others to understand the sharer's perspective. As the clinician or researcher listens to the individual, and becomes attentive to body language and cues, he/she gains a holistic view to consider the individual's experiences. The individual's experience is his/her story that significantly relates the lived experience.

This methodological inquiry, Phenomenology, is defined as the lived experience as perceived by the individual, and seeks to define a phenomenon's essential nature and structures of meaning (Connelly, 2010; Dowling, 2004; van Manen, 1990). This methodological underpinning is drawn from Heidegger's work, but we also borrow from van Manen's (1990) approach of thematic analysis to interpret

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the information gathered.

Effects of lack of Narrative in Practice and in Research

In a recent study to validate the PAINReportIt computerized version of the McGill Pain Questionnaire (MPQ), using cognitive interviewing, researchers noted that responses from African American participants with sickle cell disease (SCD) suggest limitations in capturing the heterogeneity of pain for this group (Jha et al., 2010). The MPQ is a reliable instrument that has been used and validated in many studies for over 30 years (Wilkie, Savedra, Holzemer, Tesler, & Paul, 1990). Even though, using the computerized format of the MPQ enables time saving administration, some areas of concern were evident. The researchers reported that some participants were unable to understand intended meaning of questions and their failure to understand may reflect some lack of health literacy. For example, the participants when asked when first the pain was noticed expressed confusion regarding the intended meaning of the question. For this group with chronic pain, when the first time pain was noticed could mean, first time ever in life, or first time with this episode of pain. Individuals in this study of adults with SCD were perplexed by the question as their pain occurs across the life span, from infancy, through adolescence, into adulthood. The first time noticing or experiencing pain may be at 5 years old for this adult patient. Another area where the quantitative inquiry alone posed possible improper responses was when participants selected high numbers on the pain intensity scale that ranged 0 (no pain) to 10 (greatest level of pain) to indicate their desired pain goal. Researchers concluded that seemingly participants misunderstood the question (Jha et al., 2010). The quantitative methodology provides valid responses, but if used alone may reflect paucities that could be corrected by complementing the inquiry with a narrative approach with the inclusion of a holistic and culturally relevant focus.

Current approaches to treating chronic pain often neglect the importance of evaluating it holistically from the patient's perspective or how the pain is affecting the individual's well being. Additionally, pain grading systems may not be culturally appropriate for heterogeneous groups and may not adequately reflect the patient's

intended meaning. Most pain measuring systems were designed to evaluate acute pain in an acute healthcare environment and may not capture chronic pain characteristics. Part of the problem with the treatment of chronic pain is that healthcare providers are inclined to examine pain quantitatively; but quantitative methods alone create an incomplete picture and are an imprecise measurement at best (Mitchell & MacDonald, 2009). Measurement by definition is a quantitative designation, but pain which is subjective should be assessed qualitatively and holistically. Such pain assessment should include influencing factors that will eventually give direction for appropriate interventions. Emerging qualitative pain research is complementary to quantitative inquiry or can be a standalone methodology for understanding individual's experiences in a robust manner (Mitchell & MacDonald, 2009).

Krupski, et al. suggested that "failing to examine the meaning of one's life is a risk factor for poor health outcomes" (Krupski et al., 2006). By adding a holistic dimension, a descriptive qualitative inquiry, this failure can be minimized. A tool for descriptive inquiry helps define and distinguish characteristics of chronic pain (in addition to descriptors of intensity, quality, pattern, location), and includes the individual's experience during diagnosis and treatment. An identified barrier to using this method in clinical practice is perceived lack of provider's time to invest in providing such comprehensive care. However, by including this supplemental approach, practitioners can formulate holistic, culturally specific interventions and appropriate care.

Applying Qualitative Inquiry

Nurse clinicians and researchers must strategically include more open ended qualitative inquiry in addition to other traditional communication skill sets. The clinician or researcher should use open-ended questions that address the everyday lived experiences pertaining to pain. The initial question asked could be, 'Tell me about your experience of living with pain,' or 'What is the nature [essence] of your experience of pain?' In an unhurried manner the informant will be allowed to lead the conversation or interview from this initial point with little

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interruption. The interviewer's questions should only be used to clarify an idea brought up by the participant. This narrative inquiry can be used either as an initial assessment strategy or as ongoing evaluation at anytime during nurse-patient or HCP-patient interaction.

The qualitative inquiry helps to develop a rich description of the individual in the context of human everyday life experiences. In this situation the emotion of feeling will become evident, and the practitioner can delve into the crevices of the individual's story and life experiences. The only activity that is required of the participant, is to talk to the clinician or researcher about the experiences of chronic pain. Having a basic understanding of the individual's disease process, the clinician/researcher will gain the additional contextual framework for asking clarifying questions. Narrative collected during a standardized qualitative inquiry may help explain conditions such as chronic basal pain that is intermittent in intensity. Using the narrative, clinicians and researchers can better identify occurrences and evaluate the nuances and multiple dimensions of the pain experience (Adegbola, 2011a). At the same time, clinicians will become better equipped to manage chronic pain and can offer self-care strategies. Additionally, this will help with defining chronic pain for subsequent intervention and research studies.

Progress in treating chronic pain should allow individuals to remain at home longer, fulfill their needs in their own environment and experience less pain. In addition, and perhaps most important, patients will gain more control over their disease, become better equipped to self-manage their care, and decrease the feeling of dependence on a healthcare institution or healthcare providers (Roberts & de Montalembert, 2007). The benefit of using qualitative inquiry in chronic pain management is better management outcomes, self-care management in the individual's environment and decreased hospitalization or healthcare utilization.

Chronic Pain Description

The available literature and clinical language used to describe chronic pain generally present a nebulous, temporal description. The American Pain Society refers to chronic pain as pain that persists beyond 3-6 months or the

usual healing time, and admits this temporal description does not aptly define underlying differences that encompass acute, chronic and recurring pain (Benjamin et al., 1999). Adults with chronic sickle cell disease (SCD)-related pain have most assuredly had pain beyond 3-6 months, and may have experienced pain their entire life. The chronic pain experienced with SCD has been categorized as chronic, with obvious pathologic changes such as leg ulcers and avascular necrosis, and chronic intractable pain with no obvious underlying pathology (Ballas, 2005).

Terminology used with other pain syndromes should be used cautiously when describing SCD-related chronic pain. For example, some of the descriptors of pain relate to cancer type pain and if used with other pain syndromes (such as SCD) may not connote the same meaning and potential physiologic effect. Some descriptors that may elicit different meanings among different pain syndromes include: flares, breakthrough pain, crisis and episodes. There is the need to revisit such definitions and classifications. The goal should be to clarify what is actually experienced by adults with chronic pain syndromes, utilize terminology that has equal understanding for providers and patients, and tease out management strategies for such events. In addition, providers specializing in the care of individuals with SCD and who possess longitudinal experience with this population should collaboratively describe and define SCD pain because some of the current nomenclature and care strategies may have been primarily borrowed from experts in non SCD-related fields (personal communication, S. Ballas, 3/13/2011). For the revisited definition and clarification of chronic SCD pain, the rich experiences of individuals with the disease serve as the underpinning for updating the nomenclature. Additionally, emerging evidence of the presence of both neuropathic and nociceptive pain (Wilkie et al., 2010) among this group need to be considered.

If healthcare providers lack understanding of the nature of the pain, and sub-optimally manage the pain, a compromised therapeutic alliance between the provider and the patient (Booker, Blethyn, Wright, & Greenfield, 2006) ensues. Negative or improper responses to a patient's pain pose a psychosocial burden which exacerbates the problem, further deteriorating the patient's daily life (Anie,

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Egunjobi, & Akinyanju, 2010). As a result, some patients develop pseudo-addiction behaviors (Weissman & Haddox, 1989) and the accompanying complications that pose discomfort and ill-ease for practitioners who do not have adequate and effective management strategies to offer suffering patients.

Because of the multifaceted nature of chronic pain, it is best managed using a multidisciplinary approach. Nevertheless, many important questions about chronic pain remain unanswered, especially since severe pain should be considered a medical emergency (Benjamin et al., 1999). For example, for adults with SCD, is chronic pain a basal event with added, intermittent increases in intensity that constitute acute events (Adegbola, 2011a)? What can we learn about chronic pain from patients with the disease? How do these individuals articulate their experiences to healthcare providers, and describe pain? These are the types of questions that can be addressed when one uses a holistic approach, which includes a patient's narrative that is updated with each visit or healthcare utilization.

A holistic framework directs the inquiry to collect information needed to understand chronic pain among individuals with SCD, enabling effective plans for healthcare assessments and interventions to improve their lives (Adegbola, 2011b). In addition to considering the cause of the pain, the biopsychosociospiritual (BPSS) model considers factors needed for the individual to get better and focuses on all dimensions of human life (biological, psychological, social and spiritual). This renewed focus gives credence to the holistic approach (Adegbola, 2011b). Because the literature offers little direction on what constitutes or defines chronic (SCD) pain from the individual's perspective, it is important to perform exploratory studies.

Further inquiry should identify unique themes, germane to adults with SCD, and help align health promotion strategies with real-life experiences (Harvey, 2006; Holt et al., 2009) that will ultimately give direction to clinicians, researchers, and educators regarding the stories of individuals who experience intense basal chronic pain.

Nurses Transforming Relationships with their Presence

Nurses can create a transforming and engaging presence

with patients and foster the feeling of oneness and connection with clients in a relaxed atmosphere (Newman, 2008). This transforming experience is a way of being and not just a theoretical construct. By including and weaving intentional caring into every-day HCP-patient interactions, nurses can demonstrate best practice in a practical, unhurried manner even in a busy clinical environment. Caring, which has been fundamental to nursing, doesn't take much time but does require intentionality (Newman, 2008).

Practice Intentionality

A practical, applicable approach includes nurses from all branches of the academy. Nurses should include intentional interventions that reflect the philosophical basis of nursing, and use holistic practices to benefit the needs of all who receive care. Nurse administrators, educators, clinicians and researchers should strive to re-ignite passion and core values in the profession (Keamey, 2010). Nurses should be attentive to spiritual needs (not necessarily individual religious ideations) of patients, incorporate holistic, individualized elements of spiritual care into care delivery, inclusive of active listening (Adegbola, 2006; Adegbola, 2011b). In addition to active listening, the nurse shows genuine, unconditional acceptance of patients' idiosyncrasies, uses humor, and shows humility. The nurse can ask the patient questions that evoke caring and simple cordiality, such as, "How old were you when your disease was first discovered"?

Nursing Implications for Changing the Status Quo

Nurses operate with ethical standards and have an obligation to relieve suffering, spiritual distress and offer therapeutic interventions for positive healthcare outcomes and wellness (Adegbola, 2006). In a busy environment, the nurse can portray an unhurried demeanor and include questions that provide preliminary assessment and engender a relaxed environment that allows openness to express self, void of fear of being judged. To enhance or support best practices in a practical manner, even in a busy clinical environment, all strata of nursing can contribute and become therapeutic agents. In all forums nurses must document the use of the qualitative inquiry to give validity and credence to this important nurse intervention. By using such documentation and being

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empowered through nurse led councils to leverage, nurses can force system changes that become sensitive to such appropriate therapeutic intervention. Because all branches of nursing have important roles to play in fostering the use of narrative inquiry examples will be offered for each sub-category: nurse educators, researchers/scientists, clinicians and advance practice nurses. All levels of nursing will reap improved summative outcomes.

Educators can model the use of qualitative inquiry for students and expect students to demonstrate such learned practices in clinical practice and didactic assignments. Students may be required to use therapeutic conversational practices to identify idiosyncrasies about patients being cared for. Additionally, in post conference students can use reflective techniques to identify utility of practice, how to improve on such techniques and highlight one additional care intervention based on using the qualitative inquiry. Apart from sharing laterally with colleagues, student nurses should be encouraged to share gained information with the professional nurse/preceptor and discuss inclusion of findings that can be incorporated into the plan of care. As academicians in nursing attempt to increase the registered nurse workforce, educators should be mindful of the need to educate students and registered nurses on excellent bedside decorum, civility, and caring for others.

Nurse Researchers and Scientists can utilize the qualitative inquiry singularly or in conjunction with quantitative designs. Some might argue that the use of qualitative inquiry is time consuming, and it is. However, the benefit of acquiring valid, rich information that can be translated into improving therapeutic outcomes far outweighs the relatively quick responses acquired from sterile, quantitative designs that may have very little therapeutic value for rectifying the identified deficits.

Clinicians at the bedside as well as advanced practice nurses can use their practice principles and become instruments of change by creating presence for their patients. The phenomenological qualitative methodology that was presented is also a philosophical approach that drives and dictates appropriate, relevant caring. Nurses, who care about their patients, care to listen, and despite

the busyness of their practice, while interacting with patients, institute capsules of time that foster the environment for the patient to tell his/her story.

Nurse Administrators must be sensitive to practice models that are rigid and disallow practitioners from spending time with and listening to patients tell their stories. In some clinical areas other members of the healthcare team such as nursing students, chaplains and social workers can be valuable proxies to help patients relate their stories. The shared information can be relayed to other members of the healthcare team in multidisciplinary team conferences.

Finally, a better understanding of the lived experience of chronic pain may engender a humanistic, caring approach to reports of unrelieved pain. We will use chronic sickle cell disease (SCD) as an exemplar to discuss use of the qualitative method (either alone or in conjunction with quantitative inquiry), for evaluating subjective experiences in poorly managed and under-researched conditions.

Sickle Cell Disease, an Exemplar for Qualitative Pain Evaluation

Overview of Sickle Cell Disease

Sickle cell disease (SCD) is a genetic blood disorder that can become intensely painful. It is a global health problem (WHO, 2011) that affects individuals who are vulnerable and are already at risk for disparate healthcare and inadequate pain management. Generally, adults with SCD experience chronic pain that is poorly understood and difficult to manage (Aisiku et al., 2009; Kutlar, 2005; Smith et al., 2008). For most adults, SCD pain occurs most days in the out-patient environment and is the major reason for entering the acute healthcare system (Aisiku et al., 2009; Smith et al., 2008). This pain is chronic, severe, and variable in its clinical presentation, and variable among individuals. Hence the pain is heterogeneous. This poses a major public health problem because SCD is the most common blood disorder in the US, affecting approximately 100,000 (Hassell, 2010), mostly African Americans with connections to the African Diaspora (World Health Organization (WHO), 2011).

With increased globalization, demographic changes and racial admixture, the SCD allele is spreading to new populations (Anie et al., 2010; Roberts & de Montalembert,

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2007; Weatherall & Clegg, 2001). In the US, more than 2 million individuals carry a disease-associated allele. Globally, over 300 million people are estimated to carry this HbAS gene (sickle cell trait; SCtrait); and the highest frequency occurs in Africa and the Mediterranean (Tsaras, Owusu-Ansah, Boateng, & Amoateng-Adjepong, 2009). The disease is most common in Nigeria, West Africa (population over 100 million), where 1 in 4 persons carries the SCtrait (Tsaras et al., 2009) and 2% of all newborns [150,000 per year] are homozygous (World Health Organization (WHO), 2011). Indeed, SCD now affects an emerging population of individuals who traditionally were not described as affected by the disease. In the US SCD affects 1:1400 Hispanic Americans and 1:500 African Americans (Genetics home reference. US National Library of Medicine, 2011).

The direct mechanism of pain pathway in SCD remains unknown. Hence there is no specific treatment despite SCD being first highlighted in western culture in 1910 (Herrick, 1910). Currently, the management of the chronic pain is palliative. In the literature, clinicians recommend that care should be based on a holistic, multidisciplinary approach (Benjamin et al., 1999) that includes the involvement of the patient who innately expects and desires to be cared for therapeutically and with understanding. Usually, patients have the expectation of HCP being proponents of good outcomes. Yet for some individuals with SCD this is not a perceived reality. Patients report that some practitioners in addition to doubting the patient's subjective reports, lack understanding of the pain heterogeneity (Pack-Mablen et al., 2001), and disregard the patient's symptoms (Benjamin et al., 1999; Elander et al., 2003).

The uniqueness of SCD-related pain as opposed to other pain syndromes is based on pathophysiologic changes that occur at the cellular level (Ballas, 2005). That is, in addition to chronic basal pain, there is acute pain that needs immediate, appropriate attention to attenuate damage to tissues and organs (Benjamin et al., 1999; Benjamin, Swinson, & Nagel, 2000) that may result in irreversible tissue damage (Tennant, 2009). Additionally, the pain occurs across the life span, inclusive of infancy, childhood, adolescent, adulthood (Jha et al., 2010), and

presents individual variation (Platt & Thorington, 1991; Platt et al., 1994). With increased rates of pain episodes the risk of mortality and death increases (Platt & Thorington, 1991; Platt et al., 1994).

Some of the complications of tissue hypoxia include chest syndrome, pain episodes, stroke and priapism (painful, prolonged penile erection), and in some cases, damage to the spleen, kidneys and liver (Ballas, 2005). Hence, with chronic SCD pain there has to be extreme care and attention to chronic pain mixed with acute episodes. The acute episodes herald tissue damage (Ballas, 2005) that without adequate treatment may lead to tissue infarction and permanent damage (Bunn, 1997; Steinberg, 1999). It is of utmost importance to treat pain effectively and in a timely manner to reduce permanent and irreversible damage (Benjamin et al., 2000).

Despite their disease, individuals with SCD are living longer because of scientific advancements, neonatal screening programs, early use of penicillin against childhood infections, and the use of hydroxyurea to reduce frequency of painful vaso-occlusive episodes (Ashley-Kock, Yang, & Olney, 2000; Claster & Vichinsky, 2003; Platt et al., 1994). With scientific improvement and increased years, this patient population is forecast to grow exponentially and burden healthcare services (Weatherall & Clegg, 2001). Some of the difficulties of this chronic illness will increase exponentially, especially when acute pain is mis-managed and chronic pain is inadequately treated. Patients with SCD remain underserved and undertreated (Taylor, Stotts, Humphreys, Treadwell, & Miaskowski, 2010).

Paucity of SCD Research

Similar to other chronic pain states, little research has examined chronic pain in adults with SCD (Dunlop & Bennett, 2006; Taylor et al., 2010). In a literature review of 19 studies, (Taylor et al., 2010) there was no standard definition of chronic pain and unclear and inconsistent criteria for evaluating chronic pain characteristics. Additionally, most of the 19 studies were underpowered with small sample sizes, and some had mixed samples that included children and adults in the same study (Taylor et al., 2010). Similarly, Dunlop & Bennett (2006) pointed out that no adult SCD studies met the criteria to be included in the Cochrane

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review. Thus, although SCD pain is uniquely persistent, in clinical practice, SCD patients are not graded according to a specific or exclusive definition or discrimination for that type of pain (Smith et al., 2008). There is no unique treatment or management approach for this population.

Practical Application

The following case study reflects possible clinical consideration when caring for patients with chronic pain. The HCP should, in addition to quantitative assessment, employ qualitative inquiry that includes: personalized assessment of the individual, interaction and intentional relationship building to establish rapport, listening to the individual's story, discussing plan of actions or expectations and acknowledgement of the individual's specific needs. The benefit of using the qualitative approach, in addition to promoting positive and therapeutic HCP-patient relationships, will help to defragment care. With less defragmentation of care health outcomes will become positive.

Case Study

JT is a 24 year old, single male, diagnosed at age 2 years with HbSS SCD. For most individuals HbSS results in severe pain. JT has had multiple emergency room visits and in-patient admissions within the last three months. The consistent complaint necessitating admission is intractable pain affecting his hips and in addition he has bouts of priapism.

Audrey Scott, RN on the 7p to 7a shift was assigned to JT. She had 4 other patients. The off-going shift reported that: JT watches TV all day and refuses to get out of bed. He religiously calls for his Dilaudid IV medication 25 minutes before it is due and 'seems hostile' to the staff. His pain is usually an "8" on a scale 0-10, mostly in his right hip and groin but generally 'all over'.

Audrey, after receiving report quickly checks her medications and treatment kardexes and prioritizes the order in which she will visit her patients for a cursory assessment and introduction. She decides to visit J.T. first. She knocks on the door, and entered when she heard a flat, cold response "come in." Audrey smiles, maintains eye contact, extends a handshake, introduces herself as- "Hi, I am Audrey, registered nurse . I will be working with you this

shift to make you comfortable and to assist with your needs". "How would you like me to address you, by your first name or last name?" J.T replied "Jim." "Ok, Jim, I will return to thoroughly assess you and to offer any treatment you may need once I have said hello to all my patients. Do have any immediate needs to which I can attend before seeing my other patients?" J.T, with shoulders arched high towards his ears responded "my pain is about a 4 now but when it gets to 6 or 7, I will need the Dilaudid. It becomes unbearable after level 7". "Jim, your pain is about 4 now; tell me more about the pain". Jim's shoulders relaxed and he proceeds to describe the pain. Audrey recognized that the brief opener to a conversation and the humane establishment of a professional rapport has started to melt the flat, cold demeanor. She encourages him to tell her more. Once Jim seems at ease and admits to not needing "any medication now", she gives Jim an idea of when she would return and exits the room. On the way to the next patient's room Audrey notes that she will return to Jim's room 15-20 minutes before his medication is due, assess him and offer him choices of intervention.

Later in the shift, at 2100, after she had seen the other patients, Audrey decided to 'spend some time' in Jim's room. She talked with Jim about the effectiveness of the pain medication, and completed her shift assessment. Jim seemed relaxed and talkative. Audrey decided to chart on the computer in the Jim's room to offer her presence. "Jim, within the last few months, how often have you had pain needing hospitalization or a visit to the emergency room?" Jim recounted his pain history and frequent admissions and added "I try to take care of the pain at home by drinking blended vegetable and fruit juices". "I come to the hospital when that does not work and I cannot bear it any longer". Audrey asked, "how does the pain affect your relationships with others?" Jim recounts how the pain impacts his relationship with his parents, siblings and girl friend. As a part of the disclosure Jim relates to Audrey that his girlfriend of 4 years is ready to settle down and wants to get married. He wants to get married also but is concerned about being 'so sick' when they are married and together. The stress of making the 'right decision' is making him 'more sick'. Audrey maintained the dialogue with Jim and allowed him to express his concerns and his life experiences. Jim

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was able to identify that he would benefit from seeking professional counseling to help work out some 'big decisions' he has to face. Audrey offered to refer him to the Psychiatric Nurse Practitioner who also sees patients with chronic pain.

At the end of her shift Audrey went to tell all her patients good bye. With Jim, she reiterated the plan of care and her report to the oncoming shift regarding the consultation with the Psychiatric nurse practitioner. Jim was relaxed, grateful and commented "you are so nice and caring, thank you." "You are the first person who really listened to what I had to say".

Putting Narrative Inquiry into Practice

Audrey, by conversing with Jim in a humane way, reflected value and respect that enabled Jim to share some of his personal concerns. By dealing with the patient in a personal, therapeutic manner, Audrey, RN was able to hear Jim's story, identify underlying psychosocial concerns, intentionally offer self and assist in identifying possible interventions. The following steps were used:

- Personalized assessment of individual
- Interacted intentionally and built relationship
- Established rapport and trust
- Listened to the patient's story
- Discussed possible plan of care/expectations
- Acknowledged the individual and specific needs
- Followed through with appropriate personnel

Expected Outcome and Future Impact

The expected outcome and future impact of infusing qualitative inquiry into the practice arena is improved patient outcomes and satisfaction. By collecting a qualitative narrative as part of an assessment for chronic pain, clinicians will have a record of the description of the patient's disease in their words, not the clinician's or investigator's. This holistic aspect of an assessment will help identify themes, define chronic pain and ultimately improve care for adults with SCD and other pain syndromes in complex ways by,

- Providing information useful for classifying pain as chronic, acute, mixed, or chronic with increased

(acute) intensity.

- Noting predispositions to chronic pain episodes.
- Suggesting treatment modalities and interventions that are tailored for the specific patient.
- Helping distinguish pathologic complications from chronic pain.
- Distilling content into themes to better understand how chronic pain affects individuals in their everyday lives.
- Identifying what is learnt from such themes that can serve as new therapeutic, contextual approaches to care.

Nurses have an important role in modifying delivery models that meet specific needs of individuals and capture the multidimensionality of illness and chronic pain. Nurses must become involved in improving their clinical skills and expertise that ultimately impact care delivery. Clinicians and researchers must become influential and vocal in working to replace sterile, obtuse approaches for those that capture the patient's perspective.

We suggest that future inquiry with chronic pain include a qualitative methodology such as we have described. Additionally, nurses must become involved in policy initiatives that address chronic pain healthcare provision. Nurses can collaborate with other disciplines to revise or modify measurement tools to ensure reliability, validity and cultural appropriateness. Additionally, nurses should focus on comprehensive pain assessments rather than solely using pain measurement correlates.

Conclusion

Nurses play an important role in chronic pain management by using qualitative inquiry, in addition to other assessment techniques, to capture the lived experience of the individual with pain. By using qualitative inquiry the clinician or researcher can better qualify and diagnose the pain. Nurses who utilize such holistic approaches offer comprehensive outcomes and effective healthcare management, and can positively impact potentially negative healthcare provider (HCP)-patient relationships.

Nurse clinicians and researchers are interested in having a better understanding of chronic pain experienced by adults, and desire to offer appropriate, holistic care. However,

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individuals with sickle cell disease (SCD) though living longer report poor quality of life primarily related to constant pain which is poorly understood and inadequately managed by practitioners. Unfortunately, SCD-related pain is inadequately studied, ill-defined and poorly managed. Like other chronic pain syndromes, it is necessary to understand the patient's perspective to best manage, care and to teach individuals to appropriately self-manage. To define chronic SCD pain and its many parts requires a qualitative inquiry of a subjective phenomenon, in addition to other quantitative methods or rating scales. Purely biomedical perspectives on chronic pain focus only on pathophysiology and thus so poorly reflect the complexity of chronic pain. There needs to be better clarification of chronic pain for SCD and other pain syndromes. A holistic approach includes the life experience, as described by individuals and so offers significant benefits. Nurses have a valuable role to provide good health and to ethically heal individuals with chronic pain. All branches of nursing, educators, clinicians and researchers play a significant role to foster qualitative inquiry, intentionally demonstrate caring and offer therapeutic interventions.

This manuscript suggests a mechanism for obtaining and utilizing qualitative information regarding chronic pain experiences for individuals with chronic pain. Such qualitative information will help caregivers better assess the subjective phenomenon pain, and be able to give appropriate care despite perceived clinical time-related barriers.

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