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UNDERSTANDING THE TRANSFORMATION OF
COMPASSION IN NURSES WHO BECOME PATIENTS

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Adult Education

by

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ABSTRACT

The purpose of this study was to examine how nurses who become patients learn compassion toward patients in their professional practice, and examine the role of empathy in the process of learning compassion. The process of learning compassion represents a significant change in the way nurses perceive this aspect of practice. Therefore, transformative learning theory serves as the theoretical framework for the study. In particular, the psychocritical (Mezirow, 1991) and developmental perspectives (Daloz, 2003; Kegan, 2000) of transformative learning serve as the theoretical lens. This qualitative study utilized narrative inquiry to examine the perspective of 12 nurses who became patients. Inclusion criteria specified that nurses must: self-disclose as having a significant patient experience after becoming an RN, self-disclose that compassion in professional practice changed as a result of the patient experience, nurses had direct patient interaction as part of their job after the patient experience, and nurses have at least five years of experience. Nurses in the study indicated that the patient experience, and sometimes life experiences, impact the development of compassion in their practice. Findings suggest that before the patient experience, compassion was in the background of nurses’ practice. However, after the patient experience, nurses discussed compassion as being in the foreground of practice; as evidenced by changes in their perspective of the importance of compassion and behavior changes in practice. Nurses, indicated that empathy is a necessary component in expressing compassion. In addition, nurses suggested that experiences, compassionate role modeling, and self-reflection contribute to the development of compassion in professional practice.
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Chapter 1
INTRODUCTION

The purpose of this chapter is to give an overview of a study that investigates the perceptions of the change in compassion of nurses who become patients. This chapter presents the background and purpose for the study, theoretical framework, a brief description of the research methodology, significance of the study, assumptions, limitations, and key terms.

My Patient Experience

As a critical care nurse, I have taken care of countless individuals with crises ranging from heart attacks to terminal ovarian cancer. I have always felt that working with critically ill individuals is both a challenge and privilege. It is challenging because there are many highly technical aspects of care to consider when a person has multiple physical needs. It is a privilege because I am participating in, and guiding patients and families through one of the toughest times of their lives. In light of this, I take my job very seriously, and try to provide excellent technical and emotional care.

In 2004, I became a patient. That year I began to experience intermittent upper abdominal pain. After several tests, it was determined that my gallbladder was dysfunctional and needed to be removed. In mid-December I had a laparoscopic gallbladder removal. This surgery is common in the United States, and is often considered a simple outpatient procedure. In other words, the surgery takes a relatively short amount of time, and the person is discharged to home on the day of surgery. A
laparoscopic surgery is often desirable because the incisions are small resulting in less pain and shorter recovery time. Unfortunately I sustained damage to my main bile duct during the surgery (which is a risk of this type of surgery). The damage was a small tear in my bile duct which allowed bile to leak into my abdomen. The bile leak caused exquisite pain, fever, weakness, nausea and vomiting, and ileus (immobile bowels). I stayed in the hospital for 10 days, and had several x-rays, CT-scans, and gastrointestinal procedures. During this time a stent was placed in my bile duct to allow the bile to drain into the correct place while the hole in my duct closed and healed.

Over the next few months I regained weight and strength, and slowly improved. However, in April 2005 I woke up one morning feeling extremely tired and appeared jaundiced. A trip to the hospital revealed that my bile duct had developed scar tissue and completely closed itself, preventing any bile from draining out of my liver. To correct this problem I was transferred to a large tertiary hospital where a bile-duct specialist practiced. Ultimately I had a major abdominal surgery which essentially reconstructed my bile duct. I stayed in the hospital for about three weeks. During that time I had many diagnostic tests and treatment procedures. I also experienced a lot of nausea, vomiting, and pain.

I remember many of the doctors, nurses, and staff who provided care for me. Some of them were very nice. One anesthesiologist knew that the pain medicine I was receiving was inadequate, and he gave me a new pain medicine that temporarily made the pain disappear. He was like an angel and I nearly cried when I thanked him for taking away the pain. Another person I remember is one of the nurses who took care of me. She knew I was terrified and came to my room just to talk. I think she was there for half an
hour. We talked about silly things, but it was so nice because none of my family members were able to visit me that day. Her visit relieved so much anxiety. Others were not so nice. Once, I had to use the bathroom in the middle of the night, but was too weak to walk on my own. I pressed the call button for a nurse. No one ever came. In the end, I crawled on the floor to get to the bathroom. When my nurse came, she found me sitting on the toilet and acted very put-out when I asked for help to get back to the bed.

When I returned to work in the summer of 2005, I began to see my patients in a different way. I began to be more cognizant of the emotional distress that they and their families were experiencing. I tried to pay just as much attention to their emotional needs as the technical needs in critical care. I remember being very aware of the pain that people experience when they are sick. During that time I knew that my professional practice changed as a result of my patient experience. Over time, I began to think of this change in relation to my understanding and expression of compassion toward patients.

**Nurses-as-Patients: Importance of Compassion**

As I reflected on my patient experiences and professional practice, I began to wonder what has been written about nurses and doctors who have become patients. I wondered if anyone has experienced a change in compassion like me. I began to ask myself what other healthcare providers, particularly nurses, say about compassion and how it is defined in relation to healthcare. To begin answering these questions I addressed literature of healthcare providers who have become patients, and how compassion is defined in a healthcare setting. This section discusses a working definition of compassion, and the importance of compassion in healthcare providers who become patients and the nursing profession.
**Definition of Compassion**

Compassion is a complex aspect of providing patient care and is defined as: a person who becomes aware of another’s suffering, experiences a sense of shared suffering and is compelled to act and help alleviate that suffering (Goetz, Keltner, Simon-Thomas, 2010; Jull, 2001; Schantz, 2007; Schulz et. al, 2007; Maben, Corwell & Sweeney, 2009; Davidson & Williams, 2009a; Johnson, 2008). In some sources, compassion is described as an emotion in and of itself. Compassion is different from the emotions such as empathy, sympathy or pity because it is considered to go further than these and indicates a deeper connection with the other person (Jull, 2001; von Dietze & Orb, 2000). Compassion is most often interchanged with empathy, which is described as feeling or “mirroring” another’s emotions (Mohr, Rowe, & Blanke, 2010; Moore, 2006). Where empathy is associated with the ability to interact with other humans on a fundamental level (Mohr, Rowe, & Blanke, 2010; Moore, 2006), compassion goes a step farther to involve helping to alleviate the suffering of another person.

**Compassion in Nurses and Healthcare Providers**

When I began to think about my own patient experience and the impact it had on compassion in my practice, I wondered first whether other healthcare providers discuss compassion, and what they had to say about it. I searched for empirical research, firsthand accounts, and personal opinions of healthcare providers who have been patients. Most of the literature pertaining to healthcare providers-as-patients addresses nurses. The studies and personal accounts that address healthcare providers-as-patients do not specifically focus on the concept of compassion, however, the literature revealed that compassion is discussed by those who become patients. There are three main themes
found in the literature of healthcare providers who become patients. First, providers realize the importance of compassion when they become a patient. Second, becoming a patient involves significant emotional experiences. Third, the patient experience is a learning experience that impacts perspectives and professional practice of compassion.

When becoming patients, healthcare providers discuss that they became aware of the importance of receiving compassionate care. The comments made by healthcare providers usually focused on the fact that compassion was missing. Nurse-patients and physician-patients reported that they were interested in receiving ‘caring’ or compassionate care, but did not receive it at times which resulted in dissatisfaction (Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Keoun, 1996; Schwind, 2004). In some cases nurse-patients felt that the nurses providing care were too busy or simply chose not to be compassionate (DeMarco, Picard, & Agretelis, 2004; Stevenson, 2006; Zeitz, 1999). In other cases, healthcare providers realize that high quality healthcare requires compassionate care in addition to technical care (Clar, 2006; Kalb, 2008; Klitzman, 2007).

A significant number of healthcare providers-as-patients discuss the emotional aspect of becoming a patient. Unsettling feelings such as depression, loss, fear, anxiety, and terror are often described (Bowers, 2004; Clar, 2006; Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Doell, 2008; Emerson, 2009; Gillies, Child, & Biordi, 1993; Guzman et al., 2009; Harker, 2000; Jones, 2002; Lanza, 2006; Leite, 2007; Picard, Agretelis, & DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Williams, 1998; Williams, 1997; Zeitz, 1999). In addition, nurses report feeling guilt, and loss of power or control (Cotter, 1990; Doell, 2008; Gillies, Child, & Biordi, 1993; Jones, 2002; Lanza, 2006; Leite, 2007;
Picard, Agretelis, DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Williams, 1998; Williams, 1997; Zeitz, 1999). There is no discussion of how the emotions that these individuals experience impact a change in compassion.

Even though researching compassion was not the intent of the research studies and personal accounts of healthcare providers-as-patients, this body of literature suggests that becoming a patient is a learning experience that impacts the perspectives and practice of these individuals. For example, some nurses-as-patients comment on their learning experience and express a new “understanding” of patients and what it is like to be a patient (Bowers, 2004; Clar, 2006; Gillies, Child, & Biordi, 1993; Lanza 2006; Picard, Agretelis, & DeMarco, 2004). The nurses-as-patients go on to say that they then changed their professional practice and have a stronger belief in the importance of being compassionate (Bowers, 2004; Clar, 2006; Gillies, Child, & Biordi, 1993; Lanza 2006; Picard, Agretelis, & DeMarco, 2004). One study reports that after the patient experience nurses are more patient, address pain control faster, and provide more or improved patient and family education (Gillies, Child, & Biordi, 1993). Other nurses change their practice to become “more compassionate”, self-disclosing with patients, better advocates, and volunteer to share expertise in cancer groups (Picard, Agretelis, & DeMarco, 2004).

Personal accounts of nurses and physicians also state that they became more compassionate by being more understanding, paying attention to “little” or “trivial” things, and taking more time with patients (Clar, 2006; Doell, 2008; Fawaz, 2007; Kremer, 2006; Lanza, 2006).

The themes in the literature suggest that compassion is important to healthcare providers who become patients, particularly nurses. There are some questions that the
empirical data does not address. What this literature does not ask is: How do healthcare providers, learn compassion? How does the patient experience impact the learning of compassion? The literature does not ask what aspects of the patient experience impact learning compassion. For instance, what is the significance of the emotions that the healthcare providers report?

In addition, there is little research addressing this experience from an adult learning theory perspective. Few studies addressing nurses-as-patients use a theoretical framework to guide the study. Of the studies that use theoretical frameworks, most of them use various healthcare theories as a lens for the study. Three studies use a non-healthcare lens; they use critical theory, but do not discuss the use of the theory in terms of adult learning (Williams, 1997; Williams, 1998; Cotter, 1990). In these studies critical theory is used to explain why the participants felt the way they did, but the studies do not address the individual’s learning experience. Thus, none of the studies pertaining to nurses-as-patients address the experience from an adult learning perspective.

The change in the nurses’ compassion in practice can be described as a transformative learning experience. A transformative learning experience is a process that adults go through to develop a new or different understanding of a situation. It results in a different, or more sophisticated way of understanding, relating to, or making meaning of the construct in question (Cranton & Roy, 2003; Daloz, 1986; Kegan, 1994; Mezirow, 1991; Mezirow, 2000). Transformative learning theory has not been used as a theoretical framework to understand the learning experiences of nurses-as-patients. This theoretical perspective can serve as a lens to view the patient experience of the nurses and improve our understanding of the learning that take place as a result of the experience.
Understanding the learning process that the nurses go through can inform how nurses learn compassion through experience and inform practice for nurse educators, thus impacting a change of compassion in practicing nurses.

**Compassion in the Nursing Profession**

Because nurses have expressed that compassion is important in patient care, and report a change in compassion in their professional practice, it is beneficial to understand this concept in light of the broader nursing profession. This section presents a brief discussion of compassion in the nursing profession. Discussion includes the importance of compassion in the nursing profession, the lack of compassion in practice, and compassion in research.

Compassion is a quality of nursing care that people expect in nurses, and is claimed as part of nursing’s professional role (Bevis & Watson, 2000; Coetzee & Klopper, 2010; Fagermoen, 1999; Sellers, 1991; van der Cingel, 2009). Compassion is part of the overarching humanist philosophy of the profession which is considered to be at the core of what a nurse is and why a nurse exists (Boychuck Duchscher, 2000; Clark, 2005; Fagermoen, 1999; Woodrow, 1993). Fagermoen (1999) points out that nursing is a “moral practice” (p. 135). The purpose of nursing is to provide care in the form of help, comfort, and healing to those in need, which is seen as fundamental to human life (Hartrick, 2000; Fagermoen, 1999; Woodrow, 1993). Caring and compassion in the nursing profession involves: respecting and nurturing others, developing helping-trusting relationships, promoting harmony with body-mind-spirit, and supporting human needs (Bevis, 2000; Fagermoen, 1999; Wills, 2002). Thus, compassion is considered to be an important aspect of the nursing profession, and necessary to uphold the humanitarian
foundation of the profession, and the profession’s standard of high quality nursing (Bevis & Watson, 2000; Boychuck Duchscher, 2000; Clark, 2005; Coetzee & Klopper, 2010; Fagermoen, 1999).

There is concern within the profession that nurses are inadequately expressing compassion, and that there is a general lack of compassion in clinical settings (Coetzee & Klopper, 2010; Davidson & Williams, 2009a; Frandsen, 2010; Jull, 2001; von Dietze & Orb, 2000). The lack of compassion in practice leads to burnout for the individual nurse, lower quality of nursing care for patients, poorer patient outcomes, and loss of credibility with the public. The current healthcare environment is seen as being a significant factor causing erosion of compassionate care (Davidson & Williams, 2009a; Georges, 2011; Jull, 2001; Maben, Cornwell & Sweeney, 2009; von Dietze & Orb, 2000; Weiss, Malone, Merighi & Benner, 2009). American healthcare emphasizes technical aspects of care, and monetary value. Human-to-human interactions are devalued due to lack of monetary worth (Weiss, Malone, Merighi & Benner, 2009).

Some empirical research addressing compassion has been conducted. The empirical literature discusses attributes of compassionate caregivers, relationship between compassion and health, and promoting the development of compassion. First, attributes of compassionate care includes qualities such as paying attention to physical, emotional and spiritual needs, genuine interest in and respect for the patient, willingness to be open with the patient, and being able to communicate effectively, and willingness to spend time with patients (Arman et al, 2004; Attree, 2001; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Lindholm & Eriksson, 1993; Perry, 2009; Skaff, Toumey, Rapp, & Fahringer, 2003; Torjuul, Elstad, & Sorlie, 2007;
van der Cingel, 2011; Walker, 2009; Weiss, Malone, Merighi & Benner, 2009). Second, empirical literature demonstrates that compassion is linked with better health. Research addresses compassion directed toward others and toward oneself. Higher levels of compassion satisfaction in nurses is associated with lower levels of depression, work related stress and burnout (Burton, Stichler, 2010; Collins, & Long, 2003; Heffernan, Griffin, McNulty, & Fitzpatrick, 2010; Steffen & Masters, 2005). In addition, patients receiving compassionate care have lower levels of anxiety (Fogarty, Burbrow, Wingard, McDonnell and Somerfield, 1999), increased satisfaction (Duke & Connor 2008), and better sense of well-being (Harrowing, 2011; Rushton et al, 2009). Third, there is limited research pertaining to learning or developing compassion. Most of the research is conducted in formal educational settings, and is incorporated into teaching strategies within a course (Ellison & Radecke, 2005; Wear & Zarconi, 2007). These studies do not look specifically at how individuals learn or develop compassion. In addition, most literature that addresses compassion is not theory based (Berzoff & Kita, 2010; Maben, Cornwell & Sweeney, 2010; Showalter, 2010). This demonstrates a lack of empirical understanding of compassion in nursing.

Similar to the literature pertaining to nurses-as-patients, there is a lack of empirical literature addressing ways that nurses learn compassion. There is minimal literature pertaining to compassion which is based in learning theory, and none use a transformative learning theory lens. As mentioned above, using a learning theory lens such as transformative learning can increase understanding of how nurses learn compassion. This can inform the way nursing approaches the development of compassion
in practice; thus contributing to improved compassion in nurses and ultimately improved patient care.

**Problem Statement**

Compassion is a professional responsibility of nurses, and expectation of consumers. However, as pointed out, nurses often lack compassion when caring for patients (Davidson & Williams, 2009a; Jull, 2001; Maben, Cornwell & Sweeney, 2009; von Dietze & Orb, 2000). Understanding and providing compassionate care is an essential part of high quality nursing care. In addition, compassion is linked to better health and well-being (Fogarty, Burbrow, Wingard, McDonnell and Somerfield, 1999; Harrowing, 2011; Rushton et al, 2009). Nurses who have become patients remark on a change in compassion in their practice as a result of the patient experience. They report increased or better understanding of compassion. The patient experience provides new meaning and perspective to the importance of compassion in professional practice.

Because compassion is a concern in nursing practice yet lacks an empirical foundation, it is important to bring attention to this issue. By examining the learning of compassion in nurse-patients we can have a greater understanding of how it develops in nurses and how to improve compassion for patients. Researching the learning of compassion in nurse-patients can help to identify what happened to nurses that caused a change in their perspective of compassion. This information can be shared, and suggestions for practicing nurses and nurse educators can be made.
**Purpose Statement**

The purpose of this study is to examine how nurses who become patients develop greater compassion toward patients in their professional practice, and examine the role of empathy in the process of learning compassion.

**Research Questions**

The following questions are designed to help in understanding the impact that the nurse patient experience has on nurses’ professional practice.

1. What is the process that nurses go through while learning compassion?
2. What aspects of the patient experience contribute to nurses learning compassion?
3. How do nurses experience empathy as part of learning compassion?

**Theoretical Framework**

This study focuses on the change in compassion of nurse-patients in their professional practice. As mentioned, nurses report a change in the understanding and expression of compassion as a result of the patient experience (Clar, 2006; Lanza, 2006; Picard, Agretelis, & DeMarco, 2004). An assumption in this study is that the patient experience is a major life event that potentially causes nurses to change perceptions of themselves and how they treat those in their care. Because this change in perception and practice occurs, examining these experiences through the lens of transformative learning theory is appropriate. This section will provide a brief definition of transformative learning, discuss major assumptions of transformative learning theory, the theoretical perspective being addressed in this study, and how this theory connects with the topic of compassion in nurse-patients.
Transformative learning theory is a theory of adult learning that involves a deep change (transformation) in the way a person views their world or part of their world. Transformations occur as a result of a person’s life experiences (Dirkx, Mezirow, & Cranton, 2006; Mezirow, 2000; Mezirow, 2006). An experience may cause the person to think about something or see something in a way that was never considered before, and may result in a much different way of understanding and acting. A transformative experience causes a person to change their beliefs about something, or changes the way the person behaves in relation to a certain aspect of life (Mezirow, 2000; Mezirow, 2003; Mezirow, 2006).

A major assumption of transformative learning is that it occurs in adulthood. This theory assumes that adults are able to understand and interpret their experiences on a level that children are unable to do (Mezirow, 2000). Adults are able to interpret their experiences more than children because they not only possess awareness of sources and context of knowledge, but they are more emotionally mature and are able to understand and critically reflect on different values, beliefs and aspects of an experience (Mezirow, 1991. Mezirow, 2000; Mezirow, 2003; Mezirow, 2006).

Transformative learning assumes that adult learning occurs as a result of life experiences, or that experience is essential to learning. Adults learn and make meaning of life by evaluating their experiences, comparing the experiences with their beliefs values etc., critically reflecting or consciously thinking about experiences and beliefs, and formulating new understanding of certain aspects of life (Mezirow, 1991; Mezirow, 2000; Mezirow, 2003; Mezirow, 2006). For example, a nurse who becomes a patient may be treated without compassion by the nurses providing care to her. This experience may
affect her and cause her to think about what compassion really means to her, and how she expresses it in her own practice. The experience has helped her to make new meaning of compassion, or more definitely know what compassion means to her.

There are multiple perspectives of transformative learning theory. A traditional perspective of the theory focuses heavily on rationality, or purposeful conscious thought about the situation at hand. Some concepts related to a rational perspective of transformative learning are disorienting dilemma, critical reflection, and reflective discourse. A disorienting dilemma is a situation that cannot be resolved simply by learning more about something, or learning new skills and behaviors (Mezirow, 1978a; Mezirow, 1978b). A disorienting dilemma is considered a major event that causes a person to step back and really think about themselves and their perspective of the situation. An adult who experiences a disorienting dilemma engages in critical reflection and reflective discourse and rationally considers the experience and what it means to the individual. By engaging in these activities, the person is able to rationally come to a decision or conclusion and make a more informed judgment. Ultimately the person changes the way he/she views a situation. In other words, a person may change their habits of mind, frame of reference, or meaning perspectives (Mezirow, 1991; Mezirow, 2000; Mezirow, 2003; Mezirow, 2006). Thus a deep change or transformation has occurred. This perspective is considered to be highly analytical, and acknowledges, but pays little attention to non-rational aspects of a transformative experience.

Another perspective of transformative learning theory is a constructive developmental approach. A developmental perspective takes into consideration a person’s development throughout life and believes that development can continue
through adulthood (Daloz, 1999; Eriksen, 2006; Kegan, 1980; Kegan, 1994). A
developmental perspective of transformation suggests that adults can continue to have
progressive changes and involves changes in how a person makes meaning of his or her

A constructive developmental perspective of transformation has several
assumptions as well. This perspective assumes that people construct meaning from our
individual experiences (Kegan, 1994; Kegan 2000; Daloz, 1999). It assumes that as
people develop, they begin to have more complex understanding ways of making
meaning in their lives (Kegan, 1994). In addition, when considering the meaning making
of an individual as they develop, this perspective considers development to result in a
transformation of the way in which a person makes meaning (Daloz, 2003; Daloz, 1983;
Kegan, 2000). In other words, our understanding and relation to certain things in life is
understood in a different way.

**Overview of Methodology**

This topic is appropriate for a qualitative study because the researcher is
interested in an in-depth exploration of what the individuals think and feel about
compassion in their practice (Creswell, 2009; Merriam & Simpson, 2000). Qualitative
research is interested in and in-depth understanding ways that people make meaning of
phenomena or experiences in their lives (Creswell, 2009; Merriam & Simpson, 2000;
Patton, 2002). To understand how people make meaning of their lives, consideration is
given to a person’s environment and life experiences. Environment, culture, and personal
experiences all affect the way we see the world and therefore what life events mean to us
(Finch, 2004; Webster & Mertova, 2007). In this study, attention will be paid to the
meaning that nurses place on their patient experiences, and how that affects the way they perceive compassion in their professional practice.

This study incorporated a narrative method of qualitative inquiry. A narrative is considered a personal account of experiences which tends to be in story form, or has aspects of a story in it (Patton, 2002; Riessman, 1993, Webster & Mertova, 2007). The context of the narrative and what it means to the person is taken into consideration when it is identified. The story and the person’s interpretation of that story show the researcher what it means to that individual (Riessman, 1993, Webster & Mertova, 2007). Narrative inquiry was chosen because I have noticed that when nurses talk about or write about their patient experiences, they often do so in story form. When they do not tell a specific story, narratives can still be identified in the way they communicate with others. Narrative inquiry was also chosen because the patient experience is part of a nurse’s life and is part of her overall life story or narrative.

This study utilized aspects of Clandinin and Connelly’s (2000) concept of the three-dimensional narrative inquiry, and four directions of narrative as a guide for study design. The “three-dimensional narrative inquiry space” (p. 50) addresses key aspects of the experiences in a person’s life: interaction, continuity, and situation. Interaction considers both personal and social interactions as part of experience. Continuity is the attention to past present and future as being part of the person’s life experiences and narrative process. Situation is the places that events take place in or sequence of places over time that are part of the person’s narrative process. The four directions of a narrative inquiry are inward-outward, and backward-forward (Clandinin & Connelly, 2000). Addressing inward and outward means paying attention to the inward aspects of a person,
and the outward contextual aspects of a person’s experience. An inward focus addresses a person’s thoughts, feelings, moral disposition, hopes, etc. An outward focus pays attention to the environment the person is in such as the physical context (school, home, work, a public park, etc), or the psychosocial context (welcoming, hostile, comfortable, relaxed, etc). Backward and forward refers to the concept of temporality: past, present, and future. A narrative process begins in the past, is taking place in the present and will continue into the future.

The study design addresses Clandinin and Connelly’s (2000) concept of inner and outer aspects of experiences by asking the participants to share the “inner” aspects of their experiences, or their thoughts, feelings etc. The “outer” aspect of the data will come partly by nurses naturally talking about the environmental circumstances of their patient experiences. The outer aspect of data collection included asking for clarification, and my own observations while interacting with the nurses. By paying attention to the inner and outer aspects of experience two of the three dimensions of narrative inquiry space are addressed: personal and social interaction, and situating the experience within place (or context). Personal interviews included focus on the nurses’ perceptions of compassion in their professional practice over time, such as before and after the patient experience in order to address the backwards and forwards aspect of Clandinin & Connelly’s concept of temporality.

The study analyzed data with both a narrative and thematic approach (Reissman, 1993; Reissman, 2008; Patton, 2002; Webster & Mertova, 2007). Riessman (1993) gives examples of several systematic ways that a researcher can analyze data. She identifies and draws on theorists who apply structure to narratives: Labov, Burke, and Gee. Each of
these individuals state that a narrative has specific properties that can be identified. Webster and Mertova (2007) use a critical event analysis to identify a narrative. In this method, stories and narratives can be identified by first recognizing a critical event that someone is retelling. A critical event is a type of life experience that has a significant impact on the storyteller. During data analysis, narratives were constructed using the critical event approach, paying attention to events in the nurses’ narratives that seemed to have significant impact on the nurses. Later the data was analyzed for patterns or themes, using an inductive approach (Patton, 2002).

**Significance of the Study**

Compassion is a quality of nursing care that people expect in nurses, and is claimed as part of nursing’s professional role (Bevis & Watson, 2000; Coetzee & Klopper, 2010; Fagermoen, 1999; Sellers, 1991; Van der Cingel, 2009). There is concern within the profession that nurses are inadequately expressing compassion (Coetzee & Klopper, 2010; Davidson & Williams, 2009a; Frandsen, 2010; Jull, 2001; von Dietze & Orb, 2000). This is a concern because some scholars believe that qualities such as compassion are the essence of nursing practice and is what sets a nurse apart from any other healthcare professional (Bevis, 2000; Wills, 2002). Because compassion is a concern in nursing practice, it is important to bring attention to this issue. Examining the experiences related to compassion in nurse-patients gives us a greater understanding of the complexities of compassion in nurses. A deeper understanding of compassion in nurses will help the profession to improve the way we educate nurses and lead to more compassionate care.
To improve our understanding of how nurses learn compassion, I sought to address the experiences of nurses who have been patients and the changes of compassion in practice that result from the experiences. I focused on the specific experiences that nurses perceive to affect them and their professional practice. Attention was given to the things that nurses-patients report as being significant in their patient experiences. By focusing on these things, we can know more specifically what caused the individual nurse to experience a change in compassion. This gives understanding to the specific aspects of the patient experience that contribute to learning compassion and the change in professional practice. Understanding the intricacies of how nurses learn compassion can help nurse educators know how to better focus educational activities that promote understanding and development of compassion. For example, if this study found that nurse-patients became more compassionate after their nurses sat down and simply spent time talking with them, then educators can spend more time in educational settings addressing how to improve communication with patients. Educators can incorporate more learning activities, theoretical discussions, and time to practice communication skills in the educational setting. This is a simplistic example; however the point is that educators can develop a better understanding of aspects that affect how nurses change compassion in their practice. Ultimately, with a better understanding of the development of compassion, nursing can use this information to improve compassion in nursing care.

Additionally, regarding contribution to transformative learning theory, there has been much focus and discussion regarding the importance of critical reflection, or rational aspects of a transformative learning experience (Dirkx, Mezirow, & Cranton, 2006; Mezirow, 2000; Mezirow, 2003; Mezirow, 2006). However, some scholars believe
that emotions and empathy play an important role in a transformative experience (Dirkx, 2001a; Dirkx, 2001b; Dirkx, Mezirow, & Cranton, 2006; Taylor & Cranton, In press). In somewhat recent discussion of the theory, Mezirow (2000) acknowledged that emotions and empathy are important parts of a perspective transformation because they are necessary components of reflective discourse. There has been some discussion of emotions in relation to a perspective transformation (Dirkx, 2001a; Dirkx, 2001b). Unfortunately, there is little discussion about empathy in relation to transformative learning theory (Taylor & Cranton, In press). This study, adds to theoretical discourse pertaining to empathy in a perspective transformation.

**Assumptions**

1. Nurses believe or acknowledge that compassion is part of the role of a nurse, and can identify it within their own professional practice.

2. Nurses can communicate what compassion means to them as an individual nurse.

3. The patient experience is a disorienting dilemma for a nurse.

4. Nurses transform their practice of compassion as a result of the patient experience. This may include, but is not limited to: addressing patient needs with greater speed, more emotional involvement, advocating more often or more forcefully for patients, spending more time with patients, listening to patients more etc.

5. Nurse-patients receive care from other healthcare providers during their patient experience, and it affects the way they perceive compassion in patient care.

6. Nurse patients provide direct patient care prior to the patient experience and after the patient experience.
7. Patients are people experiencing suffering and are in need of compassion.

**Limitations**

1. This study is limited to views of only nurses in the healthcare provider/receiver relationship. This study is based on the perceptions of nurses who have become patients, and the nurses’ definitions, perceptions, and ideas of what compassion is. The study focuses on how nurses see themselves being compassionate in their professional practice. Because compassion is based on the person’s perceptions, patients who receive care from these nurses may not feel that these nurses provide compassionate care.

2. My experiences as a nurse-patient affect my personal view of compassion in nursing practice, and therefore may affect the results of this study. I believe that my patient experience caused me to change my understanding of what patients go through, and ultimately changed the way I interact with and care for patients. I may unconsciously focus on ways that nurses’ experiences are similar to my own experience when collecting, analyzing, and interpreting data.

3. As a qualitative study examining the experiences of a small group of participants, the findings lack generalizability. However, additional research can examine possible similarities among other adult-learner populations.

**Definition of Terms**

*Nurse*: (In this study, nurses are referred to as “she” or “her.” This is because female nurses participated in the study. Male nurses were not purposefully excluded. Rather, male nurses simply did not volunteer to participate. For ease of writing, nurses are
The term nurse refers to a registered nurse. A registered nurse is someone who provides direct patient care in any number of healthcare settings. Nurses who provide direct patient care act as patient advocates, coordinate various aspects of patient care (i.e. scheduling tests and therapies, communicating with physician groups and ancillary healthcare providers etc.), and interact one-to-one with patients by addressing basic needs (i.e. bathing, dressing, feeding, administering medications etc.).

**Nurse-patient or Nurse-as-patient:** A nurse-patient is defined as a nurse who becomes a patient. Nurse-patients in this study have experienced a serious illness that may be chronic, life threatening, life-style changing, or dramatic enough to cause a change in perspective of health and wellness. In this study, nurse-patients have returned to work and continue to provide direct patient care.

**Empathy:** Empathy is a human emotion which is an important part of social interaction, and involves the ability of a person to perceive another person’s emotional state (Mohr, Rowe, & Blanke, 2010). In perceiving the other person’s emotions, the empathetic person is able to compare those emotions with his/her own and feel those emotions along with the other person. Some describe it as mirroring, feeling along with, or vicarious experience of the other person’s emotions (Goetz, Keltner, & Simon-Thomas, 2010; Moore, 2006; Mohr, Rowe, & Blanke, 2010).

**Compassion:** In this study compassion involves the ability of a nurse to understand or feel the emotions of someone who is suffering and takes action to help alleviate that person’s suffering. Compassion is linked to empathy as an emotion, but goes beyond empathy to incorporate action which is aimed at helping another person(s) (Goetz, Keltner, & Simon-
Compassion is integral to this study because the nursing profession exists to help alleviate the suffering of other people, particularly those who are unhealthy either mentally or physically. In this study the actions associated with compassion are the outward evidence that a nurse has changed her perspective, understanding, and display of compassion in her practice.

Disorienting Dilemma: A disorienting dilemma is a situation that cannot be resolved simply by learning more about something, or learning new skills and behaviors (Mezirow, 1978a; Mezirow, 1978b).

Transformation: A transformation is “the process by which we transform problematic frames of reference (mindsets, habits of mind, meaning perspectives)- sets of assumptions and expectation- to make them more inclusive, discriminating, open, reflective and emotionally able to change” (Mezirow, 2006, p. 26).
Chapter 2

REVIEW OF THE LITERATURE

The purpose of this chapter is to discuss literature pertinent to the topic of interest, which is the transformation of compassion in nurses who become patients. Three main bodies of literature pertaining to the research purpose are: nurses-as-patients, compassion, and transformational learning as the theoretical framework. Nurses who become patients are the population of interest, therefore they are discussed first. This section reviews personal accounts and empirical literature addressing nurses-as-patients. Next is a discussion about compassion in nursing which explains its connections with the profession, how it is defined, and review of empirical literature. The last section discusses transformative learning theory because it is the theoretical framework that guided the study. The two perspectives that inform this study are presented: Mezirow’s psychocritical perspective and a constructive developmental perspective. The theoretical framework section concludes with review of empirical research of transformative learning.

Nurses as Patients

This study was interested in the experiences of nurses who become patients and the impact it has on compassion in their practice. In order to better understand this population, literature specifically addressing nurses-as-patients was reviewed. The two types of literature that discuss nurse-as-patient experiences are personal accounts, and research studies. Both of these are included in the literature review.
Methodology for Reviewing Nurse-as-Patient Literature

The search for literature that dealt specifically with experiences of nurses who become patients fell within two areas: personal accounts and research studies. Four online databases were consulted: CINAHL, Info-Psych, PubMed, dissertations and theses through ProQuest, and ERIC. Of these, CINAHL revealed the largest amount of literature pertaining to nurses-as-patients. Search of the dissertations and theses database produced three studies directly pertaining to nurses as patients. Search terms for nursing literature included “nurses as patients,” nurses and patients, and nurs* experience* and patient*. “Nurses as patients” selected for exact major heading initially revealed several hundred results.

Most of the search results were personal accounts written by nurse-patients. To narrow criteria for personal accounts, the search was narrowed to the last decade, and articles discussing what it is like to be a patient were chosen (as opposed to accounts that strictly discuss disease pathophysiology). There were significantly fewer research studies. Criteria for research articles included those that focused exclusively or primarily on nurses’ experiences as patients. From the on-line search, 17 studies addressing nurses-as-patients were chosen. Scouring reference lists of these studies resulted in an additional 3 studies. In all, there are 20 research studies and 15 personal accounts reviewed here.

Demographic Information of Personal Accounts

Among the personal accounts selected for this review each nurse was a female, and each shared her diagnosis. Seven of the nurses who share their stories were diagnosed with cancer (Bush, 2008; Clar, 2006; Doell, 2008; Kinniard, 2009; Knight, 2010; Palmer, 2004; Stott, 2008). All of them were in remission at the time they
published their stories. Five others became intensive care unit (ICU) patients (Bowers, 2004; Fawaz, 2007; Lanza; 2006; Phillips, 2006; Stevenson, 2006). Some had long recoveries from several months (Fawaz, 2007; Phillips, 2006), to a year (Bowers, 2004), to several years (Lanza, 2006). The remaining three personal accounts involved a nurse as a labor and delivery patient (Esper, 2011), a nurse with an unidentified neurologic disease (Emerson, 2009), and a nurse with pancreatic disease (Brown, 2011). The diagnoses and patient experiences that these nurses had affected them deeply, thus compelling them to share their experiences with others. In each case, the nurse was threatened with death or a potentially life altering diagnosis. Thus it appears that nurses who have experienced a major illness or life threatening/altering disease were impacted enough that they felt the need to share their story with the wider professional community. This is significant, because it provides insight into the types of patient experiences that impact nurse and will likely be good types of illness experiences to include in the study.

**Purpose of Research Studies Addressing Nurses-as-Patients**

There are several themes within the purpose statements for the studies about nurses who become patients. The purpose of some studies was to address how the patient experience affects nursing practice. Others were interested in knowing what it is like for nurses to be patients. Another theme of purpose statements addresses finding out whether or not nurses are treated differently than other patients. Each of these is discussed below.

Four of the studies’ purpose statements posed questions pertaining to patient experience and how it affects nursing practice. DeMarco, Picard and Agretelis (2004) wanted to know how the experience of having cancer and being a recipient of care affects nurses’ practice. Harker (2000) and Gillies, Child and Biordi (1993) were interested in
the effect that being a hospital patient has on nursing practice. Schwind (2004) completed a dissertation which sought to understand the impact that a serious illness has on the teaching and practice of nurse educators. In each study nurses with serious illnesses such as chronic illness, cancer, or illness requiring hospitalization were included in the study. The researchers reported that the patient experience can impact nursing practice. (Themes of the affect are discussed later with the general themes in the literature.) Because most of the studies address nurses with serious illness, it is apparent a severe illness can impact nursing practice. These researchers were interested in understanding the general affects that the patient experience has on nurses. In other words, they were looking for general themes of the effect of the patient experience. What these researchers do not ask is what effect the patient experience has on specific aspects of professional practice. For example, they do not specifically ask what the effect the patient experience has on compassion in professional practice.

There appears to be an assumption within these studies that serious illness is more likely to affect the way a nurse practices. In each study, nurses experienced what they considered to be a major illness. What is not addressed, is whether a less severe illness can impact nursing practice.

Other researchers wanted to know what it is like for nurses to be patients. Four of these studies’ purpose statements indicated that the researchers were interested in nurses’ patient experiences with specific problems such as a musculoskeletal disorder caused by working conditions (Leite, 2007), HIV/AIDS (Jones, 2002; Minaar, 2005), and cancer (Picard, Agretelis & DeMarco, 2004). Two of these studies showed that the patient experience caused a change in perspective and practice (Leite, 2007; Picard, Agretelis &
DeMarco, 2004). Todres, Fulbrook and Albarran (2000) were interested in knowing what it is like for an intensive care unit (ICU) nurse to be an ICU patient. As a result, the researchers gained better understanding of patient emotions and importance of basic aspects of patient care. Zietz (1999) was interested in the perceptions of nurses as the recipients of care. Last, Cotter (1990) simply wanted to know the experiences of nurses who have suffered illness.

There is some overlap with the purpose of the studies. A group of researchers was interested in the nurse-as-patient experience and the perceived impact of the care they received, or the impact of nursing care on their health (Duke & Conner, 2008; Kempainen, Bartels & McCarthy-Veach, 2007; Lawson, Delamere, & Hutchinson, 2008). This is very similar to Zietz (1999) and DeMarco, Picard and Agretelis (2004). Both were interested in the experience of nurses being patients in the context of being recipients of care. The purposes of these various studies provides an empirical base to draw from. They describe general aspects of nurses’ patient experience and general ways that practice is then affected. Purpose of future research can now begin to focus on specific aspects of nursing practice that are impacted by the patient experience. This will give a more detailed understanding of how this experience can be used to benefit professional practice.

The purpose of two additional studies was to know if nurses are treated differently than other patients (Morris & Mendias, 1985; Williams, 1997). Morris and Mendias (1985) conducted an eight question survey addressing expectations that nurses have regarding nursing care and disclosure of their profession when they are patients. Most nurses (77%) expect to be treated the same as non-nurse patients. However, only 34% of
the nurses actually disclose their professional role when they are patients. The survey did not go any farther than reporting the percentages; therefore there is no explanation about why nurses do not report their professional status. Williams (1997) gives some insight into this. She found that nurses often do not disclose their profession because they are afraid of being treated differently. Some nurses in the study reported that after disclosing their professional role, they were treated poorly by nurses. Williams briefly hints that the treatment nurses receive as patients translates into a better understanding of how to treat patients. The discussion of practice is brief because the purpose of the study was not to assess the impact on professional practice. Further investigation can shed light on the impact that experiences like these can impact professional practice.

The purpose of four studies did not fit into a theme. One group of researchers were interested in understanding how a nurse-educator used hope to make-meaning during her illness (Guzman et al., 2009). Wessman & McDonald (1999) wanted to know if nurses’ personal pain experience would impact a nurse’s pain management knowledge and ability to learn about pain management. The researchers did not show a positive correlation. Kim, Boren and Solem (2001) used nurse-patients to help develop a therapeutic alliance scale. The last study was interested in understanding how hospitalized nurses perceive their bodies in relation to the influence of the dominant culture in healthcare (Williams, 1998).

**Methodology and Theoretical Framework of Nurse-as-Patient Studies**

This section will discuss the methodology and theoretical frameworks of the studies. Methodology is discussed first, followed by theoretical framework.
The majority of the studies reviewed used qualitative methodology to inquire about nurses as patients. Three of the research articles had a quantitative focus, and one was a mixed methods study. The three quantitative research articles included a descriptive correlational study (Wessman & McDonald, 1999), and two surveys (Gillies, Child, & Biordi, 1993; Morris & Mendias, 1985). Wessman and McDonald (1999) conducted a secondary analysis of a descriptive correlational study to examine nurses’ personal learning experiences with pain and their knowledge of pain management. Gillies, Child, and Biordi (1993) conducted a survey of 1,500 nurses and asked if they or a loved one had ever been hospitalized, and how that experience may have affected their practice. The survey had two questions and did not specify whether it was the nurse or the nurse’s family member that had been hospitalized. Morris and Mendias (1985) asked nurses and doctors if they think that they receive special care when admitted to the hospital with a check-box questionnaire. There was an option for comments on the questionnaire. This article simply reported the percentages of responses for each question without discussion or implications of the results. These two studies inform the current study by showing that nurses think that patient experiences impact their nursing practice, and are treated differently when they are patients. However, the reader cannot determine how many of the nurses were actual patients in either of these studies because neither specified how many of the respondents were nurses. Thus, there is no way to know how accurate the information is. Kim, Boren, and Solem (2001) used a nursing patient population to give preliminary testing on a scale that tests therapeutic relationships between nurses and patients. The qualitative phase of the study used a deductive literature review and inductive analysis of master-degree nurses’ comments about therapeutic
relationships. A therapeutic scale was formulated based on this information and preliminarily tested with statistical analysis.

The remaining 16 studies were conducted in the qualitative paradigm. Almost half of the 16 qualitative studies used a phenomenological design (DeMarco, Picard, & Agretelis, 2004; Jones, 2002; Leite, 2007; Minaar, 2005; Picard, Agretelis, & DeMarco, 2004; Todres, Fulbrook, Albarran, 2000; Zeitz, 1999). Phenomenological study designs are popular in nursing research, thus this is not surprising. In most cases, the researchers specified why phenomenology was chosen. The researchers chose phenomenology as the methodology because they wanted to explore the experiences of the nurses-patients in-depth, which was indicated in the purpose statements. Leite (2007), Todres, Fulbrook, Albarran (2000), and Zietz (1999) give a description of why they chose phenomenology and the specific phenomenological model that framed the research design. Minnaar (2005) gave no explanation of why or how phenomenology framed the research design. In the remaining studies, researchers give brief explanations of how this methodology informed the research design (DeMarco, Picard, & Agretelis, 2004; Jones, 2002; Picard, Agretelis, & DeMarco, 2004). Because the researchers were specifically interested in a detailed description of the patient’s experiences, a phenomenological approach was appropriate.

Three groups of researchers used narrative inquiry as their research methodology (Guzman et. al, 2009; Harker, 2000; Schwind, 2004). Two of the researchers used narrative to learn what it feels like to be a patient in a healthcare setting (Harker, 2000; Schwind, 2004). Guzman et al. (2009) researched the narrative of a nurse-as-patient who adopted hope while receiving treatment for breast cancer. Guzman et al. (2009) did not
explain how or why narrative inquiry was chosen, simply that they wanted to use narrative to create a portrait of the nurse in the case study. Harker (2000) and Schwind (2004) provided great detail regarding the reason for selecting narrative inquiry. Harker’s study was a master’s thesis, and Schwind’s study was her dissertation. Harker had a significant patient experience that impacted her practice and wanted to use narrative as a way to include her story in the study. Schwind views the narrative of the patient experience as part of a larger narrative about the participants’ professional growth. She wanted to place the impact of the patient experience within the larger context of the participants’ lives. In addition, she was a patient and wanted to be able to include her story in the study. These researchers saw the connection between their life experiences and the topics of their studies as being important to acknowledge. Thus narrative inquiry became the methodology through which they could accomplish this goal.

The remaining researchers used different research methodologies such as qualitative descriptive (Duke & Connor, 2008), narrative-autoethnography (Lawson, Delamer & Hutchinson, 2008), naturalistic inquiry (Williams, 1997; Williams, 1998), qualitative inquiry of grounded theory (Kempainen, Bartels, McCarthy-Veach, 2007), and non-specified qualitative inquiry (Cotter, 1990). Lawson et al. (2008) wanted to use the example of a nurse-patient to explain to readers why self-determination is an important aspect of rehabilitation. They used narrative to place the patient’s rehabilitation in the context of her illness story, and autoethnography to more deeply explore the experience. Use of interviews, stories, essays and the patient’s published articles were used as data. They effectively demonstrated the importance of the patient’s self-determination in the quality or rehab care. Cotter (1990), Duke and Connor (2008),
Kempainen, Bartels and McCarthy Veach (2007), and Williams (1998; 1997) stated that they use qualitative inquiry, but do not go into great detail about the reason and appropriateness of the methodology for the study. They seem to assume that it is natural to use qualitative inquiry given the purpose of the research. This methodology may indeed be appropriate, but it gives the reader the impression that they do not have a firm understanding of qualitative research or perhaps of the research design. Williams’ studies were very short, which gives the reader the impression that there were strict journal page limits; this possibly caused the research design section to be shortened.

Overall, the researchers that explain the methodology and choice of methodology did so appropriately, and convinced the reader that it was consistent with the purpose of the research. Unfortunately some of the researchers give little explanation for the methodology and its connection to the study.

A weakness in this body of literature was the lack of theory behind the research. Only six of the studies were placed within a theoretical context (Cotter, 1990; DeMarco, Picard & Agretelis, 2004; Kempainen, Bartels & McCarthy Veach, 2007; Picard, Agreteli & DeMarco, 2004; Williams, 1998; Williams, 1997). Tandem studies by DeMarco, Picard & Agretelis (2004), and Picard, Agreteli & DeMarco (2004) use Watson and Newman’s models of caring. These are well known nursing theories, and are particularly appropriate for the first study because the purpose was to understand the nurses’ experiences in relation to being recipients and deliverers of nursing care. The second study is about the effect of the patient experience in relation to cancer survivorship, thus it is unclear how the caring model applies to this study. Williams (1998; 1997) and Cotter (1990) use various perspectives of critical theory. Cotter used feminist systems theory to
provide the context for the experience of the nurses. She provided a critical view of the healthcare system. Williams used a critical sociological perspective, and critical theory from the perspective of Habermas, Freire, Foucoul and Tong to explain why nurses are sometimes afraid to disclose their professional background and why they view their bodies the way they do as a result of the patient experience. While it is fascinating to think about why nurses perceive their experiences the way they do, these researchers do not explain how the experience impacts nursing practice. Kempainen, Bartels & McCarthy Veach (2007) use grounded theory to develop a framework to show how healthcare providers’ behaviors influenced the patient experience. The researchers were able to suggest specific behaviors that influence the patient experience.

These six researchers that use theories based their studies in well-known and well-established theoretical frameworks, mostly within healthcare. None of these researchers focus on the patient experiences from an adult learning or adult education standpoint. While Williams and Cotter use critical theory as the framework for their studies, they do not frame their discussion in terms of adult learning or adult development. This study utilizes an adult learning theory (discussed later in this chapter) as way to understand the nurse-patient experience in terms of the learning that takes place, which can contribute to our understanding of how nurses learn compassion.

**Findings of the Nurse-as-Patient Literature: Impact of the Patient Experience**

This section examines the personal accounts and research articles in greater depth, with discussion of common themes in the literature. The major themes were: realizing the importance of compassion when becoming a patient, emotions in the nurse-patient
experience, and the impact of the patient experience. Each theme is discussed in the following sections.

**Realizing the Importance of Compassion when Becoming a Patient**

In general, the researchers discuss the importance of interactions between nurses and nurse-patients and the impact that these interactions have on the nurse-patients. Interactions between the nurse providing care and the patient directly relate to the way a patient feels (Bush, 2008; Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Duke & Connor, 2008; Guzman et al, 2009; Harker, 2000; Jones, 2002; Kempainen, Bartels & McCarthy Veach, 2007; Kinnard, 2009; Lawson, Delamere, & Hutchinson, 2008; Palmer, 2004; Picard, Agretelis, & DeMarco, 2004; Schwind, 2004; Stevenson, 2006; Stott, 2008; Todres, Fulbrook, Albarran, 2000; Zeitz, 1999). The nurses describe ways that interactions can be perceived positively or negatively. For example, Stevenson (2006) described interactions that she perceived both positively and negatively. Nurses who came into her room and sincerely asked how she was feeling made her feel better. Some nurses acted as if they did not even want to come into her room which was upsetting. Unfortunately Stevenson’s example is one of many, and discussion regarding interaction between nurses and the nurse-patients often surrounded lack of compassion in nursing care. This led to dissatisfaction in the relationship between nurses and patients, and realization of the importance of compassion.

Dissatisfaction in the nursing relationship due to lack of compassion is present in both the personal accounts and research. Several of the nurses express concern that nurses generally lack compassion when working with patients (Brown, 2011; Clar, 2006; Emerson, 2009; Stevenson, 2006; Stott, 2008). Clar (2006) questioned if she provided
enough compassion and support to patients before her own patient experience. Stevenson (2006) felt that very few nurses during her stay really cared about how she felt, and did not treat her with compassion. Each of these nurses commented that they think treating patients with compassion is important, and now pay more attention to this in their own practice. Researchers discussed negative perceptions of the nurse to nurse-patient relationship. In several studies the nurse-patients reported that they were interested in receiving ‘caring’ or compassionate care, but did not receive it at times which resulted in dissatisfaction (Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Duke & Connor, 2008; Harker, 2000; Kempainen, Bartels, & McCarthy Veach, 2007; Schwind, 2004). Others nurses mentioned the importance of “support.” These nurses said that they did not receive enough support from the nurses taking care of them (DeMarco et al., 2004; Jones, 2002; Leite, 2007; Schwind, 2004). Still others perceived that they were literally mistreated by the nurses they worked with, or nurses taking care of them (Cotter, 1990; DeMarco et al., 2004; Leite, 2007). Some nurse-patients felt that when they revealed their titles the nurse-to-patient relationship changed. Some received less care while in the hospital as a result of this disclosure (Duke & Connor, 2008; Williams, 1998). However, a few nurse-patients felt that they receive better treatment from nursing staff when they revealed that they were nurses (Duke & Connor, 2008; Morris & Mendias, 1985). With many nurse-patients reporting dissatisfaction in their nursing relationships, especially in terms of compassion, it appears that this aspect of their patient experience struck a chord. It is unfortunate that so many nurses-as-patients experienced dissatisfaction with the relationships between themselves and the nurses providing care. This is unfortunate because nurses providing care have a direct impact on a patient’s health (DeMarco et al.,
This brings into question specifically what impact the dissatisfying relationships had on the nurses-as-patients when they return to work.

*Emotions in the Nurse-Patient Experience*

This section discusses the emotional experiences that the nurses have as patients. The personal accounts and research discuss impressions and feelings that nurses have about becoming patients. Nurses discussed experiencing unsettling emotions, and the importance of emotional healing. On first glance the impressions of the patient experience seem to be incongruent with this study’s interest in a change of compassion in nurse-patients. However, so many of the nurses made comments about unsettling emotions, and the importance of emotional healing that it cannot be ignored. There is a possibility that these experiences impact the change in compassion that nurses experience. Therefore the impressions are worthy of discussion here. Discussion of the emotions comes first, followed by the importance of emotional healing.

Nurses learned first-hand about the unsettling feelings associated with being a patient, and are found in the majority of the literature reviewed. These feelings have a wide range from experiencing fear to feeling a loss of control. Most of the nurses who shared their personal patient stories mention anxiety, fear, being afraid, or being scared at some point during their patient experience (Bowers, 2004; Clar, 2006; Doell, 2008; Emerson, 2009; Lanza, 2006). One nurse provided a detailed description of the chain of events surrounding her critical illness which conveys a sense of terror, and confusion (Bowers, 2004). Many of the findings from the various research articles revealed strong unsettled feelings as well. Feelings of vulnerability, loss, sadness, anguish, depression,
fear, anxiety were discussed (Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Gillies, Child, & Biordi, 1993; Guzman et al., 2009; Harker, 2000; Jones, 2002; Leite, 2007; Picard, Agretelis, & DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Williams, 1998; Williams, 1997; Zeitz, 1999). For some, emotions of fear, and vulnerability were related to the disease diagnosis (DeMarco et al., 2004; Guzman et al., 2009). Others experienced loss and sadness while suffering from a disease (Leite, 2007).

Guilt is another emotion experienced by nurse-patients. In Doell’s (2008) personal account of cancer, she reported feeling guilty that she did not know she had cancer sooner than her doctor. She thought that she should have been able to sense that something was wrong, and even felt guilty because she survived, and other people have not. Her guilt stemmed from having preexisting knowledge about cancer as a cancer nurse, yet not being able to predict that she had cancer. Similarly, Lanza (2006) reported feeling guilty that she had to impose herself on others while she recovered from her stroke. As a nurse, Lanza is aware of the assistance that people with illnesses need. She felt guilty because she felt that needing others to assist her caused an imposition for them. In addition to Doell and Lanza, several other nurse-patients experienced guilt. These nurses directly relate their guilt to their professional nursing roles. A participant in Jones’ (2002) study felt guilty when they experienced side effects from HIV medications because as a nurse they should have known better. In other words, they should have known about the side effects and the lifestyle change that comes with this medication regime, but they had not considered it before becoming HIV patient themselves. Some nurses felt that they had done wrong when asking the nursing staff to help them, therefore the feelings of guilt caused them to do things independently when they should have called someone for help.
Overall, the guilt that these individuals experienced seems to relate to the knowledge that they have as nurses.

The unsettling feeling of loss of power or control was found in the literature. This loss ranges from feeling a loss of control over the illness situation by virtue of being a patient (Cotter, 1990; Gillies, Child, & Biordi, 1993; Jones, 2002; Leite, 2007; Picard, Agretelis, DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Williams, 1998; Williams, 1997; Zeitz, 1999), to feeling a loss of control over life itself (Jones, 2002). One study explained that nurses may divulge their profession to healthcare providers in an attempt to regain control that has been lost as a result of the illness (Williams, 1998). These feelings are not unique to nurses, but it shows that nurses experience emotions like other people.

The feelings and emotions discussed above made a lasting impression on the nurse-patients. However, the current literature cannot specifically answer how emotions during the patient experience impact nursing practice. In light of this study it begs the question of whether these types of emotional experiences are necessary for a transformation of compassion in practice; and what is it about these emotions that impacts nursing practice? This study was able to identify emotions as an important aspect of a change in compassion.

The importance of emotional healing is another aspect of the patient experience that the literature discussed. The literature mainly focused on nurses with physical illness, with none focusing specifically on nurses with emotional or mental health problems. However, many of the nurses mentioned the need for both physical and emotional healing, particularly emotional healing. This was often because nurse-patients felt it was
not adequately addressed in their healthcare. Nurses who wrote personal accounts discussed the emotional impact of illness. Some of the nurses mentioned that emotional healing takes longer than physical healing. Bowers (2004) discussed that it took only a few months to heal physically, but it was much longer before she healed emotionally. Doell (2008) mentioned that the recovery from cancer can take months, but the emotional recovery can take years. Lanza (2006) detailed her emotional state and the slow recovery process which took place over several years. With a different focus, Fawaz (2007) stated that she has an understanding of both the physical and psychological needs of patients after being an ICU patient. When Stevenson (2006) was a patient, she simply wanted a nurse to attend not only to her physical needs, but her emotional needs as well by sitting down and talking with her. Others mentioned that health care providers do not pay attention to emotional needs of patients. Providers focus on the physical aspect of a patient’s health problem instead (Brown, 2011; Stott, 2008). Some of the researchers discussed emotional health and healing. Participants in Jones’ (2002) study discussed the concept of “living under a dark cloud” when living with HIV/AIDS and taking medications that their bodies may become resistant to. They learned to live with constant worry in the back of their minds. The nurse-patient in Leite’s (2007) case study had to come to terms with her emotions of “loss, revolt, and sadness” before she could begin to transcend her disease. Prior to this however, she felt that coworkers were uncompassionate in their attitudes toward her, thus contributing to her emotional turmoil. Minnaar (2005) mentioned the importance of providing counseling services to nurses diagnosed with HIV/AIDS. The reports from nurses speak to the fact that emotional needs are important, and impact the person’s overall health and sense of well-being.
Similar to the discussion of satisfaction with nurse-to-patient relationships above, this demonstrated the power that nurses providing care have in relationships with patients. A relationship that does not pay attention to emotional needs can result in more distress for the patient.

Nurses learned about the importance of emotional support both in the acute phase of illness and in the long-term (DeMarco, Picard, & Agretelis, 2004; Jones, 2002; Minnaar, 2005; Picard, Agretelis, & DeMarco, 2004; Schwind, 2004; Tordes, Fulbrook, & Albarran, 2000). Support may come from co-workers, and nurses providing care through simple acts like holding a person’s hand, or listening (DeMarco et al., 2004; Jones, 2002; Minnaar, 2005; Picard et al., 2004; Schwind, 2004). Emotional support may be from family members in the form of advocacy, or daily rituals to help calm the nurse-patient (Tordes, Fulbrook, & Albarran, 2000). In each case, emotional support was needed to help in the physical and emotional healing process. Nurses greatly appreciated the support.

\textit{Impact of the Patient Experience}

The literature review demonstrated that the patient experience had a significant impact on nurses. The themes were placed in two main categories: learning and changes in practice and perspective. The first theme points out general learning that the nurses experienced. The second theme addresses the changes nurses experience in their perspectives and professional practice. Part of the change in perspective involves a reported change in empathy, sympathy and compassion. The themes are discussed below, beginning with significant learning.
**Significant learning.** Both the personal accounts and researchers revealed learning took place. Most of these articles do not specifically address learning in that they do not state it as the purpose for sharing personal stories or conducting research. However, there is some indirect discussion in the literature of learning that takes place as a result of the patient experience.

There are some examples of learning in the personal accounts. Bowers (2004) and Fawaz (2007) learned about the intricacies of being a patient in the ICU. Bowers has such a strong experience in the ICU that she shared what she learns with other hospital staff and spearheaded a change in patient care. Fawaz stated, “I’ve learned priceless lessons from my experience” (p. 1). She referred to learning to attend to both physical and psychological needs of patients, and taking care of “little things” (p. 1). Clar (2006) and Doell (2008) learned what it is like to be a cancer patient. Lanza (2006) shared her learning about being a stroke patient in great detail. Some of which included the psychological impact of stroke and things that no one else knows is important to stroke victims. Others learn how to respond to patients’ anxieties with compassion (Bush, 2008; Brown, 2011; Emerson, 2009; Knight, 2010; Stott, 2008). In addition, learning is discovered within the research studies. Cotter (1990) and Gillies, Child, and Biordi (1993) state that nurse-patients learned that patients often have different priorities than nurses, and a different perspective of any given situation. Picard, Agretelis, and DeMarco (2004) discussed that nurse-patients learned to be more compassionate, and better patient advocates. There is definite learning in this population; however, because discussion of learning was not the purpose of the studies and personal accounts, they are not always very specific regarding the learning that has taken place. Demarco, Picard, and Agretelis
(2004) and Picard, Agretelis, and Demarco (2004) discussed practice changes that occur as a result of the patient experience which reflects a transformative learning experience. One even describes the experiences as looking in a “transformative mirror” (Picard, Agretelis, & Demarco, 2004, p. 541). However, they did not discuss the experiences in terms of learning, but simply the themes related to nurses experiences and the impact on professional practice.

The literature shows that learning occurs in the form of “understanding” or “better understanding.” Both of these phrases were used in the literature and were in reference to understanding of patients’ feelings and emotions, patient experiences, or ways to provide better care. Several of the personal accounts state that they have a better appreciation or understanding of what patients go through. Bowers (2004) stated, “I now know how it feels…” She did not specify what her understanding is; but her account is very detailed, so the reader’s impression is that the story is describing her detailed understanding. Clar (2006) mentioned her “understanding” of what patients go through several times. Fawaz (2007) stated that she has an “understanding” of the needs an ICU patient, such as paying attention to details of patient care. Lanza (2006) discussed how she is able to understand what stroke patients are going through when they have difficulty speaking. Others discussed their understanding of the emotions that patients experience and the reassurance that patients desire to have from their nurse or healthcare provider (Bush, 2008; Brown, 2011; Emerson, 2009; Knight, 2010; Phillips, 2006; Palmer, 2004; Stott, 2008). The understanding surrounds the emotions that patients experience, and what is needed to help alleviate the suffering of patients. In the personal accounts, the nurses described aspects of empathy and compassion. The empathetic understanding is
demonstrated in the understanding of the emotions of the patients. The compassionate aspect involves their understanding of what is needed to help alleviate the patient’s suffering.

In most studies participants reported having a better understanding of patients’ perspectives, and patients’ experiences (Cotter, 1990; Gillies, Child, & Biordi, 1993; Jones, 2002; Leite, 2007; Picard, Agretelis, & DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Zeitz, 1999). Some nurses mentioned that they now know “how it feels” to be a patient (Cotter, 1990; Gillies, Child, & Biordi, 1993). Others mentioned that nurse-patients gained “new insights” regarding patient care (DeMarco, Picard, & Agretelis, 2004; Gillies et al, 1993; Jones, 2002). Some nurse-patients stated that being a patient is a much harder work as being a staff member (Gillies et al, 1993). The understanding surrounds the physical and emotional aspect of being a patient.

The descriptions of the learning that the nurses experience and the new “understanding” that they gain from the experience can be looked at as a transformative learning experience. This theoretical perspective was not addressed in the body of literature pertaining to nurses-as-patients. By using a transformative learning theory lens the process of the nurses’ learning and resulting practice changes from the patient experience can be addressed. The body of literature can gain a clearer picture of how nurses learn through the patient experience.

*Changes in practice and perspective.* As a result of the illness and patient experience, nurses experienced change. The new understanding of patient experiences contributed to changes in professional practice and perspective, and improvement in compassion, empathy, or sympathy.
Change may come in the form of a changed perspective in life, a change in lifestyle, or a change in professional practice. For example, in Bower’s (2004) personal account, her illness had such a profound effect on her that she changed her personal practice and helped make a change in policy at the hospital she works in. Her experience allowed her to see where there were gaps in patient care and address those gaps which resulted in better patient care. Doell (2008) says that she had a change in “paradigm” (p. 552) and has changed both as a person and a nurse. She now has a better understanding of what patients experience, and tries to incorporate this into her patient interactions. Others used their experience to change her practice by paying attention to the “little things” when caring for patients (Brown, 2011; Emerson, 2009; Fawaz, 2007; Palmer, 2004). Lanza (2006) now takes her time when talking with stroke patients. In addition she maintains patience when working with stroke victims, something that she feels most people lack.

The research indicated change, and was discussed in terms of changing professional practice, or a change in life perspective. Nurses in Gillies, Child, & Biordi’s (1993) study report being: more patient, addressing pain control faster, and providing more or improved patient and family education. One study found that nurses change their practice to become more compassionate, self-disclosing with patients, better advocates, and volunteer to share expertise in cancer groups (Picard, Agretelis, & DeMarco, 2004). Another study reported personal and professional growth, surrounding improvement in communication with and compassion for others (Kempainen, Bartels, and McCarthy Veach, 2007). For participants in Jones’ (2002) study, they spoke about HIV/AIDS as changing their lifestyles. This is partly due to the intense medication regimen that they
must adhere to, but it is a different perspective as they change from being HIV negative to HIV positive. In Leite’s (2007) case-study, the nurse changed her perspective of life when she came to terms with emotions surrounding her disease. These researchers demonstrated that the patient experience impacts nurses by causing a change in practice and life. However, none of them investigated how the patient experience impacts specific aspects of the nurses’ professional practice when they return to work. For example, Wessman and McDonald (1999) looked at nurses’ experience of pain and whether or not it affects their knowledge level and ability to learn about pain management; but the study did not ask if the pain experiences affect the way nurses address pain management in patient care.

Another aspect of practice change specifically revolves around compassion, and empathy. Several of the personal accounts discussed changes in compassion, either reaffirmation or increased compassion in practice. Also, the experience of being a patient allowed for more empathy on the part of the nurse. For example Clar (2006) stressed the importance of expressing compassion when caring for patients. She stated that she has greater empathy for what patients are going through. She feels that compassion and empathy come from the heart and that patients can tell when someone truly feels empathetic. Stevenson (2006) spoke strongly about compassion. She indicated that most of the nurses who cared for her in the hospital had no compassion. Only a few took the time to talk with her in a compassionate way. Stevenson ended by stating that “…patients deserve both skilled and compassionate professionals” (p. 10). Fawaz (2007), remarked that her experience allowed her to be empathetic to her patients by knowing when they need to be comforted. Lanza (2006) gave a list of suggestions for nurses who care for
stroke patients. In the list she encouraged nurses to show compassion and truly listen to patients.

Researchers found that nurses are more aware of their own compassion as a result of the illness. Participants in Cotter’s (1990) study unanimously stated that being a patient increased their empathy toward patients. Several other researchers cited increased compassion toward patients after the experience (Gillies, Child, & Biordi, 1993; Kempainen, Bartels, and McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004;). Other researchers sited that being patients helped nurses to empathize or sympathize with patients (Wessman, 1999; Williams, 1997).

Given that nurses report changes in compassion secondary to the patient experience, it would be beneficial to understand how this change takes shape. Unfortunately, none of these researchers purposefully set out to understand compassion or changes in compassion. They simply found that nurses report a change in compassion. Some give examples of compassionate behaviors as a result of the patient experience (Cotter, 1990; Demarco, Picard, & Agretelis, 2004; Harker, 2000; Jones, 2002; Williams, 1997). Because the purpose of the studies did not involve an investigation of compassion, they cannot go further than saying that compassion changes, or describe aspects of compassionate care. This study takes the body of literature to the next step, which is to ask and understand how the patient experience affects the specific aspect of compassion in professional practice, and how it is learned.

As discussed above, a transformation can be identified because nurses report changes in perspective and personal practice as a result of the patient experience. Using a transformative learning lens to research this population can look at the process that
nurses-as-patients go through as they experience significant changes. Understanding this process can inform how compassion develops in nurses-as-patients. Transformative learning theory was the lens for this study.

Summary of Nurses-as-Patients Literature

The purpose of this literature review was to provide a better understanding of the experiences of nurses as patients. Fifteen personal accounts and 20 research studies that address nurses as patients are presented. None of the articles specifically addressed the learning of nurse-patients. Three major themes were discovered: realizing the importance of compassion when becoming a patient, emotions in the nurse-patient experience, and the impact of the patient experience. Taking a broad look at this literature shows that the patient experience is significant for nurse-patients and is translated into a change in practice. Change in compassion is often reported. Therefore this study will further address compassion and the process that nurses go through to achieve this change.

Compassion (and why it is specifically addressed over empathy or sympathy in this study) is discussed in the next section of the literature review. The final section of the literature review discusses the theoretical framework.

Compassion

This section addresses the concept of compassion and its relevance to the study. As discussed previously, nurses who become patients often find the experience to be personally significant which translates into an improved understanding of patients and change in practice, specifically in relation to compassion. This is interesting because compassion is an important aspect of nursing practice (Georges, 2011; Hamilton, 1994;
Therefore the study is interested in understanding how nurses learn compassion in their practice.

The following discussion addresses how compassion is connected to nursing practice, definitions of compassion, and an explanation of how compassion is different from the terms empathy, sympathy, pity and care. A review of empirical literature addressing compassion follows. Finally, the section concludes with discussion of how the literature review pertaining to compassion informs the proposed study and demonstrates relevance of the study.

**Compassion in the Nursing Profession**

Before discussing specific definitions of compassion, it is important to understand its connection to the nursing profession. Without understanding the important place that compassion has within the profession, a discussion of how it is defined and used in this study will not make sense. This section begins with discussion of humanism as the foundation of the nursing profession followed by the connection that compassion has with this foundation. Finally, evidence of a lack of compassion in modern nursing practice is presented.

**The Foundation of Nursing**

Historically, the nursing profession rests its core values on a humanist philosophy. “Humanism focuses on humans and the human experience” (Fagermoen, 1999, p. 146). Part of a humanist philosophy is that it focuses on the individual and considers the person as a whole (Boychuck Duchscher, 2000; Hartrick, 2000; Metcalfe, 1998; Woodrow, 1993). Humanism focuses on the potential for growth, dignity, equality, tolerance, autonomy, freedom, and creativity (Elias & Merriam, 2005; Fagermoen, 1999; Metcalfe,
A humanist perspective desires to maximize potential for human growth in spirit, mind, and emotions, assumes that humans are innately good, and believes that people can actively influence the environment to change it (Elias & Merriam, 2005; Fagermoen, 1999; Metcalfe, 1998).

Humanism is considered to be at the core of what a nurse is and why a nurse exists (Boychuck Duchscher, 2000; Clark, 2005; Fagermoen, 1999; Woodrow, 1993). The purpose of nursing is to provide care in the form of help, comfort, and healing to those in need, which is seen as fundamental to human life (Hartrick, 2000; Fagermoen, 1999; Woodrow, 1993). Nursing professional practice involves: respecting and nurturing others, developing helping-trusting relationships, promoting harmony with body-mind-spirit, and supporting human needs (Bevis, 2000; Fagermoen, 1999; Wills, 2002). These acts of caring reflect the humanist philosophy surrounding the importance of each person and human dignity (Fagermoen, 1999). The humanist philosophy is therefore central to the definition of nursing.

A major aspect of the humanist philosophy is carrying out professional practice through compassion. Compassion compliments the humanist philosophy in that it involves a nurse interacting with patients on a personal level and alleviating the individual’s suffering in the manner that it is being experienced. Providing compassionate care specifically addresses the suffering that a person has on physical, emotional, or spiritual level and treating the patient as a whole person (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Graber & Mitcham, 2004; Hem & Heggen, 2004; Lindholm & Eriksson, 1993; Perry, 2009; Torjuul, Elstak & Sorlie, 2007). By addressing these
things, compassion becomes an integral part of providing holistic care to people and therefore a way that nurses maintain a humanist focus in professional practice.

**Compassion as an Essential Aspect of Nursing Practice**

This section presents scholarly literature regarding the importance of compassion in the nursing profession. It begins by discussing why some nurses believe that compassion is an essential aspect of professional practice, and historical association of compassion with the profession. This is followed by discussing the perceived lack of compassion in modern nursing practice and the implications that uncompassionate care present. A more in-depth discussion of the definition of compassion is in the section addressing the definition.

Historically, in the late 1800’s to early 1900’s, American nursing underwent a significant change that began establishing nurses as part of a formalized profession (Hamilton, 1994). Part of this change involved shifting patient care from an “individualistic and voluntary approach” in care, to a more formalized and “collective” approach (Hamilton, 1994, p. 7). As the profession began to develop official standards for care and nursing behavior, it also asserted that compassion is an essential quality of nurses and is essentially an ethical or moral obligation (Hamilton, 1994). By considering compassion to be a requirement for nurses, the profession set itself apart from other professions which consider compassion to be a desirable quality, but not necessarily a requirement. Through this, compassion became the essential quality that links nursing practice with its humanist foundation.

In addition to being a part of the humanistic philosophy, compassion is a necessary attribute of professional practice because in order to truly promote health and
well-being the nurse must make a connection with the person she is caring for (Jull, 2001; Schantz, 2007; van der Cingel, 2009). A compassionate connection helps the nurse determine the patient’s needs and ways to address the needs (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Lindholm & Eriksson, 1993). Therefore, compassion is closely linked with the profession’s purpose because it is the method by which nurses acknowledge suffering and do something to alleviate the suffering.

Another reason that compassion is considered to be integral to nursing practice is that many consider it to be a moral virtue of the profession. This moral code serves as the guiding principle that determines nursing action (Armstrong, Parsons, & Barker, 2000; Hamilton, 1994; Hem & Heggen, 2004; Jull, 2001; Schantz, 2007; van der Cingel, 2009; von Dietze & Orb, 2000; Walker, 2009). If the purpose of the nursing profession is to provide care for others with the intention of promoting health and well-being then there is a belief that the person providing care must have a genuine interest in the person who needs help (Hem & Heggen 2004; Perry, 2009; Walker, 2009). If a nurse lacks compassion for a sufferer this directly conflicts with the core of what the nurse represents. If a nurse lacks compassion, then she is not in-tune with the suffering that a person is experiencing and aspects of patient care will be missed or be unaddressed. This means that a person is not receiving all of the help that he/she needs. Nurses are supposed to help decrease the suffering of others. Hence, many in the profession believe that it is a nurse’s moral duty to provide compassionate care.

**Lack of Compassion in Nursing**

Currently there is discussion within nursing that even though the profession rests its fundamental values on compassion and humanistic care there is an erosion of these
values. This value erosion is concerning because it brings into question authenticity of the profession, quality of care provided to the public, and relevance of the profession (Jull, 2001; Maben, Cornwell & Sweeney, 2010). It brings these things into question because if nursing fails to acknowledge the human aspect of our patients then we do not holistically promote health and well-being. Furthermore, decreasing compassion in nursing care results in decreased patient satisfaction (Heffernan, Giffin, McNulty & Fitzpatrick, 2010), and decreases patient health overall (Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Steffen & Master, 2005). Patients report increased suffering when their healthcare provider does not acknowledge their suffering or treat them as a whole person (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Fenwick & Bayne, 2010; Hem & Heggen, 1997).

The modern healthcare system is often cited as a major contributor to the erosion of compassion in the nursing profession (Davidson & Williams, 2009a; Georges, 2011; Jull, 2001; Maben, Cornwell & Sweeney, 2009; von Dietze & Orb, 2000; Weiss, Malone, Merighi & Benner, 2009). Some of the reasons that compassion is reduced is due to: poor working conditions for nurses in favor of cost savings (Georges, 2011; von Dietze & Orb, 2000; Weiss, Malone, Merighi & Benner, 2009), placing a greater value on diagnosis and treatment of diseases, and technical care rather than treating people as a whole, (Davidson & Williams, 2009a; Jull, 2001; Maben, Cornwell & Sweeney, 2009). These are discussed below.

Current working conditions in healthcare agencies are believed to have a negative impact on the ability of nurses to provide compassionate care (Georges, 2011; von Dietze & Orb, 2000; Weiss, Malone, Merighi & Benner, 2009). Working conditions that affect
the ability are things such as increased nurse-to-patient ratios, or processes within the healthcare agency that reduce time spent with patients. Increasing nursing ratios and focusing work flow on technical aspects of care affect healthcare agency revenue. Nurses report frustrations with these situations saying that patient contact is not valued by healthcare administrators. Research has shown that nurses have been told by administrators that there is no monetary value in what nurses do, referring to the one-to-one patient contact of operating room nurses (Weiss, Malone, Merighi & Benner, 2009). Rather, value is placed on the speed at which nurses can prepare operating rooms to get ready for the next case. Patient interaction does not improve turn-over time resulting in fewer operating cases, which results in less revenue. By decreasing the amount of time that nurses can spend with patients, there is a decrease in development of relationships and human connections that are needed to provide compassionate care.

The current healthcare system places greater value on scientific and technical aspects of nursing care than the values that ground the profession (Maben, Corn & Sweeney, 2009). This is not to say that technical aspects of care are bad or not important, but there is greater emphasis placed on these causing the humane aspect of care to be decreased or ignored (Davidson & Williams, 2009a; Jull, 2001; Maben, Cornwell & Sweeney, 2009; von Dietze & Orb, 2000). Nurses work in systems that promote measurable outcomes and decreased hospital stays. Providing compassionate care is not seen as being essential to this objective because it is not considered an aspect of care that affects patient outcomes or revenue. Therefore compassion receives less attention in healthcare settings (von Dietze & Orb, 2000).
Compassion and Clarification of Related Terms

It is necessary to discuss compassion and terms related to compassion; and specifically why compassion is being addressed in this study. Compassion is similar to and often used interchangeably with other terms such as empathy, sympathy, pity, and caring (or care) (von Dietze & Orb, 2000). These related terms are discussed first, followed by a detailed definition and discussion of compassion and the comparison of compassion with its related terms.

When developing an understanding of the terms empathy, sympathy and compassion both nursing and psychological literature was reviewed. This is because these are terms that pertain to human emotions which psychology studies closely. In addition, the nursing profession acknowledges human psychology in practice.

Empathy

Empathy is a term that is sometimes used when referring to nursing practice, and has roots in human psychological development (Duan & Hill, 1996; Eisenberg, 2000; Eisenberg & Miller, 1987; Wispe, 1986). Empathy is an ability developed in early childhood, and involves understanding and experiencing the emotions of another person. This is referred to as matching, mirroring, sharing, or vicariously experiencing another person’s emotions (Duan & Hill, 1996; Eisenberg, 2000; Eisenberg & Miller, 1987; Elliott, Watson, Bohart, & Greenberg, 2011; Gruhn, Diehl, Rebucal, & Lumley, 2008; Mohr, Rowe, & Blanke, 2010; Moore, 2006; Richter & Kunzmann, 2011; Wispe, 1986). It is argued that empathy is the basis for human interaction (Duan & Hill, 1996; Mohr, Rowe, & Blanke, 2010; Moore, 2006).
There is some disagreement about the nature of empathy (Eisenberg & Miller, 1987). Is it an affective or cognitive emotional state? The cognitive view of empathy contends that empathy specifically involves the ability to comprehend or intellectually understand another person’s emotions (Duan & Hill, 1996; Eisenberg, 1982; Eisenberg & Miller, 1987). Whereas an affective view accepts that empathy is an automatic emotional response to another person’s emotions. More recent commentary acknowledges the complexity of empathy and includes both of these views saying that empathy involves affective and cognitive components (Duan & Hill, 1996; Eisenberg, 2000; Gruhn, Diehl, Rebucal, & Lumley, 2008; Richter & Kunzmann, 2011). Thus empathy involves both the comprehension of another person’s emotions and the experience of those emotions alongside the other person.

Empathy involves the ability to perceive, understand and experience the emotions of others. However, empathy in and of itself it does not involve an action (Eisenberg, 2000; Eisenberg & Miller, 1987). In terms of human psychology, empathy is considered a precursor to altruistic or prosocial behaviors such as sympathy or compassion, and is considered to be a necessary trait for moral development (Eisenberg, 2000; Eisenberg & Miller, 1987; Gruhn, Diehl, Rebucal, & Lumley, 2008). Altruism and prosocial behaviors are considered to be intentional acts performed to benefit another person. Specifically, altruism is an intentional action to benefit another person and is not motivated by personal gain or reward. Alternatively, prosocial behavior involves intentional action to help another regardless of personal motivation. For example, the motivation to help another person may be to alleviate personal discomfort or for the emotional joy a person experiences when helping another person (Eisenberg, 1982; Eisenberg & Miller, 1987).
In either case, prosocial and altruistic behaviors are considered to be desirable because they promote positive interactions which benefit both individuals and society overall (Eisenberg, 1982). Empathy is not considered to be an altruistic or prosocial behavior because it is simply the ability of a person to understand and experience another’s emotions. However, one needs an empathetic ability in order to then engage in prosocial or altruistic behaviors.

In nursing literature, empathy is conceptualized in two different ways. One conceptualization refers to kind and compassionate feelings experienced by a nurse toward a patient (Bush, 2008; Clar, 2006; Cotter, 1990; Williams, 1997). Another way that empathy is conceptualized is that it is a specific skill utilized in practice (Jull, 2001; Schantz, 2007; von Dietze & Orb, 2000). The former use of the word empathy indicates a personal connection or relationship developed between the nurse and patient. The connection is considered to be a positive experience for both the nurse and patient. The latter use of empathy has a less personal connotation. When referred to as a specific skill utilized in practice, therapeutic empathy is employed as a way to attempt a cognitive and objective understanding of a patient’s emotions in order to determine nursing actions (Jull, 2001; von Dietze & Orb, 2000). However, it is argued that the attempt to objectify empathy as a determiner for nursing interaction causes the nurse to maintain professional distance and a level of detachment from the patient, and impersonal care as a result of the detachment (Jull, 2001; Schantz, 2007; von Dietze & Orb, 2000). Empathy allows the nurse to identify how a patient might be feeling, but does not encourage involvement with the person and address the person’s suffering beyond the reason for seeking
healthcare. In this use of the term, it corresponds with a cognitive psychological view of empathy.

**Sympathy and Pity**

A similar term that brings understanding to compassion is sympathy. A psychological definition of sympathy states that sympathy involves the ability to understand another person’s emotion and show concern for the person’s well-being (Sympathy in APA Dictionary, 2007; Eisenberg, 2000). Sympathy stems from empathy, and is like empathy in that it develops early in life (Eisenberg, 2000; Wispe, 1986). Unlike empathy, sympathy involves greater concern for the other person, and often a desire to help alleviate suffering (Wispe, 1986). Sympathy is sometimes defined by using the word compassion, and is described as being a concern or compassion for another person brought about by reacting to another person’s emotions (Eisenberg, 2000; Sympathy in APA Dictionary, 2007). Sympathy can occur when another person is suffering, but also when another person is experiencing joy (Wispe, 1986). For example, people experience sympathetic sadness when a friend tells us about the death of a loved one. However, people can experience sympathetic joy when a friend tells us about the birth of a new grandchild.

Literature compares sympathy to compassion saying that both words stem from Greek and Latin origins meaning to suffer with another person (von Dietze & Orb, 2000; Wispe, 1986). Some argue that in the modern English language, sympathy often includes the feeling of pity, whereas the term compassion does not (Jull, 2001; von Deitze & Orb, 2000). Pity involves an acknowledgement of another’s pain and suffering and a reminder of one’s own vulnerability to pain and suffering. Pity includes a sense of feeling glad that
one-self is not the person suffering. Modern uses of the word pity, suggest a sense of superiority and even condescension (Jull, 2001; von Deitze & Orb, 2000). Therefore, someone who pities another person feels bad for that person, but at the same time maintains a distance from the sufferer because he/she is simultaneously glad that it is someone else who is suffering.

**Caring or Care**

A brief discussion of the concept of caring in nursing and the relationship to compassion is necessary. It is necessary to identify what the term care or caring means in the context of this study because it is a complex term in nursing literature.

When we think of the words care or caring, often an emotional state comes to mind, that of being caring. Someone that is nice, and has genuine concern or interest in another person is considered to be a caring person; people that are considered to be caring are liked by others. In a nursing context caring involves much more than being nice and showing concern for another person. Like compassion, it is given great importance in nursing profession, and is often referred to as a foundational or essential aspect of nursing practice (Finfgeld-Connett, 2007; Morse, Solberg, Neander, Bottorf & Johnson, 1990).

Even though caring has received a lot of attention in nursing literature, there is a lack of consensus of how the term is conceptualized within the profession (Finfgeld-Connett, 2007; Morse et. al, 1990; Sadler, 2004; Tanto-Beck, 1999). Caring is described as being complex and involving interpersonal relationships between nurses and patients (Finfgeld-Connett, 2007; Morse et. al, 1990; Tanto-Beck, 1999; Tanto-Beck, 2001). A group of scholars contributed a significant evaluation of the concept of caring in nursing (Morese, et. al, 1990). They were able to categorize literature which conceptualizes
caring into five categories. Caring is considered to be: a human trait, a moral imperative, an effect, and interpersonal relationship, and a nursing intervention. These concepts focus on different aspects of nursing. Those that see care as a nursing intervention or interpersonal relationship relate to specific actions or ways that the nurse helps a patient. An example of nursing care as an intervention might be to suction lung secretions from a patient who is on a ventilator. In this sense, care is a technical skill that nurses carry out. Those that conceptualize care as a human trait, moral imperative or affect view it more as a state of being or values that guide nurses while interacting with and taking care of patients. Others have a different description of nursing care. Caring is considered to be a context specific process (Finfgeld-Connett, 2007). Factors that influence the process are: the level of expertise held by the nurse, the nurse’s interpersonal sensitivity and skill in developing intimate nurse-to-patient relationships, the patient’s openness to caring, the nurse’s professional maturity and moral foundation, and how conducive the work environment is to caring. With this view, providing care for a patient depends heavily on a nurse’s development as a clinician. In the examples above, what is common among them is the interaction between nurses and patients, or the underlying fact that nurses exist to help people.

Sometimes the terms caring and compassion are used interchangeably (Sadler, 2004), and are defined similarly (Totano-Beck, 1999). For example, caring is described as a moral virtue and the essence of nursing (Finfgeld-Connett, 2007; Morse et. al, 1990; Sadler, 2004), which is much like compassion (Hamilton, 1994; von Dietze & Orb, 2000; van der Cingel, 2009). Some define care similarly to compassion. Tanto-Beck (1999) reviewed 11 studies addressing nursing care. Most of the researchers defined care in
terms of responding to a perceived need followed by action to promote well-being.

Finally, this is similar to compassion in that compassion involves sharing the other person’s suffering followed by an action to help alleviate the suffering (Goetz, Keltner & Simon-Thomas, 2010; Jull, 2001; Schantz, 2007; Schulz et al., 2007).

For the purpose of this dissertation, nursing care or caring refers to the complex interactions between nurses and patients that comprise the service provided by nurses. This service includes behaviors, attitudes, emotions that are meant to help the patient. Compassion is an important aspect of nursing care, and is a foundational aspect of the profession. It is not used synonymously with the term caring or care, rather it represents an aspect of nursing care.

**Detailed Discussion of Compassion**

If compassion is different than empathy, sympathy, and caring, then how is it different? Compassion involves aspects of these and is similar to these terms but is viewed differently. A simple definition of compassion involves a person who becomes aware of another’s suffering, experiences a sense of shared suffering and is compelled to act and help alleviate that suffering (Goetz, Keltner, Simon-Thomas, 2010; Jull, 2001; Schantz, 2007; Schulz et al., 2007; Maben, Corwell & Sweeney, 2010; Davidson & Williams, 2009a; Johnson, 2008). Based on this definition, it is similar to empathy in that it involves the ability of a person to perceive the emotions of another person, and experience them. Some say that empathy is a requirement or precursor to compassion (van der Cingel, 200; von Dietze & Orb, 2000). If a person is able to perceive and experience the suffering of another in compassion, then it is reasonable to think that a person must be able to empathetically experience the emotions that another person has.
Where compassion differs from empathy is in the realm of action. Descriptions of empathy involve mirroring or vicariously experiencing another’s emotions (Eisenberg, 2000; Schantz, 2007); but these descriptions refer to basic human interaction as a way to understand another person. Compassion is said to be deeper or go beyond empathy because it incorporates action to help alleviate suffering (Jull, 2001; von Dietze & Orb, 2000). It is a deeper connection with a person because there is an attempt to help him or her. This deeper connection is the diverging point between compassion and sympathy. As mentioned, sympathy is often described as experiencing another’s emotional state coupled with feelings of concern, or action to alleviate suffering (Goetz, Keltner, Simon-Thomas, 2010; Wispe, 1986). Those who compare sympathy and compassion say that sympathy is not as deep a feeling as compassion, and may involve concern for another person but is not necessarily compelled to act and help the sufferer. Whereas someone who is compassionate feels they must do something to help alleviate the suffering (Jull, 2001; Schantz, 2007; von Dietz & Orb, 2000).

Another point of difference in compassion in relation to empathy and sympathy is suffering. Compassion surrounds suffering and an attempt to remove or reduce it (Jull, 2001; van der Cingel, 2009). Compassion specifically focuses on suffering-with someone, and allows a deep connection to occur as a result of the shared suffering between the two people (Jull, 2001; Hamilton, 1994; Schantz, 2007; Schulz, 2007; von Dietze & Orb, 2000). Empathy and sympathy do not require that a person be in pain or suffering to occur. For example, if empathy involves vicariously experiencing emotions of another person, one can empathetically experience joy when someone shares exciting news. Compassion is not needed in this instance because the person has no suffering.
In addition to experiencing the suffering of others, compassion is sometimes referred to as an emotion in and of itself, which is different than the terms sympathy and empathy (Goetz et. al, 2010; Schulz et al, 2007; van der Cingel, 2009). Compassion is seen as an emotion because even though it involves experiencing another person’s emotions, it involves a combination of feelings and action to assist the person who is suffering. Thus the addition of intentional affective and cognitive behaviors associated with compassion cause some to classify it as its own emotion (Goetz et. al, 2010; Nussbaum, 1996; Schantz, 2007; van der Cingel, 2009). Goetz et. al (2010) discuss the emotional origins of compassion at length. To these scholars, compassion is an “other oriented” (p. 356) emotion and developed as a way for people to protect vulnerable offspring and community members. It is advantageous for people to be attuned to the suffering of others and alleviate it. Alleviating suffering promotes emotional and physical well-being which benefits the community as a whole (Goetz et. al, 2010). Even though compassion is referred to as an emotion, scholars are quick to point out that it is an emotion that requires rational thought (Nussbaum, 1996; van der Cingel, 2001; von Dietze & Orb, 2000). The connection with the affective aspect of compassion and the cognitive aspect is that the compassionate person experiences the suffering of the other person and decides to do something about it. In order to first decide to act, and then decide what the action is going to be, the person must involve the use of rational thought (Nussbaum, 1996). Refer to Table 1 for comparison of defined terms.
<table>
<thead>
<tr>
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<th>Definition for this study</th>
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</tr>
<tr>
<td>Empathy</td>
<td>Empathy involves understanding and experiencing the emotions of another person. This may be referred to as matching, mirroring, sharing, or vicariously experiencing another person’s emotions (Duan &amp; Hill, 1996; Eisenberg, 2000; Eisenberg &amp; Miller, 1987; Elliott, Watson, Bohart, &amp; Greenberg, 2011; Gruhn, Diehl, Rebucal, &amp; Lumley, 2008; Mohr, Rowe, &amp; Blanke, 2010; Moore, 2006; Richter &amp; Kunzmann, 2011; Wispe, 1986). Empathy in and of itself does not involve action (Eisenberg, 2000; Eisenberg &amp; Miller, 1987).</td>
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Compassion in Empirical Literature

As demonstrated, there is a lot of discussion pertaining to compassion in the literature. In addition to commentary addressing compassion, empirical evidence is part of the literature review. The method for obtaining research about compassion began with on-line searches. Databases searched include CINAHL, PubMed (Medline), PsychINFO, PsychNET, and dissertation abstract international through ProQuest. The main search term was “compassion” and classification as being empirical research. I expected few studies addressing compassion, so there was no date limit. Inclusion criteria for the studies included compassion in the title, and/or compassion as the object of study. The nursing database had the greatest number with a total of 13 studies chosen for the review. Initially there were more than 13 studies that populated the search, however some had the word compassion in the title, but were not about compassion. Others were not true research. The medical and psychological databases had approximately 25 studies pertaining to compassion. However, most were not appropriate for this review because they addressed compassion in primates (whether or not primates have emotions such as compassion or altruistic behavior) or finding and naming brain chemicals associated with different emotions (such as empathy or compassion) in humans. Ultimately 2 psychological studies and 3 medical studies related to the topic in this study and were chosen for review. The dissertations and theses database revealed 11 studies addressing compassion. Only one was appropriate; most of the studies in this database were related to compassion in major world religions. Culling reference lists of the articles resulted in an additional 7 articles for a total of 26 articles addressing compassion in this review.
The following sections begin with a discussion of the theoretical frameworks and purposes of the studies. The discussion then moves into the major themes that emerge in this body of literature. Finally implications for researching compassion are presented.

**Theoretical Frameworks in Compassion Studies**

Most of the researchers did not discuss a theoretical framework which guided the study. Among the researchers that mention a theoretical framework, several used theories that relate to clinical care of patients or interactions between nurses and patients. Two researchers incorporated the use of Jeanne Watson’s theory of human caring which views nursing through the lens of the interactions that nurses have with patients (Burtson & Stichler, 2010; Perry, 2009). It is unclear if Perry (2009) uses Watson’s theory as a theoretical basis because she referred to the theory only briefly in the discussion section. Burtson & Stichler (2010) use both Watson’s theory of human caring and Maslow’s hierarchy of needs to explain the relationship between nurses’ self-compassion. The study did not attempt to stimulate improved compassion, the researchers simply wanted to learn what the relationships are between nursing care, compassion, and job burnout.

Arman, Rehnsfeldt, Lindholm, Hamrin & Eriksson (2004) use Eriksson’s nursing theory of caring to view suffering. In this theory, suffering becomes the motive for caring and shifts focus from the illness diagnosis to treating patient suffering. The study used the patient’s perspective to describe compassion in care; patients describe ways in which nurses fail to deliver compassionate care thereby increasing patient suffering.

Four researchers develop theory or concepts during the study. Attree (2001) and van der Cingel (2011) use grounded theory as the framework for their studies. Attree discovered aspects of, “Good Quality Care” (p. 459) and, “Not so good, could be
improved quality care” (p. 461). van der Cingel (2011) discovered seven dimensions of compassion in the context of nurse and patient interactions. Two researchers used concept analysis or concept development to understand the phenomenon of compassion in nursing care (Hem & Heggen, 2004; Walker, 2009). One used the Bible’s parable of the Good Samaritan to understand interactions between psychiatric nurses and their patients (Hem & Heggen, 2004). Another used Schartz-Barcott’s concept development to develop a definition of compassion and meaningful attributes in relation to nurses caring for people with chronic illness (Walker, 2009).

In the above studies, the theoretical frameworks pertain to the interactions between nurses and patients and often used the concept of caring as a lens to explain the interactions. These are popular perspectives because compassion occurs with social interactions between nurses and patients; thus theories addressing interactions provide explanation for the ways in which nurses provide compassionate care. The researchers using grounded theory and concept development remain consistent to these frameworks in that they are able to articulate the concept of compassion in the context of the studies, which is what this type of research attempts to do. Given that several researchers have already utilized concept development or grounded theory to understand compassion, it was not necessary for the study being proposed to use this type of framework.

There are two researchers that used a learning theory lens. Harrowing (2011) used critical theory to help Ugandan nurses understand compassion in their professional roles, and inspire nurses to more effectively navigate the Ugandan healthcare system. She discussed greater awareness and ownership of compassion in the nurses who participate in the study. In addition, Harrowing discussed that the nurses experienced changes in
compassion and their practice. The way she presented the information demonstrates possible transformative learning. Since the theoretical framework was not transformative learning she does not speak to this possibility. Weiss, Malone, Merighi & Benner (2009) discuss experiential learning as the theoretical framework for their study because practitioners learn and develop skills through experience in the work setting. The authors present their findings based on different themes of experiences that nurses have with patients in the clinical setting. In both cases, the researchers were able to demonstrate relevance for conducting the study within these frameworks. Harrowing’s (2011) two-year study shows a change in the way Ugandan nurses navigate the healthcare system. Weiss et al. (2009) find compassion in practice through nurses’ discussion of compassion. None of the researchers incorporated transformative learning theory as a framework. Research using transformative learning theory, particularly a developmental perspective can serve to increase understanding of how nurses learn or develop compassion.

In summary, the body of literature has a weak theoretical foundation. Most of the researchers did not mention a theoretical framework. Some appropriately based the studies on theories pertaining to care or interactions between nurses and patients because they were interested in having a better understanding of clinical interactions (Arman, Rehnsfeldt, Lindholm, Hamrin & Eriksson, 2004; Attree, 2001; Burston & Stichler, 2010; Hem & Heggen, 2004; Perry, 2009; van der Cingel, 2011; Walker, 2009). These researchers used the theory to explain specific qualities or attributes of compassionate nurses, which are discussed in the themes below. Surprisingly, two of the researchers utilized a learning theory lens (Harrowing, 2011; Weiss, Malone, Merighi & Benner,
2009). None of the researchers look specifically at how nurses learn or develop compassion. Transformative learning theory may advance understanding of how compassion develops in nurses.

**Purposes of Studies Addressing Compassion**

The purposes of the studies varied, but there were some similarities. Several researchers were interested in understanding compassion in practice, specifically compassionate behaviors in nursing practice or practice of healthcare providers (Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Lindholm & Eriksson, 1993; Perry, 2009; Rushton et. al, 2009; Skaff, Toumey, Rapp, & Fahringer, 2003; van der Cingel, 2011; Walker, 2009; Weiss, 2009). They were interested in knowing what constitutes compassionate nursing care or uncompassionate care.

Others were interested in understanding the meaning of compassion in nursing practice (Armstrong & Barker, 2000; Hefferenan et. al, 2010; Sadler, 2004; Torjuul, Elstad, & Sorlie, 2007; Weiss, Malone, Merighi & Benner, 2009). This varied from developing a better understanding of the moral construct of compassion in practice (Armstrong & Barker, 2000; Torjuul, Elstad, & Sorlie, 2007), to revealing how nurses and nursing students make meaning of compassion in practice (Sadler, 2004; Weiss, Malone, Merighi & Benner, 2009), to understanding the impact of self-compassion on nursing practice (Hefferenan et. al, 2010; Sadler, 2004).

Some researchers wanted to understand how patients view or perceive compassion in healthcare professionals (Arman et. al, 2004; Attree, 2001; Fenwick & Brayne, 2010; Fogarty et al, 1999; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Kret, 2011). These researchers were either interested in
knowing if patients perceived that their healthcare providers were compassionate (Kret, 2011; Skaff, 2003), or wanted to learn what patients believe compassionate behaviors are (Arman et al, 2004; Attree, 2001; Graber & Mitcham, 2004; Hem & Heggen, 2004; Halldorsdottir & Hamrin, 1997).

Some researchers were interested in cultivating or enhancing compassion (Ellison & Radecke, 2005; Harrowing, 2011; Steffen & Masters, 2005), and understanding ways to prevent burnout in nurses (Collins & Long, 2003; Burtson & Stickler, 2010). Ellison and Radecke (2005) attempted to increase awareness and compassion for people at the end-of-life in undergraduate students who were entering healthcare professions. Unfortunately their data was confined to course evaluations and they were unable to discuss whether students increased compassion as a result of the course. Steffen and Masters (2005) wanted to know if adopting compassionate behaviors leads to compassionate attitudes and better health. They do not specify how the specific compassionate behaviors contribute to development of compassion. Instead they focus more on intrinsic versus extrinsic motivation for engaging in compassionate behaviors as being factors in increased compassion and health. Those with intrinsic (or internal) motivation were more likely to develop compassion. This is interesting because it brings into question if nurses who become patients are more intrinsically motivated as a result of the patient experience, and therefore more likely to develop compassion. Harrowing (2011) used a two year course and data collection to help nurses develop compassion in their practice. She was able to identify increased compassion in the nurses.

From the purpose statements of this body of literature, there is a strong message indicating what compassion means in nursing practice, and specific attributes of
compassion. It also identified how patients perceive compassion. Further study does not need to replicate this information. Rather, future research can draw from this understanding and focus more on how nurses learn or develop compassion. In the small amount of research that attempts to increase compassion, only one (Harrowing, 2011) is able to clearly articulate a change in compassion among the participants.

**Themes in the Empirical Literature of Compassion.**

Given that there were similarities in the purposes of some of the studies, there were similarities in the findings as well. Three major themes emerged in the research findings: attributes of compassion in healthcare providers, the link between compassion and health, and learning compassion. These themes are discussed below beginning with attributes of compassion in healthcare providers.

**Attributes of compassion in healthcare providers.** Several of the researchers reported attributes of compassion in healthcare providers, or described ways that providers give compassionate or uncompassionate care. One attribute of compassionate care is that caregivers are holistic, meaning that they pay attention to physical, emotional and spiritual needs of their patients (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Perry, 2009). Compassionate caregivers provided individualized care (Attree, 2001; Perry, 2009; Walker, 2009). Individualized care is slightly different terminology than holistic care, but looks much the same in practice. Patients and healthcare providers reported that compassionate care involves genuine interest in, and respect for the patient, willingness to be open with the patient, and being able to communicate effectively (Arman et al, 2004; Attree, 2001; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Lindholm & Eriksson, 1993; Perry, 2009; Skaff, Toume
Rapp, & Fahringer, 2003; Torjuul, Elstad, & Sorlie, 2007; Walker, 2009). Specific attributes of compassionate care involve attentiveness, active listening, and willingness to spend time with patients (Arman et al., 2004; Attree, 2001; Graber & Mitcham, 2004; Perry, 2009; van der Cingel, 2011; Weiss, Malone, Merighi & Benner, 2009).

An aspect of compassionate care that received a lot of attention was the importance of nurses and healthcare providers developing relationships with patients, or the aspect of care that tells a patient that the nurse is suffering with them (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Attree, 2001; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Lindholm & Eriksson, 1993; Perry, 2009; Walker, 2009). Patients report less suffering when there is a meaningful relationship with the nurse because they feel loved, cared for, and more secure (Lindholm & Eriksson, 1993; Perry, 2009). Patients report needing company during their time of suffering because without it they feel abandoned and suffering increases (Arman, Rehnsfeldt, Lindholm, Hamrin & Eriksson, 2004; Lindholm & Eriksson, 1993; Perry, 2009).

Specific ways in which nurses and healthcare providers are uncompassionate was mentioned. Being indifferent, uncaring, demonstrating incompetence, maintaining a distance from patients, and generally not being open to understanding patients’ needs are considered uncompassionate behaviors and resulted in patients’ perceptions of increased suffering due to feelings such as fear, anger and frustration (Arman et al., 2004; Attree, 2001; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Lindholm & Eriksson, 1993; Perry, 2009).

Overall, these researchers demonstrated a common perception of what people expect from a compassionate care giver. The above examples show attitudes and
behaviors that patients and healthcare providers expect when a person is seeking compassionate healthcare. Because the researchers describe similarities in regards to compassion in care, it is unlikely that another study addressing the qualities of a compassion nurse or clinician will reveal new information about these qualities or attributes. In this study, I focus on how compassion develops in nurses. Understanding how compassion develops can help nursing address compassion in education and improve compassionate care and alleviate patient suffering.

**Relationship between compassion and health.** A second theme involves the relationship between compassion and health. Several researchers discussed positive influences of compassion and health or well-being. Others addressed the concept of self-compassion in healthcare providers pointing out that taking care of oneself and being more compassionate toward oneself results in better job satisfaction and improved care of patients (Burtson, Stichler, 2010; Collins, & Long, 2003; Heffernan, Griffin, McNulty, & Fitzpatrick, 2010). Burtson and Stichler (2010) and Collins and Long (2003) use compassion scales in which nurses report their level of self-compassion. Both showed that nurses with greater compassion satisfaction have lower levels of work stress and burnout. Burtson and Stichler (2010) used Maslow’s hierarchy of needs and Watson’s theory of caring as a framework to demonstrate how increased levels of compassion satisfaction lead to improved patient care. The study showed the importance of a nurse’s satisfaction with compassion as a factor in quality patient care. However, it did not address how compassion satisfaction or self-compassion can be increased or improved in nurses.
Some researchers had a different way of investigating compassion as it pertains to health. Fogarty, Burbrow, Wingard, McDonnell and Somerfield (1999) reported that patients who receive news of a serious diagnosis from a compassionate doctor are likely to experience lower levels of anxiety. This can affect the treatment trajectory and overall response that an individual has toward their illness. Fenwick and Brayne (2010) discussed the importance of compassion in the experiences of those who are on their death-bed. In this case, improved health is not a goal, but compassion toward the experiences of those on their death-bed works to alleviate suffering during the death process, both for the patient and family. Another study reported that being genuinely compassionate toward others results in decreased levels of depression and stress in the person being compassionate (Steffen & Masters, 2005). This is a limited number of studies pertaining to compassion and its effect on health. However, these researchers are in agreement that compassion can positively affect the experiences of patients. This is important because nurses can positively affect patient health by providing compassionate care. Therefore, pursuing better understanding of compassion in nurses is a worthwhile endeavor.

The remaining researchers attempted to improve compassion in healthcare providers through educational programs (Ellison & Radecke, 2005; Harrowing, 2011; Rushton, Sellers, Heller, Spring, Dossey, & Halifax, 2009; Wear & Zarconi, 2007). By doing so the researchers hoped to improve the satisfaction that care providers had with their jobs and interactions with patients. Both Harrowing (2011) and Rushton et al. (2009) stated that participants reported rejuvenation for their jobs and increased self-compassion after participating in continuing education programs. In these studies,
participants developed greater self-awareness (Rushton et al, 2009) or improved well-being and ownership of practice (Harrowing, 2011) as a result of the educational programs. Rushton et al. (2009) discussed an educational program for people who provide care to patients at the end-of-life. During the program, participants engaged in several contemplative practices aimed at: mindfulness, honest and constructive communication, self-exploration, and connecting the mind and body through yoga practices. Participants reported that they were able to cultivate compassion by paying attention to their own personal needs. They learned to respond to their own suffering, and take time to nurture physical, emotional, mental and spiritual aspects of their lives. This study examples ways that nurses could potentially develop compassion in themselves by engaging in these contemplative practices.

Learning compassion. Two researchers attempted to use teaching strategies to improve compassion as one of the goals in the course (Ellison & Radecke, 2005; Wear & Zarconi, 2007). Ellison and Radecke (2005) did not discuss the impact of the course on compassion in the students, but reported students’ course evaluations and ways to improve the course. Wear and Zarconi (2007) discussed that medical students reported mixed impressions of compassion as a result of the course. The study attempted to help students develop compassion through critical self-reflection by requiring students to write about how their medical education fostered or hindered compassion toward patients. Students reported mixed signals regarding compassion in their education. Compassion is outwardly espoused in the medical profession, but the hidden curriculum often had deleterious effects on students’ self-perceptions of compassion (Wear & Zarconi, 2007). Therefore students found their education to be both helpful and hindering in terms of
developing compassion in medical practice, but often cited seasoned doctors and the 
clinical environment as being a hindrance to compassion. The researchers employed the 
use of an open ended essay to obtain data, therefore the researches were not able to ask 
additional questions to understand how students learn compassion, or carry it out in practice. This research begs the question: What were the specific aspects of the medical 
education and students’ clinical experiences that either helped or hindered the 
development of compassion? Because the source of data was one essay question, the 
study is not able to articulate how the students learn (or not learn) compassion. The 
researchers shared the influences that students report as being important factors, but 
cannot more specifically discuss how compassion develops. This study begins to fill the 
gap in understanding how compassion develops in clinicians.

**Implications for Researching Compassion in Nurses**

This section discusses why compassion is being addressed in the study of nurses 
who become patients. First the reason that compassion has been chosen over similar 
terms is discussed. Second, findings of the empirical literature review support further 
research of compassion in nurses.

As discussed above, compassion is considered to be a very important aspect of 
Unfortunately many believe that compassion is not well expressed in modern nursing, 
which results in decreased patient satisfaction and lower quality care (Halldorsdottir & 
Hamrin, 1997; Heffernan, Giffin, McNulty & Fitzpatrick, 2010; Hem & Heggen, 2004; 
Steffen & Master, 2005). Research that contributes to understanding how nurses develop 
compassion can help refocus on compassion in practice and improve delivery of this vital
aspect of care. Currently, there is a lack of empirical literature addressing ways that nurses learn compassion. Understanding how nurses develop compassion can inform nurse educators on ways approach the cultivation of this aspect of practice; thus contributing to improved compassion in nurses and ultimately improved patient care.

There are several reasons that compassion received focus in this study over empathy, sympathy, pity, or care. First, compassion is similar to empathy and sympathy in that it involves perceiving another person’s emotions. However, it goes beyond empathy and involves an action aimed at benefitting another person. If the goal of nursing practice is to help alleviate suffering (Lindholm & Eriksson, 1993), then the active quality that compassion involves is appropriate to examine. As mentioned, in psychological literature sympathy and compassion are often used interchangeably. In nursing literature compassion and sympathy are used interchangeably, however, the term compassion receives more attention than sympathy, and implies a deeper meaning than sympathy (Jull, 2001; Schantz, 2007; von Dietz & Orb, 2000). Last, as discussed in the literature pertaining to nurses-as-patients, nurses reported change in compassion in their practice or that their interactions with patients changed as a result of the patient experience (refer to nurses-as-patients section). This practice change involves actions or attempts to help alleviate suffering which is how compassion is largely defined. Therefore, the change in compassion that occurs in nurse-patients deserves further examination.

Empirical literature has demonstrated common attributes or behaviors of compassionate nurses (Arman et al, 2004; Attree, 2001; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Hem & Heggen, 2004; Lindholm & Eriksson, 1993;
Perry, 2009; Skaff, Toumey, Rapp, & Fahringer, 2003; Torjuul, Elstad, & Sorlie, 2007; Walker, 2009). It has demonstrated that compassion is important in promoting health and well-being (Fenwick & Brayne, 2010; Fogarty, Burbrow, Wingard, McDonnell, & Somerfield, 1999; Steffen & Masters, 2005). Nurses who have greater compassion have less burnout and are likely to provide better patient care (Burston, Stichler, 2010; Collins, & Long, 2003; Heffernan, Griffin, McNulty, & Fitzpatrick, 2010).

While the above researchers showed that compassion can be identified in nurses, and that compassion is important to well-being, there is little focus on how this quality is learned. Some researchers discussed ways to increase self-compassion (Ellison & Radecke, 2005; Harrowing, 2011; Rushton, Sellers, Heller, Spring, Dossey, & Halifax, 2009; Wear & Zarconi, 2007), while others used formal classroom settings to encourage the development of compassion (Wear & Zarconi, 2007). However, none of them addressed learning compassion with a learning theory lens and focus on specific experiences that promote the development of compassion. One study gave specific activities to improve self-compassion (Rushton, Sellers, Heller, Spring, Dossey, & Halifax, 2009), but these activities are directed at the self and do not address how compassion is learned in a clinical arena. Thus a study using an adult learning theory lens can help to understand how compassion as an important aspect of nursing care can develop.

**Theoretical Framework: Transformative Learning Theory**

As discussed in the previous section, some scholars believe that empathy and altruistic behaviors such as compassion develop in childhood (Duan & Hill, 1996; Eisenberg, 2000; Eisenberg & Miller, 1987; Eisenberg, 1982). However, review of the
nurse-as-patient literature suggests that compassion can also develop in adulthood (Cotter, 1990; Harker, 2000; Kempainen, Bartels, & McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004). If development of compassion can occur in adulthood, it is worthwhile to examine this development because compassion is an important part of the nursing profession. Understanding the development of compassion in nurses can help the profession, particularly nurse educators, formulate ways to help promote development of this aspect of practice.

Because the development of compassion in nurses represents learning in adulthood, it is appropriate to apply adult learning theory to this topic. Transformative learning theory is the theory that serves as the theoretical lens through which this study was viewed. This theory presents the idea that learning in adulthood can involve experiences that bring forth significant changes in a person’s perspective, thus resulting in a perspective transformation. Transformative learning theory allows the researcher to consider the changes of compassion in nurses after the patient experience as part of a perspective transformation and provide explanation for these changes.

Transformative learning theory has received many contributions and critiques since its introduction to adult education in the late 1970’s. The following discussion presents different explanations and perspectives of transformative learning theory and their relevance to the study. Two perspectives of transformative learning are included: Mezirow’s rational perspective (sometimes referred to as a psychocritical, or critically reflective perspective) and the constructivist-developmental perspective largely influenced by Robert Kegan. The rational perspective is included because this is the overarching concept of transformative learning, and aspects of the nurse-patients’
experiences relate to the core aspects of this perspective. The constructive-developmental perspective is included because this view addresses adult development through epistemological changes. The change in compassion in nurse-patients represents development of compassion in practice and possibly an epistemological change in the way nurses understand compassion.

The rational view is discussed first because it is the view that was presented by Mezirow, who initially developed the theory. The section includes a general definition of transformative learning, assumptions upon which the theory rests, and core concepts that are relevant to transformative learning theory. Following this is a discussion of the developmental perspective of transformative learning, concluding with a review of empirical literature.

**Rational perspective of Transformative Learning**

In the 1970’s Mezirow (1978a) conducted a study of women’s re-entry programs at community colleges. Women in the study participated in college re-entry programs and as a result of this education began to re-examine their culturally defined roles. While in the programs many women began to change their perceptions of themselves and their views. Mezirow reports that at the end of their college experience 90% of the women had more feminist viewpoints compared to 20% at the beginning of the program.

The findings of the study were that many women had a deep change in perspective while enrolled in these programs. As a result, Mezirow discovered what he believed was an important aspect of adult development and function of adult education. He (Mezirow, 1978a; 1978b) called this change in the women a “perspective transformation” and transformative learning theory began to take shape.
Transformative learning is defined as (Mezirow, 2006):

The process by which we transform problematic frames of reference (mindsets, habits of mind, meaning perspectives)- sets of assumptions and expectation- to make them more inclusive, discriminating, open, reflective and emotionally able to change. Such frames are better because they are more likely to generate beliefs and opinions that will prove true or justified to guide action (p. 26).

In other words, in a transformative experience a person faces a problem and begins to consider this problem from different perspectives rather than accepting or relying on a previously held view. The person may come to a different way of understanding and relating to the situation, thus experiencing a perspective transformation.

A transformative learning experience brings a broader more sophisticated understanding to a problem, and allows the individual to have a more validated perspective (Cranton & Roy, 2003; Mezirow, 1991). A perspective transformation is a deep change in a person’s understanding or relationship to the way he or she makes meaning, or a change in the way a person perceives, relates to, and acts upon a certain problem in life (Daloz, 1986; Kegan, 1994; Mezirow, 1991; Mezirow, 2000). In this study, the change in perspective of compassion by nurses who have been patients is being examined. Nurses have great potential for changing their understanding of treating patients with compassion as a result of the patient experience.

Transformative learning is based, in part, on the understanding that there are different types or domains of learning: Instrumental, communicative, and emancipatory (Mezirow, 1991). Instrumental learning is described as being concerned with manipulating aspects of the environment to explain or understand phenomena, or to improve an outcome. It uses hypothetical questioning, cause-and-effect or deductive logic
to determine valid solutions to problems. Communicative learning, is concerned with understanding meanings (one’s own and others’) in the context of social communication, and is more closely linked to transformative learning (Mezirow, 1991; Mezirow, 2000). Communicative learning addresses the learning that happens in a social or interactive context. This type of learning involves assessment of the meaning behind words and communication to arrive at a better understanding of something. Emancipatory learning involves critical reflection of things we take for granted such as ourselves, our environment, or culture. By critically reflecting “…we come to see our reality more inclusively, to understand it more clearly, and to integrate our experience better” (Mezirow, 1991, p. 88). Mezirow (2000) largely focuses on communicative learning in relation to transformative learning. He suggests that transformation “redefines” (p. 10) emancipatory learning as the process through which instrumental and communicative learning change.

**Core Assumptions of Rational Perspective**

To understand how a perspective transformation takes place, one must understand several core assumptions and concepts from which the theory stems. Some broad assumptions of transformation theory are that individuals construct knowledge through life experience, transformative learning is a positive experience leading to personal growth, in order for a transformation to take place an individual needs to be free from circumstances that impede transformation, and certain cultural values are more likely to promote transformation. The next sections address each of these core assumptions. First, the constructivist view of learning is presented, followed by personal growth, and ending with conditions that can promote or inhibit transformation.
**Constructivist view of learning.** First, transformative learning theory assumes a constructivist view of learning. In this view individuals socially construct knowledge and perceive the world based on personal experience. Kegan (1980) points out several components to a constructivist perspective: people make their own meaning of experiences in their lives, the way a person makes meaning affects the way he or she perceives or understands experiences, and the way a person makes meaning affects behavior. From this description a constructivist view of learning involves interaction between the person and the environment. Learning occurs when an experience is perceived as being significant or important to the person in some way (Dirkx, 1998).

A transformative learning experience involves an experience (or the interpretation of the experience) and changes in the way we understand, perceive, or make meaning of that experience. During a transformation we may develop a completely different way of interpreting an experience, or expand our understanding of how we interpret the experience (Mezirow, 2000). In both cases, the transformative experience causes us to no longer take that interpretation of the experience for granted. In each case we experience things in our lives that we interpret, and as a result of a transformation we construct a broader understanding of the experience, and construct a broader interpretation of it (Mezirow, 1991).

**Transformative learning and personal growth.** Transformative learning theory assumes that a transformative learning experience overall is a positive change leading to personal growth of the individual (Cranton & Roy, 2003; Mezirow, 2000). This personal growth involves a person becoming more open to other perspectives and critically reflective of long held assumptions (Mezirow, 1991; Mezirow, 2000). Personal growth
associated with transformative learning is considered to be irreversible (Mezirow, 1991; Kegan, 1994). Some research supports this view. For example, a longitudinal study assessed the perspective transformations of people living with HIV. It revealed that the transformations remained, and that individuals demonstrated personal growth through greater self-awareness and appreciation for life, and need to serve others (give back to the community) (Courtenay, Merriam, Reeve & Baumgartner, 2000; Baumgartner, 2002).

Sometimes this personal growth can cause the person to have conflicting emotions. Emotions may be perceived by the person as negative experiences, however during the transformation process the individual comes to a broader more meaningful understanding of the situation. This more sophisticated and transformed view is seen as a positive aspect of adult development and learning (Mezirow, 1991).

**Conditions can promote or inhibit transformation.** Transformative learning theory assumes that certain environmental conditions must exist in order for a transformation to take place. On an individual level, an assumption is made that there are some circumstances that can impede or prevent a transformation. When a person’s physical, emotional, or psychosocial needs are not met then he or she is less likely to experience a transformative learning experience. It is difficult for a person to see beyond immediate needs if he or she is homeless, hungry, intimidated, coerced or ill (Mezirow, 2003).

The theory assumes that certain cultural values are consistent with basic human needs that allow transformation to take place. Environments that meet these human needs are those that value “freedom, equality, tolerance, social justice, civic responsibility, and education” (Mezirow, 2000, p. 16). Cultural environments that infringe on these human
rights make it more difficult for its citizens to engage in transformative learning. Several researchers discuss the importance of environment when attempting to foster transformative learning. They agree that establishing a setting that allows a learner to feel safe and trusting is important, however they focus on educational settings (Dewane, 1993; Gallagher, 1997; Neuman, 1996).

**Core Concepts of a Transformation**

This section discusses different concepts that are involved in a transformative learning experience. Core concepts that are integral to transformative learning involve a significant life experience (often referred to as a disorienting dilemma), critical reflection, frame of reference, meaning schemes, meaning perspective habits of mind, reflective discourse, and action. These concepts do not necessarily follow a chronological order, but the following is an example of how a transformation may unfold. A transformative learning experience begins with a disorienting dilemma (Cranton, 2006; Mezirow, 1978a). The dilemma causes the person to begin questioning personal assumptions and beliefs (which is a part of critical reflection). The person then engages in reflective discourse (a dialogue) with self and others to assess previous assumptions and make changes based on new insights. The new insights result in action (Cranton, 2006; Cranton & Roy, 2003; Mezirow, 2000; 2003; 2006). Each of these are explored in more detail below.

**Disorienting dilemma.** A transformative learning experience is said to begin with a disorienting dilemma. A disorienting dilemma is something that comes into a person’s life which is in conflict with the person’s beliefs or assumptions (Cranton, 2006; Cranton & Roy, 2003). Often the individual perceives the event as a personal crisis which makes a
person step back and look at situation or long held belief (which may have previously been taken for granted). A disorienting dilemma is often associated with what the person perceives as a negative experience such as the death of a spouse or financial need to return to work, however it is any experience (perceived positively or negatively) that demands the attention of a person causing the individual to critically reflect on a deep seeded assumption or frame of reference. It is a situation that cannot be resolved simply by learning more about something, or learning new skills and behaviors (Mezirow, 1978b; 1991; 2000). For example, a person who becomes ill may be faced with a life threatening or life altering illness. Many people find that learning to cope with a situation like this cannot be done by simply learning more information about the illness or treatments for it. For some individuals, having facts about a disease or treatment is not enough to handle the present situation. As a result of the serious illness, a person may begin to consider what is truly important to him or herself, and begin to focus on what he or she finds to be important.

Even though a disorienting dilemma is an important aspect of a transformative learning experience, it may not be absolutely necessary for transformative learning to occur. The transformational experience may be epochal which is sudden or dramatic, surrounding an event; or it can be incremental which takes place over a long period of time. An incremental experience involves serial transformations that result in the transformation of a habit of mind (Mezirow, 2000; Mezirow, 2006). It is argued that perhaps most transformative learning is subtle, lacks the intensity associated with a disorienting dilemma, and can be associated with “everyday” experiences (Dirkx, 2006). In addition, some consider transformative learning to be largely developmental (Daloz;
1986; Kegan, 1994; Kegan, 2000) which is part of everyday life. Disorienting dilemmas do not occur on a daily basis, thus they may not be necessary for all transformations. However, Mezirow (1991) might consider incremental shifts to be changes in a person’s meaning schemes.

When considering the experiences of nurses who become patients and the transformation of compassion, it is conceivable that aspects of both an epochal or incremental change may be present. The experience of being a patient may be a disorienting dilemma for some, causing an abrupt change in practice. The disorienting patient experience may cause the nurse to have an epochal understanding of how patients want or need to be cared for. For other nurses, becoming a patient may be part of a transformative process that began before the patient experience, and the nurse may identify a change in perspective that takes place over the course of several years in bedside practice.

**Frame of reference, meaning schemes, meaning perspectives, habits of mind, and points of view.** The transformational process involves critical reflection (discussed later) of a frame of reference or meaning scheme. In order for a transformation to take place a person’s frame of reference is altered. This is a significant change for an individual because a frame of reference is comprised of life experiences, thoughts, and feelings that make a person who he or she is. A frame of reference is a “fixed set of assumptions and expectations” (Mezirow, 2003, p. 58) which are made up of a conglomeration of meaning schemes, meaning perspectives, habits of mind, and mind sets (Mezirow, 1991; 2000; 2003). A frame of reference is how we compare or filter our senses and experiences. It gives people a context in which they can make meaning
(Mezirow, 2000; 2006). The main aspects of a frame of reference are meaning perspective, meaning schemes, habits of mind, and points of view. Mezirow seems to interchange the terms meaning scheme and meaning perspective. Essentially they are the habitual way that we interpret experiences or make meaning from experiences, and meaning schemes are the things that affect how we interpret experiences such as feelings, specific knowledge, and values (Mezirow, 1991). A habit of mind (similar to a meaning scheme or meaning perspective) is a subconscious group of thoughts or attitudes which are largely determined by the environments or cultures we live in. Things that influence our habits of mind are customs, social norms, secondary socialization into a cultural subgroup, religious views, personal health, values and attitudes about beauty etc. (Mezirow, 2006). These subconscious meaning schemes and habits of mind then affect our points of view. A point of view is the feelings, beliefs and judgments we express (Mezirow, 2006). For example a practicing nurse who is embedded in the culture of the nursing profession may label a patient with a history of drug abuse as being a “drug seeker” when he or she asks for pain medication. The subconscious meaning scheme or habit of mind is the understanding that drug abusers battle their addiction for many years, and sometimes lie when saying that they are not actively abusing. This affects the nurse’s point of view making her suspect that the patient is seeking narcotic pain medication under false pretenses. Her meaning perspective is an assumption that the drug abuser is not really experiencing pain, or the pain is not severe enough to warrant strong pain medicine. In a transformative experience, we reassess our meaning perspective and change our meaning schemes and habits of mind. Our and point of view and becomes broader and more reflective. The same nurse who experiences a perspective
transformation changes her habit of mind involving drug addicts. She may suffer an injury causing the need for long term narcotic pain medication, and may begin to critically reflect on why she views drug addicts the way she does. She may consider if this is truly consistent with her role as a compassionate nurse. Her transformed view may see drug addicts as being more complex than simply people who takes drugs, and may consider the history or experiences that bring people to their current situation in life. This can change the point of view that the patient is a “drug seeker” and the nurse’s new point of view may be that she is working with a person who needs help, not judgment. Her meaning perspective and resulting point of view has been reevaluated, and her meaning perspective no longer assumes the patient is being deceptive.

**Critical reflection.** Critical reflection is at the core of a transformative learning experience and is essential for enabling a person to evaluate personal beliefs and assumptions. Without critical reflection a person can have an experience, but that experience will not lead to a change or transformation, therefore it is essential to the transformative experience (Cranton, 2006; Cranton & Roy; Merriam, 2004; Mezirow, 2000). Critical reflection is essentially a critical self-reflection of our assumptions, or the “critical assessment of the sources, nature and consequences of our habits of mind” (Mezirow, 2006).

Mezirow (1991) describes three types of reflection: content, process, and premise. (Critical reflection is associated with premise reflection.) Content reflection involves thinking about a problem and how to solve it. Process reflection involves thinking or reflection on the way in which we solve a problem. Whereas premise reflection is the process in which we question the cause of a problem.
Premise reflection involves our becoming aware of why we perceive, think, feel, or act as we do and of the reasons for and consequences of our possible habits of hasty judgment, conceptual inadequacy, or error in the process of judging (Mezirow, 1991, p. 108, italics in the source).

An important aspect of the critical reflection process is the understanding that it is not necessarily about changing one’s point of view from one to another, but about opening oneself to new points of view (Cranton & Roy, 2003). The transformative process is about engaging in a discourse, and becoming more inclusive with our frames of reference. A person has greater potential for understanding different points of view if he or she is more reflective and open (Mezirow, 2000). This makes sense because if a person simply changed from one point of view to another without considering multiple aspects of a problem then can we say that the person has truly engaged in critical reflection? Therefore, becoming more inclusive as associated with the transformative process would be an essential component of critical reflection. For example, there may be more than two sides or two perspectives in a situation. If a person engages in critical reflection then acknowledgement of this should take place (Cranton & Roy, 2003; Mezirow, 2000). Ultimately the critical reflection within a transformative process allows us to become clearer thinkers and decision makers (Mezirow, 1991; 2000).

Merriam (2004), discussed an interesting position on the nature of critical reflection. She suggests that critical reflection is something that can only occur at certain levels (higher levels) of development. Being able to critically reflect and engage in rational discourse require that a person is able to examine their own assumptions, the assumptions of others and examine different perspectives. To do this, Merriam argues that a person must be at a higher level of development according to several
developmental models. This is a double edged sword. In one way it supports an aspect of learning or development that can only occur in adulthood due to the need for higher levels of cognitive development. However, it means that many (perhaps even most) adults are not in developmental levels that support transformative learning. Merriam points to a number of studies which show that not all adults function at higher cognitive levels. Similarly, there are some researchers that show that critical reflection is not always present in situations designed to foster transformative learning. For example, Liimatainen et al. (2001) assessed nursing students as they learned to develop critical reflection of practice associated with health counseling and health promotion. Not all of the participants reached high level critical self reflection. They state that educators need to identify and assist students to develop critical reflection if transformative learning is desired (Liimatainen et al., 2001). Kreber (2004) assessed the levels of reflection in teachers regarding their practice. She wanted to know if teachers engage in the premise reflection associated with transformative learning, and found that it was not common in the participants. Kreber (2004) suggests that premise reflection be encouraged so that instructors can assess their “taken-for-granted assumptions” (p. 43). This will help teachers improve their practice and therefore enhance student learning.

**Reflective discourse.** Reflective discourse is a continuation or part of critical reflection, and involves “critical assessment of assumptions” (Mezirow, 2000, p. 11). A back and forth dialogue helps us to formulate new ideas and may involve interaction between two people, interactions within a group setting, or even inner dialogue with oneself such as a person viewing art (Mezirow, 2000). Reflective discourse is integral to Mezirow’s view of transformative learning theory, and involves a dialogue in which the
person assesses personal beliefs, feelings and values (Mezirow, 2003). Essentially, adults need to have this discourse in order to consider multiple points of view and examine their frame of reference in order to work through a transformation.

Mezirow (2000) gives a somewhat detailed description of necessary components for a person to effectively participate in reflective discourse. In this description, he acknowledges that a person must be emotionally mature, and be able to understand the emotions and view of another person. In essence, the person understands oneself, but is also exploring how other people view things. When people are engaging in reflective discourse they need to be willing to understand another person. Also, “feelings of trust, solidarity, security, and empathy area essential preconditions for free full participation in discourse” (Mezirow, 2000, p. 12). Here he mentions empathy as being a component of rational discourse. This is because empathy is the ability to understand and experience another person’s emotions. If a person is in the process of changing his or her perspective or way of meaning making, then it is necessary for the person to be able to communicate with others and be able to think about something from a different point of view.

Reflective discourse is not about arguing a point and deciphering who is right or wrong, or what point of view is right or wrong. Rather, it is about building consensus, and considering multiple points of view (Mezirow, 2000). In order for a person to engage in reflective discourse ideally he or she needs to have complete and accurate information, be able to freely dialogue, have greater awareness and reflection of varying points of view, and be willing to consider the best judgment (Mezirow, 2000). In addition, conditions that promote reflective discourse and consensus building are those that value equality, tolerance, rationality, freedom etc (Mezirow, 2000).
Reflective discourse is associated with rationality or rational thinking, and is an essential component of critical reflection and rational discourse (Merriam, 2004; Mezirow, 2000). When applying rationality to discourse it allows a person to think clearly, objectively assess one’s options, and manage emotions (Mezirow, 2000). By objectively considering various points of view in the discourse a person is ideally able to make the best judgments possible. For example, a nurse who is transforming her perception of drug addict patients may share her story and begin to talk to people she knows who have loved ones with drug addictions. She may ask how they cope with the problems that arise from the addiction, or may ask how the person entered the drug scene. The conversations and perspectives of the family members help the nurse see the problem from different angles, and provide a more sophisticated understanding of this patient population.

**Rationality.** Mezirow’s view of transformative learning theory assumes that deliberate, rational thought is essential for a transformation to take place. In this view critical reflection and reflective discourse allow a person to evaluate personal beliefs and come to a more informed view (Mezirow, 2000). In this perspective critical reflection and reflective discourse are necessary components in a transformative process. Critical reflection and reflective discourse by definition require an individual to be consciously aware of a problem and think about it in order to broaden understanding of the problem. When a person engages in critical reflection and reflective discourse he or she is assessing personal values and beliefs while considering multiple other viewpoints. The person is then able to logically come to a better, more informed decision. Thus rationality is a core assumption of this view.
Rationality may be important in this perspective of transformative learning. However, other factors that affect the transformative learning experience cannot be ignored. It is important to point out that one of the major critiques of Mezirow’s perspective of transformative learning is the importance given to rationality (Dirkx, 2000; Imel, 1998; Taylor, 1998). The argument is that rationality receives so much focus that it essentially excludes other ways of knowing that might contribute to a perspective transformation. Some believe that influences such as emotions, intuition, spiritual and non-rational ways of knowing are important factors in a transformational learning experience (Dirkx, 2000; Imel, 1998; Taylor, 1998). There is evidence in the discipline of neurobiology that supports a connection between rationality and emotions (Taylor, 2001). A brief explanation is that there is a connection between a person’s cognitive abilities and emotions. Neurobiological research demonstrates that emotions are part of the decision making process. Emotions allow us to go beyond the facts involved in the cognitive process and place a value on the choices before us. Thus people are able to make a decision based on the facts and value we place on a choice (Taylor, 2001).

In addition, relationships and the context of a transformation play an important role in the experience (Taylor, 2007). While critical reflection and reflective discourse provide some direction for a transformation, relationships may have a significant bearing on a transformational experience. This is important to consider when studying the transformative experiences of nurses who become patients. The emotions, environments in which they were ill, and the relationships during that time most likely contributed to the transformation in compassion.
**Action.** The final component of the transformative learning experience involves action. Action can come in several forms. An action may come in the form of beginning a social or political protest in order to bring about change. Actions may be more subtle and involve a person changing personal behavior or making different decisions. Action may be taken immediately upon coming to a decision, or be delayed (Mezirow, 2000). The action may in fact come in the form of reaffirmation of an already existing pattern of action, thus one may not be able to observe a different behavior from the person at the completion of the process. As in the example above, the nurse who transforms her perspective of drug addicts may act with new attitudes and behaviors toward this patient population. For instance, she may feel a stronger sense of compassion, and talk “with” the patients rather than “at” the patients.

In one of Mezirow’s (1978a) early works, he talks about a transformation cycle which people go through as they are having a transformative experience. This cycle involves 10 different action phases that occur with a perspective transformation. They include:

1. Disorienting dilemma
2. Self examination
3. Critical assessment of assumptions
4. Sense of alienation from social roles/expectations
5. Relating personal discontent to current public issues
6. Exploring new options for ways to live
7. Building competence/confidence in new roles
8. Planning a course of action
9. Trying new roles
10. Reintegration into society with new perspective
These steps do not necessarily occur in the order listed, and not all of them may be part of a person’s transformation. Working through these steps culminates in the action associated with the perspective transformation.

**Critiques of the Rational Perspective**

There are several critiques of Mezirow’s perspective of transformative learning theory. As stated previously, one critique is the emphasis placed on rationality. Some other critiques include: focus on the individual, decontextualized view of learning, universal model of adult leaning, adult development being a shift or progression, lack of focus on other ways of knowing, and problems with the model of transformation (Taylor, 1998, p. 21). The critique discussed here pertains to decontextualized view of learning, and development being a shift.

First, Mezirow is criticized for not paying enough attention to the context in which a person is situated (Gunnlaugson, 2007; Taylor, 1998; Taylor, 2008). Because of this some questions arise about the context, such as, how does the person’s environment impact the transformative experience? If the context is not taken into consideration, then what is the relationship between transformation and social change? In this study, the context of the nurses’ transformation is important. The healthcare system that nurses interact with serves as the environment which potentially catalyzes the transformative process.

Second, some find that Mezirow’s perspective of transformation and development is a series of steps or phases (Gunnlaugson, 2007; Taylor, 1998). This essentially reiterates other step or phasic developmental models (Merriam, 2004). Some argue he
does not distinguish his view of transformation or development from stages of life rather than emancipatory experiences that he talks about (Taylor, 1998).

Some believe that emotions play a significant role in adult learning (Dirkx, 2001b; Dirkx, Mezirow, & Cranton, 2006), and Mezirow is critiqued for not paying closer attention to the role of emotions in transformative learning. In a review of empirical research pertaining to transformative learning theory, Taylor (2007) points out that little is known about the specific relationship between emotions and transformative learning. In addition, as discussed in the core concepts of the rational perspective of transformative learning, Mezirow (2000) presented a description of rational discourse that includes empathy, or the ability to understand the feelings or emotions of another person. He does not spend a lot of time discussing this, only that empathy is necessary for a person to fully engage in rational discourse. At this time there is little understanding of this concept in relation to the transformative process.

This study paid attention to the emotions that the nurses discuss because the literature addressing nurses-as-patients reveals that many nurses discussed emotional aspects of their patient experience. Mezirow (2000) mentioned the importance of empathy in reflective discourse, but there is little discussion beyond that. This study considered this aspect of a transformative learning experience to further understanding of the theory.

**Developmental Perspective of Transformative Learning**

An additional view of transformative learning that informs this study is the developmental perspective. A developmental perspective takes into consideration a person’s development over the lifespan and believes that development does not stop
when a person reaches adulthood (Daloz, 1999; Eriksen, 2006; Kegan, 1980; Kegan, 1994). A developmental perspective of transformation suggests that adults can continue to have progressive changes and involves changes in how a person makes meaning of his or her experiences (Eriksen, 2006; Kegan, 1994; Stevens-Long, Schapiro & McClintock, 2012).

The nurse-patient experience helps the nurse gain a new perspective of compassion that she did not have before. This new perspective may be directly related the experiences of being a patient, or perhaps the new perspective is a result of multiple experiences over a long period of time (of which the patient experience is one). The nurse may find that as her transformation of compassion unfolds, her meaning of what compassion is changes. For example, she may begin the process by understanding what compassionate behaviors are and espouse those behaviors. However as a result of her experiences she may begin to understand compassion as an attitude of the heart rather than a specific type of behavior. This represents a dramatic change in her perspective of compassion, and the development of compassion in her professional practice.

Some view transformative learning as a developmental process, or that transformations are part of our development throughout the lifespan. This section discusses some of the important aspects of a developmental view of transformation, and how it can be applied to the transformation of compassion in nurse patients. The main aspects discussed are: humans construct meaning through experience, a transformation involves a change in the way we make meaning of our experiences, and transformations lead to better ways of making meaning.
A developmental view of transformation assumes that humans construct meaning from our individual experiences (Kegan, 1994; Kegan 2000; Daloz, 1999). This is referred to as a constructivist-developmental model of learning. Like other models this perspective considers a constructivist view of knowledge and meaning making, espousing that people construct their knowledge and understanding through experience. Yet it values a developmental component saying that people evolve qualitatively throughout the life-span and increase in their level of complexity. The combination of a constructivist and developmental perspective “…looks at the growth or transformation of how we construct meaning” (Kegan, 1994, p. 199). Explained differently, during a person’s life he or she is influenced by the environment, social settings, and experiences. However a person takes these things and constructs what they mean on a personal level. While the person’s environment affects the person, he or she decides what this means. In addition, a developmental perspective acknowledges that people do not stop changing and growing when we leave adolescence and enter adulthood.

A transformation is the process in which a person changes a way of making meaning into a new way of making meaning, or a change in epistemology which is the nature or way in which we know something (Daloz, 2003; Daloz, 1983; Kegan, 2000). In other words, the transformation causes a person to construct their understanding or relate to a phenomenon in a different way. This happens as we develop. A transformation is not the accumulation of more factual knowledge or skills. It is the transformation of a phenomenon, or is the “form” in trans-form-ation, and needs to be identified if a transformation is said to have taken place (Kegan, 2000, p. 48). A transformation changes our relationship or fundamental understanding of a particular phenomenon. It changes not
“what” we know but “how” we know it (Kegan, 2000, p. 49). In this study compassion is the “form” or phenomenon being examined, and a transformation is assumed to have taken place or is taking place. Nurses will come to the study self identifying that compassion has changed in their practice. In the development of compassion the nurses will ideally have a different way of understanding and carrying out compassion in their practice. This transformation may represent professional development as presented in the developmental view of transformation.

Part of transforming or developing our ways of making meaning involves the concept of changing what is “subject” in oneself into what is “object” (Kegan, 2000; Kegan, 1994; Kegan, 1980). When we are subject to something we are “had by” it. It is part of who we are and influences our actions without our understanding or awareness of it. However a developmental transformation allows us to identify what is subject and make it become the object. An object is anything that we can understand control, be responsible for etc. When we hold something as object we can identify it and reflect on it (Kegan, 2000; Kegan, 1994). An example is a child who is subject to her emotions (Kegan, 1980). At first she is ruled by them and is not even aware that they exist. As she develops she begins to identify her emotions (sad, happy, angry), and eventually has greater control of her emotions. Kegan (1994) gives an example of this in adulthood with a man named Peter. Recently Peter has experienced a role change at work. He is now a boss in charge of a new branch of a company. As a result of the change he feels like he is being pulled in different directions by his employees, customers, and boss. Peter want to please all of these people, but is unable to. He feels alone and frustrated with these relationships. Kegan points out that Peter is subject to his relationships. He is unable to
separate himself from the various roles and make a self-determined decision. If he were able to do this, he would be able to hold his relationships as object and not be subject to them.

In addition, when we hold something (such as our emotions) as object, we are able to become active participants in shaping our environments (Kegan, 2000). Consider a nurse who transforms her understanding of compassion. A new understanding of compassion may allow the nurse to not only identify compassionate behaviors, but also understand how and why she views compassion the way she does. In turn, she is then able to actively shape compassion in her practice. She will be more able to choose how to carry it out in her practice rather than accepting healthcare cultural values that subtly imply that compassion is optional, that nurses do not have time to be compassionate, or that nurses are no longer compassionate caregivers (Davison & Williams, 2009b).

Finally, a developmental view of transformative learning assumes that increased development leads to more and better ways of making meaning (Kegan, 2000; Daloz, 2003; Daloz, 1983). As meaning making transforms we are more flexible, open, complex, and tolerant of differences (Daloz, 2003). As a person develops he or she is able to step back and consider the views of both oneself and others when making meaning and decisions. For example, a nurse who develops compassion in her professional practice will improve her ability to understand how the patient is feeling and be able provide care according to the patient’s needs.

Part of the developmental perspective of transformation is the understanding as people develop better ways of making meaning we move away from a concrete view of the world (Daloz, 2003; Daloz, 1983; Kegan, 2000). We begin to “share reality” (Kegan,
1980, p. 378) in order to understand another person’s point of view and come to a more informed view of ourselves and the world around us. For example, the patient experience allows the nurse to share the reality of being a patient. It allows her to develop a different understanding of compassion because she is able to understand the patient experience better.

Kegan’s (1994) explanation of developing better ways of making meaning involves stages of development in which we achieve certain orders of consciousness throughout the life span. He describes five orders of consciousness which increase in complexity. The first order is called the impulsive phase which occurs during infancy and early childhood. In this order children are learning to control their impulses. The second order is the instrumental phase in which older children learn to manipulate their surroundings in order to have their needs met. The third order is referred to as socialized or institutional and occurs in late childhood through adolescence and even into adulthood. In this order individuals are able to understand the emotions of others and consider others’ needs. Individuals engage in relationships and are often defined by the relationships or positions they hold within institutions. The fourth order of consciousness is called the self-authoring phase. In this order people are able to define themselves. They are able to see themselves as being part of a relationship or organization yet separate from these. These individuals are often seen as being motivated or self-directed. The fifth order is also called the self-transforming level. These individuals not only see themselves as being part of yet separate from institutions or systems, but they are able to see similarities between apparently different systems. They are comfortable with and see
value in the differences between people and systems. Not everyone achieves the fifth order of consciousness. In fact, many adults function in the 3rd order (Kegan, 1994).

Overall, the developmental perspective of transformative learning is appropriate to consider in this study because the patient experience (and other professional experiences) help the nurse to develop her professional practice. Developmental transformation is about changing not simply our factual knowledge but our relationship to that knowledge (Daloz, 2003; Daloz, 1983; Kegan, 2000), and developing a broader understanding of ourselves and others (Daloz, 2003; Daloz, 1983; Kegan, 2000; Kegan, 1980). As the nurse is exposed to being a patient and working with patients over a period of time she develops more than a factual knowledge of being a nurse. She develops a deeper understanding of herself, her patients, and the type of practitioner she wants to be. As a result of her professional experiences she is able to develop a different meaning for clinical practice. This is desirable because professional development will lead to better clinical practice. One aspect of this is the development of compassion in professional practice.

Critique of Developmental Perspective

There are some critiques of the developmental perspective of transformative learning. One critique is that individuals may be at different developmental phases in different areas of life (Eriksen, 2006). For example, a person may operate in the fourth order of consciousness (self-authoring) in the workplace, but may operate in the third order of consciousness (socialized or institutional) in personal relationships. Another critique suggests that a developmental perspective places too much emphasis on the individual rather than the context or social change (Taylor, 2008).
Kegan’s developmental perspective focuses on the stages (orders of consciousness) that a person can go through. However, not all people go through each level of development, and some point out that this limits the contribution of this perspective to cognitive aspects of transformation (Gunnlaugson, 2007). In other words, this perspective speaks more specifically to a step-wise view of cognition and does not include multiple ways of knowing or different types of intelligence. Kegan does not directly speak to the relationship between other ways of knowing and the impact that they have on development (Gunnlaugson, 2007).

Finally, a feminist and narrative critique focuses on gender differences. These perspectives find the developmental model to be patriarchal, patronizing, and egotistical—to place someone in a developmental category (in terms of counseling) (Eriksen, 2006). Feminist theory points out that women and men are socialized differently, and according to Kegan’s model women are socialized into a lower developmental stage. It is therefore tempting to say that women are developmentally “less than” men (Eriksen, 2006, p. 297). This critique shows that the different levels of developmental transformation are awarded value; wherein higher levels of development are more valuable or perhaps more important.

These critiques show that the constructive-developmental model places emphasis on the individual and cognitive aspects of development and transformative learning. It places value on different aspects of development by placing them in hierarchical levels. The way this informs understanding of transformative learning is that two prominent perspectives (Mezirow’s psychocritical and the constructive-developmental) view
transformative learning similarly. The individual is central, rationality is necessary, and learning occurs in levels.

**Empirical Literature Review of Transformative Learning Research**

This section discusses two areas of empirical research that utilizes transformative learning theory. The first area is research that uses a developmental perspective of transformative learning as the theoretical framework. The second area includes research in healthcare that uses transformative learning theory as the theoretical framework.

**Developmental Perspective in Transformative Learning Research**

Research using the developmental perspective of transformative learning was addressed because it pertains to the perspective taken in this study. In addition, transformative learning is a broad body of literature and a manageable portion of the literature is necessary for this review.

The method for obtaining research articles involved on-line literature searches and searching reference lists. The following databases were used while searching for studies: ERIC, PsychINFO, PsychNET, and dissertations and theses through ProQuest. Several different search terms were used including transform* AND development as subjects, transformative learning AND adult development, transform* AND Kegan, transformative learning AND Kegan. These terms were used as both subject and title within the search criteria. Several hundred results initially populated. However there are a number of opinion papers and commentary addressing a developmental perspective of transformative learning. Many researchers addressing development and transformative learning focus on how it relates to psychology, counseling, or leadership development.
and not necessarily adult education. After scanning journals, conference proceedings, and
dissertations-theses 12 studies were chosen for review.

Of the 12 studies one used a quantitative research design (Bugenhagen, 2006),
three used mixed-methods (Bugenhagen & Barbuto, 2012; Drago-Severson, Asghar,
Blum-DeStefano, & Roloff Welch, 2011; King, Baxter Magolda, Barber, Kendall
Brown, & Lindsay, 2009), and seven used a qualitative design (Collay & Cooper, 2008;
Eberly, Rand & O’Connor, 2007; Erickson, 2007; Harbison, 2005; Helsing & Drago-
Severson, 2002; Smith, 2011; Stevens-Long, Schaprio & McClintock, 2012). However,
two of the qualitative studies included quantitative data collection and analysis (Erickson,
2007; Helsing & Drago-Severson, 2002), which gives the reader the impression that they
were actually mixed-methods studies. One study was a research brief and did not discuss
the type of research or data collection and analysis methods (Kegan, Broderick, Drago-
Severson, Helsing, Popp & Portnow, 2002).

Ten of the studies took place in a formal educational setting. Some of the
researchers addressed the learning of students (Eberly, Rand, & O’Connor, 2007; Helsing
& Drago-Severson, 2002; Kegan, Broderick, Drago-Severson, Helsing, Popp & Portnow,
2002; King, Baxter Magolda, Barber, Kendall Brown, & Lindsay, 2009; Stevens-Long,
Schapiro, & McClintock, 2012). Others addressed the transformational learning of
educators in terms of their development as educators or as (Bugenhagen, 2006; Drago-
Severson, Asghar, Blum-DeStefano, & Roloff Welch, 2011; Erickson, 2007; Collay &
Cooper, 2008; Smith, 2011).

A majority of the researchers specifically incorporated a general constructive-
developmental perspective, or specifically cited Kegan’s perspective of transformative
learning in the theoretical framework, (Bugenhagen, 2006; Bugenhagen & Barbuto, 2012; Collay & Cooper, 2008; Drago-Severson, Asghar, Blum-DeStefano, & Roloff Welch, 2011; Eberly, Rand, & O'Connor, 2007; Erickson, 2007; Harbison, 2005; Helsing & Drago-Severson, 2002; Kegan, Broderick, Drago-Severson, Helsing, Popp & Portnow, 2002; King, Baxter Magolda, Barber, Kendall Brown, & Lindsay, 2009; Smith, 2011; Stevens-Long, Schapiro, & McClintock, 2012). There were two main ways in which this framework was related to the studies: the level of development in relation to the learning of the participants, and the process of a transformation.

First, there were four groups of researchers that assessed the level of development and related it to the level of sophistication in the topic being studied. The researchers assessed the level of development in relation to the level of leadership (Bugenhagen, 2006), motivation (Bugenhagen & Barbuto, 2012), and level of understanding or awareness in the learning process (Eberly, Rand, & O'Connor, 2007; Helsing & Drago-Severson, 2002). These researchers wanted to know if higher levels of developmental order (such as self-authoring or 4th order of meaning making) were related to higher levels of leadership behaviors (Bugenhagen, 2006), increased work motivation (Bugenhagen & Barbuto, 2012), greater understanding of multicultural learning (Eberly, Rand, & O'Connor, 2007), or more sophisticated understanding of literacy (Helsing & Drago-Severson, 2002). All but one (Bugenhagen, 2006) demonstrated increased sophistication of meaning making with higher levels of cognitive development. Given that most of the studies occurred within a formal learning setting, it is not surprising that they were able to identify the levels of constructive-development. Students were in settings that fostered learning and ideally transformative learning. Therefore, one would
expect to identify aspects of transformation in the participants. This study did not take place in an academic setting, but rather in a workplace. Unlike the two studies that were set in a workplace which looked at intentional forms of career development (Bugenhagen & Barbuto, 2012; Harbison, 2005) this study addressed professional development as a result of personal experience. Later chapters present the ways in which the nurses experienced development.

Second, there were seven researchers that addressed the developmental level in relation to the process of a transformation (Collay & Cooper, 2008; Drago-Severson, Asghar, Blum-DeStefano, & Roloff Welch, 2011; Erickson, 2007; Harbison, 2005; Kegan et al., 2002; King, Baxter Magolda, Barber, Kendall Brown, & Lindsay, 2009; Smith, 2011). These researchers wanted to know what aspects of a transformation were common among participants. A common finding in these studies is that the transformative process involves developing a greater sense of identity and self-authoring (Collay & Cooper; Erickson; Harbison; King et al.; Smith). Self-authoring individuals are better able to understand themselves, the systems they are working in and the perceptions of others (Collay & Cooper; Erickson; Harbison; King et al.; Smith). Ideally, nurses-as-patients will have a better understanding of healthcare (due to being a patient and experiencing from two perspectives) and a better understanding of themselves (due facing the challenge of an illness). As a result these individuals may have a greater sense of identity within the healthcare system and therefore be self-authoring in terms of professional practice, especially when expressing compassion.

Several researchers looked at the process of the participants’ transformation shared another common finding. This finding involved the importance of having an
environment that both supports and challenges a person to promote development (Collay & Cooper, 2008; Drago-Severson, Asghar, Blum-DeStefano, & Roloff Welch, 2011; Kegan, Broderick, Drago-Severson, Helsing, Popp & Portnow, 2002; Smith, 2011). In order for a transformation to take place the participants needed to be faced with a challenge within their developmental order. This can be within the social, institutional, or self-authoring level of development. At the same time, participants needed support often in the form of relationships. Most of the research that mentioned the importance of challenge and support in a perspective transformation took place in a formal learning setting. Educational settings are meant to challenge a person to learn new information and new ways of understanding and relating to things. At the same time the educators and student peers are a type of support for an individual student.

**Transformative Learning Research in Healthcare**

Because the experiences of nurses were addressed in this study, it is appropriate to review literature in healthcare settings that uses transformative learning theory as a lens.

The method for obtaining research articles involved on-line literature searches and searching reference lists. The following databases were used while searching for studies: CINAHL, Medline, and dissertations and theses through ProQuest. Taylor (2007) conducted a review of empirical literature that included several studies done by healthcare providers or addressed people with illnesses. Some of these were included. Several different search terms were used including transformative learning as a major subject. Also “transformative learning” and “Mezirow,” and “transformative learning” and “development” were used. Interestingly transformative learning is a term that is often used in healthcare literature. Typing the word transformative learning into an on-line
search engine can result in hundreds of resources. Often the term is not clearly defined, and more often is not identified as a theoretical framework. Therefore, only studies that clearly used transformative learning as a way to inform the studies were chosen. In all, 17 studies were chosen for review.

The 17 studies were placed into two groups; one group includes four studies that address people who live with illness, and the other group includes 13 studies that focus on healthcare providers. The themes in the literature are discussed according to two groups below.

The researchers that address people with illness identified perspective transformations among the participants. For example a longitudinal study found that people living with HIV changed their perspectives, and continued to do so throughout the study (Courtenay, Merriam, Reeves & Baumgartner, 2000; Baumgartner, 2002). The specific way in which the participants changes is that having HIV caused individuals to see it as an opportunity to contribute to the community and serve others, and it increased their sensitivity and gratitude for life. Meaning schemes that changed were that they developed a future-orientation to life; they took better care of themselves, and identified HIV as being part of themselves. Over the course of the study, these perspective and meaning scheme changes were maintained and acted on (Baumgartner, 2002). Dubouloz, Laporte, Hall, Ashe, and Smith (2004) examined people who have rheumatoid arthritis while undergoing rehabilitation. Researchers examined the transformative process of these individuals and found that the participants changed their perspective of self-caring and self-respect during the rehabilitation process. Kroupa (1996) studied the experiences of people living with traumatic brain injury. She found that even though the participants
had cognitive impairments, they moved toward a more complex way of making meaning. The complexity involved having a greater understanding of themselves from the old versus the new self, and creating ways to accept and live with the new self.

These researchers identified aspects of transformation that are specific to the participants. Some of these aspects include increased appreciation for the human condition (Courtenay, Merriam, Reeves & Baumgartner, 2000), more future oriented view of life (Baumgartner, 2002), new perspective of self-care and self-respect (Dubouloz, Laporte, Hall, Ashe & Smith, 2004), and more complex view of self and others and relationships (Kroupa, 1996). What this research demonstrated is that the participants changed their perspectives as a result of the illness and developed a more complex understanding of themselves. Thus, the researchers support the concept that the patient experience contributes to a perspective transformation.

The remaining researchers were interested in the transformation of nurses, nursing students, physicians, and physical therapists/occupational therapists. The purpose of the studies revolved around identifying transformative learning or aspects of a perspective transformation (Foronda, 2010; Hartrick, 2000; Kanisin-Overton, McCalister, Kelly, & MacVicar, 2009; Rush, 2008), promoting transformative learning or professional development (Cahill & Bulanda, 2008; Hartrick, 2000; Mallory, 2003; Morris & Faulk, 2007), and using critical reflection to promote transformative learning or development (Chirema, 2007; Eisen, 2001; Getliffe, 1996; Liimatainen, Poskiparta, Karhila, & Sjogren, 2001; MacLeod, Parkins, Pullon, & Robertson, 2003; Wittich et al., 2011).

The researchers that were interested in identifying or promoting transformative learning were able to do so. Three of the researchers stated that participants experienced a
perspective transformation (Hartrick, 2000; Morris & Faulk, 2007; Rush, 2008). Others identified aspects of a perspective transformation in the participants (Cahill & Bulanda, 2008; Foronda, 2010; Kanisin-Overton, McCalister, Kelly, & MacVicar, 2009). Among several of these studies, they find that emotions (Foronda, 2010; Rush, 2008), relationships (Hartrick, 2000; Morris and Faulk, 2007), and critical reflection (Hartrick, 2000; Rush, 2008) are very influential in the transformative process. Interestingly, Foronda (2010) and Rush (2008) found that the participants experienced emotions such as fear, guilt, frustration, shock, discomfort and sympathy, which are similar to some of the emotions described by nurses who become patients. Foronda (2010) looked at the experiences of nursing students participating in a study abroad program in a low-income country. She found that students felt strong emotions during their study abroad program and describes this as an emotional journey. This begs the question: Were the emotions that the students experienced necessary for them to begin the transformative process? This brings into question what relationship these emotions have with Mezirow’s (2000) discussion of empathy during reflective discourse. Were the emotions that they experienced, empathetic emotions of the people living there, or general reactions to what they witnessed? Does it matter whether the emotions that the students experienced were in response to another person’s emotions or a general reaction to the environment? Rush (2008) found that students experienced emotions such as shock, guilt, and discomfort when listening to mental health patients tell their stories. She discussed that students found the actual experience of interacting with patients taught them more fully about mental health disorders. Students state that it was more “real” (p. 535) to learn about mental health this way because patients can explain how it “feels” (p. 535) to experience
aspects of mental health disorders. Students reported that the interactions with the mental health patients moved them emotionally. Were the emotional experiences empathetic experiences in these students?

As stated above, empirical literature in the healthcare setting is often conducted with the intention of promoting transformative learning. There is nothing wrong with this. However none of the researchers addressed transformation that might occur naturally as a part of professional development, or as a result of experiences that healthcare professionals have. This brings into question the transformations that healthcare providers might have without purposeful interventions. Do healthcare providers assume that a perspective transformation requires a deliberate intervention or activity? The proposed study was not attempting to promote a transformation. It assessed the changes that nurses have as a result of the patient experience.

Of the researchers that focused on critical reflection, some used writing in the form of essays or journals as a way for participants to engage in critical reflection (Chirema, 2007; Liimatainen, Poskiparta, Karhila, & Sjogren, 2001; MacLeod et al, 2003.; Wittich et al.,2011), while others used verbal reflections or reflective dialogue (Eisen, 2001; Getliffe, 1996). The use of reflection was generally considered to be positive in that it helped the learning process of the participants (Eisen, 2001; Liimatainen, Poskiparta, Karhila, & Sjogren, 2001; MacLeod, Parkins, Pullon, & Robertson, 2003). However, two researchers found that the use of a critical reflection exercise had mixed results. Both of these researchers were addressing nursing students. Chirema (2006) says that some students benefited more than others when writing in reflective journals. While Getliffe (1996) says that reflection is a skill that needs to
develop. Both believe that reflection has value, but that nursing students might need support in developing critical reflection.

In terms of transformative learning theory, healthcare research demonstrates an overall interest in identifying and promoting transformative learning. Given that there are a number of researchers attempting to promote transformative learning, an additional study attempting the same will add little to the body of literature pertaining to transformative learning. Rather, this study can begin to shed light on an aspect of transformative learning that is not well researched, which is the role of emotions and empathy in a transformative experience. Some researchers discuss emotions as being an important aspect of a transformative process (Foronda, 2010; Rush, 2008). However, these researchers do not address emotions in terms of their connection to empathy which Mezirow (2000) describes as an aspect of reflective discourse.

**Summary of Theoretical Framework Literature**

This section began by discussing Mezirow’s rational or psychocritical perspective and the constructive-developmental perspectives of transformative learning. These perspectives have been chosen to inform the study because the nurse-as-patient experience can be applied to both of these perspectives. The patient experience is a disorienting dilemma for a nurse that can stimulate change in attitudes and beliefs about professional care, particularly compassionate care. In addition, the change in compassion can be viewed as a part of development. As a result of the patient experience nurses may develop a more sophisticated understanding of themselves, their place in the healthcare system, and how they chose to carry out compassion in their care. This reflects a constructive-developmental view of transformative learning. The section concludes with
a review of empirical literature. Studies that use a developmental perspective lens were reviewed, as well as studies in healthcare that use transformative learning as a lens for the study. Among these, the developmental research is largely set in formal educational settings. The healthcare researchers are mostly interested in promoting transformative learning. This study was not conducted in a formal educational setting, and did not intend to promote transformative learning with specific interventions. Therefore the study adds to our understanding of the process of a transformation as it occurs secondary to life experiences and adult development. In addition, some researchers mention that emotions are important in the transformative process (Foronda, 2010; Rush, 2008), but they do not ask how this might be related to empathy which is a part of reflective discourse (Mezirow, 2000). Thus the study can contribute to the body of literature by focusing on the relationship that emotions and empathy have in reflective discourse.

Summary of the Literature Review

Review of the literature addressed three main bodies: nurses-as-patients, compassion, and transformative learning theory. Literature addressing nurses-as-patients reveals that a number of nurses write personal accounts of their patient experiences, and a limited number of studies have been conducted with this population. The literature shows that nurses report a change in practice as a result of the patient experience, especially in terms of compassion. The research does not focus on the specific relationship between the nurse-as-patient experience and compassion in practice. Because compassion was found to be an important part of the patient experience, the literature review also addresses compassion. Compassion is an important aspect of nursing care, but is often lacking in practice. Empirical review of literature pertaining to compassion shows that a
limited number of researchers are interested in cultivating or developing compassion in practice. Of the researchers that are interested in cultivating compassion, they are unable to articulate how this concept develops (Ellison & Radecke, 2005; Wear & Zarconi, 2007).

Very few studies in either the nurse-as-patient or compassion literature use learning theory as a lens. Transformative learning theory is the theoretical framework of this study because the literature indicates that the patient experience is transformative for the nurses who become patients. Two influential perspectives of this theory serve as the lens: Mezirow’s rational perspective, and the constructive developmental perspective. Empirical review of this literature shows that most of the studies were conducted in educational settings, and researchers intended to formally promote transformative learning. In addition, some show that emotions play an important role in the transformative process, but do not speak to how (Foronda, 2010; Rush, 2008).

This study addressed the gaps in nursing and compassion literature by specifically focusing on how the patient experience impacts the learning or development of compassion in practice. In addition, addressing emotions and empathy in the patient experience informs transformative learning theory in relation to these concepts.
Chapter 3

METHODOLOGY

This chapter addresses the methodology implemented in the study. The chapter begins by reminding the reader of the study’s purpose and research questions. Next, rationale for choosing the research paradigm and method of inquiry are provided. The chapter then discusses details regarding background of the researcher, participant selection, data collection and analysis, and trustworthiness of the study.

The purpose of this study is to examine the nurse-as-patient experience and the resulting changes in compassion in the professional practice of nurses. This study addresses nurses as individuals and their personal experiences, and revealing in-depth aspects of the nurse-patient experience is central to this study. Therefore, a qualitative research paradigm is appropriate to serve as a guide in the research. Discussion of this follows.

Research Questions

1. What is the relationship between compassion and the practice of nurses who become patients?
2. How do nurse-patients perceive compassion in their practice as a result of the patient experience?
3. How do emotions and empathy influence the nurse-patient’s experiences, and therefore compassion in professional practice?
Research Paradigm

This study is interested in understanding what individual nurses think and feel about compassion in their professional practice and how it has impacted their practice. This involved an in-depth exploration of the nurses’ experiences and their interpretation of the experience. Because an in-depth exploration of the nurses’ perceptions took place, a qualitative approach to the study was chosen. A general definition of qualitative research is that it seeks to understand how people make meaning of their experiences in relation to the topic of study (Creswell, 2009; Merriam & Simpson, 2000). It is an inductive approach to research that may evolve as the research process unfolds which allows the researcher to gain a more thorough understanding of the phenomenon being studied.

There are several assumptions of qualitative research. First is that “reality is constructed by individuals in interaction with their social world” (Merriam & Simpson, 2000, p. 97). In other words, no two people have the same experiences, and therefore no two people perceive the world in exactly the same way. Because qualitative researchers understand that that people see the world in different ways they understand that there may be no one “right” answer or “truth” about a certain topic (Creswell, 2009). The proposed study is interested in learning about compassion of nurse-patients, and the researcher understands that nurses may have similar experiences and perspectives of compassion, but no two will be exactly alike in their interpretation of the experience.

Second, in qualitative research, the researcher is the primary instrument for data collection and analysis (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). The researcher is interested in understanding the experiences and meanings of compassion in
nurses as individuals. Because of this, an appropriate way to gain understanding is through interaction between the researcher (me) and the participants (nurse-patients). By incorporating researcher and participant interaction in the research process, the researcher is able to adapt as the study develops (Merriam & Simpson, 2000). The researcher is able to clarify, revisit and ask for additional information in order to develop a more accurate understanding of the topic of research (Creswell, 2009; Merriam & Simpson, 2000).

Third, qualitative research is interested in understanding ways that people make meaning of phenomena or experiences in their lives (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). To understand how people make meaning of their lives, consideration is given to a person’s environment and life experiences. Environment, culture, personal experiences all affect the way we see the world and therefore what life events mean to us (Finch, 2004; Webster & Mertova, 2007). In order to appreciate the perceptions of compassion in nurse patients, attention was given to descriptions of where and when the patient experiences took place, the professional background of the nurses, and what they say the experiences meant to them.

Fourth, in a qualitative study, the researcher is interested in understanding the topic in great detail (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). By focusing on the person and the person’s experiences, a researcher is able to have a deeper or richer understanding of the desired topic (Creswell, 2009; Merriam & Simpson, 2000). In qualitative research this deeper understanding is obtained through the use of multiple data sources (interviews, field notes or observations, written data such as journals, etc) (Creswell, 2009; Patton, 2002). Having a qualitative focus in this study will allow the
researcher to collect detailed information about nurse-patient experiences and the 
meaning of compassion for these individuals.

There are different methodologies within qualitative research. The specific 
methodology that supports the purpose of the research should be chosen. The 
methodology chosen for this study is narrative inquiry. The reason for choosing narrative 
inquiry and details of the narrative design in this study are discussed below.

**Research Type: Narrative Method of Inquiry**

This study incorporated narrative as the method of qualitative inquiry. Narrative 
inquiry serves as the methodology for two main reasons. When reading the personal 
accounts and research studies, the nurses recount narratives about their experience. 
Several of the studies incorporated narrative inquiry as the methodology (Cotter, 1990; 
Guzman et al., 2009; Harker, 2000; Kempainen et al., 2007; Schwind, 2004). The natural 
way that nurses talk about being patients is in narrative form. Sometimes the narrative is 
about a specific experience within the overall patient experience, and sometimes the 
narrative is about the grand experience of being a patient. In my own experience I have 
talked and shared with nurses about their illness and mine. Each time the interaction 
involves talking about an aspect of the patient experience (such as feeling physically 
weak or afraid) and a narrative account accompanies this. Therefore narrative inquiry fits 
well with the way in which nurses talk about the patient experience. This section is 
devoted to discussing what narrative inquiry is, the assumptions of narrative inquiry, and 
how it will be used in this study.

Narrative inquiry is essentially the study of personal narratives, and makes the 
person’s story(ies) the object of study (Riessman, 1993). In general, a narrative is
considered a personal account of experiences which tends to be in story form, or has aspects of a story in it (Patton, 2002; Riessman, 1993, Webster & Mertova, 2007). In some circles, a narrative has a loose definition and can refer to stories about any past life event. However others more specifically say that narratives are about a specific life event and contain a plot with a chronological beginning middle and end (Riessman, 1993). Still others say that a narrative can be pieced together episodically by organizing experiences thematically (Riessman, 1993; Webster & Mertova, 2007). In all of these cases, the concept that a story can be derived from the person’s experience is at the center of the definition.

Some view narrative inquiry as a philosophical perspective of how to approach research (Clandinin & Connelly, 2000). There are two important terms used in narrative inquiry that must be addressed: personal narrative (or narrative) and narrative inquiry. A personal narrative refers to the experiences or the stories that a person talks about. Narrative inquiry is the study of those narratives, or the methodology used to study a person’s experiences (Clandinin & Connelly, 2000; Riessman, 1993; Webster & Mertova, 2007).

Narrative inquiry borrows from other methodologies within qualitative research, specifically phenomenology and hermeneutics. It borrows from phenomenology in that the researcher is attempting to understand how people make meaning of their experiences (Patton, 2002). When a person shares a story or narrative with the researcher he or she is sharing what that experience means to them. Narrative inquiry borrows from hermeneutics by considering the context and interpretation of an experience (Patton, 2002). Hermeneutics pays attention to the context of an experience because this
perspective acknowledges that the culture or environmental context impacts the way a person perceives and makes meaning of experiences. Where narrative differs from these perspectives is in the concept of the story or narrative. The narrative becomes the object of study in a narrative inquiry (Merriam & Simpson, 2000; Riessman, 1993; Patton, 2002; Webster & Mertova, 2007). In other words, the researcher places the story or narrative at the center of the research and focuses on this during data collection and analysis. The context of the narrative and what it means to the person is taken into consideration when it is identified. The story and the person’s interpretation of that story show the researcher what it means to that individual.

**Assumptions of Narrative Inquiry**

There are several assumptions of narrative inquiry. The first assumption is that people make meaning of experiences by placing them in a narrative context (Clandinin & Connelly, 2000; Webster & Mertova, 2007). To clarify what this means, people are living out life stories, and essentially see different life experiences as part of their overarching life story. Some scholars believe that narrative is a basic and integral aspect of being human, and that the use of narrative is a major aspect of human communication (Clandinin & Connelly, 2000; Riessman, 1993; Webster & Mertova, 2007). This leads the narrative inquirer to believe that if we focus on narrative as an integral form of human communication and expression, we will be able to better understand human experiences and what they mean to us. When reading the personal accounts, and research studies that address nurses as patients, nurses talk about the experiences through the use of narrative. Most nurses tell a story or aspects of a story about their experiences as patients. In one form or another, each nurse talks about what the experience means to her. If narrative is
about understanding the meanings or interpretations that people attach to their experiences, then a narrative inquiry is complementary with nurses who become patients in order to understand what the experience means to the individual nurse.

The second assumption is similar to the first in that narrative is considered a representation of our perceptions of life events (Riessman, 1993; Webster & Mertova, 2007). In other words, when we use a narrative to tell someone about something in our lives, we do so in a way that is telling of how we perceived that event. To give an example, a nurse may care for a patient recovering from surgery. The nurse administers pain medication to the patient at the prescribed intervals. When assessing the patient’s pain, she finds that the patient reports a decrease in pain after receiving the pain medication. She documents that the prescribed regimen is effective. The patient on the other hand receives the pain medicine, but finds that it never gives complete pain relief. He tells his wife that the pain medicine helps, but he wishes it were stronger. The “narratives” of these individuals reveal that they perceived the same interaction much differently. Likewise, nurse-patients’ narratives about compassion can reveal how they perceive compassion from both the nurse’s and patient’s perspective, rather than from only the nurse’s point of view.

The third assumption is that narrative inquiry is holistic, or interested in the person in a holistic manner (Clandinin & Connelly, 2000; Riessman, 1993; Webster & Mertova, 2007). For example, if participants are not bound by standardized or structured questions, they will often provide lengthy responses (Riessman, 1993). This type of interviewing allows participants to decide what is shared and express their perceptions of an experience. This may be seen as a more holistic way to obtain data because the
individual decides what is important rather than the interviewer (Riessman, 1993). For others, narrative inquiry involves looking at all of the information that participants share such as written work or interviews, the context of the stories that participants share, and the context of the interactions between researchers and participants (Clandinin & Connelly, 2000; Webster & Mertova, 2007). This approach is considered holistic because it looks not only at what the participants choose to share, but also at the larger narrative in which that the stories are being shared. When researching compassion in nurses who become patients, consideration was given not only to the nurses’ stories and experiences surrounding compassion, but also to their background as nurses, perceptions of compassion both before and after becoming patients, and the environments in which the patient experiences and nursing experiences take place. This helps to provide a holistic view of compassion in the nurses’ practice.

**Use of Narrative in this Study**

This study is not only interested in the specific experiences of compassion during nurses’ patient experiences, but also in the overarching narrative of compassion in their professional lives as a whole (Clandinin & Connelly, 2000). Nurses were selected because they have patient experiences that change their perception of compassion in their practice which is part of their individual professional narratives. However, because they thought about compassion during the study and interacted with the me, they were continuing the narrative of compassion in their practice, as well as affecting my own narrative of compassion. Because of this, the I chose to incorporate aspects of Clandinin & Connelly’s concept of narrative inquiry as a guide in the study design. In this concept, narrative inquiry is a process that involves individuals who are making their own
narratives, are affecting the individual narratives of those around them, and are co-creating a narrative with each other (Clandinin & Connelly, 2000). To support this perspective, narrative inquiry spaces are proposed, along with the concept of paying attention to the four directions of narrative inquiry which are discussed below.

**Narrative Inquiry Spaces**

Narrative inquiry spaces address key aspects of the experiences in a person’s life: *interaction, continuity, and situation* (Clandinin & Connelly, 2000). *Interaction* considers both personal and social interactions as part of experience. *Continuity* is the attention to past present and future as being part of the person’s life experiences and narrative process. *Situation* is the places that events take place in or sequence of places over time that are part of the person’s narrative process.

Narrative inquiry spaces can be identified in this study. The study addresses interaction by virtue of the fact that nurses interact with the researcher during interviews. The study addresses interaction because the nurses spoke about the interactions they had when they were patients, and as nurses who care for patients. Situation is addressed because nurses discussed aspects of their patient experience which involve the places, circumstances, and events that comprised their patient experiences. Field notes taken during interviews address the overarching narrative situation that took place during the study. Continuity is addressed in this study by addressing the nurses’ perceptions of compassion before, during, and after the patient experience, which is discussed in each part of the data collection process below.
Four Directions of Narrative Inquiry

In addition to spaces within the inquiry process, a narrative can be considered in terms of the directions that it takes the researcher and participants. This section explains this concept.

The four directions of narrative inquiry are inward-outward and backward-forward (Clandinin & Connelly, 2000). In narrative inquiry, addressing inward and outward means paying attention to the inward aspects of a person, and the outward contextual aspects of a person’s experience. An inward focus addresses a person’s thoughts, feelings, moral disposition, hopes, etc. An outward focus pays attention to the environment the person is in, such as the physical context (school, home, work, a public park, etc), or the psychosocial context (welcoming, hostile, comfortable, relaxed, etc).

The study design addresses inner and outer aspects of narrative inquiry experiences by asking the participants to share the “inner” aspects of their experiences, or their thoughts, feelings, emotions, and impressions about the experiences. The “outer” aspect of the data came partly from nurses naturally talking about the environmental circumstances of their patient experiences. The outer aspect of data collection included asking for clarification, and my own observations written in field notes after interacting with the nurses.

Backward and forward refers to the concept of temporality: past, present, and future. A narrative process begins in the past, is taking place in the present and will continue into the future (Clandinin & Connelly, 2000). Paying attention to backwards and forwards was addressed at the various stages of data collection. During the interviews I will asked them about past experiences, and asked them to consider how they might
practice compassion in the future which addressed the past and future aspects of looking backwards and forwards. I asked nurses to tell me about compassion in their practice as new nurses and how they see compassion in their practice currently.

This study is interested in the individual nurses’ perceptions of compassion in their practice. By utilizing narrative inquiry within the broader paradigm of qualitative research, I gained a deeper understanding of the meaning of compassion in the nurses’ professional practice. Using aspects of Clandinin & Connelly’s (2000) view of narrative inquiry served as a guide in deciding how data collection would take place.

**Background of the Researcher**

This section discusses the researcher’s interest, views, and role in this study. My professional background affects my role, interest, and views of this research study. Due to the qualitative research paradigm in this study, my role is that of primary instrument in data collection and analysis (Creswell, 2009; Merriam & Simpson, 2000). Being a nurse and former patient impacts my view of nurses, patients, medical or healthcare terminology, and the explanations of nurse-patient experiences. I come to the study being heavily influenced by Western medicine, nursing culture, and the culture of critical care nursing in particular. This culture values facts, figures, and objective information when deciding how to care for patients. However, I have a very strong opinion of compassion in nursing stemming from my experiences as a patient in both a small community hospital and major tertiary medical center. I believe that many nurses lack compassion toward patients, and need to improve their patient care by being more compassionate. In this study, my personal biases about the importance of compassion in nursing practice will impact how I interpret the narratives of nurse-patients. I realized at the beginning
that I may judge nurses’ views of compassion in their practice as being more or less compassionate than my own practice. I kept this in mind as the participants shared their experiences and perceptions with me. As the data collection and analysis process unfolded, I was humbled by the experiences of the participants, and how deeply they perceive compassion in their practice.

This research study was undertaken first because of a personal interest in compassion of nurses who provide patient care, and stems from a personal desire to provide excellent care. It is my professional belief that being compassionate or providing compassionate care is essential in nursing practice, and nurses should strive to improve this aspect of their professional role. Second, the study was undertaken because I have been a patient and believe that the experience changed my understanding of patients and my professional practice. Becoming a patient provided me with an enriched understanding of what people go through when they are sick. The experience helped me to become a more compassionate person because I am quicker to think about how others feel, and am much more likely to lend them a hand.

I like to believe that nurses are generally compassionate people who enter into to profession for altruistic reasons. When my faculty colleagues and I ask student nurses why they want to become nurses, they almost always say that they want to help other people, or that their lives were profoundly touched by a compassionate nurse. In practice, I hear nurses themselves talking about their desire to help others or “make a difference” in other people’s lives. As a nurse I am conflicted about this very thing. I see many nurses who are compassionate and display genuine concern for patients, and other people in general. On the other hand, I see nurses who do not seem to care about patients (or
other people) much at all. These nurses complain about patients who ask for help frequently, or do not address patient needs in a timely manner. Seeing these two sides of nursing disturbs and puzzles me personally and professionally. Therefore, conducting research on the perceptions of compassion in nurse-patients is a way to begin developing a deeper understanding of this concern.

**Participant Selection and Informed Consent**

This study incorporated participant selection that is consistent with qualitative research. In qualitative research, an in-depth understanding of a topic is desired (Creswell, 2009; Merriam, & Simpson, 2000; Patton, 2002). A way to insure this is to use an inductive process that involves a small group of individuals and uses data collection methods that allow for personal meaning to be shared (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). Therefore, 12 nurses who met inclusion criteria participated in this study. In addition, the participants were part of a purposeful sample. A purposeful sample selects participants because they will provide rich data that pertains to the topic of interest (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). In this study the compassion in nurses is the topic of interest. Nurses who have been patients participated because they are able to speak to compassion in their practice as a result of being patients.

Participants were selected based on four criteria: self-disclosing as having a significant patient experience after becoming an RN, self-disclosing that compassion in professional practice changed as a result of the patient experience, nurses had direct patient interaction as part of their job after the patient experience, and nurses have at least five years of experience. Rational for the selection criteria is presented below.
Selection criteria included nurses who self-discoe as having a significant patient experience which requires hospitalization or illness involving frequent interactions with the healthcare system as part of treatment. Examples of significant patient experiences may be (but are not limited to) hospitalization requiring surgery or in-depth medical treatment, and cancer treatments. Nurses with significant patient experiences were selected because a significant patient experience is more likely to impact nurses in a personal way. Nurses with significant patient experiences will experience strong emotions related to their wellbeing and the way they are treated during a stressful time in life. Nurses who have a significant patient experience will be more likely to evaluate or reevaluate their professional practice after receiving healthcare. Therefore, they will be more likely to think about compassion in their practice and change practice as a result.

A second selection criterion included nurses who self-disclosed that compassion in their professional practice changed as a result of the patient experience. In this study compassion is the specific topic of interest. In order to address this topic, nurses need to identify that a change in compassion has occurred. If the nurses can identify a change in themselves, they can talk about this change and give insight to the learning experience.

A third selection criterion is that nurses must have direct interactions with patients as part of their job after the patient experience. Nurses who become patients and return to patient care in their professional roles are more likely than non-clinical nurses to carry out a change of compassion in practice. These nurses are providing care to someone and are therefore likely to consider the needs of patients when returning to work. Nurses who have direct interaction with patients will be involved in situations that may be similar or
remind them of their own patient experiences, which can draw nurses’ attention to a change in compassion.

The last selection criterion includes nurses who have been in practice for at least five years. Nurses who have been in practice for five years have developed professionally and become skilled in their role as nurses (Benner, 1984). Nurses who have at least five years of experience will be established as clinicians and therefore will be able to identify what compassion was like in their practice before and after the patient experience.

Participants were recruited through snowball sampling (Patton, 2002). This was done by sending an email to nurses that I know and asking them to forward my request to others. The email included the purpose of the study, inclusion criteria and my contact information. Initially, 16 nurses responded to the request. Ultimately, 12 nurses met inclusion criteria and participated. In each case, initial contact occurred via email response to me, followed by a phone conversation to set up a time and date for a face-to-face interview. I began with 12 participants, with plans to recruit additional nurses as needed. However, data saturation occurred after approximately eight participants were interviewed for a second time.

Implied informed consent was obtained from each individual who participated in the study (see consent form in Appendix B). Implied informed consent was given because a signed form is the only document linking the individual with the study, and participating in the interviews was voluntary. Therefore, participation in the interview implied consent. In order to obtain consent from participants I explained what the study is about (i.e. explaining that I am interested in understanding how compassion changes in nurses who have become patients), the types of data I planned to collect (face-to-face
interviews), and the roles/responsibilities of myself and participants. Participants were informed that they had the right to end their participation at any point during the process, and were informed of ways that their privacy will be protected. For example participants were given a pseudonym in the dissertation. Specific dates of illness, locations of healthcare agencies, home towns, and real names of healthcare providers were not included in the study. Several participants gave a detailed description their illness that could potentially identify them to others. In these cases, terminology was changed to more general terms to prevent specific identification of these participants. After explaining the research process and individuals agreed to participant, we arranged a face-to-face meeting in a quiet location that participants chose.

Demographic information of the participants varied greatly (refer to Table 1). Participants’ ages ranged from being in their early 30’s to early 60’s. In addition, the years of nursing experience ranged from 5 to 40+ years. Most of the nurses (9) indicated that they obtained their nursing education immediately following high school, either by attending a hospital based diploma school of nursing, or attending an Associate’s degree or Bachelor’s degree program. Charo, Dancer, and Natalie became nurses after working in other fields for a number of years. In addition to variety in ages and years of nursing experience, the types of illnesses varied greatly. Illnesses included: cancer, high-risk pregnancies, acute problems requiring surgery, and chronic illness. Most of the illnesses have occurred within the last five years, or are on-going due to the chronic nature of the individual’s illness. Additional information about the individual participants is included in the narratives.
Table 2

Participant Demographic Information

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Years of Nursing</th>
<th>Age</th>
<th>Healthcare Setting</th>
<th>Type of Illness</th>
<th>Timing of Patient Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natalie</td>
<td>5</td>
<td>35-40</td>
<td>Outpatient</td>
<td>Chronic: Nervous System Disorder</td>
<td>Current</td>
</tr>
<tr>
<td>Savannah</td>
<td>5-10</td>
<td>30-35</td>
<td>Acute In &amp; Outpatient</td>
<td>High Risk Pregnancy</td>
<td>In last year</td>
</tr>
<tr>
<td>Sara</td>
<td>5-10</td>
<td>30-35</td>
<td>Acute Inpatient</td>
<td>Severe Pneumonia</td>
<td>In last year</td>
</tr>
<tr>
<td>Shaneequa</td>
<td>10-15</td>
<td>30-35</td>
<td>Acute Inpatient - Surgery</td>
<td>Gynecologic Infection</td>
<td>In last year</td>
</tr>
<tr>
<td>Dancer</td>
<td>10-15</td>
<td>50-55</td>
<td>Acute Outpatient Surgery</td>
<td>Foot Surgery</td>
<td>In last year</td>
</tr>
<tr>
<td>Charo</td>
<td>10-15</td>
<td>45-50</td>
<td>In &amp; Outpatient-Surgery</td>
<td>Cancer</td>
<td>In last 10 years</td>
</tr>
<tr>
<td>Teresa</td>
<td>10-15</td>
<td>35-40</td>
<td>Outpatient</td>
<td>Chronic: Cancer</td>
<td>Current</td>
</tr>
<tr>
<td>Gail</td>
<td>10-15</td>
<td>30-35</td>
<td>Acute In &amp; Outpatient</td>
<td>High Risk Pregnancy</td>
<td>In last 4 years</td>
</tr>
<tr>
<td>Joanne</td>
<td>25-30</td>
<td>45-50</td>
<td>Acute Inpatient-Surgery</td>
<td>Surgical Complication</td>
<td>In last 3 years</td>
</tr>
<tr>
<td>Hoku</td>
<td>30+</td>
<td>55-60</td>
<td>Acute Inpatient - Surgery</td>
<td>1. Car Accident 2. Broken Ankles</td>
<td>10 years ago</td>
</tr>
<tr>
<td>Bekah</td>
<td>30+</td>
<td>55-60</td>
<td>Outpatient</td>
<td>Chronic: Cancer</td>
<td>Current</td>
</tr>
<tr>
<td>Helen</td>
<td>40+</td>
<td>60-65</td>
<td>In &amp; Outpatient</td>
<td>Chronic: Autoimmune Disease</td>
<td>Current</td>
</tr>
</tbody>
</table>

Note: Arranged in order of least to most number of years in nursing practice
Data Collection

In qualitative research, data is collected in such a way as to obtain in-depth information. Types of data and data collection that are common in qualitative research include face-to-face interviews, journaling, observations, and even creative projects such as artwork (Creswell, 2009; Merriam, & Simpson, 2000; Patton, 2002). These types of data are also used in narrative inquiry (Clandinin & Connelly, 2000; Webster & Mertova, 2007). This study used participant interviews and the researcher’s field notes as sources of data. Below is a discussion of the types of data, and data collection process.

Types of Data in the Study

Data in this study includes field notes, and interviews (Patton, 2002). Using these different types of data is done to address trustworthiness of the study and to address aspects of Clandinin & Connelly’s (2000) proposed view of narrative inquiry (discussed above). The use of several different types of data provide rich descriptive information and are part of submersion, and triangulation (Patton, 2002). These help to increase credibility, transferability and dependability which in-turn improves the trustworthiness of the study.

Field Notes

Field notes are an integral part of the data collection process in qualitative research. Field notes provide additional description of the research process, and can serve as a reference tool for the researcher as the study progresses (Patton, 2002). In narrative inquiry, field notes are created in different ways (Clandinin & Connelly, 2000). Field notes can involve descriptions and observations of the people and situations involved in the study. Field notes can be written episodically by the researcher in journal form as well
Field notes can include the researcher’s thoughts and opinions as the study unfolds (Patton, 2002). In this study, I kept field notes by both writing and digitally recording my thoughts. (A number of the interviews were held at a time and location that did not allow for written field notes immediately after the interview. Therefore I spoke into the digital recorder as I drove home from some interviews.) I wrote additional field notes by listening to the interviews several times, and taking notes in a Word Document. I typed notes pertaining to major concepts that stood out for the individual participants. I wrote my thoughts about the individual nurses’ interviews and experiences.

**Interviews**

Individual interviews are usually conducted face-to-face or over the phone and tend to be described as structured, semi-structured, open ended, or conversational (Patton, 2002). These descriptions refer to the types of questioning in the interview process. Structured and semi-structured interviews have questions that have been decided in advance with structured interviews having each question predetermined and semi-structured allowing for some flexibility (Patton). Conversational questioning has little structure and allows those involved to explore topics as they become apparent. In narrative inquiry conversational interviews are more common than structured or semi-structured interviews (Clandinin & Connelly, 2000). This is due to the more relational quality of a narrative inquiry in comparison with other types of research.

In this study two interviews were conducted with each participant individually. Interviews were digitally recorded and transcribed verbatim. Both the first and second interview lasted an average of 45-60 minutes, with some lasting 90-120 minutes. Most
interviews took place in a quiet library room, or office. Five nurses opted to have their follow-up interviews via phone because it was more convenient for them rather than arranging a face-to-face meeting.

The interviews focused on asking questions that addressed the narrative of compassion in the nurses’ practice, and were a combination of open ended and conversational structure (Patton, 2002). The conversational aspect of the interview is appropriate for this study because it provides the greatest flexibility during the interview process, and allows the participant and researcher to explore topics that emerge (Patton). Clarification questions were included to explore concepts that seemed to be important to the participants, and provide greater detail of concepts the nurses discussed. In addition, interview questions attempted to remain true to the backwards and forwards nature of narrative inquiry (Clandinin & Connelly, 2000) by asking about the nurses’ perception of compassion in their practice before and after the patient experience and what they found to be significant in their patient experience.

Interview questions were conducted in a narrative style. Narrative interview questions are open-ended or conversational and allow the participant to include or exclude what is desired (Riessman, 1993). Narrative questions can begin by asking “Tell me about…” and follow a conversational format as the interview progresses. Doing so, gave the nurses opportunity to share stories that they considered to be important in their experiences (Riessman, 1993). During the first interview with each participant, I began by asking the participants to tell me about their patient experience, and allowed the interview to flow from there. Refer to Appendix A for sample interview questions.
There was some overlap with the data collection and analysis process. While some interviews were in the process of being transcribed and analyzed, other interviews were just being recorded. In addition, I digitally recorded my thoughts, and took notes on the individual interviews as they occurred. As a result, I was able to identify information that needed clarification between the first interview and second interview.

**Data Analysis**

Two different approaches to data analysis were utilized in this study: identifying individual narratives and a thematic analysis. Identifying narratives of the individual participants is in keeping with narrative inquiry, and thematic analysis of the narratives as a group provides additional insight into the learning that this group of nurses experience. Because of this, there are two different chapters addressing data analysis. Chapter 4 presents the individual narratives of the participants, and Chapter 5 presents the themes in the data as a whole.

There are different approaches to narrative analysis such as visual, dialogic structural, thematic, and critical event (Riessman, 2008; Webster & Mertova, 2007). A visual narrative analysis includes elements of written data and visual data through the use of art, photography and other visual mediums. A visual narrative analysis may be constructed “about” images or “with” images (Riessman, 2008, p. 141). A dialogic narrative analysis is concerned with the social interaction between researchers and participants when constructing a narrative (Riessman, 2008). In a dialogic analysis, the researcher “becomes an active presence in the text” of a narrative (Riessman, 2008, p.105). Thus analysis pays attention to who speaks, when they speak, and the meaning arrived between the people involved. In a structural analysis, the researcher focuses on
linguistic structures such as: clauses, word choice, pauses in speech, voice pitch and other aspects of how the participant speaks. Sometimes a structural analysis involves examining poetic structures in speech, or aspects of dramatization such as: act, scene, agent, agency, and purpose (Riessman, 2008; Riessman, 1993). Another form of narrative analysis is a thematic analysis. In this type of analysis the researcher pays attention to the main concepts or themes, shared by participants; it is interested in what has been “told” rather than in the “telling” like a structural analysis does (Riessman, 2008, p. 54). Last, a critical event approach to analyzing narratives is similar to a thematic type of narrative analysis in which the researcher attends to the major points or critical events that impacted the speaker (Webster & Mertova, 2007). With this type of analysis, written narratives focus on events and can be presented in a variety of ways.

During the narrative analysis, I used a critical event approach which attempts to identify key experiences, or critical events that impact the person’s narrative (Webster & Mertova, 2007). Critical events typically have three identifiable elements: a described situation, an account of what happened in the situation (i.e. a person’s behavior or actions), and an outcome (Webster & Mertova, 2007). While constructing the participants’ narratives, I included their comments that address these aspects when they were shared. To identify critical events, I began by listening to the digital recording, read the transcripts, and took notes. In the note taking process I summarized the participants’ comments, identified events that participants emphasized, and jotted my own impressions of the participants’ overall narrative. Within each participant’s patient experience, critical events could be identified.
During the first interview, I began by asking the participants to tell me about their patient experience, and left it open for them to decide what to include. Participants often chose to share their patient story in a chronological fashion, but often had side comments and stories which revealed things that they felt strongly about. Asking clarification questions assisted in constructing a narrative that represents critical aspects of their patient experiences, and the impact the critical events had on their perception of compassion and behaviors in practice.

The second type of analysis in this study involved a thematic analysis. During the thematic analysis and interpretation of data I used an inductive approach (Creswell, 2009; Patton, 2002). An inductive process allows important or key concepts to emerge during the data analysis (Patton, 2002). Inductive analysis is an ongoing, reflective process that involves reviewing the data, coding the data, identifying themes, and interpreting the meaning (Creswell, 2009). For the thematic analysis, I read the transcribed interviews. I then went back and re-read the transcript and began the coding process by identifying concepts (Creswell, 2009). To do so, I looked for common words or phrases that participants said, or concepts emphasized by the participants. For example, nurses made comments such as, “I put myself in their shoes,” or phrases very similar to this. I then transferred these to a Word Document and color coded them according to participant. After transferring the concepts and phrases to a Word Document, I examined the concepts and phrases looking for similarities or relationships; and began to group the concepts and phrases into common categories. For example, when discovering the sub-theme of fear, all of the nurses referred to having “fear,” being “afraid,” or made comments such as “I was scared to death,” and, “It was really scary.” As I reviewed these
comments I realized that they represented a common experience of fear. I reviewed the interviews and categories multiple times, and discussed my thoughts with my advisor before arriving at the major themes discussed in Chapter 5.

**Verification**

This section addresses verification strategies employed in qualitative research that are used to conduct a high quality study. There are several verification strategies used in qualitative research to accomplish this goal. Attention paid to credibility, transferability, and dependability (Creswell, 2009; Merriam & Simpson, 2000; Patton, 2002). *Credibility* and *dependability* refer to the researcher’s attempt at being fair, balanced or complete in analyzing and presenting data (Patton, 2002; Merriam & Simpson, 2000). The goal in credibility is to present information that is not distorted by the researcher’s biases (Patton, 2002). The goal with dependability is to have results that are “consistent with the data collected” (Merriam & Simpson, 2000, p. 102). *Transferability* is the degree to which a reader can relate the study context to a similar context that they are placed in or working with. For example, this study’s context is compassion in nurses who become patients, but perhaps a future reader may be considering compassion in surgical nursing specialties. If the study of nurse-patients addresses compassion in nurses, then the reader can draw on that information when considering compassion in surgical nurses. Together, these strategies address the overall *trustworthiness* of the study. Trustworthiness in a qualitative study is essentially the degree to which the findings are accurate and believable the findings of the study are (Merriam & Simpson, 2000).

To insure that the study addresses trustworthiness, researchers incorporate different strategies. Some of these strategies included in the proposed study are
triangulation, submersion, thick and rich detailed descriptions, and acknowledging biases (Creswell 2009; Merriam & Simpson, 2000; Patton, 2002). These are utilized to insure that data and conclusions based on the data are accurate.

This study intends to use triangulation which is the use of more than one type of data, and input from the researcher(s) and participants in confirming data interpretation (Creswell, 2009; Patton, 2002). Triangulation addresses dependability and credibility of results by confirming (or perhaps not confirming) that multiple types of data have similar themes. For example, this study included researcher observations, and individual interviews as different types of data. In addition, the primary researcher used member checking as a way to confirm data analysis and interpretations. Member checking involves asking participants to read quotes and conclusions to make sure that the researcher is representing the participant and their views accurately (Creswell, 2009). During the second interview, I reviewed concepts that had been discussed in our first interview and my interpretation of the participants’ comments. They gave verbal confirmation of my interpretations, and gave additional explanation when necessary. At the end of our interviews we recapped our discussion and my impression of their meaning for final confirmation of what they intended to express.

Submersion, or prolonged periods of time in the research field to help give the researcher a broader understanding of the topic is a technique used to increase credibility, and transferability with readers. Creswell (2009) states that the longer a researcher spends in the field “the more accurate or valid will be the findings” (p. 192). The researcher in this study has spent at least a decade as a registered nurse. In addition, I have been a patient and have come to understand possible changes in professional practice as a result
of the patient experience. While this entire period of time has not been spent considering compassion and professional practice, it does afford me an in-depth understanding of the nursing profession and ways that nurses may understand and carry out their professional practice. Submersion contributes to authenticity because the researcher has a more in-depth understanding of the topic and participants, making the process more authentic.

Researchers may use *thick or rich detailed descriptions* of the data to validate what is being said to the intended audience (Creswell, 2009; Patton, 2002). By helping the audience to imagine the research setting, or relate to the research, the researcher is making the information more realistic to the audience and is thereby increasing credibility, and transferability of the study. To provide detail to the participants’ experiences, each narrative includes background information, and a detailed account of the patient experience. Detailed description of the narratives involved digital recording and verbatim transcription of the interviews; in addition to the researcher’s own typed or digitally recorded thoughts and interpretation of the narratives.

*Discussion of researcher’s subjectivity* and how this may affect data collection and interpretation occurs to address authenticity and credibility of the study (Creswell, 2009). Being open and honest about the researcher subjectivity will help the researcher to see ways that data may be interpreted due to the biases. (See background of researcher and study limitations for discussion of researcher’s biases.) Readers of the study will appreciate the honesty of the researcher.

**Chapter Summary**

This chapter began with a reminder of the study’s purpose and guiding research questions. A qualitative study design was chosen because the study seeks to gain an in-
depth understanding of compassion in nurses. By nature, qualitative research focuses on in-depth understandings of the meanings that people make through life experiences (Creswell, 2009; Merriam & Simpson, 2000). Furthermore, a narrative inquiry with an additional thematic analysis was utilized in the study. Narrative inquiry is the study of the stories or narratives of people’s lives and life events (Clandinin & Connelly, 2000; Riessman, 1993; Webster & Mertova, 2007). This study is well suited to a narrative inquiry because not only do nurses have stories to tell about their patient experiences, but the concept of compassion in their practice is part of their professional narrative which is an ongoing narrative.

Data collection and analysis was consistent with narrative inquiry. Data was collected in such a way as to pay attention to the overarching narrative of compassion in the nurses’ profession in addition to the narrative of compassion within the patient experience. To produce a trustworthy research study, the researcher used techniques such as triangulation, thick and rich descriptions, submersion, and paid attention to personal biases throughout the data collection and interpretation process.
Chapter 4

NARRATIVE ANALYSIS

In this chapter the narratives of the nurse participants are explored. As discussed in Chapter 3, the type of narrative analysis employed in this study is a critical event approach (Webster & Mertova, 2007). In this method, the researcher identifies an event that impacts the participant in relation to the topic of interest. A critical event has a lasting impact on a person, and includes elements such as: a described situation, an account of what happened in the situation, and an outcome (Webster & Mertova, 2007). A critical event analysis is similar to a thematic narrative analysis in that it is interested in identifying and presenting the major concepts that the speaker tells, and can be constructed in a variety of ways (Riessman, 2008). This is different from a structural narrative analysis which focuses on linguistic structure to construct the speaker’s meaning (Riessman, 2008). For consistency, each narrative in this chapter is constructed with a similar format. Each participant has a narrative that begins with a brief description of their nursing career, and some background information. Additionally, each narrative includes an account of the patient experience. In retelling the patient experience, I try to allow the story to stand for itself and make fewer comments. Beyond the patient experience, the narratives are constructed according to what the participants discussed as being most important or most critical to them in relation to their perception of compassion. Some nurses chose to share the impact of the patient experience on their perspective of compassion by telling stories that illustrate their perspective. Other nurses
discussed specific aspects of compassion that they now consider to be important in their practice. Overall, I considered the critical events in the patient experience and the relationship with their perceptions of compassion in their practice. In keeping with Clandinin and Connolley’s (2000) concept of backward and forward in a person’s narrative, I included the participants’ perception of compassion before and after their patient experience as well.

Refer to chapter 3 for participants’ demographic information. The narratives presented below are ordered according to number of years practicing as a nurse starting with the least number of years in practice. (During the analysis chapters and discussion, nurses are referred to as “she” or “her.” This is because female nurses participated in the study. Male nurses were not purposefully excluded; rather, male nurses did not volunteer to participate. For ease of writing, nurses are referred to with feminine pronouns.)

**Natalie’s Narrative**

Natalie has been a nurse for 5 years, but had a career in a non-healthcare field prior to becoming a nurse. She has worked in several different roles in her nursing career such as: emergency room nursing, hospice nursing, urgent care, and she currently works as a school nurse. During the last two years she has experienced health problems. Her previous two jobs had an impact on her health, thus prompting the job moves. She is hopeful that the regular hours and fewer physical demands in her current position will have less impact on her health.

Natalie is a mother of two teenagers, and spends a lot of time with them at extracurricular activities. Between her job and household role, meeting face-to-face was
difficult for her. She chose to have both of her interviews via phone. She was very pleasant and willing to share her experiences and thoughts with me.

Natalie’s Patient Experience

In the last year, Natalie has been seeking medical care for a number of symptoms. However, she says that her problems probably began about two years ago when she first began experiencing symptoms intermittently. She described some symptoms below:

I can go back two years and start explaining things that nobody could explain before. Yeah, like I have had falls. My balance is really bad. I mean, I just fall over. Literally, I was in the store with my daughter and just went to turn around and the next thing, I am on the floor. I didn’t pass out. I didn’t black out. I didn’t have anything. I just fell over. And that happened about three times in a three week period. Or I would get these dizzy and nausea spells. And they (the doctor) said it may be vertigo. So they put me on medicine for that. Then I started having extreme weakness and fatigue. And the nausea and dizziness got much worse. I couldn’t focus; I would try to look at things and everything would be blurry. So I missed a good bit of work there over about 4 weeks. Plus my migraines got really bad, but they were different than they had been before.

Natalie said that it took a while for the doctor to begin thinking about her various symptoms as being related. At one point, her family doctor began to suspect that she may be having a neurological problem. She explained,

So one day, after about six weeks of this, I went into my family doctor and I said, “You know, I can’t get these headaches straightened out no matter what I take; and I am having, this, this, this and this.” He said, “You know what. You haven’t
had an MRI for about 4 years. It is probably time we just rule out anything weird because your symptoms are different from what they have always been.” And that is when they found the lesions. So the plan was to recheck in six months and see what happens, and see if there are any changes. And if any more of these episodes come up, we would treat symptomatically. So almost six months later it started up again. I was due for my six month MRI in a few weeks. In that time I just started getting really tired again and the dizziness came back. I shouldn’t have even been driving. I went for my MRI, and another lesion was there, and one of the others was bigger than before. Well, they did a spinal tap and everything came back perfectly clear.

A spinal tap involves using a large needle to draw fluid from the spinal cord and analyzing the contents for various things such as: blood, bacteria, white blood cells etc.

While Natalie was being treated for the various symptoms, and having tests done, she was referred to a neurologist at a tertiary center. Natalie has been seen several times, and at the time of our first interview was still going through different tests. In fact, she said that the specialist referred her to another specialist due to abnormal blood work. As she told her story, she mentioned that she gets frustrated with the fact that she has had all sorts of tests, but still no answer. She said,

(Frustrated tone) It just seems like with each step there are more questions. You never really get an answer you just get more unknowns. So, I don’t know. Like, the doctor ordered a whole bunch of blood work last month. He said, “I think it’s this certain diagnosis. But before I give you a final diagnosis I want to do a bunch of blood work just to rule out any other possibilities.”
Even though the doctor had a high degree of suspicion about a certain diagnosis, he chose not to begin treating her until after she has additional testing, and had an appointment with the other specialist. Natalie continued to explain her frustration. She said,

Nobody is doing anything. And I just sat there in his office and cried. I was like (upset tone), “Listen. I understand you don’t want to tell me I have something I don’t have, but in the meantime we are going on like the tenth month of me being miserable, having weird symptoms, nobody has an answer for me and I feel like crap. Nobody tells me what to do!” You know, that’s the frustrating part of it. And he was like, “I know, but until I do this and this we are just going to keep watching.” It is very frustrating. I think my biggest frustration with all of this is that no one will take responsibility. Everybody wants to push you to the next guy, and the next guy, that is his area of specialty. Well then his area doesn’t explain that area so he sends you back to the other guy. The other guy says, “Well, we’ll just wait and see.” I am the one who is still struggling while they are deciding what they want to call it.

In addition to having multiple tests over a long period of time, Natalie has continued to work. However, her symptoms caused problems with her work schedule, and she said that her health status changed the way her last employer treated her. She explained,

And then I get the other side of it. While all of this is happening I had just started my last job. So I’m having to go to these appointments at the specialist. You know, that’s a whole day event because until I get there and you wait and do the appointment and then drive back home, I mean it takes a whole day. So I’m
having to rearrange schedules and plan all of that. So I had to explain to my boss what is going on. So I went into work one day and she said (unfriendly tone), “I want you to know. I called the medical director of the company to tell them about your possible diagnosis and we are going to have to put some safety precautions in place. You know, what is your judgment going to be like if you have one of these episodes? And if you start to get sick you are going to have to tell us right away. And, oh by the way, you are not eligible for FMLA, and you don’t have short term disability.” (sigh) Yeah. So she basically said, you know, “I just want you to know we are going to be watching you. And if you need time off and you can’t work, I can’t guarantee you are going to have a job.” So that is when the wheels started turning in my head that this is not a place that is going to take care of me if something happens. You know, this is not a very stable future for me here. So that is when I started thinking I need to find a job where I have a future and where I’ve got good benefits and if something should happen they are not going to can me. Now I’m afraid to tell anybody anything.

By the time our second interview took place, Natalie had received some answers to her medical problems and had received a diagnosis from the doctor. In addition, she had started a new job, and found it to be less stressful. Thus she is hopeful that it will not have a detrimental effect on her health.

**Why Compassion is Important to Natalie**

Now that Natalie has been a patient, she understands the importance of receiving compassion from healthcare providers. To explain why it is important, she told me a story about receiving a phone call from the office staff of one of the specialists:
When the blood work came back with the thyroid being all out of whack, they just called and said, “We got the blood work back. Dr. So-and-so would like to see you in his office in two days at 12:30. Can you be there?” Well, you know, when you call and tell me that, and you don’t tell me what the results are… I was just crazy. I’m like (scared tone), “Well, can you at least tell me what blood test was abnormal?” “Well, he’ll go over all that in the appointment.” (Saying to the office worker), “Well, now you told me in 48 hours I am going to have an answer to something that is potentially life-threatening.” Like how do I know? So I was kind of frantic for a while. And I called her back and she still wouldn’t give me an answer. So, instead I called my doctor, the one I was working with. She called and got my results. So then we looked at them, and at least I knew what it was they were talking about. Once I knew what it was and we talked about it, then I stopped worrying. But if I hadn’t been a little bit sneaky and had somebody else pull my results for me, you know, those two days could have been just insane. So that was really scary. I think sometimes healthcare providers forget they are dealing with people and not just a number or a chart. I think they forget the human side of it. You know, they can sit and put their puzzle together and say well, she has this symptom, and this symptom and this is what we are going to watch for, and this is what we will wait for, and this is what we are going to test. Well all the time they are playing with their charts and figuring out what is going on, there is a real person out there going through something. So that has made me a little more aware. I have tried to be honest with my patients and ask them, “Is
there something you don’t understand? Is there a part about this that scares you that you want to talk about?”

Having an experience that involved uncertainty made her realize some of the things that people think and feel when going through situations like this. She was afraid of what the results might bring, and needed someone to be compassionate and understand what she was feeling. Being in a position of uncertainty has changed the way she thinks about patients’ situations and how she interacts with them; as evidenced by taking the time to ask patients if the need to talk, or explain things they do not understand.

**Natalie’s Perception of Compassion**

Natalie’s perception of compassion has been influenced by her patient experience. There are several ways in which she has changed as a result of the patient experience. She described how she perceived compassion before versus after her patient response. Before becoming a patient she says, “I would have said it was based on the way you treat a person, like your actions. Whereas, I see it as much more of a feeling now than I did before.” Natalie also commented that compassion is “one human to another.” She said that compassion is letting the patient know “that you care about them as a person and they are not just their diagnosis.”

While Natalie spoke about her perspective of compassion, she talked about compassion as being something that is part of the nurse, and being able to think about the patient’s perspective. Her description indicates that she sees compassion as something that comes from within, and involves anticipating or imagining what the patient might be thinking or feeling. She sees it as helping patients to better understand the situation, so that they can be better equipped to deal with the experience. She said,
I think compassion is more than words. You know, everybody says, “I’m sorry,”
or “How are you doing?” But are they really looking at you? Are they really
waiting for your answer? Or is it just their canned response because of the job
they do? And they are just going to move on to the next room and treat the next
patient. I think if you are truly compassionate it should affect you at least for the
moment. Somehow what you know and how you treat that patient has to be a part
of you. It can’t just be a canned response and, you know, you can’t just be routine.
While you are interacting with that patient it is making their feelings your own,
putting yourself in their shoes and thinking if you were them, “What would you
want to be told? How would you want to be treated? What would you need to
know?” The people who have anticipated my response are the ones I think are
truly compassionate. Compassion is being able to put myself in their shoes, or
knowing I have been where they are, and so I am going to let them know this or
that. Or, even clearing their minds when I know they are worrying about
something that they don’t have to worry about. Even just saying, “Look, I know
what you are thinking, but that is not a problem here. I know you are thinking this
is going to be something serious but you can put your mind at ease, that is not
what the doctor is looking at.” Or, “That is not what’s wrong.” I think educating
them so they know, having answers so they are not left questioning. I think not
knowing is worse than anything. I think that is part of compassion too. Giving
them the knowledge they need to put their minds at ease. Telling them what is
going to happen, what to expect, why they are doing it and reassuring them that
this is not the end of the world, it’s not life-threatening, they are going to be okay.
Why do we do this. What is going to happen next. What the doctor is going to tell you and how they are going to treat it, whatever. And, you know, you can almost see the relief on people’s faces when you take the time to do that.

**Impact of Natalie’s Life Experiences**

In addition to her patient experience, Natalie stated that her life experiences have actively helped to shape her perception of compassion. During our interviews, Natalie shared the story about her decision to become a nurse, and the relationship with her perception of compassion. She said,

And I think back…I mean that’s why I didn’t become a nurse when I went to school the first time around. I wouldn’t say I didn’t feel compassionate but I was so much more um (pause). How I was defining me and my life at that time was about what I could make myself, you know, what I could make of my life. And then after I kind of went out, and tried all that, and I found out it wasn’t as fulfilling as it was supposed to be; then it’s kind of like, “How about I look and see what I can do with my life, my talent.” Instead of what does life have to offer me and what can I go out and get. I think life experience turned me around to look for a job where I could do something for people instead of seeing what life could do for me. …And, um (pause), I think 9/11 really encouraged me to face and say, “Is anything you’re doing here that’s really worthwhile? If you were to go help them, the people in New York right now, what would you know and how would you do it?” And that’s when I thought, “You know, I need a new direction.” It was that. Wanting to do something that mattered. You know to make a difference to people, being able to help them.
As we spoke, Natalie said that her life experiences, coupled with her patient experience have impacted her perception of compassion, and her belief that compassion is very important in practice. When considering the backward and forward aspect of compassion in Natalie’s narrative, she has identified that compassion began to become important to her when she decided to seek a job in which she could “make a difference to people.” At a relatively early stage in her nursing career, she has become ill. Her patient experiences have drawn her attention to what it is like to have uncertainty, and the need to be treated with compassion.

**Summary**

Natalie has been a nurse for five years, and in the last two years has developed symptoms of a chronic illness. As a patient she experiences a variety of physical symptoms and has become very frustrated with what she perceives to be a delay in diagnosis and treatment of her illness. During our interviews, Natalie shared that her patient has solidified the importance of treating patients with compassion because she knows what it is like to be a patient and not be treated like a person. Natalie shared what compassion means to her. She said that compassion means connecting with a patient on a “human to human” level, and actually caring about a patient as a person. Natalie indicated that she believes that her current perspective of compassion is a result of her patient experience coupled with life experiences. Her life experiences encouraged her to become a nurse so that she can help others, and her patient experience has made her understand that compassion is important in nursing practice.
Savannah’s Narrative

Savannah has been a nurse for almost ten years, and as a brand new nurse worked in critical care for approximately seven years. After a period of time, she began to feel “burned out” and moved into a different setting. Currently she works in an outpatient diagnostic center, and takes care of patients before and after various diagnostic procedures. It was while working at her current job that she became a patient. Savannah’s patient story involves the process of conceiving her child, followed by a high-risk pregnancy. (A high-risk pregnancy is one in which there is danger of pre-term birth, or health risks to the mother and/or baby.)

There are several points in Savannah’s story in which she refers to the “weeks.” She is referring to the number of weeks of the pregnancy. A normal pregnancy lasts for 40 weeks, and the half-way point of a pregnancy is 20 weeks. A baby has little chance of survival if it is born before 24 weeks, and still others are at risk for many health problems throughout life if they are born before 36 weeks.

Savannah’s Patient Experience

Savannah shared her patient experience in a chronological way. She began by giving some background regarding conception:

A few years ago my husband and I were trying to conceive and we encountered some difficulties. And we ended up seeking treatment for that. Along the way we suffered several miscarriages, and we ended up pursuing probably the most aggressive treatment. We did in-vitro fertilization and that resulted in miscarriages. Then we were told that I had some kind of autoimmune disorder, and that we should pursue donor eggs. So that was very heartbreaking and
devastating. (Pause.) So we kind of took a break from treatments for a while to kind of regroup, and then we ultimately decided that would be the best way to build our family. So we did decide to go that route.

After the initial troubles with conception, the couple had a time of joy when they were able to conceive. She said that the first half of the pregnancy went smoothly. However things changed just after the half-way mark. She said,

I guess at about 21 weeks of pregnancy things were going well. I just went in for a routine anatomy scan and they found that my amniotic fluid was next to nothing. So they thought that maybe it was just I had been working that day. It was the end of the day, and I didn’t drink enough. I was on my feet. They said, “Come back the next day and I’m sure it will be fine.” I went back the next day, and it wasn’t fine. I did not have an amniotic fluid leak. So they weren’t quite sure what it was, and why my fluid was low. But they kept me on bed rest. So I ended up being on bed rest for, I guess it was a total of 14 weeks of the pregnancy.

She said that she very diligently followed the doctor’s orders of bed rest. However things continued to go wrong for the remainder of the pregnancy. She explained that at first the baby showed slow growth, and later she developed a complication related to being pregnant. She said,

I guess around Christmas time there was one day I woke up and I’m like, “I haven’t felt the baby move in a while. I just don’t feel like something is right.” So I called the obstetricians’ office and they had me come in for a stress test and that went okay but the umbilical cord flow… The doppler studies didn’t look good and baby’s growth rate had declined significantly. So that was like at 29 or 30
weeks at that point. They said they were going to admit me to the hospital for steroids, and I might be having a baby that week. It’s like (very upset and fearful tone), “Not at 30 weeks!” But things fortunately stabilized and I was able to go home. And then 2 weeks later I developed pre-eclampsia (a pregnancy disorder that can cause death in the mother if not treated). They kind of monitored me, and then after about a week or two the obstetricians decided to do a c-section; that we were done with the pre-eclampsia and I had low amniotic fluid for the past 14 weeks. And they just felt that it would be better to get the baby out. So we did a c-section at 35 weeks. And I was very fortunate to make it that long because no one thought that I would make it that far. But fortunately we both did well.

In Savannah’s account of the last five weeks of pregnancy, she expressed great fear regarding the potential birth of her baby at 30 weeks gestation. When the doctor told her that the baby might be born at 30 weeks, Savannah knew that 10 weeks early is a significant amount of time developmentally, and could mean that the baby would die shortly after birth. Therefore, Savannah was dealing fear of her baby’s death at that time.

As we talked, she expressed happiness that her baby did well after birth, and is now bringing joy to their lives. However, her patient experience left a lasting impression in her which is discussed below.

**Savannah’s Lasting Impressions**

As Savannah described in her narrative, her pregnancy was complicated, and she experienced a lot of stress. It was not the happiest time for her. As we talked, Savannah mentioned some things that occurred during her pregnancy that left a lasting impression. Two things that seem to stand out are the emotional aspect of being a patient, and the way
in which healthcare providers showed (or did not show) compassion toward her and her husband.

Savannah said that the entire experience from having difficulty conceiving, to the complicated pregnancy was very emotional. She said that even now she is still trying to “wrap her head” around the experience. She said (with a sad tone), “It was just very stressful, just to even get pregnant. And then the pregnancy was complicated. It was very stressful. I just felt like I was walking on egg shells all the time.” Her reference to walking on egg shells showcases a high level of fear during the pregnancy. Some of the emotions that Savannah specifically mentioned are fear, and fear of the unknown, anxiety, grief, and sadness. She spoke about fear of the unknown a number of times, and referred to this aspect of her patient experience when working with patients now.

Savannah said that the emotions she experienced while being a patient have affected how she interacts with patients now. She said that because of her patient experience, she is able to understand the things that patients might be feeling. She gave an example of how she now actively considers the way a person might be feeling:

I had a patient today who was told they have a rectal mass. And you know, I can’t identify with that because I have not had a rectal mass. But I can understand some of the fear that I know that they’re experiencing. Fear of the unknown, “What does that mean for the person? What does the diagnosis mean? What does that mean for the future?” So I would say fear of the unknown and probably some anger too. You know feeling some anger and frustration. “Why did that happen to me?” (Tearful tone), And just sadness. Sadness.
We paused for a few moments after this because she became tearful as she recalled her experience and the emotions it brought.

In her current practice, Savannah remembers her own feelings when she was a patient, and now considers how her patients might be feeling. She explained,

I think I tend to listen more to my patients; as opposed to talking at them, or to them. I tend to take a little more time with them. I try to address all of their questions and not be so rushed with them. I think I also tend to read more of their unspoken body language; like trying to see the fear on their faces and try to address that with them and just provide reassurance.

Another aspect of the patient experience that left a lasting impression on Savannah was the way in which some healthcare providers interacted with her and her husband. She recalls two interactions she had with healthcare providers and how they affected her. The first is an example of being treated by her obstetrician in a way that she did not appreciate:

I know on the day of my c-section they were going to bring my husband in. And I’m not sure where he was; but they were looking for him outside. I guess the OB was impatient, and got started cutting without my husband there, and I didn’t realize it. And not that I needed a play-by-play of what was going on; but he wasn’t telling me anything. It wasn’t an emergent situation either. So he could have at least told me some things. But any way, they did bring my husband in; and at that point I had already been cut open. My husband said he was a little dismayed at seeing the cutting and things, but he was okay. Then when they delivered our baby they took the baby over to the warmer. And my husband went
over and I guess my husband saw like the suction canister of blood, and saw the rags and things, and sponges. And he said he became light headed. Well, he ended up passing out. And the OB wasn’t very good at telling us what was going on. I didn’t even know that my baby was okay until I heard crying. My OB didn’t say anything. He was one of the OB’s that I really didn’t care for in the group. You obviously can’t choose who was on call for that day. I’m still kind of upset about the whole birth experience. He just wasn’t very compassionate. I don’t think he understood my fears and concerns.

The way she was treated left a lasting impression with her because she is still upset about the birth experience.

On the other hand, while she was pregnant, she had an experience with a maternal-fetal specialist that was quite the opposite. She said,

We were referred to a maternal-fetal specialist at about 26 weeks of pregnancy just for some more detailed fetal echogram and they were so compassionate there. They had a whole staff assigned to us for the day. They had a schedule of events, and it was wonderful. That was just the best place to ever go. Even 2 months after the baby was born they’re like (sweet tone), “We just wanted to know how your baby did,” and things like that. They had a maternal/fetal specialist and she sat down with us for over an hour to just go over things, and gave us undivided attention. It was just amazing. They understood. I mean, I had a list of questions and never did I feel stupid for asking those questions. You know they were awesome there. It was a wonderful place.
Savannah’s experience at the maternal-fetal specialist and the obstetrician during her baby’s birth left a lasting impression in the way that she treats patients. She considered the attention that she received from the specialist to be compassionate care. This was partly because she had fears, and they helped to allay those fears by answering questions and not conveying condescension. She felt that the care was compassionate because the specialist anticipated some of the questions and fears that she and her husband had. However, the obstetrician who delivered her baby did not really speak to her, let alone answer her questions or help to alleviate fears. The way that she carries this into her own practice is by trying to anticipate patient needs, and not make patients feel stupid. She explained,

I think again it’s being compassionate like. It’s just taking time with my patients, as much time as I can to kind of go over details and kind of anticipate their needs ahead of time so they don’t have to, you know, kind of think of things later on down the road, “Why didn’t I ask that?” And kind of reassure them that their questions aren’t stupid. Even if they think that’s a silly question. Don’t convey that to them.

Savannah’s patient experience involved situations in which her needs were anticipated, and when her needs were not anticipated. She knows what it is like to have questions as a patient. These were a critical aspect of her patient experience which she brings forward to her practice. She gave an example of how she took her personal patient experience and applies it to her care, and said,

I was very observant of my nurses and other medical professionals behavior towards me. And it kind of made me conscientious of how I treat and interact with
my patients. I had a patient today who was, she was kind of shivering and I said
(in a kind voice), “Are you cold?” She wasn’t going to speak up and say she was
cold. She said, “Yeah I am.” I said, “I can get you a warm blanket.” Things like
that. I know when I was a patient, I was always very shy and I didn’t want to
bother the nurse, and things like that. I wouldn’t want to ring my call bell or
anything, but I think I’ve learned to meet people’s needs ahead of time too.

One of the reasons she has learned to meet peoples’ needs ahead of time, or address those
non-verbal cues is that often healthcare providers did not address her needs. Often
providers will not address a person’s needs unless asked. However Savannah’s
experience brought this to her attention. The example above shows that she was paying
attention to the patient’s body language, however she said that she tries to anticipate
patients’ needs by considering what questions they might have, but are not verbalizing.

**Savannah’s Perception of Compassion**

The experiences that Savannah had while being a patient affected her perception
of compassion, and how she carries it out with patients. Savannah compares how she
understood compassion before and after her patient experience. She stated,

I think I was compassionate but I think I kind of removed myself from them and
talked at them and to them and I kind of didn’t put myself in their shoes. Whereas
now, I think that I can really understand the fears that they have with their
diagnosis, or impending tests, or whatever diagnostic studies they are having. I
think I can put myself in their shoes now and kind of understand that better. I
think I understand they have fears and concerns and just anxiety and I think I pick
up on that so that I can be more compassionate, more understanding of what they’re going through.

Savannah gave an example of her definition of compassion before becoming a patient. When she talked about her perception of compassion after being a patient, she told a story of how she treated a patient who needed an act of compassion. Her explanation is below:

I think beforehand my idea of compassion would have been just to be you know “nice” to the patient. You know just to get them what they may need, but not really listen to them. Whereas now, I think; you know, I had a patient today who was diagnosed with rectal mass and I could tell that they were very scared and concerned. And one concern or fear they had was how to get to the treatment center. That was like a huge concern. So I drew a map for them, and that just alleviated a lot of fear. It seems like a very simple thing, but that took a lot of stress off the patient and his driver. You know, whereas before, I would have probably just blown that off. But that was stressful for them to know how to get to the treatment center from our center, and things like that.

In her description of the situation, she showed that she identified the fear that the patient was having, and did something to alleviate the fear. She indicated that part of identifying the patient’s fear involved listening to her patient, and identifying the problem. She not only identified the problem, but identified with it because she was motivated to help the person. Before, her patient experience she may not have been concerned.

Savannah spoke about her understanding of compassion as a change in her attitude toward patients. She said,
I think I tend to be more empathetic whereas before I think I was a little more judgmental. You know (condescending tone), “Why is that patient so anxious about that? That’s no reason to be anxious!” You know everybody has some sort of a struggle. We may not know what it is; but we all have struggled. And I think I’m a little bit more understanding and patient with people. I definitely wasn’t before. I think I was very judgmental of people and you know well (rude tone), “Why aren’t you compliant with your treatment?” And things like that. I have definitely more empathy for people. Everybody has a struggle.

She said that empathy means being able to feel the emotions of the patient, or think of the things a patient might be thinking. Now that she has become a patient, she has a greater appreciation for the thoughts and feelings that a patient might be having. She said that being empathetic means that she is able to be more compassionate because empathy is something that comes from the heart and allows a deeper human to human connection.

**Summary**

To summarize Savannah’s experience, she had a complicated pregnancy that brought a lot of emotional stress, and fear. After her patient experience, Savannah discovered that she is much less judgmental of her patients, is more patient with them, and “puts herself in their shoes.” In other words, she takes time to think about the feelings and thoughts that patients might be having, and tries to address them when taking care of patients. She said that she is able to understand her patients, and uses that understanding to provide more compassionate care to her patients. In addition, she said that being more empathetic allows her to make a deeper connection with her patients, whereas before, she did not try to make meaningful connections with patients.
Sara’s Narrative

Sara works as an emergency room (ER) nurse who loves her job, and has been a nurse for about 8 years. During the last year, she became ill and became a patient in the hospital where she works. Her illness was life threatening, but she was treated and fully recovered.

Our meeting took place in Sara’s kitchen. We talked casually for a long time before beginning the interview. Sara has a cheerful, outgoing personality, and she seems to love life. Her children are very close in age to my own children. So we had fun talking about life and getting to know one another before starting.

Sara’s Patient Experience

Sara’s story began with the fact that she had been off work for maternity leave, and was off work for close to 12 weeks. Approximately a week after her return to work, her two older children became ill with a respiratory virus. She explained that they displayed common virus symptoms such as fever, and coughing. Several days after her children became sick, Sara became ill herself. She had similar symptoms such as coughing, congestion, and generally not feeling well. Sara also developed a fever which she said was pretty high for her because she does not normally get fevers. This went on for approximately 2 days, and she got worse and worse. She mentioned that she was not drinking enough fluids, and at one point she developed vomiting and diarrhea, so she became dehydrated. There came a point where her fever became so high that she became concerned. As she told her story she recalled,

I was waking my husband up at 6:00 a.m. with a fever of 104. And I was in the shower and I remember saying to him (with a weak tone), “I have a fever, if you
hear a thump, it’s me. I have a 104 temp and I need to take a shower to try to cool off.” That was early in the day, and then that was when he started to say (with an angry tone), “I don’t know why you’re doing this to yourself!” He’s says, “Go to the hospital!” And I was crying, I’m like, “I don’t have a doctor! I don’t get sick!” My husband said (angry tone) “Stop worrying about it! Just do something!” It was a mess (chuckles).

After this Sara decided to go to the hospital. When she arrived in the emergency room, she collapsed in the triage area and was rushed back to a patient room. While she was there the hospital staff began taking her vital signs. She had a high heart rate and respiratory rate. She had a blood pressure that was somewhat low. The healthcare team determined that she was presenting as someone with sepsis. (Sepsis is a full-body response to infection that can lead to organ failure and death if left untreated.) Because of her status, the healthcare team decided to give her fluids to treat the dehydration and the somewhat low blood pressure. She said, “I think they gave me too much IV fluid. They gave me 8 liters in 4 hours and then I had pulmonary edema.” (Pulmonary edema occurs when a person has too much fluid in their blood vessels and it begins to accumulate in the lungs, causing difficulty with breathing, and sometimes respiratory failure.) While she was receiving the IV fluids, she reported to the staff that she was experiencing pain in her chest. She explained what happened:

Every time I took a breath it was a searing pain in my chest. So they gave me morphine… My body just doesn’t handle narcotics very well. Now looking back, I ended up getting 8 milligrams of morphine within an hour, which is, in the ER, is a fair amount to somebody who is not used to it. I think that it didn’t help. I was
dehydrated. I got the morphine, and it dropped my blood pressure. Then they gave me more IV fluids to get my blood pressure up… That’s when I went into pulmonary edema.

Because of the pulmonary edema, Sara began to experience severe difficulty breathing, and her oxygen saturation in her blood decreased. This required her to be on an oxygen mask increased to the maximum amount of oxygen that a person can get. At this point one of the doctors came to discuss her situation, and present the treatment option of being placed on a ventilator. The doctors felt that she needed to be placed on a ventilator because she was showing signs of not being able to continue breathing on her own. The term for initiating mechanical ventilation with a ventilator is called intubation. She uses this term as she explained the situation:

I remember the doctor sat down next to me. At that point I sent my husband home, I said (with a weak tone) “I’m sick, they’re taking good care of me, go bring the kids to meet your parents. They’re coming from 2 hours away to watch the kids so you can get back to be with me.” So I’m there by myself. I didn’t know how to make anything out. I’m hypoxic (critically low oxygen level). (pause) I know what’s going on, but I can’t make a decision about what my care is. I know too much. This is all even more scary to me because I know what all of this means. So he (the doctor) sat down and he said, “I don’t want indecision to stop us from treating you because you can’t make a decision on whether or not you want to be intubated.” I was tiring, but I knew I had more fight in me, but honestly I remember looking at him (the doctor) and saying “I’m okay with dying.” you know. I’m a Christian, and I know I’m going to heaven when I die,
but the way I die is, I don’t want to be put to sleep and not know. And it’s crazy
the thoughts that I went through in my mind. I’m looking, and I’m like, “I feel
like I’m dying!” I just had that feeling like, “I’m not going to live to see
tomorrow. I’m okay with this but I know my husband is coming back and I want
to talk to him.” If I’m dying, I want to be awake and die; and not intubated and
asleep, and just never wake up. …I wanted to be awake and die and not asleep
and die. But at that very moment that was when my husband got there, and they
were actually wheeling me out for my spiral CAT scan and I remember telling my
husband “I’m fine. I’m okay it’s going to be fine. They’re just going to take me
for this test.” But they had everything ready to intubate me. They just wanted to
get this CAT scan done. And they laid me flat for the CAT scan, and that’s when
everything (pause), when they laid me flat to put me on that table, that’s when
everything kind of just mellowed out.

When she lay flat, some of the fluid in her lungs dispersed to another area of her body
and she was able to breathe better. Sara says that she insisted on laying flat for about 24
hours after the CAT scan. During that time, things began to get better. Her body was able
to begin taking care of the extra fluid that she received from the IV and gradually began
to improve. She spent two days in the intensive care unit, and three days on a general
medical surgical floor. While she was in the hospital, she was treated with antibiotics for
community acquired pneumonia. After she was discharged to home, she began to feel
worse within 24 hours, and returned to the hospital for a few more days. This time she
was treated with antibiotics for hospital acquired pneumonia. This is a different set of
antibiotics (typically stronger). After this she began to truly improve, and after her recovery has been fine since.

The Impact of Sara’s Patient Experience

Sara’s patient experience was an acute problem that she will hopefully not have to experience again. Even though it was a temporary health problem, Sara said it has impacted her professional practice in a more long-term fashion. There are several critical things that Sara discussed in our interview that she said she took away from the patient experience. Several times she referred to her understanding of the physical and emotional aspects of being a patient, and a new understanding of what families go through when a loved one becomes ill. The physical and emotional aspects of being a patient were critical for her because she referred to them in her patient experience, and how it impacts compassion actions in her practice.

One critical aspect of Sara’s patient experience involved the physical discomforts of being a patient, which she now addresses with the patients she cares for. She said,

These are all the things that’s affected my practice now because I’m like, “That hurts!” You know, sick people complaining about having IV’s in. And I couldn’t wait to get that stupid thing out of my arm! It’s like (irritated tone), “This is annoying!” It was itchy, it hurt. I’m like (pleading tone), “Don’t stick me anymore!”

She explained later that her experience with the discomfort with IV’s impacts her understanding of what patients are going through. In her explanation below, she indicates that before her patient experience she blew off the concerns that patients express, but her attitude is different now. She said,
Like I was saying about the IV’s you know. You kind of get annoyed with patients, thinking, “It’s just an IV. It’s nothing. Why can’t they just have it in their arm?” So now even to this day I’m always checking, and saying, “Does it hurt?” I’m just more sympathetic to those little things I used to get quite annoyed about. Whereas before I felt people were being like (upset tone), “Oh my gosh!” And I was thinking (irritated tone), “It’s just an IV you can take it for a couple of hours!” Where, it really is an annoying thing. And even the procedures that we do the blood pressure cuff that pumps up and it squeezes your arm and it’s so tight. To just have a little more compassion and say, “Okay how about I take that cuff off of your arm now that I’ve taken your blood pressure because I know that really does hurt.”

Another way in which the physical aspect of Sara’s patient experience affected her is in relation to difficulty breathing. She is able to relate to the feelings that patients have of not being able to breathe, and what it is like to have pulmonary edema. She experienced the feeling of impending doom that people describe when they have difficulty breathing. In her description she said, “I thought I was dying. I was like, ‘This is it, I’m done. Now I’m coughing up blood.’” This causes her to be extra vigilant when caring for patients who come to the emergency room with sepsis or difficulty breathing. Sara said that she has a “deeper connection” with this type of patient because she feels that she knows what kinds of things the patients might be thinking or feeling. She understands that the physical aspect of not being able to breathe brings emotional concerns such as fear and a feeling of impending doom.
Another critical aspect of Sara’s patient experience is her understanding of the emotional aspects of being a patient. She told about a patient that she met after her patient experience saying, “I remember one conversation I had after I came back to work, with a patient. They (referring to the patient and family member) were saying something about the size of the rooms. I’m like (with a tone of understanding), ‘I know, it’s just the way that the rooms are laid out.’” She went on to talk to the patient about her own fears when she was a patient in a hospital room, and some of the ways she tried to address the patient’s fears:

We were just kind of talking about, if you leave the door open, sometimes I felt comfort. I got a CD player because that kind of helped me just break up some of those feelings of anxiety; that I was all alone, and nobody is going to come and help me. Because of this she and this patient were able to connect. She explained the change that she saw in the patient as a result of the connection:

I was talking to her and she said (with a tone of relief), “Yeah!” We were just able to connect on a deeper level. Because here is a lady that is twice my age, and we’re now connecting on the same level. We had the same feeling. I saw her kind of relax and be like (relieved tone), “Oh I’m not the only one that feels that way.”

So you just kind of see them melt. You just kind of see them relax.

As in the case with the woman above, Sara said that sometimes she shares parts of her patient experience when she recognizes that someone needs reassurance, or when she needs to make a connection with a patient. She explained, “So now I’m able to relate to the patients and say, ‘Hey, I understand what you went through.’”
Sara’s experience has given her a new appreciation for what patients and families go through when they are sick. In particular, she understands the importance of family members, and the importance of her relationship with them as a nurse. She said,

I have a deeper appreciation for my patients’ families and the way that they are seeing things, and the way I am saying things, and the way I am portraying my attitudes. They are watching my every move in the room. So that definitely, I know because of my husband’s experience. That definitely has changed. So I’m always trying to be very careful and cautious as to what I say. You hear them say, “Oh the nurse was in!” It’s like they just hang on your every word, and especially if they’re in a crisis. They wait for you to come in with that next thing of what’s going on. (Anxious tone), “Can you tell me something?”

When Sara was a patient, she and her family were like other patients. They needed to have things explained to them. Sara remembers some of her own thoughts when she was receiving information from nurses. She said, “I’m sitting on the bed and I’m at their mercy. So I’m waiting for the nurse, I’m listening to every word and analyzing, “Okay she said this. Well does that mean it’s bad? Or is it good?”

During Sara’s patient experience, her husband was very scared. He did not understand everything because he does not work in healthcare. Sara was so sick that she needed support from him. She was not able to act as a nurse and explain what was happening, thus the situation was frightening for him. This helped her to realize the importance of her role as a nurse when working with patients and families. She commented about the importance of understanding that patients and families often do not understand what is happening:
You know, just being very cautious about what you say and not being so (nonchalant tone), “Well this happens all the time.” I’m used to all this stuff, and realizing they have no idea; even though it’s very comfortable for me. They don’t know. Even the simplest things are very scary. That really changed my practice, because I was coming in as a patient, and I never really thought about it…I always try to be mindful and more tolerant of questions and just more tolerant of taking my time even something very small. “This is what this means on this monitor.” And, “This is what I’m going to do now.” And, “This is what’s going to happen next. As soon as I know something I’ll be back in here.”

The most critical aspects of the patient experience for Sara seem to be the physical and emotional problems that patients encounter. She discussed several problems that she had during her patient experience and how it has changed the actions in her practice to help alleviate these problems for the patients she cares for now.

**Sara’s Perception of Compassion**

As Sara discussed her patient experience, and talked about compassion in her practice. She identified how she perceives compassion now as compared to before her patient experience. Sara said that she definitely understands compassion toward her patients differently now that she has been a patient. She described compassion in her practice before becoming a patient in a rather sterile way:

> With compassion before I kind of felt more like (formal tone of voice), “Okay, I’m your nurse. And I’ve been trained to be your nurse. I know what to say to you as my patient. I’ve been educated, and I know what the equipment is. I’m going to come in to you and I’m going to tell you what I’m going to do to you. And then
I’m going to leave the room.” That’s probably, (pause) and “I care for you because, you know, it’s just kind of more textbook.” Sort of like, “This is what I do as a nurse.”

While she was saying this, her tone of voice depicted an authoritarian, or military style of interaction with patients. This description indicates that she “cares” for patients because that is what nurses do as part of their job, but she maintained distance from patients personally.

When Sara described compassion in her practice currently, she compared it to her practice before becoming a patient. She said,

Afterwards, now I think those patients have more (pause), they’re more of a person to me now. They’re less textbook. It’s less (authoritarian tone of voice) “I’m the nurse and you’re the patient. And I’m going to come in.” (With a softer, kinder tone), now it’s more like I can see their anxiety a little more. I understand their thoughts. I see how my interactions with them change. I can just speak to it so much more; I always knew what I was doing, but now I do it with a heart.

Her description of understanding and seeing the anxieties of the patients indicates a more personal connection with her patients. She emphasizes words like “see” and “understand” to show the connections she makes with patients. She mentioned being able to “see their anxiety,” indicating that she pays closer attention to patients’ body language. This may be a reference to having a greater awareness of the anxieties that a patient experiences. She makes a more personal connection by saying that she “understands” patients’ thoughts. Last, she makes a more personal connection with compassion and her patients by saying that she does her job “with a heart,” indicating that her compassion comes from within.
Sara continued with her explanation of compassion. Readers will note that her choice of words demonstrates a more internalized view of compassion:

I think it’s more gone from a textbook “I’m doing what I’m trained to do,” to doing (pause), and I’ve always loved what I do. That hasn’t changed. But now I just feel like I’m (pause). Like when I see them being upset or I see them reacting to something that I’m doing to them, maybe in an adverse way; I kind of a have a little more patience. I have just that ability, and I think even to see it before it’s coming. Like, “This and this is going to happen to you and this is how it’s going to feel.” I tell them because I felt it. “I can tell you now that this is going to feel this way, but it will be okay and you’re going to get through this.” And just a little more close I guess. Just because I know kind of their thoughts. Before I couldn’t touch what they were feeling because I never felt it myself. Now I kind of feel like I see it in them and even without knowing it, I change the way that I talk to them; or I can read their body language and I just know exactly what they’re thinking, even without you saying it. So let me just kind of treat what I’m doing, because I know it will probably help. I think I see what they’re thinking right now. So let me just kind of change, or adapt something to make it. And I find that it does change a lot of things in their demeanor afterwards. Even not knowing it in myself but I’m looking back, and now I can kind of see the change in that way in my practice.

In this explanation she has multiple thoughts that seem to be expressed together. She talked about her ability to see, understand, and anticipate what patients are going through and her reaction to this. Being able to see, understand, and anticipate patients’ discomfort
suggests that Sara is more aware and open to making personal connections with her patients. This explanation is much more descriptive of her view of compassion compared to her understanding before her patient experience. It shows a different way of relating to her patients. Rather than describing a distanced relationship, she is now more personable with patients, and she considers what thoughts and feelings patients might be experiencing.

**Summary**

Sara is an ER nurse who became critically ill with a respiratory infection, and during her patient experience thought she was going to die. There were several aspects of her experience that left a lasting impression on her. For example, Sara now understands some of the physical and emotional distress that patients can have. She said that because of this she has more to offer patients, and can make better connections with them. In addition, when Sara described compassion in her practice after the patient experience, she described making more personal connections with patients, and caring about them as people. Before her experience, Sara described a more impersonal relationship with patients.

**Shaneequa’s Narrative**

Shaneequa is a lively person, and has been a nurse for over 10 years. She has worked in several settings including a surgical center, emergency room, and as a clinical nurse educator. Shaneequa’s patient experience occurred within the year prior to our interviews. She became a hospital patient when she developed an acute problem, and was a patient in the hospital she works for. Overall, her patient experience lasted a few weeks (from the time she developed pain to her return to work). The experience left a lasting
impression, and has changed her understanding compassion. Her account of the patient experience is below.

**Shaneequa’s Patient Experience**

Shaneequa has a fairly chronological approach to her patient experience. She began by talking about the problem that took her to the doctor:

I started out with abdominal pain. Which actually I thought I was having appendicitis. And this was right around the holiday weekend. So I ended up going to the emergency department. They did a CAT scan and did a couple other things and they said, “No it’s not appendicitis.” The doctor thought it was a little low to be an appendix. So they had done an ultrasound then and said, “Do you realize you have a lot of uterine fibroids?” (Surprised tone), “No.” I didn’t at the time. Because this occurred over the holidays, the decision was made to give her some pain medicine and send her home. Her instructions were to schedule a follow-up appointment with her gynecologist when the office reopened. However, within a few days her pain became increasingly severe. She explained what happened over the holiday weekend during a family trip:

So we were supposed to be going on a trip to Kentucky. We drove from Pennsylvania to Kentucky. I was doped up (on the pain medicine). We went down. I took pain medicine like there was no tomorrow. I didn’t take pain medicine with my C-section. So for me to be like that, and even my husband said, “You have to be hurting because you don’t take anything!” We came back, and ended up calling. Because, now this is the Monday after the holiday, I figured the office would be open. (Irritated tone), It was not.
Since the physician office was still closed, she had to go to the emergency room. When she returned to the emergency room, the physician on-call said that her fibroids were severe enough that she needed to have a hysterectomy to fix her problem. Shaneequa said that the physician was kind, and showed thoughtfulness about her status as a staff member:

So he (the doctor) said, “I’ll need to make you a direct admission.” Because he knew I worked in the ER, and he figured it would be better that way, than me having to have my co-workers see me. So I ended up being a direct admission; which is kind of nice. In the long run his thought process was in the right place; unfortunately insurance wise is what really hindered me. So I ended up going in. They admitted me for the fibroids. That was on a Monday. They said, “Okay we can’t obviously do surgery today, it will probably be tomorrow, Tuesday.”

Initially, insurance denied her claim saying that there was not enough evidence for the proposed surgery. Shaneequa explained,

They come in and tell me, “There’s an issue with the insurance. It’s going to have to be Wednesday now.” Wednesday they come in. I’m supposed to go to surgery around noon. They come in, and they send somebody from patient services to come in to say to me, “I’m really sorry but your insurance has denied this, but you can pay cash.” I’m like, “What’s the cash amount?” “$12,000 to $14,000.” At that point I lost it. I said (angry tone of voice), “I think I need to speak to somebody in care management.” (Care management is a department within the hospital whose job is to take care of problems surrounding insurance.) So they sent in the care management person who gave me two options, and that was simply, I could either
pay cash or they’d discharge me. And once the office figured how they could submit this, and the insurance would cover it, you could come in as outpatient and get this done. So that was Wednesday. I was bawling. The doctor came in and said, “Look. I know we have a person on staff who is our customer experience coordinator.” Whatever you want to call her, the fluff person that deals with patient complaints is mostly what her job is. I said (hurried tone), “Get me her.” She came up, and she’s a friend of mine. She was an educator on family birth, so I knew her through work and I said (in a desperate tone), “I need help. Help me out here. What’s going on?” So she essentially did the job of care management. She went through everything, came back and told me, talked to the doctors and they figured out whatever they needed to do. Finally they found a loophole that if they did it robotically they didn’t need pre-authorization for it.

In the meantime, Shaneequa experienced severe pain. From the time that she was admitted up to the time she had surgery she required narcotic pain medicine which did not really address her pain. The doctor ordered a patient controlled analgesia machine (PCA), which allows a patient to press a button and receive a narcotic through the IV. The machine is programmed to allow the patient to have pain relief, but not overdose. She recalled that even with the PCA she experienced severe pain and nausea:

I was having issues with a lot of nausea but they were thinking the nausea was related to pain. They were changing my PCA. I went through at least 3 to 4 syringes of morphine (which is a lot). I felt horrible. And being staff there I knew too much. The PCA machines have a light indicator on them, so that when it’s time for the next dose it lights up. My husband watched me sit there and stare at
the light, waiting for it to click on so I could have more pain medicine, because it hurt that bad.

In addition to the pain, she began to display signs and symptoms of an infection. She developed a fever, so the physician ordered antibiotics. Her oxygen saturation began to drop which meant that she had to receive oxygen through her nose. She said, “I looked at my oxygen saturation and it’s 90% on room air. I run marathons. I should not have an oxygen saturation of 90%.” (Most healthy people have oxygen saturation near 100% when breathing normal atmosphere.) After the surgery she found out that the fibroids were actually quite severe and were becoming infected. Had she not had the surgery, she would have become extremely ill, and possibly die.

As soon as the problem with insurance coverage was addressed, she had surgery. Her surgery occurred three days after she was admitted with the acute pain. Shaneequa explained what happened on the day of her surgery:

So Thursday I finally went to surgery. I don’t remember a whole lot. I came back out and felt wonderful. I mean I was up. I wanted my urinary catheter out. I wanted to get up, I wanted to move around. I didn’t even want anything for pain. She only needed to take ibuprofen for a few days after the surgery. Shaneequa said that she was in the hospital for 5 days. For this surgery, a normal hospital admission would be 24-48 hours. She said that because the hospital staff did not address the issue with insurance right away, the surgery was delayed, and she experienced a much longer hospital admission.
Shaneequa’s Perception of Compassion

As Shaneequa shared during her interviews, her patient experience involved a lot of physical pain, and emotional anguish related to the delay in her surgery. She believes that this experience was a critical factor in affecting her perception of compassion. While we talked, she identified what her perception of compassion was before her patient experience, and what it is like now. Before her patient experience Shaneequa equated compassion with comfort. She explained,

I would say before my patient experience I would look at compassion as making the attempt for comfort. I think I equated compassion more with comfort. Is the patient comfortable? How is their pain? Can I move you in the bed? How are the lights?

This description shows that she thought of compassion as a way to address physical aspects of patient care. She does not mention that comfort involves addressing a patient’s emotional needs such as fear.

During our interviews Shaneequa said several things about her perspective of compassion now, which is much different. Initially in her description of compassion in her practice she said that the patient experience has made her more compassionate. For example, she said,

I think it’s made me become more, I don’t want to say more compassionate, but it has. Compassionate for the patient in the situation that they’re in at that moment. You know, working in the ER I’ve seen all kinds of people. You know I could have the mother whose kid just had a seizure, and she’s freaking out but it’s a febrile seizure (seizure caused by a high fever). And we all know that’s not the end
of the world. But for that mother at that moment, that is the end of the world for her. So saying to her (in a kind, soothing tone), “Do you understand? This is why your child had a seizure? This doesn’t mean your kid is going to have a seizure disorder.” You know because as a parent your mind goes 100 million miles and you don’t sit back and think about that, and you can’t at that moment. I think having that compassion to sit down and say (using a soft tone of voice), “It’s okay to be upset. Your child is okay. Let’s look at what we need to do for this child. Do you understand?” Whereas before I would have gone in, we’d give him a Tylenol (with sarcasm) “Oh this is a febrile seizure, this happens when their temperature is too high.” So I would have still educated that mother but I don’t think to the point of having that empathy and that compassion toward her.

In this comment about the meaning of compassion, she describes addressing the emotional needs of a person. This is a more personal way of considering the needs of a patient, than simply addressing physical comfort. Addressing the emotional needs requires consideration of what the person might be thinking or feeling.

Possibly, one of the biggest changes in her understanding of compassion is that compassion involves looking at the whole person. Now she thinks about the person in much broader terms and withholds judgment. She explained what it means to consider the patient more holistically:

I think you have to look at the whole patient. You have to look at what their whole situation is. You can’t make a quick judgment (hurried tone), “Oh they’re just here for this.” Or, “Oh they’re just here for that.” You have to look at what it is and why they’re there. There’s probably something underlying that’s causing
them to need, whatever that basic need is, whether it’s warmth, whether it’s trust, whether it’s pain relief, whether it’s just where they are in that situation and they have no place else to go or to look for help. I think that’s sometimes where are patients are. I think nursing isn’t just going in and doing a task, but I have to look at what is it really that they need? And they might not even know, and I may not even know, but I’m there to help. And if that means I need to understand what their need is or try to understand what their need is then that’s what I’m there for.

Her explanation of looking at the whole patients involves several things. First she indicates that looking at a person holistically takes time. She mentioned that to understand the patient, the provider cannot make a hurried judgment, but rather take time to think about the patient. Second, looking at the whole person involves looking at an underlying reason for the person to seek treatment. It may help to remind the reader that Shaneequa is speaking from an ER perspective. In the ER, a number of patients are labeled “frequent flyers” meaning they come to the ER for treatment often. Many times the reason for coming to the ER is the same. In speaking about the underlying reason for coming to the ER, she is referring to patients who come to the ER frequently and do not have the underlying need met. She said that when a person is in a situation like this, “We need to ask, ‘What need isn’t being met?’” She indicated that we need to look beyond the obvious when the person comes to the hospital. Last, she indicated that considering a person as a whole involves understanding, or trying to understand what the person’s need is. Overall, she is describing taking time to think about the patient as a person, taking time to consider underlying needs that the person may not be saying, and generally trying to understand the situation from the person’s perspective.
Shaneequa said that as a result of her patient experience, compassion in her practice is more internalized. She explained,

I think it is an internal piece. I think in order to be compassionate you have to be comfortable in your own skin from the inside out and that doesn’t happen overnight. I think I’ve evolved in that compassion is understanding.

Understanding where they are and where they want to be. Not what my agenda is, not what I think they should be doing, but where they are in their health, or wants, or needs. So I think my compassion has gone from being superficial, to a more in-depth look at compassion. It’s not just the presence of being there, it’s the presence of fully being there mentally and physically.

Here she indicates that compassion is something that takes time to “evolve.” In addition, compassion has become more internalized for Shaneequa because she sees it as understanding the individual patient, and what the individual patient needs. She sees herself as fully present “mentally and physically” when she is taking care of patients.

Before her patient she was more engaged in the physical aspect of care.

**Summary**

Shaneequa’s patient experience began when she developed severe abdominal pain. After several days of excruciating pain, she was directly admitted to the hospital. Her situation was complicated by a delay in surgery due to the denial made by the insurance company. Shaneequa indicated that there were several aspects of her patient experience that left lasting impressions on her. Shaneequa said that her patient experience impacted compassion in her practice. She now believes that compassion involves thinking about patients as people. As a result she is less judgmental of patients, and
thinks about patients as a whole. Shaneequa said that her compassion now comes from within.

**Dancer’s Narrative**

Dancer has worked as an RN for over ten years, and for most of that time has worked in a clinic that provides primary healthcare for low-income individuals. During that time, she has been able to get to know a number of patients, and has a good working relationship with them. As we spoke, she discussed the importance of providing compassionate care to this population, and the importance of providing the best possible care to everyone no matter what their background is. She said that she knew that compassion was important to patients before her own patient experience, but after her patient experience she had a deeper understanding of what compassion means in her practice. Her narrative began with her patient account below.

**Dancer’s Patient Experience**

Dancer’s patient experience occurred within the last year, and was short lived. She had an outpatient procedure done to repair a problem with her foot. It was a surgical procedure, but it did not require an overnight stay in a hospital, so she went to a surgical center. While the operating room staff members were preparing her for the procedure, she experienced a panic attack. Her story begins with the surgical preparation. She said,

So I went in. The nurse came in and introduced herself; and she took me back to the OR. There was a doc sitting in the corner and there was another doc for anesthesia. She (the nurse) made me tell my name and date of birth, and what they were doing, and who was doing it, and all of that. Then they put me on the operation table. And as soon as they put me on the table, (anesthesia was behind
me) and whoever was at my foot lifted up the sheet and started to mess with my foot. Well, that must have like shot my adrenaline up, and my eyes must have been as big as saucers. The nurse said to me, (they had music playing) and she said “Does the music bother you?” and I said “No.” And when I answered, she just took my hand and wrapped her arm around my waist and the last thing I remember was her holding my hand and her arm around my waist. Because then anesthesia said to me, “I am going to give you something to relax” and that is the last thing I remember. That experience was so profound to me because I am a hand holder at work. I am the one that holds hands, but I didn’t know what that meant to the patient until I was a patient.

I asked her what it felt like to be the patient, and be the recipient of compassionate care. She said, “It was just comfort. I mean an overwhelming comfort.” Being the recipient of compassion was a critical event because not only did it make her feel better, but it also reaffirmed her own practice.

As our conversations unfolded, Dancer discussed her perception of compassion and its relationship with her professional practice. She said that her patient experience demonstrated how important compassion is, and that it is integral to her professional practice. Dancer’s perception of compassion is discussed below.

**Dancer’s Perception of Compassion**

This section presents the significant ways in which Dancer’s patient experience impacted her perception of compassion. After Dancer’s experience she is more intentional with compassion in her practice.
As mentioned, Dancer has always felt that compassion is important in nursing practice, and has always attempted to be compassionate with her patients. However, her own patient experience made her realize the importance of compassion in nursing care. Thus her change in the perception of compassion in her practice surrounds a new understanding of what it means to the patient to receive compassionate care. She said that now she is more aware of compassion in her practice, and said,

I am more conscious of it. Um, I am more in tuned that if they really are scared how much impact that makes. Where before, I just did it because that was how I practiced. I am a hand holder… The impact was unbelievable to me. So I make sure that I do it.

This comment shows that she is more intentional about providing compassionate care to her patients in comparison to her practice before being a patient. She is particularly aware of patients who are afraid and need support. In addition, Dancer commented a number of times about the use of hand holding or physical touch as an important aspect of compassion in her practice. Before her patient experience, she did it more automatically, but is now more intentional. She said,

I think I’m more inclined to hold the hand or touch someone more so than I was before. I mean, I did it kind of automatically because when people are scared they’ll grab on to you. But I think after that, now knowing what an impact it made on me, I will go one step further to touch someone or hold someone’s hand because it was so powerful for me, and not many people tell you.

In Dancer’s comment, she is referring to the difference a simple hug made in her own patient experience. Because of this she is more likely to give physical touch as part of her
compassionate care, and indicated that patients often do not say that they need someone to hold their hand.

Dancer went on to explain the connection she made between her personal experience as a patient, and what it means for other patients to receive compassionate care. She said,

I work in a clinic. We have six different clinics that we run, and one of them is Internal Medicine and one is Surgery. We also have OB/GYN. There are a lot of girls that come in that that is their first Pap Smear, and they are scared to death. So, I always try to distract or hold hands, if I know they are going to be uncomfortable. I read body language. So I can see the body language where they are upset or they’re unnerved by what is going on. I am right there with that patient. The docs, they can pretty much fend for themselves. They have everything they need. My priority is the patient, not the doc. So I am the hand holder. And I have had patients say to me, “That meant a lot to me.” But it didn’t make sense to me completely until it happened to me. And it’s like, “Oh my God!” It does make a 100% difference.

Here she explained how she now understands what it means to receive compassionate care. When she received compassion from the operating room nurse, her anxiety “evaporated.” Now she is able to understand what it means to the patients when she holds their hands.

In Dancer’s narrative of compassion, she identified that compassion is essential to her practice as a nurse, and described true nursing care as including compassion for patients. She said that compassion is:
Being able to put yourself in their shoes and the situation they’re in and be able to relate to that situation like the experience itself. To me that’s part of being a nurse. I mean, you can do anything as far as procedure wise, if you can’t read your patient that’s not a nurse to me. To me a nurse is able to get into that patient’s face and go through the experience with them as much as they’re able to and read the nonverbal. More than anything, being able to walk in their shoes or being able to be in the space that they’re at as much as we can be.

Upon clarification, “reading” the patient and “reading the nonverbal” involves looking at a person’s facial expressions, posture, and body language. After “reading” the patient Dancer attempts to put herself in the patient’s shoes by considering what it is like to be the patient. This description seems to be very similar to the concept of empathy because she places a lot of emphasis on going through the experience with the patient; and empathy involves the ability to understand how the other person is feeling. I asked her if she saw a relationship between compassion and empathy, and she said,

    It lines up right with compassion. Empathy to me, means being able to understand what someone is going through at that point in time. You have to try and understand their point of view at that moment in time. Ten minutes from now might be completely different; but at that moment in time this is how they feel, and you have to acknowledge their feelings. I don’t think you could exist one without the other. I don’t know how you could be compassionate and not empathetic. So I think they go hand in hand. Because you have to feel to be compassionate.
As we talked more, Dancer explained that you have to understand and acknowledge the feelings of the patient in order to be compassionate. She said that you need empathy in order to care enough about the patient to be compassionate toward them.

**Impact of Work Experiences**

As we spoke, it became evident that in addition to Dancer’s patient experience, her work experience has impacted her perception of compassion, and therefore needs to be included in her narrative. As Dancer stated, she said that compassion was important to her before her patient experience, and has been important in her care of patients at the clinic.

Dancer explained that the patients who come to the clinic are people with a low-income. Often this population does not have insurance, and is suspicious of healthcare providers. She explained what happens with some of the patients when they have their first few visits at the clinic. She said,

*We’re a clinic, so their (the patients’) assumption of a clinic is we’re going to treat them badly; we are not going to treat them as well because they don’t have insurance. We’ve had many of them come in with a chip on their shoulder thinking we are going to treat them badly, and we haven’t. And, to the point, that if they go forward and get commercial insurance, they will lie to us and not tell us, so they don’t have to leave. Yep, and that has happened over and over. That they become one of our favorites, because they are a challenge to us. We treat everyone the same. So when they come in with that chip on their shoulder; that makes us work just a little bit harder. That, you know, we aren’t what you anticipate us being.*
Her explanation indicates that the clinic staff tries to treat patients equally, and that they want to treat patients well. Even though she is talking about the staff, she is also speaking about herself. She said, “I used to do home health, and seen a lot of things over the years.” Here she is referring to the poor living conditions and quality of life that many of her patients have. The experiences in the clinic and things she has “seen” over the years have impacted her perspective. Dancer shared a couple of stories about the patients who have come to the clinic that demonstrate their circumstances. They are the types of experiences that can leave a lasting impression. In one story she spoke about a young woman who was in dire circumstances. She said,

“…She looked like a street person. She had dreadlocks and she was real quiet. She really didn’t make connections with anyone. But she came in. She called and said, “I delivered my baby at home in the bathroom and it’s dead.” I’m like, “Oh my God!” She goes, “I’m bringing it in.” Now what do we do? It was a 20 weeker (20 weeks gestation). She came in with a receiving blanket. That was wrapped up. And she brought this thing the size of a receiving blanket. So I took it from her. She said, “I didn’t know what to do. I was by myself.” And she said, “I washed it and I wrapped it up and I brought it in.” So I took it in the storage utility room; and I started unwrapping and unwrapping, and down in there was a washrag. (With a grief stricken tone) And here was this little body, perfectly formed. And I thought, “How traumatic for that girl!” To have delivered that baby all by herself, and saw it. (With sadness, and shaking her head.) Never saw her again. Never saw her again.
Dancer was impacted by this experience because she knew that for a woman to deliver a baby alone in a bathroom, she must be experiencing a hard life. (This story made me shudder.) Dancer shared a couple of other stories that show the types of patients that come to the clinic and their circumstances. I believe that these experiences have contributed to her perspective of compassion, and have impacted her perspective that everyone deserves equal treatment.

In addition, her experience with a low-income population has taught her that part of giving compassionate care requires the provider to accept the person for who they are, and not judge a person. She explained that if a nurse is judgmental of patients, then the nurse is not going to give the best care or most effective care to patients. She said,

My personal prejudice or anything that I have in my life that prevents me from treating someone as a patient, I have to put at the door. Any prejudice I have, any issues that I have with whatever is going on with my personal life is first and foremost dropped to take care of that patient. No matter what age, race or whatever you know. I can’t judge them. That is not my place to judge them. My place is to take care of them. (With conviction.) Because everyone is equal! There is no one that’s better than the other one. Everyone deserves to have the best care they can get and everyone is equal in that plane.

Dancer connects withholding judgment to compassion in that a person who is judgmental of another person is not going to be motivated to give the best possible care to the person. She believes that part of compassion is being motivated to give the best possible care to each person. To put it another way, being compassionate involves giving the best
possible care to someone and being judgmental of a person impacts the providers care negatively.

**Summary**

Dancer’s patient experience was significantly impacted by a nurse who showed compassion to her. She experienced a panic attack just before her surgery and experienced great comfort when the nurse gave her a hug of support. After this, Dancer realized the impact that compassion in the form of physical contact can have on a patient. In addition, she spoke a lot about the fact that to her, compassion involves going through an experience with a patient. She said that going through an experience with a patient is what nurses are supposed to do. Dancer discussed that an important part of compassion is not being judgmental of patients. Being judgmental prevents a nurse from giving the best possible care to patients, and all patients deserve the best care that a nurse can provide.

**Gail’s Narrative**

Gail is a nurse who currently practices as a nurse practitioner and works with cardiac patients. Prior to this position she has been in several nursing roles. She began as a bedside nurse in a hospital, and worked on a cardiac floor. While working there, she decided to return to school and become a nurse practitioner. She has had two other jobs as a nurse practitioner, including a position in a transplant program.

Our first interview took place in Gail’s kitchen. She had been on-call the night before; we decided to meet in the afternoon so that she had a chance to sleep before the interview. She said that she had been thinking about the ways that her patient experience impacted compassion in her practice while on-call the night before, and wrote some things on a sheet of paper so that she would not forget to share them with me.
Gail’s patient experience occurred while she was pregnant with her baby, which was approximately four years before our interviews. Her patient experience involved a complicated pregnancy. She said that her experience has made her appreciate her health (and her child’s health), and changed her understanding of patients. Her narrative begins with an account of her patient experience.

**Gail’s Patient Experience**

Gail’s patient story begins at approximately 5 months of pregnancy. At this time in her pregnancy she began taking birthing classes, which is an average time for women to take these classes. She explained,

I was maybe 24 weeks along or something. You start the birthing classes. And the teachers just talking about contractions, and the tightening of the abdominal muscles, and what not. It wasn’t until I took that class, and then I came home and I was actually just kind of relaxing in the tub, and I kind of felt my belly contracting and getting hard. I’m like, “This is kind of what they described as Braxton Hicks.” But they were pretty frequent, like about maybe 10 in the course of 20 minutes.

She learned about Braxton-Hicks contractions in her birthing class that day. Many women experience Braxton-Hicks contractions throughout pregnancy. This type of contraction is typically not very painful, and they are generally considered by obstetricians to be benign. However, Gail thought the amount she was having was a lot, and said,

That’s when I called and I’m just like, “I don’t know what’s going on here. This is kind of what they described in the birthing class, you know. It gets tight for a little
bit and then it relaxes.” They (the doctor) just said to drink some water and see if it calms down; and then call them back in however many hours. I did, and it didn’t help with drinking water. That’s when they told me to come into the hospital and be evaluated that night; because it was kind of late, and the office was closed. They put me on the monitor and they saw active contractions and they examined me and I think I was just slightly dilated, not much maybe a centimeter or so.

Gail is referring to cervical dilation. Having 1 centimeter cervical dilation was considered to be abnormal because she was only at the 5 month mark of her pregnancy, and therefore was something to be concerned about. At that time, the hospital staff gave her a medicine called terbutaline, which helps to stop uterine contractions and would allow her to continue the pregnancy to a normal term. She explained what happened next:

They sent me home with Procardia tablets and I just had to kind of watch closely but it happened you know throughout the night it continued. I ended up calling the next day and they had me come in to the office and they put me on the monitor there and saw that it was still continuing and then that’s when they had me go into the hospital. I mean I got IV magnesium and trying to slow everything down and that’s kind of when the spiral started from there.

A vicious cycle began in which she would experience a large amount of contractions which would require medication. She was in the hospital for about a week going back and forth between the labor and delivery unit and pregnancy ward. Eventually she was able to be discharged. She said,
After a week things kind of settle down and they had a nurse come in and go over everything with me and they were going to send me home on a terbutaline pump, which is kind of like an insulin pump. You know very similar you change the site every 3 days. It kind of looks like a little pager; it clips on to your pants and it’s a continuous infusion of the terbutaline with boluses every 4 hours of the medicine.

In addition to the terbutaline, Gail had specific orders that she had to follow. She had to stay at home on bed-rest, which was difficult for her. She explained,

So then I was sent home on bed-rest which was probably the most trying thing ever for a type-A personality. Plus I had just graduated from NP school; so I was still working and trying to study for my boards. I was in the middle of interviewing for jobs and all this happened. Plus trying to prep the nursery, and my husband is working night shift. And I don’t have family around so here I was on bed-rest for (pause). I guess it was like 27 weeks to when I finally had him at 38 weeks. They turned the terbutaline pump off at 36 weeks and I contracted the whole time, but I lasted 2 more weeks.

At 27 weeks gestation, the pregnancy is beginning the last trimester, or last three months. Even with the terbutaline pump, and strict bed rest, she had multiple admissions to the hospital where she received additional medicine to stop her uterine contractions. She said,

I mean in between that time I was still in and out of the hospital because I had home fetal monitoring every day. And even despite being on the terbutaline, I was still contracting, even though it wasn’t painful. It would often get the nurses in a fluster because I would do the monitoring up to 4 times a day for 20 minutes
every day. I had to lay there in bed and be very still and just the let the monitoring be done and after that translated the translation would go via phone, this telephone system that they have. (This is a technology that allows the information from the home monitor to be transmitted to the doctor’s office via phone.) And it would get downloaded, or faxed or whatever to them and then the nurses would review it and they would call me. Every day it was like, “You know, if you have so many contractions in a minute you need to give yourself an extra bolus.” They didn’t know what to do with me by the end because, I mean, it just didn’t stop. So they were constantly calling the doctors to see what I should do. And I was in and out of the hospital a couple of times even after the long bed rest period. So it was just a mess.

During her many hospital admissions, she was always sent to the wing that works with complicated pregnancies. One time she was in the hospital for a week and had a roommate who was having a complicated pregnancy. This woman was about two weeks behind Gail in her own pregnancy. They became very close friends in this short time, and became each other’s support during this difficult time in their lives. She says, “We bonded and we were each other’s rock during that hospitalization…We were on the phone every day because she was on bed rest too, so we just were able to be each other’s support.” As Gail’s pregnancy progressed, she continued to be in and out of the hospital, but still kept in touch with her friend. After some time passed, there came a day when her friend didn’t call, and in fact several days passed with no phone call. Gail suspected that something was wrong. When her friend finally called, it was to say that her baby had been born, but was too young. The baby died.
Gail describes intense feelings throughout this experience. The feelings surrounded her own pregnancy, her friend’s pregnancy and subsequent death of the baby, and the birth of her own baby. At first she talks about her feelings of guilt after the death of her friend’s baby, but she continues on with discussion of the feelings surrounding her own situation. She said,

I was just feeling so guilty. “Why did that happen to her and not to me?” We both were doing the same thing. We were supposed to both be listening to strict orders and whatever the doctor said. Just how it didn’t work out for her, and it worked out for me. And just being happy and overjoyed that I was kind of on the home stretch. Knowing that if something would happen now I would be okay. Going through the emotions with her, and grieving her baby and her loss. But just still having happiness inside of me. I just didn’t know what to feel, you know. I feel that I felt every emotion under the sun during that time because I was feeling lonely a lot without having anybody around. Pretty much she was the only person I could talk to. You’re kind of just stuck in this body; and having to do everything you can to keep going and preserve this life. Nobody really gets it, how you feel trapped inside. I mean, I probably experienced every emotion that is possible out there in that short period of time. Every day it was up and down.

Gail still thinks about her patient experience every day, and the emotional roller coaster she experienced. She still has strong emotions tied to it and said,

What I went through myself, and just seeing what she went through, I’m just so grateful that my child is healthy. And, you know, everybody is asking me, “When are you going to have another one?” They just don’t understand that I don’t want
to tempt fate. I’m just so grateful for our health. And everything that I went through, and just seeing what my friend went through. So yeah, it’s surreal.

Gail’s patient experience was powerful for her and has impacted her understanding of compassion and her professional practice which is explored below.

**Gail’s Perception of Compassion**

After talking about her patient experience, Gail discussed how it has affected her. She said that she had a new understanding of what it is like to be a patient, and the struggles a patient goes through. She said that to help her in her practice now, she frequently thinks of her own patient experience. She said, “I think about that on a daily basis and I try and treat them how I wanted to be treated in that situation.” Thinking about her experience helps her to consider what her current patients might be facing. Even though she works with cardiac patients, and her experience was related to pregnancy, she understands the emotions that people might be experiencing, and understands that people want and need to be treated like human beings.

In general, Gail’s perception of compassion is more personal to her now. As indicated below, she has a more nuanced understanding of compassion because of her own experiences. She has taken some of her personal experiences and applies them to the current situations she has with patients. Gail said that before her patient experience she remembers learning what compassion is in school, but it was not really personal to her. She said, “I mean, until you’re actually laying in that bed and know how it feels. (Pause.) I’m not sure that I would be able to take that much TLC with them, you know?” Now she has a more personal understanding of compassion and attempts to carry it out in practice. There are several things that Gail felt was important to share with me regarding her
change in compassion, and that demonstrate her more personal perception of compassion. She shared several things that she pays closer attention to when working with patients. First, she commented that she attempts to understand the situation from the patient’s perspective. She explained, “I just put myself in their shoes every day and I’m like, ‘I’m just going to approach them how I would want to be approached.’” She indicates that she sees her patients more like people by “Just really talking to them on a basic human level.”

Gail discussed several ways in which her attitude toward patients has changed such as: not being judgmental, including family members in care, and paying closer attention to patients’ needs. In these instances, she recalls her experiences as a patient and relates it to the situations that her current patients are facing. For example, she said that now she is less judgmental of patients, especially “frequent flyers,” which are people that come to the hospital frequently. She explained why she does not judge this type of patients,

I was that person being wheeled up in that wheelchair into that bed that was just discharged a few days ago, and being humiliated. Just feeling humiliated that I did something wrong. Because I know that when I was a nurse I was thinking, “What’s going on now?” Like were they not doing their meds as prescribed, were they not listening like they were supposed to? But then being there as a patient myself, and knowing that I did everything that I could, and I couldn’t help why I was there. So I’m not judging when I see these frequent flyers coming in.

Gail’s personal experience made her realize that sometimes people are unable to control their health problem and have frequent hospital admissions as a result.
Gail said that she believes compassion involves family members. Before her patient experience, she did not necessarily consider including family members as part of providing compassionate care. However, now she does and explained,

Just including the family as a whole unit, that’s super important. Because as much as I had the background you know they (the doctors) would sit there and somebody would come in and talk to me while I didn’t have family there. And just being stressed out. You’re just not in your quite right frame of mind. So I definitely go out of my way. Like if they need me to call and update somebody, because I understand it’s hard for them to recall everything.

Another way that Gail’s perception of compassion changed is that she is more in-tune with details of patient care such as making sure that patients are not missed during physician rounds. While she was in the hospital, the physicians forgot to round on her one day, and she sat there wondering what was happening until the next day. She said,

So just sitting there waiting, you know. You don’t realize how people wait for you to come in to see what’s going on that day. And here I was just waiting all day twiddling my thumbs wondering when they’re going to get here.

She understands how patients feel when they are waiting, so she is extra careful to avoid a situation like that. This demonstrates that she acknowledges that each patient is important by making it a priority to remember each one.

Gail said that after her patient experience, she began to pay more attention to “the simple things” such as helping patients to the bathroom, or allowing them to take a shower. Her job is no longer working as bedside nurse, but she will still take time out of her nurse practitioner role to help someone to the bathroom. This is significant because
hospitals are very hierarchical, and physicians, nurse practitioners, and physician assistants do not engage in personal care. Personal care is delegated to bedside staff members.

Again, Gail recalled how her own patient experience made her feel when she was able to take a bath, and how she carries that forward in her practice now. She said,

I remember the best thing ever was the first time I was able to get a bath in like 5 days, and just basic hygiene. I couldn’t believe how good a bath made me feel. Like, I just felt like a million bucks. Like a million bucks versus a bath. Like, nothing made me feel better than just getting showered. I do encourage that if patients are able to get up and move around. Like maybe I’ll write orders for the privileges to come off of the heart monitor for a little bit to hop in the shower. I will certainly take that into consideration, because I know how good that made me feel. So if that’s something that they want I will go out of my way too allow them those privileges to get a shower, because that just was the most amazing thing ever. Even if I had time and I was worried about them I would stand outside their shower just to let them do that personally. When you talk to them afterwards they’re like, (using a tone of relief) “Ahhhh.”

Her experiences have made her more aware of what patients go through, and she now has more of a concern to help alleviate the difficulties that patients suffer, even “simple things.”

Compassion in Gail’s Practice

To demonstrate her perception of compassion in her practice after the patient experience, Gail chose to share a story about a patient that she cared for while working as
a nurse practitioner for an organ transplant team. She told a story about a patient who received a transplant that failed. He had no advocate other than Gail. Her story began like this:

One particular patient really caught my attention when I first went to work on the transplant team. And it was shortly after I started working there and he ended up getting some type of infection and he ended up rejecting the organ. And to make a long story short, he passed away. The transplant got this pretty profound infection and he died. But he didn’t have any family members there. I just remember I was one of the familiar faces that he would see every day when we would go on rounds with the team. The residents would be different every month. The surgeons would be different every week, but I was consistently there every day with him. I think he was in there for probably going on 2 ½ months after this transplant. He had a tracheostomy so he never really got to speak or to communicate with us. I know he was conscious and I know he knew at some points what was going on. And he had not one family member there the whole time. I think once he got the transplant (pause). I think everybody pretty much disappeared in his life.

She further explained that she experienced significant feelings of compassion and empathy toward this man. When listening to her tell the story, it is as though she felt a moral duty to support and advocate for this patient. She said,

That was just a particular episode where I just I didn’t know what to do, just thinking of like empathy and compassion with this man. I felt like I was the only consistent person there by his side every day, and I was seeing him from a nurse’s
perspective. But the surgeons were so worried about him surviving the transplant (pause). And, you know, worrying about the survival rate numbers and what it would do to their results if this man would pass away. And it was a huge conflict of interest for me, just starting there and them having this mindset with this patient. I almost wanted to leave as I just had gotten started there. I just thought that they were torturing this poor man every day.

She recalled that she was essentially the only person on the transplant team who advocated for treating the patient with dignity and considering comfort care measures when it became clear that he would not survive. She felt a responsibility to this patient saying,

Well I mean you know I kind of wanted to be that voice for him because I knew he couldn’t speak with being on the ventilator for most of the time. I mean I just felt like I needed to be a voice for him because I put myself in his situation. And I just thought it was dehumanizing and demoralizing and (pause) appalling. I felt like I was the only advocate on the team for him. I didn’t win in the end. But I almost left that department because I thought, “If this is how it’s going to be like, this is not something I believe in.” And it didn’t really matter what I said because surgeons are surgeons, and they want their good outcomes. But then I had a whole different nursing perspective about compassion and empathy with this man. I thought what they were doing to him was not humanly right. I was furious and upset and just felt, “How could you have such lack of compassion for human life?”
As her story continues, she talks about the way she connected with the patient, and how she treated him in his final moments. She recalled,

I remember particularly one of the last days, you know, not knowing if he really knew what I was saying to him or not. But I would stand there and I would hold his hand and just talk to him. And I knew he knew I was there because he would squeeze my hand in response to me talking to him. Like I said, I think I was the only person there by his side. But it was just so sad at the end, because towards the end he was so sick that he was bleeding out of his eyes and they still would not let this man die. They would not let him be on morphine, or any narcotic, or sedative because they wanted to be able to assess his mental status. And then all of the pain medicines weren’t good for the transplant. It was just really bad at the end. I just stood there and held his hand and I cried. Not cried with him, but just mourn for him and I don’t know (pause). The surgeons were really pissed at me. Ultimately Gail did leave the transplant team. She said that she never really felt at home there.

Gail’s story shows how she considered the patient’s situation, and the big picture. Her compassion was directed toward advocacy for this patient because she felt as if he had no other person who cared about him. She took some risks in expressing a different opinion from the rest of the team considering the fact that she was a new employee. She demonstrated a personal connection because she grieved for this person, and his loss of human dignity. During the interview Gail said that she thought about her own patient experience while working with this patient. She felt humbled by his experience when compared to her own. She said that because of her own patient experience, she was
constantly putting herself “in his shoes” trying to understand what he must be experiencing.

**Summary**

Gail is a nurse practitioner who had a complicated pregnancy which involved a long period of bed rest and emotional turmoil. After her patient experience compassion in her practice became more personal to her. She now tries to put herself in her patients’ shoes and think about the things that they might be experiencing. In addition she has identified several ways in which she identifies compassion in her practice such as addressing “little things” that help a person to feel better, and include family members in a patient’s care. Gail shared a story in which she felt particularly connected with a patient in a compassionate way, and felt that the patient was treated inhumanely. Her compassion for the patient compelled her to take a risk as a new employee and express her opposing position to the surgeons in charge of the patient’s care.

**Charo’s Narrative**

Charo has been a nurse for 12 years, and nursing is a second career for her. As a new nurse, she worked in a neurologic ICU. Since that time she has had additional roles, including coordinator of stroke management at several hospitals. In this role she works with both hospital staff and patients to make sure that treatment guidelines for treating stroke are being followed. Her experience in the neurological ICU, and master’s degree helped to prepare her role as a stroke management coordinator. Now she works with both patients and healthcare workers to provide education and improve treatment for stroke care.
Charo’s Patient Experience

As we spoke, Charo intermittently shared her patient experience and did not go into great detail. After reviewing her interviews I was able to write a chronological account of her patient experience. Her patient experience began in the first few years of her nursing career. She had a type of cancer that required surgery and treatment for approximately two years. She explained that she had been experiencing a problem but was having difficulty scheduling appointments with a physician. While trying to work this out, she experienced aggressive comments from the office staff. She explained,

Well, first off when I first got my diagnosis I actually…before I had my true diagnosis I was going to a physician who I could never get in to see. I couldn’t get past the person at the front desk actually. And even when I complained about horrible pain and blah, blah, blah, I could not get an appointment for literally months! Even though I was an existing patient. … I never went back to that first doctor because she totally misdiagnosed me, and then I couldn’t get back in to see her, and her staff was absolutely horrible. You should have heard some of the voicemails that were left! Like, I couldn’t get in for a really long time and by the time I got in, my referral had ran out. So I’d get there in the morning- no, no, no! I’d get home from work the night before my appointment and, you know, it’s 6 o’clock at night and I actually have somebody screaming at me on the phone about my referral. I mean, really horrible. I don’t know why people work in healthcare that are like that.

After a period of time Charo realized that she was not receiving appropriate treatment from the first doctor, so she began to look for help elsewhere. She explained,
So then I talked to an NP who said, “I have an idea. Why don’t you go to a dermatologist because they will see anybody anyway.” And she gave me a name, and I went to this guy. And it was very funny because he seemed like a very cocky, stuck on himself person at first, which is a bad thing to say about somebody, but he turned out in the end to be extremely nice. So, he was the one who actually ended up making the diagnosis and sent me to an Oncologist. So, anyway I went to a surgeon and ended up having surgery and lymph nodes taken out, the whole nine yards. And ended up on a two-year experimental regimen which I don’t know if that worked or not. …But, anyway. I went through all of that. I had regular follow up appointments with the surgeon, all of that stuff.

She went on to explain that a significant part of her patient experience was the way she was treated by the providers who were giving her treatments and the way that she was treated at work by her nurse manager. She said,

I have to say I felt like I was pretty lucky, but I was also felt a little privileged because I was a healthcare worker. Because I would say, you know, “I can’t get off of work on this day.” And being on a research regimen they wanted your blood drawn on certain days and all of that. So they were actually like, willing to come and meet me at 7 a.m. in the morning. So I could actually have my appointment and my check up and go to work. So in that way I felt like I was incredibly lucky. But I had other ways that I didn’t feel like I was lucky. Like my nurse manager at the time was not really nice about me having to take off work. When I told her what was happening and that I would have to have surgery, she’s like, “Oh, they are going to totally mutilate you!” And, I mean, comments like
that that totally shocked me. And you could tell that, with not only me but with other employees, she had, like, a real issue with things like FMLA and all of that. Sometimes I don’t know why certain people choose to be a teacher or a nurse you know, any of those caring, helpful things that are like that.

Because her treatment regimen lasted for two years, Charo spent a fair amount of her illness both receiving treatments and working. This was a difficult experience for her and she explained,

So after all of the surgery, I went back to work in an environment that was stressful. And of course I am spending two years doing a drug regimen which makes me horribly sick at times, and feeling pretty bad on the days I was not doing that regimen.

Ultimately, Charo finished her treatment and recovered from her patient experience.

**Charo’s Perspective of Compassion**

During our interviews Charo indicated that her perception of compassion has changed. She mentioned having more “task oriented” behavior as an ICU nurse before her patient experience. However, afterward she makes more personal connections with people. She explained how she perceived compassion in her practice before the patient experience, and said,

Back then, I probably would have thought that compassion was the same thing as being polite. Just oh, calling them “Mr.” or “Mrs.” Whoever. Being respectful. I mean, I think overall I have always been respectful and generally nice. Of course, we all think we are nice. But I think I am nicer than some other people. But I wouldn’t have ever thought to go out of my way to do anything. I probably, well I
may or may not have, held somebody’s hand before. Probably not (laughs). I was probably too busy watching the monitor.

Here, she described compassion before her patient experience as being “polite,” “respectful,” or “nice.” She described a somewhat impersonal relationship because she was “too busy watching the monitor” to do personal things like holding a person’s hand. However, Charo described a change in the way she understands compassion after her patient experience. She said,

It’s being more emotionally connected. So I can say in the past I have not been (before all of this), not emotionally connected to patients. I will hug people now. And actually it won’t be like, the little lean over, and two little pats on the back (demonstrates a quick pat on the back), and walk away. If they need an actual hug, I will hug them as long as they need. You know, if they’ve had an end of life situation, or whatever.

Charo described another way in which she connects emotionally with her patients. She said, “I tell people I am reflex crier. I can be having the most happy, wonderful day and if I see somebody else cry, it’s like, “Grrrr.” And it’s like, “I’m not even sad! Why am I crying?” She said that she never cried with patients before her patient experience.

The relationship between Charo’s patient experience and willingness to hug her patients, and “reflex” crying needs to be explained in greater depth. Charo mentioned that during her patient experience, she had a number of emotions including sadness, and grief. Upon clarification, Charo explained that she believes patients go through a grieving process, because there is some form of loss when a person becomes ill. In her case, she grieved her health and a change in her physical person from the surgery and scar it left.
Charo’s patient experienced gave her a personal understanding of emotions that patients have, including grief. Now that she has had these experiences, she is more aware and open to the emotions that patients have. When she sees a patient crying, she automatically responds. When a person seems sad and like they need a hug, her response is to give a hug. These responses demonstrate a very personal connection with her patients that she said would not have occurred before her patient experience.

Overall, after her patient experience, Charo has moved from a more impersonal perception of compassion in practice and has become more open to her patients and is willing to be more emotionally connected with them.

**Changes in Charo’s Actions**

As we spoke, Charo said that she sees compassion differently after her patient experience, and as a result the way she interacts with patients has changed. She said that she is more sensitive to patients’ needs, and is more willing to “go the extra mile,” or advocate for patients. She gave an example of a patient survey that the stroke team sends out to patients after they are discharged. The survey is a data collection tool. However, she added to the survey that if they have questions at any time, they can call her work phone number. Charo said that she gets calls from patients frequently now that she has added the phone number to the survey. She said that an important aspect of compassion is willingness to be “open” to communication.

Charo indicated that she is willing to go the extra mile by taking more time and having conversations with her patients. She stopped rushing in and out of patients rooms after she became a patient, and said,
And the thing that I found, like, I would go into a room and instead of just (sarcastic tone), “Here’s your meds, blah, blah, blah, whatever.” I’d stop and say (kind tone), “Hi how are you today?” And look at them and talk. And I’d have people say, “I’ve been here for three days, and nobody has spoken to me. You are the first one that actually really had a conversation with me.”

Another way that Charo believes compassion in her practice has changed is through patient advocacy, and gave several examples of how she advocates for patients. She said,

I think I am more of a patient advocate than I probably would have been had not all of this happened. Um, the pain control is definitely an example or, you know, getting a doctor to listen to me that something is not right, you need to take care of this.

She continued by saying that after her patient experience, she was more likely to advocate for patients when she saw subtle changes in her critical care patients. She said,

I’ve also seen where a patient is getting like more antsy, and you can’t put your finger on what’s wrong, and people (doctors) are not listening. And then when you come back the next day, the patient crashed and burned that night (meaning the patient became critically ill overnight). So I don’t know if that’s just nurse’s intuition or if that is a component of compassion to be more aware of what is going on with your patient.

We discussed her comments more. She not only recognized a greater attention to detail as mention above, but also identified that she was more concerned about the patients when
they began to show subtle signs of distress. Charo said that she was more persistent when attempting to get a physician to pay attention to the details that were worrying her.

Another example of Charo’s change in patient advocacy is in relation to patient comfort. She indicated that she had pain during her own patient experience, and is now more sensitive to patients’ physical needs and to which patients are experiencing pain.

She said,

I think I am definitely more sensitive. I am more proactive in treating pain. And doing little comfort measures. Actually, like I had a reason to go back and review a chart a couple of…I don’t know, I guess six months or so after the patient that I took care of was actually there. And I documented in there “Gave the patient a hand rub to help relax them.” I’m like, “Wow! I actually documented something like that!”

Charo shared a time when another nurse was inflicting pain on a patient and she stopped the behavior. She explained,

It was a nurse who was just not paying attention- who routinely, who has a reputation for not being aware or cognizant of a patient and speaking in not so nice tones and all that. Anyway, so this patient had had, I can’t remember. They either had a stroke or they had a brain tumor or something. Their right arm was all contracted up. And the person was not verbal and I mean, they obviously had been seriously affected. So this nurse decides that it’s her job to straighten that person’s arm out. So I am sitting there and I am seeing, you know, stretching the arm out and the patient’s face is like, “Arrgh!” You know like if they could be screaming they would be screaming. So that’s actually when I said, “That is
enough! Step away from her. It is not your job to straighten out her arm!” So, I don’t know. But couldn’t that person have seen the look on the patient’s face? A very simple cue that you are doing something wrong.

Charo indicated that she pays closer attention to patients’ body language and is able to tailor her care to address a patient’s needs.

**Summary**

Charo’s patient experience involved a type of cancer that required two years of treatments. During that time she worked as an ICU nurse, and indicated that the combination of her treatments and work environment were very stressful. When examining compassion in her practice Charo described compassion as being “polite” or “respectful” before her patient experience. After her patient experience Charo said that she believes that compassion involves being more “emotionally connected” with her patients. In addition, Charo is more sensitive to patients’ needs, and is more likely to advocate for her patients, particularly those experiencing pain.

**Teresa’s Narrative**

Teresa has been a nurse for 15 years. Her first nursing job was on a medical surgical floor, however, a significant amount of her nursing career has been spent working in critical care and the emergency department. When we met she was working in the emergency department, but was considering a return to critical care.

Teresa is one of the participants who has a chronic illness. Her patient experience began over three years ago when she was having regular testing for cancer, and was eventually diagnosed. Since that time she has received treatments every three weeks, and has had a significant change in her perspective of compassion as a result.
Teresa’s Patient Experience

Before Teresa was officially diagnosed with cancer, she had been going to diagnostic centers every six months to have MRI’s or ultrasounds because she had a significant family history of cancer. She explained,

Well I was getting at the time MRI’s every 6 months and my MRI showed something and I was called back for a second look ultrasound and that radiologist thought it was a shadow and told me I was fine so when I came back 6 months for my imaging that same shadow was now a (pause). Well in the MRI report looking back, it was a 5.5 millimeter mass, but she thought it was a shadow. So now when I come back, there she could tell on my imaging that there was lymph node involvement ‘cause my lymph nodes were enlarged, and it had already spread to my liver. It’s a fast growing cancer.

Since that time three years ago, Teresa has been receiving cancer treatment every three weeks. She explained a little bit about her treatment, and said,

So it was in my liver, so it makes me stage 4 (most severe stage of cancer). But they have a drug that’s targeted for those cells. It doesn’t affect my hair, or my skin, or my nails. It only affects those cells. I did last September have it return in my lungs, so I had to start taking an oral form. I’ve had to take 5 pills each night since September. Health-wise it’s probably the worst one, the most aggressive you can get. But medical wise it’s the best one you can get, because it’s the only one that’s got a targeted type of chemo. I’ll get my chemo at 1:00. Go to work at 3:00, and not have any effects at all. Maybe if I wasn’t on the targeted chemo maybe I’d feel 10 years younger. I don’t know. Maybe it’s affected me and I
don’t realize it, but that’s what I’ve known for 3 years and I feel great. I run, I work out, I’m active with my kids. I just finished my degree; it hasn’t slowed me down.

At a different time during our conversation, she expressed her feelings about her situation. She wishes that things were different, yet at the same time tries to maintain a positive attitude. She explained,

I know now cancer is not even a terminal, it’s a chronic disease. It’s like having diabetes. It’s something I’ve got to deal with. I can’t go on vacation in my third week because I have to get my chemo, but it beats having dialysis 3 times a week. You know I have friends who say (upset tone), “That’s horrible that you have to get it every 3 weeks!” I’m not getting dialysis 3 or 4 times a week. Like, it’s not horrible. It’s a pain. You know, I wish that initial radiologist hadn’t called it a shadow. If she would have called it what was, and offered a biopsy... But things could always be worse.

In this explanation, Teresa showed that she views her cancer as a chronic illness that she has to deal with like people with other types of chronic diseases, and indicated at a different point in the interview that she will have to have treatment for the rest of her life. However, it appears that she is able to maintain a positive attitude because she is still active in the everyday activities of life such as exercising, being active with her kids, and finishing a degree.

**Teresa’s Practice**

There are several critical aspects of her patient experience that have impacted her concern for patients, and therefore her actions in practice. She said that she has improved
the quality of her technical skills, she includes families, and she tries to have more open communication with her patients. These are discussed below.

One of the critical aspects of her patient experience that has affected Teresa is the way in which the oncology nurses carry out technical skills. She began by paying attention to the nurses who take care of her when she goes to the cancer center for treatment. She said that these nurses are very diligent about maintaining sterile technique so that the patient (in this case Teresa) does not get an infection. She explained how this has impacted her practice,

I’ll give you one example real quick. Working in the ICU something happened, it’s nothing to unhook an IV, and just attach it to the bag. I know you’re supposed to use alcohol, but okay, you’re in a hurry. Now, like if anyone does that to me without alcohol— and I’ve watched it, because I think they work with cancer patients and the immune system. Like, they’re so diligent. I guess they’re concerned for the immune system of the patient, and getting an infection. I’ve noticed that they are more careful than what I think I was prior. I mean I used alcohol, but they really, really scrub, scrub, scrub! Some will use two alcohol preps. And I’m like, “Wow!” I would just lightly brush across it. So I’ve been more mindful of how my practice needs to be.

Teresa’s patient experience has shown her that the quality her technical skills was not always the best. Where this connects to compassion in her practice is that in her own patient experience, she has come to understand that she could get a serious infection if the nurses taking care of her are not careful. She takes this extra concern for patients into her
own practice and makes sure that she does things properly to avoid putting patients at risk for infection.

Another critical aspect of Teresa’s patient experience is developing an awareness of the importance of including patients’ families. She explained that as a patient her husband and family have been ignored, but as a patient their presence is very important to her. She said,

I’ve learned since to respect the families more, to the patient too of course. But there’s been situations where tests, or like I might not have focused so much on the families, and realizing how important the family is to the patient. Even like wanting to know, “Where’s my family?” I think it’s made me more mindful coming back, you know, from my husband being kind of ignored when I was having tests done, or procedures done, or him wanting to hear how I’m doing. It’s made me be more mindful of the families, of how much (pause). Like I said, as the patient, I want to make sure my kids or my husband sitting out there in the waiting room can hurry up and get back to me, and know that I’m okay. But that part of it is where I would say I’ve changed my thoughts to include, because that’s who is going to care for them when they leave. That’s who cares about you and that’s who you care about and just be mindful of them.

At one point in the interview she said that before her patient experience her practice focused almost exclusively on patients. Before, she would not have thought about her practice in terms of including families in her care.

Since becoming a patient, Teresa is more cognizant of the importance of communicating with patients. The way that providers have communicated with her has
been a critical aspect of her patient experience. She said that providers do not always give her full information. As a result, she has become more detailed in her explanations to patients. She said,

Before I was like (non-concerned tone), “Here’s some information on pneumonia. Follow up with your family doctor. Come back if you need us. Blah, blah, blah.”

Well now I give them (concerned tone), “Okay. Yes you’ve got pneumonia.” And I explain why it’s important to take all your antibiotics because if you don’t take them etc. Why it’s important to get rest, drink fluids. I try to add some extra things. It’s probably in there if I took the time to read it. Assuming that they might not read everything I try to like verbalize more and educate more that way instead of just assuming that they know…I’ve learned to try to help patients and families and try to include the spouse and always make sure if they have questions. A lot of times I’ll write or I’ll tell them, “Okay I’m off at 3:00.” 99% of the time I’ll write the ER phone number and my name and say, “I get off at 3:00, and if you get home and you have any questions call me back.” You know maybe out of the 50 patients I’ll have like 2 or 3 that will call. “Hey, we got home and we forgot to ask how we do this. I just want to…” I wouldn’t have done that stuff before.

Her experiences have impacted her concern for providing better communication with her patients. She takes greater care to help them understand while they are in the hospital.

What demonstrates a greater concern for helping patients is her openness to answering questions after the patients go home. It is not typical for a bedside nurse to tell patients that they can call back if they have questions. This is partly due to structure of healthcare.
Patients who have been discharged are instructed to contact the doctor’s office if they have additional questions about their care.

**Teresa’s Perception of Compassion**

Teresa’s perception of compassion has changed as a result of her patient experience. As we talked she identified how she practiced as a new nurse, as a nurse before her patient experience, and after her patient experience. She explained what her practice was like at that time, and said,

Looking back now from when I first started, that’s when you had to have a year of med/surg and you know I did my med/surg. I think I was more task oriented. I have to get this task done, this task done. You know, 2:00 give him this antibiotic. I think I was more task, task, task. Now, I’m here for the patient and not for the task. I think I’ve definitely changed from even the first five years. …I take more stock in like the actual patient and their being now. Not what I’m doing and what I need to get done. If that makes sense. No it’s not as much task, it’s more focused on them.

Here she shows that her practice was task oriented, which involved technical aspects of care such as giving a med on time. Now she has shifted her focus to the patient as a person.

Teresa compared what she thought compassion meant to her before and after her patient experience. She said,

Compassion to me back then was making sure they were warm, they weren’t in pain. Task stuff, obvious things. Now you know, I’ll call the chaplain for the wife who is sitting over there crying. You know there’s so much more to it. Yeah my
focus is still on the patient, and making sure they’re warm and not in pain, but there is so much more. Making sure their vital signs are fine, making sure their needs are all met, that their bladders aren’t full, just little things. But then like I said, there’s mom over here crying. Or there’s the daughter that needs child life specialist because she’s bored. (Child life specialist is a staff member whose job is to entertain children at the hospital.) There’s so much more to it now. It’s not just the patient. Where before, you know, that’s all of my focus.

Here Teresa explained that she sees compassion as being more complex than addressing “obvious things” such as physical comforts. She mentioned that she still addresses pain etc., but also pays closer attention to details. In addition, she considers the needs of family members now, whereas before, she would have only paid attention to the patient. Overall, her description indicates a more holistic approach to treating the patient. She not only addresses the necessary aspects of care by addressing the tasks, but also pays attention to the “little things” that can make a person more comfortable; and she considers family members as part of her nursing care.

In addition, Teresa now carries out compassion in her practice differently by imagining herself in her patients’ situations. She said,

Now I try to see them as me. Like if I’m in their situation, which I know when you’re in nursing school, you’re taught to imagine they’re your grandmother, your mom or your dad. I try to see them as me. Okay, the way that doctor just talked to them like, “Would I not be upset that he just talked to me that way?” Or, “Would I understand that?” So I always try to take that extra step.
This comment indicates that she uses empathy as part of compassion in her practice because she describes seeing the patient as “me,” and what she personally would think or feel in her patient’s situation.

Another change in compassion that Teresa discussed is that she now believes in giving hope to people, and encourages them not to give up. Before her diagnosis of cancer, she said that she would often write people off when she worked with patients who had cancer. She said,

Before if someone had say stage 4 cancer I’d be like, “Why aren’t they a DNR (do not resuscitate)? They’re going to die.” You know I would have. I mean not so bluntly but inside I’d be like you know—I mean that’s kind of my perception. …I think before like, I have more hope for people with illnesses. Where before, I might have written it off. Yeah we’ll treat them, but more like a hospice type thing. We’ll treat them, but you know eventually they’re going to die… I encourage people to fight more. I encourage people not to give up. I tell them that there’s always hope. I mean who would have thought; I was diagnosed in May, and they told me I probably wouldn’t be here by Christmas. It’s been 3 years. You know I don’t know if I’ll be here in 5 Christmases from now, who knows. We never know. But I give patients more hope now, where before I would have been like, “Yep, he’s going to go, and I don’t blame you.” Now I’m like, “Don’t give up. What are you doing? Like, you’re young! You know medicine nowadays, people survive this.” I think I’m more encouraging now, and I know that people can overcome things where before I don’t think I saw it as much.
Compassion in Teresa’s practice now includes giving hope to people. She understands that having cancer is very unpleasant, and can lead to death. However, her own experience has made her realize that having cancer is not necessarily a death sentence. She shows her compassion toward people with cancer by trying to encourage them.

Summary

Teresa’s patient experience began when she started having frequent diagnostic tests for cancer, and ultimately developed cancer. Now she receives chemotherapy every three weeks, and considers herself to have a chronic illness. Being a patient for over three years, Teresa has watched nurses as they care for her, and learned from her experiences. Her perception of compassion has changed from being task oriented to being more complex. She imagines herself in her patients’ situations, and said that compassion is so much more than simply addressing pain or comfort. She believes that giving people hope is an aspect of being compassionate. Teresa discussed some changes in her practice that are outward signs of the change in her perception. She is more meticulous with some of the technical aspects of care, includes family members in her care, and has improved her communication with patients.

Joanne’s Narrative

Joanne has been a nurse for approximately 25 years. She has spent a significant amount of her career working in critical care, and works specifically with cardiac patients. Both of our interviews were held in a secluded library room.

Joanne’s patient experience involved complications to a surgery that required additional surgery and a two week stay in the hospital. This experience left a lasting impression on her, and her account is detailed below.
Joanne’s Patient Experience

While talking about her patient experience, Joanne indicated that she has a chronic problem in her throat that required her to have surgery several years ago. During her interviews, Joanne did not discuss her chronic illness or this first surgery in any detail. Rather, she focused on the fact that she had a surgical complication that required her to return to the hospital and have another surgery to fix the problem. She explained,

So, it was about 3 years ago that I had a surgical procedure in my throat, it’s where they cut muscles to help with spasms. Did fine with that. Got out of the hospital after like 3 days. Went home. Two days later in the middle of the night I had this god-awful pain. I thought I had you know, just dropped a lung. Because, you know, because they had pulled my chest-tube. So then I took some pain medicine. My mom was still there. So it finally got to the point where I couldn’t breathe. I was like, “Ok (pause) we need some help.” (sigh) So she called 911, went to the hospital, and the ER experience was not good at all. As a matter of fact it was so bad I wrote to the ER afterwards. But, ah (pause), I was there for 6 hours, they finally decided I had perforated at my surgical site.

While she was in the emergency room, her surgeon explained that she would need to go back to the operating room to make repairs. She explained what he said,

So, then, we went to the ED (emergency department), you know the physicians came in. I know the physicians because I work with them. It was Dr. S and Dr. J, and I know them. Um, and he had told me that I would probably end up intubated for at least 2 days. So, I woke up in the, ICU intubated, with tubes everywhere.
After surgery she spent some time in the intensive care unit. In a few days, she was transferred to a general surgical floor and spent an additional two weeks in the hospital before being discharged. Joanne’s recovery lasted over six weeks, and during that time she had a feeding tube in her stomach.

**Joanne’s Memorable Experiences as a Patient**

This section discusses some of Joanne’s critical patient experiences and ways that it has impacted how she carries out compassion in her practice. Most of Joanne’s discussion surrounded the post-operative timeframe. In particular, she focused on the experience of being on a ventilator. Joanne explained the sensations she experienced while being on the ventilator:

> It felt like I couldn’t take a deep breath even though it apparently was giving me enough breath and everything, because I’m sure it was. But it felt like if I tried to do it I couldn’t. And it was forcing air into my lungs. It was just a very *alien* feeling. I don’t know how else to describe it besides being alien. You know, this isn’t the way it’s supposed to be. And I should be able to breathe, and do all that on my own. And I don’t know what settings they had me on or anything, but like if I tried to take a deep breath, nothing would happen.

Overall, she said that the experience of being on a ventilator was unsettling, and “very unpleasant.” She said that she does not want to have to go through it again.

Another critical aspect of Joanne’s patient experience was the feeling of loss of control. She mentioned this several times during our interviews, and indicated that it was a significant part of her experience. She discussed how being a patient means that it is dictated when you take medications, eat meals, take a bath etc. She said that the
experience of being on a ventilator was the biggest demonstration of loss of control. Joanne shared the story of a time when the ventilator tubing became disconnected, and she was not receiving air from the ventilator. She explained:

It felt like somebody else was controlling me. Like, it felt like I had actually no control over it, because I depend upon this machine and I couldn’t do anything with the machine. So whatever the machine did that’s what I had to do. I do remember one time the vent popped off. And I was still restrained at that time, because I woke up kind of crazy. So I’m banging on the rails, because nobody was coming in. Somebody, I don’t know who it was, came in and she’s like (with a condescending tone), “Oh just stop honey!” Well that was just like, total send me off into another world! Because I was so mad; I really wanted to get up and hit her. I’m thinking (very angry tone). “You don’t understand because this is my lifeline here!” And I know that, and nobody was responding. So I had no control. I couldn’t help it, I couldn’t do anything and it was just, you know. (Pause), I really, really felt like the machine was running my life. It was a very scary feeling because I’m used to being in control. Especially in that situation, being a nurse. I’m used to being in control of that patient and machine, and I wasn’t. It was just a total feeling of absolute lack of control and helplessness, essentially.

This displays her feelings of loss of control because she literally has no ability to breathe without the assistance of a machine, she has no ability to move her arms around because she has arm restraints, and the breathing tube prevents her from being able to speak with her voice. This situation was a critical aspect of Joanne’s patient experience because she was completely dependent on the ventilator, and the staff to keep her alive. Part of the
critical aspect of this experience was the fact that the staff member not only waited until she was banging on the rails to respond, but also had an uncaring attitude toward Joanne and her dependent situation. To this day, Joanne continues to remember the experience described above, and this has caused her to change her professional practice. She is now more concerned with trying to help patients maintain some control over their situations because she understands how upsetting it is for a person to have no control. She tries to give patients options in their daily care to help them feel a little more in control. She said:

I feel like I try to offer them options. You know, instead of coming in and saying (authoritarian tone), “Ok, here’s your medicine, take it,” and that’s it. Or “Ok, now we’re going to do this, and then we’re going to do this.” I say (nice tone) “Ok, so this is the plan for the day. This is what we need to get done. Ok, we need to get you up out of bed, we need to take you for a walk, you need to start eating. You need your respiratory exercises. What do you feel like doing now?”

She told a story about a patient who suffered from a stroke, and how she attempted to help him maintain some control but also let him know that she was able to understand where he was coming from. She said,

We had a patient the other day, a lawyer and he had a stroke. So the one side of his body you know, and he was having some difficulty talking. He was just getting very frustrated. So I sat and talked to him and told him I said, “You know, I kind of understand how you feel.” And kind of told him a little bit about it and he seemed to be better after that. …I was telling him, “I didn’t have an experience like you.” I said, “But I was in a position where I couldn’t talk and getting my needs known is very difficult and I said I understand it’s very frustrating because I
felt the same way.” I said, “Now my experience was different because once the tube came out I could talk.” …“Let’s take our time and we’ll work with you. You tell me what you need me to do to help you. I don’t want to come in here and just do things.” I said, “Because I know that feeling, people just come in and do things to you and don’t tell you what they’re doing and just do it and leave.” He seemed to you know settle down a little bit. He still got frustrated, but I think he was more able to take it slower because I think he felt like I was understanding part of where he was coming from. You know it’s just like I’m trying, you’re trying, we got to take it easy and he seemed to do better after that.

Joanne feels that she was able to give him some control by explaining that she could relate to how he was feeling, and letting him know that she was willing to take her time when interacting with him. Letting him know this, and taking the time to understand him gave him at least a little bit of control over his communication and helped this patient to feel less frustrated.

Even though Joanne spoke a great deal about loss of control and addressing this with her patients, she has changed her practice in terms of the way she relates to patients. For example, while being a patient, Joanne remembers that nurses and doctors would “talk over” her. They would not talk to her, and explain things to her. She said,

I don’t stand it as we’re turning patients if they’re intubated or whatever. Even if they’re sedated on something, it’s just like, ‘We don’t talk about Saturday plans or whatever!’ Just because I can remember the feeling of being so frustrated with people talking over me.
Now, Joanne says that she is a very big advocate of talking with patients and families. She takes time to sit down with her patients, explain what is happening, and answer questions. She makes sure that she explains things to patients who are sedated on the ventilator. It bothers her when nurses go into patients’ rooms and do not talk to their patients and explain what is happening. Joanne works with nursing students, and she tells her students that she expects them to clearly state their name, and explain what they are going to be doing with the patient.

**Joanne’s Perception of Compassion**

Overall, Joanne sees the above practice changes as a different perspective of her professional practice, and the role of compassion in her practice. She is able to articulate how her patient experience changed her perspective of compassion in her nursing practice. She explained,

> I think being a nurse or being in any position that we’re caring for people and everything, you have to have some empathy and some compassion. I just don’t think that I realized how much the patients need that and the nurse or doctor or whoever also needs it too. I mean otherwise you end up becoming very cold and very much the task oriented person and I don’t feel like that is the essence of nursing is getting the task done. I think the essence of nursing is that you’re at the bedside and that you’re caring for these people and you’re compassionate in your care and I think having been a patient really kind of drove that home.

Joanne said that she always thought that compassion was part of nursing practice, but her patient experience gave her a new awareness of just how important it is to patients to be treated with compassion. She said, “I think it was like (nonchalant tone), ‘Okay, you need
to be compassionate to be in this job and that’s something you need.” But, after the
experience I think that’s one of the main things.” Her change in perception involves the
fact that she’s the importance of compassion differently. She sees it as being much more
important.

She described that she now sees compassion as encompassing all aspects of
nursing practice, whereas before she saw compassion as a form of “commiserating with a
patient,” or simply addressing tasks of patient care. Now Joanne sees compassion as
“looking at the bigger picture.” She said that compassion is part of a nurse’s “whole
demeanor,” and a nurse’s “whole practice has to be compassionate.” In other words,
compassion involves not only the tasks of patient care such as administering meds
properly, calling the physician with problems, or giving a back-rub, but actually caring
about the patient as a whole. Joanne said this involves interacting with patients on a more
personal level, considering where the patient is coming from, involving the family, and
showing the patient that you care. She said that all aspects of care are encompassed in
compassion. “It’s not one particular thing. It’s just the whole attitude.” Joanne’s
explanation demonstrates a more holistic view of compassion in her nursing practice.

Summary

Joanne’s patient experience involved complications to a surgery that required a
second surgery to fix. As a result, she spent some time in the ICU followed by almost two
weeks on a general surgical floor. One of the most memorable aspects of her patient
experience involved loss of control, and she spent a lot of time discussing her own
experience and ways that she tries to give patients control. Joanne stated that she is able
to relate to patients, and gave an example of how she related to a stroke patient and tried
to give him some control with his communication. When reflecting on her perspective of compassion, Joanne realizes that compassion is very important in practice. She believes that compassion involves seeing a patient as a person, and should be a part of a nurse’s whole demeanor and practice.

**Bekah’s Narrative**

Bekah has been a nurse for 35 years and has spent the last 30 years working as a bedside nurse in critical care. As she spoke to me, it was clear that she is passionate about providing excellent care to people who are critically ill. She explained that she cares for people who are so ill when they come to the hospital that they often do not fully recover from the illness. In addition, she said that many patients who are admitted to the ICU are experiencing end stage organ failure, which ultimately leads to death. Therefore she has extensive experience working with patients and families as they are going through the death and dying process. This makes her working environment very stressful at times, however she finds it to be rewarding.

Both of Bekah’s interviews took place in a library conference room. The room was secluded from the rest of the library and we were able to close the door so that no one could hear what we were discussing. She appeared to be very relaxed and was very matter-of-fact as she spoke to me about her illness and its impact on her.

Bekah mentioned a number of times that she is a compassionate nurse, and that being compassionate is very important to her. At first it seemed that she was trying to convince me that she was compassionate, or that she was afraid I would judge her negatively if she was not compassionate before her patient experience. She indicated that her compassion developed before her patient experience, which made me wonder why
she told me during the initial contact that her patient experience affected compassion in her practice. However, after thinking about our conversations, I believe that compassion truly has been important to her, but it has become more important to her now that she is a patient, and needs compassion from others. As readers will see, she talked about her interactions with office staff and “nurse-navigators,” she does not often receive compassion from providers. Her stories depict a patient who manages her illness alone, and is treated as a number. Unfortunately she has a chronic illness which requires frequent interactions with healthcare agencies and providers, thus exposing her to this type of treatment frequently. I think her need for compassion as a patient brings her beliefs about compassion to the forefront, and reaffirms her belief in its importance when caring for patients. Because her perception of compassion has been reaffirmed through her patient experience, and she feels compelled to share her story and perspective of compassion in nursing practice with others.

**Bekah’s Patient Experience**

Bekah’s patient experience began approximately six years ago when she was diagnosed with cancer. At that time, she went through treatments and the cancer went into remission. She explained what was involved with her process,

> It will be six years in November. My first lumpectomy was the week of Thanksgiving. I had to go back in because they couldn’t clear the tumor margins. (Not all of the edges of the tumor could be removed.) So two weeks later I went back in and had the margins cleared. And then that January (they had to give me some time to heal the incisions and all that.) And then January I went through all this. I had the EKG done, baseline chest x-ray, baseline labs. Had an
echocardiogram done, a full bone scan, a full CT scan just to make sure there was no metastasis, that kind of thing, a full MRI. Then I started my chemo in February; February 2 to be exact. I didn’t have my IV port in and she kept sticking my vein, and she couldn’t get it. I said, “Well, you know it is Groundhog Day they are supposed to be hiding for six more weeks.” (Laughs.) I mean, you have to have some humor in this whole thing, you know. Well, let me see, I had the chemo and that was for 4 months. I had to add some time onto it because I got so sick. I finished that up the end of May. Then July, I started the whole process to be marked for radiology, being marked and being tattooed for the radiation. And then I did 5 days a week for 7 weeks of radiation. I was off work my entire 6 months of chemo. I was off the beginning of January ‘til the end of June for the chemo. The doctor wouldn’t let me go to the hospital at all, period.

Bekah explained that the oncologist wanted her to stay out of the hospital at all costs because the treatment she received decreased her white blood cell count, which is essential for a person to fight infections; hospitals are infested with infectious germs. At one point during her chemotherapy, Bekah was extremely sick and weak, and explained what happened when she asked if she could stay in the hospital for a little while. She said,

Even the one day when they gave me 2 liters of fluids because I was just so sick…I mean I couldn’t keep anything down. They said, “Well whatever you throw up drink it back down.” Well, I may as well just not move because, you know, it’s coming back out. I literally laid on the bathroom floor for just days because I had no energy to get to the couch. And I had to have somebody drive
me in. But the one day they gave me two liters of fluid and I said (in a pleading voice), “Can I please just stay? I don’t have anybody to stay overnight with me. I am just so exhausted. I am afraid something is going to happen and there’s not going to be anybody around.” And he (the doctor) said, “I absolutely will not admit you into the hospital if at all I can help it!”

She said that she has never been admitted to the hospital during her cancer treatments.

While talking about her patient experience, Bekah shared that she had a period of time when she did not need treatments or diagnostic procedures. However, within the last year the lab values that the oncologist looks at have been changing. The levels have been rising, thus she has had a number of MRI’s and other diagnostic tests to find out if she has a recurrence of the cancer. During our first interview, she recalled a number of encounters that she recently had with various healthcare providers. The overriding theme in her accounts is that of frustration, and some anger. In fact our interview began with her sharing the frustrations she has with a healthcare provider called a “navigator.” A navigator is a provider whose job is to help patients understand things such as the overall plan of care, and different treatment options. Navigators answer questions and make calls to other providers to get answers for patients. Bekah said that she has two navigators; one navigator is an oncology nurse to help her understand her cancer, and the other is an insurance navigator to help her understand insurance coverage for her illness. She indicated that the cancer navigator was only available when she was receiving chemotherapy, and the insurance navigator only contacts her when she has been spending a lot of money. She told a story about a time when she really needed a navigator, but did
not think to ask for help, and received a call from the navigator after the fact. It caused her to be very frustrated and angry. She said,

But, just like back in April, I had a CT scan, PET scan, bone scan, MRI all done; and then I had 2 open bone biopsies after that. And the one day I spent 6 hours on the phone between Dr. T and his office and Dr. E, which was the bone guy and his office and his Physician Assistant and Dr. K’s office in Radiology and his assistant. (Exasperated tone) I spent 6 hours! Now that is when I could have used a nurse navigator. Seriously! I didn’t even think about her. And she goes (snotty tone), “Well, why didn’t you call me?” I’m like (exasperated tone), “I don’t know. If you are supposed to be navigating why aren’t you calling me, putting forth some effort?”

Bekah continued with the story explaining that she essentially did the job that the navigator could have done,

They want me to go for an open bone biopsy now, which is my next move to take about a dime sized piece out of my spine to get a better sample. So that is where I could have used even this second navigator. I called the insurance company; this could have been something else that the navigator could have helped me with, was “What questions do you have about your insurance? What can I answer for you? Is everything going to be covered for you? How do you want me to look into this?” I think that is where she could have been more beneficial to me. But instead I called our healthcare provider.

Bekah expressed her frustrations when trying to communicate back and forth between three different physician offices. She needed to speak with the doctor who was
performing her procedure. Unfortunately the office staff tried to schedule her for an appointment several months after the procedure was to take place. It resulted in a mess.

She explained,

I talked to Dr. T, then I talked to Dr. T’s office, then I talked to Dr. E’s office, and they couldn’t get me scheduled in until like July, and I am like (angry tone), “I’m sorry, that is really totally unacceptable! This is March. That is totally unacceptable to me to wait that long.” You know. So then they called me back and the secretary is like, “We are going to have the Physician’s Assistant call you back.” And I am like, “This is for a surgical consult. Can the Physician’s Assistant do surgery?” If the Physician’s Assistant can’t do surgery then I am thinking she’s not the right person that needs to be calling me. …And, this Physician’s Assistant calls me back and is like, “Well, this is what we are going to do.” I said, “Can you do the surgery?” She said, “No, I am not allowed to do the surgery.” “Will you be in the OR?” “No, I won’t be in the OR.” “Can you get a surgical consent?” “Well, not for this one I can’t.” (Exasperated tone), “Then why am I wasting my time talking to you?” I have become very vocal about; let’s just not waste my time anymore. “I want to talk to Dr. E, Dr. E is who I need to see. I am not satisfied with waiting until July to get in there so you need to step up when I am coming in.” She (the physician’s assistant) said, “Well, we are going to put you in with me and that way you’ll be in the system and we can get you in.” I said, “No. That is not how it’s going to work. I am having a bone biopsy done this week and I need to be seen by him sooner than July.” So then I had him calling me back. …So, I mean literally, I spent 6 hours on the phone just calling people
back. That is when I needed to have the nurse navigator. So I am kind of angry.
Not angry at her, but kind of like, “You are just kind of worthless to me right now.” And I really wasn’t being smart when I asked her, “How’s this navigator business working for you?” I was not being smart at all because it’s not working for me. And if you are supposed to be a patient navigator, somewhere the patient ought to be involved, not just every six months.

This story depicts her frustration and anger with healthcare providers. The office staff did not indicate to her that they understood what she was frustrated with. She was frustrated with the fact that the doctor needed to explain the procedure to her and obtain consent before going through with it. However, the staff did not acknowledge that this is what she needed. It seemed that the staff was trying to essentially shut her up by having the physician’s assistant call her.

**Bekah’s Perspective of Compassion**

As Bekah spoke during our interviews two things became apparent. First, her patient experience has reaffirmed her belief that compassion is important in nursing practice. Second, the critical events in her patient experience have affected her understanding of patients and some of the ways she treats patients. Each of these is explored below.

Bekah’s patient experience seems to have reaffirmed her belief in compassion. She indicated that compassion has always been something that is important to her. However, since her patient experience, she has experienced a lot of frustration and anger, and been the recipient of some rather uncompassionate care, which has brought her attention back to compassion. Toward the end of our discussions, she mentioned that her
desire to participate in the study partially came from this awareness and desire “to maybe help other nurses develop their skill in this.”

Bekah said that compassion has always been an important part of her professional practice, and that her experiences as a nurse have had a significant impact on her development of compassion. She has been a nurse for 35 years, and has become a patient within the last six years. Therefore Bekah believes that compassion in her practice began to develop before her patient experience. She indicated that it is something that develops over time, and said, “I do think it has changed just because over time, as you are a nurse longer, if you don’t have that compassion, if you don’t develop that to a certain level, then you don’t stay in nursing very long.” Bekah went on to say that compassion is necessary for nurses to possess. She believes that if a nurse is not compassionate, they will not stay in the profession very long, and said,

I think that probably 95% of the people that have gone into nursing because they want to do something good for people… Yeah, if you don’t have compassion and empathy you won’t last very long in nursing. You will burn out because you don’t have those.

Bekah added another descriptor to her perception of what compassion is. She thinks about the way she would want to be treated in her patients’ situations, and tries to treat them the same way. She explained,

I think I tend to treat people the way that I would want to be treated. So if I want to be treated nice, I treat other people nice and I try to go that extra little mile like if I can wash your hair today or if I can give you a shave or things like that. As far as using that in my practice again it comes back to if that was my mom laying
there or if that was my dad or one of my brothers or sisters, how would I want them to be treated? If it was me laying there how would I want you to be treating me? So I kind of go about it in that aspect of looking at it as: What is the best thing that I can be doing for you?

Overall, Bekah expressed that compassion has been an important aspect of her nursing practice, and is necessary for nurses to possess if they are to remain in the profession.

Bekah indicated that her patient experience has helped her to improve the way she treats patients because she has a better understanding of what patients go through. She is able to see aspects of the patients’ hospital experience that might be frustrating or cause anger, and directs her care toward preventing some of those feelings. Her own critical experiences of frustration and anger have the outcome of a heightened awareness or sensitivity to this in her patients. She said,

I think one of the things I have kind of learned is the fact that I got to remind my patients and families that it is hospital time, not your time. You know, like if they say “We are going to take you down for a test at 9:30. It might not happen until 11 because of other circumstances. If you don’t hear from us then everything is okay until such point that you hear.” And I think that is one of the biggest things. But myself, I think I have also learned how to be a better navigator for my patients. Just the little things like contacting doctors’ offices, or getting things in progress. We had somebody who had a consult done that was over the weekend and it wasn’t done by Tuesday, and I’m like, “Why hasn’t this been done?” “Well it never got called in.” You know, like, kind of be able to be better on top of those kinds of things. The other night they ordered a sample off of a bronchial washing,
I’m like, “She didn’t have any bronchial washings today. What is going on?” So I had to call the doctor, “Did you mean sputum, or is this the wrong patient.” You know, “I can do a sputum and get it.” And the doc is like, “No, no she had a bronch done.” I’m like, “Not today she didn’t. She had one done on the 6th. Is that what you are talking about?” “Yeah, we are going to add it to that.” I’m like, “Do you realize this is a week later? What am I supposed to do with this?” But, because of her diagnostic issues it was important to have had that added onto it. So then I spent time calling the lab, finding out about it. Well, you know, of course it is Saturday. We have to find out about it on Monday. And so today I called into the Unit to make sure it had really been dealt with and taken care of and that everything was taken care of. And it was, but because I took the initiative. So I think that is one aspect. So I think those are probably the two biggest things that I have learned.

It is worth noting that Bekah’s explanation of her change in practice surrounds the same kinds of problems that she experiences as a patient. Her stories about her personal patient experience surround situations that cause frustration; or situations in which she needed an advocate to help her. She identifies situations that might frustrate a person and helps to alleviate it. She advocates for her patients and makes sure that various aspects of care are taken care of, or not overlooked.

**Summary**

Bekah’s narrative reveals that she has been a nurse for 35 years, and has practiced in an ICU for 30 years. She was diagnosed with cancer six years ago and within the last year has been receiving a number of diagnostic procedures to determine if it has returned.
As she discussed her patient experience, she expressed a lot of frustration and anger in the management of her illness.

Bekah’s patient experience has reaffirmed her belief in the importance of compassion, and has drawn her attention to it because as a patient, she is in need of compassionate care. Bekah believes that compassion has been an important part of her practice for a long time, and began to develop before becoming a patient. She thinks that compassion is a necessary quality for nurses to possess if they are going to remain in the profession. While caring for patients now, she identifies with her own need for a patient advocate and situations that cause patients to feel frustrated or angry. She tries to be more of a patient advocate and address details of patient management that may be overlooked.

**Hoku’s Narrative**

Hoku has been a nurse for over 35 years. When we spoke, it was evident that she is passionate about the nursing profession, and has enjoyed a fulfilling career. She has worked in many different roles including, staff nurse in ICU’s, clinical nurse specialist for critical care areas, nursing educator, and wound care nurse. Currently she works as a wound care nurse, and nurse educator for a hospital.

Hoku has been a patient several times. During our interviews she focused her story around two patient experiences. The first story is about a car accident and the “lousy” care that she received from the entire healthcare team. The second story is about a severely broken ankle, and the compassionate care she received from a nurse, which impacted her entire patient experience.

**The Car Accident**

Hoku began talking about her patient experience by recalling a car accident that
she had a number of years ago. The accident occurred when she was working as a clinical nurse specialist for a hospital’s ICU and ER. At that time she was in the process of finishing her master’s degree. A brief explanation is necessary to help the reader understand her story. Hoku was broad sided in her car, and her car was significantly damaged. While she was at the scene of the accident, she had a sore neck. As a nurse, she knows that this could have indicated a spinal injury. People who have spinal injuries (or people with potential spinal injuries) need to keep their spines completely still until thorough x-rays can be completed. It is a standard of care for the healthcare team to make sure a patient has an immobilized spine until proof is given that there is no spinal injury. If a person has a spinal injury and moves their spinal column, this can severely compound an injury and have debilitating results, including paralysis. Her story centered on the lack of attention to this detail during her visit to the ER. She said,

I think the one that impacted me the most was a car accident. And it was lousy care. I got taken to our sister hospital. I was on my way to work, and I was broadsided by a pickup truck. I drove a little Neon at the time. He hit me on my passenger side. But he crushed my car into me because what hit me was my passenger door, and I was in the driver’s seat. So I was just like massive bruises and everything. I got to the ER (and it’s very clear I’m a nurse- wearing my badge). And I got the lousiest care you could possibly have imagined. The radiology tech came. I was in a neck-collar, and on a backboard for spinal stabilization of course. The Radiology tech comes in to transport me to radiology and says, “Here let me take this collar off so we can do your x-rays.” And I’m going, “Um, no! You leave the collar on to do the x-rays. Don’t take my collar
off, if I have a spinal injury you could make it worse.” The tech said, “Well, it will be difficult to get x-rays of your shoulder.” I’m like, “Okay. Well do it with the collar on anyway. It won’t matter for the x-ray.” (Accurate x-rays can be obtained even with equipment.) And it was just like (confused tone), “What kind of care is this?” I remember just laying there thinking, “Good grief! They could kill someone if they took the neck collar off!” After that, my IV infiltrated, of course. (This means that the IV catheter damaged her vein and began leaking the IV solution into her tissues instead of her blood vessel.) And I’m putting my call light on saying, “My IV infiltrated.” And in comes the nurse and she literally looked at me and said (with a condescending tone), “How do you know it’s infiltrated?” I’m in blue scrubs. My name badge was still on my jacket. And I’m going (exasperated tone), “Because I’m a nurse. And my arm is swollen up, and it hurts like all get out. And I know it’s infiltrated.” And she’s like (irritated tone), “Well, I’ll check it, if you insist.” And I just remember her saying “if you insist.” It was like (firm tone), “Yes, I insist!” By that time my x-rays are back, the doctor comes in and says, “There is nothing wrong with your shoulder. You didn’t break anything. You didn’t break your hip. You didn’t break your knee or your lower leg, femur. We can’t find any fractures.” And I said (because I still had my collar on), I said, “What about my c-spine?” (neck portion of the spine). And he’s like, “Oh I forgot to look at that x-ray.” He said, “But I don’t think…” And I said, “Could you please go look at the x-ray?” And so he went out in a huff. So he went out, and in comes a radiology tech again. And she said, “Here, I’ll take that collar off so you are more comfortable.” I said, “Did he read the c-spine?” And she said
(in an unsure tone), “No, not yet. Not that I know of. Well, maybe. Well, I’ll go ask the nurse.” (Exasperated tone) It’s like, okay. So the nurse comes in and says, “You know, Hoku you are really being difficult.” And I said, “You know what. My neck is attached to my body, not yours.” And I said, “If I need to be difficult to get adequate patient care in this ER, I am going to be difficult.” And she said, “Well, staff nurses just don’t know anything about ER.” And that pissed me off, and I said, “I am not a staff nurse.” I said, “I am the clinical specialist for ICU and ER at the sister hospital.” And, I said (raising volume), “At our ER, our docs clear those x-rays before that collar comes off!” I said, “That’s the standard of care, that’s policy and procedure!” And I said, “If you think I’m difficult, you haven’t seen nothin’ yet.” I said, “I’m getting difficult. I’m warning you, I’m getting difficult!” And so she stomped out, got the doc and the doc came back in. The doc says, “Hoku you are causing problems for our ER staff.” And I said, “Have you cleared my c-spine?” And he said, “Yes. I see no fractures.” And I said, “Thank you.” And I reached up and took off my own collar and I said, “Can you help me sit up a little bit. I am really stiff. I’ll get off the backboard so you can get it off the stretcher.” And he said (apologetic tone), “Oh! Oh!” And I said, “I am not as difficult as you think. Your perception is I am difficult because I am asking basic care questions.” So I actually got discharged. They didn’t keep me.

Hoku said she has spent a lot of time thinking about that experience over the years. She has questioned why she received that type of care, and wonders if she received that type of care because she was a nurse or because the staff did not really care about what
happened to her. As part of mentally processing the experience, she chose to write a paper about it for one of her graduate classes. She said,

I remember I wrote my paper about the lack of the standard of care. But when I was writing my paper, and I remember I went back and read it. It was like (tone of having an epiphany), “Oh my heavens. I am also talking about the lack of compassion!”

**The Broken Ankle**

During our interview, Hoku segued into her story involving her experience with a broken ankle. This story is in stark contrast to the account of her previous experience. In this patient experience, she was a patient in the hospital that she worked and received what she considered to be particularly compassionate care from an ER nurse. Later in our interview, Hoku discussed what she learned from this experience and how it impacted her perception of compassion. Hoku began her story of the broken ankle from the beginning. She said,

One morning before work. I was walking, (pause) running; I was running. I had laundry in my arms. I am trying to get the dog out of the way, and I’m telling my son to move his gym bag and, “No you can’t drive, and have the car today.” All these kinds of conversations going on. And I’m literally running down the stairs because I thought, “Boy it’s 6:30 in the morning. If I can get this load in the wash in the next 15 minutes, I can still get to work by 7.” And so I was flying down the stairs, and I tripped. And I fell the last five steps. And I fractured my ankle. And being like a good 16 year old, my son says, “What was that?” I’m like, “It’s your mother. I fell down. Go get your father. I broke my ankle.” So when my husband
walked in the hallway he said, “How do you know?” And I said, “Because my foot is over here, and my leg is over here.” (She used her hands to demonstrate that her ankle was jutting sharply off to the side.) And he said, “Oh yeah, you broke that one!”

Hoku and her husband decided to call the ambulance because her foot was literally jutting off her leg at a very sharp angle. Hoku thought that the EMT’s would properly splint the leg and ankle to prevent jostling and pain on the way to the emergency room. When they arrived at the ER she was taken care of by a nurse that she knew, but did not know terribly well. She recalled,

This is where I had such a wonderful, wonderful experience with compassionate nurses. Maria was the ER charge nurse, and she came over and she said, “Well Hoku, I think you’ve done a number.” I’m like, “Yes, I have.” She said, “We are going to get your IV in.” And she said, “We are going to get you something for pain.” And it was like, “Thank God for Maria!” Because it’s like, “I really need something for pain, because I am going to cry any minute because this is really hurtin’ really bad. I’ve already dug my fingernails in, I got marks on my hand because it really hurts.” But she got my IV started. She gave me some pain medication.

Hoku continued with the story, discussing the technical aspect of her injury. One of the emergency room doctors came into her patient room to tell her what was wrong. The doctor explained that she had a fracture that was in a straight line. However the fracture was so severe that she would need to have a surgery to reset the bone and have a metal plate with screws inserted to keep the bone in place. After explain her situation, the
doctor asked which orthopedic group she wanted to have perform the surgery. At this point she had difficulty making a decision because of a combination of severe pain and narcotic pain medicine that she had received, but she explained that her nurse Maria came to her rescue. She remembered,

I remember thinking (frightened tone), “Oh my goodness. I have drugs on board! This is not good because I know there is one group I want, and one group I don’t want.” And I remember I looked at Maria, because she was still there. And I said, “Maria, who do I want?” And she said, “You want to wait another five minutes to make that decision.” And I said, “Ohhh! For the next on-call group.” And she said, “Yes.” And I said, “Thank you.” And I remember saying to Dr. W (with a drunk tone of voice), “Whoever comes on.” And I remember him looking at me and going, “Huh?” And Maria said, “She wants the M group.” And I said, “Yes. That’s who I want!” And he said (with a tone of understanding), “Okay. That will take me about 5 minutes to put the call in.

The call was put in to the surgical group and she was placed on the operating room schedule. In the meantime, Hoku began to think about her job. At the time, she was working as one of the nursing educators for the hospital. She was supposed to be teaching a certification class called ACLS that day, and needed someone to cover for her. She explained how Maria anticipated her need and said,

I was supposed to be teaching ACLS too. …And it was amazing that Maria was doing all of this thinking. Because I remember, I finally said to Maria, I said, “How did you know about ACLS?” And she said, “Well, you told me.” And I said (in a surprised tone), “I did?” She said, “I asked you what your schedule was
today.” I said, “Ohhh, okay.” And she said, “Drugs are a wonderful thing. You don’t remember what you are saying.” And she’s like, “I called Julianna like you said. I had Julianna call Kerry. Kerry came in as soon as she got here. I’ve got Julianna down there.” And I’m like (thankful tone), “Oh, okay.” She said, “It’s all fixed.” And I’m like, “All right! But we are going to need another instructor besides Kerry. Because Kerry was going to come help me so we are still one instructor short.” And she said, “Not to worry. I called Martha (who was the ER manager) and told her. And she’s on her way in, too. And she’ll cover what Kerry was to cover.” And so everything worked out. And it’s like, this is the most compassionate nurse who is taking care of a nurse who goes okay, “You (the patient) are worried about this, this, and this. And you are in pain.” Looking at that total… *I love Maria.* And it’s like, oh my heavens, what a fantastic experience, broken ankle and all. Just a fantastic experience because it’s like (tearful), “Wow, you give really good care!”

Hoku’s story continued later that day after her surgery was complete, and she was at home beginning her recovery. She said that Maria went above and beyond, and called her at home. She said,

During surgery I got a plate and 8 screws and reattached my ligaments on both sides. Go home. My husband gets me home, gets me upstairs, gets me propped up on a million pillows in bed. And all of a sudden he brings me the phone and he says, “Maria is on the phone.” I said (surprised), “Okay.” And she said, “So how’re you doing?” I said, “My leg is *really, really* hurting.” She said, “What did they give you for pain medication?” And I said, “One Percocet every 6 hours.”
And Maria said (irritated tone), “I was afraid of that.” She said (in a motherly tone), “You’ve had a really bad fracture. You have a lot of swelling, and edema because it was a dislocation. And you have a plate and 6 screws in there, right?” I said, “Yep. A plate and 8 screws.” She said, “Hoku, I want you to listen carefully to me as one nurse to another. You know that people can take more than one Percocet at a time.” And I said, “Yeah, I know that, Maria.” And she said, “And you’ve worked ER and you have seen the ER docs order it every 4 hours.” I said, “Yeah, I know.” And she said, “Well, I think maybe you should use your own nursing judgment.” And it’s like, you know, (with gusto) now there is a nurse! (chuckles) It was my choice to do that. I did do that. I did that for about 24 hours until I got a little control of my pain. And she was funny, too, she said, “And you know, a little ibuprofen on top of that would probably reduce all those bruise pains that you have from falling down the stairs.” I got off the phone. I said to my husband, “Go get me a glass of water. “I want 800 milligrams of Motrin, because that’s a loading dose, so I want 800 of Motrin and give me two of the Percocet.” …But the care and the compassion. She didn’t have to call me back that afternoon, or evening, whenever it was. She didn’t have to do that.

During the interviews, Hoku said several times that Maria was an excellent role model for demonstrating compassionate care. Hoku spent a lot of time getting to know Maria after her patient experience and began to adopt changes in her own practice as a result.

**Hoku’s Critical Events**

The impact that these patient experiences had on Hoku was that she learned about her own perception of compassion by reflecting on the care that she received from
healthcare providers. She mentioned several times in our interviews that she thought about her own practice after each of her patient experiences. Hoku’s experience as a car accident victim showed her how exasperated patients can become when healthcare providers do not pay attention, take the time to listen to patients, or treat patients rudely. This experience taught how she does not want to behave as a nurse. She said,

So that was like my really lousy, lousy experience as a patient. And it was like,

Oh, this had an impact on me because it’s like, you know what, I will never, ever roll my eyes and huff and tell my patient, “You are being difficult!” So it was one of those things of that was like totally what I don’t what to do, I don’t want to be.

Hoku was impacted by the nurse telling her that she was “being difficult.” In Hoku’s mind, it was appropriate for her neck to be immobilized until the x-ray confirmed no injury. As she stated, movement of her spine could have compounded a spinal injury if she had one. In addition, Hoku’s nurse seemed to be annoyed that Hoku informed her that the IV had infiltrated. An infiltrated IV needs to be addressed right away. (This is something that nurses are taught as students.) Yet the nurse only assessed the IV after Hoku insisted. These things resulted in Hoku’s perception of a lousy experience, and that the staff did not care. In her reflections, Hoku identified what she thought was the critical element that resulted in the lousy care and overall lousy experience. She said,

The experience with the car accident was indifference; total indifference. Like,

“We don’t care.” And in hindsight, you know, years past writing that grad school paper, I remember thinking in the paper, “Was it because I was a nurse? Or was it because they didn’t care?” And it’s like, “It is because they didn’t care.” It was
like I was cluttering up their ER. And I didn’t do exactly what they wanted me to do in the timeframe that they wanted me to do it. So I had to be wrong.

In contrast, when she broke her ankle, Hoku received compassionate care from the nurse in the emergency room. She came away from the experience thinking about the qualities that the nurse exhibited, and how to impart that to new nurses. She mentioned over and over again the compassionate qualities Maria exhibited, which are qualities that she now personally espouses. She said,

So it was doing the little things. It was the caring, the dignity. And she was an advocate. And I think compassion has to be related to advocacy. Because you have to care enough to advocate for someone. If you don’t care, you’re not going to advocate. You don’t care which doctor they get. Or you don’t care if they have enough pain medication on board. So I think that really is a big piece of it. I think, too, with compassion the person doesn’t care, um, they don’t care where the patient came from. They accept every patient or every person as is. And I think that is an important piece of compassion. To accept the person as they are, as drunk as a skunk trying to change an ostomy pouch, or coming into the ER, no matter what. Whether you were a nurse who broke an ankle or whether you were a child that broke an arm.

Hoku identified dignity, advocacy, care, and acceptance as qualities that Maria showed to her when she was a patient. Maria’s quick action of inserting and IV and giving pain medicine to Hoku right away made her feel that Maria cared about the pain she was experiencing. Hoku felt that Maria advocated for her and demonstrated caring by helping her choose the surgical group to perform her surgery. In addition, Maria cared enough to
ask Hoku about her schedule and make arrangements to cover the class she was teaching. These actions from Maria left a lasting impression on Hoku. She shared a number of stories in which her interactions with patients has changed as a result of receiving care from Maria. In one instance, she told a very long story in which she stayed on the phone trying to help a patient change his ostomy bag while he was falling-down-drunk. (An ostomy is a piece of bowel that has surgically been brought to the outside of the body. Stool then drains through the ostomy into a collection bag, which is emptied as needed.) While talking on the phone with the patient, she orchestrated the immediate dispatch of a home health nurse to get to his house to help him. She said that without her exposure to Maria,

So I just don’t know if without having had that experience, if I would have had as much follow through to keep checking on him. And to spend an half an hour on the phone with a drunk trying to change an ostomy pouch, or empty it. And to flag down my secretary and have a sidebar conversation with her so she was calling home care. I am not sure I would have went that far. …I think I would have said, “Mr. Smith, I’ll tell you what. I am going to hang up and call the home care nurse and have her come back.” And I would have left it at that. Which would have been quite adequate. Yeah, it would have been adequate. It wouldn’t have been what he needed.

Hoku wanted to make sure the patient was safe, and did not damage his surgical site, so she stayed on the phone with him until the home nurse arrived. Her exposure to Maria’s demonstration of care was a critical aspect of her patient experience because it impacted her concern for patients and how she carried it out.
My observations of Hoku’s critical aspects of the patient experience include her relationships with healthcare providers and being the recipient of indifferent care versus the recipient of compassionate care. Even though Hoku said at the beginning that her most influential patient experience involved the car accident, I believe her interactions with Maria were more influential because she talked about the specific qualities that Maria possessed and how it impacted her practice. In addition, she spent time thinking about what makes Maria different than other nurses, and how to influence other nurses to care the way Maria does. Ultimately, she decided that Maria’s influence on others was her living example; Maria role modeled compassion. Hoku explained,

Umm…Maria, I don’t know. I really thought about Maria (gets tearful) a long time. It’s like, golly, I wish she still worked here. It would solve a lot of my problems with teaching. Because then I would have hired her as an educator. I would have made her go back to school, and I would have said, “Come on, you need to teach this stuff because…” (With emphasis) How do you teach someone to be nice? You role model it (still tearful). And it’s like, ok, so that’s the difference with Maria. She was just an excellent role model. And when I got to know Maria, the unique thing about her was she had had a really severe accident as a nurse, and she had decided she didn’t want to be like the nurses that took care of her. And so she changed how she took care of patients. It was like, “Oh cool!” I was the benefit of Maria having an accident and having lousy care. Um, so I hope that patients, um, get good care from me (tearful) because I had good care, but I also had lousy care.
This quote shows Hoku’s reflection on Maria and the realization that compassion her practice was influence by Maria’s role modeling, and her own desire to provide “good” care to patients. It shows Hoku’s realization that others’ compassion can be influenced by role modeling.

**Summary**

Hoku is a nurse with over 35 years of experience who shared two patient experiences. In her first experience, she received “lousy” care, and this experience demonstrated how she does not want to behave as a nurse. In the second experience, she was cared for by a nurse who she believes exemplifies compassion in practice. She has spent time reflecting on these experiences over the years. Her perception of compassion and the way she carries it out in practice has changed as a result.

**Helen’s Narrative**

Helen has been a nurse for 40 years, and has a very rich nursing career. She has worked in a wide variety of settings including critical care, cardiovascular care, nursing management, and patient education. As a patient, Helen has experienced both acute and chronic illness, along with both inpatient and outpatient experiences. In addition to her experiences as a patient, she was exposed to compassionate healthcare providers in her childhood. Therefore, Helen’s narrative of compassion in her professional practice has two major stories. One story pertains to her exposure to healthcare providers when she was a child, and the other pertains to her chronic illness and subsequent patient experiences as an adult. Throughout our interviews, Helen interchangeably referred to her patient experiences and childhood experiences. She did not talk about these stories chronologically. However, upon review of the interviews a chronology can be presented.
In order to understand Helen’s development of compassion both of these stories are presented. Interwoven with her experiences is her description of how the experiences impacted her.

**Helen’s Childhood Experiences**

Helen’s childhood experiences impacted her understanding of compassion and inspired her to become a nurse. When Helen was approximately five years old, her mother (who was also a nurse) became ill. Her mother’s symptoms were vague at first because her chief complaint was fatigue and weight loss. Helen recalled that the local family doctor blew her off and said,

> My mom, she got real sick when she was in her mid-30’s and the doctor kept saying...She was pregnant or had just had my sister, so she would have had 4 kids at the time. Now she was a nurse, and they were spaced out. We have like 5, 3, 5 years between us, so it wasn’t like she had them all at once. And she went to her family physician. She was just really sick, she was losing weight, she can’t keep any food down, she’s got, you know, everything’s going right through her and she just kept losing weight and her skin was changing. She just didn’t look good. And she went to her physician and he told her...now this was in the 50’s...but he told her (non-concerned tone), “Aw, it’s all nerves. You just have too many kids and you weren’t meant to have that many kids.”

Soon after this, Helen’s mother became very sick and was taken to Pittsburg for medical treatment. It was here that Helen described her first encounters with compassionate healthcare providers. One example she gives is that of a young resident physician who sat...
in her mother’s hospital room scouring pages and pages of medical textbooks to try and discover what disease she had.

The night they didn’t expect her to make it, she had a resident sit at her bedside with medical books, looking through medical books trying to figure out what in the world was going on with her. Because they couldn’t figure out why she was dying. He found out she had Addison’s disease. She was dying because she had Addison’s disease.

This resident discovered what her mother’s disease was, and as a result Helen’s mother received effective treatment. Helen believes that this act of compassion by the resident played a critical role in her mother’s outcome.

Another doctor in Pittsburg became her mother’s primary doctor. Helen says that this doctor was her “hero” because of the kind, caring, compassionate way he treated Helen’s mother and family. He was her mother’s doctor until her death at age 72.

Because of his care, her mother eventually recovered, and was able to resume her roles as a mother and nurse.

The acts of compassion by the doctors and nurses who cared for Helen’s mother played a significant role in her decision to become a nurse. She said that because of them, “I wanted to be in the field, because I wanted to be somebody that could help people get better.” Helen’s exposure to compassionate caregivers during childhood showed her what compassion looks like. This laid the foundation for the type of nurse that she wanted to be. She recalled that as a child she saw experienced nurses role-modeling compassion in their practice. Helen said,
That’s what I did over the years is try to make myself more like those people that I saw, and that I experienced either their compassion, or I watched them as they were showing compassion towards somebody else. You know, they were my role models so to speak, and that’s what I wanted to do, is be more like that.

**Helen’s Patient Experience**

The other major story in Helen’s development of compassion involves her experiences as a patient. As an adult, Helen has a number of patient experiences, and due to her chronic illness, will continue to do so. She said that her patient experiences have made her “…understand what it is like to be a patient, to understand what they’re going through.” This section discusses some specific experiences that Helen has experienced and ways that it has impacted how she carries out compassion in her practice.

Helen’s patient experiences began when she was in her early 30’s. She said that one day she went to the doctor for a tetanus vaccine, and several days later became so swollen, stiff, and sore that she was unable to move. It was during this experience that she was diagnosed with a chronic illness which causes inflammation. She explained,

Believe it or not, I (pause) well you know, I always had these aches and pains and stuff. But I didn’t think anything of it, you know. I was a nurse. I just thought that is just part of your body. I didn’t pay attention to my body, let’s put it that way. And, I cut my finger. And when I cut my finger, I did a good cut on it. And, of course, I had two little kids at the time. I couldn’t get to the Emergency Room right away. And when I did get there they couldn’t stitch it but they wanted to give me a Tetanus shot. So, okay give me a tetanus shot. Three days later I couldn’t walk. I was having trouble walking. I had gone to teach; at that time I
was teaching childbirth classes and I went to teach one of my classes. And when I came home I kept telling my husband, “Something is wrong with my feet. They feel funny.” And I looked down and my ankles were over my tennis shoes. And right away, I’m an ICU nurse, so I thought congestive heart failure. So, I got to the doctors immediately the next day. They threw me on the table, did an EKG and everything was fine as far as my heart. And the doctor called a rheumatologist and asked if they could see me right away. So I went to the rheumatologist and that is how it started. And as the days went on I could move less. You know, I was moving, but it was very difficult and I became house-bound for 8 months. I would go up and down the stairs at home; I couldn’t go up and down walking. I had to go up and down on my rear end in order to get up and down. You know I used to sit around and try to rest up as much as I could because my kids were little. So I didn’t want my kids to know that I was sick. So I would rest up as much as I could so that I could be myself when they came home. Because I didn’t want them to have a sick mom. You know. I grew up with a sick mom, and that was the last thing I wanted my kids to do.

Helen remembered that during this period of exacerbation she spent a lot of time feeling angry and scared. She knew that her illness had the potential to be completely debilitating, and even cause death. She said,

Thirty some years ago when I was diagnosed, I had taken care of patients in ICU and they were all end stage patients, and they all died. I thought, “Here we go. I have little kids.” I mean they were kindergarten, first grade, second grade and I was going to die, and I was going to leave my little kids. That’s what was in my
mind the day that I was diagnosed. You know I was very angry and very scared to
say the least, but I decided you know, after thinking about it for a while, sitting
home and not being able to do anything else, thinking about it I was not going to
let this get me and I was going to control it. Within 8 months I was better and
back to doing my job and doing things. I think mind over matter has a lot to do
with it and as a nurse you got to be there to help your patients have a positive
outlook as much as possible.

Helen’s belief in “mind over matter” is a coping mechanism that helps her maintain a
positive attitude in regards to her chronic illness. She said that the illness causes a lot of
pain, but she has told herself that, “Pain is my friend. As long as I have pain, I know I am
alive.” She said that she uses the techniques in childbirth classes in managing her pain
and said, “And you can learn to ignore it. I taught childbirth classes. I taught women to
ignore their pain during labor and delivery. If you can ignore that, you can ignore
anything. (Laughs.)”

Since the time of immobility, Helen has experienced several illnesses including
heart problems which required admission to the hospital. There are several critical things
that Helen discussed in regards to her hospital admissions. These critical aspects of her
patient experiences include: unsettling emotions, unequal treatment as a woman, and
inadequate communication from healthcare providers.

Helen said that as a patient she often experiences unsettling emotions such as:
feeling scared, fear of the unknown, and having a loss of control. She said that when a
person becomes a patient,
You don’t know what’s going on, you’re always waiting for results or you’re waiting for a procedure to be done or you’re worrying about what if they find something that you don’t want them to find… Different things like that go through your mind and it’s scary. That’s what our patients are going through. That fear of the unknown.

Here, her fear of the unknown is in regards to tests or procedures and the possibility of receiving bad news. As a person who has been a patient and had numerous tests and procedures, Helen is able to identify that patients experience fear when waiting for results. In addition to fear, Helen discussed her dislike of having a loss of control, and why. She said,

'It is the fear of losing control and not being able to make my own decisions. And that’s always been important for me, making my own decisions. And even the physicians that I have dealt with over the years, they know that’s how I am. I like to be included in the decision making. I don’t want someone just telling me they are going to do this. Talk to me about it. I want to be included in this. And if it is not what I want, you know, patients have rights. (Laughs) And that is what I teach my patients all the time. And I tell them all the time (encouraging tone), “It is your right to say no if you don’t want that.”

Helen’s desire to be in control of her healthcare decisions carries over to her interactions with patients. Her comment above indicates that part of her interactions involve encouraging patients to speak-up when talking to physicians, and make their wishes known. She helps patients to know that they have the right to say no to different things that a doctor might suggest.
Another critical aspect of Helen’s patient experiences is that she learned firsthand that women are not given equal treatment to men when seeking healthcare. She has gone to the hospital for heart related problems several times. One time she said that she had a very rapid heart rate, and her heart was beating over 200 beats per minute. (A normal heart rate is from 60-100 beats per minute.) She shared what happened in the ER,

The nurse was excellent. You know, she took good care of me. She started my IV, she got the EKG going, she got my blood drawn and everything. My heart rate was going 200 or better and I am laying in this bed. I was a little short of breath, but I was fine. I wasn’t having any pain. I was, typically, asymptomatic at this point. But I was one of two patients in the ER. The other one was a woman. And I listened to the physician, that I knew. He was head of the ER. This was at night, this was around midnight. So I knew they weren’t busy. I was one of two patients, and we were both women and he was sitting in the nurses’ station, across from the room I was in, eating cookies, having coffee, talking and carrying on. And my monitor, I knew where the monitors were because I worked there, so I knew that he could see what my heart rate was. And he wasn’t coming, and wasn’t coming and a half hour is going. And I think to myself, “I am going to have to say something. I am going to have to say something.” Because, you know, it’s just that I knew sometimes how women were treated in the ER. Well, all of a sudden I hear him say after about a half hour of listening to him talk, he looked up at the monitor and said, “Hm, that heart rate is pretty fast.” So he saunters into the room and said, “You have a rapid heart rate.” And then he took one look at me and realized who I was. And immediately things were flying. It was like slow motion
to rapid motion. Because all of a sudden he realized I was one of the Unit Coordinators in the hospital and things started flying and I was taken care of immediately. I don’t think the woman who was there right before me ever got taken care of until after they finished with me. I don’t know what her problem was. But, it was just the idea that I saw the other side of it. The nurses were wonderful. You know, it wasn’t that I had any problem with the nurses. They were wonderful. My problem was with the physician. So after everything was taken care of and I was back to my normal rhythm at home and back to work, you know, I had to let somebody know. They have to start treating women like men. If that had been a man in that bed I felt he would have been in there taking care of it.

She then went on to explain how this experience affected her practice. She said,

How it helped me was making sure that the next woman that came in with chest pain was treated the same as a man. It just made me more of a, I don’t know, fanatic about it. I did. I became fanatical about it, because I saw firsthand there could be a difference.

She began to see a change in the treatment of women with cardiac symptoms before she moved away. Since this experience she says that medical treatment of women has improved a lot. However, this is an issue that she continues to pay attention to in her career.

The last type of critical event in Helen’s patient experiences is that healthcare providers do not adequately communicate with her and her family. During her interviews Helen described several situations in which physicians never spoke to her, or her husband. This is an example she gave when providers did not speak to her husband,
They stopped my heart to see if they could get it to slow down and also to see what type of rhythm I had. And when they did that, nobody said to my husband, “We are going to stop her heart.” You know, “We are going to give her medicine. She may pass out” or anything. I had to explain all of this to him. He thought I was joking. Because he didn’t believe that they were actually going to do this. But I felt, you know, people need to talk to the family. They need to talk to the family. They need to tell them what is going on. I really got into a lot more patient education after that.

Helen said, “I had a few doctors who didn’t respect me enough to even talk to me regarding the results of my tests, and that’s really upsetting.” Now in her professional practice she places a lot of focus on talking with patients and families. In addition she tells other nurses that they need to do the same. She will say to nurses,

You need to talk to your patients. You know, someday you are going to be in a situation and you are going to want that nurse to talk to you and explain what they are doing. You need to talk to the families.

Helen believes patients and families need good communication from healthcare providers so that they know what is happening to them, and so they are able to make informed decisions about their care.

**Helen’s Perception of Compassion**

In the sections above, Helen talked about some specific experiences, and how it affected the way she carries out compassion in her practice. This section discusses how her patient experiences have has a broader impact on her perception of compassion. First, her experiences as a child caused her to want to become a nurse, and believe that
compassion is an important part of her professional practice. However, she said that before her patient experience, she had a different perception of compassion as compared to now. Before her patient experience Helen said that, “I am sure I cared about the patients back then, and I am sure I had compassion for them, but not how I feel about them now.” At that time in her practice Helen had a greater focus on task related aspects of her nursing care. She said, “I was more into taking care of my patients and making sure they were taken care of and that I was doing the right thing for them.” Helen recalled that in particular, she was not comfortable making personal connections with patients and had difficulty talking with patients and families.

Helen said that her patient experiences have “fine-tuned” her perception of compassion, and helped her to “mature”. Helen’s experiences have helped her to see her patients a different way. She said, “When I walk into a patient’s room, that patient is the most important thing there. Nothing else going on is important.” She now focuses her energy and attention on the patient. She is able to make a deeper connection with patients, and sees compassion as being more complex than seeing to the tasks of nursing care. She went on to describe what compassion is, and said,

Compassion is somebody that will let someone express their feelings and not make judgments; will listen to them and if they ask for help will be there for them, will let them know they are not alone. Sometimes it is just sitting and holding their hand. I have done that a lot (chuckles). You know, if they want to be quiet, we will be quiet. If they want to talk, you are going to be there and you are going to listen.
This comment shows that Helen wants to provide support for her patients in the way that they need it. Her compassion may look different from one person to the next based on their expressed needs.

Because of her experiences Helen realizes the importance of treating her patients like a real person. Helen believes in treating the patient as a whole person and not just a disease. For example, rather than seeing a patient as “a diabetic,” she sees the patient as “a person with diabetes.” She realizes that patients are much more than the disease or illness that they are seeking treatment for. She said, “I think that being compassionate is allowing a person to remain being a person and not a patient, being there to listen to them.” Helen explained that this is important because when a person seeks healthcare, “You’re no longer the person that you were before you came in.” Therefore, compassion involves treating patients like the human beings that they are.

**Summary**

Helen’s perception of compassion has evolved over the course of her entire life. Her first impressions of compassion arose when she witnessed the compassionate care of doctors and nurses toward her mother. She wanted to be like these role models and chose to become a nurse. In the beginning of her nursing practice, compassion in Helen’s practice focused more on tasks and physical aspects of patient care. Over the course of her career and chronic illness, Helen’s perspective of compassion has matured and now focuses on treating the patient as a human being.

**Chapter Summary**

This chapter presented the narratives of the individual participants who had a wide range of patient experiences. Some nurses have chronic illnesses, while others had
acute or short lived illnesses. Some of the nurses’ experiences were in the hospital, while others have had significant patient experiences but have never been admitted to the hospital.

In each case the nurses described how their patient experience impacted their perception of compassion. Many of the nurses compared their compassion before and after their patient experience and described a more personal view of compassion toward patients. The nurses discussed some of the specific changes in their practice of compassion as a result of the patient experience. In addition, some of the nurses made strong comments about how important compassion is in nursing practice.
In the previous chapter, the nurses’ individual narratives were presented, and showed that there were a variety of patient experiences; this chapter presents the thematic analysis. Even with the variety of experiences, there are some commonalities in the group which surround the patient experience itself, and perceptions of compassion in their practice before and after the patient experience. I conducted the thematic analysis with an inductive approach which allows important concepts to emerge through a process of continual observation and reflection (Creswell, 2009; Patton, 2002). Following this approach, I read each transcript looking for concepts expressed by participants. To identify concepts, I began by underlining phrases, words, and ideas expressed by the participants. These were transferred to a Word Document and color coded according to participant. I then examined the concepts and phrases looking for similarities or relationships; and began to group the concepts and phrases into common categories (Creswell, 2009). The process involved examining and reflecting on the categories multiple times before identifying the themes presented in this chapter.

There were five major themes discovered in the analysis. Three of them pertain to the conception of compassion before and after the patient experience. Another major theme addresses the similarities in the patient experience that were significant to participants. The last major theme involves the participants’ perspective on how
compassion develops. The major themes are presented according to the overall chronology of the patient experience, and are as follows:

- Before the Patient Experience: Compassion in the Background
- Being the Patient: Nurses’ Memorable Experiences
- Changes in the Conception of Compassion: From Background to Foreground
- Changes in Behavior as a Result of Compassion in the Foreground
- Developing and Keeping Compassion in the Foreground

**Before the Patient Experience: Compassion in the Background**

During the interview process, nurses often verbalized that they were compassionate before becoming a patient; however discussions reveal that compassion seems to be in the background of their practice. The participants’ comments demonstrated a different focus in practice because their comments were directed toward their practice in general rather than compassion. They mentioned several themes that can be identified: being “task oriented,” they equated compassion with doing their job, and describe impersonal relationships with patients.

Many of the nurses discussed their perceptions of compassion before the patient experience as a comparison to their perceptions of compassion after the patient experience because they identified a difference before and after their patient experience. This section specifically addresses the nurses’ perceptions before the patient experience.

**Task Oriented**

When thinking about compassion in professional practice before becoming a patient, six of the nurses said that they were more task oriented. The term task oriented in
nursing jargon refers to providing care that does not focus on personal interactions with patients. To help the reader understand, it is very common for nurses to create a to-do list while receiving report at the beginning of a shift. Lists often consist of plotting out the hours in the shift and adding specific tasks to each hour. It serves as a reminder to the nurse throughout the shift of the tasks that need to be accomplished, and at what time the tasks should be completed. However, the discussion that the nurses provide has more depth than this. Some of the nurses stated that they were more task oriented, and what they meant was that they were less focused on personal interactions with patients.

Perhaps Teresa explains this meaning best:

> I think I was more task oriented. I have to get this task done, and then this task done, then at 2:00 give him this antibiotic. I think I was more task, task, task. You know if we spend a little more time chatting, or doing your bath, or me sitting down with the family and explaining stuff. You know if the antibiotic doesn’t get hung right at 2:00, I have a window. It doesn’t have to be so exact. I’m here for the patient and not for the task. I think I’ve definitely changed from, even the first five years. I’ve changed a lot.

At first Teresa stated that her practice was task oriented. Then she gave examples of interpersonal behaviors that she did not do in her practice at first, such as take time to “chat” with the patient, or sit down to explain things to the family. However, she identified that she has changed to consider some of the interpersonal aspects of care because now she says she is here for the patient rather than the task. Similarly, Charo pointed out that before she became a patient, she was more focused on the “taskiness” of her job as an ICU nurse. She said, “And, you know, I went through all the steps of
making sure I got done what needed to get done; explained things to families, if I *had* to.”

Here Charo is referring to the various tasks that needed to be accomplished in her role as a critical care nurse, and placed more focus on this aspect of her job rather than interpersonal aspects such as talking with families.

Similar to being task oriented, seven of the nurses stated that as new nurses they spent a great deal of time and energy trying to learn technical skills associated with their jobs. Several nurses mentioned that before the patient experience and in the early part of their careers, they were very busy trying to learn the technical aspects of their jobs and were simply not able to focus on the compassionate side of their practice. For example, Bekah stated, “As a new nurse for the first year, you are so busy learning what it is that you don’t know. I don’t think you necessarily think about the compassion part of it.” In Bekah’s statement, she points out that new nurses learn a lot, and essentially that compassion is not the first thing being learned as a new nurse. Helen explains her own learning as a new nurse. She said,

In the beginning I saw myself just trying to get through the day and making sure that I did everything to get through the day… In the beginning it was geared all around making sure I got those things I needed to do, done for the patient. Not that I didn’t care about the patient, but I think you know, you’re new and that’s what you hone in on. But I think as time goes on those things become easier because of your experience. You do those easier and it gives you more time to key in on the emotional part of the patient.

Helen believes that she cared about patients but needed to learn how to fulfill her job duties at first. Savannah said that she spent a lot of time learning as a new nurse, and that
compassion was not the first thing on her priority list. Savannah said, “Yeah I just remember being petrified and wanting to do everything correctly and not make any mistakes. I wanted to just learn everything, but sometimes the compassion got put to the wayside.” In each case the nurses have a similar experience in that they focused on learning technical job skills first, followed by compassion.

**Compassion is Doing My Job**

Another finding among the nurses is that before the patient experience some nurses equated compassion with doing their job or addressing physical comfort. For example, when Hoku recalled her understanding of compassion before her patient experience she said:

> But as a diploma grad, we were told (with an authoritarian tone), “You *will* be compassionate. You *will* be empathetic. You *will* be an advocate for your patient. You *will* respect your patient.” And so if you would have asked me the definition of compassion I would have told you those things. I would have functioned on; I am compassionate if I do my job.

The description above reflects a perception of compassion that she says was “drilled” into her head while in nursing school. On the surface the description of compassion seems to be appropriate, and somewhat comprehensive. However, Hoku said that the definition of compassion from nursing school was not her own personal definition of compassion and indicated that compassion in her practice was not in the foreground of her practice at first.

Similar to equating compassion with “doing my job” is the concept that compassion involved physical comfort of the patient or the tasks associated with addressing physical care. Nurses often attempt to make a patient feel more comfortable as
part of their daily work routine and may consider that to be an aspect of compassionate
care. Joanne, Shaneequa and Teresa discussed that before becoming a patient they
essentially equated compassion with addressing a patient’s physical comfort or specific
tasks. For instance, Shaneequa mentioned, “I think I equated compassion more with
comfort.” Joanne said that she attempted to do things such as “commiserate with
patients” and addressed patient’s physical discomfort. In both Shaneequa and Joanne’s
descriptions they compare compassion with addressing pain medication, adjusting the
lighting in the room, getting a warm blanket, or helping the patient to feel comfortable in
the bed which is part of a nurse’s daily job activities. Teresa said that she equated
compassion with specific tasks such as administering medications “on time” and keeping
an “accurate account of fluid intake and output.” Teresa said that compassion was
directed solely at the patient, and did not direct compassion toward patients’ family
members.

In this section, some of the nurses said that before their patient experience they
equated compassion with doing their job. They indicated that compassion specifically
involved addressing physical comfort.

Impersonal Relationships with Patients

Another example of compassion being in the background of practice involves
impersonal nurse-to-patient relationships. In the nurses’ descriptions of these
relationships, eight of the nurses mention behaviors such as distancing themselves from
patients, forgetting that patients are humans, judging patients, and not including families
in their nursing relationships.
One description of impersonal relationships with patients is the concept of distancing themselves from patients. For example Joanne simply stated that “I really didn’t get involved with the patient as a person.” Like many nurses, she would refer to patients as their disease status, “The heart in room 12, or the gallbladder in room 6.” Savannah describes distancing herself by “blowing off concerns” that patients expressed to her, or “not listening” to her patients. By not attending to patient’s concerns she did not have to become as involved with patients. She said, “I kind of removed myself from them and talked at them and to them and I kind of didn’t put myself in their shoes.” Similarly, Sara describes her relationship with patients as being “more textbook.” Here she describes her patient interactions (with a formal tone),

I’m your nurse and I’ve been trained to be your nurse, I know what to say to you as my patient, I’ve been educated and I know what the equipment is. I’m going to come into you, and I’m going to tell you what I’m going to do to you, and then I’m going to leave the room. That’s probably (pause), and I care for you because, you know, it’s just kind of more textbook, like this is what I do as a nurse.

Sara’s description was an almost robot feel in regards to the way she interacted with patients before her patient experience. Her description indicates that she was not focused on personable interactions with patients. Another example of being distanced from patients is Shaneequa’s relationships. In her explanation she literally discussed her physical distance from the patient. She said, “Just going in and talking to a patient, I used to stand at the end of the bed, and I know you’re not supposed to do that. Or I’d stand at the side of the bed.” After her own patient experience, she recognized placing a physical
distance between her and patients was a way to distance her relationship with patients and not become personally involved with them.

Some nurses mentioned that having impersonal relationships helped them to forget that patients are humans. Helen, Joanne, Sara and Teresa mentioned that before their own patient experiences, it was easy to not see patients as human beings. In each case their comments were related to being focused on being task oriented. For example, Teresa says that she did not think of patients as being humans before her patient experience, and said, “I think before, it’s horrible to say, but I think before I knew they were a person…” Joanne remarked that when a person comes to the hospital, healthcare providers take away patients’ clothing and dictate how life in the hospital will be for the patient. Therefore, it is easy to forget that patients are people who have lives outside the hospital. Joanne commented, “We’re so focused on getting the patient better in tasks and this, that and the next thing. We forget that they’re people that have lives of their own.”

Another way that nurses describe an impersonal relationship with patients is by judging them. Savannah and Shaneequa described being judgmental of patients before their own patient experience. For instance, Savannah said,

Before I think I was a little more judgmental. You know, (with a snobby tone of voice) “Why is that patient so anxious about that? That’s no reason to be anxious!” I think I was very judgmental of people and you know well, “Why aren’t you compliant with your treatment?” and things like that.

Shaneequa stated that she was judgmental as an emergency room (ER) nurse where many patients come to the ER frequently with the same medical problem. These patients are labeled “frequent flyers” or patients who are “noncompliant” with their medical care.
Before her patient experience, Shaneequa says that she was judgmental of these types of patients, and did not ask herself “Why isn’t this person following through with their treatment? Why isn’t this working for them?” Instead she was judgmental of the fact that patients come to the ER with the same problem over and over again.

One last example that nurses describe impersonal relationships with patients before the patient experience is in regards to including family members in care. Before becoming a patient, Teresa did not appreciate the importance of including families when addressing patient care. She says,

Well the difference is I never would include the family before. To me when I was younger it was all about the patient. The families were, I don’t want to say it point blank, an annoyance if they were there, but my focus wasn’t on family.

Helen described not being as involved with patient’s families at first. She said that she was not comfortable talking with families or including them in patient care. As a result of not including patients’ families in their nursing practice, Helen and Teresa indicated they had a more impersonal relationship with the patients themselves.

In summary, when discussing their practice before becoming a patient, the nurses described things such as providing task oriented care, and equating compassion with doing their job or addressing physical comfort. Several commented that early in their careers they were focused on learning the technical aspects of the job and compassion was not in the forefront of their concerns. Nurses describe different ways in which they had impersonal relationships with patients before their patient experience by doing things such as distancing themselves emotionally and physically, or by not thinking about patients as being people. By discussing practice as being more task oriented, focusing on
doing the technical aspects of the job, and having impersonal relationships with patients, overall the nurses described compassion as being more in the background of their practice before the patient experience.

**Being the Patient: Nurses’ Memorable Experiences**

In the previous chapter, the participants shared their personal narratives of the patient experience. While examining the patient experiences of the entire group, a number of similarities began to emerge. Some of the themes from the patient experience that emerged include emotions such as fear, anger, frustration, and loss of control. Other themes emerged which surround interactions with healthcare providers and described interactions with uncompassionate and compassionate healthcare providers.

**Fear**

Every nurse stated that they felt fear at some point during the patient experience; although they used different words to express this emotion including fear, afraid, scared, scary, “scared to death,” petrified etc. In addition to using different words, nurses gave different reasons for their fears, and some mentioned more than one reason that they experienced fear or anxiety.

Sometimes the fears and anxieties were attributed to “fear of the unknown.” As an example, Savannah expressed “fear of the unknown” as being a significant aspect of her patient experience. She experienced fear of the unknown during her pregnancy in particular. Due to the complications she had to face the possibilities that her baby might be born too early, that the baby might die, or have disabilities due to an early birth. She carries this experience with her into practice and relates to her patients. What she said about the patient experience is, “Fear of the unknown. What does that mean for the
person? What does the diagnosis mean? What does that mean for the future?” Savannah is not the only nurse to express fear of the unknown. Helen said that she has experienced fear of the unknown as a patient. She stated,

That fear of the unknown… You don’t know what’s going on, you’re always waiting for results or you’re waiting for a procedure to be done or you’re worrying about “What if they find something that you don’t want them to find?” Different things like that go through your mind and it’s scary. That’s what our patients are going through you know. That fear of the unknown. Never knowing what was causing the problems that you’re having.

Both Helen and Savannah gave examples of thoughts that might be going through a patients mind because they have had these thoughts. They were afraid of not knowing what was going to happen, and afraid that something bad might happen.

In addition to experiencing fear of the unknown, nurses were afraid because they knew what terrible things could happen to them while being a patient due to their knowledge as nurses. For example, Sara’s illness involved a severe infection that threatened her ability to breath. She felt scared because of her difficulty breathing, but she says, “This is all even more scary to me because I know what all of this means.” She understood that her breathing difficulty could mean being placed on a ventilator or even death, whereas a lay person may not necessarily know that. Like Sara, Joanne experienced fear related to her knowledge as a nurse. Due to Joanne’s experience as an ICU nurse, she felt afraid because she knew about complications that can occur after the surgery she had. She says, “All these different things were running through my head, of course knowing all the bad things that can happen.” In addition to Joanne and Sara,
Helen experienced fear of what might happen to her when she experienced heart problems one time. She said,

You know when I went in the hospital down in Texas that was a real problem for me because I was scared to death that I was going to have to have heart surgery. I didn’t know what was going on. I knew that I had an irregular heartbeat but I didn’t know, wondering “Are they going to have to cardiovert me? (Cardioversion involves shocking a patient with electricity to reset the heart’s rhythm.) Is this going to work? Am I going to have to have a pacemaker?” There were so many things going through my mind because I knew too much.

These nurses were afraid because they know about the many things that happen to people when they go to the hospital. Sara was afraid of being placed on a ventilator. Joanne was afraid of the many complications that can occur with surgery. Helen, was afraid of the different treatments for irregular heart rhythms. Knowing too much enhanced their fear.

Similar to experiencing fear related to a nurse’s knowledge, some nurses expressed fear because they thought something bad might happen to them. For example, during Bekah’s illness there was a time that she became very weak, and dehydrated. She was so dehydrated that she had to go to the hospital to receive IV fluids. She said,

The one day they gave me two liters of IV fluid and I said, “Can I please just stay at the hospital? I don’t have anybody to stay overnight with me. I am just so exhausted. I am afraid something is going to happen and there’s not going to be anybody around.”

She explained during the interview that she was afraid that she would become so weak that she would not be able to get off the floor, or that she would faint and suffer an injury
but not be able to call someone. Like Bekah, Sara had fear that something might happen to her when she moved from the ICU to a regular hospital ward. Sara was afraid that she would experience a problem with her breathing again, and would end up in an emergency situation, but no one would know, and said,

I was just scared… I was all alone and nobody was there and nobody is going to come and help me. How would they know? I could fall asleep, and I could have a real problem and nobody would even know it!

Joanne experienced similar fears when she was in the ICU on a ventilator because she did not have the ability to speak to someone and said, “I could lay here and die, and nobody would know because I have no way of telling anybody.”

Two nurses mention fear due to their lives being threatened. For example Sara clearly discusses her thoughts of death. During her illness, she was having such difficulty breathing, that she thought she was going to die. She explained, “I’m looking at, and I’m like I feel like I’m dying, I just had that feeling like I’m not going to live to see tomorrow.” Eventually her breathing improved enough that the feeling of impending doom passed, but she still experienced fear during the rest of her hospital stay as explained above. Helen experienced thought of death when she was first diagnosed with her chronic illness. She said,

Thirty some years ago when I was diagnosed, I had taken care of patients in ICU with my same illness and they were all end stage patients and they all died. I thought “Here we go. I have little kids.” I mean they were kindergarten, first grade, second grade and I was going to die and I was going to leave my little kids. That’s what was in my mind the day that I was diagnosed.
Fortunately, Helen has not had such a severe exacerbation of her illness since that time. In addition she explained that she made up her mind that the disease was not going to run her life.

As evidenced by the descriptions above, nurses clearly experienced fear as patients. Nurses experience fear of the unknown because they do not know what is coming next, and what this will mean for them in the future. In addition, nurses experience fear because of the knowledge they have, and are afraid of the things that they know happen to patients. Similarly, nurses experienced fear because they thought something specific might happen to them, such as breathing difficulty, or becoming too weak to move. Lastly, some nurses experienced fear due to their lives being threatened.

**Anger Toward Providers**

Eight of the nurses experienced anger, and in each case the anger was related to interactions with healthcare providers. The descriptions indicate that the anger was a result of the way providers treated or communicated with the nurses. Most of the nurses who expressed anger, seemed to be highly affected by the experiences. There is one exception, Sara. For Sara, her anger seemed to be short-lived, and was related to her physical comfort. She described an interaction with an ICU nurse that left her feeling angry, and explained,

I just remember this one ICU nurse. I had this alpaca blanket that we had just gotten for Christmas. And my chills were so bad and she comes in and took my temp and I guess it must have been high, and she said “Okay no blanket!” And whips the blanket off, turns the air conditioning down to like some God awful low
temp, and it was cold in there! I’m like, “You are so mean you took my blanket away!” I was so mad!

Sara went on to say that she was sure that the nurse did it because she thought that she was doing the right thing by trying to bring her temperature down. Even though she recalled this incident in our conversation, it did not seem to have the same impact as the other nurses.

Other nurses such as Joanne, Shaneequa, and Helen recall interactions that made them angry, and seem to be more affected than Sara. (This section points out the emotional experience of the nurses, a later section points out the changes nurses have as a result of some of these experiences.) For example, Joanne was angry with an ICU nurse when she was on the ventilator. The nurse did not come into her room right away when the ventilator started to alarm. Joanne said with an angry tone of voice,

I was very, very angry because I’m thinking, “You just don’t know because I can’t fix this, and this is breathing for me, and this needs to be fixed!” So I was pissed off about that for one thing because I was still restrained, so I couldn’t do anything more beside bang on the bedrails. So I was very, very mad…

Joanne was angry because the nurse was not coming to help her when she was literally attached to a machine that was breathing for her. Not coming in to the patient’s room when an alarm is sounding demonstrated to her that the nurse was not concerned about her. Similarly, Shaneequa experienced anger towards a provider who she perceived as being uncaring. In her narrative, Shaneequa spoke quite a bit about a person in care management who did not take responsibility and communicate with the insurance company. She said with an angry tone of voice, “I was angry. I was extremely angry…
I’m still angry. When I see certain people in care management I’m angry…You didn’t help me, you didn’t make an attempt to help me, how are you helping others?” At the time of our interview, her patient experience had occurred at least six months prior and she still felt angry.

Another example is of Helen, and the way some physicians communicate with her. She gave several examples of physicians in particular who did not communicate with her or her husband, which made her angry. One brief example involved a time when she had a procedure done. She explained,

The doctor walked in, did the procedure, never introduced himself to me. Because I wasn’t sedated yet. Walked out of the room. My husband was standing out side, never walked up and told him what the results were, if I was okay or anything. And never came to see me afterward. Left it for my family physician to see me.

So, it was, I was a little not happy about that.

Helen explained that as a patient, she had a right as a patient to know what was happening. She linked some of her anger regarding poor communication to a lack of respect on the provider’s part. She said, “I had a few doctors who didn’t respect me enough to even talk to me regarding the results of my tests and that’s really upsetting.”

As described above, nurses experienced anger while being a patient. The anger that they describe relates to interactions with healthcare providers. The anger stemmed from the way nurses perceived they were being treated, such as nurses not caring about them, or physicians not communicating with them.
Frustration

Another emotion that nurses felt besides fear and anger was frustration. Frustration occurred in six of the nurses’ patient experiences, with some nurses experiencing frustration more than others. The nurses that expressed the most frustration are Natalie, Bekah, and Shaneequa. Each of them expressed frustrations with the healthcare system. In Natalie’s case, she says that frustration is a major concern for her as a patient because she has seen several doctors and none of them have given her a definite answer regarding what type of chronic illness she has. She said,

Definitely I think frustration is my biggest problem. Nobody is doing anything... I think my biggest frustration with all of this is that no one will take responsibility. Everybody wants to push you to the next guy, and the next guy, that is his area of specialty. Well then his area doesn’t explain that area so he sends you back to the other guy. The other guy says, “Well, we’ll just wait and see.” You know, I am the one who is still struggling while they are deciding what they want to call it.

Natalie said that not knowing exactly what her illness is, and not having her symptoms treated is a major source of frustration for her. Similarly, Bekah experiences a high degree of frustration. However, Bekah’s frustration comes from managing her chronic illness which often requires invasive diagnostic tests, treatments, and visits to multiple doctors. Because of this, Bekah spends a lot of time traveling to and from doctors’ offices, communicating with doctors and office personnel. She indicated that it is quite time consuming and frustrating. She said, “The one day I spent 6 hours on the phone between Dr. T and his office and Dr. E, and his office and his physician assistant, and Dr. K’s office in radiology and his assistant... I spent 6 hours!” In fact, much of Bekah’s
interviews surrounded management of a chronic illness, and her frustrations associated with it.

Similar to Bekah and Natalie, Shaneequa expressed frustration with the healthcare system. However, her frustration stemmed from the fact that her insurance company initially denied payment for the surgery she needed, and the person responsible for addressing these types of problems did not address it. She explained,

"It was frustrating for me, here I was a patient, here I thought I had a good understanding of the health care system, and it was an issue in how I was titled for admission; but nobody wanted to take on that issue. Nobody wanted to take ownership of it."

Shaneequa’s insurance initially denied payment because she was not admitted through the ER. It was frustrating to Shaneequa because if she had known this fact, she would have simply made sure that she went to the ER. However none of the care management staff attempted to find out why the surgery was being denied.

As described here, an emotional aspect of the patient experience for nurses was frustration. The nurses vocalized frustrations surrounding difficulties navigating the healthcare system. Frustrations arise when providers do not take responsibility and when managing complex health problems with multiple doctors.

**Loss of Control**

Another memorable experience for the nurses was what they termed loss of control. Half of the nurses did not mention loss of control as part of the patient experience, however those who did stated that it was a very hard thing to go through. The nurses stated that loss of control was difficult for several reasons. One reason that loss of
control is difficult is because they literally had no control over some of their bodily functions. Another reason is that the nurses were used to being the person in control of the patient. Nurses found loss of control difficult because they were not in control of making their own decisions. Each of these is explored below.

Some nurses commented on lack of control over bodily functions. For example, Sara commented on lack of bodily control and how it made her feel. “I’m sitting on the bed and I’m at their mercy. I don’t have control to go to the bathroom. I don’t have control to get up and leave. I feel trapped.” Similarly, during Joanne’s patient experience, she had loss of control over her body and stated, “The last thing you remember you were rolling into the OR with full control of your faculties and now you have tubes everywhere you can’t talk, you can’t move, everything hurts…and it’s very disconcerting.” Like Sara and Joanne, Helen wanted to maintain control over her body. During our interviews she mentioned that she does not like to have certain medications, and will even refuse them in order to maintain control. In fact she said, “I wouldn’t let them give me any pain medication or anything when I was going through labor because I wanted to be in control.” For these nurses, loss of control of bodily functions was upsetting and brought unsettling feelings such as feeling trapped or disconcerted.

Another reason that nurses said loss of control is difficult is that they are used to being the person in control of the patient. For example, Joanne is an ICU nurse, and she became a patient in the ICU after her surgery. She said,

Again the whole loss of control thing. That’s a really big thing with me just because I’ve always been in control of things, you know. Especially in that situation because I’m usually the one standing at the bedside in control of
whatever is going on with the patient. It was just very disconcerting. I was not thrilled with the whole idea.

Helen is similar to Joanne in that losing control is hard because she is used to being in control. She said,

When you have been the nurse and you have taken care of patients it is very hard to get on the other side. I really I don’t like to give up control. And I always blame it on being an ICU nurse, because ICU nurses always had to be in control. And maybe that is why I stayed in ICU for so long as a nurse because I liked having control over my patient.

Both Joanne and Helen have experience as ICU nurses, and are the two that mentioned discomfort with loss of control because they are used to being in control of patients.

Helen stated that she does not want loss of control because she wants to be included in healthcare decisions. She has been a patient several times and wants to have a say in her care. She explained, “It is the fear of losing control and not being able to make my own decisions and that’s always been important for me, making my own decisions.” She explained during our interview that part of the reason that she wants to make her own decisions is that she has witnessed physicians making decisions about patient care without discussing them with patients at all. Helen, said that there have been times when physicians do not even speak to her, and this bothers her greatly.

The two nurses who experienced high risk pregnancy, Gail and Savannah, also discussed loss of control. They did not specifically state the phrase “loss of control,” however they described how they felt in their situations which were suggestive of feeling a loss of control. Gail discussed her time of bed rest and her attempt to follow the
doctor’s orders in order to have the pregnancy continue to term. She said, “You’re kind of just stuck in this body and just having to do everything you can to keep going and preserve this life and just nobody really gets it how you feel trapped inside.” She felt “stuck” and “trapped” which is a way of describing her inability to control what was happening during the pregnancy. Savannah commented that she felt like she was “walking on eggshells” during her pregnancy which describes her fear, but also suggests feeling a loss of control because the cliché indicates that something bad that you cannot control can happen at any time.

As stated, the nurses experience loss of control while being patients, and this is upsetting for them. The loss of control is upsetting because they lose control of bodily functions, they become the patient who is in control of the nurse which is the opposite of what they are used to, and they are afraid of losing control over decisions regarding their healthcare.

**Uncompassionate Care**

Ten of the nurses discussed interactions with healthcare providers in which they perceived they were not treated well. During the analysis process, I came to see these interactions as being uncompassionate. Most of the nurses did not specifically share the experience to example uncompassionate behavior; the intention was not to be a “tattle tale” and talk about uncompassionate providers. Rather, they were explaining something that impacted them, and on examination these interactions can be described as involving uncompassionate care. There are two ways in which the uncompassionate care was described. First, nurses described mean treatment from providers. Second, nurses
described un-caring or indifferent attitudes from providers. Both of these are explored below.

A particularly memorable part of the patient experience for the nurses was receiving mean treatment from healthcare providers and they shared some examples. Eight nurses mentioned experiences in which they perceived providers being mean to them. While retelling their experiences nurses mimicked the tone of voice and body language to convey the meaning of what they were saying, and described providers who sometimes used a rude or abrupt tone of voice, mean choice of words, and rude body language. For example, Joanne’s experience with the ventilator becoming disconnected made her angry as stated above, but she also made comments indicating that the provider was mean toward her. When Joanne became disconnected from the ventilator, the provider did not come into the room until after Joanne began banging on the bed rails. Joanne explained the nurse’s behavior,

> And the nurse came in and was like (rude tone of voice), “Well what do you want!?!?” And she was just very short with me, you know. So that whole thing I was like, “Ohh, I need to remember this when I take care of my patients!” So when she came in, like I said, she just had this very condescending attitude like, “Okay just stop banging! You’re a child, stop it!” …So that really stood out to me and I remember that vividly and her whole attitude.

Clearly Joanne did not appreciate the way the nurse treated her. While retelling the story, Joanne mimicked the staff member’s tone of voice and body language which demonstrated condescension, and an overall rude attitude toward Joanne. Similarly,
Teresa shared a time when a provider was mean to her. In Teresa’s experience, it was a physician who treated her with a short tone of voice. She said,

The doctors like the shortness, the being told stuff... I had this doctor as I’m crying waiting to get my news, my husband is with me, they’ve done the biopsy. I’m waiting and she walks in and she said (with a mean tone of voice), “You need to quit crying because had you come back in 6 months you would not have had cancer! You were told to come back in 6 months and you waited a whole year.” …She walked in and told me it was my fault. So you know they say that what the doctor’s say makes such a lasting impression, especially if it’s bad news. It was tough to handle telling me to stop crying; it was my own fault.

One can see how the doctor’s “shortness” and mean choice of words can leave a lasting impression with patients. Like Teresa, Natalie experienced an interaction with a physician that left an impression. The doctor demonstrated a short tone of voice, and a condescending attitude. Natalie said,

So they sent me to a Neurologist. I had already been going to a Neurologist for migraines. Well, he absolutely refused to look at my MRI. He just said (with a condescending tone), “Well! I’ve known you for six years. If you had a brain lesion I would know it. I don’t need to see your MRI just to show me you have migraines. That is why family doctors shouldn’t do MRI’s. Only Neurologists should!” I was like, “That’s why they order them and you are supposed to read them because you are the expert.” So, needless to say, I went to a neurologist, a different one. I canned him.
In this situation the doctor’s attitude and refusal to look at a diagnostic test caused Natalie to find another doctor altogether.

Charo felt that the mean treatment she received was in the form of outright discrimination from her nurse manager. She said,

I was close to the end of the two years and an opportunity came up to apply for the assistant manager, which I have always been on the management track. When the nurse manager was gone I was filling in for her. I was signing off, you know, on people’s raises, signing like I was the manager on their evaluations. I was doing a lot of manager stuff. So I thought, “Okay here comes the opportunity to become the assistant manager.” And I felt like I had proven myself. And she said (with a rude tone), “I am not even going to accept your application, or interview you because of your health status.” That is discrimination! I could have hired a lawyer. I wanted to hire a lawyer. And I decided I needed to step out of that environment.

In this case, the interaction was not with a provider giving her care. However, the way the manager treated her was uncompassionate. Charo had been sick for two years, and during that time had demonstrated interest in a managerial position by filling-in for the manager when she was away. Charo was mistreated because she had been doing some of the managerial work, yet her application was not even accepted. If Charo’s health status was a factor in the position, then the manager should not have allowed her to fill-in when she knew for two years that Charo was ill.

Another patient memory that nurses talked about was lack of caring from healthcare providers. The nurses stated that providers did not “care” about them or that
providers were “indifferent.” For example, Hoku described two patient experiences, and her first experience involved a car accident that caused her to spend some time in the ER. She said,

> I think the patient experience that impacted me the most was a car accident. And it was like lousy care. The experience in Florida was indifference; Total indifference. Like, “We don’t care.”

Hoku’s first patient experience left an impression on her because she was disturbed by what she perceived to be “lousy” care. Several times during our interviews she mentioned that the care was so poor that the staff was “going to kill somebody.”

During Joanne’s interviews, she compared compassionate providers with uncompassionate providers. She said that uncompassionate providers did not convey an attitude of caring toward her. She explained how she perceived uncompassionate providers,

> You have people that aren’t real compassionate and they know all the tasks and they understand all the disease pathophysiology. But when it comes right down to it the patient is going to remember the person that was caring as opposed to the person that did all the tasks and everything perfectly…they really weren’t all that interested in me as a person.

Joanne did not appreciate the impersonal nurses who cared for her, and perceived this as a lack of compassion and lack of concern for her as a person. Caring on the part of nurses was important to Joanne because she mentioned caring versus uncaring nurses several times during our interviews, and is addressed later.
Bekah, struggles with being a person who needs a lot of outpatient care for her chronic illness, and expressed that providers do not care about her. For example, Bekah has been assigned a “nurse navigator” to help her manage her illness and navigate the healthcare system. During our first interview, Bekah said that the nurse navigator does not contact her except when she is “spending a lot of money.” One time she asked the navigator, “How’s this navigator business working for you?” Bekah said the navigator was somewhat offended by the question. However Bekah felt that the concept of a navigator is supposed to help people, yet she only receives phone calls after major episodes of her illness. Thus Bekah does not receive help when she truly needs it. Bekah said,

And I really wasn’t being smart when I asked her, “How’s this navigator business working for you?” I was not being smart at all because it’s not working for me.

And if you are supposed to be a patient navigator, somewhere the patient ought to be involved.

It seems to Bekah that the company is only concerned when she is spending money and not truly concerned about her as a person.

Similarly, Teresa notices providers who care and who do not care when she gets treatments. She sits back and watches the nurses caring for patients and mentioned that she can tell who really cares about the patients, and who does not. She said,

Some (nurses) are either burned out or busy and don’t really care. And sometimes of course there’s a couple of them that stick out in my mind, it could be the slowest day ever and they would still take the shortcuts.
Teresa perceives that nurses who take shortcuts while providing cares as not really caring about their patients.

In the comments above, the nurses describe uncompassionate healthcare providers. Sometimes the descriptions involved mean treatment from providers, while other discussed lack of caring or indifference. In each case, it left an impression on the participants. Some of them still feel anger toward providers. A later section discusses how some of these interactions have affected the participants.

**Poor Communication from Providers**

Seven nurses recalled that a number of healthcare providers had poor communication. This may possibly be considered to be an aspect of uncompassionate care. However, because the examples were specifically about communication, they were grouped into their own sub-theme. Sometimes the nurses gave examples of providers that did not give enough information, or explain things clearly, and other nurses felt that providers did not speak with them because they did not respect the patient.

In Teresa’s situation, she received poor communication from a provider in that she did not receive full disclosure of an MRI report. She had an MRI and ultrasound which were looking for tumors. The MRI report suggested additional ultrasound and biopsy, but the radiologist did not clearly state the MRI report to Teresa. She said,

That’s what this radiologist said. My MRI found a mass, but the ultrasound found a shadow. Now looking back, if I had gotten a copy of my MRI report like I always do, it says 5.5 millimeter mass suggest ultrasound *and* biopsy. Had I known that, I would have known it was a mass and I would have demanded a biopsy. But I was so thrilled that it wasn’t a tumor because I was convinced
“Okay this is my year.” So as I’m laying on that table and they’re conducting an ultrasound and I got tears rolling down my eyes and she tells me, “It’s nothing it’s a shadow.” I was thrilled. She told me, “You don’t need to come back in 6 months. We did an MRI we just did an ultrasound you’re fine. You’re getting so much radiation exposure you need to come back in a year.” You know I wish that initial radiologist hadn’t called it a shadow. If she would have called it what was and offered a biopsy (pause) but things could always be worse.

The lack of clear communication about the MRI report had devastating consequences for Teresa and caused her to wait one year instead of six months to return. By the time she returned, she had an advanced stage of cancer, and must now have treatments for the rest of her life.

During Sara’s patient experience, her husband experienced a significant amount of anxiety related to the way he received information from a healthcare provider. The provider gave her husband unclear information over the phone. Sara explained,

So I just know from my husband’s experience, even the phone call that he received saying where I was, I don’t know exact wording but I know the doctor was kind of, “Get back here because she doesn’t look so good.” Just those words you known and he just flew back to the hospital…Now, I’ll try to have better communication because that was such a big thing with us.

She indicated in our interview that her husband does not work in healthcare, so he did not have an understanding of what was happening. The provider’s choice of words caused him to have a lot of fear and anxiety because he thought Sara was going to die. Sara’s
experience made her realize the impact that a provider’s choice of words can have on patients and families.

Communication from healthcare providers is very important to Helen. She talked about communication several times during our interviews, and gave examples of poor communication from physicians, such as the incident mentioned above when the doctor performed a procedure on her and never said a word to her. Another time she was in the ER and the staff did not explain what was happening to her husband. She said,

They stopped my heart to see if they could get it to slow down and also to see if it was a certain rhythm. And when they did that, nobody said to my husband, “We are going to stop her heart.” You know, “We are going to give her medicine. She may pass out” or anything. I had to explain all of this to him.

Her personal experiences with poor communication from providers make her sensitive to the need for communication. She feels very strongly that physicians in particular need to include patients in discussions, respect them, and communicate their plans with patients.

Like Helen, Joanne experienced poor communication while she was in the ER. She said that the staff did not give adequate updates to her and her mother, and the ER physician came to conduct an admission assessment, but never came back. Joanne said,

I saw the doctor once, I saw an ER doctor once in the entire 6 hours that I was there… Nobody was saying, “Ok we’ve talked to your physician, the surgeon, or we’ve talked to the surgeon on call. This is what we’re doing now, this is what we’re doing next”
Joanne and her mother experienced a lot of fear and frustration because she returned to the hospital with severe pain and knew that something was terribly wrong. However, they received no word from the staff explaining what was wrong or what was happening.

Shaneequa’s experience with poor communication involved her discharge instructions when she left the hospital, and did not receive enough information. She explained,

I’ll be honest I thought my discharge instructions stank. They did. I did things I shouldn’t have done, because they didn’t clearly articulate what I should do and what I shouldn’t do. They didn’t make it black and white… I ended up having some bleeding issues. How much is too much to bleed? I wasn’t bleeding beforehand, what did I do to make myself bleed? I vacuumed. I really think that was part of it. Nobody told me that. They told me to limit steps and don’t lift heavy things. Well vacuuming is pushing. I didn’t see an issue with that.

Shaneequa went on to explain that she had to return to the hospital to correct the bleeding. She believes that if her instructions were more clearly stated, she would not have vacuumed, and would not have had bleeding that required an intervention.

In the descriptions above, the nurses give examples of ways that healthcare providers demonstrated poor communication with them and their families. With the exception of Shaneequa, all of them discussed poor communication that involved physicians. The poor communication brought emotional distress, and in Teresa and Shaneequa’s cases contributed to additional health problems.
Recipients of Compassionate Care

Nine of the nurses’ patient memories involve compassionate care from healthcare providers. When recalling these interactions, the nurses made comments about the attributes of the compassionate providers, or the way compassionate care made them feel, and always appreciated compassionate care. The nurses almost exclusively described compassion from nurses and doctors, with most of the compassionate care being from nurses.

Dancer and Hoku are somewhat different from the other participants in that they were both profoundly affected by compassionate nurses. In fact, their discussion of the patient experience largely surrounded the compassionate care they received from nurses. For instance, Dancer said that her patient experience was “highlighted” by an act of compassion from a nurse. As stated before, Dancer was having a surgical procedure for her foot. She experienced a panic attack as the final surgical preparations were being made. The nurse caring for her identified her anxiety and simply wrapped her arms around Dancer. She says that this act of compassion brought “… an overwhelming sense of comfort. I wasn’t scared. I mean it just evaporated. I was like (excited voice), ‘Oh my God!’ The impact was unbelievable to me.” Dancer mentioned the comfort and relief that this simple act brought to her, and now understands the impact she has on patients when she is compassionate. Similarly, Hoku was affected by Maria, who she considers to be a compassionate nurse; and who cared for her when she had a broken ankle. In fact, Hoku spoke at great length about the impact Maria had on her. Hoku said,

Looking at the total picture, I love Maria. And it’s like, “Oh my heavens, what a fantastic experience!” Broken ankle and all. Just a fantastic experience because
it’s like (tearful) “Wow, you give really good care!” And it’s like, you know, now there is a nurse!

Over time Hoku thought a lot about Maria and her qualities and decided to emulate the qualities in her own professional practice. Hoku mentioned several qualities that she identified in Maria that she considers to be aspects of a compassionate nurse. Maria was caring toward Hoku even though the ER was extremely busy and stressful that day. She anticipated Hoku’s need for pain medication and began addressing it. Hoku did not even have to ask for pain medicine. Maria advocated for additional pain medicine and the more desirable surgical group to operate on Hoku. She anticipated Hoku’s worries about her job and contacted someone to take care of an immediate need. Finally, Maria had follow through by calling Hoku at home to make sure that she was getting enough pain medication.

Other participants were less impacted by compassionate care from nurses, but they still discussed the impact that compassionate nurses had on them. For example, Joanne spoke about her perception of compassionate nurses. She was a patient in the hospital for over two weeks and had a lot of interaction with nurses. She came away being appreciative of compassionate nurses, and spoke about the impact that a compassionate nurse versus and uncompassionate nurse has on patients. She said, There was one traveler on the med/surg floor that at 2:00 in the morning I couldn’t sleep, she actually came in and had a long conversation about travel nursing and everything. I mean she was one of the people that stand out in my mind.
To Joanne, the traveling nurse was compassionate because she sat down and talked with her and brought her comfort when she was experiencing difficulty. She said that the compassionate nurses are the memorable nurses. Similar to Joanne, Teresa has a lot of exposure to nurses. She has been receiving treatment for three years, and has become very familiar with the staff. She identifies nurses that she believes show compassion to her. She said,

I found some excellent, excellent nurses though. Really caring that will just go above and beyond and watching them interact with the patients. You can just tell, you know, some people whose hearts are really there to help people… They do little things like remembering (kind tone), “Oh your daughter’s graduation was last week, how did she do?” Like I said, sitting on the bed with me and talking and, “How are things going?” For me it’s just the remembering, and taking the time to talk. Taking the time to act like I’m a person not just a patient, but you know, “How are things going at your job?” Just caring about me. I don’t want to be known just by name and my date of birth. I want them to talk to me and remember if I was here… They know you have kids. It’s nice when some remember things and that they talk to you as a person. Like I said just knowing you by your name and date of birth and it’s all business it’s just not as enjoyable. It’s better when they act like they care about you and know stuff about you or take the time to learn stuff about you.

In this example Teresa identified several things that she considers to be aspects of compassionate care in the nurses. For example, compassionate nurses “go above and
beyond,” and “do little things.” However Teresa’s comment overall points to compassionate nurses taking the time to talk with her and treat her as a person.

When considering the descriptions of compassionate providers from the participants, they describe aspects of compassionate care and how it made them feel. For example, the nurses described compassionate nurses as being proactive, advocates, going above and beyond, taking the time to talk, and treating them as a person. Compassionate care made the patient nurses feel comforted, and like the nurse cared about them.

**Changes in the Conception of Compassion: From Background to Foreground**

As the nurses talked about their patient experience and perceptions of their practice before and after the patient experience, they indicated that compassion moved from the background to the foreground. The movement of compassion to the foreground of their practice is demonstrated in-part by discussing compassion with more depth, and with conviction of the importance of compassion.

The themes that demonstrate a movement of compassion from the background to the foreground include realizing: patients are people too, the importance of compassion, and compassion is the essence of nursing. In addition, the nurses said that compassion is in the foreground because they are able to put themselves in their patients’ shoes. Each of these is addressed below.

**Patients are People too**

As some of the nurses talked about compassion moving to the foreground in their practice they said it began with an acknowledgement that patients are people. This is an important part of bringing compassion to the foreground because nurses need to make a personal connection in order to be compassionate toward someone. Seven nurses
mentioned seeing patients as a person and making personal connections with patients as a change in themselves.

Some comments surrounded the fact that it is easy to think about patients in terms of their disease, the room number, or data on a chart, but after being a patient themselves the nurses acknowledge the humanity of their patients. Joanne made a comment that expressed what several of the nurses tried to articulate. She said,

I think it’s more personal. Before I really didn’t get involved with the patient as a person. Ok, like you walk around saying, “The heart in 12,” or, “The gallbladder in 6.” Or something like that, and I think since I had my experience, I tend to focus more on not so much “The heart in 6,” but Mr. Jones… Not so much going in because it’s a patient, but that it’s a person.

Joanne went on to say that acknowledging the patient as a person and working with that person is part of showing compassion. She said, “I acknowledge that you’re a person and that you have your own issues and we’ll work through them together to the extent that we can in this relationship, just shows the compassion.” Similarly, Natalie’s patient experience has made her realize that healthcare providers do not always see patients as people. She indicated that she believes some of her doctors do not think about her as a person, but more as a puzzle to be solved or a disease process. She said,

I think sometimes healthcare providers forget they are dealing with people and not just a number or a chart. I think they forget the human side of it… I think the minute you forget that you are talking about a human being, not a number, or a slide, or a test result I think you shouldn’t be in nursing.
Natalie, indicated that she makes a conscious effort not to think about her patients as a chart because she knows what it is like to be treated that way.

Others commented that the patient experience impacted their perception of patients as well. For example, Teresa said, “It’s helped a lot. It helped me recognize the patient as a person, and what their needs are.” Sara sees patients as people, and said, “I think afterwards now I think those patients have more, they’re more of a person to me now. They’re less textbook.” Previously Sara described her interactions with patients before her own experience as being “textbook,” which was describing an impersonal relationship.

In one of Savannah’s interviews, she discussed compassion in her practice. One of the changes she identified in herself is making a “person to person connection” or “spirit to spirit connection” with her patients. She said that making a personal connection is a part of compassion because the nurse must make a connection with a person in order to carry it out.

As these nurses indicated, the patient experience impacted their compassion in terms of how they perceive their patients. The nurses said that they see patients more as people now. Part of seeing patients as people is acknowledging that the patient is not a room number or disease on a chart. One nurse said that she now sees making person to person connections is part of being compassionate. Seeing patients as people is an example of moving compassion from the background to the foreground because part of compassion is first acknowledging another person and their suffering.
Realizing the Importance of Compassion

Another example of nurses moving compassion to the forefront of their practice is in their realization of the importance of compassion. Six of the nurses said in particular they were compassionate before their patient experience, but the experience triggered a new awareness of the importance of compassion toward patients. For instance, Dancer was one of the most vocal participants and said that her experience of being the recipient of compassion from a nurse gave her an epiphany in understanding how important compassion is. She stated,

I’ve always been compassionate but I didn’t connect the dots until that moment. Like, how much it really did mean. It was an “ah ha” moment… I am more conscious of it. I am more in tuned that if patients really are scared how much impact that makes. Before, I just did it because that was how I practiced. I am a hand holder. The impact was unbelievable to me when I was a patient. So I make sure that I do it.

Before her patient experience Dancer thought that compassion was important and carried it out in practice. However, being the recipient of compassion as a patient gave her a new understanding of how important compassion is to patients. She is now able to carry it out with greater intention as a result of her new understanding.

Natalie’s patient experience has made her aware that patients need a compassionate person providing care, because she said her doctors are more interested in the chart than the person that the chart represents. She said, “All the time they (the doctors) are playing with their charts and figuring out what is going on, there is a real person out there going through something. So that has made me a little more aware.”
this statement Natalie lamented that she is a real person who is going through a hard time in life, but some providers do not acknowledge this aspect of being a patient and give her support.

Joanne did not realize how important compassion and empathy were until she became a patient. She said,

I don’t think I realized how important compassion was. I think part of that is I think being a nurse or being in any position that we’re in caring for people, you have to have some empathy and some compassion. I just don’t think that I realized how much the patients need that and the nurse or doctor or whoever also needs it too.

Like the others, Shaneequa, and Hoku expressed a new understanding of the importance of compassion, but they expressed their thoughts in terms of a more complex or more personalized perspective of compassion that focuses more on their patients. For example, Shaneequa said with heart,

I’ve evolved in that compassion is understanding. Understanding where they are and where they want to be. Not what my agenda is, not what I think they should be doing, but where they are in their health or wants or needs, however you want to say that. So I think my compassion has gone from being superficial to a more in-depth look at compassion. It’s not just the presence of being there, it’s the presence of fully being there mentally and physically.

She explained that her patient experience gave her an understanding of the importance of trying to understand a patient’s problem from their perspective. This is more complex than her understanding of compassion before becoming a patient, which was simply
“addressing a patient’s comfort.” In addition, she spoke with conviction indicating that the importance of compassion has changed for her. Similarly, Hoku discussed her perception of compassion, and said that her understanding of compassion was learned from a combination of her many years as a nurse (over 35) and her experiences as a patient. She said,

I think compassion is caring. I think it is doing the little things, going the step beyond, having the follow through, accepting the patients, or people, in general wherever they are at, being able to put yourself in their place and understand their feelings, whether their feelings are positive or negative, being able to keep that professional demeanor when you are dealing with that totally, totally dirty patient who hasn’t had a bath for a year because they are homeless. But giving them that respect. I think respect and dignity tie into compassion. I am trying to think what else how would I define that. Just an overall nice person.

The attributes she mentioned are an accumulation of her experiences, including her patient experience, and what she believes are important aspects of compassionate care. Hoku said that as a younger nurse she understood compassion to be whatever her nursing instructors told her compassion was, but now personally realizes the importance of compassion in practice.

In summary, the nurses felt that they were compassionate before becoming a patient, but the patient experience brought a new understanding of compassion. Some specifically stated they did not understand how important it was until they became patients. Others showed that they understand how important it is by sharing a more complex or personal perspective of compassion.
Compassion is the Essence of Nursing

As the nurses discussed a movement of compassion to the foreground of their practice they not only said that it is important but began to identify compassion as being part of their identity as a nurse. Nine of the nurses indicated that they now consider compassion to be an integral or essential aspect of their practice. For example, Joanne said that her patient experience reminded her why she is a nurse, and that it cemented her belief that compassion is integral to nursing practice. She said that without compassion,

You end up becoming very cold and very much the task oriented person and I don’t feel like that is the essence of nursing is getting the task done. I think the essence of nursing is that you’re at the bedside and that you’re caring for these people and you’re compassionate in your care and I think having been a patient really kind of drove that home and said yeah you know kind of cemented that in my belief of what a nurse needs to do.

Here Joanne indicated that her patient experience confirmed her belief that compassion is important and began to see that compassion is the “essence” of nursing practice.

Similarly, Helen said that nursing is her “passion” and that compassion is part of who she is as a nurse. She said, “It’s my job. It’s my job. It’s what I became a nurse for. If you’re not compassionate then you shouldn’t be there… It’s just what I believe nursing is.”

Helen clearly believes that compassion is an integral part of nursing. Like Helen, Charo sees that compassion is an essential part of nursing. She said, “I would say compassion is absolutely an integral part of nursing practice. I mean, you can’t separate it from care. And I mean physical care of someone, or caring about someone.” Charo’s perception of compassion indicates that compassion involves not only physical care, but also being
involved personally by caring about the person. Hoku articulated her perception of
compassion and her nursing practice saying, “They’re the same thing. I mean, I look at it
as they are the same thing. I don’t think you can separate them…To be a professional
nurse you have to be compassionate.”

Some of the nurses indicated that compassion is a necessary part of nursing by
talking about satisfaction as a nurse, or longevity in the profession. The consensus was
that if nurse is not compassionate or if they do not develop compassion, a person will not
be happy or remain in the profession very long, thus indicating its necessity in nursing
practice. For example, Bekah said, “You can’t be a very good nurse if you don’t have
compassion, at least in my thinking. And I have known a few nurses who didn’t have the
compassion, and after a year or two of nursing they are out.” Helen has a similar
experience to Bekah and believes that those who lack compassion do not stay in the
profession long. She said, “A lot of them don’t last long in nursing. They end up leaving
and going into another career. If they are going to last they are going to be a good,
compassionate nurse.” Joanne echoes Bekah, and Helen’s comments and believes that to
be a happy and successful nurse, a person must possess compassion. She said,

You know I don’t know that I could do this job without having compassion. I
really don’t think that somebody would be happy as a nurse without being
compassionate… I really think that people need to have that as part of their
overall character to even—well to be a successful nurse.

Similarly, Natalie believes that compassion is necessary for being a nurse, and said,

I don’t know how you could be a nurse that deals with patients and families and
not be compassionate. Um, because I think the minute you forget that you are
talking about a human being, not a number, or a slide, or a test result I think you shouldn’t be in nursing. You don’t have that compassion for people.

This group agrees that compassion is important in the practice of nursing and that if it is not present or developed quickly a nurse will be unhappy in their work and very likely look for a different type of job.

Overall, participants made comments about their perception of compassion and its relationship to nursing practice. The nurses believe that not only is compassion important, but that it is an essential aspect of nursing practice and indicated that it is a part of their identity as a nurse.

**Putting Myself in Their Shoes**

Another example of the nurses moving compassion from the background to the foreground of practice is when they spoke of imagining what it is like to be the patient. Every nurse made comments such as “putting myself in their shoes,” “putting yourself in their shoes,” “understanding what they’re feeling,” or “understanding what they are going through.” The nurses said that they are more likely to imagine themselves in a patient’s position after the patient experience than they did before. For example Teresa said that before her experience she did not necessarily think about things from a patient’s perspective, but now things are different and said, “Now I try to see them as me. When you’re in nursing school you’re taught to imagine they’re your grandmother, your mom, or your dad. I try to see them as me.”

The overall message that the nurses tried to convey is that when they put themselves in another person’s shoes they are trying to personally understand a situation from the patient’s perspective. For instance, Natalie made a comment that essentially
summarized what the group verbalized. She said that putting yourself in another person’s shoes involves, “Thinking of how it must feel, imagining the thoughts, the emotions and all those responses that go with it. Trying to imagine what it is like to be that other person.” This shows that she actively makes a personal connection with patients and their situations in order to understand them. The other nurses’ comments are similar in that they show an active attempt to make a personal connection. For example, Dancer said that putting yourself in someone else’s shoes means “…being able to understand what someone is going through at that point in time. You have to try and understand their point of view at that moment in time.” Similarly Shaneequa said, “It’s not just understanding or wanting to understand what the person is going through, but also looking forward to what they could possibly be experiencing.”

On first glance, the nurses’ comments reflect the concept of empathy because they generally describe feeling the way another person feels, or being able to understand what the other person is experiencing. However, the nurses said that it is necessary for them to put themselves in another person’s shoes in order to understand the needs of the person, and give better, more compassionate care. For example, Natalie said that putting herself in another person’s shoes helps her to be more compassionate. She said,

If I put myself in their place and try to think and feel and understand where they are coming from, I think it allows me to be more caring and compassionate; and helps because I can anticipate the things that they are going through. So I think that makes it easier to identify ways to comfort.

In other words, by understanding what a person is going through, Natalie is able to understand how she can help her patients and carry out compassion toward them. Like
Natalie, Savannah believes that putting herself in her patients’ shoes helps her to be more compassionate. She mentioned several times that she tries to anticipate and meet patients’ needs ahead of time now that she has been a patient, and begins the process by putting herself in her patients’ shoes. She said,

I think mostly I try to put myself in their shoes. But I try to think of what questions they may have, you know for instance for their diagnosis. I try to look from their perspective and think, “Well what questions would they have?”

Savannah said that putting herself in patients’ shoes enhances her compassion because it helps her to “…understand patients better, as well as to better treat them and provide better care.” Similar to Savannah and Natalie, Teresa uses putting herself in someone else’s shoes to anticipate patients’ needs and be compassionate toward them. She said

I try to put myself in the patient’s shoes… understanding what they’re going through, just caring for them and seeing them as a person. And understanding what they’re going through and how it might affect them, and understanding, “Okay what might they need? How might it affect them if they don’t have it?”

In this comment Teresa said that she tries to understand what the person is going through and care for them as a person. She then takes it a step farther and tries to anticipate what the person’s needs might be in order to help them. Like the others, Joanne said that she is much more likely to put herself in her patients’ shoes now that she has been a patient, and discussed it in reference to carrying out compassion in her practice. When asked, she explained that putting herself in a patient’s shoes involves,

…Understanding what they’re feeling and where they’re coming from and then you know kind of internalizing that and say, “Okay I was not in your exact
situation but I can understand what you’re feeling.” Not saying that I’m feeling
exactly what you’re feeling, but that I can understand it and move on from there.

Joanne mentioned that part of putting herself in another person’s shoes involves an
internal or personal understanding of what a person is experiencing. She said later that
being able to understand how a person might be feeling helps her to be more personal
with patients, and they seem to respond to her better as a result.

The nurses frequently mentioned “putting myself in their shoes” or similar
phrases; and do this to personally connect with and understand what patients are
experiencing. This is an active process because the nurses indicated that they
purposefully think about, or imagine what it might be like for the other person. In
addition, their comments have similarities to the concept of empathy because the nurses
are attempting to understand the experiences of another person. However, they indicated
that this is a necessary part of compassion because this is what allows them to better
understand patients, identify their needs, and take action to address the needs. Thus,
putting themselves in their patients’ shoes is helpful in carrying out compassion in
practice.

Changes in Behavior as a Result of Compassion in the Foreground

As the nurses shared how compassion moved to the foreground their practice they
gave examples of how their behaviors changed as an outward reflection of this. The
nurses gave many examples of ways that their behaviors changed, and linked the changes
in these behaviors with their concern for providing compassionate care. The most
prevalent examples of changes in actions are presented in this section. The changes
include: relating to patients better, taking more time with patients, advocating for
patients, improved communication, and considering family members. Each of these is discussed below.

**Relating to Patients Better**

While talking about their change in compassion, at least half of the nurses indicated that they are better at relating to patients, or that they are more empathetic to what a patient is experiencing. Sometimes the nurses referred to specific aspects of the patient experience that they are now able to relate to. For example, Sara gave an example of relating to a patient who expressed feeling trapped in the tiny hospital rooms. Sara felt trapped when she was in a hospital room as well and said,

You know, just having that feeling of like “I know.” I was able to talk to my patient and I said “I know what that’s like. I was just up there you know…” So now I was able to relate to the patient and say, “Hey I understand what you went through.”

Sara said that because she was able to relate to the patient, she was able to help the patient feel better. She feels that because of this ability to understand her patients, she has more to offer. She said, “I feel like I got more to give to them because I’m like, ‘I know where you’ve been.’” Similarly, Joanne gave a specific example of being able to relate to a patient. She recalled that a day or two before our interview, she worked with a patient who was unable to speak because he had just suffered a stroke. She said,

I was telling him, “I didn’t have an experience like you. But I was in a position where I couldn’t talk and getting my needs known was very difficult.” And I said, “I understand it’s very frustrating because I felt that way…It’s just like, “Let’s take our time and we’ll work with you. You tell me what you need me to do to
help you. I don’t want to come in here and just do things.” I said, “Because I know that feeling, of people just coming in and doing things to you and don’t tell you what they’re doing. And they just do it and leave.” He seemed to settle down a little bit. He still got frustrated but I think he was more able to take it slower because I think he felt like I was understanding part of where he was coming from.

Joanne was able to relate to this patient because she had been frustrated as a patient who could not speak to her providers.

Others gave more general ways in which they relate to patients now that they have been patients. For example Savannah did not give a specific example of relating to patients, but said that in general she is able to relate to patients. She said,

I think I understand they have fears and concerns and just anxiety and I think I pick up on that so that I can be more compassionate, more understanding of what they’re going through. You know I may not know exactly what they’re going through because I probably didn’t have that same experience but I still had an experience of being a patient and just that general fear of the unknown and you know I think I just try to listen to their fears and concerns now more than I did before.

In Savannah’s case, she relates to patients general fear of the unknown and is more willing to listen to their concerns as a result. Similarly, Natalie is able to relate to the general fears and concerns of patients now that she has been a patient. She said,

I also know now what it is like to, you know, I’ve had to call results to patients.

Now I know what it is like to be the one having anxiety over the test, or worrying
what it is, or waiting to hear the results. So, I think I am a little more sensitive to what they are going through waiting.

Natalie has had a lot of tests that she has worried over the results, and can relate to the way patients may be feeling.

After the patient experience, the nurses said that they are able to relate to patients better. They understand the physical aspects of being a patient such as experiencing pain, and the emotional aspects such as being frustrated or afraid. When they relate to the patients, they are able to alter their interactions to help the patients they are working with.

**Taking More Time with Patients**

Six of the nurses talked about taking more time with patients after their patient experience, which involves spending more time in patients’ rooms and interacting with them. Some of the nurses described how they were more likely to rush in and out of patients’ rooms before their patient experience, but now they do not rush as much. For example, Sara is more likely to spend time with patients, and said,

I do find that I see them changing because I think I’m taking more time with them and I’m not just trying to be so quick about to get in and get out of the room as quickly as I can. You know it just kind of slowed me down a little, little bit.

Similarly, Shaneequa said she spends more time with patients, and they are more aware as a result. She explained,

I make a strong effort in the ED, we usually always have stools in the room. So if nobody is sitting on it I will gladly pull that stool up and I sit there when I push my meds. I don’t stand over the patient you know. I’ll say, “Hey, I need to sit, it’s going to take me a couple of minutes till you get some medication. I have to give
it to you slowly. This is what it is.” As I’m talking to them and as I’m starting to give it, I sit down. That’s when I say, “Do you have any questions for me. Do you understand what we’re doing and why we’re doing it?” So I think my explanations have gotten better. It’s not just come in, “Here’s your pain medicine and I’ll check in on you in a little bit to be sure it worked.” I don’t rush as much. I don’t have to do everything, but if you do it right the first time you don’t have to rush.

Shaneequa’s explanation shows that she takes the time to sit down next to patients, and begin a conversation with them. As she described these interactions, her tone of voice and body language showed a relaxed way of interacting with patients.

Natalie shared that her patient experience has helped her to slow down when interacting with patients and help them to understand what is going on. Her time with patients is noticed by others. She said, “Yeah, and I get in trouble for it all the time. (Laughs) Because I ‘talk too much’ to my patients.” It is important to point out that the comment from her co-workers is an example of healthcare culture. The culture in many healthcare arenas is that of being extremely busy, and not having time to talk to patients. Those who do take time to talk to patients are often seen as spending too much time with patients. Thus there is little incentive to spend time with patients.

**Advocating for Patients**

As the nurses talked about compassion in their practice after the patient experience seven indicated that they are better patient advocates. Patient advocacy is generally an action that nurses take to make sure that a patient gets something that they need in their care such as adequate pain control, proper home care services etc. Nurses
learn in school that they are supposed to be patient advocates as part of their professional role. However, patient advocacy occurs at varying degrees, and does not always happen. The participants indicated that after their patient experience, they have a greater appreciation for patient advocacy and are more likely to advocate for their patients as part of carrying out compassion in their practice. For example, Helen said that during one of her hospital experiences, she had heart trouble, and felt that she received substandard care because she was a woman. After the experience she became a public advocate for better healthcare for women. She explained.

How it helped me was making sure that that next woman that came in with chest pain was treated the same as a man. It just made me more of a, I don’t know, fanatic about it. I did. I became fanatical about it because I saw firsthand there could be a difference. They have to start treating women like men. If that had been a man in that bed I felt he (the physician) would have been in there taking care of it. And, you know, I did see after that things were a tiny bit better.

Helen explained that she was later interviewed by a local news station about heart disease in women. She told them about her personal experience and her nursing experience and advocated for more equal treatment of women with heart disease. Helen’s experiences inspired her to take patient advocacy to the hospital level to make patient care changes, and also the community level when she consented to the news interview.

Other nurses said that they are more likely to advocate for patients now. Their patient advocacy tends to focus on individual patients and their direct patient care. Sara said that she is more likely to question physician orders to make sure that it is not something that will harm patients because when she was sick, the resident meant well,
but ordered too much IV fluid which made her respiratory problem worse. She said, “I just do not just go ahead and give IV fluids. Let me question this before I go ahead and do it. I take it more gently and talk it over with the doctors before we just start doing things.” Sara advocates for patients by making sure that she does not give too much IV fluid, and make their situation worse than it already is. Similarly, Hoku shared how she advocated for a patient with nerve damage who had decreased sensation in his foot, but was still able to feel pain with dressing changes. She explained,

He is having deep pain and it’s like we need to get something on board for pain. And when I had been over to see him, the resident had blown me off… And so I literally tracked down Dr. S and he was really cool. He said, “Why didn’t the resident order that?” I said, “Because the resident doesn’t believe me. But this guy’s having some pain. He definitely needs something to take the edge off.”

Hoku shared additional stories about patient advocacy, and said that she is more of a patient advocate because a nurse advocated for her when she was a patient.

As shown, several of the nurses reported that they are better patient advocates as a result of their patient experience. Most nurses described how they advocate for individual patients, and Helen shared how she advocates for a group of patients, namely women with heart disease.

**Improved Communication**

Ten of the nurses identified that communication in their practice changed after the patient experience because their patient experiences helped them to understand the impact that communication has on a patient. The nurses said they improved their communication by giving better explanations to patients, giving better patient education,
and updating patients and families more frequently. For example, Joanne is one nurse who said that after her patient experience she improved her explanations to patients. She said,

I’m very aware of explaining things to patients even if they are sedated and intubated. I don’t care. You know, “We’re going to turn you now.” Or, “We’re going to put your head up.” Or, “We’re going to put your head down.” Or whatever. And I think my experience as a patient really has brought that to the forefront when I do things. I always try to explain to them that it’s going to get better.

For Joanne, explaining things has become more important because she understands how important it is for providers to communicate with patients. She can recall when providers did not communicate with her, and it bothered her. She said, “…That was one thing when I was intubated (pause) people didn’t tend to talk to me. They tended to talk over me. And I try not to do that, because it’s very frustrating, you know.”

During our interviews Shaneequa said that communication is more important to her now, and she gives better explanations and updates to patients. Her change in communication has been noticed by the managers in the ER. She explained,

One of the things that managers have to do is go in to patients rooms and they kind of spot check because we’re supposed to be doing hourly rounding, even in the ED. And one of the questions they ask is, “Do you know what you’re waiting for? Do you know what your plan of care is? Do you know what the next step is?” I’ve had the ER management comment and say, “Shaneequa your patients know what they’re waiting for. They can tell me that, ‘Oh none of my labs were back. 
Oh I had a CAT scan and the radiologist didn’t read it yet.’” You know she’s like (excited tone), “I walk in and they know!” I think it’s because of that, trying to make sure they are as informed as possible with the care that they’re getting. Shaneequa indicated that she really appreciated staff who kept her informed when she was a patient, and recalled a particular nurse who was good at updating her. She said, “So she (the nurse) was good about updating my family and she was good about saying, ‘I’ve called this person.’ And, ‘I’ve called that person.’ You know, ‘I’ve paged so and so.’” Shaneequa appreciated the effort and communication of the nurse because at the time she was waiting for a surgery, but things were not moving along. She is able to understand that her patients appreciate knowing what is going on behind the scenes.

Teresa said that her communication has improved in regards to her patient teaching and discharge instructions. She explained,

I’ve gotten better at like teaching, better at my discharges. Before I was like (nonchalant tone), “Here’s some information on pneumonia, follow up with your family doctor, come back if you need us, blah, blah, blah.” Well now I give them, “Okay. Yes you got pneumonia.” And I explain, “It’s important to take all your antibiotics because if you don’t take them etc.” And why it’s important to get rest, drink fluids. I try to add some extra things. I try to like verbalize more and educate more that way instead of just assuming that they know.

Teresa sees this as being important because in her own patient experience, she does not always receive the best instructions. She said,

Because I don’t know it all, and I’m a nurse. And you know I get told stuff, and I don’t get good directions. Like if I have a PET scan, and if someone doesn’t tell
me, and a lot of them don’t, they don’t tell you to make sure you drink lots of fluids after all the contrasts. And you know it’s something little, but I know that. Like little things; like if someone gets a CAT scan I tell them. Because they don’t know that stuff.

By giving better education to her patients, Teresa believes she can help them in their illness. She used the example of PET and CAT scans, and the “contrasts” that are part of the tests. She knows that the radioactive contrast can cause kidney failure, and drinking lots of fluids can help to flush the chemical out of the body to help prevent this. Providers do not always tell her this information; therefore she tries to help her patients by sharing the information. Like Teresa, Helen has changed her communication as a result of her patient experience, and takes care when providing patient education. To recall, Helen verbalized displeasure with the way providers have communicated with her. In reference to a time when a doctor did not talk to her she said, “I got into a lot more patient education after that.” Currently, she works with patients who have diabetes and does a lot of patient teaching, and makes sure there is nothing that will affect a patient’s ability to understand what she is talking about. She explained,

I know it as soon as I walk in and if they can’t really focus with what I am doing, I start talking to them and say, “You are going for a test today, right?” And they’ll say “Yes.” And I’ll say, “Tell me what you know about that test.” “Well, nobody told me about the test” they’ll say. So I sit down and will explain it to them. It’s not really what I am supposed to be doing, but it is what I’m supposed to be doing because I’m a nurse. And so I’ll sit down, and I’ll tell them about the test they are going to have. “What are your other concerns? What else do you need to know
about that is going to make you comfortable?” And then we get into the Diabetes part.

Helen understands that patients have a lot of concerns, and she knows that her patient education will not be effective if the person is more concerned about something else because she has been in that situation as a patient.

The nurses are more cognizant of their communication and make an effort to be better communicators as part of carrying out compassion in their practice. They are more likely to explain things to patients, and take more time in providing patient education.

Consider Family Members

Seven of the nurses mentioned that their perspective changed in regards to family members, and indicated that now they consider family members as part of their nursing care because they understand how important family is to patients. Caring for family members was described differently for each nurse, and their examples are below.

Teresa said that her patient experience has made her realize the importance of families in her nursing care, and now includes them when taking care of patients. She said,

I’ve learned since to respect the families more… I think it’s made me more mindful coming back from tests. My husband being kind of ignored when I was having tests done, or procedures done, or him wanting to hear how I’m doing. It’s made me myself, be more mindful of the families; of how much the patient wants to make sure their kids or husband sitting out there in the waiting room can hurry up and get back to them and know that they’re okay. So just little things that I’ve learned to try to help families, and try to include the spouse.
In Teresa’s experience her husband was ignored sometimes. Therefore she is much more careful to acknowledge family and realizes that patients and families want to be together. Similarly, Joanne realized the importance of families during her patient experience and gave some examples of how she takes extra steps to include them. She said,

I like to involve the families. And if they’re willing, offer them options to help the patient. Give them an idea of what the plan is. Because, you know I remember in the ER there was like no communication, with me or my mom.”

As a result of Joanne’s experience she tries to help the patient and families feel better by trying to involve family in the patient’s care. She experienced what it is like to be a patient and need the support of family members, which has affected her interpretation of visiting hours in the ICU. She explained,

I also tell the families, I say, “The visiting hours are not set in stone.” You know, “If you have a job that you work and you don’t get off until 8:30, and you want to come in and see your loved one. Give us a call, come on in, it’s not a problem.”

You know, I tend not to be so overly strict with that. You know, just because I know it was comfort to me to have somebody at my bedside.

In this Joanne shows compassion for the distress that strict visiting hours can cause. It is quite common for ICU’s to have strict visiting hours, and some nurses can be very forceful with families in adhering to visiting hours.

Bekah is somewhat different in that she connects compassion with demonstrating strength and confidence as a nurse to the family. She explained,

I do what needs to be done for my patients. I don’t get rattled very easily. And when there is a bad situation, what is best, is to keep it all under control until later.
And that includes, if you keep the situation under control that compassion, that sympathy extends into the family because they can see that you are working through things, that you seem to know what you are doing, and that exudes a confidence to them. It keeps them (reassured tone), “Okay, this nurse, she knows what she is doing.”

In this explanation, Bekah is referring to times in the ICU when patients are unstable and many things need to be done quickly for the patient. Sometimes families are present when the healthcare team is working at a very fast pace to save a patient. When a family thinks that the nurse “knows what she is doing” they are able to relax a little bit, and know that their loved one is in good hands. To Bekah, this is part of compassion, because it gives them at least some reassurance about their loved one.

As compassion moved to the foreground of the nurses’ practice one of the outward changes involves considering families. The nurses in the examples above are more likely to pay attention to families, be concerned about families, and include families in patient care.

**Developing and Keeping Compassion in the Foreground**

As the nurses discussed their patient experiences and compassion moving to the foreground of their practice, they discussed several factors beyond the patient experience that have helped to move compassion to the foreground of their practice and keep it there. The nurses indicated that their memories of the patient experience continue to impact their practice. In addition the nurses firmly believe that compassion comes with experience, whether it is the patient experience, life experience or professional experience. They said that part of developing compassion involves watching the
examples of compassionate role models. Last, some of the nurses discussed self-reflection as a contributing force to developing compassion. Each of these themes is discussed below.

**Powerful Memories: Remembering the Patient Experience**

All of nurses referred to their memories of being a patient in relation to compassion in their practice now. Sometimes the nurses had a specific memory that was related to a current situation in their professional practice that encourages them to be compassionate. For example, Joanne stated outright “I remember” a particular experience several times and indicated that she carries out a more compassionate response to patients as a result. She said, “The whole thing of loss of control. That’s one thing I really remember.” Joanne remembers this when working with ICU patients who have very little control and tries to give them some level of control. In addition, Joanne remembers not being treated like a person when she was on the ventilator and said, “I try to remember that they have feelings too. And even if they’re intubated and sedated, they’re still people in there.” Overall, Joanne’s memory of her experience continues to impact her, and she was probably the most vocal participant regarding her memories as a patient. She explained,

I think it’s always gonna be there because it was VERY memorable. And I think that as I go on and get farther away from it, if I tend to get into the whole cynical idea about things, then I think that just by remembering it, that I’ll remember all the good things that came out of it in my practice… And again thinking about the experience. Things that happened and how it went. Some days it seems like yesterday that it happened. So it will stay with me.
Here she indicated that she may experience some of the “cynical” attitude that nurses can have, but if her memory of the patient experience stays with her, she will continue to have a positive change in her practice.

Other nurses did not necessarily state “I remember,” but the context of their conversation indicated that their interaction with a patient was related to a memory of their own patient experience. For example, Sara works in the ER and takes care of patients who have similar problems to her. She said, “I’m reliving it with all these people…Every time I see even a little bit of it I always think, “Okay this is like my case, this is me again and I don’t want you to get where I was.” In Sara’s job, she is frequently reminded of her particular illness and how critically ill a person can become if they do not receive appropriate care, and strives to help her patients avoid the situation that she experienced.

Similarly, Savannah particularly remembers her fears as a patient, and mentioned addressing patient fears more than once in our interviews. When working with patients she asks herself, “What experience or what knowledge do I have that I can impart to them about that? And is there any way that I can help alleviate their fears? Because I’ve experienced that personally and professionally.” Savannah focuses on minimizing patients’ fears because it was such a significant aspect of her patient experience, and she remembers what it is like to have “fear of the unknown.”

Teresa’s patient experience is on-going because she has a chronic illness, but she said takes the time to remember what she appreciates in the care she receives from nurses, and incorporates that into her practice. She said, “It’s just for me, it’s just the remembering you know, taking the time to talk, and taking the time to act like they’re a
person.” This statement reflects her earlier sentiments of appreciating nurses who talk to her. She now remembers this and does the same.

Overall, the nurses often remember their patient experiences. Sometimes a specific memory, such as being in the ER, comes to mind. Other times, the nurses remember the fears associated with being a patient. When the nurses recalled these memories, they mentioned the changes in professional practice that have occurred because of the experiences. They adjusted their practice to help patients have better experiences.

Compassion Comes with Experience

As the nurses spoke about compassion being in the foreground of their practice, they strongly felt that compassion was influenced by multiple experiences. Some of them felt that the patient experience was integral to the change. Others commented that compassion is impacted by all kinds of experiences whether the experiences are related to professional work or life experiences in general.

Several of the nurses found the patient experience to be essential in bringing compassion to the foreground of their practice. For example, Savannah indicated that her patient experience was necessary in order for her to develop a different perception of compassion. She said that without her patient experience, “I don’t really think I would eventually find that compassion in my career.” To Savannah, her patient experience played a key role in her current perception of compassion. Similarly, Teresa stated that her patient experience was a necessary aspect of her change in perspective. She commented,
I probably would have just been doing what I had always done. I would have you know with time gotten a little softer maybe. I don’t know… I mean you see more, and maybe if this hadn’t happened to me maybe I’d be in the same boat. Probably. Life experiences that I, I’ve aged and I’ve seen a lot. And now with this; like, it’s helped me.

Teresa hints that life experiences can contribute to change but that her patient experience has had a bigger impact in her change. In addition, Shaneequa stated that her patient experience caused her to change her perception of compassion. She said,

I think in this situation I didn’t have a choice (to be a patient). It was a last resort. So that did change who I was and who I am. I think just experiencing it all from the other side of the bed.

Shaneequa stated that her experience “from the other side of the bed” triggered her change.

As shown, the nurses’ patient experiences were an important contribution to their understanding of compassion. However, several said that both their life experiences and professional nursing experiences contributed to their current perception of compassion and keeping it in the foreground of practice. For example, Natalie worked in a non-nursing field before entering the nursing profession, and had life experiences that inspired her to become a nurse. Natalie believes that her patient experience has contributed to her understanding of compassion, but also sees her development of compassion as a natural part of her human growth. She said,

I think it is through *experience and maturity* too. I mean, I think that probably, you know, a 20 year old, versus a 40 year old, versus a 60 year old have probably
seen experiences and the interactions and the trials that you go through either as a nurse or as a person develop your ability to be compassionate.

Natalie identified in our interviews that she was not developmentally ready to be a nurse in her early 20’s. She said, “I think I needed life to get me to where I was so I could appreciate it.”

Bekah believes that compassion has changed more so due to her experience as a nurse than her patient experience. As a reminder, Bekah has been a nurse for over 30 years, and has become a patient only in the last five to six years. Therefore, she believes that while her patient experience has been extremely significant, she had a multitude of personal and professional experiences prior that also influenced her development of compassion. She said,

As time goes by you have different experiences that teach you how to be compassionate. Your compassion has to be something that is always ever evolving… As you grow as a nurse in general, your compassion and empathy and sympathy has to change because you are involved in it in a long term basis.

Bekah mentioned that had she not had compassion, and continued to develop it, she would not have remained working as a critical care nurse for 30 years.

Hoku said that compassion changes as a result of “evolving in the profession,” and this evolution is brought about by experiences. She said,

I guess what the big difference was that I realized in the continuum of care I evolved. But to actually give good care, to be a compassionate person and to carry it from work to home to everything that you do, that had to evolve. And, by evolving, you can’t evolve without experience because you don’t have the pieces.
Hoku said that in addition to her patient experience, “experience at work” and “life experience” contribute to this evolution. Similarly, Helen believes that compassion in her practice has “evolved” over the years. She said, “I think the more experience you have in nursing I think you change… It’s just that I have evolved into a different type of a nurse as the years have gone on.” She believes that both her patient experiences and nursing experiences have impacted compassion in her practice. Shaneequa described something akin to an evolution of compassion in practice. She said,

I think your compassion grows with your practice. I think compassion is a learned behavior through multiple encounters both positive and negative. I don’t think it’s something you can learn overnight and I think it grows with experience.

Rather than using the word evolution, Shaneequa said that compassion “grows.” Similarly, Teresa referred to compassion as something that grows. She stated, “I think I’ve definitely changed from even the first five years. I’ve changed a lot. I mean every day I think we’re growing and learning.”

As discussed, these nurses said that patient, professional, and personal experiences contributed to their current understanding of compassion. Several of them said that the patient experience was either essential or very significant in their understanding of compassion. However, they said professional and life experiences contribute to their development of compassion. Several nurses mentioned that their compassion continues to grow or evolve which helps them to keep compassion in the foreground. In summary, the group felt strongly that experience, whether it be life experience or patient experience, has the potential to impact the growth and development of compassion. This needs to be mentioned in relation to the backward and forward
concept of Connoley and Clandinin’s (2000) perception of narrative. Even though this is the thematic analysis, the nurses’ comments show that they believe in the development of compassion over a long period of time, and it seems to correspond with both their patient experience and life experiences.

**Compassionate Role Models Impact Practice**

While the nurses said that their patient experience and overall life experiences were important contributors to compassion in their practice, four also said that witnessing other nurses role model compassion is an important aspect of developing compassion, and contributes to keeping compassion in the foreground.

Two nurses said that role models as early nurses can serve as a foundation to developing compassion. For example, Joanne indicated that new nurses develop compassion when they see it being role modeled in more experienced nurses. She said,

I think that it’s up to the more experienced nurses to kind of show them (new nurses) what compassion is. Not necessarily saying in their orientation, “Okay this is what compassion is, and let me show you.” Not like you do, “This is how you draw blood from an A-line.” But just in your general demeanor and how you practice nursing… Essentially showing them in your practice and how you treat patients and how you deal with things.

She said that role modeling compassion shows other nurses that it is and important and expected part of professional practice.

Hoku and Helen more clearly related compassionate role models with their personal growth of compassion. The participant that expressed this most was Hoku, who spent a lot of time discussing Maria, one of the nurses who cared for her when she had a
broken ankle. Hoku stated that Maria role modeled compassion, which inspired Hoku to “get to know her better” and learn what made Maria so special. She said,

Like I said, I got to know Maria a lot better after that. Because I spent more time as an educator, I went down and it’s like, “I’ve got to know how she does this! What is it about Maria?”…How do you teach someone to be nice? You role model it. So that’s the difference with Maria. She was just an excellent role model.

Hoku’s personal practice was impacted because of the compassionate role model that Maria provided and encouraged her to bring compassion to the foreground of her practice.

Helen’s professional practice and perception of compassion has not only been influenced by her patient experience, but also her exposure to compassionate role models. She said,

I mean when you’re a child you see people and you see what you’re doing and use compassion as a young nurse, as a student nurse. I mean you see other nurses. I told people that I wanted to be like them. You know, I’d see maybe a nurse that I would just think that it was a wonderful nurse. I thought she was very compassionate, you know, she was very caring, she was very knowledgeable. And I would think to myself, “This is what I want to be like. I want to be that type of a person; I want to be that type of a nurse.” That’s what I did over the years is try to make myself more like those people that I saw and that I experienced either their compassion or I watched them as they were showing compassion towards
Helen’s comments show that she began to bring compassion to the foreground of her practice early in her career.

Some nurses believe that their perception of compassion was not only impacted by their patient experience, but also exposure to role models. Some mentioned that compassionate role models in general contribute to the development of compassion in the nursing profession. Others mentioned specific nurses during their patient experience that impacted compassion in their practice.

**Self-reflection Enhances Compassion**

Some of the nurses demonstrated that self-reflection has contributed to keeping compassion in the foreground of their practice. Most of them reflected on their patient experience, compared it with their professional practice, and changed as a result. At least one nurse mentioned a reflection on her life and previous career in the reflective process.

Sometimes the nurses’ reflections involved how compassion in the nurses’ practice has changed as a result of the patient experience, and is continuing to change, thus keeping compassion in the foreground of practice. For example, Sara stated that she thinks about her patient experience every day, and her practice continues to change as a result. She said,

I thought about being a patient, and how that would have affected me and I’m sure even now I mean I still to this day have conversations every day about when I was a patient. …It’s been a couple months out and it’s changing me and as I see these patients come in who are sick. You know it’s continuing to change in the
way I do things or sometimes I’m like, “Oh I should have done this better.” You know, “I should have been a little more patient.”

In this comment Sara demonstrated that she not only reflects on her patient experience, but she also reflects on the way she interacts with patients and what she can do to be better at providing care.

Hoku demonstrated self-reflection in relation to her patient experience in two ways. She said that she spent a lot of time reflecting on the way she was treated by staff members when she had a car accident. She even wrote a paper for a master’s degree course as part of her reflection. She said,

I remember I wrote my paper about the lack of the standard of care. But when I was writing my paper and I remember I went back and read it was like ‘Oh my heavens. I am also talking about the lack of compassion.

Hoku said that she thought about her own practice after that and used it as an example of how she did not want to practice as a nurse. In addition, Hoku reflected on the behavior that Maria exhibited when she broke her ankle. As a result, she thought about her own professional practice, and said, “I really thought about Maria a long time. I became much more aware of my own practice after that point.”

Unlike the others Natalie discussed that before becoming a nurse, she engaged in self-reflection in regards to her previous career and overall happiness with life. Her self-reflection helped her to decide to enter nursing. She said that during her 20’s her career and life experiences left her feeling “unfulfilled” and “searching.” She said,

And then after I kind of went out and tried all that (the other career), and I found out it wasn’t as fulfilling as it was supposed to be; then it’s kind of like, “How
about I look and see what I can do with my life, my talent.” Instead of “What does life have to offer me and what can I go out and get?” I think life experience turned me around to look for a job where I could do something for people instead of seeing what life could do for me…I think 9/11 really encouraged me to face it, and, “Is anything you’re doing here worthwhile? If you were to go help them, the people in New York right now, what would you know and how would you do it?” And that’s when I thought, “You know, I need a new direction.”

Natalie took the time to reflect on her life and think about what really mattered to her. Ultimately she said that she wanted a career that would allow her to “make a difference” and “make personal connections.” Natalie’s self-reflection helped her to identify that personal connections are important to her, which has played a part in bringing compassion to the foreground in her practice in conjunction with her patient experience.

This section shows several ways that contribute to keeping compassion to the foreground of practice. The ways that they keep compassion in the foreground is by remembering the patient experience, and having other life or professional experiences that help them develop compassion. The nurses said that role modeling helps them to see compassion in action and encourage its development. Last, some nurses demonstrated that they engage in self-reflection which contributes to bringing compassion to the foreground.

**Chapter Summary**

This chapter examined the similarities among the nurses’ patient experiences and their perspective of compassion. When examining the narratives as a group, they shared a number of similarities in their patient experiences. They experienced a number of strong
emotions such as fear, anger toward providers, frustration, and loss of control. Nurses shared common interactions with providers such as mean treatment, being treated with a lack of caring, and poor communication. Several nurses shared examples of compassionate care from healthcare providers. The nurses discussed not only their memorable patient experiences, but also what compassion meant to them before and after the patient experience. Before the patient experience nurses described practice that was task oriented and impersonal relationships with patients that showed compassion being in the background. After the patient experience the nurses described a different perspective of how important compassion is in practice and several indicated that compassion and their professional practice are intertwined. The nurses said that they began to see patients as people, and many discussed that now “I put myself in their shoes.” Doing this allows the nurses to make more personal connections with patients and helps them deliver more compassionate care. In addition to describing a change in perspective the nurses gave a number of examples of outwardly compassionate actions that they carry out in practice now. They describe being able to relate to patients more, taking more time with patients, advocating, improved communication, and a new consideration of family members. In the last major theme, the participants discussed several ways that help to bring compassion to the foreground of their practice, and help to keep it there. They said that powerful patient memories remind them of what it is like to be a patient. The nurses said that compassion is developed through experiences including the patient experience, professional experience, and life experience. Compassionate role models were mentioned by several nurses as a way to see compassion in other nurses’ practice and emulate in
their own practice. Last, some nurses reflected on their practice as part of bringing compassion to the foreground.
Chapter 6

DISCUSSION

The purpose of this study was to understand how nurses who become patients learn compassion toward patients in their profession, and examine the role of empathy in the process of learning compassion. The following research questions helped to guide the study: What is the process that nurses go through while learning compassion? What aspects of the patient experience contribute to nurses learning compassion? How do nurses experience empathy as part of learning compassion? Findings of the data collection were presented in the narrative analysis chapter, and thematic analysis chapter. This chapter presents discussion of relevant findings in relationship to the literature and theoretical framework grounding the study, followed by implications for practice, limitations and suggestions for future research.

Discussion of Findings

This section presents relevant findings pertaining to nurses-as-patients and compassion. The most relevant findings when compared with the current body of literature involve the nurses’ observations of: compassion after the patient experience, factors that impact the development of compassion, impact of emotions on compassion, and impact of relationships with providers on compassion.

Compassion after the Patient Experience

This study sought to reveal the nurses’ perceptions of compassion in their practice after the patient experience so that a better understanding of how nurses learn compassion
can be achieved. There are several observations nurses in this study made that can add to the current body of literature. Nurses identified that a change in compassion involved a greater awareness and intention with compassion in their practice, a more relational focus of compassion, and that the inner changes of compassion resulted in outward changes in actions.

The literature review indicated that nurses who become patients reported a change in compassion or compassionate behaviors after the patient experience (Cotter, 1990; Demarco, Picard, & Agretelis, 2004; Harker, 2000; Jones, 2002; Williams, 1997). However, they do not discuss what the nurses’ compassion was like before the patient experience, and simply report that a change occurred or that nurses said they were “more compassionate” (Gillies, Child, & Biordi, 1993; Kempainen, Bartels, and McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004). This study allowed nurses to talk about compassion in their practice before and after their patient experience and examined their comments. Nurses were like those in the literature review, saying that they saw a change in their compassion. One of the changes that the nurses reported was more awareness and active involvement in providing compassionate care after the patient experience. This awareness and involvement is evident in the form of having greater intention when carrying out compassion and a realization that compassion is important in practice. For example, Dancer said that she is more aware of what compassion means to patients and is much more conscious of being compassionate toward her patients. Joanne commented that she was unaware of how important compassion was, but now sees it as an integral part of her professional practice. It is possible that having a greater awareness and integration of compassion in practice is what nurses referred to in previous research.
as being “more compassionate” (Gillies, Child, & Biordi, 1993; Kempainen, Bartels, and McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004).

Another change brought to light in this study is that nurses discussed the most significant change involved a more relational perception of compassion. Literature addressing compassion points out patients want compassionate care to involve personal connections between providers and patients (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Attree, 2001; Graber & Mitcham, 2004; Halldorsdottir & Hamrin, 1997; Lindholm & Eriksson, 2004; Perry, 2009; Walker, 2009). These connections are made through the provider being attentive, willing to communicate with and be open with patients, and spend time with them (Arman et al, 2004; Attree, 2001; Graber & Mitcham, 2004; Perry, 2009; van der Cingel, 2011; Weiss, Malone, Merighi & Benner, 2009). Some of the themes in this study echo these attributes of compassion such as taking time with patients, and improved communication. However this study goes further and brings to light that a relational aspect of compassion was the most significant change for nurses. This relational aspect of compassion manifested both as a change in their inner perception and meaning of compassion, and the outward change in how compassion was expressed behaviorally. The inner changes that the nurses describe relate to several themes: recognizing patients as people too, realizing the importance of compassion, and “putting myself in their shoes.” These themes that represent a change in the perception of compassion also represent a more relational view of compassion. By viewing patients as people nurses acknowledge the personal aspect of providing patient care and recognizing the importance of compassion and the impact it has on patients, nurses are more likely to engaged in acts of compassion. By putting themselves in the patient’s shoes, nurses can
have a more personal understanding and connection with patients. As mentioned in the findings, before the patient experience, nurses described impersonal care and a view of compassion that reflected a focus on accomplishing “tasks.”

The participants in this study were able to identify behavioral changes in their practice after their patient experience and discussed these changes in relationship to compassionate care. In other words, the outward changes in practice were considered to be a result of the inward change in compassion. As seen in the findings, approximately five subthemes addressing specific practice changes were identified including: relating to patients better, taking more time with patients, advocating for patients, improved communication, and considering family members. There is evidence in the literature that identifies similar changes. For example, some researchers identified that nurses reported improved communication and patient advocacy after the patient experience (Gillies, Child, & Biordi, 1993; Kempainen, Bartels, and McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004). However, these changes in practice were not related to compassion specifically among nurses, but identified simply as changes in practice. The nurses in this study suggest that their practice changes came as a result of a change in compassion toward patients because the nurses were describing changes in actions that they saw as a result of their change in compassion.

Factors that Influence the Development of Compassion

The nurses presented their thoughts about factors that influence the development of compassion. The current body of literature has little discourse surrounding the development of compassion. Some researchers attempted to help students develop compassion by using teaching strategies in college courses (Ellison & Radecke, 2005;
Wear & Zarconi, 2007). However the method of data collection did not allow the researchers to: determine if a change in compassion occurred (Ellison & Radecke, 2005), and know what aspects of education helped or hindered students in the development of compassion (Wear & Zarconi, 2007). While this study did not attempt to cause a change in compassion, the nurses made many comments about factors they believe influence the development of compassion. There are three factors that the nurses indicate impact the development of compassion: personal experiences, exposure to compassionate role-models, and self-reflection.

First, the nurses said that experience (both the patient experience and general life experience) contribute to the development of compassion. Some of the nurses, such as Shaneequa and Savannah indicated that the patient experience was critical to a change in compassion in their practice. When considering these comments in light of the theoretical framework, this potentially could be viewed as a disorienting dilemma (Mezirow, 1978b; 1991; 2000), which served as a catalyst for the change in these nurses. Others, such as Hoku and Bekah see both their experiences as professionals and as patients contributing to their change in compassion. These nurses indicated that their patient experience had a significant impact on compassion in their practice, but also identified general life experiences as contributing to their development of compassion.

Overall, the nurses indicated that compassion develops over a long period of time. For example, Hoku mentioned that compassion in practice “evolves” as the nurse continues to practice. Similarly, Shaneequa indicated that a person can’t “learn compassion overnight.” Teresa pointed out that she has changed over the course of time in her career. This suggests that a transformation of compassion may occur incrementally.
over a long period of time (Dirkx, 2006; Daloz, 1986; Kegan, 2000). This study took place over a short period; therefore we cannot know what the nurses would say about compassion if they were interviewed years later. Literature that discusses a change in compassion when nurses become patients does not address the concept of time. The researchers that observed a change in compassion were not looking for factors that influence the development of compassion, and therefore were not considering the influence of time. Given that nurses in this study stressed time being important to the development of compassion, it begs questions pertaining to the relationship between the two. Is a “long” period of time necessary for the development of compassion? If so, how can educators promote the development of compassion when students are in educational settings for limited amounts of time? Additional research pertaining to the relationship between time and learning compassion can contribute to our understanding of the development of compassion in adults.

Second, nurses said that seeing compassionate role-models helps nurses as they develop their own practice. For example, Joanne said that she thinks more experienced, compassionate nurses can help younger nurses develop compassion by demonstrating it in practice. By watching compassionate role models, nurses can see specific actions, and attitudes of compassionate nurses and begin to imitate and emulate these qualities. Helen indicated that this is how she began to develop compassion in her practice. She watched compassionate providers and said that she wanted to be like them. Current literature does not mention the influence of role-models on compassion. Consideration of role-modeling in relation to the development of compassion may be important in both educational settings and work settings. Nursing programs arrange clinical experiences for students
each semester. Exposure to compassionate role-models during this period of education may have significant impact on the development of compassion in young nurses’ professional practice. Nurses who are new to a healthcare agency go through a period of orientation. This is a time when the nurse is learning the technical aspects of a job, and the culture of the institution. Exposure to compassionate role models during this period may also be influential to the development of compassion in nurses. For example, a nurse who orients to a particular unit with compassionate nurses will see the way in which the unit functions. If nurses carry out compassion in their practice, it is more likely that the new nurse will as well.

Finally, some of the nurses indicated that self-reflection impacted the development of compassion in their practice. Self-reflection generally involved comparing compassion in practice before and after the patient experience, and identifying changes. This was not done in a formal way. Most of the nurses were like Sara who described thinking about her previous and current practice, and engaging in a critical examination of her current practice by asking herself how she could have done better. Current literature does not specifically discuss the concept of self-reflection in relationship to compassion. There is evidence that nurses beyond this study engage in self-reflection. For example, in Clar’s (2006) personal account, she wondered if she was compassionate enough before her patient experience. Some researchers said that nurses reported being more compassionate after the patient experience, indicating that they reflected on compassion in their practice (Cotter, 1990; Gillies, Child, & Biordi, 1993; Kempainen, Bartels, & McCarthy Veach, 2007; Picard, Agretelis, & DeMarco, 2004). Overall, in order for the nurses to identify a change, a certain amount of self-reflection
was necessary; otherwise they would not have been able to identify the change. By engaging in reflection, the nurses are able to evaluate the change of compassion in their practice and think about what they want their practice to look like. For example, Hoku said that she reflected on her patient experience and her practice so that she could emulate compassionate behaviors.

When considering the factors that influence the change in compassion, one may question the impetus for this change. There is some discussion within transformative learning theory that a transformation is can be triggered by an epochal event or disorienting dilemma (Taylor, 2000). There are some indications from the participants in this study that the patient experience was a disorienting dilemma (Mezirow, 1978a; 1978b; 1991; Taylor, 2000); yet at the same time there are indications that the change is incremental or takes place gradually (Dirkx, 2006; Taylor, 2000). Nurses commented that the patient experience was highly influential in their understanding of the patient experience and a change in compassion. The experience of being a patient was a powerful experience that potentially triggered the change in compassion. This suggests that the patient experience was a disorienting dilemma. Some of the same nurses commented that they have observed a gradual change in compassion over the course of their careers, and has been affected by many experiences including the patient experience. This also suggests that the transformation of compassion is a complex experience and has the potential for a number of influences (Taylor, 2000). It is possible that the participants have experienced gradual changes over time from various life events, and found the patient experience to be an event that was particularly influential in the change in compassion.
The Impact of Emotions on Compassion

The participants felt strong emotions during the patient experience. Findings echo current literature, but this study adds to the discourse by demonstrating a connection with the emotional experiences and development of compassion. The impact of emotions was discussed by participants in two main ways: emotions felt by virtue of being a patient, and emotions felt as a result of relationships with healthcare providers. Both of these are discussed below.

There are a number of emotions described by nurses who become patients in the current literature. Some of the emotions discussed include anxiety, fear, being afraid, vulnerability, loss, sadness, anguish, and depression (Bowers, 2004; Clar, 2006; Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Doell, 2008; Emerson, 2009; Gillies, Child, & Biordi, 1993; Guzman et al., 2009; Harker, 2000; Jones, 2002; Lanza, 2006; Leite, 2007; Picard, Agretelis, & DeMarco, 2004; Tordes, Fulbrook, Albarran, 2000; Williams, 1998; Williams, 1997; Zeitz, 1999). Nurses indicated that these emotions were an important part of the patient experience. The participants in this study echo that emotions are a significant aspect of the patient experience, and reported similar emotions such as fear, anger, frustration and loss of control.

There are two emotions in particular that appear to have a very powerful impact on the nurses in this study: fear and loss of control. Fear came out strongly in the findings as part of the patient experience for the participants because every nurse stated that they experienced fear while being a patient. Fear came in several forms such as fear of the unknown, and fear of the bad things that can happen to patients. For both Savannah and Gail, they experienced fear over the potential loss of a baby. Sara experienced fear for her
life when she explained the “feeling of impending doom” and feeling as if she was “going to die.” In addition, loss of control resonated deeply with some of the nurses, and these same nurses speak to ways that they specifically attempt to help give the patient some control. For example, Helen indicated that she tells patients that they are in control of their healthcare and decisions. Joanne gave examples of ways that she attempts to give control to patients. It is possible that having intense fear or loss of control gives nurses and understanding of the patient experience that continues to resonate with them when they return to work. Perhaps experiencing fear for oneself or personally experiencing loss of control is important in becoming aware of the fear and loss of control that others have when they are patients.

Even though literature indicates that emotions are a significant aspect of the patient experience, it does not explain the impact of emotions on learning compassion (Bowers, 2004; Clar, 2006; Cotter, 1990; DeMarco, Picard, & Agretelis, 2004; Guzman et al., 2009). There are two ways in which emotions appear to impact learning compassion in the participants of this study: the emotions were felt strongly and continue to be felt, and nurses remember their emotions as patients and consider the emotions of current patients in their care. First, when the nurses told stories about their patient experience, they not only specifically identified various emotions, but they conveyed a continued connection with these emotions through their body language, and tone of voice. Some of them stated outright that they still felt a certain way. For example, Shaneequa said, “I’m still angry.” She mentioned this more than once, and her tone of voice indicated as such. Another example is Gail’s comment that she experienced “every emotion under the sun” during her patient experience, and said that she is “so thankful
everyday” for her health and her child’s health. This indicates that the nurses continue afterward to have an emotional connection with their patient experience. Additionally, the nurses in this study mentioned that they remember the emotions they experienced when caring for patients now. This memory impacts the nurses’ motivation to be compassionate for their patients. For example, Savannah frequently mentioned experiencing “fear of the unknown” and how she remembers this when taking care of patients. She realizes that they may be experiencing the same fear that she had, and attempts to do things to help alleviate that fear. In addition, Sara commented that she knows what patients might be thinking and feeling because she remembers how she felt, and alters the way she cares for patients to help them feel better.

The nurses in this study went on to say that they can relate or feel the emotions that their patients feel now that they have been patients. For example, Sara mentioned “knowing” what a patient might be thinking or feeling now that she has been a patient. In addition, they link emotions with empathy, or “putting myself in their shoes.” All of the nurses mentioned that they now try to consider how the patient is feeling when caring for patients. Perhaps the patient experience brings some of the emotions that patients experience into the forefront of the nurses’ awareness and contributes to their ability to empathize which in turn contributes to a change of compassion in their practice.

Another way that nurses appeared to be emotionally impacted during the patient experience was through relationships with healthcare providers. There is evidence in the literature to suggest that behavior of healthcare providers and compassion in practice impact the patient experience and health of patients. Literature addressing nurses-as-patients shows that behavior from the healthcare providers toward patients can be
perceived positively or negatively and impact the way a patient feels. (Bush, 2008; Cotter, 1990; Guzman et. al, 2009; Jones, 2002; Kempainen, Bartels & McCarthy Veach, 2007; Kinnard, 2009; Lawson, 2008; Palmer, 2004; Picard, Agretelis, & DeMarco, 2004; Schwind, 2004; Stott, 2008; Todres, Fulbrook, Albarran, 2000; Zeitz, 1999). For example, compassionate care from providers can make a patient feel better (Stevenson, 2006), whereas uncompassionate care can increase feelings of anger, fear, and frustration (DeMarco et al., 2004; Duke & Connor, 2008; Leite, 2007; Harker, 2000). In addition, some researchers show that compassion can promote health and well-being (Fenwick & Brayne, 2010; Fogarty, Burbrow, Wingard, McDonnell, & Somerfield, 1999; Steffen & Masters, 2005). Overall, scholars suggest that healthcare providers can impact the patient experience, and compassionate care also impacts patients.

This study affirms that providers impact the patient experience in that relationships can impact the emotions nurses experience, but goes farther to show how these relationships impact compassion in the nurses’ practice. A number of participants gave examples of ways in which a provider impacted their patient experience. For example, Joanne told a story about a provider who treated her rudely when Joanne was attempting to get her attention. Joanne’s ventilator had become disconnected and she needed help, but the provider acted as if Joanne was being unreasonable when trying to get help. Joanne, felt very angry as a result of the way she was treated; and it compelled her to not treat her patients the same way when she returned to work. She said, “Oh, I have to remember this when I’m taking care of my patients.” Teresa shared how a doctor told her that it was her fault that she had cancer, this was very upsetting to her and left a lasting impression. She indicated that now she attempts to do a better job of
communicating with her patients. Another participant, Helen, was “not happy” when a doctor did not talk to her or her husband about the results of a diagnostic procedure. Helen learned from her upsetting experience with the doctor that communication is important, and focuses on communication in her own practice. In these cases, the nurses perceived these behaviors to be negative which left them feeling angry or upset, and it impacted them enough to change their practice. However, some of the nurses shared experiences that left a positive impression. For example, both Hoku and Dancer received compassionate care from nurses while they were patients. The compassionate care that Hoku received from Maria demonstrated to her what a compassionate nurse looks like, and afterward Hoku wanted to be the same in her practice. Hoku wanted to advocate for her patients, and have follow-through. Compassionate care from a nurse made Dancer feel “comforted” and helped her understand what a positive impact compassion can make in a nurse’s practice. The experiences of these participants made them feel as if the nurses cared about them as a person. In both cases the nurses became more cognizant of compassion in their practice afterward. Overall, the relationships with providers brought emotions that were perceived both positively and negatively by the participants; and nurses expressed ways in which their practice changed as a result of these experiences, thus showing that emotions experienced as a patient impacted compassionate behaviors afterward.

In summary, it appears that there is a connection between the emotions of the patient experience and professional practice because nurses continue to remember the emotions when caring for patients. These memories and connections the nurses have
result in motivation to help the patients currently in their care. The outward sign of this occurs when the nurse does something to help the individual patient feel better.

**Findings Relevant to the Theoretical Framework**

This section addresses relevant findings pertinent to the theoretical framework which is transformative learning theory. This theory was chosen to ground the study because it is a theory addressing learning in adulthood that can help in understanding the changes of compassion in nurses who become patients. Most specifically, the psychocritical and constructive-developmental perspectives of this theory grounded the study (Mezirow, 1991; Mezirow, 2000; Kegan, 1994; Kegan 2000; Daloz, 1999). Because two perspectives of transformative learning theory were used in this study, the significant findings are examined in relation to both of these perspectives. Rather than giving examples of all the different ways that participants demonstrated a perspective transformation, the most relevant aspects are presented in light of the theoretical framework. The most relevant findings include participants developing a more complex view of compassion, the role of empathy in reflective discourse, making a new meaning of compassion.

**Moving Toward a More Complex View Compassion**

At the core of transformative learning is the idea that a perspective transformation brings a more sophisticated understanding or way of making meaning of our experiences (Cranton & Roy, 2003; Kegan, 1994; Mezirow, 2000). The findings in the study suggest that this group of nurses have experienced a perspective transformation concerning compassion toward patients, and suggest that this change in perspective involves a more complex understanding of compassion. The overall change of perspective that the
participants describe is moving from a static, impersonal, and background view of compassion to an active, relational, and foreground view of compassion.

Before becoming patients, the nurses gave brief descriptions of compassion. For example, Shaneequa said that she saw compassion simply as addressing comfort. Her comment is representative of several nurses’ sentiments in that they did not have a robust description of compassion before the patient experience. The nurses indicated that they thought being compassionate meant doing their job. One of Hoku’s comments demonstrates this concept. She said, “I am compassionate because I do my job.” In addition, the nurses indicated that they had impersonal relationships with patients before becoming patients themselves. Several described ways in which they distanced themselves from relationships with patients such as rushing in and out of patients’ rooms, or physically putting distance between themselves and the patients. One example from Joanne reflects the general sentiments of the group when she commented that she did not involve herself with patients on a personal level before her own patient experience. In general, the nurses’ description of how they perceived compassion and its presence in practice before the patience experience lacks depth, and indicates an impersonal view of compassion in practice.

However, as the nurses’ stories continued to unfold, they described a much different perspective of compassion after becoming patients. After the patient experience, nurses described compassion as being an active process in which they are able to relate to patients and intentionally incorporate compassion into practice. For example, Dancer said that after receiving compassionate care she is able to understand how important it is to patients that they receive compassionate care. Therefore she is much more intentional
with compassion in her own practice. The nurses provided much richer descriptions of what compassion means to them after the patient experience. Rather than giving brief explanations of compassion, the nurses gave detailed explanations. For example, Hoku gave a detailed description of compassion that included a number of specific attributes of compassionate care that have become important to her personally over the years. She said that compassion is part of what it means to be a nurse.

As the nurses’ perspective of compassion continued to unfold they gave examples of specific ways in which their practice has changed with the new perspective, such as advocating for patients and improving communication with patients. Another way in which the nurses described a change of perspective involves a relational aspect of compassion. After becoming patients, the nurses indicated that making personal connections with patients is important, and is part of providing compassionate care because being compassionate involves personal interactions.

Ultimately, the nurses’ new perspective of compassion involves actively engaging compassion in the foreground of practice. This new perspective shows a broader, more sophisticated understanding of compassion which demonstrates an important concept in transformative learning theory (Cranton & Roy, 2003; Mezirow, 1991).

**Making a New Meaning of Compassion**

An important concept in transformative learning theory is the assertion that a transformative learning experience represents an epistemological change in a person (Daloz, 2003; Daloz, 1983; Kegan, 2000; Mezirow, 1991; Mezirow, 2000). Epistemology is the way a person understands, interprets, or makes meaning of their experiences; and an epistemological change involves a deep seeded change in the way a person makes
meaning of experiences (Daloz, 2003; Daloz, 1983; Kegan, 2000; Mezirow, 1991). A developmental perspective of transformative learning espouses this concept and suggests that a person continues to grow or develop throughout adulthood by going through changes in the way they make meaning of prior experiences (Daloz, 2003; Kegan, 2000). In addition, a developmental perspective of transformative learning suggests that part of this growth and epistemological change involves a movement away from a concrete view of the world toward more informed and shared view of the world (Kegan, 1980). There are several findings in this study that speak to a constructive-developmental perspective of transformative learning and are explored below.

The study participants demonstrated a new epistemological view of compassion when they discussed compassion as the essence of nursing. The nurses generally said they thought compassion was important to them before becoming a patient, but didn’t understand how important it was until they became patients. Nurses demonstrated the development of compassion in their practice by discussing how they understand compassion differently. Instead of seeing compassion as part of their job or as a task to accomplish they now see compassion as an integral part of who they are as a nurse, and as a way to make a personal connection with their patients. For example, several nurses described compassion as being an essential part of nursing practice which they would not have done before the patient experience. Hoku explained that as she has grown in nursing, she has come to understand compassion as being one-and-the-same with her identity as a nurse. Joanne explained that after her patient experience she realized that compassion is the essence of nursing practice. Before her patient experience, she thought that it was important, but did not have such a deep personal view of compassion until she
became a patient. The epistemological change in the participants is that they moved from having an impersonal or background perception of compassion to perceiving it as being important and integral to their practice.

Another component of a developmental view of transformative learning involves changing what is “subject” to what is “object” (Kegan, 2000; 1994; 1980). In this view, part of a transformation involves developing a more sophisticated understanding of something. When doing so, the person is no longer controlled by something, but rather is able to identify and control it. The findings suggest that the nurses move their practice of compassion from being “subject” to holding compassion in their practice as “object.” The nurses hold compassion in their practice as object because they are able to clearly identify it and can actively engage and shape compassion in their practice. To give background to this assertion, the literature review indicated that compassion is not as prevalent as it once was because nurses are burdened with poor working conditions that take nurses away from spending time with patients (Georges, 2011; Weiss, Malone, Merighi & Benner, 2009). The assumption is that nurses have less opportunity to provide compassionate care because they have less 1:1 time with patients. Nurses in this study are subject to the same working conditions as others, however after the patient experience they demonstrate the ability to take control of their interactions with patients and provide compassionate care. An example of this is the nurses’ comments of “taking more time” with patients. Several nurses indicated that they now take the time to be with patients and the patient experience has caused them to slow down when providing care rather than rushing in and out of patients’ rooms. Rather than being thrown about by job responsibilities, nurses are taking the time to be with patients and show how they care. Instead of being “subject” to the
working environment and believing that outside forces determine compassion in practice, the nurses now have ownership of compassion in their practice.

**The Role of Empathy**

A significant amount of research has used transformative learning theory as the theoretical framework, thus creating to a large body of knowledge about the theory. One way that this study attempts to contribute to the body of knowledge is by considering the role of empathy in a transformative learning experience. As a reminder, empathy is the ability of a person to understand and experience the emotions of another person (Duan & Hill, 1996; Eisenberg, 2000; Eisenberg & Miller, 1987; Wispe, 1986). Psychological scholars suggest that empathy possesses both cognitive and emotional aspects in that person must be able to intellectually comprehend another person’s feelings, and involves an emotive response to the other person (Duan & Hill, 1996; Eisenberg, 2000; Gruhn, Diehl, Rebuca, & Lumley, 2008; Richter & Kunzmann, 2011).

There has been some discussion that empathy is essential when a person is engaging in reflective discourse during a transformative learning process. Reflective discourse, coupled with critical reflection, is the part of a transformative process that allows a person to examine previously held beliefs and consider other points of view (Mezirow, 1991; Mezirow, 2000). Reflective discourse involves a “critical assessment of assumptions” (Mezirow, 2000, p.11) through the use of dialogue, and helps a person to think about a problem from other points of view. Mezirow (2000) commented that when people engage in reflective discourse, they are not trying to find out who is right or wrong. Rather, reflective discourse is about understanding other people’s point of view and coming to a consensus. Also, Mezirow (2000) said that “feelings of trust, solidarity,
and empathy” (p. 12) are essential when people participate in reflective discourse. Here, empathy is listed as an important part of reflective discourse; however, he does not go into great detail about the concept of empathy and its role.

In more recent discussion of transformative learning theory, questions are raised about empathy, and its role in a transformative learning experience. Some question the relationship between empathy and emotions, and their relationship with critical reflection and dialogue (Taylor & Cranton, In-press). This observation is made in light of the fact that some researchers suggest emotions are linked with a transformative learning experience (Foronda, 2010; Rush, 2008; Stevens-Long, Schapiro, & McClintock, 2012). Taylor & Cranton (In-press) suggest that empathy is what connects the emotions a person experiences and the ability to understand another person’s point of view. This occurs because empathy “provides the learner with the ability to identify with the perspectives of others; lessens the likelihood of prejudgment; increases the opportunity for identifying shared understanding; and facilitates critical reflection through the emotive valence of assumptions” (Taylor & Cranton, In-press, p. 10). In other words, if emotions are a part of a transformative learning experience as some research suggests, then empathy allows the person to consider the emotions and perspectives of other people when engaging in a transformative process. If empathy is involved in reflective discourse as Mezirow (2000) suggests, then its role is in considering another person’s emotions as part of examining their point of view.

There are several observations pertaining to empathy in this study. First, empathy appears to be present in the process of transforming compassion. Second, empathy may be a necessary component of the transformation of compassion. Last, there is an
indication that the use of empathy is on-going in the participants. Each of these will be discussed below.

Findings in this study suggest that empathy is present in the nurses’ transformative process of compassion. Nurses often made comments such as “I put myself in their shoes” as a way to understand the perspective of the patient. When the nurses spoke about “putting myself in their shoes” they were referring to a way of empathizing with the patient by considering the thoughts and emotions that the patient might be feeling. As the nurses empathize with patients, they are able to gain a better understanding of the patient; this understanding serves as a guide in caring for individual patients. By using empathy to better understand the patient, nurses are able to translate that into the change in compassionate behaviors they described. For example, Sara talked about “knowing” or “understanding” what patients are thinking and feeling when interacting with patients. In order to know and understand what a patient is going through, she must utilize empathy to think about and experience what patients are experiencing. She then takes this understanding and “adjusts” what she is doing with patients to help alleviate pain, or prevent distress. Before the patient experience, Sara and the other participants did not discuss the use of empathy in compassion. The discussion of empathy after the patient experience suggests that it has a role in the transformation of compassion.

The findings suggest that empathy was a necessary component for the transformation of compassion. As mentioned above, few nurses mentioned the use of empathy as part of compassion before their patient experience. However, it became apparent that empathy was a significant part of compassion after the patient experience.
One indication is that after the patient experience, all of the participants discussed that they try to think about what the patient might be experiencing in order to help their patients. In addition, a number of nurses mentioned that empathy is a necessary part of compassion. For example, Natalie commented that she needs to be able to “put myself in their shoes” when being compassionate toward someone. She said,

If I put myself in their place, and try to think and feel and understand where they are coming from, I think it allows me to be more caring and compassionate; and helps because I can anticipate the things that they are going through.

Her thoughts were echoed by others who shared that putting themselves in their patients’ shoes helps them to be more compassionate; therefore the participants consider empathy to be a part of compassion. If empathy is a part of compassion, then it appears for the transformation of compassion, the use of empathy was necessary.

Last, there is evidence that in the transformation of compassion, the use of empathy is an ongoing process. This is because the nurses continually consider the patient’s perspective in order to provide compassionate care. When referring to current practice, the nurses made comments such as “I put myself in their shoes.” Comments such as these were in reference to interactions that occur in the present, or something that actively occurs in the interactions nurses have with patients. In order to understand individual patients and their needs, the nurse must continually consider the patient’s perspective. This suggests that the nurses are continually carrying out empathy as part of their transformation of compassion.
Implications for Practice

In this study transformative learning theory served as the framework for examining nurses who learn compassion. The findings provide implications for practice in adult education, particularly in professions that espouse compassion. Because the study addressed learning in nurses, implications for practice will focus on education for nurses. The main implications of practice focus on the factors that participants said impact the development of compassion: life experiences, role-modeling, and self-reflection. Given the fact that nurses maintain a connection with the emotions in the patient experience, this provides implications for practice.

The participants shared aspects of their compassion narrative beyond the patient experience that influenced their development of compassion. Findings suggest that life experiences, self-reflection, and compassionate role-models can influence a nurse’s development of compassion. If so, then nursing educators, both in academic and clinical practice settings can address these when promoting development of compassion.

Not surprisingly, nurses said experiences impacted their personal development of compassion. In this study nurses did not engage in activities designed to promote compassion. Rather, compassion changed as life happened, and they shared the changes during interviews. On first glance, educators may not see how they can influence life experiences. However, nurse educators can incorporate teaching strategies that hold potential for learners to experience compassion, or growth of compassion. For example, pre-licensure nursing programs include clinical simulation in the laboratory and clinical experiences. Educators could potentially design learning activities in these settings that encourage compassion. In simulation experiences, an educator can create scenarios in
which the objective is for the nurse to recognize a patient’s suffering and do something to
address it. A simple simulation scenario may involve an objective of the nursing
recognizing that a patient is distraught about contacting a family member, and placing a
call to the family member for the patient. Another simulation experience may be more
complex in which the nurse must help a family understand the stages of the dying
process, and support them as a loved one dies. In the clinical setting, educators can ask
students to identify the various needs of a patient that might be outside the realm of
nursing tasks, and think of ways they can address the patient’s needs. Educators can
discuss compassion in post-conference and ask students to discuss how they saw nurses
being compassionate toward patients. These learning experiences can contribute to a
nurse’s development of compassion.

Educators should keep in mind that compassion appears to develop over time. The
nurses in this study referred to both the patient experience and other experiences
throughout life that impacted their learning of compassion. For example, Helen stated
that she witnessed compassion of nurses and doctors toward her mother when she was
growing up, and she wanted to be like them. Natalie said that when she took the time to
think about what she wanted to do with her life, she realized she wanted a career that
involved helping others. Compassion in Natalie’s practice began to develop before she
became a nurse. Others such as Hoku, said that compassion in practice evolves over a
long period of time. Given that these comments point to compassion developing over a
long period of time, educators should understand that learning compassion is not a
destination, but a journey. Educators can provide learning experiences that focus on
compassion, but should not expect immediate changes.
Another way that educators can assist the process of learning compassion is through the use of self-reflection and reflective-discourse. Findings suggest that nurses reflected on their patient experience and their own practice. They were able to examine compassion in their own practice and make changes they thought necessary. In addition, participants engaged not only in self-reflection, but also showed evidence of reflective discourse through the use of empathy. Because these are important aspects of a perspective transformation, educators should allow for the opportunity to engage in these processes. Educators can design learning experiences focused on compassion, coupled with a self-reflective exercise, and opportunity for reflective discourse. This may come in many forms. An example of this in an academic setting may involve a simulation scenario in which a patient needs compassionate care from someone. Afterward students may be given the opportunity to reflect on their role and behaviors in the scenario. Later, discussion in a group setting can promote the sharing of ideas and perspectives about the situation.

In conjunction with the use of simulation and experiential teaching strategies, and purposeful reflective activities, nurse educators can incorporate both patient narratives, and personal narratives. A patient narrative may include a story about the course of a patient’s illness and important relationships and environmental influences in the patient’s life. By incorporating a patient narrative in a simulation students can make personal connections with experiences that patients have. Using students’ personal narratives, can help students reflect on their own experiences and consider how they might feel in different situations that their patients experience.
Participants mentioned that being near compassionate role-models impacted their development of compassion. By watching other nurses demonstrate compassion in practice, nurses can be inspired to incorporate compassion in their practice. In addition, seeing other nurses demonstrate compassion can expose them to the core values of nursing practice. Educators can use role-modeling as another way to support nurses as they learn compassion. A way for clinical educators to help nurses develop compassion is by espousing a culture of compassion. By espousing a culture of compassion, nurses can begin to understand its importance. Educators in clinical practice settings can encourage a compassionate culture by paring orientees with compassionate preceptors. Showcasing nurses who demonstrate compassion can help others identify compassionate colleagues and encourage a culture of compassion. Educators in academic settings can role-model compassion and build a foundation for espousing compassion in practice.

If educators are interested in promoting the transformation of compassion in nurses, they should acknowledge the impact that emotions may have in the learning process. As discussed, emotions in the nurses’ transformation appear to be felt strongly and continue to impact them after the experience. The most influential emotions appear to be fear and loss of control. If these emotions have an impact in the learning process, educators may focus activities involving critical reflection and reflective discourse on the emotions that students had during the learning experience.

**Limitations**

Some limitations for this study were suggested in chapter one. Comments will address these limitations and any additional limitations discovered during the research process. One limitation acknowledges the fact that compassion is based on the
perceptions of the nurses, and not those they provide care to. It is possible that nurses may perceive themselves as being compassionate, yet not be compassionate toward patients. There are two comments addressing this limitation. First, as the nurses shared their experiences and commented about compassion in their practice before and after the patient experience, they discussed changes both inward and outward. These changes demonstrated growth in the nurses. The assumption being made is that growth of compassion results in more compassionate care. Another comment addresses the fact that compassion appears to change over a long period of time. Therefore, compassion in these nurses is likely still changing, and will continue to change.

Another limitation recognizes my own experience as a nurse-patient and the potential influence this may have had on my interpretation of the data, and the possibility that aspects of the participants’ narratives may be “missed” when analyzing the data. To address this, I acknowledged that there would most likely be similarities between my patient experiences and those of the participants. Indeed, there were several times during the data collection process that participants’ experiences reminded me of my own experiences. However, during those times, I did not interject and share my “story” with participants which would have led the interview in a different direction. I allowed them to continue with their story, and asked clarification questions as needed. I was amazed at how the participants had similarities, but ultimately had very different experiences. I acknowledged this while constructing the participants’ narratives and tried to remain true to the aspects of the experience that seemed to be the most significant to the participants.

A third limitation is the lack of generalizability of this study, which specifically examined the learning of compassion in nurses who became patients. Some insights in
learning compassion were gained in this study, however there may be other factors that contribute to learning compassion in other populations, such as nurses who have not been patients, or groups of student nurses.

Last, during the research process, it became apparent that time impacts the development of compassion. This study attempted to acknowledge Clandinin and Connelly’s (2000) concept of backwards and forwards in a narrative which recognizes that a narrative develops over time. I paid attention to nurses’ perceptions of compassion in their practice over time, and asked them to comment on this if they did not address it without prompting. Even with attention to this detail, it became apparent that nurses believe compassion develops over a long period of time, and essentially changes throughout a nurse’s career. Because this was a short-term study involving two interviews, only their current perceptions of compassion were revealed.

**Suggestions for Future Research**

This study contributes to the body of knowledge in nursing, adult education, and transformative learning theory by providing a closer look at how adults (specifically nurses) learn compassion. Suggestions for future research are based on some of the limitations, and concepts that need additional inquiry.

Longitudinal research addressing the development of compassion in nurses may be helpful. Given that nurses indicated a time element to development of compassion, long-term research can reveal nuances of this attribute throughout a nurse’s career. Having a more nuanced understanding of how compassion is learned can help educators at various levels of a nurse’s career develop learning strategies to help nurses develop compassion. Longitudinal research would best involve collaboration between nursing
programs and clinical practice agencies to follow nurses from novice to expert levels of practice (Benner, 1984).

Findings suggest factors that may influence the development of compassion. Future research should focus on incorporating these factors into education to help foster compassion. For example, research involving experiential learning activities such as laboratory simulation and clinical learning can focus on compassion, and be followed with exercises aimed at critical reflection and reflective discourse.

In relation to research of transformative learning theory, additional research should address the role of empathy in reflective discourse, because additional evidence of this role is needed. This study sought to understand the change in compassion of nurses who become patients and the role of empathy in this process. One of the reasons for examining the role of empathy is that Mezirow (2000) indicates empathy as being an important aspect of reflective discourse, but does not go into great detail to explain this. Understanding the role of empathy can help in understanding reflective discourse in a transformative experience. In this study, empathy appears to be an important aspect of reflective discourse because the nurses often use empathy to understand a situation from the patient’s perspective. It seems to be a significant aspect of carrying out compassion in the nurses’ care. By actively thinking about a situation from a patient’s perspective the nurses are able to understand what the patient might be thinking or feeling. However, the importance of empathy may be related to the fact that empathy is necessary in order for nurses to carry out compassion. The participants in this study indicated that empathy is part of compassion; and empathy is necessary in order to be compassionate or to carry out compassionate care. It is likely that empathy is necessary in a perspective
transformation of compassion because it is necessary to understand another person in order to know how to help that person. However, not all perspective transformations involve a transformation of compassion. Given the context of Mezirow’s (2000) discussion of empathy, he meant empathy as a necessary aspect of reflective discourse because it allows a person to understand how another person might think or feel about something thereby promoting a more inclusive view of a situation. The question remains: What is the role of empathy in reflective discourse in other transformative experiences? For example, what is the role of empathy when a person has a transformation about social injustice toward victims of sexual assault? Does the person experiencing the transformation in this situation utilize empathy as a way to understand the perspective of a victim as part of developing a new understanding? This seems reasonable. Additional study, should focus on empathy in many different perspective transformation to understand how people engage in empathy, and how it impacts the change in perspective.

**Conclusion**

This chapter addressed the relevant findings of the study in relation to the current body of literature and transformative learning theory as the theoretical framework. In addition, implications for practice, limitations, and suggestions for future research were presented.

The findings in relation to the current body of literature both confirm some aspects of the research topic, and provide additional insight. Some new insights to compassion in nurses who become patients include nurses have a greater awareness and intention of compassion in their practice after becoming patients. Nurses have a more relational perspective of compassion, and inner changes of compassion result in outward
changes in actions. Nurses verbalized factors that they perceive as being influential in the development of compassion such as life experiences, role-modeling, and self-reflection. Findings suggest that emotions during the patient experience, and behaviors of healthcare providers impacted the development of compassion. Findings in relation to transformative learning theory suggest that nurses develop a more complex view of compassion. Before the patient experience, nurses described an impersonal, static and background perspective of compassion. After the patient experience, nurses described a more active, relational, and foreground perspective of compassion. In addition, when looking at the findings from a constructive-developmental perspective of transformative learning, participants demonstrated a change in view by discussing compassion as being a part of who they are as nurses, and as a way to make more personal connections with patients. Before the patient experience, nurses thought that compassion was important, but did not make this personal connection. In addition, findings suggest that nurses continually use empathy as part of reflective discourse in order to understand individual patients, and improve care for those individuals.

Implications for practice involve including teaching strategies at all levels of nurses. Teaching strategies should include experiential learning coupled with opportunity for self-reflection and reflective discourse. In addition, if educators want to promote the development of compassion, they should consider the importance of compassionate role-models and supporting a culture that espouses compassion in nurses. Limitations of the study were addressed during the research process and involved: only nurses perceptions of compassion in their practice, the researcher’s bias when collecting and analyzing data, lack of generalizability, and the short term of the study. Suggestions for future research
include: conducting longitudinal study of the development of compassion in nurses, and conducting research that includes influential factors for the development of compassion. Additional research addressing the role of empathy in reflective discourse should be conducted in a variety of populations.

In closing, I would like to comment on my personal observations of this narrative dissertation and my perspective of compassion. As mentioned in the limitations, I acknowledged that my personal experience as a patient could influence the data collection and analysis process. I was very aware of this and did not share my experiences with participants in order to give voice to their stories. As I listened to the participants, I was moved by the stories they had to share. There were moments during the data collection and analysis that I became tearful with sadness and sometimes disbelief. I was most moved by the account of Teresa’s experience of being diagnosed with cancer, and the stories surrounding Gail and Savannah’s complicated pregnancies. Upon reflection, Teresa’s story was almost unbelievable in that she now has a chronic illness which seemingly resulted from poor communication and follow-up from the healthcare team. I am still moved by her experience. When reflecting on the stories of Gail and Savannah, I realize that I was just as affected by their experiences of becoming parents as I was by the fact that they were patients. I have been a new mother in the last five years, and it has now been eight years since my patient experience. In recent years, stories about children and parenting affect me more than before becoming a parent. However, I believe that the combination of being a patient and new parent was something that struck a chord with me. If I had been in their situations, I would have been overwhelmed with fear and grief.
As I reflect on the research process and the findings, I am humbled by the powerful way in which the participants identify compassion in their practice. As the participants spoke, they strongly identified with compassion in their practice, and proudly claim it as part of their identity as a nurse. I was humbled in that the nurses had clearly thought about compassion in their practice after the patient experience and identified personal definitions of compassion. They had much to say about what compassion means to them personally and professionally.

At I finish this study, I realize that my own perspective of compassion has changed. First, I have greater hope that nurses can not only remain compassionate in practice, but that they have the capacity to develop compassion throughout their careers. I have a deeper understanding of what compassion means to me. I have come to believe that compassion comes from within, and involves the willingness to make personal connections and genuinely care about the person you are interacting with (whether the person is a patient or not).

Finally, after considering the comments of the participants, I believe that empathy is a part of compassion, and is a necessary precursor to engaging in compassionate behavior. If compassion involves suffering with another person, and doing something to alleviate that suffering, then empathy is needed in order to first understand what the person is going through. If a nurse lacks the understanding of another person’s experiences then she will not be able to suffer with that person and be moved to do something about it. Thus compassion begins with understanding the experiences of another person.
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Appendix A

Sample Interview Questions

1. Questions addressing the nurses’ narratives as patients:
   • Tell me about your patient experience.
   • Can you tell me what affected you most in your patient experience?

2. Questions addressing narratives of nurses’ perceptions of compassion in current professional practice:
   • Tell me about compassion in your practice now that you have been a patient.
   • Tell me how you care for patients now that you have been a patient.
   • Tell me about your relationships with patients now that you have been a patient.

3. Questions addressing narrative of perceptions of compassion in nurses’ professional practice over time:
   • Can you tell me what compassion was like in your practice before you became a patient?
   • Can you tell me about the differences in your understanding of compassion before and after your patient experience?
   • Tell me about your relationships with patients before your patient experience.
Appendix B

Sample Implied Consent From

Implied Informed Consent Form for Social Science Research
The Pennsylvania State University

Title of Project: Understanding the transformation of compassion in nurses who become patients

Principal Investigator: Carrie L. Pucino
Address: (Contact info in official consent form)
Phone:
Email:

Advisor: Dr. Edward Taylor
Penn State Harrisburg
Address: (Contact info in official consent form)
Phone:
Email:

1. Penn State Researcher: As a doctoral student at Penn State University the principal investigator, Carrie Pucino, is a Penn State researcher. This study is being conducted for research purposes.

2. Purpose of the Study: The purpose of this study is to examine how nurses who become patients learn compassion toward patients in their professional practice, and examine the role of empathy in the process of learning compassion.

3. Procedures to be followed: You will be asked to participate in 2 interviews. With your permission they will be digitally recorded and transcribed. You may be asked to review information obtained from you interview to confirm accuracy.

4. Discomforts and Risks: There are no risks in participating in this research beyond those experienced in everyday life. Some of the questions are personal and might cause discomfort. Only the principal investigator will have access to identifying information. Under no circumstances will that information be shared with others.

5. Benefits: This study may give you an opportunity to reflect on past experiences and your professional practice. You may be able to identify growth in your professional practice as a result of the study. Also, your participation will help nurses to understand how compassion is learned after becoming a patient. Information from
this study can be used to make recommendations for teaching and learning compassion in the nursing profession.

6. **Duration/Time:** There are two interviews each lasting approximately 1-2 hours.

7. **Statement of Confidentiality:** Your participation in this research is confidential. The interview data will be secured in a locked file cabinet (printed copies) in my home and on my password secured computer (digital recordings). The data will be destroyed 5 years after the completion of the research. Only the principal investigator and her advisor Dr. Edward Taylor, will have access to the data. Pseudonyms will be used in place of your real name. Also, any specific references that could potentially identify you will be changed to general terms to prevent identification. A code correlating the participant with the pseudonym will be kept in a locked file cabinet and will be destroyed at the completion of the study.

If we decide to correspond via electronic communication, your confidentiality will be maintained to the degree permitted by the technology used. No guarantees can be made regarding the interception of data sent via the internet by any 3rd parties.

The Pennsylvania State University’s Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared nor will your name be linked in any way to your responses.

8. **Right to Ask Questions:** Please contact Carrie Pucino at __________ or email __________ with questions, complaints, or concerns about this research. You can also call the above number if you feel this study has harmed you. If you have any questions, concerns, problems about your rights as a research participant or would like to offer input, please contact The Pennsylvania State University’s Office for Research Protections (ORP) at (814) 865-1775. The ORP cannot answer questions about research procedures. Question about research procedures can be answered by the principal investigator.

9. **Voluntary Participation:** Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 18 years of age or older to take part in this research study.

Please keep this form for your records or future reference.
Vita

Carrie L. Pucino

Education

Doctor of Adult Education            Pennsylvania State University
Master of Science in Nursing         York College of Pennsylvania
Bachelor of Science in Nursing       York College of Pennsylvania

Teaching and Professional Nursing Experience

Assistant Professor, York College of Pennsylvania  2012-Present

Courses: Adults in Acute Care, Senior Practicum

Visiting Professor, York College of Pennsylvania  2007-2012

Courses: Adults in Acute Care, Senior Practicum, Health Assessment

Adjunct Faculty, York College of Pennsylvania  2004-2007

Courses: Basic Principals, Adults in Acute Care, Health Assessment

Clinical Registered Nurse, Holy Spirit Health System  2004-2009

Specialty: Surgical ICU

Clinical Registered Nurse, Wellspan Health  2001-2003

Specialty: Medical/Surgical ICU

Professional Organizations

Sigma Theta Tau, Nursing Honor Society  2000-Present

Certified Critical Care Nurse, AACN  2006-Present