**Review Article**

**Perceptions of Safety through the Experiences of Registered Nurse Family Caregivers**

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**Introduction**

In 1999, the Institute of Medicine (IOM) released a ground-breaking report that estimated approximately 44,000 to 98,000 people die in the United States each year due to preventable medical error, with a resultant loss of over $17 billion to $29 billion in healthcare costs, not including medical error that did not result in death [1]. In the twenty years since that IOM report was first published, better statistical methods and data sources have resulted in better estimates [2]. According to Makary and Daniel [2], approximately 250,000 to 440,000 deaths are actually occurring each year in the United States alone due to preventable medical error. Additionally, medical error is not an official cause of death on death certificates, which likely lead to the gross underestimation of deaths in the original reports [3].

Another IOM report was published in 2001, providing a framework of six aims with the goal of improving safety and quality of care [4]. The implementation of patient-centered care to improve care was presented as one of those six aims4. Patient-and Family-Centered Care (PFCC), now considered a best-practice method for providing care, builds on the idea of patient-centered care, and is inclusive of family members [5]. The implementation of PFCC has been shown to reduce hospital lengths of stay, decrease healthcare costs, and improve patient satisfaction [5,6]. Moreover, applying PFCC consistently can reduce the incidence of adverse safety events which can, in turn, reduce the number of suits for malpractice and decrease operational costs for healthcare organizations [7].

Family caregivers make up a large portion of the healthcare team, and their numbers grow each year as the population ages, lives longer with chronic diseases, and more healthcare is required in the home setting [8,9]. In fact, family caregivers provide such a vital role in United States healthcare that they are likened to an invisible workforce, with approximately 43.5 million family caregivers providing over 37 billion hours of unpaid care that is unpaid, offsetting $470 billion per year in healthcare spending [9-11]. Consequently, healthcare providers must better understand the experiences and perceptions the family caregiver has in order to form an effective partnership and provide better support for this important healthcare workforce [8,10].

Oftentimes, family caregivers are also Registered Nurses (RNs) [12-14]. While there is no way to know the exact number of these RN Family Caregivers (RNFCs), it is known that RNs comprise the largest portion of the healthcare occupation, with more than 2.7 million actively employed [15]. Due to their specialized knowledge and work experience, these RNFCs are in a unique position to be able to recognize and avert patient safety issues across multiple healthcare settings [16,17].

Little research has been conducted to better understand the RNFC experience or their perceptions on patient safety, and the few studies found in the literature were either conducted in countries other than the United States or were limited to the northern region of the United States [7-10]. Currently, there are no studies have been found in the literature related to RNFC experiences and perceptions of safety that were conducted in the southern region of the United States. Since philosophies and cultures can be regional in nature, the purpose of this study was to explore the lived experiences of RNFCs during an adult family member’s episode of care in the southern United States. The aim of this study was to explore the RNFC’s perceptions of the safety of care provided throughout an adult family member’s episode of care.

**Keywords:** Descriptive; Family caregivers; Interview; Patient- and family-centered care; Patient safety; Phenomenology; Qualitative; Registered nurse family caregivers

**Methods**

A descriptive phenomenological approach was chosen in order to capture the RNFCs’ humanistic perception of safety. The Institutional Review Board granted a waiver of documented consent was granted by the Institutional Review Board due to this study posing no more than minimal risk. Purposive sampling was used in order to recruit potential informants with rich experiences as RNFCs. Potential informants were asked for to participate in semi-structured interviews that would be conducted one-on-one and face-to-face with the Principal Investigator (PI). Potential participants were informed they could withdraw from the study at any time. Those who were eligible to participate were asked for verbal consent to participate in the study, to complete a demographics form, participate in the interview, and to be audio recorded.

**Sample and Screening**

The sample consisted of RNs who reported being a primary family caregiver for an adult family member hospitalized within the previous five years. For the purposes of this study, hospitalization was defined as an admission to an acute care hospital lasting more than 23 hours. Participants needed to have been working as an RN at the time of the experience and at the time of the interview. Participants were asked to discuss their experience as an RNFC during an episode of care, which could begin with any events leading up to a hospitalization and then any following care. If the family member that was hospitalized was younger than 18 years of age at the time of the experience or if the hospital was outside of the southern region of the United States, the RNFC was excluded from the study.

The PI gained permission to recruit at a large metropolitan hospital in Arkansas via an email list of employed RNs. The email included information about the study. The PI’s telephone number and email address were provided for anyone interested to contact the PI. The same recruitment message was posted on social media in a private page for Arkansas graduate nursing students in an attempt to gain participants from other locations. Snowball sampling also occurred as participants identified coworkers and other acquaintances with RNFC experiences. Screening took place via telephone conversation using the inclusion and exclusion criteria. Those who were eligible were asked to participate a one-on-one interview with the PI. Every participant wanted to interview as quickly as possible so that their stories could be heard. The PI continued to recruitment and screen potential participants until saturation of data occurred.

**Data Collection**

The PI met face-to-face with 25 RNFCs over a 2-week time frame in June 2018. Demographics were obtained via a PI-developed demographics form, and semi-structured interviews were conducted using a PI-developed interview guide. The interview guide was developed based on the core concepts of PFCC, as well as the purpose and aim of the study. Interviews were recorded using a digital audio recorder, and the PI kept field notes throughout each interview to record non-verbal communication to improve the richness of the data. Field notes were typed and expanded for inclusion in the data analysis.

During the interview, participants were asked to describe their perceptions of the safety of care provided for their loved one during the hospitalization and any subsequent care. Supplementary probe questions were asked if there was a need for clarification. Each participant could recall their experiences with great clarity and they were excited for others to know their stories.

**Data Analysis**

Demographic information was entered into Microsoft Excel and was analyzed using descriptive statistics. Microsoft Excel. The PI listened to each audio recording and wrote a verbatim transcription of each interview. Each transcript was reviewed for accuracy by the PI. Transcripts and field notes were then transferred into a qualitative data management software program for analysis. The PI chose to use the NVivo 12 for Mac [18] data management software due to its user-friendly interface.

After placement in the data management program, qualitative data were then analyzed using constant comparison and Colaizzi’s step-by-step method for descriptive data analysis. Colaizzi’s method involves familiarization with the data, identification of significant statements related to the phenomenon, formulation of meanings from the significant statements, clustering of similar themes major themes, producing a summarized but rich summary of the phenomenon, and seeking corroboration of the findings from the participants [19,20].

Data were coded in an inductive manner rather than developing a priori codes a priori [21]. A descriptive approach to coding was also undertaken to ensure congruence with the descriptive philosophical underpinnings of the study. The PI summarized ideas and concepts into short phrases to capture the basic subject of a text or quotation. Data saturation was thought to have been reached after 20 interviews were conducted, transcribed, and analyzed. In order confirm saturation had occurred, the PI conducted five additional interviews, after which it was established that data saturated had occurred.

**Results**

**Participant Characteristics**

Twenty-two women and three men participated in the study from seven counties in the state of Arkansas. Mean years of participant experience as an RN was 18.62, and a range of 3.5-39 years. The mean age of the participants was 47.6 with an age range of 30-65. Most of the participants were White (19; 76%). Other participant self-reported races included Black or African American (2; 8%), Native American or Pacific Islander (2; 8%), Asian and White (1; 4%), and American Indian or Alaska Native and White (1; 4%).

Most RNFCs were a staff nurse or a charge nurse at the time of their RNFC experience (19; 76%). Other working roles included manager/director (4; 16%), advanced practice registered nurse (4; 16%), researcher (2, 8%), and ‘other’ (nursing informaticist) (1; 4%). Highest nursing degrees earned at the time of the experience were Doctorate, (4; 16%), Master’s (7; 28%), Bachelor’s (10; 40%), Associate’s (3, 12%), and diploma (1; 4%).

Family members that were hospitalized during the experience included including parents (10; 40%), spouses (9; 36%), grandparents (2, 8%), mother-in-law (1; 4%), father-in-law (1; 4%), an aunt or uncle (1; 4%), and a sibling (1; 4%). No hospitalizations occurred in federal hospitals. All hospitalizations occurred in either local or state hospitals. Teaching hospitals comprised 13 (52%) of places of experiences, and non-teaching hospitals comprised 12 (48%) of the places of experience. While participants were invited to talk about an entire episode of care that could potentially include multiple healthcare facilities, specific data were not obtained regarding facilities that were not acute care hospitals. However, it was determined that the following care areas were discussed: emergency care, medical-surgical care, progressive or intermediate care, intensive care, rehabilitative care, long-term care, and hospice care.

**Qualitative Findings**

Qualitative data analysis of the interviews and field notes revealed a major theme, “Being Vigilant.” Subthemes included “Trusting Staff” and “Mistrusting Staff.”

Most participants equated trusting staff with staff they already knew or with staff that communicated well and provided a basic level of care. “Communication was great. I just cannot ask for anything better. “I know that doctor down there has always wanted to do the best for his patients and so I just felt like, ‘Okay, I’m going to go talk to you because you’re here and I have had positive prior experiences with you.’” “Part of me feels like she got that exceptional care because they knew who I was, because I had relationships with those nurses outside.” One RNFC discussed a situation where she recognized her grandmother was acting strangely. Nurses had not been by to assess that shift, so she went to the nursing staff. The grandmother’s oxygen saturation was in the 60s and they had to intervene. “Luckily from there on out it got better and they won my trust back. And boy, they were on their assessments. But what if I wasn’t a nurse and you know, she might not be here today because of that.”

Most participants described having a basic level of care that they expected nurses and other healthcare staff to provide, and they were very disappointed when that basic level of care had not been met. “I’d gone back in [the patient room] and he had urinated everywhere. And you could tell it had been there a really long time because it was sticky. Feet were sticking to the floor. I called the administration number. You feel like if you’re not there to make sure that they’re doing basic care, then they’re not [going to do it].”

RNFCs often compared their own care standards to the care being provided to their loved ones. “I found myself comparing what I would have done in that situation to what actually happened. I don’t know how well they are able to communicate, if they’re able to take time to communicate with families, but they need to.” Another RNFC said, “I guess the level of care, it was minimal compared to what I would think, what I’ve provided at my own workplace, and what I have seen provided at my workplace…it’s not what I would, as a manager, expect my staff to deliver.”

One RNFC initially thought she probably expected a higher level of care, but as she spoke, she realized she only wanted the same type of care she would herself provide. “As a nurse, I expected better. I expected more. Maybe my expectations were too high, but I don’t think so. I wanted the same care that I give my patients. I wanted somebody to listen and hear and acknowledge what we were saying. Not just bulldoze over it, which is kind of what I felt the physicians were doing.”

When RNFCs perceived that the level of care their loved one was receiving did not meet their minimal standard, they felt as though care was unsafe, suboptimal, or even unacceptable. This lead to a mistrust of staff and an increased vigilance on the part of the RNFC. “A lot of times…the nurses were slow to respond, or they just didn’t come and do it. Because ‘family is in the room, so they’re taking care of it.’ I mean, we might not be. And that’s part of the reason I probably stayed with her so much, is because I didn’t trust them as much to take care of her, like I felt she should be. And so I stayed more.” Another participant said, “As an RN, we have to, or we feel in our mind that we have to kind of double check what everyone’s doing. What are they doing? Are they doing it right? That’s not how you do it.” One RNFC recalled a time when his wife had undergone surgery and he asked for extra pillows. “She just had a human being torn out of her with cold steel and lots of prying instruments, and so I felt like [asking for pillows] was a reasonable request. I came back an hour and a half later and my wife was really complaining. I asked if she wanted medicine and she told me, ‘No, I want the pillow we asked for. I didn’t want to bother them because I thought it might be people you knew.’ So then I felt really crappy and I go up to the nurses…and I got this sob story [about having other patients]. And I said, ‘Yeah, but I’m one of those people, too. Furthermore, my wife is one of these people. If…you’re discompassionate [sic] toward me, I’m probably not gonna care because I’m a pretty tough guy and I try to be low maintenance. But this is my wife, this is somebody, who in the code that I live my life by, this is somebody I am charged with protecting and providing for and taking care of at every turn. I felt comfortable leaving this facility because I thought that you guys lived by that same code, and now I’m coming back an hour and a half later finding out that you just blew us off.’ And it was a simple request.”

Lack of communication or a perception that the RNFC was not being heard was a major factor in the RNFC losing trust in the healthcare staff. “There was this person who was coordinating care…we talked about what she was gonna do at the rehab, however long that goes, whatever the insurance pays for, and then she was gonna come home. But on the day she was to be discharged, he was really surprised that she was going home. He was preparing for her to be transferred down to the other end of the building. Never a word was said about that [to me]. He said, ‘You mean she’s not going to be long-term care?’ No. No she’s not. So that was a really poor way to plan care. Poor, poor, poor way to plan that because no word was ever mentioned of her being admitted to long-term care. It was always the plan to come back to my house.” One RNFC’s explicit request was ignored. “I told them, ‘You watch how much morphine you give her.’ Well, I got a call back at 4:00 in the morning, she’d gone into respiratory distress. They had kept giving her morphine until she just wasn’t breathing. When I got there they were intubating her…I do remember being very angry, very angry with the night staff and with the APRN because I had asked her specifically not to order morphine for Mother because of that very thing. And she did anyway…I felt that she wasn’t listening to me. And I even told her, I said, ‘You know, I’m not just her daughter. I’m a nurse as well. I know what’s going on.”

Once trust was lost, it was very difficult for the RNFC to leave their loved one for any period of time. Another RNFC stated, “It was hard to leave her there [in the long-term care facility]. [I would] worry and think about what was going on when I wasn’t there.”

**Discussion**

The purpose of a descriptive, phenomenological study is to deliver a dense description of the phenomenon in question [22-24]. The participants in this study were eager for their voices to be heard. The passion they had in their voices emphasized how important this topic was to them. As they spoke about safety issues they experienced along with their loved ones, it was as if they were reliving the experience. The participants simply wanted a basic level of care, and many of them felt that basic level of care had not been met. The unique perspective of RNFCs observing care for safety issues could potentially start the conversation for practical safety initiatives.

**Limitations**

This study is subject to limitations. All participants lived in similar geographical area within one state in the southern region of the United States, which could limit the transferability of this study. Also, an attempt was made to recruit a more diverse group of RNFCs, including more male participants, but the majority were white females. As cultural norms can differ amongst different peoples, a more diverse group of participants could result in different outcomes. Additionally, this study explored the experiences of RNFCs, and their perspectives mainly focused on the safety of care staff nurses provided. Therefore, additional studies including other types of healthcare staff is warranted to determine if safety issues are as evident to healthcare staff with different areas of expertise. Other future studies could include gathering suggestions for practical patient safety initiatives from those (such as RNFCs) who have observed or experienced safety issues from the other side of the bed.

**Conclusion**

Little research has been performed in the area of perceptions as experienced by RNFCs, but the findings from this study indicate that RNs in the southern United States are vigilant, almost as if they are on duty, when they are in the role of family caregiver. Their unique perspective from the other side of the bed could provide unique insight into practical, real-world application of patient safety initiatives.

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