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Ugandan Nurses' Experience of Caring for Persons Dying From Ebola Hemorrhagic Fever

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Abstract

Written narratives of 15 Ugandan nurses' experience of caring for persons dying from Ebola Hemorrhagic Fever were analyzed using van Manen's (1990) phenomenological approach. From these narratives emerged the description of caring for persons as affirmation of knowing and the uncertainty of living life while consciously waiting and protecting self through isolation from family and society, and the selfless dedication of giving one's life for others. Within this description is attributed the foci on health promotion, illness prevention, and early intervention as recommendations for effective nursing in community wellness practice.

Key Words: Caring, communicable life-threatening disease, Ebola Hemorrhagic Fever, dedication, knowing, lived world, phenomenology, Ugandan, uncertainty, waiting

"As a nurse I was obliged to care for these patients but it was a horrible experience. The whole place was 'smelling' death…and I can still recall that unique smell."

Introduction

Some experiences are very difficult to forget even with the passing of time. This is particularly true for nurses who have witnessed deaths from Ebola Hemorrhagic Fever (Ebola). Yet, the nurses' experiences of caring for persons dying from Ebola are not well-known. The purpose of this study was to describe the experience of nurses caring for persons dying from Ebola in Uganda.

Knowing nurses' experiences of caring for persons dying from Ebola eventually inform future nursing care of persons, not only those who will die of Ebola, but also the nursing care of those who will have similar life-threatening experiences.

Background

Ebola Hemorrhagic Fever

Ebola is a severe acute life-threatening contagious disease that has sporadically appeared in Uganda since 1976. The Ebola virus, identified as causing illness in humans, is of the Filoviridae family, which is comprised of four subtypes: Cote d'Ivoire, Sudan, Gabon, and Zaire. A large epidemic of Ebola occurred in 1995 in Kikwit, Democratic Republic of the Congo, with 315 persons infected of whom 254 died. The identified virus for this outbreak was the Ebola-Sudan subtype, similar to that found in 2000 to 2001 in Uganda where infections occurred in three districts: Gulu, Masindi, and Mbarara. These deaths included many healthcare workers in the hospitals. From 2001 to 2003, several Ebola outbreaks of the Zaire subtype were reported in Gabon and the Republic of the Congo with 302 persons diagnosed and 254 deaths (World Health Organization [WHO], 2004). In 2007 the Ebola pandemic occurred again in Uganda. Hundreds of people were suspected of being infected, including healthcare workers (Health Note, 2007).

Persons can be exposed to Ebola virus from direct contact with the blood, secretions, and body fluids of an infected person, including exposure through contact with objects, such as needles contaminated with infected secretions. Any person with close physical contact to patients should be kept under strict surveillance: body temperature checks twice daily with immediate hospitalization and strict isolation recommended in cases of fever onset. The incubation period for this virus is 2 to 21 days. There is no specific treatment or vaccine for Ebola (Centers for Disease Control and Prevention, 2002; WHO, 2004).

Literature Review

Studies about caring for persons with Ebola were scarce. Many studies investigated the epidemiology, laboratory detection, treatments, and vaccine-possibilities of the disease (Clercq, 2006; Geisbert et al., 2006; Hewlett & Amola, 2003; Hyde-Price, 2000; Ksiazek, West, & Rollin, 1999; McDonald, 1995) and only a few studies were performed regarding Ebola in relation

to caring and nursing. These studies explored the experiences of persons exposed to patients who were diagnosed with Ebola in Uganda (Locsin, 2002; Locsin, 2003; Locsin & Matua, 2002) and the experiences of survivors of Ebola (Locsin, Barnard, Matua, & Bongomin, 2003; Matua & Locsin, 2005).

In one study (Locsin & Matua, 2002), the phenomenon of waiting to know was studied during a pandemic of Ebola by using descriptions of those who were exposed to Ebola patients. The participants were physicians, medical students, and nurses. The findings provided understandings of waiting to know, such as "anticipating death while hoping for life" and "ceaseless fear." In addition, Locsin (2002, 2003) used artworks to communicate these descriptive statements, facilitating an understanding of the experience of waiting to know. In 2003, the experiences of survivors from Ebola were explored (Locsin et al., 2003). In this study, survivors' experiences were expressed in the form of arts. In 2005, the experience of persons who survived Ebola was published in a book (Matua & Locsin, 2005). These prior studies were not specifically directed to uncover the experience of nurses. Therefore, this current study was designed to explore the experience of nurses caring for persons dying from Ebola.

Methodology

Setting and Sampling

Approval to conduct the study was obtained from the Ethics and Research Committees of Mbarara University of Science and Technology. Data were collected in 2006, 5 years after the Ebola pandemic in Uganda. A purposeful convenient sampling was used to recruit participants from three hospitals that had admitted patients in their respective Ebola units during the 2000 to 2001 pandemic. The hospitals were Mbarara University Teaching Hospital, the Masindi District Hospital, and the Lachore Hospital in Gulu, Uganda.

Participants

The criteria for participant selection included nurses who experienced caring for persons dying from Ebola, were able to describe their experiences in writing and in English, and agreed to participate in the study. With written descriptions, stigmatization as a person exposed to patients dying from Ebola was avoided. Otherwise, being known as a participant in the study can mean that the person had contact with persons dying from Ebola, increasing the likelihood to be socially ostracized. This likelihood may be possible if the participants were being interviewed. In the study by Locsin and Matua (2002), they used this process of data generation, i.e., using written descriptions of participants' experiences that successfully yielded rich data.

Fifteen nurses who worked in Ebola units in Uganda voluntarily participated by completing the questionnaire and the demographic forms, and by returning signed consent forms. There were 14 female nurses and 1 male nurse whose ages ranged from 28 years old to 53 years old (Mean 36.4 years old). Their educational achievement was between 14 to 20 years (Mean 15.6 years). The extent of exposure to patients who had Ebola ranged from 2 days to 120 days (Mean 62.5 days).

Data Generation and Analysis

The narrative descriptions of the participants' experiences were guided by the following questions:

- What was your experience like caring for patients with Ebola?
- What does/did it mean to you to care for patients with Ebola?
- Please describe/relate all your experiences, including stories and other situations that you believe may be relevant to your experience. Kindly do this until there is nothing more you can say about your experience.

Written narratives from these questions were analyzed using van Manen's (1990) hermeneutic phenomenological approach. Van Manen's hermeneutic phenomenological approach is an approach that explores the structure of human life worlds as experienced in everyday existence. The structure of these life worlds comprises the complex union of four fundamental existentials of the lived world of time (temporality), space (spatiality), relation (relationality), and body (corporeality).

The researchers read and reread the descriptions of the experience of "caring for" persons dying from Ebola many times while highlighting particular, essential statement(s) or phrase(s). The themes were identified, interpreted, and categorized.

The thematic categories reflecting the phenomenon of "caring for" persons were considered within the four life worlds (van Manen, 1990). The rigor of research was established using credibility, auditability, and transferability as considered by Lincoln and Guba (1985).

Findings

The participants of the study ably and vividly recalled their experiences as if these were very recent experiences. As one participant wrote, "It left an everlasting sad memory in my mind, such that every time I evoke these memories these feel fresh in my mind."

To understand the meaning of the experience of caring for persons dying from Ebola, four thematic categories derived from the analyzed data were reflected on the four lived worlds as described by van Manen (1990). These are the lived worlds of time, space, relations, and body.

Lived Time (Temporality)

Thematic category: Uncertainty of life while consciously waiting to know. Uncertainty of life while consciously waiting to know whether or not they are infected with the Ebola virus is the theme that depicts the participants' consciousness of the lived world of time. Waiting to know the result of one's exposure to Ebola contributed to the ultimate uncertainty of life and the anticipation of dying from the highly contagious and life-threatening illness.

Uncertainty was felt over time because of contamination—the longer one is exposed the more the likelihood of contamination.

Participants expressed their hopelessness and that they might die anytime. They thought that they might be the next victims and would have no chance of living their lives fully. Dying was a constant reminder of life as a temporary condition. The participants focused their thoughts on their own deaths rather than on their living in the present and concerns for the future, as one participant claimed:

> Ebola makes people die prematurely. Here, I mean, every day you think that by tomorrow I will be dead, hence you cease to plan for tomorrow. You live a wired life because you know any way, any time you may be gone.

Uncertainty is vividly expressed by the participants including the feeling of self-doubt, whether or not they consistently exercised the right procedure to maintain a contagion-free workplace, thus decreasing the chance of exposure to Ebola. Furthermore, uncertainty was experienced even though the participants had passed the period of self-monitoring (incubation period of the disease is from 2 to 21 days [Bwaka et al., 1999]) and no longer worked at the Ebola units. The participants lived with self-doubt, continuing to express the anguish and anticipation of death while "waiting" for Ebola to return, continually thinking that Ebola might be activated and will render them more susceptible to it. One participant exclaimed:

> For one to actually understand what we went through is not easy, for it cannot be clearly explained like this, because once in a while you always think that maybe one day it will explode. Maybe the Ebola is in a dormant stage. Many things keep going round and round my mind. As for now, I believe I am safe but who knows? I am waiting for the unknown in the future to come.

The appreciation and willful hope of future time was foremost in their minds, although this was constantly debunked by the now—uncertainty of being infected by the Ebola virus. The understanding of the lived world of time provided a general appreciation of caring for the patient as other—that time in the present was more appreciated because the conscious concern is the now and the realization of the uncertainty of waiting to know.

Lived Space (Spatiality)

Thematic category: Being isolated resulting in self-isolation from family and society. This isolation was tantamount to discrimination—being isolated resulted in self-isolation from family, friends, and society. This is a consistent view within the appreciation of space—spatiality as the lived world encountered by the participants in their experience of caring for persons dying from Ebola. Being known as working in an Ebola unit creates fear that often clouds the understanding by friends and family members. The fear of contracting the disease and not knowing how the disease is spread affects the perception of lived space—the perceived space of the victim of Ebola, that those caring for them now have the disease. Participants expressed that people feared them and kept away from them, "They distanced themselves from us," as claimed one participant.

People understood that the participants' were contaminated with the Ebola virus, thereby acknowledging the limited space of the participants. That is, the participants lived space could not be shared with family members and with others because of the fear of being infected with the disease and the uncertainty that envelops the condition, enhancing susceptibility to the life-threatening illness. This space became a guarded space—no place for the public, including the participants, especially when the participants made it known that they were not communicable and that they were not the bearer of the virus of the Ebola. As a participant claimed:

> Colleagues would move away from us. The issue of "chasing" us from the main hospital included when I would go to the pharmacy to collect drugs. They would shout, "Stop there! Do not enter please!" And would go as far as giving you more drugs than you have requested so that you take longer to come back for more drugs.

The understanding of isolation within a social world is feeling useless in care situations. This isolation often occurs in situations that limit the occasion of a patient's social activities, such as the limitation of the patient's social environmental being controlled by a lasting self-doubt – of feeling useless in a caring social world. As a participant exclaimed:

> You meet nurses on the way and they would not even want to look to your direction or they do not want to meet with you or they simply turn away and take another direction so that you do not recognize them. They would not even allow you to greet them or spend some time discussing anything with them.

The participants were limited in their space—living in the Ebola units in uncomfortable and defined space destined to be sequestered away from family members and not being in their homes until the declaration that Uganda was free of Ebola. However, this occurred only when the apprehension of contamination of the neighbors and friends were also curtailed. Not only were the participants isolated by family and the community, the participants were isolated themselves and kept their space from others. A participant revealed, "I stopped breastfeeding my baby. My children were concerned, asking me question after questions why I had isolated myself from them. I tried to discuss it with them but all were in vain."

Lived Relation (Relationality)

Thematic category: Self-dedication by giving one's life for others. Self-dedication by giving one's life for others is the thematic statement that describes the lived experience of relationality. The participants devoted themselves to care for others—

those who were diagnosed with Ebola. The participants conveyed that they gave their own selves to be with the victims. This self-dedication for others depicted a conscious giving of self in an intentional relationship. In this situation, the participants had courage and conscious commitment to care for and be with the victims in an uncertain situation. The participants described their relationships with others as being compassionate, inspiring them to be brave and trusting, and withstanding the isolation, the expected stigmatization, and social discrimination. As a participant declared:

> Caring for Ebola-infected patients needed self-dedication. One needed to be empathetic because I can only imagine myself getting the disease and feeling bad about it. Many questions were going on in my mind, I asked, "If we don't nurse these infected patients who else will?" I sympathized with them, giving me courage. I kept away from those colleagues who were discouraging me, who even stated that we shall also die as those patients we were nursing.

Even though the participants were stigmatized as Ebola nurses, they had the compassion to continue their care for patients in the Ebola units. They recognized this as a responsibility of professional nurses, realizing that persons with Ebola have the same rights to be cared for as anyone else. As one participant verbalized:

> It was a commitment. If I am to quote from the code of nursing profession, it says, "Nursing patients is to promote health, prevent illness and alleviate the sufferings." Ebola patients had equal rights too.

Additionally, the participants described that they had to devote themselves to working hard in the Ebola units. Hard work entailed their presence—providing extensive physical, psychological, and spiritual care. For physical care, the participants worked hard to relieve and reduce the physico-physiological effects of the symptoms of the disease and, to most of their patients, provide palliative care. For psychological and spiritual care, the participants realized that patients with Ebola needed love, and that caring for them was a privilege as their relatives could not be with them and support them while they were in the Ebola units. Because of this situation, patients could be perceived as demanding a lot of kindness from the participants who were providing care. Building trusting relationships between the participants and the victims was critical because the participant was the only person whom the Ebola victims could trust to deliver their wishes to their loved ones. As a participant claimed:

> It wasn't just caring for their physical and psychological needs, but also the spiritual needs. It meant that you might be last person the patient will ever talk to in his life, so being there for them was very important. Building confidence was another important consideration because some of them needed to confide in someone who can deliver their wishes to their beloved ones. They were very anxious. They were very depressed and they needed an understanding person to be with them. No one can imagine what those patients were going through.

Self-dedication by working hard also meant that the participants worked overtime with caring for the victims while being conscious about maintaining universal precautions. Hence, caring for Ebola patients required adequate staffing. The nurses needed to be physically and spiritually fit in order to provide care for the victims. As a participant expressed:

> Enough trained manpower is very essential for the care of Ebola patients. A friend of mine died because of overworking herself. There should be enough people caring for Ebola patients so that they are not overworked, hence reducing the risk of accidents, which is common when one is tired.

Lived Body (Corporeality)

Thematic category: Affirmation through knowing and protecting self. In caring for persons with Ebola, the participants described their experiences as meaningful in relation to the lived body. The participants used their bodies in every possible way to maintain self-worth, even when faced with the unpleasant feelings of fear, hopelessness, and aloneness brought about by the thought of stigmatization - of being exposed to Ebola patients. The participants revealed that their bodies succumbed to the apprehension of being contaminated with Ebola. Psychosomatic signs and symptoms associated with Ebola were commonly exhibited, including fever and body malaise. While exhibiting these physiological uncertainties, the participants' physical bodies showed physical and mental exhaustion. Working too many hours in the Ebola units and being vigilant and alert to protect them from contracting the "killer" disease were exhausting demands on the psycho-physical nature of the human body.

With nurses and healthcare workers dying from contracting the disease while caring for persons in Ebola units, this type of work assignment became more voluntary. In addition, outside organizations provided various supports, including a team of foreign-educated healthcare team members that was assigned to Mbarara University Teaching Hospital. Knowing how to protect oneself and provide care of the person with the disease were significant aspects made known to the participants who worked at the Ebola units. One participant explained:

> So when nurses and other medical staff began to hear that there is an unknown disease coming, nurses began to avoid working until they were called "by force" when the expatriate team came in to join us. They started to teach us how to "handle" this disease.

Furthermore, counseling and time were the vital matters found to be supportive—to be consistent and firm about the routine care of persons with Ebola. Knowing about how to protect oneself and doing self-reflection during counseling sessions enhance self-confidence in caring for persons who

had Ebola. One participant exclaimed:

> At first I used to think that I was harboring the disease, but as time went by I started consoling myself, reflecting back to what we were doing—that actually we did the right thing. If there were another outbreak of Ebola, I would go back and nurse those patients, so long as there are protective gears and teamwork.

The strength to endure and meet the demands and expectations experienced by participants seemed to have come from the continuous counseling and reflection of their conscientious practice—being reminded about proper use of protective gear, adhering to guidelines, and, more importantly, working as a team.

Description of the Unique Meaning of the Experience

The experience of caring for persons dying from Ebola is comprised of a common description of knowing the experience of being with a person in a life-threatening situation and understanding what it was like caring for these persons living in illness that may create a deadly situation for one's own life. The unique meaning of this lived experience of caring for persons dying from Ebola is affirmation of knowing persons through the uncertainty of living life while consciously waiting to know, and protecting self, and achieving these through isolating self from family and society as the selfless dedication of giving one's life so others may live.

Describing the Experience Through Artistic Expression

Artistic expression is a way to facilitate appreciation of the meaning of the lived experience (Locsin, 2002). This study used artistic expression to reflect the meaning of the experience of caring for persons dying from Ebola. This is exemplified in Figure 1. The painting, *Gulf Stream*, by Winslow Homer in 1889, is an artwork that employs a representation of the unique meaning of the experience. In this painting, a man lived with uncertainty teetering between life and death—surviving strong winds and waves that batter his boat while sharks swim, encircling his boat, depicting a visual imagery of a precarious life and the eventuality of death. This represents the uncertainty of living life - consciously waiting to know whether or not the nurses caring for persons dying from Ebola will succumb to the disease, realizing, like the man on his boat, that over time the Ebola virus (the swimming sharks) will eventually succeed by successfully setting out from its dormant stage.

The man, alone in the boat was battling with the sharks, representing his isolation of self within the boat, including from his family and society. Yet, in all these efforts, the understanding of selfless dedication—giving one's life so others may live—becomes the consummate appreciation of living life fully as professional nurses with the responsibilities and hopefulness of living life more fully as person. The man in Homer's painting knew how to protect himself from the sharks—keeping balance and keeping a lookout for the ship in the horizon. This presumptive action affirms the man's presence to secure life while living in uncertainty and a life-threatening situation.

Figure 1. The Gulf Stream, Winslow Homer, 1889.
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Discussion

This hermeneutic phenomenological study reveals Ugandan nurses' experience of caring for persons dying from Ebola after the epidemic period. The delayed study is because of the difficulty in recruiting the participants during the actual outbreak. However, the participants evoked and reflected their experience well, as if they were presently living the phenomenon. This study may serve as an example of possible retrospective studies for similar experiences from contagious life-threatening diseases.

This study provides findings in the theme of uncertainty of life while consciously waiting to know, affirming the findings of prior studies (Locsin, 2002, 2003; Locsin & Matua, 2002; Locsin et al., 2003) in which the phenomenon investigated was the experience of waiting to know whether or not healthcare providers were infected with Ebola when they were exposed to patients dying from Ebola. The findings of the previous studies and the current study illustrate that while the monitoring period had passed and the nurses knew that they were not in-

fected, they continued to live a life that was uncertain. For years after the outbreak the nurses continued to be anxious about possible infection with the virus and continued to experience the anguish while waiting to know whether or not Ebola will unleash its fury, again.

In this current study, the nurses' fear of death while hoping for life was experienced similar to the experience of the previous studies, in which feelings of hopelessness for the future dominated the expression of uncertainty of life. This finding of uncertainty of life was also experienced by those nurses caring for persons who were diagnosed with Severe Acute Respiratory Syndrome (SARS) in Hong Kong during the epidemic (Chung, Wong, Suen, & Chung, 2005; Mok, Chung, Chung, & Wong, 2005).

The theme "Being Isolated Resulting In Self-Isolation from Family and Society" is a consequence of being exposed to Ebola patients. This theme affirms the finding in Locsin and Matua's (2002) study in which resident medical students felt they were socially isolated from family and friends because of the perceived exposure they had being in proximity of persons dying from Ebola. The findings of this theme also affirm the stigmatization of those exposed to patients with Ebola as found by Hewlett and Hewlett (2005). They examined the experiences of nurses who provided care in the Ebola units during the three outbreaks of Ebola in Central Africa, between 1995 and 2003. Stigmatization was described as the fear and rejection that nurses, their families, colleagues, and community felt for them as nurses who worked in the Ebola unit. They were called "Ebola people." Hewlett and Hewlett noted that the stigmatization ensued because of the lack of knowledge about the disease and the contamination spectrum, i.e., incubation period, vehicle of transmission, and sequel. Like Hewlett and Hewlett's findings, stigmatization was also described in studies about the experiences of people during the SARS epidemic in Hong Kong (Cava, Fay, Beanlands, McCay, & Wignall, 2005; Mok et al., 2005).

Two themes that were not reported in the prior studies (Locsin, 2002, 2003; Locsin et al., 2003; Locsin & Matua, 2002; Matua & Locsin, 2005) include "Self-Dedication By Giving One's Life for Others" and "Affirmation Through Knowing and Protecting Self." However, the theme "Self-Dedication By Giving One's Life For Others" was found to be similar to the findings of Hewlett and Hewlett (2005).

In this current study, the findings of the theme "Self-Dedication By Giving One's Life for Others" illustrate the realization of professional commitments as crucial to nurses' devotion to self and to others. This devotion is characterized by unconditionally being with – a demanding opportunity to know persons more fully as persons. The lived experience of nurses caring for persons dying from Ebola suggests a focused understanding on commitment to the profession. This was similarly described by the nurses in the study by Hewlett and Hewlett (2005). The nurses described that they were committed to provide care for the persons infected with Ebola even though they lacked the proper training to deal with this epidemic, were at high risk for infection, received little pay, and were eventually stigmatized.

The theme "Affirmation Through Knowing and Protecting Self" is one of the recent themes that described the experiences of nurses caring for persons dying from Ebola. This lived experience of nurses caring for declares the valuing of knowing persons as significant to caring for persons. This knowing of persons is focused on the appreciation of the other (the person dying from Ebola) as an authentic expression of understanding self and other—truly being with the nursed even in situations of isolation and being isolated. Empathy was an expression of the relationship—the lived world of relations—feeling for the other as the other succumbs to the expression of a shortened life. The experience of affirmation through knowing and protecting self assisted the nurses to build trusting relationships with those persons dying from Ebola, while providing compassionate and holistic nursing care. Additionally, the nurses declared that knowing about Ebola and protecting themselves from it, assisted them well to be confident about their knowing and not to be afraid and not to fear caring for persons who are infectious.

Implications

The findings of the study suggest that awareness about life-threatening illnesses and diseases is a global healthcare concern. Organizations and international nursing professional communities need to create policies that support standard and effective practices in caring for persons with life-threatening illnesses whose deaths are impending. Following are implications based on the findings of the study:

- Developing an effective system of care to prepare nurses and other healthcare providers, or others in high-risk areas, to know more about the disease and its dissemination, and how they can be protected and to care for themselves as a community. Continuing focus on health promotion, illness prevention, and early intervention are critical aspects of community care. This includes providing training and consulting services.
- Providing adequate staffing and supporting with appropriate funding.
- Rewarding and honoring nurses and healthcare providers who dedicate themselves to care for these often isolated and stigmatized patients.
- Enhancing research to improve and develop quality of life of the nurses and other healthcare providers before, during, and after caring for persons with life-threatening illnesses.
- Enhancing research to explore factors to encourage nurses and other health care staff to provide care for persons with life-threatening and communicable disease with fervor, dedication, compassion, and diligence.

Study Limitations

Limitations of the study focus on the concern about including only those participants who were fluent in oral and written English. Having participants describe their experiences in their own local language may have provided more rich descriptions perhaps producing other perspectives of the phenomenon of caring for persons dying from Ebola. Positing this limitation magnifies the realization and recognition of excellent language translations as a critical determinant to obtaining rich descriptive data and in ensuring trustworthy, rigorous, and valuable study findings.

Conclusion

This study launches the descriptions of the phenomenon of "caring for" persons—that uncertainty of life, stigmatization, and self-dedication to care are universal experiences of nurses caring for the persons who succumb to unpredictable situations, particularly those involving life-threatening illnesses. Knowing a person as a complete human being and knowing how to protect oneself are necessary to caring for persons who may succumb to life-threatening illnesses such as Ebola Hemorrhagic Fever.

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