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The Experience of Separation and Grief Among Family Members of Hospitalized African American Patients Who Expired From COVID-19

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ABSTRACT

The coronavirus disease (COVID-19) pandemic highlighted multiple consternations in our healthcare system, among which were the lack of preparedness of our federal public health response, impact on our frontline responders, recognition and contributions and burden on our essential workers, and disparity in health challenges and outcomes among minority patients diagnosed with the disease. However, little focus has been given to understanding the experience of abrupt separation and grief on the family members of COVID-19 patients. The purpose of this study was to understand, using a phenomenological design, the experience of separation and grief among family members of a group of African American patients who were hospitalized and subsequently expired from COVID-19 during the first surge of the pandemic. A purposive sample of 10 family members of patients who were hospitalized with and later expired from COVID-19 were recruited. Data collection was conducted using unstructured interviews. To capture the essences and meaning of this lived experience, the study was underpinned by Heidegger's (1962) phenomenological perspective and was guided by van Manen's (1990) methodological activities. The findings revealed that, for these participants, lived time was a marker of the rhythmic patterns of events during the experience, lived space was the confrontation of new limitations amid the dynamics of chaos and uncertainty, and lived relation (i.e., relationality) highlighted the caring/noncaring attributes of social and healthcare networks and their embrace of spirituality while coping with stigma and blame. Lived body emoted the parallel physical and emotional manifestation of the disease.

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Introduction

In New York City, between February 2020 and June 2020, 202,000 persons were diagnosed with coronavirus disease 2019 (COVID-19) of whom 18,0600 persons died [1-2]. Older people, those with underlying medical conditions, those residing in lower socioeconomic neighborhoods, and racial and ethnic minorities were disproportionately affected [3]. This pandemic focused attention on the multiple disparities in the healthcare system, lack of preparedness of federal response, impact on frontline responders, disproportionate adverse burden on essential workers and the health challenges, and outcomes of patients diagnosed with the disease. One of the areas that was and continues to be highly problematic is the health inequity that exists between non-Hispanic White people and racial/ethnic marginalized populations. The Center for Disease Control reported that in the United States, African Americans, Hispanics/Latinos, Native Americans, Native Hawaiians, and Pacific Islanders were more likely than other racial/ethnic groups to die of COVID-19 [4].

Racism, intentionally or unintentionally, has been identified as one of the driving forces of the social determinants of health [5]. Recent studies have revealed that despite the improvements in the overall health in the United States, racial and ethnic minorities experience a lower quality of health care. These patients were less likely to receive routine medical care, and they faced higher rates of morbidity and mortality than non-minorities. These studies also showed that racial and ethnic discrimination from providers towards persons of color negatively affected health outcomes, thus preventing persons of color from attaining their optimum level of health [6,7,8]. These issues are further supported by the Institute of Medicine (IOM) report which highlighted that bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in health care and that a greater understanding of the prevalence and influence of these processes was needed and should be sought through research [9].

Historically, African Americans have had ongoing mistrust of the healthcare system that dates back to when enslaved Black women were used for the development of gynecological instruments, the forced sterilization of Black women, and the Tuskegee Syphilis studies that were conducted on unsuspecting Black males [3]. A study by Hoffman et al. found that 50% of medical students and residents believed that the Black body is biologically different and, in many cases, stronger than the white body [10]. This false perception, the authors stated, influenced racial bias in the prediction of Black patients' pain. Findings from other studies have indicated Black patients, including children, are less likely to be prescribed pain medication, and in the event they are prescribed pain medications they are likely to be given smaller dosage and quantities as compared to White patients [11,12].

The life and death risks associated with transmission during the first wave of COVID-19 infection resulted in drastic changes to most hospitals' admission and visiting protocols. Jaswanie, et al. found inconsistent hospital visiting protocols during this time [13].

However anecdotal information from one epicenter community showed that, during the first surge of the pandemic, family members were restricted from accompanying patients into the emergency department (ED) or any other area of the hospital. For some family members in the current study, the last time they saw their family member alive occurred in handing over a loved one to emergency staff. The unasked expectation was for families to trust that, in this time of crisis, healthcare providers would provide safe and unbiased care. For families of color, overcoming the hurdle of ingrained mistrust of the healthcare system was challenging and contributed to feelings of anticipated loss and grief.

Studies have shown that grief is a natural response to loss [14]. Grief can also occur in response to drastic changes to lifestyle and daily routine. During the initial phase of the pandemic, family members faced the high possibility that a diagnosis of COVID-19 was fatal. So, these family members were likely to experience a wide range of pre-loss grief (PLG) responses even before their family member had died. These reactions could range from what might be considered normal such as anger, sadness, and tearfulness to more severe reactions. Severe PLG is a syndrome characterized by debilitating grief symptoms prior to the death of a loved one, and it is highly correlated with prolonged grief disorder. The unpreparedness for the separation, loss, lack of communication or misinformation by providers, and isolation intensify the pre-loss grief symptoms [9]. These factors, in addition to mistrust of the healthcare system, may be particularly challenging for African American families.

Purpose

The purpose of this study is to understand, using a phenomenological design, the meaning of the experience of abrupt separation, PLG, and grief among family members of African American patients who were hospitalized and subsequently expired from COVID-19 during the first surge of the pandemic. Prior studies related to COVID-19 had focused on the pathophysiology, management, and treatment of COVID-19 [1] as well as the experiences of those diagnosed with COVID-19 [2] and frontline healthcare providers [15,16,17] overlooking family members of COVID-19 patients specifically members of minority population.

Protection of Human Participation

Institutional Review Board (IRB) approval was obtained from Molloy University. Pseudonyms were used to protect confidentiality, and transcripts were vetted to remove any means of identification. Informed consent and demographics documents were transmitted to and from participants and researchers via a secure encrypted line. When not in use by the researchers, recordings and transcriptions were kept in a password-protected electronic file accessible only to the researchers.

Design and Method

The focus of this study was to uncover from the participants rich descriptions of their lived experiences, the essences of the phenomenon. A qualitative approach using a phenomenological design underpinned by Heidegger's philosophical framework and van Manen's methodological activities guided this study [18-19]. This perspective assisted the researchers in bringing forth meaning from the participants' descriptions of their lived experiences, thus enabling a deeper understanding of the phenomenon. Adhering to van Manen's perspective that all phenomenology is hermeneutical, the researchers proposed the following assumptions: the descriptions provided by participants of their lived world experiences were already meaningfully interpreted by them and researchers' tasks of communicating participants' descriptions of their lived experience into text and the processes of reflection and analysis were also considered to be meaningful interpretations of the phenomena under investigation. These perspectives suggest that the findings arise not only from the pure description but also the interpretation of the researcher [20].

Purposive criterion sampling was used to identify persons who had experienced the phenomenon. Recruitment of prospective candidates was conducted using snowballing technique and professional referrals. Prospective participants were given information about the study's purpose, inclusion criteria, and duration and extent of interviews. A sample of 10 participants who met the inclusion criteria and were willing to participate were selected. Inclusion criteria comprised of having a family member of an African American person who was hospitalized with, and subsequently died, of COVID-19; possessing the ability to speak and understand English; and expressing a willingness to share the experience. The sample consisted of seven females and three males. Six were spouses and four were children of the deceased. The ratio of family member to patient was 1:1. Seven of the participants currently worked at or had retired from various areas of health care.

Data Collection

Data collection was conducted during the last quarter of 2020 and the first two quarters of 2021. After signed informed consent was obtained, participants were requested to complete a short demographic form related to age, education level, income, relationship to the patient, and insurance (data on insurance helped to address access to care). Lasting between 45 and 90 minutes, in-depth unstructured interviews were employed to access the first-hand lived experiences of the participants. Due to the restrictions imposed due to the COVID-19 pandemic, interviews were conducted via Zoom platform, and as such, they were visually and auditorily recorded. Interviews were conducted in a private office of the first two researchers. Participants identified a private space of their own. The phenomenological request posed was "Please tell me what your experience was during the time your family member was diagnosed with COVID-19, admitted to the hospital, and subsequently died?" For most of the participants, this question resulted in a comprehensive description of their lived experiences with the phenomenon. As the participants described their experiences, the researcher used specific probing and reflective questions and comments to obtain clarity as needed. The interviews were then transcribed verbatim. All transcripts and recordings were coded and placed in an encrypted file on the primary researcher's computer. Field notes were created with each interview and memos were generated throughout the process. These served as additional forms of data collection and functioned also as audit trails.

Data Analysis

Each recorded interview and transcript was reconciled and reviewed individually and together by all members of the research team. This ensured accuracy and facilitated the process of data familiarity and immersion [20]. The guide employed to explore, analyze, and categorize the data was four existential or lived worlds: lived space (spatiality) referred to the one's physical or emotional world, lived body (corporeality) referred to the idea that one is always bodily in the world, lived time (temporality) which captured one's subjective clock that identifies points along the experiences, and lived other (relationality) that captured the interconnection with others[21].

The researchers immersed themselves in each of the ten transcripts by reading and reading, using the line-by-line highlighting method to identify words, phrases, and sentences that responded to the research question. Thematic analysis was done by grouping the identified responses into categories, subcategories, and emerging themes, which described the lived experiences of being a family member of a patient who was hospitalized and subsequently expired from COVID-19. The transcripts and emergent themes were then examined, to identify commonalities and differences of the evolving concepts within the lived world of space, time, relation, and bodily experiences of these participants. From this process significant themes, those without which the phenomena would not be, were developed.

Findings

Van Manen's (1990) four lived world existential were used as a lens to uncover the essences of the participants lived experiences and illuminate the meanings of their rich descriptions. The meaning of the experience of pre-loss separation and grief for these participants was as follows: Lived Time (Temporality)
Lived time was a marker of the rhythmic patterns of events during the experience. It referred to the ways in which participants experienced their world not only in the objective or factual clock time but also on a temporal level.

The paradoxical context of time was evident in the participants' descriptions. Participants referred to their perception of the slow movement of time while anxiously awaiting a response to their phone calls seeking a condition update from the clinical staff. Others acknowledged their appreciation that the staff was busy and that donning and doffing protective equipment took time; some verbalized feelings of guilt knowing that nurses took time away from patient care, to respond to their phone calls. On the other hand, others articulated perceptions of feeling slighted and belittled when encountering perceived negative or devalued tone by staff this resulted in participants perception that their time was not of value. Georgia reported frequently being "placed on hold for 45 to 60 minutes, only to be told he is not my patient . . . or he is ok."

The stillness of time was fueled by anxious anticipation and fear. Participants reported the accelerated anguish of waiting, and then receiving that unsolicited call from the hospital, which signaled deterioration in the patient's condition. The perceived speed at which it all happened confirmed Kurt's statement that his father died within 24 hours of admission to the hospital conveyed another dimension of time as a marker of the events as they unfolded. "When that call came, everything went silent for a minute or so. Then I said, 'okay.'"

They acknowledged the precious nature of maximizing the passage time. This was evident as Gigi stated, "After almost two weeks of hospitalization, [my husband] was discharged home. We spent that week talking, watching movies, just chatting. It was as if we knew that time was precious. He was readmitted one week later, coded, and expired after 31 days on the ventilator."

Lived Space (Spatiality)

Lived space (spatiality) encapsulated the confrontation of new limitations amid chaos and uncertainty. For these participants, lived space signaled the confrontations of new limitations amid chaos and uncertainty. The issue of space and location was a recurring theme. Some participants reported difficulty locating loved ones once they were turned over to the healthcare system. Ana related that, though she followed the ambulance to the hospital, when she arrived and waited for hours outside, staff informed her that "your husband is not here." Pat recalled that, during April [2020] the hospital was no place to be: "My mother called an ambulance herself; she was having trouble breathing . . . the paramedics advised her to go to an urgent care center rather than the hospital." Gigi and Kurt, participants living in two widely separate locations, reported sitting for hours in their cars in the hospital parking lot as they endeavored to decrease the proximity between their loved ones and themselves. Gigi stated, "I only left because I had to go home to the kids, but I returned the next day." Georgia spoke about balancing the care of her sick husband in their small apartment with the preventative measures needed to keep her young daughter from contacting the virus. "I felt guilty when he went to hospital and I did not see him, and he died, but I thought about my daughter."

Even after death, space remained a major concern. Ana expressed the urgency in collecting the burial money: "I was fearful of losing the online spot [designated] for the burial . . . I did not want him to end up lost, deposited in a large grave."

Lived Relation (Relationality)

Lived relation (relationality) highlighted the caring/noncaring attributes of the social and healthcare network and the embracement of spirituality while coping with stigmatization and blame.

Three relational sub themes were uncovered: participants' reported relationships with affected and extended family members, interaction with the healthcare system and teams, and relationality with a higher being. Ana said, "He was a good husband within and outside of the home. . .. My spirituality gives me strength. . .. I am grateful to God for the opportunity of having him in my life for 45 years."

When describing her interaction with healthcare staff, Georgia (an essential worker) said, "I wonder if it would have been different if he was white or if I spoke differently." Dee said: "It's networking. . .. My neighbor is a doctor; I reached out to her . . . the nurse's aide was my biggest fan . . . [and] I had my sorority sisters who were on staff. . .. They kept me informed."

Pia, a nurse and employee of the facility where her mother was hospitalized, said, "I was well known I knew a lot of people there—residents, nurses, respiratory therapist. The nurses would gear up and go in to take care of her." However, Pia's uncle, the apparent patriarch of the family, launched an investigation to determine who was responsible for transmitting the virus to his sister. This fear of being blamed, shamed, and intimidated by other family members fostered a climate of secrecy in which participants concealed both their own cOVID-19 diagnosis as well as that of their loved ones. Pia shared her extended family's response "They sought to blame someone for her [Pia's mother's] death, so it was easy to blame me. I brought [the virus] home."

Kurt said, "We are a close-knit family. It was hard to stay away from the facility and the house. No one called from the hospital to give us an update. The only call we got was to say he expired. Only my sister and I attended the 20-minute graveside burial ritual."

Lived Body (Corporality)

Lived body emoted the parallel physical and emotional manifestation of the patients', other family members, and the participants' own disease. It captured the manifestations of the participants' physical bodies or bodily presence in their everyday lives while experiencing this phenomenon, including how they felt, revealed, concealed, and shared through their lived body. Van Manen stated that we are always present in the world through the body; as such, it is through our lived body that we communicate, feel, interact, and experience the world [22]. The following narratives captured the bodily experiences related to the emotional and physical experiences of the phenomenon as described by the participants.

Many participants voiced concern regarding fear of self-contagion and or transmission to others. Some were providing self-care or caring for other family members with COVID-19 symptoms. Pat said, "I had not yet been diagnosed, but I was not feeling well. I had alternating feelings of hot and cold. I did not have a thermometer." While coping with her mother's demise, Pia was faced with her husband's acute illness and extended rehabilitation.

Kurt expressed a range of emotions: "I did not know how to feel. I was not sleeping . . . [I was] unable to move forward" (depression); "At not being able to say goodbye, Mom was not able to attend her husband's burial" (regret); "Not insisting that EMS take father to hospital of his choice rather than the nearest accepting hospital" (guilt); "Dad had just passed. . .. Mom and sister were hospitalized and were on ventilators. . .. The undertaker would not take his suit. They buried him in double body bags" (helplessness).

Discussion

The purpose of this study was to understand and describe, using a phenomenological design, the meaning of the experience of the abrupt separation, pre-loss grief and grief experience among family members of hospitalized African American COVID-19 patients during the first surge of the pandemic. The phenomenological approach through the lens of van Manen's four lived world or existential: time (temporality), space (spatiality), relationship (relationality), and body (corporality) provided the structure through which the meanings of descriptions of the participants experiences were revealed. The findings revealed that time in all its varieties was a critical element throughout the experience of this phenomenon [23].

Participants described a mixed variety of physical and psychological manifestations, partially due to disease process and some due to physical and emotional exhaustion of coping with the pandemic environment and the separation and loss of their loved ones. This was further complicated by the ongoing fear of intrafamilial transmission. At the time of data collection, family members were often reluctant to acknowledge and name the illness. These findings are supported by Grau-Abalo & Infante -Pedreira [17]. The issues of disclosure reluctance, stigma, and blame related to COVID-19 appeared reminiscent of that seen in the HIV environment [22]. However, determining the type and extent of these concepts is beyond the scope of this study, and further investigation is warranted to understand the experience of them within the COVID-19 environment. For these participants, the pain was still raw as sufficient time had not yet passed for healing to occur. They were not able to accompany or say goodbye to their loved ones in their last moments. For many, makeshift rituals had to suffice.

Implications

The findings of this study suggest that, despite the challenges of the COVID-19 pandemic, most participants reported a positive relationship with nurses and other healthcare providers. However, some descriptions of perceived devaluing and disrespect were conveyed through clinicians' tone or omission. Participants who received or perceived support and caring from the clinicians and members of the health care team verbalized a reciprocal care for and trust of the system despite the chaos and emotional burden they were experiencing. Historically rooted distrust was further reinforced by those family members who believed they were not supported or respected. This indicates that, even in times of crisis, nurses and other health care professionals must demonstrate cultural humility when caring for and interacting with family members of patients, especially historically disenfranchised people. The report on the Future of Nursing 2020-2030 challenges nurses to lead the charge for the attainment of Health Equity. Nurse educators and researchers must thread health equity throughout the curriculum at all levels and integrate health equity as a critical component of health care research [23].

Limitations of the Study

Many of the participants were currently employed or retired middle-class health care professionals. The experiences captured were related to the first surge of the COVID-19 pandemic. Within this context, limited knowledge was available regarding more effective COVID-19 responsive strategies that came later in the pandemic[24,25].

Conclusion

For these participants, the meaning of this lived experience of separation and pre-loss grief was a dynamic interplay of rhythmic passage of time; confrontation of new limitations amid chaos; manifestations of the physical and emotional reactions to the process; and the paradoxical interplay of relationality characterized by effective/ineffective communication and networking and the embracement of spirituality while coping with stigmatization and blame.

Replication of the study is warranted to expand recruitment to family members of persons who are at the lower end of the economic strata, are less connected to health care, and who may not have been privileged to have had the insurance and networking connections that most of these participants had. Future research that includes other ethnic groups may bring us closer to understanding and responding to Georgia's original reflection: "I wonder if it would have been different if he was white or if I spoke differently."

Declaration of Conflicting Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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