

Experience of Uncertainty: A Phenomenological Study Among Kidney Transplant Recipients

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ABSTRACT

The experience of uncertainty which is the phenomenon of the research study strengthens the kidney transplant recipients to live despite many overwhelming circumstances and challenges encountered with their health conditions, families, relatives, people around, and the material things necessary for their survival and existence. The study was conducted with the aim of exploring and understanding the essences of the experience of uncertainty in a phenomenological study among kidney transplant recipients. Uncertainty in Illness Theory explained that people with health issues face the phenomenon of uncertainty. The study was established with the work of Ricouer's hermeneutic phenomenology, and his approach was utilized as the methodology of analysis. A snowball sampling was utilized in identifying and recruiting the eight (8) participants following the criteria for selection that was set. An online interview through messenger was conducted in Cebuano, Tagalog and English languages, and was recorded and transcribed for data analysis. Utilizing the Ricouer's Hermeneutic Approach, the findings of the research study were analyzed and interpreted. Based on the five (5) existential lifeworlds of Van Manen (2014) the main themes were developed and categorized as lived body (corporeality), lived thing (materiality), lived space (spatiality), lived self/others (relationality) and lived time (temporality). The research study revealed five main themes which gave meaning to the kidney transplant recipients. These are the wearying encounter (lived body), pressing needs (lived thing), frightening encounter (lived space), conflicting encounter (lived self/others) and distrusting moment (lived time). The study concluded that the experience of uncertainty is an existential phenomenon. Thus, the phenomenon of uncertainty by people who went through major operations like organ transplantation needs a thorough understanding by the people in the healthcare industry.

Keywords: Uncertainty, Kidney Transplant Recipients, Interpretive Phenomenology, Life Worlds

Chapter I

INTRODUCTION

Living life with a positive outlook makes a person feel driven and excited to engage in tasks (Harackiewicz & Hulleman, 2010). However, when unexpected circumstances arise—especially those involving health challenges—the drive and excitement a person feels can diminish. This shift in outlook underscores the impact that health struggles have on an individual's mental and emotional state.

For example, Greenberg et al. (2020) posited that individuals facing health challenges are likely to experience negative thoughts and a sense of uncertainty (Lin et al., 2010). Chronic kidney disease (CKD), one of the renal disorders affecting either one or both kidneys, exemplifies such a challenge. Currently, there is no known cure for CKD, making it a life-altering condition. In severe cases, organ transplantation

becomes the most viable medical solution. Schulz and Kroencke (2015) emphasized that transplantation is preferred for end-stage organ failure, especially in kidney disease, where the procedure offers the possibility of renewed life.

The procedure of kidney transplantation, however, presents its own complexities. Heinrich and Marcangelo (2009) argued that individuals with renal failure might not live long without this medical intervention. Yet, Tucker et al. (2019) observed that kidney transplant recipients often grapple with inexplicable fears rooted in uncertainty. The longevity of the transplanted kidney and its ability to sustain life raises questions that recipients find difficult to answer. This fear, coupled with the challenges encountered during recovery, as Lin et al. (2010) explained, exacerbates the uncertainty surrounding their health progression and future quality of life.

Uncertainty, however, is not unique to those with health conditions; it is a universal human experience. The inability to predict the future is a reality everyone must confront, but for those with serious illnesses, this uncertainty takes on a more immediate and existential form. When illness threatens one's health, life, and roles, individuals may feel disoriented and unsure about the implications of their condition. Mishel (1988) argued that understanding and coping mechanisms are crucial to alleviating the adverse effects of uncertainty, helping individuals regain a sense of stability and well-being.

The Uncertainty in Illness Model provides a framework for addressing this phenomenon. It highlights the importance of processing illness-related events through clear and consistent communication, enabling patients to better understand their situation. For example, organ transplant recipients can benefit significantly from the explanations provided by their medical teams, which can help them build resilience against the unknown consequences of their procedure. As Mishel (1988) noted, coping with uncertainty is not merely a response to adversity but a mark of adaptation and growth.

METHODOLOGY

Hermeneutic phenomenology was utilized in exploring and understanding the meaning of the experience of uncertainty in a phenomenological study among kidney transplant recipients. The research question "What is the experience of uncertainty among kidney transplant recipients?" Snowball sampling was utilized in identifying the eight (8) participants of the study.

Data Collection Process

After the Research Ethics Committee approval, the researcher commenced the invitation to the identified participants. The researcher started with a known person/s who had experienced kidney transplantation through Audio-Video Call or mobile call. Audio-Video recording was done during the interview.

Data Analysis

The theory of interpretation by Ricoeur was utilized for the data analysis (Lindseth & Norberg, 2004). Analyzing and interpreting the data occurred at three levels: (1) naïve reading, (2) structural analysis, and (3) comprehensive understanding. Since Ricoeur has not formulated a comprehensive method for analyzing the essential themes, Max Van Manen's five (5) lifeworld existentials (Corporeality—Lived Body; Materiality—Lived Things; Relationality—Lived Self-Other; Spatiality—Lived Space; and Temporality—Lived Time) were utilized as a point of departure for reflection.

FINDINGS OF THE INQUIRY

The following thematic meanings resulted from the various iterative analysis of the phenomenon using

Ricoeur's phenomenological approach. These include (1) wearying encounter; (2) pressing needs; (3) frightening exposure; (4) conflicting encounter; and (5) distrusting moment.

Wearying Encounter. It is the theme describing the thoughts and experiences of a person who underwent a series of devastating events in life. It is a narrative revealing how the person faced the obstacles and complications that disturbed and wearied the entire body. The wearying encounter was comprised with feelings hopeless, feeling apprehensive, giving up personal desire, and doubting organ viability.

Pressing Needs. Despite difficulties in life, the kidney transplant recipients were still pursuing to live in the world. The participants expressed their experience of difficulties and comfort. The pressing needs were encompassed with struggling for provisions and overlooking medication regimen.

Frightening Exposure. The theme of frightening exposure emerged because of the many factors that caused the participants to be very uncertain of their condition. Nevertheless, the participants have come to a point of deciding to be free, not confined or imprisoned on something. This is formed with debilitating places and disquieting moments.

Conflicting Encounter. Participants experienced struggles within themselves caused either by their own perception of themselves or strife with other people. The conflicting encounter encompassed the sub-themes of feeling of resentment and feeling of distress.

Distrusting Moment. This theme pertained to the experience of the participants who experienced uncertainty of what is to happen at a certain time of their lives. The theme encompassed the sub-themes of doubting the subsequent situations and reckoning the failures in the past.

DISCUSSION OF FINDINGS

This section presents the discussion of the findings for the research question, "What is the experience of uncertainty among kidney transplant recipients?" The discussion of findings is presented in the thematic categorization in the Five Lifeworlds of Van Manen.

Lived Body (Corporeality)

The physical and psychological predicament of dialysis emboldens them to take a tougher stance in facing the life realities of physiological illness. For the KTRs, they need to muster the courage to consider having a new organ. Hence, the participants of this study had their transplantation hoping that their bodies would embrace it well. However, the uncertainty and frailty of the human body have become the most crucial concern of kidney transplant recipients.

Wearying Encounter is the theme of the lifeworld on lived body. Uncertainty is a phenomenon that severely disturbs the lives of kidney transplant recipients (KTRs). It causes the individuals to feel weak, even disinterested, and doubtful about things that matter to their lives. Anxious KTRs experience wearying moments while ensuring that they keep themselves in good shape after the organ transplantation. With the new kidney organs transplanted, they are constantly struggling to keep themselves whole amid the uncertainty of their physical bodies.

Feeling hopeless. The feeling hopeless encompasses the loss of energy, the fear of rejection, and worry about their present conditions, which generally point to hopelessness. The study participants claimed desperation of their condition while clinging to a speck of hope over their condition.

Hope may be viewed as a motivating factor for individuals to move on with their lives despite the various struggles they may be facing. Rzeszut and Assael (2021) claimed that the phenomenon of uncertainty overwhelms the whole being of the KTRs, causing them to be hopeless, not only on the condition of the

new organs making kidney organ rejection even more possible but also in relationships and coping responses, which are important considerations to being humans living in the world.

Feeling apprehensive. Forte et al. (2020) claimed that this metabolic complication resulting in weight gain is common after successful kidney transplantation. However, weight increase after a kidney transplant can be addressed with increased physical activity and a low dose of corticosteroids (Moreau et al., 2021). In relation to the present study, the KTRs are bothered by their physical changes, which can indicate the result of the medication for the kidney transplant. Furthermore, they surmised that the uncertain chemistry of the new organs and their natural bodies may have caused the weight, which may not necessarily point to good health but the other way around.

Giving up personal desire. The participants expressed the willingness to give up their personal, human desires as they know that they cannot live the way they used to it. Thus, they opted to let go of people who presumably could make them happy. In this study, some participants claimed uncertainties about having or entering a new relationship before or after the transplant. Martin et al. (2010) posited that organ transplant individuals might experience uncertainty in social relations due to physical health impairment. Abarca et al. (2021) strengthened the finding that KTRs face a relational challenge because of fear of organ rejection and uncertainty of the health condition with stressors that may negatively influence the sexual interest of the recipients.

Doubting organ viability. They worried about tissue compatibility and organ integrity. Though their kidney operations were successful, the procedures did not provide the recipients with a guarantee as to how long the transplanted organs could be useful to their bodies. Almgren et al. (2017) claimed that kidney transplant recipients endeavor to improve their well-being by gaining a sense of control over their daily activity and healthy life. Their emotional status, the concept of normality, and feelings and thoughts of uncertainty about the future are related to the perceived control, which plays an important function in making sense of the recipients' mental and social well-being and health condition. Doubting organ functionality as a form of uncertainty causes fear. However, Pinillos (2003) stressed that the indefiniteness of the condition of the new organ is due to worldly imperfections.

The Coping with the Lived Body (Corporeality). The participants undoubtedly have experienced the seemingly endless struggle against the phenomenon of uncertainty. However, they realized the need to be firm in facing the realities of their lives as KTRs. As a result, they have adapted ways to alleviate their physical health condition. The following were the coping strategies adopted by the participants: diverting one's attention by having a hobby and doing something; choosing to live happily with the people around; shunning away from situations that can affect well-being; having good thoughts about life at present; joining a various actual and online organizational activity helps revitalizing morale; avoiding from thinking about being physically different by acting as if they have no health issues; putting off pressures and stresses by deciding to live cheerfully and freely; and, living with normalcy, free of self-alienation or personal deprivation.

Lived Thing (Materiality)

Anxiety and the phenomenon of uncertainty brought about by corporeality relate to the other spheres of their existence, all impacting these people's lives. The lived thing or materiality serves as a crucial contributor to the phenomenon of uncertainty because they have material needs to be met for the greater chances of sustaining the transplanted kidney organs, apart from the basic needs for day-to-day living.

Pressing needs refer to what the participants consider essential, such as medication, finances, and other sources. It also refers to how the participants feel towards things they no longer have, such as sustainable

jobs, good health, career, higher education, and even personal relationships with their loved ones. Martin et al. (2010) & Denzen et al. (2016) posited that the recipients experience financial instability after organ transplantation. Rescher (2013) explained that a critical phenomenon like uncertainty is an experience that confuses individuals who are confronted with pressing needs; seeking the essential things like a lifetime medication without certainty of providing it poses a burden to the KTRs.

Struggling for provisions. While the KTRs are confronted with intangible concerns about their existence, they are likewise engrossed with tangible objects that need to be met, food, and other essential things. In addition, most of the participants claimed that their health condition has been difficult because of financial demands, which could be of serious concern. LeWine (2020) cited those millions of adults skip medications due to the high cost. Likewise Martin et al. (2010) found out that where to get their medication needs is a common concern among the organ recipients. Lorenz et al. (2019) mentioned that an experience of excessive treatment burden might make an individual unable to meet their health demands. Individuals who struggle to meet their health demands demonstrate non-adherence to prescribed therapy, thereby experiencing a poorer quality of life.

Overlooking Medication Regimen. The medication is for a lifetime. The KTRs, without their means of income, admitted that they could never be certain how long they would be able to take the medicines consistently. It has been a hard reality that they could not avoid due to financial constraints. Gordon et al (2009) stressed that OTRs should become accustomed to a new medication regimen designed to prevent rejection of the new organ. Non-adherence to medication regimens results in severe consequences for transplant patients' health, a common problem for OTRs.

The Coping with the Lived Thing (Materiality). The change in perspective over health condition diligently makes them care for the new kidney organ – the only hope for the longevity of life. They evenly recognized the special importance of water apart from their prescribed medicines.

Lived Space (Spatiality)

The lived space is an equally critical world that these organ recipients need to face daily for a lifetime. They experience the phenomenon of uncertainty in their physical environment, as well as in their inner thoughts.

Frightening Exposure. The phenomenon of uncertainty is viewed as part of the world of the KTRs who have to make choices despite being frightened and uncertain of the consequences. Lived space or spatiality is an experience of internal and external environments in which the KTRs live. It also refers to an individual's thoughts, emotions, feelings, and inner struggles experienced (Kole, 2017). The condition means having a troubled mind and emotion or the inner struggles leading to confusion. In this vein, lived space or spatiality by Van Manen (2014) requires kidney transplant recipients to reflect on how they continuously live in the world as they experience uncertainties. Spatiality focuses on the space and places the recipients are in – the inner and outer world experiences.

Debilitating place. A debilitating place jeopardizes the well-being of kidney recipients, especially those inhabited by other residents with sickness or health issues. Non-conducive places create uncertainty in the life of kidney transplant recipients. These places threaten the well-being of the already health-compromised individuals. The lived space of a kidney recipient can be exhausting to live in because of the untoward possibilities that may occur. As emphasized by Ågård and Harder (2007), the choice of a place to stay for recovery and make a living contributes to the uncertainties experienced by the KTRs. They resist the idea of changing places to stay and live, as it may entail a possible change of lifestyles.

Disquieting moment. The participants felt disquieting moments when they received negative news about their fellow kidney recipients. They felt more distressed with their condition. Also, hearing negative remarks from other people as to the adverse of the operation could make them feel discouraged over their situation, especially since people around could have a negative perception of the after-effects of the kidney operation.

Schulz and Kroencke (2015) postulated that the psychosocial burden continues to be present even after transplantation. Unsuccessful readjustment develops in lower quality of life and psychiatric morbidity (Heinrich et al., 2009; Butt et al., 2012; Goetzmann et al., 2008). Affective and anxiety disorders are common disorders before and after transplantation (DiMartini et al., 2008; Heinrich et al., 2009). As claimed by Peters et al. (2017), brain function and systemic physiology alter due to uncertainty which could change individuals' ability to take pleasure in daily activities. Such change can lead to a more serious problem - depression (Jiang & He, 2012).

The Coping with the Lived Space (Spatiality). They reach the point of realization and decision to do something that may impact their well-being. Deciding for the good of the self may be an essential therapeutic activity. It is the utmost concern of a person to gain back the integrity or wholeness that was once severely challenged. Many of the study participants have chosen to discern what is good for them by letting go and keeping away from negative thoughts or simply ignoring the odds around them.

Lived Self-Others (Relationality)

Relationships with other individuals in close or distant connections may contribute to the uncertainties that the KTRs face.

Conflicting encounter. Conflicting encounter emerges because of the strife experienced within the person and with the other people around, involving reminiscing of the past, causing them to fall into kidney transplantation and its subsequent outcomes. In addition, the participants felt uncertain about what their new kidney organs might bring them, making these individuals resort to self-blame for the life-threatening conditions they put themselves into. The relational conditions of the self and the others describe how KTRs deal with the intrapersonal and interpersonal issues aggravated by uncertainty with their new kidney organs. In this study, relationality refers to how the kidney transplant recipients see their worth as individuals amid the inner struggles they need to address and external conflicts they have to deal with if not resolved to find meaning in their lives regardless of all the possibilities that may transpire with their new kidney organs.

Feeling resentful. Resentment is a feeling of being utterly angry. Desperate acceptance of one's condition can cause it without other options but accept the existing situation. They recognized that the dysfunction of their biological organs was their own doing. Though not wanted, the outcomes of their actions or lifestyles settled on their physical bodies. Hampton et al. (2010) claimed that resentment as a conflicting encounter is an emotion that arises from the harmful treatment experienced by a person. Such feelings can be translated to anger about one's action or a feeling of guilt, which is a common response of every person who experiences life-threatening situations (Khatri, 2021). Masterclass (2021) alluded that self-conflict commonly includes the inner struggle with self-doubt, moral dilemma, or the self-own nature.

Feeling distressed. The KTRs are already in the struggle within themselves. However, what aggravated their situation was the conflict they needed to face with the people around them, either with their immediate families or other relatives. Their relations with other people became strained because of the economic implications of being KTRs.

Distress is often felt by individuals who see themselves as a burden because of their health situation. They perceived that their presence causes distress or frustration to other individuals for not meeting the other's expectations (Joiner, 2005; Joiner et al., 2002). An individual who perceives oneself as burdensome to the family and others experiences greater pain and a higher level of uncertainty (Kamenov et al., 2016).

The Coping with the Lived Self-Others (Relationality). Amid the many psychological and relational concerns they have experienced, they found refuge in individuals who did not see them as a burden but as people who needed help and understanding. In coping with the hard realities of their conditions, the KTRs found solace from other persons, especially in God.

Appreciating togetherness is well recognized by the participants who value the presence of other people in times of fear, doubts, and uncertainties. The togetherness releases spiritual soundness, peace, joy, and love. The moment of being with other people makes them realize the essence of their existence.

Lived Time - Temporality

The kidney organ recipients acknowledged the very reality of the transience of their time, the impermanence of their existence. With the varied struggles that the participants live through after the kidney transplantation,

Distrusting Moment. Distrusting moments relate to the essential elements of time in the experience of uncertainties of kidney transplant recipients. Uncertainty is a prominent feature of individuals who have been through a critical illness (McCormick, 2002). The concept of lived time or temporality symbolizes when the recipients tremendously participate in the world as they experience uncertainties.

The thoughts of events and situations help them become what they need to become of themselves. The element of time reveals an important learning experience as they live in the world. However, the theme of distrusting moment occurs when the kidney transplant recipients dread unfortunate eventualities and reckon with their failures in the past.

Doubting the subsequent situation. The KTRs can never tell how long their existence may last, with complete reliance on the transplanted kidney organs. Before the transplantations, all they had to hold into was the possibility that the organ transplantation could extend their lives and, therefore, extend their time left in the world. Human as they are, the recipients hope to live longer in the world. However, the lived time of the kidney transplant recipients is focused on doubting the outcomes of the kidney transplantation. The participants expressed fear of what might happen to them at any time. They admitted being uncertain of the time left for their existence. The transplanted kidneys might not last longer than they were initially told before the transplantation. Living for more than ten years is said to be a graceful extension of ones' life.

Reckoning the failures in the past. The lived time of the KTRs could be one of the hardest facets of their existence. Uncertainties emerge, making them reflect on their lifestyles. Thinking of how they spent their lives led to the feeling of guilt self-blame, questioning why they allowed themselves to be in a condition of relying on other people's kidney organs.

The Coping with the Lived Time (Temporality). Despite the various encounters with uncertainty, the recipients learned and have been driven to continue living in the world. Besides, they have tried to restructure their lives by learning from the past because they intend to live longer as human beings. The meaningful experience they encountered made them proactive and strong as they continued to overcome challenges in life.

Conclusion

The study's findings disclosed the kidney transplant recipients' experience of uncertainty. The wearying encounter, pressing needs, frightening exposure, conflicting encounter, and distrusting moment provide a vivid depiction of the varied concerns and issues they face. Beyond the physical challenges, the very thought of the uncertainty surrounding the outcomes of their transplantation weighs heavily on their minds. While these kidney recipients aspire to prolong their lives, they remain uncertain if the transplanted kidney will fulfill its intended purpose. This persistent doubt and fear, which may exacerbate their health conditions, underscores the prominence of uncertainty in their lives, leaving them grappling with the precariousness of their existence.

Despite surviving for years with their new kidney organs, the experience of uncertainty remains a constant presence for these individuals. Life events—some unforeseen—pose a perpetual threat to their health, and no assurances can be made about their current condition. This reality, coupled with the various struggles they face, often leaves recipients in a state of waiting, unsure of what the future holds. Such ongoing ambiguity exemplifies the enduring nature of their psychological and emotional burden.

This sense of uncertainty aligns with the five lifeworlds outlined by Van Manen: the body, space, self/others, things, and time. Across these dimensions, one common theme emerges—the psychological turmoil that kidney transplant recipients endure. The fear of kidney rejection persists, lodging deeply in their minds. To cope, these individuals strive to apply the health education and information provided to them, demonstrating their efforts to mitigate the unpredictability of their condition.

Furthermore, the experience of uncertainty expressed by the kidney transplant recipients in this study reveals itself as an existential phenomenon. It reflects how these individuals perceive their present lives while contemplating the potential implications for their future. This highlights the need for a deeper understanding of the phenomenon of uncertainty by those in the healthcare industry, particularly for patients who have undergone major operations like organ transplantation. Addressing these concerns with empathy and knowledge is essential for providing holistic care to such patients.

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