

FROM DYSTOPIA TO UTOPIA: THE PERCEPTIONS OF OSTOMY CLIENTS

Adrian A. Moreno, Julius C. Daño*

Cebu Normal University, Philippines

*Corresponding Author's Email: juliuscoloniadano@gmail.com

ABSTRACT

Following ostomy surgery, patients experience overwhelming changes which often affect their overall well-being (Ito *et al.*, 2012). Surprisingly, there is paucity on the perceptions and views of clients with an ostomy in a Filipino understanding. A phenomenological lens anchored on the philosophy of Husserl was used to discover and describe the lived experience of clients with ostomy. Purposive-Snowball sampling was utilized in the study. Conversational, formal and semi-structured interviews were the methods used as means to unravel the experience of the participants. Data analysis was based on Colaizzi's methodology. The whole process was based on the data, transcribed interviews, sorting, categorizations (cool analysis), categories as thematized (warm analysis) and a repertory grid or a dendrogram that paved the way to discovering the value of the lived experiences of clients with ostomy. The description of the experience revealed two major themes namely, the Dystopia experience that emanate from the participants' negative perceptions of alienation, desolation and desperation. Moreover, the second theme is the Utopia experience that derives from the participants' understanding of acceptance, gratitude, and enlightenment. It is imperative that there is a need to understand the perceptions of clients with ostomy to devise an appropriate plan of care that addresses the main goal of a healthy transition.

Keywords: *Ostomy, Phenomenology, Perceptions, Transition, Dystopia, Utopia*

INTRODUCTION

Background and Rationale of the Study

Following ostomy surgery, patients experience overwhelming changes which often affect their overall well-being (Ito, 2012). For some individuals, having a physical apparatus outside their abdomen is an embarrassment, but to others this is a sense of relief. Surprisingly, there is paucity on the perceptions and views of clients with an ostomy in a Filipino understanding. The abdominal stomas are being constructed with increasing frequency as of present time. In the United States, approximately 100,000 people undergo operations that result in a colostomy or ileostomy each year (Sheets *et al.*, 2014). According to Wiedermann (2017), approximately 700,000 people have an ostomy in Europe. The exact incidence and prevalence of ostomy surgery in the Philippines remain to be unknown. However, the most common causes of stoma creations are cancers of the colon, rectum, and bladder. Specifically, approximately 8,000 new cases of colorectal cancers are diagnosed yearly making it the fourth leading cause of cancer-related deaths in the country and will likely continue to rise, according to Philippine Cancer Society (2013).

The creation of an ostomy is a perplexing event that a

patient must manage on a daily basis over a significant period of time, often permanently. Although the purpose of an ostomy is to treat and reduce patient's discomfort, it also leads to intensified distress and suffering of the patients. Following ostomy surgery, patients experience overwhelming lifestyle changes (bowel routine, body image, sexuality, social, physical and leisure activities) which often affect their overall well-being (Ito *et al.*, 2012). Some patients may view the surgery as mutilating and a threat to their sexuality; some fear impotence. Others may express worry about odor or leakage from the pouch. For nurses caring for the patient with an ostomy, interventions focused mostly on providing emotional support and wound care, maintain optimal nutrition, supporting a positive body image and provide colostomy care (Smeltzer *et al.*, 2010).

Understanding and exploring the lived experience of clients with an ostomy will contribute to the paucity of studies being conducted to these groups in a local perspective. This study will pave the way to future researchers to investigate further and unravel new findings from ostomy clients that would help make the delivery of care efficient and effective. Consequently, ET nurses will gain recognition owing to their importance in taking care of Filipino ostomy clients.

This would lead to the adoption of ostomy nursing guidelines from other countries and would then be integrated to the nursing practice.

The stoma itself and its care management are one of the challenges for these clients. Hence, it requires an in-depth understanding of healthcare professionals, more specifically to the nurse in order to be better prepared with the competencies required to effectively handle these clients. To understand the phenomena of the life of ostomy clients, the proponent of this study aims to investigate the lived experiences of clients having an ostomy. The result of the study will be used in generating a model of nursing care that may prove to be effective in handling ostomy clients.

Objective

The study aims to explore the lived experience of patients with an ostomy.

RESEARCH METHODOLOGY

Research Design

The study was grounded on the qualitative inquiry. Specifically, a phenomenological approach was utilized since the study aims to gain a deeper and profound exploration of the meaning of the lived experiences of patients with an ostomy. Phenomenology is a qualitative research methodology rooted in philosophy and psychology (Polit & Beck, 2008). This approach allows informants, through in-depth interviews, to open their own meaning of experience. The methodology was used to establish a description of how an individual lived an experience on a deeper level of understanding (Simon, Maekawa & Smith, 2011).

Research Locale

The study was conducted in the Province of Cebu, Philippines.

Research Participants

A purposive snowball sampling was employed to gather participants for the study. Purposive sampling is a sampling technique in which the researcher relies on his or her own judgment when choosing members of the population to participate in the study. Snowball sampling is defined as the referral of a subject of people who have similar traits (Polit & Beck, 2008). The selection of the participants followed the inclusion

criteria which includes the following: a male or a female, 18 years old and above, who has undergone an ostomy surgery, who is able to speak English, Filipino or Cebuano and who is willing to consent to the interview. However, exclusion criteria were also considered in the study particularly with mental incapacities and problems of communication.

Research Instrument

The study utilized three interviewing processes namely: formal, conversational and semi-structured interviews. The formal interview facilitated as the main source of data collection to help participants reveal their lived experiences. The semi-structured interviews were used to develop friendly rapport between the researcher and the participants that promoted evasion of strange feelings of hesitation, fast it created a healthy atmosphere. Through an interview, the subjects can easily express their inner thoughts of their real-life experiences (McQuerrey, 2017). The interview procedure utilized a close or open-ended question in finding the individual's variation of his or her lived experiences. Questions were directed towards participants' experiences, feelings, perceptions, and convictions geared towards achieving the purpose of the research study.

Data-Gathering Procedure

In the actual data gathering, the researcher directed questions that would describe the lived experience and perceptions of clients with an ostomy. The data gathering was satisfied when the researcher determined data saturation. Data saturation in qualitative research means that the researcher finds that no new descriptive codes, categories or themes are emerging from the analysis of data (Rebar, 2011). According to Fusch and Ness (2015) when no new themes emerge, it goes hand-in-hand with no new data and no new coding. If one has reached the point of no new data, one has also most likely grasped the point of no new themes; therefore, one has touched data saturation.

The language in the interview used was a bilingual language using English and the local dialect Cebuano as per participants' choice. To ensure and preserve sensitivity of the topic, audit trailing and field notes were fully utilized. Audit trailing guided the researcher to keep track with the essential chronological features that has happened during the study. Field journals were produced to keep note with the important meaningful cues such as facial

expressions and gestures.

Ethical Consideration

The study was guided by the use of well-established ethical principles. The researcher provided informed consent where the participants were oriented about the topic of the study on its significance, and objectives. The freedom to not participate and withdraw at any time from the study by the participants were well respected by the researcher. To further enhance confidentiality, the researcher also informed the participants that code names were used to protect their true identities. By performing this, harm in any form was avoided.

Mode of Analysis

In analyzing the data, the transcribed interviews were sort out, categorizations were made (cool analysis) and thematized (warm analysis) in a repertory grid or dendrograms that will pave the way to discovering the value of the lived experiences of clients with an ostomy. The researcher followed the steps of analysis as proposed by Colaizzi in 1978 (Speziale & Carpenter, 2007). First step: Repetitive reading analysis; in order to grasp the whole idea or opinions of the interviewees. In this step, the researcher sensed the "feeling" for the materials. The focus was to single out relevant psychological phenomena without the purpose of testing the validity of any particular hypothesis. The second step: Extraction of highlighted responses (Lebenswelt) from each participant. The researcher distinguished 'small units' called the meaning units. No revisions on grammatical errors may be found. Third step: Decoding key responses (by participant number under each interview question. Keywords and phrases within each response were highlighted. The researcher then transformed each meaning unit from the language of the interviewees (emic) to the language of the researcher (etic). Step four: Formulation of categorical themes. The researcher sought to describe 'how' (noeses) the phenomenon express as itself and 'what' (noema) the phenomenon is. Step five: identifying the 'emergent themes' underpinning the relevance to the target study. Each theme was labeled as succinctly and accurately as possible to maintain interviewees' ideas while showing their participation in the common idea. The researcher then presented the findings to the participants thus far as a final validating step. These techniques served as feedbacks to ensure trustworthiness of the captured findings. (McWilliam *et al.*, 2009).

Rigor of the Study

To establish rigor in the study, the researcher made use of reflexive journaling and careful documentation trail was observed. The use of a reflexive journal also improved the researchers' credibility in the study through efforts to be self-reflexive and to taking into his prejudices and perspectives into account (Polit & Beck, 2008). To fortify the credibility of the study, the researcher performed a member check wherein he provided feedback to study participants about the emerging interpretations and obtain participants' reactions. Member checking was carried formally after data have been fully analyzed.

RESULTS

This phenomenological study describes the individual and collective experiences of a selected group of clients with an ostomy (2 males and 3 females). Interestingly, the perceptions of clients with ostomy revealed fascinating occurrences which are categorized into two themes. The first theme is the Dystopia experience that emanates from the participants' internal and external environment of alienation, desolation, and desperation. Moreover, the second theme is the Utopia experience derived from the participants' understanding of acceptance, gratitude, and enlightenment.

Dystopia Experience

The dystopia experience operates in the context of individuals undergoing major changes in their lives. These major changes include those individuals who are ill and undergoing surgical operations. Dystopia is a state in which everything is unpleasant, and people are unhappy. The clients with ostomy experienced the feeling of unpleasantness after undergoing ostomy. They perceived themselves liken to that of a voyager who is faced with adversities along the course that may hinder them from achieving new lands. It is a transition in their lives that they experience from being normal to abnormal.

Sub-theme 1: Alienation

After the ostomy surgery, they felt they were alienated from their perceived reality. Alienation is a state of depersonalization or loss of identity in which the self seems unreal. For the participants, they thought of themselves as having an altered sense of self and physical being. They said:

P1 "It is different because I feel when I wear it it's different. You have an abnormality. I didn't imagine myself to be like this. That's all. Abnormal. (crying) Just it's ugly having this. Different from a normal person."

P2 "Sometimes I would be away already from...I was thinking to myself that I was away from everybody." "Especially if I'll go on a trip or parties. I really have to think about that. I won't attend parties anymore because after two hours of eating you feel that the bag is already full."

Sub-theme 2: Desolation

As the time and days passed by, desolation was experienced by the participants. They felt absolutely physically and emotionally destructed. They had difficulties and discomfort in their normal ways of living and thought of as being drowned by annoyance and displeasure. They verbalized this as:

P4 "It's really unpleasant. It's not easy. It's hard being like this." "I can't turn properly. If on this side, I can't because it might leak. There might be leakage." I want this gone. Hehe (teary eyed). Have it operated again because it is really bothersome?"

P5 "Tiring, it stings and painful. I got discouraged. It really stings and there are no more fun activities to do. I can't drink anymore, I did not go to the cockfight arena anymore, I can't spend."

Sub-theme 3: Desperation

The discomfort and difficulties of clients with ostomy purged the thought of desperation. Desperation is defined as loss of hope and surrendering to despair. Participants experienced a strong feeling of sadness, fear, and loss of hope. They lost self-control and courage to live. Three participants said:

P1 "I feel like I'm useless (cries). Of course, It is not anymore. You need to call other people. You have to call them." "It is so hard, if this will be here forever, nothing, I will be alone. It will be lucky if someone will help. It's not easy."

P2 "When I knew about my sickness, I was already calling my parents. My dead parents, my sisters saying take me! Take me! (teary eyed)

P5 "All is lost, I got discouraged on myself. Can you believe lifetime pain and it stings. I was not able to adjust

during that time."

Utopia Experience

The utopia experience elucidates from the optimistic experiences of clients with an ostomy. Utopia is defined as any ideal state free of poverty and suffering (Utopia, n.d.). Participants realized that life with an ostomy is not the end for them. They recognized that having an ostomy should not be a hindrance to go on with life. It is a new beginning of recognition receded by hope and faith.

Sub theme 1: Acceptance

Accepting the critical event of having an ostomy was an overwhelming choice for the participants. They had to go through difficulties and destitutions providing them a transition to the new reality. In human psychology, acceptance is a person's assent to the reality of a situation, recognizing a condition which is often negative or uncomfortable without attempting to change it or protest against it (Fish, 2014). This was exhibited by the participants as they shared:

P1 "Just accept it because you don't have a choice. If there was a choice, I really won't. I don't have a choice;

P3 "Yes, that I just have accepted this "like" now, this one, that this happened to me."

P4 "In my age, (laughs) I think I won't expect that I will be given installments. For me I will be given. I believe in second life."

P5 "I was able to adjust now no matter how painful it is. I'll fight no matter the pain. I will eat no matter what, although it will be stingy when the waste comes out, no matter just so."

Sub theme 2: Gratefulness

Gratefulness is defined as an acknowledgement of having received something good from another (Gratefulness, n.d.). As participants sail through new horizons after sinking from their perceptions of desolation and despair, they are grateful and reminded of the value of family and their strength. It is known that Filipino culture places the highest value on family. One of the most treasured values held by Filipinos involves maintaining a close tie to the family. Every day spent living with an ostomy is a challenge and the family is

considered a source of strength for the participants with deep gratitude. They shared:

P2 "I realized that I should go on for my family. "My friends gave me so many prayers for healing... They always tell me that don't get discouraged. Live up. My best friends. So many friends around" "I always think about my daughter."

P4 "Financially, I call my children because I don't have a work."

P5 "I'm really grateful for my brother. My wife, Ensure. I now go out, going to other places."

Sub theme 3: Enlightenment

Enlightenment is the act or means of enlightening and the state of being enlightened (Enlightenment, n.d.). In connection to the study, spiritual enlightenment was uncovered. As the participants journeyed to a new horizon, they surrendered and submitted themselves to the Almighty. They turned to faith as a driving force like that of a serene wave which brought them solitude and peace. They expressed:

P1 "Of course, I can't force myself, from above. Why this happened to me. Like just. You can say if you lack in prayers, this happens. As of now, I am praying more."

P3 "I just keep asking "like" from God, that I be completely healed of my illness because I still have my child, who needs me still."

P4 "For me, I always keep in mind I won't get tired. I call the Lord. I would just really call the Lord. Help me on this Lord because you gave me a reason to overcome this, to regain it" "I'll just give my service. (referring to the Church)

DISCUSSION

This study explored the lived experience of clients with an ostomy. Particularly, this study sought to answer the question: "What are the perceptions of clients with an ostomy?" After the analysis, the themes that emerged in the study were recognized into two perceptions namely *Dystopia* and *Utopia*. Sub-themes also contributed to the emergence of the major themes. In the major theme *Dystopia*, participants experienced *alienation*, *desolation*, and *desperation*. On the other hand, the second major theme *Utopia*, sub-themes that occurred

were acceptance, *gratefulness and enlightenment*.

The first theme *Dystopia* mainly describes the negative perceptions of the participants as they venture on a new life with an ostomy. They experienced feelings of being different and being hopeless as they tried to cope and adjust. Their will to live were drowned in alienation, desolation and desperation. The perception of being different is vividly described in the sub-theme *Alienation*. Participants viewed themselves with an abnormality and having an altered sense of self and physical being. *Desolation* describes the difficulties and discomforts of the participants brought about by the critical event that caused changes in their normal ways of living. Lastly, *Desperation* emanates from the participants' sadness and loss of hope. Their experience of life was taken away from them and that they lost the courage to live.

Despite all the adversities and challenges, participants came to the realization of the importance of life. This became the second theme of the study. *Utopia* reveals the discernments of the participants as they cope to the altered reality. They realize that life with an ostomy is not the end of life but the start of a new beginning. A beginning of acceptance, hope and faith. Acceptance describes the recognition of participants to the life with an ostomy. *Acceptance* of one's life has nothing to do with resignation; it has nothing to do with running away from the struggle. On the other hand, it means accepting it as it comes, with all the handicaps of heredity, of suffering, of psychological complexes and injustices (Steffe, 2013). Finally, the participants accept the new reality of having an ostomy as it is and recognize it as a part of their lives.

In the sub-theme *Gratefulness*, participants were forever grateful to their families and support networks. They expressed that they consider their family as their source of strength which greatly helped them adapt to the altered reality. The family is considered the basic unit of society. The family is an environment where it creates and promotes emotional and physical health and psychological well-being for its members. Filipinos are known to treasure the value of family in all aspects of life. A trait wherein family members should be taken care of, supported regardless of whether he/she did something wrong, and should not be abandoned. According to Bowen's Family Systems Theory, a family

is viewed as an emotional unit which is composed of interconnected beings that affect their functioning as a family. (Brown, 1999).

Among the many characteristics that describe a Filipino, the significance of faith is everlasting. A spiritual enlightenment is unfolded for the participants. This became the sub-theme *Enlightenment*. To this day, Filipinos continue to cherish and value their faith in God. Their innate religiosity allows them to comprehend and accept reality in the context of God's will and plan (Jake, 2011). The faith of the Filipinos is considered as a positive psychic energy which they can lean on during hard times. For the participants, the positive psychic energy of faith allowed them to live on and act despite the uncertainty of the future.

Clearly, the findings of this study can be applied to the nursing practice. When caring for patients with an ostomy, it is then necessary for nurses to also collaborate with the families as well in the plan of care since clients with an ostomy lean on their families for strength and assistance. By means of integrating them especially in health education, clients with an ostomy will then move towards a healthy transition in life with less difficulties. Furthermore, it is also essential for nurses to incorporate the spiritual aspects of care. Spiritual care has been known to have positive effects on patients' stress responses, well-being, and interpersonal relationships (Zehtab & Adib-Hajbaghery, 2014). Assessing and supporting clients' individual spiritual needs may help them cope with their illness and situation.

Participants' lives were forever altered following the placement of an ostomy. As they transitioned to their new reality, it was apparent that they had to adjust in relation to the changes in their sense of self, physical being, lifestyle and social relationships as manifested in vivid descriptions. Despite all these challenges, participants continued to live on, guided by faith, supported by their loved ones and accepting the ostomy with a strong will to survive.

CONCLUSION

The explicit and vivid description of the lived experience of clients with an ostomy has contributed to the paucity of literature on their experiences in a local perspective. Participants' experience detailed their

adversities and optimistic views of having an ostomy. It is imperative that there is a need to understand the perceptions of clients with an ostomy so as to devise an appropriate plan of care that addresses the main goal of a healthy transition and inspire nurses to be sensible of how they themselves can meaningfully influence the transition of clients with an ostomy.

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