

# **“Masked, Ruled and Needled”: A Glimpse into the World of Filipino Adolescents Undergoing Chemotherapy**

Rudolf Cymorr Kirby P. Martinez, PhD, MA, RN  
Arellano Graduate School of Nursing  
San Beda College of Nursing

## Abstract

This study, employing phenomenological approach, explored the Filipino adolescents' life during chemotherapy. Five participants were utilized as co-researchers and were carefully chosen based on the following criteria: 1) They are willing to share, participate, and describe their lived experiences, 2) They have undergone at least the second chemotherapy sessions, And 3) that they are Filipino adolescents between 12-18 years of age. Moreover, the co-researchers were carefully chosen to ensure that the three (3) main phases of chemotherapy (Induction, Consolidation & Maintenance) are equally represented.

The co-researchers' experiences were subsequently gathered and enriched via the following methods: 1) Interview, 2) Storytelling, 3) Participant Observation, 4) Art and 5) Group Discussion. Subsequently, three (3) levels of reflective analysis was done on the narratives of the co-researchers following the process specifically developed by the researcher, inspired by the phenomenological methods of Max van Manen and Colaizzi. Through the process of reflective analysis, three (3) insights were drawn and are as follows:

- a) Behind the Mask: The Blurring Self
- b) Forbidden: Not Forgotten
- c) Nasty Needles, Nothing More, Nothing Less

Further reflection reveals the essence of the phenomenon under investigation that the life of Filipino adolescents undergoing chemotherapy is a phenomenon of conflict. Of constant struggle between meeting the desire of normalcy and autonomy of the adolescents to letting oneself succumb to the dictum and demands of chemotherapy.

Insight from this study further revealed that care rendered toward adolescents undergoing chemotherapy must be tailor-fitted to their needs, genuine, holistic, emphatic, humanist and individualized.

Keywords: Adolescent, Chemotherapy, Cancer, Phenomenology

## **I. INTRODUCTION**

### **Global Realities of Cancer**

Cancer in its simplest definition is a group of diseases that involves uncontrolled growth and spread of certain abnormal cell in the body creating disequilibrium in the normal functioning of an individual (American Cancer Society (ACS), 2011; National Cancer Institute (NCI), 2011). Childhood cancer then, is a general term used to describe ranges of cancer types found in children between the ages of 0-19 years (American Society of Clinical Oncology (ASCO), 2011).

Worldwide, it is the second leading cause of death among children majority of which afflicts those below fourteen (14) years of age, and continues to be the major cause of childhood death in Asia, as 60% of Asian children afflicted with cancer die. It is not surprising therefore that childhood cancer still continue to be the number one cause of childhood death between the age of 1-15 years old in the USA and rank as second cause of childhood mortality in the world with an approximated 161,000 new cases worldwide, 80% of which are found in developing countries especially in Asia(King, et al 2007; ACS, 2011; NCI, 2011)

In Asia alone, it has become an emerging cause of childhood death (King, et al 2007; ACS, 2011) as 60 % of Asian children afflicted with cancer die, a high percentage as compared to other races. In the Philippines, it ranks as the 4th leading cause of death in 2007 contributing to 9.7% of the total mortality rate for the said year. Likewise, this rate is tantamount to approximately 44,000 people dying of cancer for the said period and is projected to rise in the years to come (WHO, 2008).

With the abovementioned realities,major advances on the treatment of cancer are continually being developed. Nowadays, because of quality researches and improved healthcare delivery system, childhood cancer with adequate diagnosis and proper treatment poses a 77% mean survival rate (King et al, 2007) with an 80% five (5) year survival rate from the less than 50% five (5) year survival rate during the 1970's and more than 75% ten (10) year survival rate (ACS, 2011; NCI, 2011).

## **Chemotherapy**

One of the advancement with regard to treatment of cancer is the development of chemotherapy and is currently the mainstream treatment of choice for childhood cancer (King et al, 2007; Otto, 2007). This choice was supported by the fact that it has the highest success rate reaching more than 80% as compared to other treatment modality (i.e. radiation, & surgery). This high success rate is attributed to the major innovation and modernization in the field of cancer care through intensive research work (Gloeckler-Ries, 2008; ACS, 2011; NCI, 2011).

Chemotherapy is defined as the use of cytotoxic (cell killing) drugs in the treatment of cancer. Its prime aim is to prevent cancer cell from multiplying and adjacent tissue developing metastasis (spreading of cancer cell to various part of the body). It accomplishes this objective by having a systemic effect in the body thus, it reaches metastatic and sanctuary sites that other treatment modalities fail to achieve. As a result, chemotherapy prevents cell replication and halt cell division upon contact with the cancer cells.

The number of cycles of chemotherapy varies from as low as six (6) to as many as fifty (50) and may depends on the individual protocol of the treatment which varies within institutions. Though the protocol varies on a case to case basis, chemotherapy treatment can be basically divided into three distinct phases namely, Induction, Consolidation/ Intensification and Maintenance. The goal of the induction phase is to eliminate as much as possible cancer cells inside the body while during the consolidation/ intensification phase, treatment is directed on eliminating residual cancer cells and is more aggressive compared to the induction phase. On the other hand, the maintenance phase sees to it that the cancer cells will be suppressed for the longest time possible (Coward & Coley, 2006; Abrams, 2007; Otto, 2007; ASCO, 2011).

As chemotherapy affects cell replication and cell division of fast growing cells specifically cancer cells and as such, healthy rapidly dividing cells such as bone marrow, hair, and gastrointestinal tract are consequently affected giving way to the common side effect of chemotherapy, bone marrow depression, alopecia and gastrointestinal disturbances. It must be noted that the side effect of chemotherapy mainly depends on the individual as well as the dose and drugs used. (Abrams, 2007; Otto, 2007; ASCO, 2011).

Chemotherapy when viewed on the basis of its effects then is comparable to a coin which possesses two (2) sides; the one side serves its purpose of treating cancer while the other represents its multitude of physical and psychological effects. Hence chemotherapy does not only attack the disease of the patient, it affects the totality of the person.

## **II. REVIEW OF RELATED LITERATURE**

From the comprehensive search from a range of database which includes journals, article, books, thesis and dissertation, the researcher found that there was no study exploring the lived experiences of adolescents undergoing chemotherapy. On the contrary, there were numerous quantitative studies, utilizing adult respondent, that explored on the needs of the cancer patient, more specifically their spiritual needs (Soothill et al, 2002; Clark et al, 2003; Frick et al, 2005; Rademacher, 2005) as well as their unmet needs (Soothill et al, 2003; Aranda et al, 2005). Many of these studies show the complexity and importance of holism in the continuous, comprehensive and coordinated care of a cancer patient. Moreover, these studies echoes those already emphasize in the literature, that psychological, economic and emotional distress of the cancer patients are as painful as the disease they experience which highlight the fact that cancer affects the totality of the human being and not just the physical domain of the person.

In addition to that, still utilizing adult respondents, most studies focus on how cancer together with it treatment affect the patients quality of life (McEwen et al, 1998) zeroing in on its psychological effects (Chen et al 2000, Matsushita et al, 2005; Ryan et al, 2005) which stresses that the quality of life of patients with cancer is being degraded with the different psychological distresses that they encounter. This further shows that anxiety and depression plays a huge role in the degradation of their quality of life. Moreover, the review shows that cancer does not only affect the patient but those around him as well (Maliski et al, 2002). Additionally, the review emphasize how the physical environment during treatment affect the quality of life as well as the experience of cancer patient exemplified by studies of Edvardsson et al (2006), Peter and Sellick (2006) and McIlpatrick et al (2007).

It must be noted however that all of the studies mentioned above employed adult cancer patient as its respondent and that most are quantitative. Though there exist studies that are qualitative in nature, such as those of Halldorsdottir & Hamrin (1996), Maliski et al (2002), Anjos & Zago, (2006), Edvardsson et al (2006), McIlpatrick et al (2007) and Siqueira (2007), they explore a different phenomena compared to this study. In must be noted moreover that the result of this studies cannot be generalized to children afflicted with cancer.

Pediatric patients, adolescents in particular, view and experience things and phenomenon differently. They have a unique perspective of events especially of illness as compared to that of the adults (Sylvester, 2007; Santrock, 2008; Anonath, 2009). It is therefore not sufficient and proper to generalize adult based cancer researches to this unique population.

On the other hand, it was noted that though there were studies revolving around childhood cancer, there was none which specifically focus on the treatment modalities especially that of chemotherapy. Those researches that employ the quantitative approach tends to focus more on the effect of cancer itself to the quality of life of children (Varni et al, 2007) or to that of adolescents (Elkateb et al, 2002) patient. Beside the effect on the quality of life of pediatric patients, some studies deals specifically with the psychoemotional aspect of these effects like that of MacLeod (2005) and Kyung-ah (2009) while others focus on the symptoms (Jalmsell et al, 2006) especially the experience of pain (Cleve et al, 2004). Two studies meanwhile focus on the effect of cancer to the cancer survivor's psychological well being (Zebrack et al, 2002) and their character strength (Eracleous, 2008)

Also, though there are qualitative studies on the other side of the spectrum, they more or less focuses on a different phenomenon like unveiling the children's experiences of having a chronic illness like that of Woodgate (1998) and Cardillo (2004). Others focus specifically with the cancer experience of children with different age group like the studies done by Rechner (1990), Hockenberry-Eaton, (1994), Yeh (2002), Larouche (2006) or with a specific type of cancer like that of Hicks et al (2003) or with a specific type of symptoms (Woodgate et al, 2003). Additionally, there are studies which explore the cancer experience in terms of the psychoemotional aspect like the experience of uncertainty (Stewart, 2003), of depression (Woodgate, 2006) and that of hope (Danielsen, 1995 & Turner, 2005). Meanwhile, other researchers shift their attention to explore the children's experiences of cancer in terms of its effects on their sense of self (Woodgate, 2005), their coping mechanisms during the disease (Till, 2004), during the treatment (Weekes & Kagan, 1994) or their coping mechanism in terms of their social support (Woodgate, 2006), their parent's involvement (Griffith, 2009) as well as their communications (Clarke, 2005).

Of all these pediatric qualitative researches, only one was found to deal with the experience of being treated in an adolescent's cancer unit (Kelly et al, 2004) while the bulk of the studies reviewed focuses on the experience of cancer and not of any treatment modalities.

As was noted, while there are quantitative and qualitative researches focusing on how cancer and its treatment affect the life of the adolescent, there were no studies focusing on how the adolescent experience the cancer treatment per se. It therefore further epitomizes the need for a study that would take into consideration the adolescents' account of the treatment specifically chemotherapy.

Locally, Pena-Alampay and colleague (2003) have found that the researches done in the Philippines about adolescent's life experiences, is at its novice stage. As was shown by their review of 147 researches on adolescence done locally in the past two decades, the results show that "fully a quarter" of the studies were only *incidentally* about adolescent. Their study therefore recognized the need for more scholarly works on the lives of the Filipino youth for clearer definitions of Filipino adolescents and their experiences.

As the universal uniqueness and distinctiveness of adolescence as a period of development and adolescents as individuals is stressed and emphasized in the literature, it is then a must for the researcher to explore the phenomena that they themselves experience to better understand them and consequently fill the gap that has existed due to the limited research regarding this phenomenon.

In conclusion, the review of related literature and studies show the necessity for a qualitative study, which echoes the adolescents' experience of undergoing chemotherapy be made. It consequently justifies the need for a study on the adolescents' lived experiences of undergoing chemotherapy be explored and undertaken as a venture for research

### **III. METHODOLOGY**

#### **Aim of the Study**

This study aims to explore the experiences of adolescents undergoing chemotherapy and its implications to the nursing profession.

#### **Research Approach**

This study utilized the phenomenological approach to glean an understanding of the lived experiences of adolescents undergoing chemotherapy. Phenomenology is a science whose prime intent is to describe and explore the meaning and essence of unconsolidated phenomena as lived experiences. (Woodgate, 2006; Speziale & Carpenter, 2007; Taylor et al, 2007; Polit & Beck, 2008). As Spiezelberg puts it “it is a special kind of phenomenological interpretation, designed to unveil otherwise concealed meaning in the phenomena” (as cited by Speziale & Carpenter, 2007:88) by means of entering another’s world to discover the practical wisdom, possibilities and understanding found there (Polit & Beck, 2008) by specifically using inductive method to depict a phenomenon as the individual experience it rather than transforming it into operationally defined behavior (Colaizzi as cited by Beck, 2004), thus it bridges the gap between what is familiar in our worlds and what is unfamiliar (Gadamer as cited by Speziale & Carpenter, 2007).

#### **Selection of the Co-Researchers**

This research employs purposive sampling, in selecting the five (5) co-researchers. Purposive sampling is defined as the careful handpicking of participants that will most likely benefit the study (Finlay & Ballinger, 2006; Todres & Holloway, 2006; Munhall, 2007; Polit & Beck, 2008).

Polit and Beck (2008) emphasized that in selecting participants in a phenomenological research, they should have experienced the phenomenon under study and be able to articulate what it is like to have lived that experience. For that matter, the following three criteria are set in the selection of the five co-researchers in this study: 1) They are willing to articulate, share, participate, and describe their lived experiences, 2) They have undergone at least the second chemotherapy sessions, either as an in-patient or out patient, as one of their treatment modality



for their cancer regardless of its type and severity. The selection of the co-researchers was carefully done so as to represent the three main phases of the treatment (Induction, Consolidation & Maintenance) ensuring that the phenomenon under investigation is fully represented. And 3) that they are adolescents between 12-18 years of age, the phase that best exemplify the characteristic of adolescence stage of development. This ensures that they are able to understand, verbalize and describe their lived experiences distinct to their developmental period as they have perceived it.

All of the co-researchers were, during the time of data gathering and reflection (July 2009 – February of 2010), housed at CHILD HAUS, a halfway house where the researcher was both a volunteer nurse and a clinical instructor since July 2009. After following the appropriate institutional protocol, the researcher carefully selected five adolescents who both fit the criterion.

Of the five co-researchers, one was having his chemotherapy as an in-patient while the other four as out-patients. The in-patient co-researcher was in his induction phase of chemotherapy while another was in his consolidation phase. Two of the other co-researchers were on their maintenance phase while the last co-researcher has just finished his chemotherapy treatment but not his other modalities.

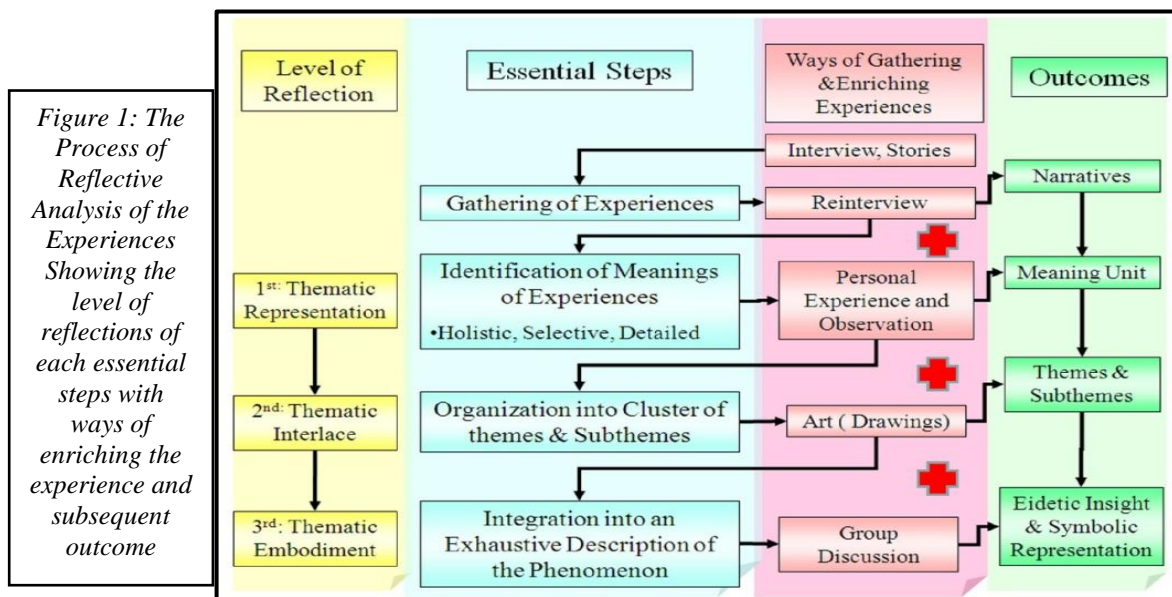
To maintain anonymity and in strict confidence the identities of the co-researchers, their real names were replaced with pseudo-names. In this case that, of the archangels.

### **Ways of Gathering the Experiences**

The lived experiences were gathered by multiple means and they are as follows: 1) Interview (Pakikipag-usap), 2) Storytelling (Pakikipagkwentuhan), 3) Participant Observation (Pakikipamuhay), 4) Art (Sining) and 5) Group Discussion. Moreover, the personal experience and observations of the researcher in taking care of adolescents undergoing chemotherapy further enriched the gathering of lived experiences.

## Process of Reflective Analysis of the Experiences

Narratives from the tape recorded interviews were transcribed verbatim on a computer which were then reflectively analyzed using an approach specifically developed by the researcher (Figure 1), combining characteristics of Max van Manen and Colaizzi's methodology. Specifically, it shows the process of reflective analysis of the experiences, together with its concurrent level of reflection, essential steps, ways of enriching the experiences and their outcomes.



The yellow shaded boxes shows the level of reflections utilized in this study, opposite of which, blue shaded boxes, are the essential steps in the reflective analysis related with each level. In addition to that, the pink shaded boxes represent the ways on how the experiences were enriched, validated and counter-validated, by the co-researchers' experiences. The green shaded boxes represent the outcomes of each essential steps as well as each level of reflections.

The following are the essential steps in the reflective analysis of the co-researchers' experiences

1. Interviews and stories of the co-researchers served as the primary way of gathering the experiences after which they were encoded and synthesized. This represents the first essential steps termed as the "gathering of experiences". Thereafter, the encoded and synthesized interviews and stories were given back to the co-researchers to validate their content via a reinterview which then result into the *narrative*, a validated account of the individual co-researchers' experiences.
2. After the reinterview, the researcher then identifies the meanings found in these experiences via three distinct ways, as was described above by Max van Manen, the holistic, selective and detailed approach. This step, known as the first reflection: *thematic representation* which was further enriched by the personal experiences of the researcher as well as the observation of the co-researchers during the period of immersion and of gathering of the experiences. As a result of this first reflection, subsequent enrichment through observation and personal experiences, and further validation and counter validation of the co-researchers, the enhanced and validated *meaning units* of the experiences were produced.
3. Next, after the meaning units of the combined experiences were reflectively analyzed, the researcher then organized these meaning units into cluster of themes and subthemes, representing the second level of reflection, the *thematic interlace*, which was further enriched by incorporating the meanings of significant artworks (drawing) of the co-researchers. This enrichment further provided both breadth and depth to the experience of the co-researchers. Additionally the resulting themes and subthemes were again validated and counter validated by the co-researchers which then resulted into the enriched and validated *themes and subthemes*.
4. The last step, dubbed as the third reflection: *thematic embodiment*, the researcher then utilized the themes and subthemes gathered through the second reflection and integrated these into final exhaustive description of the phenomenon, which shall finally be validated and counter-validated by the co-researchers through a group discussion facilitated by the researcher. This process of multiple and on-going validation and counter-validation throughout the process of reflective analysis ensured

that the final outcome resonates the co-researchers' experiences as they are lived, producing the *eidetic insight* of the phenomena, the core narrative description of the adolescents lived experiences of undergoing chemotherapy, visually embodied through its *symbolic representation*.

#### IV. RESULTS AND DISCUSSION

##### 1<sup>st</sup> Level of Reflection: Thematic Representation

The narratives of the co-researchers were condensed into significant meaning units to facilitate further reflective analysis. From the five (5) narratives, 707 meaning units were drawn which were then further reflectively analyzed to yield three (3) themes.

##### 2<sup>nd</sup> Level of Reflection: Thematic Interlace

After the first reflection was done and the meaning units derived, second reflection then follows from which three (3) themes were subsequently derived and are as follows: (1) Behind the Mask: The Blurring Self, (2) Forbidden: Not Forgotten, & (3) Nasty Needles: Nothing More, Nothing Less, each representing the unique veiled world of the co-researchers.

##### *Theme 1) Behind the Mask: The Blurring Self*

*[Sa Likod ng Takip: Sarili'y Papalit palit]*

The mask worn during chemotherapy constitutes for the co-researchers varied things. It symbolizes the disease they have, seen as a remnant of their hospital experience and serves as a cover to the real person they want others to see. For them these representations let them feel that indeed they are different.

*“Tapos siyempre titignan ka ng iba pag nakamask ka, ayun, alam na na nagchechemo ka agad (Then everybody*



Figure 2: "Hospital"

else will look at you when you have a mask, they will instantly know that you're having chemotherapy)" (Jophiel)

For them, wearing a mask is a clear symbol that you have a disease, a tangible proof that you are different. As Jophiel stated above, the mask send signals to other persons that you are not like them. Another co-researcher then added that wearing mask is a giveaway that you are undergoing chemotherapy. This notion of the mask representing the disease and the treatment was also evident in the drawing done by Chamuel (*Figure 2*) when he depicts patients inside the hospital as those who wear a mask.

Wearing a mask would then give them the feeling that people stare at them, that they are the center of interest that they don't want, in places they would rather not have. It is the social stigma and unwanted attention the mask brings that makes it unattractive to wear.

It also brings back the memory of their hospital experience; of the time they were fighting for their lives while trying to combat the negative effects of chemotherapy. As all the patients in the hospital are obliged to wear a mask, to wear it outside let them feel as if they are still in the hospital making them feel sicker, as they have a notion that in-patients are sicker compared to OPD chemotherapy patients.

As the mask covers almost half of the individual face, the co-researchers feels that it hides the true person within, the person who still consider himself normal. Though they are sick, they wanted to be appreciated as normal as possible. Jophiel concurred:

*"Sa mask mainit, kaso kahit meron mask na hindi mainit di ko pa din isusuot, nakakairita e, di makita yung mukha mo talaga, nakatago parang pati kung sino ka nakatago na rin (The mask, it's hot, but still if there were a mask that does not make you feel warm I still won't wear it, it's irritating, it covers your real face, it hides it, that you feel the real you is hidden as well)"*

It is not surprising therefore that of five (5) co-researchers, four (4) of them do not wear any mask when they are outside the hospital. On the contrary, the researcher observed that children and adult patient undergoing chemotherapy are constantly wearing mask may they be inside or outside the hospital premises. Moreover, it is worth noting that the only co-researcher who does constantly wear mask is the only one who is currently undergoing chemotherapy as an in-patient whereas the other four (4) who are out-patient do not wear one.

The co-researchers know that it is a must to wear mask when undergoing chemotherapy. They very well can articulate the rationale and benefits of wearing one but it seems that for them, the negative connotations that wearing a mask evoke are enough to overshadow its benefits. Deep inside they are indeed in constant struggle trying the mediate things, hoping to make both ends meet. Thus, balancing the need to wear a mask and their wish to be seen as normal individuals, they would only wear it in places where it is considered a normalcy rather than an exception (i.e the hospital, which in a sense would fulfill both desires.

Beside the meanings they have placed behind their mask, physical appearance is another significant aspect of self for the co-researchers. They believe that it is the first thing people see in them, the one which leave an impression of who they are. In their opinion, if the eye is the window to the soul, the face is a great giant gate to the self. The hair which serves as the “crowning glory” of the person has indeed become important for the co-researchers.

It is not surprising therefore that the co-researcher unanimously agree that hair fall (as a primary effect of Doxorubicin and other drugs) followed by moon facies and pimples (as a direct effect of Prednisone) constitute the most hated and disturbing change they have to endure.



Figure 3: “Lagas Buhok, Tusok Buto” (Falling Hair & Drilling Bone)

The news that their hair will eventually lose is faced with a mixed feeling of surprise, regret, fear and sadness. The great importance the co-

researchers gave to their hair as well as their experience of losing it is also evident when Barbiel entitled her drawing (*Figure 3*) "Lagás Buhok, Tusok Buto (Falling Hair and Drilling Bone)".

It became evident that for them undergoing chemotherapy is tantamount to submitting themselves to various physical changes, which is not a matter of choice but a forthcoming reality. This ordeal somehow brings into their consciousness the truth that they are indeed undergoing chemotherapy. Since this physical change is not a subject of preference, the co-researchers are left with only one thing to do, adapt.

From seeing these changes as negative effect of chemotherapy, in their mind they have transform it to represent their body adapting and in a way conquering the treatment itself, reflective of their uttermost desire to feel normal again. This view of the changes as an adaptation serves as a mean by which they have maintained a sense of relative normalcy amidst the difficulty the changes brings.

In the end, though they have adapted and redefined their experience to suit their needs, the permanent marks that these transition leaves behind do not only serve as a physical memento of their ordeal but a constant reminder that no matter how they desire to be normal again, they can never be the same person as before.

*"Tapos nagiba siya nung tumubo, kulot siya, parang dikit na dikit sa balat, tingnan mo, di na tulad na dati, marka na yan, tatak, remembrance habangbuhay (It's different when it grows back, it's curly, like it sticks to your skin, see this, it's not like before, this is a mark, a remembrance for all eternity)" (Jophiel)*

#### *Theme 2) Forbidden: Not Forgotten*

*[Pinagbawalan: Di Kinalimutan]*

Restrictions, in the world of the co-researchers, are tantamount to two things, change and control. They feel that obeying restriction means changing the very things they are used to do, their routines, their ways, their habit. These things are seen by the co-researchers as part of their

self before undergoing chemotherapy, the self they longed and considered normal. It would be logical therefore for them to keep this sense of their old self alive for after the treatment is over, it is still how they want to be. Simply put, keeping this old self alive means doing things as if there is no restriction at all.

Changing a habit that is inculcated in an individual is hard, especially if it serves as a reminder of a distant past where everything is normal, a far cry from the present situations they are in. Doing their old habits, which for them the restriction is trying to change, gives them a sense of comfort, knowing that they can still do the things as if they are not undergoing treatment. May it be considered as a big offence or small ones (eating raw foods), they would rather give in to the temptation of feeling temporarily normal again by disobeying than reaping the future effect of following an order.

It seems that for the co-researchers, living life at the moment is as essential as living for the future. Being impulsive, giving in to their temporal desire would make them feel as if they don't have any disease, as if they are not undergoing treatment. They are well aware of the possible effect of not abiding on the restriction but for them, these effects are not felt right at the moment when they would crave to do the forbidden things, rather these effects are but found on a distant future. As Jophiel would simply put it:

*“Masarap ang bawal, kain lang ng kain, saka na isipin yung epekto. (What is forbidden feels good, just eat and eat, think of the consequences later)”*

For them, complying with a recommended restriction as part of the treatment regimen means letting the treatment takes control over their lives. In a way, the feeling of losing control is seen as losing one's sense of autonomy, the very thing they try to preserve. Rules make them feel as if they don't have a choice but to follow.

The association of losing ones autonomy and following a restriction is very much reflected inside the hospital, for in here, rules govern the daily activities of the co-researchers. As the researcher have observed, those people around and in constant interaction with the co-researchers, may it be their parents or the medical team, are more obsessed in reminding the co-



researchers of the things they could not do rather than focus on the things they could do. They would reprimand simple deviations from the regulations but won't praise the adolescent when they did follow one. Clearly, the co-researchers were not given a choice but an order.

Once outside, they would see the restrictions as the extension of the hospital itself, thus when given the chance they'd rather go back to their old habits than adhering to the orders. This feeling of relative freedom from the hospital rule makes them more vulnerable to give in and disobey the restrictions. This was reflected by Uriel when he said:

*“Pag nasa labas ng hospital nawawala ang bawal pansamantala pag nasa loob na ulit, madami nanamang bawal (When you're outside the hospital those that are forbidden temporarily goes away, once you're inside (the hospital) once more, there are many restrictions again)”*

It may seem that the co-researchers disregard the rule all in all but there are times when they have nothing to do but follow. As observed by the researcher, there are three prominent occasions when they did abide to these restrictions: when they are inside the hospital, when their OPD treatment is nearing and when they feel the effect of their on-observance of restrictions.

### *Theme 3) Nasty Needles: Nothing More, Nothing Less*

*[Mapaglarong Karayom: Siya at Walang Iba ]*

When asked what single thing represents chemotherapy for them, a resounding “needle” would definitely be the answer. By far, the needle serves as the tangible proof of their treatment, the very thing that touches and in a sense penetrated their whole being. For them, the full effect of chemotherapy, both positive and negative, can only be felt when it has successfully infiltrated their body and inescapably their lives. In their minds, to undergo chemotherapy is synonymous to

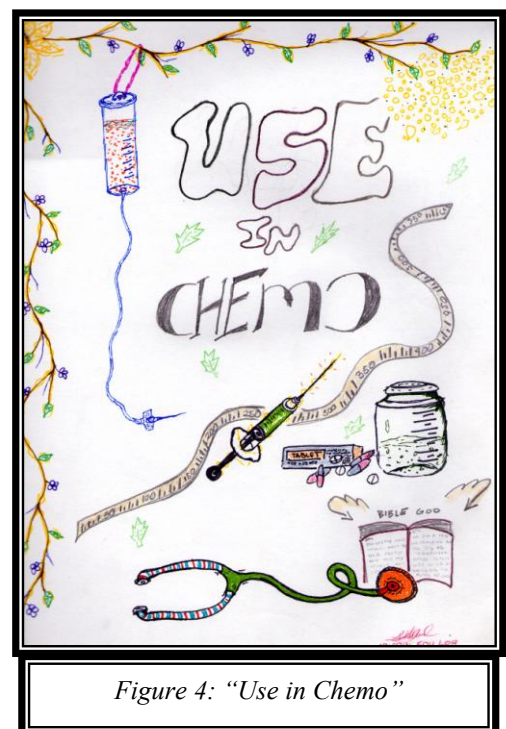


Figure 4: "Use in Chemo"

accepting the needle as a constant intimate companion as what Chamuel has expressed below:

“*Kung magchechemo ka, di ka makakatakas sa injection* (When you’re undergoing chemotherapy, you can’t escape the injection)”

It is not surprising that the drawings done by the co-researchers are full of images of the different kinds of needle like one done by Chamuel (*Figure 4*).

Akin to chemotherapy itself, the needle can be seen neither as a friend or a foe but the two sides can never be separated. It is a friend for it serves as the most efficient and effective way by which the drugs are introduced to the body. It is an indispensable part of the treatment. It is also a foe for it is the single thing for which all the discomfort and pain can be directly or indirectly associated with. Its indispensability makes it more potent as the negative sides can’t be escaped but rather must be endured. The discomfort and pain that is linked with the needle is clearly evident in the following response of Micheal:

“*Summary?! Injection equals sakit, yan ang summary, di mo kasi matakasan* (Summary? Injection equals pain, that’s the summary, you just can’t evade it)”

Besides the ill effects attributed to the needle is the reality that it is the source of most of the marks on the co-researchers’ body. These marks serves as a living testament that they have undergone chemotherapy, a constant reminder of their ordeal.

For the co-researchers, the needle denotes not only intrusion, and pain but the phases of their treatment. For them, the type of needle marks their progress through the treatment. In their view, the IV cannula both symbolizes the early phase of treatment (induction) and being an in-patient for during this period, majority of the chemotherapeutic drugs are given intravenously and all of them are being treated as in patients. On the other hand, the spinal needle signifies for them the later phase (consolidation and maintenance) of their treatment and that of being an out-patient as in this period, all of them are treated as an out-patient. The spinal needle is used to deliver the drugs intrathecally. Like in the IV cannula, they view on the spinal needle more with negativism. If the IV cannula is equated to the gnawing relative *chronic* pain and the evident marks it left

behind, the spinal needle on the other hand represents excruciating *acute* pain and the hidden marks it left on the psyche of the co-researchers. Though the pain is acute, the repetitive cycle of torment and distress the co-researchers felt each time they come under the mercy of the spinal needle leaves more of a psychological imprint.

If the chemotherapeutic drugs are the things they dreaded during their hospital stay, it is the adjunct therapies they fear most during their OPD treatment. This opinion is unanimously shared by those who experienced BMA. In many occasions, when the researcher asked how it is like to undergo chemotherapy as an out-patient, the co-researchers would certainly relate their experiences of having BMA. The immense importance of the experience of BMA is clearly evident when Barbiel entitled her drawing (*Figure 3*) "Lagas Buhok, Tusok Buto (Falling Hair and Drilling Bone)".

This experience has been the central event in their OPD treatment, even though it is not commonly done as compared to the other adjunct therapy or the delivery of chemotherapeutic drugs. It seems that the experience of BMA overshadows the other modalities when it comes to the pain and discomfort it induced, for in their view, it is not the quantity of the experience but the quality which makes it worth remembering.

In all its essentiality, the goodness of undergoing chemotherapy, as the co-researchers see it, is the fact that it *saved* their lives. The primitive and natural craving of human being to preserve and sustain life is embodied in the goodness of chemotherapy. For them, chemotherapy was seen as a plausible source of hope when all things seem to fall apart when they have a disease. If not for chemotherapy, they would have not survived. It seems that for the co-researchers, it has become a choice between living with chemotherapy or simply dying without it.

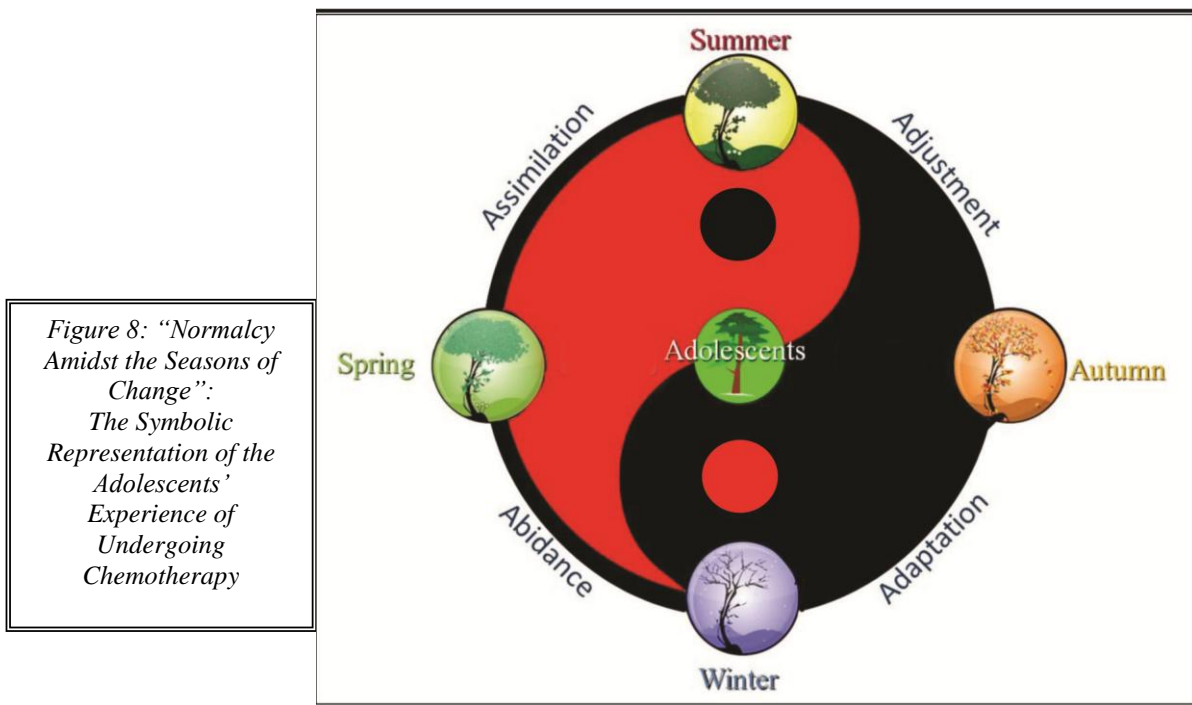
Soon after starting the treatment which in a sense is a miracle for them, the realities of its negative side little by little was made known. For every yang (goodness) there is a corresponding yin (badness), chemotherapy was not an exemption. If chemotherapy *saved* their life, the bad news can be summed up by saying that chemotherapy *changed* their life.

### 3<sup>rd</sup> Level of Reflection: Thematic Embodiment

#### i. Eidetic Insight

Undergoing chemotherapy in the eyes of an adolescent is analogous to a tree journeying through the four seasons of change, eternally struggling to adjust, adapt, abide and assimilate the alterations brought by the seasons, chemotherapy, while trying to maintain a normal sense of self. It is a phenomenon of conflict, of constant struggle between meeting the desire of normalcy and autonomy of the adolescents to letting oneself succumb to the dictum and demands of chemotherapy. In all its essentiality, the adolescents are torn between fulfilling their needs for self assertion as an adolescents and their assumption of their perceived idea of society's notion of asick child.

#### ii. Symbolic Representation



"Normalcy Amidst the Seasons of Change" (Figure 8) is the symbolic representation drawn from the subsequent reflections from this study. At the center of the figure is the tree, personifying the adolescents who are at the heart of the experience. The tree embodies the adolescents' internal desire to be normal as during the season, only the outside appearance of the

tree is changed but inside remains to be essentially the same. Surrounding the adolescents is the symbol of the yin and yang representing the overall complexities, intricacies, and elaborateness of chemotherapy. It also demonstrates the intertransformation and mutual consumption of the opposites such that the yin would fail to develop without the destruction and transformation of the yang and vice versa, that the out-patient regimen would only start after the hospital in-patient treatment have been finished, that the essential drugs would always precede the adjunct therapies.

Moreover, the experience of undergoing chemotherapy represented by the yin and yang is further elaborated by the seasons around their symbols. These seasons correspond to the unique phases of their journey through their treatment while the essential task as one travels from one season to another is placed in between these seasons.

#### *Autumn (Lagas Buhok/ Falling Hair)*

For the adolescents, the realization that they are indeed undergoing chemotherapy starts with the inevitable hair fall. Like the tree shedding its leaves during autumn, it signaled the start of their journey through the season, through chemotherapy. During this time, physical changes little by little surmount the adolescents' life as the effects of both chemotherapy and the disease takes its toll on their body. The autumn also epitomizes the beginning of metamorphosis in the adolescents' self, an image that dominates their inner being during this time. As the night begins to noticeably get longer than the day and the horizon starts to chill as the sky turns grey, the feeling of melancholy starts to sink into the adolescent's psyche as the hospital environment begins to slowly take control of their life and gradually consume their being. It is in this season that they start to turn themselves inward for the possibilities of the summer is gone and the reality of a harsh weather to come is imminent. They start to feel that things will never be the same again, that their old normal lives will be like the summer in a distant past. Deep inside, they know that in order to survive this phase they must be able to *adjust* as quickly as they can or lose their sense of self and be early overwhelmed by the treatment

#### *Winter (Higa Hintay/ Lie & Wait)*

As time moves and their journey continue, the intensification phase of their in-patient chemotherapy then ensures, symbolically marking the start of the season of winter. Like the cold snow covering the trees in winter, the co-researchers' true self were hidden behind the façade of

the mask. And like the trees shrouded with snow, limiting the very movement of its leafless branches, the adolescents' view of the hospital takes its form of a prison cell where they themselves are the prisoners. Because of the changes brought about by the season, the appearance of the trees is drastically altered, like the adolescents undergoing the process of change because of chemotherapy. Like the tree, the adolescents know that one only the outside appearance is transformed but deep inside they are still the same person. Just as the snow totally covers the now leafless trees and have its life within its mercy, chemotherapy then took full control over the life of the adolescents. It is in this period that the compounding discomforts, agony and suffering from both the drugs and the disease reached its peak letting the adolescents to move a passive state, whereby they completely turned themselves inwards, and detach from social interaction.

As the night becomes longest and the surroundings is filled with dullness and coldness, lacking the vitality and vigor of summer, the melancholy of autumn turns into depression. It is in this period that the adolescents may at times feel alone, lose hope and just let others decide for them as they know that the negative effects of chemotherapy cannot be avoided but must be endured. Choice and autonomy during this time seems to be at a lost. As the things during winter conserved their remaining energy to surpass the season, the adolescents then symbolically hibernate, letting time pass, tolerating all that must be endured, dreaming that things will come to an end. Through the winter, the adolescents must learn to *adapt* or otherwise be overcome by the frostiness of time and sleep without the hope of ever waking up again.

### *Spring (Tusok Tubo/ Prick and Sprout)*

As the adolescents, surpassed the critical moment of their chemotherapy and shift from being an in-patient to an out-patient, their journey through the spring is then embarked upon. Through the again lengthening of the day, the spring begins to melt the snow that seals the trees, the adolescents during this period start to regain themselves, reclaim their lives and recover from the devastation of winter.

The spring symbolizes growth as it creates a kaleidoscope of colors, of different flowers blooming, and brings back the vitality and life that seems to desert the winter period. The spring revitalizes their river of energy as it liquefies the ice of winter, indicating the start of a better time. Spring is also the time when rain starts to fall, which for the adolescents signifies the

multitude of injections that they have to endure during their out-patient treatment. Since the growth of the seedlings of spring necessitate a forceful penetration from the ground below to the surface soil, it in a way represent the essentiality of their experience of being pierce (BMA, intrathecal injection, push) so their lives will be renewed as they recover from their disease. As the adolescents move away from the hospital and back into the outside world, their sense autonomy is recoup and their feeling of being in control is redeemed letting them feel that somehow they are normal again. This feeling of autonomy, of being in control and relative normalcy may sometimes be overwhelming that the adolescents may forget that they are still undergoing chemotherapy and turns the otherwise unbreakable restrictions of the treatment into a mere meek advises, which at times they would disregards. Through the season of spring, the adolescents must learn to *abide* by the restrictions of their regimen so they would be on the road to full recovery or overindulge themselves in their relative feeling of freedom and autonomy and subsequently drown in their own river of energy.

*Summer (Takot at Tuwa/ Dread and Delight)*

As the adolescents geared toward full recovery, and well into their maintenance phase, their journey to the summer is initiated. It is during the summer that the day starts to fully lengthen and the outdoors are flooded with the sun's ray of life. It is this phase that the adolescents aspire to attain as it represents the road to full recovery. It is a state of overflowing warmness, of vitality, of hope, of aspirations the very things that the adolescents dream of. As much as the summer represents the future for the adolescents, this future is but a re-creation of their old life which they have always seen as the normal one. It seems that the road toward recovery and the future is but a way back into their past normal life. Though the summer is filled with delight, deep inside the adolescents are beads of dread, for they always fear that anytime their disease might return and again they have to undertake the journey through the season. Like a tree that has now formed a new bark as the journey nears its end, the adolescents themselves have become better individuals, stronger than they used to be. As they progress toward the peak of summer, they must learn to *assimilate* into their life their experiences they had overcome so as to acquire a meaningful life changing insight from their ordeal or just let the warmness of the sun burn away the memory of the treatment into a meaningless events of their past life.

Lastly, inside the yin and yang surrounding the tree representing the adolescents are the four (4) things which serve as their sources of hope and motivation to move on during the entire ordeal.

## V. IMPLICATION TO NURSING PROFESSION

From the insights gathered from the subsequent reflections of the co-researchers' narratives, the following are the implications drawn from the results of this study.

As a summary, may it for those taking care of adolescents undergoing chemotherapy (health care providers, family), educators or policy makers (hospital administrators, government body), the acronym “**CHEMO DRUGS**” can serve as a basis for the improvement of care rendered to this special population. This acronym (**CHEMO DRUGS**) is the synthesis of the implications of the result of this study to the nursing profession.

Caring with genuine empathy directed on the whole person not on the disease

Health teaching focusing on what to expect on chemotherapy and what the adolescents can do while undergoing the treatment

Encouraging the adolescent and their family to be an active member of the health care team

Management of all kind of discomforts throughout the treatment process

Ongoing counseling services and providing meaningful interactions to improve the adolescents' adjustment and adaptation to chemotherapy

Doing follow up care at home to ascertain the compliance of the adolescents outside the hospital

Respecting and treating the adolescents as normal as possible

Uplifting the adolescent's sense of well being by providing meaningful leisure time specifically tailored to the need of clients while inside the hospital

Group meetings and interaction with other adolescents undergoing chemotherapy to form a sense of camaraderie and evade feeling of being alone

Staying and being there with the adolescent as much as possible especially during painful procedures



Insight from this study revealed that care rendered toward adolescents undergoing chemotherapy must be tailor-fitted to their needs, genuine, holistic, emphatic, humanist and highly individualized.

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