Aesthetic Expression of the Life-World of School-Age Children with Advanced Cancer

Barbara Lyn A. Galvez

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy in Nursing (International Program)
Prince of Songkla University
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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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Major Program Nursing (International Program)
Academic Year 2018

ABSTRACT

This study purposed to describe the meanings of the life-world of school-age children with advanced cancer through aesthetic expression using hermeneutic phenomenological approach informed by Gadamer as framework to study the children's lived experience with advanced cancer. The aesthetic expressions of the experiences of ten school-age children living in Negros Island, Philippines, were recruited through snowball sampling who met the inclusion criteria and voluntarily participated in this study. The participants revealed how they experienced through drawing, writing and expressing thoughts in the interviews. The analysis of data was guided by Farokhi and Hashemi's steps and based on van Manen's approach. Trust worthiness was established following Lincoln and Guba's criteria.

The findings of nineteen thematic categories were reflected within five lived-worlds according to van Manen's. The thematic categories under each lived-world are presented as follows: Lived Body (1) Cancer never owned me, (2) Having physical discomforts, (3) Feeling "not normal" and (4) Changing body image; Lived Relation (1) Supportive family, (2) Appreciated compassionate school, (3) Living strength through kindness companionship; (4) Bullying was worse than cancer and (5) Inspiration from God's blessings; Lived Time (1) Hopeful thoughts for the future, (2) Remembering the past active life, (3) Feeling left-behind by others, and (4) Waiting for comfort from discomfort; Lived Space (1) So near yet so far, (2) Living in secure places; (3) Nature nurturing living with cancer and (4) Being close in cyberspace; Lived Things (1) Enhanced connectedness and knowledge through technology, and (2) Hope for technology-cured from cancer. These themes structured the participants' existential life-worlds with advanced cancer.

The lived experience of the school-age children with advanced cancer as expressed through aesthetic means revealed a very positive expression of the life-worlds. Advanced cancer generally crippled the school-age child but the participants redirected their focus on the treatment towards recovery. It is recommended that the findings of this study can be used to enhance the future direction of nursing practice, education and even health policies in the care of school-age children with advanced cancer. Furthermore, future researches on this area must be done.

ACKNOWLEDGEMENTS

First and foremost, I give thanks to God, the Almighty Father for everything He does for me every single day. For taking care of my needs and the needs of my loved ones. For being right by my side through thick and thin. For being my wonderful Saviour! I give back all the glory in your name.

I am so indebted to Thailand’s Education Hub for ASEAN Countries (TEH-AC) scholarship Award at Prince of Songkla University, Hat Yai, Songkhla, Thailand, for awarding me this grant and making it possible for me to study here in Thailand. I am very grateful to Assoc. Prof. Dr. Aranya Chaowalit for her kindness in helping me see the deeper levels of my work, and to the professors and lecturers at the Faculty of Nursing- Graduate International Program, the librarians, staff and other workers of the faculty for the warm welcome and accommodation and allowed me to utilize all needed resources for my study.

My special and heartily appreciation to my major advisor, Assoc. Prof. Dr. Urai Hatthakit who inspired, encouraged and directed me. My PhD has been an amazing experience and I thank her wholeheartedly, not only for her tremendous academic support, but also for giving me so many wonderful opportunities. The challenges brought this work towards a completion. It is with her mentorship and supervision that this work came into existence.

Similar, profound gratitude goes to Assoc. Prof. Dr. Waraporn Kongsuwan, as my co-advisor, who has been a truly dedicated mentor. I am particularly thankful for her constant faith in my thesis work, and for the motivation and support when so generously allowing me to attend International conferences to present my works.

I am also extremely grateful to Prof. Dr. Rozzano Locsin, especially for sharing his expertise so willingly, and for being as steadfast to his role as my expert.

I want to express my gratitude to Dr. Ben S. Malayang, Faculty Development Committee (FADECO) and the Silliman University Administration for giving me the break to study abroad and allowed me to go on a study leave.

I will forever be thankful to Dr. Maria Teresita Sy-Sinda and Luis Montebon-Sy, for encouraging me to embark on a higher learning path, and for providing me with financial resources.

My heart is full of gratitude to my informants whose names cannot be disclosed, but I want to acknowledge and appreciate their help and transparency during my research. Their information has helped me complete this thesis.

I am also gratified to my fellow Thai friends for the friendship and bonding moments that made my study here in PSU Hat Yai Campus an enjoyable one. And to the many other Thai friends, who I have not mentioned here, I extend my warmest gratitude for the help and encouragement which enabled me to walk through my PhD journey.

Finally, and most importantly, I want to thank my family, my husband, Theodore, and children, Tara Bianca and Aaron Daniel, the most significant people in my world, who encouraged, lifted my spirits up and prayed for me throughout the time of my research and PhD journey. You are my life, so this thesis is heartily dedicated to you. May the Almighty God richly bless all of you.

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CHAPTER 1

INTRODUCTION

Background of the Study

Globally, cancer has been identified as the second most important cause of death (World Health Organization [WHO], 2018). Moreover, children with cancer comprise the fastest-growing sector of hospital patients in the Philippines, with their numbers rising by an alarming 30 percent annually (Lecciones, 2015). Cancer-related deaths among 0-14 years old in males account for 1,277 cases and 963 cases in females with the highest number of children's deaths occurring in the National Capital Region (Central Intelligence Agency, 2016). Lecciones (2015) further confirmed that leukemia topped the killer diseases at the Philippine Children's Medical Center (PCMC) among 10-14 years old children. In fact, Kyle and Carman (2017) affirmed that cancer accounts for the most deaths from the disease in children aged 15 years old and below.

Children who had been diagnosed with cancer faced changes in nearly every area of their lives. They faced physical changes which may be temporary, such as hair loss and weight loss or gain, or disfigurement or amputation. As Scheurer, Lupo and Bondy (2016) suggested, these changes served as a constant bodily reminder of their illness and the uncertainty of their future.

According to Kyle and Carman (2017) children do not only struggle from cancer itself but also from the hospital experience, related procedures for assessment and evaluation and treatment interventions for cancer (surgical removal of the tumor, chemotherapy, radiation therapy and bone marrow transplant) that caused negative feelings and fear in children. The negative feelings involved emotional distress (lack of energy, sadness, sensitivity or irritability), fear of the unknown and changes in life priorities of the child and family (Hockenberry, Wilson & Rodgers, 2017). Pain, lack of strength, and fatigue constituted the most common physical symptoms, while changes in appearance, as well as dyspnea and altered sleep patterns were also reported (Silbert-Flagg & Pilliteri, 2018).

An illness in a child is stressful especially if it includes hospitalization. School-age children view the hospital experience as a threat and worry about pain and changes that may occur to his/her body. He/she may miss school and the interaction with peers because friends are important to children of this age group and they may think that their friends will forget them while they are ill (James, Nelson & Ashwill, 2013). Their concerns are particularly intensified when they expect symptoms to be more serious as it will interfere with activities they want to do (Foster, Whitehead & Maybee, 2016). Chemotherapy contributes substantially to the children's misery, but this suffering diminishes with time as the disease is controlled (Wolfe et al., 2008).

Even though there are many undesirable difficulties and problems of advanced cancer and chemotherapy treatment effecting on the life-worlds of school-age children such as stress, pain, lack of energy, and sadness (Lanzkowsky, Lipton & Fish, 2016), sharing their life-worlds of living with advanced cancer through aesthetic expressions such as artworks can help the healthcare providers to understand these children. The experience of art is a starter for understanding thoughts, feelings, and perspectives (Gadamer, 2006). van Manen (1990) also explained that art work could be a source of the lived experience. Since some meaning of the lived experience is difficult to verbalize and describe in words. Aesthetic expression through graphic representation may facilitate the communication of the meaning of the life-world of school-age with advanced cancer.

Phenomenology will give meaning structures that can be described and interpreted and assist in understanding the significance of human phenomena. Since this study aims to understand the life-world and in order to find meaning of that, hermeneutic phenomenology is appropriate to guide this study. Aesthetic expression in art work through drawing is expected to provide greater and deeper understanding of the lived experience of school-age children with advanced cancer. Graphic representation with individual face-to-face interview will describe the school-age experience to find meaning of this phenomenon.

According to previous studies, no research has aimed to describe the meaning of children's experiences living with advanced cancer. While it is true that there were numerous studies on children and cancer, these studies emphasized more on disease conditions rather than on children's experiences regarding advanced cancer. Only one study has been conducted that considered aesthetics as being helpful for both nurse and patient to arrive at an understanding of the human meaning of illness and care (Koithan, 1996). The results showed that aesthetics provided a unique avenue allowing patients and nurses to explore individual perceptions and aspects of their social environment and fostered self-awareness in a creative manner.

However, children's experiences should also be emphasized, and this area describing the experiences of school-age children living with advanced cancer using aesthetic expression has not yet been researched as much. The absence of research studies focused on the aesthetic expression of these children constitutes an obstacle in terms of understanding them more fully. A better understanding of this aesthetic expression is necessary and will be central to nursing practice when children encounter the situation. Hence, the researcher attempted to describe the life-world of school-age children with advanced cancer, their perspectives, feelings, thoughts, and difficulties and gained a desirable understanding from what they experienced concerning cancer and how they interpreted those experiences through drawing and writing. The experience is a valuable source of knowledge (Himelstein, 2006). Consequently, this study intended to contribute to the literature on school-age children with advanced cancer that should be understood as integral to nursing knowledge.

Objective of the Study

The objective of the study was to describe the meanings of the life-world of school-age children with advanced cancer through aesthetic expression.

Research Question of the Study

What were the meanings of the life-world of school-age children with advanced cancer through aesthetic expression?

Philosophical Underpinning

This study employed hermeneutic phenomenology as a framework to study the school-age children's life-world with advanced cancer. Gadamer, a philosopher of hermeneutic phenomenology and aesthetics, focused on the importance of language in shaping both our experience and our interpretations with an aim to explain lived experience and reveal the lived meaning through a process of understanding and interpretation of this basic experience (Gadamer & Hahn, 1997).

Gadamer and Hahn (1997) explains hermeneutics as the art of interpretation that operates on what is said that is not instantly clear. He further clarifies that ordinary beauty does not say anything. However, works of art created by and for humans, say something to us. By using Gadamer's hermeneutics, the researcher was guided as to how one interprets whatever the aesthetic outputs (drawing and writing) of the children would mean to them. The interpretation is open to reinterpretation and dialectical in nature (Gadamer, 2006). The method of interpretation and aesthetics by Gadamer were joined together in the process where the drawing and writing, as aesthetically understood, were interpreted by the researcher with critical thinking ability.

Palmer (2006) argues that interpreting and understanding are more than ways of knowing; they are how people deal with reality. It is a process that engages both parties whose central concern is orientated towards the phenomenon and its articulate reporting dictates a kind of richness that is unique (Kafle, 2011). There is a back and forth movement between the experience of a person and the larger themes of human experience such as illness, suffering, and death. Thus far, our everyday way of being-in-the-world is not one of detachment but one of engagement because sometimes the depth of human life may become flattened, simplified, and even polarized by traditional thinking (Bergum, 1989). For nursing, it means that in meaningful ways we may experience and understand the nursing world and the relations that comprise it (Cameron, 2004).

Draw and write was the prime aesthetic expression of school-age children with advanced cancer. It is for this reason that they must draw and express reflectively in writing their experiences including their positive and negative thoughts, feelings and perceptions that affected them. The process of the draw and write for this purpose is knowing. The outcome to inform the practice of nursing is understanding and the result is known.

As a nursing practitioner interested in the experiences of school-age children with advanced cancer, this researcher was convinced that hermeneutic phenomenology as the philosophy and as a methodology was the most appropriate to describe the experiences one wishes to bring to light based on this study. Relying on hermeneutic phenomenology as research methodology allowed the researcher to give voice to the experiences that children had.

Scope of the Study

This study was conducted in Negros Island, Philippines to understand the meanings of the life-world of school-age children with advanced cancer. The school-age children with advanced cancer were the participants in the study. The data were collected by using drawing, writing, and interviewing during February to June, 2018.

The Significance of the Study

This study provides new information and knowledge about the life-world experiences of school-age children with advanced cancer through the interpretation of their aesthetic expression in terms of draw and write. It must be noted that not much is written about the aesthetic expression of the draw and write; thus, this study tried to fill that gap. The results of the study can equally be used to better understand children's feelings, thoughts, and awareness regarding their life-experiences and improve the nurses' role and quality of nursing practice regarding creative response in providing holistic patient care. The findings may help nurses in guiding knowledge, in possessing sensitive understanding, and in developing novel nursing responses to integrated care among children. For general nursing practice, the findings of this study can be used as a reference to develop better policies regarding school-age children with advanced cancer. When intended for nursing education, the results will aid students' (both undergraduate and graduate) sensitive understanding and skills when caring for children with advanced cancer and assist them to reflect on the precious meaning of nursing practice. As research in the field of nursing, the findings will be useful for providing baseline data to gain insights into the lived experiences. This study could inspire further research from the nurses' perspective on children's experiences the latter often have difficulty communicating.

CHAPTER 2

LITERATURE REVIEW

This chapter focuses on reviewing the relevant literature of the existing knowledge providing a more complete overview of advanced cancer in children, and the philosophical and theoretical concepts underpinning the study. For reviewing the literature, the following outline is adhered to:

1. Overview of Advanced Cancer in Children
    - 1.1 Definition and trajectory of advanced cancer in children
    - 1.2 Problems and needs of children with advanced cancer
    - 1.3 Factors affecting health of school-age children with advanced cancer
2. Hermeneutics and Aesthetics
    - 2.1 Hermeneutics and aesthetics as philosophy
    - 2.2 Aesthetic expression
    - 2.3 Life-world concept
3. Life-World of School-Age Children With Advanced Cancer
    - 3.1 Life-world of school-age children before cancer
    - 3.2 Life-world of school-age children after advanced cancer
4. Summary of Literature Review

Overview of Advanced Cancer in Children

This section describes definition and trajectory of advanced cancer in children, problems and needs of children with advanced cancer, and factors affecting health of school-age children with advanced cancer.

Definition and trajectory of advanced cancer in children. The term childhood cancer is defined by different studies. Childhood cancer is defined as cancers that occur between birth and 15 years of age (National Cancer Institute, 2018). The World Health Organization (2017) defined childhood cancer as the most common malignancy that arises in children before the age of 18 years. Another definition was stated by Lanzkowsky et al. (2016) that explained childhood cancer as cancer diagnosed in children and adolescents under age 20. Thus, childhood cancer is a malignancy that occurs in children between the ages of 0-20.

Nevertheless, Hinkel and Chever (2018) explained that if a child is diagnosed with advanced cancer it is unlikely to be cured because abnormal cells divide and multiply in an uncontrolled way growing slowly, advancing rapidly, and others behave unpredictably. According to Lanzkowsky et al. (2016) leukemia, brain tumors and other central nervous system tumors and lymphomas are the types of cancer most often diagnosed in children aged 0-14 years.

As regards the kind of treatments they receive, these are chemotherapy, surgery and other treatments like radiation and other drugs to help slow cancer growth and control symptoms. Physicians select the treatment depending on the type of cancer and the stage it is in (Siegel et al., 2012). For the treatment of leukemia, combination chemotherapy is preferred. Physicians attempt to induce remissions during the first month of chemotherapy with the intention of reducing immature cancer cells found in the bone marrow. According to Tubergen, Bleyer and Ritchey (2011), approximately 98% of children with acute lymphocytic leukemia achieve remission within one month.

However, for early stage cancer surgery is suggested while advanced stage will necessitate chemotherapy (Hinkel & Chever, 2018). Children with cancer are often treated with chemotherapy in a unit of the hospital that specializes in treating children with cancer. The goal of the treatment is to eliminate cancer completely or to extend survival in children suffering from advanced cancer (Lanzkowsky et al., 2016).

The diagnosis of cancer and its treatment impacts children tremendously as they go through an experience as they find it stressful and threatening. The study of Li, Chung and Chiu (2010), indicated that children experienced high state anxiety on admission in the hospital. Moreover, children presented some depressive symptoms during their stay in the hospital and expressed different degrees of sadness and worry. In addition, Lanzkowsky et al. (2016) stated that children afflicted with cancer experience side effects accompanied by several symptoms as they undergo active treatment. Pain, fatigue, and emotional distress constitute the symptoms that were usually reported.

Problems and needs of school-age children with advanced cancer. Cancer causes negative effects on the physical, social, psychological and spiritual dimensions of the patient. This is because cancer is an uncontrollable cell growth that harms the body and causes excessive pressure and demands for children who undergo treatment (Silbert-Flagg & Pilliteri, 2018).

Physical dimension. The physical problems of childhood cancer start from initial diagnosis of the condition and admission in a hospital to the administration of chemotherapy (Gerali et al., 2011). According to Ricci and Kyle (2009) both cancer and its treatment may change how a child will look. Children worry about being different. Their body image is intimidated, and this at a stage in life when children are very much aware of their bodies and how they belong to a group of friends. Hair loss, weight loss related to nausea and vomiting brought about by the effects of treatment, or other changes in their appearance become a cause of insecurity. Peer relationships at this age are given much importance (Hockenberry, Wilson & Rodger, 2016). Children are aware about their appearance and how others view and respond to them. Former friends stop playing with them because their appearance frightens others. At the same time, other children are also afraid of catching cancer (Dehkordi, Baratian & Zargham-Boroujeni, 2014).

The physical symptoms of advanced cancer and its treatment are fatigue, pain, appetite changes, hair loss, weight loss/gain and breathing problems (National Comprehensive Cancer Network, 2016). Cancer-related fatigue is described as being physically, mentally and emotionally tired due to extreme tiredness that does not go away even with rest (Coyle & Ferrell, 2001). More than anything else, children with cancer are terrified by pain. Because of pain, the child feels irritable, sleeps poorly, their appetite decreases, and he or she cannot concentrate on what they want to do (Foley, Back & Bruera, 2005).

In a study by Wolfe et al. (2000) aside from fatigue, pain, dyspnea, and poor appetite were the problems most commonly reported in children with cancer. A different study by Enskär and von Essen (2008), described fatigue as the most frequently reported physical problem among children with cancer. Hence, it is imperative to understand these effects as children find it difficult to recover and adjust to life again after cancer, and to move on (Potts & Mandleco, 2012).

Social dimension. Social issues may arise while the treatment is on-going or afterward. The child's friendships are put to the test, and it can happen that some friends are lost during a prolonged, serious illness. Occasionally, the child's old friends no longer wish to be with them or they have stopped caring. Some children with cancer take the first step and reach out to friends. Children may acquire new friends because of this experience. Some recurrent family concerns during treatment include financial burdens, the need to travel to the cancer center and staying there, and the need to file a leave of absence of parents from work (Ricci & Kyle 2009). It is not easy for families to sort through these issues because some individuals do not understand their state of condition (Potts & Mandleco, 2012).

Children with cancer and treatment feel anxious, experience depression or anger, and these feelings influence aspects of their developmental growth. They become obstacles for relationships, in school, at home, and other aspects of life (James, Nelson & Ashwill, 2013).

Evidently, children feel resentment, having experienced cancer or having to go through treatment when others stay healthy. They are concerned about people treating them differently or being discriminated against by friends and classmates whom they consider to be a great source of support and encouragement during this time of their crisis (Berger, 2011). During treatment, children suffering from advanced cancer focus on getting through their crisis together with their families day by day in overcoming the disease (Hockenberry et al., 2017).

Psychological dimension. Childhood cancer is classified as “a chronic, life-threatening disease”. It is regarded as a period of crisis the patient him/herself goes through, but also one that involves his/her family and even their social environment (Ricci & Kyle, 2009). According to Gerali et al. (2011), although most children with cancer are still young when the condition is first diagnosed, still, children suffer from emotional or psychological issues. Even after the treatment is completed, various concerns can arise. Some of these are long-term concerns putting a burden on both children and their families (Willis, 2003).

Regarding psycho-social health, most studies indicate that childhood cancer survivors are comparatively more likely to experience emotional problems. For instance, it is reported that they suffer from depression and anxiety and their psychological well-being, mood, and levels of liveliness and self-esteem are at lower levels (Eilertsen, Rannestad, Indredavik & Vik, 2011). Researchers have argued that discomforts accompanying a chronic health condition produce symptoms of depression (von Essen, Enskar, Kreuger, Larsson & Sjoden, 2000). Facial defects and relentless hair loss have been linked to emotional distress (Kinahan et al., 2012).

In the study of Hedström, Haglund, Skolin and von Essen (2003), they mentioned that the experience of facing frequent stressors, including painful, invasive medical procedures, physical side-effects related to the treatment, and obvious changes in appearance is traumatic for the child. Enskär and von Essen (2008) indicated in their study, that the time span marked by illness and its treatment is an emotionally and physically stressful time for children and their families. In addition, the latter is forced to adapt to a hospital setting presenting physical and psycho-social challenges. Because of these challenges, disruptions occur in normal family, social-, and school life, as the child is separated from his/her brothers and sisters, school friends, and peers. This is further supported by Marcus (2012) when he said that children suffering from cancer frequently demonstrate higher levels of anxiety together with lower levels of coping skills. This problem can manifest itself in higher levels of depression, apprehension, and thoughts about death.

Spiritual dimension. For children and their families, the initial diagnosis, its consequent treatment and everything it implies are experienced with physical discomfort and distress. Aside from the physical pain, the distress these young patients have to go through has other dimensions as well, namely on the emotional, social, existential and spiritual level (Menossi, Zorzo & Lima, 2012). The motivation to remain hopeful and maintain spiritual connections offer some form of energy for a cure (Barrera, d' Agostino, Gammon, Spencer & Baruchel., 2005). Children exhibit their values, beliefs, and needs because they want the sensitivity of other people to understand their feelings and complaints and value what is significant for them while being free from judgment. Knowing that stress is associated with the experience of having cancer, it is dominant that praying and going to church is embedded to suit their distress as they journey through the advanced stages of cancer (Corcioli, EspinhaI, Aparecida & de Lima, 2012).

Factors affecting health of school-age children with advanced cancer. Factors are influences and contributions that bring about certain effects or results towards a better outcome in the health situation of school-age children with advanced cancer. These are health care services and policies, single parenting, family and peer support.

Healthcare services and policies. Childhood cancer constitutes an important global health issue. Cancer has an impact on public health and this impact continues to grow as it rises in some cancer incidence rates (National Cancer Institute, 2015). When parents discover their child is diagnosed with cancer, the first thing that comes to their mind is not usually about paying for the treatment, but rather making sure they have health insurance coverage to pay for the cancer treatment as well as for the needed follow-up care (Steliarova-Foucher, Hery & Pisani, 2006).

The availability of healthcare programs and services, as well as health insurance, provides an important assistance to families who need to meet the many emotional, social, and financial needs when a serious pediatric illness like cancer strikes (Yantzi, Rosenberg, Burke & Harrison, 2001).

In this regard, the Millennium Development Goals made major contributions in improving public health services by introducing national cancer plans. Government support for childhood cancer registries increased. Moreover, much-needed research and development are now focused on funding from sustainable sources and on establishing more research networks and engaging in clinical research specifically targeting the needs of low-income and middle-income countries. Current plans are prioritizing the delivery of better care and educating professionals as well as patients (Sullivan et al., 2013). Government programs with adequate support to households taking care of children afflicted with serious medical conditions such as cancer are helpful (Miedema, Easley, Fortin, Hamilton & Mathews, 2008). In hindsight, at present, all Filipino children with cancer have access to a national health plan which covers all medical costs for physicians and hospitals and pays for medicine available in the hospital particularly for poorer patients (Ribeiro, Steliarova-Foucher, &

Magrath., 2008). For this reason, diagnosis of the disease tends to ease families of children with cancer since they can solve daily situations in crisis moments (Rosaleen, 2003).

Family and peer support. Family support is the most important element in children's lives (Cronin, Arnstein & Flanagan, 2015). As part of their growth experience, children expect a great deal of relief from their parents (Newman, Lohman & Newman, 2007). Families help children live a life that is as normal as possible. Most often, families are in communication with physicians and other care team members to find out what to expect in terms of changes the child can go through, so they can plan for the sake of the child (de Witt & Kumagai, 2013). Alderfer et al. (2006) mentioned that families accompany children with cancer as they go through many tests to an unfamiliar medical facility for complete evaluation. As the child spends considerable time in a hospital environment and little time in school while being treated, parents are there for their child being treated for cancer to make sure that the child is safe, comforted and protected (Bowden & Greenberg, 2010).

Alongside family support, peer support is also a significant factor because they substitute their friends from getting social support when attention from their parents is inadequate. Children expect and rely upon their friends to provide emotional, social or practical help when they need it especially when they are sick (Alderfer & Hodges, 2010).

Social peer support has a positive impact on academic performance. Their support serves as a protective factor when children are considered at risk for potential difficulties (Domagala-Zysk, 2006). In addition, it also influences children with cancer positively in other areas of school activities where they were enthusiastically involved before their illness. Emotional adjustment and resilience are better assured when they are given social support by friends or classmates once they return back to school (Demaray & Malecki, 2002a, 2002b). School-age children suffering from cancer who have good relationships with their family and friends showed higher resiliency (Kim & Yoo, 2010). Notwithstanding their illness, children with cancer find it essential to become successful with themselves and achieve a satisfactory level at school (Suzuki & Kato, 2003). Thus, social support assists the families of children with cancer maintain ties with classmates and teachers during sickness and treatment. This is favorable as it will assist them to adjust to school re-entry after treatment (Kim & Yoo, 2010).

Once the child is medically stable, most chemotherapeutic treatment for leukemia is given on an outpatient basis. The child is usually healthy and can return to school and engage in most age-appropriate activities (James et al., 2013).

Hermeneutics and Aesthetics

This section provides knowledge and understanding of concepts and philosophies regarding hermeneutic and aesthetics, aesthetic expression, and life-world as a background knowledge for the researcher to develop research design and method to understand the meanings of the life-world of school-age children with advanced cancer.

Hermeneutics and aesthetics as philosophy. Phenomenology is a philosophical discipline that reflects the meaning of life as we live it and the nature of responsibility of personal actions, behaviors, intentions and intentions as we meet them in the life-world (van Manen, 2014). This study used phenomenology focused on hermeneutic phenomenology.

Hermeneutic phenomenology is a method of creating meaning and understanding of human experience as it is lived. Furthermore, van Manen (2014) also stated phenomenology transforms “lived experience into a textual expression of its essence, in such a way that the effect of the text is re-living and a reflective statement of something meaningful”. Phenomenology is said to look at traditions, languages, assumptions, recalls and cognition in order to understand the existential truth of everyday life. Lived experience as explained by van Manen (2014) is the experience we live through before taking a reflection of it. Thus, the experience is lived through results in the meaning that is reflected from the experience.

Hans-Georg Gadamer (1990-2002) was the German philosopher and one of Heidegger’s students who was the decisive figure in the development of twentieth century hermeneutics who posited philosophical hermeneutics. According to Gadamer, one cannot interpret reality without presupposition or background (Alawa, 2016).

According to Bourgeois (2007) Gadamer paid attention to the phenomenon of art. Gadamer detailed that hermeneutics should not be considered as just a method of interpretation. Instead, it refers to “a mode of human understanding of dialogue between interpreter and text”. This renders relevance to aesthetics in discussions about the human search for truth. By using the aesthetic model, it is only natural to be affected and possibly transformed by an individual who encounters the truth expressed by an art work or a text. This is the only way for true interpretation to take place. van Manen (1990) recognized art as a source of lived experience. According to van Manen art objects are “visual, tactile, auditory, and kinetic texts” that consist of non-verbal communication but constituting a language with its own grammar.

According to Gadamer (2006) hermeneutics and aesthetics, mean the self-understanding of each person. Furthermore, Gadamer’s work on the experience of art is a starter for understanding thoughts, feelings, and perspectives. Gadamer believes that the experience of art is communicated to each person as something present and concurrent. Experiences and encounters with art speak and connect directly with those who encounter them. Hence, hermeneutics, the study of understanding, embraces aesthetics, as far as Gadamer is concerned.

Aesthetic expression. Aesthetics is a branch of philosophy dealing with matters related to beauty and artistic taste. Aesthetic expression is using one’s skill and imagination to create aesthetic objects, settings, or experiences that are accessible to others (“Aesthetics”, n.d.). According to Tolstoy, (as cited in Van Camp, 1998) the most common belief about art is that it is essentially a form of expression, particularly the expression of feelings.

Aesthetic expressions had been used in nursing research mostly among adult patients. Previous studies used drawing (Kongsuwan & Locsin, 2010; Locsin, Barnard, Matua & Bongomin, 2003) and another study looked at scenes from nature and examined the use of photo albums (Wikstrom, 2004). The following are studies on aesthetic expressions in nursing research.

A study by Locsin et al. (2003) used drawing through a picture reflecting the meaning of living as survivor of Ebola hemorrhagic fever. After drawing was finished, participants were asked to explain the meaning of the pictures. The experience illustrated as living in fear while concurrently hoping for life.

Furthermore, Wikstrom (2004) examined how important aesthetic forms of expression are in Sweden by randomly selecting a population between the ages of 65 to 89 and interviewing them. Semi-structured interviews with 166 participants were served as data. Participants expressed that viewing scenes from nature and going through photo albums can be considered as important aesthetic activities. The aesthetic forms of expression made them engage in physical and intellectual activities, and increased interaction with other individuals. Aside from serving as sources of gratification, aesthetic experiences generated feelings of “timelessness and spacelessness”.

In addition, Kongsuwan and Locsin (2010) in a research study conducted in intensive care units (ICUs) in southern Thailand, mentioned that art and aesthetic expression by drawing, illustrated and illuminated the experiences of persons who were taking care of relatives, assuring them a peaceful death. Participants joined in face-to-face interviews using hermeneutic phenomenology approach by van Manen for analysis. The results revealed aesthetic expression, falling into the category of ‘descriptive thematic experience,’ allowed those involved to appreciate the experiences more, resulting in a more holistic end-of-life care.

The Life-World Concept

The term life-world articulates how individuals’ truths are constantly influenced by the world in which they live (Heidegger, 2002). According to van Manen (2014), the way to employ the reflective inquiry process, is to engage in the existential themes of ‘lived relation’ (relationality), ‘lived body’ (corporeality), ‘lived space' (spatiality), 'lived time' (temporality) and 'lived thing' (materiality). van Manen (2014) affirms that existentials are universal themes which are helpful when one engages in an exploration of meaning regarding aspects of our lived world experience and when studying a phenomenon. Lived relation (relationality) guides our reflection with respect to the phenomenon being studied as to how people or things are connected. Lived body (corporeality) serves as a guide to reflect on how one experiences the body vis-à-vis the phenomenon that is being studied. It is also a way to find out how we pay attention to our body, how our desires, fears, anxieties incarnate themselves in the world in which we dwell.

In the same way, it pertains to how the phenomenon under study is perceived, sensed, touched by the body. Lived space (spatiality) guides our reflection as to how one experiences space in relation to the phenomenon under study. It relates to how we are shaped by space and vice versa, as well as how space is experienced from place to place. 'Lived time' or temporality is a guide to our reflection to question how time is being experienced differently. For instance, the time spent waiting is experienced differently as compared to when an individual is actively involved in something. It also shares the experience of wishes, plans, goals that an individual strive for in life. The sense of identity is generated by recollecting the time of one's childhood, times of exercising professional activity and one's love life. It likewise guides our reflection on the sign of maturation and growth. Lived things (materiality) guide one's reflection as to how one experiences things. Materiality informs one of how experiences of things and of the world contribute to the vital meaning of phenomena like global warming, the atmosphere of a city and the spectacle of a grand vista.

Life-World of School-Age Children With Advanced Cancer

This section presents the literature relevant to life-world of school-age children before cancer and after advanced cancer. Research studies respecting to school-age children with advanced cancer also are included.

Life-world of school-age children before advanced cancer. A fundamental concept of the life-world is the world of lived experience that we as conscious beings inhabit, integrating the way we view phenomena like events, objects, and emotions in our cognizant everyday life experience (Brooks, 2015).

The life-world of school-age children is constantly influenced by the world in which they live. They are continuously developing their abilities and arrive at a growing understanding of concepts as well as the world they live in (Berger, 2011). This spirals with the assurance that every child gets the best start in life. As regards their body, school-age children are very active and full of energy. This is related to major muscles gaining control giving them a good sense of balance. They enjoy testing muscle strength and skills. Their bodies go through many physical changes as it moves into physical maturity. This involves height, weight, and development of secondary sexual characteristics. The physical changes make them especially self-conscious.

Furthermore, school-age period is a period during which the child’s development is vulnerable. This is due to the significant physical and emotional changes occurring (Berger, 2011). At this stage the child’s focus on physical appearance is increased. Their self-esteem and psychosocial functioning are affected by how they view their physical appearance. They observe changes in their own bodies and worry about these. They tend to compare themselves with their peers. (Hockenberry et al., 2016).

As far as cognition is concerned, according to Jean Piaget, the intellectual abilities of school-age children are based on gaining knowledge, experience, and wisdom. They make clear reasoning and thorough ideas. They are increasingly aware of external accomplishments. They understand that one's own thoughts and feelings are special. They also have concepts of time, space, and number (Santrock, 2010). Older children ages 10 to 14 years old, have keener metacognition, a sense of their own inner world. They quickly develop the ability to speak and articulate their ideas and feelings. These children become increasingly skilled at problem-solving. They have a longer attention span and can follow stories that are more challenging (Berger, 2011).

The children at first develop a relationship with their family but soon outside relationships develop with classmates, friends, and even with their teachers, coaches, or caregivers. As the world of their experiences expands, many dynamics modify the children’s behavior and influence how they learn to get along with others (Santrock, 2010). They communicate with others telling them about themselves and about their families. Playing provides an opportunity to practice the vocabulary and language they have learned in school (Hockenberry et al., 2016).

The school-age years are considered a time of eager exploration and discovery aside from home, due to their regular contact with the larger world, for instance, the neighborhood, hospital, community, and school which expand the child's world beyond the family environment (Berger, 2011).

During this eventful phase of development, school-age children experience tremendous physical, social/emotional, and cognitive growth. From a dependent toddler in the past, at school age years, children establish independence, gain confidence, and develop unique and different personalities. New and exciting abilities are developed progressing at different rates and generating diverse interests (Hockenberry et al., 2017). Parents set limits on what is acceptable and provide guidelines and clarify expectations, while at the same time consistently enforcing discipline and moral values (Santrock, 2010).

Life-world of school-age children after advanced cancer. Life-world is the direct and personal human experience of the world that provides a realistic, clear and smart illustration of everyday life. The life-world determines how our everyday connections with our realm are enriched. Our association takes place in our everyday being as we are involved with the things that really matter. It is the starting point of our foundation of being in the world (van Manen, 2007).

The life-world of school-age children changes after having been diagnosed with cancer and undergoing treatment. Children enduring cancer often have to undergo a lengthy treatment. This treatment may be painful and is accompanied by feelings of discomfort (Ångström-Brännström & Norberg, 2014). Bjork, Wiebe, and Hallström, (2005) revealed in their descriptive hermeneutic phenomenological approach study, that the lived experience could be described as "a broken life-world" and an "immediate striving to survive." Challenges are faced by the child and their families (Sadruddin & Hameed-ur-Rehman, 2013).

In the long term, the nature of the treatment and its side-effects raises significant health and psychosocial concerns not only for the children themselves, but also for their families, school, communities and the health system (Rudolph, Rudolph, Lister, & First, 2011). In a study of Sadruddin & Hameed-ur-Rehman (2013) children show awareness of changes in their physical capabilities, their appearance, and moods identifying them as major concerns. Aside from producing physical changes, cancer in children also adds to a weakening of their sense of self related to the punitive disease experiences involving their bodies that bring a menace to body image.

The perception of children with cancer reflected lower levels of social acceptance by their peers (Freeman, O'Dell, & Meola, 2003). Generally, children feel safe at home and get excessive protection from their parents and families. Children with cancer need the love of their parents and siblings, as these enable them to cope with anxiety. They need to be supported socially and morally to generate a positive emotional development and help them gain a positive insight (Sadruddin & Hameed-ur-Rehman, 2013).

Additionally, school is seen as more than just a place for learning. It is also a place for fun and friendship (Hockenberry et al., 2016). Going back to school is challenging as well. Children want to be treated as they were before their treatment. Classmates and peers might single them out or tease them and make them feel prone to criticism or failure. They become dismayed when others criticize or ignore their behavior or school work (Ricci & Kyle, 2009). According to Kyle, & Carman (2017), when children with cancer have low self-esteem, this becomes an obstacle to adjust and accept the changes in their physical appearance. The low confidence in their abilities is caused by the side-effects of chemotherapy, which alter their looks, as they may undergo hair loss or fluctuations in weight.

If the children are afraid of being rejected and teased by their peers, these emotional difficulties may be aggravated (Sadruddin & Hameed-Ur-Rehman, 2013). Specific treatments for childhood cancer are determined by the type of cancer and the stage it is in. Some children may not be able to go back to school. Others may be in and out of school. For those who return to school, it necessitates extra attention. This is due to the reason that their body is delicate, so it can easily acquire infections, become overly tired, experience hair loss, weight loss, and fatigue (Rudolf et al., 2011). The child and families' secure everyday life disappears and is replaced by a chaotic life characterized by fear and loneliness. In their efforts to assure the survival of child and the family, family members go the extra mile to stay hopeful and maintain a positive focus, not to lose control, and to feel supported by other people (Bjork, Wiebe & Hallström, 2005).

Studies Regarding School-Age Children With Advanced Cancer

From the literature review, we can find two articles regarding school-age children with cancer in advanced stage. The first study was a qualitative research study using descriptive phenomenology conducted by Menezes (2010). This study found that if children acquire adequate explanation about procedures and treatment that they receive from healthcare professionals, and their thoughts, feelings, and experiences are heard, they can share of themselves.

A second study conducted by Heinonen (2015) described children’s experience with cancer focused on phenomenological inquiry. Children described and interpreted their experiences with cancer as a different animal that they must struggle and fight with for their everyday existence.

In terms of study conducted in Philippine, a descriptive exploratory study of Flores, Gepte, Lecciones and Rigor (2008) gathered responses and reactions of parents. Parent's perceptions were identified regarding disclosure of their children's diagnosis of malignant neoplastic disease. Various emotional reactions to the newsworthiness were elicited. Several factors, like the relationship and communication between physician and parent, contributed to their understanding of the disease and deciding to go for treatment. Based on the parent's perception, physicians must be guided as to the manner and quality of information to be given with prudence regarding their children's disease condition.

A different study carried out by de Peralta, Gonzales-Santos and Santos (2014) consisted of a six-year cross-sectional retrospective study using an in-hospital based registry. Prevalence of childhood malignancy and profile was measured based on age, sex, family history of cancer and type of childhood malignancy. Results revealed childhood malignancies were predominant in males. Leukemia was the most common malignancy followed by lymphoma, then malignant bone tumors.

There is a substantial amount of knowledge on childhood cancer and its treatment. Nursing studies have also described how parents and health caregivers perceived and experience life with a child with cancer. Other studies on advanced cancer covered to a great extent affect older persons. One study described and interpreted experience of children living with cancer. However, no study acknowledged the lived experience of school-age children with advanced cancer using artwork. Thus, this study describes how school-age children diagnosed with advanced cancer find meaning in their life, living with cancer through aesthetic expression.

Summary of Literature Review

Childhood cancer is a malignancy that occurs in children between the ages of 0-20. When children are diagnosed with cancer, the experience is stressful and threatening. The hospital is one setting where children with cancer are confined for diagnosis and medical procedures. In addition, admission to the hospital is experienced with different degrees of sadness and worry. However, literature review regarding experience of children with advance cancer is limited. The effect of cancer on the lives of school-age children result to negative effects on the child's health physically, psychologically, socially, and spiritually. The factors affecting the health of the school-aged children with cancer that were considered as significant are adequate support from government programs, as well as support from family and friends. The life-world of school-age children before advanced cancer is a continuous development of their physical, emotional, intellectual abilities and relationships with their family, friends, classmates and teachers. Having been diagnosed with advance cancer, children endure the pain of lengthy treatment accompanied by feelings of discomfort. Subsequently, two important conclusions were formed from the literature review on the use of aesthetics in studying the life-world of several groups of patients. First, aesthetic research uncovers profound understanding of life-worlds and second, there have been no aesthetic studies of the life-world of children experiencing advanced cancer.

CHAPTER 3

RESEARCH METHODOLOGY

This study aimed to describe the meanings of the life-world of school-age children with advanced cancer through aesthetic expression. The purpose of this chapter is to describe the methodological aspects which are composed of the research design, setting of the study, participants, researcher background, instrumentations, data collection procedures, ethical consideration, data analysis, and trustworthiness.

Design of the Study

This study was a qualitative research design with a hermeneutic phenomenological method based on Gadamerian philosophy and van Manen. Hermeneutic phenomenology was used to reveal the meaning of the life-world of school-age children with advanced cancer by uncovering details as it was experienced by the participants. The participants were asked to illuminate meanings of their experience living with an advanced stage of cancer through graphic representations (drawings) followed by narrative descriptions (writings). After that an individual face-to-face interview was employed.

The Setting of the Study

The setting of the study was lodged in Negros Island, Philippines. There were two university hospitals in this island. These two university hospitals provided services for pediatric oncology patients such chemotherapy, surgery, and radiation. In Negros Island, Philippines, all schools have a policy to allow the school-age children with advanced cancer to have a rest period for two weeks after chemotherapy treatment before they return back to the schools.

Participants

The participants of this study were school-age children who have been diagnosed with advanced cancer who lived within the geographical region of Negros Island, Philippines. The inclusion criteria for participants' selection were as follows: 1) 10 –14 years old; 2) Diagnosed with advanced cancer (2^{nd} stage) as verbalized by parent/guardian; 3) Able to communicate in English; 4) Willingness to participate in the study; and 5) Able to express their experiences through graphic representation such as drawings and narrative description such as writing.

The number of study participants based on Creswell (1998) for phenomenology ranges from 5-25 participants. However, the number of participants who participated in this study was based on saturation. Data saturation was appreciated when no additional perspectives or information was gained by increasing the number of participants (Grove, Burns & Gray, 2015). Data saturation was attained when the researcher observed data redundancy among the participants. Furthermore, van Manen (2016) stated that there is no point of saturation in the context of phenomenological meaning.

Snowball sampling was utilized to recruit the participants. The researcher prepared a letter of permission for parents and guardian which were signed by her supervisor. An explanation of the use of snowball sampling and the target population was attached together with a copy of the Certificate of Approval of Human Research Ethics, Center for Social and Behavioral Sciences Institutional Review Board, Prince of Songkla University, Hat Yai, Songkhla, Thailand.

The researcher selected a parent of a school-age child known to have advanced cancer based on the inclusion criteria. The researcher did not contact the hospitals to recruit the participants; instead the researcher carefully and discreetly asked the parent whether she would be willing to pass some information about the study she just completed to other potential parents. At the same time, to inquire if she can assist in identifying other potential parents with the same situation and participate in the study. The researcher provided a copy of the letter of permission that she can give to another parent that she thought might be interested, and a contact number for the potential parent/guardian to contact the researcher.

The researcher implemented the said process to ensure that privacy or confidentiality was maintained. The potential parent/s or guardian/s were not known by the researcher. The researcher was fully aware of the consequences of the rights to privacy and confidentiality of information and what would be the consequence if the diagnosis of advanced cancer was obtained without the clients' permission. Measures were taken to ensure that the potential participants' privacy was not violated such as, disclosing information to others without permission from the participants and protecting participants from potential harm including psychological harm such as embarrassment or distress. The researcher was also obligated to guard all information gathered from a participant about others.

Researcher's Background

The researcher is a devout Roman Catholic and a registered nurse with experience as a lecturer and clinical instructor in Pediatrics in the College of Nursing Silliman University, Dumaguete City, Negros Oriental, Philippines. The researcher is a certified advanced pediatric life support provider having been trained under the American Heart Association basic life support. The researcher had experienced taking care of children with advanced cancer during her clinical time, supervising both baccalaureate undergraduate and graduate students in the hospital. As a clinical instructor, she experienced caring for young children with advanced cancer. She possessed a positive outlook in dealing with every child who had to be cared for. She made to bring coloring book, crayons, clay, drawing book, colored pens and colorful butterflies and floral stick-on to divert the attention of sick children. As Christmas time drew near, she wore multi-colored blinking string necklace to attract children especially those who have difficulty taking oral medications. The experience and feeling of taking care of children with cancer matter to the researcher. From those experiences, the researcher believed that children should be given time to be listened to as far as their health issues are concerned. By doing this, the researcher understood feelings, behaviors, perspectives, and insights of children with cancer better and considered them significant.

Ethical Considerations

Approval to conduct the research was provided by the Institutional Review Board of the Social and Behavioral Sciences, Faculty of Nursing, (number 2017 NSt – Ql051) Prince of Songkla University, Thailand. Moreover, the researcher asked permission from the school-aged children with advanced cancer and their parents/guardian before conducting the study.

The school-aged children with advanced cancer were voluntary in this study and were provided with essential information for informed consent (Appendix A). They were informed of the title, the objectives, the benefits and the methodology (design, conduct, what they would receive, and how long they needed to participate) of this study. They were informed that all the information collected would be kept anonymous by using codes. Furthermore, the results of the study would be reported without any reference to anyone and the participants' name were not shown or used. In addition, all interview transcriptions and photographs taken of artwork were stored in a password-protected file saved on an external hard-drive and this was securely stored in a locked storage box. The persons that could access the data were only the researcher and researcher's thesis advisors.

The participants could ask any question related to this study and could withdraw from the research at any time. If the methodology or anything in this study changed, the participants would receive notification immediately. This study posed no physical and/or physical or emotional risks on the participants. However, there was a possibility that sometimes during the interview some participants may get bored. In addition, the participants were informed that there might be potential tiredness while answering the questions. Recollecting some of the experience was a little painful for the children. Some instances involving tearful moments during the recollecting and recalling aspects of the lived experience caused moments of discomfort for the participants. The researcher was a nurse experienced in comforting children. She acknowledged momentary discomfort/sadness/pain for these children and helped the child deal with it constructively.

The sensitivity of the topic and its potential intense interpersonal exchange was recognized. Interviews were conducted in locations of participants' choice which were quiet, private and safe. The participants as well as the parent/guardian were advised if they needed psychological support and preferred to speak to a psychologist, the researcher has contacted a child psychologist before data collection. In general, there were no difficulties or remarkable incidents encountered in the data collection procedure except for one instance when the participant paused the interview for nutrition and elimination break. The researcher offered sandwiches and bottled water which she personally prepared. The interview was resumed after 10 minutes and ended well.

The risk-to-benefit ratio was assessed for this study to specify minimized risk and more benefits for children with cancer-based on the maximized benefits and the minimized risks (Gray, Grove & Sutherland, 2017). The benefits of this study for the participating school-age children with advanced cancer was to experience better emotional health in terms of increased awareness of their condition, being able to express their experiences living with cancer through graphic illustrations such as drawings and narrative descriptions, like, writing.

Data Collection Procedures

Data in this study consisted of the demographic data of the participants, drawing and writing description, and interview data.

1. Demographic data form (Appendix B) was used to collect information including age, gender, religion, education, illness history, medical diagnosis, and treatment.

2. Draw and short writing description was used as a means of expression to assist the child from getting started on a story.

3. An interview was carried out to allow the participants to reflect, recollect and recall all about their experiences which transpired before, during and after diagnosis of advanced cancer including treatment. An audio-tape recording was done to aid the researcher in transcribing the data in full. An observation was undertaken during the interview to understand the participant's behavior, facial expressions, position changes, body movements and non-verbal indications of boredom.

Data collection consisted of two parts. The first data collection stage consisted of, preparation phase, and initial phase. The second data collection stage comprised of graphic representation, narrative description phase, and interview phase.

First data collection stage. The process of data collection included preparation and initial phase which are described as follows:

Preparation phase. The researcher conducted a preliminary study to assess the suitability and practicability of the study.

1. The preliminary study has been undertaken with two participants.

2. The data have been analyzed and findings have been considered based on van Manen’s existential themes.

Initial phase. Approval for this study has been granted by the Institutional Review Board, from the Social and Behavioral Sciences, Prince of Songkla University, Thailand number 2017 NSt – Ql051.

1. The researcher invited the school-age children with advanced cancer with their parent/guardian as the initial contact with the participants to participate in this study.

2. The researcher discussed the study (purpose, eligibility of participants guided by the inclusion criteria, and benefits of the study).

3. Parent/guardian who was willing to have their child join this study and children who were aged 10-14 years old signed the consent form to participate.

4. The researcher confirmed with parent/guardian and school-age child with advanced cancer the date, time and place for the next appointment of data collection (drawing and writing).

Second data collection stage.

Graphic representation phase.

1. The participants laid out the aesthetic expression of their experience being persons with advanced cancer.

2. The participants were provided with a drawing pad, pencil, eraser, crayons, colored pens and pencils, and watercolor.

3. The participants could choose the materials which suited their preference to use for drawing.

4. The researcher emphasized to the participants that the drawing should be without any help from any member of the family.

5. Drawing materials were properly arranged in the table beside the participant for easy accessibility.

6. Once the participant was ready, he/she started to draw and write.

7. Each participant was instructed to show by drawing or illustrating their life or living experiences with advanced cancer.

8. Participants were allowed 30-45 minutes to draw their pictures.

***Narrative description phase*.**

1. The participants described the expressions/images in the drawing through writing on paper provided by the researcher.

2. If the child opted to verbally describe the picture, the researcher audiotaped the description (as indicated in the informed consent form) and clarified with the participants' uncertain statements.

Interview phase.

1. After drawing and writing, the face-to-face interview followed.

2. The semi-structured open-ended interview questions were validated by five experts. Two experts were from the Faculty of Nursing, Prince of Songkla University, Thailand with the expertise in pediatrics and three from the College of Nursing, Silliman University, the Philippines, with expertise in phenomenology.

3. The researcher was unstructured in approach and used probes in response to the participants’ answers eliciting further information.

4. Interview sessions were conducted in quiet, private and safe locations of the participants’ choice.

5. Interviews were carried out for one hour and thirty minutes with audio-taped record.

6. The researcher made it clear to the participants that they only needed to divulge what they felt comfortable with.

7. The participants were interviewed on at least 3 occasions. In the initial interview (30 minutes), the researcher obtained a demographic profile of participants from parent/guardian and participants. The second interview was the in-depth interview (1 hour and 30 minutes) where participants explained their drawings and writings and the last interview, (30minutes) was initiated to validate answers from participants.

8. The observation was done on three occasions during a face-to-face interview with participants. The researcher recorded observations, such as changing position frequently in his/her seat, tapping of a pencil on the table, feelings of sadness and or happiness, conversations, and experiences regarding advanced cancer.

9. The researcher noted the participants' tone, expressions, and associated actions and what was occurring in the setting.

10. Handwritten recording of observations and the overall settings and experience of the data collection process was completed while in the interviews.

Translation Procedure

The entire interview transcriptions of two participants during the preliminary study with some Cebuano language (local idiom) from participants were translated into English by the researcher and by the expert who was bilingual both in English and Cebuano language. The expert was an oncology head nurse in the pediatric oncology unit of the hospital. Those two transcriptions were then analyzed with the advisor. This was performed to establish the trustworthiness of this study and served as a training for the researcher in data analysis. The data of the ten participants that contained some Cebuano and Ilonggo language were likewise translated into English by the researcher and were validated by the expert who was a bilingual nursing professor. The translated versions then were further analyzed with the thesis advisor and co-advisor.

Data Analysis

To understand, thoughts, feelings, perspectives and values of school-age children lived experience with advanced cancer, analysis was done in two steps. First, analysis of data generated by participants which were drawings was performed. Second, the analysis of narrative descriptions and interview transcriptions were conducted.

The analysis of drawing data. First, drawings from each participant were inspected, one by one. The steps of analysis guided by Farokhi and Hashemi (2011). Images, symbols, objects, places and events were noted. Participants' interpretations were recorded. Next, written and audio-recorded narrative descriptions of the drawings were examined individually, and field notes made.

The analysis of narrative descriptions and interview data. In accordance with van Manen's hermeneutic phenomenological approach, the researcher made use of reflective methods such as thematic reflection and existential reflection, as well as writing methods to come up with an interpretation of the meanings associated with aesthetic expression, as it is lived (van Manen, 1990, 1997, 2014).

Thematic reflection. Thematic reflection was undertaken in the study to reveal something meaningful from the various experiential accounts of the participants. Thematic reflection on each individual participant's data was done by reading and re-reading, the transcripts, and then brought all those themes together and endeavored to find common themes from the individually produced themes. The structure of the text was described in terms of meaning units, and significant statements to analyze them and identify the thematic aspects of the participants' experience.

As for the interviews that were transcribed word for word, all transcripts were read several times for familiarity, marking any sentences or phrases that were particularly significant in terms of clarity. Participants were asked to describe the hidden meanings observed in the repeated symbols in the participants' drawing. Next, the documents were analyzed by applying van Manen's (1990) three approaches for identifying thematic aspects of a phenomenon. The researcher discovered that applying each of the three approaches helped her to reflect on the lived meaning of school-age children with advanced cancer and to identify broader themes. Furthermore tables and diagrams (Appendix J) of themes were created to visualize the findings, which was helpful in generating further meaningful descriptions.

First, the **holistic/sententious approach** was used. The researcher attended to the entire text, which captured the fundamental meaning of the text, to generate a narrative or paragraph. Meanwhile, not all participants have the same result. Pieces of information of the past with inference to the present as evidenced by children's drawing, narrative, interview excerpts and observation were brought together, analyzed, and merged into the whole picture of the life-world. Then when the researcher began to pool themes from the entire set of data and analyze the pooled theme, a model representation of the life-world of school-age children with advanced cancer emerged.

Next, utilizing the **selective/highlighting approach**, the text was read again and the phrases highlighted that particularly revealed significant statements about participants' experience.

Finally, the **detailed/line-by-line approach** was used wherein each individual sentence or cluster of sentences was carefully examined. This process generated thematic statements regarding what each sentence or cluster of sentences revealed. Themes that emerged were identified.

Guided existential reflection. To complete the data analysis process and thematic reflection, existential reflection served as a guide grounded on the five life-worlds: 'lived body,' 'lived relation,' 'lived time,' 'lived space,' and 'lived thing' (van Manen, 2014). Thus, these five existential were particularly helpful in engaging in reflection for this study, considering the lived experience of school-age children with advanced cancer was more profoundly understood when this existential ground was considered. The data were then sorted and the themes organized around the five life-worlds, and the themes were further refined by making sure that each life-world was represented as completely as possible.

Writing as analysis. To become more immersed in the lived experience of school-age children with advanced cancer, the researcher embarked on a process of writing and re-writing. Firstly, after each participant's first interview, a draft was composed out of the conversation and the contents later transcribed. The researcher then discussed significant statements that were captured in the discussion with respondents in the course of the second interview. These ‘hermeneutic conversations’ provided an opportunity for the participants to reveal further insights about their experience.

After the completion of all the second interviews, the researcher wrote and re-wrote. In doing this, she further refined and re-defined the themes. The writing process assured that the transcribed interviews were made into a textual quality of documentation wherein the researcher’s understanding of school-aged children with advanced cancer was improved and to make sure that each participant’s voice was reflected in each of the study’s themes.

According to van Manen (1997), “when qualitative descriptions of human experience integrate aesthetically textured descriptions, it can deepen the sense of understanding in the reader. This experience is so strong or striking that it may stir us at the core of our being” (p. 364). This study could lead to a deeper understanding of the lived experience of school-aged children with advanced cancer in a novel and touching way. The five existential elements guiding the researcher's reflection (‘lived body,’ ‘lived relation,’ ‘lived time,’ ‘lived space,’ and ‘lived thing’) constituted a practical framework for organizing the findings.

Trustworthiness

Trustworthiness of this study was maintained by using four criteria developed by Lincoln and Guba (1985) which are:

Credibility. Credibility is defined as the integrity in the truth of the findings. Credibility established the integrity that the truth of the findings was consistent with the reality. In this study, the data collected were from participants who had experience advanced cancer and could reflect and describe the experience.

Dependability. Dependability was accomplished following the process of an external audit to evaluate the accuracy and whether the results, discussions, and conclusion are consistent with the data. The external audit was done by consultation with a thesis advisor and peer review from an expert.

Confirmability. Confirmability displays that the findings were formed by the participants and not by the researcher's bias, motivation or interest. Confirmation was attained by triangulation which used multiple data sources including graphic representation through drawings, narrative descriptions, interview transcriptions, observation form, and field notes written by the researcher during data collection.

Transferability. Transferability assures that the findings can be applied in another context. Transferability was achieved by thick descriptions in which the researcher described the phenomenon in detail.

CHAPTER 4

FINDINGS AND DISCUSSION

The results of this study were based on the data of ten school-age children with advanced cancer. This chapter presents the following: demographic characteristics participant's profile, graphic representation and narrative description as aesthetic expression, findings, and discussion.

Demographic Characteristics

Table 1 shows the demographic characteristics of the data obtained from participants' own individual booklet acquired from the time of diagnosis up to treatment sessions and follow-up visits comprising instructions and prescriptions. The data included age, gender, grade level, onset of illness, diagnosis, treatment facility and chemotherapy type.

Ten participants who met inclusion criteria belonged to the age range of 10 – 14 years old. Four were 10 years old, two were 12 years old, two were 13 years old and another two were 14 years old. Five were boys and five were girls. The highest-grade level attained was grade 8 while the lowest is grade 2. Six participants were diagnosed with acute lymphocytic leukemia (ALL), two with acute myeloid leukemia (AML), one with osteosarcoma and the last one with retinoblastoma. Seven were admitted in private teaching hospitals while the three were in a public government-owned teaching hospital. Six are still going on with their chemotherapy treatment while four are on maintenance course.

Table 1

Participants' Demographic Characteristics

Participants	Age	Gender	Grade Level	Onset of Illness	Diagnosis	Treatment Facility	Chemotherapy
P1	13	Girl	7	12/7/15	ALL	Private Hospital	3rd year IV/oral
P2	10	Boy	3	2/21/17	ALL	Private Hospital	1.5 year Intrathecal/ Oral
P3	12	Girl	5	3/16/13	ALL	Private Hospital	Oral chemo maintenance
P4	10	Boy	5	2/10/12	AML	Public Hospital	3rd year IV/oral
P5	12	Boy	6	11/15/15	AML	Public Hospital	3rd year IV/oral
P6	10	Girl	2	5/6/16	ALL	Private Hospital	2nd year IV/oral
P7	14	Girl	8	7/24/17	ALL	Private Hospital	1st year IV/oral
P8	13	Boy	8	12/7/09	Osteosarcoma	Public Hospital	Oral chemo maintenance
P9	10	Girl	4	1/28/12	ALL	Private Hospital	Oral chemo maintenance
P10	14	Boy	3	3/02/2010	Retinoblastoma	Private Hospital	Oral chemo maintenance

Participants' Profiles

Participant 1. She is the daughter of a well-off Protestant family. She had a brother who was two years younger than her age. Her father was a seafarer in an international overseas cargo vessel while her mother was a plain housewife.

She was a happy child, full of positivity. She has round face, fair skin, round brown eyes, and thin lips. Her black hair is growing by two inches in length after she experienced hair loss from treatment. She smiled most of the time by showing her teeth and liked to talk because she was confident about herself. She was 13 years old, born last October 31, 2004, Protestant, from Negros Oriental, Philippines.

She was diagnosed last December 7, 2015 with advanced cancer acute lymphocytic leukemia (ALL). She stayed in the hospital for two weeks for further observation and confirmation of diagnosis. After diagnosis was confirmed, chemotherapy treatment was started last January10, 2015. She is now on her third year for parenteral, intravenous and oral chemotherapy.

She has returned to school as Grade 7 pupil with good academic standing and is actively involved in school activities as member of various clubs such as science, camera and book club.

Figure 1. Cancer never had me.

This drawing (figure1) portrays the participant standing in the middle of a garden. It is reflective of her positive outlook despite her diagnosis of advanced cancer, the setting in which she feels comfortable, and her self-reliant approach to coping and dealing with her condition. Optimism is immediately apparent as the girl in the drawing, which is a depiction of the participant herself, is smiling and is surrounded by reassuring words and phrases. The choice of a garden with growing flowers maintained personally by her mother as a hobby as the background shows the participant's affinity for nature which is therapeutic and helped her cope with her condition. The participant chose to make herself the primary subject of her drawing and four of the seven phrases on it start with "I". This expresses a highly personal and independent approach to what she calls her "battle" with cancer; the phrases connote that key to this battle is her condition and attitude. At the same time however, the phrase in her drawing which reads "Everything happens for a reason" connotes an acceptance of things beyond her control. Overall, the drawing reflected a highly introspective and personal account of dealing with advanced cancer which reinforced the experiences the participant shared in the interview.

Participant 2. He was the only child of separated parents. His father was jobless, living with another woman, while his mother, remarried, and worked in Metro Manila supporting his treatment. He stayed with his paternal grandparents who took care him since he was 4 years old.

He was a handsome young boy, with round face and brown skin, deep seated eyes, with dimples on both cheeks when he smiled. He looked tidy, dressed neatly, and looked clean. His voice was low and rough because of a sore throat. He frowned when he was worried that he could not answer a question. Anxious and perspiring he asked for a small towel from his grandmother. He was 10 years old, born last October 15, 2007, Roman Catholic, living in Negros Occidental, Philippines.

He was admitted in a private hospital in Bacolod City last February 2, 2013 for two weeks. After routine procedures were performed and laboratory results were confirmed, a diagnosis of acute lymphocytic leukemia (ALL) was revealed to the father. He was discharged last February 18, 2013. He was started on intrathecal chemotherapy and oral treatment right away last February 25, 2017. It has been 1½ years since he started the treatment.

At present his health was better because his appetite was back to normal, and he did not experience joint pains. He was in Grade 3. He had to stop schooling for a year due to his condition. When he resumed schooling he was a top performing student in Mathematics and an honor student in his class.

MY SAD STORY

My family story is a sad one. We live in a house owned by my grandparents since I was one year old. My mother left my father to work in Manila because my father has no means of income. At 6 years old, I got sick and diagnosed with Acute Lymphocytic Leukemia. My grandmother took care of me. She will bring me to the hospital for my check up and chemotherapy treatment. My father would carry me to my school which is nearby our house. He lived with another woman and had two kids. It was a hard life. Sometimes we have food to eat but most of the time, we have to eat less because my grandmother would save for my treatment. My chemotherapy is very expensive. She asks help most of the time to sponsor my treatment. In return I repay her with good grades in school. My mother does not care about me. I study hard to help my grandparents.

Figure 2. My sad story

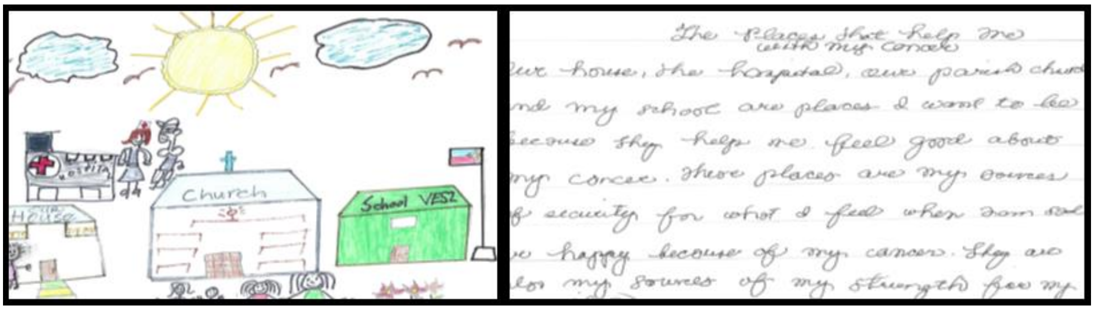
This drawing (figure 2) expresses the participant's experience of advanced cancer in different contexts: as a son, a grandson, and as a student and friend. Portraits of the participant himself in a group or pair of people recur throughout the drawing. Several portraits are shown with family members. There were different sections in this drawing pertaining to different relationships. The first section shows the participant hand-in-hand with his father. His father, the participant said, carried him to school when he was too weak to go on his own power and physically supported him during chemotherapy sessions. The second section depicts the participant, his mother, and a broken heart between them. This, the participant said, was meant to show how his mother left the family and the sadness he felt and continued to feel because of this. The third section shows the participant together with his grandmother who was his primary caregiver. She, the participant said, had taken on the responsibility of finding funds for his treatment. The fourth section illustrates the participant between his grandparents. He lives in his grandparents' house which is also shown in the drawing. These portraits are reflective of the participant's avowed reliance on his family as his physical, emotional, and financial support system. Each family member offered different type of support to him except for the mother towards whom the participant shows much bitterness and sadness. Other than the participant himself, the grandmother is the only figure which recurs in the drawing. This shows her particular significance in the participant's life. The last section represents the participant playing with his friends. The friends embody a social support system to the participant. He played and found comfort with them. The school implies hope for the participant as he saw getting good grades as a way of helping and repaying his family, particularly his grandmother, and it was his means for showing them how much he valued their support. The participant's narrative is titled "My Sad Story" as a reflection of the financial strain his condition had put on his family and the absence of his mother throughout his young life. The drawing and the narrative depicted the emotional struggles the participant has had to face because of his condition.

Participant 3. Participant 3 was the youngest in the family of two older siblings who were both boys in their late adolescent years. Her mother was a bookkeeper in a sugar central company and his father, a sales agent in a car company.

She looked untidy during the first interview; her hair was messy, coarse and loose. Her face was wide and oily. She has dark brown skin with round brown eyes and full lips. She was plump, casually clothed in t-shirt and denims. She was anxious by swaying both legs and tapped the ball pen on the table. Head bowed down when her mother called her attention to stop making extra movements. She was 12 years old, born last November 2, 2005, Roman Catholic, living in Negros Occidental, Philippines.

Last February 13, 2013, she was admitted in a private hospital in Bacolod City for two weeks. Medical procedures revealed leukemic cells in the spinal fluid and she was discharged on March 29, 2013 with a diagnosis of acute lymphocytic leukemia (ALL). Chemotherapy treatment started April 30, 2013. She had been on oral chemotherapy maintenance for 2 years now.

After one year of absence from school, she was now in grade 5. She had some problems with memory retention. Her parents maintained her on regular monthly laboratory tests and physician's clinic visit.



The Places that help me
with my cancer
ur house, the hospital, our parish chur
nd my school are places I want to be
ecause they help me feel good about
my cancer. These places are my sources
f security for what I feel when I am sa
e happy because of my cancer. They are
lso my sources of my strength for my

Figure 3. The places that help me with my cancer.

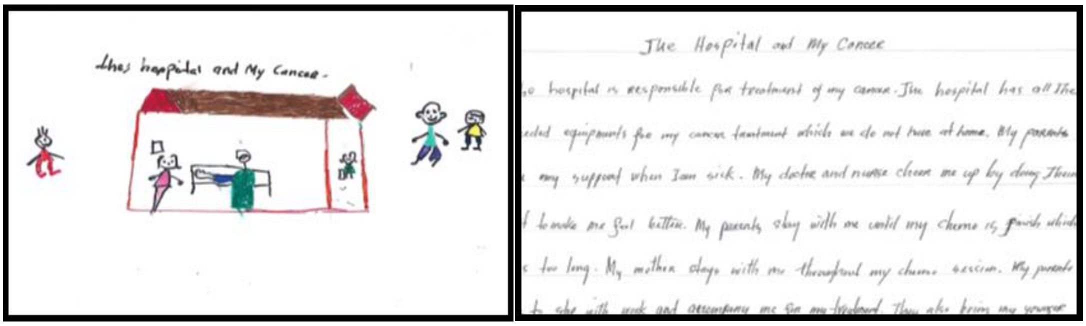
In her drawing (figure 3), the participant highlights significant locations which she said “help her feel good” about her cancer. She chose her family’s house, the church, her school, and the hospital. She wrote that these places provided her with security and strength for her condition. There are also images of persons in her drawing. In the middle, the participant depicted her mother, her siblings, and herself hand-in-hand. When probed as to where her father is, she said that her father was often away at work; it was her mother who took care of her and brought her to the hospital for treatment. Another detail to note is the person depicted in front of the house frowning. The participant said that this was her and showed the situation which followed chemotherapy sessions; she was usually alone at home resting with her mother coming to visit from work. She said that she preferred being alone while resting after her treatment sessions. The participant’s write-up entitled, “The Places that Help Me with my Cancer” elaborated further on her feelings towards the institutions she showed in her drawing.

Participant 4. Participant 4 was the middle child in the family of 5. He had an elder sister aged 16 years old and a younger brother whose age is 4 years old. His father worked in a sugar plantation and his mother was a laundry woman.

He was frail, small for his age, pale, thin and not active. He had large bulging eyes and thin lips and gap toothed. His outfit was an old pair of shirt and shorts and black rubber slippers. He was shy and cautious of his actions. He covered his face when he committed mistakes in answering a question. He was 10 years old, born last October 9, 2007, Roman Catholic, living with his parents in Negros Occidental, Philippines.

He was admitted to a public hospital for 14 days last February 10, 2012 to seek consultation from a physician about his health problems. Medical procedures were completed and he was discharged on February 24, 2012. He was prescribed monthly OPD laboratory work up to monitor blood cell counts. After confirmed laboratory results, the physician's diagnosis of advanced cancer acute lymphocytic leukemia (ALL) was communicated to the parent. Intravenous and oral chemotherapy 5 sessions was started at once on April 30, 2012. After he finished 3 years of chemotherapy, he recovered but because he did not tolerate the side effects of the treatment, he stopped taking his oral medications. In 2016, physical symptoms reappeared. He stopped schooling last year and only returned back to school this year. He was in Grade 5. He had poor academic performance in the past by getting failing marks in his subjects related to frequent absences from classes.

At present, he was under the care of a cancer foundation to monitor his health due to abdominal distention which had been felt for signs of an enlarged liver by the attending physician. The tests of blood cell count results revealed leukemia recurred and he is back to chemotherapy treatment.



The Hospital and My Cancer

hospital is responsible for treatment of my cancer. The hospital has all the
eded equipments for my cancer treatment which we do not have at home. My parents
my support when I am sick. My doctor and nurse clean me up by doing their
to make me feel better. My parents stay with me until my chemo is finish which
too long. My mother stays with me throughout my chemo session. My parents
[illegible] with work and accompany me for my treatment. They also bring my younger

Figure 4. The hospital and my cancer.

The participant opted to make the hospital the focal point of his drawing (figure 4). He represented himself and his family, as well as the nurse and doctor, as he goes through treatment for his cancer. The hospital, he said, has all the equipment that is needed to treat his cancer, “which we do not have at home”. Through this, the participant showed awareness of cancer and its treatment. However, he also expressed the importance of the people around him, highlighting his doctor, nurse, and his family. He felt that the doctor and nurse tried to cheer him up and did their best to make him feel better. Though it is not clear if the statements he made were from a purely clinical standpoint, the emotional impact of his doctor and nurse’s actions were clearly illuminated.

He also talked about his family’s role in his treatment. The participant said that his family accompanied him to the hospital whenever he received treatment with his parents having to forego work to have to do so. He stressed that chemotherapy sessions took “too long” and that his parents stayed with him until it was finished. His mother, in particular stayed with him during the session, and he also made it a point to mention that his younger brother was also present. The participant showed a high regard for his family’s presence and its importance in his treatment. He also showed an understanding of the sacrifices (i.e. “my parents have to stop work”) that go hand in hand with his treatment. His drawing and narrative clearly showed that the participant had awareness of the multiple aspects of cancer and its treatment such as pain, fatigue and hair loss.

Participant 5. Participant 5 belonged to a small family living a simple modest life with his parents, grandmother and a younger brother, aged 5 years old. His father was a farmer while his mother was a housewife looking after her two children.

He had thin face with fine hair, dry, dark brown skin, hollow brown eyes and thin lips. He smiled, with relaxed mouth. He was short and small for his age, protuberant abdomen, with light rashes in some areas of his hands. He wore red cotton t-shirt with some holes, khaki shorts and blue plastic sandals. He was in the best mood to share his experience with cancer. He was 12 years old, born last July 7, 2005, Roman Catholic, living in Negros Occidental, Philippines.

He was admitted in a public hospital in Negros Occidental, last November 15, 2015. According to the mother he stayed in the hospital for a week for laboratory tests which revealed the diagnosis of acute myeloid leukemia (AML). Intravenous and oral chemotherapy was started at once after a month. Now, he was on his 3rd year for chemotherapy and felt better than the first time he started with it.

He was in Grade 6 attending a public school in Negros Occidental. He had not stopped attending school in spite of his diagnosis and treatment.

MY LIFE WITH cancer
Our home and school is helpful in my condition.
y Life with cancer in the mountain is beneficial
d relaxing because i can breathe fresh air and
t fresh vegetables which is favorable for my illness.
ide from my family and friends our pet dog gives
e happiness and forget about my cancer.

Figure 5. My life with cancer.

The participant highlighted the home and the school settings in his drawing (figure 5). He made a conscious attempt to avoid references to his cancer as evidenced in a phrase in his narrative; “forget about my cancer”. Instead, he talked about things he liked and what made him feel good. The participant talked about his immediate surroundings, particularly the mountain and what it provided; the fresh air and fresh vegetables, he said, were beneficial and acted as a treatment for his cancer. He alludes to his family and his dog as giving him “happiness” and allowing him to forget about his condition. The participant, it seemed, is much more concerned with his life beyond and outside his cancer diagnosis and treatment as evidenced in his drawing and narrative. There is a distinct lack of any references to anything medical; rather, he has elected to draw and write about the emotional and psychological supports he has turned to while living with his condition.

Participant 6. Participant 6 was the only child in the family. She lived with her father who worked in a bank in their hometown and her mother was an overseas foreign worker as a caregiver in Canada. Her paternal grandparents took care of her since both her parents were employed.

She was a pampered young girl as she was the only child of her parents. She had a lean body and looked pretty, neat and smartly dressed in her baby pink colored dress and fuchsia pink glass slippers. As she smiled, she showed her set of full white teeth. She was sensitive to how people around her handled her feelings and needs and stayed away if she was treated with indifference. She was 10 years old, born last March 12, 2007, Roman Catholic, living in Negros Occidental, Philippines. She had to stop school due to the treatment. She came back to school this year as a Grade 2 student.

She was admitted in a private hospital in Negros Occidental last May 5, 2016 for a week. The results of the procedure and laboratory tests collectively confirmed acute lymphocytic leukemia (ALL) as diagnosed by the doctor according to the grandmother. At present, she had regular monthly check up with her pediatric oncologist. She was on her 2nd year with chemotherapy treatment.

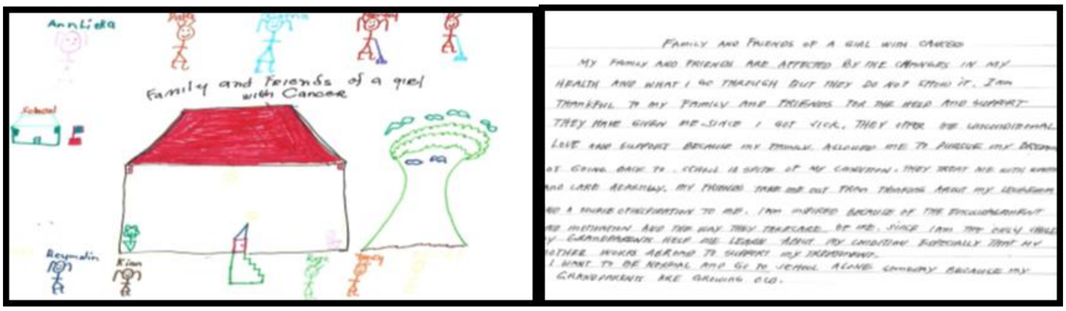


Figure 6. Family and friends of a girl with cancer.

The participant's drawing and narrative center on her family and social life. It is very clear that this is very important to her; her works give the impression that these are a tribute to them. She has drawn (figure 6) and written at length about the effect of cancer on her family and friends. She depicts her home, school, family and friends in her drawing. The participant stressed that going back to school was her dream and that she is thankful to her family for allowing her to do so. Her write up is full of expressions of thankfulness towards the people around her who were affected by her cancer diagnosis but do not show it. They are also her source of strength, comfort, and motivation. Despite her diagnosis, the participant still took the time to show care and compassion for her grandparents who were her primary caregivers as her mom is working abroad. She is eager to be "normal" so that she can go to school alone as her grandparents are getting older she said.

Participant 7. Participant 7 is the third child of five children in the family. Her two elder bothers before her were both working. Her mother was a housewife and her father, worked as a company body guard to a rich sugar planter.

She was a willowy-figured, average in height girl with an oval shaped face, brown-eyed, and thin lips with dark brown skin. She smiled with exposed teeth. Her hair was growing back after hair loss from chemotherapy. She was casually dressed up in green cotton t-shirt and denims matched with white sneakers. She was 14 years old, born last October 17, 2003, Protestant, living in Negros Occidental, Philippines. She had to stop schooling this year.

She was admitted in a private hospital in Negros Occidental, Philippines last July 24, 2017. She stayed in the hospital for one week and was diagnosed with acute lymphocytic leukemia (ALL) according to her mother. The doctor tried to regain back her health first before intensive intravenous and oral chemotherapy treatment started August 31, 2017. According to the mother, the doctor considered a bone marrow transplant if remission was not achieved. She was on her first year chemotherapy treatment.

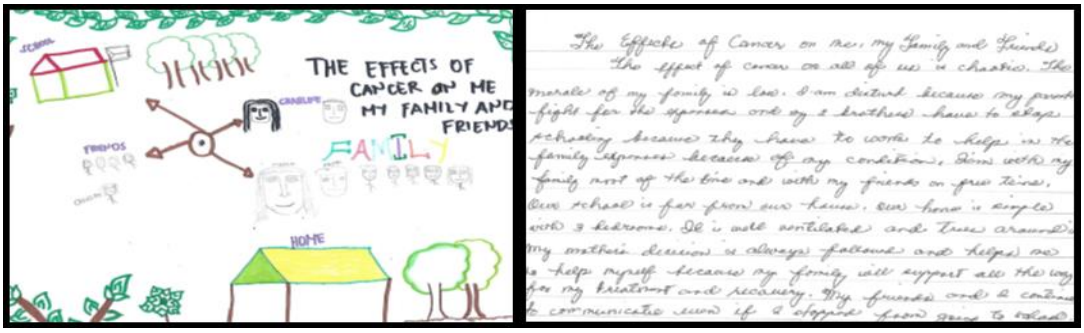


Figure 7. The effects of cancer on me, my family and friends.

The participant was very conscious of how her cancer diagnosis had affected her family emotionally and financially. In her narrative, she detailed the negative effects of her cancer diagnosis on her family. She expressed a lot of guilt that her family, including her siblings had to stop school, had to work very hard to finance and support her treatment. Her drawing (figure 7) illustrates two settings: the home and the school. The home, which she described in detail in her write up, where she spent most of her time as she had to stop going to school due to her cancer. It is evident in her drawing and narrative that there was longing in the participant to go back to school and that she understood the gravity and the importance of education as she mentioned negatively to her and her siblings having to stop schooling. She has also drawn and mentioned her friends who also appeared to be an important aspect of her life. The drawing and the narrative both display that the participant was fully aware about the situation her cancer that put her family and herself in, as well as the sacrifices needed to commit to her treatment.

Participant 8. Participant 8 was the only child. His mother had a small business in the market who retailed dry goods and took care of him since he was small. While his father worked as a foreman in a construction site. Sometimes his assignment was out of their hometown so that it took months before he could be home again with his family.

He had a full round face with fair complexion drenched with perspiration. He beamed a wide grin showing a gap tooth. His round, full disfigured body walked with 2 wooden crutches because he lost his right leg to amputation at a very young age. He felt so loved by his mother. He said, he could get over calmly after a stressful experience. He was 13 years old, born last March 12, 2005, Roman Catholic, living in Negros Occidental, Philippines. He was in Grade 8, studying in a private school.

He was admitted to a hospital for more than a month (December 2, 2009 to January 9, 2009) after having been diagnosed with osteosarcoma. At age 4 years old, he underwent surgery followed by intravenous and oral chemotherapy treatment. He has been on 6 years chemotherapy maintenance course.

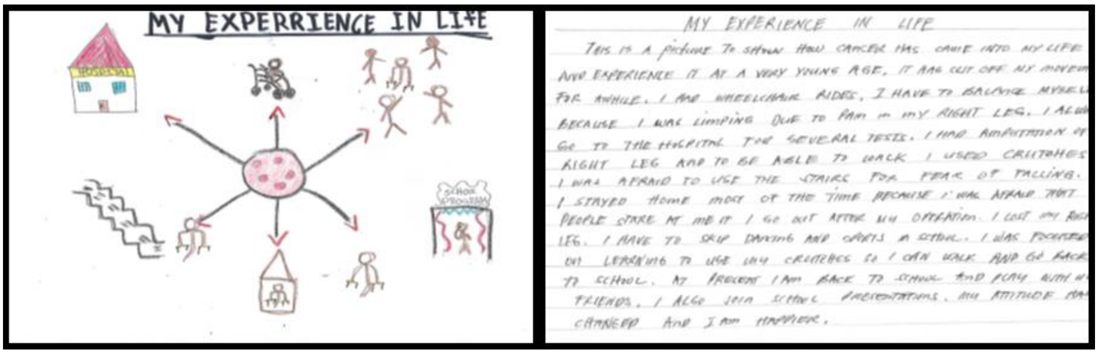


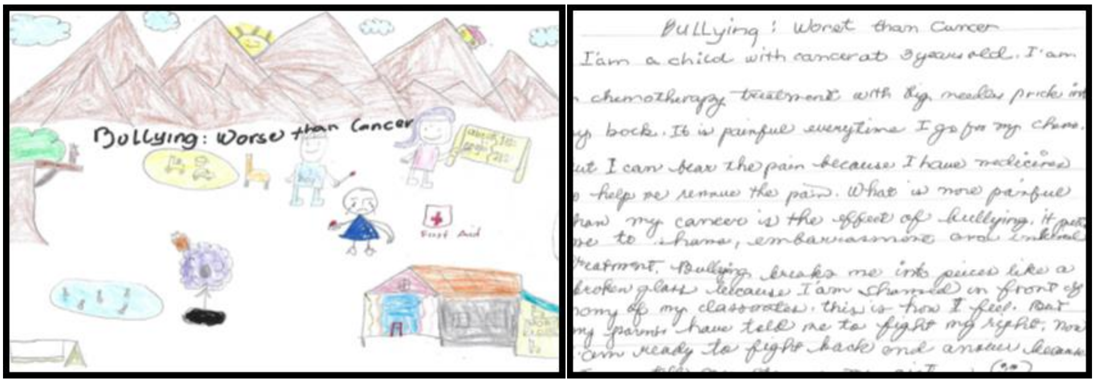
Figure 8. My experience in life.

The subject the participant had in mind for his drawing (figure 8) and write up appear to be that of transition. In his works, he details the physical, emotional, and social changes he underwent as he dealt with cancer. He started by describing the intense pain he experienced in his legs and how it affected his mobility and balance; this caused him to start using a wheelchair as the pain rendered him almost unable to walk. After several tests, his right leg was amputated, and he transitioned into the use of crutches to be able to walk. The participant then specified the fears he experienced after the amputation. He mentioned the fear of falling from stairs or while walking and the fear of being ridiculed by others. As he came to terms with his situation, he began to use going back to school alone as motivation to learn how to use his crutches. He then underwent his next transition; that of going back to school, to regain his confidence, and rejoining school activities. He cited a positive emotional and personality change ending his write up with a statement about being happy again. The stages of these transitions were all represented in his drawing. These stages included: loss of his limb, acceptance of cancer and connecting with people for support, and finally, he found a new beginning with his crutches to keep him going like normal as the others in school.

Participant 9. She was the only child and well attended by her mother who was a full-time housewife. Her father was a policeman in the city of Dumaguete, Negros Oriental, Philippines.

Her heart shaped face was lovely with her bright eyes, and thin lips. Her mouth wearing a smile exposing her light yellowish teeth. She was petite, lean, and her skin was lightly dark. She was 10 years old, born last January 9, 2008, Roman Catholic, living in Negros Oriental, Philippines. She was in Grade 4 in a private school. She had continued attending school in spite of the diagnosis and treatment.

She was admitted in a private hospital in Negros Oriental, Philippines last January 28, 2012. According to her mother, last February 28, 2012 the physician confirmed a diagnosis of acute lymphocytic leukemia (ALL) at age 3 years old. The following month, March 15, 2012, she began receiving intrathecal chemotherapy treatment for 3 years. Last 2015, parenteral chemotherapy was stopped and she was given chemotherapy oral maintenance until this time. She was also kept on daily multi vitamins by her mother.



Bullying : Worst than Cancer
I'am a child with cancer at 3 years old. I'am
chemotherapy treatment with big needles prick in
y back. It is painful everytime I go for my chemo.
ut I can bear the pain because I have medicines
help me remove the pain. What is more painful
han my cancer is the effect of bullying. it pu
e to shame, embarrassment and unkind
reatment. Bullying breaks me into pieces like a
broken glass because I am shamed in front of
many of my classmates. this is how I feel. But
my parents have tell me to fight my right. now
am ready to fight back and answer becau

Figure 9. Bullying worse than cancer.

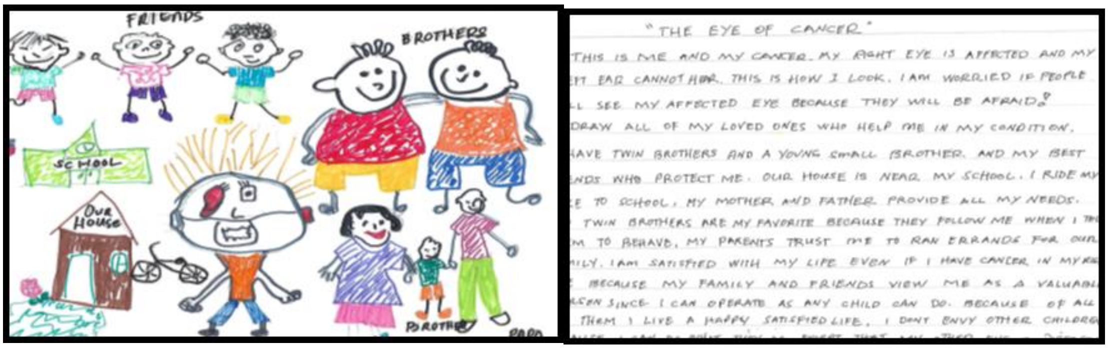
The participant boldly asserted in her drawing and narrative description from the interview that bullying is worse than cancer. The title references her experiences of getting bullied at school due to her cancer and therapy. When she went bald while her chemotherapy was then ongoing, the participant said that she was mocked and ostracized by several of her classmates, with some saying that her cancer is contagious and thus, she should be avoided. She was even physically assaulted at one point when one of her classmates stabbed her hand with a ballpoint pen; the participant's drawing (figure 9) shows this. This experience, the participant opines, was worse than the cancer itself, the pain of which, she said, was manageable through medications. The bullying on the other hand did not seem to have a reprieve. The participant opened up to her parents regarding her experience and they encouraged her to stand up for herself. This, she said, triggered within her the confidence needed to remain happy and positive despite her experiences at school.

Participant 10. Participant 10 was the eldest of two other brothers. His mother was a housewife, while his father worked as a staff in the municipal office of the province of Valencia, Negros Oriental, Philippines.

He had a thin face, and tanned skin. His head had scars of blisters of the past and some bald spots. Both eyes covered with dark sunglasses. He was wearing a black cap on his head. He wore a navy blue walking shorts and green cotton t-shirt with black rubber slippers. He was14 years old, born last December 8, 2004, Roman Catholic, living in Negros Oriental, Philippines. He was in Grade 3 studying in a public school. He has stopped schooling for three times due to poor grades.

In 2010, he was hospitalized for one month in a private hospital due to his worsening headache, tearing, swelling, and bulging of the right eye, with the eye extending out of its socket abnormally. The pediatric oncologist discovered that the patient was experiencing rare and unpleasant tumor of the retina called

(Retinoblastoma) affecting young children. CT scan (Computed Tomography) was done to check for details of the affected eye and spread of the tumor. It was found out that the tumor was confined to the retina of the right eye only. Since the parents denied surgery of the right eye, the oncologist prescribed intravenous and oral chemotherapy. Chemotherapy started April 25, 2010. The participant has been on oral chemotherapy maintenance course for 8 years now.



"THE EYE OF CANCER"
THIS IS ME AND MY CANCER. MY RIGHT EYE IS AFFECTED AND MY
EFT EAR CANNOT HEAR. THIS IS HOW I LOOK. I AM WORRIED IF PEOPLE
LL SEE MY AFFECTED EYE BECAUSE THEY WILL BE AFRAID.
DRAW ALL OF MY LOVED ONES WHO HELP ME IN MY CONDITION.
HAVE TWIN BROTHERS AND A YOUNG SMALL BROTHER. AND MY BEST
ENDS WHO PROTECT ME. OUR HOUSE IS NEAR MY SCHOOL. I RIDE MY
E TO SCHOOL. MY MOTHER AND FATHER PROVIDE ALL MY NEEDS.
TWIN BROTHERS ARE MY FAVORITE BECAUSE THEY FOLLOW ME WHEN I T
M TO BEHAVE. MY PARENTS TRUST ME TO RAN ERRANDS FOR OUR
MILY. I AM SATISFIED WITH MY LIFE EVEN IF I HAVE CANCER IN MY R
E BECAUSE MY FAMILY AND FRIENDS VIEW ME AS A VALUABL
LEEN SINCE I CAN OPERATE AS ANY CHILD CAN DO. BECAUSE OF ALL
THEM I LIVE A HAPPY SATISFIED LIFE. I DONT ENVY OTHER CHILDRE

Figure 10. The eye of cancer

The participant’s drawing and narrative (figure 10) focus on family and friends, his physical appearance because of his cancer, and the feelings he has towards these topics. It is apparent through his drawing, write up, and interview that he was very self-conscious of the physical appearance of his eye, which is why he has made a habit of wearing sunglasses wherever he goes. He believed that the grotesque appearance of his eye will make people be afraid of him. Most of his works however center on his family whom he relies on for care, love, and support. In his narrative, he details his family life, the interactions between himself and his parents, as well as among his siblings and friends. Despite his condition, he still believed and fulfilled what felt more are his responsibilities to his family such as doing errands and making sure his siblings behaved properly. He ended his narrative by proclaiming that he felt happy and satisfied with his life and asserted that he does not feel envious towards other children despite his condition.

Findings

The ten participants in the study shared stories about their experiences through aesthetic expressions by drawing and narrative. Aesthetic expressions ascertained an easy way to gather precise evidence from and about the participants. It gave information about their association to the world and with others. They freely expressed what they wished to share.

The analysis of drawing data. The participants expressed in their drawings not only positive and negative messages but also those of great importance to them such as their family, friends, education and faith in God. They were aware of their surroundings. Furthermore, they showed sensitivity toward feelings of joy, sadness, anger which enriched the understanding of their health condition.

However, participants demonstrated different drawing styles based on what they know. The choice of colors depended on their mood and personality. Happy participants used crisp and sharp colors while others made symbolic representation as an emotional indicator of feeling hurt such as a broken heart, bald head, bleeding finger, wheel chair and crutches. Moreover, some presented images of self as a single focus and majority incorporated images of others such as family, and friends, a pet and bike. It was also noteworthy, that some participants illustrated repetition of shapes and recurring details which signified implications on the meaning of their experience.

The analysis of narrative descriptions and interview data. Based on the analysis of data gathered through drawings, narrative descriptions, and interview, nineteen thematic categories were uncovered, representing the life-world of school-age children with advanced cancer. These life-worlds are: Lived Body was revealed in the following four thematic categories (1) Cancer never owned me, (2) Having physical discomforts, (3) Feeling “not normal” and (4) Changing body image. Lived Relation was seen as in five thematic categories (1) Supportive family, (2) Appreciated compassionate school, (3) Living strength through kindness companionship, (4) Bullying was worse than cancer and (5) Inspiration from God’s blessings. Lived time included four thematic categories (1) Hopeful thought for the future, (2) Remembering the past active life, (3) Feeling left-behind by others and (4) Waiting for comfort from discomfort. Lived space consisted of four thematic categories (1) So near yet so far, (2) Living in secure places, (3) Nature nurturing living with cancer, (4) Being close in cyberspace; Lived things comprised two thematic categories (1) Enhanced connectedness and knowledge through technology, and (2) Hope for technology - cured from cancer.

The narratives of the ten participants were unique and individualized, each generating their own distinctive stories. Nevertheless, similarities may also be observed across the lived existential of body, relationship, time, space, and things. These similarities found in their stories combined and merged to a picture which appeared their lived experience with advanced cancer. Each thematic category will be described in each lived world as follows:

Lived Body. Lived Body comprised four thematic categories which are: (1) Cancer never owned me, (2) Having physical discomforts, (3) Feeling “not normal” and (4) Changing body image.

Cancer never owned me. It denotes the conscious awareness of the participants that even if they had cancer, they did not allow cancer to control them. Some participants expressed their sadness, loneliness and fear that took over their body. Cancer tried to strike them down but the strength of character to survive was firm in the struggle to be treated and focused on surviving. Some participants shared this idea as shown in the following:

As participant 1, who came from a well off family, was a happy child, full of positivity and confident about herself, illustrated a picture reflective of her positive outlook despite her diagnosis of advanced cancer explained that,

> “My positive belief that I will get well from advanced cancer, pushes me more to be optimistic that I will survive.” (P1, L-16- L-17)

Participant 5, a 12 years old boy, on his 3rd year chemotherapy, living a simple modest life with his parents, grandmother and a younger brother, aged 5 years old, said,

> “I will fight this cancer!” (P5, L-401)

Another participant, who was an only child of her parents, pampered and well provided with love and attention revealed,

> “I feel more positive that I will recover from cancer.” (P6, L-7)

The illustration of positivity by saying cancer never owned me experience is represented by a girl with a smiling face, surrounded by reassuring words and phrases standing in the middle of a garden, with optimism in coping and dealing with her condition (figure 1). Her optimism expressed a highly personal and independent approach to what she calls her “battle” with cancer. The phrases connoted that key to this battle is her condition and attitude.

Having physical discomforts. This refers to the manner of accepting the uncomfortable corporeal uneasiness. The most distinct characteristic of cancer and chemotherapy was its physical impact such as pain, hair loss and weight loss as experienced by most of them. The participants had to undergo chemotherapy by intravenous, intrathecal and oral. In addition, some had blood transfusion, and one participant had surgery. In addition, some experienced partial loss of control over certain body parts. One participant proclaimed:

> “I feel my body was behaving differently. It was more like of a sickly feeling *(daw sige ko masakit)* that would not go away and came back the next day. I also woke up in the middle of the night completely soaked in sweat.” (P5, L-388 – L-389)

Another participant commented on the impact of cancer treatment on her body:

> “When I had my first cycle of chemotherapy, I had severe headache. I vomited many times a day.” (P1, L-83)

A participant drew a picture of himself as a young child being an amputee in wheelchair, with crutches and one leg, as a difficult growing up experience (figure 8). The physical and emotional effects having had cancer were disturbing because of his physical appearance. He stated:

> “My hard and painful experiences were so much focus and pressure around physical good looks.” (P 8, L14 – L-15)

Feeling “not normal”. It indicates that participants have in some degree about themselves that did not fit the typical practice they are used doing, whether it is in physical features, psychosocial circumstances and interactive tendencies. Following their cancer diagnosis and treatment, some participants experienced feeling not usual about their bodies, along with their thoughts and how things were carried through the way they wanted it done. Some of the excerpts are presented below:

> “When I feel sick and my body is not normal I am too tired to get up and I am not free to do what I want to do and a way too different from my normal daily routine.” (P3, L-423 - L-434)

> “When I had leukemia, I am tired and lazy and troubled with suffering from body weakness. I am not normal anymore because I cannot help in the house chores like I used to.” (P4, L-143 - L-144)

Changing body image. It denotes the mindfulness of the participants about their physical self after chemotherapy treatment. For many, their cancer diagnosis resulted in changed body image. They focused on undesirable messages around them and made destructive comparisons between their bodies and what they see as ideal bodies. One participant said:

> “Some children in school give me mysterious looks as if I am an ’alien’ and they whisper and laugh at me.” (P8, L-13 – L-14)

Another participant expressed:

> “I look weird in the eyes of other children since I was small for my age, my abdomen was protruding, eyes were bulging and my head is bald.” (P4, L-180 – L-181)

One participant, a 14 year old boy, was conscious about his looks depicted in his drawing (Figure 10). He was concerned how he appeared to others. The excerpt supported this idea.

> “My right eye is colored red because it is swollen and bulging due to my cancer. It has changed how I look which is embarrassing.” (P10; L-381- L-382)

Lived Relation. Lived relation included five thematic categories of (1) Supportive family; (2) Appreciated compassionate school; (3) Living strength through kindness companionship; (4) Bullying was worse than cancer and (5) Inspiration from God’s blessings.

Supportive family. It exemplifies the importance of being with and encouragement in the participants’ life as a child which formed their first relationship with parents and family. The participants had their family with them especially during the critical stages of their illness. They understood and experienced how every member of their family tried to be present for them. They gained strength in the support their family provided them. A parent or both parents, sibling or grandparent stayed with them at the hospital, and took care of them. A male participant, 10 years old who was separated from his mother mentioned:

> “My grandparents and father are all important to me because they are present and visible always.” (P2, L-195 - L-196)

Another female participant, 10 years old, whose mother was away from her because of work, felt the support and unconditional love of his father and grandparents who took care of her while her mother was in a foreign land to earn a living for them. She stated:

> “How thankful I am to my family for the help and support they have given me since I got sick they are always there for me. They treat me with warmth and care heartily. My family always stands by me.” (P6, L-489 - L-490)

Appreciated compassionate school. It means the readiness of the school to assist the participants from the difficulty of the disease and sensitive to the participants’ feelings**.** In this study, all participants acknowledged the concern and flexibility of the teachers and school administrators. Special attention by their teachers and school administrators were granted to them. The most poignant one was the experience shared by one of the participants. The school held a fund-raising campaign which provided her financial support. Before leaving for the big city to start her chemotherapy, she was surprised when she was called by the school principal to attend the giving away program and handed her an envelope with cash coming from the school and students. Her mood was lightened and unexpectedly happy for everyone’s gesture. She was grateful to the school administrators for their concern. Her peers also sent her get well soon cards. She indicated:

> **“**My school has granted me a leave of absence and I can come back after my treatment. I thank the school administrators for their concern.” (P7, L-201 - L-202)

Another male participant, 12 years old with acute myeloid leukemia on his third-year chemotherapy treatment appreciated the way his school received him every time he returned from his treatment and how his teacher recognized his condition. He stated:

> “My school treats me like a normal child without cancer every time I go back from my chemo. My teachers welcome me to continue my studies.” (P5, L-330 - L- 331)

Living strength through kindness companionship. It denotes that there were people who were concerned for the participants and respected their needs with kindness. It was like standing by the participants for encouragement and faced the problems together. The events during the critical period of their illness allowed the participants to experience the support from their peers. The participants were inspired by friends on their journey back to health. Their friends did not help in restoring physical discomforts but encouraged them to be back to normal activities. Friends were important for the participants especially during their absence from school due to chemotherapy treatment and rest periods. Friends in school connected the participants to the world. The participants felt they were still part of the group even if they were absent from classes.

> "I am happy when I can play with my friends especially on weekends when we are off from school. They help me forget about my cancer." (P2, L-311 - L-312)

> "My friends avoid talking about my condition and treat me like a normal classmate and I like to feel this way." (P 3, L-424 - L-425)

Participants also valued the role of healthcare providers who educated them about their illness and explained why changes in their bodies come about as a side effect of chemotherapy. The participants felt comforted when healthcare providers dealt with them with concern and saw them lived through their condition. Participant 1, 13 years old with ALL on her third year for chemotherapy treatment mentioned:

> "Dr. Sheila, my attending pediatric oncologist, Nurse Christine my chemo nurse are important to me because they touch, smile and talk to me in soft voice. They encourage me to be strong and fight cancer." (P1, L-76 - L-77)

Another participant, 10 years old male, with ALL, on his one year and a half of chemotherapy, wanted to discontinue his treatment because he felt uncomfortable every time he went to the hospital for his chemotherapy, stated:

> "I feel uneasy. I don't like to continue my chemotherapy. But I cooperated because the doctors and nurses were nice and handled me with concern and kindness." (P2, L-359 - L-361)

Bullying was worse than cancer. It refers to the unpleasant intimidation that was considered to be more unpleasant than the participants' disease. A cancer diagnosis and the side effects of chemotherapy treatment changed the appearance of participants. They looked different from other school age that they met in school every day. The participants' physical features were not acceptable to other children in school which caused them hurt, insecurity, rejection, shame and embarrassment. The following interview excerpts are related to the theme:

> "When I was in grade 3, a group of boys didn't like me and they would draw ugly pictures of me or leave stuff on my desk. They put trash in my backpack." (P8, L-41 - L-42)

Another case was experienced by a female naïve participant 10 years old, Grade 4 who was involved in a worst mistreatment. She was a victim of hostile intent where she was bullied with deliberate harm. She was passionate in sharing her story through her drawing and its narrative as she detailed what exactly happened. The participant specified the following:

> "My swollen finger was red, and the point of the ball pen was red because of the blood stain from my finger. My tears were falling on my face because of the pain of the point of the pen which stabbed me hard. I started to cry and our teacher dismissed our class to apply first aid on me." (P9, L-119 – L-120)

The illustration of this experience is shown by a picture of a girl with a swollen finger as she colored it red with tears falling from eyes and turned her back from her classmate who attacked her (Figure 9).

Inspired by God's blessings. It refers to the motivation of the participants to have the will to live by asking God's protection against their prevailing condition through a prayer. Cancer impacted the relationship of the participants with God. The relationship inspired them to keep going on with their life despite diagnosis and treatment with advanced cancer. The participants felt that their faith and trust in God was challenged. The strong belief in God was one reason for participants to be inspired because God is more powerful than anyone to bring them to the state of balance. They expressed that with God on their side, everything is possible. One participant made a very strong statement about her faith in God declared:

> "There are times that I want to give up. Because I feel that the world is against me. If I stay on the positive side, I am reminded that it is just another challenge because if I want to surpass this challenge God has given me, I can do it!" (P1, L-31 - L34)

Participant 3, was the youngest in the family of two older siblings whose motivation was derived from her faith in God. She mentioned:

> "I read the Bible and I am encouraged by God's word to be strong and never surrender." (P3, L-133)

Another participant stated:

> "I count myself blessed and thank God every day for the improvement I get from my treatment." (P5, L-220 – L-221)

Lived Time. Lived time included four thematic categories: (1) Hopeful thoughts for the future. (2) Remembering the past active life; (3) Feeling behind the others; (4) Waiting for comfort from discomfort;

Hopeful thoughts for the future. It is defined as positive viewpoints of the participants in the forthcoming days as cancer constituted a threat to the normal school-age development over a period of time. In this study, participants decided to stay positive and handled cancer each day. The lives of the participants were temporarily put on hold because of cancer. The waiting time for cancer to be over was experienced differently among them. They held on to their dreams, hopes, faith and determination, and gathered strength from support systems because when they fought against cancer, they would not give up. Participants hoped for a chance or a different light of comfort that their cancer will end. As one of the female participants stated:

> “I am excited for the day that I will be free of cancer.” (P1, L-61)

The general view articulated by participants was to continue living their life and convey their hopes and endure the treatment. Some of the participants stated:

> “I will move forward with my life and focus on my treatment so I can recover fast.” (P 7, L-336)
>
> “I endured the side effects of chemotherapy with the belief that I will recover.” (P10, L- 490)

Remembering the past active life. It pertains to the recollection of the participants regarding the earlier energetic activities while they were growing up. Cancer allowed participants to remember the past events that occurred vividly in their minds when they were lively, active, energetic and happy children. They missed the moments of being in that instant. In this study, the participants felt that they were in a weak position imposed by the side effects of cancer and treatment that limited common opportunities and enjoyable time, leading to loneliness. In addition, they had to strive for life and made every effort to cope with the demands of school achievements. There were several reactions from the participants related to the past life before diagnosis and when they were sick. The responses were as follows:

> "There were times in the past that I was absent for a week from school. It was sad because I was weak and frail. That was when my father would carry me on his back because I cannot walk. My limbs were not strong enough to support my body." (P 2, L-326 - L-328)
>
> "Before my leukemia, I was energetic at home because I help in the chores and I can help clean entire day with my sister and in school I joined group of boys to play running, skipping rope and hide and seek. Now I cannot do it because of my leukemia." (P5, L-356 - L357)

Feeling-left behind by others. It relates to the feeling that threatens participants' world precipitated by big life changes brought about by advanced cancer especially when it was related to their school. Some participants experienced the progressive ups and downs of academic performance caused by advanced cancer. Participants in this study explained that the effect of their diagnosis and treatment on their schooling was all-encompassing. In fact, many reported prolonged absences from school, put them at a disadvantage compared with their peers and siblings. The most significant effect on school life which was interaction and mingling with others, turned out to be separation from friends during their treatment.

Participant 3, had leukemic cells in the spinal fluid. She had been on oral chemotherapy maintenance for 2 years now. She was bothered if leukemia in the spinal fluid would continue because it would mean she will stop schooling again. She stated:

> "I have been delayed for a year in school already and it burdens me, because my classmates have proceeded to the next grade." (P3, L-19 - L-20)

Participant 6, had to stop school because of chemotherapy treatment that resulted to poor academic performance. Her statement shows this.

> "Because of my low grades, I needed to repeat grade 2. I should have been in Grade 4 but since I have 2 years of delay I am still in Grade 2. I am left behind by my classmates. And I am sickly that I kept failing in my class performance due to my absences." (P 6, L-47 - L49)

Participant 7, is a 14 year old girl, who was the third child of five children stopped going to school. She had a willowy figure, frail and pale. She had to gain weight before chemotherapy could be started since the physician was hesitant to begin with the treatment because of the side-effects that would incur on her physical state.

> "I have to stop going to school because I may not be able to handle school and treatment at the same time. I was downhearted and alone." (P7, L-319 - L-321)

Waiting for comfort from discomfort. It means holding on to obtain relief from the physical discomforts brought about by cancer treatment. The participants eagerly waited for physical discomforts to disappear and chemotherapy treatment to end. The waiting time was stressful for the participants and their families. Every hour seemed like a time without end. They had to wait for cancer test results to be known. The length of time to wait for hospital appointment and follow up visit to the doctor to hear positive news seemed endless. The time to wait for days, months or even years while the disease or symptoms has made a great effect on their bodies and how they look, led them to feel tired and weak. They wanted to conclude and recover from the effects of cancer and chemotherapy. Participants in their statements remained positive in waiting to be cancer free. The excerpts braced this awareness.

> "I have been waiting for a long time. I like to be cured to happen sooner, so I can do what normal healthy kids also do." (P1 L-113 - L-114)
>
> "I am waiting for leukemia to end because this is my last year to complete my chemotherapy." (P3, L-32)
>
> "I stay happy while I wait for my leukemia to end so I can be cured and become whole again. I like to feel happy without worries of chemotherapy." (P9, L-361 - L-362)

Two out of the ten participants, who were both males have different types of advanced cancer. Despite the difference in the type of cancer that they had compared with the rest, they too waited. The participants stated:

> "On my 9th year on chemo maintenance, I am waiting for my doctor to tell us I am safe because cancer did not spread to other parts of my body." (P8, L-102 - L-103)
>
> "I am looking forward to be free of cancer after 8 years of long wait. Stay positive always so we can recover!" (P10, L-67 - L-68)

Lived Space. Lived space consisted of four thematic categories (1) So near yet so far, (2) Living in secure places (3) Nature nurturing living with cancer, (4) Being close in cyberspace.

So near yet so far. It means the space that the participants experienced was not the physical space but their environment and surroundings, the secured and healing space they experienced. Regardless of nearness they were from their family and friends, some participants realized there was still a problem of isolation because of the physical discomforts that created a field that separated them from others. One participant mentioned:

> "I feel lonely even if I have my family and friends around me. This is because my family and friends may not really be in harmony with what is going on with me." (P7, L-329 - L-330)

In addition, a mother helped a daughter forget the discomforts of chemotherapy but there was an apprehension due to the distance. She declared:

> "My mother is cheerful. She makes me forget the discomforts I feel with my body every time we do a face time. But it is hard because I cannot hug her. I miss her a lot!" (P 6, L-445 - L-447)

A participant with a lonely facial expression talked about how he envied his classmates with parents especially when he had school-related activities because his grandmother was there for him all the time. He wished his parents can be in his school activities too. This claim was made.

> "I want my father will also come to my school activities too not only during my chemotherapy and my mother can see me not just talk to me on my cellphone. They are both away from me all the time because they have their own families to attend." (P 2, L-194 - 196)

The participant portrayed his experience of the theme in his drawing which showed him hand-in-hand with his father every time he went to the hospital for his treatment repeated twice in the picture. Next, he drew his mother, and a broken heart between them which indicated how his mother left the family and the sadness on his face continued up to now (Figure 2).

The cyberspace is the World Wide Web the participants logged in to connect with their friends online. A male participant regularly logged in to internet and to stay connected with his friends online stated:

> "I met another amputee like me in the internet. It is amazing to hear another child my age talk. It is enjoyable to hang around with people in the internet even they are from far in other foreign places since we can still share with the same life's experiences. I can have someone to talk about my concerns. I felt better." (P8, L-73 - L-76)

Living in secure places. It describes the importance of the different places that aid the participants' needs to rebuild themselves after the diagnosis and treatment of advanced cancer. Two places were mentioned as significant. On the one hand, when their condition was good they went back to school. The school had a warm, enjoyable atmosphere that made them normal again. Going back to school was a source of accomplishment. On the other hand, the hospital was the place to go when their condition was bad. There was a need for them to do it because of the vital intervention required, to be treated, and to monitor the progress as far as their reaction to chemotherapy was concerned. This was evident in the statement of one participant.

> "The hospital is the only way to help me about my cancer. If there was no hospital maybe I cannot last long because I believe in my doctor and nurse who takes care of me." (P4, L-78 - L-79)

The illustration of this experience of a 10 year old boy, who described a picture that made the hospital as the focal point of his drawing (Figure 4). He represented himself and his family, as well as the nurse and doctor, as he goes through treatment for his cancer. The hospital, he said, has all the equipment that is needed to treat his cancer and made him safe, which is unavailable in their home and the rural health center.

Another participant expressed:

> "Most important to me is the hospital because it is where I am treated for my leukemia." (P3, L-433 - L-434)

In the process of switching places, the participants experienced the security and strength needed for their condition in the hospital. They believed in the doctors and nurses who took care of them. A participant felt safe when he was in the hospital because the doctor and nurse knew what was going on with his condition and gave him medicine to aid the difficulty he felt. He stated:

> “I feel harmless (*dili makadaot*) when I am in the hospital because the doctors and nurses know what is going on with my condition and give me medicine to aid the difficulty I go through.” (P4, L-66 - L-67)

Moreover, there was a sentiment that participants gained from their schools. The mood when they were in school was not the same as when they were in the hospital. The participants felt negative vitality in the hospital but positive in school. Some of the excerpts are presented below:

> “I am treated with warmth and care heartily going back to school in the face of my condition. My friends take me out from thinking about my leukemia.” (P6, L-493 - L494)

The most significant effect of school to participants was the awareness of their teachers and classmates about their condition and maintained their attachment to each other to cope with the demands of school work. All ten participants continued to go back to school since they enjoyed being in school. The participants stated:

> “My school allows us to have a close bond between our teachers and classmates.” (P6, L-467 - L-468)

> “I enjoy school because I have friends and classmates to learn and play with.” (P2, L-181)

> “I enjoy my school life. Even if I fail every year I keep coming back. My teacher encouraged me to make good grades. My friends influenced me to be energetic as well. I have a crush too.” (P10, L-413 - L414)

Aside from the hospital and school, the participants also experienced being in church, a place to go with their families to pray to God for participants' condition as a source of strength and security. The church provided an opportunity to experience the support from family in seeking intercession for recovery. This was evident in the statements of the participant as stated.

> "When we go to church, I can feel the healing power of God *(pagayo sang Guinoo sa akoa)* working on me. That is why I do not miss going to mass with my family every Sunday." (P2, L-356)
>
> "I feel happy when I am inside the church because I feel the blessings of God to cure my cancer." (P3, L-464 - 465)
>
> "Sometimes I visit the church alone. I feel renewed when I am in the church because it is a holy place." (P10, L-467 - L-468)

Furthermore, the home was a place that participants felt they were comfortable, safe and sheltered. It was also a place where they could play and be themselves with their families.

A participant mentioned:

> "I feel safe and protected when I am home with my grandparents because I am important to them." (P2, L-207 - L-208)

Another participant stated:

> "At home I'm safe since nobody can bully me." (P8, L-423)

The illustration of shifting in the different places to feel secure was characterized in the drawing of a 12 year old girl with acute lymphocytic leukemia. Her drawing highlights significant locations which she said "help her feel good" about her cancer (Figure 3).

*Nature nurturing living with cancer***.** It refers to the gifts of nature that fostered therapeutic effect on participant's recovery. The challenges of treatment became less stressful for participants because of the life they still enjoyed exemplified by the beautiful nature that surrounded them. Nature provided the participants with unburdened physical, emotional, and spiritual place with personal significance and recognized the wonders of God's creation as nurturing in their condition as cancer patients. It became a safe and protected ground which gave them a familiar and nurturing setting from where new perspectives arose. As such, nature supported participants to divert their attention away from the clinical and personal moments of cancer. A few mentioned how they felt:

> "I chose the garden. I love and enjoy nature. Clean and attractive nature full of greenery and flowers. It's very calming for my condition." (P1, L-26 - L-27)
>
> My mom has garden of roses and flowering plants at home that is pleasing to the eyes and gives me relief." (P1, L-26 - L-27)
>
> "My life with cancer in the mountain side is beneficial and relaxing because I can breathe fresh air and eat fresh vegetables which are favorable for my illness." (P5, L-28 - L-29)

The beneficial and therapeutic effects of nature on participants' recovery were represented by one participant as the picture of the home and school is situated in the mountainside where he caught fresh air and ate healthy foods (Figure 5).

Being close in a cyberspace. It describes how participants gave emphasis on connecting to the internet which impacted the interactions with family, friends and school during their illness. The connectedness with others with the use of gadgets like mobile phones, tablet, and desktop computer facilitated varied support from finances to emotional states. These gadgets as adopted by the participants enabled them to remain with their important support system towards a future goal. This was evident in the statements of the participant as stated:

> "I also stay updated with my friends through mobile phone. We send messages and sometimes I call them for updates about school."
> (P2, L-318 - L319)

> "From advices told and shown by my friends online I clearly understood how I can function efficiently even with one leg."(P8, L-491 - L-492)

> "His sharing changed the way I think by making use of my skills and became more practical, useful to my parents, efficient and worthy as a grown-up child and I'm happier." (P8, L-491 - L-492)

Lived Things. Lived things comprised two thematic categories (1) Enhanced connectedness and knowledge through technology, and (2) Hope for technology - cured from cancer.

Enhanced connectedness and knowledge through technology. It explains the source of technology by means of the gadgets used by participants as way to communicate and gain knowledge and information about cancer and its treatment. Nowadays children are keen on using computer technology, mobile phone and tablet. They can easily access information and communication by its use. Much as they were separated from others by geographical distance during their illness they used technology to connect with the world and others and brought them back to normal life. The relationship with family, friends and school were maintained and sustained using the gadgets. Participants stated:

> "My grandmother always wants me to keep my cellphone open so she can call me anytime." (P2, L-323)

> "My mother calls me during my recess time in school if I am all right." (P6, L-17)

On the other hand, there were two participants who accessed the internet easily with the use of their tablets and acquired information about their condition and communicated with parents abroad through social media. Participants mentioned:

> "I also use my tablet to connect to the internet to get information about my leukemia and chemotherapy. And talk to my father through my Facebook who works in a ship." (P1, L-66 - L-67)
>
> "I have my tablet as well to check my mother and Friends online through Facebook and we talk. I knew about leukemia in the internet too." (P6, L-16 - L-17)

However, there were several responses from participants who experienced things which diverted their attention from physical discomforts of illness which gave comfort and relief. The participants detailed:

> "I write poems based on photos that I see." (P1, L-66)
>
> "I play with my Barbie dolls and dress them up with different styles because it gives me happiness that I don't think about my leukemia." (P6, L-8 - L-9)
>
> "I keep a diary where I arrange my recordings by date and I write down on what have happened over the course of a day I also write down my prayers asking the Lord to help me with my cancer and my parents to stop fighting." (P7, L-186 - L-189)
>
> "I play with our pet dog at home because our pet dog gives me happiness." (P5, L-342)

Hope for technology-cured from cancer. It denotes that participants accepted and expected chemotherapy treatment as the courage to be cured from cancer. They believed that treatment could help save their lives. A participant, stated:

> "I believed that the hospital has the needed equipment (*may ara ang ospistal gikinahanglang ekipo para sa akon bolong*) for the treatment of my cancer which we do not have at home." (P4, L-96 - L-97)

The general understanding expressed by participants in anticipation of a better health, free of cancer is the hope to be cured from their cancer as presented as follows:

> "No matter how hard it is, what is important is to comply with doctor's instructions and prescriptions so, I can get out of cancer." (P 2, L-386 - L-387)
>
> "I hope that my chemotherapy will be successful and my leukemia will be over, and I will survive cancer." (P 6, L-65)
>
> "I will move forward with my life and focus on my treatment, so I can recover fast. I learned from my family that I should believe that my treatment will help me get over my sickness and recover early." (P 7, L-336 - L337)

Discussion

The findings of this study showed the meaning of the life-world of school-age children with advanced cancer. They shared the experiences of their life-world before and after advanced cancer. These children had unique individual experiences of a life-world perspective having fallen ill with advanced cancer, and they were given the opportunity to put their feelings and thoughts through aesthetic expression into their own words. Hermeneutic phenomenology allowed the researcher to understand the meaning of their lives with advanced cancer. Aesthetic expression through draw and write helped school-age children with advanced cancer uncover their lived experiences as they existed in their worlds in relation to their body, relationship with others, time, space and things as they told their stories.

The meaning of lived body. The body changes experienced by several of the participants were a challenge for them. They stated that having physical discomforts was the aspect of treatment that disturbed them the most. The physical change in appearance was a major negative issue which affected the ability of the participants to effectively cope in the initial stages of their diagnosis and treatment. This was similar to what was reported by Bambach (2016) when children undergoing cancer treatments described their experience with numerous hurdles as well as susceptible to noticeable changes in physical appearance. According to the participants, the diagnosis and treatment of advanced cancer was a very stressful journey. Aside from changes in physical appearance, this was complicated by many emotional issues like feeling “not normal” as well as changing body image. Even if they came up with statements like “cancer never owned me”, and eventually came to see their situation in a more positive light, the journey was not easy. The diagnosis and treatment required a number of adjustments in order to effectively deal with physical symptoms and treatment effect. The physical problems of childhood cancer start from initial diagnosis of the condition and admission in a hospital to the administration of chemotherapy (Gerali et al., 2011).

The meaning of lived relation. The participants’ life with advanced cancer revolved around being and dealing with relationships. Equally, the participants presented themselves in the hospital, school, church, and their respective homes in their bodily state and met other people in this manner. At the same time, advanced cancer and hospitalization separated the participants from their family and friends for a short time at the beginning of chemotherapy. But participants managed their condition better because the support systems provided them with strength, courage and motivation to successfully achieve and face the different stages of treatment and adjustments. Family, friends, teachers, and health care team as participants’ support systems were reported as valuable by participants. This is similar to a previous study by Rosenberg-Yunger et al. (2013) where children with cancer reported that many of them received support from family, friends, community, teachers, religious organizations and cancer organizations, and government programs that assisted them with their condition. A strong family support was significant since their family stood by them during the critical stage of their illness. This is consistent with the study of Vrijmoet-Wiersma (2010) and da Silva Pedro, Galvão, & Rocha (2008) who found in their studies that childhood cancer is one of the most challenging experiences a parent can have but with support from other members of the family, a great deal of the burden is lessened. Meanwhile, help from friends and teachers gave encouragement which brought them back to be normal again especially in school. Even if they looked different from other school-age children and their physical features were not ‘acceptable’ to other children in school, they kept going on with their lives. The strong belief in God was the ultimate reason for the inspiration to move on because participants believed that God is most powerful to bring them to a state of balance.

The meaning of lived time. The participants were young individuals whose disposition and vision were yet to come despite having advanced cancer. They recognized those around them by learning what shaped their past, present and future as these embodied possibilities of their experiences. Embedded with time were encounters of the past that always remained as memories. The chronological things of the past determined their present and the future awareness of their sphere. For instance, they recalled past experiences such as energetic and happy children, the prolonged absences from school, which placed them at a disadvantage compared with their peers and siblings, and the interaction and associating with others which led to separation from others during treatment. However, the present burdens, effects of treatment, encouragements from family and friends and inspiration from God changed the past. Similarly, Thompson et al. (2015) stated that returning to school after diagnosis and treatment with cancer promote positive adjustment for children with cancer. In the same manner, the past changed. As the participants continued to live a life towards a future, they stayed positive and handled cancer each day because they were joined by their support systems with hopes and expectations which gave them a perspective of a life free of cancer. School-age children have an expanded knowledge about the world and about bad things that can happen (Bares & Gelman, 2008). The participants in this study had a good sense of how their condition affected their lives and how they intended to respond to the challenges. Santrock (2010) noted that school-age children ages 10 to 14 years old have a deeper sense of their inner world. What was remarkably recalled was the passage of time from the past active life to the present sickly condition. The recollection of the past became the yardstick in becoming hopeful for the future.

The meaning of lived space. The surroundings in which the participants moved and found themselves at home influenced the way they experienced and interpreted the space whether at home, at the hospital, school and church. For instance, the space of home gave them a special experience of being comfortable, profoundly safe, and sheltered and be themselves with their families, whereas, the felt space of the hospital was the venue to go when their condition was bad. The findings concur with the previous study of Enskär and von Essen (2008) who mentioned that the child with cancer spends more time at the hospital and less time at school during treatment. However, while the participants’ individual home offered them protection and security it also made them susceptible to change. The adjustment was influenced by circumstances under which they encountered such as feeling isolated and separated from others because of the physical discomforts from treatment. In contrast, the participants acknowledged the nurturing effects of nature which diverted their attention away from cancer and resulted to a less stressful treatment. A previous study by Blaschke (2017) discussed how nature provides cancer patients with unburdened physical and psyche space. According to the study of Blaschke, nature could offer a familiar and nurturing context especially when the patients might move in and out of the home. Additionally, the school was experienced with an enjoyable atmosphere. The participants appreciated their good form that brought them back to school after treatment and rest period. They felt normal again. This finding corresponds with the previous study of Rudolf et al. (2011). Their study found that the school to a child with cancer was seen more than just a place for learning. It was also a place for fun, friendship and belongingness where a child who came back after treatment suffered several challenges. Under other conditions, they sought refuge in the church as they felt the power of God restored their health from cancer as they asked for divine intervention and intercession for recovery. This finding accords with the previous study by Corcioli, EspinhaI, Aparecida & de Lima (2012) who found that it is dominant that praying and going to church is embedded in the life of children with cancer to lessen their distress as they journey through the cancer. Finally, online networking retained the participants’ correspondence with family, friends and school during their illness. It provided opportunity for participants to share personal experience and feelings to fill the gap between treatment and the need for emotional support.

The meaning of lived thing. In this study, lived things were experienced as relating technologies in acquiring knowledge and information as well as hope for cure from cancer. The participants lived in the information age and they were surrounded by information. This was evident through technology like computer, mobile phone and tablet. According to Hockenberry et al. (2017) children spend a significant amount of time every day involved in media-related activities including the use of tablets, videogames, and cell phones. In this study, the participants utilized two forms of technology which helped them understand and accept their diagnosis and treatment. Apart from medical technology, the participants made use of communication technology to acquire knowledge and information about advanced cancer and chemotherapy as well as online support. Similarly, previous study by Rutten, Arora, Bakos, Aziz & Rowland (2005) stated that information technology is vital resources in fulfilling patients' treatment-related information needs. In this study, technology went beyond information seeking, by providing resources for social and emotional support of participants. Virtual support from friends was a way for participants to share experiences and find effective coping strategies.

Participants correspondingly encountered things during their illness which diverted their attention from physical discomforts of illness and provided them comfort and relief. The experience directed a positive motivational influence on their lives which developed their physical, emotional, cognitive and social traits. Similarly, previous study by Li, Chung and Chiu (2010) stated that cancer brings restrictions to the life of the child that interfere with their development. Playing is a source of pleasure for the child; it is when she/he, for a moment, forgets the difficulties of the illness and treatment and what they are going through to enter a fantasy world.

The holistic analysis. A narrative of the holistic analysis of the nineteen themes representing the lived experience of school-age children with advanced cancer through aesthetic expression across the five life-worlds was presented to elucidate the themes. The participants' narratives stayed attuned to the essential quality of aesthetic expression though draw and write.

The themes related to the five life-worlds of, 'lived body,' 'lived relation,' 'lived time,' 'lived space,' and 'lived thing,' were organized to allow the lived experience of aesthetic expression to be more easily understood.

Indeed, all participants shared aesthetic expressions by interacting with their bodies, other people, and time, the social and natural environment, and technology/things. Even though the themes were arranged into the five life-worlds certainly, these five existential elements were present at all times since they were interrelated and it was impossible to completely separate them. Furthermore, these themes were presented in a linear manner, as participants shared their experiences moving freely among their ideas representing the various themes in a circular, non-linear design. Because of the nature of cancer, the participants lived in a world with negative experiences during the initial stage of the diagnosis and treatment.

The time axis journeyed by the participants began with a negative point of view as can be seen in the themes presented in the inner circle in Figure 11. For the medical technology, even though it brings suffering experiences but the expected results is cure. Nevertheless, they turned negative experiences into a positive one (themes presented in the outer circle in Figure 11). By changing their perception about cancer by acquired knowledge and information from technology, such as complying with hospital technology—patiently going through chemotherapy towards recovery—

as well as others, they became hopeful and recognized the positive outcome which later benefited them. They connected to the world through technology and gained information about cancer. They also used technology to communicate to others and complied with the technology of the hospitals to recover from cancer. The other factors that made the shift from negative to positive possible were: support from family and school administrators; self-transforming negative experiences and developing inner strength; and inspiration from God, As they vividly recollected the various events when they were lively, active, energetic and happy children, they saw a positive outcome in their negative experience, namely: recovery as a result of chemotherapy. Despite the difficulty of transition, the participants waited for comfort to follow discomfort and were able to do it. Even though the change in their perspective was not easy, it did happen as they anticipated the positive results coming their way. They turned their experience around and transformed it into something beneficial. They made a decision of seeing cancer from another viewpoint and chose to react differently. They acknowledged nature that nurtured them in a therapeutic way. They lived in places where they could be secure and protected.

Although the circumstances happened beyond their control and having physical discomforts was initially the most distinct character of cancer and chemotherapy treatment that impacted on the participants' body, they found a way out of it. No matter the extent to which the negative events were very much part of their lives, they found ways to overcome them. 'Cancer never owned me' was a theme because they had control over their thoughts and emotions. The participants did not have control over the external events that happened to them but their internal reactions made a powerful turning point. They accepted and thrived not feeling normal and the way cancer changed their image. Cancer made them tough and in the same way, they became resistant to emotions. They prepared their minds for cancer. They worried less about being bullied in school because they were aware it was going to happen after the treatment.

The participants filled their thoughts with possible scenarios that would make the situation positive with the support from their families and friends as well as the compassion and empathy from their teachers and school administrators. They did not ponder about cancer as long as their prayers were answered by God. The negative problems gave the participants the ability to dictate their response. These allowed them unaffected by the disorder of life with cancer because of the comfort provided by the help from others.

The experience of school-age children with advanced cancer through aesthetic expression was described as living the experience in a world with negative experience while simultaneously existing as hopeful persons for a better life. It is in understanding of participants' experience with cancer that the researcher came to know ways to appreciate and recognize the fundamental nature of being human in the world.

The summary of how school-age children with advanced cancer uncovered their lived experiences as they existed in their worlds in relation to their body, relationship with others, time, space and things as they told their stories is presented as the following diagram.

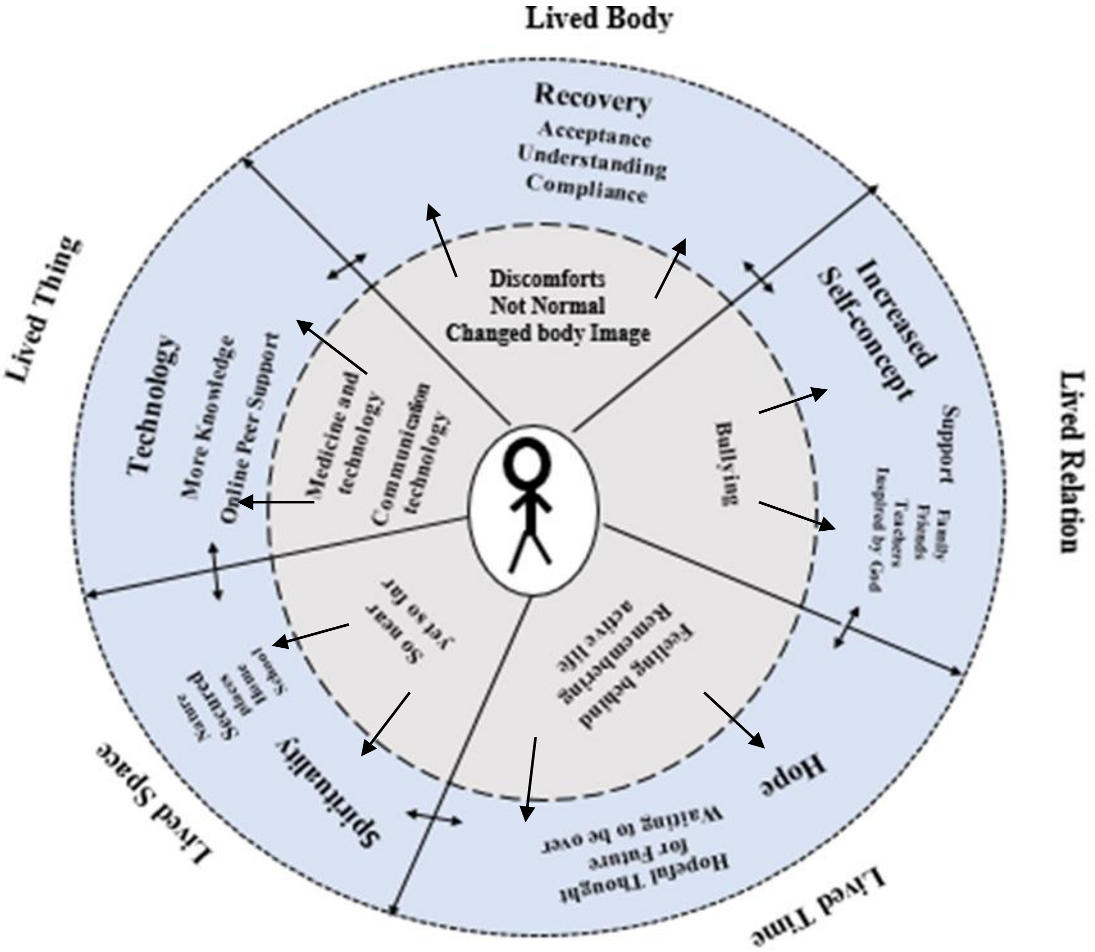


Figure 11. Model representation of the life-world of school-age children with advanced cancer.

Aesthetic expression linked to art and connected to human experience drew the participants into different realms and expanded their perceptual capacities so that the fullness of the meaning of the experience was appreciated. The understanding of the experience through aesthetic expression provided sensitivity to know the variation of experience among school-age children with advanced cancer. Awareness of the circumstances and value of the experience was completed. More importantly, the participants described the meaning of the experience. It is hoped that aesthetic expression for this kind of patients will be understood with more thoughtfulness as health professionals embark on their job to restore a comfortable relationship with children.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This study described the meanings of the life-world of school-age children with advanced cancer through aesthetic expressions using hermeneutic phenomenology as informed by Gadamer hermeneutic philosophy and van Manen's hermeneutic phenomenological approach. This chapter consists of the summary of the findings, strengths, limitation, recommendations, and researcher's phenomenological reflection.

Summary of the Findings

The study was conducted during February to June 2018. The aesthetic expressions of the experiences of ten school- age children who met the inclusion criteria were done through snowball sampling. The data were collected by using drawing, writing short descriptions, and interviewing with audio recording. Analysis of the drawings was done as guided by the steps suggested by Farokhi and Hashemi (2011). Analysis of written descriptions and interview transcriptions were conducted by employing van Manen's approach (1990, 1997, 2014).

In this study, the participants were school age from 10-14 years old. Ten participants had advanced cancer and experienced chemotherapy treatment. One participant had undergone surgery and used an assistive device such as crutches to aid in his locomotion. Nineteen thematic categories structured the lived experience and were reflected within the five life-worlds of van Manen consisted of lived body, lived relation, lived space, lived time and lived thing. Lived Body was revealed in the following themes, having physical discomforts, cancer never owned me, feeling “not normal” and changing body image. Lived Relation was seen as, bullying was worse than cancer, supportive family, compassion and empathy, comfort with help from others, and inspiration from God’s blessings; and Lived time included hopeful thought for the future, remembering past active life, waiting for comfort from discomfort. Lived space encompassed so near yet so far, living in secure places; nature nurturing living with cancer and being close in cyberspace; while lived things elaborated enhanced connectedness and knowledge through technology, as well as hope for technology - cured from cancer. The lived experience of school-age children with advanced cancer revealed as expressions of their life-worlds. Activities at home, in school, with friends and the community in general, were struggle for physical and emotional balance. The discomforts from treatments hindered their activities of daily living. Changed body image resulted in bullying, while prolonged school absence led to reduced academic accomplishments, compared with their peers. The hospital became the focus of their lives finding strength to understand and accept pain, struggle and limitations because of supportive families, comfort from hospital technologies, online support from friends which gave them joy. Being back to school was fun and faith brought them to the state of balance, the participants remained hopeful positive thinking to cope and be free from cancer while looking beyond for a better future.

Strengths

The informants were all first timers in the process of research. The drawing of their lived experiences was also a first time for them. Most of them were excited in coming up with an artistic expression of their stories. The school-age group appreciated the method of conveying insights. Palmer (2006) stated that understanding is not only a way of knowing but consequently a way of dealing with reality. The experience as participants was both revealing and liberating thus generating candid responses. In the process of validating the meanings behind every representation, the participants provided unrehearsed and truthful narratives.

The participants were also very familiar with the English language so that their articulation was not questionable. Most of them were in the cognitive stage capable of abstraction. They were able to use abstract thinking in explaining their drawings. The process of allowing them to explain their drawings allowed an in-depth understanding of their life-worlds.

The researcher had been previously exposed to the age group being studied. She was a Masters prepared major in Maternal-Child Health pursuing a Doctor in Philosophy in Nursing Science International Program. She collected all data and exercised the protocols to enhance the strength of the findings. She was familiar with the local language in case the participants would use the idiom. She has twenty-seven (29) years' experience in teaching the subject of growth and development in children including pediatric nursing exposure. She had a good foundation for the appreciation of the findings and analyzing them to reflect the life-worlds under van Manen.

The setting of the study enhanced the gathering of data since the participants were visited in their home residences where they feel safe and protected. It covered a wide area in the Negros Island of the Philippines, which has an increasing number of cases of children with advanced cancer. The participants were identified through “snowball” method to minimize uniformity in their conditions and appreciate uniqueness as a strength in coming up with shared meanings. The setting was also an advantage to reflect the cultural background of the study since the recommended actions will be implemented in the areas covered. The utilization of research findings in the advocacy for health reforms in the area studied will be more reliable.

Limitation

One limitation of the study was that it had to be conducted in several areas in Negros Island. In these areas, the participants used some local idioms more than the official language which the researcher might not understand the meanings fully. The researcher asked the meanings of words from the participants again and also from the local persons.

Recommendations

The findings of this study may have the potential to advance nursing knowledge and practices. There are implications for nursing practice, research in the field of nursing and nursing as an academic course. The implications are explained as follows:

Nursing practice. The results presented by this study may be used to enhance the positive feelings and emotions of school-age children with advanced cancer in a manner that is easy to practice and does not cost anything for the patient. For example, pediatric nurses can provide a paper pencil and crayon and instruct the pediatric patient to draw and describe the drawing. This may help pediatric patients with other diseases and procedures during hospitalization to translate their feelings in their drawings. In another way, parents/guardian, caregivers or pediatric nurses may provide an approach for the expression of feelings through other aesthetic means such as photographs or paintings. Nurses can likewise encourage children to create their own website as online support for other children with the same condition as they are now technologically competent to make decisions related to their condition.

Nursing education. Findings of this study showed that participants were waiting for comfort as relief from their present discomfort. Artwork can be used as an educational aide for developing student nurses' sensitive comprehension and skills in the care of children with advanced cancer. Aesthetic expression may assist students to become fully engaged in realizing the valuable meaning of understanding. The meaning of the lived experience can thus make a contribution to curricula development in nursing education. For example, undergraduate and graduate nursing students should be made aware that the use of aesthetic expressions through artworks can constitute a creative and helpful way to represent stories of caring for persons who are sick. By doing this, students or nurses will increase their appreciation of the value of getting to know and understand children who are in advanced stage of cancer, thus facilitating the promotion of acceptance of their condition.

Nursing research. The use of aesthetic expression in children especially in children with threatening illnesses, such as cancer, is less well known. Thus, the results of the present study provide the guideline of using aesthetic expression in children with cancer for further studies. This study described the life-world of school-age children with advanced cancer. Thus, further research should study the effects of aesthetic expression on the emotional status or the feelings of children.

Researcher's Phenomenological Reflection

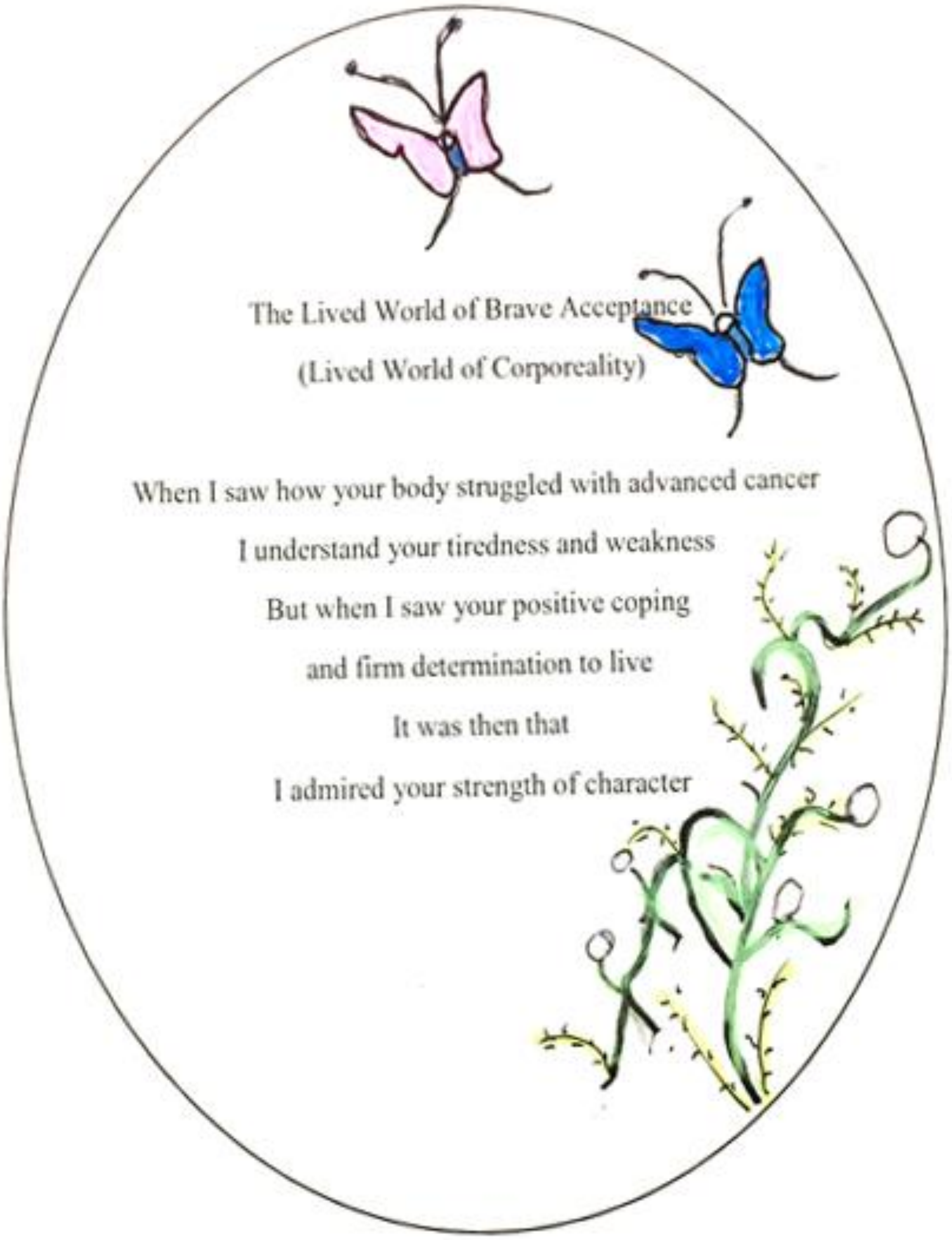
This section of the paper is the phenomenological reflection. The researcher's phenomenological reflection was derived from her own experience in the process of gathering her data for the research - the lived experience of the school-age children with advanced cancer. Her reflection was a fruit of deep appreciation and indebtedness to the children whom even for few hours of her encounter brought her a profound understanding about the meaning of life. Firstly, in her drawing, she made used of a character that symbolized cancer cell which confronted the ten participants as represented by capsules indicating different emotions brought about by chemotherapy treatment. It included the secure places that helped them with cancer. Secondly, she enthusiastically composed poems and designed them with Sampaguita, the national flower of the Philippines. It symbolized love, devotion and purity. In addition, the butterfly symbolized freedom, freedom from the terminal illness of the children. The butterfly implied the possibility of transcendence. It symbolized hope for the children. Thirdly, the researcher witnessed how the faith in God of these children allowed them to be more accepting even in the midst of pain and suffering.

God became the beckon of their lives while they struggled for life. Lastly, this phenomenological reflection was the researcher's way of expressing her own lived experienced in the whole process of her research.

Figure 12. Mr. Wobble and the Wibbles.

Mr. Wobble and the Wibbles is a story of a deadly cancer cell Mr. Wobble, who spreads wherever, whenever and whatever he wants. Ten school aged children were invaded, attacked and made their bodies sick. And left them crippled with advanced cancer. What followed next was another heartbreaking news of chemotherapy to treat them. These children have no choice to escape. They were trapped by the wickedness of Mr. Wobble with his fierce set of teeth. He turned the ten school aged children into Wibbles due to the overwhelming emotions brought about by chemotherapy. The Wibbles were messed up. Their feelings burst into overwhelming emotions. At times they cried, other times too weak and strained to carry their bodies. They agonized on pains and headache. They were thin and frail with no appetite to eat. All of them lost their hair. They were saddened with what they have gone through. Their life stopped for a moment. They were delayed from the rest. Their life revolved around, home their haven to rest. When they felt better, they bounce back to school because they love the feeling of being normal and fun. They sought refuge from GOD in the church and the hospital was the place to go for treatment and follow up even they do not want it. They also stayed connected with families and friends with technology to link with them. The Wibbles never gave Mr. Wobble another chance. They stayed away from him this time and redirected their focus on the treatment towards recovery. Wibbles wait for the day that they will win the battle against the “evil” Mr. Wobble. They remained sincere with their faith and trust in God. And they were all back to school with hair grown back. Despite the hurts and scars of being bullied by other children, because of their appearance, they endured the test and trials. They remained positive that they will one day be free of Mr. Wobble. The end.

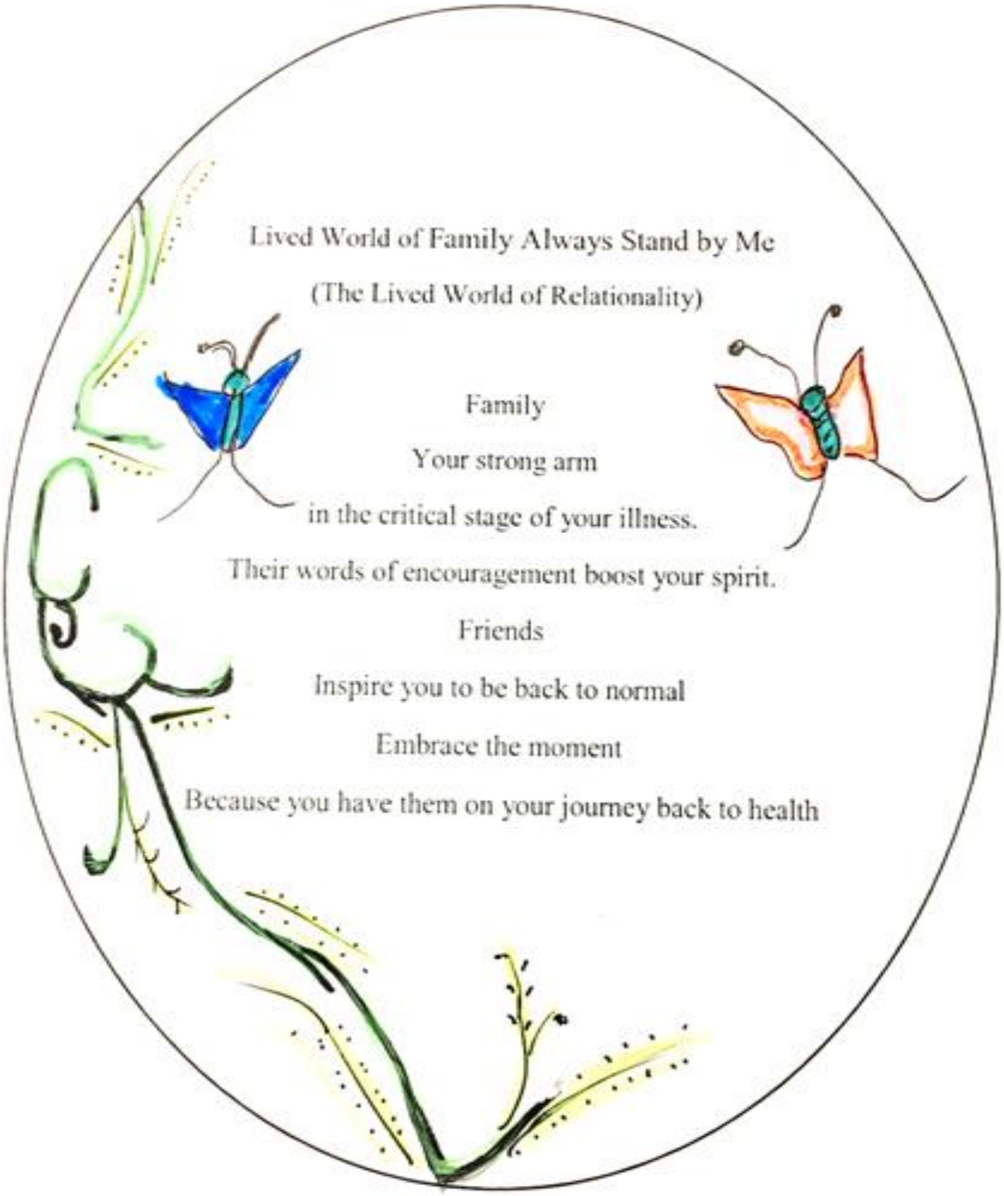
Poems. These poems are dedicated to the ten brave school-age children with advanced cancer and in their life-world.



The Lived World of Brave Acceptance
(Lived World of Corporeality)

When I saw how your body struggled with advanced cancer
I understand your tiredness and weakness
But when I saw your positive coping
and firm determination to live
It was then that
I admired your strength of character

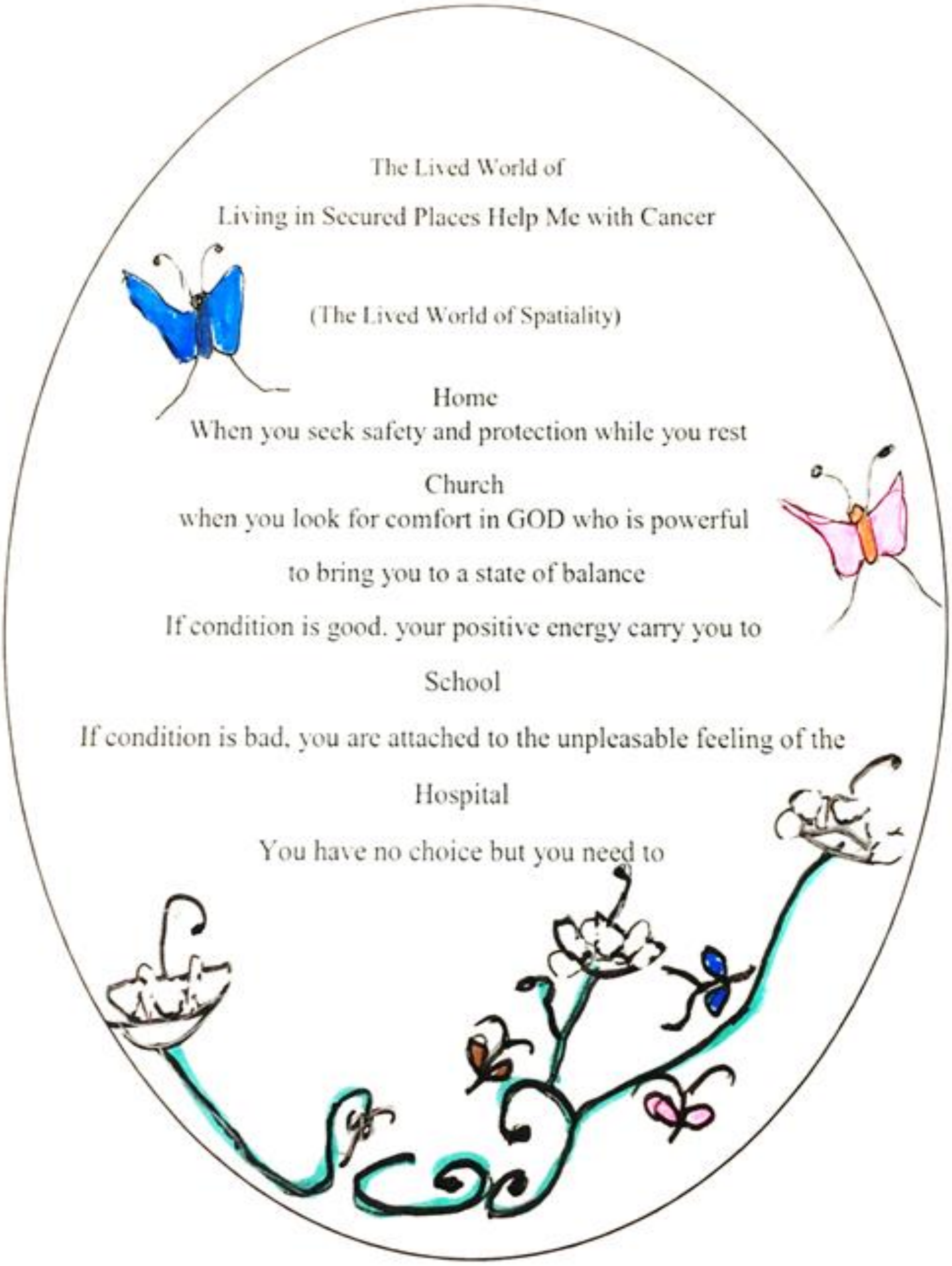
The Lived World of Brave Acceptance



Lived World of Family Always Stand by Me
(The Lived World of Relationality)

Family
Your strong arm
in the critical stage of your illness.
Their words of encouragement boost your spirit.
Friends
Inspire you to be back to normal
Embrace the moment
Because you have them on your journey back to health

Lived World of Family Always Stand by Me



The Lived World of
Living in Secured Places Help Me with Cancer

(The Lived World of Spatiality)

Home
When you seek safety and protection while you rest

Church
when you look for comfort in GOD who is powerful

to bring you to a state of balance

If condition is good. your positive energy carry you to

School

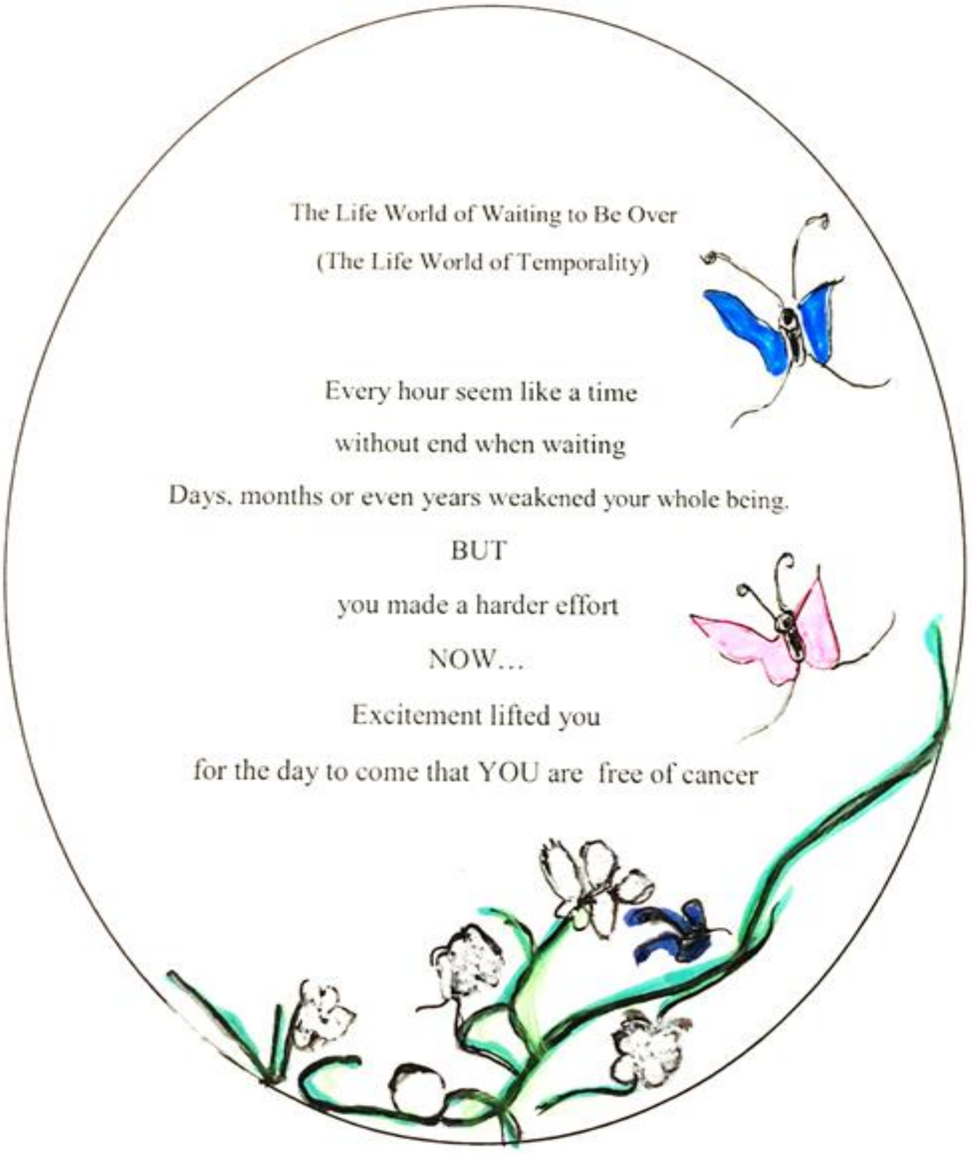
If condition is bad, you are attached to the unpleasable feeling of the

Hospital

You have no choice but you need to

The Lived World of

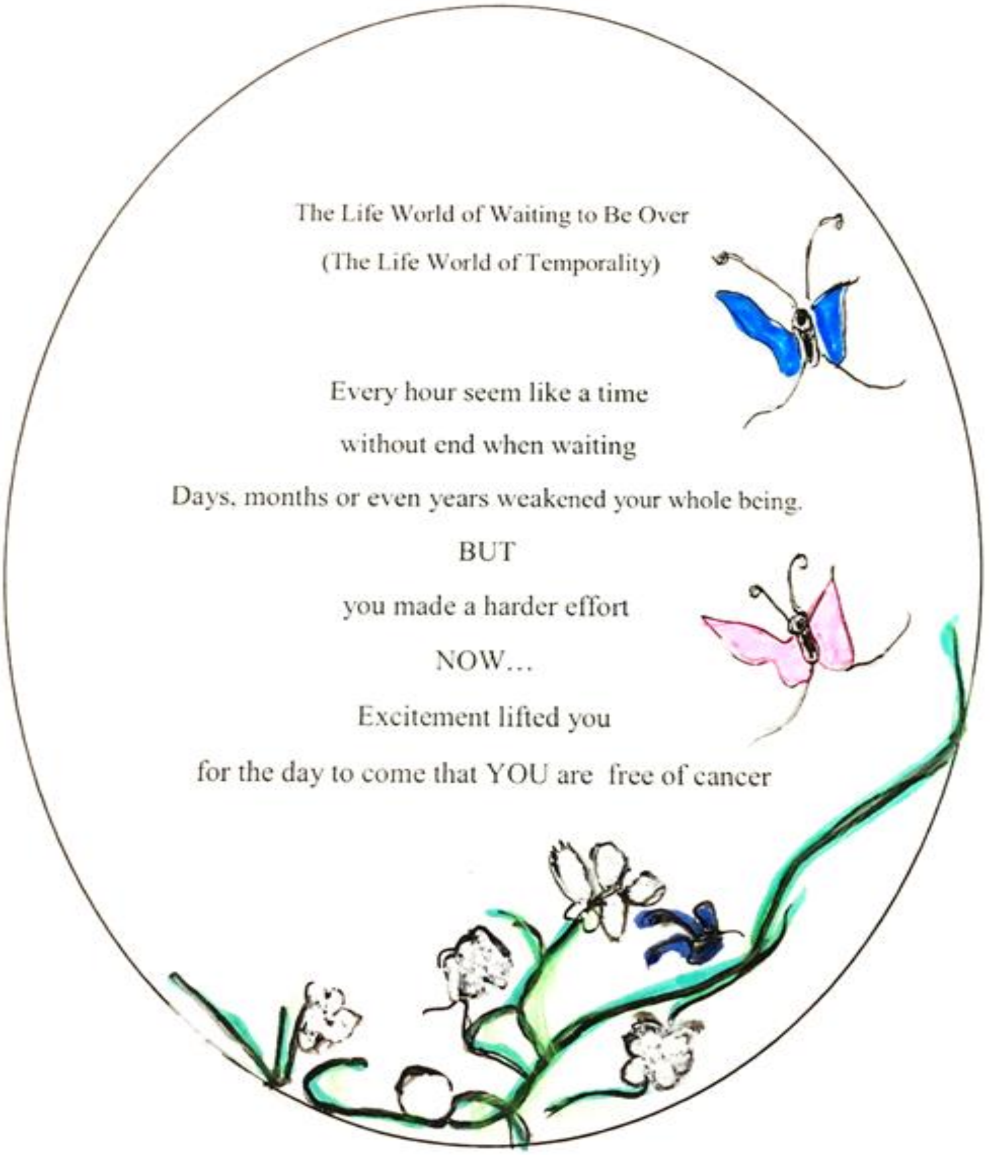
Living in Secured Places Help Me with Cancer



The Life World of Waiting to Be Over
(The Life World of Temporality)

Every hour seem like a time
without end when waiting
Days, months or even years weakened your whole being.
BUT
you made a harder effort
NOW…
Excitement lifted you
for the day to come that YOU are free of cancer

The Life World of Waiting to Be Over



The Life World of Waiting to Be Over
(The Life World of Temporality)

Every hour seem like a time
without end when waiting
Days, months or even years weakened your whole being.
BUT
you made a harder effort
NOW…
Excitement lifted you
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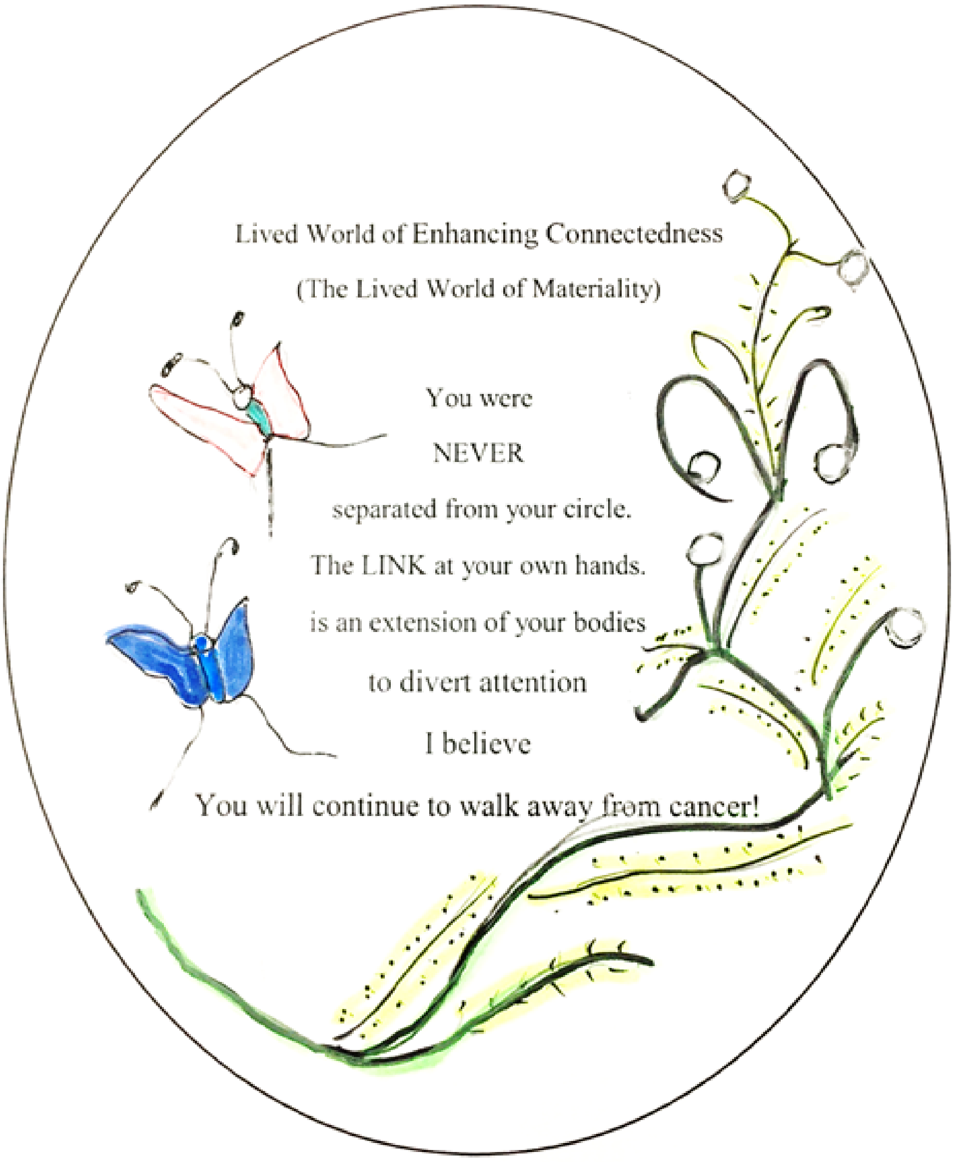
The Life World of Waiting to Be Over



Lived World of Enhancing Connectedness
(The Lived World of Materiality)

You were
NEVER
separated from your circle.
The LINK at your own hands.
is an extension of your bodies
to divert attention
I believe
You will continue to walk away from cancer!

Lived World of Enhancing Connectedness

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APPENDICES

APPENDIX A

INFORMED CONSENT

Dear Participants,

My name is Barbara Lyn A. Galvez. I' am a maternal and child nurse lecturer at Silliman University College of Nursing. I 'am presently a PhD student at Faculty of Nursing – Prince of Songkla University, Thailand. I'm conducting a research study on the Aesthetic Expression of the Life-World of School-age Children with Advanced Cancer with the use of Draw and Write. My research is under the supervision and direction of Associate Professor Dr. Urai Hatthakit and Associate Professor Dr. Waraporn Kongsuwan. I am conducting the study to gain better understanding of children's feelings, thoughts and perceptions regarding their lived experiences as children with advanced cancer. The purpose of the research is to describe the meanings of the life-world of the school age children with advanced cancer. This study has been approved by the Institutional Review Board of the Faculty of Nursing, Prince of Songkla University, Thailand (PSU IRB 2017-NSt 048). This study will use snowball sampling wherein the researcher will identify participants through parents/guardian and asking the parent whether she would be willing to pass some information about the study to other potential parents. At the same time, if she can assist in identifying other potential parents of the same situation who can participate in the research.

I would like to invite your child to participate in the study as your child meets qualifications of this study. I ask you to please read my explanation of the study and if you and your child have any doubts or questions about participation, please don't hesitate to ask me. If you understood and clear about the study, I request that you confirm whether to participate. The decision to participate or not in this study, depends on your willingness. Your personal identity and all information will be kept confidential and will be used only for the purpose of this research. You can withdraw from this study at any time. If you decide to allow your child to join in this study voluntarily, she will have 30-45 minutes of drawing and writing. This will be followed by an in-depth interview. You will be asked to describe your experience during advanced cancer which will last approximately one hour at your convenient time. The researcher will ask you to indicate your permission to be audio- recorded.

What is the risk of this study?

This study has very low physical and emotional risks. If you show signs of anxiety and hesitation or feel sad or are having a difficult time accepting the situations, the researcher will provide support and offer to end the interview. All data from participants will be kept confidential and will be reported as an overview. That is not specific to any one person and participants' names will not be shown. The users who can access the data are only the researcher, my advisor, and the Institutional Review Board (IRB) only when it is necessary. All the data will be kept for two (2) years after this study has finished at which time the data will then be destroyed. If the methodology or anything else in this study changes you will be notified immediately.

What are the benefits if you participate in the study?

Children will directly benefit from this research. The results of this study may help school-age children with advanced cancer to experience better emotional health in terms of increased awareness of their condition, being able to calm when upset, and greater well-being by being happy.

The remuneration and custodies

Your child will not receive remuneration from this study and it is provided free of charge. Lastly, if you need further information or have any questions regarding this study please do not hesitate to contact either the researcher or advisor listed below. Thank you for your willingness and cooperation to participate in this study.

Researcher:
Asst Prof. Barbara Lyn A. Galvez, MAN, RN
Doctor of Philosophy in Nursing Science student - Faculty of Nursing Prince of Songkla University Hat Yai, Songkla, Thailand 90110
Email: barbaralyngalvezgmail.com (+6641427098) or (+63 9778239963)

Advisor:
Assoc. Prof. Dr. Urai Hatthakit
Associate Dean of Graduate School for Student Affairs and International Relations
Graduate School, Prince of Songkla University
Hat Yai, Songkhla, 90110, Thailand
Email: urai.h@psu.ac.th (+66896558767)

I, as the parent/guardian of the child, understand the information provided about the study and I allow my child to participate in this study.

Signature of Parent / Guardian: ____________________________Date: ___________

After I read all the statement above, I understand and I will join this research: "Aesthetic
Expression of the Life-World of School-age Children with Advanced Cancer" without coercion from anyone.

Signature of Participant: ________________________________Date: ___________

APPENDIX B

PARTICIPANT'S DEMOGRAPHIC DATA FORM

Instruction: Please fill in the blanks or check (√) that is true of the child's information.

1. Participant code: ___
2. Age: ___
3. Date of birth: (mm/dd/yyy): ____________
4. Gender: ( ) 1. Male ( ) 2. Female
5. Religion:
   ( ) 1. Roman Catholic ( ) 3. Islamic
   ( ) 2. Protestant ( ) 4. Others ______________

6. Education:
   ( ) 1. Grade 1
   ( ) 2. Grade 2
   ( ) 3. Grade 3
   ( ) 4. Grade 4
   ( ) 5. Grade 5
   ( ) 6. Grade 6
   ( ) 7. Grade 7
   ( ) 8. Grade 8
   ( ) 9. Grade 9
   ( ) 10. Grade 10

7. Is the child treated in an institutional setting?
   ( ) 1. Yes
   ( ) 2. No

8. If YES, Type of facility?
   ( ) 1. Private
   ( ) 2. Public

9. In an institutional setting, the child is:
   ( )1. Confined /admitted in the hospital
   ( ) 2. OPD

10. Date of illness onset: (mm/dd/yyyy) _______________
11. Was the child evaluated by a physician for this illness?
    ( ) 1. Yes ( ) 2. No
12. Medical Diagnosis:
    ( ) 1. Acute Lymphocytic Leukemia (ALL)
    ( ) 2. Acute Myeloid Leukemia (AML)
    ( ) 3. Others ________________________________

13. Received chemotherapy:
    ( ) 1. Yes (if yes) When? ____________ ( ) 2. No

14. Type of Chemotherapy:
    ( ) 1. Intravenous
    ( ) 2. Intravenous and Oral
    ( ) 3. Intrathecal
    ( ) 4. Intrathecal and oral
    ( ) 5. Oral maintenance

15. Duration of chemotherapy treatment: __________
16. Side effects from chemotherapy treatment:
    ( ) 1. No
    ( ) 2. Yes there is / are:
        ( ) 1. Nausea / vomiting
        ( ) 2. Alopecia/ hair loss
        ( ) 3. Weight loss
        ( ) 4. Fatigue
        ( ) 5. Loss of appetite
        ( ) 6. Pain
        ( ) 7. Head ache
        ( ) 8. Skin changes

APPENDIX C

DRAW AND WRITE GUIDELINES

The drawing activity can be completed easily in an enjoyable way for participants to express their views and interpretations of experiences.

Drawing

1. Participants will draw as the aesthetic expression of their experience being persons with advanced cancer. This may take 30-45 minutes.

2. They will be provided with drawing pad, pencil, eraser, crayons, colored pens, colored pencils and water color.

3. They will be allowed to choose which suits best for their preference to use for their picture to fashion their own individual originality, imagination and inspiration in expressing what they feel.

4. The drawing don't have to be 100 per cent precise.

5. It is alright if shapes like round, circles, square, rectangle, and triangle are not picture-perfect.

Written/oral description

1. Participants will describe the expressions/images in the drawing through writing on paper provided.

2. If the child opts to describe his/her drawing verbally, this will be audiotaped (as indicated in the informed consent form).

3. Telling and unfolding their own interpretation will clarify the participant's expressions of lived experience having advanced cancer that was aesthetically expressed through their drawing.

4. An eraser will be provided so they can remove easily statements that need to be improved.

5. There is unrestricted number of words, sentences or paragraph in his/her description.

APPENDIX D

INSTRUCTIONS FOR DRAW AND WRITE

Drawing instructions:

1. You are provided with drawing pad, pencil, eraser and different drawing materials that you can choose from that will suit your preference to use.
2. Can you please show me by drawing (or illustrating) your life (or living) experiences of having advanced cancer?
3. You are given 30 -45 minutes to do this activity.
4. You have to draw it by yourself without help from any member of your family.
5. I will lay all the drawing materials beside you for easy accessibility.
6. Once you are ready, you can start.

Written/oral description instructions:

1. Can you please describe your drawing to me?
2. You can write your description on the paper provided for you.
3. If you prefer, you can also describe it to me orally.
4. I will record your description using an audio-taping gadget.
5. By using an audio-taping gadget the researcher will not miss any statements.
6. Another thing, the audio recorder will be used to play and replay in case the researcher has missed important statements unintentionally.

APPENDIX E

GUIDELINES FOR IN-DEPTH INTERVIEW

1. The activity will encompass guiding participants in separate interviews intensively.

2. The researcher will need detailed information about a participants' feelings, thoughts, difficulties and behaviors about his/her lived experience on advanced cancer and explore new issues in-depth.

3. Interview will provide an understanding on how they interpret those experiences through drawing and writing.

4. The pictures and narrative done by participants will be the tools to be used for in-depth interview.

5. As the interview will proceed observation of the participants will be done. The points for observation are : Participants' space, actions, activity, objects, event, time and emotions or feelings which are expressed

APPENDIX F

SEMI-STRUCTURED INTERVIEW GUIDE QUESTIONS

The researcher will be unstructured and use probes in response to the participants' answer to elicit further information.

1. Please describe the images or figures of any persons, places or events that you just drew.
2. Please tell me about this line, color, shape, etc.
3. Please tell me about the facial expressions that are shown on the drawing.
4. What is the reason for you to draw this picture?
5. What did you feel about your drawing?
6. Please tell me about the places depicted in the drawing?
7. Has this picture you drew happened? If yes, Please tell me when.
8. If you want to name this picture, what is this picture's name?
9. Please tell me the reason why you name the picture that way?
10. How would you describe your relationship and the pictures in your drawing?
11. What were you thinking while you were drawing?
12. What did you feel while drawing the picture?
13. What made you happy/sad while you draw the picture?
14. How do you react being happy/sad while you draw the picture?
15. How do you cope (like get by to forget) being a child with cancer?
16. How do you feel after coping?

17. What experience do you accomplish in this drawing that you would like to tell?

18. Do you have any concerns while drawing the picture?

19. Do you think about some differences in the past and present being sick? How different? And why?

20. Could you please tell me what is your experience like being an advanced cancer patient?

21. Generally, what do you feel being an advanced cancer patient?

22. How do you handle it?

23. In your experience of being an advanced cancer patient, what are your concerns?

24. Do the concerns of your experience disturb what you feel?

25. How do you feel about it? How do you react to it? And what did you feel after you react to it?

26. What will you do to enhance your hopes/expectations in the future?

27. During your drug treatment, can you please tell me what you feel?

28. And how do you break out (cope) from what you feel?

29. What problems do you encounter and how do you cope with it?

30. Anything else you want to tell me or others being an advanced cancer patient?

APPENDIX G

LIST OF EXPERTS

About five experts were invited to evaluate interview guide questions and gave suggestions for developing and modifying the interview questions. The experts were as follows:

Faculty of Nursing – Prince of Songkla University, Thailand

1. Asst. Prof. Dr. Wantanee Wiroonpanich
   Child and Adolescent Nursing
   Faculty of Nursing, Prince of Songkla University, Thailand

2. Asst. Prof. Dr. Kallaya Wiriya
   Maternal and Newborn Nursing
   Faculty of Nursing, Prince of Songkla University, Thailand

College of Nursing, Silliman University, Philippines

3. Professor Dr. Rozzano C. Locsin
   Nurse Theorist
   Knowledge and Practice expert on Phenomenology
   Professor of Nursing Tokushima University, Japan
   Professor Emeritus, Florida Atlantic University, USA
   Visiting Professor at universities in Thailand, Uganda, and the Philippines

4. Assoc. Prof. Evalyn E. Abalos
   Adult Nursing
   Former Dean, College of Nursing, Silliman University, Philippines
   Knowledge expert on van Manen Phenomenological approach

5. Assoc. Prof. Theresa A. Guino-o
   Adult Nursing
   Acting Dean, College of Nursing, Silliman University, Philippines
   Knowledge expert on Phenomenology and Phenomenography

APPENDIX H

DATA ANALYSIS (SAMPLES)

Full Transcriptions of Participant 1

Date: February 11, 2018
Venue: Scooby’s, Silliman Avenue, Dumaguete City
Time started: 3:00pm
Time ended: 4:00pm
Researcher: Barbara Lyn A. Galvez

ME: are you ready for the interview? (*AC1 nodded her head with a smile. She requested that her mother to stay away from our interview session but within range of vision*).

Participant 1: Ok, I am ready now.

ME: Please describe the images or figures of any persons, places or events that you just drew.

Participant 1: The girl in the drawing is “me”. It is a representation of myself thinking positive thoughts to survive cancer.

ME: Please tell me about this line, color, shape, etc.

Participant 1: (*coughing*) yes, the young girl represents me actually. I colored it orange because I saw a picture in the internet that orange signifies a color for cancer survivors. The shape compliments my body shape because I am a chubby girl. Before I got sick. I play eat and sleep well, I was healthy kid.

ME: Please tell me about the facial expressions that are shown on the drawing.

Participant 1: I show a happy face because of my positive belief that I will get well from advance cancer. *(Directed her attention to the drawing pad with picture from her drawing)* If I think negatively like I will not get well, it brings me down. I get depressed.

ME: What is the reason for you to draw this picture?

Participant 1: this picture reflects my personality and pushes me more to be optimistic that I will survive. (*Fixed her growing hair).*

MEANING UNIT	CODE
ME: Please describe the images or figures of any persons, places or events that you just drew. **AC1**: The girl in the drawing is “me”. It is a representation of myself thinking positive thoughts to survive cancer. **ME: Please tell me about this line, color, shape, etc.** **AC1** ***:(****coughing*) yes, the young girl represents me. I colored it orange because I saw a picture in the internet that orange signifies a color for cancer survivors. The shape compliments my body shape because I am a chubby girl. before I got sick. I play eat and sleep well, I was healthy kid. **ME: Please tell me about the facial expressions that are shown on the drawing**. **AC1:** I show a happy face because of my positive belief that I will get well from advance cancer. *(Directed her attention to the drawing pad with picture from her drawing)* If I think negatively like I will not get well, it brings me down. I get depressed. **ME: Thank you this is the end of our interview.** **END OF 1st INTERVIEW** **Date:** February 11, 2018 **Venue:** Scooby’s, Silliman Avenue**,** Dumaguete City **Time started :** 3:00pm **Time ended :** 4:00pm **Researcher :** Barbara Lyn A. Galvez	***AC1-1*** The girl in the drawing is “me”. ***AC1-2*** It is a representation of myself thinking positive thoughts to survive ***AC1-3*** The young girl represents me. I colored it orange ***AC1-4*** I colored it orange. Orange signifies a color for cancer survivors. ***AC1-5*** The shape compliments my body shape because I am a chubby girl. before I got sick. ***AC1-6*** I play eat and sleep well, I was a healthy kid. ***AC1-7*** I show a happy face because of my positive belief that I will get well from advance cancer. ***AC1-8*** If I think negatively like I will not get well, it brings me down. I get depressed.

Significant Statements from Lived Experience Narratives	Initial themes	Five lived-worlds
***AC1-10* -** I felt happy and excited because I learn more about myself which I have never felt before.	Awareness of feelings	Lived Body
***AC1 – 40* -** When I became bald due to my chemotherapy, I was miserable. I experienced being laughed at and bullied.	Feeling of being devalued	
***AC1 – 73* -** I feel that my head is bigger than my whole body.	Being laughed at and bullied	
***AC1 – 74* -** .I feel sick due to due to body weakness and sleepiness. ***AC1 – 75* -** My head aches and I vomit. ***AC1 – 77* -** I loose appetite to eat ***AC1 – 78* -** I usually lose weight because my school uniform is inaccurately fit.	Physical discomforts	
***AC1-12* -** I chose the garden. I love and enjoy nature. ***AC1-13* -** It's very therapeutic for my condition. ***AC1-14* -** without nature we cannot live.	Enjoying nature	Lived space
***AC1 – 46* -** Yes, there is a big difference in the past and now that I am sick. ***AC1 – 50* -** At present I cannot join any sport team because my doctor will not allow me strenuous activities because of my compromised immune system. ***AC1 – 64* -** Yes definitely, because I have been waiting for a long time.	Awareness of diagnosis and treatment	Lived time
***AC1-22* -**The nature of Life is a God-given gift that's why I accept the challenge of advance cancer since it's a test of my faith, trust and strength in God.	Keeping faith and trust in God	Lived relation
***AC1 – 38* –**My Family, friends and my doctor and nurse are all important to me. They encourage me to be strong and fight cancer.	Acknowledging support	

Significant Statements from Lived Experience Narratives	**Initial themes**	**Five lived-worlds**
.***AC1 – 33-*** After I write poems I can direct myself from not thinking about my cancer. This way I feel more energetic. ***AC1 – 51-*** I listen to music, draw, compose songs and write stories to keep myself busy during free time and dismiss myself from leukemia.	Dismissal of negativity Distracting away from cancer	Lived things

P-Code	Theme	Drawing	Interview	Observation
P1	Lived Body: 1) Cancer never had me)	 Cancer never had me	*"I want to tell other children like me with leukemia not to give up. Just think that cancer never really have you".* (P1-L-100).	She is a happy child, full of positivity. She smiles most of the time by showing her teeth and likes to talk because she is confident about herself. Her hair is black, growing by two inches in length because of chemotherapy reactions. Because of cancer, she experienced weight loss, she has gained back her full-figured body.

Initial themes	Thematic Categories
▪ Awareness of physical condition ▪ Awareness of capacity ▪ Awareness of limitations ▪ Awareness of feelings ▪ Awareness of diagnosis and treatment ▪ Feeling confident ▪ Feeling better expressing self ▪ Feelings of differences in physical appearance	Awareness of the state of self and capacities
▪ Positive thoughts ▪ Positive beliefs ▪ Being optimistic for recovery ▪ Positivity ▪ Excited to be free from cancer	Positive expectancy for survival
▪ Enjoyment ▪ Demanding privacy ▪ Unforeseen occurrence ▪ Feeling of victimization ▪ Being bullied and laughed at ▪ Contemplating quietly ▪ Poor body image ▪ Pain related to physical harm	Vulnerability
▪ Different body sensation: pain GIT symptoms ▪ Body changes ▪ Feeling sick ▪ Suffering from unbearable physical symptoms ▪ Sad from effects of medicine ▪ Physical difficulty	Physical discomfort/ Annoyance
▪ Feeling stressed and not relaxed ▪ Feeling of being devalued ▪ Fear ▪ Feeling worried ▪ Feeling disturbed ▪ Feeling shy ▪ Impatient ▪ Sadness ▪ Feeling burdened ▪ Negative attitude towards side effects of chemo	Emotional discomfort
▪ Showing strength and bravery ▪ Being inspired ▪ Cooperating with doctor and treatment ▪ Distracting from cancer	

Initial themes	**Thematic Categories**
▪ Play with friends ▪ Connecting to the spiritual ▪ Enjoying nature ▪ Self – care ▪ Inspire others ▪ Seeking rest ▪ Acknowledging support ▪ Social connections maintained ▪ Motivated on recovery	Positive coping
▪ Insufficient finances ▪ Financial difficulty	Financial burden
▪ Awareness of physical condition ▪ Awareness of capacity ▪ Awareness of limitations ▪ Awareness of feelings ▪ Awareness of diagnosis and treatment ▪ Feeling confident ▪ Feeling better expressing self ▪ Feelings of differences in physical appearance	Awareness of the state of self and capacities

Thematic Categories of Live-World of School-Age Children with Advanced Cancer AC1

Themes	Spatiality	Corporeality	Temporality	Relationality	Materiality
Meaning	***AC1-12 -*** I chose the garden. I love and enjoy nature. ***AC1-13 -*** It's very therapeutic for my condition.	***AC1-9 -*** This picture reflects my personality in such a way that I am optimistic that I will survive. ***AC1-15 -*** Yes it happened. I encourage myself to be useful because it helps me to think positive.	***AC1-6 -*** I play eat and sleep well, I was a healthy kid. ***AC1 – 46 -*** Yes, there is a big difference in the past and now that I am sick. ***AC1 – 47 -*** Before I was allowed to indulge in sports.	***AC1-22 -*** . The nature of Life is a God-given gift that's why I accept the challenge of advance cancer since it's a test of my faith, trust and strength in God. ***AC1 – 38 -*** They are all important to me. They encourage me to be strong and fight cancer.	***AC1-32-*** I manage by thinking that I will get over this situation by writing poems, looking at the photo albums of my family and loved ones and reminisce how happy we were when we are complete like presence of my father and grandmother.
Concerns	***AC1 – 62*** - My uneasiness is related to school. For not being active in school activities.	***AC1 – 56-*** As far as I' m concerned I feel tested on how far I can go to sustain the challenge. ***AC1 – 73 -*** I feel that my head is bigger than my whole body. ***AC1 – 74 -*** .I feel sick due to due to body weakness and sleepiness.	***AC1 – 48-*** . I used to play volleyball, tennis and badminton. ***AC1 – 50 -*** At present I cannot join any sport team because my doctor will not allow me strenuous activities	***AC1 36 -*** yes I was worried that I will not give justice to the people that I want to include in the picture. ***AC1 – 37 -*** I don't want to miss anyone who are part of my journey with leukemia. there are so	

Themes	Spatiality	Corporeality	Temporality	Relationality	Materiality
		AC1 – 75 - My head aches and I vomit. ***AC1 – 77 -*** I loose appetite to eat ***AC1 – 78 -*** I usually lose weight because my school uniform is inaccurately fit.	because of my compromised immune system. ***AC1 – 65 -*** I like to be cured to happen sooner so I can do what normal	many of them like my parents, brother, Dr. Sheila, my attending pediatric oncologist, Nurse Christine my chemo nurse, teachers ,classmates friends and relatives.	
Feelings	***AC1 – 76 -*** I want to lie down in my bedroom at home all the time. ***AC1 – 80 -*** I try to stay in my bedroom and sleep all the time**.**	***AC1-10 -*** I felt happy and excited because I learn more about myself which I have never felt before. ***AC1-16 -*** There are times that I want to give up ***AC1-17 -*** Because I feel that the world is against me. ***AC1-27 -*** I felt happy that I will be able to display myself in a representation. ***AC1-28 -*** I can see myself proud that I can survive the	***AC1-24 -*** I returned to the time that I did not feel good about myself when I had on and off fever with rashes, joint pains and I have to be brought to the hospital where I have to stay for seven days for many laboratory tests and the doctor revealed to my Mom about my leukemia. ***AC1 – 66 -*** I feel angry because of	***AC1-31 -*** I am excited for the day to come when my doctor will announce that I will be free of cancer.	***AC1 – 33-*** After I write poems I can direct myself from not thinking about my cancer. This way I feel more energetic.

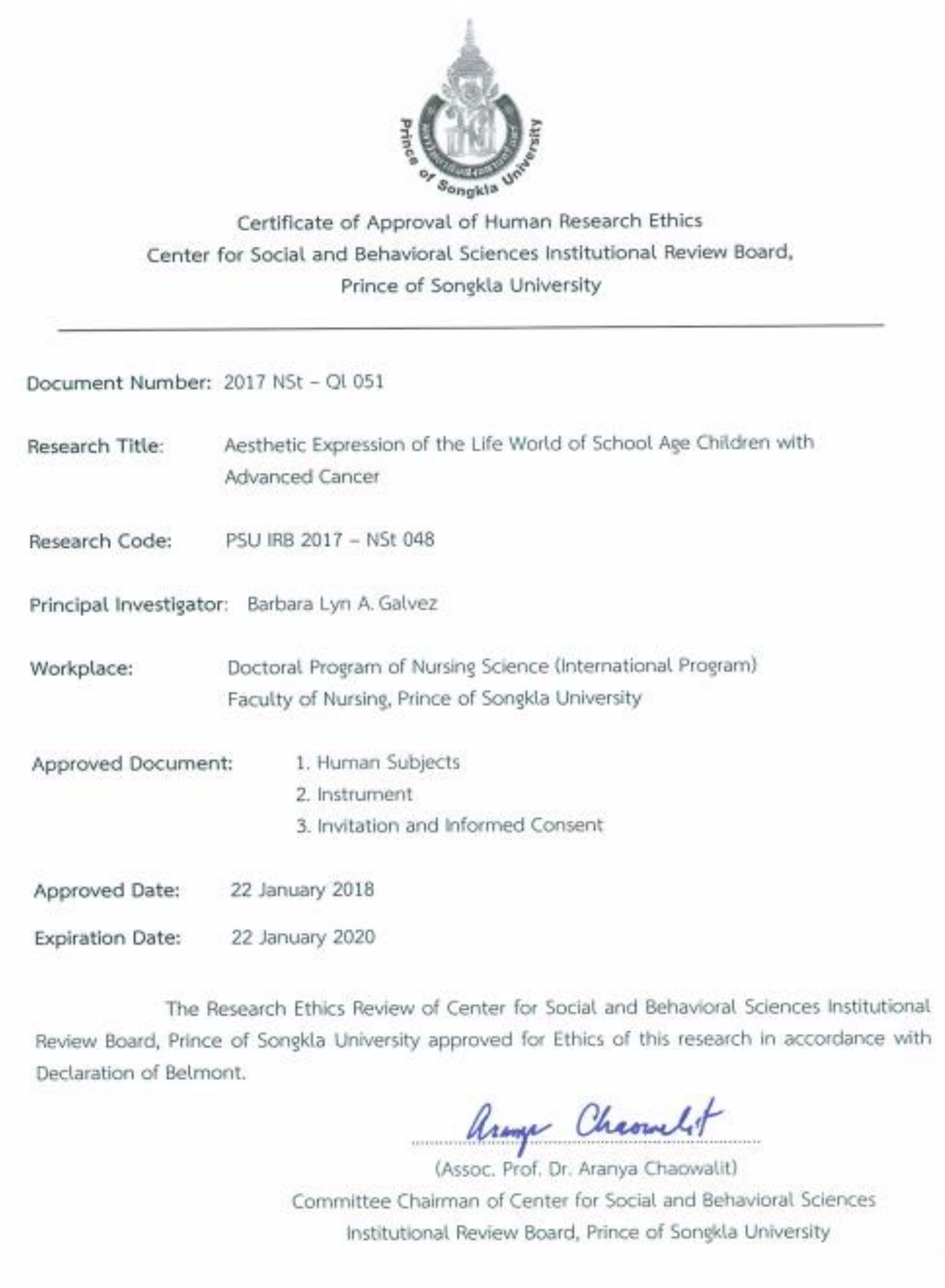
Themes	Spatiality	Corporeality	Temporality	Relationality	Materiality
		dreadful trials of cancer. ***AC1 – 45 -*** All I care is I will surpass cancer. ***AC1 – 52 -*** For me, it does not mean I am unlucky ***AC1 – 53 -*** I show my strength and try to be brave.	long wait. ***AC1 – 67 -***I felt hopeless and that there was no point going on. ***AC1 – 68 -*** It took a long time to accept it and find a way forward. ***AC1-25 -*** I felt that my Mom was hiding some information from me.		
Changes		***AC1 – 40 -*** When I became bald due to my chemotherapy, I was miserable. I experienced being laughed at and bullied. ***AC1 – 74 -***I feel sick due to due to body weakness and sleepiness. ***AC1 – 75 -*** My head aches and I vomit. ***AC1 – 77 -*** I loose appetite to eat ***AC1 – 79 -*** I force myself to take in food and fluids but			

Themes	Spatiality	Corporeality	Temporality	Relationality	Materiality
		I vomit everything that I ingest.			
Coping		***AC1-32* -** I manage by thinking that I will get over this situation by writing poems, ***AC1 – 33* -** After I write poems I can direct myself from not thinking about my cancer. This way I feel more energetic.	***AC1 – 82* -** I cope by preparing myself ahead of time or anticipate that will vomit immediately after administration.	***AC1 – 57* -** I pray a lot. I don't keep my problems to myself. ***AC1 – 58* -** I cling to my Mom and tell my friend Lara. ***AC1 – 59* -** My Mom help me with comforting words only a mother can give. ***AC1 – 71* -** I cooperate and follow my doctor's advice and instructions strictly. ***AC1 – 72* -** I also follow my Mom's recommendations	***AC1 – 51*-** I listen to music, draw, compose songs and write stories to keep myself busy during free time and dismiss myself from leukemia.
Hopes and fears		***AC1 – 69* -** I hope to respond to chemotherapy.	***AC1 – 65*-**I like to be cured to happen sooner, so I can do what normal healthy kid can do. ***AC1 – 70* -** My fear is temporary	***AC1 – 67*-** I felt hopeless and that there was no point going on	

Themes	**Spatiality**	**Corporeality**	**Temporality**	**Relationality**	**Materiality**
			recovery and leukemia will come back		
Problems		***AC1 – 81 -*** my number one problem is my body's reactions to IV chemotherapy. I suffer from the effects of the medicine which most the time I cannot tolerate. ***AC1 – 79 -*** I force myself to take in food and fluids but I vomit everything that I ingest.			

APPENDIX I

LETTER OF ETHICAL APPROVAL FOR HUMAN RESEARCH



Certificate of Approval of Human Research Ethics
Center for Social and Behavioral Sciences Institutional Review Board,
Prince of Songkla University

Document Number: 2017 NSt – QI 051

Research Title: Aesthetic Expression of the Life World of School Age Children with Advanced Cancer

Research Code: PSU IRB 2017 – NSt 048

Principal Investigator: Barbara Lyn A. Galvez

Workplace: Doctoral Program of Nursing Science (International Program)
Faculty of Nursing, Prince of Songkla University

Approved Document:
1. Human Subjects
2. Instrument
3. Invitation and Informed Consent

Approved Date: 22 January 2018

Expiration Date: 22 January 2020

The Research Ethics Review of Center for Social and Behavioral Sciences Institutional Review Board, Prince of Songkla University approved for Ethics of this research in accordance with Declaration of Belmont.

Aranya Chaowalit

(Assoc. Prof. Dr. Aranya Chaowalit)
Committee Chairman of Center for Social and Behavioral Sciences
Institutional Review Board, Prince of Songkla University

VITAE

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Educational Attainment

Degree	Name of Institution	Year of Graduation
Master of Art in Nursing (Maternal and Child Nursing)	Silliman University, Philippines	2001
Bachelor of Science in Nursing	Celegio de San Agustin, Philippines	1980

Scholarship Awards during Enrollment

2015 – 2018	Thailand Education Hub for ASEAN countries, Thailand

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October 1989 – present	Lecturer, Maternal and Child Nursing, College of Nursing Silliman University, Philippines
April 1989 – January 1990	Staff Nurse, Silliman University Medical Center, Philippines
June 1980 – December 1987	Product specialist, Astra Pharmaceutical Inc. Philippines

International Nursing Conference

Galvez, BL.A & Hatthakit, U. (2016). Aesthetic Experience of the Life-World of School-age Children in End of Life. Poster presentation at the Sigma Theta Tau Honor Society and Phi Omega Chapter at-Large “Leadership Development through Graduate Education, Research and Practice”, September 14-15, 2016 Maruay Garden Hotel, Bangkok, Thailand.

Galvez, BL.A. Hatthakit, U. & Kongsuwan, W. (2017). Gadamerian Philosophy and Aesthetics of Death and Dying Among Children. Poster presentation at the International Conference on ;” Ethics, Esthetics and Empirics in Nursing : Driving Force for Better Health.” July 5-7, 2017International Convention Center, Prince of Songkla University, Hat Yai Campus.

Galvez, BL.A. Hatthakit, U. & Kongsuwan, W. (2017). Expressions of the Life-World of School age Children with Advanced Cancer. A Preliminary Study. Poster presentation at Thailand Nursing Honor Society and Sigma Theta Tau Honor Society of Nursing Phi Omega- at –Large, “Towards Nursing Leadership in Thailand 4.0 Era.” November 9-10, 2017, Maruay Garden Hotel, Bangkok, Thailand.