

Aesthetic expressions as data in researching the lived-world of children with advanced cancer

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Abstract

Background: Understanding the true world of children needs a special method. Using aesthetic expressions through artworks with reflections assists nurse researchers in exploring children's feelings, thoughts, and behaviors in relation to their health and well-being.

Objective: This article focuses on the use of aesthetic expressions as innovative data sources in a study of the lived worlds of children experiencing advanced cancer.

Method: The use of aesthetic expressions in Gadamerian hermeneutic phenomenology and aesthetics, by means of van Manen's approach using draw and write, is examined as a suitable approach in a study of the lived worlds of children experiencing advanced cancer.

Results: The aesthetic expressions through the Draw-and-Write method of data generation were well-suited to a hermeneutic phenomenological study involving the group of Filipino children living with advanced cancer. The children drew images and figures of themselves, their families, classmates, friends, and teachers in several places and events during the series of two days. The drawings showed their facial expressions, home, parents, hospital stay, school activities, extracurricular activities, and other daily activities.

Conclusion: 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 and awareness of the variation of experience among children with advanced cancer. It is hoped that this paper can contribute to an understanding of aesthetic expressions as pathways to understanding and support health professionals as they embark on their goal of creating or restoring a comfortable relationship with children.

Keywords

aesthetic expressions; cancer; children; lived world; hermeneutics; nursing

Aesthetic expression is essentially conveying and communicating feelings. The experience of beauty can allow us to contemplate and enjoy created images of our own freedom. Aesthetic freedom liberates us to inform others who we are as a way of thinking, behaving, or working that exists (Gadamer, 1997). An aesthetic philosophical stance enables the practice as a creative humanistic discipline involving processes of dynamic interactions expressed through actions, bearing, conduct,

attitudes, and narrative (Carper, 1999). Aesthetic expressions had been used in research mostly with adult persons. Previous studies used drawing (Kongsuwan & Locsin, 2010), and another study investigated the use of aesthetic expressions in promoting successful aging (Wikström, 2005). Sadruddin and Hameed-ur-Rehman (2013), using phenomenology to study the self-perceptions of children with cancer, reported that the approach helped gain insight into the data through drawing. Their study

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concludes that most of the children under the treatment of cancer view themselves in isolation and their self-image is often poor due to baldness and mask-wearing; few children drew positive self-images (particularly children ages 11 and 12).

The focus of this paper is the use of the aesthetic expression as a viable, valuable data source in a study of the lived worlds of children experiencing advanced cancer. Creativity is a bridge to learning (Farrell-Kirk, 2007). When a child is creative and curious, the child can come up with answers to the problems the child encounters. Drawing is a fun and pleasurable activity for children wherein they can express themselves in ways that tell stories of their experiences (Fargas-Malet et al., 2010). Aesthetic expression is especially useful when dealing with sensitive issues like advanced cancer in children. It allows them to step back from their own experience and discuss broader issues first until they feel safe enough to relate the unique meaning of their own lived experience.

Gadamerian hermeneutic phenomenology as a research methodology, elucidating lived experience and revealing lived meaning, involves isolating themes (van Manen, 1997) from texts, producing understanding and interpretation of the lived experience. The themes can be viewed as written interpretations of lived experiences. Thus, in the application of hermeneutic phenomenology, the requirement is to examine the text, to reflect on the content to discover something telling, something meaningful, something thematic. Having isolated phenomenal themes, one rewrites the theme while interpreting the meaning of the phenomenon or lived experience. van Manen (2014) recognized art as a source of lived experience and asserted that art objects are "visual, tactile, auditory, and kinetic texts" (p.353) that consist of non-verbal communication but constitute a language with its own grammar.

The aim of this paper is to present the research methodology of the hermeneutic phenomenological approach by using aesthetic expressions as data sources in a study of the lived worlds of children experiencing advanced cancer. Philosophical underpinning research methodology and the details of data generation and analysis are described and discussed.

Gadamer's Hermeneutics and Aesthetics Philosophy

To study the life-world of children suffering from advanced cancer, this study employed hermeneutic phenomenology as a framework. As a philosopher, Gadamer explored the fields of hermeneutics as well as aesthetics. The focus of his work was on how language shaped experience as well as the interpretation of that experience. The intention of this approach was to provide an explanation for the lived experience. The lived meaning would then be revealed by a process involving understanding and interpretation (Gadamer & Hahn, 1997).

Hans-Georg Gadamer (1990-2002), a German philosopher, posited philosophical hermeneutics. According to Gadamer, one cannot interpret reality without

presupposition or background (Alawa, 2016). 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" (Bourgeois, 2007, p. 3). This renders relevance to aesthetics in discussions about the human search for truth. Using the aesthetic model, it is only natural to be affected and possibly transformed by an individual who encounters the truth expressed by an artwork or a text.

Gadamer (2006)'s 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.

According to Gadamer, hermeneutics is the art of interpretation and operates wherever what is said is not instantly clear. He further explains that natural beauty does not say anything. This means that natural beauty does not need enhancements to bring out the beauty and some of us have to work harder to shine. It is not even about physical beauty. It is something that a person radiates from within that makes them beautiful. At that point, works of art, created by and for men, say something to us (Gadamer, 1997).

Aesthetics inspire art and its motivation lies within an experience rather than an activity that is indefinite in terms of form, function, interpretation, and practice. Aesthetics is concerned with the perception, appreciation, and production of art. Aesthetic experiences, such as graphic representation (drawing), narratives, and storytelling, are linked to the perception of external objects, which tell us about the world outside our bodies. Using our senses of sight, hearing, touch, smell, and taste, we perceive colors, sounds, textures, etc., of the world at large.

van Manen's Hermeneutic Phenomenology

The discipline of phenomenology may be defined primarily as the study of structures of experience or consciousness. Literally, it is the study of "phenomena": appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. By the same token, phenomenology studies conscious involvement as experienced from the personal or first-person point of view (Smith, 2013). According to van Manen (2014), 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.

Hermeneutic phenomenology is a method of creating meaning and understanding of human experience as it is lived, such as the phenomenon in this study, children's

lived experience with advanced cancer.

Furthermore, [van Manen \(1997\)](#) 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” (p.36). Lived experience, as explained by [van Manen \(2014\)](#), is the experience we live through before reflecting on it. Thus, the experience is lived through, and meaning is developed from reflection on that experience.

Gadamer’s hermeneutics guided the researcher in interpreting the meaning the children drew from the aesthetic outputs (drawing and writing). However, the interpretation has the possibility to be seen in a new light by others with different points of view about a subject ([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 applying reflection and critical thinking.

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](#) affirms that existentials are universal themes that are helpful when one engages in an exploration of meaning regarding aspects of our lived world experience and when studying a phenomenon. Followings are the explanations of each lived world ([van Manen, 2014](#)).

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 bodies and how our desires, fears, and anxieties incarnate themselves in the world we dwell in. 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 (temporality) is a guide to our reflection to question how time is being experienced differently. For instance, the time spent waiting is experienced differently compared to when an individual is actively involved in something. It also shares the experience of wishes, plans, and goals an individual strives for in life. The sense of identity is generated by recollecting the time of one’s childhood, times of exercising a professional activity, and one’s love life. It likewise guides our reflection on the signs 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 the world contribute to the vital meaning of phenomena like global warming, the atmosphere of a city, and the spectacle of a grand vista.

Methods

The qualitative research design of this study employs a method based on hermeneutic phenomenology underpinned by Gadmerian philosophy as well as the approach suggested by [van Manen \(Galvez et al., 2021\)](#) to reveal the meaning of the life-world of children with advanced cancer by uncovering details as they were 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), with follow-up individual face-to-face interviews.

Ethical Considerations

Before conducting the research, required approval was obtained from the Institutional Review Board of the Social and Behavioral Sciences, Faculty of Nursing, (number 2017 NSt – QI051) Prince of Songkla University, Thailand. Moreover, before conducting the study, the researchers asked permission from the parents of the children suffering from advanced cancer or from their guardians. After obtaining ethical approval, the children and their parents or guardian were invited to establish initial contact and ask them to become participants in the study.

Access to Participants

The participants were children diagnosed with advanced cancer who lived in the central Philippines. Snowball sampling was utilized to recruit the participants. The number of participants was based on data saturation ([Grove et al., 2015](#)). Selection of participants was based on the following inclusion criteria: (1) Ages 10 to 14 years old; with a diagnosis of advanced cancer (2nd stage) as reported by their parent or guardian; (2) Capable of communicating in the English language; (3) Expressing their willingness to become participants in the study; and (4) Physically and mentally capable of expressing their personal experience by relying on graphic representations as well as verbally in the form of narrative descriptions (drawing and writing).

Once appropriate ethical approval was obtained, the researcher launched the process of finding prospective participants. The researcher approached a parent who had a son registered in a cancer foundation, described the study, and discussed the nature of the child’s participation; permission was then obtained to approach the child. At the same time, the researcher enlisted the parent’s assistance in identifying other parents with the same situation, so they could also be invited to participate in the study.

With each prospective child participant, the nature of the study and measures to protect human rights were described fully in language understandable to the child. Any

questions the child had about participation were answered thoroughly. Everyone approached consented to participate in this study.

Establishing Trust and Connection

After written consent was obtained, the researcher established emotional connections with the young participants based on trust and understanding (Hockenbury et al., 2017). The researcher established rapport with the children first by presenting the research study as an experience that would not cause harm and could even bring happiness by conveying their experiences of being sick (Silbert-Flagg & Pillitteri, 2018). The researcher was consistent and demonstrated to the child participants what they were being asked to do. When the researcher promised that she would telephone the children, she followed through by calling them and subsequently moved to engage them in data collection tasks. Interactions in each child-researcher dyadic relationship were friendly and unguarded, characterized by trust and connection.

Data Generation

Data generation methods in this study consisted of participants' characteristics, drawings and written descriptions, and observations made during the interviews. (1) Participants' characteristics collected included gender, age, cancer type, family and school background; (2) Draw and write" was used to assist the child's expression of the story of their lived experience; (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; (4) An audiotape recording was done to aid the researcher in transcribing the data in full; (5) Observational data were recorded during the interview to understand the participant's behavior, facial expressions, position changes, body movements and non-verbal indications of boredom.

Drawings and writings (narratives). During the graphic representation phase, the experience of the participating children afflicted with advanced cancer was expressed by them in their aesthetic outputs. The researchers provided them with the following materials: drawing pad, crayons, pencils, eraser, watercolor, and color pens, and chose the materials which suited their preference for drawing. The researchers instructed each participant to come up with a drawing illustrating their lived experience as a child diagnosed with cancer. The time limit allotted for drawing was 30 to 45 minutes.

Afterward, for their descriptive narration (phase 2), the children were asked to describe in writing the images or pictures they had created. Paper was provided for this purpose. The children also had the option to express their descriptions verbally rather than in writing. Their account was then recorded on audiotape, as this was also agreed on in the consent form.

Interviews. Following the drawing and writing activity, personal face-to-face interviews were conducted with the

participants. The interview questions were open-ended and unstructured in approach; probes were used in response to participants' answers, eliciting further information; for example, "What made you feel that way?", "What does this remind you of?" The participants were given a choice to select an interview location that provided safety, privacy, and a quiet environment for one hour and thirty minutes with the audiotaped record. The participants disclosed what they felt comfortable with sharing.

Interviews were completed over at least three occasions. In the initial interview (30 minutes), a demographic profile of participants from parent/guardian and participants was obtained. Participants' characteristics collected included gender, age, cancer type, family, and school background. The second interview was the in-depth interview (1 hour and 30 minutes) in which participants explained their drawings and writings. The last interview (30 minutes) was conducted for follow-up clarification of the second interview.

Observation. The observation was done on three occasions during face-to-face interviews with participants. Observations of behaviors were recorded, e.g., changing position frequently in the seat, tapping a pencil on the table, and facial expressions indicating feelings of sadness and or happiness. Observations were recorded by handwritten notes during the three interviews. Observations included participants' tones, expressions, and associated actions during the interviews, as well as descriptions of the overall settings and the experience of the data collection process.

Data Analysis and Interpretation

The data analysis process of hermeneutic phenomenology involves arranging the interview transcripts, observation notes, or other non-textual materials that the researcher gathered to increase the understanding of the phenomenon. Analysis was done in two steps. First, analysis of data generated by drawings made by participants was performed. Second, the analysis of narrative descriptions and interview transcriptions was conducted. Last, the analysis of observational data was done.

Analysis of drawings. The researcher first inspected, one by one, the drawing created by each participant. For the analytical steps, the principles formulated by Farokhi and Hashemi (2011) served as the guide. Particular attention was given to symbols and images, objects, and places.

Analysis of narrative descriptions and interview transcriptions. After recording the interpretations of the participants, the researchers examined the written and audio-recorded narrative descriptions while they made field notes. Guided by the approach formulated by van Manen (2014) as part of hermeneutic phenomenology, thematic and existential reflections, as well as the writing method, were utilized by the researcher to interpret the lived meanings associated with aesthetic expressions (van Manen, 1990, 1997). The five life-worlds of the lived body, lived space, lived time, lived relation, and lived thing were

used in thematic reflection (van Manen, 2014). The researcher used exact quotes from the interview session and described activities in the order in which they occurred. Descriptions were provided without inferring meaning.

Analysis of observational data. Observations were analyzed as directed by Kawulich (2005). The researcher kept a separate notebook for personal observations made during interviews with each participant. Field notes included jottings, diagrams, individual notes, and diary-type entries with date, time, place, and pseudonyms to protect participants' confidentiality. The entries for each participant were summarized each day and organized with page numbers and a short identifying description.

Trustworthiness

To assure trustworthiness, the study observed four criteria developed by Lincoln and Guba (1985). These were credibility, confirmability, transferability, and dependability. Credibility was obtained by triangulation and member-checking. The triangulation methods used in this study involved the use of four data sources, including graphic

representations, narrative descriptions, interview transcriptions, and observation.

After each interview, the researcher summarized the results of the interview and asked the participant to confirm their responses. These data were clarified in the daily journal written by the researcher during data collection. The daily journal was used to achieve confirmability by recording the time and date of data collection, features of the context, the physical setting where the data collection took place, the researcher's own reflections, and questions and interpretations that came up during interviews. Transferability was established by providing 'thick' or detailed descriptions of the phenomenon. Dependability was established by an external audit with an expert review.

Results

Examples of participants' characteristic data (in Table 1), data generation, data analysis, and interpretation of the participants (in Table 2) are presented.

Table 1 Participants' characteristics ($n = 3$)

Participant number	Gender/Age	Cancer Type	Family Background	School Background
P2	Male / 10 years old	Acute lymphocytic leukemia (ALL) at the age of 10	He came from separated parents whose father was unemployed and lived with another woman while his mother worked in Manila and is remarried. He stayed with his grandparents, who took care of him. His mother paid for his chemotherapy sessions. He excelled in math and was an honor student.	He is in Grade III. Goes to a Town elementary public school. Maintains good grades in Math and Science subjects.
P7	Female / 14 years old	Acute lymphocytic leukemia (ALL)	She was 14 years old when diagnosed with advanced cancer. She had to stop schooling. Very conscious of how her cancer diagnosis had affected her family emotionally and financially. She expressed a lot of guilt that her family, including her siblings, had to stop school and work very hard to finance and support her treatment.	She is in Grade 8 from a private elementary school in their province. Her favorite subjects are English, Language, and Spelling. She is praised by her teachers for her good performance in school before cancer treatment.
P10	Male / 14 years old	Retinoblastoma at the age of 14	He was an errand boy who would buy food for his family using his bike. Also, being an eldest, he realized his younger brother was still very dependent on his parents while he enjoyed the company of his twin brothers.	He is still in Grade 3 on account of failing marks in his report card related to absences from the classroom and school activities due to advanced cancer. He goes to a public school in the city

Table 2 Examples of data analysis and interpretation


Participant Number	Data Analysis and Interpretation
P2	<p data-bbox="304 271 526 297"><u>Graphic representation</u></p>  <p data-bbox="304 929 502 956"><u>Narrative description</u></p> <p data-bbox="304 956 1436 1153">The drawing “My Sad Story” depicted his understanding of his medical situation. He experienced physical discomforts and felt not normal because of his frail body and inability to walk. And yet, with the presence of his grandparents, who would give him the foundation to fight his struggle, he found trust in them. Moreover, he remembered his absences vividly in school due to chemo sessions. He was weak and frail. That was when his father would carry him on his back because he could not walk to school due to his limbs which were not strong enough to support the body. He equated this to his past active life when he would walk to school with his friends, laughing, having fun, playing, and sharing jokes on their way to school.</p> <p data-bbox="304 1182 422 1209"><u>Observation</u></p> <p data-bbox="304 1209 1436 1294">(Misty eyed) when he mentioned his mother. He added that his mother never cared for him while he had cancer at a young age. I held his hands at the table. At this point, I asked if he was ok? If he wanted to go with the interview? (He smiled and nodded his head and said yes, we would continue. Wiping his eyes. Then smiled.)</p> <p data-bbox="304 1323 710 1350"><u>Reflection of themes within the lived world</u></p> <p data-bbox="304 1350 430 1377">Lived body:</p> <p data-bbox="304 1377 798 1404">Theme: physical discomforts and feeling not normal</p> <p data-bbox="335 1404 1436 1462">“My father lifts me in his back to school because my extremities were painful and weak. I would limp when I walk to school, and I fall on the way to school” (P2, L-162-63).</p> <p data-bbox="304 1462 454 1489">Lived relation:</p> <p data-bbox="304 1489 734 1516">Theme: having support from extended family</p> <p data-bbox="335 1516 1436 1574">“My grandpa provides my daily school allowance.” (P2L-164.). “My grandma takes care of our family’s needs and gives me extra attention.” (P2L-166).</p> <p data-bbox="304 1574 654 1601">Theme: friends to play with at school</p> <p data-bbox="335 1601 1436 1628">“I am happy when I can play with my friends, especially on weekends when we are off from school” (P2L-308-309).</p> <p data-bbox="304 1628 526 1655">Theme: a broken heart</p> <p data-bbox="335 1655 1181 1682">“There comes a moment when I cry in my sleep because I miss my mother.” (P2, L-192).</p> <p data-bbox="304 1682 949 1709">Theme: signified a child’s sadness felt due to a maternal separation</p> <p data-bbox="335 1709 1436 1767">“I draw my mother last because of the fact that she does not care about me. It makes me sad when I was drawing her.” (P2, L-300-301).</p> <p data-bbox="304 1767 422 1794">Lived time:</p> <p data-bbox="304 1794 917 1821">Theme: walked with friends and classmates to school every day</p> <p data-bbox="335 1821 1436 1879">“I really enjoy walking with my friends and classmates to school every day because we tell stories and laugh out loud.” (P2, L- 183-184).</p> <p data-bbox="304 1879 438 1906">Lived space:</p> <p data-bbox="304 1906 901 1933">Theme: living well at home and enjoying with friends at school</p> <p data-bbox="335 1933 1436 1991">“I get enough rest and sleep at home. But I always look forward to good health again so I can enjoy the fun with my friends in school.” (P2, L-378-380).</p>

Table 2 (Cont.)

P7

Graphic representation



Narrative descriptions

It is evident in her drawing and narrative that there was longing in the participant to go back to school. She has also mentioned in her drawing that her friends were an important aspect of her life. The drawing and the narrative both displayed that the participant was fully aware of the situation that cancer put her family and herself in, as well as the sacrifices needed to commit to her treatment.

Observation

(*Eye brows brought together with the wrinkled forehead*) when she mentioned that her family and friends learned about her cancer. (*Sides of the mouth flexed*) When the news was revealed by her mother about her diagnosis of cancer.

Reflection of themes within the lived world

Lived body:

Theme: physical health affected

"I was made to understand by my mother that as a child with cancer, it will affect my physical health." (P7, L-119-122).

Theme: feelings not used to deal with

"I was made aware that it will also bring up an extensive kind of feelings that I am not used to dealing with." (P7, L-121-122).

Lived relation:

Theme: family over-protective

"My parents and brothers turned strong and overprotective of me because they want to do what is right for me." (P7, L-162).

Theme: absence of peer interaction

"The ability to get together with my friends was lost. I feel separated from my friends who denied the fact that I have cancer." (P7, L-319-320).

Lived time:

Theme: hopeful of recovering and starting treatment immediately

"I feel hopeful that I can recover and move forward to the future as I start the treatment immediately." (P7, L-165-166).

Lived space:

Theme: family and friends are not really in harmony with what is going on with her

"It is hard to have leukemia. I feel lonely even if I have my family and friends around me. This is because my family and friends may not be really in harmony with what's going on with me." (P7, L)-331-332).

Lived thing:

Theme: mobile texting and calling teacher for updates about the present condition

"I keep connected with my teacher in school through mobile texting and calling for updates about my condition." (P7, L-206-207).

Table 2 (Cont.)

P10

Graphic representation



Narrative description

He was very self-conscious of the physical appearance of his eye, which he made a habit of wearing sunglasses wherever he would go. He believed that the grotesque appearance of his eye would make people afraid of him.

Observation

(adjusting his sunglasses) At home, when sent to do errands for his family from a nearby store or market to buy food, he would ride his bike. Also, being an eldest, he realized his younger brother was still very dependent on his parents while he enjoyed the company of his twin brothers (*swinging his legs*). He also had three best friends who were his buddies and protectors in school (*transferred to another chair. Smiling*).

Reflection of themes within the lived world

Lived body:

Theme: physical discomforts

"My right is swollen, and my left ear has hearing difficulty." (P10, L-381-382). "I was tired and losing weight." (P10, Line-475).

Lived relation:

Theme: supportive family

"My mother and father took care of me During my chemo because I was too frail." (P10, L-499-500).

Lived time:

Theme: remembering the past active life and hopeful thoughts for the future

"When I was a young child, I was energetic and playful. I helped my parents in farming jobs." When I first learned of my eye cancer, I ignored thinking about it and continued helping my parents (P10L-409-411). "I endured the side effects of chemo with the belief that I will recover and live a normal life." (P10, L-491). "I have a strong will to live, allowing me to continue my usual activities in helping my family and continue schooling." (P10, L-512-513).

Thematic Reflection

From data analysis and interpretation of some participants, a narrative of the holistic analysis of the different distinctive qualities and characteristics representing the lived experience characteristics representing the aesthetically expressed lived experience of school-aged children afflicted with advanced cancer was presented. The presentation of this lived experience embracing the five life-worlds was carried out to elucidate the themes. Thematic reflection was undertaken by the researcher 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 rereading 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 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' drawings. Next, the documents were analyzed by applying van Manen (1990)'s three approaches for identifying thematic aspects of a phenomenon.

The researcher read all of the transcripts repeatedly to familiarize herself with them. While doing so, she marked any phrases or sentences she considered particularly significant and clear. The researcher then inquired from the participants whether they could elucidate any hidden meanings behind the symbols and imagery found in their drawings. Next, the researcher analyzed the documents.

For this, van Manen's three approaches for identifying thematic aspects of a phenomenon were applied.

The researcher discovered that applying each of the three approaches helped her reflect on the lived meaning of school-age children diagnosed with advanced cancer and identify broader themes. Furthermore, tables and diagrams 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 researcher reread the text and highlighted certain phrases that were of particular significance in revealing the experience of the participants.

Finally, the detailed/line-by-line approach was used wherein each individual sentence or cluster of sentences was carefully examined. As a result of this process, thematic statements were generated about what exactly was revealed by every sentence or sentence cluster. The researcher then identified the particular themes that emerged from this procedure.

Guided existential reflection. Existential reflection embracing van Manen's five life-worlds (lived body, - relation, - time, - space, and - thing) functioned as a guide to finalize the process of data analysis and thematic reflection. Thus, in this study, the researcher found these five existential elements to be particularly helpful when engaging in reflection. Considering this existential ground allowed the researcher to better understand the lived experience of school-age children diagnosed with advanced cancer. 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 children afflicted with cancer in an advanced stage, the researcher embarked on a process, writing and rewriting. Firstly, after each participant's first interview, a draft was composed out of the conversation, and the contents were later transcribed. The researcher then discussed significant statements that were captured in 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 experiences.

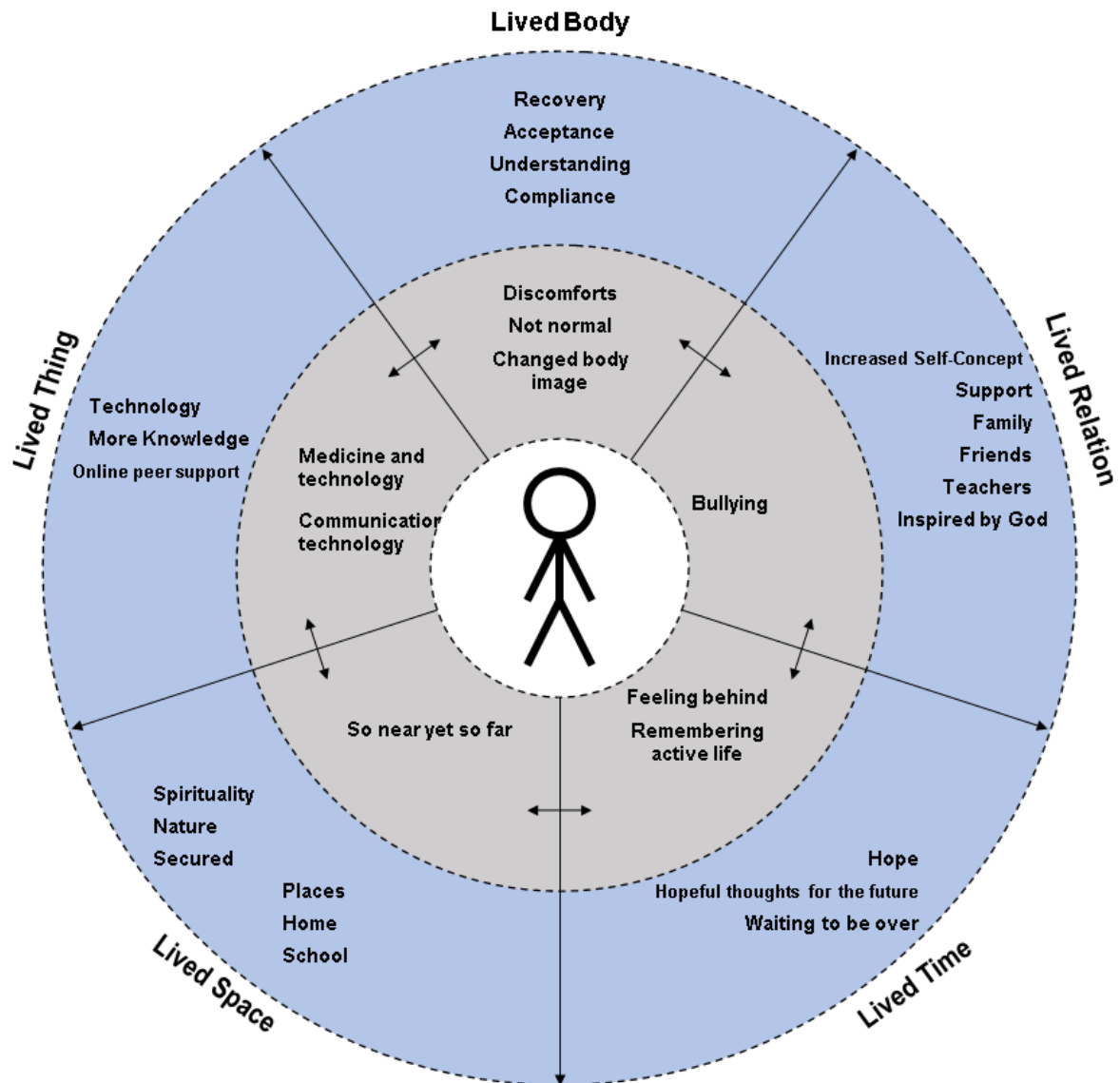
After the completion of all the second interviews, the researcher wrote and rewrote. In doing this, she further

refined and re-defined the themes. The writing process assured that the transcribed interviews were done 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.

Initially, the journey of the participants, as reflected in the time axis, began with a negative viewpoint, as can be seen in the themes presented in the inner circle in **Figure 1**. Nevertheless, they were able to transform these negative experiences into positive ones (themes presented in the outer circle in **Figure 1**). By changing their perception about cancer through technology, they became hopeful and cognizant of 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 with others and comply 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 extended family and school administrators, self-transforming negative experiences and developing inner strength, and inspiration from God. 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. They turned their experience around and transformed it into something beneficial. They made the decision to see cancer from another viewpoint and chose to react differently. 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 the participants' bodies, they found a way out of it. The participants did not have control over the external events that happened to them, but their internal reactions made a powerful turning point. Cancer made them tough, and in the same way, they became resistant to emotions. The aesthetically expressed life experience of children with cancer was described as living life in a world with negative experiences while simultaneously existing as hopeful persons for a better life.

The diagram below presents the summary of how children diagnosed with cancer in an advanced stage uncovered through their stories how they experienced their life worlds of body, relation, time, space, and thing.



(Galvez et al., 2021)

Figure 1 Model representation of the life-world of school-age children with advanced cancer

Discussion

The results were achieved in the study of the life-world of Philippine children with advanced cancer (Galvez et al., 2021). This paper presented a more detailed description of the process of using the draw-and-write data gathering procedure together with interviews suggesting two important points. First, this data collection approach may be useful in any phenomenological nursing study with children. Further, there is some evidence that this approach may have praxis elements and could be used to enhance the positive feelings and emotions of children with advanced cancer in a manner that is a therapeutic intervention that is cost-effective and easy to practice.

As nurses, we are expected to have a more sensitive understanding of the existing condition of children suffering from advanced cancer. Knowing and understanding the

experiences of children is vital in healthcare. This need also challenges the nursing profession to promote acts of caring that are meaningful and relevant to children's needs. The importance of children is often reduced to triviality and insignificance in an adult-dominated world. However, nurses recognize that the young in society are as important as the aged since all persons are of equal worth. Children often communicate their needs in different ways, which may not be easily recognizable by their adult caregivers. Their expressions are based on their young and immature perspectives, which may not be congruent with common adult understanding.

It is the responsibility of the nurses as the researchers to enter into an interview/conversation with an awareness of their place and role in relation to the other in that setting (McCaffrey et al., 2012). The researcher's compassionate feelings change with a deepening sense of the

interconnectivity of the topic with children. It is the strength and adaptability of children to have the potential to endure better and effectively use their emotions, thoughts, and behavior to extract the best possible outcomes in their cancer situations. Hermeneutic phenomenology paved an opportunity for the researcher to describe what it means to live in and among a world experienced by each child with advanced cancer in their own way through “draw and write.” The procedures functioned effectively to communicate a topic, collection of pertinent data, and then analyze.

Implications of the Study

The results of this research study would further enhance the understanding of the experiences of children with advanced cancer. The insights collected from the participants could be valuable in addressing the identified needs and concerns of these children. This may help pediatric patients with other diseases and procedures during hospitalization to translate their feelings in their drawings. This way, nurses can provide an appropriate therapeutic response.

The findings of this study may contribute to the expansion of the body of knowledge involving the most effective scheme to move through the burden of advanced cancer in children and improve outcomes with a focus on improving health experience in ways that heal and comfort.

The outcome of this research may raise worldwide mindfulness of the impacts of cancer on children. The use of the aesthetic expression in children with life-threatening illnesses, such as cancer, could be a therapeutic intervention among nurses in administering care and managing conditions of children with cancer.

Limitations of the Study

The location of the study was in a number of areas on the island of Negros in the Philippines. The participants in these areas used some local idioms in communicating with the researcher whose meaning was not fully understood. This compelled the researcher to verify their meaning by asking for clarifications from the participants and other locals. The highly sensitive nature of the topic and its potentially high level of intensity in interpersonal exchanges need to be recognized as constituting a possible limitation even if the safe and quiet venues for the interviews were chosen by the participants themselves and privacy was assured.

Conclusion

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 in the community were struggles 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 the

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 a state of balance; the participants remained hopeful with positive thinking to cope and be free from cancer while looking beyond for a better future.

Aesthetic expression linked to art and connected to human experience drew the participants into different realms. It 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 and awareness of the variation of experience among children with advanced cancer. It is hoped that this paper can contribute to an understanding of aesthetic expressions as pathways to understanding and support health professionals as they embark on their goal of creating or restoring a comfortable relationship with children.

Declaration of Conflict of Interest

The authors have no conflict of interest to declare.

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Authors' Contributions

BLAG: Research design, data collection, data analysis, writing, and editing of the manuscript. WK: Research design, data analysis, writing, and editing of the manuscript. SOS: Writing and editing of the manuscript. UH: Writing manuscript. All authors agreed with the final version of the article to be published and are accountable for all aspects of the work.

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Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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