

BEST PRACTICE RECOMMENDATIONS TO SUPPORT COPING STRATEGIES
FOR PEDIATRIC ONCOLOGY PATIENTS
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Abstract

This best practice thesis aims to identify the current research and recommendations for coping strategies for pediatric oncology patients. Childhood cancer is a prevalent issue in our society, that can lead to both short and long term negative psychological effects (Aguilar, 2017).

Therefore, it is vital to address and expand coping strategies currently used within the pediatric oncology population to ensure that patients are receiving the best individualized and holistic care possible. The articles discussed during the literature review focus on causes of psychological stress as well as methods to improve psychological well-being through incorporating multiple points of view and various intervention strategies. The literature review introduced coping methods for patients to utilize as well as for nurses and parents to use to support their patient's/child's coping strategies. Following the identification of the best practice recommendations, a hypothetical implementation will be explained and evaluated through the use of the Plan-Do-Study-Act (PDSA) Cycle. Strengths and limitations of the theoretical implementation and overall thesis will be discussed during the concluding portion of this thesis.

CHAPTER 1

Introduction

Statement of Purpose

The purpose of this thesis is to identify the various coping methods that can aid in benefitting the overall psychological well-being of pediatric oncology patients, so that best practices for care can be developed. The best practices discussed in this thesis were developed based off of evidence-based research that studied various psychological issues found in pediatric oncology patients and the coping methods that were found to be most effective. In order to fully understand the importance of an adequate coping method, one must first examine the background of this issue as well as the significance of the problem. Using the data that was found during this research of the background of the issue, significance of the problem, and overall coping methods that have already been tested, best practices for coping in pediatric oncology patients will be recommended.

Background of Issue Importance

For a child with the diagnosis of cancer, there are many intimidating and threatening components of the diagnosis and treatment. “Childhood cancer affects one in 285 children in the United States yearly, equating to an estimated 15,980 children living with cancer each year” (Aguilar, 2017, p. 173). The most prevalent types of childhood cancer include leukemia, lymphoma, brain and central nervous system tumors, bone cancer, and neuroblastoma (Aguilar, 2017). Many children perceive the hospital as an unfriendly place that could cause a potentially traumatic situation due to the fact that hospitalization is isolating the child from their daily routine. While inside of the hospital, children are separated from their friends and family members and are exposed to many new faces as well as numerous medical devices (Sposito et

al., 2015). The “typical” childhood experience is taken away from children who have to spend a large amount of time in a hospital and because of that, they often experience some degree of psychological distress before their treatment even begins.

One of the main forms of treatment, chemotherapy, is associated with various side effects that range from nausea and vomiting, to hair loss, dry mouth, and constipation (American Cancer Society, 2017). The consistency and reoccurrence of these side effects can lead to extreme physical as well as psychological strain. Due to the fact that pediatric oncology patients are treated for months to years at a time, the repetitive strain accumulates and can lead to both short-term and long-term side effects (Laing, Moules, Estefan, & Lang, 2017). These side effects differ from person to person and are often dependent on the type of cancer, however, some common side effects include cognitive impairments, issues with muscle and bone growth, decreased sexual development, and many emotional issues such as worrying, resentment, concern of discrimination, and adjusting to the physical changes (American Cancer Society, 2017). Because of these potential side effects, it is vital to ensure that pediatric oncology patients have the proper resources to coping methods to ensure psychological well-being.

Significance of the Problem

Survival rates of children with cancer have greatly increased over the past few years due to advancements made in medicine; however, survival comes at a cost of their physical, emotional, social, and economic states, often leading to emotional instability and anxiety (Sposito et al., 2015). Most children and their families are able to develop coping strategies related to cancer and treatment, but one quarter to one third exhibit extensive issues related to this process (Hildenbrand, Alderfer, Deatrck, & Marsac, 2014). In order to properly deal with the emotional toll that cancer takes children must learn adequate coping methods that aid in

decreasing anxiety and stress (Hildenbrand, Clawson, Alderfer, & Marsac, 2011). Children's coping can be defined as, "what children actually do (their profile of emotional, cognitive, and behavioral responses) in dealing with specific difficulties" (Hildenbrand et al., 2011, p. 345).

Due to the fact that patients deal with traumatic situations in various ways, it is vital that healthcare professionals are educated on a variety of coping strategies (Sposito et al., 2015).

With an increase in the number of coping strategies that healthcare professionals are educated on, it will aid in meeting the psychological needs of each individual patient.

In order to determine the proper coping method, the healthcare professional must learn about the children's previous experiences, current coping strategies, and their overall outlook on their diagnosis of cancer. Similarly, it is important to determine the child's age and developmental level in order to provide coping strategies that will provide the most benefits. Some children have an increased ability to cope with the strenuous treatment that they endure, but others struggle finding something that works for them (Foster et al., 2017). Even for those who have effective coping strategies, it is still vital to assess them and to introduce alternative methods in case their current coping strategies reach a point of ineffectiveness. Coping strategies give pediatric oncology patients the outlook that they have the ability to control their own outcomes. In addition, the use of individualized coping strategies has been proven to be associated with a better health-related quality of life. Positive coping strategies that are developed during this strenuous time are not only beneficial in the short-term, but often serve as methods of coping throughout one's lifespan (Foster et al., 2017).

Summary

Pediatric oncology patients face many physical and psychological hurdles both during and after their course of treatment. From the hospital setting to the various procedures that are

performed on these patients, there are many unfamiliar and alarming actions occurring on a regular basis. These struggles can cause immediate distress which can develop into other psychological problems in the future. In order to aid in providing the best outcome, it is necessary to determine the most beneficial coping strategies for those who are battling cancer. Educating healthcare providers on a number of effective coping strategies will allow patients to receive the highest quality of care. The use of proper coping methods assists in decreasing psychological issues and increasing overall well-being.

CHAPTER 2

Review of Literature

Chapter two addresses a review of the literature regarding coping strategies for pediatric oncology patients. The PICOT(S) question that was used to guide this literature review was, what methods can be used to improve psychological well-being in pediatric oncology patients within the hospital and clinic setting? The only database that was used to find applicable articles was CINAHL. The publication dates the author used were between the years of 2013 and 2017, with the exception of one article published in 2011. The search terms used to find the articles included, “coping,” “pediatric oncology,” “patients,” and “intervention.” The author did not use any filters when searching for articles on CINAHL.

Facilitators, Barriers, and Interventions: Coping Strategies for Pediatric Oncology Patients

Hildenbrand et al. (2011) used a qualitative study that aimed to develop a more comprehensive understanding of the methods used by both the children and their parents, in hopes of helping their children, that are used to cope during cancer treatment. The researchers developed three research questions to guide their study: “what cancer-related stressors (by child and parent report) do children experience during cancer treatment,” “what coping strategies do children employ to manage cancer and cancer treatment-related stress,” and “what types of coping assistance do parents provide to their children to manage cancer and cancer treatment-related stress?” (Hildenbrand et al., 2011, p. 345). Purposive sampling was utilized to recruit 15 child-caregiver dyads who were within the ages of 6-12, were actively receiving treatment for cancer, were cognitively capable of participating in an interview, and had the consent and participation agreement of at least one parent. This study was carried out in a large pediatric center that is located in the northeastern region of the United States. Participants completed a

semi-structured interview that focused on answering three questions: “what was hard for (you/your child) when you found out that (you/he or she) had cancer,” “what has been hard for (you/your child) during cancer treatment,” and “what things do you do to (cope/help your child cope) or deal with (yours/his or hers) cancer/cancer treatment?” (Hildenbrand et al., 2011, p. 345). From the data collected in the interview, four themes regarding cancer-related stressors were discovered: “cancer treatment and side effects, distressing emotional reactions, disruption in daily routines and activities and social/peer group challenges” (Hildenbrand et al., 2011, p. 346). In order to adequately deal with the variety of stressors, children and their parents primarily used approach-oriented coping strategies including cognitive restructuring, using relaxation, practical strategies, seeking social support, and expressing feelings. In addition to the multitude of approach-oriented coping strategies, the sole avoidance coping strategy promoted by patients and their parents was distraction. Overall, the data showed that children used zero to three different coping strategies, while adults used two to six coping assistance strategies. These questions were followed up with various other questions that aimed at expanding upon the participant’s response. It was determined that a high level of communication between patients and their parents was linked with better psychosocial outcomes, therefore, the facilitation of communication between family members in regard to cancer-related stressors may lead to an increase in support from parents for their children (Hildenbrand et al., 2011). Due to the fact that each individual child and family are different, it is vital to identify the most prevalent stressors and specific needs to develop a tailored approach for coping. The use of data saturation aids in the strengthening of the findings. A weakness includes a difference in interpretation of the questions between the children and their parents, leading to some of the adults going in a little more depth than the children with their answers. In the future, interventions should be focused

on improving the child-parent dyad to increase communication and coping strategies.

Lam, Cohen, & Roter (2013) sought to determine if adolescent cancer patients were interested in engaging in a qualitative, participatory study to focus on their personal coping needs. The researchers used purposive sampling by posting fliers in inpatient and outpatient areas at a tertiary pediatric oncology center in the United States. Eight participants, ages 13-19, were recruited based on the criteria of “having a malignancy diagnosed at least three months earlier, a stable clinical status, an interest in the study, and the English skills to participate” (Lam et al., 2013, p. 11). The eight participants were divided into five focus groups that met once or twice either online or in person to carry out the tasks of the study. During the first session, all participants completed a survey that consisted of questions regarding their age, cancer time, and time since diagnosis. Participants used semi-structured, open-ended questions such as, “what are the messages ‘out there’ about being a teen with cancer?” and “how may it affect how you or other teens deal with cancer?” (Lam et al., 2013, p. 11) to lead their discussion. In addition, the participants were given the opportunity to be creative by designing a t-shirt or joining an online blog to interact with other adolescents with cancer. The study found two overall categories of themes: “themes on needs in coping with cancer” and “themes on coping strategies and t-shirt messages to support adolescents with cancer” (Lam et al., 2013, p. 12). In regard to the first theme, four inter-related themes surfaced. They included: adjustments related to physical and social participation, social perceptions, physical effects, and health-related communication needs. For the second theme, participants commonly emphasized humor and resilience as a part of their coping methods as well as for their t-shirt design. Participants preferred designing a t-shirt over writing a blog post, which was most likely due to the fact that the t-shirt design was accompanied by a higher level of social interaction. Social support from their peers lead to the

realization that many others had endured similar experiences. The use of these interventions allowed the participants to develop their own coping strategies and to express their emotions. A strength of this study is that the data was analyzed for transferability, resonance, and implications; all of which contribute to the trustworthiness of the data. The small sample size and the restriction to participant recruitment from one pediatric oncology center can be viewed as weaknesses because only a limited portion of the entire population was included in the study (Lam et al., 2013).

This exploratory, qualitative study by Sposito et al. (2015) analyzed the various coping strategies children used while receiving chemotherapy treatment on a pediatric oncology ward at a teaching hospital in Brazil. Purposive sampling was used to recruit the sample size of 10 people. Participants were chosen based on age (7-12 years), having completed at least three months of chemotherapy, and having the ability to communicate in Portuguese. Interviews were conducted with each participant using a puppet, made by the child prior to the interview, as a representation of the child. The interview began with the interviewer asking about the child's experience in the hospital and then expanded upon the question based on the child's response. After all interviews were completed, the data was analyzed and the researchers distinguished six common themes among coping strategies: the need to understand the importance of chemotherapy, discovering methods to relieve the side effects and pain caused by chemotherapy, finding pleasure in nourishment choices, participating in activities that were fun and entertaining, remaining hopeful that there will be a cure, and looking to religion for support (Sposito et al., 2015). Understanding the need for chemotherapy helped decrease complaints from children and increased their ability to cope with the associated side effects. Providing relief for pain and the side effects of chemotherapy aided in improving psychological status. Distraction through

engagement in activities lead to the patient having fun and decreased idle time. Religion and optimism served as methods to “keep the hope of a cure alive” and increased acceptance of treatment regimens (Sposito et al., 2015, p. 147). Coping strategies should be addressed on an individual basis to appropriately match the child’s age and maturity level. One of the strengths of this study is the use of puppets in the interviews with the children. The puppets make the children feel more comfortable and increase their willingness to open up about their thoughts and feelings regarding their life with cancer. A limitation that the researchers mentioned is that the participants were all at different stages of their treatment, which could lead to some varying results in the data (Sposito et al., 2015).

The purpose of Foster et al.’s (2017) mixed methods study was to ask young adult survivors of childhood cancer to further reflect on their overall cancer experience by determining the methods they used to cope with their cancer. Purposive sampling was performed primarily by identifying possible participants through the use of patient records at an urban pediatric hematology/oncology outpatient clinic. Following this, letters were sent in the mail and given through in person appointments at the clinic to those the researchers thought could qualify (Foster et al., 2017). Researchers aimed to recruit those between the ages of 18-30, had completed all cancer-related therapies at least six months prior, did not have any pre-morbid neurological impairments, and were proficient in the English language. The participants of the study completed a demographic questionnaire and the How I Coped Under Pressure Scale (HICUPS) which consists of a 45-item Likert-scale used to assess situational coping. In addition, HICUPS includes writing a short essay or paragraph that describes the participants experience with cancer (Foster et al., 2017). Demographic data was analyzed using SPSS Version 22.0 which discovered that there were no significant differences in demographics among

participants and nonparticipants. The qualitative data was analyzed using consensual qualitative research-modified methodology (CQR-M). The analysis of the data discovered five themes, most of which contain subthemes. The themes were: initial reactions to cancer, 31.9%; adjustment to and coping with cancer diagnosis and treatment (optimism, spirituality/faith), 70.2%; provisions of social support (friend support, family support, loss of support), 57.4%; perceived effects of cancer experience (disruption to developmental trajectories, increased social comparison, late effects), 68.1%; and reflections on the cancer experience (benefit finding, survivor accomplishments, and profound effects), 48.9% (Foster et al., 2017). Participants reported that distracting themselves and staying busy was an effective way to cope during their cancer treatment. In addition, many patients found spirituality/faith to be an important component during the transition from diagnosis to survivorship (Foster et al., 2017). The utilization of optimism by anticipating future positive events and outcomes lead to persisting through treatment. Social support by friends and family provided shared experiences, distraction, and general support through their presence. This study recommended frequent, ongoing conversations with patients to decrease psychological distress and increase education. Similarly, cognitive behavioral therapies are recommended to increase individual and familial resilience. The researchers did not address statistical significance in the article. One strength of this study is data saturation. This ensures that there were enough participants in the study as well as consistency within the data collected to establish quality results. A weakness of this study is that it lacked a culturally diverse sample due to the fact that 89.36% of the participants were Caucasian/White (Foster et al., 2017).

A philosophical hermeneutic study conducted by Laing et al. (2017) strived to understand the meaning of, value for, and effect that the creation of a digital story can have on a child or

adolescent/young adult (AYA) with cancer (past or present). A digital story is a short narrative video created by compiling recorded voice, videos, pictures, and music/sounds. This study utilized purposive sampling by hanging up posters at the Alberta Children's Hospital and posting them on the Kids Cancer Care Foundation of Alberta's website. Eligibility criteria, which was used to recruit 16 participants, consisted of children/AYAs ages 5-39 years old who are currently being treated or are survivors of pediatric/AYA cancer. Each participant created a digital story with the help of a trained research assistant and then completed a semi-structured interview, within one week of their digital story completion, with a member of their research team. The findings of this study showed that there was an overall need for participants to have other people understand what their cancer story/experience was like for them. The digital stories were said to serve as a "brick in the pathway to healing" for many of the participants (Laing et al., 2017). Many walked away from this study feeling that the use of digital stories helped them heal in a way that they did not necessarily know they needed. Each digital story was slightly different, for participants were able to discover their "truth" from their experience with cancer which is what then served as a guiding factor for the creation of their digital story (Laing et al., 2017). A main theme from the participants reports was the need for others to understand "what it is like" and to make others truly feel their experience. The researchers emphasized that this intervention of making a digital story is "therapeutic – not therapy" (Laing et al., 2017, p. 279). The benefit of a digital story differed from participant to participant, for the outcome was individualized based on the participant's needs. Overall, it was found that digital stories are a beneficial way for children and AYAs to cope with their cancer diagnosis, treatment progress, and other emotional aspects. A strength of this study is that it discovered a creative way for pediatric oncology patients to cope with their cancer. Everyone copes differently, therefore, the development of new methods

is beneficial for helping those that feel they have not been able to discover their personal coping strategies. A weakness of the study is the small sample size. An increase in the number of participants would aid in establishing the validity of the data (Laing et al., 2017).

The purpose of Platschek et al.'s (2017) quantitative pilot study was to utilize a 12-week computer-based exercise intervention to establish the benefits on perceived physical, motivational, and psychological state as well as on fatigue syndrome. Participants were selected based on exclusion criteria consisting of age not between 6-18 years, parent not consenting, the inability to perform exercise sessions due to physical or cognitive impairments, and a lack of language proficiency. This study consisted of nine inpatient and outpatient pediatric oncology patients and was performed at the Department of Pediatric Oncology at the University Hospital of Cologne in Germany. The computer-based exercise program allowed the participant to choose between a fitness and gymnastics game, a dance game, three different adventure games, and a sports game. Each session was about 45 minutes in length, which included breaks, and the difficulty of the intervention was decided on by both the provider and the participant. In order to assess the effects of the intervention, mood and fatigue were assessed pre- and post-intervention. Mood was assessed using the MoodMeter questionnaire before and after the exercise intervention at weeks four, eight, and twelve. Fatigue was assessed by the German version of the PedsQL Multidimensional Fatigue Scale at baseline and weeks six and twelve (Platschek et al., 2017). Power analysis was performed using G*Power version 3.1 and statistical analysis was performed using SPSS version 23.0. Participants improvement in mood from pre- to post intervention is seen through increases of perceived physical state ($p = 0.011$), perceived psychological strain ($p = 0.017$), and perceived motivational state ($p = 0.008$). The data was found to be statistically significant if the p value was less than 0.05. In addition, progress in

sleep/rest fatigue occurred following the 12-week intervention (Platschek et al., 2017). It is believed that treatment success will only occur through one's relationship between physical exercise, psychological health, and the desire to be both socially and physically active. Reducing cancer-related fatigue by exercising improves physical performance and psychological status. While exercise may cause additional fatigue, it is recommended that daily exercise can increase mobility and decrease fatigue. In addition to these benefits, participants reported that this intervention served as a distraction technique, further positively impacting their mood. Exercise alone is correlated with an improvement in mood, most likely due to an alteration in neurotransmitter concentration and changed within the central nervous system (Platschek et al., 2017). The fact that the findings are statistically significant is a strength because it informs readers that the relationship between the variables is reliable. This study did not have a control group, which is viewed as a limitation because there is no data to compare the experimental group to (Platschek et al., 2017).

Weinstein and Henrich (2013) conducted a cross-sectional study to identify whether or not psychological interventions are being used by pediatric oncology nurses to help their patients effectively cope with their illness and treatment. For the nurses who stated that they used interventions with their patients, Weinstein and Henrich (2013) sought to identify specifically which interventions they thought were the most effective. In addition, this study assessed whether or not nurses would be willing to be trained in additional psychological interventions which they could then implement in their patient's care. Nurses were deemed eligible for this study if they were a pediatric oncology nurse practicing in a hospital setting either as a registered nurse or as a nurse assistant. Participants were selected through the use of snowball and purposive sampling methods at twelve of the leading pediatric oncology departments in the

United States. A total of 88 pediatric oncology nurses participated in the study and comprised the sample size. This study was carried out through a web-based survey that was distributed via email. The email contained a link to the survey on the SurveyGizmo website, making the data collection process anonymous. The survey questions consisted of multiple choice, open questions, Likert scale questions, and yes/no questions which covered topics including: patient-nurse relationships, nurse's previous training, and nurse's opinion on current/best interventions used (Weinstein & Henrich, 2013). The closed questions were analyzed through quantitative methods using the statistical software SPSS, version 19. The open questions were analyzed through qualitative methods using report narratives. Likert scale questions were analyzed through non-parametric tests such as Friedman's test and the Mann—Whitney test. From the data collected, the top three types of support that were found include: educating children on the procedure, providing emotional support by listening to and providing feedback to the child's worries, and distracting them through a variety of passive and active forms (Weinstein & Henrich, 2013). In addition, the least common interventions used by pediatric oncology nurses consisted of breathing exercises, providing informational material such as a book or video for education, and hypnosis. The findings were statistically significant. Nurses reported that they value relationship-oriented support rather than technical skills to help their patients cope emotionally. In other words, it was a consensus that nurses felt "being" with their patient was more beneficial than "doing" a task for their patient (Weinstein & Henrich, 2013). Nurses suggested that these interventions should be tailored to the patient's age group and developmental level. For example, younger children tend to benefit from play as a distraction where older children prefer to talk with their nurse to share their thoughts and feelings. The second part of this study targeted the nurses' opinions on the best strategies, resulting in seven

themes. The most common was patient education, followed by distraction techniques, emotional support, social support, mental wellbeing, relaxation, and hospital staff restructuring. Overall, 93% of the nurses that participated in this study said they would be willing to be trained in new techniques. The use of psychological interventions assists the patient in taking an active role in their treatment plan and can help prevent the development of psychological illnesses later in life. One of the limitations of this study is lack of depth of the questionnaire. Weinstein & Henrich stated that it would have been useful for some of the questions to be more detailed, that way they could have had more specific answers regarding their patient's symptoms, procedures they endured, type of cancer, age/sex of the child, etc. In addition, while the study was fairly large, it was not as diverse as it could have been. It focused on the leading hospitals in the United States and the interventions conducted there, but the interventions could very well vary in hospitals in a different country or in those that are not ranked as high. Some strengths of this study include statistical significance in the findings and anonymous data collection which ensures there is no bias while analyzing the results (Weinstein & Henrich, 2013).

An integrative literature review was conducted by Aguilar (2017) to determine the efficacy of art therapy in pediatric oncology patients. The integrative literature review was completed based on Whittemore and Knafl's framework which consists of "following the steps of the problem identification, literature search, data evaluation, data analysis and presentation" (Aguilar, 2017, p. 174). Aguilar performed a literature review using CINAHL, OVID Medline, and PsycINFO databases. Inclusion criteria consisted of primary source utilizing an art therapy intervention, participants with cancer, patients between the ages of birth to 18-years-old, article written in English, and article published between 2000 and 2016. Following the literature search, seven articles matched the criteria, consisting of six qualitative articles and one

quantitative article. The articles were read twice to ensure quality and to extract pertinent data (Aguilar, 2018). Qualitative and quantitative data were collected and entered into their respective matrices while adhering to the guidelines of the Critical Appraisal Skills Programme checklist. Each data matrices consisted of the article source, purpose/problem, framework, sample, method/design, themes/results, instruments, and limitations. The use of these matrices helped facilitate the analysis to uncover relationships, themes, and concepts while comparing and contrasting the data. Keele's ten steps of analyzing qualitative and quantitative data was used for the evaluation process. These steps lead to the determination of the overall quality of the article, with articles ranking as excellent, good, fair, or poor. While analyzing the seven articles, it was discovered that a total of 316 children were involved in the studies, two studies were inpatient and five were outpatient, all of the participants were undergoing treatment at the time of the intervention, and five out of seven studies were rated as excellent. The systematic review determined that children who participated in a drawing intervention demonstrated enhanced communication with their family members as well as with healthcare professionals. Art therapy was useful in assisting children to express underlying emotions, develop effective coping strategies, and lead to an overall decrease in adverse effects. Family members were often unaware of underlying emotions discovered by art therapy; therefore, the use of this intervention helps family members become more knowledgeable about what their loved one is experiencing emotionally. The coping skills developed by participants of these studies extended beyond the intervention. Drawing helped distract patients and lead to an increase in understanding between their illness and physical symptoms. An overall increase in quality of life was found through an increase in self-esteem, excitement, relaxation, and happiness. In addition, art therapy helped nurses better understand and address their patients individual coping strategies and needs. A

limitation that Aguilar pointed out is the fact that all of the studies chosen art intervention was drawing, therefore, it is unknown whether other forms of art would have the same outcome as drawing. Another limitation listed is the variation in setting. Two studies were inpatient and seven were outpatient. This means that results may vary in those settings due to factors such as level of fear/anxiety of the patient. One of the strengths of this study is that two people read every article that was considered and that was a part of the literature review. This ensures that the data collected is accurate and consistent, increasing reliability (Aguilar, 2018).

A mixed methods assessment of coping with pediatric cancer was conducted by Hildenbrand et al. (2014) to “describe child coping and parent coping assistance with cancer related stressors during treatment” (p. 3). The research questions that guided this study included: “What strategies do children report for coping with cancer-related stressors during treatment,” “what strategies do parents report to facilitate their child’s coping with cancer related stressors during treatment,”, and “what complementary and unique contributions do quantitative and qualitative data provide to understanding child coping and parent coping assistance?” (Hildenbrand et al., 2014, p. 3-4) Participants were selected from a large, pediatric cancer center in the United States. Additional inclusion criteria for this study consisted of being between the ages of 6-12 years old, diagnosed with cancer within the past year and currently receiving treatment, cognitively capable of answering questions and participating in the interview, and having one parent consent to the study. There were 15 families that participated in the study. Interviews were conducted with the children and also with the parents to individually assess the child’s perspective on their coping strategies as well as the parent’s perspective. In addition, children completed the How I Coped Under Pressure Scale (HICUPS) and parents completed the Parent Socialization of Coping Questionnaire (PSCQ). These assessments further analyzed the

coping strategies used and the degree to which the parent assisted with the coping. The interviews were audio-recorded, transcribed, and then coded to help develop common themes. The quantitative data, the HICUPS and PSCQ, were analyzed with subscales and then compared to the themes discovered through the interviews. The results of the qualitative analysis showed that children utilized strategies such as “relaxation, seeking social support, distraction, and cognitive restructuring” (Hildenbrand et al., 2014, p. 7). Parents utilized a variety of coping assistance strategies that aided to promote relaxation and social support, encourage distraction, facilitate emotional expression, provide information, and encourage their child to take control. It was discovered that the qualitative data provided more detail, but the quantitative data suggested a larger number of coping strategies used per family. Overall, the quantitative and qualitative data suggested that children most commonly use approach coping strategies (i.e., cognitive restructuring, problem solving, emotional expression, acceptance, relaxation, etc.) and avoidance coping strategies (i.e., cognitive avoidance and distraction). The parents also most commonly approach assistance strategies (i.e., emotional expression, emotion-focused support, providing information, seeking understanding, acceptance, religious/spiritual coping, etc.) and avoidance coping assistance strategies (i.e., cognitive avoidance and distraction) (Hildenbrand et al., 2014). In addition to approach and avoidance coping strategies, unique approach and avoidance strategies were used, meaning that these strategies were reported in the interviews, but not endorsed on the HICUPS/PSCQ. For the children, they used unique approach strategies such as maintaining normalcy and social support but did not use any unique avoidance strategies. On the other hand, the parents used unique approach coping assistance strategies included: maintaining normalcy, establishing a routine, encouraging social support, etc., and the unique avoidance coping assistance strategies consisted of behavioral avoidance. Limitations include a small

sample size and the inability to examine the influence of the patient's demographics on their coping ability. Similarly, the study did not address the usefulness of the coping strategies over time, therefore, it is difficult to determine whether or not they are beneficial for the long term. A strength of this study is that data saturation was reached after interviewing the 12th child-parent dyad, meaning that no new themes were identified following that interview (Hildenbrand et al., 2014).

Conclusion

This literature review consists of nine articles addressing the psychological and physical strain of pediatric cancer, interventions used to help children with cancer cope with their diagnosis and treatment, as well as limitations and implications for future practice. These articles consisted of a diverse group of studies such as a qualitative review, meta-analysis, and a philosophical hermeneutic study. It is known that pediatric cancer and the associated treatment for pediatric cancer can cause physical and psychological trauma, therefore, it is essential for the patient, family members, and the healthcare team to be educated on coping strategies. The use of coping strategies can help improve mood in pediatric oncology patients (Platschek et al., 2017). The literature suggested a variety of methods for patients to use when coping with their illness and treatment as well as methods for nurses and family members to use to assist the patient with coping. In addition, these articles addressed the importance of diversifying coping strategies based on the patient's needs, for it is necessary to develop innovative and creative ways to address psychological needs instead of relying on traditional interventions (Laing et al., 2017).

In the future, it would be useful for researchers to analyze the long-term effects of the different coping strategies recommended to determine if the benefits are short lived or have a long-term impact (Platschek et al., 2017). Most of the studies found through the literature search

were qualitative, therefore, it would be beneficial for future research to consider mixed methods designs to obtain a more comprehensive assessment (Hildenbrand et al., 2014). In addition, a more culturally diverse sample would be telling as to whether or not religious and spiritual beliefs, racial and ethnic norms, and socioeconomic status play a role in the preferred coping strategy of the patient and their family (Foster et al., 2017). A few of the studies contained targeted populations that included patients who were not actively receiving treatment. Future research should analyze if the same coping strategies used while patients were in remission were beneficial for those who were actively receiving treatment. Development and refinement of assessment measures would create an adolescent-appropriate, patient-reported mean to evaluate physical and psychological status in this population (Lam et al., 2013). Similarly, additional research should be conducted on outpatient settings such as clinics, home, and school, to consider the specific stages of pediatric oncology to determine if coping interventions vary throughout the course of the disease (Sposito et al., 2015). While the current literature has provided an immense amount of information regarding beneficial coping strategies for pediatric oncology patients, the use of further research would aid in validating and expanding the findings.

CHAPTER 3

Best Practice Recommendations: Support Coping Strategies for Pediatric Oncology Patients

The purpose of this thesis was to determine best practice recommendations for coping strategies to improve psychological well-being for pediatric oncology patients. Table 1 summarizes the best practice recommendations for coping strategies for pediatric oncology patients to aid nurses and family members in providing the highest quality of support for this population. The literature reviewed in chapter two illustrates the significance of coping strategies for children who have cancer as well as for their family members. Research shows that pediatric oncology patients and their families benefit most from early interventions that educate them on more than one coping strategy for managing cancer and the stress associated with treatment (Hildenbrand et al., 2011). The use of a variety of coping strategies allows the patient to have a diverse range of techniques to apply during a time of distress. In addition, children's coping changes over the course of their diagnosis and treatment, therefore, not all coping interventions will remain effective for varying stressors (Hildenbrand et al., 2011). The literature review implied that the best interventions are broad-based, low-cost, easily-accessible, and can be adjusted to each patient's individual needs (Hildenbrand et al., 2014). Due to the wide range of age in pediatric oncology patients, interventions that are the most beneficial for younger patients, might not always be the ones that are most beneficial for the older patients. Therefore, it is recommended that nurses are educated on many coping strategies to provide multiple options. The review of literature supported that those with adequate coping strategies have a reduced negative psychological impact compared to those who do not. There is a need for psychological screening and intervention during the early stages of treatment to establish coping strategies and prevent extensive psychological distress (Foster et al., 2017).

Table 1

Best Practice Recommendations for Coping Strategies for Pediatric Oncology Patients

Recommendation	Rationale	References	Level of Evidence (Appendix)
Distraction Techniques	<ul style="list-style-type: none"> • Aids children in “forgetting” about their cancer, passes time faster, and gives them something fun to look forward to 	Foster, R. H., Brouwer, A. M., Dillon, R., Bitsko, M. J., Godder, K., & Stern, M. (2017). “Cancer was a speed bump in my path to enlightenment.” a qualitative analysis of situational coping experiences among young adult survivors of childhood cancer. <i>Journal of Psychosocial Oncology</i> , 35(4), 377-392. doi: 10.1080/07347332.2017.1292575	Level VI
		Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. <i>Journal of Pediatric Oncology Nursing</i> , 28(6), 344-354. doi: 10.1177/1043454211430823	Level VI
		Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. <i>Journal of Psychosocial Oncology</i> , 31(1), 37-58. doi: 10.1080/07347332.2013.855960	Level VI
		Laing, C. M., Moules, N. J., Estefan, A., & Lang, M. (2017). Stories that heal: Understanding the effects of creating digital stories with pediatric and adolescent/young adult oncology patients. <i>Journal of Pediatric Oncology Nursing</i> , 34(4), 272-282. doi: 10.1177/1043454216688639	Level III
		Platschek, A., Kehe, L., Abeln, V., Berthold, F., Simon, T., & Strüder, H. K. (2017). Computer- based exercise program: effects of a 12-week	Level III

intervention on mood and fatigue in pediatric patients with cancer. *Clinical Journal of Oncology Nursing*, 21(6), E280-E286.
doi: 10.1188/17.CJON.E280-E286

Sposito, A. P., Silva-Rodrigues, F. M., Sparapani, V. C., Pfeifer, L. I., de Lima, R. G., & Nascimento, L. C. (2015). Coping strategies used by hospitalized children with cancer undergoing chemotherapy. *Journal of Nursing Scholarship*, 47(2), 143-151. doi: 10.1111/jnu.12126

Level VI

Weinstein, A. G. & Henrich, C. C. (2013). Psychological interventions helping pediatric oncology patients cope with medical procedures: A nurse-centered approach. *European Journal of Oncology Nursing*, 17(6), 726-731.
<https://doi.org/10.1016/j.ejon.2013.04.003>

Level VI

Social Support	<ul style="list-style-type: none"> • Provides patients with a sense of normalcy and the realization that they are not alone 	<p>Foster, R. H., Brouwer, A. M., Dillon, R., Bitsko, M. J., Godder, K., & Stern, M. (2017). "Cancer was a speed bump in my path to enlightenment." a qualitative analysis of situational coping experiences among young adult survivors of childhood cancer. <i>Journal of Psychosocial Oncology</i>, 35(4), 377-392. doi: 10.1080/07347332.2017.1292575</p> <p>Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. <i>Journal of Pediatric Oncology Nursing</i>, 28(6), 344-354. doi: 10.1177/1043454211430823</p> <p>Hildenbrand, A. K., Alderfer, M. A., Deatrick, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with</p>	<p>Level VI</p> <p>Level VI</p> <p>Level VI</p>
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pediatric cancer. *Journal of Psychosocial Oncology*, 31(1), 37-58.
doi:10.1080/07347332.2013.855960

Lam, C. G., Cohen, K. J., & Roter, D. L. (2013). Coping needs in adolescents with cancer: a participatory study. *Journal of Adolescent and Young Adult Oncology*, 2(1), 10-16.
doi: 10.1089/jayao.2012.0011

Level VI

Laing, C. M., Moules, N. J., Estefan, A., & Lang, M. (2017). Stories that heal: Understanding the effects of creating digital stories with pediatric and adolescent/young adult oncology patients. *Journal of Pediatric Oncology Nursing*, 34(4), 272-282.
doi: 10.1177/1043454216688639

Level III

Weinstein, A. G. & Henrich, C. C. (2013). Psychological interventions helping pediatric oncology patients cope with medical procedures: A nurse-centered approach. *European Journal of Oncology Nursing*, 17(6), 726-731.
<https://doi.org/10.1016/j.ejon.2013.04.003>

Level VI

Cognitive
Restructuring &
Optimism

- Children with cancer adjust their point of view to focus on the positives to increase motivation to complete treatment and reach remission

Foster, R. H., Brouwer, A. M., Dillon, R., Bitsko, M. J., Godder, K., & Stern, M. (2017). "Cancer was a speed bump in my path to enlightenment:" a qualitative analysis of situational coping experiences among young adult survivors of childhood cancer. *Journal of Psychosocial Oncology*, 35(4), 377-392.
doi: 10.1080/07347332.2017.1292575

Level VI

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. *Journal of Pediatric Oncology*

Level VI

Nursing, 28(6), 344-354.
doi:10.1177/1043454211430823

Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. *Journal of Psychosocial Oncology*, 31(1), 37-58.
doi: 10.1080/07347332.2013.855960

Level VI

Lam, C. G., Cohen, K. J., & Roter, D. L. (2013). Coping needs in adolescents with cancer: a participatory study. *Journal of Adolescent and Young Adult Oncology*, 2(1), 10-16.
doi: 10.1089/jayao.2012.0011

Level VI

Sposito, A. P., Silva-Rodrigues, F. M., Sparapani, V. C., Pfeifer, L. I., de Lima, R. G., & Nascimento, L. C. (2015). Coping strategies used by hospitalized children with cancer undergoing chemotherapy. *Journal of Nursing Scholarship*, 47(2), 143-151. doi: 10.1111/jnu.12126

Level VI

Education	<ul style="list-style-type: none"> • When patients understand what is going on with their body and the details of a procedure, it provides them with a sense of ease and prevents additional worry 	<p>Foster, R. H., Brouwer, A. M., Dillon, R., Bitsko, M. J., Godder, K., & Stern, M. (2017). "Cancer was a speed bump in my path to enlightenment." a qualitative analysis of situational coping experiences among young adult survivors of childhood cancer. <i>Journal of Psychosocial Oncology</i>, 35(4), 377-392. doi: 10.1080/07347332.2017.1292575</p> <p style="text-align: right;">Level VI</p> <p>Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. <i>Journal of Psychosocial Oncology</i>, 31(1), 37-58. doi: 10.1080/07347332.2013.855960</p> <p style="text-align: right;">Level VI</p> <p>Sposito, A. P., Silva-Rodrigues, F. M., Sparapani, V. C., Pfeifer, L. I., de Lima,</p> <p style="text-align: right;">Level VI</p>	
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		R. G., & Nascimento, L. C. (2015). Coping strategies used by hospitalized children with cancer undergoing chemotherapy. <i>Journal of Nursing Scholarship, 47</i> (2), 143-151. doi: 10.1111/jnu.12126	
		Weinstein, A. G. & Henrich, C. C. (2013). Psychological interventions helping pediatric oncology patients cope with medical procedures: A nurse-centered approach. <i>European Journal of Oncology Nursing, 17</i> (6), 726-731. https://doi.org/10.1016/j.ejon.2013.04.003	Level VI
		<hr/>	
Emotional Expression & Support	• Patients can express verbally how they are feeling, increases other's understanding of what they are going through, and gives children the opportunity to "let go" of pent up emotions	Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. <i>Journal of Pediatric Oncology Nursing, 28</i> (6), 344-354. doi: 10.1177/1043454211430823	Level VI
		Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. <i>Journal of Psychosocial Oncology, 31</i> (1), 37-58. doi: 10.1080/07347332.2013.855960	Level VI
		Laing, C. M., Moules, N. J., Estefan, A., & Lang, M. (2017). Stories that heal: Understanding the effects of creating digital stories with pediatric and adolescent/young adult oncology patients. <i>Journal of Pediatric Oncology Nursing, 34</i> (4), 272-282. doi: 10.1177/1043454216688639	Level III
		Weinstein, A. G. & Henrich, C. C. (2013). Psychological interventions helping pediatric oncology patients cope with medical procedures: A nurse-centered approach. <i>European Journal of Oncology</i>	Level VI

Nursing, 17(6), 726-731.
<https://doi.org/10.1016/j.ejon.2013.04.003>

Relaxation
Techniques

- Aid in regulating the patient's emotions and behaviors

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. *Journal of Pediatric Oncology Nursing*, 28(6), 344-354. doi: 10.1177/1043454211430823

Level VI

Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. *Journal of Psychosocial Oncology*, 31(1), 37-58. doi: 10.1080/07347332.2013.85596

Level VI

Weinstein, A. G. & Henrich, C. C. (2013). Psychological interventions helping pediatric oncology patients cope with medical procedures: A nurse-centered approach. *European Journal of Oncology Nursing*, 17(6), 726-731. <https://doi.org/10.1016/j.ejon.2013.04.003>

Level VI

Maintaining
Spirituality/Faith

- Provides patients with a sense of support and encouragement to endure treatment

Foster, R. H., Brouwer, A. M., Dillon, R., Bitsko, M. J., Godder, K., & Stern, M. (2017). "Cancer was a speed bump in my path to enlightenment:" a qualitative analysis of situational coping experiences among young adult survivors of childhood cancer. *Journal of Psychosocial Oncology*, 35(4), 377-392. doi: 10.1080/07347332.2017.1292575

Level VI

Sposito, A. P., Silva-Rodrigues, F. M., Sparapani, V. C., Pfeifer, L. I., de Lima, R. G., & Nascimento, L. C. (2015). Coping strategies used by hospitalized children with cancer undergoing chemotherapy. *Journal of Nursing*

Level VI

Scholarship, 47(2), 143-151. doi:
10.1111/jnu.12126

Coping Assistance by Parents	<ul style="list-style-type: none"> Parents play an important role in providing assistance with coping strategies for their child to help decrease their stressors 	<p>Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. <i>Journal of Pediatric Oncology Nursing</i>, 28(6), 344-354. doi: 10.1177/1043454211430823</p> <p>Hildenbrand, A. K., Alderfer, M. A., Deatrck, J.A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. <i>Journal of Psychosocial Oncology</i>, 31(1), 37-58. doi: 10.1080/07347332.2013.855960</p>	<p>Level VI</p> <p>Level VI</p>
Providing Relief of Treatment Side Effects	<ul style="list-style-type: none"> Increases the child's ability to cope with the treatment if they can identify methods to decrease their side effects 	<p>Platschek, A., Kehe, L., Abeln, V., Berthold, F., Simon, T., & Strüder, H. K. (2017). Computer- based exercise program: effects of a 12-week intervention on mood and fatigue in pediatric patients with cancer. <i>Clinical Journal of Oncology Nursing</i>, 21(6), E280-E286. doi: 10.1188/17.CJON.E280-E286</p> <p>Sposito, A. P., Silva-Rodrigues, F. M., Sparapani, V. C., Pfeifer, L. I., de Lima, R. G., & Nascimento, L. C. (2015). Coping strategies used by hospitalized children with cancer undergoing chemotherapy. <i>Journal of Nursing Scholarship</i>, 47(2), 143-151. doi: 10.1111/jnu.12126</p>	<p>Level III</p> <p>Level VI</p>
Art Therapy	<ul style="list-style-type: none"> Allows pediatric oncology patients to express their emotions without verbally stating 	<p>Aguilar, B. A. (2017). The efficacy of art therapy in pediatric oncology patients: An integrative literature review. <i>Journal of Pediatric Nursing</i>, 36, 173-178. doi: 10.1016/j.pedn.2017.06.015</p>	<p>Level V</p>

	them and allows parents/nurses to further understand these emotions	Lam, C. G., Cohen, K. J., & Roter, D. L. (2013). Coping needs in adolescents with cancer: a participatory study. <i>Journal of Adolescent and Young Adult Oncology</i> , 2(1), 10-16. doi: 10.1089/jayao.2012.0011	Level VI
Provider Supervised Exercise	• Correlated with an improvement in mood, most likely through alterations in nervous system activity	Platschek, A., Kehe, L., Abeln, V., Berthold, F., Simon, T., & Strüder, H. K. (2017). Computer- based exercise program: effects of a 12-week intervention on mood and fatigue in pediatric patients with cancer. <i>Clinical Journal of Oncology Nursing</i> , 21(6), E280-E286. doi: 10.1188/17.CJON.E280-E286	Level III

Summary of Best Practice Recommendations

The literature reviewed in this thesis focused on pertinent information regarding the negative psychological impact of cancer and its treatment, the influence of developmental stage and age on preferred coping strategy, interventions to improve coping for pediatric oncology patients, and multiple perspectives on the most useful strategies. It was determined that younger children prefer distraction techniques, where older children prefer emotional support (Weinstein & Henrich, 2013). Similarly, nurses expressed that they viewed “being” with their patient as more beneficial than “doing” for their patient (Weinstein & Henrich, 2013). A total of eleven recommendations to support coping strategies for pediatric oncology patients were gathered from the literature review of nine articles. Out of all the recommendations given, distraction techniques were supported by the most articles. Distraction techniques such as video games, watching television, and a multitude of other interventions serve as the primary avoidance coping strategy reported by children with cancer (Hildenbrand et al., 2011). Social support from family, friends, and other pediatric oncology patients gave patients the opportunity to discover that they are not alone in their treatment, helped to maintain normalcy, promoted interaction amongst patients to share common experiences, and prevented excessive isolation (Lam et al., 2013; Weinstein & Henrich, 2013). Implementing cognitive restructuring and optimism in patients has been used as an adaptive tool to support positive coping and an improvement in quality of life (Foster et al., 2017). Education is viewed as the number one most important intervention by nurses because education informs the patients, so they can understand their diagnosis and are better prepared for their treatment regimen (Weinstein & Henrich, 2013). The ability for other people to “understand what it was like” helped alleviate pent up emotions related to having cancer (Laing et al., 2017). Similarly, emotional support through the nurse-patient relationship

allowed patients to have the opportunity to open up about their thoughts and fears with a trusted individual (Weinstein & Henrich, 2013). Nurses reported that the incorporation of relaxation techniques such as breathing exercises, massages, self-imagery, and hypnosis were shown to enhance emotional and behavioral regulation in this population (Weinstein & Henrich, 2013). Maintaining one's spirituality and faith has been reported as an important source of support for many children, as it strengthened their hope for remission and a cure in a way that cannot be explained in words (Sposito et al., 2015). The findings of the study conducted by Hildenbrand et al. (2014) highlighted the crucial role that parents play in helping their children cope with cancer-related stressors, therefore, incorporation of the family should be considered a priority to medical teams. Relief of treatment side effects is correlated with an improvement in psychological well-being, for research has shown that there is a strong relationship between psychological and physical health (Platschek et al., 2017). The use of drawing and creating t-shirts as art therapy lead to an increase in emotional expression/communication with nurses and family members through sharing anxieties, fear, and pain (Aguilar, 2017). In addition, art therapy served as a distraction technique that lead to the development of beneficial coping skills and a decrease in physical symptoms (Aguilar, 2017). Lastly, provider supervised exercise is positively correlated with an improvement in mood, most likely due to a connection in the alteration of neurotransmitter and central nervous system activity (Platschek et al., 2017). Health providers should be educated on a variety of strategies to ensure they can accommodate the vast demographics of their patient population, for often times an intervention that works for one patient will not benefit another. Overall, the use of coping strategies helps patients to engage in their treatment and can aid in the prevention of post-treatment psychological issues (Weinstein & Henrich, 2013).

CHAPTER 4

Implementation and Evaluation

The introductory section of this chapter aims to explain the implementation of a best coping strategy fact sheet given to pediatric oncology patients and their parents within 24 hours of the patient's admission to a pediatric oncology unit. The proposed fact sheet will contain information that is up to date and evidence-based, to ensure that patients and their families are educated based on current, reliable data. The fact sheet will consist of data that aligns with the best practice recommendations noted in chapter three. This includes information related to coping strategies for various developmental stages and ages, the importance of beneficial coping strategies for this population, signs of psychological stress, and how a parent can provide coping support. In addition, this flyer will provide patients and their family members with information on who to contact if they have additional questions about the facts given to them. The fact sheet will be geared towards the patients and their parents; however, the nurses will be responsible for implementing the fact sheet and facilitating a conversation regarding the information. A brief educational session will be conducted with the nurses during change of shift report to inform them of the implementation of the fact sheet as well as to educate them on the current best practice recommendations for pediatric oncology coping strategies.

This fact sheet will be implemented using the Plan-Do-Study-Act (PDSA) cycle. The PDSA framework has been used by hundreds of health care organizations to guide a test of change (Institute for Healthcare Improvement, 2019). The implementation and evaluation of the fact sheet will incorporate the techniques and aspects utilized in the PDSA cycle to ensure effectiveness in the transfer of information to the patients and their families. The PDSA cycle is beneficial when testing a change and then analyzing the various steps of the change – “develop a

plan to test the change (Plan), carry out the test (Do), observe, analyze, and learn from the test (Study), and determine what modifications, if any, to make for the next cycle (Act)” (Institute for Healthcare Improvement, 2019, p. 1). Initially, the implementation will be based on a small scale, but following multiple revisions with the use of the PDSA cycle, this change can then be implemented on a larger scale.

The primary purpose of the implementation of the fact sheet is to provide patients and their families with reputable information on a variety of coping strategies for pediatric oncology patients to minimize psychological stress and promote holistic healing. The implementation of this fact sheet will draw attention to the importance of psychological well-being as well as physical. In addition, it will aid in promoting conversations about this topic between patients, family members, nurses, and providers to ensure the information was conveyed appropriately and was retained by patients and their families. The latter portion of this chapter will discuss the evaluation of the proposed fact sheet implementation. Lastly, this chapter will examine the strengths and weaknesses of the best practice fact sheet and the overall thesis. In addition, recommendations for further research related to best coping strategies for pediatric oncology patients will be reviewed.

Implementation

Implementing an Informative and Evidence-based Fact Sheet

As previously mentioned, the PDSA cycle will be used as a framework for the theoretical implementation of an informative and evidence-based fact sheet containing information about coping strategies for pediatric oncology patients. The objective of the implementation is to test, using the Teach-Back method, patients’ and their family members’ understanding of the coping strategies presented to them on the fact sheet. The theoretical implementation will take place on

the pediatric oncology unit of a local hospital.

Plan. The first stage of the PDSA cycle is Plan. This stage consists of planning the test, as well as planning a method for data collection (Institute for Healthcare Initiative, 2019). This stage will guide the implementation of the fact sheet in a pediatric oncology unit of a hospital. The focus question is: does the implementation of a fact sheet increase knowledge of coping strategies for pediatric oncology patients and their families? Based on this question as well as the objective, it is predicted that patients' and families' understanding and use of coping strategies appropriate to the child's age will increase. The next step in the planning process is to determine the necessary supplies needed as well as the cost for those supplies. In this situation, the only supply needed is paper, which is commonly stocked on units, therefore, it would not be much of an additional cost.

When designing the fact sheet, it is vital to consider the Centers for Disease Control and Prevention's (2009) article, "Simply Put: A guide for creating easy-to-understand materials." This article discusses the importance of considering culture and literacy skills when designing health communication materials. In addition, it informs readers how to design communication materials that can be understood by a wide variety of audiences (Centers for Disease Control and Prevention, 2009). The guide provides ways to organize material on the fact sheet using proper language and visuals to ensure key information is being properly reciprocated by the audience. Some of the components that will be taken into consideration when developing the fact sheet include limiting the number of messages, clearly stating what the audience needs to know, talking to the reader as if you were talking to a friend, using concise words, as well as many more. In addition to the language on the sheet, this guide also focuses on the overall appearance of the text and the visuals on the fact sheet (Centers for Disease Control and Prevention, 2009).

For the purposes of this theoretical fact sheet development and implementation, the fact sheet will contain information regarding coping strategies for various developmental stages and ages, the importance of beneficial coping strategies for this population, signs of psychological stress, and how a parent can provide coping support.

The planning stage includes the determination of who, what, when, and where this implementation will be carried out (Institute for Healthcare Initiative, 2019). In regard to this population, the who is patients' and their families', the what is understanding of coping strategies, where is an inpatient pediatric oncology unit, and the when is within 24 hours of their admission to the unit. The nurses will be educated on the fact sheet by the unit manager, then the nurses will then evaluate the patient and their families current prior knowledge on the subject, implement the use of the fact sheet with their patients, and lastly, evaluate using the Teach-Back method the effectiveness of the fact sheet.

Do. The second stage of the PDSA cycle is Do. In this stage, it is recommended to carry out the test (implementation) on a small scale, then determine problems and any unpredicted observations, and finally collect and analyze the data gathered (Institute for Healthcare Initiative, 2019). This change will first be implemented in the pediatric oncology unit of a single hospital, then if successful, later in additional hospitals. All 11 best practice recommendations mentioned in Table 1 will be incorporated in the fact sheet given to pediatric oncology patients and their families. The fact sheet will contain coping strategy recommendations regarding multiple developmental stages and age groups. Although the patient will only fall within one age category currently, it is useful for the patient and the parents to have knowledge of how beneficial coping strategies might change as the child gets older.

The theoretical implementation plan consists of three components: first a brief, five

minute teaching of the fact sheet from the unit manager to the nurses during change of shift report, second the evaluation of prior patient and family member coping strategy knowledge and implementation of the fact sheet with the patients' and their families', and third, evaluation using the Teach-Back method of the patient and family members retention and understanding of the information presented to them on the fact sheet. The patient's nurse will give the patient and their family members the fact sheet within 24 hours of their admission to the hospital and briefly discussing the fact sheet with them. Prior to the discussion of the fact sheet with the patient and their family members, the nurse will evaluate their prior knowledge of coping strategies for pediatric oncology patients and the risk of not having a beneficial coping strategy by asking them what they currently know about the subject. Some questions that can be used to prompt this discussion are, "what is a coping strategy," "what coping strategies do you (or your child) currently use," and "how do coping strategies help emotional and mental well-being?" It is vital when evaluating their current knowledge to keep the questions open-ended, to allow for more than a yes/no answer.

Next, the nurse will follow up with the patient and their family members within 24 hours of giving the fact sheet to them to determine what they learned and retained from the fact sheet using the Teach-Back method. The nurse will also inquire about whether or not the patient/family members thought the fact sheet was beneficial and if they would recommend it to other pediatric oncology patients and their families. In addition to completing the post-intervention Teach-Back, the nurse will have an opportunity to answer any additional questions the patient and their family members may have about the material. Lastly, this conversation will provide the nurses with an opportunity to explain the coping strategies on the fact sheet that are available on the unit and facilitated by child life staff as well as nurses. The use of the nurse

when implementing the fact sheet will help promote an open line of communication between the patient, family members, and nurse regarding psychological status and coping strategies to help promote holistic well-being. Following the implementation of the fact sheet and the post implementation Teach-Back, the nurse will document the completion of these two steps on the patient's electronic chart. This will ensure that each patient receives the fact sheet as well as the post-implementation follow-up.

Summary

The implementation of the best practice recommendations to support coping strategies for pediatric oncology patients was developed based on data gathered from the literature review and the use of the PDSA cycle for implementing a change. The author is aware that most nurses have the common knowledge of coping strategies for their patients to use, however, it is less likely that the patients and their parents are properly trained on these resources. The use of a fact sheet regarding coping strategies for pediatric oncology patients, provides the patients as well as their family members with information they can reference as needed throughout their course of treatment. In addition, providing the patient and their family members with this fact sheet will help them realize the importance of coping strategies and will aid in facilitating an increase in conversations regarding this topic. This initial portion of the chapter focused on the first two steps of the PDSA cycle, Plan and Do, with the next two steps of the cycle, Study and Act, to be discussed in the remainder of the chapter (Institute for Healthcare Improvement, 2019).

Evaluation

The last two stages of the PDSA cycle are Study and Act (Institute for Healthcare Improvement, 2019). The Study stage will contain the evaluation portion of the theoretical implementation, for this stage focuses on the analysis and comparison of the results to the

previous predictions as well as to the PICOT(S) question (Institute for Healthcare Improvement, 2019).

Study. The Study stage of the PDSA cycle aims to “analyze the results and compare them to your predictions” (Institute for Healthcare Improvement, 2019). This will be achieved through analyzing the patients’ and their families’ prior knowledge of the topic, the feedback given from patients and parents regarding the effectiveness of the fact sheet, and the results from the Teach-Back method completed with the nurse and the patient/family members. According to the PDSA cycle, it is beneficial to analyze the data as a group, rather than on an individual basis. Because of this, the theoretical analysis will be completed during change of shift report, 1-week, 2-weeks, and 1-month post implementation of the fact sheet. Due to the fact that these meetings are often brief, nurses will have had the opportunity to previously discuss their findings with the unit manager, who will then be responsible for presenting the findings to the nurses during report. Nurses will then have the opportunity to briefly discuss the strengths, weaknesses, and areas for improvement within the intervention.

When comparing the data with predictions made prior to the intervention, the hopeful outcome is that the patients and their family members found the fact sheet to be informative and beneficial. In addition, it is expected that the patients and family members were able to Teach-Back the information provided to them on the fact sheet. Nurses are expected to implement this intervention, facilitate conversations with their patients and family members, accurately report back their findings to the unit manager, and participate in the discussion regarding the results and areas for improvement.

Act. The fourth and final stage of the PDSA cycle is the Act stage (Institute for Healthcare Improvement, 2019). This stage consists of incorporating the findings and feedback

from the Study stage to either adapt, adopt, or abandon the change idea (Institute for Healthcare Improvement, 2019). Hopefully, the change idea will be successful and will either need to be adapted through making modifications and completing another test or will be adopted and can be implemented on a larger scale. Some possible changes include developing a more consistent pre- and post-intervention questionnaire instead of various conversations between nurses and their patients/family members. The closing portion of this stage includes developing plans for the next PDSA cycle made as a result of the findings and discussion during this stage (Institute for Healthcare Improvement, 2019). This implementation and evaluation address the PICOT(S) question introduced in chapter one, for the implementation and evaluation targets methods that can be used to improve psychological well-being in pediatric oncology patients within the hospital. When determining the best method for implementation, it was decided by the author that focusing on one setting, inpatient, rather than two settings, inpatient and outpatient, would initially be most beneficial. However, if this implementation is successful in the inpatient, hospital setting, the findings can later be adapted and transferred to the outpatient, clinic setting.

Strengths and Limitations of Thesis Project

One of the main strengths from this best practice recommendation thesis includes the variety of recommendations obtained from completing the literature review. With 11 recommendations given, it aids in increasing the variety of coping strategies healthcare providers are able to implement with their patients and patients' family members. In addition, a large range of recommendations allows the information presented on the fact sheet to be applied to a wide range of ages and demographics. This helps to ensure inclusivity and applicability to as many people within the population as possible. The use of the fact sheet will aid in reminding nurses of the best recommendations for coping strategies and educating patients and their family members on the best way to reduce psychological stress and promote holistic well-being.

This thesis is limited due to the overall lack of current research regarding this topic. In addition, a majority of the articles that were discussed during chapter two and chapter three are qualitative studies. In order to get a more complete view of coping strategies currently implemented for pediatric oncology patients, it would be beneficial to include more mixed-methods and quantitative studies. When considering the implementation, a possible limitation is variation in age, amount of time since diagnosis, as well as other demographic factors. While demographics were taken into consideration when developing the implementation strategy, a factor such as period of time since diagnosis may alter the effectiveness of the intervention. In addition, the method of data collection is simply through word of mouth and report from the nurses. This could possibly lead to inaccurate reporting of data as well as inconsistency in detail reported amongst the nurses. When making revisions for future implementations, these limitations would be vital to acknowledge.

Summary

The purpose of this thesis was to identify and determine best practice recommendations to support coping strategies for pediatric oncology patients. Research gathered through the literature review determined that pediatric oncology patients endure a significant negative psychological impact as well as physical impact. Therefore, when caring for patients of this population it is vital to be properly educated on coping strategies to prevent short as well as long term psychological illnesses. The comprehensive literature review completed in chapter two depicted the current coping strategies patients, nurses, as well as parents implement to help improve psychological well-being. This literature review lead to a total of 11 recommendations for coping strategies, consisting of a wide variety of interventions. These recommendations prompted the implementation of a fact sheet containing information regarding the best coping strategies for each developmental and age group of patients enduring cancer and its associated treatment. Through evaluating the theoretical implementation with the PDSA cycle, it would allow for patients and their family members, as well as nurses, to give their feedback regarding the implementation and to suggest changes for further replications or implementations of the proposed fact sheet. One of the most vital components of this recommendation and of the implementation is to consider the patient's age, developmental level, current coping strategies, and knowledge of coping strategies when suggesting additional methods to use. Implementing a fact sheet on pediatric oncology units would help ensure that care is individualized and patient-centered and will aid in providing a focus on psychological well-being in addition to physical. Through prioritizing psychological well-being with the use of proper coping strategies, pediatric oncology patients have the potential for a decrease in suffering and an increase in quality of life.

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Appendix

Rating System for the Hierarchy of Evidence

Level I: Evidence from a systematic review or meta-analysis of all relevant RCTs

Level II: Evidence obtained from well- designed RCTs.

Level III: Evidence obtained from well- designed controlled trials without randomization

Level IV: Evidence from well-designed case control and cohort studies

Level V: Evidence from systematic reviews of descriptive or qualitative studies

Level VI: Evidence from single descriptive or qualitative studies.

Level VII: Evidence from the opinion of authorities and or reports of expert committees

From Guyatt, G. and Rennie, D. (2002) as cited in Melynck, B.M. & Fineout-Overholt, E. (2011).

Evidence-based practice in nursing and healthcare: A guide to best practice.