2015

Nurses' Perceptions of Best Practices to Assess Pediatric Patients and Educate Their Families Experiencing Effects of Cancer Chemotherapy: "Chemo Brain" A Pilot Study

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By

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Submitted in partial fulfillment of the requirements of the Department of Nursing and the Honors Program Dominican University of California 2015

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Abstract

With more advanced and more aggressive chemotherapy cancer treatment leading to higher survival rates, complications with quality of life are becoming more prominent. Of these complications, delayed cognitive processing, commonly known as "chemo brain," is becoming a topic of interest. Cognitive changes are some of the most common as well as the most challenging complications associated with central nervous system (CNS) directed treatment, such as chemotherapy. The term "chemo brain" is often used to describe self-reported or observed cognitive processing delays in patients who receive chemotherapy as a form of cancer treatment (Raffa, 2009). Although these cognitive delays have the potential to be serious side effects, little education is given to the patients and families regarding these possibilities prior to the initiation of cancer treatment. The purpose of this paper is three fold: 1) to define and discuss the etiology of "chemo brain," 2) to discuss the best assessment and evaluation of presence and severity of "chemo brain," and 3) to explore pediatric oncology nurses' reports of practice implications for teaching and supporting pediatric patients and their families experiencing "chemo brain." A theoretical framework that will guide the research is Erikson's Theory of Psychosocial Development with a focus on the school age stage of industry versus inferiority. With the possible gap in knowledge and skill that may be present in these children who have undergone chemotherapy, there is a significantly higher chance of them developing a sense of inferiority rather than the preferred sense of industry. Convenience and snowball sampling was used to locate pediatric oncology registered nurses to complete the research instrument. Research data was collected through a short survey created by the primary investigator that has construct and content validity from two advanced practice pediatric

oncology nurses. Twelve instruments were completed and returned to the researcher. It was discovered that 100% of the participants had seen the neurological and cognitive symptoms of "chemo brain" in their patients. Even with this unanimous result, many of the participants were unaware of their facility's protocols to assess the presence and severity of "chemo brain." In addition, it was discovered that nurses' reports of best educational practices most often included frequent repetition and review of educational material throughout chemotherapy treatment.

Acknowledgements

I would like to acknowledge and thank my parents, Jonathan and Janis Tapping, for supporting me in every way possible throughout my education. I would also like to acknowledge my late Nana who instilled in me the caring personality that comes with being a nurse. Her picture above my desk gives me motivation everyday to become as good and as caring of a nurse as she was. Lastly, I would like to thanks Dr. Luanne Linnard-Palmer for supporting me throughout the research process.

Background

With more advanced and more aggressive chemotherapy cancer treatment leading to higher survival rates, complications with quality of life are becoming more prominent, especially delayed cognitive processing, commonly known as "chemo brain" (CB). At diagnosis and throughout treatment, patients and families are routinely educated about the plan of care, but according to oncology nurses' reports, too often details regarding the possibility of cognitive declines or deficits are omitted. Patients and families are noticing cognitive difficulties that can cause symptoms such as poor academic performance and

mental fogginess without receiving sufficient education about what they are experiencing.

Cognitive changes are some of the most common as well as most challenging complications associated with central nervous system (CNS) directed treatment, such as intrathecal chemotherapy, for cancers such as acute lymphoblastic leukemia (ALL) and brain tumors. The estimated incidence of patients who experience deficits in cognitive processing related to their CNS directed treatment is approximately 20% to 40% for children with ALL and 40% to 100% for children with brain tumors (Moore et al., 2013). The term "chemo brain" (CB) is often used to describe self-reported or observed cognitive processing delays in patients who receive chemotherapy as a form of cancer treatment (Raffa, 2009). The clinical manifestations of CB can "affect multitasking, create stress, and weaken performance when patients are challenged by high-level cognitive demands" (Staat & Segatore, 2005).

Purpose

The purpose of this paper is three fold: 1) to define and discuss the etiology of "chemo brain," 2) discuss the best assessment and evaluation of presence and severity of "chemo brain," and 3) to explore pediatric oncology nurses' reports of best practice implications for teaching and supporting pediatric patients and their families experiencing "chemo brain."

Literature Review

Introduction

"Chemo brain" (CB) is a term used to describe the general cognitive deficit that results from cancer chemotherapy treatment. According to Evens & Eschiti (2009), CB

can be simply described as "dysfunction, weakening, or impairment" of the memory in patients who have undergone chemotherapy treatment for cancer. Raffa et al. (2006) suggested that these impairments can be self-reported or observed by close peers such as family, friends, or schoolteachers. A more specific definition of CB stated that it presents as "weakened cognitive abilities, speed of information processing or reaction time, and organizational skills" along with the negative impact on "language ability, memory, concentration, and attention" (Staat & Segatore, 2005). Many of these core symptoms have been termed "executive functions," mainly including the "ability to allocate attentional resources and to plan and organize behavior" (Mulhern & Palmer, 2003). Although these deficits may seem to cause deteriorating effects, it is suggested "young children aren't actually dementing, but rather are not acquiring new information and skills at an appropriate age" (Duffner, 2009).

According to Staat & Segatore (2005), the patient's quality of life may be significantly affected due to the severity of the CB symptoms. Cognitive deficits may be so subtle that only the patient and close relatives notice, but they also may be severe enough to cause others to notice – which is noted to be most difficult for the patient, as well as their family and close friends.

Moore et al. (2013) and Evens & Eschiti (2009) both presented the statistic that as many as 40% of pediatric acute lymphoblastic leukemia (ALL) patients who are treated with chemotherapy alone will report CB. Overall, studies have shown that cognitive difficulties affect 25% to 35% of all patients that undergo systemic chemotherapy (Evens & Eschiti, 2009).

Deficits of CB often appear gradually instead of having a sudden onset. In fact, myelination changes in the central nervous system from a chemotherapy drug, 5-fluorouracil, can be delayed for several months and may become progressive (Evens & Eschiti, 2009). By the late 1990's, reports began to suggest that children who were treated for ALL without cranial radiation therapy but with chemotherapy alone developed progressive cognitive declines three to four years following the completion of their chemotherapy treatment (Duffner, 2009). Even more detrimental, it has been suggested that in a small minority of patients, CB is still perceptible ten years after the completion of treatment (Staat & Segatore, 2005).

Etiology of "Chemo Brain"

The deficits of CB are believed to occur because of alterations in the blood-brain barrier (BBB), vascular injury, and myelination changes. With this BBB impairment, toxic agents are allowed access to the brain more readily than in normal circumstances where entry would not usually happen (Evens & Eschiti, 2009). In addition to these abnormalities, Mulhern & Palmer (2003) suggested that the late effects might also include diffuse and multifocal white matter abnormalities, microvascular occlusion, and calcifications. While Raffa (2009) stated that primarily white matter abnormalities were related to chemotherapy treatment, Evens & Eschiti (2009) discussed how researchers have also shown a decrease in the brain's grey matter along with the demyelination of white matter fibers following chemotherapy treatment. In neuro-imaging studies discussed by Raffa (2009), changes were evident at about two months, appeared to plateau at about six months, and persisted for the duration of the study (which was about one year).

Staat and Segatore (2005) discussed three possible mechanisms that cause CB: direct neurotoxicity, inflammatory mechanisms, or a vascular mechanism. The theory of direct neurotoxicity implies that chemotherapy agents cause direct toxicity to the brain, producing demyelination. The theory of an inflammatory response is an effect of chemotherapy agents destroying healthy cells in addition to cancer cells. This destruction of healthy cells produces a physiologic stress and the brain interprets the inflammatory response and the increase release of cytokines as stress, which may result in a decreased ability to learn, memory difficulties, and poor concentration (Evens & Eschiti, 2009). The last theory involves a vascular mechanism where injury obstructs the microvasculature of the brain, causing ischemia or infarction of dependent brain tissue leading to the deficits of CB (Staat & Segatore, 2005).

Because cancer treatment is often multi-modal, it is important to understand that both chemotherapy and radiation may be used. If this is the case, it makes it very difficult to determine if the adverse effects are related to the chemotherapy or the radiation, or a combination of both (Raffa et al., 2006). According to Evens & Eschiti (2009), Cyclophosphamide and 5-fluorouracil are two of the most commonly used chemotherapy drugs that can readily cross the BBB. Because of this, they are thought to significantly contribute to CB symptoms. Although chemotherapy drugs such as methotrexate (MTX) and vincristine are not believed to penetrate the BBB, they are believed to play a role in altering its permeability, which allows the drugs to gain easier entry to the brain, also contributing to CB. According to Staat & Segatore (2005), cyclophosphamide, MTX, and fluorouracil in high doses are known to have the strongest association with the development of CB. As expected, more cognitive impairments were noted in patients

who were given high doses of chemotherapy compared to a standard dose, and more cognitive impairment was seen in patients given a standard dose of chemotherapy than in control groups (Raffa et al., 2006). High dose chemotherapy, especially with MTX, has been associated with the previously discussed white matter injury (Mulhern & Palmer, 2003).

There are many risk factors and contributing factors relating to CB. Both Duffner (2009) and Mulhern & Palmer (2003) discussed the finding that early age at diagnosis and chemotherapy treatment has consistently been identified as a major risk factor for developing CB. Mulhern & Palmer (2003) also discussed how being of female gender confers a greater risk for developing CB. They also stated that the factors of early age at diagnosis and start of chemotherapy treatment along with low socioeconomic status were associated with more severe CB in females, but did not reliably correlate in males. It has also been suggested that people who carry the APOE e4 gene (a gene associated with Alzheimer's) may be more susceptible to CB (Evens & Eschiti, 2009).

Assessment of Presence and Severity

Deficits of CB may be so subtle, that they may only be noticeable to the patient and close peers but not to the health care team. Evens & Eschiti (2009) provided the statistic that only 38% of nurses assessed patients for CB. While longitudinal evaluation of cognitive functioning for childhood cancer survivors is not yet considered standard of care, many pediatric oncology programs emphasize cognitive assessment for high-risk patients (Ullrich & Embry, 2012).

Because there may be different contributing factors to the cognitive decline, there are differential diagnoses that must be ruled out in order to conclude that the deficits are

caused by the chemotherapy (Evens & Eschiti, 2009). According to Staat & Segatore (2005), observational assessment is the most appropriate method to screen for CB.

The neurocognitive assessments are essential in facilitating access to the necessary special education services and in tracking the child's development over time. Ullrich & Embry (2012) suggested that a comprehensive neurocognitive assessment should focus on global intellectual functioning and academic achievement along with other specific high-risk areas of deficit. They also discussed the recommendation that high-risk survivors should be evaluated when they transition into a long-term follow-up program. This should be done both to detect subtle impacts on overall functioning and to serve as a baseline for future assessments since it is known that CB late effects can progress over time. This reevaluation should look at factors such as academic performance, any acute changes or new difficulties, and the individual child's specific risk factors.

Ullrich & Embry (2012) also provided a table listing commonly used assessment tools for assessing specific neurocognitive domains in children. To assess global cognitive functioning (IQ), the WISC-IV is often used. The CPT-II or Trail Making Test Part A are often used to assess attention. The CMS may be used to assess memory. Processing speed may be assessed by the WISC-IV Coding/Symbol Search. Executive functioning may be assessed by a few tests, including the BRIEF or the Trail Making Test Part B. Finally, academic achievement may be assessed by the WIAT-III or WJ-III assessment tools.

Practice Implications

According to Mulhern & Palmer (2003), interventions can be divided into two approaches: those that aim to avoid or reduce the neurotoxicity of the CNS therapy, and those that aim to minimize or rehabilitate deficits that are not preventable. First, in order to determine potential interventions, the cognitive deficits must be distinguished from brain metastases and other medical conditions (Evens & Eschiti, 2009). The earlier the deficits are recognized and attributed to chemotherapy treatment, the earlier potential treatments can begin.

One of the first implications of practice is education. Nurses play a significant role in educating patients and families about the diagnosis, treatments, and potential side effects. According to Staat & Segatore (2005), there is a huge debate about whether or not the risk of CB should be disclosed during the consent process. On one hand, when a treatment regimen has a known central neurotoxicity, it is required to provide informed consent. On the other hand, there is limited knowledge regarding CB, and the incidence of CB must be confirmed before including it in routine discussion and as part of the informed consent process. Patients and families who have experienced CB first hand emphasized the desire for full disclosure or risks, including the potential for CB (Staat & Segatore, 2005). Education can allow patients to cope more effectively and the resulting awareness may be able to provide some sense of control and encourage the family to connect with an appropriate resource. As of 2009, there were no nationally known support groups for CB, so the pediatric oncology nurse should strongly consider finding a way to develop local groups (Evens & Eschiti, 2009).

Another intervention that is suggested to mitigate CB symptoms is exercise. Evens & Eschiti (2009) stated that because exercise improves blood flow and oxygenation to the brain, it might lead to improved cognitive functioning. They also stated that acupuncture has recently been shown to dilate cerebral blood vessels, which improves circulation as well as increases oxygenation to the brain.

When the non-pharmacological interventions are not sufficient, there are some proposed pharmacological interventions to minimize the deficits of CB. Both Ullrich & Embry (2012) and Staat & Segatore (2005) mentioned the use of methylphenidate (Ritalin) as an option to help with inattention, organizational skills, as well as forgetfulness. Both Evens & Eschiti (2009) and Staat & Segatore (2005) discussed the use of erythropoietin and epoetin alfa. These drugs are used to treat chemotherapy-induced anemia – they increase the oxygen carrying capacity of blood, which in turn can lead to decreased ischemia and hypoxia in the brain, leading to cognitive improvement. Both sources also discuss the use of Gingko Biloba. This herb is thought to have a neuroprotective, antioxidant, and membrane-stabilizing effect as well as possibly inhibiting the loss of cholinergic receptors, which are known to have an impact on memory and cognition (Staat & Segatore, 2005).

Theoretical Framework

A theoretical framework that will guide the research is Erikson's Theory of Psychosocial Development. In this theory, Erikson divides the "life cycle" into eight stages, and the focus of this project will be on the school-age stage of "Industry versus Inferiority." During this stage children will either begin to develop a sense of pride in their accomplishments and abilities (industry) or will doubt their ability to be successful

(inferiority). According to Erikson (1950), when a child develops a sense of industry, bringing "a productive situation to completion" is a goal that will gradually "supersede the whims and wishes of play". Simply put, the child will feel great satisfaction from completing a task. Erikson also discusses the danger of this stage – feelings of inadequacy or inferiority. Erikson (1950) states that if a child "despairs of his tools and skills or of his status among his tool partners, he may be discouraged from identification with them", which may pull him away from peers and result in isolation. In summary, if a child feels inadequate and incompetent in what he does, he will start to pull back and consider himself "doomed to mediocrity or inadequacy" (Erikson, 1950).

In the research, it is suggested that there are treatment related cognitive changes that children experience both throughout treatment and in the long term. Cognitive changes have become some of the most common and challenging problems associated with the CNS-directed treatment for certain forms of cancer (Moore et al., 2013). This can lead to increasing gaps in their skills and knowledge compared to that of their classmates. This gap can greatly impact their development of either industry or inferiority. Industry is developed when a child can be confident and feel accomplished for tasks they are completing, while inferiority can develop when a child feels they are unable to accomplish tasks or be successful. With the gap in knowledge and skill that may be present in these children who have undergone chemotherapy, there is a significantly higher chance of them developing a sense of inferiority rather than the preferred sense of industry. These children will notice they are unable to keep up and begin to doubt themselves and their ability to be successful, further isolating them from their classmates.

Research Question

Based on what was reviewed and learned form the literature review, this study will investigate the following questions:

1. How is "Chemo Brain" (CB) defined by the pediatric oncology nurses who assess it?
2. According to these nurses, how is the presence and severity of CB assessed?
3. How do pediatric oncology nurses describe their best practices to teach and support patients and their families experiencing CB?

Methods

Design

This is a qualitative/descriptive pilot study. In descriptive studies, there is no manipulation of variables, and the focus is describing a phenomenon. The use of a descriptive study design in this case is beneficial because this is a pilot study where the researcher is soliciting personal experiences and knowledge. Pilot study results will enable the researcher to determine if the instrument is valid for the proposed research questions. This design can help to discover specific variables to manipulate and include in future experimental research.

Subjects

Overall, the subjects of this study will be pediatric oncology registered nurses (RNs) practicing in hospitals throughout the state. A majority of the subjects will be members of the Bay Area/Northern California chapter of the Association of Pediatric Hematology/Oncology Nurses (BAHPON) who attend the chapter educational event on

February 5, 2015. In addition to these nurses, other pediatric oncology RNs will be recruited as subjects for the study through snowballing.

Sampling Procedure

Primarily, convenience sampling will be used. Convenience sampling is a non-probability sampling technique where the research subjects are selected because of their convenient accessibility and proximity to the researcher, such as access to members of the BAHPON. With convenience sampling, the subjects are not representative of the entire population. Snowball sampling will also be used to obtain subjects for the study. Snowballing is also a non-probability sampling technique and may also be known as chain referral sampling. Researchers use this technique when the subjects may be hard to locate. Potential subjects are found through referral from existing subjects. In the case of this study, snowballing is used to reach out to other pediatric oncology RNs that may not be members of BAHPON or may have not been in attendance at the meeting. The reason for non-probability sampling for this study is that childhood cancer is rare and very few nurses select to work in this discipline. See Appendix A for a copy of the consent letter.

Sample Size

For a small pilot study, the nursing research literature encourages approximately 15-50 subjects or elements for each variable identified. The goal sample size for this study is 15-30 pediatric oncology RNs because the identified variables include assessment of presence and severity and best practices for education. Purposeful sampling techniques will continue until the desired number of participants is achieved or the date of March 1, 2015 dictates the completion of data collection. While the goal was 15-30 participants, 11 completed instruments were returned to the researcher.

Instruments

Research will be gathered through a survey given to pediatric oncology RNs. This instrument begins by inquiring demographic information about the participants. It then asks both open-ended questions that explore RN's perceptions and practices related to CB and closed-ended questions using a Likert scale. See Appendix B for a copy of the instrument.

Reliability

For this pilot study, the researcher is concentrating on the development of a valid instrument. When replicated, reliability will be tested using the techniques of Chronbach's Alpha.

Validity

Two advanced practice RNs in pediatric oncology provided instrument construct and content validity. Construct validity is the extent to which the instrument adequately assesses the theoretical concept the research is based on. Content validity refers to whether or not the items on the instrument truly test what the study is looking at, and that the instrument is representative of the research questions.

Step-by-Step Procedures

1. Receive IRB approval from the Dominican University of California Institutional Review Board.
2. Contact the president of BAPHON and request for permission to attend the February 5, 2015 meeting to give a short presentation of the study aims, methods, and time frame.
3. If allowed, attend BAPOHN meeting and hand out copies of instrument.

4. Request contact information of BAPOHN members for sending out another round of surveys to increase the amount of responses returned to primary investigator.
5. Contact and send out copies of the instrument to pediatric oncology nurses reached through snowballing.
6. Continue to send out copies of the instrument to members of the BAPOHN and other pediatric oncology nurses.
7. End collection of data on March 1, 2015.
8. Review all collected data.
9. Analyze collected data.
10. Look for common themes in the open-ended responses.
11. Discuss the significance of the results.
12. Disseminate discovered data and information through presentations.

Results

The data collected from the survey instrument produced eight tables. See Table 1 for a summary of demographics on the survey participants.

Table 1: Demographics

Sample Size	n=11
Gender	Female: n=10 (90.9%) Male: n=1 (9.1%)
Ethnicity	Caucasian: n=10 (90.9%) Asian: n=1 (9.1%)
Education Level	Associate's (AA): n=2 (18.2%) Bachelor's (BSN): n=4 (36.3%) Master's (MSN): n=3 (27.3%) Doctorate (PhD): n=2 (18.2%)
Years in Nursing	Range: 6-38 years Mean: 17.5 years
Years in Pediatric Oncology Nursing	Range: 4-23 years Mean: 11.5 years
Observed children with neurological symptoms of CB	100% of participants reported that they have seen the neurological toxicity symptoms associated with "chemo brain."

A majority of the participants were female, and there were varying levels of education as well as a wide range of experience in both nursing and pediatric oncology nursing. One of the most significant pieces of data collected in the beginning of the survey instrument was that 100% of the participants had seen CB symptoms in their patients. To clarify, this did not mean that they had seen CB symptoms in 100% of their patients, rather, that all participants have seen CB symptoms throughout their career and none of them denied its existence.

See Table 2 for participant's definition of "Chemo Brain."

Table 2: Definition of "Chemo Brain"
"Chemo Brain is a CNS drug toxicity leading to confusion, learning disabilities, and poor academic performance."
"A general slowness/fogginess in the patient's speech and processing of information."
"Not being able to concentrate in school, difficulty learning math and staying focused with reading."
"Impaired cognition, both short term and long term, following chemotherapy administration."
"Cognitive, emotional/psychological changes during chemotherapy administration."
"Neurological defects and complications due to chemotherapy treatment."
"I have seen methotrexate toxicity. Patients exhibit neurological changes, loss of control, and facial drooping."
"Inability to think clearly, trouble in school."
"Fuzziness, slow, headaches, blurred vision."
"School difficulties, such as testing."
"Cognitive defects and dysfunction related to chemo/radiation and stress. May or may not be reversible."

These personal definitions of the participants were collected and analyzed by the researcher to find common themes. These themes are explored in the "Discussion" section of this paper.

See Table 3 for the primary symptoms of CB observed by the participants.

Table 3: Primary Observed Symptom of CB
"Regression in math skills, forgetfulness."
"Slowness in response time."
"Learning for school age."
"Difficulty recalling facts."
"Malaise, memory loss, loss of cognitive function, loss of appetite."
"Speech delays, ambulation issues, delayed processing."
"Neurological changes."
"Problems with reading comprehension, poor memorization skills and poor math skill."
"Poor school performance."
"School difficulties."
"Memory and processing difficulties."

Many of the primary symptoms described by the participants were related to one another – difficulty with memory being a common answer. The themes that the researcher found in the responses from the participants is further explained in the "Discussion" portion of this paper.

See Table 4 for the descriptions and definitions of CB that the participants give to their patients and families.

Table 4: Description/Definition of CB Given to Patients and Families
"Chemo brain is a side effect of the medications that you are receiving to treat your cancer. At this time we don't have any prevention for it."
"I never describe or explain it to families. As an inpatient nurse I don't see it as often and it is dealt with more in the outpatient world."
"I describe it as something real and not to ignore the issues."
"Chemotherapy administration – oral, systemic, or intrathecal – can impair cognition (data recall, short term memory loss)."
"Cognitive loss or changes, school work struggles, balance coordination, mood changes."
"Possible side effects of chemo – neuro deficits. Speech or physical therapy may be needed."
"I only bring it up if a patient has a history of it or extreme sensitivity. Coordinators give out handbooks."
"I don't, this is the responsibility of the oncologist."
"Doctors do, nurses don't."
"Nurses don't do this."
"I do not refer to it as 'chemo brain', but risk of cognitive dysfunction."

These dialogues gave descriptions and definitions given to patients and families by the participating nurses. While some nurses felt the doctors were the ones to explain and define this to the patients, the majority of definitions had similar themes to the nurses' personal definitions. Again, the analysis of these responses and exploration of the themes is discussed in the next section of this paper.

See Table 5 for when the participants stated the discussion about CB takes place.

Table 5: Timing of CB Discussion
"Almost always at the end of induction."
"In outpatient care."
"After the fact."
"At diagnosis. Then families forget until the end of therapy when patients/children don't do well in school."
"Frequently, during chemotherapy administration and prior and follow up."
"When they are getting chemos that are more likely to cause these side effects."
"Doctors address this in consent, teaching handbook, before MTX therapy (occasionally)."
"Consent at induction and at maintenance phase."
"At diagnosis or soon after."
"I imagine at diagnosis."
"Consent conference, new patient education, at presentation of symptoms."

Because the researcher knew that CB would not be included in all consent processes, she asked the participants when they had the discussion about CB with their patients and families. The themes are described in the "Discussion" part of this paper.

See Table 6 for how facilities assess the presence of CB.

Table 6: Assessment of Presence of CB
"Our facility will make a referral to a psychologist if it is affecting academic performance."
"I don't know."
"Not as often as we should."
"We assess, ask about school/academic performance."
"Physician, school teachers, mom's report."
"During physical exams and by use of therapy programs."
"CT/MRI"

"I don't know, so maybe not."
"With our cognitive psychologist."
"I have not seen this."
"Assessment, family concern."

See Table 7 for how nurses assess the severity of CB.

Table 7: Assessment of Severity of CB
"Learning instruments are used by the psychologist."
"I don't know."
"I am not sure. Working in Chicago we would refer patients to the psych/child life."
"Unknown"
"Don't know – based on symptoms."
"Unknown, through physical exams."
"Overall pictures, scans."
"Unknown"
"I don't know"
"Testing by schools."
"NCI (National Cancer Institute) Grading."

Surprisingly, many of the participants were unaware of the protocols of their facilities to assess the presence and severity of CB. There were a few responses that are further discussed in the final section of this paper.

Finally, see Table 8 for the reported best educations practices to teach families under stress about CB.

Table 8: Reported Best Education Practices to Teach Families Under Stress About CB
"I would illuminate it after consenting, but during induction. I would remind parents of it at the start of maintenance."
"To reiterate that it is normal and potentially temporary."
"Patience"
"Teach at diagnosis and readdress at every phase of treatment. Readdress at the end of therapy."
"Repetition. Get them involved. Proactive and prevention. Make it fun."
"Written education, review frequently, give them signs and symptoms of what to look out for."
"Patient handbook, reminders before procedures."
"Refer to school counseling office, ask for testing if child is struggling."

"Don't talk about it until after induction - too stressful and they can't do anything about it."
"Wait until child shows signs of chemo brain."
"Written materials for future reference."

Perhaps one of the most important and vital responses from the participants was the exploration of their reported best education practices to teach their patients and families. While the main theme was repetition, there were some variations in practices. These variations and themes are discussed in the following section of this paper.

Discussion

Of the educated and experienced participants, 100% reported that they have seen the neurological/CNS toxicity signs of CB. With such significant results, it can be interpreted that CB is quite prevalent in the pediatric oncology population.

One of the research questions explored in this study was the definition of CB by pediatric oncology RNs. Personal definitions of CB were found to have a couple of common themes. In a majority of definitions provided by participants, CB was described or defined as a mental slowness or fogginess as well as varying difficulties in academic performance. When asked how participants would describe or define CB to their patients and their families, the major themes were quite similar. While a number of the participants stated that doctors were most often the ones to define and describe CB to the patients and families, the remaining participants had a common theme. In general, they would describe CB as a side effect from chemotherapy treatments that included cognitive changes in memory and recall. The researcher was surprised to see the results indicating that a number of the participants did not feel that it was their responsibility to describe and define CB to their patients and families.

On a 5-Point Likert Scale, seven of the eleven participants (63.6%) reported that they saw symptoms of CB "Sometimes," three of the participants (27.3%) reported that they saw CB in their patients "Almost Always," and one participant (9.1%) reported that they saw CB "Always" in their pediatric oncology patients receiving chemotherapy treatment. Although most participants described CB symptoms to effect neurological and cognitive functioning, one participant reported ambulation and balance issues and another reported appetite issues. Some of the most common neurological and cognitive CB symptoms seen by participants included forgetfulness (including difficulty with recalling facts and memorization), slowness in response time, difficulty in school, and regression in math skills.

Although 100% of the participants reported that they have seen CB present in their patients and reported that they saw CB sometimes, almost always, or always, more than half of the participants reported that they only "Sometimes" include the possibility of CB in their treatment consent procedures. One participant even reported that the possibility of CB was "Never" included in the treatment consent process. These results relate back to previous research mentioned in the literature review that discusses the controversy of including CB in the consent process. Although it is present in many cases, there is limited knowledge regarding CB and the incidence of CB must be confirmed before including it in routine discussion and as part of the informed consent process.

With the assumption prior to the data collection that CB would not always be included in the consent discussion, the researcher asked participants when the discussion about CB took place with their patients and families. There were three main themes – at diagnosis, during the induction phase of chemotherapy, and at presentation of symptoms.

It was interesting to see the contradiction between the timing of the discussion and how often the possibility of CB was included in the consent process. Although a majority of participants stated that the possibility of CB was only included in consent procedures "sometimes," more than half of the participants reported that the discussion about CB took place at diagnosis, before the induction of chemotherapy, and two participants even reported it occurred at the consent conference with the doctors. The researcher can only speculate that although CB may not be discussed often during the consent process, it is still mentioned to the families as a possibility before the chemotherapy treatment begins or soon thereafter.

Another important research question explored in this study was the best evaluation and assessment of presence and severity of CB according to the pediatric oncology nurse. When asked how their facility assessed the presence of CB in their patients, many nurses were unsure of their facility's protocol. Two participants reported that they make referrals to psychologists who will further assess the child. Another participant also reported that presence of CB was assessed during physical exams and assessments. Some participants stated that further assessment and referrals were made only if there were reports of problems in academic performance. Two participants noted that they often made referrals and complete further assessments if the parents report any problems or show any concern. One participant noted that the presence of CB was assessed by CT or MRI scans. Overall, the participants that were aware of how their facility assessed for the presence of CB suggested that this assessment most often took place once symptoms had already been occurring and some concern had been brought forward by the patient or family.

When asked about how their facility assessed for severity of CB, again, a majority of the participants were unaware of their facility's protocol for this assessment. From those who answered, most of the participants stated that they would refer the child to the psychologist who would use learning instruments and tools such as the NCI (National Cancer Institute) Grading for toxicity criteria. The NCI scale rates toxicity from 0 (Within Normal Limits) to 4 for the toxicity level in different systems of the body – and included a scale for the neurological toxicity criteria that included sensory, motor, cortical, cerebellar, and other neurological domains. One participant said they assessed the severity through the academic performance of the child in school – often based on testing results. The same participant who stated that presence was assessed by MRIs and CTs reported that the severity of CB was also measured by the results of these scans.

Perhaps the most important focus of this study was to discover the pediatric oncology nurses' perceptions of the best educational practices to teach families and patients under stress about CB. When presented with this question, there were a wide variety of responses. In some form, six of the participants reported that repetition and reiteration of the education was essential. One participant stated that it should be readdressed at every phase of treatment and again at the end of treatment. Other participants said that it should be reviewed frequently and patients and families should be reminded before treatment procedures. Three of the participants noted the importance of providing written materials such as a handbook in the education practices. While a majority of the participants agreed that repetition was important, two participants reported that education about CB should be postponed until after the induction phase of chemotherapy treatment or after symptoms have appeared. One participant stated that

during the time of diagnosis and up to induction of chemotherapy, it is too stressful to begin education. The participant suggested that since there is no known prevention for CB and "[the family] can't do anything about it," education should be put off until after induction.

Conclusion

After the unanimous result indicating that all the participants have seen the neurological and cognitive symptoms of CB and the lack of knowledge of facility assessment of presence and severity, it is evident that further investigation should be completed. With such high prevalence of CB symptoms reported, there should be more awareness of assessment by the nurses who care for these patients everyday. This knowledge gap directly affects the ability of these nurses to best educate their patients and families about CB. This warrants further investigation about best practices to educate patients and families and help them to identify CB. Based on participant response, some areas of further education that should be addressed include better nurse education on CB, the development of a chemoprotective agent for the brain or some kind of prevention practice, as well as some kind of universal scoring tool for assessing the presence and severity of CB. Because this data is a result of a pilot study, it is recommended that further research be completed to explore more in depth the best practices for early identification, assessment, and education practices for CB in order to further validate the data produced in this research.

References

Evens, K., & Eschiti, V. (2009). Cognitive Effects of Cancer Treatment: "Chemo Brain" Explained. *Clinical Journal of Oncology Nursing, 13*(6), 661-666.

Duffner, P. (2009). Risk factors for cognitive decline in children treated for brain tumors. *European Journal of Paediatric Neurology, 14*, 106-115.

Moore, I., Hockenberry, M., & Krull, K. (2013). Cancer-Related Cognitive Changes in Children, Adolescents and Adult Survivors of Childhood Cancers. *Seminars in Oncology Nursing, 29*(4), 248-259.

Mulhern, R., & Palmer, S. (2003). Neurocognitive late effects in pediatric cancer. *Current Problems in Cancer,* 177-197.

Raffa, R., Duong, P., Finney, J., Garber, A., Pham, L., Matthew, S., ... Weng, H. (2006). Is 'chemo-fog'/'chemo-brain' caused by cancer chemotherapy? *Journal of Clinical Pharmacy and Therapeutics, 31*, 129-138.

Raffa, R. (2009). Is a picture worth a thousand (forgotten) words?: Neuroimaging evidence for the cognitive deficits in 'chemo-fog'/'chemo-brain' *Journal of Clinical Pharmacy and Therapeutics, 35*.

Staat, K., & Segatore, M. (2005). The Phenomenon Of Chemo Brain. *Clinical Journal of Oncology Nursing, 9*(6), 713-721.

Ullrich, N., & Embry, L. (2012). Neurocognitive dysfunction in survivors of childhood brain tumors. *Seminars in Pediatric Neurology*.

Appendix A

To Whom It May Concern:

My name is Jennifer Tapping and I am a senior nursing student at Dominican University of California. I am currently working on my senior thesis research study.

I would like to invite you to participate in a research study that will be conducted between December 2014 and March 2015, among pediatric oncology nurses. The project is titled, *"Nurse's Perceptions of Best Practices to Educate and Support Pediatric Patients and Their Families Experiencing "Chemo Brain:" A Pilot Study"*

Background: With more advanced and more aggressive chemotherapy cancer treatment leading to higher survival rates, complications with quality of life are becoming more prominent, especially delayed cognitive processing, commonly known as "Chemo Brain" (CB). At diagnosis and throughout treatment, patients and families are routinely educated about the plan of care, but according to oncology nurses' reports, too often details regarding the possibility of cognitive declines or deficits are left out.

Cognitive changes are some of the most common as well as challenging complications associated with central nervous system (CNS) directed treatment, such as intrathecal chemotherapy, for acute lymphoblastic leukemia (ALL) and brain tumors. The estimated incidence of patients who experience deficits in cognitive processing related to their CNS directed treatment is approximately 20% to 40% for children with ALL and 40% to 100% for children with brain tumors (Moore et al., 2013).

Purpose: The purpose of this study is three fold: 1) to define and discuss the etiology of CB, 2) to discuss the best assessment and evaluation of severity of CB, and 3) to explore pediatric oncology nurses' reports of best practice implications for teaching and supporting pediatric patients and their families experiencing CB.

Procedures: Data will be collected through a two-page survey instrument created by the researcher that has construct and content validity provided by two advanced practice registered nurses in pediatric oncology.

Risks: This research study has no potential risks.

Benefits: By participating in this research, further exploration and understanding of the best education and support practices related to CB in pediatric patients and their families may be reached. This may benefit the future practical implications related to CB.

Costs: There are no costs involved in this research study other than the time given completing the instrument.

Payments: There will be no payments for participation in this study.

Questions: If there are any questions about this study, the primary investigator, Jennifer Tapping, may be contacted by email at jennifer.tapping@students.dominican.edu. In addition, if there are concerns or any distress occurs as a result of this study, the research advisor, Dr. Luanne Linnard-Palmer, who is a practicing pediatric oncology nurse, may be contacted at (415)-257-1364

Consent: By completing the following instrument, **consent is implied**.

Thank you!

Appendix B

Nurse's Perceptions of Best Practices to Educate and Support Pediatric Patients and Their Families Experiencing "Chemo Brain:" A Pilot Study

Date:_____

Gender (circle one): Male Female Age:_____

Ethnicity:_____

Education Level:_____

Years in Nursing:_____

Years in Pediatric Hematology/Oncology_____

Have you seen children with the neurological/central nervous system (CNS) toxicity signs of "Chemo Brain" (CB)? (Circle one)

Yes No

How do you define CB?_____

_____

_____

How often do you see CB? (Circle one)

Never Almost Never Sometimes Almost Always Always

What primary symptom of CB have you seen?_____

_____

How often do you include the possibility of CB in your treatment consent procedures? (Circle one)

Never Almost Never Sometimes Almost Always Always

How do you describe/define CB to your patients and families?_____

_____

_____

_____

When does this discussion take place?_____

_____

How does your facility assess the presence of CB in your patients?_____

_____

_____

How does your facility assess the severity of CB in your patients?_____

_____

_____

In your opinion, what are the best educational practices to teach families under stress about CB?_____

_____

_____

Is there anything else about CB you would like to share?_____

_____

_____

_____

Thank you for your time!