

**THE NURSE'S ROLE SUPPORTING QUALITY OF
LIFE IN SCHOOL AGED CHILDREN WITH BRAIN
TUMORS: ROLE IN CLINIC AND SUPPORT GROUP**

Honors Thesis

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Abstract:

Background: The United States is home to approximately 13,000 Pediatric Nurse Practitioners (PNP), professionals whom are deemed capable of providing care to the growing number of children with chronic illnesses (Dunham, Freed, Lamard, Loveland-Cherry, Martyn, 2010). Some 2,000 children are affected by brain tumors each year and are often cared for by a PNP. They can suffer from affected Health Related Quality of Life (HRQOL) factors or sequela that the PNP is responsible for addressing.

Objective: To gain insight into the PNP's role in caring for the pediatric patient with a brain tumor and observe how she addressed HRQOL factors and long-term sequela the child is faced with.

Methods: An observational descriptive study was conducted. A convenience sample of six children undergoing treatment in clinic and nine children in remission at a support group were observed, specifically appraising the PNP's role in caring for them.

Results: Children seen in both the clinic and the support group experience HRQOL factors, and the PNP addressed them in several different ways. She assessed the children's signs and symptoms, made plans of care, identified referrals needed, and made them feel as though they had were a part of a group with hope for the future.

Conclusion: The PNP plays a pivotal role in caring for children with brain tumors through continuity of care; they are one of the first people to meet the patient and family members, and are responsible to ensure their comfort. PNP's also play the vital role of assessing the patient and identifying the child and family needs, any abnormalities, as well as addressing sequela. Finally, in support group, the PNP is a facilitator for the children's peer support, reflection on their experiences and promotes hope for their future.

Introduction:

Purpose:

Pediatric brain tumors, and the life of the journey of the child faced with this diagnosis, takes on three phases; the diagnosis, the treatment, and the long term follow up for sequela. The purpose of this paper is to highlight the Pediatric Nurse Practitioner's (PNP) role in caring for the school aged population (ages 7-17) in the ambulatory clinic and older adolescents (up to 21) in the support group setting in relation to supporting health related quality of life factors (HRQOL factors).

Background and Significance:

Brain tumors, and other tumors affecting the central nervous system, are the second most common cancers the pediatric patient are faced with, only preceded by leukemia; they account for about 25% of all childhood cancers (American Cancer Society, Inc., 2013). Nearly fifty years ago, there was a shift from inpatient treatments to caring for this population in the clinic setting, and this has continued through to today. Due to the care by PNPs, children are able to get their treatments in the clinic, as well as health promotion, and only need to be hospitalized for serious issues such as infections (Wood, 1978).

It is estimated that 2,000 children are diagnosed with brain tumors each year in the United States. These children receive some form of treatment, including a combination of surgery or chemotherapy or radiation plan. The placement, type, or size of tumor can lead to symptoms including mental status changes, headaches, nausea and vomiting, macrocephaly, drowsiness, irritability, depression, or even coma (Johns

Hopkins University). Several of the same symptoms, along with others such as endocrine issues, lack of appetite, and behavioral issues, to name a few, can be followed with outpatient clinic treatment. The significance is that these sequela and HRQOL factors will stay with the child long after treatment is complete, may carry on into the long term follow up phase, and in some instances into adulthood.

Operational Definitions:

Ambulatory Pediatric Nurse Practitioner: The role of the ambulatory PNP is to provide direct care and support in multiple settings to both the family and the pediatric patient diagnosed with a brain tumor. PNPs often follow patients over years into young adulthood within a collaborative team approach.

Health Related Quality Of Life factors: HRQOL factors are those affecting the pediatric patient's quality of living either during or after diagnosis such as physical symptoms and disease state, physiological functioning, social functioning, and functional status (Drotar, 1998).

School aged children: Those children seen in the ambulatory clinic setting between the ages of 7 and 17 years old; for this specific convenience sample, patients only fell between the ages of 7 and 13 years old.

Older adolescent group: Those adolescents seen in the support group setting with ages ranging from 15-21 years. It is not uncommon for young adults who experience chronic and/or critical illnesses to attend group until their early/mid twenties.

Clinic: An ambulatory outpatient setting where children are seen on a regular basis to both receive treatment and for follow up appointments for care for long-term sequela.

Support group: A place for "survivors" to go, feel welcome, and know that they are not alone; it's a way for them to get away from the everyday struggles they are faced with and be around others who are often very similar to them in dealing with HRQOL and

enjoy time. (They could possibly talk, play games, do arts and crafts, etc. in a safe milieu facilitated by a PNP or other health discipline group leader.)

Medical Home Model of Care: A model relying on providers as a group (physicians, pharmacists, nurses, social workers, nutritionists) to meet the needs of the patient. The goal is to pay attention to the patient as a whole and bring in every aspect of health care to improve one's health (NCSL, 2012).

Review of Literature:

The Pediatric Nurse Practitioner's Role in Clinic:

The Patient-Centered Medical Home Model (PCMH) of ambulatory care in pediatrics is being practiced (Carver, Jessie, 2011). This model includes the collaboration of physicians, nurse practitioners, nurse care coordinators, social workers, and others as a team providing patient centered care with the child and family as part of the team. It is with the intent that the patients' continuity of care is more personalized and coordinate (Carver, Jessie, 2011). This model is outside the scope of this paper, as the focus is on the role of the PNP as currently practicing in the pediatric brain tumor clinic environment where the observations took place.

When the pediatric patient with a tumor will be receiving most of his or her care in the clinic setting, the PNP establishes a relationship with the child and family as well as provides physical assessment skills and develops an ambulatory treatment plan from the initial visit. The PNP assesses the child and gathers necessary health information/health history to be able to make sure the child is growing and developing properly throughout treatment. She may ask about their usual state of wellbeing, prior interactions with health professionals, and how the child is handling and living with this new diagnosis of a brain tumor and treatments. The PNP is then able to reinforce the plan of care each time the child comes back to the clinic and can adjust the care plans accordingly (Wood, 1978).

When the child was receiving care in an inpatient setting, there may have been time for initial teaching and patient education. Now, the child is leaving the inpatient

cancer center and has more freedom and control. The PNP reinforces teaching and education to the family and child about the type of tumors, what they can expect to see in their child, and the types of therapy he/she might be undergoing. The family must also be made aware of some possible negative health consequences of surgery or treatment because they can often times require prompt medical attention (Wood, 1978).

Inevitably, these children with brain tumors are going to be ill at times. They have a compromised immunize system and are more vulnerable to infections based on both their tumor and the treatment regimens they are faced with. An infection that may hardly affect an otherwise healthy child may affect these children to the point where intensive antibiotics are ineffective and may prove to be fatal. This population needs to be more aware of common viruses, such as chicken pox for example, or a seasonal virus in their community, and need to take extra precautions (Wood, 1978). The PNP's role is to educate the child and family about preventing infections and responding to early symptoms.

Finally, the PNP has two very important goals when sending a child in remission back into their normal home life; this could include going back to school, sports, daycare etc. First, is to advocate for the child and encourage them to get back to doing previous activities. They can do so by encouraging the child as well as informing the school officials on how important it is for the student to be participating again. On the other hand, they need to identify the limitations and provide anticipatory guidance that not everything will be just as it was before for a while. Secondly, is also important for the parents to check to make sure the child is not falling behind in school (Wood, 1978);

although they can make an effort to schedule appointments when there is no school, this becomes a trying issue when a child is going in for treatments often.

The Pediatric Nurse Practitioner's Role in Support Group:

A pediatric support group has also been called a survivor program. The purpose of these groups is so that children can find a way to adjust to their “new normal.” Life might not go back to exactly what it was before the diagnosis and treatment. These groups help them to transition into their “new life” as a survivor. The PNP is often times the person who sets up and facilitates the support group for these patients (Lewis, 2006).

Support groups have different arrangements based on the region (urban or rural), demographics of the patients, or just the PNP's running the clinic. Some are monthly groups where patients, and their families, (in a separate group environment), can go and discuss what it has been like for them throughout their transition from being on cancer treatment to being a survivor. This type of group is a way for the children to connect with others who went through similar experiences and share their journeys with one another (Lewis, 2006, p. 90).

- “A key component of any program is the ability to connect survivors, to let them have some sort of community where they can share information” –(Lewis, 2006).

Another way of providing a group would be to have a virtual, web-based group (2006). This could benefit children who were traveling a far distance to get to the clinic for their treatments. They could still connect with other cancer survivors, and share experiences, in the same way that others would in a more face-to-face group, but just do so from their own home.

With so many more people surviving cancer, and making it to the follow-up care stage, it is important to educate nurses on survivorship and not have them focus on just treating the patients' current cancer diagnosis. They should be thinking past the treatment phase (Lewis, 2006).

- “A nurse practitioner is the survivorship expert on a multidisciplinary team” –
(Lewis 2006, p. 88).

The PNP constructs the ideas, meeting themes, and relationship building for the survivor program and puts it all into action.

Sequela Following Treatment for Brain Tumors:

Those who survive 5 years after being diagnosed with cancer often consider it a milestone and something to celebrate. But, many warn that this may not be the case for those who have been diagnosed with any tumor affecting the central nervous system. A shocking study revealed “more than 25% of former patients will die within 30 years of their diagnosis-due primarily to recurrence and/or progression of primary disease (Twombly, 2009). In addition, 82% of survivors reported having at least one chronic medical condition, 38% of which were deemed serious or life threatening” (Twombly, 2009). Looking at the long-term effects the children who are treated for cancer are faced with is almost as impacting as the stress of the early diagnosis and treatment.

As a large number of children are affected by brain tumors, the care needs for the child from when they are diagnosed to treatment to getting them back into a “normal” setting again is extensive. Defining “normal” is a rather difficult thing to do. Almost a third of children who undergo treatment for a brain tumor need special services from their

schools. From a medical standpoint, the child may be forced to deal with neurological problems like seizures or poor coordination, endocrine problems (such as growth deficiencies) sensory deficits leading to cataracts, or even being blind or deaf. The probability of a number of other sequela also increases. (Twombly, 2009).

Health Related Quality of Life:

Health Related Quality of Life is “the extend to which the effect of illness impacts on satisfaction with life and how individuals adjust to meet life’s demands with the sequela of illness. Self-perceived HRQOL measures allow participants to comment on the extent to which their basic needs are being met, to the opportunity to pursuer and achieve goals” (Goodes, 1990).

When suffering from a chronic illness, it often times becomes “hard” to live with the diagnosis. They suffer from things such as pain, activity restrictions, and an increase in worry, but most are able to find ways to adjust. Some even find it easier to cope by giving themselves credit for doing something successful or talking to a friend about what they are dealing with (Woodgate, 1998). Talking to a friend who is also a brain tumor survivor can be validating and reaffirming.

HRQOL tools have been established to assess the medical care and their outcomes over periods of time. They may look at a patient’s experiences with their medical care or be asked to describe thing they experienced in relation to their diagnosis (Drotar, 1998). The purpose of having health tools such as these are for “ morbidity screening and prediction, evaluations of the usefulness of drug therapies, policy analyses, and cost benefit analyses for medical treatments” (Aaronson et. al, 1991). After examination, it is

then possible to look further into how a condition impacts a patient's quality of life (Drotar, 1998).

Summer Camp for Children with Chronic Illnesses:

Summer camps for children who have chronic illnesses, such as cancer or blood disorders, are conducted so that they have a place to go and "just be kids for a while" (Baer, 2013, p. 1). These children often times need a place to get away from things they are facing at home, like being in the hospital or having treatments. When they have such a diagnosis, and are frequently having to prioritize medical care, they are "robbed" of a childhood. (Baer, 2013, p. 1).

These camps can change their life. Children aren't supposed to worry about difficult things in their life. Instead they are supposed to worry about being kids. Once at the camp, these children can participate in activities similar to children at a regular camp; they can play different sports, fish, go boating, do arts and crafts, take part in theater classes or clowning, go to a wood shop, go camping, or to recreation. Activities are modified to fit the needs of this population to make it safe for them based on their diagnosis (Baer, 2013).

At the camp, the children feel as though their peers accept them, giving them a true feeling of community. While living at home with cancer, they can often feel isolated from other children they are around at school or feel as though not everyone accepts them. But once they come to camp, there are other children just like them allowing them to be themselves when they get a true feeling of affirmation and safety (Baer, 2013).

- "I know I'm at a camp that's really fun and that I can have a good time at. I don't think about the hospital, and I don't think about cancer. Even though there may be kids there who are sick, I still don't think about it." – an 11-year old camper (Baer, 2013, p. 1).

Camps for children with cancer are staffed with recreational camp councilors and routinely PNP's with expertise with this population. The PNPs enjoy the recreational experiences with the campers as well as providing coverage in the health/treatment room, oversee medications, first aid, and other health care needs. Their presence at camp enables families to relax and feel confident about sending their child to a camp staffed and co-sponsored by cancer clinicians when they might not otherwise (Edwards, 1999).

Methods:

Design:

This project utilized a qualitative observational design with two areas of focus which included identifying the PNP's roles in the ambulatory clinic and support group regarding areas of HRQOL factors in school aged children. The study was approved by the Salem State University IRB as well as a letter of support from the pediatric brain tumor clinic supporting the nursing student to observe in clinic and support group.

(Appendix A.)

Setting:

This project took place over 2 sessions at the pediatric brain tumor clinic in private exam rooms with the PNP, the school aged child, and the parent(s)/guardian or family. There was also one session that took place at the support group in a conference room, with older adolescents, facilitated by the PNP.

It was noted that in each of the two settings, the PNP had a very different presence about her. In clinic, she was the primary care provider, assessing the child and making the decisions as to what should be done next. Then in the support group, she was a quieter facilitator. She was there for support and guidance, but is not as hands on; these differences were further evaluated.

Sample:

A convenience sample of six children seen on two separate occasions in the clinic setting, and a convenience sample of nine adolescents of long-term follow-up or

remission attending a pediatric neuro-oncology outcomes clinic support group, were used for this project for a total of 15 children and adolescents. A disclosure form was made to inform parents of the student researcher as an observer and the purpose of the study. Parents were informed that participating was voluntary and anonymous. The IRB approved form is attached. (Appendix B.) As suggested by the Salem State University IRB, a letter for informed consent was not needed for this project. The researcher was not conducting any research on the children themselves, but more so looking at the PNP's role in caring for those pediatric patients with a brain tumor.

Data Collection:

A demographic observation log was created by the student researcher. It included non-identifiable factors including the child's sex, age in years, diagnosis, HRQOL factors, and the PNP's role. (Appendix C). The log adapted ideas from previous HRQOL factors studies found in literature by Marcoen and Van den Bergh, 1999.

Limitations:

Limitations to this study were that there was only access to those children who came to the clinic on the days the researcher was there. Due to that, there was no say in what types of brain tumors or specific ages children would be seen. Only six children were observed for the study as well (in clinic), which is a small percentage compared to the number of children who are actively attending the clinic on a regular basis. Also, those children in support group chose to not talk about their brain tumors or reveal much information about their past experiences. Although the entire point of having a support group for these children is to give them hope for the future and a place to feel as if they

are not alone, it limited the study in not allowing the researcher to know what type of tumor they had or any of their treatments. Again, the focus and scope of this project was primarily focused on the PNP's role in this unique care environment, the support group of adolescent survivors of brain tumors.

Observations/Results:Table 1: Demographics (Children Seen in Clinic):

Child	Gender	Age	Diagnosis
1	male	9	medulloblastoma
2	male	13	low-grade glioma
3	male	9	medulloblastoma
4	female	7	glioma
5	male	9	unknown
6	female	11	glioma

Pediatric Nurse Practitioner's Role in the Ambulatory Clinic Setting:

The PNP plays a vital role in health assessment and management in the clinic setting. This is true for both those children currently undergoing treatment and those there for their annual follow-up/well-visit. But the specifics for each of these types of patients meetings with the PNP do vary in some ways.

For those who are currently undergoing treatments, the PNP first looks over the child's labs, specifically looking at his or her absolute neutrophil count (ANC) and vital signs; these are both an important factor as to whether or the child can receive his or her chemotherapy treatment for the day. Once this is complete, the PNP goes into the private assessment room or bay area to meet with the child and accompanying family.

She makes sure that the child is feeling well and checks in briefly with the parents and child. Then, she will listen to the child's heart and lungs as well as briefly assessing

their ears, eyes, nose and throat. If everything looks normal, and nobody has any questions, she can move on to telling the nurse that it is safe to give the dose of chemo for the visit. But if there is an issue, for example a sore throat, then the PNP will order a throat culture. Or if there is a low ANC and blood count, the PNP will be responsible for ordering the blood for an infusion. She would also be responsible for ordering Tylenol for pain that a patient is experiencing in the clinic. The potential examination issues goes on, but in general, the PNP is required to assess the child and make the best decision as to what she needs at the moment, including to decide when she needs to be admitted to the hospital based on ANC elevated, temperature, and or other symptoms of infection.

For those who have been off treatment and are back at the clinic for their annual checkup, the PNP starts off by having a casual conversation with the child. She may ask how the child is doing or feeling or may ask if anything is new with him or her. Once this is established, then specific health related questions are asked. These are all specifically related to HRQOL factors that the child either is or was faced with from the tumor, treatment, or long term sequela.

Table 2: Possible questions the PNP will ask the child or family member at long term follow-up clinic:

-
- Have you had any new health issues since your last visit?
 - Have you been to the PCP for a physical?
 - Have you been having any recurring headaches?
 - Are there any behavioral issues going on?
 - How are things in school? ... Physical Therapy/Occupational Therapy ? Individualized Education Program (IEP)? Adjusting to harder schoolwork or social pressures?
 - How are things with eating? Is he/she eating health meals/drinking milk?
 - Are things going OK on the current medications?
 - Are there any issues with incontinence?
 - Are there any other questions or concerns you have for me?
-

- Note that the above questions are casual, open ended and easy to be addressed and that more directed questions can be added to any feed back or problems.

Once these questions are fully answered and the PNP has a good understanding of where the patient stands for this visit, she will go ahead and do a physical exam. If the child is stable, it is a quick 5-minute assessment. This includes growth and development, listening to their heart and lungs as well as checking the child's ears, eyes, nose and throat. Next, she often times performs a full neurological exam; this includes things such as having the child walk on their heels and toes across the exam room, having them push and pull or squeeze on the PNP's hands, and tap their fingers as fast as they can. Sometimes a deficit can be seen on one side from where the tumor affected the brain. But, if everything seems to be normal, or stable, then they are allowed to be sent home and will come back to the clinic in a year for another Magnetic Resonance Imaging (MRI) and check-in with the PNP. (They are reminded to call with any questions or concerns that may arise between visits.)

Being part of a neuro-oncology clinic, and working closely with so many children also requires working with radiology. Due to that, the PNP also attends meetings where other nurse practitioners and doctors meet in a conference style room to go over MRI films of the patients being seen in the clinic. Here they can all go over previous MRI's as well as the most recent ones. This allows them to see a comparison and then decide if the current treatment is working properly or if the child needs it to be changed; having other experts in the field there allows for other input on the children the PNP is seeing in the clinic setting as well.

Table 3: Observed symptoms and treatment which may affect HRQOL:

Behavioral:

- Children often have behavioral issues that were not present before the tumor
- Get an IEP/504 plan: be integrated into special classes in school or assistance as needed for a least restrictive environment (for example: extra time on exams)

Symptoms:

- Missing adult teeth from the chemo affecting dividing cells at such a young age
- Increased/severe ataxia
- Become nonverbal
- Lose vision or hearing/have a decrease in both
- Be aware of going to bathroom but due to the tumor not getting up to go
- Recurrent fevers
- Not being able to eat a regular diet
- Delayed or precocious puberty

Treatment:

- PT/OT/SLP

- Using AFO braces or other assistive devices to help with weakness
 - Having to receive tube feeds through a G-tube
 - Needing to go to clinic often for chemo/blood or platelets
 - Endocrine or hormonal treatments
-

Observation of the Pediatric Nurse Practitioner's role in the support group setting:

The PNP plays a much different role in the support group setting than she does in clinic; here she is more of a councilor and facilitator than someone actually giving medical advice. The children at the support group have already gone through their treatments and now are attending group with others from the clinic. They may still suffer from sequela factors, and this support group is somewhere they can go to feel as though they fit in and belong.

The children appear to love seeing the PNP at the support group; they have been through thick and thin with him or her in the clinic setting throughout their treatments for their brain tumors. Now they are here sharing their hopes for the future with someone that they have grown to trust.

Often times other people from camps for children with cancer may attend as well, such as the camp counselors. The children attend the camps over the summer so spend time bonding with both one another and the counselors. They share memories about the times they shared at camp. The PNP sits back and gives them that time and freedom to be children and feel free. But she also engages and helps them with whatever activity it is they may be participating in when they may need help; they will often go to him or her.

This support group truly does show their hope for future advancements throughout their reflections and optimism.

Table 4: Positive actions observed of adolescents during group:

-
- Hope for the future
 - Going to school to be a nurse
 - Getting a job
 - Living on their own
 - Finding a talent→art
 - Finding true friends who accept them for their differences after treatment
-

Table 5: Adolescent’s reflection during the support group:

-
- “I love going to the camp! Remember when we all went last year and went to the ‘house?’ That’s always all of our favorite place to go!”
 - “He’s the artist but never wants to admit it. He’s so good at painting and drawing. We love to see what he makes.”
 - “I’m going to school now. I’m going to be a nurse!”
 - “He lives on his own now. He tries his best to be as independent as he can.”
 - “This is my best friend. He comes to support group with me. He’s been there with me through it all and helps me so much.”
-

The previous quotes were said so effortlessly. The children were so open about how they were feeling and knew they could act however they wanted to because the group provided a safe and trusting environment.. They felt comfortable opening up to one another, to the PNP and to the researcher. The support group truly made them feel better about themselves and it was something they looked forward to every month. They knew they would be with friends and supporters...fellow survivors...who have similar stories to share and truly understood them.

Conclusion:

From the physician's perspective, "a more comprehensive appreciation of the nature and scope of PNP care provision is essential to understanding their role in the changing landscape of the organization of care for children" (Dunham, Freed, Lamard, Loveland-Cherry, Martyn, 2010, p. 850). The PNP in an ambulatory brain tumor clinic is responsible for direct patient care and continuity over time. In doing so, she devises a care plan for the child, gives the child a sense of hope for the future and continues with follow-up care after treatments.

Table 6: Nursing Implications:

-
- Look after vital signs/blood counts
 - Complete neurological exams/5 minute assessments
 - Check in on child's overall well being
 - Make sure current treatment regime is working appropriately for the child
 - Collaborate with other medical staff (PNP, MD, RN)→medical home model
 - Place orders when necessary for things such as blood, platelets, chemo, etc.
 - Send referrals for things such as rehab, psych consults, or to an endocrine specialist
 - Be a supporter throughout the entire 3 phases of the child's brain tumor
-

Furthering the research:

This study only observed a very small portion of the total population of those children who are currently living either with a brain tumor or who have survived and now are suffering from sequela. To further the research, one could expand the number of children seen. Also, with it being a convenience sample, observations were only children who came to the clinic on any random day. Specific HRQOL factors may be present due to diagnoses or sequela.

Another option to further this research would be to expand on the HRQOL factors portion itself. This study only focused on the actual factors the child presented with and how the nurse addressed them. One could use a scale to actually measure the HRQOL factors and their significance.

As a senior BSN nursing student, this study was able to better prepare me for a career choice and vocational pursuits. I was able to be placed in a pediatric placement for my senior thesis and am working as a nursing assistant at a children's hospital, so it is clear that my true passion is in working with children. Yet people still question why I would ever want to work either with children with cancer or in a clinic setting. "Kids with cancer? That is crazy!" or "A clinic? Why would you do all of this education to work in a clinic?" I have heard it all before.

After seeing what takes place in a “clinic” and how well cared for the children are, and how amazing the staff are, I challenge everyone to say: why wouldn’t I want to be there? I truly had no idea just how much care and compassion the children needed while going through chemotherapy. But I also didn’t know what strong was until I saw such young kids toughing it out, fighting for another day, laughing and playing with me after suffering from so many long term sequela.

There is no other place I would rather be, and no other career path I would rather take, and I consider myself very fortunate to have been able to experience this first hand and learn from such an amazing PNP while still in school for a BSN. Next time someone questions me, I will be sure to remind them the value of the PNP in a pediatric brain tumor setting. I will tell them she is the one who cares for the child receiving care, how she is often a child’s hope for the future, how she often provides light at the end of the tunnel for the family, and of course that when everything is all said and done, the children look up to her as a true supporter.

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Appendices:

Appendix A,1:



Notice of Expedited Review {45 CFR 46.110 and 21 CFR 56.110}

The Office of Sponsored Programs and Research Administration has evaluated the project named above. According to the information provided, you intend to study 1. Nurses role supporting quality of life in school-aged children ages 8-17 with brain tumors;. This study presents no more than minimal risk to human subjects, and involve only procedures listed in one or more of the following categories as authorized by 45 CFR 46.110 and 21 CFR 56.110 (*Department of Human Services, Part 46: Protection of Human Subjects; effective 7/14/2009; <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm>*).

The activities listed should not be deemed of minimal risk simply because they are included on this list. Inclusion on this list merely means that the activity is eligible for review through the expedited review procedure when the specific circumstances of the proposed research involve no more than minimal risk to human subjects.

Appendix A, 2:



DANA-FARBER/CHILDREN'S HOSPITAL CANCER CENTER

Stop & Shop Family Pediatric
Neuro-Oncology Outcomes Clinic

Dana-Farber Cancer Institute
450 Brookline Avenue, SW 331
Boston, Massachusetts 02215-5450
617.632.2680 tel
617.632.4897 fax
pedibrainumor@dfci.harvard.edu
www.dana-farber.org

10/15/13

To Whom It May Concern,

Nichole Dunnebie has been approved to observe the nurse and nurse practitioner role at Dana-Farber Cancer Institute.

Please direct questions to Christine Chordas. 617-632-2385.

Sincerely,

Christine Chordas, PNP

Kathleen Houlahan, RN, BA, MHA



Teaching Affiliates of Harvard Medical School

Appendix B:

Salem State University
Institutional Review Board
Disclosure Statement

My name is Nichole Dunnebier and I am a senior nursing student at Salem State University. I will be conducting an observation in both the clinic and support group for my undergraduate senior honors thesis. I am going to be looking at the nurse practitioner's role in caring for children with brain tumors, for example how he/she addresses symptom management and in facilitating the quality of life for your child.

I have a checklist of nursing roles and type of interactions that will be used while I am observing the nurse practitioner (APRN). I may record your child's age, gender, and diagnosis however, no names or other identifying information will be collected. With that said, your child's name or other identifying information will not be used in any reports or findings of this senior honors thesis.

This research project has been approved by the Institutional Review Board at Salem State University. Thank you for your help.

For questions or concerns about the research, please contact my faculty mentor/sponsor Robin R. Leger, RN, MS, PhD. (rleger@salemstate.edu)

For concerns about your treatment as a research participant, please contact:

Institutional Review Board: (IRB)
Sponsored Programs and Research Administration
Salem State University
352 Lafayette Street
Salem, Ma 01970

(978) 542-7556 or (978) 542-7177 or irb@salemstate.edu

A copy of this signed form is as good as the original

Appendix C:

Observation Log

Ambulatory Nursing (APRN) Role with School-age Children with Pediatric Brain Tumors

Date	Site	Child Sex/age	Child Dx	QOL factors	Nursing role
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KEY

Site: C = Clinic G = Support Group

Sex/Gender m = male; f = female Age range 7 – 17

HRQOL Factors

APRN Role with Pedi Brain Tumors:

Appendix D:

Clinical Services for Survivors of Childhood Cancer

STEPS for Young Brain Tumor Survivors

STEPS, or "Success Through Education, Psychosocial support, and Socialization," is a support program that holds monthly events for adolescent and young adult brain tumor survivors and their parents or caregivers.

Organized by survivorship experts from Dana-Farber, these activities offer attendees a chance to connect with one another, learn new skills, and have fun.

For parents and caregivers, STEPS events offer a chance to talk with experts, attend presentations, and interact with others who are also coping with survivorship challenges.

For both survivors and parents, STEPS provides an opportunity to be with others who understand the difficulties associated with brain tumor survivorship. It's also a chance to gather valuable resources to address concerns. STEPS is designed to promote self-confidence, communication, and the ability to work with others.

Who can attend STEPS?

The program is for brain tumor survivors who:

- Have been off cancer treatment for at least two years
- Are age 13 or older
- Are currently being seen in the [Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic](#) at Dana-Farber

Eligible survivors are welcome to attend STEPS events with or without their parent or caregiver. Similarly, parents and other caregivers are welcome to come to STEPS events even if the survivor does not attend.

(Dana Farber, 2014).