

# Symptoms, Coping, and Quality of Life in Pediatric Brain Tumor Survivors: A Qualitative Study

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**P**ediatric brain tumors are the most common solid neoplasm in children (Faria, Rutka, Smith, & Kongkham, 2011). From 2001–2005, 4,181 children aged 0–14 years were diagnosed with cancer in Canada, and 676 died from this disease (Ellison, De, Mery, & Grundy, 2009). The incidence of primary pediatric brain tumors is about 2.76–4.28 cases per 100,000 children (Maher & Raffel, 2004). As more children survive cancer, the need for long-term monitoring and follow-up care continues to grow (Ellison et al., 2009).

Current management strategies for children diagnosed with brain tumors aim to optimize long-term survival in children with high-risk tumors, while maintaining high survival rates in children with low-risk disease (Pollack, 2011). Treatment for pediatric cancers usually involves one or more of three main modalities: localized surgical resection, radiation therapy, and/or chemotherapy. The trend in neurosurgery for pediatric neuro-oncologic conditions has been toward less invasive procedures and non-surgical interventions, where possible (Mainprize, Taylor, & Rutka, 2000), because treatment toxicities are cumulative (Eiser, 2004). The outcomes for children diagnosed with and treated for cancer are largely dependent on host factors, the type of cancer diagnosed, timing, and treatments received (Bhatia & Landier, 2005). Aggressive therapy often is needed to cure this potentially lethal disease; however, late effects, such as injury to the developing brain, remain a profound concern (Walter & Hilden, 2004).

With surgical resection, craniospinal irradiation, and chemotherapy, cure rates as high as 85% can be achieved in average-risk cases; however, improved survival can affect quality-of-life (QOL) outcomes in survivors (Gottardo & Gajjar, 2008). Survivorship is conceptualized as the phase of cancer care that begins after the completion of definitive therapy (Grunfeld & Earle, 2010). Brain tumor survivors include children

**Purpose/Objectives:** To explore the symptom experience, coping strategies, and children's descriptions of their quality of life (QOL) after treatment for a brain tumor.

**Research Approach:** An interpretive descriptive qualitative study.

**Setting:** A pediatric hospital setting in Ontario, Canada.

**Participants:** 12 children aged 9–18 years.

**Methods:** Content analysis of semistructured interviews was guided by interpretive description methodology.

**Findings:** Children described symptoms including feeling tired, pain, headaches, emotional problems, difficulty thinking and remembering, problems with sleep, physical problems, and weight changes. Symptoms interfered with physical activity, keeping up with school, maintaining appearances, and communication. Coping strategies included reconditioning, taking breaks, taking medication, challenging themselves, volunteering, maintaining friendships, laughing, and using aids.

**Conclusions:** Survivors experienced multiple symptoms that had an effect on their life, but overall, they described good QOL.

**Interpretation:** Caregivers need to understand the complexity of their patient's symptom experience and its impact on his or her daily life. Coping strategies can be identified to help mitigate potentially negative QOL outcomes.

**Key Words:** pediatric oncology; neurologic malignancies; nursing research qualitative; quality of life; survivorship

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and youth who have completed treatment for a brain tumor and who have received surgery, chemotherapy and/or radiation therapy. Cure from this disease can come at a high price in terms of late effects that may impair long-term QOL (Pollack, 2011). Treatment for children with brain tumors can result in many neurologic complications, such as neurocognitive problems that can affect daily function (Monje & Fisher, 2011). Brain tumors and their treatments in children result

in a range of neurologic complications that can affect daily function and rehabilitation potential, including neurocognitive sequelae, ototoxicity, seizure disorders, stroke, and peripheral neuropathy. Deficits in cognitive function, particularly learning, memory, attention, and speed of information processing, can be debilitating. With new insights to the cellular and molecular etiology of these deficits, new therapies for cognitive decline after therapy are emerging. Management strategies for other neurologic complications are also emerging. Long-term survivors of childhood central nervous system malignancies are at increased risk for late mortality, development of second neoplasms, multiple endocrinopathies, and adverse neurologic health conditions (Armstrong, 2010).

In a systematic review of symptom experience and QOL in pediatric brain tumor survivors who had completed treatment, survivors had significantly lower QOL scores across domains when compared to other cancer survivors, healthy peers, or normative data (Macartney, Harrison, VanDenKerkhof, Stacey, & McCarthy, 2014). In this review of available evidence, no qualitative studies were found that describe the link between symptoms and QOL during survivorship.

Quantitative studies provide an important perspective on the symptoms experienced by children with cancer; however, they are limited by the characteristics of the tool measures. Discrepancies between self-assessment by children and proxy measures (e.g., parents or teachers) may be a result of quantitative questionnaires or because children are not as attentive as parents to reporting (Carpentieri et al., 2003). Such data collection approaches address research questions about quantitative properties of symptoms without elaborating fully on the symptoms experienced (Vatne, Slaughter, & Ruland, 2010; Woodgate, 2008; Woodgate, Degner, & Yanofsky, 2003). For clinicians to effectively help children with their illness and symptoms, it is important to communicate with them in a language they can understand.

Semistructured interviews were used to investigate how well six children with cancer understood 44 physical symptoms terms compared to eight healthy peers (Vatne et al., 2010). The assessment included children's understanding of the symptom causes, consequences, and cures, and described other terms used to express these symptoms. Study findings helped to identify differences in understanding between the two groups. Both groups of children indicated a good understanding of the physical symptoms terms; however, children with cancer had a more varied vocabulary for describing symptoms and could specify symptom intensity. Clinicians need to be sensitive to the broad variety of expressions used by children to describe their symptoms (Vatne et al., 2010). Unfortunately, little is known

about the symptom experience among various age groups and how symptoms interfere with daily life in pediatric brain tumor survivors (Ruland, Hamilton, & Schjodt-Osmo, 2009). Few studies have explored the symptom experience in children who are aged younger than 18 years and have completed treatment for a brain tumor.

## Qualitative Study

This study was part of a larger cross-sectional inquiry in which the symptom experience and QOL in 50 children who had completed treatment for brain tumors were evaluated (Macartney, VanDenKerkhof, Harrison, & Stacey, 2014). Sixty-four percent of children had low-grade disease and 42% were treated with surgery alone. Children reported a median of six symptoms. Lack of energy, pain, headache, difficulty with concentration, and difficulty with sleep were consistently rated the highest across all symptom domains measured. Lack of energy, pain, difficulty with concentration, and shortness of breath explained 48% of the variance in the Pediatric Quality of Life Inventory total scores (Macartney, VanDenKerkhof, et al., 2014).

The purpose of the current study was to qualitatively explore the symptom experience and its effect on QOL in a subset of children involved in the previously mentioned study. Research questions include: (a) How do children describe symptoms experienced? (b) How do these symptoms affect their QOL? (c) What coping strategies are used by children to manage symptoms? and (d) How do children describe their QOL?

## Methods

### Research Approach

This study was based on an interpretive, descriptive qualitative research design. Interpretive description is a qualitative inquiry that helps to develop new knowledge by understanding the reality of the lived health and illness experience and provides clinicians with the contextual knowledge required to apply evidence in the clinical setting (Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, 2008). Ethics approval was obtained from Queen's University Research Ethics Board and from the Hospital's Research Ethics Board.

### Setting

The pediatric hospital located in Ontario, Canada, serves a population of 1.5 million people of all ages. Currently, about two children per month are diagnosed with a brain tumor at this center. Over a five-year period (2004–2009), 62 children were diagnosed with a brain tumor, and about 10–12 survivors attend monthly follow-up clinics at this center.

## Participants

Children first completed a survey exploring symptoms and QOL that is reported elsewhere (Macartney, VanDenKerkhof, et al., 2014). Children were eligible for the qualitative study if they were aged from 8–18 years and were a minimum of three months after completion of therapy. They were excluded if they were undergoing active treatment or were unable to express themselves verbally because of cognitive impairment. Over the course of eight months (December 2011 to July 2012), 55 children met the inclusion criteria, and 50 agreed to participate in the quantitative study. All 35 children who met the age requirements for the qualitative study agreed to be contacted for a follow-up interview.

Using purposeful sampling, 14 participants across a range of developmental stages were selected for interviews with at least three participants from each age group: 8–12 years, 13–15 years, and 16–18 years. Because symptoms could vary depending on the time since completion of treatment, the current study's researchers aimed to stratify the groups to include children who were less than two years since completion of treatment and those who were greater than two years since completing treatment. The researchers also aimed to include an equal number of males and females. Recruitment continued until no new ideas were being generated (Francis et al., 2010).

## Methodologic Approach

Written consent was obtained from parents or legal guardians, as well as from participants who were aged 14 years or older. A semistructured interview guide was used. Children were first asked to talk about their cancer experience, including diagnosis and treatment, followed by a description of the symptoms they identified in the prior survey (Macartney, VanDenKerkhof, et al., 2014). Prompts were used to help them describe how these symptoms affected their QOL and what helped them cope with the symptoms. Children were asked to describe their QOL and any other symptoms that had not already been discussed. Interviews took place in a private conference room at the hospital. Parents were welcome to attend the interviews. Interviews were audio recorded, and field notes were written.

Consistent with interpretive description methods, inductive analysis was used (Thorne et al., 1997). Data analysis using verbatim transcripts was concurrent with data collection, supporting a constant comparative methodology (Lincoln & Guba, 1985). Analytic techniques outlined in Giorgi's (1985) framework were used. First, the entire transcript was read to get a general sense of the whole. Second, transcripts were re-read with the specific aim of discriminating meaning units with a focus on the phenomenon of interest (e.g.,

symptoms, coping, impact, QOL). Next, all of the meaning units were reviewed to more directly identify the insight contained in them. Lastly, all of the transformed meaning units were synthesized into a consistent statement regarding the children's experience.

## Credibility and Rigor

The research questions and design are consistent with interpretive descriptive methodology, enhancing epistemologic consistency (Lincoln & Guba, 1985; Thorne, 2008). An audit trail was maintained to identify how text was coded and thematically organized, optimizing analytic logic and ensuring that the study could be replicated. A nurse researcher with oncology expertise independently analyzed two interviews completely and audited the results. The other nurse researcher conducted member checking with three participants by presenting and reviewing a summary of the findings to verify the accuracy of interpretation. Quantitative and qualitative findings were triangulated in this inquiry, optimizing representative credibility and enhancing substantive completeness (Thorne, 2008).

## Findings

Of 14 children invited to participate, 12 consented; two males, aged 14 and 16 years, declined (see Table 1). Following consent, 11 children were interviewed alone, and one child was accompanied by her mother who quietly observed. Participants of both genders were equally represented. Age at diagnosis ranged from 2–15 years (median = 10.3) and children were between 1–14 years since diagnosis (median = 3). Participants had been diagnosed with low- and high-grade brain tumors, for which they received a variety of treatments including surgery, chemotherapy, and/or radiation treatment. Half of the participants had ventriculoperitoneal shunts in place. Interviews were 10–21 minutes in length (median = 17). When asked to validate findings during member checking, participants agreed that their thoughts and feelings were represented in the summary figure. They did not want to add anything else to the figure.

## Symptoms

Children described symptoms of feeling tired, pain and headaches, emotional problems, difficulty thinking and remembering, problems with sleep, physical problems, and/or weight changes. Children did not identify any new symptoms that were not previously identified in the survey.

**Feeling tired:** The most common symptom described by seven children was feeling tired, described as low energy, having less energy, or feeling drowsy, particularly at the end of the school day. They said their energy

was the worst after treatment (particularly radiation), and it improved over time but remained suboptimal, “Well, like in gym, I can’t do all the stuff that the other kids can do [because] I get tired more quickly.”

**Pain and headaches:** Pain was described as headaches, shunt-related pain, or extremity pain following physical exertion by seven children. Some children experienced mild to moderate headaches described on a numerical pain rating scale as 2–5 out of 10. Headaches were experienced infrequently or weekly and exacerbated by dizziness, fatigue at the end of the day, or loud noises.

The shunt, it hurts sometimes. It causes pain and, also, when you do a lot of effort, it can cause a headache. Like, if you’re lifting something heavy, pushing a lot, or whatever, it starts to hurt.

**Emotional problems:** Six children described emotional distress as feelings of anger, stress, worry, nervousness, sadness, and irritability. Some children felt frustrated and sad related to functional impairments such as unilateral limb weakness.

When you go through [treatment] like that, well, it makes you down, I guess, a little bit. I was also angry because of my right arm.

I do worry when I come to the doctors. I think because I got so many needles, I was scared that the visits may be about needles, and I have to get one or something. I worry about not being on time, to something like school. And . . . I worry about . . . I think about . . . what if someone is mean to me at school today or something like that?

**Hard to think or remember:** Six children described having difficulty thinking, remembering, focusing, doing schoolwork, or paying attention in class.

I will tell my educational assistant that I have to go to the bathroom and we will be walking to the bathroom, and I will walk right into another classroom. She will be like, “Where are you going? You said you had to go to the bathroom.” Oops.

**Sleep problems:** Six children described difficulties falling asleep, waking up in the middle of the night and having trouble falling back to sleep or simply not getting enough sleep. Sleep was impaired because of weight gain associated with endocrine dysfunction with two children who were diagnosed with obstructive sleep apnea requiring bilevel positive airway pressure treatment. Another child with a history of treatment-related diaphragmatic paralysis described having her sleep interrupted by apnea alarms.

**Physical problems:** Physical problems from direct effects of treatment with surgery, chemotherapy, or ra-

**Table 1. Sample Characteristics (N = 12)**

Characteristic	Median	Range
Age at diagnosis (years)	10.3	2.5–14.9
Age at interview (years)	14.8	9.5–17.7
Time since diagnosis (years)	3	1.4–14

  

Characteristic	n
<b>Gender</b>	
Male	6
Female	6
<b>Age at interview (years)</b>	
9–12	3
13–15	5
16–18	4
<b>Time since diagnosis (years)</b>	
Less than 2, male	3
Less than 2, female	2
More than 2, male	3
More than 2, female	4
<b>Tumor grade<sup>a</sup></b>	
Grade 1 (low grade) (N = 9)	
• Astrocytoma	5
• Germinoma	2
• Other	2
Grade 4 (high grade) (N = 3)	
• Medulloblastoma	2
• Other	1
<b>Shunt</b>	
Yes	6
No	6
<b>Treatment</b>	
Surgery alone	3
Surgery and chemotherapy	2
Surgery and radiation therapy	2
Chemotherapy and radiation therapy	1
Surgery, chemotherapy, and radiation therapy	4

<sup>a</sup> Per World Health Organization classification

diation treatment, such as unilateral paralysis, aphasia, loss of vision, hearing loss, decreased muscle strength, shortness of breath, dizziness, and balance issues, were identified by five children.

My right hand and my right leg . . . I can’t pick things up like most people can. I can sometimes, but it takes me more time. I can’t do the same things with other kids. I can’t do sports like other kids.

I have had no vision in my left eye since I was I think, around 3 or 4 and, um, I got my cataract removed. . . . I gained back some vision, but not all.

**Weight changes:** Three children described decreased appetite, weight gain, or “chubbiness” following completion of treatment.

I gained weight after surgery. They want me to lose weight; my mother does too. I eat a normal diet. My mom wants me to be active, which I am.

## Symptom Effect on Quality of Life

Children described how symptoms affected their physical activities, keeping up with school, their appearance, and communication, and provided many examples.

**Doing physical activity:** Physical challenges limited six children's ability to complete certain tasks and participate in certain activities, or required more time compared to their healthy peers. Some children described activity intolerance because of fatigue or headaches. Children also described how symptoms affected their ability to do things that they used to be able to do. They described having difficulty fully participating in physical education class or performing routine tasks, such as chores around the house or lifting objects.

Um, my vision loss affects me for driving purposes. Because when I started driving with my G1 [learner permit], I steered more towards the right side because that is the side that I can see out of. . . . In sports, I play baseball, I am a right-hand batter, and it affects me because I have to turn my whole head and not just like the side of my head or face like most people do. And then, for rugby, you can't see through mulls of people.

**Keeping up at school:** Five children described that their schoolwork was affected by their symptoms (e.g., fatigue, headaches), that they missed school for follow-up appointments, and on some occasions, felt too tired to attend school. Memory problems, including forgetting things and losing things, contributed to difficulties succeeding at school. One child described having difficulty reading and not getting work done because he could not understand the teacher.

I was not able to go to school because I had so little energy. . . . I only started off with going half days because I would get so tired, and now we have worked up to full days.

**My appearance:** Four children described how changes in their physical appearance or ability to communicate affected how they felt about themselves and their relationships with peers. Weight gain also interfered with their appearance. Some children described being teased about their physical appearance, including weight.

They always say I'm a fatso, but now that has stopped because that was back in grade one and last year in grade two. . . . When I would touch them, they would have to touch somebody else or, if they don't, they get my "cooties" unless they have their fingers crossed.

**Hearing and speaking:** Three children described that their communication was impaired because of difficulties hearing and speaking fluently.

I also developed aphasia, so I have difficulty reading and speaking. . . . Well, I don't think I talk as much as I used to. I'm more reserved. I have difficulty starting conversations. . . . I have difficulty explaining things precisely. My parents keep telling me, "You're not explaining it properly; you are just saying what you see in your head." I don't understand what they're trying to tell me.

## Coping Strategies

Children recounted ways they found to cope with their symptoms, including reconditioning, taking breaks, managing themselves, challenging themselves, volunteering, keeping up friendships, laughing, and using aids.

**Get my conditioning back:** Nine children described wanting to get back to their baseline function or improve their current physical condition. They achieved this by trying to participate as much as possible in regular physical activities, taking courses (e.g., lifeguarding), learning new sports (e.g., mountain biking, fencing), participating in community activities (e.g., dance classes), or participating in fundraising walks for cancer.

I am trying to work up, I try to exercise more often and do sports. I'm trying different kinds of sports and outdoor stuff, so my energy is coming; it is better than it was before, a lot better, but [low energy] is still there. I am trying to get it back. . . . I'm trying to get my conditioning back.

Well, I would like to start hockey again next year. . . . I'm not sure if I am going to do a sport in the summer or not. Probably just road hockey with my friends and get more exercise because I haven't done much.

**Take breaks:** Despite a desire to get back into physical shape, nine children verbalized energy deficits over the course of the day or during physical activities requiring them to take a break or lie down. Children were aware of their limitations with respect to energy conservation and were cautious not to over-expend their limited resources. Strategies like resting or lying down were employed to manage symptoms, including headaches or fatigue. Children described slow reintegration to school starting with half days and building to full school days. Some children described having to take time off school, whereas others limited their extracurricular involvements so that they could focus more on their schoolwork, "When I am walking, like around a store for a long time, I have to sit down because I get tired."

**Take medications:** Six children managed symptoms, such as headaches, when they interfered with their daily activities by taking over-the-counter medication.

Once a month or so [I get headaches]. I got one this morning because I was reading in the car. If it

is at night . . . they will just go away as soon as I lie down, but they just last for a couple of hours. I usually take [ibuprofen].

**Challenge myself:** Six children described wanting to move forward by challenging themselves or learning new skills. They viewed their physical deficits as obstacles that they wished to overcome. Even if at first they were not successful, they did not want to give up.

I try to test out and challenge my vision in the left eye, as it is changing. And I, like, cover my right eye, so I don't always favor it. I just kind of do it off and on to see what I can see out of my bad eye.

**Volunteer:** Five children described volunteering in the community with their church, youth groups, or cancer awareness fundraising activities. Some children described supporting their parents who spoke on their behalf at cancer awareness or fundraising activities. Other children described telling their stories at school assemblies to motivate students to get involved in cancer fundraising events. These various activities helped children cope with the challenges they faced post-treatment.

And I did a brain tumor walk last year and my goal was 50 bucks. That is not very much. And, then, I ended up raising \$583. . . . This year, I already got \$200 in one week and a corporate sponsorship. So, really, it just keeps me going knowing that things are going to get better, not worse. And people are supporting you.

Volunteering feels good to give back to the many different things when I was a kid. I kind of see where they were when I was there and kind of helping people who are in my situation that I was in. The youth team is getting together to do activities at night of awareness, so we are doing different surveys and whatnot to kind of see. . . . Health and different types of cancer prevention, different types of things that cause cancer, how you can avoid it. It helps me kind of go forward.

**Keep up friendships:** Five children described the importance of maintaining relationships with their family and friends. Children also described the importance of the healthcare team members or support staff in helping them during their journey. Social networking (e.g., Facebook, Skype) was described as a mechanism for maintaining relationships with friends.

My family, they've been so supportive. That really helped me. I always knew there was always somebody there to help me.

**Laugh:** Four children used humor and laughter to cope with their symptoms. One boy spoke about "pranking" his sister. One girl mentioned the impor-

tance of her dad "making jokes all the time" to help her remain positive. Another girl made a joke about herself saying her "blonde hair" explained her forgetfulness.

No one sees my shunt. I do not mind if people see it. They did not even know it is there. I like it because I gave it a name. I called it "Bumpy." So, I had some fun with it.

**Use aids:** Creative techniques helped four children cope with functional deficits and cognitive challenges, including maintaining detailed calendars for upcoming events or reliance on others to facilitate recall (e.g., events, spelling words, mathematical calculations). Some children needed physical aids like hearing aids, walkers, and power chairs.

Sometimes I just forget to bring things like I will just forget to do something. . . . I write it down somewhere noticeable and I keep a calendar. My mom helps me to remember things as well. . . . I use my walker at school.

## Subjective Assessment of Well-Being

Eleven children described their QOL as "good" or "fine," and one child described his or her QOL as better than before. One child said, "I have a good life. I am happy." Another child was able to recognize that her QOL had actually improved since treatment because she was not "getting headaches all the time and stuff" and did "not have to sleep all day." One child described feeling "mostly good about his life," but was "exasperated with the shunt." Another male described how his chubbiness negatively affected his QOL.

Um, before, I guess, before my brain tumor started growing and stuff, I was, like, a little superstar athlete. . . . I was . . . doing quite well. I was, like, in U9, which was, like, the best hockey for initiation, and I was . . . scoring, and I was, like, really fit. Like, [I was] extremely fit. Now . . . [points to himself] . . . my chubbiness does affect my quality of life. . . . It's more or less, like, well, "You were a really fit kid, and then you got a brain tumor, which made you chubby." So it's . . . yeah, I used to be like a superstar in like gym and . . . make all the teams. And, now, I'm not making much teams [laughs]. . . . I think I have a good quality of life, although I won the bad luck lottery a couple of times. . . . I just think that everything is going to get better, and it has.

## Discussion

To the authors' knowledge, this is the first reported qualitative study exploring the breadth and depth of the symptom experience, coping, and QOL outcomes in children who have survived a brain tumor. Frequently cited

## Knowledge Translation

Quantitative tools provide important information regarding symptom experience in children that can be supplemented by rich qualitative data.

Parents and healthcare professionals need to be aware of the breadth and depth of symptoms experienced by pediatric brain tumor survivors, as well as the effect of symptoms on children's daily lives.

Providers can mitigate negative quality-of-life outcomes by supporting a range of coping strategies.

symptoms included feeling tired, pain and headaches, emotional issues, difficulty thinking and remembering, problems with sleep, physical impairments, and weight changes. Symptoms affected children in a variety of ways, including their participation in physical activities, managing at school, maintaining appearances, and communicating. Coping strategies included reconditioning, taking breaks, taking medication, challenging themselves, volunteering, keeping up friendships, laughing, and using aids.

In spite of the many symptoms, children rated their QOL as quite good. Perhaps the experience of the cancer diagnosis and treatment somehow changed their frame of reference with respect to what they consider important in life, such as maintaining friendships and volunteering, compared to their peers. This appears to be similar to post-traumatic growth (PTG), which is defined as positive change experienced as a result of a struggle with trauma (Meyerson, Grant, Carter, & Kilmer, 2011). Most studies of PTG have been conducted with adults; however, a systematic review identified 25 studies of PTG in children, the majority of which had been completed in the past five years (Meyerson et al., 2011). The types of traumatic events included natural disasters or terrorist attacks. Four studies included adolescent patients with cancer. Each oncology study used a different tool to measure the central construct of PTG. Environmental characteristics, distress responses, social processes, psychological processes, positive outcomes, and demographic variables could be associated with PTG in children (Meyerson et al., 2011). A more recent study found that PTG was unrelated to time since diagnosis (Turner-Sack, Menna, & Setchell, 2012). Adolescents who believed they were more likely to relapse and used coping strategies of acceptance had higher levels of PTG (Turner-Sack et al., 2012).

Zebrack et al. (2012) explored psychological adjustment among young adult survivors of childhood cancer survivors (4% with central nervous system [CNS] disease) compared to their siblings, and found that survivors reported greater PTG than their siblings or

survivors diagnosed at older ages. Cognitive capacity to understand the implications of cancer treatment may be a required antecedent to PTG. When compared to childhood leukemia survivors, survivors of CNS disease reported significantly less PTG. Ongoing cognitive, behavioral, and physical conditions may contribute to a more negative assessment of effect of cancer in these individuals, precluding them from PTG (Zebrack et al., 2012). Although the notion of PTG is intriguing, some believe that the ongoing nature of chronic cancer-related treatment side effects makes it different from other acute traumas. Therefore, an indeterminate interpretation of the relationship between PTG and emotional well-being remains (Sumalla, Ochoa, & Blanco, 2009).

The children in the current study articulated the importance of friends, family, and maintaining social relationships. These coping strategies may help to buffer or mitigate the negative impact between symptoms and QOL outcomes. A literature review exploring QOL in young people with chronic illness identified eight concept analyses, all based on adult literature (Taylor, Gibson, & Franck, 2008). The perceptions or experiences of young people, consideration of their developmental changes, language level, or their understanding of health and illness were not well represented in the identified concepts in the review. Although the illness experience imposes constraints that vary according to developmental stage and can be altered by the interaction of friends and family, young people living with chronic illness generally view themselves and their lives similarly to their healthy peers (Taylor et al., 2008). The attributes of developmental stage and the importance of peer group and family were identified as important in the conceptualization of QOL in young people with chronic disease (Taylor et al., 2008).

Children in this study described a strong desire to give back to the cancer community through volunteerism. The cancer diagnosis may provide children with a unique motivation to get involved in activities that bring quality to their lives in different ways. Despite challenges to their appearance described by four children and physical problems affecting mobility, requiring use of aids described by four children, participants described getting involved with cancer awareness and fundraising activities. The positive experience of volunteerism also may help children seek to enrich their lives and enjoy a better QOL after completing treatment for a brain tumor. Volunteering after a stressful personal experience may be an opportunity for personal growth and provide opportunities to be with others who share a similar experience or illness (Cohen & Numa, 2011; Matthews, Baker, Hann, Denniston, & Smith, 2002). Similarly, helping or volunteering behaviors, which are important to

youth development, have been shown to benefit both the recipient and the volunteer. Volunteers may grow through the development of appropriate, prosocial norms and the sense of improved well-being (Siu, Shek, & Law, 2012).

### Strengths and Limitations

Children were interviewed specifically to further explore the symptoms identified in a prior quantitative study. For this reason, participants may have been less inclined to discuss other symptoms affecting them. Transferability of study findings is limited by this single-institution study in children who had good cognitive and verbal abilities. However, member checking revealed that the children had nothing to add or change. To enhance the credibility of the findings, the current researchers maintained an audit trail, had independent auditing of the qualitative analysis, and used member checking. Finally, to facilitate transferability of the findings, a rich description was provided of the setting and the participants' characteristics.

### Implications for Nursing

Quantitative tools provide important information regarding symptom experience in children that can be supplemented by rich qualitative data. This study highlights the complex nature of children's symptom experience and its effect on their daily activities. The need to explore coping strategies used by children needs to be done on an individual basis. Coping can be facilitated by helping children and their families identify distressing symptoms and by exploring strategies that may be useful in mitigating negative QOL outcomes. More research is needed to continue to understand the role of nursing in identifying distressing symptoms, optimizing symptom management, and enhancing QOL in pediatric brain tumor survivors.

Interprofessional healthcare teams who are involved in the care of children treated for brain tumors should be aware of the multitude of symptoms experienced during survivorship and the diverse nature of the symptom experience. This study highlights the importance of developing a systematic way of identifying and addressing the most bothersome symptoms in pediatric patients with cancer. This can be realized through standardized assessment and use of evidence-informed clinical practice guidelines to optimize patient outcomes.

### Conclusions

Children surviving brain tumors experience multiple symptoms, which affect their daily lives in a variety of ways. Despite this fact, most children in this study described having a "good" QOL. This dissonance may be partially explained by what has been described in the literature as PTG. Children used different coping mechanisms to deal with symptoms, including maintaining social relationships with friends and families, as well as community engagement.

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