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The Art of Living With Symptoms: A Qualitative Study Among Patients With Primary Brain Tumors Receiving Proton Beam Therapy

KEY WORDS

Symptom experience
 Symptom management
 Proton beam therapy
 Brain tumor
 Qualitative study

Background: Symptom management in conjunction with proton beam therapy (PBT) from patient's perspective has not been explored. Such knowledge is essential to optimize the care in this relatively new treatment modality. **Objective:** The aim of this study was to explore the process of symptom management in patients with brain tumor receiving PBT. **Methods:** Participants were 22 patients with primary brain tumor who received PBT, recruited in collaboration with a national center for proton therapy and 2 oncology clinics at 2 university hospitals in Sweden. Interviews using open-ended questions were conducted before, during, and/or after treatment. Verbatim interview transcripts were analyzed using classic Grounded Theory. **Results:** "The art of living with symptoms" emerged as the core concept. This encompassed 3 interconnected symptom management concepts: "Adapting to limited ability," "Learning about oneself," and "Creating new routines." These concepts were summarized in a substantive theoretical model of symptom management. Despite the struggle to manage symptoms, participants lived a satisfactory life. **Conclusions:** Symptom management in conjunction with PBT comprises a process of action, thoughts, and emotions. The concepts that emerged indicated patients' symptom

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management strategies were based on their own resources. **Implications for Practice:** It is important that PBT facilities develop an approach that facilitates the symptom management process based on patients' experiences of symptoms, as well as their actions and available resources.

Primary brain tumors (both benign and malignant) are predicted to occur in approximately 1400 adults in Sweden each year.¹ Brain tumors affect people of all ages but commonly occur in individuals older than 60 years. Radiotherapy is used to treat brain tumors, either as the primary treatment modality or as a supplement to surgery, and is often combined with chemotherapy.² Conventional photon radiotherapy treatment is associated with patient-reported acute and late symptoms.³ Optimizing radiation parameters in terms of the lowest efficient total doses and (when possible) limiting radiation volume may improve outcomes and reduce neurotoxicity for patients with brain tumors.⁴ Proton beam therapy (PBT) is a radiotherapy modality in which proton particles penetrate deep into the target and stop at a certain depth depending on their energy. This spares normal tissues beyond the target from unnecessary radiation, thereby reducing the risk for adverse effects in patients with brain tumors.⁵ Proton beam therapy may reduce the risk of damage to healthy tissues; in some cases, the dose targeted at the tumor may be increased, meaning control over the tumor is also increased.⁶ There is emerging evidence that PBT has lower toxicity in treating brain tumors and thereby achieves better patient-reported health-related quality of life (QoL) than conventional radiotherapy does.^{7,8} However, most available literature is quantitative and is based on studies that used retrospective or cross-sectional designs. The diagnosis of a primary brain tumor and the effects of treatment have a major impact on patients' QoL, particularly as treatment is often extensive.⁹ In addition to suffering from treatment adverse effects, patients must manage fear and psychosocial distress associated with the disease. Symptoms may remain unnoticed and underdiagnosed but still have a major impact on daily life.¹⁰ Debilitating symptoms may affect a patient's cognitive and physical abilities. Studies on symptom prevalence in connection with a brain tumor describe physical symptoms (fatigue, headache, double vision, nausea, vomiting, seizures, sleep disturbance), emotional symptoms (mood disturbances, depression, and anxiety), and neurocognitive symptoms (confusion, memory loss, speech difficulties, and decreased concentration).^{2,11-13} The distinction between a cancer diagnosis and a benign tumor in the central nervous system when it comes to patient-related outcome before treatment, during treatment (surgery and/or radiotherapy and/or chemotherapy), and months after treatment may not be 2 distinct separate categories divided by the prognosis. However, little is known about how patients with brain tumors experience these symptoms and how they manage them during radiotherapy.

■ Symptom Experience and Management

In healthcare settings, the experience of symptoms is central to communication and dialogue about illness between patients and

professionals. Various theories have been developed to explain the occurrence of symptoms and their relationships with other factors.^{14,15} Symptoms generally become known through reports of the person experiencing those symptoms. The present study defines a symptom as "a subjective experience reflecting changes in the biopsychosocial functioning, sensations or cognition of an individual."¹⁶ Both symptoms and signs disrupt patients' QoL, and they are important in evaluating a patient's health and illness. Symptom management aims to prevent or delay negative outcomes through biomedical, professional, and self-care strategies. A basic assumption is that all troublesome symptoms require management. Symptom management should influence or control the symptom experience, rather than only symptom outcomes.¹⁶ It is well known that the burden of symptoms that affect QoL for patients with brain tumor undergoing PBT is significant.¹⁷ Despite existing theories and models, there is a gap in the literature regarding symptom management from the perspective of patients with brain tumor receiving PBT.

No previous studies in the target patient population have explored the symptom management and the effects on patients' everyday life. Such knowledge is essential to enhance understanding of the experiences and needs of patients with brain tumors. Increased understanding in this area will inform new hypotheses for future research and identify practice issues that healthcare professionals should address in more depth. Therefore, the present qualitative study aimed to explore the process of symptom management in patients with brain tumor receiving PBT.

■ Methods

Study Design

This study used a prospective, longitudinal design and incorporated the procedures and principles of classic Grounded Theory (GT).¹⁸ The approach described by Glaser and Strauss¹⁸ was used to answer the research question "How do patients manage the symptoms they experience?" Data were collected through individual interviews with participating patients.

Methodology

Glaser and Strauss¹⁸ and Glaser¹⁹ stated that the constant comparative method is essential in GT analysis. Furthermore, Glaser and Strauss¹⁸ presented GT as a method that aims to generate a substantive or formal theory. A substantive theory means that the result is applicable in a specific area, whereas a formal theory can be applied in different areas. Grounded Theory studies create concepts through constant comparative methods that include all parts of the data as well as interpreted emerged codes, categories, and main concerns to explore variations, similarities, and

differences. All extracted categories, concepts, and their indicators should be grounded in data. With this method, the analysis process proceeds as the researcher continuously writes theoretical drafts or memos.^{18,19} Classic GT indicates that the researcher should include existing preunderstanding in parentheses, by raising consciousness about the preunderstanding and thereby controlling influence as far as possible. This study used a deductive/inductive approach that stressed the process rather than the meaning of the studied phenomenon. An inductive approach allows participants to describe their thoughts and actions in their own words, and at the same time a deductive approach focuses on finding new indicators for the concepts or main concern. We aimed to develop a substantive theoretical model based on empirical data to show the process of how patients with brain tumor receiving PBT managed their symptoms.

Setting

Interviews were conducted at the Skandion Clinic and 2 university hospitals in Sweden. The Skandion Clinic is the first Nordic clinic to offer PBT treatment, and patients travel to the clinic from all over Sweden. Patients are referred for PBT after preparation (including imaging and treatment planning) at their home university hospital. Most patients are unable to commute between their homes and the Skandion Clinic and therefore have to stay in a nearby patient hotel during treatment. Costs for the stay are covered by the national public health insurance system.

Participants

This study was a multicenter study, including participants who were referred for PBT from 1 of Sweden's 7 university hospitals. Participants were 22 adult patients with primary brain tumor who were receiving PBT. The patients were all selected for PBT and included into the Proton Radiotherapy for Primary Central Nervous System Tumours in Adults study²⁰ and subsequently into the current study owing to nonresectable brain tumors, substantial tumor volumes, and continuous tumor growth on repeated computed tomography scans before start of treatment. One patient declined to participate, with the explanation that she lacked time. Patients who agreed to participate provided written informed consent before the interview. Ten participants were interviewed during the treatment period. Another 12 were interviewed both before and immediately after the treatment period.

Ethical Consideration

The Ethics committee in Gothenburg, Sweden, no. 433-15, approved the study in July 2015. All participation in the study is based on informed consent.

Procedure


This study is a part of a larger multicenter study that is approved by the research committees at all involved hospitals. All patients were informed about the study and invited to participate via telephone by the first author (U.L.). Face-to-face interviews were conducted by the first author (28 interviews) and another experienced oncology nurse (6 interviews). Having 2 experienced nurses conducting the

interviews enabled inclusion of participants from all parts of Sweden. Five interviews were conducted by telephone when face-to-face interviews were not possible. To ensure dependability, interview techniques were discussed between the 2 interviewers according to the recommendations of Morse et al²¹ about stepwise verification strategies. The same interview guide was used by the 2 interviewers. The interview guide was modified over time according to GT principles,¹⁸ with changes based on identified concepts.

Data Collection

Interviews were conducted with the aim of exploring how participants managed their symptoms. In the first step of the recruitment process, participants were strategically selected to provide a broad perspective, with selection based on age, sex, and civil status (Table 1) and on how participants managed their symptoms. Most of included participants had malignant tumor at this stage of the sampling. After analyzing the initial interviews, we replaced the strategical sampling with theoretical sampling based on the emerging findings. In this second step, participants with benign tumors were primarily selected. This was done to gain variation of symptom management during the treatment period and also to confirm saturation. Recruitment of new participants and data collection concluded when saturation was reached, which was the point at which the most recent interviews did not seem to make a substantial contribution to the model that was successively generated from earlier data. Three participants were selected to confirm the extracted concepts, giving a total of 34 interviews.

Interviews started with the open-ended question, "Can you please tell me about your situation based on your current illness, including how you manage the symptoms you experience?" Follow-up questions were asked, such as "What does it mean to you in your daily life?" This resulted in a deeper narrative in

 **Table 1 • Participant's Demographic Information (n = 22)**

Parameters	n
Gender	
Women	10
Men	12
Age, y	
26–35	5
36–45	4
46–55	8
56–65	1
66–75	4
Diagnosis	
Malignant brain tumor	14
Benign brain tumor	8
Civil status	
Married with children living at home	11
Single	6
Married	5
Education	
Elementary	3
Secondary	11
University	8

which participants reflected on how they managed their symptoms. Memos describing what was experienced were written immediately after the interviews. The interviews lasted 30 to 70 minutes. All interviews were performed in Swedish, as well as the data analysis. Translation to English was made when writing the manuscript. Manuscript was then reviewed by a professional translator.

Data Analysis

Interviews were transcribed verbatim and consecutively analyzed using the constant comparative method.¹⁸ NVivo (version 11; QSR International, Melbourne, Australia) was used for categorizing the transcribed verbatim. The first step involved open coding. Data were examined line by line to identify each patient's description of their thought patterns, feelings, and actions related to the themes mentioned in the interviews. The derived codes were formulated in words used by the patients to maintain the semantics of the data. Codes were compared to verify their descriptive content and confirm they were grounded in the data. Indicators of symptom management were identified. Table 2 illustrates the analytical process and includes an example of a memo. The second step involved sorting the codes into categories using constant comparisons between categories, codes, and interview protocols. In the third step, identified categories were fitted together using the constant comparative method. The theoretical sampling was a process of taking information from the data collection and comparing it to emerging categories. The parallel process of data collection and data analysis allowed specification of relationships between categories and abstraction to theoretical concepts. The analysis resulted in a substantive theoretical model with 8 categories resting on 3 concepts and 1 core concept. The analysis process was discussed by 3 of the authors (U.L., K.A., and K.S.), who read and/or analyzed a sample of the transcripts. Emerging codes and categories were compared and collectively discussed with all the authors. Final concepts were then agreed. All the authors are experienced researchers, and 1 has long experience from working with GT (K.A.). The authors are either clinically experienced nurses (U.L., K.S., P.F., B.J., E.O.N., and K.A.) or clinically experienced physicians (T.B.E. and P.W.). During the whole analysis process, the researchers' pre-understanding was constantly discussed.

Results

The aim of this study was to explore the process of symptom management in patients with brain tumor receiving PBT. An overall model (Figure 1) describing symptom management as a process was developed. The analysis extracted "The art of living

with symptoms" as a core concept, which encompassed 3 interconnected symptom management concepts: "Adapting to limited ability," "Learning about oneself," and "Creating new routines." The symptoms that the participants experience ranged from severe symptoms (eg, consequences of epilepsy) to less severe symptoms (eg, low-intensity headaches). Participants' experiences of symptoms were not different in relation to whether it was a benign or malignant tumor that was treated. Common for all participants were the increasing intensity of symptoms over time and the major impact on daily life. Despite the presence of symptoms and significant restrictions on everyday life, participants expressed living a satisfactory life as they handled the situation by different strategies based on their own action and personal resources.

Adapting to Limited Ability

The theoretical concept "Adapting to limited ability" described how the patients manage the challenges related to the symptoms and comprised 4 categories: "Lack of multitasking," "Priority of doing," "The body as a barrier," and "Limitations in daily life." "Lack of multitasking" reflected participants' diminished capacity to perform daily chores owing to limited multitasking capability. They expressed an ability to only perform 1 activity at a time. Several participants spoke of experiencing difficulties after completing treatment every day and returning home to their family and multiple obligations.

Then it's not only to get back into the everyday routine. To get back when you have kids, take care of daycare and school and that is the home, which is a stress in itself. Right after the radiation. It's just a lot. (10)

"Priority of doing" included the ability to prioritize and opt out of certain actions, including social activities (eg, holidays) and domestic labor.

Partly I have to think first... before I head into things... almost every weekend we were on a summer holiday and other adventures. And all of those things we have to set aside because of my illness. (1)

"The body as a barrier" was a category that became obvious when participants described how they had to adapt their daily lives after being diagnosed and started treatment. They described how ordinary events, such as going to the toilet, now demanded rigorous planning, effort, and time. The same was reported for more extensive activities. *Because one is not fast. Just to go to the bathroom takes 3 times as long. I just sit down. I sit down like this. Then I sit. I almost have to count 'til 3 to get up and do something. I don't know what it is. (20)*

The category "Limitations in daily life" reflected how participants became aware of possible obstacles because of symptoms

 **Table 2 • The Analytical Process**

Quote	Category	Concept	Memo
"Because one is not fast. Just to go to the bathroom takes 3 times as long. I just sit down. I sit down like this. Then I sit. I almost have to count til 3 to get up and do something. I don't know what it is".	The body as a barrier	Adapting to limited ability	"The patient is very limited in everyday life. She feels a strong worry for the future and is significantly affected by her disease. She shares her emotions and trying to describe how the disease and treatment affects her."

The table gives an example in the analysis process through coding, category and concept, including a memo in the category "The body as a barrier."

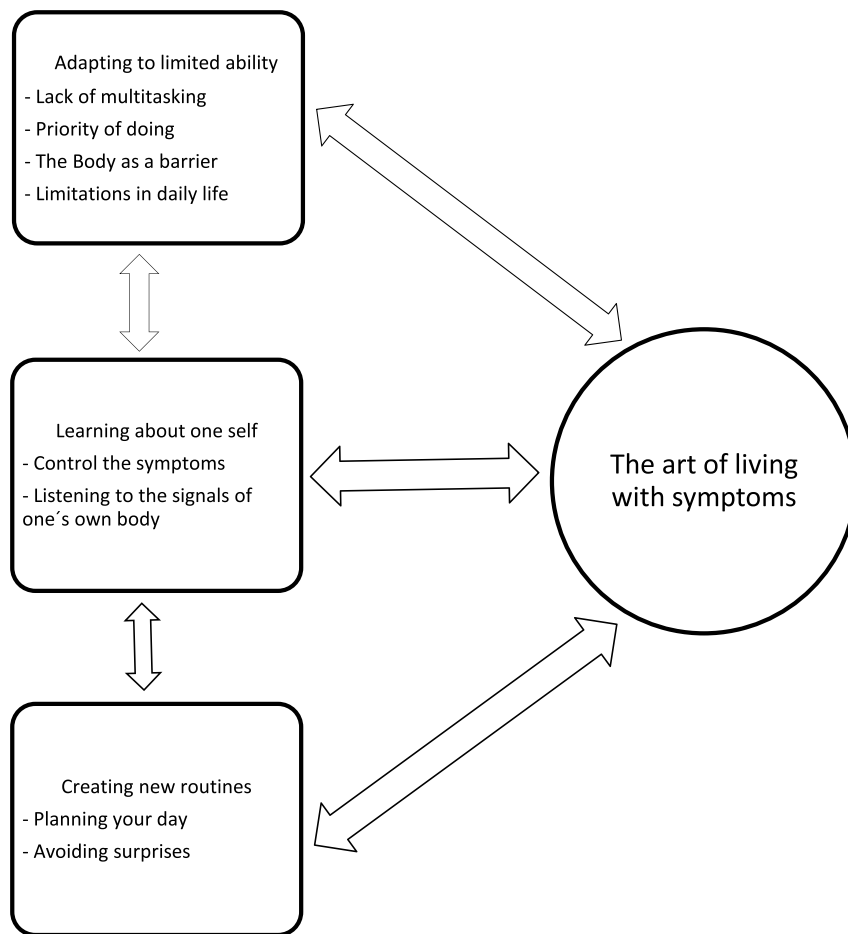


Figure 1. Process of symptoms management in patients with brain tumor receiving proton beam therapy.

experienced and how even simple chores (eg, emptying the dishwasher) became impossible tasks. Furthermore, participants reported having to give up beloved pastimes. Concurrent with existing obstacles, they were no longer allowed to perform activities such as driving a car, which placed major limitations on their everyday lives.

What are obvious are the epileptic cramps. And that I get tired in public but otherwise I am not in pain. There are some things I cannot do. I cannot drive a car. I shall not expose myself to some contexts. One shall not be intoxicated. One shall not be at high altitudes. One shall not swim in deep water. So one is a little limited. (13)

Learning About Oneself

The theoretical concept “Learning about oneself” was also a way to manage the symptoms and comprised 2 categories: “Controlling the symptoms” and “Listening to the signals of one’s own body.” In the “Controlling the symptoms category,” participants described the importance of managing their daily lives by gaining control of the intensity and frequency of their symptoms. Participants reported experiencing several symptoms of varying intensity that had a major influence on their daily lives and led to considerable changes in most cases. Participants managed to control their symptoms by getting to know their own body. They expressed

developing increased awareness of how to lead their life to gain control over symptoms by prioritizing good sleep, obtaining a balance between rest and physical activity, and having regular meals; otherwise, an increased intensity and number of symptoms was expected.

But it's one of those things that the brain has taught itself. Furthermore, I know how to act to get more or less of the symptoms. Healthy living. Too little sleep, too little food, and too much work. Then the symptoms increase. (11)

The category “Listening to the signals of one’s own body” reflected how participants learned to anticipate symptoms by listening to their own body’s signals and taking them more seriously. Not listening to one’s own body led to an increase in symptoms.

With the epileptic cramps it's the same. Too much stress and it says “bang.” Stress is bad. It cannot be eliminated through medication. I have to live normally. If I live badly the cramps will come knocking at my door. (3)

Creating New Routines

“Creating new routines in daily life” was a distinguishing that reflected how participants found a new daily balance. This encompassed creating practical routines and new roles. Participants’ life patterns underwent radical transformation as a result of their symptoms. The theoretical concept of creating new

routines comprised 2 categories: “Planning your day” and “Avoiding surprises.” In the category “Planning your day,” participants expressed the importance of planning or structuring their day in advance. This involved scheduling minor to major activities, from taking care of personal hygiene to performing work. All chores needed to be planned in detail. Before committing to different activities, participants reflected on what was required to ensure that they could manage those activities. Several participants mentioned the need to write notes about how their day would be structured. Fatigue that increased over time was considered an enemy; participants endeavored to create new routines to avoid fatigue. For example, resting at midday was a routine that was not included in earlier life patterns.

It has to do with my brain tiredness; I sort of want to plan everything ahead. (1)

The category “Avoiding surprises” reflected how participants experienced increased stress levels. This left no room for surprises, such as a friend or relative asking for help or making a spontaneous visit. Fatigue increased when habitual routines were disrupted, which in turn increased the risk of other symptoms such as epilepsy and headache. Most life events were undertaken in low gear. *I have to know in advance what the day will look like. Something unplanned cannot happen that I have to focus on. It will only mess up the head. (7)*

■ Discussion

This is the first qualitative study worldwide to explore symptom management among patients who received PBT for primary benign or malignant brain tumors. “The art of living with symptoms” emerged as the core concept, illustrating an ongoing process of action and thoughts throughout the treatment period. Our findings showed that participants had to consider how to live their life in terms of the new conditions of illness and treatment. In the process of achieving symptom relief, participating patients used themselves as a resource through strategies such as adapting to their limited ability, learning about oneself, and creating new routines. The present results are discussed in relation to existing theories in the field.

Participants' comments indicated that they were important actors in the process of symptom management. The data showed that participants managed their symptoms in similar ways, regardless of whether they were treated for a malignant or benign tumor. However, it is important to note that most participants stayed at the patient hotel during their 5-week PBT treatment. These circumstances might have influenced the experience of a better QoL and also increased capability for self-care compared with those who received conventional treatment at their local clinic. In addition, participating patients might have been selected for PBT because of their better health-status.

The number of symptoms that the participants described and the treatment period contributed to a perception of increased intensity of symptom experience. The present analysis highlighted the challenge of understanding how patients managed to live a satisfactory life despite the presence of symptoms and

limited ability in their everyday lives. Similar findings have been described in other studies among patients with primary brain tumor.^{22–24} Bitterlich and Vordermark²² found no decrease in patients' QoL despite radiotherapy and associated side effects. Piil et al²⁴ reported that patients adjusted to symptom limitations through an ongoing process of becoming aware of, and adapting to, the loss of functioning. Bennett et al²³ explored the impact of symptoms on QoL and found that a consistent theme was an underlying determination to “get on with life” and not be bound by symptomatic implications. These studies showed how patients maintained their QoL by taking part in daily living and focusing on positive aspects in their lives. Therefore, how well an individual participant tolerated symptoms over time may reflect a higher tolerance for perceived symptoms in that person and indicate their symptom management strategies were effective.

Participants in this study perceived that it was important to establish a balance and create new everyday routines when their existence and fundamental security were threatened by illness. During the latter part of the treatment period, participants were affected by fatigue; despite this, they reported that it was important to continue with their everyday life routines. Participants planned their days carefully, which gave them control and reassurance. This is consistent with the response shift theory, which describes how a patient confronted with a life-threatening disease adapts to the disease and modifies his/her internal norms, values, and conceptualization of what he/she is experiencing. When health is no longer manageable and available energy does not allow work to be performed as before, attention may be refocused on developing resources and properties other than professional accomplishments, such as intimate relationships.²⁵

Response shift processes have been documented in various cancer populations.^{26–28} Sprangers and Schartz²⁵ discussed the integration of response shift in QoL. When participants in the present study were confronted with a life-threatening or chronic disease, they also faced the need to adapt to their illness and symptoms. Sprangers and Schwartz interpreted response shift as an important mediator in this adaptation process, involving changing internal standards, values, and the conceptualization of QoL. An explanation for why most participants in this study achieved a satisfactory life might be that they had the resources to change their internal standards.²⁵

Most participating patients had no permanent symptoms before diagnosis with a brain tumor. A debut symptom of a tumor may be an acute epileptic seizure or slowly deteriorating eyesight. Therefore, a patient's adaptation to being diagnosed with a tumor and experiencing symptoms might have been abrupt. This transition represents dramatic changes in health status, relationships, and roles. It also involves a change in human needs, as an individual has to assimilate new knowledge and change their behavior accordingly. This transition includes meaning, expectations, knowledge, environment, planning, and well-being. Participants in the present study talked about their own essential personal development when transitioning from a state of good health to facing a potentially life-threatening primary brain tumor. An important factor indicating how well participants managed their symptoms was their reflection on how they perceived their surroundings, how their life should be lived, and what

relationships were important to them, as well as learning how to accept their new situation.

Several previous studies have discussed posttraumatic growth as an outcome of highly stressful life events. Posttraumatic growth may result in greater appreciation for life, better relationships with others, and a commitment to live a healthier life.^{29,30} Groarke et al³¹ presented evidence to support a hypothesis that stress was related to higher posttraumatic growth; higher cancer-specific stress was found 6 months after diagnosis. The findings of the present study provide additional support for positive growth among those who struggle with a challenging illness.

The substantive theoretical model developed during the present analysis (Figure 1) described the process of how participants expressed their symptoms, and presents the abstracted core concept and an interpretation of how they managed their symptoms. The arrows illustrate the development of participants' personal resources and how they reached the core concept ("The art of living with symptoms").

Methodological Considerations

Data from 22 participants provided diverse views on patients' experiences, particularly regarding how participants managed their symptoms. A strength of the present study was the large number of interviews included in the analysis. In addition, the wide age range of participants, inclusion of both sexes, and participants recruited from all over Sweden increased the likelihood that our findings may be transferable to other patients in the studied diagnosis group. The present study focused on exploring symptom management in patients with primary brain tumors receiving PBT. We chose not to separate the analysis based on whether the patient had a benign or malignant tumor, as benign tumors may become life threatening if they are not treated.

Furthermore, when collecting and comparing data on patient reported symptom during the treatment for patients with benign or malignant brain tumor, we saw that reported symptoms seem to be as frequent among the 2 groups. However, further research is required to elucidate potential differences that might affect the patient with brain tumor during and after the process of treatment. Qualitative studies with focus on the disease experience as well as comparative studies of the 2 groups treated with PBT and with adequate follow-up are suggested.

The Skandion Clinic is a novel facility using a new care strategy and required most patients to stay at a hotel. These circumstances may limit the transferability of the findings to patients treated in ordinary Swedish cancer care facilities. To ensure credibility, 2 authors (U.L. and K.A.) started the analysis process and created the concepts together, using classic GT.¹⁸ The first author (U.L.) has many years of experience in oncology nursing. During the inductive phase, memos and regular discussion were conducted among the research group. The memos provided a trustworthy data source for the analysis, as they were obtained by regular use of a reflective research diary. To gain a deeper understanding of symptom management, many participants completed 2 interviews. Interviews were conducted by telephone when face-to-face interviews were not possible, but we assessed these telephone interviews as being of value.

Implications for Nursing

It is important to increase knowledge about how patients manage the symptoms to effectively support patients with brain tumors receiving PBT. When nursing for these patients, it is essential to support their own personal resources and their strategies in symptom management and, thus, maintaining daily life. The substantive theoretical model developed in this study can be used to increase caregivers' understanding of a patient's individual resources in managing symptoms and can be used for initiating discussion about a patient's symptom experience and symptom management.

Conclusion

Grounded Theory was used to develop a substantive theoretical model to explain the symptom management process in patients with primary brain tumors receiving PBT. Most participants in the present study struggled with their symptoms (eg, fatigue, seizures, and sleep disorders). In finding new rhythms and routines, they reported that it was important to establish a balance to avoid symptoms becoming overwhelming. Increased fatigue was central to the development of other aggravating symptoms (eg, seizures). Although participants experienced symptoms differently, symptom management was described as a process of action, thoughts, and emotions. Increasing symptoms over time and the major impact of symptoms on daily life were factors common to all participants. Participants described how they used their own resources to manage their symptoms. "The art of living with symptoms" was the core concept that reflected how participants achieved a satisfactory life by "Adapting to limited ability," "Learning about oneself," and "Creating new routines" despite the number and intensity of symptoms experienced.

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