



# Psychosocial Support for Pediatric Patients at Proton Therapy Institutions

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## Abstract

**Purpose:** Pediatric patients with cancer benefit significantly from psychosocial support during and after treatment, but to date, limited data exist regarding the patterns of psychosocial support provided to patients in radiation oncology departments. The purpose of this study was to assess the supportive care services provided at proton therapy institutions in the United States with a specific focus on education, parental involvement, and coping techniques.

**Materials and Methods:** Physicians, nurses, and child life specialists at 29 operational proton therapy facilities in the United States were sent an online questionnaire regarding pediatric treatment support. The survey consisted of 10 questions exploring strategies employed to educate and support pediatric patients before and during radiotherapy.

**Results:** Staff members from 23 of 29 operational proton centers (79%) in the United States completed the survey. Three centers (10%) declined to participate, and three (10%) did not complete the questionnaire. Respondents permitted parental presence for body positioning on the first day of treatment and every day of treatment if needed at 95.6% (22 of 23) and 73.9% (17 of 23) of the centers, respectively. Primary education methods included a facility tour (91.3%; 21 of 23) and psychological preparation (78.3%; 17 of 23). Physicians (82.6%; 19 of 23), nurses (73.9%; 17 of 23), and child life specialists (69.6%; 16 of 23) most commonly provided education to pediatric patients and their families. Only 21.7% (5 of 23) of the facilities reported documentation of a psychosocial support policy. Common coping techniques included music (87.0%; 20 of 23), parental presence for positioning (73.9%; 17 of 23), listening to audio recordings (73.9%; 17 of 23), aromatherapy on or near the patient (73.9%; 17 of 23), and use of a stress ball (65.2%; 15 of 23).

**Conclusion:** Proton therapy institutions frequently offered psychological preparation before treatment and employed various coping strategies. Based on this survey, we propose several recommendations to raise awareness and improve the experience of pediatric patients at radiation oncology centers.

**Keywords:** coping; stress; patient education; psychosocial support; patient experience

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## Introduction

Every year, nearly 9000 children are diagnosed with cancer [1]; of whom, approximately 3000 (33.3%) will receive radiation therapy. Radiation therapy has an essential role in the treatment for many pediatric cancer patients, notably central nervous system (CNS) tumors, sarcomas, and hematologic malignancies [2]. Proton therapy is an advanced form of radiation therapy that employs charged particles to precisely target tumors and decrease collateral radiation exposure to healthy tissues, which can significantly reduce

the risk of treatment-related toxicities. These favorable dosimetric advantages combined with the opening of new proton therapy centers in the United States have led proton therapy to become a preferred radiation therapy modality for pediatric patients [3].

Because of the higher incidence of cancer in adults, most pediatric patients receive care in outpatient facilities that are not solely devoted to pediatric care. As a result, the inherent distress provoked by an unfamiliar medical environment may increase because of the lack of a pediatric-friendly setting and experienced professionals trained to work with children. Radiation therapy also requires the use of constrictive medical devices for daily immobilization and for patients to remain in the vault alone during treatment delivery. Collectively, these factors create an environment in which children may experience distress. Despite these risks, psychosocial support services are often limited in radiation oncology. Position statements from numerous professional organizations emphasize the importance of this support in pediatric oncology care and employing staff with training and expertise in child development, emotional adjustment to illness, and family systems [4, 5].

Limited data exist regarding practice patterns for supportive care provided to pediatric patients at proton therapy facilities, and the care and services offered differ greatly from one treatment facility to another. The purpose of this study was to measure the pediatric supportive care services provided at United States proton therapy institutions, including parent involvement, patient education, and coping strategies and to identify common practice standards.

## Materials and Methods

The survey was formulated with interviews and feedback provided by psychosocial support staff at several proton therapy centers for reasons unrelated to research. Variations in the methods employed across different institutions motivated the development of a survey to measure and analyze practice patterns at proton therapy centers. The questionnaire was created using freely available online survey software. The survey, included as an **Appendix**, consisted of 10 questions with variable formats, including multiple choice and short answer. The survey remained open from June 2018 to February 2019. The study was evaluated by the institutional clinical trials office, and institutional review board approval was not required.

All proton therapy facilities in the United States were identified through the National Association of Proton Therapy (NAPT) website (<https://www.proton-therapy.org/>). The NAPT maintains a list of all proton therapy centers in the United States, including NAPT member centers that are operational or under construction and non-NAPT member centers that are operational. During the study period, 29 proton therapy institutions were operating in the United States and 4 were under construction. Physicians, nurses, and child life specialists at the 29 operational centers were contacted to identify the most knowledgeable staff member to complete the questionnaire. The survey was distributed electronically to the staff member at each institution who agreed to participate. Descriptive statistics were used to describe frequencies.

## Results

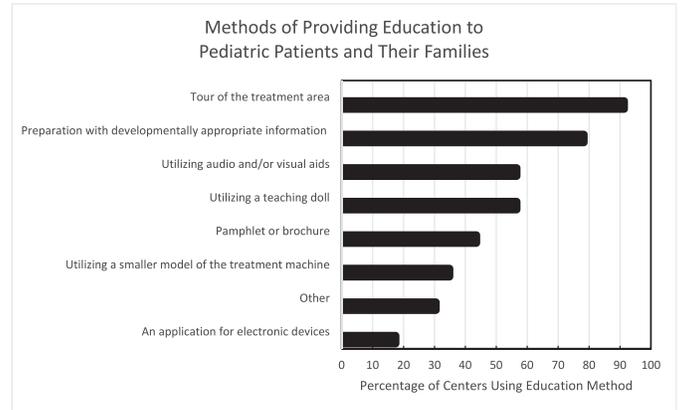
Of the 29 operational centers in the United States, staff from 23 centers (79%) completed the survey. Three institutions (10%) elected not to participate: two centers did not treat minors, and permission to participate was denied at the third institution. The remaining three institutions (10%) agreed to participate, but did not complete the survey before closure. The institutional staff member completing surveys included nurses, child life specialists, or advanced practice providers. Two of the 23 facilities (9%) elected for two staff members to complete the survey to enable each to provide answers that were relevant to their individual areas of expertise. The researchers assimilated responses from these centers into one combined survey for analysis.

Participating centers reported between 1 and 5 proton therapy vaults, with a median of 3 vaults. Wide variation was observed in the number of pediatric patients treated daily, from a minimum of zero to as many as 30 pediatric patients on average. More than 50% of respondents marked “uncertain” regarding the average total number of patients (adult and pediatric) treated per day.

Survey respondents reported permitting parents in the treatment vault for initial body positioning on the first day of treatment at 22 centers (95.7%) and for every day of treatment at 17 centers (73.9%). All participating centers (100%) allowed parents to be present during induction of anesthesia. Two centers (8.7%) indicated that anesthesia induction occurred outside of the vault, and that patients were subsequently transported inside the treatment room.

**Figure 1** indicates the methods employed to educate pediatric patients and their families. The most commonly reported education strategy was a tour of the treatment area (91.3%; 21 of 23). According to the questionnaire, nine facilities (39.1%) aimed to provide the tour on the day of the consultation with the physician. The staff member responsible for giving the tour varied, but, at centers employing a child life specialist, tours were generally within their scope of responsibilities. Preparation

**Figure 1.** Methods of providing education to pediatric patients and their families.



with developmentally appropriate information was the next most common form of education (78.3%; n = 18). Respondents also indicated use of audio and visual aids (56.5%; n = 13), teaching dolls (56.5%; n = 13), and informational pamphlets (43.5%; n = 10). Other responses included periodic group facility tours and informational sessions, medical play, and virtual reality platforms.

**Figure 2** illustrates responses for all health care professionals that assisted with providing education to pediatric patients and their families. Respondents indicated that responsibility for patient education rested with physicians (82.6%; n = 19), nurses (73.9%; n = 17), and child life specialists (69.6%; n = 16) at participating facilities. For those respondents who selected “other,” most wrote that radiation therapists also assisted with education.

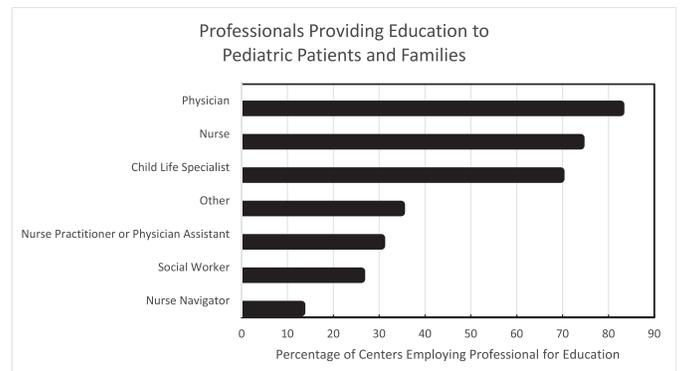
Eighteen facilities (78.3%) indicated that their organization had not created any specific policies and procedures related to patient psychosocial support at their center. Five centers (21.7%) indicated that a policy existed, but only 2 of the 23 (8.7%) specified the type of policy used. One policy stated that all pediatric patients must meet with the social worker and child life specialist within their first few visits to the department. The second policy stated that only one caregiver could accompany the child to the treatment area at any given time.

**Figure 3** enumerates the coping strategies employed at participating institutions. Music was the most common coping technique offered (87.0%; n = 20). Additional commonly reported coping strategies included parental presence for treatment immobilization and setup (73.9%; n = 17); listening to podcasts, audio books, and other recordings (73.9%; n = 17); aromatic scent placement on the treatment mask or near the patient (73.9%; n = 17); and use of a stress ball (65.2%; n = 15). Nine respondents (39.1%) described other techniques used, including possession of a comfort item (such as a favorite stuffed animal), staff speaking/reading over the intercom, and use of movie goggles.

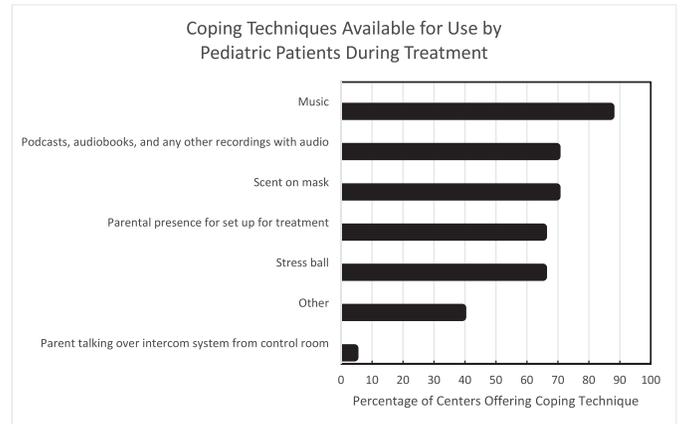
## Discussion

Pediatric patients with cancer can experience severe anxiety, social withdrawal, behavioral difficulties, depression, and posttraumatic stress disorder when confronted by an unfamiliar medical environment [6, 7]. Moreover, that distress can be present at diagnosis and persist during and after treatment [4]. If unaddressed, that anxiety can develop into severe and unremitting toxic stress, which is associated with greater risk of developmental delays and chronic health problems in later life

**Figure 2.** Health care professionals responsible for providing education to pediatric patients and families.



**Figure 3.** Coping strategies available for use by pediatric patients during proton therapy.



[8, 9]. Cancer therapy, such as radiation therapy, can negatively affect adjustment and increase distress in pediatric patients. Child life interventions can help to mitigate coping deficits, fear, anxiety, emotional distress, and limited understanding of medical procedures [10]. Child life specialists can help to address stressors faced by pediatric patients through psychological preparation for medical experiences, education, coaching, play therapy, and family support [9]. Establishing evidence-based practices to identify common challenges and support successful coping strategies in childhood cancer patients and their families are an unmet need [6].

Psychologic preparation and education can help to address fears and concerns regarding treatment, increase familiarity and comfort with clinical staff, and improve compliance during radiation therapy [11]. Therapeutic play can lead to decreased levels of anxiety, increased compliance during medical procedures [12], and decreased needs for anesthesia in radiation oncology clinics [5, 13]. Coping strategies are essential to help children remain calm and immobile during medical procedures [14] and radiation therapy. Barry and colleagues [15] reported that music provided distraction from the discomfort children experienced when laying with their immobilization devices for radiation therapy. Use of age-appropriate audiovisual stimuli, including movies and cartoons, were reported to help young children avoid sedation for radiation therapy [16]. Finally, child functioning is often highly correlated and dependent on parental and family functioning [4]. Caregivers should be actively involved in the preparation and discussion of coping strategies to improve patient adjustment and compliance [9].

A recent systematic review on interventions used to address distress and anxiety in pediatric patients receiving radiation therapy identified only 9 articles, all from single institutions, published on this topic between 1996 and 2016 [17]. Two publications reported on the value of therapeutic play in pediatric patients receiving cranial radiotherapy [13, 18]. Reduction in the use of sedation and general anesthesia was another common theme [5, 13, 19]. Our publication adds to the current body of literature on the value of psychosocial intervention in pediatric patients with cancer but also helps to underscore the limited number of publications on this important topic.

To our knowledge, our study provides the first multi-institutional assessment of the psychosocial support provided to pediatric patients and their families at radiation therapy centers in the United States. Our study suggests that most proton therapy centers in the United States provide similar forms of psychosocial support to pediatric patients and their families. Parental presence during body positioning before treatment was permitted at most centers, if deemed beneficial to the child. Department tours and age-appropriate psychological preparation were the primary education methods employed. Respondents identified that responsibility for patient and family education was generally shared by more than 1 staff member at each institution, including physicians, nurses, child life specialists, and radiation therapists. One surprising finding was that only 21.7% (n = 5) of the respondents indicated that their center had created a policy regarding psychosocial support for pediatric patients.

This study is valuable in that most proton therapy centers (23 of 29; 79.3%) in the United States who treat children participated. The descriptive nature of the survey helped to not only enumerate commonly employed education and coping strategies but also enabled centers to share responses that were not considered in the creation of the final questionnaire and may provide novel ideas to other centers. This study has several limitations, including the potential for responses being subject to recall bias, a known shortcoming in survey data. In addition, the study was neither designed nor intended to measure the efficacy of the interventions in the clinic or to delineate which strategies may be most effective in pediatric patients. Another potential limitation is the variability in the professionals who completed the survey. Institutions were encouraged to have the

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professional that worked most closely with pediatric patients and their families complete the survey, but staff members with different roles, backgrounds, and training may lead to variations in responses at different facilities.

In summary, this survey suggests that many proton therapy centers in the United States understand the importance of psychosocial support and education for pediatric patients and their families and employ multiple strategies to improve patient experience during radiation therapy. Future research should focus on quantifying the comparative advantages of different coping techniques and forms of education, with particular attention to quality-of-life metrics, such as by the use of anxiety and depression scales. The results of this study indicate that few proton therapy centers (5 of 23; 21.7%) have codified their policies related to psychosocial support standards. With the increasing use of proton therapy for pediatric cancer treatment in the United States, proton therapy centers should consider evaluating the psychosocial support programs employed for pediatric patients at their institutions. We propose that every institution should aim to establish policies that support consistency in the care provided to each child and family. Policies may include recommendations that a psychosocial health professional meet with each child at their first visit to the facility, that communication be provided in a developmentally appropriate manner, and that a psychosocial health professional be present whenever medical information is presented to a child and should offer ongoing support during radiation treatment. This study can serve as a benchmark for future research aimed at developing evidenced-based practices and highlights the value of providing appropriate psychosocial support staff to improve pediatric patient care, treatment compliance, and emotional adjustment.

## ADDITIONAL INFORMATION AND DECLARATIONS

**Conflicts of Interest:** The authors have no relevant conflicts of interest to disclose.

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**Ethical Approval:** This study was evaluated by the institutional clinical trials office, and institutional review board approval was not required.

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