

CLINICAL SOCIAL WORK IN THE PROTON TREATMENT SETTING: CONSIDERATIONS FOR A CULTURALLY AND GEOGRAPHICALLY DIVERSE PATIENT POPULATION



Heather Oakley, LCSW, OSW-C
University of Florida Health Proton Therapy Institute
Jacksonville, FL

Laura Dickman, LICSW
Massachusetts General Hospital
Boston, MA

Learning Objectives

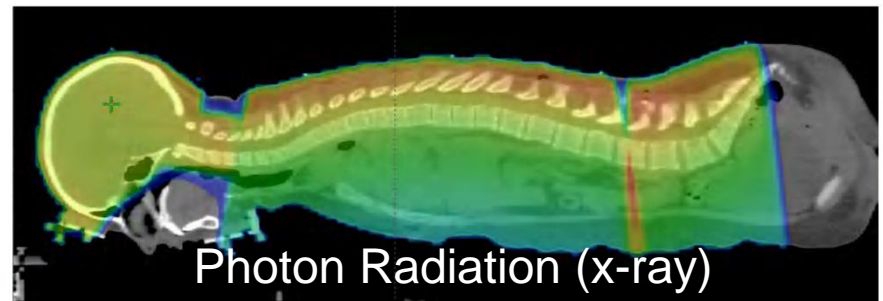
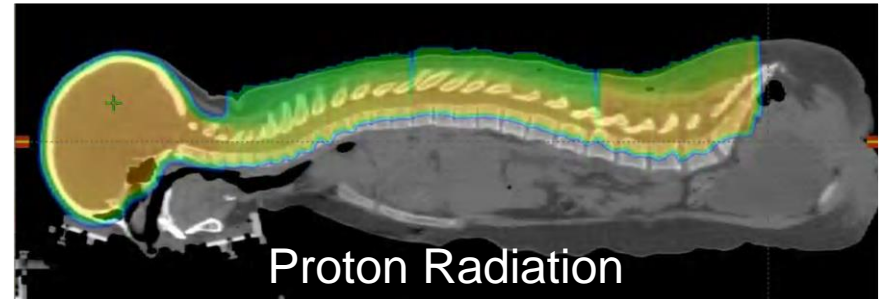
1. Describe proton therapy treatment and when it may be indicated to treat pediatric cancer.
2. Identify key logistical challenges families face in the proton therapy setting.
3. Discuss essential cultural considerations in the proton therapy setting.
4. Describe the role of the social worker in the proton therapy setting.
5. Prepare families being referred for proton therapy treatment.

Outline

- What is proton therapy?
- Key logistical, cultural, and family systems considerations with composite case examples
- Social work role in the proton therapy setting
- Tips for preparing families for proton treatment
- Composite case examples for discussion

What is Proton Therapy?

- A **targeted** type of radiation treatment
- Standard radiation therapy utilizes x-rays which delivers the majority of the radiation dose immediately upon entering the body while traveling to the tumor.



- Protons deliver the majority of radiation dose at the tumor site. Protons **STOP** after depositing the radiation dose in the tumor; x-rays do not.

Clinical Benefits of Proton Therapy

- Highly indicated for radiation treatment of pediatric cancers due to the high risk for secondary cancers from their initial treatment later in life.
- Can limit radiation dose to healthy tissues while delivering curative doses to the tumor thus reducing patients' risks of experiencing long-term side effects.
- The only radiation treatment available that can treat recurrent tumors that have previously been treated with radiation.
- Treatments are non-invasive and painless during delivery.
- Studies have consistently demonstrated that proton therapy patients experience a higher quality of life during and after treatment.

Who is Referred and Why?

- Who?

Pediatric patients with CNS tumors, sarcomas and lymphomas

- How?

Referred by pediatric oncologists, neurosurgeons, or other radiation oncologists

- When?

Timeline depends on diagnosis (e.g. medulloblastoma is treated within 4-6 weeks of surgery; Hodgkin lymphoma is treated after chemotherapy)

Proton Centers in the United States



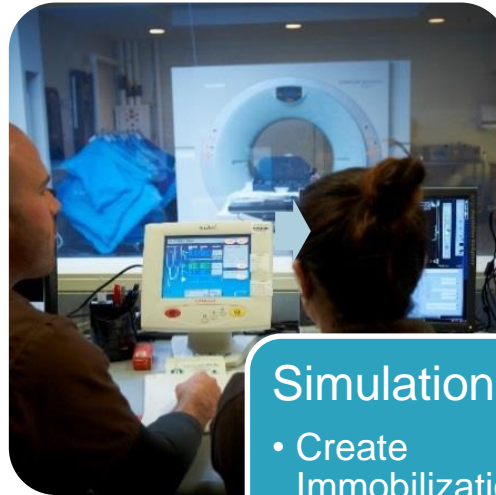
-  Member Centers Under Construction/Development
-  Member Operating Centers
-  Non-Member Operating Centers

The Road Map to Proton Therapy



Consultation

- Meet with Pediatric Team
- Develop Plan of Care



Simulation

- Create Immobilization Devices
- Assess for Non-Sedation



Daily Proton Radiation

- Avg. 6-8 Weeks
- 20-90 min table times

Anesthesia vs. No Anesthesia

- Primary focus is on younger children (~4-7 years old)
- Education & preparation is key
- Consider the length of each treatment, use of additional treatment equipment
- Child Life plays a critical role
(Scott, M. T., Todd, K. E., Oakley, H., et al, 2016)

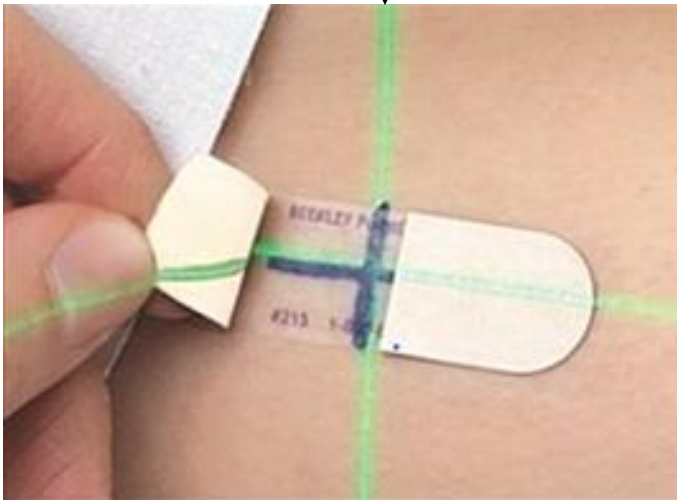


Recovery Room



Alignment Strategies

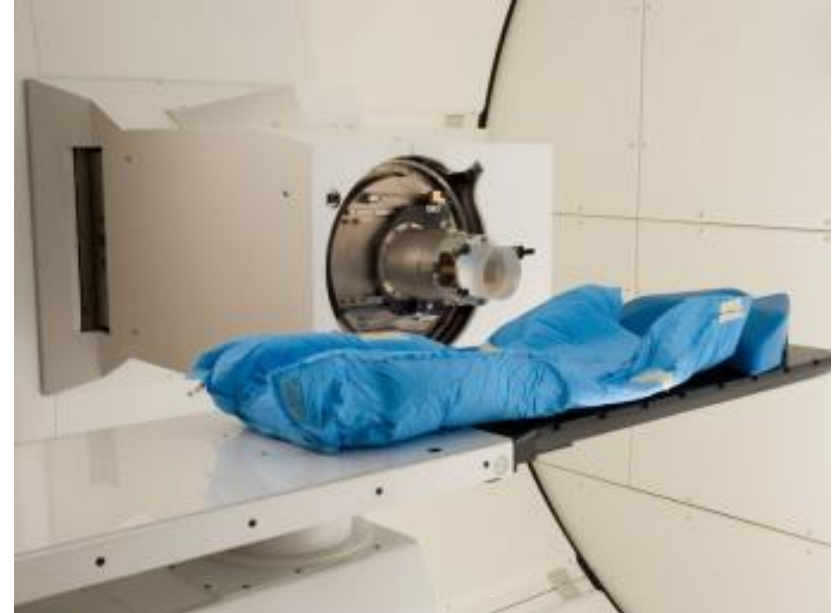
Temporary Marks



Permanent Marks



Immobilization Devices



Treatment Room



The gantry rotates 360 degrees enabling the treatment nozzle to be positioned at the optimal treatment angle for each patient.

Logistical Considerations

Transportation

Travel to the facility (often for consult and later return for treatment); daily travel for outpatient treatment

Housing

Finding local accommodations (Ronald McDonald House, etc.)

Day-to-Day Tasks

Medications, food, toiletries, laundry, school, activities

Financial Burden

Running two households, extended time away from work resulting in lost income, added costs associated with treatment (medications, parking, childcare, etc.)

Cultural Considerations

Culture & Language

- Beliefs about illness
- Information sharing with child/other family members
- Family structure
- Health literacy/translation
- Navigating an unfamiliar environment

Food/Diet

- Access to familiar foods, (affordable) grocery stores, kitchen access

Family Systems Considerations

Relocation and family restructuring

- Family separation or relocating whole family
- Staying connected
- Academic and routine disruptions

Separation from support networks

- Both personal supports and medical team supports

Disrupted employment/income

- Lost income
- Added costs (running two households)

Social Work Role in the Proton Center

- Full assessment
 - Illness and treatment understanding, logistical plan and potential barriers to care
 - Coping with illness and adjustment to new treatment facility, medical team and environment
 - Assessing support systems – addressing areas of need
- Short term counseling
- Early rapport building
- Offering activities for community-building and meaning-making in collaboration with the interdisciplinary team
- Working with and supporting interdisciplinary colleagues
- Collaborating with “home hospital” social workers and medical teams
- Preparing families for transition home





How to Prepare Families



- Talk about the treatment process from consult to radiation therapy
 - Show pictures related to treatment
 - Share names and photos of proton SW and CLS before they travel
 - Talk with caregivers about bringing an extra adult for support and to allow for the child/siblings to step out of the consult
- Help families anticipate challenges before they become crises
 - You know them best! How might this new environment/treatment be challenging?

How to Prepare Families

- Collaborate with Social Work – call us!
 - Educate proton SW about pertinent patient and/or family dynamics, financial issues, school/employment issues, other social risk factors and/or anything that may impact care in unfamiliar environment
 - Keep open lines of communication between home SW and proton SW
 - Consider a Getting to Know You document with photographs of patient and family

Getting to Know You

All about ME	Name
Favorite Food 	Who Do You Live With 
Favorite Movie/TV	Grade/Year in School 
When I grow up I want to...	Favorite Subject
Favorite Music 	Other Important things for us to know
	Favorite Books to Read
	Questions for Us

BREAKING THE ICE
<u>NAME:</u>
<u>THE BASICS</u>
Who do you live with? _____
Are you in school and/or working? Where? _____
Do you have a partner/significant other? _____
Hobbies/Interests? _____
What else would you like us to know? _____
<u>DIGGING A LITTLE DEEPER</u>
Three words that best describe you • • •
Your strengths: _____
What gives you comfort when you are upset or in pain? _____
Do you have any questions about treatment or your time in Jacksonville that you would like answered? _____ _____
 UFHealth PROTON THERAPY INSTITUTE 

Feedback From the Experts (Parents)

- It would be helpful to have pictures of the primary proton staff ahead of time, along with description of their roles.
- If patient is going to be treated prone (on belly), prepare patient and parents ahead of time.
- Prepare parents for separation from patient during CT simulation and treatment.
- Shifting the sleeping and eating schedule can help ensure your child gets enough calories despite the NPO period.
- Helpful to know that there can sometimes be treatment delays or cancellations due to machine issues.
- Calendars or other ways to countdown days of treatment can be helpful.
- Engage in the other activities like art therapy and music therapy.

Questions / Discussion



Thank you to all of our colleagues across the nation and world who have collaborated with us to improve the care of the families treated at our centers.



References

- Cockle, S. G., & Ogden, J. (2016). The 'radiation vacation': Parents' experiences of travelling to have their children's brain tumours treated with proton beam therapy. *Health Psychology Open*, 3(1), 205510291664976. doi:10.1177/2055102916649767
- National Association of Proton Therapy. (n.d.). Retrieved March 1, 2019, from <http://www.proton-therapy.org/>
- Scott, M. T., Todd, K. E., Oakley, H., Bradley, J. A., Rotondo, R. L., Morris, C. G., . . . Indelicato, D. J. (2016). Reducing Anesthesia and Health Care Cost Through Utilization of Child Life Specialists in Pediatric Radiation Oncology. *International Journal of Radiation Oncology*Biophysics*Physics*, 96(2), 401-405. doi:10.1016/j.ijrobp.2016.06.001
- Semenova, J. (2009). Proton Beam Radiation Therapy in the Treatment of Pediatric Central Nervous System Malignancies: A Review of the Literature. *Journal of Pediatric Oncology Nursing*, 26(3), 142-149. doi:10.1177/1043454209334357
- Sreeraman, R., & Indelicato, D. J. (2014). Proton therapy for the treatment of children with CNS malignancies. *CNS Oncology*, 3(2), 149-158. doi:10.2217/cns.14.16