

A top-down photograph of two hands, likely belonging to a child, gently cupping a bright red, textured heart. The hands are positioned symmetrically on either side of the heart, with fingers slightly curled. The background is a light-colored, wood-grained surface. The text is centered over the heart in a white, serif font.

A Quality Initiative
Improves the Treatment
and Experience of
Pediatric Radiation
Oncology Patients

Nebraska Medicine, Omaha, Nebraska, is one of the primary academic health systems in the Midwest region, with 718 inpatient beds, a team of more than 1,000 physicians, and 40 specialty and primary care clinics in Omaha and the surrounding areas. Nebraska Medicine's Fred & Pamela Buffett Cancer Center opened in June of 2017. This dedicated cancer facility includes 98 research labs, 108 inpatient beds, a 24/7 outpatient infusion center, as well as diagnostic and radiation oncology services for both adults and children. The Fred & Pamela Buffett Cancer Center is the primary provider of pediatric radiation oncology services in the state of Nebraska, treating between 35 and 50 pediatric patients per year. Most patients referred to pediatric radiation oncology come from the region's only children's hospital.

In 2010 Nebraska Medicine hired a certified child life specialist dedicated solely to outpatient pediatric hematology-oncology patients. Certified child life specialists provide evidence-based, developmentally appropriate interventions. Responsibilities include:

- Alleviating fear of the unknown for children and their caregivers utilizing developmentally appropriate preparation techniques
- Educating children and teaching caregivers and staff how to appropriately reinforce these teachings
- Developing coping strategies for a variety of situations to reduce fear, anxiety, and pain.

Setting the Stage

Most children receiving radiation therapy at the Fred & Pamela Buffett Cancer Center are referred from outlying facilities or practices that have had no previous affiliation with Nebraska

At the time of initial diagnosis, caregivers and family members can be overwhelmed and have difficulty understanding how chemotherapy and radiation therapy will impact both their child and subsequent daily family life.

Medicine. Historically, consultation visits to the radiation oncologist were scheduled in the same manner as adult patient consults, without taking into consideration the unique needs of the pediatric patient population. Key information about a pediatric patient's previous therapies, coping strategies, social situation, and educational needs, all of which impact development of the treatment plan, were often unknown. The certified child life specialist would need to fill these information gaps in order to address the psychosocial needs of pediatric patients undergoing radiation therapy and their caregivers.

At the time of initial diagnosis, caregivers and family members can be overwhelmed and have difficulty understanding how chemotherapy and radiation therapy will impact both their child and subsequent daily family life. This anxiety results in added stress that can affect every conversation and interaction with the healthcare team. Multidisciplinary team members must be aware of and sensitive to the underlying pressures that caregivers are experiencing.

For example, children with newly diagnosed brain tumors and their caregivers should receive education from a certified child life specialist on their implanted port or central line access and teaching on all aspects of radiation therapy, including preparation for radiation simulation and introduction of immobilizing techniques with use of the radiation mask. Unfortunately, the cancer center was finding that one or more of these critical teaching opportunities was consistently missed.

Patient education for implanted ports and central line teaching is often completed during inpatient admission by a certified child life specialist. In most situations, children remain inpatient for their initial therapy, allowing for adequate child life interactions. However, a subset of patients, often those with brain tumors, may not receive inpatient treatment and are discharged either before implanted port placement or immediately after. At the time of radiation oncology consultation in the outpatient setting, it became apparent that these children and families had missed an important learning opportunity. A tender, or even painful, port access is even more traumatic when children have had no preparation. As a result of this experience, pediatric patients may become guarded and uncooperative and caregivers may become understandably anxious, which can make completion of the outpatient visit difficult or even unattainable.

During the radiation consultation process, pediatric patients are introduced to immobilization devices, specifically the face mask, which is intended to keep patients completely still during radiation therapy. Placing a mask over a child's face can be frightening for both patients and caregivers. To make the mask, a warm, sometimes wet, sheet of plastic mesh is placed over the face of a child who is lying flat on a simulation table. This mesh stretches down around the head and is then secured to the table. Holes allow patients to see and breathe; however, children often fear suffocation. For children who are not prepared in advance, this experience can negatively impact every return visit to radiation oncology. During future radiation therapy sessions, the face mask is secured to the table, preventing children from moving. Even under the best circumstances, this scenario is anxiety-provoking.

Bottom line: patient education for our pediatric radiation oncology patient population was inadequate and lacked a well-defined referral process to the outpatient certified child life specialist at Nebraska Medicine.

Making Improvements

A study by Grissom et al. published in 2015 revealed that utilization of a certified child life specialist for play-based preparation reduced the use of sedation in children receiving cranial spinal radiation, therefore significantly decreasing hospital-related costs.¹ Additionally, a retrospective analysis of 390 children receiving radiation revealed that children three years of age and younger required anesthesia and/or sedation, decreasing to approximately half of patients by age 7-8.²

An analysis of children receiving radiation therapy from 2010 to 2014 at Nebraska Medicine showed that only 31 percent of children consulted for radiation therapy were seen by the outpa-

tient certified child life specialist. Yet 31 percent of all children and 100 percent of children under the age of 5 received sedation to complete their radiation therapy. These findings highlighted the need for a change. Led by the outpatient certified child life specialist and the outpatient advanced practice RN, a robust quality improvement initiative began.

As team members were being recruited for the quality improvement initiative and word of the project began to spread, the certified child life specialist discovered a valuable tool, the Virtual Environment for Radiotherapy Training (VERT™) system, already in place at Nebraska Medicine. VERT provides a virtual radiotherapy treatment room, including a life-size model of a linear accelerator. The technology allows users to interact with the virtual room, control the equipment, and set up radiation treatments, simulating the actual experience. Patients can control the VERT by using an iPad or an Xbox controller, which is familiar to children. Likened to a flight simulator, the VERT can be done in 3D, resulting in a “fully immersive” experience. VERT teaching has been used to provide real-life training scenarios to prepare radiation therapists for practice.³ Radiation therapy instructors from the University of Nebraska Medical Center proposed the addition of VERT simulation for children undergoing radiation therapy to improve education and the patient experience. For cancer programs that lack VERT technology, the authors suggest using linear accelerators to familiarize pediatric patients and caregivers with the treatment process.

Quality improvement strategies require innovative thinking to drive improvements in the delivery of care. The Institute of Medicine (now known as the National Academy of Medicine) proposes six aims for 21st-century healthcare systems. Specifically, healthcare systems should strive for improvements in care that are⁴:

1. Safe
2. Effective
3. Patient-centered
4. Timely
5. Efficient
6. Equitable.

Nebraska Medicine embraced these aims as the guiding principles for its quality improvement project.

Forming a Team and Establishing Goals

Nebraska Medicine formed a project team comprised of pediatric oncologists and radiation oncologists, nurse practitioners, radiation oncology nurses and management, radiation therapists, pediatric anesthesiologists, post-anesthesia care unit staff, VERT instructors, and the certified child life specialist. A kick-off meeting was held in August 2015. The team established project goals that aligned with the Institute of Medicine aims for improvement. Team members were assigned to appropriate focus groups. Over a two-month time frame, these focus groups met to:

- Evaluate the current referral process for pediatric radiation oncology patients



A certified child life specialist introduces a patient to the face mask, an immobilization device intended to keep patients completely still during radiation therapy.

- Map out the patient flow through radiation oncology
- Begin to strategize changes to the referral processes that would ultimately allow for optimal interactions between patients, caregivers, and the certified child life specialist.

Developing a Process Map

Team members next developed a process map for pediatric radiation referrals. Key elements of this referral process included:

- New patient intake
- Consult visits
- Simulation
- Daily radiation treatment visits both with and without sedation
- Routine appointments with radiation oncologist
- Special considerations for inpatients.

The team immediately recognized two areas for focused improvements. First, there was a lack of communication of patient-specific

needs from the referral center to the radiation oncology center. Second, referrals were not initiated in a timely manner to allow for appropriate preparation and teaching to occur prior to simulation and the beginning of radiation therapy. With the development of the process map, team members were now able to easily identify patient interactions where the certified child life specialist could be introduced and initiate teaching.

Improving the Referral Process

Next the team addressed deficits in the referral process. A flow-sheet was created that clearly detailed the newly developed referral process and education was given to providers at both Nebraska Medicine and its primary referral center. The new referral process focused on earlier identification of radiation therapy by the primary pediatric oncologist with direct physician communication to the radiation oncologist. As part of this new process, the pediatric oncology nurse at the primary referral center contacts the outpatient certified child life specialist when a radiation

consultation is scheduled. Patients and families receive an introduction to the Nebraska Medicine care team from the primary referral center. Next, the primary referral center and Nebraska Medicine improved email communication to provide a more seamless transition to Nebraska Medicine. Information commonly shared included:

- Details about the specific teaching already provided
- Communication of any specific patient and or family needs
- Additional areas for the outpatient certified child life specialist to focus ongoing teaching and preparation.

To improve patient education, the team determined that children and caregivers should receive an overview of radiation therapy. Prior to the consultation with the radiation oncologist, the certified child life specialist meets with the patient and caregivers to initiate the teaching.

The team established a process for the outpatient certified child life specialist visit to be placed in the electronic health record at the time of initial radiation oncology consultation. This prompt became the communication tool between radiation oncology and the outpatient certified child life specialist.

To improve patient education, the team determined that children and caregivers should receive an overview of radiation therapy. Prior to the consultation with the radiation oncologist, the certified child life specialist meets with the patient and caregivers to initiate the teaching. The certified child life specialist uses an iPad to walk children and caregivers through the radiation therapy process. Education includes an introduction to the Fred & Pamela Buffett Cancer Center radiation oncology facility, as well as information about the equipment, including the computed tomography scanner, linear accelerators, immobilization devices, and the face mask. The educational content was developed by the child life specialist and is modified to meet the developmental needs of each individual patient and family.

The team then initiated direct communication between the outpatient certified child life specialist and VERT instructors to coordinate VERT experiences for pediatric radiation oncology patients and their caregivers. To ensure that patients and parents received the most effective learning experience, VERT simulations were conducted as a collaborative effort between VERT instructors and the certified child life specialist. Building upon their introductory knowledge of radiation oncology, the VERT simulation

intends to provide a unique, hands-on experience with the equipment and atmosphere encountered during radiation treatments. Patients have the ability to make a radiation mask to take with them and they are encouraged to practice for their upcoming treatments in the simulated environment.

A pediatric radiation oncology brochure was created to introduce patients and caregivers to Nebraska Medicine's radiation oncology services. This brochure streamlined all radiation oncology teaching materials into a single document, including:

- An introduction to the radiation oncology team
- A list of scheduled radiation appointments
- An explanation of VERT and its benefits
- Pre-anesthesia instructions for patients needing sedation, as well as post-anesthesia discharge instructions
- Pediatric oncology "When to Call" instructions
- A campus map, including parking instructions and directions to the radiation oncology department.

This brochure was made available to referring providers so that information could be given to patients and families before their consultation visit with the outpatient certified child life specialist.

Implementation of the improved referral process began in January 2016. Through monthly staff and faculty meetings, education on the improved referral process was provided to all nursing staff, radiation oncology staff, child life staff, anesthesiologists, pediatric oncologists, and radiation oncologists at both Nebraska Medicine and its main pediatric referring partner. Participants were encouraged to provide feedback through verbal or email communication.

Evaluation and Revision

Ongoing communication among team members allowed for early identification of problems and quick resolution. Unique patient situations highlighted areas of potential "misses." For example, if a pediatric patient receiving radiation therapy is unexpectedly admitted to the hospital, at Nebraska Medicine or another facility, radiation therapy should be notified immediately. This allows adequate time to arrange for patient transport and to make scheduling changes so that daily radiation can continue without interruption. Accordingly, the team developed a direct pathway for communication of pediatric inpatient admissions.

Any change requires staff buy-in and willingness to participate. Not every team member realizes or embraces the need for improvement. New processes can be forgotten or overlooked. The referral process is only effective if personnel are accountable for completing their required steps. Initially, it was difficult to identify gaps in specific patient referrals, leading to immediate revision of the information given at the initial phone call to schedule the patient consult. Now, along with pertinent patient information, intake staff document the nurse who was scheduling the referral and the primary pediatric oncologist directing care. If steps are missed, the oncology nurse or oncologist is contacted to investigate the communication gap, provide direct feedback, and resolve issues in a timely manner.

Outcome Measures

From January 2016 through March 2017, 39 children were referred to pediatric radiation oncology at Nebraska Medicine and 33 children completed therapy. Adoption of the revised referral process and improved communication among team members led to an increase in referrals to the outpatient certified child life specialist from 31 percent to 91 percent. Almost immediately, the outpatient certified child life specialist and caregivers provided direct feedback that appropriate education and preparation for radiation therapy was being completed. The outpatient certified child life specialist reported a noticeable decrease in patient anxiety and caregiver stress and improvement in the working relationships and camaraderie among radiation oncology staff members. Specifically, radiation oncology team members realized that allowing the outpatient certified child life specialist extra time to work with children at the beginning of therapy can save hours of time during and at the end of treatment. The outpatient certified child life specialist found that using iPads during radiation sessions and other creative distraction techniques continues to improve patient outcomes.

The VERT simulation experience was offered to pediatric radiation oncology patients and caregivers at every reasonable opportunity. (Due to limited availability of VERT instructors who facilitate the immersive 3D experience, it is not possible for all patients and caregivers to receive this unique opportunity.) Despite these limitations, nearly half (48 percent) of patients and caregivers attended a VERT session. Patient feedback has been positive and continued efforts are being made to eliminate barriers to participation, including using the linear accelerator in place of VERT.

Overall use of sedation for this patient population declined from 31 percent to 24 percent of patients during the initial 15 months of the quality improvement project. A total of 23 patients completed therapy without use of any sedation, 2 patients received sedation for only one treatment, and 8 patients required sedation throughout treatment. The mean age of children receiving sedation for the duration of therapy was 2.6 years.


Compare these data to historical data that showed that all children under the age of 5 received sedation. Our data analysis revealed that six children aged 4 to 5 completed radiation therapy without the use of sedation during the initial period. These six patients completed a total of 91 radiation therapy sessions. On average, each session of radiation therapy done without sedation is a cost savings of \$1,000 for the hospital. In total, treating these six patients without anesthesia saved Nebraska Medicine \$91,000. Furthermore, a patient is scheduled for only 15 minutes on the linear accelerator when sedation is not required compared to 60 minutes with the use of sedation. This cohort of 6 patients resulted in 66.75 fewer linear accelerator hours, freeing up linear accelerators for an additional 275 treatment sessions.

Additional downstream benefits were realized by decreasing post-anesthesia care unit staff time, thereby increasing the availability of anesthesia services for other procedures. Most important, the reduction in the use of sedation and the time-saving measure

improves patient safety, as well as patient and caregiver quality of life. No longer requiring patients to be NPO (nil per os or “nothing through mouth”) and significantly reducing the time spent in therapy is a win-win for all.

Lessons Learned

Pediatric radiation oncology services are frequently housed in academic medical centers and referrals for therapy may come primarily from outside organizations. This quality improvement initiative highlights the importance of pediatric patient preparation and teaching, which ultimately leads to improved patient safety, a better experience for patients and caregivers, and better quality of life. For cancer programs looking to make similar improvements in the care of their pediatric radiation oncology patients, it is key to have in place a comprehensive referral process to ensure that patients and families receive all necessary education to help mitigate and/or reduce legitimate anxiety and fear related to radiation therapy. This coordinated referral process coupled with utilization of certified child life specialist services and creative tools, such as VERT technology, to enhance understanding has led to a reduction in the use of sedation to complete radiation therapy, additional radiation therapy capacity, and cost savings for the organization.

A Nebraska Medicine institutional review board-approved study is ongoing to determine whether utilization of a certified child life specialist and VERT simulation teaching and preparation leads to a measurable decrease in patient and caregiver anxiety during radiation therapy. 

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