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# Family-Centered Pediatric Radiation Therapy: A Nurse-Led Quality Improvement Collaboration Model

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Family-Centered Pediatric Radiation Therapy:  
A Nurse-Led Quality Improvement Collaboration Model

By

Elizabeth Anne Austin

A doctoral project submitted in partial fulfillment of the  
requirements for the degree of Doctorate of Nursing  
Practice in the California State University,  
Northern California Consortium,  
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May 2015

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Family-Centered Pediatric Radiation Therapy:  
A Nurse-Led Quality Improvement Collaboration Model  
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May 2015

## Abstract

**Problem:** Parents of children diagnosed with cancer face a number of physical, emotional, and social hurdles in the race for a cure. Family schedules shift dramatically to accommodate daily radiation therapy treatment appointments. Ambulatory procedure unit nursing staff attempt to teach and interpret the process without the benefit of a family-centered intradepartmental structured communication process to promote safe care with these families.

**Methods:** Implementation of a structured family-centered interprofessional standard work model to promote interdepartmental collaboration. The project implemented a structured family-centered interview and standard work algorithms to improve the radiation therapy family experience.

**Results:** A structured, streamlined, interdepartmental interview, teaching format, and educational resources for nurses to use with families. Standardized work roles were formulated to improve the communication algorithm and collaboration between departments.

**Conclusion:** The implementation of a nurse-led, standardized work process increased interprofessional collaboration, resulting in increased communication and a family-centered perioperative care model.

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Parents and children state that they need more support, information, and engagement with the healthcare team to maintain overall health during complicated cancer treatment schedules (CLIC Sargent, 2013). Multiple studies conclude that parents and children identify respectful and relational communication with providers as increasing satisfaction with their experience (Hsiao, Evan, & Zeltzer, 2007; Milton, 2007; Siddiqui, Sheikh, & Kamel, 2011). The communication process between parents of radiation oncology therapy children and the hospital staff nurses is an interpersonal relationship that can include a great deal of uncertainty. This project examines the nurse's role in communicating with these parents in a family centered manner, increasing parental knowledge, and reducing their anxiety about the radiation therapy schedule. The ultimate goal of this project is to formulate a collaboration model for an interdepartmental family-centered communication policy/structure.

Cancer is the second leading cause of death in children, second only to accidents (American Cancer Society, 2014; Hoyert & Xu, 2012). Family life disruptions include long treatment plans, multiple surgical procedures, isolation from the general public due to immune suppression, and disconnected communication processes between many hospital departments (Costelloa, Patak, & Pritchard, 2010). These families experience additional stress with daily hospital visits, native language differences, and fear of their child's possible reactions to the treatments (Tomlinson, Peden-McAlpine, & Sherman, 2012). The emotional impact of the process and treatment options for the parents can be overwhelming (Franck, Winter, & Oulton, 2007). The parents receive an enormous amount of information in a short amount of time (surgery, scans, chemotherapy, and the radiation therapy plan) and are expected to make the best

decisions for their child (Coulson & Greenwood, 2012; Elder, Ymaokoski, Wittman, & Kodish, 2007; Franck, Winter, & Oulton, 2007). The team communication process can impact parental anxiety with the healthcare experience. Sixty-six per cent of medical errors are due to ineffective interprofessional communication (Institutes of Medicine, 2003). The current decision-making process for the radiation therapy treatment team is an uncoordinated effort (Figure 1). Hospital nursing staff attempt to deliver family centered information and teaching without a standardized interdepartmental policy. The parents and staff verbalize a lack of a comprehensive family centered orientation about radiation therapy to optimize the coordination of care throughout the month-long treatment cycle. The Joint Commission (2010) explains that family centered communication is an essential component of safe, quality patient care.

Standard work is a process-improvement technique for analyzing work place activities for areas that could be streamlined by reducing waste and increasing value for the customer (Hintzen, Knoer, Van Dyke, & Milavitz, 2009; Lean Enterprises Institute, 2014). This method was adopted from the airline industry and the Toyota Motor Company that both emphasize improving workflow productivity through process improvement, problem solving, and teamwork (Liker, 2004). The goal of implementing this quality improvement initiative is to eliminate low value activities and adopt work patterns that improve accountability and efficiency (Hintzen, Knoer, Van Dyke, & Milavitz, 2009). The pediatric hospital adopted this approach to workflow analysis and is recognized as a national leader for implementing this approach (Hullinger, 2014). The application of the principles of standard work should increase teamwork through the analysis of the collaborative processes involved with the radiation therapy treatment schedule. This quality improvement project focus is a nurse-led standardized collaboration model for a family-centered pediatric radiation therapy process.

## Theoretical Framework

Austin Babrow and colleagues developed the Problematic Integration Theory (PI) in 1992 after frustration over finding a theoretical framework that encompassed situations that are uncertain, how people handle these situations, and the role of communication within this dynamic (Baxter, & Braithwaite, 2008). Babrow identifies the social, psychological, emotional, and knowledge factors involved with an experience of uncertainty as a human state during certain situations (Babrow, 2007) and the role of communication (Baxter, 2009).

Peplau's practice-based theory analyzes the beneficial and detrimental components of interaction during the nurse-client interaction (Peden, 2006). She proposed that the interaction between the patient and the nurse followed a four-step sequence (Nelson, 2010). Peplau formulated her interpersonal theory influenced by humanistic psychologists, developmental psychology, and interpersonal psychiatrists (Nelson, 2010).

### Type

Peplau's interpersonal relationship theory identifies four phases of the therapeutic nurse-patient relationship that includes orientation, identification, working, and resolution (Nelson, 2010). Babrow's problem integration theory is a communication theory used with numerous health care situations. This theory addresses the interactions between participants in situations that include uncertain components, such as participant roles, outcome, and expectations (Babrow, 2007). The themes of Problematic Integration are reducing uncertainty, and thus anxiety, which speaks to the focus of the project intervention. One of the proposals of Babrow's theory is that anxiety is increased when expectation and reality conflict through the communication process.

## Assumptions

Peplau's interpersonal relationship theory assumption is that nursing itself is a therapeutic interpersonal process (Chinn & Kramer, 2008). This theoretical framework delineates how nurses and clients progress in their relationship, the effect of this relationship on health, and how the components of the relationship are identified and measured (Hagerty & Patusky, 2003).

Problematic Integration assumptions are that people associate an expectation with a feature of their world [in this case, parental anxiety (associated expectation) about the radiation therapy experience (feature of the world)] (Babrow, 2007). A second theme of Problematic Integration is that people form judgments and evaluations of their world based on whether their perception of this feature is good or bad (Babrow, 2007). Another assumption of this theory is the tension of how the client comprehends uncertainty about their situation and how the healthcare provider communication process validates or negates this perception. The Problematic Integration theory includes role theory components of expectations, discrepancy, and clarity (role congruence) that can affect performance (Babrow, 2007). Babrow's theory focus is how these communicating participants clarify the experience. The concepts in the Problematic Integration theory are the uncertainty of the experience, the value system of participants, their experiences and expectations, and communication. Communication is viewed as a tool that shapes the perception of an experience as either negative or positive (Babrow, 2001).

The assumptions of Peplau and Babrow's theories are consistent with the view of starting and end-points to the nurse-client relationship in the radiation therapy experience which contains multiple components of uncertainty with communication. Parents facing this new procedure experience with their child do not have a large support group or resources assisting them with this process, which can lead to heightened anxiety (Ruble & Kelly, 1999). An interpersonal

relationship communicating the components of an unknown experience between the nurse and parent is a theoretical framework that includes all the components of this clinical scenario.

### **Application**

The four phases of Peplau's interpersonal theory relate to the month-long radiation therapy schedule. There is an introduction to the schedule, staff, side effects, and hospital location for the procedure (orientation, phase one). Nursing staff observes and identify (phase two) how the parents are responding to the schedule and what additional knowledge or support systems they may need to reduce anxiety and care for their child. Nurses develop client-specific interventions to resolve parental anxiety (working phase, phase three) (Nelson, 2010), such as encouraging parental participation, therapy room music choices, or alternative equipment used for transportation to recovery-crib versus gurney. The resolution phase (Nelson, 2010) (phase four) includes celebrating the child's end of radiation therapy sessions, plan for additional cancer treatment, and nursing staff review of the case and recommendations for future client care planning.

### **Concepts and Definitions**

The basic concepts of this project theory are the parents, the nurse, the communication process, the prescribed radiation therapy, and the set schedule. The group of parents for this project focus is those with children diagnosed with central nervous system cancer, as this composes the largest candidate population (Hill-Kayser, Lustig, & Tochner, 2013). The communication from the nurse is the process by which the nurse and parent exchange and interpret information during the 30 to 37 day radiation therapy schedule.

Both Peplau and Babrow consider the value system and experience of the nurse and client as influencing communication (Peden, 2006; Babrow, 2006). The combination of the theories provides a framework for the interpersonal communication of the nurse and parent.

### **Propositions**

The theory proposition that specifies the relation between concepts is that parental anxiety is related to the unknown experience of radiation therapy, which is reduced by therapeutic communication with the nurse. The nurse assesses the parental experience and perception of radiation therapy and develops an individualized interpersonal plan of continuous therapeutic communication to reduce anxiety. The nurse-parent relationship begins and concludes with the radiation therapy schedule. The structure of the nurse/parent encounter is defined by the experiences of the nurse and parent and their sociocultural and psychological stages (Miller, 2012). The nurse communicates the expectations of the radiation therapy, increasing the predictability of the situation and potentially decreasing anxiety for the parents (Tomlinson, Peden-McAlpine, & Sherman, 2012).

### **Selection Relevancy and Rationale**

Peplau's theory of interpersonal relationship fits nicely with this project as the focus is on determining the patient-identified challenges to work through during the radiation therapy schedule. Peplau's theory contains the value analysis, framework for the time schedule, and relationship between the nurse and radiation therapy parent, but lacks the uncertainty involved in the communication dynamic that Babrow's theory contains. Babrow's theory demonstrates the dynamic of the uncertainty, expectations, and integration of information for parents coping with critical healthcare decisions. The combination of these two theories incorporates the complexity of the radiation therapy parent's experience and the nurse-communication dynamic.

## Literature Review

The overall body of literature supports a family-centered communication between the nurse and parents of critically ill children with administrative support (Wright & Leahey, 2011). The literature universally states that administrative support is a key factor for successful family centered care. The data supports family centered communication to improve parental empowerment and perception of quality of life (McCabe, 2004; Svavarsdottir & Sigurdardottir, 2013).

A review of the literature and meta-analysis was done with key terms: family centered practices and communication, support, locus of control, quality of life, parental well being, family-centered communications, nursing, and anxiety/emotional distress that reveal common themes (Dunst, Trivette, & Hamby, 2007; Northouse, Katapodi, Song, Zhang, & Wood, 2010). The search strategy, clarity of the findings, and informative findings of all of these articles were cohesive, although derived from a variety of sources and scientific fields.

These themes highlight the need for nurses' involvement, promoting parental empowerment and coping, and the role of administration support. The literature review includes eight research articles from nursing, medical, and child development sources including two meta-analyses of family-centered studies (Appendix A). The theoretical/conceptual framework of the research is family-centered care, family-system, and communication (Babrow, 2007; Wright & Leahey, 2013). The meta-analysis (Northouse, Katapodi, Song, Zhang, & Wood, 2010) theoretical framework for organizing data domains is that of illness appraisal factors, coping resources, and quality of life.

The cited articles research questions parallel the project question of how family-centered communication from the nurse can influence the parental experience (anxiety level). The



collective authors discuss the choices of methodology based on prior research (Bloomer & O'Connor, 2010; LeGrow & Rossen, 2005; McCabe, 2004; Nelms & Eggenberger, 2010; Siddiqui, Sheikh, & Kamel, 2011; Svavarsdottir & Sigurdardottir, 2013).

The meta-analysis review of over 75 studies provides a rigorous review of the themes and implications for research/practice that are family-centered communication (Dunst, Trivette, & Hamby, 2007; Northouse, Katapodi, Song, Zhang, & Wood, 2010). Northouse et. al. (2010) includes a consensus between disciplines of core outcomes important to measure. LeGrow & Rossen (2005) ask for more research on the topic to expand the population, time frame, and the benefits of a control group.

### **Evidence for the Study**

All of the literature (Appendix A) discusses evidence for the benefits of family centered communication improving parental coping skills and perception of nursing care. The variety of methodology in the literature, including: before and after interviews, unstructured interviews, retrospective review of medical records, focus groups, and the meta-analysis add to the weight of the evidence as all agree on these conclusive themes. A detailed description of the method of data collection for the broad-spectrum studies adds further weight to this evidence (O'Mathuna, Fineout-Overholt, & Johnston, 2011). The Agency for Healthcare Research and Quality (2002) states that strong evidenced based research should include consistency, quantity, and quality (Stevens, 2011, p. 76). Implementing a structured interview, a parental satisfaction survey, and opportunities for parental feedback and questions follow evidenced-based research recommendations.

More than one researcher extrapolates the same themes in the two meta-analysis articles (Dunst, Trivette, & Hambly, 2007; Northouse, Katapodi, Song, Zhang, & Wood, 2010). These

researchers agree on the meaning and implications for practice of family-centered care empowering parents, assisting them to cope, and maintaining quality of life. The selected criteria for the project of the parental anxiety level and the nurse communication are consistent with the literature aim and design (Powers, 2011b, p. 445). The range of research methodology design, analysis, and data validate a project focus on the benefits (reduced anxiety) of a family centered communication with the nurse.

One issue with the literature is that much of the Wright & Leahey theory based literature (1999, 2013) appears in the *Journal of Family Nursing*, which calls into question the peer review process and lack of publication of findings in other peer reviewed nursing or healthcare journals (Bloomer & O'Connor, 2010; Legrow & Rossen, 2005; Nelms & Eggenberger, 2010; Svavarsdottir & Sigurdardottir, 2013).

## Methods

The timeline for the project consisted of: (1) a nurse-led structured communication process for parents (Appendix B); (2) an anxiety assessment of the parents at specific set intervals during the treatment schedule (Appendix C); (3) coordination of key personnel; and (4) a review of the interdepartmental process (Appendix E, F, and H) (See Figure 1); and (5) evaluation of parental data and the implications for practice. The pediatric radiation oncologist, project advisor, and the project manager reviewed the structured communication plan for parents (Appendix B). This meeting determined the best time frame for the nurse intervention (before the start of the radiation therapy patient schedule), the methodology, and the administration of the anxiety assessment tool. A discussion of an expanded role for a nurse-coordinator and the benefits of this additional communication process were identified as a priority (Appendix G) (See Figure 2). The internal review board application was reviewed and determined that this initiative could proceed as a quality improvement project. Quality improvement studies do not require consent but a discussion about the project was initiated with the parents, an information sheet provided (Appendix D), and an agreement for participating in the study obtained.

Figure 1

Pediatric Radiation Therapy Interdepartmental Coordination Chart

Current Practice Algorithm

This figure illustrates the interdepartmental communication algorithm for the pediatric radiation therapy care coordination prior to the start of the project.

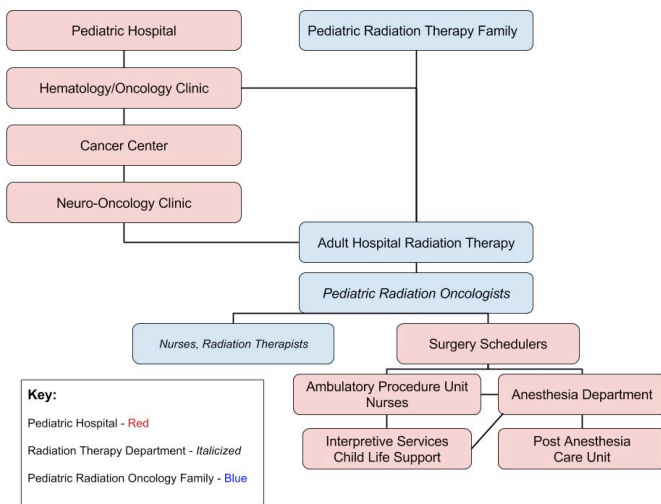
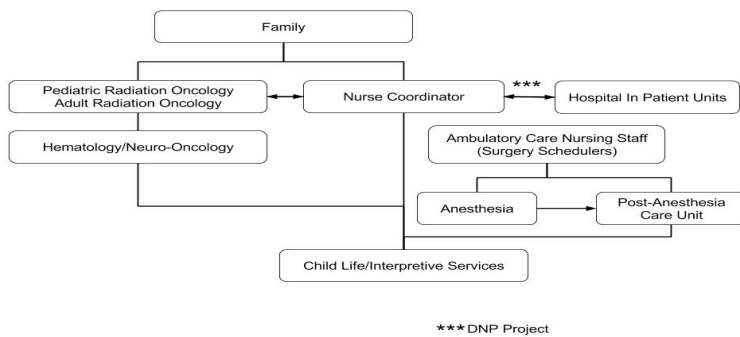


Figure 2. Proposed Organizational Change

This figure illustrates the proposed communication algorithm for the pediatric radiation therapy care coordination to maximize family-centered care.



The project population was lower than projected which changed the methodology. A formal structured communication process between the nurse and family, the pediatric healthcare team, and the radiation therapy team was explicated and implemented. Interprofessional and educational paperwork was streamlined, shared, and reviewed by all levels of departmental staff. Standard work and role expectations were shared with all stakeholders (Appendix E, F, G,

H). The framework of the interdepartmental collaboration provided a basis of standard work for evaluating parental anxiety, with sufficient study population.

### **Structured Interview**

Research supports the benefits of implementing a standardized structured interview for families (Gawande, 2011; Svavarsdottir, Sigurdardottir, & Tryggvadottir, 2014; Wright & Leahey, 2014). A structured interview was formulated based on the literature recommendations (Appendix B). It includes an introduction, family structure assessment, social system assessment, family responses to the child's diagnosis and treatment schedule, and a teaching outline for the radiation therapy process. The current family teaching does not follow a standard format for the important topics specific for radiation therapy pediatric patients. The structured interview (session one and session two) (Appendix B) concludes with a commendation for the family about their observed strengths by the nurse. Leahey & Wright (2014) emphasize the importance of commending the families for their strengths and resourcefulness as a means of encouragement.

The communication with the project manager and the radiation therapy parents (Session 1) (Appendix B) (See Figure 2) occurred prior to the child's first treatment. The radiation oncologist and ambulatory procedure unit scheduler informed the project manager about the child and the prescribed treatment schedule. The average time frame for notification of a start of the radiation therapy schedule is one to three days (Wilhite, personal communication, October 2014)(versus the three to four week ideal scenario) (Gibbs, personal communication, October 2014). The project manager shared key topics from the family interview with all members of the healthcare team (anesthesia, ambulatory procedure unit, pre-op/post-operative care unit, child life, interpretive services, radiation therapists, and nurses), and included a copy

of the interview sheet (Appendix B) in the patient's radiation therapy chart. The project manager communication with the family and child and offered subsequent information for coordination of care (support) on an as needed basis. Session two took place after the second week of therapy (10th treatment day) following administration of the third anxiety assessment. Themes from the interviews were coded, categorized, and compared to the literature. Recurring themes can add to further process understanding, meaning, and revision of standard work to reflect improved family centered care (Melnyk & Cole, 2011). This information can highlight what we know from the current body of evidence as compared to what the project data reveals or adds.

Hospital staff (nurses and anesthesiologists) comment that the parents of the children receiving treatment display signs of heightened anxiety before the set-up/simulation and with first treatment. However, after the second week (the 10<sup>th</sup> scheduled treatment), the parents leave the waiting area and staff are often unable to locate them. The hypothesis from this observation is that after the two weeks of radiation treatment, parental anxiety decreases. Holland & Goen-Piels (2000) describe this as a normal response sequence to the cancer crisis. The State-Trait Anxiety Scale (Marteau & Bekker, 1992) (Appendix C) is a short, validated assessment that the Patient Experience staff translated to an iPad survey format for the parents to enter their self-assessment of their feelings. The data did not include patient identifiers and the database was secure. This assessment was offered to the parents to complete before the first treatment and orientation [nurse-led structured communication (Appendix B)]. The assessment scale was offered for parents to complete after the first treatment and after 10 treatments, or the second week of their child's radiation therapy. The duration of the intervention with parents was from August to December, 2014 (no children were scheduled for radiation therapy in July). Data

collection and compilation concluded in January 2015 with the analysis and interpretation of the results.

### **Assessment Tool**

The State-Trait Anxiety Inventory short form (Appendix C) (Marteau & Bekker, 1992) was given to the parents before the first treatment, after the first treatment, and after two weeks (10 treatments) of the child's radiation therapy treatment. This form is only six questions and tested to be reliable for cognitive and emotional indicators. This tool was chosen, as it is short and, taking into consideration the parent's emotional response, would be feasible for the parents to complete with the treatment schedule. The other instrument is the family therapeutic conversation intervention (interview form) (Svavarsdottir & Sigurdardottir, 2013; Wright & Leahey, 1999, 2013) (Appendix B). This tool offers a brief nurse-led family centered intervention for parents of children actively receiving cancer treatments (Svavarsdottir & Sigurdardottir, 2013). A comparison of the nurses' and parental expectations and impressions from the structured communication process and nurse reflections offered valuable information (Blank, Tobin, Jaquen, Smithline, Tierney, & Visintainer, 2013). This information offered an optional format for consideration with the family interviews and radiation therapy historical work pattern (Appendix E, F, G, H, ambulatory procedure unit radiation therapy binder).

### **Coordination of Key Personnel**

An analysis of the coordination and communication process of key personnel is one of the main factors affecting the success of this project. The radiation oncologist initiates a communication tree that flows to the surgical schedulers, the ambulatory procedure unit nursing staff, the Child Life Specialists, interpretive services, anesthesia team, post-anesthesia, and inpatient unit nurses (Appendix E, F, G, and H) (See Figure 1).

The surgical schedulers communicate to the ambulatory procedure unit nursing staff the radiation therapy schedule information (child's name and duration of therapy). When the ambulatory procedure unit nurse is informed of the child's schedule by the radiation oncologist or the scheduler, they initiate the parental radiation communication process (parental interview and teaching plan) as well as coordinate with the key members of the healthcare team.

Child Life and Interpretive services have an active role as partners in the project. The Child Life Specialists developed a radiation therapy photo book that provides a photo journey/introduction to the process for children prescribed therapy without anesthesia. Due to the child's severe illness and response to intervention, this photo book can be a tool for the parents rather than the child, which presents a change of focus to the parent rather than the child for the Child Life Specialist. Viewing the radiation therapy physical area and machinery involved prior to the simulation/set-up could assist with reducing parental anxiety by providing visual background to the verbal explanations. The photobook provides visual tour of the radiation therapy environment when a physical tour with the nurse is not possible. The nurse practitioner or the ambulatory procedure unit nurse informs the Child Life Specialist about the radiation therapy treatment prescription. Interpretive services translate and assist with teaching and explanations between staff members and the families.

Additional assistance from the organization research oversight department was a consideration with data collection and analysis [Stanford University Center for Research Informatics, 2014; Stanford Center for Clinical and Translational Research and Education, 2015]. A meeting with management of the cancer center, the ambulatory procedure unit, post anesthesia care unit, and the radiation therapy department was important to present and obtain feedback for introducing the project details to the entire team. A meeting with the Family

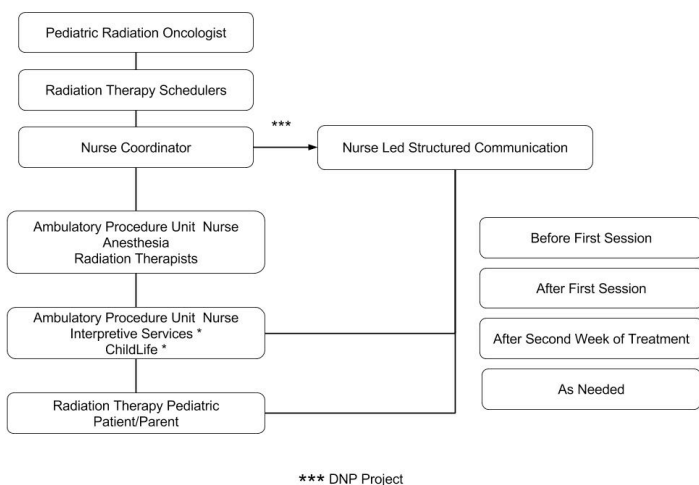


Advisory Council provided an additional layer of support, population specific insight, and assistance with the project. A presentation of the proposed intervention of the nurse-led communication program and research process for the radiation therapy pediatric oncology parents orientated ambulatory procedure unit and hospital staff to the process (Appendix E, F, H, and I) (See Figure 2, 3). This staff meeting explained and solicited feedback on the project and facilitated communication between the departments to allow for adoption and validation of the process. Monthly updates for all levels of interdepartmental staff continued for the duration of the project.

Figure 3.

Communication Process for Radiation Therapy Pediatric Patients and Parents

This figure illustrates the communication algorithm for the pediatric radiation therapy care-coordination after implementation of the Doctorate of Nursing Practice project.



The statistician (Stanford University Center for Research Informatics, 2014; Stanford Center for Clinical and Translational Research and Education, 2015) reviewed the anxiety scale and quality improvement plan (McMillan, personal communication, February 24, 2105). The

Patient Experience Department assisted the project manager with web-based data collection, methods for insuring quality data, and a secure and confidential data bank.

### **Sampling Method**

A convenience sampling was chosen due to the potential low number for the pediatric radiation therapy parent population. This proposed sampling method would normally provide data that describes what is typical for this institutional population but might not be evidenced-based research that can be applied to the general population (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2013). A collection of control group data before the project intervention provided comparative data for the process of administering the questionnaire and anxiety assessment. The population available from July to December 2014 was unusually low. The control population was four, which was much lower than expected (8-10 expected, 20 annually) (Gibbs, personal communication, July 2014). The sample population was two. The literature recommends that an advanced practice nurse familiar with the structured interview process conduct the family interactions (Svavarsdottir & Sigurdardottir, 2013; Wright & Leahey, 1999, 2013). The project manager conducted the family interview (Appendix B) for consistency of administering the interview and information.

### **Review of the Interdepartmental Process**

Staff roles and communication algorithms were reviewed in detail to assess methods to improve or streamline communication and decrease redundancy or miscommunication (Figure 1,2, Appendix E, F). All stakeholders were interviewed about their roles/expectations, important radiation therapy family teaching topics, and the current communication process. Role function and expectations were explicated and sent to all stakeholders for feedback and validation (Appendix E, F, G, and H). Standard work processes were reviewed, analyzed, and shared

amongst all radiation therapy participants. All stakeholders reviewed resources, teaching material, and communication processes for consistency and input (Child Life Radiation Therapy photobook, Appendix I, J).

### **Data Collection**

Collection of parental data on the anxiety inventory (Marteau & Bekker, 1992) was at specific intervals for the child's radiation therapy sessions (before the first treatment, after the first, and after the second week or 10th treatment). The literature recommends that the nurse-led family centered communication intervention (Appendix B) with the parents occur at least three days before the first radiation therapy treatment (Svavarsdottir & Sigurdardottir, 2013). The anxiety scale data was collected electronically into sessions (before the first treatment, after the first treatment, and after the 10th treatment), responses, and categorized by before and with the nurse-led intervention. The qualitative data from the family interviews and project manager reflections was reviewed, coded, compared with the literature, and analyzed for themes and further information that might be valuable to the healthcare team and add to the current body of evidence (Appendix K). The statistical support for data analysis (Stanford University Center for Research Informatics, 2014) was waived due to insufficient data and a question about the anxiety tool being the best tool for parental assessment (McMillan, personal communication, February 24, 2015).

### **Evaluation of Data**

The Patient Experience Department validated that the data from the iPad anxiety scale was compiled in a secure and confidential database (Tonicforhealth, 2015). The limited population and assessment tool were identified as problematic by the statistician (McMillan, personal communication, February 24, 2015). The population numbers were estimated to be at

least ten (versus the actual six) to yield a starting point for valuable data (McMillan, Nasr, personal communication, February 2015). The evaluation of the data results with the statistician noted a lack of sufficient data to extrapolate trends. The analysis of the control and research study data could not determine the magnitude of the relationship between the predictors and significance of targeted outcome (O'Mathuna, Fineout-Overholt, & Johnston, 2011). The qualitative interview data from the structured communication between the project manager and the parents, parental feedback, and nurse reflections, although limited data, revealed recurring themes, family concerns/questions, and the need for further radiation therapy information (Appendix L, K).

### **Validity and Reliability**

The project advisory panel (Rosenblum & Nasr, personal communication, April 2014) recommended the comparison of the assessment tools [including the anxiety scale (quantitative) and the parental interview data (qualitative)] to avoid a mono-operational bias that could affect external validity (Ferguson, 2004). Research supported validity with the chosen anxiety scale (Marteau & Bekker, 1992). Each of the tools (interview and anxiety scale) was considered reliable in the literature (Marteau & Bekker, 1992; Svavarsdottir & Sigurdardottir, 2013).

### **Potential Challenges**

The potential challenges to implementation of this project were the organizational structure (See Figure 1), parental anxiety about their child (unwilling to participate in the study), institutional communication pathways, and interdepartmental challenges to implementation of the process, comparatively low population sample size, and the child's disease process. The radiation therapy process for pediatrics is shared between the Radiation Therapy department (pediatric radiation oncologists, nurses, and radiation therapists) and hospital staff (the cancer

center, ambulatory procedure unit nurses, pre-op/PACU nurses, and the anesthesia physicians and technicians) (See Figure 1). Parental anxiety about their child's diagnosis and treatment plan could have precluded additional effort (completing the anxiety assessment) to participate in the research. Interdepartmental challenges include lack of communication about the child treatment start date, duration of the treatment plan, the child's hospital admission or stay duration, therapy schedule changes, interdepartmental staff cooperation and communication, or provider lack of family centered care approach. The actual challenges for this project were the lack of sufficient population and the interdepartmental communication process.

A concern for internal validity is the potential for the families' positively skewed expectation of the care of their child (Blank, Tobin, Jaquen, Smithline, Tierney, & Visintainer, 2013). Bell & Wright (2011) discuss the family belief system and how it affects the approach to illness and interpersonal relationships. Dr. Wright suggested (Personal communication, August, 2014) that instead of anxiety, this study might assess the family belief system to focus on how this is displayed by the parental anxiety.

## Results and Discussion

### Data Collection

After obtaining internal review board approval for proceeding with the project as a quality improvement project, the project manager discussed the process with the control and intervention families (information sheet, Appendix G) to ascertain if the family would be willing to participate. Four families completed the anxiety scale as the controls (current preparation for the radiation therapy schedule). Two families received the structured interview and teaching following the family-centered process recommended by Wright & Leahy (2013) and completed the anxiety scale. The timetable for completion of data collection was July to December 2014. The structured interview provided staff with a structured template for family-centered communication (family dynamic and social information to complement medical history notes and structured teaching plan).

The Patient Experience staff placed the State-Trait anxiety assessment scale on an iPad for parents to complete before the first treatment (Appendix C), after the first treatment, and after the tenth treatment. The anxiety scale was available in English and Spanish. The project manager reviewed the iPad questionnaire with the parents and presented it to them prior to the first treatment. Depending on the parental preference for waiting for their child, the iPad was given to the parent or the parental waiting room staff gave the iPad to the parent. After the tenth treatment, the iPad was either given to the waiting room staff to give to the parent, given to the parent in radiation therapy to return to the waiting room, or retrieved from the parents on the in-patient unit.

The many information sheets given to parents by the ambulatory procedure unit nurses were combined into one comprehensive and colorful pamphlet that contained all of the

information from the prior sheets as well as educational resources (Appendix H). The information for the child's appointment times, feeding requirements for anesthesia, radiation therapy room number, the child's pediatric oncologist, and internet resource sites are included in the pamphlet. The pamphlet was sent to interpretive services for translation into Spanish.

### **Population**

The typical population for radiation therapy averages between one and four per month (20 annually). Between July and December 2014, there were only six pediatric patients scheduled for the treatment. One potential candidate was excluded due to ethical considerations (delicate physical condition per anesthesia). An outpatient (non-anesthesia) patient was included to increase the population data.

### **Data Analysis**

**Session One Family Interview.** The structured family interview revealed many common themes (Appendix B). The children ages ranged from two years of age to seventeen. Three families were Hispanic, one was Asian, and two were Caucasian. All of the interviews with the Hispanic families were conducted with interpretive services. Three were single parent families and three were two parent families. Two were out patient therapy schedules and four were with anesthesia.

During the interview, all of the families characterized the main response to the diagnosis as "shock." The 17 year-old patient stated to his mother an overwhelming fear of dying. Life following the diagnosis was described as "chaotic," "jumbled," stressful, problematic, and much like a roller coaster. The parent interviewed did not self-identify whom the diagnosis had the most impact on, even when they were obviously distraught and identified by other family

members. The parents stated that their child's siblings or the other parent were most impacted by the diagnosis.

The greatest challenge identified varied per family social situation. Two families faced transportation issues (out patient therapy sessions). One family attempted to "normalize" life by arranging daily therapy sessions after the child's school schedule. Coordinating work and finances with the therapy schedule was emphasized by two of the families.

The main recommendation from all of the families was to receive clear communication and explanation of the schedule and expectations. One family cited a disconnection between the coordination of chemotherapy and the radiation schedule.

**Session Two Family Interview.** The second interview found that the parents described themselves as fearful, "but better," trying the "new normal," and stressed. They are balancing the treatment schedule, the child's health status, and life demands. Questions about the treatment schedule ranged from how to treat mouth sores to transportation and social issues. Family coping issues centered on siblings feeling left out (acting out in anger) and the caretaker parent feeling obligated to be optimistic. Sibling issues were a common theme with the other children questioning or being angry, with one stating, "I need a parent to be with me, too!" Parents stated that they had to "be strong and fight" for their child but that they were scared and anxious (which they hid from the child).

Parental plans for the future were "cautiously optimistic." The theme of "new normal" and outlook on the future "changed" but all mentioned plans for their child and schooling. Beliefs that they relied on to be helpful were advancing technology, religious beliefs (prayer, Bible reading), adherence to treatment plan, and maintaining an optimistic outlook. One father stated, "I have to stay positive, because I have seen others take a negative outlook, and I don't



want to go down that road.” Two of the families had a history of central nervous system cancer and experience with radiation therapy with family members.

### **Role and Workflow Analysis**

A complete review and review and revision of the interdepartmental resources, standard work, and communication process identified best practices and issues (Appendices E, F, G, and H) (See Figures 1, 2, and 3). Child Life Specialists shared a photo book of a photo tour through the radiation therapy process that is available on iPad and book form. This photo book was transposed into a slide presentation to include a picture of the anesthesia machine and a descriptive narrative. The slides were presented to the technology department to upload to the hospital television system as a parent and child educational tool.

The ambulatory procedure unit nursing staff educational materials for parents was organized into a colorful pamphlet for parents (Appendix I, J). The information for the child’s appointment times, feeding requirements for anesthesia, radiation therapy treatment room number, the child’s pediatric oncologist, and internet resource sites are included in the pamphlet. The pamphlet was sent to the Patient Experience Staff and interpretive services for translation into Spanish.

Standard work processes were developed for all levels of staff to provide a clear description of roles and expectations (Appendix E, F, H, and L). A sequential list of standard work and a list of roles and expectations (Appendix E) were refined based on staff feedback and input. A check-off list for preparing for the child’s simulation/set-up and first treatment (Appendix H, L) improved the communication of tasks accomplished within ambulatory procedure unit nursing staff and the unit/floor staff. An additional step-by-step instruction of standard work for the ambulatory procedure unit nursing staff from set-up to first treatment to

the potential for child discharge (Appendix L) outlined standard work and communication processes.

The ambulatory procedure unit nursing staff contacted Child Life in advance of the first treatment to share the radiation therapy photo book with the families. The radiation oncologist does not access the children's hospital electronic record to write a consult for Child Life. An exploration of the Neuro-Oncology Nurse Practitioner including this in their workflow is in progress. The radiation therapy scheduler is reminded to contact Child Life with their standard work. The Child Life Specialists had to re-work their process to use the book as a teaching tool for parents as the children tended to suffer posterior fossa syndrome and were medicated with anti-anxiety medications.

Interpretive services assisted the nursing staff with the radiation therapy family teaching and procedural translation before and during the procedure. [In the past, interpretive services were only available before (pre-op or family waiting room) and did not stay in the radiation therapy treatment room with the parents]. The administration of anesthesia can be very emotional for the parents and they share important information with the team after the child is asleep. Interpretive services work flow changed to have them stay with the families until all staff and family agree that all information and communication is complete.

Increased interdepartmental collaboration and standardized communication processes are a direct result of the project. The radiation oncologist scheduling children for therapy sends ambulatory procedure unit nursing staff informative emails in advance (one to two weeks). The ambulatory procedure unit and radiation therapy schedulers discuss details of therapy and scheduling of these children for radiation therapy. The schedulers include the treatment room number and the number of treatments that the child will receive (on the surgical schedule

comment section). Including the number of treatments prescribed assists the anesthesiologist in completing the consent in an informed manner (such as 28 treatments prescribed, the consent will be obtained for 34 treatments providing for emergencies or interruptions). When the standard work is followed, the child's treatment pre-certification sent in advance (at least two to three days ahead of the prescribed treatment) and schedulers inform the APU nursing staff, family teaching can occur in a timely manner. The structured interview reveals important social and emotional factors that could affect patient care. The project nurse shares the parental interview information with the ambulatory procedure unit nursing staff, the radiation oncologist, the radiation therapists and nurses, and the anesthesia team to promote transparent communication. An additional communication log is included in the patient's radiation therapy binder to chronicle changes in the child's status and family-centered information for members of the healthcare team (such as topics that upset the family, music the child prefers, and isolation status) (lined paper with space for notes and dates).

The Family Council suggested a post-therapy family perception questionnaire (Appendix J). The qualitative analysis of the results is found in Appendix K. The initial findings were overwhelmingly positive even from parents who were quite vocal initially about their dissatisfaction with the radiation therapy process. The information sheet for the parents includes space for questions for the families to take notes on their suggestions during the process rather than a summary at the end of the therapy.

### **Challenges**

Due to the low possible patient population, the data is insufficient to make substantial conclusions. (The study will be continued beyond the time limitation of the project). The fact that fewer children necessitated radiation therapy prescribed for cancer treatment is considered a

good outcome for the population (fewer children meeting the cancer treatment criteria during the project time frame). Out of the six potential population candidates, four were identified as control. By pairing the population into three controls and three study patients, there would be an even comparison of data. A structured standardized work process for providing and promoting collaborative care for these families was instituted (official policy proposed). Numerous forms were compiled into a colorful pamphlet to provide information and resources for families.

Limited time during staff meetings led to email informational sessions for ambulatory procedure unit nursing staff. Additional review of the changes in the teaching/workflow, teaching for ambulatory procedure unit nursing staff, and monitoring competency is required to assure compliance with family-centered care. Ambulatory procedure unit nursing staff stated that they did not see a value in the family-centered interview until a discussion of the family emotional status, legal implications (consistent use of interpretive services) and increased family satisfaction with the structured interview improved their perception and opinion of the project.

Although the radiation oncologist states that the therapy was scheduled three to four weeks in advance, the schedulers received notice of pre-certification to schedule the children on average of two to three days during the project time frame. The limited time frame rushed the interview, teaching, and orientation of the parents and unit/floor nurses.

The State-Trait anxiety scale was a validated tool, however, the data from the parental self-assessment found that the parents describe themselves as calm, neither upset, nor tense even though the health care team observed the opposite. The statistician recommended a review of the scale or including the healthcare team members' perception of the parental anxiety as a comparison (McMillan, personal communication, February 24, 2015)(such as comparing the parental self-assessment to the APU nurses or radiation therapist impression of the parental

anxiety). Consideration of a behavioral assessment tool for parents should be explored is a recommendation for further projects such as the FACIT questionnaires (2010) or the National Comprehensive Cancer Network distress thermometer (2013).

A few families could not work the electronic questionnaire. Screen shots of the scale were provided on paper copies for the parents to mark their responses. When the child's physical state improved and they were discharged to home and it was challenging to obtain the post-therapy questionnaire. The paper copy of the anxiety scale questionnaire was given to the radiation therapists with a stamped/self-addressed envelope for the family to mail the project manager. The children who received treatment without anesthesia were difficult to locate on the radiation therapy schedule (not readily available between hospital electronic systems)(changed daily and one child did not regularly attend the treatment appointments). Phone calls to the parents for information, sometimes with a phone interpreter, were necessary. The sensitive nature of the interview and parental emotional state made it difficult for some parents to answer the anxiety scale questions with an interpreter (when the parent could not work the electronic or paper method).

The acuity of the children's illness and physical status impacted population candidates. One potential patient required a tracheotomy and the anesthesia team requested an in-depth discussion of the child's prognosis and condition with the neurosurgical and radiation oncology team prior to proceeding with the treatment schedule.

### **Conclusions and Future Study**

The entire team identified many advantages with the implementation of this quality improvement project. The interdisciplinary communication process was improved from start to finish amongst all levels of staff. The structured teaching approach for parents instituted a standardized method of information delivery. The teaching included the unit/floor nurses who reported that their understanding of the process improved with the shared information.

The Child Life Radiation Therapy photo book was virtually unknown to the ambulatory procedure unit nursing staff until this project began. Now, the revised version, to include information about anesthesia and is scheduled to be included in the television educational system for family teaching purposes. The Child Life Specialists have expanded their teaching with the photo book to include a focus on the parents who require anticipatory guidance about the radiation therapy geography (rather than the child who may not be in a physical or mental condition to comprehend the teaching).

Implementing a structured interview and teaching process incorporates evidenced-based research into the ambulatory procedure unit nurse clinical practice (Wright & Leahey, 2011). The parental interview was consistently timed to be 15 minutes as stated in the literature (Wright & Leahey, 1999), yet included all of the required teaching and parental commendation. Incorporating a state of the art care model increased all levels and departmental team satisfaction (Griffin, Wilhite, Wu, personal communication, December 2014). The structured interview gleaned family, social, and emotional information for the team to provide comprehensive and collaborative family support. The information from the interview process provided valuable data to share with all levels and departments of staff to increase efficiency of care. The efficiency of care could be considered a cost-saving initiative in terms of time saving.

Gawande (2010) offers evidence that a structured and standardized method of implementing healthcare practices improves team collaboration and efficiency. Wright & Leahy (2011) describe how a 15-minute interview can be family-centered and supportive for those dealing with sick relatives. This quality improvement project increased team collaboration, communication, and efficiency. Legal implications are that this standardized proposed policy assures that parents are informed of the care that their child will receive and that it is communicated clearly by healthcare team members, as well as interpreted in their native language, if needed. Multiple levels of staff reported increased process satisfaction with the detailed communication of team role expectation. Further study should provide data on parental anxiety associated with the radiation therapy treatment schedule with a behavioral analysis tool.

“This is a big thing, getting these two huge hospital systems to coordinate care,” (Singleton, personal communication, August 2014) declared a colleague when discussing the details of the family-centered care project and the families dealing with a child prescribed radiation therapy. The innovative and evidenced based quality improvement project that promoted collaborative healthcare team communication has made a positive impact on the radiation therapy experience of parents.

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## Appendix A

### Literature Review

Author/ Date	Theoretical/ Conceptual Framework	Research Question(s)/ Hypotheses	Methodology	Analysis & Results	Conclusions	Implications for Future research	Implications For practice
Ólafur Davarsdóttir, K., & Sigurdardóttir, A., 2013	Based on Wright & Leahey multi- dimensional model and theoretical framework (family systems, com- munication, change, cognition)	If a family therapeutic conversation intervention (FAM- TCI) effects family perceived support	Support and family functioning questionnaire, FAM-TCI interview,	Normal distribution; Higher family support after FAM-TCI; higher ability to communicate; no benefit to secondary care givers	Nurses trained in FAM-TCI benefit primary caregivers perception of support; efficient process	Brief beneficial interventions to families possible	Use of the FAM-TCI may result in better/more effective evidenced based family care
Mohammed Siddiqui, S., Abdullah Sheikh, F., & Samuel, R. ,2011	Family centered care	Do family-centered rounds improve parents and healthcare professional satisfaction/time utilization	Before and after outcome after implementation of family centered rounds	Parents expressed greater inclusion and satisfaction with family centered rounds; high team work scores	Family centered rounds improve parental satisfaction	Comparisons with additional studies needed.	Health care professionals should use this intervention and consider it a valuable tool for patient care.
McCabe, 2004	Com- munication	How does the communication of the nurse relate to the patient experience	Unstructured patient interview	Four themes- lack of com- munication', 'attending', empathy' and 'friendly nurses'.	Nurses can communicate effectively when supported by management and value oriented (vs. task)	Assess Patient centered communication and promote positive organizational attitude towards patient centered communication	Patient centered communicati improves care.



Appendix B

Parental Interview Form

**DNP Project Session Structure Expanded**

**Session 1:**

***Engagement-(First Encounter with parents and nurse)*** Y=Yes; N=No

NURSE	Child		Parent	
	Y	N	Y	N
Introduction	Y	N	Y	N
Purpose of Study Explained	N/A		Y	N
Estimate of Interview/Orientation time frame	Y	N	Y	N

“The purpose of this quality improvement project is to understand how the healthcare team provides family centered care for families with children scheduled for radiation therapy. We are trying to improve our process of providing a positive family-centered process.”

***Assessment-FAMILY STRUCTURE***

NURSE	Parent	1	2	3	4	5	Distance From hospital	Language			Nurse Drawn Schematic of Family
								E	S	O	
Tell me about your family	Father										
Nurse Draws Schematic of family	Mother										
	Brother										
	Sister										
	Grand-parents										
	Extended family										

1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried

Distance from hospital-in miles

E-English; S-Spanish; O-other

**Assessment-FAMILY SUPPORT**

Nurse	Child	Parents			Notes
Tell me about your Family support system		M	F	O	
Friends					
Relatives					
School					
Work					
Religious Group					
Social Media					
Other					
<b>Resources Needed</b>					
Interpreter (language)					
Child Life					
Social Work					
Housing					
Nutrition Services					
Transportation					

***M-mother, F-Father, O-other***

**HISTORY OF CHILD'S DISEASE PROCESS-Behavioral, Cognitive, Emotional**

Initial Diagnosis- Date: \_\_\_/\_\_\_/\_\_\_

Reaction to Child's Diagnosis: 1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried

	1	2	3	4	5
Child					
Father					
Mother					
Other					

Since the initial diagnosis, life has been: A=Appointments; B=One day at a time; C=Roller coaster; D=Scary; E=Uncertain

	A	B	C	D	Other
Father					
Mother					
Other					

Who in the family do you think that this illness has had the most impact on? F-Father; M-Mother; S-Sibling; O-Other

	F	M	S	O
Father				
Mother				
Other				

What is the greatest challenge facing your family? D=Diagnosis; T=Transportation; H=Housing; W=Work; S=School; OC=Other children;

\$=Money; O=Other

	D	T	W	S	OC	\$	OTHER
Father							
Mother							
Other							

**Conclusion about family structure and support, life cycle, recognition of strengths and challenges (function).**

**NURSE-** "Now that I have a picture of your family and support system, and your child's history, I would like to talk with you about the radiation therapy process."

1. "First, tell me what you know about the treatment plan."

Surgeon explanation \_\_\_\_\_  
 Radiation Oncologist explanation \_\_\_\_\_  
 Nurse Practitioner explanation \_\_\_\_\_  
 Other \_\_\_\_\_

Reinforce or clarify answers.

2. Video of Simulation set-up-Child Life XRT photobook

Discuss simulation set-up: Anesthesia-monitor child's comfort \_\_\_\_\_  
 Nursing care-stay with child during procedure,  
 Recovery, communicate, teach \_\_\_\_\_  
 Radiation Technologists-monitor, assist with  
 Treatment plan \_\_\_\_\_

Radiation Oncologist-monitor child, prescribe  
Treatment plan \_\_\_\_\_

3. Daily Schedule/Treatment plan-Video of XRT Room and Equipment

Nursing/Anesthesia assessment \_\_\_\_\_

Radiation Oncologist assessment \_\_\_\_\_

Radiation Technologists \_\_\_\_\_

XRT Waiting Room \_\_\_\_\_

Procedure Room \_\_\_\_\_

Therapy Room and Equipment \_\_\_\_\_

Recovery Room \_\_\_\_\_

Packard Family Waiting Room \_\_\_\_\_

Common Concerns:

Fatigue\_\_ Depression\_\_ Emergencies\_\_ Headache\_\_ Nausea\_\_ Nutrition\_\_ Skin  
care \_\_\_\_\_

Other \_\_\_\_\_

4. Family Recommendations/Requests for Healthcare team

\_\_\_\_\_

5. Questions \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

***NURSE-Comment family about strengths, care of child, coping  
END OF INITIAL INTERVIEW***

**SESSION 2-After Tenth Treatment**

	1	2	3	4	5	1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried Other
How is family coping with XRT schedule						
Child						
Mother						
Father						
Other						

**Questions:**

	D	RX	H	C	HCP	D=Diagnosis;RX=Treatment Plan; H-Child's Health; C=Care; HCP=Healthcare Team OTHER
Father						
Mother						
Other						

Other family members coping?

	1	2	3	4	5	Other
Brother						
Sister						
Grandparents						
Extended family						
Other						

What beliefs have you and your family found helpful to rely on when dealing with the disease and the daily treatment plan?

R=Religion; H=Hope for cure/child's life; F=Friends; S=School; W=Work; M=Social Media

	R	H	F	S	W	M	OTHER
Father							
Mother							
Other							

What do you think the future will be for your family and your child?

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*Termination*-NURSE-“ This is the end of the quality improvement interview process but know that your family and child will be supported throughout the rest of the treatment cycle and beyond.”

### **Commendation**

Emphasize family strengths-being there for their child, supporting child, positive attitude, optimism

Thank the family for their participation

The family can contact the project team if they have questions or concerns about the project or ask any member of your healthcare team for any questions or concerns

### Reference

Svavarsdottir, E. K., Sigurdardottir, A. O., & Tryggvadottir, G. B. (2014, February). Strengths-oriented therapeutic conversations for families of children with chronic illnesses: findings from the Landspítali university hospital family nursing implementation project, *Journal of Family Nursing*, 20(1), 13-50. doi: 10.1177/1074840713520345

Wright, L. M., & Leahy, M. (1999, August). Maximizing time, minimizing suffering: The 15-minute (or less) family interview, *Journal of Family Nursing*, 5: 259-274. doi: 10.1177/107484079900500302

Wright, L. M., & Leahey, M. (2013). *Nurses and families, a guide to family assessment and intervention*, F. A. Davis: Philadelphia, PA.

## Appendix C

***Anxiety Inventory***

Self-evaluation questionnaire

Date \_\_\_\_\_

*A number of statements that people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel RIGHT NOW, at THIS moment.*

*There are not right or wrong answers. Do not spend too much time on any one statement but give the answer that seems to describe your present feelings best. If you want to add any comments, there is a box at the end, after the questions only if you want to write anything or add any thoughts.*

	Not at all	Somewhat Moderately		Very Much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

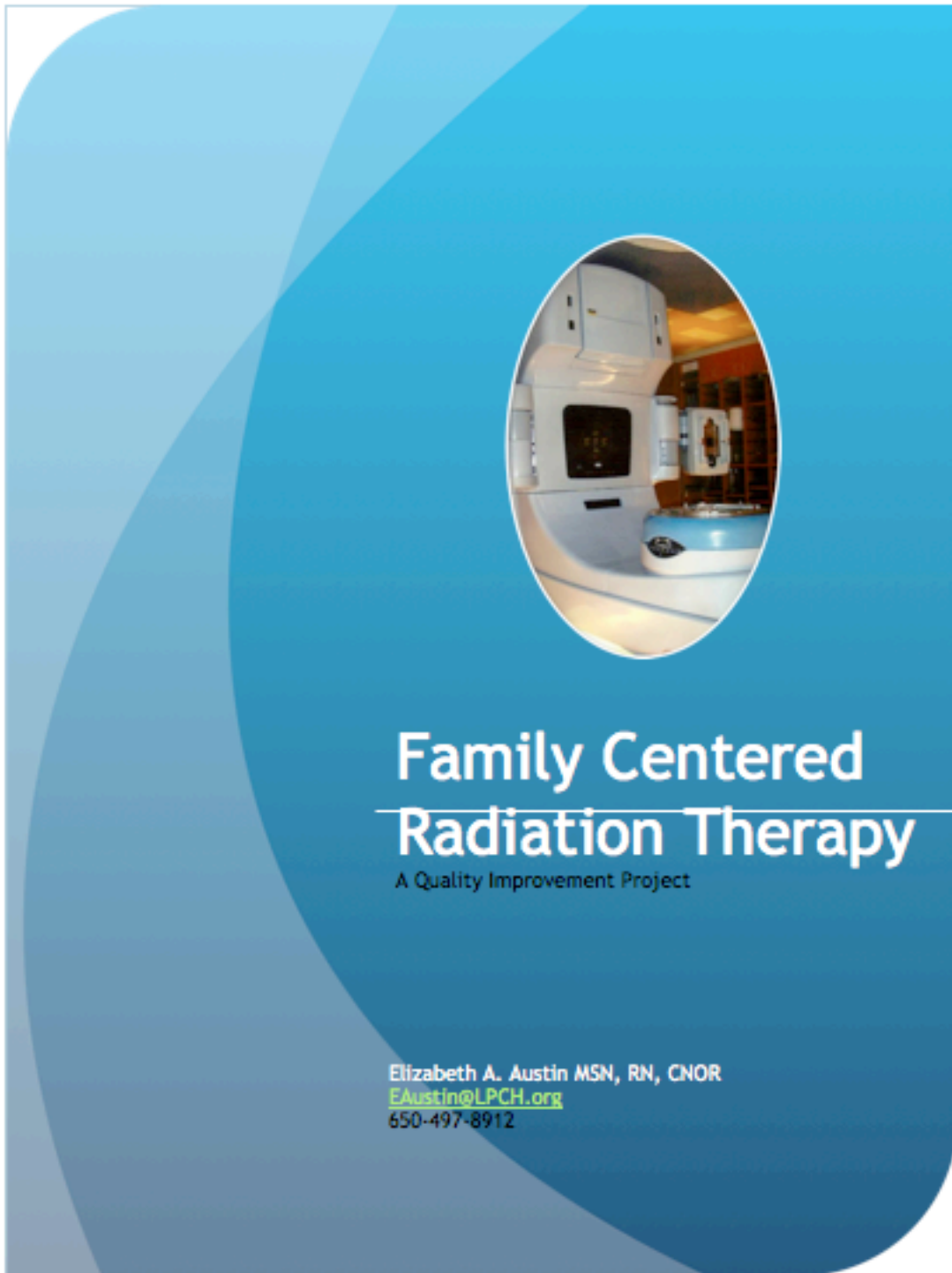
*Comment Box:*

A \_\_\_\_\_ B \_\_\_\_\_ C \_\_\_\_\_ D \_\_\_\_\_ E \_\_\_\_\_

(A: Before first treatment, B: After first treatment, C: after 10<sup>th</sup> treatment, D: Before intervention, E: With intervention)

Marteau, T. M., & Bekker, H. (1992). The development of a six-item short form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI), *British Journal of Clinical Psychological Society*, 31, 301-306. Retrieved from [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8260](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8260)

## Appendix D



**Family Centered  
Radiation Therapy**  
A Quality Improvement Project

Elizabeth A. Austin MSN, RN, CNOR  
[EAustin@LPCH.org](mailto:EAustin@LPCH.org)  
650-497-8912



**A Quality Improvement Project to increase communication with the families of a child scheduled for radiation therapy.**  
**The components of the project are:**



**1. An interview to find out more about your family's preferences for your child's care**

Information about the radiation therapy process will be shared.



**2. A Tour of the Radiation Therapy area.**

The Child Life Radiation Therapy photo book and a tour of the radiation therapy unit will be available for you to learn more about the area and process before your child's therapy begins.



**3. An assessment of your feelings before the first treatment, after the first treatment, and after the tenth treatment.**

An iPad with 6 questions about how you feel about the process will be available. You can choose not to complete



**4. A questionnaire about how you feel the process is and your feedback for the team caring for your child.**

What is going well? \_\_\_\_\_

\_\_\_\_\_

What could be improved? \_\_\_\_\_

\_\_\_\_\_

Suggestions for the team: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix E

## Standard Roles

**Pediatric Radiation Therapy Standard Work by Roles**

- Anesthesia-** Communicate plan for anesthesia to nursing/therapists  
-Support patient during treatment schedule  
-Receive report from and give report to intensive care unit attending/fellow  
-Coordinate with respiratory care practitioner airway/oxygen concerns
- Anesthesia Tech-**Set up anesthesia machine and cart in radiation therapy room prior to patient arrival  
-Be available for patient care support for anesthesia/nursing staff as needed  
-Remove anesthesia machine when treatment completed
- Ambulatory Procedure Nurse-**Verify location and time of patient's treatment  
-Consult with schedulers and pediatric radiation oncologist patient radiation therapy schedule time and room location  
-Obtain report from unit/floor nurse  
-Organize radiation therapy binder for daily treatment use  
-Service leader initiates family-centered structured interview and teaching about the radiation therapy process (use interpretive services if needed)  
-Offer a tour of the area for the family  
-provides information pamphlet to family about radiation therapy schedule  
-Contact Child Life Specialist to share radiation therapy photobook with parents/child  
-Arrange interpretive services  
-Obtain report from ambulatory procedure nurses from prior treatment sessions  
-Communicate with anesthesia prior treatment session experiences and any relevant family preferences/status concerns  
-Verify consent for treatment/emergency code sheet to accompany

- patient to radiation therapy (usually in patient's radiation therapy binder /bag).
- Initiate time out in radiation therapy room-verify patient identity per policy and duration of treatment (and any extra procedures necessary)
  - Consult with radiation therapists and nurses
    - pediatric radiation oncologist requested consults time with family
  - Ascertain duration of treatment and inform scheduler, and anesthesia scheduler (to assure correct scheduled time allotment)

**Child Life Specialists-** Share radiation therapy photobook information with child/family prior to simulation

- Support child on Mondays if necessary for port access

**Floor nurses-**Complete pre-op check list

- Verify time for patient to leave unit and meet with ambulatory procedure/anesthesia staff/respiratory tech (if per policy) in radiation therapy
- Call report to ambulatory procedure nurse at least 20 minutes prior to scheduled treatment (such as 0710 for 0730 treatment schedule)
  - Report to ambulatory procedure nurse/anesthesia staff- fasting time, changes in status, pain level, respiratory concerns, completion of pre-op check list
- Escort patient to cancer center for radiation therapy treatment (after first treatment-patient reports to pre-op holding for anesthesia consult and parental consent)

**Interpretive Services-**Translation services for radiation therapy consents, family interviews

- Remain available until nurse/anesthesia dismiss

**Nurse Coordinator**-Communicates with ambulatory procedure nurse the start of radiation therapy patient process

- Communicates with ambulatory procedure unit nurse the pediatric radiation oncologist's consultation with family prior to treatment requests
- Checks in with family about any new symptoms, social, nutritional, skin issues and reports to pediatric radiation oncologist

**Pediatric Radiation Oncologist-**

- Coordinate radiation therapy treatment schedule for pediatric patient
- Initiate time-out prior to simulation
- Verify positioning equipment during time out
- Assesses patient response to treatment and radiation therapist's assessment of treatment process

**Respiratory Care Practitioner**-Coordinate with ambulatory procedure unit nurse/anesthesia the time for patient to depart unit for radiation therapy

- Provide respiratory support for patient coordinated with anesthesia
- Accompany patient to adult cancer center for radiation therapy treatment
- Responsible for tracheostomy travel kit and special suction catheters as needed
- All questions should be referred to ambulatory procedure unit

**Radiation Therapists**-Introduce self to family prior to photos or intervention (name, role, expected activity, such as John Smith, radiation therapist, I will be taking pictures and assisting with the set-up/simulation)

- Participate in time-out process
- Daily treatments-introduce self to family
- Communicate with ambulatory procedure unit/anesthesia staff requested pediatric radiation therapy consult time prior to treatment
- Communicate to ambulatory procedure unit nursing

- staff estimated radiation therapy treatment time for scheduling purposes
- Coordinate and administer radiation therapy set-up/ simulation and daily treatment schedule
- Communicate with pediatric radiation oncologist/ambulatory procedure unit staff changes in patient's condition/reaction to therapy

### **Radiation Therapy Registered Nurses-**

- Communicate with ambulatory procedure unit nursing staff treatment/pediatric radiation oncologists' requests and patient's condition/changes
- Obtain contrast consent for simulation from parents in pre-op holding
- Provide back-up support for ambulatory procedure unit/anesthesia staff in case of emergency (bring code cart to room)
- Communicate with ambulatory procedure unit/anesthesia staff requested pediatric radiation oncologist consult time prior to treatment
- Arrange interpretive services with pediatric radiation oncologist and ambulatory procedure unit nurses

### **Schedulers-**Schedule patient for simulation/set-up

- Schedule child for radiation therapy time frame for entire treatment cycle
- Inform service lead of simulation/treatment schedule immediately
- Radiation therapists/pediatric radiation oncologist to inform ambulatory procedure unit nurse attending first treatment of expected duration of treatments for scheduling purposes
- Inform service lead of any changes in the radiation therapy schedule

### **Unit Nurses**

#### **Pediatric Intensive Care Unit-**Complete pre-op check list

- Verify time for patient to leave unit with ambulatory procedure unit/anesthesia staff/respiratory tech (if per policy)
- Report to ambulatory procedure/anesthesia staff-fasting time, changes in status, pain level, and respiratory concerns

- Coordinate with respiratory tech-oxygen/suction support
- Accompany patient to the cancer center for radiation therapy treatment
- Questions refer to ambulatory procedure unit nurses

## Appendix F

### Standard Work Sequence for Pediatric Radiation Therapy Team

**Pediatric Radiation Oncologist** orders radiation therapy set up/ schedule

**Neuro Oncology Nurse practitioner** orders Child Life consult for parents/ child (If not completed, ambulatory procedure unit nurse to consult Child Life)  
NOTE-Child Life has a Radiation Therapy orientation for children in photobook and iPad photobook format. This is very helpful for the parents-the child may not be physically or emotionally ready.

**XRT Scheduler-** Stanford radiation therapy scheduler sends pre-certification form to surgical scheduler

**Surgical Scheduler** informs **ambulatory procedure unit nurses** of radiation therapy planned set up date and prescribed schedule

**Ambulatory procedure unit nurses** - review patient chart for pt history and need for interpretive services and initiate family centered teaching (see teaching form)

- Consult child life to review teaching and patient history
- Send fax for interpretive services if needed
- Review results of family teaching with ambulatory procedure unit nurses, anesthesia, pre/post anesthesia recovery unit manager, radiation therapy staff
- Review inpatient standard work with inpatient charge/ primary nurse
- Set up-call Radiation Therapy Nurse** to ascertain simulation room, contact number, and staff
- Radiation Therapy Nurse and staff** will inform **ambulatory procedure unit nurse** about the use of contrast during simulation
- Contrast- Radiation Therapy Nurse** needs to know patient weight, height, glucose, creatinine level, and intravenous access information  
The child's parent will be asked to sign a form acknowledging the need for hydration following the administration of contrast

#### **Pre-op**

**Unit/ floor nurse** will assist with completion of pre- op patient requirements- fasting status, pre-op bath, documentation, moving patient to pre-op holding.

**Pre-op nurse-** completes pre-op check list

**Anesthesia technician-** prepares simulation room for patient ( anesthesia machine and computer for documentation)

**Anesthesia**-complete consent with the parents or designated guardian after review of patient history and discussion.

**Ambulatory procedure nurse, anesthesia, interpretive services** " accompany family/patient to radiation therapy simulation room.  
Pediatric radiation oncologist, radiation therapy nurses, and radiation therapists meet patient and family  
First procedural time out performed-anesthesia to address parental presence during induction\*

**Radiation therapy technologists** photograph patient for record purposes

**Patient** anesthetized for the procedure-**Anesthesia** to direct **parent** presence during induction\*

**Pediatric Radiation Oncologist** speaks with parents and informs team of parent location (for waiting for child).

**Parents** wait in hallway just outside set-up/simulation room or at the Family Waiting room

**Team time-out**-confirmation of procedure time estimation,  
**Pediatric Radiation Oncologist** confirms prescription for positioning patient with **Radiation Therapists**

#### **After set-up/simulation, before first treatment**

**Ambulatory procedure unit nurse** compiles radiation therapy binder and bag for therapy sessions.

**Ambulatory procedure unit nurse** confirms treatment schedule, start/end dates, and patient location.  
Ambulatory procedure nurse completes parental interview if not completed prior to simulation

**Ambulatory procedure unit nurse** completes family information pamphlet and gives a copy to the parent (make a copy for chart and floor/unit nurses)



**First Treatment-**

**Floor/Unit** nurses are informed of patient's scheduled first treatment by the **Nurse Navigator**.

**Pre-op Nurses** receive report from the floor/unit nurses and send for the patient. (NOTE: Consent for radiation therapy set-up/Simulation available in electronic record for confirmation).

**Anesthesia** confirms number of treatments scheduled with **ambulatory procedure unit nurse** and completes a Radiation Therapy Serial Consent form for the number of treatments plus 4 (in case of unplanned changes in the therapy schedule) **ambulatory procedure unit nurse** copies serial consent and places the copy in the patient radiation therapy binder

**Ambulatory procedure unit nurse** reviews teaching parent about the treatment process  
Confirms treatment room with **the radiation therapy unit nurses**

**Anesthesia Tech**-prepares simulation room for patient ( anesthesia machine and computer for documentation)

**Anesthesia and ambulatory procedure unit nurse** accompany patient and parent to the designated radiation therapy room

**Radiation Therapists**-introduce selves to parent (s), provide a calendar for patient schedule, assist Packard Team as needed

**Pediatric Radiation Oncologist** speaks with parents and informs team of parent location to wait

**Team time-out**-confirmation of procedure time estimation,  
**radiation therapists** confirms time estimation and positioning

**Ambulatory procedure unit nurse** calls the **post-anesthesia unit** and **anesthesia tech** when the radiation therapists confirm 15 minutes until the end of treatment session

**Ambulatory procedure unit nurse/Anesthesia Team** takes patient to **post-anesthesia unit** for recovery.

**Post-anesthesia care unit nurse** returns patient travel circuit and blood pressure cuff to patient radiation therapy bag that is stored in the post-anesthesia care unit

## Regular Treatment Schedule

**Ambulatory procedure unit nurse** provides **floor/unit nurses** with standard process for in-patient radiation therapy (see attachment)

**Floor/Unit Nurse**-assures compliance with pre-op policy for pediatric radiation therapy patients  
Completes pre-op check list

**Ambulatory procedure unit nurse** obtains report from floor/unit nurse

**Floor/Unit Nurse**-calls report to ambulatory procedure unit nurse at least 20 minutes prior to patient's scheduled treatment time and sends the patient to radiation therapy

**Anesthesia/ Ambulatory procedure unit nurse** review patient status with parent(s), answer questions, and address issues

**Parent(s)**-will stay with child/patient as needed/desired  
Confirm with Radiation Therapists about **Pediatric Radiation Oncologist** consulting with **parents** prior to parental departure from radiation therapy treatment room (see NOTE)

**Team time-out**-confirmation of procedure time estimation,  
**Radiation Therapists** confirms time estimation and positioning

**Ambulatory procedure unit nurse** calls **post anesthesia care unit and anesthesia tech** when the radiation therapists confirm 15 minutes left for treatment

**Ambulatory procedure unit Nurse/Anesthesia Team** takes patient to **post anesthesia care unit** for recovery.

**Post anesthesia care nurse** returns patient travel circuit and blood pressure cuff to the patient's radiation therapy bag that is stored in the **post anesthesia care unit**

**NOTE: Pediatric Radiation Oncologist and Nurse Coordinator** may want to  
Speak with parent(s)-ambulatory procedure unit nurse and radiation therapists confirm prior to parent(s) leaving the radiation therapy treatment area

## OTHER

**Patient discharge-**If the patient is discharged, the **Floor/Unit Nurse** will confirm with the **ambulatory procedure unit Nurse**, discharge directions for the Radiation Therapy schedule

**Intavenous Access- Patients** with **ports**-the port will be accessed on Mondays and remain accessed until Friday (**post anesthesia care nurse** will obtain heparin orders from **Anesthesia**)  
Parents will place prescribed lidocaine cream over the port area on Monday as ordered

**Illness-**Child will report to the Stanford/Packard Emergency Room for any issues relating to illness

**Child Life and Interpretive Services** can be contacted to assist with the Child and family for the entire treatment schedule

**Parents and Child** have the right to revisit and review the need for anesthesia at any time during the treatment schedule. Families may determine that the child is able to tolerate the treatment without anesthesia or may need to have anesthesia (when they didn't prior). This is a family and physician decision.

## Appendix G

### Proposed Policy: Radiation Therapy Pediatric Patient and Parent Orientation

Goal: To coordinate interdepartmental communication with the radiation therapy pediatric patient families.

1. The pediatric radiation oncologist will communicate with the Nurse Coordinator the treatment plan for the patient (diagnosis, schedule, expected outcome and potential side effects).
2. The Nurse Coordinator will communicate with the nursing units (Inpatient, ambulatory procedure unit, post anesthesia care unit) and anesthesia department the radiation therapy treatment plan (treatment schedule and process of the patient moving to radiation therapy, post anesthesia care unit, and returning to the unit).  
The Nurse Coordinator will communicate with the pediatric radiation therapy patient family at least 3 days prior to the first treatment/simulation according to the following family centered communication tool: (See Appendix A).
3. The Nurse Coordinator will arrange Child Life and Interpretive Services as needed to assist the family.
4. The Nurse Coordinator, Ambulatory procedure unit, Radiation Therapy physicians and technologist, nursing staff (post anesthesia care unit, inpatient unit representative, radiation therapy), and family council representatives will meet monthly and as needed to improve interdepartmental communication and family centered care.
5. Changes in the patient's radiation therapy plan or condition will be communicated by the pediatric radiation oncologist to the nurse coordinator who will communicate the changes with the nursing units (Inpatient, ambulatory procedure unit, post anesthesia care unit), radiation therapy nurses and technologists, and anesthesia department.

## Appendix H

**Radiation Therapy Check-Off Sheet**  
**for**  
**Unit/Floor Staff**

\_\_\_\_\_ Time confirmed for child's Radiation Therapy  
Monday \_\_\_\_\_  
Tuesday-Friday \_\_\_\_\_

\_\_\_\_\_ NPO time \_\_\_\_\_

\_\_\_\_\_ NPO Time documented

\_\_\_\_\_ Pre-Op Check List Completed

\_\_\_\_\_ Report Called to Pre-op -simulation/set-up,  
first treatment

\_\_\_\_\_ Report Called to Ambulatory procedure unit

\_\_\_\_\_ (Child's Name) \_\_\_\_\_ to be in  
Radiation Therapy Room \_\_\_\_\_  
by \_\_\_\_\_ on Mondays and  
by \_\_\_\_\_ Tuesday-Friday

Any DELAYS/Questions should be called as soon as possible  
to the ambulatory procedure unit numbers listed above

\_\_\_\_\_ Any extra requests should be confirmed VERBALLY with report to  
ambulatory procedure unit nurse

Appendix I

Parent Brochure for Radiation Therapy with Anesthesia

**Resources**

National Cancer Institute  
*Radiation Therapy and You*  
<http://www.cancer.gov/cancertopics/coping/radiation-therapy-and-you/radiationtherapy.pdf>

Child Life Radiation Therapy Photobook  
 Nutritionist: \_\_\_\_\_  
 Social Worker: \_\_\_\_\_

**Notes:**

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**Pediatric Radiation Therapy**

Stanford University Medical Center  
 Radiation Therapy  
 875 Blake Wilbur Dr, Palo Alto, CA 94304

Stanford University Medical Center  
 Stanford Children's Health

## 's Schedule:

Monday: \_\_\_\_\_

Tuesday: \_\_\_\_\_ (Weight check day) through Friday

\_\_\_\_\_ should stop eating at \_\_\_\_\_ and can drink milk/formula between \_\_\_\_\_ and \_\_\_\_\_. Drink ONLY water from \_\_\_\_\_ until \_\_\_\_\_ and

**NOTHING** after \_\_\_\_\_, before their treatment.

The Ambulatory Procedure Unit Nurse and Anesthesiologist will meet you at the Stanford Radiation Therapy Pediatric waiting room at Stanford Cancer Center after you check in at Packard Admissions office. If you have challenges being on time,

call 650-497-8912.



## “What can we expect?”

Radiation Oncologist: \_\_\_\_\_

Nurse: \_\_\_\_\_

Treatment Room: \_\_\_\_\_

Ambulatory Procedure Unit Phone Number:

**650-497-8912**

The Stanford Children's Health team of anesthesiologists, and Ambulatory Procedure Unit nurses, and Radiation Therapists will take care of your child every day during the treatment schedule under the direction of your child's pediatric radiation oncologist.

Your child's treatment schedule is from:

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ to \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Where to wait: Family Waiting Room  
At Stanford -OR-

Packard Family Waiting Room (#070)

### Common Side Effects of Radiation Therapy:

- Appetite changes
- Skin irritation
- Fatigue
- Nausea

# Appendix J

## Parent Brochure for Radiation Therapy without Anesthesia

### Resources

National Cancer Institute  
*Radiation Therapy and You*  
<http://www.cancer.gov/cancertopics/coping/radiation-therapy-and-you/radiationtherapy.pdf>

Child Life Radiation Therapy Photobook

Nutritionist: \_\_\_\_\_

Social Worker: \_\_\_\_\_



**Notes:**

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## Pediatric Radiation Therapy



Stanford University Medical Center  
 Radiation Therapy  
 875 Blake Wilbur Dr., Palo Alto, CA 94304

**Stanford University Medical Center**  
Stanford Children's Health



# \_\_\_\_\_’s Schedule:



Monday: \_\_\_\_\_

Tuesday: \_\_\_\_\_ (Weight check day) through Friday

\_\_\_\_\_ should stop eating and drinking at: \_\_\_\_\_ before their treatment.

The Radiation Therapist team will meet you at the Stanford Cancer Center after you check in at the front desk. Your child will be treated in room LA\_\_\_\_\_. If you have challenges being on time,

call \_\_\_\_\_.

A...

## “What can we expect?”



Radiation Oncologist: \_\_\_\_\_  
Nurse: \_\_\_\_\_  
Treatment Room: \_\_\_\_\_

The Stanford University Pediatric Radiation Oncologists and Radiation Therapists will take care of your child every day during the treatment schedule.

Your child’s treatment schedule is from:

\_\_\_\_/\_\_\_\_/\_\_\_\_ to \_\_\_\_/\_\_\_\_/\_\_\_\_

Where to wait: Family Waiting Room  
At Stanford -OR-

\_\_\_\_\_

### Common Side Effects of Radiation Therapy:

- Appetite changes
- Skin irritation
- Fatigue
- Nausea

Appendix K

Family Feedback Questionnaire\*

Questions-

1. What was helpful for you and your child during your child's radiation therapy treatment?

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2. What are your suggestions for improving the radiation therapy process?

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3. What are your recommendations for other families?

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\*Suggestion from Packard Family Council

## Appendix L

## Family Feedback Questionnaire Results

1. What action was positive that we should continue with other families?

Thorough explanations  
Teamwork  
Positive, helpful, and nice staff  
Keep the present plan-helpful

2. What should we not continue in the future?

Call ahead for changes in the schedule  
Three out of four surveys stated no complaints or changes  
-positive experience emphasized

3. What are your recommendations for other families?

Stay calm  
This is one step in a journey  
Ask questions even though you might think that they are silly-ask anyway!  
Stay positive and keep it fun  
Keep things as normal as you can  
Positive attitude helps it be easier and better

Appendix M

Family Interview Data

Session #1

#	Reaction To Dx	Life	Impact Answer/ impression	Greatest challenge	Recommendations	Questions
1P	M.F-2	C "chaotic"	s-sister/ F	Home-Out of town	Clear directions on family waiting area	X
2P	Shock Disbelief	C "jumbled" no set schedule	s-brother/ F	\$	No surprises Clear expectations and explanations	X
3P	C-2,4 "I don't want to die" nervous and crying M-2-5 "crying all the time not in front of "	A, C, E- Full of stress, problematic	M	T, H, S, \$ "everything"	Interpretive services Communication of schedule and coordination with chemo	Communication of schedule and coordination with chemo

Reaction: 1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried

M-mother; F-Father, C-child, O-other

Life: A=Appointments; B=One day at a time; C=Roller coaster; D=Scary; E=Uncertain

Impact: F-Father; M-Mother; S-Sibling; O-Other

Greatest Challenge: D=Diagnosis;T=Transportation; H=Housing;

W=Work;S=School;OC=Other children; \$=Money;O=Other\_\_\_\_\_

**Session #2**

#	Coping	Questions	Family Coping	Helpful Beliefs	Future
1P	C-3, “but better” Not as angry, Laughing and joking M-optimistic Reviewing quality of life of child, “cheerleader” “warrior mom”	X	S-2,3 G-2	“hoping that future technology will give ____ 2-5 more years”	M-planning for 2-5 years out New outlook on future, Cautiously optimistic
2P	C-mouth sores F-work is accommodating Time crunch with other child Tired	H-How to treat mouth sores	S- “rambunctious” feels left out G-help manage	R-large part of family Read Bible and pray Work to “clear head and stay positive”	6-7 months of chemo focused on radiation therapy and nutrition
3P	C-“so-so” O-demanding to eat Out not mother’s cooking M-“ok”	C-Other transportation Distance from Hospital-c wants to live closer to hospital	Other-“so-so” M-I told X to Be strong and fight I pray with him	C-walk and eat more Mother taught how to pray	__ will finish school

Coping-1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried  
Other

Questions-D=Diagnosis;RX=Treatment Plan; H-Child’s Health; C=Care; HCP=Healthcare  
Team, OTHER

Family Coping-1-Angry; 2-Anxious/worried; 3-Fearful/scared; 4-Sad; 5-Stressed/worried  
Other

Beliefs-R=Religion; H=Hope for cure/child’s life; F=Friends; S=School; W=Work; M=Social  
Media

NOTE: The first (1P) family was eliminated from the study after the initial interview due to ethical reasons related to the child’s health issues. However, the child’s parent addressed all of the interview points of the second interview in a casual conversation and are included.

Appendix N

Radiation Therapy Binder Check-Off Sheet

Item	Date Completed
_____ Binder and Bag	_____
_____ History/Physical/Emergency Sheet/Info Sheet in Binder	_____
_____ Family Teaching (pamphlet, Child Life)	_____
_____ Interpretive Services form faxed (or N/A)	_____
_____ Child information sheet completed in binder	_____
_____ Unit/floor nursing staff informed of process for simulation	_____
_____ Unit/floor nursing staff informed of process for first treatment	_____
_____ Unit/floor nursing staff informed of process for treatment schedule	_____
_____ Serial consent copied and in binder	_____
_____ Ambulatory procedure unit Nursing staff communication sheet in binder	_____
_____ Parental pamphlet (Appendix I)	_____



