Alleviating anxiety in children with cancer facing radiotherapy

The creation of a serious game

CATARINA CEDERVED
Abstract


Children undergoing radiotherapy (RT) can experience anxiety, and explaining the procedure through a serious game could be a means to alleviate anxiety. Children have the right to take part in research that concerns them. Through co-creation stakeholders can be part of the process and thereby ensure that the developed product is suitable for the end users. The overarching aim was to investigate the developmental process of a serious game about RT, with a focus on the influence of co-creation, the feasibility of the game, and the game’s effects on self-rated anxiety by children undergoing RT.

The thesis consists of four studies, where the first three describes the developmental process of the serious game from different aspects. Study I describes the children’s and their parents’ contributions to the game development based on data from interviews, audio recordings from workshops, and filmed gameplay. Nine children participated, 7 to 10 years old. Study II describes the experiences of seven parents who participated in the first study through interviews. Study III consist of interviews made with thirteen researchers, game designers and hospital staff. The interviews describe the participants’ experiences of taking part in the developmental process of the game. In study IV, reach and acceptability of the game was tested through a feasibility study at one clinic. It was a randomized pilot, waiting list based study where 22 children participated. Analyses were performed by thematic analysis (Study I and III), content analysis (Study II) and statistical calculations (Study IV).

The results showed that every participant involved in the development of the game contributed to the process. The method used in study I can be applied by researchers to co-create serious games with children. The children were active participants and had a consulting and informative role in the development, and their participation led to numerous changes. The interdisciplinary work was challenging but with ample time and an open climate it worked. A majority of children reported anxiety at the start of RT. In conclusion, the children’s participation impacted the game’s design and its content. The children’s abilities to participate in workshops was affected by their disease. Not all of the feasibility criteria set for study IV were reached. There were too few participants enrolled in the study to conclusively answer if the game had an effect on self-reported anxiety.

Keywords: anxiety, game design, participatory design, pediatric oncology, psychological preparation, proton radiotherapy, serious game, interdisciplinary research

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If you say run  
I'll run with you  
And if you say hide  
We'll hide  
Because my love for you  
Would break my heart in two

David Bowie, Let’s Dance (1983)

To Tindra
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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<td>App</td>
<td>Digital application</td>
</tr>
<tr>
<td>CCC</td>
<td>Child-centered care</td>
</tr>
<tr>
<td>PAR</td>
<td>Participatory Action Research</td>
</tr>
<tr>
<td>PENS</td>
<td>Player Experience of Need Satisfaction</td>
</tr>
<tr>
<td>RT</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>STAI</td>
<td>State-Trait Anxiety Inventory Adult</td>
</tr>
<tr>
<td>STAIC</td>
<td>State-Trait Anxiety Inventory for Children</td>
</tr>
<tr>
<td>STAIC-T</td>
<td>State-Trait Anxiety Inventory for Children (Trait)</td>
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<tr>
<td>STAIC(S)</td>
<td>State-Trait Anxiety Inventory for Children (Short adapted form)</td>
</tr>
<tr>
<td>UNCRC</td>
<td>United Nations Convention on the Rights of the Child</td>
</tr>
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<td>VR</td>
<td>Virtual Reality</td>
</tr>
</tbody>
</table>
Preface

With the birth of my daughter in 2001, my life took on a whole new course. My interests changed, and I changed the direction of my studies, and in January 2005, I graduated as a nurse. A few years later, I became a pediatric nurse. I was intrigued by children’s development, how to mitigate their fears, and how to support them when in need of care. I spent eight years working as a school nurse with children between the ages of 6 to 16 years. During health assessments, healthy and ill children cross the path of the school nurse when the children are enrolled in school. During those years, I found that if I knew what video games children played, I could use this knowledge when talking to children to get closer to them. I, therefore, learned more about how they thought, felt, and understood the world. The potential of games as a means of learning and understanding the world was what made me interested in the research project of developing a game for children who are to face radiotherapy. It inspired me to apply for the PhD position.
Introduction

Every year, around 350 children are diagnosed with cancer in Sweden (1). Through extensive and lengthy medical treatment, more than 80% of the children survive (2). The type of cancer together with the treatment given will affect the child’s development (3, 4). The treatment the children are subjected to can include chemotherapy, surgery, and radiotherapy (RT) (5). The disease and the treatment induce feelings of fear and anxiety in the family and the children (6), also when faced with RT which makes it important that the care chosen should cause as little anxiety and discomfort as possible to minimize the impact on the child’s experience of RT (7). Therefore, healthcare should psychologically prepare the children in a child appropriate way (8).

Cancer and the fears it evokes

Cancer does not only affect the patient but also the whole family (9). It disrupts ordinary life and the disease induces feelings of worry and fear (10). These feelings are also present when faced with the aggressive treatment protocols the children need to undergo (11-13). Consequently, younger children have expressed fear of the healthcare staff because of the painful procedures they had been exposed to (14). Children experience anxiety concerning the treatment, its side effects, and fear of the unknown (14, 15). Carleton has suggested that anxiety is based on the fear of the unknown (16). The emotion evoked in fear of the unknown has been described by Lazarus (17) as that which a person feels when facing an uncertain, existential threat. For example, within the context of cancer, being hospitalized and receiving treatment, children might not have a sense of what will happen, when it will happen, and their possibilities to influence the situation (18). Anxiety is explained as the subjective notion of unease, dread, and premonition (19). Hence, cancer in children causes distress to both the children and their families in the form of anxiety and worry as the children tend to be subjected to a variety of treatments during longer periods of time (20). Pediatric oncology care should strive to work towards child-centered care (CCC) which means to place the children in focus and be aware that the relationship within a family is asymmetric (21). The relationship is considered to be asymmetric because the children are not completely autonomous and are dependent on their parents. 
Since 2020, the United Nations Convention on the Rights of the Child (UNCRC) has been incorporated into Swedish law. It states that children have the right to information about their care and to be part of the decision making in matters that affect them (22). Within pediatric oncology, children can have misconceptions about procedures and treatments, also about proton RT (14, 23).

Being treated with radiotherapy

Approximately 100 children receive RT each year in Sweden (Radtox, 2019). The children can be considered for either proton or photon radiation depending on the cancer type, tumor location, and whether the treatment is curative or palliative (24). Proton therapy is often the preferred choice since less irradiation end up in organs and structures nearby the tumor (24). Children who undergo proton RT can become nauseated and/or vomit (25), and some experience visual and olfactory sensations (26). The treatment does not induce pain per se, but at later stages, it can cause skin irritations and hair loss (23). This occurs in the areas where the radiation beams meet the skin (23). Children who have undergone both photon and proton RT to treat brain tumors can show signs of decline in their neurocognitive functions years after treatment (4).

During RT, the children need to remain still while the radiation is being administered (20) to avoid damage to healthy tissue surrounding the tumor (23, 27). Further, the children need to be left alone in the room to protect others from the radiation, and immobilization devices are used to fixate them (23). If RT is given to the head, a mask is made to fit the patient’s head and is firmly fixated to the table (28). The fixation helps the child to be in the same position at each new radiation so that the healthcare providers can position the radiation on the tumor to minimize damage to healthy tissue (29). There are still several children up to the age of eight who are sedated so that they stay in position during the treatment and do not risk irradiation on healthy tissue (30) and age has been seen to be the predominant factor for them being sedated when undergoing proton RT (31).
There are six pediatric oncology centers that are responsible for and can administer photon radiation in Sweden (32). For proton radiation, patients need to attend the Skandion Clinic, located in Uppsala. About 40-50 children undergo proton therapy at the clinic each year. The children and their families receive information about the treatment from healthcare providers at their pediatric oncology center. Further information is given when they arrive in Uppsala at the pediatric oncology center. The day before the treatment starts the family has a meeting at the Skandion Clinic with the staff and they are given the possibility to play with a miniature model of the machine (see Figure 1). They also have access to play therapy, information on the clinic’s homepage and they are given children’s books about RT (see Figure 2).
A treatment protocol is prescribed by the physicians who decide what dose and consequently how many fractions the therapy should include which sometimes can last for more than six weeks (23, 33). This means that the child and their family can have to stay in Uppsala for several weeks. The treatment is given during weekdays and the family is free to go home during the weekends when the clinic is closed.

The child’s right to be informed about treatment

In Sweden, Patientlagen (2014:821) chapter three stipulates that every patient has the right to receive information about their health condition. It also states that the patient shall receive information about how the treatment works, what to expect from the given care and any side effects they can expect from it. Together with the UNCRC it has become evident that when caring for children, the hospital staff should strive to make the information the patient receive age-appropriate (22). Within Proton RT in the United States, various methods have been reported to be used to inform and psychologically prepare children before treatment (7). The methods include age-appropriate information provided by a nurse or physician, visiting the facilities, and playing with a replica of the machine and a doll (7) (see Figure 1). Psychological preparation can be described as what the pediatric patient needs to do to become mentally and emotionally prepared to feel that they can handle a situation (34, 35). Earlier studies preparing children for RT have used patient information brochures or applications on tablets to provide age-appropriate information, however, these studies were unable to significantly decrease the children’s perceived anxiety even though they could see tendencies toward some alleviation (36, 37). Children have expressed that they wish to be able to decide when they are given information in the cases when they feel fear of hospital procedures or treatments (38). There is also a correlation between the
children’s abilities to understand what to expect when provided with information about treatments and their current developmental stage (39).

The importance of play in child development

Development from child to adult means bodily growth, development in motor skills and cognitive abilities. This development includes interpreting bodily functions, understanding language, and the ability to communicate (39). Many researchers have studied children’s play in relation to development (40). Child play has historically been described as being driven by intrinsic forces (41), which refers to the inherent satisfaction that derives from engaging in a task (42). Children’s pretend play has been argued as being the main way they learn about cultural norms (41). Today, play is recognized as a contributor to the development of intellectual growth in addition to fostering the child’s social, emotional, and physical development (43, 44). Play has therefore been used as a method in teaching as well as in the hospital setting (45).

Developmental psychologist Piaget was interested in how logical thinking develops, he focused his research on children’s cognitive development through how the children he studied played and explained the world. He drew conclusions about how they understood it and suggested age-specific developmental stages (see Table 1). Piaget’s theory is still widely used but has been criticized for being too age specific. Nevertheless, the stages are representative of how children think even though this may not occur at the exact time that Piaget predicted (39, 40).

<table>
<thead>
<tr>
<th>Ages</th>
<th>Stages</th>
<th>Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2</td>
<td>Sensorimotor</td>
<td>Thinking is limited to action schemes</td>
</tr>
<tr>
<td>2-6</td>
<td>Preoperational</td>
<td>Intuitive but no logical thinking occurs,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symbolic thinking</td>
</tr>
<tr>
<td>6-11</td>
<td>Concrete operational</td>
<td>Systematic and logical thinking</td>
</tr>
<tr>
<td>12-</td>
<td>Formal operational</td>
<td>Abstractions, logical thinking</td>
</tr>
</tbody>
</table>

When children are exposed to sensory input, they need to be able to extract meaning from it and to be able to do so they need to label the input with words. The more refined the children’s language is, the better they understand and
can express the sentiments they feel. Hence, the suggestion is that emotions and how to convey them are something children learn from experiencing the world and are not innate abilities (46). Thus, children’s sense of the world is constructed according to the feedback they receive from their surroundings (47). Psychologist and educational theorist, Lev Vygotsky, investigated how the social connections children have influence their development and he states that children are subjected to environmental factors (40, 48). He suggests that children can make leaps in their development if they are subjected to knowledgeable adults or peers because their support will make the child evolve certain abilities quicker than if they did not have that support (48). The aforementioned theories adhere to social constructionism that implies that all individuals are subjected to their surrounding and interpret them respectively, and we socially agree upon how we understand the world (49).

With each new understanding of the world children work toward becoming independent beings, with the end point being to gain agency. Sudarsan et al (50) define agency for children as “the ability of children to comprehend, actively participate in, and influence the world around them, demonstrating competence in all matters affecting their wellbeing” (p.490). Agency is a crucial aspect in play and games. Player agency is a commonly used term referring to the player’s ability to make decisions within a game, impact the narrative, and influence the course of the game (51).

An introduction to games
A brief history of games and serious games
Games have been around for a very long time as a leisure time activity (52) and the first known boardgame is the game of Ur which dates as far back in history as 2400 BC (53). From around 1960, computer games started to be developed and rose in popularity with the introduction of computers (54). Game studies theorist, Jesper Juul, describes playing video games as a learning experience (55). In Sweden, children are often introduced to different sorts of screen-based games early on, usually in the form of applications (hereafter referred to as apps) on their parents’ smartphones, tablets, or computers (56). During the pandemic, children, aged three- to seven-years-old, increased their screen time both concerning entertainment and educational apps (57). Hence, children are familiar with digital games both as a leisure time activity and for educational purposes. With the introduction of digitalization within schools, games became a popular classroom learning activity (58) and now games are designed specifically for the purpose of educational tools in education (59).
The term serious games was first used by Abt in 1970 who explained it as being a game where the main goal was not amusement but learning (60). Today, serious games are games with the intended purpose to engage the player in activities to inform and provide meaning about events, as training or preparation (61). The idea is that when playing the game, a transfer occurs and the player can use the new knowledge in other contexts (44, 62). When training for real events that can occur in hospital environments serious games have been used to educate healthcare providers (63). Educational apps and serious games have also been designed to be used within pediatric care in an effort to prepare children before procedures, to inform them about cancer or as a means of talking about experiences (64, 65).

A brief statement about the designing of games

When designing a game, the purpose of the game needs to be established early. Games can have different purposes such as the aforementioned educational or as a leisure activity, and the gameplay can vary. It can provide the player with an adventure (example: Tomb Raider, the player plays Lara Croft, an archeologist who adventurously explores the world (66)). It can be to experience a certain feeling (67) (example: Dear Esther, the player gets to play an elderly character and the designers have focused on setting the mood for the player (67)). Sometimes it is designed as a leisure time activity but has the purpose of making the player become more knowledgeable within a certain field (example: Monopoly, where the player gets to simulate real estate trade through buying and building property). Further, games can be played in a variety of ways, for example to solve puzzles or follow a linear story (platform games) where the player joins the character on their journey (68). An example of this is the first version of Super Mario Bros, where the objective is to finish new levels on time without getting the character killed. If all levels are achieved Mario reaches the princess and the game is finished (69).

A conceptual framework can be used when designing games. The framework put forward by Alexiou and Schipper focuses on mechanics, aesthetics, and narrative in relation to user experience and learning (44). Mechanics can be explained through the rules the game adheres to, how the game operates and how the player interacts with the game (as explained earlier with the examples of the different games). The mechanics determine what challenges the player needs to overcome to progress in the game. The aesthetics pertain to how the gameworld and characters are portrayed. The narrative is the storyboard the game follows, what story the game tells and how it evolves during gameplay (44, 68). However, when designing games for meaningful play it is the player’s willingness to accept the designed experience that is at its core (70). The challenges can be multiple when trying to find the balance between
 educational perspectives and entertainment (71). A game provides an experience for its player, referred to as player experience, which relates to the behavioral, emotional and affective influence playing the game has on its player (72). It can be of interest to measure different aspects of the player experience, especially if it is a serious game, to understand how the player perceived the game (68, 72). Aspects of autonomy, competence, and relatedness are areas that can be addressed to measure the player experience. Autonomy refers to the player’s freedom or ability to influence the gameplay. Competence is the player’s ability to succeed when faced with the game’s challenges, while relatedness refers to the connection the player forms with other players within a multiplayer game (44).

To involve children in game development has been of interest in several studies where children are the target group. Children have been involved so that their ideas are implemented when designing games with the intended purpose of educating about procedures connected to medicine as a means to better reach the intended target population (73-75). In such studies, workshops have been used where a facilitator interacts with the children and gets their input on the game through the use of worksheets, drawings, or interviews (75, 76). This process has been termed *co-creation* within health research and it refers to when stakeholders from different areas come together to engage in innovative problem-solving. Stakeholders can be, for example, patients, patient organizations, healthcare service providers, or politicians (77).

** Participatory Action Research  
**

Article 12:1 in UNCRC states that children should be free to express their opinions in matters that affect them (22) and is referred to in research that include children (78-80). It is argued that children should be part of research where the end product is targeted at them (81, 82). Co-creation can be applied when designing serious games. Participatory Action Research (PAR) is a form of research that can involve children as co-creators in the process of the actual research where the children contribute and take part at different levels of the study (83). Using PAR can improve the end result (84). However, children’s participation varies and there is no gold standard regarding to what extent participants should contribute (85). In Hart’s (86) ladder of children’s participation (Figure 3), it is possible to establish to what degree the children’s participation was in studies. The ladder was introduced to ensure that children’s participation was not solely tokenism or decoration but that it was the actual involvement of the children that had occurred. The ladder starts at the bottom with three steps where the children’s participation in studies is described as non-participation. The five further steps explain the degrees of the children’s participation (86).
Hart’s model of children’s participation has been subjected to criticism, that it focuses on a stepwise participation when it could be seen as a more fluent event (87). Hart himself explained that the ladder can be seen as to what extent adults enable and permit children to participate in research (88). Others such as Shier and Lundy have developed their own models of children’s participation in research to give further insight to the complex subject of children’s participation (89, 90).

PAR is the study of the production of knowledge and has been used in a variety of fields, including health (83). PAR is intended to promote the dialogue between the researcher and the consumer of the researched and is not research on but rather research with participants from the target group of the research (83).
Rationale

Children are often worried and anxious when starting their RT treatment and younger children sometimes need to be sedated. Swedish legislation prompts the children’s right to information and to participate in their healthcare. Providing age-appropriate information that the children find inviting and interesting could be a means to inform and alleviate anxiety in children prior to treatment. In a previous study performed by the research team, a booklet on a tablet was used to prepare children psychologically before RT. The children who took part in the intervention suggested that something interactive could be useful as preparation. Using serious games to inform children could be a possibility. Yet, to use serious games within pediatric care is still novel and their functionality has not been fully evaluated and even less so within pediatric RT. Using play through a serious game to learn about the treatment of RT could be a means to decrease anxiety before and during the procedure. Thus, the goal of the research was to gain knowledge about how to create a functional serious game for children who are to undergo RT. The means to gain knowledge was through evaluation of the co-creation process and evaluation of the game at a proton RT clinic.
Aim

The overarching aim was to investigate the developmental process of a serious game about proton RT, with a focus on the influence of co-creation, the feasibility of the game, and the game’s effects on self-rated anxiety by children undergoing RT. The four studies’ specific aims were:

I. To outline the contributions made by children and their parents through participatory action research when designing a serious game about radiotherapy.

II. To illuminate, from the parents’ perspective, the experience of their children being part in the co-creation of a serious game and their previous experiences of RT.

III. To investigate and describe the experiences of members from the design team, the expert team, and the research team during the production phase of a serious game about radiotherapy, designed for children aged 5-14 years.

IV. To investigate the feasibility in terms of reach, usability, and acceptability, of a serious game about radiotherapy, and to pilot whether it can decrease anxiety levels in children aged 5 to 14 years undergoing radiotherapy.
Methods

The thesis is a compilation of four studies. The studies include both qualitative and quantitative approaches, see Table 2.

Table 2: Overview of the four studies’ methodological approaches.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Data acquisition</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative participatory,</td>
<td>9 Children, 10 parents</td>
<td>Videos of gameplay, group meetings, observations, semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td></td>
<td>descriptive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Qualitative, descriptive</td>
<td>7 Parents</td>
<td>Semi-structured interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative, descriptive</td>
<td>13 Interdisciplinary</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>team members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Feasibility randomized pilot</td>
<td>22 Children</td>
<td>Standardized questionnaires</td>
<td>Descriptive statistics,</td>
</tr>
<tr>
<td></td>
<td>trial</td>
<td></td>
<td></td>
<td>correlations, comparative</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>statistics</td>
</tr>
</tbody>
</table>

Description of the work in the research project

In 2019, researchers from a pediatric medical department started a collaboration with the game design department with the intent to produce a serious game about radiotherapy. The idea was that the game was going to serve as psychological preparation for children undergoing radiotherapy at a
clinic with a nationwide scope. The research team had representation from three departments from two Swedish universities. The research team had experience in the fields of pediatric nursing, medical science, informatics, and media sciences. A PhD student (CC), who is specialized in pediatric nursing was recruited as project coordinator and started in the summer of 2019. The game design department’s role within the project was primarily production. The department appointed one of their lecturers to oversee the game development and supervise students working on the project from the department. The students had been hired to work with the game design and produce the game. Within the same time span, an expert team had been organized comprising staff from different departments in the hospital knowledgeable in radiotherapy, pediatric oncology, and play therapy. To initiate the collaboration, the game design team, the research team, and the expert team met and had lectures about the intentions of the project and visited the clinic that the game was to depict. In the early summer of 2019, the initial design and production of the game began.

Table 3. Overview of participants in development of RT game.

<table>
<thead>
<tr>
<th>Teams</th>
<th>Participants in each team (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child team</td>
<td>Girls (8)</td>
</tr>
<tr>
<td></td>
<td>Boys (1)</td>
</tr>
<tr>
<td>Parental team</td>
<td>Mothers (7)</td>
</tr>
<tr>
<td></td>
<td>Fathers (3)</td>
</tr>
<tr>
<td>Game design team</td>
<td>Senior adviser (1)</td>
</tr>
<tr>
<td></td>
<td>Game design students (4)</td>
</tr>
<tr>
<td>Expert team</td>
<td>Preschool teachers (2)</td>
</tr>
<tr>
<td></td>
<td>Oncology nurses in Radiotherapy (3)</td>
</tr>
<tr>
<td></td>
<td>Pediatric Oncology nurse (1)</td>
</tr>
<tr>
<td>Research team</td>
<td>Professor in Pediatrics (1)</td>
</tr>
<tr>
<td></td>
<td>Associate Professor in Pediatrics (1)</td>
</tr>
<tr>
<td></td>
<td>Assistant Professor in Pediatrics (1)</td>
</tr>
<tr>
<td></td>
<td>Assistant Professor in Informatics and Media (1)</td>
</tr>
<tr>
<td></td>
<td>PhD student in Pediatric Nursing (1)</td>
</tr>
</tbody>
</table>

a Representing four departments from the hospital.
b Representing three departments from two universities.
c Children were between 7 through 10 years old at the start of project, some turned 11 during participation
During late fall of 2019, the research team invited children who had undergone radiotherapy and their parents to be part of the design process. The children were invited to workshops where they were encouraged to come up with ideas for content in the game, they also played the game prototype and provided feedback on the game. The plans for the future meetings between the research team and the game design team were not decided but they came to be held over Skype or Zoom except for one which took place between a limited number of members from the teams at campus Gotland. Neither were the plans set for further meetings between the members of the expert team and the design team after their initial meeting. For the rest of the project time, the expert team met in workshops with members of the research team. With the eruption of the pandemic caused by the coronavirus disease 2019 (COVID-19, 2020-2021) and thus following the national recommendations, no gatherings with several teams present took place. The production of the game was finished in early 2021 and the feasibility study was launched.

The Radiation World and the Search of the Curious Cuddlies
The game was named through the help of the participating children and parents; Strålningsvärlden och jakten på de nyfikna mojisarna (in English: The Radiation World and the Search of the Curious Cuddlies). The final design of the game, before the feasibility study started, was an exploration of the medical facilities where proton RT takes place and the surrounding environments. The game was digitally based and was accessed through internet connection. It could be played with the computer’s mouse or on a tablet. The player chooses one out of three avatars who are coming to a proton RT clinic to have treatment. To be able to explore the game environment independently a map was used within the game which the player could click on to access the different rooms displayed within the game. The rooms that could be accessed from the map were the reception area, the RT room, the monitor room, a room for preparation before RT, and a room containing information about the treatment. Further, a kitchen and a bedroom at the hotel the families stay at during RT could be accessed from the map. For educational purposes, the rooms held information about the procedure of RT. However, to make exploration of the play setting interesting for the intended children the game also contained game elements of surprise and mini-games as described in study I. There were no winning conditions present in the game. It was instead set up as an explorative journey through RT where the players themselves decide in what order they want to explore the environment.
Study I

Design

The study was designed to be participatory where children who were undergoing or had undergone RT were to be part of the design process of a serious game about RT through PAR. The game development followed an iterative process (91) (see Figure 4). A prototype of the game was presented to the children participating to play at iterations 2 through 6. The children met in groups or individually at workshops and were observed when they played the game prototype. After they had played, a semi-structured interview with questions relating to their play and the game was conducted. At every workshop, the children and parents were offered refreshments.

![Diagram of iteration process during the game development.](image)

Participants

A nurse at a pediatric oncology center contacted families with a child who had undergone RT during the previous year at one of the two RT clinics in Uppsala. A convenience sample was used which meant that it was families that lived within traveling distance that were contacted. If the parents gave their consent, they were contacted by telephone and given further information about the study by a member of the research team. Children were informed in person about the study at the first workshop and asked for their assent. After the second iteration children who were currently at the clinic to undergo treatment were contacted for inclusion since there were dropouts from the study. In total, 13 families were contacted during the two inclusion rounds.
Inclusion criteria were that the children had undergone or were undergoing RT, were fluent in Swedish, and were between 6 and 15 years old.

In all, nine children between the ages of 7 through 10 years old participated in the game design process. When the study commenced eight children were recruited. Further into the development one additional participant was recruited. All children were accompanied by one parent at the iterations. One family chose to alternate which of the two parents accompanied their child. Two children withdrew their participation at the fourth iteration. At the point of inclusion, the children who chose to participate were between seven and ten years old, one boy and eight girls. The children were suffering from various diagnoses: brain tumor, rhabdomyosarcoma, spinal cord cancer, and Ewing sarcoma. Five families that chose not to participate explained that they did not have interest in a game project, did not have the time, the child would start treatment again, the child prioritized school, or gave no explanation.

Data collection
Data collection from the meetings with the children was made in several ways. On the computer, the children’s play was recorded, observational notes were taken when the children played, and audio recordings of the entire workshops were made where the interviews were included (see Figure 5).

Figure 5. Participating child playing the game during workshop.
At the first iterations workshops, the children and accompanying parents met at a venue where they discussed their experiences of RT, and what games they preferred playing. They also discussed what they thought the game that was going to be developed should contain. The project coordinator led the interaction while another researcher (GE) had an observatory role and took field notes. At the workshop, the Bears cards, created by St Luke’s Innovative Resources, were used (see Figure 6). The cards can be used as a facilitating tool to talk about feelings. The children were asked to choose two cards to show how they had felt the first time they had gone to RT. They were then encouraged to tell what the cards signified. They also got to choose two cards to show how they had felt the last time they had gone to RT and talked about what that day had been like.

Figure 6. Examples of The Bears. Images reproduced from The Bears, revised edition 2005, with the permission of the publisher, Innovative Resources: www.innovativeresources.org. All rights reserved.
At the second iterations workshops, the children were presented with a prototype of the game and played in groups of two or individually. After the second iteration, the pandemic erupted in Sweden which meant that the way the workshops were planned needed to be changed. The plan for the workshops became more flexible and the families were given multiple options to choose from. They could meet with one investigator and one other family, meet only with the investigator, or have a virtual meeting with one investigator over the Internet. The workshops contained the same elements and were conducted as similarly as possible independent of which option the family chose. At the workshops, the children played the game prototype and had the possibility to show their parents the game and talk about it with their parents if they wanted to. Consequently, there were multiple workshops for each iteration where the children were presented with the same version of the prototype (see Table 4).

Table 4. Number of participating children in each workshop per iteration (n=9).

<table>
<thead>
<tr>
<th>Workshop</th>
<th>Iteration</th>
<th></th>
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</tr>
<tr>
<td>6</td>
<td></td>
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<td>1</td>
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</tr>
</tbody>
</table>

Sum 7   5   8   5   4   5

Each child was never present more than one time per iteration

a the workshop was conducted online
b newly recruited participant

Data Analysis

The screen recordings of gameplay were observed multiple times and coded for player activities regarding game mechanics, narrative and aesthetics. A similar approach was then applied to field notes, summary notes, and the interviews to identify codes. All four datasets were compared to find commonalities between the children’s play and what they had discussed about the game. Codes were grouped as belonging to mechanics, narrative, or aesthetics. However, they were also coded to what room within the game that the element should or did occur in to help the project coordinator when communicating the results to the design team. The codes were design suggestions that were prioritized into a list of proposed changes. The list was
presented to the design team within one to two weeks after iteration 2 through 6 were finished.

The prioritization followed the same outline each time which was; 1, sort out major bugs that interfered with gameplay, 2, add or change interactive elements, 3, add or change RT elements, 4, add or change text within the game, 5, aesthetics that needed adjustments, and 6, sort out minor bugs. After discussion of feasibility and time, the design team made as many of the changes as possible within the given timeframe before the next iteration could commence. The iterative procedure with the children was repeated six times over a period of eight months during 2020. The children did not take part in the design of the study or the analysis processing of the material that was produced.

A thematic analysis based on the list of proposed changes underpinned by all gathered data was later performed to capture the children’s and parents’ participation in the development of the game. Data was analyzed through a thematic analysis inspired by Braun and Clark (92). Codes were identified, grouped and themes and subthemes were formulated, discussed with co-authors of paper I and revised, when necessary, until consensus was obtained. Finally, quotes and figures were added to illustrate the content.

Study II
Design
The design of study II was a descriptive qualitative interview study. The study was a means to illuminate the experiences of the parents who had agreed to their children participating in the participatory action research study.

Participants
All ten parents who had accompanied their children in study I were invited to a follow-up interview and seven parents consented to be interviewed. Among the interviewed, both female and male gender were represented. Two of the interviewees were parents of the same child who had been equally involved in their child’s participation.

Data collection
A semi-structured interview guide was followed during the interviews. The interview guide inquired about the parents and their children’s experiences of RT. The parents were further asked to share their experiences of participating
in the web game development. They were asked why they had given consent for their children to participate and to elaborate on why they thought their children wanted to participate. The interviews were conducted over the telephone and lasted between 16 to 29 minutes, they were tape-recorded and then transcribed verbatim. An experienced investigator (CÅB) who was unknown to the participants conducted the interviews.

Data Analysis
The transcribed interviews have been analyzed through a manifest and inductive qualitative content analysis, inspired by Graneheim, Lindgren, and Lundman, and Granheim and Lundman (93, 94). To become familiarized with the data it was read multiple times. Text not relevant to the aim was removed. The identification of meaning units, codes, and search for patterns commenced, being the beginning of the categorization process by looking for similarities and differences within the data. To formulate sub-categories, the condensed text was read, compared, and discussed. Codes and sub-categories were formulated when agreement had been established within the research group. At the final stage, an overarching theme was developed that could tie all the text together to show the meaning of the whole.

Study III
Design
The design of Study III was a descriptive qualitative interview study. The study was a means to illuminate the experiences of participants from a diverse set of teams who had been part of the development of the serious game in Study I.

Participants
The game designers and hospital staff as well as the researchers who had been part of the process of developing the serious game were invited to an interview about their experiences of the project. All six participants that were hospital staff and had constituted the expert team consented to be interviewed. Of the five persons who had been part of the game design team four consented to be interviewed. The game design team had been assembled and given the task of developing the game. There was an adjunct lecturer at the game design department who was appointed the assignment of leading the project at their end. An advertisement was posted to students within the department, and four were subsequently hired to work on the project. The research team also consisted of five persons, three of them were asked to participate in the study
through an interview. The other two conducted the data collection and made the initial analysis of the study and were therefore not interviewed.

Data collection
All team members, except two, who had participated in workshops, research meetings, or had worked on the design of the serious game were invited to the study. An email invitation was sent out regarding information about the forthcoming interview study and asking about interest in participating. The participants who had displayed interest in the study were then emailed a consent form after the initial email (Appendix 1). Thirteen replied and agreed to take part in the study, which resulted in thirteen interviews (93%). Twelve interviews were performed online via Zoom and one over the telephone during the spring and summer of 2021. Eleven of the interviews were performed in Swedish and two in English. The two members interviewed in English were fluent in the language, but it was not their native language. The interview guide was developed by CC and JB (Appendix 2) and they divided the participants between themselves and conducted the interviews. The shortest interview lasted 15 and the longest 47 minutes. Quotes from the Swedish participants have been translated to English by the authors. Further, an authorized translator has read them and ensured that they represent the same meaning as in Swedish.

Data Analysis
The analyzed material consisted of the 13 transcribed interviews. The six steps approach introduced to conduct thematic analysis by Braun and Clarke (92) was used for the inductive, reflexive thematic analysis (95, 96). The interviews were read several times for the author to get familiarized with the material. Then coding commenced that included all data. Data that was considered relevant to the research questions and held similarities were grouped together. The grouped codes were rechecked so that they conveyed the interviewees’ sentiments and answered the research question. The patterns between the codes served as a foundation for the formulation of themes and the text was written. These initial steps were performed by CC with supervision from JB. Then the text was emailed to all interviewees to give them the chance to read the text and provide feedback. This is considered to be a reflexive collaborative approach (95) that was finished when all co-authors had agreed on the naming of the themes and its content.
Study IV

Design

The design is a feasibility and pilot randomized control trial that offered an intervention using a prospective waiting list for the control group. The study was designed to investigate the feasibility in terms of reach, usability, and acceptability, of the serious game produced. Further, it was to pilot test whether the game could decrease self-rated anxiety in children undergoing radiotherapy, aged 5 to 14 years.

Participants

Prospective participants for the study were, children between the ages of 5 and 15 years, living in Sweden, who had been scheduled to have RT at the proton clinic in Uppsala. They were informed of the study by a letter of invitation. An invitation was not sent if one or more of the exclusion criteria were met: they were not living in Sweden, limited proficiency of Swedish, and/or were suffering from severe mental disability. A couple of days after the invitation letter, a pediatric/oncology nurse or a coordinator at the children’s hospital contacted the parents about the study and asked if researchers could contact them. Upon permission, the researchers phoned the parents, gave further information, and answered questions about the study. If oral consent was given, an email was sent containing all further information. When at the clinic, to participate, the children signed their assent, the written consent form was signed by the children’s legal guardian on their child’s behalf and their own. In February 2021 recruitment was started and ended in August 2022. Within that timeframe, 28 children were assessed for inclusion. However, four children were excluded, one due to language barriers, one due to administrative issues and three declined participation during recruitment (see Figure 8). Directly after inclusion another child was excluded due to language barriers.

The children who agreed to participate were divided into three groups based on age: ages 5-7 years, 8-10 years, and 11-14 years. The stratified randomization in blocks were done to achieve balanced groups. The children were then randomly assigned into one of two study arms. An email was sent containing information about which arm (Group 1 or 2) the child had been randomized into. Early intervention was given to the children assigned to Group 1 from before the start of RT and Group 2 received the intervention after their third day of RT.
Data collection

Children who had been randomized into arm 1 (Group 1) received information about how to access the game approximately 1-3 days before their first visit to the clinic. The children in arm 2 (Group 2) received the same information after their third day of treatment. The instructions were that they were free to play the game according to their own needs. Both arms were presented with the same questionnaires on different days into their treatment (see Figure 8). Children who were not able to read were helped by their parents to answer the questionnaires and interpret the scale alternatives. During participation in the study, the children and their parents received information about RT according to standard care.

Self rated anxiety questionnaire

The Short State-Trait Anxiety Inventory for Children (STAIC) is a validated questionnaire using six of the original 20 questions of STAIC and is developed with a 3-point Likert scale (97). The original STAIC was developed to measure children’s self-rated anxiety when faced with a certain situation and was tested and validated for situations in school (98). The children answer questions about how they feel at a particular moment in time (98). The questionnaire has been widely used and tested in hospital situations (99, 100). For this study two additional questions were added from the long version of STAIC to the short form of STAIC which thereby ranged from 8-24 points, the form will hereafter be referred to as STAIC(S). According to the guidelines for interpretation, a calculation based on eight questions indicated 12 points as the cut-off for anxiety. In order to not overestimate children’s anxiety, the cut-off in the current study was set at 13 points for feeling anxious. The shorter form of the STAIC-T is a questionnaire consisting of ten questions on a 3-point Likert scale (98).

Player experience questionnaire

The Player Experience of Need Satisfaction (PENS) questionnaire consists of 16 questions, developed using a 7-point Likert scale (101). The questionnaire measures how satisfied a player is with a digital game by asking questions about their feelings of competence, autonomy, presence/immersion during gameplay, their relatedness to other players if the game is a multiplayer game, and how intuitive they found the game controls. It was originally developed in English and has been validated on university students (101). The owner company, Immersyve, approved that the questionnaire was translated into Swedish and adapted for children. First it was translated from English into Swedish by a group consisting of two pediatric nurses, one researcher in informatics and media, and one pediatric psychologist. The questionnaire was then translated back into English by an interpreter for language validation. Two questions related to multiplayer games were excluded since the studied game is a single-player game. Further, the questionnaire was tested for face
validity through interviews with four healthy children between the ages of five and eleven. The consequence of this step was that two different versions of the questionnaire were adapted, one for younger children (5-7 years) and one for older children (8-14 years). The younger population had difficulty understanding the 7-point Likert scale. Therefore, it was changed to a 3-point Likert scale. Furthermore, the language was adapted to the young population and consisted of eight questions (range 8-24). For the older children (8-14 years), the questionnaire consisted of 14 questions (range 14-98). The cut-off level for the game experiences need satisfaction was set at 16 for PENS (5-7 years) and at 65 for PENS (8-14 years) reaching 2/3 of the total score (66%) for both scales.

Study Protocol

On study protocol days the participants had been asked to arrive earlier than the time they were appointed. They were handed the questionnaires upon checking in at the clinic. Completed questionnaires were left in a mailbox placed in the reception area at the clinic. The total time spent playing the game was collected digitally for each participant. There were four different questionnaires distributed to participating children: the aforementioned versions of STAIC(S) and STAIC-T, and the two translated and modified versions of PENS. Not included in the thesis results is the additional data that was collected through diary notes about experiences of gameplay and a questionnaire (RT.Q) especially designed for the study population. Parents answered a shorter adult version of the State-Trait Anxiety Inventory (STAI), which included 10 questions on a 4-point Likert scale (102). They also answered a questionnaire providing background variables. STAIC(S) was collected on all five measurement points, PENS at one point and RT.Q questionnaire at four points. Parents answered demographic questions and STAI at the first measurement point.

Data Analysis

The feasibility criteria for success were that 80% of the participants should have played the game for 20 minutes or more. The estimate was that 70% or more of the participants should have returned PENS and all the questionnaires of STAIC(S). Further, the children in the early intervention group (Group 1) should communicate anxiety levels lower than children in Group 2.

To gain insights into the collected quantitative data, descriptive statistics were employed. To analyze differences between the groups Fisher’s exact test, Pearson’s Chi-square, Mann-Whitney U test and Wilcoxon matched-pair Signed-rank were used. Spearman’s rank order correlation was utilized to analyze associations between variables within the sample. In addition,
Cronbach alpha was used to calculate the internal consistency between concepts of PENS and the STAIC(S). SPSS version 28.0 was used for the analyses and the findings were considered to be statistically significant if a $p$-value of $<0.05$ was reached.
Ethical considerations

All four studies followed the ethical principles of the Declaration of Helsinki (103). Studies I and II were ethically approved by the Regional Ethical Review Board in Uppsala, Sweden (Register number 2018/264). For study III, after careful revision of the Swedish ethical review authorities’ guidelines, it was concluded that the study design did not need to be approved since the participants were sharing experiences of work-related issues and not pertaining to sensitive personal data. According to the European Commission (104), data is considered sensitive when it is about personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs; trade-union membership; genetic data, biometric data processed solely to identify a human being; health-related data and data concerning a person’s sex life or sexual orientation. None of these issues were asked about or brought up during the interviews. All participants were offered the opportunity to read the analyzed results and comment upon them before publication. An additional application was performed for study IV at the Swedish Ethical Review Authority in 2020 (Register number 2020-05578). Study IV protocol was also registered on ClinicalTrials.gov before recruitment started.

In Study I and IV parents were asked for written consent and children for assent as relevant. In Study I oral information was given by the researcher to the children when they meet at the first workshop, before it started. The children were informed of the aim of the study, that participation in the study was voluntary, and that the children were free to withdraw their participation from the study at any time without explanation (SFS 2003:460 §16).

In Study IV it was not considered ethical to include children in an intervention related to a game and subsequently deny those children the opportunity to engage with the game (105). Therefore, children that were randomized to Group 2 received the game three days into their treatment.

Within ethical discussions children with cancer are considered a vulnerable group. The reasons are that they are children, suffering from a serious disease and therefore unable to make a truly informed decision about study participation (106). Hence, the material was coded to ensure the confidentiality of the participants. It was voluntary to take part in the studies and the children and parents chose what they wanted to share during
interviews. The studies conducted were not intrusive, they consisted of playing a game and sharing experiences related to RT, the content of the game or the developmental process.
Results

Synthesized results of contributions made to the serious game and experiences of the process

Study I explored the children’s and parents’ contributions to game development. Study II explored the parents’ experiences of their children’s participation and their own involvement. Study III explored the experiences of the game development process of the expert team assembled from the hospital, the research team, and the game designers that all contributed to the game development or the design of the research project.

Earlier knowledge about RT, games, and game development

The experiences of anticipating RT differed within the group of children. Most children had been worried about what would happen or how it would feel. Others had been happy upon arrival at the RT clinic but described that they lacked knowledge about the procedure in Study I. The parents conveyed that they had been worried and that it had felt tough when their children were having RT. The sentiments had arisen because their children had looked vulnerable, uncomfortable, frightened, or had struggled with the treatment or its side effects (Study II). Within the teams interviewed in Study III, most of the participants had extensive experience of children and RT, while others had limited experience and none pertaining to RT. Almost everyone with experience of children and RT was within the expert and research teams. However, the roles were reversed regarding knowledge about games and game development. The children in study I, had different gaming habits, ranging from playing advanced video games and having their own gaming computer to others rarely playing at all.

Contributions to the serious game

Analysis of the material collected in Study I revealed that the children contributed to significant game changes that also affected gameplay. The children were able to convey what the game was lacking. However, mostly they were not able to provide ideas of how things should look or be implemented within the game. Yet, appreciation of the game grew within the group with every new iteration. The game designers developed the initial
game prototype. Their role during the process would be to decide what was possible to accomplish from the wishes made by the children, expert team, and research team. However, to be able to explain what the possible outcomes were and what could be done proved challenging to convey to the parties with no prior knowledge of design or programming. The parents interviewed in Study II described that their own participation in the project had been to be there for their children. They had supported their children and furthermore brought them to the meetings but their contributions to the game had they felt been minor. The game had initially been designed as a linear event. The children in Study I did not enjoy being forced to play events in the designed order and displayed through comments that they wanted more agency. They wanted to decide the order events in the game should occur. These sentiments were enhanced when the parents questioned the parts of the game in which the player had no freedom to choose and the game was played linearly.

The children in Study I wanted the game to be fun to play. Within one scene, a water tap in a kitchen sink that did not act according to expectations created laughter and interest in the children. The water tap was designed so that it sounded like an elephant trumpeting which was interpreted as a delightful surprise. The interaction led to more game elements being implemented with the same intent. One implementation made was that an entire changing room from the clinic was hidden within a bedroom’s wardrobe (see Figure 7). A comment when playing was: “This room is so cool!” When asked why it was cool the reply came: “But the wardrobe is so small and then all of this shows up.” The children then started to search more within each scene to see if there were more items or rooms they had missed which was interpreted as the children found the interaction interesting. Parents in Study II conveyed that most of the changes that their children had noticed within the game had to do with elements of fun and little to do with RT.
The expert team in Study III, and also the children in Study I contributed to the comprehensibility of the language within the game and reviewed everything related to radiotherapy and hospital care. The children continuously expressed that they wanted more information related to RT within the game, which resulted in additional items and scenes. A design choice was to display a segment during treatment through a moving avatar. It was to display that the avatar could hold a string of yarn, and through it feel the presence of their parent on the other side of the door to the treatment room. The scene displayed something some children use to be able to cope with the procedure and was therefore considered important to display in the game. However, the children objected to the avatar’s hand moving during treatment since it is important to be still. The scene had to be changed, in the end it was portrayed through a string of comic strips. The children agreed to the content of the comic strips.
Shared experiences of the process

In Study II the parents expressed that it was nice to be able to contribute after all the medical care their children had received and it was a reason to let their children participate. They expressed that it was for the sake of their child that they had participated and had found it interesting and exciting to watch their children taking part in the study. The experience from Study III was that the project meetings were conducted in an open climate, which created a healthy dialogue and led to the progression of the process. In addition, the more time that was spent working in the project the easier it became to get one’s message across and be understood. However, the children had not been able to meet in larger groups after the pandemic broke out which led to some leaving the study because what they had enjoyed was meeting the other children, according to their parents’ reflections in Study II.

Some in the expert team from Study III shared that they had become more knowledgeable about how RT worked and what the children went through and felt that it would help them in their future work with children. Parents from Study II had been surprised when they realized that their children had noticed changes made in the game even though they had seemed indifferent when playing.

Strains due to cancer and beliefs about the game’s use

The children’s ability to participate in Study I was affected by their health and the current treatment they were having which had implications on when the meetings could occur and/or the meetings duration. In the recordings from the workshop with the children, audible yawns from the children were apparent. Also, parents expressed when it was time to schedule workshops that to accommodate for the lack of strength that was due to the children’s scheduled treatment protocols, the workshop had to be at specific times.

Within Study III there was a common belief that the game under development would benefit the end users. When talking about the game the participants hoped it would create a feeling of comfort for the player so that they, if having RT, perhaps would be able to better manage the procedure. In Study II the parents expressed that the game could be used to prepare children before they are to undergo RT and they thought that it would be suitable for younger children. They expressed their appreciation for the opportunity to make a meaningful contribution following the medical care provided to their children.
Study IV

The study was designed as a feasibility and randomized pilot study with a waiting list.

Reach

Twenty-six out of the 28 children assessed were eligible for inclusion (see Figure 8). Of the 26 children, three declined and one was lost due to administrative issues. This resulted in 22 children completing at least one of the questionnaires provided in the study (85%). Eleven children were randomized into Group 1, and another 11 into Group 2.

Figure 8. Enrollment and questionnaires distribution flow chart.
The feasibility in terms of usability and acceptability

To determine if the children found the game acceptable, the predefined feasibility criterion was that 80% of the children should play for 20 minutes or more. When combining the groups six participants (27%) played the game for less than 20 minutes, however, 18 of the participants (81.8%) played more than 15 minutes. The mean time playing the game was 31 minutes for the combined group (median of 27 minutes) spanning from not playing the game at all to playing for 85 minutes (see Table 5). The mean time playing in Group 1 was 32.1 minutes, while the mean time was 29.9 minutes in Group 2. There were no statistically significant differences in playtime between the two groups.

The usability of the game, the children’s experiences of the game, were measured through the two versions of the PENS questionnaire. The feasibility criterion was that 70% were going to return the questionnaire, and 16 participants (73%) returned them. Eight participants answered the version of the questionnaire for 5-7-year-old children and eight participants answered the PENS questionnaire (8-14 years).

Measuring the effect of the serious game

No correlation could be found between time played the game and reported anxiety levels on day one in the early intervention group. Nor was it found when combining the two groups on day six (the measuring point where both groups had received access to the intervention). A correlation between time playing the game and the scoring of the questionnaire for the PENS (5-7 years) was not found. Of the participants, seven (88%) had a score that was 16 or higher, an indication of finding the game experience satisfying (Table 5). A correlation between time playing the game and the scoring of the questionnaire for the PENS (8-14 years) could not be found with a p-value of 0.05. However, the group had a p-value of 0.06. Four of the participants (50%) had a score that was 65 or higher, indicating that they found the game experience satisfying.
Table 5. Description of children’s time spent playing the game, PENS score, and if they received RT awake or sedated (n=22).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Time played</th>
<th>PENS score</th>
<th>Sedated/awake</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>E1</td>
<td>5</td>
<td>29</td>
<td>11&lt;sup&gt;A&lt;/sup&gt;</td>
<td>Sedated</td>
</tr>
<tr>
<td>E2</td>
<td>7</td>
<td>18</td>
<td>19&lt;sup&gt;A&lt;/sup&gt;</td>
<td>Sedated</td>
</tr>
<tr>
<td>E3</td>
<td>7</td>
<td>20</td>
<td>18&lt;sup&gt;A&lt;/sup&gt;</td>
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</tr>
<tr>
<td>E4</td>
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<td>58</td>
<td>19&lt;sup&gt;A&lt;/sup&gt;</td>
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</tr>
<tr>
<td>E5</td>
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<td>18&lt;sup&gt;A&lt;/sup&gt;</td>
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</tr>
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<tr>
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<td>45</td>
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<td>12</td>
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<tr>
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<td>38</td>
<td>67&lt;sup&gt;B&lt;/sup&gt;</td>
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</tr>
<tr>
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<td>32.1</td>
<td>A</td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>2.4</td>
<td>23.78</td>
<td>B</td>
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</table>

<p>| Late intervention | | | | |</p>
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Time played</th>
<th>PENS score</th>
<th>Sedated/awake</th>
</tr>
</thead>
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<td>0</td>
<td>NA</td>
<td>Sedated</td>
</tr>
<tr>
<td>L2</td>
<td>5</td>
<td>10</td>
<td>NA</td>
<td>Sedated</td>
</tr>
<tr>
<td>L3</td>
<td>5</td>
<td>20</td>
<td>16&lt;sup&gt;A&lt;/sup&gt;</td>
<td>Sedated</td>
</tr>
<tr>
<td>L4</td>
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<td>22&lt;sup&gt;A&lt;/sup&gt;</td>
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</tr>
<tr>
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<td>6</td>
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<td>20&lt;sup&gt;A&lt;/sup&gt;</td>
<td>Sedated</td>
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<td>29.1</td>
<td>A</td>
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<tr>
<td>SD</td>
<td>2.3</td>
<td>18.97</td>
<td>B</td>
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</tbody>
</table>

A: PENS (5-7 years) calculated score on both groups: Mean 17.88. SD 3.27 (Total PENS score (5-7 yr) range 8-24 points)
B: PENS (8-14 years) calculated score on both groups: Mean 55.38. SD 20.78 (Total PENS score (8-14yr) range 14-98 points)
Time played displayed in minutes
NA = Not Available, did not respond to the item
Reports of anxiety within the sample

A predefined feasibility criterion was that 70% of participants should return all five measures of STAIC(S). However, nine children completed all five forms of STAIC(S) (40.9%), and 13 children failed to return one or more forms (59.1%). Another feasibility criterion was that children in the early intervention, Group 1, should communicate anxiety levels lower than children in Group 2. However, there were no differences in anxiety between Groups 1 and 2 across all five measurement points. For STAIC(S) the items’ internal consistency was calculated by Cronbach’s alpha based on 89 questionnaires that had been obtained during the study and the alpha value was 0.85.

To assess the number of children who indicated anxiety (13-24 points) the two groups were first calculated separately and then combined using STAIC(S) at the five occurrences of measurement (Table 6). According to the children’s scoring, 11 children reported anxiety on day zero, the same number reported anxiety on day one (first day of treatment), on day three seven children reported anxiety, the same number reported anxiety on day six, and on day fifteen six reported that they were anxious. The response rate at each measurement point was for day zero 73% (n=16), day one 77% (n=17), day three and six 82% (n=18) and 86% (n=19) for day 15 (see Table 6). When comparing day one to day six there was a statistically significant decrease in anxiety levels ($p<0.02$) also when comparing day one to day 15 ($p<0.04$). There was no correlation between STAIC-T (trait anxiety) and STAIC(S) (state anxiety) in the present sample ($p=0.34$).

Table 6. The number of children reporting anxiety (cut-off 13-24) at five measurement points.

<table>
<thead>
<tr>
<th>STAIC(S)</th>
<th>Early Gr. 1 n</th>
<th>Late Gr. 2 n</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Zero</td>
<td>6 (37.5)</td>
<td>5 (33.3)</td>
<td>11 (68.8)</td>
</tr>
<tr>
<td>Day One</td>
<td>5 (33.3)</td>
<td>6 (41.7)</td>
<td>11 (64.7)</td>
</tr>
<tr>
<td>Day Three</td>
<td>4 (26.7)</td>
<td>3 (21.4)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Day Six</td>
<td>5 (31.2)</td>
<td>2 (13.2)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Day 15</td>
<td>4 (24.2)</td>
<td>2 (13.2)</td>
<td>6 (31.6)</td>
</tr>
</tbody>
</table>

Upon first arrival at the clinic the parental STAI was administered, 33 answers were obtained out of the 43 questionnaires that had been handed out. No correlation could be found between the mother’s stated trait anxiety levels and the children’s. Neither could a correlation be found between the mother’s stated anxiety levels before treatment started and that of the children.
Discussion

Main findings
The work of this thesis focuses on how to alleviate anxiety and misconceptions regarding the treatment of proton RT by providing information about the treatment through a serious game to children and their families. Everyone involved in the development of the game contributed to the possibility to create the game and its final state. The children’s participation contributed to changes in the game which also impacted how the game was played. The cancer and its treatment affected the children’s abilities to participate in workshops. It was more challenging than anticipated to develop the game. However, participants had a belief that the game could benefit children that are to undergo RT. For Study IV the recruitment and randomization worked according to the pilot study protocol. Not all of the feasibility criteria set for the study were reached. There were too few participants in the groups to be able to conclusively answer if the game had an effect on self-reported anxiety. However, no indication was found that it increased the anxiety either. When merged, the two groups anxiety levels decreased over the trajectory of the study’s time.

Designing games through co-creation
Within the project, children who had faced RT, their parents, and staff working with children undergoing RT were part of the development of the game. This prolonged the developmental phase since analysis had to be made between the workshops with children and staff before adjustments could be made to the game and the next iteration could occur. Working interdisciplinarily as well as co-creatively has been stated as being time consuming (107). It proved to be challenging to work interdisciplinarily, something earlier studies that have explored interdisciplinary work have also concluded (108). The team members expressed that their personal knowledge expanded on several levels during their involvement in the development of the game. While working in the project, the members deepened their understanding of the processes of game design and of how video games in particular work, and they understood how they could contribute to the project. Elements that were brought up by the participants as facilitating the work were that they experienced that they worked in an open climate. In an open climate
trust is built between team members which is important for the collaboration to work (109). The parents expressed in Study II that their contributions to the game had been minor. However, it could be argued that since they facilitated their children’s possibility to take part in the process, their contribution could be seen to be a significant factor in how the game development proceeded. The children who stayed with the project noticed changes within the game, that it went from boring to fun and that there was more information about RT included.

Both children and parents objected to events in the game that were linear. The children wanted to be able to decide how to play for themselves and not let the game decide for them. Their wishes correspond to player agency, to feel that you as a player are in charge of events in the story (51). Since the objection was noticed in several workshops the way to accommodate the participants was through taking away as much linearity from gameplay as possible without losing comprehensibility of the procedure of RT. Most of the children who participated were younger, between the ages of seven through eight years old, and their knowledge of the world and their current developmental stage influenced the content of the game in a positive way. The assumption can be made that through their participation the game is comprehensible for children sharing their understanding and knowledge of the world (48, 110). The children in the group expressed a wish for the game to be fun so that they would enjoy playing it. The children were entertained by the designed elements that deviated from their expectations. Enjoying the designed elements of surprise within the game can be considered to correspond to their current development stage. It is possible to think that children with no previous experience of RT would perhaps be able to find value in the game beyond the fun trajectory. This concept is of interest when building serious games for children and is something that should be investigated in future studies. However, Mader, Natkin and Levieux (111) recommend focusing on the entertaining and fun elements when designing to even out the medical details in the game.

Ethical perspectives of participation

When the treating physician informs and asks about participation in studies, parents can feel obliged to agree to research due to the asymmetric power relationship and worry that their child will miss out on treatment (112, 113). In the current studies great effort was put into giving the parents the possibility to understand the research they were asked to participate in to be able to make a voluntary decision. In Study I, a coordinating nurse phoned the parents with information about the study. During the call the parents decided if they wished more information about the study and if they agreed to receiving a phone call from a member of the research group. They were then emailed information
about the study, all to make sure that they made a truly voluntary decision. The procedure for participation was similar in Study IV, except that the parents first received a letter with information about the study. However, due to the shortage of time before the children had to start their RT, the parents reached an oral agreement to participate during the phone call with the researcher. At that point the children were randomized to their groups. But it was only after they arrived at the clinic that they chose if they wanted to answer the questionnaires. Within Study II, the parents expressed that they let their children decide if they wanted to participate in Study I. They further expressed that they as parents wanted to do something good for the community that had helped them during their child’s disease and that was also a reason to join the study.

The thought that children are vulnerable and cannot make a weighed and considered decision about participation in research has earlier been the norm (114). However, with the introduction of the UNCRC a shift has occurred, and children are now considered to be competent to be part in the decisions about matters that affect them if they are informed in an age-appropriate manner (115). As a notable shift has occurred, there is growing recognition of the significance of including children in research endeavors that stand to influence or impact them (79, 116). Furthermore, in Sweden for children under the age of 15, parents are gatekeepers and give consent for the child to participate in research (Swedish Law 2003:460 § 18). The children are asked for assent. According to Hart’s model the children’s role in the development of the game in Study I was that of consulting and informative (86).

There is a conception that through participation the participant can become empowered (49). Within Study I the concept of empowerment of the participating children was not explored. Something not mentioned in the presentation of the study but relevant when discussing empowerment is that the children were offered the possibility to disseminate the work they had performed in the project at their schools. Unfortunately, the pandemic made this difficult and it was only possible to do at one school. Yet, the experience from the presentation made by the child at that school was that it had a positive effect on the child.

It is important to think about the design of the material provided for the children upon which they make their decision to participate (117). Within Study I it became evident after meeting the children that they were tired because of their cancer and the current treatments they were undergoing, making it important to think about how to use their time. Hence, this is something the researchers should be constantly aware of (105). After the second workshop the study frame changed and became more flexible. The families could choose when they thought would be a good time to participate.
They were also free to decide the duration of the meetings. This became a decision in line with the children’s and their parents’ interest instead of something the researcher decided upon.

Anxiety when facing RT and how to alleviate it

There are different methods at hand to evaluate procedure-related anxiety in children (100). Some studies use proxy reports from hospital staff or parents together or without the children’s self-evaluated reports (118). Within the project, STAIC(S) became the method of choice because it has been used in several studies before and has proven to be reliable for children with cancer (100). The shorter form of the instrument used for Study IV showed a high Cronbach alpha score when calculated on the 89 questionnaires obtained in the study, indicating that it has high internal consistency.

When writing Study I the concept of fear of the unknown seemed a plausible explanation for the worry and fear the children expressed before RT. It has been shown that children were worried when faced with photon RT (11, 36) and fear of the unknown (16) was a model that fit and is still used as an explanation (119). It has also been used before to explain children’s dread during their cancer trajectory (15). However, as described by Jibb et al. concerning children and their experiences of having cancer (14) and after working with data from this project, another explanation could be that the children are anxious because they already have plenty of procedure-related experiences of pain and dreadful situations connected to what has happened when receiving treatment. Hence, the children deduct that this too (the RT) will be another hardship for them (23), and they feel anxious before they start the treatment. However, in Study IV their anxiety decreases a while into their RT, something that happened with both awake and sedated children. A possible explanation to the phenomenon is that, to begin with, they endure the situation and then a while into the treatment they have learnt what will happen and have adapted to the situation and can therefore handle it without worrying about it.

The children that are going to undergo RT have already faced several procedures at the hospital due to their cancer diagnosis and should have developed a language that is consistent with the surroundings they have been subjected to and developed an understanding of the same (46, 48). It can therefore be assumed that also younger children than those for whom the instrument was originally developed and tested should be able to understand and respond to it according to how they feel. Presently, STAIC lacks validation for younger children aged 5 to 7 years, suggesting that an alternative instrument may be more suitable. For instance, a potential option
is the redesigned short form of STAIC with incorporated age-appropriate visuals for younger children (120). This option was not used in the current study because it had not been published when the study started.

Serious games in the context of RT

Serious games have great potential to prepare players for the events they portray. The games are accessible when the user wants to learn about a specific event and are not subjected to the limited timeframe hospital staff have to inform their patients. As such it meets the needs of the children who want to have information when it suits them (38). Today, there are at least three serious games, including the one presented in this thesis, that have been developed to prepare children before proton RT. However, the other two are produced as mobile apps (119, 121). One of the mobile apps is a virtual reality (VR) serious game, that included five children during the game’s development and five children in the initial evaluation. The children were from the ages of 8 to 16 years and they had a positive response to the game (119).

It has also been proven that serious games can work as psychological preparation for children facing cancer (122). Within Study IV a dosage time was not set so the children had unlimited access to the game after they received it. Instead, to determine if the children found the game acceptable, the predefined feasibility criterion was that 80% of the enrolled children played the game for 20 minutes or more. In all 73% played the game for 20 minutes or more and the feasibility criteria was hence not met with a few children not playing at all. Although, there seems to have been an interest in the game among the participants that played since the average time playing was more or less similar in the groups. There are studies that have used specified game dosages for the minimum duration for play of the interventions which in some cases resulted in positive outcomes that were statistically significant (65). Since the children in the late intervention group have already encountered RT and therefore know what it involves, a suggestion would be to change the feasibility criteria concerning time playing the game and not include them. Within the context of RT, there is a short timeframe between the children receiving the message that they are to have proton treatment and the actual start of it which can make a game suitable as one of several ways for the children to prepare themselves for what it is they are to expect upon arrival at the proton clinic. If the timeframe of the introduction of the intervention in Study IV had been longer it might have been easier to demonstrate differences between the groups. According to Swedish law the hospital staff has a responsibility to inform their patients (22) and a game can never take away that responsibility. However, to evade some misconceptions about RT (23) it could, if used, give the patients a head start. It would give them a chance to use the time they have with the staff to inquire about what they have already
learned about the treatment instead of it being a novel concept to them. In that sense, it will become like a flipped classroom situation and promote agency for the children since they get to be in charge of their own learning (123). So, before the children arrive at the clinic they need to be informed of the game and that it is accessible to them.

To measure the player experience of a serious game
The parents in Study II considered the game more appropriate for younger children. The findings of Study IV point in the same direction since 88% of the children ages 5 through 7 gave the game a high rating according to the PENS questionnaire. There were no children between the ages 12 through 15 years who took part in the game development. According to developmental psychology, children of those ages are more advanced cognitively (39, 48, 110). Consequently, they might not find the game fulfills their need for information before RT. In Study IV there were only two participants from that age group with the oldest being 13, making it impossible to know how the game corresponds to children of that age.

To measure knowledge transfer
Within the project, the assumption was made that with age-appropriate information about RT given within a game, children would feel less anxious before they started the treatment. Hence, before treatment started anxiety levels through a shorter version of STAIC were used to measure the children’s stated anxiety in two groups, one which had had the possibility to play the game before treatment and one which did not have access to the game. The children assessed the game through an adapted player experience questionnaire (PENS). However, questions to assess what knowledge the children who had played the game had compared to those who had not played were not asked. Lööf assessed knowledge transfer in her study of a webpage containing information for children about sedation (124). In the study she compared the children who had access to the webpage and compared their knowledge to children who had received information through an information leaflet with specific questions pertaining to the procedure they were to experience. The study concluded that children who had received information through the webpage had higher accuracy in responses than their counterparts (124). Lööf showed a way to establish how much knowledge the children gain, but this will not provide information about the children’s experiences of the intervention nor the likelihood that the webpage would be used outside the context of research. In a serious game on nutrition education, for children aged 8 through 10 years, the researchers found a positive correlation between learning outcome and player experience and enjoyment (125). Therefore, both knowledge transfer and the player experience should be measured when
conducting studies to assess the feasibility of serious games within pediatric care. It would also give an indication as to whether the game was age-appropriate.

Methodological considerations

Social constructionism

In the first three studies within the thesis a qualitative approach was used. The material analyzed for the result consisted of films and observational notes of gameplay, audio recordings from workshops and interviews conducted with participants. In Studies I and III, the framework brought forward by Braun and Clarke of thematic analysis was used (92). For Study II content analysis as described by Graneheim and Lundman was used (94). There are similarities between the methods as to how the researcher should go about the process of analyzing text and explain to the reader how the results from said text were interpreted (126). A difference between the methods are that Braun and Clarke give credit to the context of the researcher’s background, be it realist or constructionistic (126). The constructionistic philosophy claims that the researcher constructs meaning from what the participants have shared and understands it from the framework that the researcher holds (95). Knowledge should be seen as contextual when generated through reflexive thematic analysis. Further, Braun and Clarke state that the researcher’s subjectivity should be understood as an asset when generating knowledge and should not be thought of as a threat to credibility (127). In the current research it has been through the lens of the aforementioned theories of child development. Also, it has been through Berger and Luckmann’s theory of the social construction of knowledge (47) and Burr’s explanation of social constructionism (49). The process of the game development has been understood through the framework brought forward by Alexiou and Schippers (44).

Addressing questions of credibility and trustworthiness

The data collection time lasted over a period of eight months for Study I, suggesting that the children involved and their parents became emotionally invested in the project. The use of a qualitative approach, including several data collection methods as well as the inclusion of rich descriptions can probably strengthen the credibility of Study I and promote transferability to studies using a similar approach (128). Of the initial 13 families contacted in Study I, nine chose to participate and two children left the study before it was finished. The majority of the participants were girls. Perhaps more boys in the group would have provided additional information. However, even though there was a lack of gender diversity, data collection was rich, and the group
was diverse in its gaming habits which was valued higher in the current context. Maheu-Cadotte et al. (129) suggest that researchers should use different methods and involve end users with varying gaming habits to prompt input under the development of serious games.

In study II, seven out of 10 parents chose to participate. In Study III, all but one of those invited to participate in the interview accepted. To accomplish trustworthiness and for the reader to be able to judge the analysis process in Studies II and III, quotations from the participants were presented throughout the results to show how categories were extrapolated (94, 130). In both studies, time had elapsed between the events asked about which can cause the participants to make a re-interpretation and reconstruction of the events. The parents in Study II reported similar accounts on many issues. The same was true for the reports from the teams in Study III. In Study III the experiences of the project coordinator and one of the researchers are not included. Their experiences could have added further understanding of the developmental process. To include their experiences within the research project would have prompted the study to in part become autoethnographic, being an altogether different method seldom used within the field of medical science and nursing (131).

Interview guides were used in Study II and III in order that the questions posed to participants would be similar and to help the interviewer to not forget any relevant questions. The interviewer is together with the participant in a dialogue and the interview guide ensures that areas of interest for the research question are not missed (49).
Conclusion

The children played an active role in developing the game, offering valuable input that led to numerous game improvements. The applied method in study I functioned and can be used by researchers to co-create serious games with children. The cancer and its treatment affected the children’s ability to participate. Therefore, the layout of the study needed to be constantly revised. It proved to be ethically reasonable to involve children with cancer in the complex intervention study based on how the study was administered. For researchers, there is a responsibility to adapt tools to facilitate the participation of children with diseases in research.

Parents were sensitive to their children’s wishes of participation, both when they wanted to take part or end it. The parents expressed that they wanted to contribute to research due to all their encounters with healthcare during their children’s cancer as a means to do something good.

It was challenging to work interdisciplinarily. Participants expressed that their knowledge increased due to participation. Key elements that improved the project’s odds of success were to have confidence in the product being produced together with an open climate and generous time working with the production of the game.

The feasibility study showed that the study protocol needed to be modified. There was no indication that playing the serious game decreased the children’s stated anxiety toward undergoing RT but power was low. However, it did not increase their anxiety either.
Future directions

The next step is to implement the game into the Skandion clinic and make all the clinics that refer children to it aware of the game’s existence so that it gets used.

The serious game about RT is a means for children to learn about RT and future directions would be to find ways to assess the knowledge transfer from games to real-life situations in children of different ages. It would also be of interest to test the serious game on a larger group of children. However, since only one proton facility exists in Sweden the study would need to be multicenter and probably multinational. The game would need to be translated and perhaps culturally adapted to be tested on children in other countries since the psychological preparations before proton RT might vary.

Further, to validate the translated modified version of PENS for children is needed so that the instrument can be used when evaluating serious games for children.

For future studies that are having children with diseases participating in designing serious games it could be of interest to investigate the impact the process has on them and if it is empowering.

Further, it could be of interest to write an autoethnographic paper on the developmental process of the game to give voice to the complexity of the project as seen by the coordinator’s perspective.
Sammanfattning på svenska


Barn är idag vana vid att använda digitala spel som underhållning, fritids sysselsättning eller som ett läromedel i skolan. Inom sjukvården har digitala spel börjat att användas för att förbereda barn inför olika typer av behandlingar med avsikten att informera eller minska oro inför behandlingar. För att minska barns oro inför strålbehandling kan det behövas fler eller andra förberedelser än de som används idag. Ett datorspel som lär barnen om behandlingen innan de kommer till kliniken skulle kunna fungera som förberedelse.

Syftet med avhandlingen var att tillsammans med olika aktörer skapa ett datorspel om strålbehandling för barn samt att beskriva utvecklingsprocessen och vilken påverkan deltagandet hade på slutprodukten. De aktörer som deltog i spelutvecklingen var barn som genomgått strålbehandling, deras föräldrar, personal som arbetar med barn som ska genomgå strålbehandling samt spelutvecklare och forskargruppen som ansvarade för genomförandet av studierna. Ytterligare ett syfte i avhandlingsarbetet var att testa spelet på målgruppen utifrån att mäta acceptansen av interventionen samt att mäta barnens självskattade oro inför behandling.

Delstudie I beskriver skapandet av ett datorspel tillsammans med barn som genomgått strålbehandling och deras föräldrar. Datorspelet var tänkt som information och psykologisk förberedelse av barn inför att de ska genomgå
behandling på Skandionkliniken. Metoden som användes i studien för det
gemensamma skapandet av spelet var deltagarbaserad aktionsforskning. Barn
som genomgått strålbehandling och var mellan åldrarna 6 och 15 år och kunde
prata och förstå svenska blev tillfrågade om deltagande i studien. Nio barn av
13 tackade ja till att delta i studien. Barnen som deltog var mellan 7 och 12 år,
varav 8 flickor och en pojke. Barnen blev inbjudna till 6 workshops under en
period av åtta månader. Under workshopsarna fick de komma med idéer om
vad de tyckte att spelet skulle innehålla samt spela en prototyp av spelet och
berätta hur de upplevde det.

I delstudie II beskrivs 7 föräldrars upplevelse av sitt eget och deras barns
deltagande i delstudie I. Alla föräldrar som varit delaktiga i delstudie I fick en
förfrågan när studien var avslutad om att delta i en intervju om ina upplevelser
av den tidigare studien. Förfrågan gick ut till 9 föräldrar och 7 valde att delta.
Föräldrarna fick svara på frågor om hur det kom sig att de valde att delta i
delstudie I, hur de upplevt sitt eget deltagande, deras barns deltagande samt
deras erfarenheter av strålbehandlingen. Intervjuerna genomfördes på telefon
och analyserades i en innehållsanalys.

Delstudie III beskriver spelutvecklare, forskarlagets samt en arbetsgrupp från
sjukhusets upplevelse av att delta i framtagandet av ett datorspel om
strålbehandling. En tematisk analys genomfördes och det analyserade
materialet består av intervjuer genomförda med alla de personer som ingick i
den specialistgrupp som skapades på sjukhuset i syfte att kontrollera
spelinnehållet. Personerna arbetade med barn som skulle genomgå
strålbehandling (4 personer) samt lekterapeuter (2 personer). Intervjuer
genomfördes även med fyra utav fem spelutvecklare och tre personer från
forskarlaget. Intervjuerna genomfördes på Zoom eller på telefon. En tematisk
analys genomfördes av materialet för att beskriva deltagarnas upplevelser.

Studie IV var utformad som en randomiserad klinisk pilot studie med
fördefinierade genomförbarhetskriterier. Barn i åldrarna 5 upp till 15 år som
skulle genomgå strålbehandling vid Skandionkliniken bjöds in att delta i en
interventionstudie där datorspelet som utvecklats skulle testas. Tjugotre barn
tackade ja till att delta och randomiserades till en av två grupper. Ett barn
exkluderades direkt efter randomisering eftersom det visade sig att det fanns
större språkstötdelningar än vad som tidigare framkommit. Om barnen
randomiserades till grupp 1, fick de spelet innan strålbehandlingen började.
Barn i grupp 2 fick tillgång till spelet tre dagar efter att de hade påbörjat sin
behandling. En förkortad version av frågeformuläret STAIC bestående av åtta
frågor användes för att bedöma barnens upplevda oro inför strålbehandling.
Mätningarna skedde på specifika dagar under behandlingen. En till svenska
översatt och åldersanpassad version av det engelska frågeformuläret Player
Experience of Need Satisfaction (PENS) användes för att mäta barnens spe luupplevelse. Även tiden barnet spelade spelet registrerades.


Slutsatser som kan dras från forskningsprojektet är att barnen hade en aktiv roll i designarbetet och deras medverkan bidrog till den slutgiltiga utformningen av spelet. Föräldrarnas deltagande bidrog lite till själva spelutvecklingen men var viktig för att de bistod deras barn att kunna medverka. Det var utmanande att arbeta interdisciplinärt men fungerade på grund av ett öppet arbetsklimat samt en tilltro till nytan av projektet och deltagarnas kunskaper ökade under tiden som arbetet pågick. I studie IV var deltagarantalet i grupperna för litet för att kunna dra slutsatser om spelets påverkan på barnens upplevda oro men inget påvisade att oron ökade hos barnen av att spela spelet. När de två grupperna slogs samman påvisades att den upplevda oron inför strålbehandling minskade allteftersom studien pågick.
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Tindra, I love you to the moon and back (because that is how far my mind can grasp distance and wrap its limitless affection) a mother’s love knows no boundaries.
References


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Appendix
Request for your participation in an explorative study investigating the development of an online game about Radiotherapy

To you who work at the children’s hospital, the radiation clinic, the Skandion clinic, with game design, or Uppsala University. You are hereby invited to participate in a study examining the developmental process that took place when making a game about radiotherapy for children. We wish to hear your experiences and thoughts of the work that took place and that you were involved in.

We wish to carry out an interview with you. You decide upon a time that is of your convenience, the interview will be conducted over zoom and be tape-recorded. Participation is voluntary and you can end the participation at any time without stating why you wish to withdraw from the study. Your answers will be reported at group level to unidentify your statements to the best of our ability.

It is GDPR (General Data Protection Regulation) that regulates how personal information shall be handled. The data protection manager at Uppsala University is Jakob Håkansson, email: dataskyddsombud@uu.se. Jon Back is project manager of this study, contact information at the bottom of the page. The data will be kept for 10 years according to university policy. Only persons within the research group will have access to the information provided by you.

We are interested in your experience and the material could lead to new knowledge about how to work in projects like the one you were involved in. The results will be published in scientific journals. If you have any questions, do not hesitate to contact us.

Kind regards:
Catarina Cederved
PhD-student
Dept. of Women’s and Children Health
XXX
Catarina.cederved@kbh.uu.se

Jon Back
Associate Professor
Dept. of Informatics and Media
XXX
jon.back@im.uu.se
Consent form

I hereby give my consent to participate in an interview about the developmental process of an online game about Radiotherapy.

Participation will include:
- State how I experienced the process
- Describing what my role was in the project
- The answers will be tape-recorded
- I can at any time withdraw my participation

Name: ____________________________________________
Signature: _________________________________________
Telephone number: _________________________________
City and current date: _______________________________

Kindly send the signed consent form to Catarina.cederved@kbu.uu.se
Appendix 2

The aim is to describe the development of an online game for learning and the experience of the development process from the perspective of the project participants.

We are very interested in hearing how you experienced it to participate in this type of developmental project. The interview will be tape-recorded.

First:
How old are you and what gender?
What do you do when you are not involved in the project?
How did you become involved in the project?
What was your role in the project?

Experiences of work:
What memorise do you have from working with the project?
What have your contributions been to the project?
How have your voice been heard in the project?
What did you experience worked well in the project?
What obstacles did you experience in the work?
If a similar project were to be conducted what would you recommend be done differently?
Personally, what were your biggest revelation from the project?
Would you want to be part of similar projects in the future? Why?

The game:
What do you think about the game?
What is good?
What can be improved?
How do you think it can be used?

Last questions: Your areas of expertise!
What are your experiences of radiation therapy?
  Game design?
  Children?
  To treat children?
  Of pedagogy and learning?

Anything you would like to add?
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