Parents' experiences of having their children take part in participatory action research creating a serious game about radiotherapy

C. Cederved a,*, C. Ångström-Brännström a, b, G. Ljungman a, c, G. Engvall a

a Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden
b Department of Nursing, Umeå University, Umeå, Sweden
c Children's University Hospital, Uppsala, Sweden

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A B S T R A C T

Introduction: Radiotherapy (RT) is one of several treatment modalities used for children diagnosed with cancer. Several studies have designed interventions aimed to alleviate the stress that can occur in conjunction with RT. To include children in the design of interventions is rare and dependent on the parents giving consent to participation in research on their children's behalf. The aim was 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.

Methods: Ten parents of children taking part in a participatory action research study of the development of a serious game were invited to an interview and seven parents consented. An inductive, manifest content analysis was performed.

Results: The analysis resulted in an overarching theme: Parents' pre-understanding from their child's cancer treatment created a sensitivity to their child's wishes and a willingness to contribute to science. Four categories are presented: Intrinsic factors influenced the intent to participate, Extrinsic factors that had an effect on participation, Parents role in the game development, and Radiotherapy impinged the child and the parent.

Conclusion: To be able to pay it forward to healthcare and other families with a child diagnosed with cancer was a contributing factor for parents' willingness to consent to participation after their children had undergone RT, especially since their children wanted to do so. Parents indicated interest in the developmental process and in following their children being part of the creation of a serious game about RT.

Implication for practice: To understand why parents allow their children to participate in studies creates opportunities for the research community to structure studies that facilitate participation.

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Introduction

Parents of children diagnosed with cancer described feelings of how their world turned upside down and how they were worried because of their children's severe disease and the treatments the child had to undergo such as radiotherapy (RT). RT is one of several treatments that can be considered when a child is diagnosed with cancer. During RT, the children need to be left alone in the treatment room and have to be completely still. RT can be provided for up to six weeks and preschool children often need anesthesia. Some time into the treatment with RT, the parents described how they felt trust towards the staff and that they could cope with the situation. Several studies have designed interventions aimed to alleviate the stress that occurs in conjunction with RT that has been successful for some children but not for the entire study population. What motivates parents to include their child in studies is the thought that it will benefit other children in the future. Other reasons stated in randomized controlled studies in oncology and heart surgery were trust in the person who enrolled the child and, furthermore, altruism. However, little is known of how parents experience their child's enrolment in participatory action research ranging over several months.

In order to conduct studies together with children and not for children, it must be recognized that children have rights which include that they not merely be studied but shall have their voice heard during study design. Therefore, a previous study was
conducted together with children that had undergone RT to design a serious game. A serious game is a digital game where the main purpose is not to entertain but to educate, and it can be used in a variety of fields where one is healthcare. Further it can influence the player’s view of the displayed phenomenon in the game. The children needed their parents’ consent to be enrolled in the previous study and their assistance to be accompanied due to their young age of between seven and ten years. The perspective from the accompanying parent could also be essential when designing serious games. It is of interest to understand how the parent perceives the experience since they determine whether their child can participate, sometimes regardless of the child’s own wishes, and since they are most often the first person to receive information about studies. In the current study, parents whose children were enrolled in the previous study to co-create a serious game about RT were included, to comprehend why they allow their children to participate, and further, their experience of participation from a parental perspective. The aim was 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.

Method

Participants and inclusion

There were nine children taking part in a participatory action research study of the development of a serious game and to the current study their parents were invited to a follow-up interview. In the previous study there had been six meetings over a period of seven months, either at a venue or online. Participants were invited to take part in the previous study by the radiotherapy coordinating nurse. The sample was a consecutive convenience sample, for further information see previous study. All ten parents that had given written consent in the previous study were asked to participate and seven of the eligible parents agreed to be included. Participants of both female and male gender were represented among those interviewed. Two of the interviewed were parents of the same child but had been equally involved in their child’s participation. The ages of the six children at the start of the previous study were: three ten-year-olds, two eight-year-olds and one seven-year-old. Of the six children, one had been sedated during the treatment, and another child had RT both awake and on a few occasions under sedation. The participating parents gave both written and oral consent to participate. Both studies were approved by the Regional Ethical Review Board in Uppsala, Sweden (Ref no. 2018/264). The study followed the ethical principles of the declaration of Helsinki.

Data collection

The interviews were conducted over the telephone, tape-recorded and then transcribed verbatim. The interviews were performed by an experienced investigator, who had not been part of the data collection of the previous study and was therefore unknown to the participants. The choice of interviewer was made to enable participants to speak openly and sincerely about their experiences. A semi-structured interview guide was used. The interview guide included questions about the experience of RT, asking the parents about their own experiences and about their child’s. The parents were asked to talk about their experiences of participating in the serious game development study. They were asked to elaborate on why they thought their children chose to participate and why they had given consent for their children to participate. The interviews were conducted in 2020 and lasted between 16 and 29 minutes.

Qualitative data analysis

An inductive and manifest qualitative content analysis of the transcribed interviews was performed, inspired by Granhein, Lindgren and Lundman, and Granheim and Lundman. An inductive analysis is conducted by interpretation of the specific data to discover new explanations and/or concepts, and when the analysis is manifest the author’s stays close to the written text during the analysis. The data was first read multiple times to become familiarized with the text. The data was then condensed during which text not relevant to the aim was removed. The first author identified meaning units, created codes and searched for patterns in the text, specifically looking for similarities and differences, which formed the beginning of the categorization process. Preliminary sub-categories were formulated based upon the codes. The first and the last author read, compared and discussed the condensed text, codes and sub-categories until agreement on the categories and the sub-categories was established. At the final stage, an overarching theme was developed that could tie all the text together to show the meaning of the whole. All co-authors participated in the final discussion of the content and labeling of the categories and the theme.

Developmental process of the serious game

An iterative approach was used when developing the serious game. The game design team built a version of the game. The children met with the research team and played, and assessed the current version of the serious game. After the play session the children together with their parents were interviewed about their experiences of the serious game and provided ideas of improvement. The ideas from the children and parents were assembled in a priority list and sent to the design team. The game went through six iterative cycles. At certain points during the iterative process an expert team provided comments on the accuracy of the information and content regarding RT in the serious game and came up with suggestions for improvements in the gameplay. The first two sessions were in groups of three to four children. The following sessions were in groups of two, or individually due to the Covid-19 pandemic.

Results

An overarching theme emerged: Parents’ pre-understanding from their child’s cancer treatment created a sensitivity to their child’s wishes and a willingness to contribute to science (Table 1). The results describes the parents’ experiences of their children being part in the development by co-creating a serious game about RT and the parents’ descriptions of how they experienced their children’s RT. The results include quotations from the interviews, marked with parent’s (P) and study number (1–7).

The parents’ experiences of having their children take part in the development of a complex intervention were illuminated. Three categories were formulated: Intrinsic factors influenced the intent to participate; Extrinsic factors that had an effect on participation, and Parents’ role in the game development. Something extrinsic is factors that are external and that someone therefore cannot control while intrinsic factors come from the person’s own thoughts and insights. Six subcategories describe aspects of participation and aspects of the serious game under development. A fourth category was formulated: Radiotherapy impinging the child and the parent. In three subcategories the parents’ experiences are illuminated with aspects from the parents’ perspective about their children undergoing RT.
Unable to come to where the meetings were held. Time was settled upon. Another was that it was never a problem to slots and that they were included in the decision regarding what suited them, they said that they could choose from several time-penses. Some parents expressed that the times of the meetings to the meetings by taxi and being reimbursed for the travel ex-
as facilitating participation, or being given the opportunity to come

Facilitating factors to stay with the project

Extrinsic factors had an effect on participation

Covid-19 impacted participation

Intrinsic factors influenced the intent to participate

Being motivated for participation

Some parents expressed that they as parents thought that it was nice to be able to contribute after all the medical care their children had received. This was a reason to agree to have their children take part in the development of the serious game.

“I thought it was fun to be able to see how much work is actually behind a thing like this. I don’t know if my child really thought so much about it. And I also think that it feels like it is very nice to be able to contribute in some way, well after all the treatment, sure one pays taxes and stuff, but it is very nice to be able to do something tangible.” (P6)

Other parents conveyed that they encourage all sorts of activ-
ties that their child wants to participate in and that they found it pleasant that their child chose to take part. The parents stated that it was for the sake of their child that they had participated.

“We try to encourage all activities that s/he wants to take part in. And this was such an activity.” (P1)

Expressing their children’s motivation for participation

Parents expressed that they were not completely sure why their children had agreed to participate. They speculated that it must have been because it was a computer based game and that interested or tempted them. Other parents were confident that it was because it was a game that they had agreed to participate.

“That’s a good question, I don’t really know. It was more like: Look we can do something that’s to do with RT and is fun, shall we agree to do it? Yes… Nice to do something positive in all the negative… I feel that we can contribute to something and like s/he thinks it is fun to talk and do things.” (P7)

Extrinsic factors that had an effect on participation

Facilitating factors to stay with the project

Living close by to where the meetings were held was mentioned as facilitating participation, or being given the opportunity to come to the meetings by taxi and being reimbursed for the travel ex-

Factors that were challenging for participation were that the parents expressed being tired of having appointed meetings after all the time they had spent traveling back and forth to the hospital during treatment.

“And it was so damn much to drive back and forth to the hospital, and then to go back and forth for this, it felt like, well it was not great. I felt that there were other things to do.” (P3)

Covid-19 impacted participation

Parents described that the first meetings were held together with other families, where the children interacted with each other. However, due to Covid-19 the meetings outlined had to change due to the risk of spread of infection. Instead, the meetings were more individualized where the participating family either did not meet any other families or just one other family. One parent explained that they had left the project because their child did not enjoy taking part anymore when the meetings were no longer with the whole group. The child had liked the interaction with the other children.

“S/he thought it was fun, or kind of fun. It was fun to meet some of the others, the children. But then after, because of Covid-19 we stopped meeting in a group… I know s/he enjoyed it more when they were several children there than when s/he was the only one there.” (P3)

Parents role in the game development

Self reflection of participation in the project

Some parents expressed that they had hardly seen anything of the serious game under development. They conveyed that they had been in another room than where their child had been when playing. Other parents had noticed more and had enjoyed watching and found it interesting and exciting to watch their child playing.

“Yes, well it has been interesting to sit and watch over my child’s shoulder.” (P5)

The parents described that their own participation in the project had been to be there for their children, to support them, and furthermore to take their children to the meetings.

“No, I would say I was just an accompanying parent.” (P1)

The value of the game and being part of the development

Some parents described that they had a hard time recollecting if their children had noticed changes in the game from one meeting to another, but they thought so. They were quite sure that they had
noticed changes. The changes the parents described that their children had noticed were put in the game for amusement and had little impact on the learning about RT. Other parents could recollect that they had wondered if their child had noticed any changes considering their relaxed attitude but had been surprised when their child had answered the investigator that such and such had been changed in the game. However, parents agreed that no major changes had been made.

“Well yes, she noticed changes. There was some fruit or vegetable that was in a room that later was not there anymore... She knew what she had done before, and then she looked to see if there was anything new.” (P2)

Parents expressed that the serious game, when ready, could be used to prepare children before they are to undergo RT. Some parents thought the serious game could be used as an information supplement for the children.

“But to be able to test it and see how it looks in the game, yeah because it can be difficult to fully comprehend from a text or oral information.”(P4)

Parents to some of children aged 10–11 years expressed that they thought the serious game would be suitable for a younger age group. They thought their children had not enjoyed it so much and that it might have been a bit childish.

“I can think that maybe, my child who is 10, 11 years now and maybe my child is a little bit too old for the game ... Maybe a five year old would have found it more enjoyable.”(P6)

Radiotherapy impinged the child and the parent

In this fourth category the parents’ experiences of the procedure of RT will be presented in three subcategories to illuminate aspects from the parent’s perspective about their children undergoing RT.

The parents initial worry and thoughts about the treatment

The parents described that they had experienced worry when their child had to undergo RT. Some had found it difficult to see their child struggle with the treatment and its side effects. Parents described how they had found it hard to force their children to go for treatment when the children did not want to. Further, some parents had noticed that their children looked uncomfortable or frightened.

“Well of course it was tough to sit next to her. On the one hand to drag her there for treatment and then the wait, during the waiting time, when she had treatment, and then to sit next to her when she slept after sedation... That is tough, and then somehow you got used to it too.” (P7)

Their children’s ability to handle the treatment

The parents expressed that the treatment could look cruel since their children had to wear a mask that was secured firmly to the table. However, when they noticed that their children did not have a problem handling the situation the parents felt that it was okay. Some parents described that their children managed the RT well and they believed that their children had not experienced it as tough as they did themselves.

“I would say that it was no problem at all because my child is supercool in situations like these.” (P5)

The staff supports the family to cope with the situation

The parents had noticed that the staff working at the RT facility had been supportive both to their child and to them which made the experience of RT a memory they found they could cope with. The parents expressed that they trusted the staff’s technical expertise during the treatment procedure. Some said that the staff had been very nice and that their children missed them when the treatment was finished. They expressed that the staff had acknowledged their children and individually adapted what they could in the treatment to make the experience as endurable as possible for the child and family members.

“They joked with my child too, and s/he got to help with different things before s/he was put to sleep, so about a week or so ago s/he said s/he missed the staff, that s/he wanted to go back, that it was so much fun there.” (P4)

Discussion

The overarching theme was: Parents pre-understanding from their child’s cancer treatment created a sensitivity to their child’s wishes and a willingness to contribute to science. The theme captures all data from the interviews with the participating parents and could be put into categories and sub-categories that aligned with the theme as well as providing an underlying meaning of the content.

The parents had been worried and uneasy when their child had to undergo RT and they found the experience easier thanks to the help provided by the staff working at the clinic and when they noticed how well their child could handle the situation in line with findings in earlier studies. The parents described how they had noticed that the staff had individually adapted what they could in the RT for the child and had acknowledged the child, something staff delivering RT to children have expressed in earlier studies. On account of their experiences of RT, the parents wanted to encourage their children to participate in the previous study to develop a serious game about RT. They were themselves interested to see how a serious game was developed. They also wanted to pay it forward to healthcare and other families with a child diagnosed with cancer, in the sense that they wanted to do something useful as a response to the support they had received when their child had undergone treatment, in accordance with findings from earlier studies. To meet other children when taking part in the study contributed to the children’s participation, but due to Covid-19 the possibility to meet in bigger groups was not an option and the study lost participants. To live close by or by making the journey to and from meetings easy by offering the families travel by taxi, facilitated continued participation.

Children that are treated for cancer and their parents are often asked to give consent to participate in research. The families that were asked to participate were asked by an investigator and not by the treating healthcare team in an effort to make the consent voluntary and not influenced by the treating healthcare team. They were informed that they would receive the same care irrespective of whether they participated in the present research. They were informed that they were free to leave the study at any point and did not have to inform why. It can be considered important to give parents the opportunity to make their voice heard when studies are conducted involving their children and taking up the time of both the child and the parent. However, the results reveal that the parents found it interesting and allowed their children to participate. At the same time, parents were sensitive to their children’s wishes to end participation when they did not want to continue. This was described in the interviews, supporting the awareness of voluntary participation among parents.
Furthermore, to create a serious game about a procedure that children already have gone through and know about is a challenge. Since the children taking part in the co-creative development already possessed the knowledge the game intended to teach, they were more focused on the gameplay as such and not the educational aspects. To create a combination of amusement and educational elements within a game is intricate and it could have influenced some of the children’s perceptions and contribution. Finally, a co-creation study involving young children and thereby their supportive parents can provide a more realistic serious game. However, further studies will determine for what ages it is appropriate.

Methodological considerations

When performing a qualitative analysis the investigators need to be aware of their own preunderstanding of the phenomenon being investigated to not influence the material. Investigator CB and CC who performed the interviews had little knowledge of how the previous study had been executed and therefore no preconception of what she would encounter during the interviews, hence it is considered less likely that leading questions would have been posed. Further, an interview guide was used so that the questions would be similar for all participants. The interviews were conducted over the telephone which has been argued would put the interviewee at ease and result in more honest data. Investigators CC and GE who were both involved in the analysis of the material also conducted the previous study. Consequently, they had to consider and keep in mind their preunderstanding in order to not taint the results with their preconceptions, but instead approach the material without judgement from prior knowledge. In an effort to accomplish truthworthiness and for the reader to be able judge the analysis process, quotations from the participants have been presented throughout the results to show how categories were extrapolated.

Due to the time elapsed from when the previous study was performed the participants re-interpret and reconstruct the events that are asked about. However, the results reveal that the parents accounted for similar experiences and perceptions during the interviews. Both male and female gender are represented among those interviewed. Although the results are merely based on seven participants, different parents described various experiences thus supporting that the data set was rich. All authors contributed to the interpretation of the qualitative analysis which strengthens credibility. However, transferability to other areas of research is difficult to judge, but transferability to studies of similar design may be possible if the parents consider that their children could benefit directly during the participation.

Conclusion

A contributing factor for the parents to participate in the study was, after their children had undergone RT, to be able to pay it forward to healthcare and other families with a child diagnosed with cancer, especially since their children wanted to do so. The parents indicated interest in the developmental process and to follow their children being part of the creation of a serious game about RT. If radiotherapy services provide the serious game before RT to children it will provide the possibility for them to gain further knowledge about the procedure through its interactive play. The children enjoyed meeting other children during the study and it provided an opportunity to be together with peers who had experienced the same treatment. It is essential to consider the parents’ experiences of allowing their children to be part of studies since the research community, through them, can obtain more knowledge about how to facilitate participation.

Data availability statement

The authors elect to not share data for confidentiality reasons. The study was carried out in accordance with ethical research principles as stated in the Declaration of Helsinki (World Medical Association 2013).

Conflict of interest statement

None.

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