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**Innovations in pediatric oncology care:
Interactive tools for psychosocial support
for children with cancer and their families
during treatment**



Kelly van Bindsbergen

**INNOVATIONS IN PEDIATRIC ONCOLOGY CARE: INTERACTIVE
TOOLS FOR PSYCHOSOCIAL SUPPORT FOR CHILDREN WITH
CANCER AND THEIR FAMILIES DURING TREATMENT**

Kelly van Bindsbergen

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Innovations in pediatric oncology care: Interactive tools for psychosocial support for children with cancer and their families during treatment

ACADEMISCH PROEFSCHRIFT

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aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
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ten overstaan van een door het College voor Promoties ingestelde commissie,
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General introduction

When a child is diagnosed with cancer, it has a major impact on both the child and the family. Cancer treatment causes a certain level of medical traumatic stress, and the family is disrupted. Coping with this stress is important to reduce the psychosocial impact of the disease and its treatment. Advances in technology have offered new opportunities for psychosocial support for children and families during treatment both at the hospital and at home. This thesis is about interactive tools that were developed and scientifically evaluated for this purpose.

CHILDHOOD CANCER

In the Netherlands, about 650 children are diagnosed with cancer every year [1]. The most common types of cancer among children are leukemia, lymphomas, brain tumors, and solid tumors. For treatment, children usually receive complex systemic therapy (e.g., chemo therapy), including hospitalization and outpatient clinic visits. Many children are additionally treated with surgery, radiation therapy, a bone marrow transplantation, immunotherapy, or a combination of these treatments. Medical procedures such as blood draws, bone marrow aspirations and lumbar punctures are also part of treatment for diagnostic purposes and to monitor treatment responses [1]. With these intensive treatment strategies, overall five-year and ten-year survival rates have now reached 81% and 78% respectively, although there is a large variety between diagnoses and disease stages [2]. A cancer diagnosis and the often lengthy, demanding treatments have a significant impact on the child, as well as on the whole family [3].

PSYCHOSOCIAL IMPACT OF CHILDHOOD CANCER AND COPING

Cancer treatment and its inherent procedures are potentially traumatic events (PTE) that cause stress and anxiety in children. The subjective experience of PTE by children and parents is one of the most powerful predictors of the level of Pediatric Medical Traumatic Stress (PMTS) that children experience [4]. PMTS has been defined as “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” [5]. Reduction of PMTS in the pediatric oncology setting is important for many reasons, including reducing significant adverse psychological reactions and prevention of potential long term traumatic stress. Here, coping plays an important role in the emotional adjustment of children to stress. Coping strategies are “balanced

reactions to stress that enable children and families to tolerate, minimize, accept, and/or ignore what cannot be mastered” [6]. Children and families who are able to adapt to stress and cope with PTE, develop resilience to recover after stress [7]. Therefore, early interventions are important and needed to change the subjective experiences of families of PTE by supporting their coping during cancer treatment.

INTERVENTIONS FOR PSYCHOSOCIAL SUPPORT AT THE HOSPITAL

The international standards of psychosocial care strongly recommend psychosocial interventions for invasive medical procedures [8]. In the Netherlands, as part of standard care during treatment, child life specialists are available to prepare and support children during medical procedures, and social workers are available to support parents emotionally and help them continuing their family life and overcoming practical issues. If needed, a team of psychologists is available to provide specialized additional psychosocial care [9]. Also, as a standard of care, the KLIK intervention is implemented, where families are screened on their psychosocial functioning and the quality of life of the child is monitored and discussed during outpatient clinic visits [10-12]. In recent years, advances in technology have created opportunities to supplement these currently available psychosocial interventions at the hospital. More and more innovations have emerged, such as virtual reality glasses [13], mobile applications (apps) [14], gamification and serious gaming [15], telepresence robots [16] and social robots [17-19]. These innovations have lots of potential, because they are interactive and playful, and therefore appealing to children and developmentally appropriate [20].

Social robots

Social robots can be defined as “new types of robots whose primary goal is social interaction with humans” [21]. In other words, robots designed to have meaningful social interactions. Social robots could be a new and appropriate form to meet the unique care needs of children [22]. Children seem to be able to form relationships with social robots, and consider them to be a buddy or friend [23-25]. Social robots are regarded as fun and motivational by children, and parents appreciate that social robots have a lot of patience, are not judgmental, and can help their child [26]. Children also accept the instructions of social robots and enjoy the company [27], and social robots seem to be able to achieve educational outcomes similar to human tutoring in specific tasks, and to improve cognitive and affective outcomes [28].

Social robots in pediatric health care

In the past years, social robots have been used in health care in various ways. Four reviews have been published recently that provide an extensive overview [29-32]. The reviews outline the different types of social robots that exist, ranging from self-developed prototypes, to robotic pets and stuffed interactive animal toys (e.g., Pleo and Paro), to humanoid robots (e.g., the NAO and Pepper). The reviews also demonstrate how social robots have been applied in the health care setting in various ways (e.g., for amusement, distraction, emotional support, education), and for different purposes (e.g., improve well-being, reduce pain, stress and anxiety, and self-management with disease). Table 1 shows more details about the reviews. Overall, the reviews conclude that social robots hold significant promise and potential to help children in a broad range of health care settings [29,30,32], but evidence is limited or not clear [31].

Social robots in pediatric oncology

When looking more specifically at social robots in pediatric oncology, research is much more limited. The few studies that exist, can be divided into two types. First, there are studies that focused on the design and embodiment (e.g., physical appearance) of social robots. These studies included the conceptual design of Arash, and the engagement and interest of children with the prototype [33,34], and the robotic plush teddy bear Huggable that was compared to a virtual character on a screen and a plush teddy bear [35,36]. Second, there are studies that used existing social robot hardware and software, and examined clinical outcomes. Here, positive results were found regarding feasibility and preliminary effectiveness to reduce pain and distress during subcutaneous port access [37], as well as positive reactions from children to a social robot as a psychotherapy assistant to reduce anger, anxiety and depression, and its usefulness in providing instructions [38]. Table 2 shows more details about the studies that were conducted with social robots in pediatric oncology patients. From the studies, it can be concluded that children generally show positive reactions towards social robots, yet they are at an emergent stage. Also, we do not know how health care providers who have to work with social robots feel about this development. Since social robots seem to have positive effects on children, there may be a future for social robots in the care for pediatric oncology patients. Therefore, it is worth to explore this development further, as social robots could provide novel opportunities and benefits by supplementing currently available methods of psychosocial care for children to reduce PMTS.

TABLE 1
Overview of reviews on social robots in health care

Source	Aim	Results	Conclusions
[29] Moerman et al. (2019) Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review	Inventorize the use of socially assistive robots in hospitals to support children's well-being and what the effects are	<ul style="list-style-type: none"> 10 publications were found, from 8 different studies 6 different robots were used: One humanoid, five pet-like For distraction during medical procedure, emotional support for dealing with a disease or support of well-being during hospital stay Positive effects on children, such as distraction and engagement, less stress or pain, more relaxation, smiling and openness or better communication Some youngsters felt unsafe with the robot 	<ul style="list-style-type: none"> Socially assistive robots may have a potentially positive influence on a child's well-being
[30] Dawe et al. (2019) Can social robots help children in healthcare contexts? A scoping review	Review research on social robots to help children in healthcare context to describe current state of literature and explore future directions	<ul style="list-style-type: none"> 73 publications included, of which 50 user studies with a range of samples ($n = 2-70$) At least 26 different robots were used, many still in development, NAO robot most commonly used Only one randomized controlled trial and limited number of experimental designs (low evidence quality) 	<ul style="list-style-type: none"> Social robots hold significant promise and potential to help children in healthcare context, but higher quality research is required with experimental designs and larger sample sizes
[31] Trost et al. (2019) Socially assistive robots for helping pediatric distress and pain: A review of current evidence and recommendations for future research and practice	Review the literature on socially assistive robot interventions for reducing pediatric distress and pain in medical settings	<ul style="list-style-type: none"> 8 studies included, representing 206 children Of the 2 studies using Wong-Baker's FACES scale, 1 study claimed to be effective at reducing pain, while the other appeared effective only when parents and child interacted with socially assistive robots together Distress was evaluated using validated measures in 4 studies, 3 of which showed reduction in distress while one showed no difference Satisfaction surveys from 4 studies showed that children were interested in using socially assistive robots again 	<ul style="list-style-type: none"> There is limited evidence suggesting that socially assistive robot interventions may reduce distress and no clear evidence showing reduction in pain for children in medical settings Engineers are conducting interventions using socially assistive robots in pediatric populations Health care providers should be engaged in technology research related to children to facilitate testing and improve the effectiveness of these systems

TABLE 1 (Continued)			
Source	Aim	Results	Conclusions
[32] Lopez-Rodriguez et al. (2020) New technologies to improve pain, anxiety and depression in children and adolescents with cancer: A systematic review	Analyze the available evidence and to describe the benefits of the new technologies in the treatment of pain, anxiety, and depression in children and adolescents with cancer	<ul style="list-style-type: none">• 5 studies were included• Robots were used in two studies, providing amusement and social interventions that showed significant improvements• Virtual reality, a mobile application, and a videogame were used in three studies and obtained beneficial results in pain and anxiety	<ul style="list-style-type: none">• New technologies can be used as an innovative form of non-pharmacological intervention with therapeutic benefits

TABLE 2
Overview of journal papers and conference proceedings on social robots studies with pediatric oncology patients

Journal publications				
Authors, year and title	Country	Journal of publication	Population	Type of social robot
[34] Meghdari, et al., 2018 Arash: A social robot buddy to support children with cancer in a hospital environment	Iran	Journal of Engineering in Medicine	5 to 12 year olds with cancer (n = 14)	Own design
[37] Jibb et al., 2018 Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial	Canada	Pediatric Blood & Cancer	4 to 9 year olds with cancer (n = 40)	NAO robot
				<ul style="list-style-type: none"> • Aim: Assess feasibility and preliminary effectiveness of an interactive robot to decrease pain and distress during needle insertion • Design: Pilot randomized controlled trial, cognitive-behavioral strategies vs. distraction • Conclusion: The MEDiPORT study appears feasible to implement as an adequately-powered effectiveness-assessing trial following modifications to the intervention and study protocol
[38] Alemi et al., 2016 Clinical application of a humanoid robot in pediatric cancer interventions	Iran	International Journal of Social Robotics	7 to 12 year olds with cancer (n = 11)	NAO robot
<ul style="list-style-type: none"> • Aim: Exploring the effect of utilizing a social humanoid robot as a therapy-assistive tool in dealing with pediatric distress • Design: Randomized controlled trial, social robot-assisted therapy vs. psychotherapy • Conclusion: Utilizing a humanoid robot with different communication abilities can be beneficial, both in elevation of efficacy in interventions, and fomenting kids to be more interactive and cooperative in their treatment sessions; humanoid robot was significantly useful in teaching children about their affliction and instructing them in techniques such as relaxation or desensitization in order to help them confront and manage their distress themselves and take control of their situation 				

TABLE 2
(Continued)

Conference proceedings				
Authors, year and title	Country	Conference	Population	Type of social robot
[33] Meghdari et al., 2016 Conceptual design of a social robot for pediatric hospitals	Iran	4 th International Conference on Robotics and Mechatronics (ICROM)	Children with cancer ($n = 50$)	Own design
				<ul style="list-style-type: none"> • Aim: Design a social robot to improve quality of life for children with cancer during treatment • Conclusion: This social robot is able to move around in various areas of the hospital and interact with children in order to answer their questions, to motivate, to entertain, to help relieve their physical sufferings and distress, and to enhance their cooperation with the clinical staff
[35] Jeong et al., 2017 Huggable: The impact of embodiment on promoting socio-emotional interactions for young pediatric inpatients	USA	26 th IEEE International Symposium on Robot and Human Interactive Communication (RO-MAN)	3 to 10 year olds, including oncology patients ($n = 54$)	Robot teddy bear
				<ul style="list-style-type: none"> • Aim: Investigate how three different companion-like interventions (plush toy, virtual character and social robot) affected child-patients physical activity and social engagement • Design: Randomized controlled trial • Conclusion: Children are most physically and verbally engaged when interacting with the social robot than the other two interventions
[36] Jeong et al., 2015 A social robot to mitigate stress, anxiety, and pain in hospital pediatric care	USA	10 th annual ACM/ IEEE International Conference on Human-Robot Interaction (HRI)	5 to 10 year olds, including oncology patients ($n = 4$)	Robot teddy bear
				<ul style="list-style-type: none"> • Aim: Compare effects of the Huggable robot to a virtual character on a screen and a plush teddy bear • Conclusion: Children are more eager to emotionally connect with and by physically activated by a robot than a virtual character (preliminary), illustrating the potential of social robots to provide socio-emotional support during inpatient pediatric care

PSYCHOSOCIAL IMPACT OF CHILDHOOD CANCER ON THE FAMILY

Not only children, but also their families experiences distress. The shock of a cancer diagnosis, and the burden of treatment and daily caretaking have an impact on family functioning [39-42]. Among the consequences is the loss of normality: Everyday routines change, family relationships are challenged, and social activities get hampered by the distress that comes along with the disease and its treatment [43]. Much of the cancer treatment is managed at home, which may prevent children and their families from obtaining supportive care services from medical and psychosocial staff members that are available at the hospital. Therefore, it is important to provide support to families at home as well to cope with distress and to safeguard their normal everyday family life.

INTERVENTIONS FOR PSYCHOSOCIAL SUPPORT AT HOME

The Pediatric Psychosocial Preventative Health Model (PPPHM) is a biopsychosocial framework that can be used in assessment and treatment of families of children in pediatric health care settings [44]. According to the PPPHM, all families that are affected by childhood cancer experience some level of distress, and should therefore have access to a certain level of support. This universal support should have a preventative goal and incorporate general interventions or services to assist families [44]. In the Netherlands, as mentioned earlier, various preventative sources of support are available at the hospital for families during treatment. However, there are limited general preventative interventions or services available to provide (all) family members with support at home.

Interactive tools

Most of the interventions that are available at the hospital, cannot be used at home. These interventions are usually highly specialized (i.e., specific facilities and technical support are needed) and too expensive to purchase for every family to take home. However, there have been interactive tools developed that can be used by families independently at home. These tools mostly emerged from the field of industrial product design where products are designed or developed for a specific group for a specific problem, called tactful design.

Interactive tools for the general population

When looking at research in the general population, some conference proceedings and book chapters can be found describing interactive tools for families at home. For example Ritual Machine V, a bespoke machine (telescope and totem device) for a family with parents who travel a lot for work to do playful location sharing with their child [45]; The Other Brother, a semi-autonomous device (helmet) that captures images and video of spontaneous moments in domestic environments that can be re-experienced as a new way of capturing and sharing life events [46]; and Family Circles a communication media for intra-family messaging for families with working parents and teenage children who are starting to find their own way in life, developing separate routines and social networks outside the family [47]. Table 3 shows more details on the studies that were carried out with these interactive tools.

Interventions for families at home with a sick child

The tactful designs as described before, unfortunately have not been translated to the health care context of families with a sick child. When searching more specifically for what is available for these families to be used at home, only one interventions can be found: The Cellie Coping Kit. The Cellie Coping Kit is a coping tool that is designed to support parents or other caregivers in helping their child and child's sibling(s) manage the medical experience [48,49]. It includes a plush "Cellie" toy, coping cards for children, and a book for caregivers to promote coping and decrease distress in children. Table 3 shows more details on the studies that were carried out with this interventions. The Cellie Coping Kit seems to be the only intervention that targets the whole family, and the only one that is not dependent on health care providers. Therefore, using tactful design could provide opportunities to create interactive interventions that support the whole family with self-management and coping with distress at home.

PROJECTS IN THIS THESIS

To complement currently available psychosocial interventions and to explore the opportunities of interactive technological tools in the support for children and their families during cancer treatment at the hospital and at home, two projects were initiated.

TABLE 3

Details of some examples of interactive (playful) interventions for families at home in the general population and pediatric patients

General population					
Source	Design	Purpose	Description	User studies/ participants	Conclusions
[45] Chatting et al., 2017 Ritual machine V: Where are you	Ritual Machine V	Playful location sharing	For children to remain connected to parents who are traveling abroad with a telescope machine for to explore an illustrated world in search of a flag, which is placed by parents on their travels using a companion totem device	Single family	<ul style="list-style-type: none">• Description of design process, tool, considerations and situation of the work in Research through Design practice and broader discourse
[46] Helmes et al., 2009 The other brother: Re-experiencing spontaneous moments from domestic life	The Other Brother	Re-experience moments in a playful way	Small knight's helmet that captures images and videos of spontaneous moments in the course of everyday life	Two user studies in respectively three and two families	<ul style="list-style-type: none">• It is not the quality of individual images or movie clips that necessarily matter to people, but the way in which these materials trigger the evocation of an atmosphere and a moment in time• People were surprised and delighted by the captures fragments and began to relate to The Other Brother in ways that were both unexpected and worthy of further exploration
[47] Schatorjé & Markopoulos, 2013 Intra-family messaging with family circles	Family Circles	Intra-family messaging	Portable voice messaging solution system to support transitory indirect messaging in the household for working parents and teenaged children with separate routines	Two families	<ul style="list-style-type: none">• Family Circles can give rise to expressive, informal communication and that storing and distributing spoken messages is an appealing notion for intra family communication

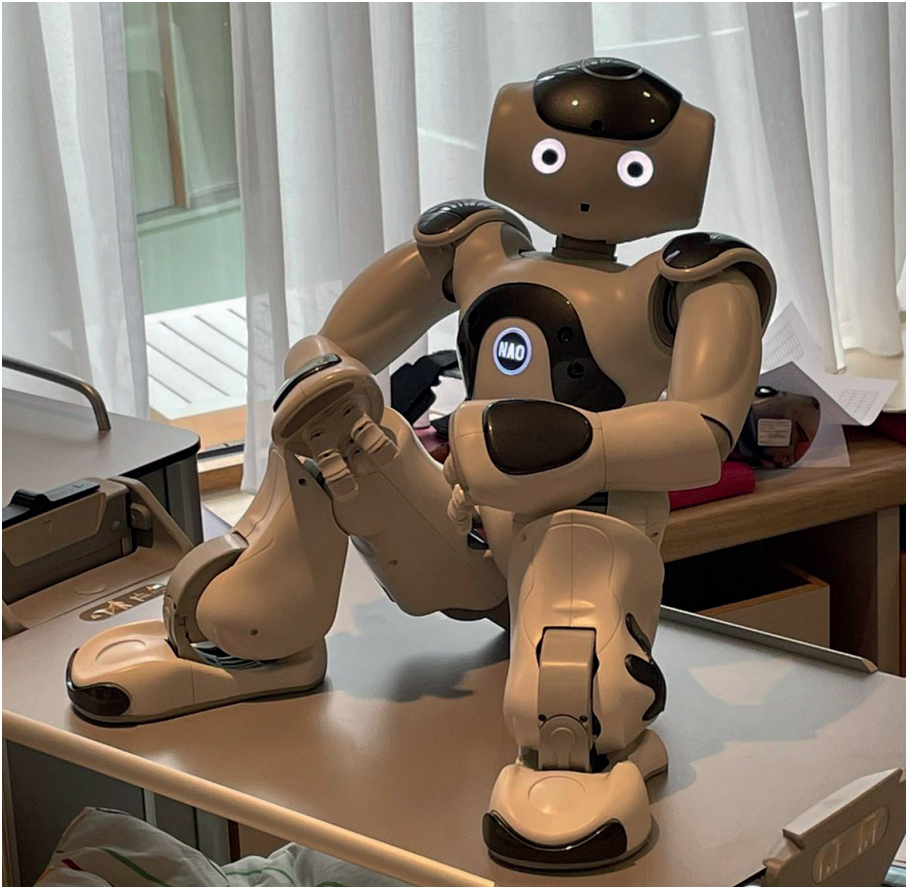
TABLE 3 (Continued)				
Pediatric patients				
Source	Design	Purpose	Description	User studies/ participants
[48] Marsac et al., 2012 Acceptability and feasibility of family use of the cellie cancer coping kit	Cellie Cancer Coping Kit	Promote coping and decrease distress	Plush toy, coping cards, and a book for caregivers	Two studies in 15 children (6-12 years old) undergoing cancer treatment and their parents
[49] Marsac et al., 2014 The cellie coping kit for sickle cell disease: Initial acceptability and feasibility	Cellie Coping Kit	Education on adaptive coping	Stuffed “Cellie” toy, coping cards for children, and a book for caregivers (adapted from Cellie Cancer Coping Kit)	15 children with Sickle Cell Disease (6-14 years old) and their caregivers
				<ul style="list-style-type: none">• The Cellie Cancer Coping Kit is an engaging, helpful, and easy-to-use coping tool for families facing pediatric cancer treatment• Results are promising as families engage with the kit and learn new strategies when using the Cellie Coping Kit• Promising tool to support children with Sickle Cell Disease and their families

Project 1: A social robot for children at the hospital (Hero)

As described before, social robots are being developed and tested more and more in the context of pediatric health care, yet limited in pediatric oncology care. Therefore, we examined the introduction of a social robot into pediatric oncology care. The social robot hardware that was used for this project is the NAO⁶ robot (Figure 1). The NAO robot is one of the most used social robots worldwide. The robot is 57 centimeters long and fully programmable. The robot has human features in appearance (i.e., it is a humanoid robot), and any of its parts, including its head, arms, legs, and fingers, can move. The NAO robot was developed by Aldebaran robotics, which is now part of SoftBank Robotics ©.

FIGURE 1

Picture of the NAO robot at the hospital sitting on the nightstand of a child



The NAO robot has built-in software support for various basic tasks, including speaking simple sentences and making movements. However, more advanced features were necessary to successfully deploy the robot for use in pediatric oncology. Therefore, this project was a collaboration between the Emma Children's Hospital at the Amsterdam University Medical Centers (Amsterdam UMC) and later the Princess Máxima Center for pediatric oncology, the Centrum Wiskunde & Informatica (CWI), Delft University of Technology (TU Delft), and the Vrije Universiteit Amsterdam (VU Amsterdam). Also, Cancer Health Coach, ASolutions B.V., Vereniging Kinderkanker Nederland, and Wintertuin were companies and organizations that contributed to the project. This collaboration allowed us to use an advanced social robot that could behave autonomously in a socially intelligent way. This means that the robot was able to have a conversation with children without the help of a human controlling the robot via a laptop, and attuned (i.e., personalized) to the response of the child whereby also using earlier answers of the child (i.e., it had a memory).

The project started in October 2017 and was originally planned to be carried out at the Emma Children's Hospital of the Amsterdam UMC. However, with the centralization of pediatric oncology care in the Netherlands to the Princess Máxima Center for pediatric oncology, the project moved to Utrecht in May 2018. Here, the robot was named Hero, a name that was chosen by the children at the Princess Máxima Center via an open-question voting. The main aim of the project was to investigate whether a social robot could contribute to the reduction of PMTS in children with cancer during treatment as well as for educational purposes.

Project 2: Interactive tools for families at home (AscoltaMe and Mr.V)

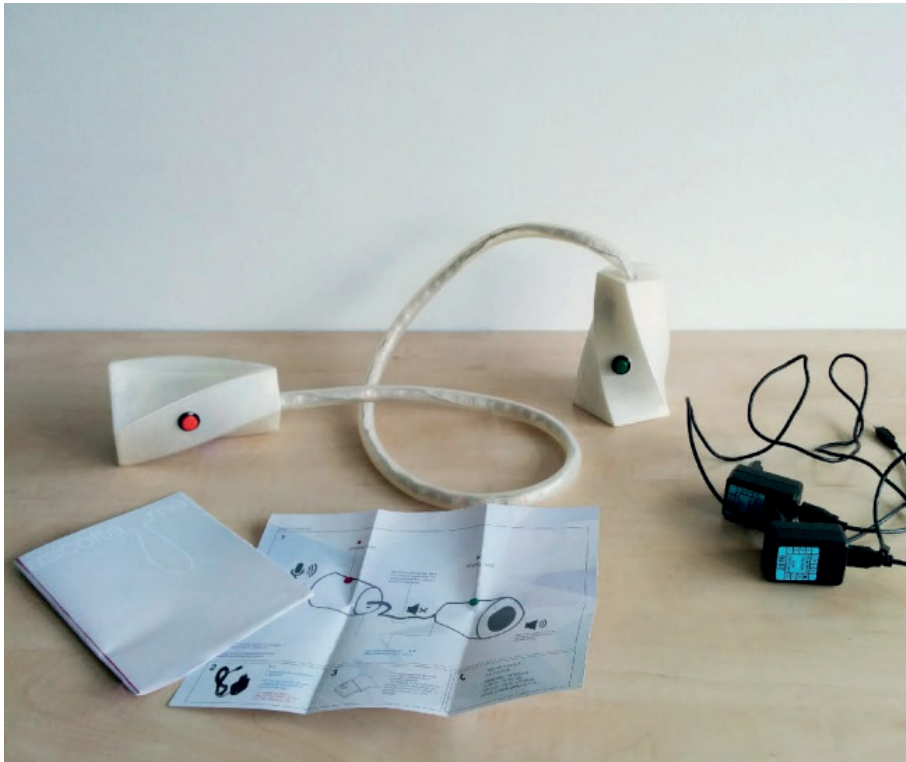
We examined the introduction of two interactive tools for families with a child with cancer into the home context. As described before, we only found limited coping tools available for psychosocial supportive care for families at home during childhood cancer treatment. Therefore, two completely new and innovative tools were developed to contribute to this gap. The tools were developed from scratch with substantive input from health care providers from the Princess Máxima Center in another collaboration with TU Delft as part of the *Meedoen=Groeien!?* project.

The first tool was aimed at enhancing communication in the family. The tool was called AscoltaMe (Italian for 'listen to me') and was designed based on the tin-can-telephone game (Figure 2). The tool consisted of a microphone and a speaker that were

connected via a flexible silicon tube. The microphone captured voice messages from family members. The message lingered in the tube, and was presented by a pulsating light in the middle of the tube to indicate there was a message waiting for someone to listen to. When someone pressed the button to listen to the message, the light moved from the middle of the tube to the speaker while the message was played. If the message was not completely released, the light (i.e., message) returned back into the tube and remained there until fully listened to. The tool was intended to be used casually and to be left around the house to encourage families under stressful circumstances to stay connected with each other and to motivate them to keep communicating.

FIGURE 2

Picture of AscoltaMe and its accessories



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The second tool was aimed at enhancing family functioning. The tool was called Mr.V (short from *Verrassing*, Dutch for 'surprise') and was designed based on a gumball

vending machine (Figure 3). The tool consisted of a large transparent head filled with little balls including notes. These notes were personally written by family members, enabling families to decide themselves what content was appropriate and suitable for them. Families were advised to suggest small activities they could do together as a family, to share a memory, or to make jokes or give compliments to another family member. Mr.V comprised an internal clock with which it randomly decided when to drop surprises for families throughout the week. When dropping a surprise, Mr.V shuffled the balls and made a sound to invite families to come check for it. A small button on the back of Mr.V offered the possibility of dropping a surprise on demand. The tool was intended to be placed in a common area of the house and to include all family members to stimulate them to do more things together and to continue normal, everyday family life. In a later stage of the project, Mr.V was further developed and redesigned into Mr.V the Spaceman (Figure 4).

FIGURE 3

Picture of Mr.V and its accessories



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FIGURE 4
Picture of Mr.V the Spaceman



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GENERAL AIM

The general objective of this thesis was to develop and investigate the introduction of innovative and interactive interventions into pediatric oncology care to support children with cancer and their families during treatment, both at the hospital and at home. More specifically, our research questions were: (1) Is it feasible to introduce innovative technology-based interventions for psychosocial support in pediatric oncology in- and outpatient care and at home? (2) How do children, their families and health care providers experience these innovative technology-based interventions for psychosocial support during cancer treatment? (3) Is there preliminary evidence that these innovative technology-based interventions can reduce stress or be supportive (effective) during cancer treatment?

RESEARCH METHODS

The interventions were developed in close collaboration with the respective partners, with substantial input from children, their parents and health care providers, as well as based on literature in related domains from the fields of human-robot interaction and product design for families. The required software for the social robot was established,

and the interactive tools for families at home were designed and prototypes (hardware and software) were made. The interventions were all pilot-tested either in children from the general population at schools or by families with a child with cancer. Feasibility data was collected by researchers at the hospital using logbooks and observations, and at home by the interactive tools themselves on how they were used and how they performed (i.e., machine data). Using multiple methods (both quantitative and qualitative), the experiences of families and opinions of health care providers were analyzed by diaries, pictures and videos, questionnaires and interviews. The measures were mostly developed by us because of a lack of validated measures in this area of research. In total, five prospective clinical studies were carried out.

OUTLINE OF THIS THESIS

This thesis contains two parts, describing the two projects that were carried out to answer our research questions and fulfill our objectives.

Part I – Psychosocial support for children at the hospital: Exploration and investigation of a social robot in pediatric oncology care

Chapter 2 starts with describing the opinions of almost three hundred health care providers working in pediatric oncology care around the world regarding social robots, and examining differences in their opinions based on their background characteristics.

Chapter 3 describes our first experiences with introducing a social robot in pediatric oncology care as a buddy for children during treatment. Twenty children interacted with Hero multiple times during hospitalization and received support from Hero during a medical procedure. Feasibility, experiences of children and parents with the social robot, and preliminary effectiveness were investigated. **Chapter 4** describes our first experience with introducing a social robot at the pediatric oncology outpatient clinic for sleep education. Twenty-eight families participated in this study, and practical implementation, experiences of families and preliminary effects were evaluated.

Part II – Psychosocial support for families at home: Development and investigation of two interactive tools

Chapter 5 starts with describing the designing and development of AscoltaMe and Mr.V as tactful objects. Eight families with a child receiving cancer treatment tried one of the two tools at home, and the experiences of families with these interactive tools in

their homes were evaluated. **Chapter 6** describes how Mr.V was further developed and redesigned into Mr.V the Spaceman based on the results from the previous chapter. Mr.V the Spaceman was pilot-tested in ten families with a child with cancer in the home context to investigate how it was used, how families evaluated the tool, and how it could be further improved.

Chapter 7 concludes with a general discussion, including the main findings of this thesis, reflections on these main findings, project reflections, methodological considerations, clinical implications and future directions, and overall conclusions.

REFERENCES

1. Kaspers, G.J.L.; Benoit, Y.; Pieters, R. Inleiding in de kinderoncologie. In *Leerboek kinderoncologie*, Kaspers, G.J.L., Dors, N., Luijpers, W., Benoit, Y., Eds.; De Tijdstroom: Utrecht, the Netherlands, **2019**.
2. Schulpen, M.; Visser, O.; Reedijk, A.M.J.; Kremer, L.C.M.; Zwaan, C.M.; Eggermont, A.M.M.; Coebergh, J.W.; Pieters, R.; Karim-Kos, H.E. Significant improvement in survival of advanced stage childhood and young adolescent cancer in the Netherlands since the 1990s. *European Journal of Cancer* **2021**, *157*, 81-93, <http://doi.org/10.1016/j.ejca.2021.08.001>.
3. Price, J.; Kassam-Adams, N.; Alderfer, M.A.; Christofferson, J.; Kazak, A.E. Systematic review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2016**, *41*, 86-97, <http://doi.org/10.1093/jpepsy/jsv074>.
4. Kazak, A.E.; Kassam-Adams, N.; Schneider, S.; Zelikovsky, N.; Alderfer, M.A.; Rourke, M. An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2006**, *31*, 343-355, <http://doi.org/10.1093/jpepsy/jsj054>.
5. Network, N.C.T.S. Definition of medical traumatic stress. *Paper presented at the Medical Traumatic Stress Working Group meeting* **2003**.
6. Lazarus, R.S.; Folkman, S. *Stress, appraisal, and coping*; Springer publishing company: **1984**.
7. Last, B.F.; Grootenhuis, M.A. Emotions, coping and the need for support in families of children with cancer: a model for psychosocial care. *Patient Education and Counseling* **1998**, *33*, 169-179, [http://doi.org/10.1016/s0738-3991\(97\)00077-3](http://doi.org/10.1016/s0738-3991(97)00077-3).
8. Flowers, S.R.; Birnie, K.A. Procedural preparation and support as a standard of care in pediatric oncology. *Pediatr Blood & Cancer* **2015**, *62*, S694-S723, <http://doi.org/10.1002/pbc.25813>.
9. Huisman, J.; De Ridder-Sluite, J.G. Ontwikkelingsgerichte zorg. In *Leerboek kinderoncologie*, Kaspers, G.J.L., Dors, N., Luijpers, W., Benoit, Y., Eds.; De Tijdstroom: Utrecht, the Netherlands, **2019**; pp. 153-162.
10. Schepers, S.A.; Sint Nicolaas, S.M.; Haverman, L.; Wensing, M.; Schouten van Meeteren, A.Y.N.; Veening, M.A.; Caron, H.N.; Hoogerbrugge, P.M.; Kaspers, G.J.L.; Verhaak, C.M.; et al. Real-world implementation of electronic patient-reported outcomes in outpatient pediatric cancer care. *Psycho-Oncology* **2017**, *26*, 951-959, <http://doi.org/10.1002/pon.4242>.
11. Haverman, L.; Van Oers, H.A.; Limperg, P.F.; Hijmans, C.T.; Schepers, S.A.; Sint Nicolaas, S.M.; Verhaak, C.M.; Bouts, A.H.; Fijnvandraat, K.; Peters, M. Implementation of electronic patient reported outcomes in pediatric daily clinical practice: The KLIK experience. *Clinical Practice in Pediatric Psychology* **2014**, *2*, 50-67, <http://doi.org/10.1037/cpp0000043>.
12. Haverman, L.; Engelen, V.; Van Rossum, M.A.; Heymans, H.S.; Grootenhuis, M.A. Monitoring health-related quality of life in paediatric practice: Development of an innovative web-based application. *BMC Pediatrics* **2011**, *11*, 1-7, <http://doi.org/10.1186/1471-2431-11-3>.

13. Eijlers, R.; Utens, E.; Staals, L.M.; De Nijs, P.F.A.; Berghmans, J.M.; Wijnen, R.M.H.; Hillegers, M.H.J.; Dierckx, B.; Legerstee, J.S. Systematic review and meta-analysis of virtual reality in pediatrics: Effects on pain and anxiety. *Anesthesia & Analgesia* **2019**, *129*, 1344-1353, <http://doi.org/10.1213/ANE.0000000000004165>.
14. Weekly, T.; Walker, N.; Beck, J.; Akers, S.; Weaver, M. A review of apps for calming, relaxation, and mindfulness interventions for pediatric palliative care patients. *Children* **2018**, *5*, 16, <http://doi.org/10.3390/children5020016>.
15. Sardi, L.; Idri, A.; Fernandez-Aleman, J.L. A systematic review of gamification in e-health. *Journal of Biomedical Informatics* **2017**, *71*, 31-48, <http://doi.org/10.1016/j.jbi.2017.05.011>.
16. Weibel, M.; Nielsen, M.K.F.; Topperzer, M.K.; Hammer, N.M.; Moller, S.W.; Schmiegelow, K.; Baekgaard Larsen, H. Back to school with telepresence robot technology: A qualitative pilot study about how telepresence robots help school-aged children and adolescents with cancer to remain socially and academically connected with their school classes during treatment. *Nursing Open* **2020**, *7*, 988-997, <http://doi.org/10.1002/nop2.471>.
17. Breazeal, C. Social robots for health applications. In Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC), Boston, MA, USA, **2011**; pp. 5368-5371.
18. Oborn, E.; Barrett, M.; Darzi, A. Robots and service innovation in health care. *Journal of Health Services Research & Policy* **2011**, *16*, 46-50, <http://doi.org/10.1258/jhsrp.2010.010001>.
19. Logan, D.E.; Breazeal, C.; Goodwin, M.S.; Jeong, S.; O'Connell, B.; Smith-Freedman, D.; Heathers, J.; Weinstock, P. Social robots for hospitalized children. *Pediatrics* **2019**, *144*, e20181511, <http://doi.org/10.1542/peds.2018-1511>.
20. Nijhof, S.L.; Vinkers, C.H.; Van Geelen, S.M.; Duijff, S.N.; Achterberg, E.J.M.; Van der Net, J.; Veltkamp, R.C.; Grootenhuis, M.A.; Van de Putte, E.M.; Hillegers, M.H.J.; et al. Healthy play, better coping: The importance of play for the development of children in health and disease. *Neuroscience & Biobehavioral Reviews* **2018**, *95*, 421-429, <http://doi.org/10.1016/j.neubiorev.2018.09.024>.
21. Lee, K.M.; Park, N.; Song, H. Can a robot be perceived as a developing creature? Effects of a robot's long-term cognitive developments on its social presence and people's social responses toward it. *Human Communication Research* **2005**, *31*, 538-563, <http://doi.org/10.1111/j.1468-2958.2005.tb00882.x>.
22. Kuo, A.A.; Etzel, R.A.; Chilton, L.A.; Watson, C.; Gorski, P.A. Primary care pediatrics and public health: Meeting the needs of today's children. *American Journal of Public Health* **2012**, *102*, e17-e23, <http://doi.org/10.2105/AJPH.2012.301013>.
23. Kahn, P.H.; Gary, H.E.; Shen, S. Children's social relationships with current and near-future robots. *Child Development Perspectives* **2013**, *7*, 32-37, <http://doi.org/10.1111/cdep.12011>.
24. Van Straten, C.L.; Peter, J.; Kühne, R. Child-robot relationship formation: A narrative review of empirical research. *International Journal of Social Robotics* **2020**, *12*, 325-344, <http://doi.org/10.1007/s12369-019-00569-0>.
25. Neerinx, M.A.; Van Vught, W.; Blanson Henkemans, O.; Oleari, E.; Broekens, J.; Peters, R.; Kaptein, F.; Demiris, Y.; Kiefer, B.; Fumagalli, D.; et al. Socio-cognitive engineering of a robotic partner for child's diabetes self-management. *Frontiers in Robotics and AI* **2019**, *6*, 118, <http://doi.org/10.3389/frobt.2019.00118>.

26. Smakman, M.; Vogt, P.; Konijn, E.A. Moral considerations on social robots in education: A multi-stakeholder perspective. *Computers & Education* **2021**, *174*, 104317, <http://doi.org/10.1016/j.compedu.2021.104317>.
27. Fridin, M.; Belokopytov, M. Embodied robot versus virtual agent: Involvement of preschool children in motor task performance. *International Journal of Human-Computer Interaction* **2014**, *30*, 459-469, <http://doi.org/10.1080/10447318.2014.888500>.
28. Belpaeme, T.; Kennedy, J.; Ramachandran, A.; Scassellati, B.; Tanaka, F. Social robots for education: A review. *Science Robotics* **2018**, *3*, eaat5954, <http://doi.org/10.1126/scirobotics.aat5954>.
29. Moerman, C.J.; Van der Heide, L.; Heerink, M. Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review. *Journal of Child Health Care* **2019**, *23*, 596-612, <http://doi.org/10.1177/1367493518803031>.
30. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.
31. Trost, M.J.; Ford, A.R.; Kysh, L.; Gold, J.I.; Matarić, M. Socially assistive robots for helping pediatric distress and pain: A review of current evidence and recommendations for future research and practice. *The Clinical Journal of Pain* **2019**, *35*, 451-458, <http://doi.org/10.1097/Ajp.0000000000000688>.
32. Lopez-Rodriguez, M.M.; Fernandez-Millan, A.; Ruiz-Fernandez, M.D.; Dobarrio-Sanz, I.; Fernandez-Medina, I.M. New technologies to improve pain, anxiety and depression in children and adolescents with cancer: A systematic review. *International Journal of Environmental Research and Public Health* **2020**, *17*, 3563, <http://doi.org/10.3390/ijerph17103563>.
33. Meghdari, A.; Alemi, M.; Khamooshi, M.; Amoozandeh, A.; Shariati, A.; Mozafari, B. Conceptual design of a social robot for pediatric hospitals. In Proceedings of the 4th International Conference on Robotics and Mechatronics (ICRoM), Tehran, Iran, **2016**; pp. 566-571.
34. Meghdari, A.; Shariati, A.; Alemi, M.; Vossoughi, G.R.; Eydi, A.; Ahmadi, E.; Mozafari, B.; Amoozandeh Nobaveh, A.; Tahami, R. Arash: A social robot buddy to support children with cancer in a hospital environment. *Proceedings of the Institution of Mechanical Engineers*, **2018**, *232*, 605-618, <http://doi.org/10.1177/0954411918777520>.
35. Jeong, S.; Breazeal, C.; Logan, D.; Weinstock, P. Huggable: Impact of embodiment on promoting verbal and physical engagement for young pediatric inpatients. In Proceedings of the 26th IEEE International Symposium on Robot and Human Interactive Communication (RO-MAN), Lisbon, Portugal, **2017**; pp. 121-126.
36. Jeong, S.; Logan, D.; Goodwin, M.; Graca, S.; O'Connell, B.; Goodenough, H.; Anderson, L.; Stenquist, N.; Fitzpatrick, K.; Zisook, M.; et al. A social robot to mitigate stress, anxiety, and pain in hospital pediatric care. In Proceedings of the 10th Annual ACM/IEEE International Conference on Human-Robot Interaction (HRI), Portland, OR, USA, **2015**; pp. 103-104.
37. Jibb, L.A.; Birnie, K.A.; Nathan, P.C.; Beran, T.N.; Hum, V.; Victor, J.C.; Stinson, J.N. Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial. *Pediatric Blood & Cancer* **2018**, *65*, e27242, <http://doi.org/10.1002/pbc.27242>.

38. Alemi, M.; Ghanbarzadeh, A.; Meghdari, A.; Moghadam, L.J. Clinical application of a humanoid robot in pediatric cancer interventions. *International Journal of Social Robotics* **2016**, *8*, 743-759, <http://doi.org/10.1007/s12369-016-0382-7>.
39. Long, K.A.; Marsland, A.L. Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Review* **2011**, *14*, 57-88, <http://doi.org/10.1007/s10567-010-0082-z>.
40. Pai, A.L.; Greenley, R.N.; Lewandowski, A.; Drotar, D.; Youngstrom, E.; Peterson, C.C. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology* **2007**, *21*, 407-415, <http://doi.org/10.1037/0893-3200.21.3.407>.
41. Van Schoors, M.; Caes, L.; Verhofstadt, L.L.; Goubert, L.; Alderfer, M.A. Systematic review: Family resilience after pediatric cancer diagnosis. *Journal of Pediatric Psychology* **2015**, *40*, 856-868, <http://doi.org/10.1093/jpepsy/jsv055>.
42. Alderfer, M.A.; Long, K.A.; Lown, E.A.; Marsland, A.L.; Ostrowski, N.L.; Hock, J.M.; Ewing, L.J. Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology* **2010**, *19*, 789-805, <http://doi.org/10.1002/pon.1638>.
43. Patterson, J.M.; Holm, K.E.; Gurney, J.G. The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology* **2004**, *13*, 390-407, <http://doi.org/10.1002/pon.761>.
44. Kazak, A.E. Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health* **2006**, *24*, 381-395, <http://doi.org/10.1037/1091-7527.24.4.381>.
45. Chatting, D.; Yurman, P.; Green, D.P.; Bichard, J.-A.; Kirk, D.S. Ritual machine V: Where are you. In Proceedings of the 3rd Conference on Biennial Research Through Design, London, UK, **2017**; pp. 131-147.
46. Helmes, J.; Hummels, C.; Seilen, A. The other brother: Re-experiencing spontaneous moments from domestic life. In Proceedings of the 3rd International Conference on Tangible and Embedded Interaction (TEI), Cambridge, UK, **2009**; pp. 233-240.
47. Schatorjé, R.; Markopoulos, P. Intra-family messaging with Family Circles. In *Connecting families: The impact of new communication technologies on domestic life*, Neustaedter, C., Harrison, S., Sellen, A., Eds.; Springer: Berlin, Germany, **2013**; pp. 57-74.
48. Marsac, M.L.; Hildenbrand, A.K.; Clawson, K.; Jackson, L.; Kohser, K.; Barakat, L.; Kassam-Adams, N.; Aplenc, R.; Vinsel, A.; Alderfer, M.A. Acceptability and feasibility of family use of The Cellie Cancer Coping Kit. *Supportive Care in Cancer* **2012**, *20*, 3315-3324, <http://doi.org/10.1007/s00520-012-1475-y>.
49. Marsac, M.L.; Klingbeil, O.G.; Hildenbrand, A.K.; Alderfer, M.A.; Kassam-Adams, N.; Smith-Whitley, K.; Barakat, L.P. The Cellie Coping Kit for sickle cell disease: Initial acceptability and feasibility. *Clinical Practice in Pediatric Psychology* **2014**, *4*, 389-399, <http://doi.org/10.1037/cpp0000062>.

I

Psychosocial support for children at the hospital: Exploration and investigation of a social robot in pediatric oncology care

Social robots in pediatric oncology: Opinions of health care providers

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ABSTRACT

Background

We aimed to describe the opinions of health care providers in pediatric oncology regarding social robots and to examine differences in their opinions based on their background characteristics.

Methods

Health care providers working in pediatric oncology care were approached globally to participate online in a cross-sectional questionnaire study with multiple choice and open-ended questions. Open-ended questions were coded and collapsed into categories by two researchers independently. Frequencies were used to describe the answers. Differences in opinions were studied using logistic regression analyses.

Results

Health care providers' ($n = 286$) first thoughts about social robots were mostly positive (81.0%). They saw value in social robots (83.6%), mostly during hospitalization or procedures and when used for distraction. They were willing to use one (67.8%), but also expected difficulties (67.1%), mainly concerning technical errors. Psychosocial staff members less often saw value in social robots, more often expected difficulties and were less willing to use a social robot than other health care providers ($ps < 0.05$). No other differences were found.

Conclusions

Social robots may be a promising addition to pediatric oncology care, since health care providers were generally positive about this innovation. However, psychosocial staff members seemed more reluctant. Important potential barriers were defined that should be addressed upon implementation.

INTRODUCTION

Social robots are increasingly being developed, used and evaluated in healthcare for children [1,2]. Social robots can be defined as “new types of robots whose primary goal is social interaction with humans” [3]. In other words, robots designed to have meaningful social interactions. Social robots could be a new and appropriate form to meet the unique care needs of children [4], and children seem to be able to form relationships with social robots, and consider them to be a buddy or friend [5,6].

In the past years, social robots have been applied in various ways. Four reviews have been published recently, providing an overview of how social robots have been applied in pediatric healthcare [7-10]. These reviews show the different kinds of social robots that exist (e.g., robot pets vs. humanoid robots, interactive vs. non-interactive robots) and the various ways in which these robots have been applied in healthcare (e.g., for support, as distraction). Overall, these reviews conclude that social robots hold significant promise and potential to help children in healthcare context [8], and seem to positively influence a child's well-being [7], and reduce stress [10]. Thus, it may change the experience of potentially traumatic medical procedures, and prevent medical traumatic stress [11]. Opinions of health care providers about this new development are unknown. Only the experiences of seven child life specialists from a children's hospital in Canada have been described showing how they incorporate a social robot into their practice [12].

When looking more specifically at social robots in pediatric oncology, research is much more limited. The few studies that exist, found potential for the use of a social robot as a companion [13,14], reported on the feasibility and preliminary effectiveness to reduce pain and distress during subcutaneous port access [15], and on the effectiveness as a psychotherapy assistant to reduce anger, anxiety and depression [16,17]. From these studies, it can be concluded that children generally show positive reactions to social robots, yet they are at an emergent stage in pediatric oncology.

Since social robots seem to have positive effects on children, there may be a future for social robots in care for pediatric oncology patients. To allow future adequate implementation, it is important to examine how health care providers feel about social robots, as they are the ones who will be introducing them to children, and their daily work will be affected by this. Therefore, we aimed to: (1) Describe the opinions of health care providers in pediatric oncology regarding social robots, and (2) examine

differences in their opinions according to their background characteristics and experience with social robots.

MATERIALS AND METHODS

Participants, design and procedure

Health care providers working in pediatric oncology care were approached to participate in an online global cross-sectional questionnaire study between October 2019 and February 2020. Participation in the study was voluntarily, and the study was classified as exempt of the Medical Research Involving Human Subjects Act by the institutional medical ethics review board (number W18_051 # 18.069). Inclusion criteria were: (1) Being a health care provider currently working in clinical pediatric oncology care, (2) working with children between 4-12 years, and (3) understanding the English language well enough to complete an online questionnaire in English.

Health care providers were recruited globally in three different ways. First, they were approached during the 51st congress of the International Society of Pediatric Oncology (SIOP) in Lyon, France. Flyers were handed out, professional network connections were asked, and a call was made to participate at the end of talks. Second, health care providers were invited via e-mail through the members lists of several major pediatric oncology societies, such as the SIOP and the Pediatric Psychosocial Oncology Professionals International (POPPI) mail list, including members of the SIOP, the American Psychosocial Oncology Society (APOS) and the International Psycho-Oncology Society (IPOS). Third, we personally asked several (international) colleagues to distribute the questionnaire in their hospital and/or network. If possible, reminders were sent once or twice within 6-8 weeks.

Measures

We developed a questionnaire to gain insight into the perceptions and preferences of health care providers about the purpose and use of social robots in the pediatric oncology setting. The questionnaire was designed based upon interviews with pediatric oncology patients, parents, and health care providers (i.e., pediatric oncologists, child life specialists, psychologists, and nurses) at the Princess Máxima Center for pediatric oncology and Emma Children's Hospital of the Amsterdam UMC. Next, the questionnaire was evaluated for face validity by the psychosocial research group of the Princess Máxima Center for pediatric oncology during three different sessions, and

was revised each time accordingly. The final questionnaire was pilot-tested by ± 15 clinical researchers (who did not participate in the study) and took 5-10 minutes to complete.

The final questionnaire consisted of 20 questions, preceded by a definition and examples of social robots (see Appendix 1) and was divided into four parts: (1) Socio-demographic and clinical background information and current experience with social robots (8 items), (2) first idea about social robots (1 open-answer item), (3) possible value and purpose of social robots (8 items), and (4) possible barriers and willingness to use social robots (3 items). Most answers could be given on a 4-point Likert scale (1 'no value' or 'no difficulties' to 4 'great value' or 'great difficulties') or via 'yes, no, maybe' options. Seven questions had the additional option 'other, namely...'. Five questions asked for an elaboration of the respondent when they chose the answer 'maybe, if...' or 'no, because...'. The questionnaire was carried out in a separate section of the online portal for care and research at the Princess Máxima Center for pediatric oncology, the KLIK Patient Reported Outcome Measure (PROM) portal (www.hetklik.nl) [18]. The questionnaire could be completed anonymously and the researchers had no access to any identifying information of the respondents.

Data analyses

Data was extracted from the PROM portal including only a participant number, and was analyzed in IBM SPSS Statistics, version 25. For the one open-answer question, and the five elaborative answers, a thematic approach was used [19]. With this approach, the topic of each open-answer was identified and given a code, which were collapsed into categories. Open answers to the question on first ideas were additionally classified as positive, neutral or negative. For the seven questions with the answering option 'Other, namely...', answers were coded and collapsed in additional answering categories and added to the original answering options. Two researchers (K.v.B. and M.v.G.) who are not health care providers themselves and trained in qualitative analyses (K.v.B.) independently collapsed the answers into categories, discussed their differences and reached consensus. Answers containing personal information of the participant or unrelated to the question were removed. Descriptive statistics (frequencies and percentages) were used to describe all data.

Multivariable binary logistic regression analyses ($p < 0.05$) were used to analyze differences in opinions of health care providers regarding the value they see in social

robots (dichotomized as no-limited-average vs. much-extreme), the difficulties they expect (no-limited vs. average-much-extreme), and their willingness to use a social robot (no-maybe vs. yes) based on their background characteristics and current experience with social robots. All characteristics were included in the three models to correct the relation of each characteristic for the other characteristics, since these may be related (e.g., many nurses are female and relatively young). This was done after evaluating the appropriateness of the sample size, for which we used the rule of thumb of ten cases per predictor [20]. For the purpose of these analyses, primary profession was classified into medical staff (including pediatricians, pediatric oncologists/hematologists, pediatric surgeons, radiation oncologists, radiologists and pediatric neurologists), nurses (including nurses and nurse practitioners), and psychosocial staff (including child life specialists, psychologists, social workers and physical therapists). Country of practice was classified into The Netherlands, Europe (without the Netherlands), North-America, and Other. However, this background characteristic was not interpreted for differences in the three outcomes due to the dispersion of the data (i.e., overrepresentation of the Netherlands and many countries being categorized as other).

RESULTS

Three hundred fourteen health care providers gave informed consent and completed the questionnaire. Twenty-eight health care providers did not meet all inclusion criteria and were excluded, including 286 health care providers in the study.

Background characteristics and current experience with social robots

Most health care providers were female, between 31-50 years old, and were early (38.8%) or mid-career (38.6%). The most common professions were nurse (36.7%), psychologist (21.7%) and pediatric oncologist/hematologist (11.9%). Health care providers worked in 36 different countries. Most of them worked in the Netherlands (51.4%), followed by the United States of America (11.5%), and Canada (6.3%). Other countries of practice were mainly other European countries (22.7%). Almost half of the health care providers had heard of social robots being used in pediatric hospitals, about a quarter was aware of a social robot being used in the pediatric hospital where they work, and about one in ten health care providers had worked with social robots themselves. More details and information about the background characteristics of the health care providers and their current experience with social robots can be found in Table 1.

TABLE 1

Background characteristics and current experience with social robots of the health care providers in pediatric oncology (n = 286)

	n	%
Gender		
Male	49	17.1
Female	237	82.9
Age		
<30 years	68	23.8
31-50 years	140	49.0
>51 years	78	27.3
Primary profession		
Medical staff	69	24.1
<i>Pediatricians (n=11), pediatric oncologists/hematologists (n=34), pediatric (neuro)surgeons (n=4), (pediatric) radiation oncologists (n=13), pediatric radiologists (n=1), pediatric neurologists (n=2), medical doctor or pediatric resident (n=3), physician assistant (n=1)</i>		
Nurses	106	37.1
<i>Nurses (n=105), nursing assistant (n=1)</i>		
Psychosocial staff	111	38.8
<i>Child life specialists (n=21), (neuro) psychologists (n=62), social Workers (n=17), (pediatric) physical therapists (n=4), pediatric psychiatrists (n=3), clinical counsellor (n=1), music therapist (n=1), psychosocial counselor (n=1), (neuro) linguist (n=1)</i>		
Work experience		
Early career		
<1 year	21	7.3
1-5 years	90	31.5
Mid-career		
6-10 years	46	16.1
10-20 years	64	22.4
Late career		
>21 years	65	22.7
Country of practice		
The Netherlands	147	51.4
Europe	65	22.7
<i>Austria (n=3), Belgium (n=14), Bulgaria (n=1), Czech Republic (n=2), Denmark (n=2), Finland (n=1), France (n=1), Germany (n=3), Greece (n=2), Ireland (n=1), Italy (n=5), Lithuania (n=1), Norway (n=1), Poland (n=2), Portugal (n=1), Serbia (n=1), Slovenia (n=2), Spain (n=6), Sweden (n=7), Switzerland (n=1), United Kingdom (n=8)</i>		
North-America	51	17.8
<i>United States of America (n=33), Canada (n=18)</i>		
Other	23	8.0
<i>Argentina (n=1), Australia (n=8), Brazil (n=1), China (n=1), Ghana (n=1), India (n=2), Iran (n=1), Japan (n=2), Jordan (n=1), New Zealand (n=2), Russia (n=2), Uganda (n=1)</i>		
Experience with social robots		
Heard of social robots being used in pediatric hospitals (yes)	130	45.5
Knows social robots in the pediatric hospital where they work (yes)	68	23.8
Have worked with social robots themselves (yes)	34	11.9

TABLE 2
Differences in opinions of health care providers ($n = 286$) regarding the possible value of social robots, expected difficulties when working with a social robot and willingness to work with a social robot

	Value (%)			Difficulties (%)			Willingness (%)		
	OR	CI	<i>p</i>	OR	CI	<i>p</i>	OR	CI	<i>p</i>
Gender									
Female vs Male	1.74	0.88 - 3.45	.113	0.39	0.17 - 0.86	.020	1.74	0.84 - 3.60	.136
Age									
31-50 years vs <30 years	0.86	0.42 - 1.75	.667	1.79	0.80 - 4.01	.156	0.57	0.26 - 1.26	.167
>51 years vs <30 years	0.55	0.22 - 1.35	.191	0.87	0.33 - 2.29	.783	0.67	0.25 - 1.83	.435
Primary profession									
Nurses vs Medical staff	1.05	0.52 - 2.12	.890	0.98	0.47 - 2.07	.961	0.78	0.34 - 1.78	.548
Psychosocial staff vs Medical staff	0.51	0.25 - 1.03	.062	2.61	1.19 - 5.75	.017	0.22	0.10 - 0.49	.000
Psychosocial staff vs Nurses ^A	0.48	0.27 - 0.88	.017	2.66	1.38 - 5.15	.004	0.28	0.15 - 0.55	.000
Work experience									
Mid-career vs Early career	1.24	0.64 - 2.42	.522	0.55	0.26 - 1.19	.129	1.94	0.93 - 4.04	.077
Late career vs Early career	1.52	0.64 - 3.61	.341	0.65	0.25 - 1.66	.366	0.90	0.36 - 2.26	.823
Experience									
Not heard of vs Heard of	1.04	0.59 - 1.86	.890	0.81	0.42 - 1.55	.520	1.39	0.74 - 2.62	.311
Does not know about vs Knows about use in own institution	1.16	0.56 - 2.40	.699	1.18	0.53 - 2.65	.684	0.53	0.23 - 1.20	.129
Not worked with vs Worked with	0.84	0.35 - 1.99	.693	0.91	0.35 - 2.32	.835	0.96	0.36 - 2.58	.937

Note. The three multivariable models were additionally corrected for country of practice and bold fonts indicate statistical significance.

^A Obtained in a separate model after changing reference category

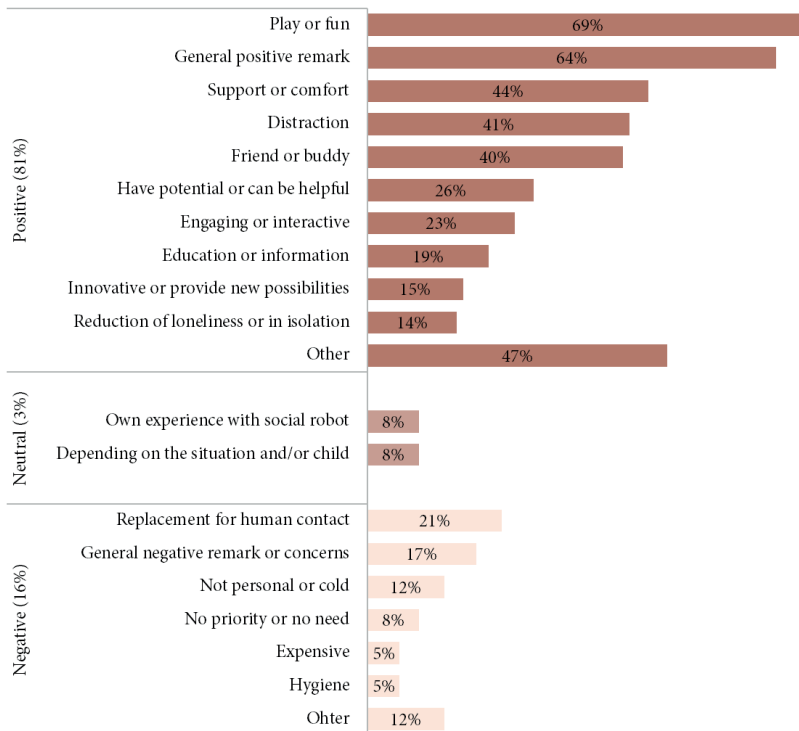
Opinions of health care providers

First thoughts about social robots

Health care providers together described 498 first thoughts about social robots. Most of these first thoughts were positive (81%): Social robots are fun to play with, general positive remarks (such as ‘interesting’ or ‘exciting’), social robots can support or comfort children during treatment and/or procedures, distract them or be a friend or buddy. Some first thoughts were negative (16%): Social robots should not replace human contact, general negative first thoughts (such as ‘awkward’ or ‘unsettling’), and that social robots are impersonal or cold. Finally, a few first thoughts were neutral (3%): Describing previous experiences with social robots, and that the success of social robots may depend on the child. More detailed information can be found in Figure 1.

FIGURE 1

First thoughts ($n = 498$) of health care providers ($n = 286$) in pediatric oncology about social robots



Note. Open answers were sometimes quite diverse. For positive first thoughts, answers that were given less than 10 times were merged into the category ‘Other’. For negative first thoughts, answers that were given less than 5 times were merged into the category ‘Other’.

Possible value and purpose of social robots

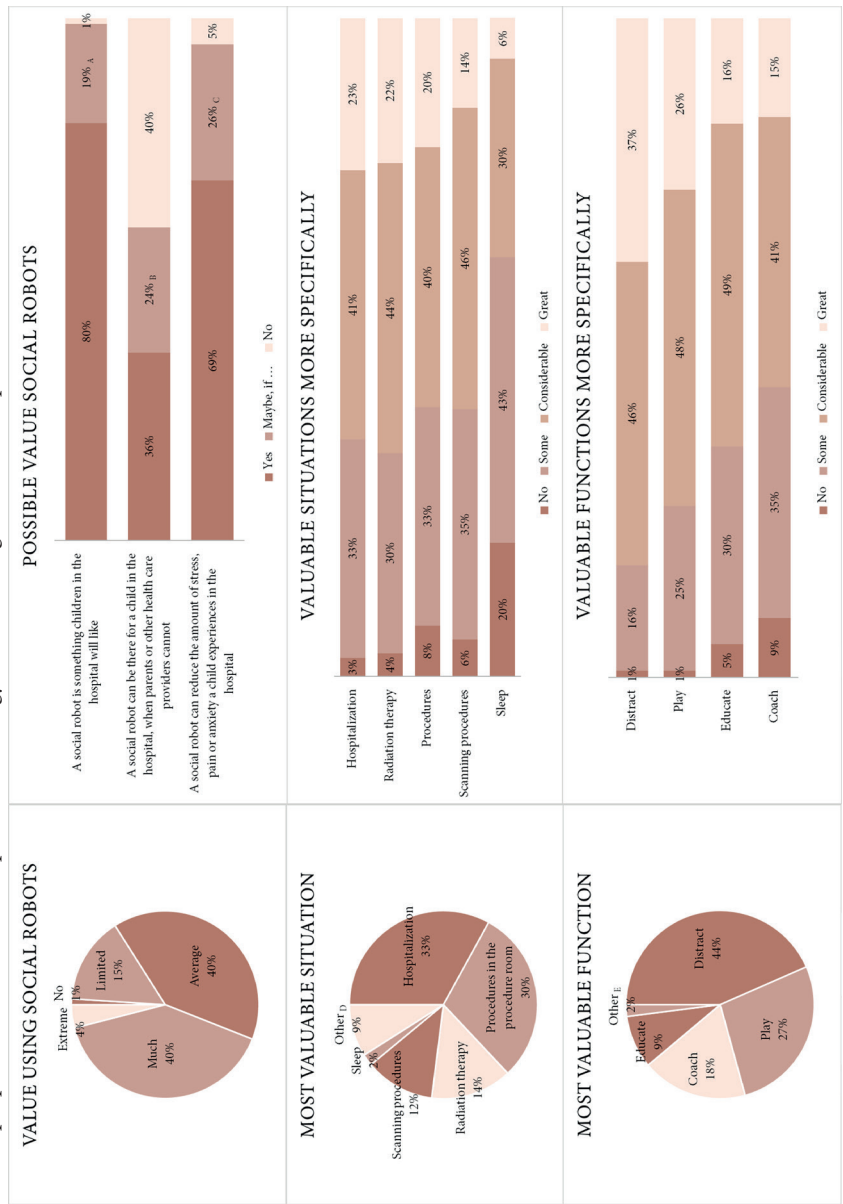
About four-fifths of the health care providers thought a social robot is something children will like, and almost all others thought children would maybe like them, mostly mentioning that it would depend on the child and the age of the child. About two-thirds of health care providers thought that a social robot can reduce the amount of stress, pain or anxiety a child experiences in the hospital, and around a quarter thought a social robot maybe can, mostly adding that the child should like the robot or already be familiar or bonded with the robot. About one-third of the health care providers thought that a social robot can be there for children when parents or health care providers cannot, but more health care providers thought a social robot cannot. Some health care providers thought the robot can maybe be there for children, mostly adding that it should not be seen as a replacement of parents or staff.

The majority of health care providers saw value in using social robots during hospitalization, radiation therapy, long hospitalizations, procedures in the procedure room, and scanning procedures. They saw little value in using a social robot to support children with sleeping in the hospital. Regarding the functions of the robot, the majority of the health care providers saw value in using a social robot for distraction, play, education, and coaching. They considered hospitalization and procedures in the procedure room the most valuable scenarios, and distraction as the most valuable function. More detailed information about the opinions of health care providers on the possible value and purpose of social robots can be found in Figure 2.

Possible barriers and willingness to use social robots

Around two-thirds of the health care providers expected difficulties when using a social robot in their work. Almost half of the health care providers expected difficulties with regard to technique (i.e., errors with the robot in executing its task), and about a quarter with regard to resistance (i.e., from themselves, colleagues, or the child and/or parents). About one-fifth of the health care providers expected difficulties with regard to time (i.e., procedures may take too much additional time because of the robot) or usefulness (i.e., the robot may not have a significant contribution). Other main expected difficulties were: Hygiene or maintenance issues, customizing or adapting the robot to fit the situation or the child's needs and costs.

FIGURE 2
Possible value and purpose for social robots in pediatric oncology care according to health care providers ($n = 286$)



Note.

^A Depending on the child and age of the child; it is not instead of human contact

^B It is not seen as a replacement of parents or staff; if the child and parents want to; if the child is already familiar or bonded with the robot

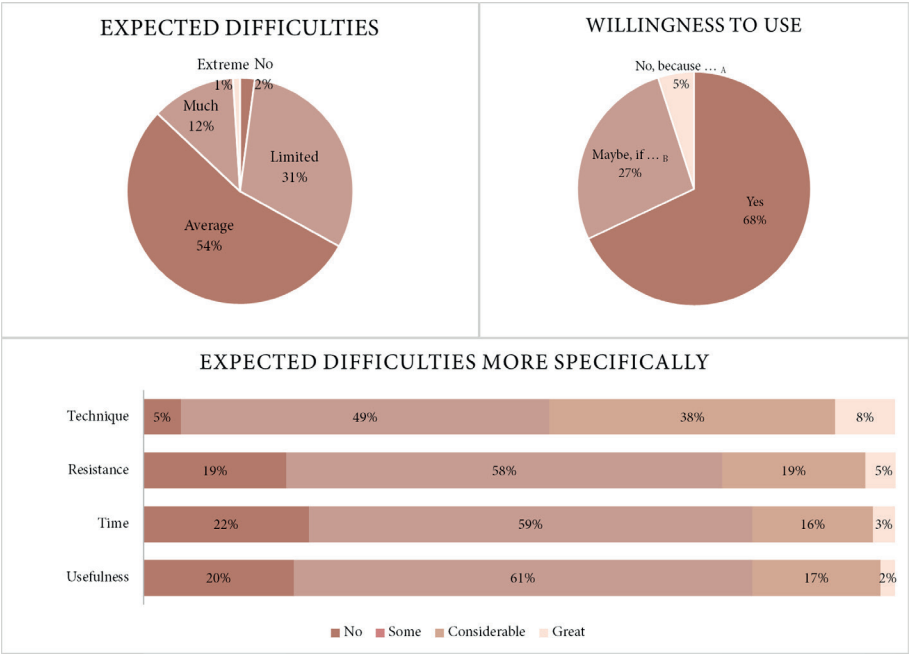
^C You know the child likes or accepts the robot; depending on the child and age of the child

^D Mostly mentioned: School, phlebotomies or fearful procedures, waiting times

^E Mostly mentioned: A buddy or friend, connect with others, communication

More than two-thirds of the health care providers was willing to use a social robot themselves. About a quarter may be willing to use a social robot, mostly depending on the aim and the functioning of the robot, and if research demonstrates its effectiveness. They would also like to be well-informed as staff and see the added value themselves. A few health care providers were not willing to use a social robot in their work, mainly because they prefer human contact. More detailed information about the opinions of health care providers on possible barriers and their willingness to use social robots can be found in Figure 3.

FIGURE 3
Possible barriers and willingness to use social robots in the pediatric oncology according to health care providers ($n = 286$)



Note.
^A Depending on the aim and purpose of the robot; better informed as staff; the added value is visible; research demonstrates evidence-base
^B Human contact is preferred

Differences in opinions of health care providers

We found one difference regarding possible value in using a social robot to support children during treatment: Psychosocial staff members (35.1%) less often saw value in using a social

robot than nurses (50.9%) (OR [CI] = 0.48 [0.27-0.88], $p = .017$). With regard to expected difficulties, females (65.0%) less often expected difficulties than men (77.6%) (OR [CI] = 0.39 [0.17-0.86], $p = .020$), and psychosocial staff (81.9%) more often expected difficulties than medical staff (62.3%) (OR [CI] = 2.61 [1.19-5.57], $p = .017$) and nurses (55.7%) (OR [CI] = 2.66 [1.38-5.15], $p = .004$). In their willingness to use a social robot, the psychosocial staff (51.4%) was less often willing to use a social robot than medical staff (76.7%) (OR [CI] = 0.22 [0.10-0.49], $p < .001$) and nurses (79.2%) (OR [CI] = 0.28 [0.15-0.55], $p < .001$). More details and information about the results of the multivariable analyses on differences in opinions between health care providers can be found in Table 4.

DISCUSSION

We aimed to describe the opinions of health care providers in pediatric oncology regarding social robots and to examine differences in their opinions based on their background characteristics and experience with social robots. We found that a large majority of first thoughts about social robots were positive. Most health care providers thought a social robot is something children will like, and can reduce the amount of stress, pain or anxiety a child experiences. They considered hospitalization and procedures in the procedure room as the most valuable scenarios, and distraction as the most valuable function to use the robot for. Most health care providers also expected difficulties when using a social robot, mainly concerning technique. Nevertheless, most of them were willing to use a social robot themselves.

Opinions of health care providers in pediatric oncology on social robots have not been reported before. In fact, very few studies were done with social robots in pediatric oncology. Our results seem to fit well with the use of the robot in those few studies and studies in other healthcare areas. Our finding that social robots should be used in addition to care, and not as replacement, is in line with the reported use of a social robot as a psychotherapy assistant [16,17] and emphasized in other studies [21]. A minority of health care providers thought that social robots could 'be there' for a child. We did not specify whether 'being there' referred to physical presence or psychosocial support. Because health care providers saw lower value for this purpose and their most often mentioned negative first thought was that social robots should not replace human contact, it may be interpreted as psychosocial support.

Furthermore, our findings about the most valuable scenario and function for social robots are in line with the reported use of a social robot for distraction during needle

insertion [15,22]. However, little value was seen in using social robots for educational purposes, even though many social robots are used for this purpose outside the field of pediatric oncology, for example in children with diabetes [23,24]. Furthermore, health care providers saw remarkably little value in using social robots with regard to sleep, even though two recent reviews reported sleep disruptions are frequent in children with cancer during treatment [25,26], and no effective sleep interventions are known to exist. This finding could be explained by the manner in which the opinion of the health care provider was asked. The questionnaire did not specify on how the robot would be used in the context of sleep. This could potentially have resulted in an assumption that the robot would be used right before bedtime, or during the night, which could distract and excite children rather than help them sleep (better). Since the use of robots for educational purposes has been successful in children before and there is a need for sleeping interventions, the use of social robots for sleeping education should not be abandoned yet.

We also found marked differences in opinions of health care providers of different professions. Psychosocial staff members were less positive. This is especially relevant, since social robots are likely to be implemented mainly by psychosocial staff members, like child life specialists, when used for support during treatment. For psychosocial staff members, direct and personal contact with children is important. In their work, they tailor to the specific needs of children, and the (therapeutic) relationship between psychosocial staff members and children are an important part of the effectivity of their work. Therefore, they may not see possibilities for social robots to fulfill this role and to be flexible enough to meet the specific needs of each child, which was a concern that was reported by health care providers in this study as well. We also found that age, years of work experience and experience with social robots did not make a difference. Especially the finding that the opinions of health care providers who have experience with social robots did not differ from those who do not, was surprising to us as other research showed a positive association between experience with an innovative intervention and acceptance [27].

Clinical implications

A social robot may be a promising tool in care for children with cancer. First clinical implementation of social robots seems most likely as a distraction during medical procedures, based on health care providers opinions and previous studies. However,

introducing such innovations in care may have a great impact on daily work, which is known to be complex, and brings along challenges and barriers. The concerns of health care providers that were found in this study can therefore be helpful in anticipating on these challenges and improve implementation.

One prominent concern was that social robots should not replace human contact. We suggest that social robots are introduced as an addition to care, and not as a replacement of humans. There are situations, however, where parents or professionals are not allowed to be with the child, like during radiotherapy, where the role of a social robot could be explored. To address the concern of social robots as replacement, and because health care providers indicated that they would like to be well informed and convinced of the added value themselves, the involvement of staff when implementing a social robot, and proper training and practice time are recommended. This is in line with recommendations from other literature on social robots [21]. This may also reduce the expected difficulties of health care providers regarding working with a social robot.

Another concern health care providers frequently mentioned was that it will depend on the child and the age of the child whether they feel a social robot is appropriate. In addition, they find it important that children are familiar or bonded with the robot before using it during treatment. As such, clear plans should be made about how children will be introduced to the robot, and health care providers should be educated on personalized use.

Limitations

Health care providers were recruited globally via multiple convenience sampling strategies, so we do not know how representative our sample is of the population of health care providers in pediatric oncology. Our sample shows a variety in representation of health care providers with different ages, professions, and years of work experience, but health care providers from the Netherlands were overrepresented. Moreover, most health care providers worked in more developed countries according to the Human Development Index. This is likely related to our method of recruitment and that the topic of social robots is less relevant for health care providers working in less developed countries. In general, the sample might be biased in favor of health care providers with interest in this topic. This all warrants caution when interpreting and generalizing the findings of this study.

Future research

The largely positive opinions of health care providers add promising new knowledge to the pediatric oncology field, and may encourage further research in this area towards successful implementation of social robots. More research on the experiences of health care providers with social robots is needed. About 10% of the health care providers in this study reported to have worked with social robots themselves, and it would be informative to look more specifically into their experiences. Also, more research is needed on the effectiveness of social robots when applied in different children, with different ages, focused on different functions in different settings. The information of the experiences of health care providers, together with research on the effectiveness for different children and settings, could help with further shaping the science around this relatively new and unknown field of social robots in pediatric healthcare.

Conclusions

Social robots may be a promising addition to standard care, since health care providers in pediatric oncology were generally positive about social robots. They saw value in using social robots, and were willing to use one, but they also expected difficulties, mainly concerning technical errors. Psychosocial staff members were less positive about social robots than other health care providers. When wanting to implement social robots in pediatric oncology care, the reported potential barriers should be considered.

REFERENCES

1. Breazeal, C. Social robots for health applications. In Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC), Boston, MA, USA, **2011**; pp. 5368-5371.
2. Oborn, E.; Barrett, M.; Darzi, A. Robots and service innovation in health care. *Journal of Health Services Research & Policy* **2011**, *16*, 46-50, <http://doi.org/10.1258/jhsrp.2010.010001>.
3. Lee, K.M.; Park, N.; Song, H. Can a robot be perceived as a developing creature? Effects of a robot's long-term cognitive developments on its social presence and people's social responses toward it. *Human Communication Research* **2005**, *31*, 538-563, <http://doi.org/10.1111/j.1468-2958.2005.tb00882.x>.
4. Kuo, A.A.; Etzel, R.A.; Chilton, L.A.; Watson, C.; Gorski, P.A. Primary care pediatrics and public health: Meeting the needs of today's children. *American Journal of Public Health* **2012**, *102*, e17-e23, <http://doi.org/10.2105/AJPH.2012.301013>.
5. Kahn, P.H.; Gary, H.E.; Shen, S. Children's social relationships with current and near-future robots. *Child Development Perspectives* **2013**, *7*, 32-37, <http://doi.org/10.1111/cdep.12011>.
6. Van Straten, C.L.; Peter, J.; Kühne, R. Child-robot relationship formation: A narrative review of empirical research. *International Journal of Social Robotics* **2020**, *12*, 325-344, <http://doi.org/10.1007/s12369-019-00569-0>.
7. Moerman, C.J.; Van der Heide, L.; Heerink, M. Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review. *Journal of Child Health Care* **2019**, *23*, 596-612, <http://doi.org/10.1177/1367493518803031>.
8. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.
9. Robinson, N.L.; Cottier, T.V.; Kavanagh, D.J. Psychosocial health interventions by social robots: Systematic review of randomized controlled trials. *Journal of Medical Internet Research* **2019**, *21*, e13203, <http://doi.org/10.2196/13203>.
10. Trost, M.J.; Ford, A.R.; Kysh, L.; Gold, J.I.; Matarić, M. Socially assistive robots for helping pediatric distress and pain: A review of current evidence and recommendations for future research and practice. *The Clinical Journal of Pain* **2019**, *35*, 451-458, <http://doi.org/10.1097/Ajp.0000000000000688>.
11. Kazak, A.E.; Kassam-Adams, N.; Schneider, S.; Zelikovsky, N.; Alderfer, M.A.; Rourke, M. An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2006**, *31*, 343-355, <http://doi.org/10.1093/jpepsy/jsj054>.
12. Beran, T.; Pearson, J.R.; Lashewicz, B.; Baggott, S. Perspectives of child life specialists after many years of working with a humanoid robot in a pediatric hospital: Narrative design. *Journal of Medical Internet Research* **2020**, *22*, e23496, <http://doi.org/10.2196/23496>.
13. Jeong, S.; Breazeal, C.; Logan, D.; Weinstock, P. Huggable: Impact of embodiment on promoting verbal and physical engagement for young pediatric inpatients. In Proceedings of the 26th IEEE International Symposium on Robot and Human Interactive Communication (RO-MAN), Lisbon, Portugal, **2017**; pp. 121-126.
14. Jeong, S.; Logan, D.; Goodwin, M.; Graca, S.; O'Connell, B.; Goodenough, H.; Anderson, L.; Stenquist, N.; Fitzpatrick, K.; Zisook, M.; et al. A social robot to mitigate stress, anxiety, and pain in hospital pediatric care. In Proceedings of the 10th Annual ACM/IEEE International Conference on Human-Robot Interaction (HRI), Portland, OR, USA, **2015**; pp. 103-104.

15. Jibb, L.A.; Birnie, K.A.; Nathan, P.C.; Beran, T.N.; Hum, V.; Victor, J.C.; Stinson, J.N. Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial. *Pediatric Blood & Cancer* **2018**, *65*, e27242, <http://doi.org/10.1002/pbc.27242>.
16. Alemi, M.; Ghanbarzadeh, A.; Meghdari, A.; Moghadam, L.J. Clinical application of a humanoid robot in pediatric cancer interventions. *International Journal of Social Robotics* **2016**, *8*, 743-759, <http://doi.org/10.1007/s12369-016-0382-7>.
17. Alemi, M.; Meghdari, A.; Moghadam, L.J.; Ghanbarzadeh, A. Effect of utilizing a humanoid robot as a therapy-assistant in reducing anger, anxiety, and depression. In Proceedings of the RSI/ISM International Conference on Robotics and Mechatronics (ICRoM), Nottingham, UK, **2014**; pp. 748-753.
18. Haverman, L.; Van Oers, H.A.; Limperg, P.F.; Hijmans, C.T.; Schepers, S.A.; Sint Nicolaas, S.M.; Verhaak, C.M.; Bouts, A.H.; Fijnvandraat, K.; Peters, M.; et al. Implementation of electronic patient reported outcomes in pediatric daily clinical practice: The KLIK experience. *Clinical Practice in Pediatric Psychology* **2014**, *2*, 50-67, <http://doi.org/10.1037/cpp0000043>.
19. Saldaña, J. *The coding manual for qualitative researchers*, 3rd ed.; SAGE Publications Ltd: Arizona State University, USA, **2015**.
20. Agresti, A. *An Introduction to Categorical Data Analysis*, 2nd ed.; John Wiley & Sons: New Jersey, USA, **2007**.
21. Vänni, K.J.; Salin, S.E. Attitudes of professionals toward the need for assistive and social robots in the healthcare sector. In *Social Robots: Technological, Societal and Ethical Aspects of Human-Robot Interaction. Human-Computer Interaction Series*, Korn, O., Ed.; Springer: Berlin/Heidelberg, Germany, **2019**; pp. 205-236.
22. Smakman, M.H.J.; Smit, K.; Buser, L.; Monshouwer, T.; van Putten, N.; Trip, T.; Schoof, C.; Preciado, D.F.; Konijn, E.A.; Van der Roest, E.M.; et al. Mitigating children's pain and anxiety during blood draw using social robots. *Electronics* **2021**, *10*, 1211, <http://doi.org/10.3390/electronics10101211>.
23. Henkemans, O.A.B.; Bierman, B.P.B.; Janssen, J.; Looije, R.; Neerincx, M.A.; Van Dooren, M.M.M.; Vries, J.L.E.; Van der Burg, G.J.; Huisman, S.D. Design and evaluation of a personal robot playing a self-management education game with children with diabetes type 1. *International Journal of Human-Computer Studies* **2017**, *106*, 63-76, <http://doi.org/10.1016/j.ijhcs.2017.06.001>.
24. Looije, R.; Neerincx, M.A.; Peters, J.K.; Henkemans, O.A.B. Integrating robot support functions into varied activities at returning hospital visits. *International Journal of Social Robotics* **2016**, *8*, 483-497, <http://doi.org/10.1007/s12369-016-0365-8>.
25. Lee, S.; Narendran, G.; Tomfohr-Madsen, L.; Schulte, F. A systematic review of sleep in hospitalized pediatric cancer patients. *Psycho-Oncology* **2017**, *26*, 1059-1069, <http://doi.org/10.1002/pon.4149>.
26. Walter, L.M.; Nixon, G.M.; Davey, M.J.; Downie, P.A.; Horne, R.S.C. Sleep and fatigue in pediatric oncology: A review of the literature. *Sleep Medicine Reviews* **2015**, *24*, 71-82, <http://doi.org/10.1016/j.smrv.2015.01.001>.
27. Hennemann, S.; Beutel, M.E.; Zwerenz, R. Ready for eHealth? Health professionals' acceptance and adoption of eHealth interventions in inpatient routine care. *Journal of Health Communication* **2017**, *22*, 274-284, <http://doi.org/10.1080/10810730.2017.1284286>.

APPENDIX 1

Online questionnaire

Social robots survey for health care providers



2

Welcome

Dear colleague,

We are pediatric oncology researchers, and we are developing a social robot with the aim of supporting children with cancer during their treatment. As this provides new opportunities in care for children with cancer, we would highly appreciate your expert opinion as a health care provider on this topic. Your opinion is very important to us in establishing the role and developing the behavior of this social robot. Therefore, we would like to ask you to participate in our study by filling out our survey. The survey consists of 20 questions and takes 5-10 minutes to complete.

You can participate in this study if you are:

- A health care provider currently working in pediatric oncology practice;
- working with children between 4-12 years;
- understanding the English language well enough to complete an online survey.

Data will be collected anonymously and is not traceable to individuals. By filling out the questionnaire you consent with using your data for scientific purposes.

Should you have any questions about the study, please contact Mrs. Kelly van Bindsbergen via K.L.A.vanBindsbergen@prinsesmaximacentrum.nl.

Thank you in advance for filling out our survey.

Yours sincerely,

Kelly van Bindsbergen, MSc

Hans Merks, MD, PhD

Prof. Martha Grootenhuys, PhD

Princess Máxima Center for pediatric oncology, the Netherlands

Socio-demographic and clinical background information

With these first five questions, we would like to know more about you and your clinical background.

1	<p>What is your gender?</p> <p><input type="radio"/> Male</p> <p><input type="radio"/> Female</p>
2	<p>What is your age?</p> <p><input type="radio"/> Younger than 18 years</p> <p><input type="radio"/> 18-30 years</p> <p><input type="radio"/> 31-50 years</p> <p><input type="radio"/> 51-70 years</p> <p><input type="radio"/> Older than 70 years</p>

Chapter 2

3	What is your <u>primary</u> profession? <ul style="list-style-type: none"><input type="radio"/> Pediatrician<input type="radio"/> Pediatric oncologist/hematologist<input type="radio"/> Pediatric (neuro) surgeon<input type="radio"/> (Pediatric) Radiation oncologist<input type="radio"/> (Pediatric) Radiologist<input type="radio"/> Pediatric neurologist<input type="radio"/> Nurse (practitioner)<input type="radio"/> Child life specialist<input type="radio"/> (Neuro) Psychologist<input type="radio"/> Social worker<input type="radio"/> (Pediatric) Physical therapist<input type="radio"/> Other, namely <input type="text"/>																																												
4	How long have you been working in the field of pediatric oncology? <ul style="list-style-type: none"><input type="radio"/> Less than 1 year<input type="radio"/> 1-5 years<input type="radio"/> 6-10 years<input type="radio"/> 10-20 years<input type="radio"/> More than 20 years																																												
5	In what country do you practice your profession? <table border="0"><tr><td><input type="radio"/> Argentina</td><td><input type="radio"/> Australia</td><td><input type="radio"/> Austria</td><td><input type="radio"/> Belarus</td></tr><tr><td><input type="radio"/> Belgium</td><td><input type="radio"/> Brazil</td><td><input type="radio"/> Bulgaria</td><td><input type="radio"/> Canada</td></tr><tr><td><input type="radio"/> China</td><td><input type="radio"/> Croatia</td><td><input type="radio"/> Denmark</td><td><input type="radio"/> Finland</td></tr><tr><td><input type="radio"/> France</td><td><input type="radio"/> Germany</td><td><input type="radio"/> Greece</td><td><input type="radio"/> Hungary</td></tr><tr><td><input type="radio"/> Iceland</td><td><input type="radio"/> India</td><td><input type="radio"/> Indonesia</td><td><input type="radio"/> Iran</td></tr><tr><td><input type="radio"/> Ireland</td><td><input type="radio"/> Italy</td><td><input type="radio"/> Japan</td><td><input type="radio"/> Luxembourg</td></tr><tr><td><input type="radio"/> The Netherlands</td><td><input type="radio"/> Norway</td><td><input type="radio"/> Pakistan</td><td><input type="radio"/> Poland</td></tr><tr><td><input type="radio"/> Portugal</td><td><input type="radio"/> Romania</td><td><input type="radio"/> Russia</td><td><input type="radio"/> Saudi Arabia</td></tr><tr><td><input type="radio"/> Serbia</td><td><input type="radio"/> Singapore</td><td><input type="radio"/> Slovenia</td><td><input type="radio"/> Spain</td></tr><tr><td><input type="radio"/> Sweden</td><td><input type="radio"/> Switzerland</td><td><input type="radio"/> Tanzania</td><td><input type="radio"/> Turkey</td></tr><tr><td><input type="radio"/> Ukraine</td><td><input type="radio"/> United Kingdom</td><td><input type="radio"/> United States of America</td><td><input type="radio"/> Other, namely</td></tr></table> <input type="text"/>	<input type="radio"/> Argentina	<input type="radio"/> Australia	<input type="radio"/> Austria	<input type="radio"/> Belarus	<input type="radio"/> Belgium	<input type="radio"/> Brazil	<input type="radio"/> Bulgaria	<input type="radio"/> Canada	<input type="radio"/> China	<input type="radio"/> Croatia	<input type="radio"/> Denmark	<input type="radio"/> Finland	<input type="radio"/> France	<input type="radio"/> Germany	<input type="radio"/> Greece	<input type="radio"/> Hungary	<input type="radio"/> Iceland	<input type="radio"/> India	<input type="radio"/> Indonesia	<input type="radio"/> Iran	<input type="radio"/> Ireland	<input type="radio"/> Italy	<input type="radio"/> Japan	<input type="radio"/> Luxembourg	<input type="radio"/> The Netherlands	<input type="radio"/> Norway	<input type="radio"/> Pakistan	<input type="radio"/> Poland	<input type="radio"/> Portugal	<input type="radio"/> Romania	<input type="radio"/> Russia	<input type="radio"/> Saudi Arabia	<input type="radio"/> Serbia	<input type="radio"/> Singapore	<input type="radio"/> Slovenia	<input type="radio"/> Spain	<input type="radio"/> Sweden	<input type="radio"/> Switzerland	<input type="radio"/> Tanzania	<input type="radio"/> Turkey	<input type="radio"/> Ukraine	<input type="radio"/> United Kingdom	<input type="radio"/> United States of America	<input type="radio"/> Other, namely
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<input type="radio"/> Ireland	<input type="radio"/> Italy	<input type="radio"/> Japan	<input type="radio"/> Luxembourg																																										
<input type="radio"/> The Netherlands	<input type="radio"/> Norway	<input type="radio"/> Pakistan	<input type="radio"/> Poland																																										
<input type="radio"/> Portugal	<input type="radio"/> Romania	<input type="radio"/> Russia	<input type="radio"/> Saudi Arabia																																										
<input type="radio"/> Serbia	<input type="radio"/> Singapore	<input type="radio"/> Slovenia	<input type="radio"/> Spain																																										
<input type="radio"/> Sweden	<input type="radio"/> Switzerland	<input type="radio"/> Tanzania	<input type="radio"/> Turkey																																										
<input type="radio"/> Ukraine	<input type="radio"/> United Kingdom	<input type="radio"/> United States of America	<input type="radio"/> Other, namely																																										

First impression and current experiences

Definition social robot

Social robots can be defined as "new types of robots whose primary goal is social interaction with humans".¹ In other words, robots designed to have meaningful social interactions. Some example pictures of social robots are shown below.



N.B. So social robots are not robots that have a solely functional purpose, such as telepresence, performing or assisting surgery, helping with rehabilitation, making deliveries or sanitizing hospital rooms.

With the next four questions we would like to know how much you know about social robots and whether you have any experience with social robots.

6

What is the first thing that comes to your mind when you think about a social robot for children in the hospital? (Please answer shortly in a few words)

7

Have you ever heard of a social robot being used in pediatric hospitals in general?

- ☐ Yes
☐ No

Chapter 2

8

Is a social robot being used **in the pediatric hospital where you work** (as far as you know)?

☐ Yes
☐ No

9

Have **you** ever worked with a social robot for children in the hospital?

☐ Yes
☐ No

Possible value and purpose

Background information

Social robots are becoming more and more popular in the healthcare context, and possibilities and effects are actively explored and studied. Four examples of what social robots have been used for in pediatric healthcare are:

1. **Play** to promote the socio-emotional wellbeing of hospitalized children.²
2. **Educate** to improve self-management in children with diabetes.³
3. **Coach** to help children with cancer deal with feelings of distress.⁴
4. **Distract** to reduce procedural pain and distress in children with cancer.⁵

With the next eight questions, we would like to know whether you see any value in using a social robot for children in the hospital and if so, for which purpose.

10

In general, a social robot is something children in the hospital will like.

☐ Yes
☐ No
☐ Maybe, if

11

In general, I see value in using a social robot to support children in the hospital during treatment.

☐ 1. No value
☐ 2. Limited value
☐ 3. Average value
☐ 4. Much value
☐ 5. Extreme value

12

More specifically, I see value in using a social robot in the hospital to support children during:

	No value	Some value	Considerable value	Great value
Scanning procedures (i.e. PET/CT-scan)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiation therapy (including MIBG therapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Procedures in the procedure room (i.e. port-a-cath access, probe insertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep (when being hospitalized)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitalization (in the playroom or patient room)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, namely <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13

If I would have to pick one scenario where a social robot would be most valuable, it would be:

☐ Scanning procedures
☐ Radiation therapy
☐ Procedures in the procedure room
☐ Sleep
☐ Hospitalization
☐ Other, namely

14

A social robot can be there for a child in the hospital, when parents or other health care providers cannot.

☐ Yes
☐ No
☐ Maybe, if

15

With regard to the function of the robot, I see value in using a social robot in the hospital to:

	No value	Some value	Considerable value	Great value
Play (games)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educate (information about treatment)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coach (coach children during treatment)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Distract (entertain during treatment, i.e. dance)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, namely <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16

If I would have to pick one function that would be most valuable for a social robot, it would be:

☐ Play
☐ Educate
☐ Coach
☐ Distract
☐ Other, namely

17

A social robot can reduce the amount of stress, pain or anxiety a child experiences in the hospital.

☐ Yes
☐ No
☐ Maybe, if

Chapter 2

Possible barriers

Using social robots in the pediatric healthcare context is relatively new and promising, but still in its infancy. There are opportunities, but also barriers. With these last three questions, we would like to know what you anticipate as potential barriers in using a social robot in pediatric oncology.

18

In general, when I (imagine to) use a social robot in my work, I expect:

☐

1. No difficulties

☐

2. Limited difficulties

☐

3. Average difficulties

☐

4. Many difficulties

☐

5. Extreme difficulties

19

More specifically, I expect difficulties with regard to:

	No difficulties	Some difficulties	Considerable difficulties	Great difficulties
Time (procedures will take too much additional time because of the robot)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Technique (errors with the robot in executing its task)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resistance (from myself, my colleagues, or the child and/or parents)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Usefulness (the robot will not have a significant contribution)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, namely <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20

I would be willing to use a social robot in my work to provide care for my patients in the hospital.

☐

Yes

☐

Maybe, if

☐

No, because

Thank you and open-end question or remarks

Thank you

Thank you so much for filling out this questionnaire and for sharing your expertise and experiences with us. We are very grateful that you took the time to contribute to our research!

Do you have any final questions or additional remarks?



1. Lee, K. M., Park, N., & Song, H. (2004). Can a Robot be Perceived as a Developing Creature?: Effects of Artificial Developments on Social Presence and Social Responses toward Robots in Human-Robot Interaction. Paper presented at International Communication Association conference, May 2004, New Orleans, LA.
2. Jeong, S., Breazeal, C., Logan, D., & Weinstock, P. (2018). Huggable: The Impact of Embodiment on Promoting Socio-Emotional Interactions for Young Pediatric Inpatients. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (p. 495). ACM.
3. Henkemans, O. A. B., Bierman, B. P., Janssen, J., Neerincx, M. A., Looije, R., van der Bosch, H., & van der Giessen, J. A. (2013). Using a robot to personalise health education for children with diabetes type 1: A pilot study. Patient education and counseling, 92(2), 174-181.
4. Alemi, M., Ghanbarzadeh, A., Meghdari, A., & Moghadam, L. J. (2016). Clinical Application of a Humanoid Robot in Pediatric Cancer Interventions. International Journal of Social Robotics, 8, 743-759.
5. Jibb, L.A., Birnie, K.A., Nathan, P.C., Beran, T.N., Hum, V., Victor, J.C., & Stinson, J.N. (2018). Using the MEDIPORT Humanoid Robot to Reduce Procedural Pain and Distress in Children with Cancer: A Pilot Randomized Controlled Trial. Pediatric Blood & Cancer, 65, e27242.

Submit

3

Introducing a social robot as a buddy into pediatric oncology care: Feasibility, experiences, and bonding of children with the robot over multiple interactions

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Mark A. Neerincx, Tanja Alderliesten, Peter A.N. Bosman, Martha A. Grootenhuis,
& Johannes H.M. Merks

Submitted

Van Bindsbergen, K.L.A., Van Gorp, M., Ligthart, M.E.U., Hindriks K.V., Neerincx, M.A., Alderliesten, T., Bosman, P.A.N., Grootenhuis, M.A., & Merks, J.H.M. Introducing a social robot as a buddy into pediatric oncology care: Feasibility, experiences, and bonding of children with the robot over multiple interactions. *Submitted.*

ABSTRACT

Purpose

Social robots are increasingly used to support children in health care. We developed software for a social robot to interact autonomously and have personalized conversations with children. We explored the introduction of this robot as a buddy into pediatric oncology care, and specifically evaluated the feasibility, experiences of children and parents, and bonding of children with the robot over multiple interactions in different settings.

Methods

Children (6-12 years old) receiving anticancer treatment in a pediatric oncology center were asked to interact with a social robot three times. The first two interactions were planned during hospitalizations and the third interaction while undergoing a medical procedure. Assessments consisted of a logbook and observation forms (feasibility) and questionnaires in interview form with children and parents (experiences and bonding).

Results

Twenty (of 22 approached) children participated, and in total 51 interactions were accomplished. There were technical issues during respectively 35%, 53%, and 7% of the interactions. All children found the robot age-appropriate, and children reported to feel better, on average, after the interactions. 90% of children appreciated the support of the robot during a medical procedure, and 89% of parents were positive about a robot buddy for their child. Bonding scores were high at all interactions.

Conclusion

Children were highly interested to interact with the robot, had positive experiences, and perceived continuously high levels of bonding. Further software development is needed to improve technical functioning, yet the concept of a social robot buddy at multiple moments during cancer treatment holds promise as an addition to supportive care.

INTRODUCTION

Cancer treatment and inherent procedures cause stress and anxiety in children, and induce a certain level of Pediatric Medical Traumatic Stress (PMTS) [1]. PMTS has been defined as “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” [2]. Reduction of PMTS in the pediatric oncology setting is important for many reasons, including reducing significant adverse psychological reactions (e.g., anxiety, fear, or posttraumatic stress). The international standards of psychosocial care therefore strongly recommend psychosocial interventions for invasive medical procedures [3]. In the Netherlands, as part of standard care during treatment, child life specialists are available to prepare and support children during medical procedures, and if needed, a team of psychologists is available to provide specialized additional psychosocial care [4].

To supplement currently available methods of supportive care for children, social robots are increasingly used in health care [5-7]. Social robots meet unique care needs of children [8], and have been used in healthy children to reduce pain and distress during vaccinations using cognitive-behavioral strategies [9] or distraction [10]. In pediatric patients, social robots have been used for distraction to diminish pain and anxiety during blood draws using by for example singing, dancing, and telling jokes [11], and to reduce pain and fear during painful medical procedures by doing activities that children choose themselves [12]. Several reviews can be found that describe the use of social robots in pediatrics [13-17]. Specifically in pediatric oncology, a social robot was used in a pilot randomized controlled trial to reduce procedural pain and distress in children during subcutaneous port needle insertions using either cognitive-behavioral strategies (vocalizations and movements) or active distractions (dancing). Results showed no difference in pain between the two strategies, but less distress in the active distraction arm [18].

Even though these single encounters between children and social robots in a medical setting show promising results in reducing pain, stress, and anxiety, children receiving cancer treatment undergo repeated hospitalizations and medical procedures over longer periods of time. Children seem to be able to form relationships with social robots, and consider them to be a buddy or friend [19-21]. Therefore, having multiple encounters with a social robot throughout treatment, and developing a longer-term

bond could provide opportunities and benefits as a novel way of supportive care for children to reduce PMTS.

This study explored the introduction of a social robot as a buddy into pediatric oncology care. Previous studies so far used a Wizard-of-Oz approach whereby the robot is operated by a researcher or health care provider and/or the behavior of the robot was usually simple, such as play or dance. In this study, a social robot was developed that interacted autonomously and could have personalized conversations. These features are novel in this context and likely contribute to a buddy experience for children. Therefore, we aimed to evaluate context and technical feasibility, experiences of children and parents, and bonding of children over multiple interactions with a social robot in different settings.

METHODS

Participants and recruitment

In this prospective study, children were eligible to participate if they were: (1) Between 6-12 years old, (2) currently hospitalized at the stem cell transplant unit or solid tumor department of the Princess Máxima Center for pediatric oncology between April 2021 and July 2021, and (3) fluent in Dutch. Children who met all inclusion criteria were identified via child life specialists, and families received both written and oral information about the study within the first few days of their hospitalization. Reasons for not participating were registered, and parents of participating families signed informed consent. The study was classified as exempt of the Medical Research Involving Human Subjects Act by the medical ethics review board of Utrecht University (number 21-074).

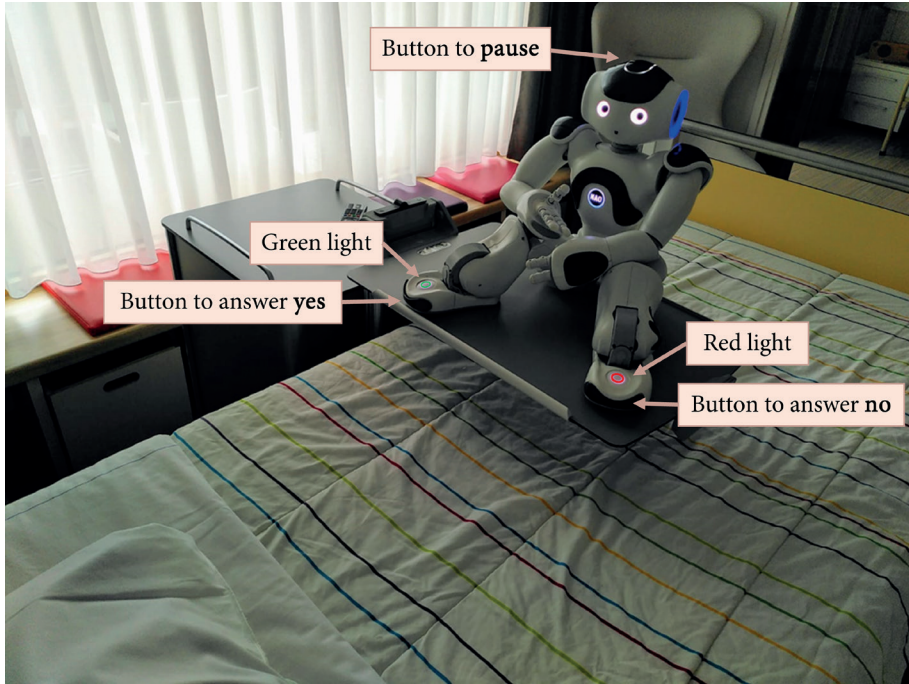
Procedure

Children were invited to interact with the robot three times: The first two times in their patient room while being hospitalized, and the third time during a medical procedure. The children were allowed to select themselves if and during which medical procedure they wanted to have the third interaction. The interactions were guided by a trained researcher, and at least one parent had to be present. In the patient room, the robot was usually placed on the nightstand of the child, which extended over the bed or chair, so that the robot and child were sitting in front of each other at the same level (Figure 1). During the medical procedure, the robot was placed as close as possible to the child. All

interactions were started by the researcher via a laptop. The robot could be paused at any time via the laptop or by a touch on its head. All three interactions lasted 5-10 minutes.

FIGURE 1

Hero sitting on the nightstand over the bed of the child (set-up) and visualization of the functionalities presented to children



Interactions and setting

For the interactions, the NAO⁶ robot was used (hardware produced by SoftBank Robotics ©). A software framework was developed to let the robot behave autonomously in a socially intelligent way [22]. This means that the robot was able to understand answers of children independently, and responded differently based on the input of children. Conversational scripts were created for three different interactions (Table 1). To provide a buddy experience, all three interactions were personalized, whereby the robot used the name and answers of children throughout the interaction, but also in the next interaction. Besides personalization, this also served the purpose of triggering curiosity in children for the next interaction, and taking away possible additional stress that may come with unfamiliarity with the robot during a medical procedure (interaction 3). The robot was named Hero, a name that was chosen by children in our center.

TABLE 1
Activity, setting, aim, and content of the three interactions between children and the robot

	Interaction 1	Interaction 2	Interaction 3
Activity	Getting acquainted	Co-creating a story	Listening to and watching the co-created story
Setting	While hospitalized	While hospitalized	While undergoing a medical procedure
Aim	To introduce the robot to children, and let them become acquainted	To facilitate bonding with the robot, and collect input for a story the robot will tell them at the next interaction	Distract children during a medical procedure by performing the co-created story
Content	<ul style="list-style-type: none">• The robot introduced itself as Hero, a robot who is learning how to become a buddy for children• After mutual introductions, there was a tutorial in which children learned how to talk to the robot and practiced with using the repair mechanism• The robot asked children questions about various topics, to get to know them, for example about their favorite color, animals, food, and family• The robot answered by reacting to the answer of the child and sharing an answer or story about itself	<ul style="list-style-type: none">• Children were asked to select a song they liked (from Tiktok ®), followed by a tutorial on how they could co-create the story with the robot• Children chose one of the two preprogrammed stories in which the robot told them about its past experiences where it tried to be a refrigerator or an excavator• Children helped creating the story by making or choosing sounds, movements, and lights without actually hearing the story yet	<ul style="list-style-type: none">• Children or health care providers started the storytelling when it was appropriate by pressing the button on its foot (indicated by a green light above the button)• Children then listened and watched the robot perform the story, including answers given by themselves in the first interaction, and the effects made in the second interaction• After the story, children could press the button with a green light above it again when they were ready to say goodbye

During the interactions, the robot asked children open-ended or close-ended questions. To open-ended questions, any answer could be given and the interaction continued regardless of the answer. To close-ended questions, children had to give a specific answer the robot needed to understand, and the robot replied differently based on this answer. Here, children had two attempts to answer, and in case of no success, the robot used a repair mechanism to reduce frustration and assure the interaction could continue properly [23]. The buttons on the left and right foot of the robot corresponded to a yes or no answer (indicated by a green and red light above the buttons). In case of a multiple-choice question, the robot would list some answer options and children could push the yes-button when they wanted to select the mentioned answer.

Measures

A logbook and observation form were filled out by the researcher to register feasibility, including: Reasons for families not completing all three interactions, technical issues, use of pause function, and course of the interactions between children and the robot. Additionally, children were asked to report on the intelligibility of the robot (good/sometimes good, sometimes bad/bad) and easiness to talk to the robot (easy/sometimes easy, sometimes difficult/difficult).

Questionnaires were filled out in interview form with children and parents to evaluate experiences. At the first two interactions, children were asked before and after the interaction how they were feeling at that moment on a scale of 0-10 (with a higher score indicating feeling better). After the interaction, children rated the age-appropriateness of the robot (yes/no), feelings towards the robot using adjectives such as kind, funny, and scary (yes/a little bit/no), and how much they liked the activity with the robot on a scale of 0-10 (with a higher score indicating liking the activity more). At the third interaction, if the interaction was during a medical procedure, children rated their experiences regarding stress and anxiety (less/same/more) and pain (less/same/more) compared to previous medical procedures, ability to focus on the story (well/sometimes/bad), and perceived support by the robot (yes/some/no). Parents rated whether their child's stress and anxiety (yes/maybe/no) and pain (yes/maybe/no) were less compared to previous medical procedures, as well as progress of the procedure (easier/similar/more difficult), and supportiveness of the robot during a medical procedure (yes/somewhat/no).

Bonding was assessed after each interaction using a self-report questionnaire that consists of 13 items representing three different domains of child-robot relationship formation: (1) Closeness (5 items), (2) trust (4 items), and (3) perceived social support

(4 items) [24]. The questionnaire was developed and validated for children 7-11 years old, so we did not administer it for the 6-year-olds. Each item could be answered on a 5-point Likert scale running from “does not apply at all” to “applies completely”. The items of each scale provide an average score ranging from 1 to 5, where higher scores indicated either more perceived closeness, trust, or social support. Reliability of the three scales were found to be acceptable to good, with Cronbach’s alpha’s of 0.84 (closeness), 0.86 (trust), and 0.71 (perceived social support). Additionally, we asked children after the third interaction whether they would want to talk with the robot about hospital related topics (yes/maybe/no) and feelings (yes/maybe/no).

Data analyses

Data was analyzed using IBM SPSS Statistics, version 25. For bonding, averages were calculated for all three scales of closeness, trust, and perceived social support separately. Descriptive statistics (frequencies, percentages, and averages) were used to describe participants, feasibility, experiences, and bonding as reported by children and parents.

RESULTS

Participants

Twenty-two children met the inclusion criteria, and these families were invited to participate in the study. Two families did not participate: One because parents disapproved of the use of robots in health care and the other because it was not the right moment (the family was too overwhelmed). Thus, twenty children and their parents participated in this study (91% response rate) (Table 2). Children were on average 8.5 years old ($SD = 1.96$, median = 9 years old), and evenly divided with regard to sex. Most children (80%) had their first interaction with the robot within 4 months after their diagnosis ($M = 3.78$, $SD = 6.28$, range 0-25 months).

Feasibility

Hospital context

All 20 families completed the first interaction, 17 families (85%) completed the second interaction, and 14 families (70%) participated in all three interactions, resulting in a drop out of 30%. In total, 51 interactions with the robot were accomplished (85%). Reasons for drop-out were lack of additional hospital visits (4/20), disliking the robot (1/20), and the child becoming too ill (1/20). Of the 14 families participating at the third interaction, the robot accompanied 11 children during a medical procedure.

Reasons for the robot not accompanying a medical procedure were families not wanting to change the regular routine (2/14, interactions done at the patient room), and a change in schedule (1/14, interaction done at the outpatient clinic). On average, there were 34 days between the first and third interaction ($SD = 24.14$, range 11-99).

TABLE 2
Patient characteristics ($n = 20$)

	<i>n</i>	%
Age		
6 years	6	30.0
7 years	1	5.0
8 years	1	5.0
9 years	5	25.0
10 years	3	15.0
11 years	4	20.0
Gender		
Boys	10	50.0
Girls	10	50.0
Department		
Stem cell transplantation unit	3	15.0
Solid tumor department	17	85.0

Technical functioning of the robot

At the three consecutive interactions, technical issues were encountered at respectively 35%, 53%, and 7% of the interactions. In respectively 15%, 6%, and 7% of the interactions, the issue could not be solved by restarting the robot, and resulted in early termination of the interaction after which the interaction was planned again. The option to pause the robot was used once in 15% of the first interactions, once or twice in 12% of the second interactions, and between one and multiple times in 29% of the third interactions. Reasons to pause the robot in the patient room were mostly bathroom breaks or interruptions by (medical) staff. At the first and second interaction, respectively 80% and 13% of the children could not answer the robot the way they wanted to even when using the repair mechanism at least once. Most children (90%) needed help from the researcher during the first interaction (median = 4, IQR = 2-5, range 0-16 times), and all children (100%) needed help during the second interaction (median = 4, IQR = 2-5.75, range 1-12 times). This help consisted mostly of extra instructions or timing of answers. Children reported good intelligibility of the robot both during the first and second interaction (83% and

67% respectively). After the first interaction, 59% of the children reported that talking to the robot was not easy, which changed to 33% after the second interaction.

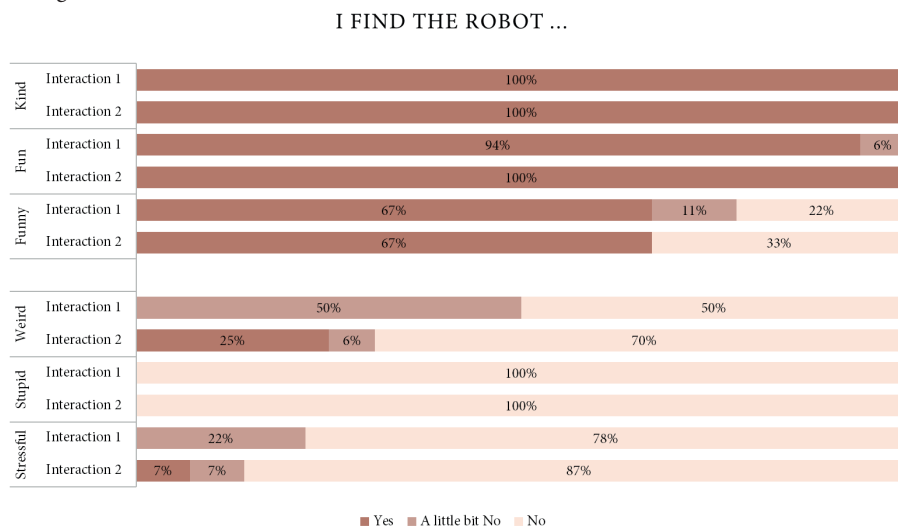
Experiences

During hospitalization (interaction 1 and 2)

All children experienced the robot as age-appropriate in both interactions. Children found the robot fun and kind, and none of the children thought the robot was stupid. Some children thought the robot was a little bit stressful and weird in the first interaction (22% and 50% respectively), but this became less in the second interaction (14% and 31% respectively) (Figure 2). Children on average reported to feel slightly better after the first two interactions with the robot (8.3 and 8.6 respectively) compared to before the interactions (7.9 and 7.9 respectively). Children rated interaction 1 on average an 8.7 (range 5-10), and interaction 2 a 9.2 (range 6-10).

FIGURE 2

Ratings of children about the robot



Note. Interaction 1, $n = 18$; interaction 2, $n = 16$.

During a medical procedure (interaction 3)

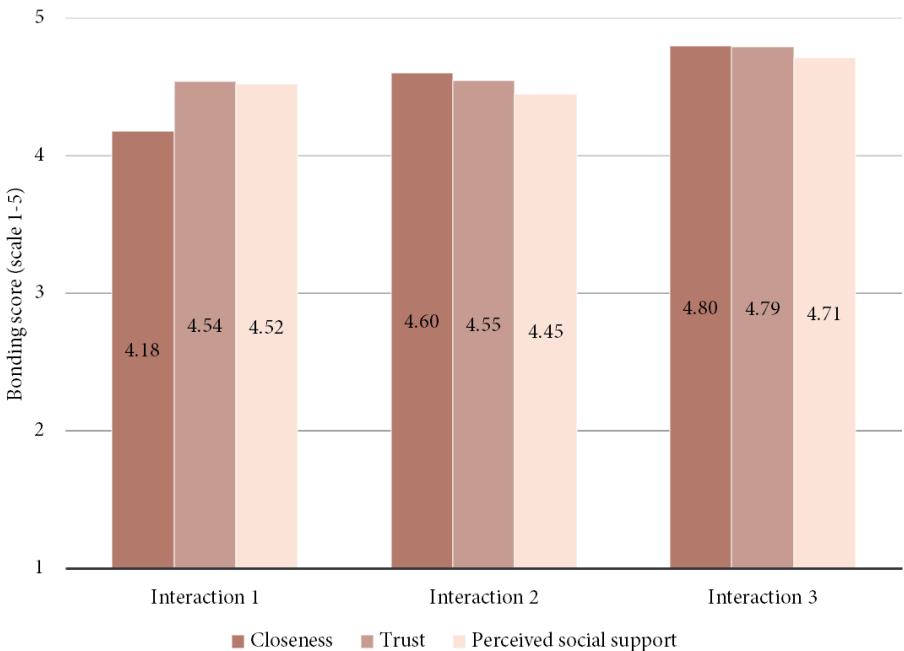
The robot was present during subcutaneous venous port insertions (55%), Hickman plaster changes (18%), a probe insertion (9%), going under anesthesia (9%), and

removing a needle (9%). After the procedure, most children (70%) reported to have experienced less stress and anxiety, and a proportion (30%) less pain now that the robot was present. Three-quarters of the children reported they were able to adequately listen to and watch the story of the robot. Almost all children (90%) appreciated that the robot was there to support them. Most parents (78%) reported that they thought their child experienced less stress and anxiety, and half of them (50%) less pain. They also reported that the procedure mostly went similar to normal (78%) or easier (22%). Almost all parents (89%) were positive about using a robot as a buddy to support children during medical procedures.

Bonding

At all three interactions, bonding scores were on average high and above 4 for perceived closeness, trust, and social support. Scores were also quite stable across the three interactions (Figure 3). Children were divided about whether they would prefer to talk with the robot about hospital related topics or not (42% yes, 42% no, 16% maybe).

FIGURE 3
Perceived bonding by children with the social robot over three interactions



Note. Interaction 1, $n = 13$; interaction 2, $n = 10$; interaction 3, $n = 7$.

Around half of the children (58%) would like to talk with the robot about how they feel, yet a quarter of the children would not (25%).

DISCUSSION

We explored the introduction of a social robot as a buddy into pediatric oncology care, using an autonomously interacting robot, capable of personalized conversations. With regard to feasibility, we found that participation among children during treatment was high, even within the first few months after diagnosis. This confirms the strong attraction of children to a social robot, and indicates that social robots can provide unique opportunities to reach children in a health care context. However, completing multiple interactions was not always possible (in about 1/3 children unsuccessful), and accomplishing the interactions required a lot of effort from the researcher.

There were many technical issues, although only few that resulted in early termination of the interaction. The technical issues that were experienced most were the automatic speech recognition not working, the robot not continuing the interaction when it was unable to process the answer of a child, and the robot rambling through the script. Almost all children experienced at least once that they were unable to respond to the robot, even with the repair mechanism that was put in place. Therefore, the current repair mechanism did not seem to work adequately enough. Many children explained that they struggled with the timing of pressing the button because options were listed too fast or there was no appropriate alternative in the list of suggestions by the robot. This was especially the case during the first interaction, where the conversation with the robot was personal, and included answers of children about for example their favorite color or animal (which mattered to them to be correct). This may be facilitated by using a tablet in communication with the robot [25] or as a repair mechanism when verbal communication fails [26] as was previously done in social robot studies.

Looking at experiences during hospitalization, children were positive overall, which is in line with the literature [5,6,13,15,27]. Children even reported on average to feel somewhat better after their interactions with the robot. However, some children also reported they found the robot a bit stressful or encountered difficulties in talking with the robot. Possibly, some children were too young for the more complex interactions that were designed for this study. In another study, where a social robot was used to teach children a second language using games, positive results were obtained in

young children of 5-6 years old [28]. In our study, the robot expected a certain type of answers in a specific time frame, and especially younger children were less flexible in changing their answer when the robot did not understand them. Nevertheless, young children found the robot age-appropriate and liked the robot as a buddy. Therefore, future efforts may be directed toward programming the robot differently to attune better to younger children, for example by adjusting the vocabulary, timing, and answering possibilities. Other suggestions from younger children in our study for future developments were more free play with the robot, hearing and sharing more stories, or just its company (being there).

During medical procedures, about 1/5 children did not prefer the presence of the robot. Children who did, reported less stress and some of them also less pain, which was also confirmed by parents. We attempted to include the experiences of child life specialists with a robot buddy supporting children, but did not succeed because of their absence during the medical procedures. Considering that child life specialists were found to be more reluctant towards social robots than other health care providers working in pediatric oncology [29], it would be valuable to further investigate how to integrate social robots into their work when used for stress reduction. We observed that children experiencing lots of stress during the medical procedure, had no attention for the robot. Storytelling may therefore not be suitable to distract children enough during very stressful events, as it requires active attention from the child. Therefore, active distraction, as was done in previous studies with promising results, may work better [10-12,18]. However, for these highly stressed children, introducing a social robot upon a medical procedure may cause additional stress, and having bonded with the robot could be especially beneficial. More generally, repeated interactions may be more meaningful in overall stress and anxiety reduction in the hospital context, and more research is needed on effectiveness, as well as meaningful time points during treatment for a robot buddy.

Almost all children appreciated the company of the robot as a buddy, and ratings on bonding over three interactions remained high. In previous research, in which the bonding questionnaire was validated, scores were also high after one encounter [24]. Our study showed that children did not seem to have lost interest in the robot after three interactions in a time period within one month. Future research should determine whether loss of interest occurs after more interactions or time to further explore the extend of a buddy during longer-term treatment. Bonding may increase further if the robot discusses topics more personally related to children, such as the

child's illness and/or feelings. But, because of ethical and data safety concerns when using software that is connected to the internet, we were unable to realize this.

Limitations

For younger children (<8 years old) it was difficult to reflect on the interactions with the robot. They were very excited about the robot, and sometimes their scores did not seem to match the reality (e.g., the robot was never able to process the responses of the child, but the child answered that it was very easy to talk to the robot). Also, only a limited number of interactions could be realized during medical procedures in which limited stress was encountered. Therefore, we cannot draw conclusions about experiences under more stressful circumstances.

Future directions

We developed and tested a robot that is capable of autonomous interactions with children, whereby also tailoring conversations based on answers of children and using answers of children in later conversations. Especially the functionality of autonomous conversations is important for future implementation whereby not relying on or burdening health care providers. However, further technical development is needed. The robot should better understand the child, and alternative speech recognition software that can be used without internet connection is needed for more advanced and safe interactions in the hospital context. Also, an alternative route for continuing the interaction when the robot does not understand the child is needed. Additionally, when the interaction is not going smoothly (i.e., multiple times reaching the maximum number of answering attempts) the robot should be able to adapt by for example making the interaction simpler (i.e., switching to yes-no questions only or answering through buttons). Furthermore, children should be trained properly in using a social robot to improve independent use, as children usually show a learning curve in using new technologies.

Conclusions

We found that children were highly interested to interact with the robot, had positive experiences, and perceived high levels of bonding over three interactions. Therefore, we believe that the concept of a robot buddy for children for multiple interactions during cancer treatment for supportive care is promising. However, further software development or simpler interactions are needed to overcome some technical issues and ensure smoother interactions.

REFERENCES

1. Kazak, A.E.; Kassam-Adams, N.; Schneider, S.; Zelikovsky, N.; Alderfer, M.A.; Rourke, M. An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2006**, *31*, 343-355, <http://doi.org/10.1093/jpepsy/jsj054>.
2. Network, N.C.T.S. Definition of medical traumatic stress. *Paper presented at the Medical Traumatic Stress Working Group meeting* **2003**.
3. Flowers, S.R.; Birnie, K.A. Procedural preparation and support as a standard of care in pediatric oncology. *Pediatric Blood & Cancer* **2015**, *62*, S694-S723, <http://doi.org/10.1002/pbc.25813>.
4. Huisman, J.; De Ridder-Sluiter, J.G. Ontwikkelingsgerichte zorg. In *Leerboek kinderoncologie*, Kaspers, G.J.L., Dors, N., Luijpers, W., Benoit, Y., Eds.; De Tijdstroom: Utrecht, the Netherlands, **2019**; pp. 153-162.
5. Breazeal, C. Social robots for health applications. In Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC), Boston, MA, USA, **2011**; pp. 5368-5371.
6. Logan, D.E.; Breazeal, C.; Goodwin, M.S.; Jeong, S.; O'Connell, B.; Smith-Freedman, D.; Heathers, J.; Weinstock, P. Social Robots for Hospitalized Children. *Pediatrics* **2019**, *144*, <http://doi.org/10.1542/peds.2018-1511>.
7. Oborn, E.; Barrett, M.; Darzi, A. Robots and service innovation in health care. *Journal of Health Services Research & Policy* **2011**, *16*, 46-50, <http://doi.org/10.1258/jhsrp.2010.010001>.
8. Kuo, A.A.; Etzel, R.A.; Chilton, L.A.; Watson, C.; Gorski, P.A. Primary care pediatrics and public health: Meeting the needs of today's children. *American Journal of Public Health* **2012**, *102*, e17-e23, <http://doi.org/10.2105/AJPH.2012.301013>.
9. Beran, T.N.; Ramirez-Serrano, A.; Vanderkooi, O.G.; Kuhn, S. Reducing children's pain and distress towards flu vaccinations: A novel and effective application of humanoid robotics. *Vaccine* **2013**, *31*, 2772-2777, <http://doi.org/10.1016/j.vaccine.2013.03.056>.
10. Rossi, S.; Larafa, M.; Ruocco, M. Emotional and behavioural distraction by a social robot for children anxiety reduction during vaccination. *International Journal of Social Robotics* **2020**, *12*, 765-777, <http://doi.org/10.1007/s12369-019-00616-w>.
11. Smakman, M.H.J.; Smit, K.; Buser, L.; Monshouwer, T.; Van Putten, N.; Trip, T.; Schoof, C.; Preciado, D.F.; Konijn, E.A.; Van der Roest, E.M. Mitigating children's pain and anxiety during blood draw using social robots. *Electronics* **2021**, *10*, 1211, <http://doi.org/10.3390/electronics10101211>.
12. Farrier, C.E.; Pearson, J.D.R.; Beran, T.N. Children's fear and pain during medical procedures: A quality improvement study with a humanoid robot. *Canadian Journal of Nursing Research* **2020**, *52*, 328-334, <http://doi.org/10.1177/0844562119862742>.
13. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.
14. Lopez-Rodriguez, M.M.; Fernandez-Millan, A.; Ruiz-Fernandez, M.D.; Dobarrío-Sanz, I.; Fernandez-Medina, I.M. New technologies to improve pain, anxiety and depression in children and adolescents with cancer: A systematic review. *International Journal of Environmental Research and Public Health* **2020**, *17*, <http://doi.org/10.3390/ijerph17103563>.

15. Moerman, C.J.; Van der Heide, L.; Heerink, M. Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review. *Journal of Child Health Care* **2019**, *23*, 596-612, <http://doi.org/10.1177/1367493518803031>.
16. Robinson, N.L.; Cottier, T.V.; Kavanagh, D.J. Psychosocial health interventions by social robots: Systematic review of randomized controlled trials. *Journal of Medical Internet Research* **2019**, *21*, e13203, <http://doi.org/10.2196/13203>.
17. Trost, M.J.; Ford, A.R.; Kysh, L.; Gold, J.I.; Mataric, M. Socially assistive robots for helping pediatric distress and pain: A review of current evidence and recommendations for future research and practice. *The Clinical Journal of Pain* **2019**, *35*, 451-458, <http://doi.org/10.1097/Ajp.0000000000000688>.
18. Jibb, L.A.; Birnie, K.A.; Nathan, P.C.; Beran, T.N.; Hum, V.; Victor, J.C.; Stinson, J.N. Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial. *Pediatric Blood & Cancer* **2018**, *65*, e27242, <http://doi.org/10.1002/pbc.27242>.
19. Kahn, P.H.; Gary, H.E.; Shen, S. Children's social relationships with current and near-future robots. *Child Development Perspectives* **2013**, *7*, 32-37, <http://doi.org/10.1111/cdep.12011>.
20. Van Straten, C.L.; Peter, J.; Kühne, R. Child-robot relationship formation: A narrative review of empirical research. *International Journal of Social Robotics* **2020**, *12*, 325-344, <http://doi.org/10.1007/s12369-019-00569-0>.
21. Neerincx, M.A.; van Vught, W.; Blanson Henkemans, O.; Oleari, E.; Broekens, J.; Peters, R.; Kaptein, F.; Demiris, Y.; Kiefer, B.; Fumagalli, D.; et al. Socio-cognitive engineering of a robotic partner for child's diabetes self-management. *Frontiers in Robotics and AI* **2019**, *6*, 118, <http://doi.org/10.3389/frobt.2019.00118>.
22. Ligthart, M.E.U. Shaping the child-robot relationship: Interaction design patterns for a sustainable interaction. Vrije Universiteit Amsterdam, Culemborg, **2022**.
23. Ligthart, M.E.U.; Fernhout, T.; Neerincx, M.A.; Van Bindsbergen, K.L.A.; Grootenhuis, M.A.; Hindriks, K.V. A child and a robot getting acquainted - Interaction design for eliciting self-disclosure. In Proceedings of the 18th International Conference on Autonomous Agents and MultiAgent Systems (AAMAS), Montreal, Canada, **2019**; pp. 61-70.
24. Van Straten, C.L.; Kühne, R.; Peter, J.; De Jong, C.; Barco, A. Closeness, trust, and perceived social support in child-robot relationship formation. Development and validation of three self-report scales. *Interaction Studies* **2020**, *21*, 57-84, <http://doi.org/10.1075/is.18052.str>.
25. Blanson Henkemans, O.A.; Bierman, B.P.B.; Janssen, J.; Looije, R.; Neerincx, M.A.; Van Dooren, M.M.M.; De Vries, J.L.E.; Van der Burg, G.J.; Huisman, S.D. Design and evaluation of a personal robot playing a self-management education game with children with diabetes type 1. *International Journal of Human-Computer Studies* **2017**, *106*, 63-76, <http://doi.org/10.1016/j.pec.2013.04.012>.
26. Van Bindsbergen, K.L.A.; Van der Hoek, H.; Van Gorp, M.; Ligthart, M.E.U.; Hindriks, K.V.; Neerincx, M.A.; Alderliesten, T.; Bosman, P.A.N.; Merks, J.H.M.; Grootenhuis, M.A.; et al. Interactive education on sleep hygiene with a social robot at a pediatric oncology outpatient clinic: Feasibility, experiences, and preliminary effectiveness. *Cancers* **2022**, *14*, <http://doi.org/10.3390/cancers14153792>.
27. Moerman, C.J.; Jansens, R.M. Using social robot PLEO to enhance the well-being of hospitalised children. *Journal of Child Health Care* **2021**, *25*, 412-426, <http://doi.org/10.1177/1367493520947503>.

28. Rintjema, E.; Van den Berghe, R.; Kessels, A.; De Wit, J.; Vogt, P. A robot teaching young children a second language: The effect of multiple interactions on engagement and performance. In Proceedings of the HRI Companion: Conference on ACM/IEEE International Conference on Human-Robot Interaction (HRI), Chicago, USA, **2018**.
29. Van Bindsbergen, K.L.A.; Van Gorp, M.; Thomassen, B.; Merks, J.H.M.; Grootenhuis, M.A. Social robots in pediatric oncology: Opinions of health care providers. *Journal of Psychosocial Oncology Research and Practice* **2022**, *4*, e073, <http://doi.org/10.1097/OR9.0000000000000073>.

Interactive education on sleep hygiene with a social robot at a pediatric oncology outpatient clinic: Feasibility, experiences, and preliminary effectiveness

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ABSTRACT

Objectives

Children with cancer often experience sleep problems, which are associated with many negative physical and psychological health outcomes, as well as with a lower quality of life. Therefore, interventions are strongly required to improve sleep in this population. We evaluated interactive education with respect to sleep hygiene with a social robot at a pediatric oncology outpatient clinic regarding the feasibility, experiences, and preliminary effectiveness.

Methods

Researchers approached children (8 to 12 years old) who were receiving anticancer treatment and who were visiting the outpatient clinic with their parents during the two-week study period. The researchers completed observation forms regarding feasibility, and parents completed the Children's Sleep Hygiene Scale before and two weeks after the educational regimen. The experiences of children and parents were evaluated in semi-structured interviews. We analyzed open answers by labeling each answer with a topic reflecting the content and collapsed these topics into categories. We used descriptive statistics to describe the feasibility and experiences, and a dependent-samples t-test to evaluate the preliminary effectiveness.

Results

Twenty-eight families participated (58% response rate) and all interactions with the robot were completed. The children and parents reported that they learned something new (75% and 50%, respectively), that they wanted to learn from the robot more often (83% and 75%, respectively), and that they applied the sleeping tips from the robot afterwards at home (54%). Regarding the preliminary effectiveness, children showed a statistically significant improvement in their sleep hygiene ($p = 0.047$, $d = 0.39$).

Conclusions

Providing an educational regimen on sleep hygiene in a novel, interactive way by using a social robot at the outpatient clinic seemed feasible, and the children and parents mostly exhibited positive reactions. We found preliminary evidence that the sleep hygiene of children with cancer improved.

INTRODUCTION

Sleep problems are common during and after treatment for childhood cancer [1-4] and they are related to a lower quality of life [5-7]. The prevalence of sleep problems in children with cancer during treatment ranges from 74 to 95% [5]. In this population, the sleep problems that are most frequently reported are bedtime resistance, sleep onset delay, and sleep anxiety. We can address these sleep problems with behavioral and educational interventions [1,6,8]. In the general population, parental knowledge about sleep hygiene is limited [9-11]. However, it has been shown that a greater parental knowledge of sleep is associated with healthier sleep practices [11,12] and that sleep hygiene education for parents and children is effective at improving sleep [13-16]. A multicomponent sleep intervention for children with brain tumors was tested in a pilot randomized controlled trial, which showed a modestly positive effect on nighttime sleep duration [17]. However, this intervention included education as well as relaxation training and stimulus control; thus, the effects of an education-only session on sleep hygiene in this population remains unknown.

To effectively change sleep hygiene in school-aged children, education should not only target parents, but it should also positively engage children. Social robots are considered fun and motivational by children, and parents appreciate that robots have a lot of patience, are not judgmental, and can help their children [18]. Children also accept the instructions of social robots and enjoy the company [19]. In a recent review on social robots for education, it was found that robots can provide outcomes that are similar to human tutoring in specific tasks, and that they can improve cognitive and affective outcomes [20]. Social robots also showed promise in improving the knowledge of children in health care settings through the provision of information [21]. For instance, in a previous study, it was found that social robots can support health education for children with diabetes. When compared with a control group, the social robot group experienced more enjoyment and engagement, and there was an increase in their health knowledge [22].

Supporting families of children with cancer with an educational sleep hygiene intervention is important for improving their knowledge of sleep hygiene. A social robot could be an appropriate tool, but it has not been previously used for this purpose. Therefore, this study aimed to explore the use of a social robot for interactive sleep hygiene education among school-aged children with cancer and their parents. Specifically, we aimed to evaluate the feasibility, the experiences of the children and their parents, and the preliminary effectiveness on sleep hygiene.

METHODS

Participants and recruitment

In this prospective study, children participated in an interactive sleep education session with a social robot together with one or both of their parents. Children were eligible to participate if they: (1) Were between 8 and 12 years old, (2) had received active anti-cancer treatment, (3) visited the outpatient clinic of the Princess Máxima Center during the two-week study period, (4) were accompanied by at least one parent, and (5) were fluent in Dutch. Children did not have to experience sleep difficulties to participate. We selected the specific age range of 8 to 12 years for multiple reasons. We based the lower age limit on previous clinical experience with this specific robot, from which we concluded that children between 4 to 7 years old seemed too young for the type of interactions that were created. In addition, 8-year-old children are old enough to independently participate and go to bed autonomously. The upper age limit was set to prevent the inclusion of children with shifting circadian rhythms in adolescence [23,24], or the perception of the robot as too childish or patronizing.

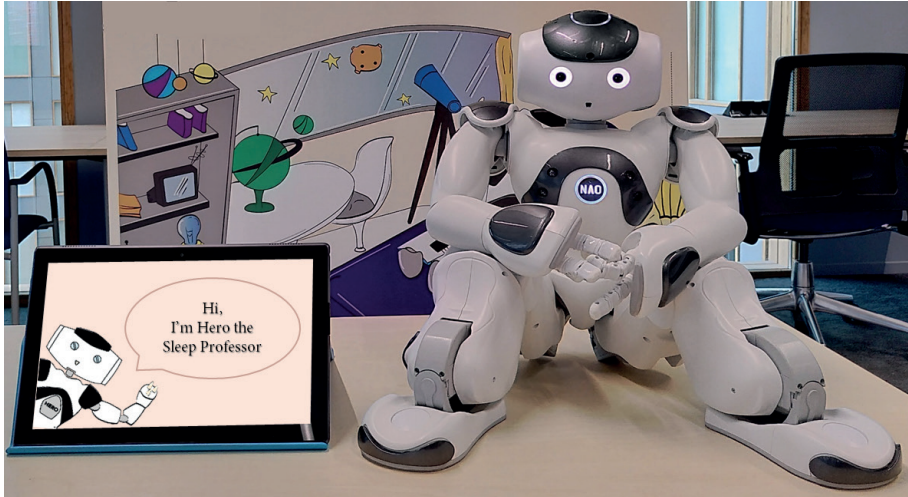
We identified children who met all inclusion criteria and informed these families about the study by mail one week prior to their outpatient clinic appointment. Additionally, we contacted families by phone on the day before their visit to discuss any remaining questions regarding study participation, or to record reasons for nonparticipation. Parents of participating families signed informed consent. The institutional medical ethics review board (number 21/640) classified this study as exempt from the Medical Research Involving Human Subjects Act.

The interactive sleep education

For the interactive sleep education, we used the NAO6 robot (hardware produced by SoftBank Robotics ©). Figure 1 shows a picture of the robot and set-up. A software framework was developed to allow the robot to autonomously behave in a socially intelligent way. We selected six health behaviors that are important for healthy sleep hygiene to implement in the education session [25]: (1) Minimal activities and screens before bedtime, (2) a consistent sleep routine, (3) an adequate sleep environment, (4) management strategies for worries, (5) daytime exercise, and (6) limiting food and drinks. We developed the content to be appropriate for children from 8 to 12 years old by using simple and appropriate language, providing visual support in the form of pictures, and fitting the content into a session with a duration of 10 min, at most (to ensure that children could sustain their attention).

FIGURE 1

Picture of the robot and set-up



The education started with the robot introducing itself as Hero the Sleep Professor, and with some small talk about sleep. The robot then discussed the sleep hygiene topics through 14 questions. The robot provided feedback on the children's answers and delivered explanatory information. Whenever the robot provided a sleep hygiene tip, its lights turned orange to increase awareness. A tablet visually supported the information provided by the robot, and children were able to select a virtual avatar to represent themselves when performing exercises, such as creating a bedtime routine. Figure 2 shows the illustrations of the avatars and examples of the use of the tablet. At the end, the robot said goodbye, and then children received a magnet with a summary of the tips and a written relaxation exercise to take home. Table 1 shows more information regarding the content of the education and interactions.

The 14 questions were either generic ($n = 8$) or personalized ($n = 6$). For the generic questions, children could give any answer using speech or the tablet, and the robot would react the same regardless of the answer. For the personalized questions, children had to give specific answers, and the robot replied differently based on the answer. Here, children had two attempts to answer using speech. In case of repeated failures, the robot would use a repair mechanism by displaying multiple-choice options on the tablet to reduce frustration and to ensure that the interaction could properly continue [26].

FIGURE 2

Examples of visual support by the tablet

(a) The avatars that the children could choose from



(b) Options when showing or creating a bedtime routine



(c) The robot describing its bedroom before asking children what their bedrooms looks like



Illustrations were made by Patrizia D'Oliveo ©

TABLE 1 Components of the interactive sleep education			
Topics and questions	Type of interaction		
	Open-ended (n = 8)	Close-ended (n = 6)	Activity (n = 4)
Introduction and general talk about sleep Hello, my name is Hero. What's your name? Can you pick a character you like or that looks most like you? How do you sleep?	Speech [any] Tablet Tablet		
1. Activities and screens before bedtime Wat do you do before you go to bed?	Speech [any]		
2. Consistent sleep routine Do you have a consistent sleep routine before you go to sleep? Do you want to show me your sleep routine using the tablet? / Shall we make a sleep routine together on the tablet? Can you put the images in the order of your own sleep routine / Can you put the images in an order that seems convenient to you?		Speech [y/n/s] Speech [y/n]	
Break 1: Co-creating Could you applaud me? Just do in 3, 2, 1. Could you cheer, as if you've just won a game? Just do in 3, 2, 1. Could you let me hear how you snore? Just do in 3, 2, 1.	Tablet		Participate Participate Participate
3. Sleep environment What does your bedroom look like? Is your room dark when you go to sleep?	Speech [any] Tablet		

TABLE 1 Continued			
Topics and questions	Type of interaction		
	Open-ended (<i>n</i> = 8)	Close-ended (<i>n</i> = 6)	Activity (<i>n</i> = 4)
4. <u>Managing worries</u> When you go to bed, do you fall asleep easily? I sometimes have trouble falling asleep because I'm worried, and I have to think about it all the time. Do you ever experience that? Break 2: Dancing Shall we dance for a moment?		Speech [y/n/s] Speech [y/n/s]	Participate
5. <u>Daytime exercise</u> Exercise, like sports, playing outside or riding your bike can help you to sleep better. Do you exercise often?		Speech [y/n/s]	
6. <u>Food and drinks</u> I'm curious what food and drinks you think you shouldn't take before you go to bed. Just click on them on the tablet. <u>Goodbye</u> Did you enjoy our conversation as well? <i>Note.</i> y/n(s) = yes/no/(sometimes).	Tablet		Speech [y/n]

We included two small breaks to allow children to relax and to support their attention span. During the first break, children recorded their own voices, which were used later in the education (i.e., co-creation) [27]. During the second break, children were invited to perform a popular TikTok dance together with the robot to music. The children could respond to the break activities by either participating or not, and the education continued regardless of their responses.

Procedure and measures

In the assessment of feasibility, researchers asked eligible patients whether it was possible for them to participate, as well as their reasons for wanting to participate. If they participated, then parents completed a questionnaire on their child's sleep hygiene before the education session. One of the five trained research staff members guided the education session. To further assess feasibility, researchers completed an observation form to log the technical functioning of the robot, engagement of the child, and the course of the interaction between the child and the robot during the session. After the education session, researchers conducted semi-structured interviews with children and parents about their experiences with the robot. The interviews consisted of open and closed questions using an overall rating on a scale of 0 to 10 (with a higher score indicating a better experience). Two weeks after the interaction, parents completed the sleep hygiene questionnaire again, with two additional questions to evaluate the use of the tips. The total time investment for families was about 30 min.

Sleep hygiene was assessed with the Dutch version of the Children's Sleep Hygiene Scale (CSHS) [28,29]. This parent-report questionnaire consists of 25 questions about sleep hygiene that can be answered on a 6-point scale (1 = never and 6 = always). The CSHS provides an overall measure of sleep hygiene, where higher scores indicate better sleep hygiene. Reliability of the Dutch version is acceptable, with a Cronbach's alpha of 0.78 [30].

Data analyses

Data was analyzed using IBM SPSS Statistics, version 25. We used descriptive statistics (frequencies, percentages, and averages) to describe the sample, feasibility (possibility of and reasons for participating, technical functioning of the robot, engagement of children, and course of the interactions), and the experiences of children and parents. For the latter, we analyzed the open answers of the semi-structured interviews by

labeling each answer with a topic reflecting the content. Two researchers (KvB and HvdH) independently identified and coded the topics of the open answers and collapsed them into categories. The researchers discussed the differences until they reached a consensus. To determine preliminary effectiveness of the program on sleep hygiene, a total mean score was calculated for the CSHS. We used a repeated measures t-test ($p < 0.05$) to analyze differences in sleep hygiene scores before and two weeks after the education. We estimated Cohen's d to interpret the magnitude of the effect, where we considered 0.2 as small, 0.5 as medium, and >0.8 as large, based on Cohen's guidelines [31].

RESULTS

Participants

The participants ($n = 28$) were 9.4 years old ($SD = 0.99$), on average, and they were evenly divided regarding sex (50% boys). Most children were diagnosed with a hemato-oncological disease. The parents of eight children (29%) shared additional information about their children: They reported two cases of Down syndrome, a developmental delay, a visual impairment, Gilles de la Tourette, speaking and performance anxiety, selective mutism, and autism with ADHD. Table 2 shows more details about the participants' characteristics.

TABLE 2 Patient characteristics ($n = 28$)		
	<i>n</i>	%
Age		
8 years	7	25.0
9 years	6	21.4
10 years	12	42.9
11 years	3	10.7
Gender		
Boys	14	50.0
Girls	14	50.0
Diagnosis type		
Hemato-oncology	19	67.9
Neuro-oncology	7	25.0
Solid tumor	2	7.1

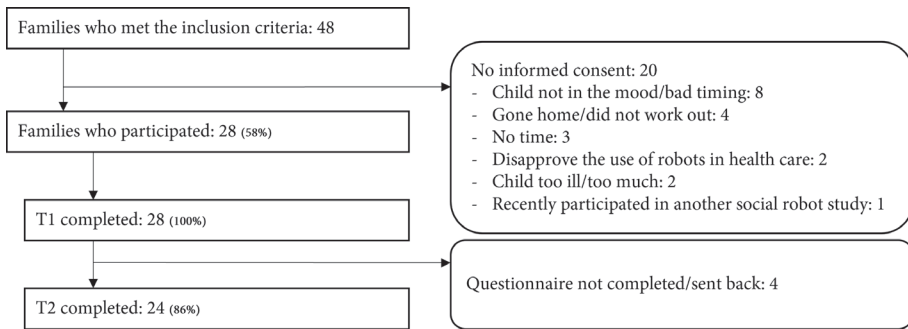
Feasibility

Possibility of participating when visiting the outpatient clinic

A total of 48 families met the inclusion criteria and were invited to participate in the study. There were 28 families that participated (58%). There were 20 families that did not participate, which was mostly because the children were not in the mood/it was not a good moment (42%). Of the 28 families that participated, 24 families (86%) also completed the questionnaire two weeks later. Figure 3 shows more details about the inclusion process and reasons for not participating.

FIGURE 3

Flowchart of participants and reasons for not participating



Note. T1 = interactive sleep hygiene education at the outpatient clinic, T2 = completing sleep hygiene questionnaire two weeks later.

Reasons for wanting to participate

Children reported that they participated because they were interested in the robot (61%), but also because their parents wanted them to (32%), or they wanted to learn more about sleep (7%). The reasons that the parents participated were more diverse: Being interested in the robot (29%), helping researchers and science (29%), because their children wanted to (21%), to learn about sleep (18%), and to pass time at the hospital (4%).

Technical functioning of the robot

The robot functioned without any problems in almost all the cases (89%). In the three cases where the robot did not function properly, restarting the robot solved the problem. For all the children (100%), the interaction with the robot could be fully completed.

Participation of children

Almost all the children (93%) were involved in the interaction with the robot, and they maintained their engagement from beginning to end. Two children sometimes lost their attention span, but they still completed the interaction.

Course of the interaction between child and robot

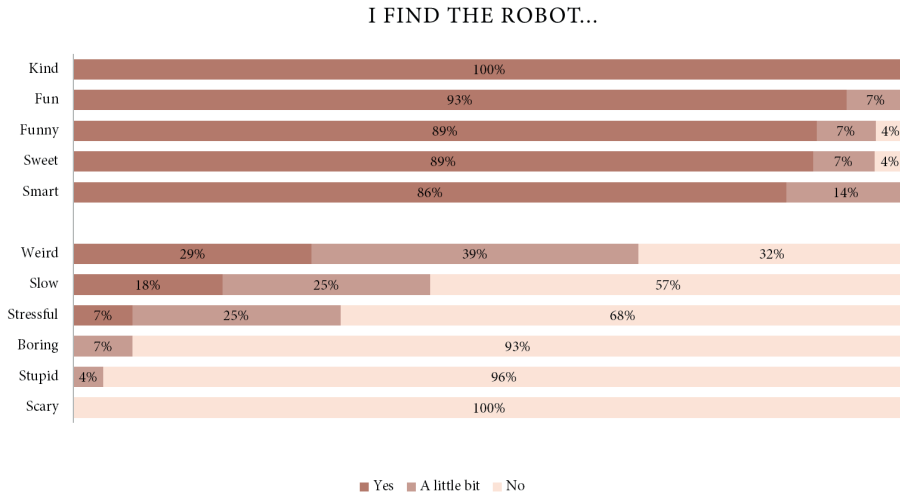
Most of the children (89%) responded to all of the generic questions; two children did not respond one time, and one child did not respond twice. Children needed 1.5 attempts, on average, to provide an answer to a personalized question that the robot could understand and process. More than half of the children (54%) needed to answer using the repair mechanism on the tablet: Eight children once, six children twice, and one child three times. The researcher often helped the children (50% with generic questions and 72% with personalized questions) during the interaction, mostly by providing extra instructions. The children (59%) needed the most help with the first two questions, and barely any help (3%) with the last two questions. At the breaks, most children (71%) participated in all of the activities. The children responded least to the robot asking them to dance and snore.

Experiences of children and parents

Evaluation by children

The children were generally enthusiastic about their interactions with the robot. The majority (55%) did not dislike any aspect of the robot, and none thought that the robot was scary. The children mentioned the interactive elements, such as talking and dancing with the robot, as the parts that they liked as well as disliked. Most of the children (75%) indicated that they learned something new about sleep from the robot, mostly regarding food and drinks and the sleeping routine. Furthermore, most of the children (75%) indicated that they intended to follow up on the sleeping tips of the robot, mostly with regard to limiting screen time before bed, paying attention to food and drinks, and sleeping in a dark room. Most of the children (82%) wanted to engage in interactive education with the robot more often. On average, the children rated their interaction as 8.6 (range: 5 to 10). Figure 4 shows more details about how the children evaluated the robot.

FIGURE 4
Ratings of children about the robot



Evaluation by parents

Almost all of the parents (96%) were positive about the use of a robot for educational purposes at the hospital, and most of the parents (86%) found the education appropriate for their children. The following are what parents considered the positive aspects: Suitability for children, a playful way of learning, and the interactive nature of the robot. Most of the parents (71%) thought that their child learned something new from the education, and half of the parents (50%) learned something new themselves. Many of the parents did not have any suggestions for improvements (52%); however, if they did, they consisted of the following areas of inquiry: Appropriateness for other ages (younger or older), presentation of the robot (location and looks), speaking pace (both faster and slower), and further software development (a better understanding of answers). Most of the parents (75%) indicated that they would want to engage in interactive education with the robot more often. In addition, parents suggested other topics for this: Medical procedures; pain, stress, and anxiety; nutrition; and medication. They suggested that the robot could be helpful for distraction, entertainment, physical activity, and to accompany the children as a buddy. On average, the parents rated the interaction as 8.0 (range: 7 to 10).

Preliminary effectiveness on sleep hygiene

Two weeks after the sleep education session with the robot, about half of the parents (54%) reported to have implemented something from the education at home, which mostly included rules to limit screens and stimulus control before bed. The parents who did not implement elements from the education indicated that they already applied most of the tips. Before the education, the sleep hygiene scores of the children ranged from 4.40 to 5.56 ($M = 5.11$, $SD = 0.27$). Two weeks after the education, the sleep hygiene scores ranged from 4.76 to 5.68 ($M = 5.26$, $SD = 0.25$), which was a statistically significant improvement ($M_{\text{diff}} = 0.10$, $t(22) = -2.1$, $p = 0.047$), with a small to medium effect size ($d = 0.39$).

DISCUSSION

In the current study, we investigated interactive education with respect to sleep hygiene with a social robot at a pediatric oncology outpatient clinic. The execution of the education at the outpatient clinic was feasible, as more than half of the families were able to attend, and the interest in participation was high. Moreover, the setting of the education session with the social robot was inclusive, as several children with (developmental) comorbidities were able to participate and complete the educational session together with their parents. The robot functioned well, and all the children were able to complete the educational regimen. The repair mechanism and the support of the tablet were important factors that contributed to the feasibility of the education session. The children responded well to the interactive parts, and they were able to maintain their attention for the 10-min session. Even though they often needed help from the researcher, the children quickly learned (in minutes) how to interact with the robot as their education progressed, which is similar to another study in healthy children [32].

The children and parents reported positive experiences regarding the education session, which is comparable to other social robot studies [18,33,34]. Contrary to previous research, the children did not remark on the repetitive aspects of the education regimen and the slow responses of the robot [22]; however, we had a one-session interaction, compared with the multiple-session education of the other study. Considering that families reported that they would like to learn from the robot more often, multiple sessions seem appropriate and could be beneficial for educational purposes [22,35].

The children enjoyed the interactive parts of the educational session, but some of the children disliked the interactive activities during the breaks. This result was also found

in another study with healthy children who engaged in interactive storytelling with a social robot [36]. A minority of the children disliked the interactive parts, and in a follow-up study, the researchers made parts of the interaction optional, which resulted in an improved sense of agency and acceptance [27]. Nevertheless, most of the families indicated that they learned something new from the robot, which we expected based on the literature [20-22], and this confirms that these results also apply to our pediatric outpatient oncology setting and for the purpose of sleep education.

The preliminary effectiveness of sleep education from a social robot in the outpatient pediatric oncology care setting was promising, as we found a statistically significant improvement in sleep hygiene two weeks after the interactive educational session. These results are remarkable, as one review concluded that while most sleep education programs in healthy children increased their sleep knowledge, this did not necessarily equate to sleep behavior changes, such as improved sleep hygiene [37]. However, in this study, most of the families followed up on the sleeping tips from the robot and applied the tips at home, such as less screen time and more relaxing activities before bedtime. This result may underline the additional value of including parents in the educational session and providing education through a social robot. The magnet with a summary of the sleep hygiene tips may have contributed to this effect as well.

Clinical implications

Most children with cancer experience sleep problems due to treatment effects, treatment-related toxicities, the hospital environment, and psychological and social factors [38-41]. These sleep problems are associated with many negative physical and psychological health outcomes [42,43], and consequently with a lower quality of life [6]. Therefore, interventions are paramount for improving sleep in this population [44], which may be achieved by improved sleep hygiene [14,16]. Our study achieved positive results in terms of feasibility, the experiences of the children and parents, and the indications of the program's effectiveness, demonstrating that administering sleep hygiene education to children and parents via a social robot is a promising form of intervention for sleep problems.

Future directions

A larger study of the program's effectiveness is needed before a social robot that provides sleep education can be considered effective at improving the sleep hygiene

of children with cancer. We evaluated the effects of one education session shortly after the intervention, and it is unknown whether these results will last over the long term, or whether repeated interactions would be meaningful for better or longer-lasting behavioral change. Future developments should focus on how to best design such interactions with social robots in a way that keeps children optimally engaged [45,46], and by taking into account the role of novelty [47]. In addition, researchers should investigate whether the intervention is specifically effective for children who experience sleep difficulties, as they are in the most need of support.

Upon further implementation of a social robot in a pediatric oncology setting, it would be interesting to consider whether the educational session should be supervised. On the one hand, the presence of a researcher during the educational session was essential to provide guidance and address difficulties, but it was also a potential barrier. However, previous research on health care providers in pediatric oncology worldwide has shown that the majority of them would be open to using a social robot in their work [48]. On the other hand, social robots that can be independently used by families (for example, in the waiting room at the outpatient clinic) could be appealing as well and could provide opportunities for easily accessible (and fun) information and prevention, with a minimal burden on the health care staff.

Limitations

During the interactions with the robot, the researcher sometimes helped the children. This was mainly based on the researcher's judgement of its necessity, which may warrant caution when interpreting these results. Regarding our measures on sleep, asking the children whether they adopted any changes based on the educational session with the robot would have been a meaningful addition, as we only asked the parents.

Conclusions

In this study, it was feasible to provide education on sleep hygiene in an interactive and playful way through a social robot at an outpatient clinic. The children undergoing cancer treatment and their parents were mostly positive about their experiences, and according to the preliminary results, the educational session had positive effects on the sleep hygiene of the children. Therefore, social robots appear to be a promising tool for education on sleep hygiene in pediatric oncology groups.

REFERENCES

1. Steur, L.M.H.; Grootenhuis, M.A.; Van Someren, E.J.W.; Van Eijkelenburg, N.K.A.; Van der Sluis, I.M.; Dors, N.; Van den Bos, C.; Tissing, W.J.E.; Kaspers, G.J.L.; Van Litsenburg, R.R.L. High prevalence of parent-reported sleep problems in pediatric patients with acute lymphoblastic leukemia after induction therapy. *Pediatric Blood & Cancer* **2020**, *67*, e28165. <https://doi.org/10.1002/pbc.28165>.
2. Steur, L.M.H.; Kaspers, G.J.L.; Van Someren, E.J.W.; Van Eijkelenburg, N.K.A.; Van der Sluis, I.M.; Dors, N.; Van den Bos, C.; Tissing, W.J.E.; Grootenhuis, M.A.; Van Litsenburg, R.R.L. The impact of maintenance therapy on sleep-wake rhythms and cancer-related fatigue in pediatric acute lymphoblastic leukemia. *Supportive Care in Cancer* **2020**, *28*, 5983-5993. <https://doi.org/10.1007/s00520-020-05444-7>.
3. Daniel, L.C.; Wang, M.; Mulrooney, D.A.; Srivastava, D.K.; Schwartz, L.A.; Edelstein, K.; Brinkman, T.M.; Zhou, E.S.; Howell, R.M.; Gibson, T.M.; et al. Sleep, emotional distress, and physical health in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Psycho-Oncology* **2019**, *28*, 903-912. <https://doi.org/10.1002/pon.5040>.
4. Peersmann, S.H.M.; Grootenhuis, M.A.; Van Straten, A.; Kerkhof, G.A.; Tissing, W.J.E.; Abbink, F.; De Vries, A.C.H.; Loonen, J.; Kremer, L.C.M.; Kaspers, G.J.L.; et al. Prevalence of sleep disorders, risk factors and sleep treatment needs of adolescents and young adult childhood cancer patients in follow-up after treatment. *Cancers* **2022**, *14*, 926. <https://doi.org/10.3390/cancers14040926>.
5. Steur, L.M.H.; Kolk, R.H.E.; Mooij, F.; De Vries, R.; Grootenhuis, M.A.; Kaspers, G.J.L.; Van Litsenburg, R.R.L. The prevalence and risk factors of sleep problems in pediatric oncology: Its effect on quality of life during and after cancer treatment. *Expert Review of Quality of Life in Cancer Care* **2016**, *1*, 153-171. <https://doi.org/10.1080/23809000.2016.1168265>.
6. Van Litsenburg, R.R.; Huisman, J.; Hoogerbrugge, P.M.; Egeler, R.M.; Kaspers, G.J.; Gemke, R.J. Impaired sleep affects quality of life in children during maintenance treatment for acute lymphoblastic leukemia: An exploratory study. *Health and Quality of Life Outcomes* **2011**, *9*, 25. <https://doi.org/10.1186/1477-7525-9-25>.
7. Gordijn, M.S.; Van Litsenburg, R.R.; Gemke, R.J.; Huisman, J.; Bierings, M.B.; Hoogerbrugge, P.M.; Kaspers, G.J. Sleep, fatigue, depression, and quality of life in survivors of childhood acute lymphoblastic leukemia. *Pediatric Blood & Cancer* **2013**, *60*, 479-485. <https://doi.org/10.1002/pbc.24261>.
8. Daniel, L.C.; Schwartz, L.A.; Mindell, J.A.; Tucker, C.A.; Barakat, L.P. Initial validation of the sleep disturbances in pediatric cancer model. *Journal of Pediatric Psychology* **2016**, *41*, 588-599. <https://doi.org/10.1093/jpepsy/jsw008>.
9. Owens, J.A.; Jones, C. Parental knowledge of healthy sleep in young children: Results of a primary care clinic survey. *Journal of Developmental & Behavioral Pediatrics* **2011**, *32*, 447-453. <https://doi.org/10.1097/DBP.0b013e31821bd20b>.
10. Owens, J.A.; Jones, C.; Nash, R. Caregivers' knowledge, behavior, and attitudes regarding healthy sleep in young children. *Journal of Clinical Sleep Medicine* **2011**, *7*, 345-350. <https://doi.org/10.5664/JCSM.1186>.
11. McDowall, P.S.; Galland, B.C.; Campbell, A.J.; Elder, D.E. Parent knowledge of children's sleep: A systematic review. *Sleep Medicine Reviews* **2017**, *31*, 39-47. <https://doi.org/10.1016/j.smr.2016.01.002>.

12. McDowall, P.S.; Elder, D.E.; Campbell, A.J. Relationship between parent knowledge of child sleep, and child sleep practices and problems: A pilot study in a children's hospital cohort. *Journal of Paediatrics and Child Health* **2017**, *53*, 788-793. <https://doi.org/10.1111/jpc.13542>.
13. Mindell, J.A.; Sedmak, R.; Boyle, J.T.; Butler, R.; Williamson, A.A. Sleep well!: A pilot study of an education campaign to improve sleep of socioeconomically disadvantaged children. *Journal of Clinical Sleep Medicine* **2016**, *12*, 1593-1599. <https://doi.org/10.5664/jcsm.6338>.
14. Gruber, R.; Somerville, G.; Bergmame, L.; Fontil, L.; Paquin, S. School-based sleep education program improves sleep and academic performance of school-age children. *Sleep Medicine* **2016**, *21*, 93-100. <https://doi.org/10.1016/j.sleep.2016.01.012>.
15. Tan, E.; Healey, D.; Gray, A.R.; Galland, B.C. Sleep hygiene intervention for youth aged 10 to 18 years with problematic sleep: A before-after pilot study. *BMC Pediatrics* **2012**, *12*, 189. <https://doi.org/10.1186/1471-2431-12-189>.
16. Rey, A.E.; Guignard-Perret, A.; Immler-Weber, F.; Garcia-Larrea, L.; Mazza, S. Improving sleep, cognitive functioning and academic performance with sleep education at school in children. *Learning and Instruction* **2020**, *65*, 101270. <https://doi.org/10.1016/j.learninstruc.2019.101270>.
17. Rogers, V.E.; Zhu, S.; Ancoli-Israel, S.; Liu, L.; Mandrell, B.N.; Hinds, P.S. A pilot randomized controlled trial to improve sleep and fatigue in children with central nervous system tumors hospitalized for high-dose chemotherapy. *Pediatric Blood & Cancer* **2019**, *66*, e27814. <https://doi.org/10.1002/pbc.27814>.
18. Smakman, M.; Vogt, P.; Konijn, E.A. Moral considerations on social robots in education: A multi-stakeholder perspective. *Computers & Education* **2021**, *174*, 104317. <https://doi.org/10.1016/j.compedu.2021.104317>.
19. Fridin, M.; Belokopytov, M. Embodied robot versus virtual agent: Involvement of preschool children in motor task performance. *International Journal of Human-Computer Interaction* **2014**, *30*, 459-469. <https://doi.org/10.1080/10447318.2014.888500>.
20. Belpaeme, T.; Kennedy, J.; Ramachandran, A.; Scassellati, B.; Tanaka, F. Social robots for education: A review. *Science Robotics* **2018**, *3*, 21. <https://doi.org/10.1126/scirobotics.aat5954>.
21. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371. <https://doi.org/10.1136/bmjpo-2018-000371>.
22. Blanson Henkemans, O.A.; Bierman, B.P.B.; Janssen, J.; Looije, R.; Neerincx, M.A.; Van Dooren, M.M.M.; De Vries, J.L.E.; Van der Burg, G.J.; Huisman, S.D. Design and evaluation of a personal robot playing a self-management education game with children with diabetes type 1. *International Journal of Human-Computer Studies* **2017**, *106*, 63-76. <https://doi.org/10.1016/j.pec.2013.04.012>.
23. Carskadon, M.A. Sleep in adolescents: The perfect storm. *Pediatric Clinics of North America* **2011**, *58*, 637-647. <https://doi.org/10.1016/j.pcl.2011.03.003>.
24. Crowley, S.J.; Wolfson, A.R.; Tarokh, L.; Carskadon, M.A. An update on adolescent sleep: New evidence informing the perfect storm model. *Journal of Adolescence* **2018**, *67*, 55-65. <https://doi.org/10.1016/j.adolescence.2018.06.001>.
25. Galland, B.C.; Mitchell, E.A. Helping children sleep. *Archives of Disease in Childhood* **2010**, *95*, 850-853. <https://doi.org/10.1136/adc.2009.162974>.

26. Ligthart, M.E.U.; Fernhout, T.; Neerincx, M.A.; Van Bindsbergen, K.L.A.; Grootenhuis, M.A.; Hindriks, K.V. A child and a robot getting acquainted - Interaction design for eliciting self-disclosure. In Proceedings of the 18th International Conference on Autonomous Agents and MultiAgent Systems (AAMAS), Montreal, Canada, **2019**; pp. 61-70.
27. Ligthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Co-creation as a facilitator for co-regulation in child-robot interaction. In Proceedings of the Companion of the ACM/IEEE International Conference on Human-Robot Interaction (HRI), Boulder, CO, USA, **2021**; pp. 298-302. <https://doi.org/10.1145/3434074.3447180>.
28. Harsh, J.R.; Easley, A.; LeBourgeois, M.K. A measure of children's sleep hygiene. *Sleep* **2002**, *25*, A316.
29. Van der Heijden, K.B.; Smits, M.G.; Gunning, W.B. Sleep hygiene and actigraphically evaluated sleep characteristics in children with ADHD and chronic sleep onset insomnia. *Journal of Sleep Research* **2006**, *15*, 55-62. <https://doi.org/10.1111/j.1365-2869.2006.00491.x>.
30. Van der Heijden, K.B.; De Sonnevile, L.M.; Swaab, H. Association of eveningness with problem behavior in children: A mediating role of impaired sleep. *Chronobiology International* **2013**, *30*, 919-929. <https://doi.org/10.3109/07420528.2013.790041>.
31. Cohen, J. The effect size. In Statistical Power Analysis for the Behavioral Sciences; Routledge: New York, NY, USA, **1988**; pp. 77-83.
32. Ligthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Getting acquainted for a long-term child-robot interaction. In Proceedings of the Social Robotics: 11th International Conference (ICSR), Madrid, Spain, **2019**; pp. 423-433. https://doi.org/10.1007/978-3-030-35888-4_39.
33. Jones, A.; Castellano, G.; Bull, S. Investigating the effect of a robotic tutor on learner perception of skill based feedback. In Proceedings of the Social Robotics: 6th International Conference (ICSR), Sydney, Australia, **2014**; pp. 186-195. http://doi.org/10.1007/978-3-319-11973-1_19.
34. Alemi, M.; Meghdari, A.; Haeri, N.S.; Young EFL learners' attitude towards RALL: An observational study focusing on motivation, anxiety, and interaction. In Proceedings of the Social Robotics: 9th International Conference (ICSR), Tsukuba, Japan, **2017**; pp. 252-261. http://doi.org/10.1007/978-3-319-70022-9_25.
35. Rintjema, E.; Van den Berghe, R.; Kessels, A.; De Wit, J.; Vogt, P. A robot teaching young children a second language: The effect of multiple interactions on engagement and performance. In Proceedings of the Companion of the ACM/IEEE International Conference on Human-Robot Interaction (HRI), Chicago, IL, USA, **2018**. <https://doi.org/10.1145/3173386.3177059>.
36. Ligthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Design patterns for an interactive storytelling robot to support children's engagement and agency. In Proceedings of the AMC/IEEE International Conference on Human-Robot Interaction (HRI), Cambridge, UK, **2020**; pp. 409-418. <https://doi.org/10.1145/3319502.3374826>.
37. Bluden, S.L.; Chapman, J.D.; Rigney, G.A. Are sleep education programs successful? The case for improved and consistent research efforts. *Sleep Medicine Reviews* **2012**, *16*, 355-370. <https://doi.org/10.1016/j.smrv.2011.08.002>.
38. Hinds, P.S.; Hockenberry, M.; Rai, S.N.; Zhang, L.; Razzouk, B.I.; McCarthy, K.; Cremer, L.; Rodriguez-Galindo, C. Nocturnal awakenings, sleep environment interruptions, and fatigue in hospitalized children with cancer. *Oncology Nursing Forum* **2007**, *34*, 393-402. <https://doi.org/10.1188/07.ONF.393-402>.

39. Walter, L.M.; Nixon, G.M.; Davey, M.J.; Downie, P.A.; Horne, R.S. Sleep and fatigue in pediatric oncology: A review of the literature. *Sleep Medicine Reviews* **2015**, *24*, 71-82. <https://doi.org/10.1016/j.smrv.2015.01.001>.
40. Dupuis, L.L.; Lu, X.; Mitchell, H.R.; Sung, L.; Devidas, M.; Mattano, L.A., Jr.; Carroll, W.L.; Winick, N.; Hunger, S.P.; Maloney, K.W.; et al. Anxiety, pain, and nausea during the treatment of standard-risk childhood acute lymphoblastic leukemia: A prospective, longitudinal study from the Children's Oncology Group. *Cancer* **2016**, *122*, 1116-1125. <https://doi.org/10.1002/cncr.29876>.
41. Lee, S.; Narendran, G.; Tomfohr-Madsen, L.; Schulte, F. A systematic review of sleep in hospitalized pediatric cancer patients. *Psycho-Oncology* **2017**, *26*, 1059-1069. <https://doi.org/10.1002/pon.4149>.
42. Itani, O.; Jike, M.; Watanabe, N.; Kaneita, Y. Short sleep duration and health outcomes: A systematic review, meta-analysis, and meta-regression. *Sleep Medicine* **2017**, *32*, 246-256. <https://doi.org/10.1016/j.sleep.2016.08.006>.
43. Jike, M.; Itani, O.; Watanabe, N.; Buysse, D.J.; Kaneita, Y. Long sleep duration and health outcomes: A systematic review, meta-analysis and meta-regression. *Sleep Medicine Reviews* **2018**, *39*, 25-36. <https://doi.org/10.1016/j.smrv.2017.06.011>.
44. Daniel, L.C.; Van Litsenburg, R.R.L.; Rogers, V.E.; Zhou, E.S.; Ellis, S.J.; Wakefield, C.E.; Stremler, R.; Walter, L.; Crabtree, V.M.; International Psycho-Oncology Society Pediatrics Special Interest Group. A call to action for expanded sleep research in pediatric oncology: A position paper on behalf of the International Psycho-Oncology Society Pediatrics Special Interest Group. *Psycho-Oncology* **2020**, *29*, 465-474. <https://doi.org/10.1002/pon.5242>.
45. Leite, I.; Martinho, C.; Paiva, A. Social robots for long-term interaction: A survey. *International Journal of Social Robotics* **2013**, *5*, 291-308. <https://doi.org/10.1007/s12369-013-0178-y>.
46. Gockley, R.; Bruce, A.; Forlizzi, J.; Michalowski, M.; Mundell, A.; Rosenthal, S.; Sellner, B.; Simmons, R.; Snipes, K.; Schultz, A.C.; et al. Designing robots for long-term social interaction. In Proceedings of the IEEE/RSJ International Conference on Intelligent Robots and Systems, Edmonton, Canada, **2005**; pp. 1338-1343. <https://doi.org/10.1109/IROS.2005.154530>.
47. Smedegaard, C.V. Reframing the role of novelty within social HRI: From noise to information. In Proceedings of the 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI), Daegu, Korea, **2019**; pp. 411-420. <http://doi.org/10.1109/HRI.2019.8673219>.
48. Van Bindsbergen, K.L.A.; Van Gorp, M.; Thomassen, B.; Merks, J.H.M.; Grootenhuis, M.A. Social robots in pediatric oncology: Opinions of health care providers. *Journal of Psychosocial Oncology Research and Practice* **2022**, *4*, e073. <https://doi.org/10.1097/OR9.0000000000000073>.

II

**Psychosocial support for families at home:
Development and investigation of two
interactive tools**

5

Designing tactful objects for sensitive settings: A case study on families dealing with childhood cancer

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ABSTRACT

In the field of Human-Computer Interaction (HCI), there is an increasing interest in designing for well-being. With this contribution, we introduce *Tactful Objects* as a design perspective on interactive artifacts that empower people in sensitive settings. We explore the concept of *tactfulness* by designing two interactive artifacts addressing the needs of families dealing with childhood cancer. The first, Mr.V, is an interactive dispenser to stimulate social activities in the family. The second, AscoltaMe, is a kind of walkie-talkie to enhance communication between family members. Eight families in treatment were invited to try out one of these artifacts at home. We report on how they perceived the objects' impact on family life, how they used and appreciated the objects and how the objects embedded at home. The findings highlight that Tactful Objects enable people to act with respect for their vulnerabilities and circumstances by establishing partnerships and collaborations that are inviting and appropriate for the setting in which they are embedded. We then reflect on the contribution of the work for research in healthcare and design for other sensitive settings. We conclude by presenting the limitations of the study and provide directions for future work.

INTRODUCTION

Childhood cancer is an example of a disruptive life event [1], such that the everyday life of families dealing with childhood cancer becomes a sensitive setting to design for [2]. Childhood cancer generates social, physical and emotional challenges that significantly impact the development of the child [3] and put stress on interpersonal family relationships [4]. Current research in pediatric cancer care highlights the extreme importance of enhancing the well-being of the entire family during the treatment; and of promoting interventions to help both child and family members in coping to decrease distress [5-8]. In addition, studies in Design and “Sensitive” HCI [9], have reported how interactive artifacts can be helpful in moments of crisis [10] because they can facilitate activities, support everyday routines or encourage new ones [11,12]. While stimulating changes [13] such artifacts may help in re-establish the *normality* that got impacted by disruptive life events [14]. In other words, they can help families to recreate the combination of spaces, habits, memories [15] that support their lifestyle [1].

Developing interactive artifacts for people dealing with crises requires tact in order to account for vulnerabilities and to avoid overwhelming the users [16-20]. We advance tactfulness as a design quality to attune the objects’ meaning, expressivity and embodiment to the needs of people in sensitive settings. We have explored this quality in the context of childhood cancer to help shape in appropriate and sensitive ways [21] the material qualities [22] and temporal form [23] of two interactive artifacts that we designed. As such, tactfulness was found to be useful in form giving practices for interaction design. However, in order to apply this to a broader design perspective, we need to understand how tactfully designed interactive artifacts perform in sensitive settings and how they provide empowering experiences. This is what this study aims to achieve.

The paper is organized as follows. In the Related work section, we elaborate on childhood cancer as a sensitive setting and present some of current supportive tools in cancer supportive care. We also present design examples that illustrate tactful approaches when designing for well-being. We then explain the rationale that brought us to develop two interactive artifacts for families dealing with childhood cancer in tactful ways. Following this, we report on a study conducted with eight families with a child in treatment for cancer, that were willing to try out one of these artifacts in their homes. We report on families’ experiences and reflect on how these insights

helped us to articulate the qualities of Tactful Objects. We continue by discussing the contribution of our work for research in healthcare and reflect on the value of Tactful Objects when designing for other sensitive settings. We conclude by presenting the limitations of the study and provide directions for future work.

RELATED WORK

In the field of developmental psychology, the growth of the child is described as a process where genetic factors that govern the biological development are continuously influenced by proximal environmental stimuli [8,24-26]. These proximal stimuli are described in Bronfenbrenner and Ceci's *bio-ecological* model [27]. In this model, the family is understood as an interdependent system where each member influences the other [28]. As such, the family is the most critical proximal social context influencing the optimal development of the child [29,30] especially in case of stressful and disruptive conditions.

Challenges in life, which generate stress and trigger profound changes, are described as disruptive life events [1]. These events, such as illness, death, divorce, and relocation, can have an impact on the individual and on the family as a whole. For instance, by influencing relationships and family coherence, the well-being of each family member can be affected [1]. Childhood cancer can be considered a disruptive life event because it significantly changes a family's *normal interactions and structures* [31]. Despite the support provided by professionals and healthcare institutions, families describe it as a long and lonely process [14] that creates stress on relationships [32], and generates a surreal experience [14]. The point that we would like to make here is that childhood cancer as a disruptive life event becomes a sensitive setting to design for, involving the family as a whole.

Much of the attention in psychosocial supportive care in pediatric oncology goes to preserving and fostering normality despite the many challenges and uncertainties caused by the illness. New approaches adopted during clinical interventions integrate playful activities and digital games to assess and stimulate the child's development [8]. Social robots have been introduced in the hospital environment to distract and interact with the children during distressing procedures [7,33,34]. Attention to the families has been promoted with the use of new tools like the *Cellie Cancer Coping Kit* that uses a puppet and illustrated cards to stimulate communication between children, family

members and caregivers, to promote coping and to help decrease distress [6]. Other examples implement user friendly web-based platforms to let children, sibling and parents communicate with the medical staff throughout the trajectory of treatment [5].

Research in design [35,36] as well as in clinical studies [37] points out how our feelings of well-being and happiness depend upon the activities we engage in. Artifacts and technologies are considered *mediators* that shape behaviors and activities, trigger reflection, awareness, and offer support in everyday routines [12,38-42]. However, there are some important considerations when designing such interventions in sensitive settings. For instance, technologies in domestic environments should be designed with an understanding of the family setting in their rituals and rhythms [43-46]. Many of the activities, relationships and values in this context are idiosyncratic and highly personal [47]. A tactful approach is even more warranted when families are faced with disruptive life events and are hereby likely to become vulnerable users [48].

We draw inspiration from some design examples that illustrate tactful approaches when designing for well-being. The *Cellie Cancer Coping Kit*, mentioned earlier, is a good example of how to design for children with cancer as vulnerable users [6]. What we consider to be tactful is the friendly appearance of the puppet, suitable for children to hold and cuddle with, that allows it to become a companion to the child during medical procedures. Another example is the *Chocolate Machine* by Kehr and colleagues [12] which is tactfully designed as a behavior change strategy by challenging a person's self-control in a playful way. By releasing chocolate balls and counting how many times the chocolate balls are placed back in the machine without eating them, a person becomes playfully aware of the temptation. In the *Ritual Machine V* by Chatting and colleagues [49] we see an example of how artifacts can be tactful when they are designed with a sensitivity for a family's character and values. Ritual Machine V is a smart monocular toy for children to remain connected to parents who are traveling abroad. It involves a deep understanding of the needs and rhythms of the particular family for which the object is designed. The *Other Brother* [50] is an example that illustrates a tactful approach in the design of a semi-autonomous object embedded in a domestic environment. It is a tangible object, resembling a small knight's helmet, that takes pictures and records sounds of spontaneous social events taking place in the environment when it is triggered by directional sound cues. It is tactfully designed to be experienced as an intelligent character that feels part of the family. Finally, the interesting concept of the *Family Circle* [46] is a portable voice messaging solution

system to support transitory indirect messaging in the household for working parents and teenaged children with separate routines. The design is based on the use of cylindric tokens that, if pressed, can record, store and play voice messages. This allows both flexibility and freedom in use through the house and in communicating secondary information. Families can play with color and brightness of the tokens' integrated lights to convey visual information about the sender, intended receiver, or the nature or urgency of the message.

Design cases

We will now describe how we have explored tactfulness when designing interactive artifacts to support families dealing with childhood cancer as a disruptive life event. The work described here is part of an ongoing Research-through-Design (RtD) project in collaboration with the Princess Máxima Center for Pediatric Oncology of Utrecht in the Netherlands [21]. RtD is a research approach in which design activities are an inherent part of doing research [51]. In this project this entails developing prototypes based upon a concept or vision, which are then tested in the field to learn from it. To get acquainted with the sensitive setting under investigation, we first conducted an observation of a cancer survivors meeting [52] and interviewed medical professionals working in pediatric oncology. We identified two recurrent challenges encountered by children with cancer and families during treatment: The reduced amount of *quality time* [14] generated by the profound stress caused by the illness and treatment, and the inability to talk openly about one's feelings, worries and hopes [53]. To address these challenges we developed two prototypes in consultation with psychologists, child-life specialists, and social workers of the participating pediatric oncology center. We will first explain the two prototypes (i.e., Mr.V and AscoltaMe) and then reflect on their tactful qualities.

Mr.V

Family life is based on shared routines and collective activities. In difficult times these should be preserved to give sense of continuity and motivation. Social activities often get hampered by the distress and the demotivation generated by the long cancer treatment. Mr.V aims at stimulating social activities that the family can engage in together (Figure 1). The V in Mr.V comes from the Dutch word *verrassing*, which means *surprise*. Mr.V is an interactive dispenser resembling a gumball vending machine that provides ideas for family activities instead of gum. The ideas are notes written by the family members and contain various activities that they would like to

do together. The notes are inserted into small plastic balls, which are stored in the machine. The ideas are then dispensed by the machine as *surprises* during the week, at unexpected moments. When Mr.V decides that it is time for a surprise, it will start shuffling the balls and making funny sounds to invite the family to check the surprise that is waiting for them. Family members can also receive a surprise on demand by pressing a button located on the backside of Mr.V.

FIGURE 1

Mr.V, an object that aims to stimulate social activities in the family

(a) Concept sketches

(b) Prototype

(c) Scenario of use

The sequence of actions is indicated in numerical order



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AscoltaMe

Sharing personal thoughts but also worries is important in order to maintain healthy connections among family members and reduce the burden of carrying something in mind. AscoltaMe (which means *listen to me* in Italian) encourages family members to talk about their feelings, worries, and hopes. It works like an alternative kind of walkie-talkie offering the possibility to engage in conversations in a playful way (Figure 2). Its translucent body presents two elements: A microphone and a loudspeaker connected through a flexible silicone tube. The microphone captures messages that family members want to share and *holds* them into the tube. Voice messages are visualized as light, which begins to fill the tube. The light then lingers in the tube and pulsates, indicating that there is a message waiting to be listened to. A red button placed on one end of the object allows to record a message and a green button placed on the other end allows to listen to the message. When someone presses the button to listen to the message, the light flows through the tube towards the loudspeaker, after which the message is played. If the message has not been completely listened to, the light will flow back into the tube, indicating that the message is still available.

Tactful qualities

Tactfulness has been the leitmotif in the design of Mr.V and AscoltaMe as a mean to design these artifacts to be appropriate and sensitive. Although the notion of Tactful Objects had not fully crystallized yet at this stage, tactfulness was intuitively applied in crafting both artifacts.

We relied upon *familiar childhood metaphors* in the design of both objects to stimulate curiosity and wonder in children and parents and to provide familiar forms of interaction. For example, Mr.V resembling a *gumball vending machine*, which hints at childhood memories of surprises; while for AscoltaMe the metaphor of the *tin-can-telephone* indicates playful ways of communicating. The interaction with these objects was designed to follow the metaphor. For example, the use of Mr.V involved filling the small plastic balls with ideas written on notes, which would be dispensed automatically or by pushing a button. AscoltaMe involved speaking into one end of the *phone* and listening to the other end of it, as if the message were conducted by the wire in between.

We designed the *expressiveness* of the objects to communicate their intent clearly but subtly. Mr.V shows that it will drop a surprise by shuffling the containers around, accompanying the event with light effects coming from within the machine. When

FIGURE 2

(a) Concept sketches

(c) Scenario of use

ascolta me



We designed the *embodiment* of the objects to be appropriate in the family home setting considering their aesthetics and robustness. As such, both objects were designed as interactive tangible artifacts with eye for detail, use of color and use of materials. Mr.V was designed to be valued as a decorative object in the home. The iconic features of an existing gumball machine were modified and presented as human clothing. The front lever was designed as a bow-tie and the top opening to introduce the containers in the machine, as a hat. Its metal and glass materials felt sturdy and safe. AscoltaMe was designed as a mysterious yet familiar-looking object that we hoped could find its place in the home as an electronic toy. Its white translucent embodiment revealed the embedded Arduino™ technology in suggestive ways and allowed the light to shine through. Printed plastic shells with intricate patterns formed the case for the recorder and loudspeaker that were connected by a flexible silicone tube.

FIELD STUDY

An empirical study was conducted to understand how families dealing with childhood cancer experienced these interactive artifacts in their homes. The study was designed, approved and conducted in accordance with the regulations of the Medical Ethics Committee of the University Medical Center Utrecht in the Netherlands. In consultation with the pediatric oncology center, we decided to limit the prototype testing for each family to one week in order to avoid generating stressful and overwhelming experiences. We also decided to avoid making use of design research techniques that might be experienced as intrusive (e.g., videotaping the interviews, etc.), and proposed to conduct participant recruitment and fieldwork under medical professional supervision. Throughout this contribution the word *we* acknowledges the collaborative effort of all the authors and research assistants from both the design and the medical domains, in framing, conducting and discussing the research.

Participants

Eleven families with a child with cancer were approached to participate in this study. Inclusion criteria were: The child being in active treatment for cancer; not being hospitalized; between 6 and 16 years of age (10 to 16 years for Mr. V, and 6 to 10 years for AscoltaMe). Families received an information letter about the study. After one week, the families were contacted by telephone to ask whether they wanted to participate. Two families declined to participate in the study with Mr.V: Because the patient was almost at

the end of the treatment ($n = 1$) and because the family found the study too childish for their teenager to participate in ($n = 1$). One family declined to participate in the study with AscoltaMe because the parents did not feel the need of a new communication device at home ($n = 1$). In total, eight families (72.7%) were included and written consent was obtained from all family members ($N = 33$; $n_{\text{children}} = 8$, $n_{\text{siblings}} = 9$, $n_{\text{parents}} = 16$). Once enrolled, two families could not continue the study with AscoltaMe because the child's physical condition worsened throughout the week ($n = 2$). Family demographic characteristics divided according to the artifact used are shown in Table 1.

TABLE 1Participant descriptions ($N = 33$)

Mr.V	Child (patient) ($n = 4$)		Siblings ($n = 5$)	Parents ($n = 8$)
	age	gender		
Kevin's family	10	Male	3	2
John's family	12	Male	0	2
Mary's family	13	Female	1	2
Sammy's family	14	Female	1	2
AscoltaMe	Child (patient) ($n = 4$)		Siblings ($n = 4$)	Parents ($n = 8$)
	age	gender		
Rachel's family	6	Female	2	2
Simon's family <i>a</i>	10	Male	0	2
Monica's family <i>b</i>	7	Female	1	2
Leon's family	8	Male	1	2

Note. Names are fictional.

a Simon stopped, but shared data through the diary

b Monica stopped the study (no data)

Procedure

The study consisted of three phases. In the *introduction phase*, either Mr.V or AscoltaMe was presented to the families at their home or at the hospital. Instructions about the main functions of the artifacts were given, as well as a user manual and a diary (Figure 3). Families were invited to try them out and ask questions, which took about 15-30 minutes. Then during the *use phase*, families were asked to keep the artifacts in their homes for at least one week, and to take notes in a diary about their daily use. In the concluding *evaluation phase*, families were interviewed either at home or at the hospital and filled out a questionnaire. This last phase took about 60-75 minutes.

FIGURE 3

Overview of the materials provided to the participants

(a) Mr.V with surprise-containers, power cable and user manual (a.1 notes papers and marker; a.2 plastic containers; a.3 diary; a.4 envelopes to collect used surprises, surprises suggested by Mr.V - see examples in Appendix 1 - and empty notes papers)

(b) AscoltaMe with power cable and user manual (b.1 diary; b.2 marker)



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Measures

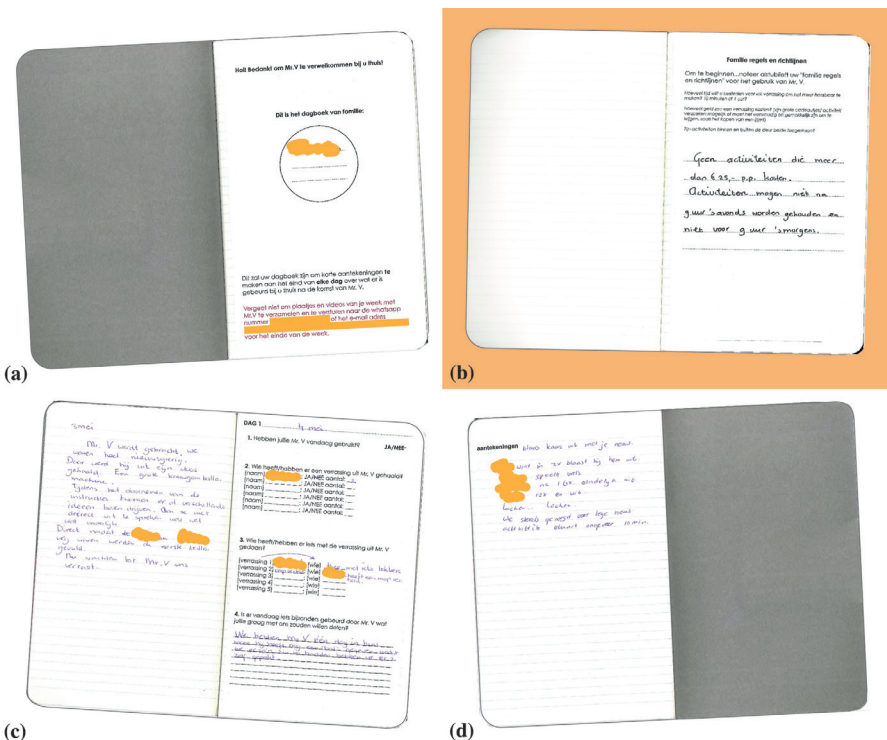
Different types of measures were used. Families were given a *diary* (Figure 4) in which they could take notes of what happened each day when using the artifact (e.g., whether they used it, who used it and what happened). For the families using Mr.V, the diary included an extra page in which families could set rules for the family activities they could consider (e.g., rules concerning the location, duration, and costs of the activities) (see Appendix 2 for details). Secondly, families were invited to take pictures and/or videos when using the artifacts, and shared them with the researchers through an encrypted instant messaging chat on WhatsApp™. Thirdly, a semi-structured interview was performed after the testing week, asking participants to

detail their experiences. We asked how/whether they felt the objects made an impact on family life, the ways in which they used and appreciated the objects, and how they perceived the objects to embed into their home context (see Appendix 3 for details). The interviews were organized as group interviews in which multiple family members participated together. In total, 18 family members were interviewed ($N = 18$; $n_{\text{children}} = 6$, $n_{\text{siblings}} = 3$, $n_{\text{parents}} = 9$). Lastly, a questionnaire consisting of five statements to rate the artifacts on a scale from 1 (strongly disagree) to 10 (strongly agree) was presented (see Appendix 4 for details). In total, 24 family members filled out the questionnaires ($N = 24$; $n_{\text{children}} = 6$, $n_{\text{siblings}} = 7$, $n_{\text{parents}} = 11$). We aimed to use this quantitative data to corroborate the results from the qualitative analysis. However, due to the limited contribution of these quantitative findings, we decided to exclude these measures from the analysis.

FIGURE 4

Diary structure

- (a) 1 introduction-page with family's name
- (b) 1 rules-page available only for families using Mr.V
- (c) Example of one of the 7 daily-pages with questions for the family
- (d) Extra space for notes



Data collection, processing and analysis

The data were collected by first and second authors and one assistant researcher (R.G.V.). The interviews were transcribed verbatim by two assistant researchers (M.R. and J.P.), anonymized by the first author and translated into English by a professional translation agency. The translated interviews were analyzed according to each interview question that addressed a different level of experience. The *mapping on the wall technique* [54] was used to organize the quotes in statements cards, cluster themes and subdivide the clusters in knowledge levels [55]. Collected pictures and videos were inserted in the statement cards as well as linked to an interpretation following the dual coding approach [56] (see Appendix 5 for examples). In total, 421 statements were collected. The statement cards were clustered following a thematic analysis approach in order to emphasize, examine, and record patterns within the data. The first author that conducted the field study and the interviews, and the last author, who wasn't involved in the fieldwork, collaborated on the interpretation of the data. The second author, who co-conducted the fieldwork and interviews, cross-checked the interpretation of the findings and the clustering for validation.

RESULTS

We will report on the results of the data analysis by summarizing the themes that emerged according to the different questions (i.e., impact on family life, ways of using the objects, objects appreciation, and embedding of the objects in the home context). Participant quotes are presented in *italic*.

Impact on family life

When asked about the effect of the object on their everyday life, parents, siblings, and children described Mr.V as a reminder to engage in quality time, while both Mr.V and AscoltaMe provided them enjoyable and playful experiences with a sense of normality and relieve from the situation they were in.

Parents mentioned that Mr.V helped them think about different activities to do, and felt like it acted as a *co-parent* that reminded them to engage in quality time with the whole family. John's mother said that *Mr.V invited to do things that we were not doing often: Things and activities that normally would come in second place due to the busy schedule of the hospital*. Kevin mainly noticed that Mr.V had the advantage of *simplifying the*

planning of things that were normally postponed. Furthermore, both siblings in Kevin's and Mary's family mentioned how Mr.V strengthened their connection with their brother or sister, giving them *the motivation to do things together.* For instance, Kevin's sister specified that she and her brother *came up with a special surprise for their parents.*

AscoltaMe was only used for a short period of time, with only one or two moments of active exploration. The usage was rather different than we expected in the concept design, and did not remind children to share thoughts and emotions to help parents and siblings understanding how they felt. Rachel's mother mentioned that *no new content has been shared within the family and no references to the disease have been made.* She also explained how, together with her partner, they played an active role in starting a conversation through AscoltaMe because the children would have not done that by themselves. Simon's mother *hoped that AscoltaMe would have helped to understand Simon better or share more personal things,* but this did not happen.

However, both artifacts provided a distraction from the child's illness. Families felt that Mr.V motivated them in a funny way and provided a new form of entertainment. Parents were relieved to see their children playing and engaging in the activities because, as John's father mentioned: *When the child is sick but still manages to do the usual activities, the child looks healthy.* Siblings mentioned that during treatment Mr.V brought *great fun and motivation and something to look forward to;* since their ill siblings were often really tired, Mr.V stimulated them to do something. The funny messages, jokes and social games triggered by AscoltaMe, even if only briefly, generated lighthearted moment for parents, children and siblings.

Ways of using the objects

When asked how they used Mr.V, families explained how they created and received surprises with Mr.V by writing notes, filling the plastic balls and opening them, and how they decided how and when to do the activities that were written down in the surprises. For AscoltaMe, families explained that its use entailed recording messages and listening to them. In general families described both artifacts as being easy to use but requiring some creativity, as in coming up with activities for Mr.V or which messages to record with AscoltaMe.

Families shared that they liked to create surprises with Mr.V because they experienced it as being a special family moment. In Kevin's family *all the surprises have been written*

down in the same evening when the family was sitting together and in John's family they made all the surprises in one go at the beginning of the week. Generally, participants explained that every family member contributed to the surprises. However, at times they also found it challenging to come up with so many surprises because as John's mother mentioned *it was difficult to come up with new ideas*. The surprises created by the families with Mr.V reflected their specific interests, capabilities and resources in the particular moment of the treatment (Figure 5) (see Appendix 6 for details). For example, in Kevin's family, food choice and consumption was a major concern during treatment. We found that most of the surprises concerned *food preparation and eating*. Sammy, instead, had an active and sporty family and their surprises were mainly based on sport and outdoor activities such as *playing tennis together or having a walk*. Families also mentioned how the experience of receiving surprises generated nice moments that created excitement and expectations for the whole family, as Kevin's father said: *Receiving little presents makes always someone happy*. Every family had a personal way of using Mr.V, showing freedom in choosing what to do and what not to. For instance, John's father said that *all the surprises have been dropped and opened, but not all of them were acted upon*.

For AscoltaMe, Rachel's mother reported that Rachel used AscoltaMe with her siblings *to tell jokes and say funny things, or to make funny noises*. She also explained that Rachel and her siblings were using AscoltaMe to make sound while playing a kind of *hide and seek* and used the device while hiding under a blanket or behind the couch. She further shared the observation that *it was fun to play with AscoltaMe but the children did not share any emotional feelings*. Moreover, the creation of and listening to the content was real-time rather than asynchronous and children did not leave any messages for the parents to listen to later. As Rachel's mother mentioned: *It was not a natural thing for them to do*.

Objects appreciation

When asked how they understood and appreciated the objects, participants shared their impressions about the associations the objects elicited, how they behaved, and how they experienced different aspects and details of the artifacts' embodiment.

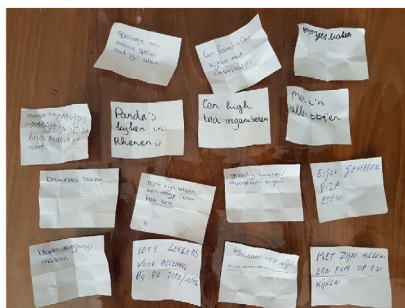
The two artifacts were described in relation to the associations they elicited. Families used different ways to describe them, as *devices, familiar artifacts* or in the case of Mr.V, as a kind of *character*. For example, John's father described Mr.V as a *smart*

device and as a *complete system* in which each feature is designed to accommodate different functions but he also noticed its resemblance to a *gumball* or *peanuts machine*. Mary's family considered Mr.V to be a character; *a member of the family who entertained them*. AscoltaMe was described in similar ways. Rachel's mother and Leon's mother talked about AscoltaMe as a *technical device*. However, Rachel's mother associated AscoltaMe with a *walkie-talkie* or a *kind of phone*, mentioning the old game of the *tin-can-telephone*. In contrast to Mr.V, nothing was mentioned about AscoltaMe resembling a kind of a character.

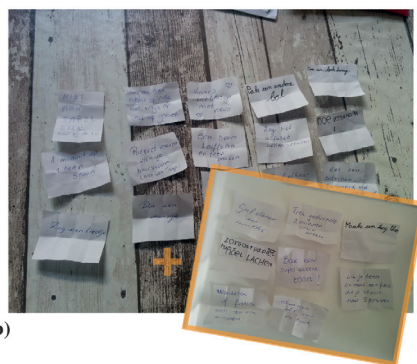
FIGURE 5

Impression of the collections of surprises

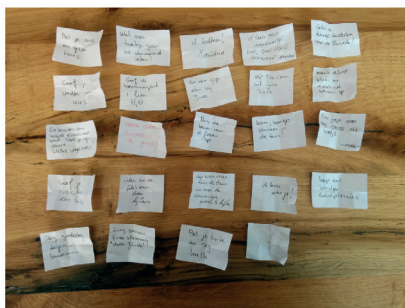
- (a) Kevin's family
- (b) John's family
- (c) Mary's family
- (d) Sammy's family



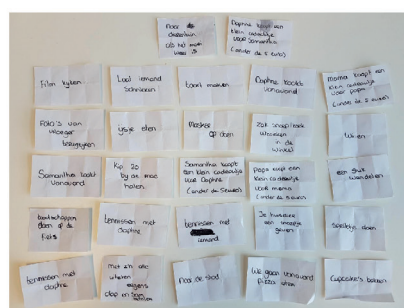
(a)



(b)



(c)



(d)

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Concerning the behavior of the artifacts, Kevin's father noticed that Mr.V was following a *schedule [that] is not predictable* and that was *funny and surprising*. However, parents

and children also liked the button that they could press to receive a surprise on request. Mary's mother said that it *felt good to have the possibility to control the device through the button* since sometimes a *predictable schedule is reassuring*. For AscoltaMe, parents felt mostly in control because the basic functions of the device were clear, and the interaction happened through recording and listening; something that was familiar to them. Rachel's mother explained how she found it logical *to press the red button to record a message and pressed the green button to listen to the message* (Figure 6).

FIGURE 6

Rachel's mother demonstrates how she used AscoltaMe



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When reflecting on their embodiment, Mary's mother appreciated the *vintage look* of Mr.V and the details, and Kevin's father describe it as *well-crafted* and *precious*. However, the sound that Mr.V made when a ball was dropped, felt disappointing to most of the families as it was described as being *too sad* in relation to its cheerful look. Parents further mentioned how important the robustness of the artifact was for them. Concerning Mr.V, Kevin's father pointed out that the *glass doesn't feel safe* and

Kevin himself mentioned that the *small hard plastic containers looked fragile*. The two mothers who interacted with AscoltaMe really liked the light effect and Rachel's mother specified that also the *children found the lights attractive* but that its white translucent embodiment *looked unfinished*. Furthermore, they were not that satisfied with the sound emitted by the artifact, which was described as being of *low and poor* quality by the mother of Simon. Leon's mother mentioned that she felt hesitant to give it to the child to play at day care since was not looking *resistant enough* nor *safe to be used and left outdoors*. Regarding AscoltaMe's embodiment, Simon's mother mentioned that *the part that needs to be hold in [the] hands is quite heavy for smaller and/or weaker children, and even a little awkward*.

Embedding of the objects in the home context

When asked about how the artifacts embedded into the home context, the participants' comments highlighted three specific themes: The presence of the artifacts at home, the way the artifacts were shared and coordinated amongst family members, and ways in which the use of the objects blended in family routines.

Most parents mentioned that these artifacts nicely fitted into their homes. John's parents mentioned that Mr.V felt like *part of the house*. Mr.V was usually placed in the living room or otherwise close to the kitchen (Figure 7a). Families explained that this was the ideal location, as it was a common room for everyone and a place where the sound of the device was easy to hear. Children particularly mentioned that in order to use Mr.V it was necessary to have a spot close to a power socket, which was not always a place that was most accessible for them. They also found it important to have Mr.V in an area in the house where they spend most of their time because it could suddenly attract their attention by *producing sounds and displaying lights*. AscoltaMe was often placed on the couch and mostly remained there. Rachel's mother indicated that it was convenient because *when you find AscoltaMe on the sofa and you sit down next to it, you will play with it*. Leon's mother explained that the child used it on the sofa (Figure 7b) and in the kitchen; he would have liked to use it to communicate with his brother in different rooms, but the length of the cable did not allow for it.

Results showed that Mr.V and AscoltaMe encouraged collective activities that included the ill children, their siblings and parents. For Mr.V, family members were sitting down together to write the surprises and in John's family *even the neighbor added some surprises* (Figure 8). In Kevin's family, the use of Mr.V was socially coordinated in

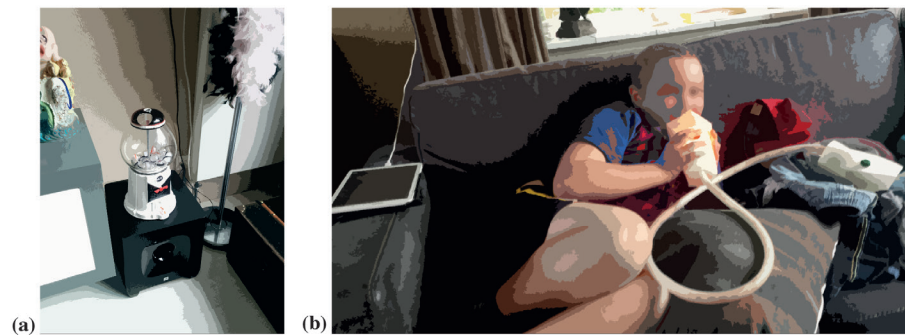
a specific way. The child was encouraged to open most of the surprises, and Kevin's father admitted to have *secretly opened the surprises and then put them back into the slot to let the Kevin open them later*. AscoltaMe was used by children to play with their siblings or with one of the parents. In Leon's family, mother and child used AscoltaMe together but Leon also tried to use it with his brother. For Rachel, AscoltaMe became integrated in games she played with her two older sisters.

FIGURE 7

Objects inside the families' houses

(a) Mr.V in the living room of John's family

(b) AscoltaMe on the couch with Leon



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FIGURE 8

Screenshots of the video shared by John's family dealing with a funny challenge proposed by the neighbor through Mr.V: "Blowing a candle with the nose"



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Since the use of Mr.V was quite elaborate (i.e., requiring different steps such as creating, receiving, and doing activities), participants mentioned that its use required some planning in relation to hospital visits and other family routines. John's family performed the activities provided by Mr.V randomly during the day whenever possible,

while for Mary's family the *preferred time was afternoons between 3 and 5*. John's parents expressed disappointment about Mr.V because *some surprises came out when John was not at home or he did not receive anything once back at home*. Particularly, family stressed that they would have engaged with Mr.V much more if it could have been used according to their own schedule. For AscoltaMe, parents noted that the children and their siblings used the device mainly during the weekend when they were all together or during the week in the afternoon when they were back from school.

DISCUSSION

In this section we will discuss how the results of the field work have helped us to articulate the qualities of Tactful Objects and account for what we have learned can hinder their tactfulness. We will continue by discussing the contribution of Tactful Objects to research in the healthcare field and other sensitive settings.

Articulating tactful objects

Based on the results of the fieldwork Tactful Objects are articulated as objects that establish *partnerships* and *collaborations* with people that are *inviting* and that are *appropriate* for the settings in which they are embedded. This articulation will be unpacked in more detail below in relation to the empirical findings.

We consider Tactful Objects to make an impact by establishing partnerships that are empowering by providing support in ways that leverage people's intrinsic motivations and that channels their strengths and capabilities. For example, Mr.V can be described as encouraging partnership in families by reminding them to do things together, by having a sustained presence in the home, and by simplifying planning by suggesting surprise activities to do proactively. At the same time Mr.V created a sense of normality by bringing fun and excitement to the family and distracting them from the severity of the situation. AscoltaMe was found to provide new forms of short-term play, although without being able to encourage family members to talk about their feelings, worries and hopes. By reflecting on these results we came to the conclusion that AscoltaMe could not realize a partnership to the extent that Mr.V did. This could have been caused by two reasons. First, AscoltaMe might have felt patronizing, as it suggests that families have a problem communicating that AscoltaMe must solve. The lack of interest of families to participate in a study with AscoltaMe might substantiate this claim. Second, for the families who did use AscoltaMe, the playful conversations it

afforded did not lead to talking about emotionally difficult topics, which might signify a problem in the underlying design goal and strategy.

We further envision Tactful Objects to establish partnerships through *collaboration*. We observed how interactions that struck a balance between *steering* users toward desired forms of behavior, yet allowing them *freedom*, were considered to be empowering. For example, Mr.V proactively dropped a ball containing a surprising activity at an unexpected moment during the day, yet Mr.V did not specify what these activities were, or exactly when or how to carry them out. This was up to the families themselves to decide based on their own needs and circumstances. The interaction with AscoltaMe seemed to be less of a collaboration. AscoltaMe is designed to trigger conversations by translating voice messages into light, and by having the light lingering and pulsating in the tube. Family members could decide what messages to record and when to listen to them (i.e., similar to Mr.V concerning what activities to do and when to do it). However, this pulsating light effect might not have been dominant or outspoken enough to trigger conversation. None of the participants addressed (or perhaps even perceived) this communicative quality of AscoltaMe, demonstrating that the pulsating light-signal might have been too subtle for AscoltaMe to play an active role in a collaboration.

We understood that Tactful Objects should be *inviting* to use. People's willingness to use an object can be considered a prerequisite for Tactful Objects to become empowering. When objects are not inviting it becomes nearly impossible to achieve any kind of change since prolonged engagements will be difficult to establish. For example, the gumball machine embodiment chosen for Mr.V generated pleasant memories in parents and raised curiosity in children. Additionally, the human-like characteristics of Mr.V expressed by its anthropomorphic cues led to the perception of the object as being a kind of character that meaningfully unified its pro-active behavior with its purpose, and strengthened the perception of being a *co-parent*. This underlying metaphor both provided enjoyment and helped people to understand its function and use. Similarly, this happened with AscoltaMe that embodied the metaphor of the *tin-can-telephone*. However, AscoltaMe was too large to hold for young children and the plastic it was made of felt too fragile. This made people less willing to use it, as it might not have withstood interactions with children in the home context.

Lastly, Tactful Objects need to be *appropriate* for the setting in which they are embedded and the circumstances in which they are used. Families were sensitive about where objects lived in their homes. For example, Mr.V was placed in the living room for everybody to

see, hear, and use. AscoltaMe was mainly placed on the couch in the living room due to the personal conversations it aimed to stimulate. We noticed how the use of the objects was socially coordinated and how the appropriateness of the objects depended upon the extent to which they fostered inclusivity. Mr.V was used by all family members, and although AscoltaMe was designed for two people, it also triggered social play. Families also talked about the particular moments in which they used the objects based on their schedules and availabilities, and mentioned feeling annoyed when objects decided to act at inappropriate moments (e.g., Mr.V dropping balls when nobody was at home) .

In the RtD approach that we have followed, tactfulness was intuitively explored in crafting Mr.V and AscoltaMe. Thus, we can ask how the results of the field study informed these tacit understandings of tactfulness. The use of *familiar childhood metaphors* in the design of the objects worked out well for this particularly sensitive setting. The metaphor was perceived in both Mr.V and AscoltaMe (i.e., gumball vending machine and tin-can-telephone, respectively) and triggered the associations and feelings that we had anticipated. The *expressiveness* of both objects that we designed to be both clear and subtle led to different observations. For AscoltaMe, we noticed how the translation of a voice message into light might have been difficult to grasp conceptually (i.e., lack of clarity) and not have enough provocative power to trigger families to have conversations over time (i.e., being too subtle). We noticed how the *embodiment* of the objects had an impact on their perceived appropriateness and invitingness. The aesthetics and robustness of the objects was designed with the home context in mind. Though it worked well as a decorative object, parents noticed how the glass and metal frame of Mr.V felt unsafe to be used by children. AscoltaMe was ambiguous; the poetic and aesthetic approach of the electronics with plastics was considered less fit to be used as a toy and looked unfished as a decorative object.

Summarizing, Tactful Objects are articulated as objects that enable people to act with respect for their vulnerabilities and circumstances by establishing *partnerships* and *collaborations* that are *inviting* and that are *appropriate* for the setting in which they are embedded. An integral design approach is required to design Tactful Objects, as these qualities are interdependent. Empowering people in sensitive settings thus require a design strategy that is *participatory* in the sense that people are given a voice and allowed freedom to act (as individuals and as collectives); while at the same time providing people support that is not experienced as patronizing. When Tactful Objects reflect this participatory approach through their appearance,

form and interactivity, we believe these objects can tactfully mediate behaviors and activities within specific contexts of use.

The contribution of tactful objects

Tactful Objects could be an interesting point of departure to design interventions to support engagement and coping for families in this specific healthcare domain [32,57]. Research in psychosocial and developmental domain for cancer care can look at this exploration as a way to understand how meaningfully make use of those objects by implementing them in standard interventions to support coping, resilience and family cohesion. Professionals can also think to use Tactful Objects to help families in the hospital or at home, to plan playful assignments that feel less stigmatizing or therapeutic, to indirectly assess the patients or involve neglected siblings [58]. Furthermore, as observed for the Cellie Cancer Coping kit [6], which was also tested later with sickle-cell disease patients [59], Tactful Objects could be proposed to patients and families dealing with other kind of illnesses. For instance, Tactful Objects could offer support to users dealing with illnesses that require stressful medical procedures and where the patients should be reassured and distracted [7,33,60]. Furthermore, Tactful Objects could be proposed during medical treatment to engage adolescents, that are considered to be difficult target users [61] as compared to children or adults.

Tactful Objects highlighted features that can potentially support other groups of users in crisis. Uncertainty, emotional distress, and loss of family cohesion can also be observed during other disruptive life events, such as death, divorce, relocation, etc. [1,19,62]. This means that we could consider tactfulness and Tactful Objects for a broader spectrum of application in sensitive settings. For sensitive settings it is mandatory to ensure an empathetic approach [63], to address people's and researcher's vulnerabilities [20,64] and to carefully manage the impact of any form of intervention [65]. Within the framing of Tactful Objects that we developed in this contribution, we arrived at an articulation of Tactful Objects as an outline or an initial design approach that takes these considerations into account. We continue the discussion by reflecting on the qualities of Tactful Objects that we have articulated in the context of childhood cancer and how they can be generalized to other kinds of sensitive settings.

Embody an appropriate metaphor in a Tactful Object helps in trigger users' interest and motivation in interacting and using something that has been designed to empower them [41,66]. The familiar childhood metaphors of the *gumball vending machine* and

the *tin-can-telephone* led to the design of particular kinds of objects that could mediate beneficial activities (i.e., engaging in social activities and fostering interpersonal communication) in a way that appealed to curiosity and wonder, and that could intrinsically motivate. Hence, we propose that choosing an appropriate metaphor for Tactful Objects for any sensitive setting must be done consistently with the specific aspects of the context, the users involved, and the kind of support required. This appeals to adopting a *practice perspective* that meaningfully connect objects and activities as continuously evolving and determined by culture [39,67,68]; and to the understanding of how metaphors can trigger *emotional values* by embodying personally significant associations [15].

We also noticed how enabling collaborations with Tactful Objects involved carefully balancing the behavior of the object in alignment to the support that is required. For example, the objects that we designed could gently nudge or trigger families to act while the families themselves had the freedom to decide when and how to act in response to the objects' behavior. Thus, the interplay between humans and objects can be described to involve freedoms and efforts. These *freedoms* and *efforts* can be composed (and balanced) differently for the type of support that is required [69] and result into different behavior change strategies [70]. For instance, a design like the *Connected Stones* [71] facilitates a strategy for the elderly to help them remember activities that involve the use of multiple objects. This particular design can help them remember to take the keys, wallet, and scarf when going out for groceries on a cold day. The series of stones glow in a sequence; once the first pebble positioned close to an object (e.g., the keys) is turned off by shaking it, the second stone that is placed next to another object (e.g., the wallet) starts to glow, and so on. The concept is inspired by the idea of leaving a trail with crumbs around the house. The connected stones afford people freedom in how they can use them because a person can choose which kind of objects the pebbles connect to. The pebbles do not impose much effort in providing direction, specifying actions, or enforcing a particular kind of behavior, but rather provide gentle suggestions by glowing. *Diem*, instead, is a design example that illustrates how these freedoms and efforts might be balanced differently and can change over time. *Diem* is a bedside lamp that lulls the person into sleep by dimming the light as the evening progresses [72]. A person is allowed to increase the brightness of the lamp (i.e., allowing freedom in action) but this will require more physical effort in doing so, the later at night it gets. The longer sleeping time is postponed, the more assertive the lamp becomes in its demands. These examples, show how we might

approach collaborations with Tactful Objects as ongoing negotiations that requires an understanding of how people may respond to, follow, or wish to overrule the behavior of an object, thus balancing freedoms and efforts in different ways.

Finally, we would like to discuss how designing Tactful Objects requires a deep understanding of the context in its particularities and the sensitivities at play. In designing for families with children with cancer, the invitingness and appropriateness of the designs related to how well the design embedded in the home context; which required understanding the needs of the family members, their everyday routines and characteristics of the setting. This leads to the question of whether we should consider Tactful Objects as being bespoke designs. The work conducted by Kirk and colleagues with the series of Ritual Machines [44,49] shows how it is relevant for a design's embodiment and behavior to be built "with encoded elements of the family character and values within" so that the objects could fit into the family everyday lives and appeal to what matters most to its members. Similarly the field study with the Family Circles system shows how a particular design intervention aiming to support intra-family communication should fit with families' own idiosyncratic ways of communicating, and that it should be clear the benefits that it brings to the family compared to their existing ways of communicating [46]. In this regard, AscoltaMe embedded an interesting childhood metaphor, but it did not allow for an idiosyncratic appropriation and did not fulfill the needs of the parents in understanding their children's feelings. A one-size-fits all approach does not align well with the approach of designing Tactful Objects, but it does require careful consideration about how these objects could function and appeal to different people in similar circumstances. This could be achieved through ethnographic work combined with in-situ prototyping [73] to understand how Tactful Objects perform within particularly sensitive settings.

Limitations and future work

Our findings have been constrained by people's recollections of their behavior. Using only participants' recollections might determine the loss of some detail and aspects of the experience [74]. We noticed how the participants were hesitant to prompt us regularly during the study on a day to day basis by writing notes in the diary and taking photographs while using the objects. Our participants perceived filling out the diary to be an additional task, and most of them felt uneasy about sharing personal pictures and videos due to privacy issues. Scholars have pointed out that reporting or

collecting ethnographic data through diaries and pictures is not always ideal [48,75]. Therefore, in future studies we should think about ways in which we can obtain insights without burdening participants in their difficult circumstances. For example, we might consider experience-sampling techniques that are fun and easy to use for children and adults [76], or by allowing the objects themselves to collect use information in real-time [77,78] in an ethical and transparent manner [47].

The results were also influenced by the two prototypes that we developed. For AscoltaMe, the use of standard Arduino™ based electronic components didn't allow it to be as light and small as we intended. This negatively affected its embodiment, especially for small children, because it was too large to hold and too heavy to play with. Applied mechatronics and computation sometimes negatively influenced Mr.V. From time to time a ball got stuck in the machine, requiring human intervention to free it up. Exploring the tactful behavior of objects in daily life requires the use of prototypes with an even higher level of engineering sophistication. Future work should focus on reaching this level of robustness in form of *research products*, which Odom and colleagues [79] describe as products used in longitudinal research carefully fine-tuned on their appearance, behavior and interactivity before actually being deployed in the field.

We acknowledge that the one-week deployment of the prototypes in families' homes limits any generalizations about the long-term embedding of Tactful Objects. To measure the long-term impacts of the intervention on well-being and quality of life of the families involved, longitudinal approaches are warranted [80]. However, due to the sensitive context and the necessity to be granted permission from a Medical Ethical Committee to recruit participants undergoing treatment, we encountered limitations that we had to respect. Still, our results report more than an initial excitement from the families about the objects that were deployed and could pass beyond the *trajectory of novelty* [47]. For example, we observed how people's impressions of the artifacts were constructed after multiple use-episodes, and how people coordinated their use within the complex daily schedules of the family. Despite these limitations, we think that our study allowed us to investigate Tactful Objects intended for a vulnerable group of people who are often difficult to engage and approach [20,48].

The articulation of Tactful Objects presented in this study could be used further as a design framework by engaging in new design activities that take this articulation as a starting point. For instance, researchers could create new prototypes that could

serve as physical hypotheses about tactfulness (informing their embodiment and expressive capabilities), and that could be assessed on their empowering qualities over a longer period of time. The Tactful Objects perspective could open up a new design space to imagine and create intelligent objects that express intent with sensitivity and tact. Future Tactful Objects could be designed as tactful data-enabled agents [73,81] capable to sense people's needs and vulnerabilities [20,48], and to mediate complex interactions among group of users in sensitive settings [44,46]. Therefore, our next step will look into expanding the sensing capabilities of Tactful Objects. This will allow us to understand how they might attune to and adapt to the needs of people and demands of the situation in a semi-autonomous fashion. We look forward to expanding our understanding of Tactful Objects, as this will ultimately help designers in creating interactive artifacts that are sensitive, supportive, and respectful for people in challenging life circumstances.

Conclusion

In this paper we have introduced Tactful Objects as a design perspective on interactive artifacts that empower people in sensitive settings. We have explained how childhood cancer is a disruptive life event that affects the children and their families as a whole by causing uncertainty, emotional distress, and break-up their family routines, and which becomes a sensitive setting to design for. We have presented two interactive artifacts that were designed to empower families dealing with childhood cancer in tactful ways. The first, Mr.V, is an interactive dispenser to stimulate social activities in the family. The second, AscoltaMe, is a kind of walkie-talkie to enhance communication between family members. We evaluated these two interactive artifacts during a one-week field study with eight families in treatment for childhood cancer. The results provided insights into how families experienced these artifacts concerning their impact, use, appreciation and embedding in the context of the home. Based on these findings we conclude that Tactful Objects enable people to act with respect for their vulnerabilities and circumstances by establishing partnerships and collaborations that are inviting and that are appropriate for the setting in which they are embedded. We have then reflected on the possible contribution of Tactful Objects for research in healthcare and for design in other sensitive settings.

REFERENCES

1. Massimi, M.; Dimond, J.P.; Le Dantec, C.A. Finding a new normal: The role of technology in life disruptions. In Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW), Seattle, WA, USA, **2012**; pp. 719-728.
2. Davis, H.; Waycott, J. Ethical encounters: HCI research in sensitive and complex settings. In Proceedings of the 32nd Australian Conference on Human-Computer Interaction (OzCHI), Sydney, Australia, **2015**; pp. 667-669.
3. Li, H.C.W.; Lopez, V.; Chung, O.K.J.; Ho, K.Y.; Chiu, S.Y. The impact of cancer on the physical, psychological and social well-being of childhood cancer survivors. *European Journal of Oncology Nursing* **2013**, *17*, 214-219. <https://doi.org/10.1016/j.ejon.2012.07.010>
4. Dixon-Woods, M.; Findlay, M.; Young, B.; Cox, H.; Heney, D. Parents' accounts of obtaining a diagnosis of childhood cancer. *Lancet* **2001**, *357*, 670-674, [https://doi.org/10.1016/S0140-6736\(00\)04130-1](https://doi.org/10.1016/S0140-6736(00)04130-1).
5. Haverman, L.; Engelen, V.; van Rossum, M.A.; Heymans, H.S.; Grootenhuis, M.A. Monitoring health-related quality of life in paediatric practice: development of an innovative web-based application. *BMC Pediatrics* **2011**, *11*, 3, <http://doi.org/10.1186/1471-2431-11-3>.
6. Marsac, M.L.; Hildenbrand, A.K.; Clawson, K.; Jackson, L.; Kohser, K.; Barakat, L.; Kassam-Adams, N.; Aplenc, R.; Vinsel, A.; Alderfer, M.A. Acceptability and feasibility of family use of The Cellie Cancer Coping Kit. *Supportive Care in Cancer* **2012**, *20*, 3315-3324, <http://doi.org/10.1007/s00520-012-1475-y>.
7. Moerman, C.J.; van der Heide, L.; Heerink, M. Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review. *Journal of Child Health Care* **2019**, *23*, 596-612, <http://doi.org/10.1177/1367493518803031>.
8. Nijhof, S.L.; Vinkers, C.H.; Van Geelen, S.M.; Duijff, S.N.; Achterberg, E.J.M.; Van der Net, J.; Veltkamp, R.C.; Grootenhuis, M.A.; Van de Putte, E.M.; Hillegers, M.H.J.; et al. Healthy play, better coping: The importance of play for the development of children in health and disease. *Neuroscience & Biobehavioral Reviews* **2018**, *95*, 421-429, <http://doi.org/10.1016/j.neubiorev.2018.09.024>.
9. Waycott, J.; Wadley, G.; Schutt, S.; Stabolidis, A.; Lederman, R. The challenge of technology research in sensitive settings: Case studies in 'ensitive HCI'. In Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction (OzCHI), Parkville, Australia, **2015**; pp. 240-249.
10. Liu, L.S.; Inkpen, K.M.; Pratt, W. I'm not like my friends: Understanding how children with a chronic illness use technology to maintain normalcy. In Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW), Vancouver, Canada, **2015**; pp. 1527-1539.
11. D'Alessandro, D.M.; Dosa, N.P. Empowering children and families with information technology. *Archives of Pediatrics and Adolescent Medicine* **2001**, *155*, 1131-1136, <http://doi.org/10.1001/archpedi.155.10.1131>.
12. Kehr, F.; Hassenzahl, M.; Laschke, M.; Diefenbach, S. A transformational product to improve self-control strength: The chocolate machine. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Austin, TX, USA, **2012**; pp. 689-694.

13. Ryan, R.M.; Deci, E.L. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist* **2000**, *55*, 68-78, <http://doi.org/10.1037//0003-066x.55.1.68>.
14. Patterson, J.M.; Holm, K.E.; Gurney, J.G. The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology* **2004**, *13*, 390-407, <http://doi.org/10.1002/pon.761>.
15. Orth, D.; Thurgood, C.; Van den Hoven, E. Designing objects with meaningful associations. *International Journal of Design* **2018**, *12*, 91-104.
16. Cheverst, K.; Clarke, K.; Cobb, S.; Hemmings, T.; Kember, S.; Mitchell, K.; Phillips, P.; Procter, R.; Rodden, T.; Rouncefield, M. Design with care. *New Technology in the Human Services* **2001**, *14*, 39-47.
17. Crabtree, A.; Hemmings, T.; Rodden, T.; Cheverst, K.; Clarke, K.; Dewsbury, G.; Hughes, J.; Rouncefield, M. Designing with care: Adapting cultural probes to inform design in sensitive settings. In Proceedings of the OzCHI Conference on New Directions in Interaction Information environments, Media and Technology, Brisbane, Australia, **2003**; pp. 4-13.
18. Mori, J.; Howard, S.; Gibbs, M. Designing in sensitive settings: Workshops to design a technology to commemorate black saturday. In Proceedings of the 9th Australasian Conference on Interactive Entertainment: Matters of Life and Death (IE), Melbourne, Australia, **2013**. pp. 1-9.
19. Massimi, M.; Odom, W.; Kirk, D.; Banks, R. HCI at the end of life: Understanding death, dying, and the digital. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Atlanta, GA, USA, **2010**; pp. 4477-4480.
20. Vines, J.; McNaney, R.; Lindsay, S.; Wallace, J.; McCarthy, J. Special topic: Designing for and with vulnerable people. *Interactions* **2014**, *21*, 44-46.
21. D'Olivo, P.; Rozendaal, M.C.; Giaccardi, E. AscoltaMe: Retracing the computational expressivity of a tactful object for sensitive settings. In Proceedings of the Conference on Designing Interactive Systems (DIS), Edinburgh, UK, **2017**; pp. 943-955.
22. Wiberg, M. *The materiality of interaction: Notes on the materials of interaction design*; MIT press, **2018**.
23. Vallgård, A.; Winther, M.; Mørch, N.; Vizer, E.E. Temporal form in interaction design. *International Journal of Design* **2015**, *9*, 1-15.
24. Bronfenbrenner, U.; Morris, P.A. The ecology of developmental processes. In *Handbook of child psychology: Theoretical models of human development*, Damon, W., Lerner, R.M., Eds.; John Wiley & Sons: Hoboken, NJ, USA, **1998**; pp. 993-1028.
25. Canning, N. Children's empowerment in play. *European Early Childhood Education Research Journal* **2007**, *15*, 227-236.
26. Goldstein, J. *Play in children's health, development and well-being*; Toy Industries of Europe: Brussels, Belgium, **2012**.
27. Bronfenbrenner, U.; Ceci, S.J. Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review* **1994**, *101*, 568-586, <http://doi.org/10.1037/0033-295x.101.4.568>.
28. Minuchin, P. Relationships within the family: A systems perspective on development. In *Relationships within families: Mutual influences*, Hinde, R.A., Stevenson-Hinde, J., Eds.; Oxford University: Oxford, UK, **1988**; pp. 7-26.

29. Ashiabi, G.S.; O'Neal, K.K. Child social development in context: An examination of some propositions in Bronfenbrenner's bioecological theory. *SAGE Open* **2015**, *5*, 1-14, <http://doi.org/10.1177/2158244015590840>.
30. Saarni, C. Emotional development in childhood. In *Encyclopedia on early childhood development* Lewis, M., Ed.; UMDNJ-Robert Wood Johnson Medical School: Piscataway, NJ, USA, **2011**; pp. 1-7.
31. Cox, M.J.; Paley, B. Families as systems. *Annual Review of Psychology* **1997**, *48*, 243-267.
32. Folkman, S.; Lazarus, R.S.; Dunkel-Schetter, C.; DeLongis, A.; Gruen, R.J. Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology* **1986**, *50*, 992-1003, <http://doi.org/10.1037//0022-3514.50.5.992>.
33. Breazeal, C. Social robots for health applications. In Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society, Piscataway, NJ, USA, **2011**; pp. 5368-5371.
34. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.
35. Diefenbach, S.; Hassenzahl, M.; Eckoldt, K.; Hartung, L.; Lenz, E.; Laschke, M. Designing for well-being: A case study of keeping small secrets. *The Journal of Positive Psychology* **2017**, *12*, 151-158.
36. Petermans, A.; Cain, R. *Design for wellbeing: An applied approach*; Routledge London, **2019**.
37. Halliday, G.C.; Miles, G.C.P.; Marsh, J.A.; Kotecha, R.S.; Alessandri, A.J. Regular exercise improves the well-being of parents of children with cancer. *Pediatric Blood & Cancer* **2017**, *64*, <http://doi.org/10.1002/pbc.26668>.
38. Dorrestijn, S.; Verbeek, P.-P. Technology, well-being, and freedom: The legacy of utopian design. *International Journal of Design* **2013**, *7*, 45-56.
39. Kaptelinin, V.; Nardi, B.A. *Acting with technology: Activity theory and interaction design*; MIT press, **2006**.
40. Laschke, M.; Hassenzahl, M.; Diefenbach, S. Things with attitude: Transformational products. In Proceedings of the Create11 Conference, London, UK, **2011**; pp. 1-2.
41. Verbeek, P.-P. *What things do: Philosophical reflections on technology, agency, and design*; Penn State University: University Park, PA, USA, **2005**.
42. Waelbers, K. *Doing good with technologies: Taking responsibility for the social role of emerging technologies* Springer: Berlin, Germany, **2011**.
43. Huisman, S.; Edwards, A.; Catapano, S. The impact of technology on families. *International Journal of Education & Psychology in the Community* **2012**, *2*, 44-62.
44. Kirk, D.S.; Chatting, D.; Yurman, P.; Bichard, J.-A. Ritual machines I & II: Making technology at home. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), San Jose, CA, USA, **2016**; pp. 2474-2486.
45. Odom, W.T.; Sellen, A.J.; Banks, R.; Kirk, D.S.; Regan, T.; Selby, M.; Forlizzi, J.L.; Zimmerman, J. Designing for slowness, anticipation and re-visitation: A long term field study of the photobox. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Toronto, Canada, **2014**; pp. 1961-1970.

46. Schatorjé, R.; Markopoulos, P. Intra-family messaging with Family Circles. In *Connecting families: The impact of new communication technologies on domestic life*, Neustaedter, C., Harrison, S., Sellen, A., Eds.; Springer: Berlin, Germany, **2013**; pp. 57-74.
47. Gaver, W.; Sengers, P.; Kerridge, T.; Kaye, J.; Bowers, J. Enhancing ubiquitous computing with user interpretation: Field testing the home health horoscope. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), San Jose, CA, USA, **2007**; pp. 537-546.
48. Vines, J.; Clarke, R.; Wright, P.; McCarthy, J.; Olivier, P. Configuring participation: On how we involve people in design. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Paris, France, **2013**; pp. 429-438.
49. Chatting, D.; Yurman, P.; Green, D.P.; Bichard, J.-A.; Kirk, D.S. Ritual machine V: Where are you. In Proceedings of the Proceedings of the 3rd Conference on Biennial Research Through Design, London, UK, **2017**; pp. 131-147.
50. Helmes, J.; Hummels, C.; Seilen, A. The other brother: Re-experiencing spontaneous moments from domestic life. In Proceedings of the 3rd International Conference on Tangible and Embedded Interaction (TEI), Cambridge, UK, **2009**; pp. 233-240.
51. Stappers, P.; Giaccardi, E. Research through design. In *The encyclopedia of human-computer interaction*, 2nd ed.; Soegaard, M., Dam, R.F., Eds.; Interaction Design Foundation: Aarhus, Denmark, **2017**.
52. D'Olive, P.; Rozendaal, M.C.; Giaccardi, E.; Grootenhuis, M.A.; Huisman, J. Reconfiguring a new normal: A socio-ecological perspective for design innovation in sensitive settings. *She Ji: The Journal of Design, Economics, and Innovation* **2018**, *4*, 392-406, <http://doi.org/10.1016/J.SHEJI.2018.10.003>.
53. Stiefel, F.; Stiefel, F.C. *Communication in cancer care* Springer: Berlin, Germany, **2006**.
54. Sanders, E.B.-N.; Stappers, P.J. *Convivial toolbox: Generative research for the front end of design*; BIS: Amsterdam, the Netherlands, **2012**.
55. Ackoff, R.L. From data to wisdom. *Journal of Applied Systems Analysis* **1989**, *16*, 3-9.
56. Clark, J.M.; Paivio, A. Dual coding theory and education. *Educational Psychology Review* **1991**, *3*, 149-210.
57. Grootenhuis, M.; Van den Bergh, E.; Vrijmoet-Wiersma, J.; Jankovic, M. Psychosocial care. In *Cancer in children: Clinical management*; Oxford University: Oxford, UK, **2012**; pp. 111-117.
58. Woodgate, R.L. Siblings' experiences with childhood cancer: A different way of being in the family. *Cancer Nursing* **2006**, *29*, 406-414.
59. Marsac, M.L.; Klingbeil, O.G.; Hildenbrand, A.K.; Alderfer, M.A.; Kassam-Adams, N.; Smith-Whitley, K.; Barakat, L.P. The Cellie Coping Kit for sickle cell disease: Initial acceptability and feasibility. *Clinical Practice in Pediatric Psychology* **2014**, *4*, 389-399, <http://doi.org/10.1037/cpp0000062>.
60. Jibb, L.A.; Birnie, K.A.; Nathan, P.C.; Beran, T.N.; Hum, V.; Victor, J.C.; Stinson, J.N. Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial. *Pediatric Blood & Cancer* **2018**, *65*, e27242, <http://doi.org/10.1002/pbc.27242>.
61. Christiansen, H.L.; Bingen, K.; Hoag, J.A.; Karst, J.S.; Velazquez-Martin, B.; Barakat, L.P. Providing children and adolescents opportunities for social interaction as a standard of care in pediatric oncology. *Pediatric Blood & Cancer* **2015**, *62*, S724-749, <http://doi.org/10.1002/pbc.25774>.

62. Talhouk, R.; Bustamante, A.; Aal, K.; Weibert, A.; Charitonos, K.; Vlachokyriakos, V. HCI and refugees: Experiences and reflections. *Interactions* **2018**, *25*, 46-51.
63. Thieme, A.; Vines, J.; Wallace, J.; Clarke, R.E.; Slovák, P.; McCarthy, J.; Massimi, M.; Parker, A.G.G. Enabling empathy in health and care: Design methods and challenges. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Toronto, Canada, **2014**; pp. 139-142.
64. Groeneveld, B.; Dekkers, T.; Boon, B.; D'Oliveo, P. Challenges for design researchers in healthcare. *Design for Health* **2018**, *2*, 305-326, <http://doi.org/10.1080/24735132.2018.1541699>.
65. McNaney, R.; Vines, J. Blurred lines: A reflection on the ethical dilemmas encountered during the 'Google glass for Parkinson's' project. CHI Workshop on Ethical Encounters in HCI: Research in Sensitive and Complex Settings, Seoul, Korea, **2015**.
66. Janlert, L.-E.; Stolterman, E. The character of things. *Design Studies* **1997**, *18*, 297-314.
67. Kuijer, L.; Giaccardi, E. Co-performance: Conceptualizing the role of artificial agency in the design of everyday life. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Montreal, Canada, **2018**.
68. Kuutti, K.; Bannon, L.J. The turn to practice in HCI: Towards a research agenda. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Toronto, Canada, **2014**; pp. 3543-3552.
69. Rozendaal, M. Objects with intent: A new paradigm for interaction design. *Interactions* **2016**, *23*, 62-65.
70. Tromp, N.; Hekkert, P.; Verbeek, P.-P. Design for socially responsible behavior: A classification of influence based on intended user experience. *Design Issues* **2011**, *27*, 3-19.
71. Nicenboim, I.; Giaccardi, E.; Kuijer, L. Designing connected resources for older people. In Proceedings of the Conference on Designing Interactive Systems (DIS), Hong Kong, China, **2018**; pp. 413-425.
72. Van Boheemen, F.A.D. Diem: An animated house that cares with intent. Unpublished master's thesis, Delft University of Technology, Delft, the Netherlands, **2016**.
73. Rozendaal, M.C.; Boon, B.; Kaptelinin, V. Objects with intent: Designing everyday things as collaborative partners. *ACM Transactions on Computer-Human Interaction* **2019**, *26*, 1-33.
74. Vermeeren, A.P.O.S.; Law, E.L.-C.; Roto, V.; Obrist, M.; Hoonhout, J.; Väänänen-Vainio-Mattila, K. User experience evaluation methods: Current state and development needs. In Proceedings of the 6th Nordic Conference on Human-Computer Interaction, Reykjavic, Iceland, **2010**; pp. 521-530.
75. Jorgensen, D.L. Participant observation. In *Emerging trends in the social and behavioral sciences: An interdisciplinary, searchable, and linkable resource* Scott, R.A., Kosslyn, S.M., Eds.; John Wiley & Sons: Hoboken, NJ, USA, **2015**; pp. 1-15.
76. Rozendaal, M.C.; Vermeeren, A.P.O.S.; Issidorides, D.C. Using mobile technologies to capture the visitor experience. In *Museum experience design*, Vermeeren, A., Calvi, L., Sabiescu, A., Eds.; Springer: Berlin, Germany, **2018**; pp. 239-258.
77. Cila, N.; Smit, I.; Giaccardi, E.; Kröse, B. Products as agents: Metaphors for designing the products of the IoT age. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), Denver, CO, USA, **2017**; pp. 448-459.

78. Giaccardi, E.; Cila, N.; Speed, C.; Caldwell, M. Thing ethnography. In Proceedings of the ACM Conference on Designing Interactive Systems (DIS), Brisbane, Australia, **2016**; pp. 377-387.
79. Odom, W.; Wakkary, R.; Lim, Y.; Desjardins, A.; Hengeveld, B.; Banks, R. From research prototype to research product. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), San Jose, CA, USA, **2016**; pp. 2549-2561.
80. Karapanos, E. User experience over time. *Modeling Users' Experiences with Interactive Systems* **2013**, 436, 57-83, http://doi.org/10.1007/978-3-642-31000-3_4.
81. Giaccardi, E.; Kuijer, L.; Neven, L. Design for resourceful ageing: Intervening in the ethics of gerontechnology. In Proceedings of the DRS Conference on Future-Focused Thinking, London, UK, **2016**; pp. 1-14.

APPENDIX 1

Examples of surprises provided to the families testing Mr.V to facilitate the ideation of the activities

Example activities

Time to relax? Shall we play a video game together? ... let's see who will win!!!

Let's watch a cartoon together on the couch.

Home sweet home! When is time for the meal ... shall we sit at the table together and have a nice chat about what we did today?

Shall we eat an ice cream ?

What is the menu today? Let's prepare something together!

How's the weather today? Shall we go for a walk outside or watch a nice movie together in the living room?

Who is the best painter in the family? Let's draw something together and give it as a gift to the person we want to make happy!

Let's plan something relaxing for next weekend!

It's always time for tea! ... or maybe cookies? Let's take a break together!

Shall we bake something today? Pizza or cake?

Give each other a compliment!

Is the hug-day! To whom would you give the first hug?

Let's dance!!!

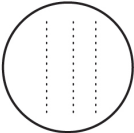
APPENDIX 2

Diary structure

Introduction

Hi! Thank you for welcoming "the object" to your home!

This is the diary of family



This will be your diary to take short notes at the end of each day about what happened in your home after the arrival of "the object".

Don't forget to collect pictures and videos of your week with "the object" and send them to the Whatsapp number of ***** or the email address ***** before the end of this week.

Mr.V diary: Family rules page

Family rules and guidelines

To get started, please write down your "family rules and guidelines" for using Mr. V.
(Questions for inspiration)
How much time do you want to spend to execute each surprise?
10 minutes or 1 hour?
Would the surprise cost money? (ie the surprise a big gratiscity or should it be simple and easy?)
Is the surprise concerning something indoor or outdoor or both?

Mr.V diary: Example of daily page

DAY #

1. Have you used Mr.V today? Yes/No
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
2. Who has/have taken a surprise from Mr.V?
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
3. Who has / have done something with the surprise from Mr.V?
[surprise 1] _____ [who] _____
[surprise 2] _____ [who] _____
[surprise 3] _____ [who] _____
[surprise 4] _____ [who] _____
[surprise 5] _____ [who] _____
[surprise 6] _____ [who] _____
4. Has anything special happened today by Mr.V that you would like to share with us?

Ascotable diary: Example of daily page

DAY #

1. Have you used Ascotable today? Yes/No
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
2. Who has / have recorded something in Ascotable?
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
[name] _____ yes/no n. times ____
3. Who has / have listened to a message in it Ascotable?
[message 1] _____ [who] _____
[message 2] _____ [who] _____
[message 3] _____ [who] _____
[message 4] _____ [who] _____
[message 5] _____ [who] _____
[message 6] _____ [who] _____
4. Was there anything special that you recorded/listened to today through Ascotable that you would like to share with us?

APPENDIX 3

Example semi-structured interview quotes for Mr.V

Mr.V	
Sections (N = 5)	List questions (N = 56) Main questions (n = 7) Sub-questions (n = 31) Related questions (n = 18)
Usage	<p><u>1. What was it like to have Mr. V at home for a week? (Initial reaction / warming up)</u></p> <ul style="list-style-type: none"> • Was it fun? • Did everyone use it? <ul style="list-style-type: none"> - Did everyone add a surprise in Mr.V? - Did everyone collected and opened a surprise from Mr. V? • Who used Mr. V the most? <ul style="list-style-type: none"> - Who put most of the surprises in Mr. V? - Who collected and opened most of the surprises from Mr. V? <p><u>2. Would you like to describe one of the times you have used Mr.V?</u></p> <ul style="list-style-type: none"> • Who took the surprises? <ul style="list-style-type: none"> - Who took the initiative? - Who participated? • When was this? (In the morning, after school, in the evening) • Location: Where did you use Mr.V in the house and where did you read the surprises? • What was the content of the surprises? <ul style="list-style-type: none"> - What did you do with the surprises? What happened? - How long have you been busy with the surprises? • Was it fun? What did you think about it? <ul style="list-style-type: none"> - What did you do with the surprises? What happened? <p><u>3. How did you used Mr.V?</u></p> <p><i>In practice</i></p> <ul style="list-style-type: none"> • Where was Mr.V positioned in your house? <ul style="list-style-type: none"> - Why there? - Did Mr.V ever moved from that position? • How much did you used Mr.V? <ul style="list-style-type: none"> - How many surprises (approximately) did you add in Mr.V? - (<i>One person every day, or each day a different person?</i>) - How many surprises were delivered (approximately) by Mr. V? - (<i>One, two, three every day?</i>) - Did you use the button of Mr.V to get more surprises? - Did you opened/executed all the surprises from Mr.V? How many you didn't? - Were the surprises opened quickly (or did the containers pile up during the week)? • When and with whom did you open the surprises from Mr.V? - (<i>Time of day, together or alone?</i>) • About how long have you been busy with the surprises from Mr.V? - (<i>Per surprise / per day?</i>) <p><i>Content</i></p> <ul style="list-style-type: none"> • What kind of surprises did you add in Mr.V? <ul style="list-style-type: none"> - What kind of surprises did you prefer to repeatedly put into the containers? - What kind of surprises did you put in the containers only once? • Did the kind of surprises you put in the containers change during the week? • Were the surprises related to illness or not? • Did you do something because of Mr.V which normally you wouldn't do? <p>(Examples?)</p>

Example semi-structured interview quotes for Mr.V (Continued)

Mr.V	
Sections (N = 5)	List questions (N = 56) Main questions (n = 7) Sub-questions (n = 31) Related questions (n = 18)
Technology and design	<p><u>4. What did you think of the product itself?</u> Did you understand how to use it? Was it easy to use?</p> <ul style="list-style-type: none"> • Was it unclear/difficult? Were there any problems? (Did you need to call/text the researchers to ask for help?) • Was the material resistant? • Were there enough containers? • Was it attractive? What about the shape, color, sound, weight? • Is it suitable for all ages? Or too difficult? Or too childish?
Evaluation/ rating	<p><u>5. Did you notice something different this week because you used Mr.V?</u> (Has Mr.V added anything to the atmosphere or activities in the house?)</p> <ul style="list-style-type: none"> • Have you done different or new things? • Have you done more things together? • Which is your greatest memory? <p><u>6. How would you rate Mr.V?</u></p> <ul style="list-style-type: none"> • Would you like to keep Mr.V another week at home? Why or why not? • Do you think it is a good product? Do you see added value in it? • Would you recommend Mr.V to other families? • Would you consider it a good product for the home? Or would it also be something ideal to be used for example in the hospital with nurses or child life professionals?
Improvements	<p><u>7. Do you have any improvements or good ideas to ameliorate Mr.V?</u></p> <ul style="list-style-type: none"> • Is there something you missed about the product? • Is there anything that you think it would make it even more fun?
Other comments ...	

APPENDIX 4

Evaluation questionnaires



Evaluate Mr.V

Indicate who you are, I am: father / mother / brother / sister / child (patient)

1. Was fun to have Mr.V at home for a week.

ABSOLUTELY NOT FUN 1 2 3 4 5 6 7 8 9 10 VERY MUCH FUN

2. Mr.V was easy to use.

REALLY DIFFICULT 1 2 3 4 5 6 7 8 9 10 VERY EASY

3. Mr.V is appropriate for children from 10 to 16 years old.

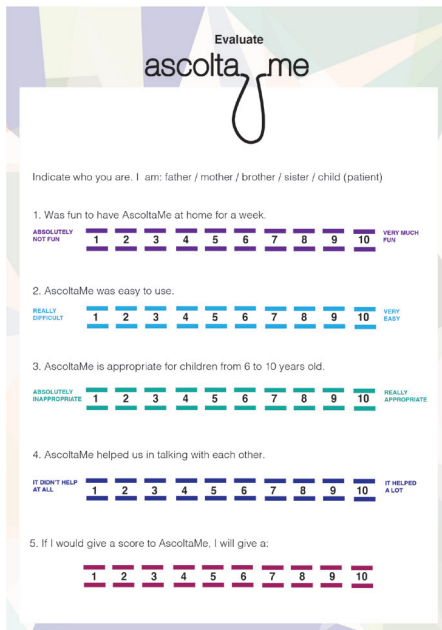
ABSOLUTELY INAPPROPRIATE 1 2 3 4 5 6 7 8 9 10 REALLY APPROPRIATE

4. Mr.V helped us in doing more fun things together.

IT DIDN'T HELP AT ALL 1 2 3 4 5 6 7 8 9 10 IT HELPED A LOT

5. If I would give a score to Mr.V, I will give a:

1 2 3 4 5 6 7 8 9 10



Evaluate ascolta me

Indicate who you are, I am: father / mother / brother / sister / child (patient)

1. Was fun to have AscoltaMe at home for a week.

ABSOLUTELY NOT FUN 1 2 3 4 5 6 7 8 9 10 VERY MUCH FUN

2. AscoltaMe was easy to use.

REALLY DIFFICULT 1 2 3 4 5 6 7 8 9 10 VERY EASY

3. AscoltaMe is appropriate for children from 6 to 10 years old.

ABSOLUTELY INAPPROPRIATE 1 2 3 4 5 6 7 8 9 10 REALLY APPROPRIATE

4. AscoltaMe helped us in talking with each other.

IT DIDN'T HELP AT ALL 1 2 3 4 5 6 7 8 9 10 IT HELPED A LOT

5. If I would give a score to AscoltaMe, I will give a:

1 2 3 4 5 6 7 8 9 10

APPENDIX 5

Example of the statement cards generated during the analysis according to the typology of data

STATEMENT CARD
INTERVIEW DATA

REFERENCE (timing
interview, family
member, card number,
family, object)

TENTATIVE LABEL
AND RESEARCHER
COLOR ID

PARAPHRASE

QUOTE

00:00:33.14

MOTHER

N.D.

MARY'S FAMILY

MLV

EFFECT OF USING MR.V

Excitement and engagement starts with writing down all the activities together. Then it continues with the suspense generated by the unknown schedule of Mr.V.

"So ultimately we didn't have it for very long, at least in our experience. Yes, yes. But that's kind of interesting. Because, of course the first few days we were quite enthusiastic about it and started working with it straight away. Writing those notes the same night and waiting for the balls to come out every time."

BACKGROUND
COLOR CODING
PER FAMILY

STATEMENT CARD
PHOTOS DATA

REFERENCE (photo
data, family member,
card number, family,
object)

TENTATIVE LABEL
AND RESEARCHER
COLOR ID

IMAGE

DESCRIPTION

PHOTO


MARY

N.D.

MARY'S FAMILY

MLV

FAMILY RITUAL DURING TREATMENT



Mary shared with us the gift box prepared by her aunt for her. This box contains several tiny presents, cards and games. Mary was allowed to read only one card per day and open the present linked to that.

STATEMENT CARD
DIARIES DATA

REFERENCE (diary
page, family member
who wrote the note,
family, object)

TENTATIVE LABEL
AND RESEARCHER
COLOR ID

PARAPHRASE

DIARY SEGMENT

DIARY page 3

MOTHER

SIMON'S FAMILY

ASCOLTAME

PROTOTYPE WEAKNESS

The sound quality is poor

Opname afsped kwaliteit is best slecht te horen.

STATEMENT CARD
SURPRISES DATA

REFERENCE (photo data, family,
object)

TENTATIVE LABEL
AND RESEARCHER
COLOR ID

CONTENT

PHOTO NOTES

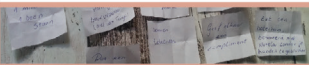
PHOTO

JOHN'S FAMILY

MLV

TYPE OF SURPRISES

1. Don't eat at the dining table but in front of the TV.
2. Bring a piece of cloth in the garden and throw paint on it.
3. Blow a candle with your nose.
4. Take another bath.
5. Do a funny dance.
6. Imitate someone.
7. Sing the alphabet inverted.
8. Hug a tree and mean a photo.
9. Make a portrait of your neighbor.
10. Sing one rhyme on one leg.
11. Sing a song.
12. Do a dance.
13. Make a drawing all together.
14. Give each other a compliment.
15. Eat a slice of bread covered with Nutella without using your hands.
16. Give each other a hug.
17. Make funny faces for 2 minutes.
18. Make a cup of tea.
19. Dance a waltz with you.
20. Make sure that mom and dad laugh.
21. Walk on circles for at least 20 minutes.
22. Take a picture of the garden.
23. Take a picture of yourself kicking your big toe and send it to five different people.



APPENDIX 6

List of surprises collected in each of the four families testing Mr.V

Family (N = 4)	List of surprises (N = 88)	Surprises per family
Kevin's family	Choose a game and play together; Watch together a family movie and eat chips/snacks; Bake cookies; Let's do a BBQ together; Organize a high tea; Let's go to watch the Pandas in Rhenen; Mom and dad will receive breakfast in bed thus they don't have to make it for us; Bake brownies; Let's have a day together in the wood; Have a cozy lunch/dinner somewhere; Eat a home-made pizza; Watch together a movie on TV; Have a cozy day out; Have a coffee/tea with some tasty snacks; Bake puff pastry sausages;	(n = 15)
John's family	Don't eat at the dining table but in front of the TV; Hang a piece of cloth in the garden and throw paint on it; Blow a candle with your nose; Take another ball; Do a funny dance; Imitate someone; Say the alphabet inverted; Hug a tree and make a photo; Make a portrait of your neighbor; Stay one minute on one leg; Sing a song; Do a dance; Make a drawing all together; Give each other a compliment; Eat a slice of bread spread with Nutella without using your hands; Give each other a hug; Make funny faces for 2 minutes; Make a cup of tea; Bake a super tasty pie; Make sure that mom and dad laugh; Walk or cycle for at least 30 minutes; Take a picture of the garden; Take a picture of yourself licking your big toe and send it to five different people;	(n = 23)

List of surprises collected in each of the four families testing Mr.V (Continued)

Family (N = 4)	List of surprises (N = 88)	Surprises per family
Mary's family	Call grandma and greet her; What are we going to eat tonight for dessert?; Today I treat! (Mom); I will read a story to Mary tonight (Mom); Let's buy the tickets for the parade!; Make a smoothie and drink it together; Look together at the photo album from 2012; Go and eat an ice-cream at Jacco; Give 1 liter of water to the banana plant; Give a kiss to your dad!; Go outside hand in hand with someone else, walk with your eyes close ...which bird do you heard?; Fancy go to the swimming pool?; Pump the wheels of the bikes; Go and collect the little beans in the garden; Eat an ice cream at Jacco as dessert (Mary); Have a walk in Goudplevier; I love you !; Walk with me to the garden and look at the grapes and vegetables; Let's look together at the photos from Peru'; Give a kiss to mom; Say good morning to the neighbor; Sing together two tunes from 'Vader Jacob'; Call your aunt and say hello;	(n = 23)
Sammy's family	Go to the zoo if it is nice weather; Sammy's sister buys a small present for Sammy (under 5 euros); Mom buys a small present for dad (under 5 euros); Sammy's sister cooks tonight; Bake a pie; Startle someone; Watch a movie; Look at old pictures; Eat an ice cream; Make a face-mask; Choose a bag of candies/cookies from the store; Play together with the Wii; Have a walk; Dad buys a small present for mom (under 5 euros); Sammy buys a small present for her sister (under 5 euros); Get 20 McChickens from the McDonald; Sammy cooks tonight; Let's go and do the grocery by bike; Play tennis with your sister; Play tennis all together; Give a treat to the pet; Play a game; Bake cupcakes; Go out to eat pizza tonight; Go downtown; Let's eat together out. Sammy's sister and Sammy will pay; Play tennis with your sister;	(n = 27)

6

Support for families at home during childhood cancer treatment: A pilot study with Mr.V the Spaceman, a family-based activities tool

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ABSTRACT

Purpose

It is important to support families in dealing with the distress that comes along with the diagnosis and treatment of childhood cancer. Therefore, we developed a playful tool that families can use at home to support their family functioning and safeguard their normal family life. We pilot-tested this new tool called Mr.V, and describe how families used and evaluated the tool, and how it could be further improved.

Methods

Mr.V is an interactive dispenser that looks like a spaceman and proposes family activities. These activities are suggested by family members themselves and dispensed by the machine at unexpected moments. Mr.V produced data on how it was used, and a questionnaire and a semi-structured interview were used to evaluate the experiences of families and the potential of this tool.

Results

Ten families with a child with cancer between 5 and 9 years old ($M_{\text{age}} = 6.7$ years) who were in active treatment (mixed diagnoses) participated ($n = 47$; $n_{\text{patients}} = 10$, $n_{\text{siblings}} = 9$, $n_{\text{parents}} = 16$). All families used Mr.V for multiple days, and were very satisfied with the tool regarding its acceptability, feasibility and potential effectiveness. They also had suggestions on how the tool could be further improved.

Conclusions

Mr.V is an acceptable and feasible tool that can be implemented by families independently at home, regardless of their level of need for support. Mr.V promoted family activities, and therefore has the potential to support family functioning and normal family life at home. Future research should further investigate the effectiveness of this tool.

INTRODUCTION

In the Netherlands, about 650 children are diagnosed with cancer every year [1]. This diagnosis and the often lengthy, demanding treatments have a significant impact on the child, as well as the whole family [2]. The shock of a cancer diagnosis, and the burden of treatment and daily caretaking have an impact on family functioning [3-6]. Among the consequences of this impact on the child and the family is a loss of normality [7]. Everyday routines change, family relationships are challenged, and social activities get hampered by the distress that comes along with the disease and its treatment. Therefore, it is important to support families in dealing with this distress, and to safeguard their normal everyday family life.

The Pediatric Psychosocial Preventative Health Model (PPPHM) is a biopsychosocial framework that can be used in assessment and treatment of families of children in pediatric health care settings [8]. According to the PPPHM, all families that are affected by childhood cancer experience some level of distress, and should therefore have access to a certain level of support. This universal support should have a preventative goal and incorporate general interventions or services to assist families [8].

In the Netherlands, various preventative sources of support are available at the hospital for families throughout the treatment of the child. As part of standard care [9], child life specialists are available to prepare and support children during medical procedures to prevent medical traumatic stress. Also, social workers are available to support parents emotionally and help them continuing their family life and overcoming practical issues. If needed, a team of psychologists is available to provide specialized additional psychosocial care. However, there are limited general preventative interventions or services available to provide all family members with support at home.

An important way of supporting family functioning at home, and maintaining a normal family life, is by supporting family activities or promoting family quality time. According to the Core and Balance Model of Family Leisure Functioning [10], core family leisure includes experiences that are typically home-based, relatively accessible, low-cost, and common. Such activities often require minimal planning and resources, can be spontaneous and informal, and provide a safe, consistent, and typically positive context in which family relationships tend to be enriched and feelings of family closeness increased. Therefore, play is an appropriate way to provide family centered care [11].

A tool that was developed to support families with a child with cancer at home using a playful-approach, is the Cellie Cancer Coping Kit [12]. The Cellie Cancer Coping Kit is designed to promote coping and decrease distress in children undergoing cancer treatment, and encourages parents and children to use the tool together. However, the focus of the tool is on the child and not the whole family, and also relies on psycho-education.

To address these gaps in family-centered and home-based supportive care for families with a child with cancer, we developed a playful tool that stimulates family activities. This tool was created in collaboration with design researchers and called Mr.V (short for “Mr. Verrassing”, which translates to “Mr. Surprise” in English). Mr.V is an interactive dispenser that looks like a spaceman and proposes family activities. These activities are suggested by family members themselves and dispensed by the machine at unexpected moments (i.e., as a surprise). The aim of Mr.V is to help families engage in behavior that supports their family functioning and normal family life at home.

The purpose of this pilot study was to describe the experiences of families with this new tool, and to evaluate its potential to support families with a child with cancer during treatment at home. Specifically, our research questions were: (1) How do families with a child with cancer use Mr.V with regard to time and frequency of use? (2) How do families evaluate Mr.V in terms of acceptability, feasibility (ease of use) and potential effectiveness? (3) How do families think Mr.V can be improved?

METHODS

Description of the prototype of Mr.V: A vending machine

We first developed a prototype of Mr.V (Figure 1). This prototype resembled a gumball vending machine, but dispensing surprises instead of gumballs. The surprises were notes written by family members, ranging from activities they would like to do together, to compliments and jokes. The notes were inserted into small plastic balls and stored in the machine. These plastic balls with notes were dispensed by the machine at unexpected moments during the week. Family members could also request a surprise on demand by pressing a button located at the backside of Mr.V. Before dropping a surprise, Mr.V shuffled the balls and made sound effects.

The prototype of Mr.V was pre-piloted by four families with a child with cancer to evaluate its functionality, and whether families were open to use it and positive about the concept. Families received some example surprises, and a diary to keep track of their use of the machine. The detailed results of this study can be found in D'Olive et al. [13].

FIGURE 1
Prototype and final version of Mr.V
Prototype version of Mr.V



Final version of Mr.V



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Description of the final Mr.V: A spaceman

Based on the results of this pilot study, changes were made to the prototype creating Mr.V the Spaceman (Figure 2). Adaptations consisted of a new spaceman look and new features, such as a build-in pen, a build-in drawer, a little booklet, a time knob, and the possibility to collect data on how it is used. Also the sound effects, lights, and button to request surprises on demand were modified.

The antenna on the head of the spaceman was a detachable pen that could be used to write the notes for the surprises. A drawer at the bottom of the machine was added to store the plastic balls when empty, together with a booklet. The booklet contained information about the study, a page where families could establish rules regarding the surprises (i.e., kind of surprises and possible costs of surprises) and colored removable paper stripes to write the notes on. Four different colors were available so that families could make distinctions in the surprises. Colors could for example represent a family member the surprise was from or for, or a type of surprise (i.e., for good or bad days, or for indoors or outdoors). The oxygen hose of the spaceman served as the opening to add the filled plastic balls to the machine. Mr.V was also equipped with an electricity plug, an instruction manual, and a one-page letter about how Mr.V came from space to stay with the family and provide surprises.

To anticipate the surprise dropping moment, the lights in the helmet of Mr.V start to twinkle, and the balls (visible through the helmet) start to shuffle, followed by a sound effect. The button to request a surprise on demand was redesigned as an emergency switch on the side of Mr.V. A time knob was added, with which families could set a preferred time range for obtaining the surprises: Either in the morning, afternoon or evening. During the night, Mr.V turned off automatically, to avoid children getting up at night to check for surprises. Different kinds of sound effects were linked to the time knob, and when Mr.V was turning off and on.

Participants

Families were recruited via an information letter handed out by their pediatric oncologist or child life specialist. After one week, the families were contacted by telephone by one of the researchers to ask whether they wanted to participate. Inclusion criteria were families with a child who was: (1) In active treatment for cancer, (2) not hospitalized, (3) between 4 and 12 years of age, and (4) spoke Dutch sufficiently.

Procedure

Two copies of Mr.V were available, and the study consisted of three phases. In the introduction phase, Mr.V was presented to the families either at their home or at the hospital. Instructions about the main functions of Mr.V were given, as well as the user manual and booklet. Families were invited to try out Mr.V and to ask questions (± 15 minutes). Next, during the usage phase, families were asked to use Mr.V for at least one week at their homes. In the concluding evaluation phase, families were interviewed either at home or at the hospital and filled-out an evaluation questionnaire (± 60 minutes). The study was conducted with permission of the Medical Ethics Committee of the University Medical Center Utrecht in the Netherlands and in accordance with their regulations.

Measures

Machine data

To gain insight into how families used Mr.V, it registered: How many days it was used, how many balls were added to it and when, how many surprises were dropped automatically and at what time of the day, how many times families used the button, time knob or unplugged Mr.V. Separately, the researchers counted the number of days the families had Mr.V at home, and how many notes were made (i.e., how many paper stripes were taken out of the booklet).

Questionnaire

The evaluation questionnaire consisted of statements about Mr.V's feasibility (ease of use; 5 items), acceptability (4 items) and potential effectiveness (4 items). All statements were rated on a 5-point Likert-scale ranging from (1) Strongly disagree to (5) Strongly agree. Examples of the statements were "Mr.V is easy to use", "Mr.V provides the surprises in a positive way", and "Mr.V helped to do more things together". The questionnaire was filled out by all family members who used Mr.V (± 10 minutes).

Interview

Semi-structured group interviews, in which all family members participated together, were performed and recorded to evaluate the experiences of families with Mr.V and to discuss possible improvements (± 30 minutes). The interviewer tried as much as

possible to obtain answers from all family members, including younger siblings. Example questions were “Who made the surprises”, “Did you encounter any difficulties (if so, what difficulties)”, “Do you think Mr.V was valuable for your family during times of treatment (if so, how exactly)” and “Would you recommend Mr.V to other families with a sick child (if so, why)?”.

Data analysis

Data collected from the machine and from the questionnaire were entered to IBM SPSS Statistics (version 25) and described using descriptive statistics. For the questionnaire data, the 5-point Likert-scale was dichotomized into disagree (answers 1 to 3) and agree (answers 4 and 5). Data collected through the interviews were transcribed verbatim and translated into English by two research assistants (R.V. and M.S.). The transcriptions were anonymized and analyzed in ATLAS™ by the second author. The analyzed data was checked by the third author who was not involved in the interviews, and discrepancies were discussed with the first author until consensus was researched. Using content analysis, all the responses from families were marked as statements and clustered in a top-down manner and given a theme [14]. Then, the number of themes was reduced according to their relevance (i.e., small themes with only a few statements were included in larger related themes), and clustered in relation to acceptability, feasibility, potential effectiveness or improvements.

RESULTS

Eighteen families with a child with cancer were approached to participate in this study. Eight families declined to participate, because of hospitalization of the child with cancer ($n = 3$), no interest ($n = 2$) or finding it too demanding at this point of treatment ($n = 3$). In total, ten families (55.6%) were included and written consent was obtained from all family members ($n = 47$). The families participated in the pilot study between June and December 2018. The children were between 5 and 9 years of age ($M = 6.7$, $SD = 1.34$), and their diagnoses were mixed. More details about the characteristics of the children and their families can be found in Table 1.

Use of the tool

On average, the families had Mr.V at home for 12 days, of which they used it 8 days. They made between 8 and 36 notes and added 4 to 97 balls to the machine. The notes

were added to the machine on the first day, as well as throughout the week, with the exception of one family who added all the surprises on the first day. The content of the notes ($n = 168$) varied within and between families, but mostly contained indoor family activities (e.g., dance together with mom or dad; roasting marshmallows together; play a game together) or outdoor family activities (e.g., eating out, going to the swimming pool, go for a walk in the forest), but also compliments and/or personal messages to each other (e.g., you are a champion and therefore get a big hug; dad, go for a tour in the cabriolet) and jokes (e.g., get another ball; put make-up on mom and dad; give your dad a face mask and take a picture). Mr.V dropped between 2 and 15 surprises during the time the families used it, with an average of 9 surprises. Most surprises were dropped in the afternoon, which was the preferred time setting of most families. The evening was the least favorite time setting. All families used the time knob at least twice to change the preferred timing of the surprises, as well as the button to obtain surprises on demand. This last button was used on average 37 times per family. The machine was unplugged (i.e., turned off) on average 3 times. More specific data on how Mr.V was used by each family can be found in Table 2.

TABLE 1
Patient ($n = 10$) and family member ($n = 47$) characteristics

	<i>n</i>	%
<u>Patient characteristics ($n = 10$)</u>		
Age		
5 years	3	30.0
7 years	5	50.0
8 years	1	10.0
9 years	1	10.0
Gender		
Boys	8	80.0
Girls	2	20.0
Diagnosis type		
Leukemia or lymphoma	4	40.0
Brain or central nervous system tumor	4	40.0
Solid tumor	2	20.0
<u>Family member characteristics ($n = 47$)</u>		
Patients	10	21.3
Siblings	16	34.0
Parents	21	44.7

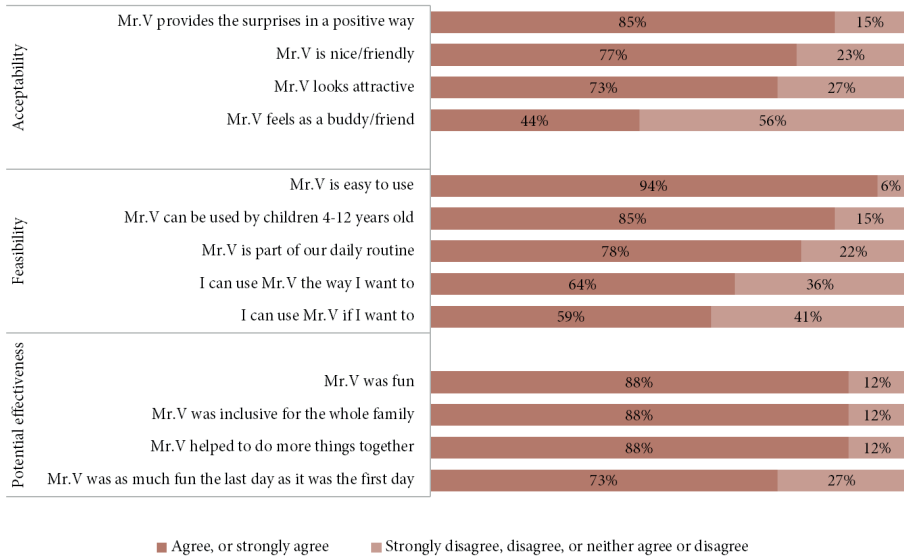
TABLE 2 Use of Mr. V by each family ($n = 10$)												
	Families										Statistics	
	1	2	3	4	5	6	7	8	9	10	M	SD $range$
<u>Availability</u>												
Mr. V at home (days)	10	8	21	29	11	12	9	7	7	7	12.1	7.3 [7-29]
Mr. V used (days)	4	7	13	15	8	10	8	7	6	4	8.2	3.6 [4-15]
<u>Preparation</u>												
Notes made	10	18	11	8	17	24	36	15	9	20	16.8	8.5 [8-36]
Balls added to machine	4	38	49	31	24	97	56	13	12	26	35.0	27.2 [4-97]
On the first day	1	22	31	8	23	17	4	13	10	13	14.2	9.2 [1-31]
Later days	3	16	18	23	1	80	52	0	2	13	20.8	26.0 [0-80]
<u>Machine actions</u>												
Surprises dropped automatically	2	6	14	15	13	10	11	10	8	4	9.3	4.3 [2-15]
Morning	2	6	0	11	7	1	5	2	0	2	3.6	3.6 [0-11]
Afternoon	0	0	6	4	5	7	3	4	7	2	3.8	2.6 [0-7]
Evening	0	0	8	0	1	2	3	4	1	0	1.9	2.6 [0-8]
<u>Family actions</u>												
Time knob used	2	12	51	57	44	10	63	12	16	16	28.3	22.7 [2-63]
Button used	4	37	34	15	18	87	51	4	12	10	27.2	26.1 [4-87]
Unplugged	3	4	8	7	1	1	0	1	1	4	3.0	2.8 [0-8]

Evaluation of the tool

The questionnaires were filled out by 35 family members ($n = 10$ patients, $n = 9$ siblings, and $n = 16$ parents) and 31 family members were interviewed ($n = 10$ patients, $n = 6$ siblings, and $n = 15$ parents). An overview of the questionnaire ratings can be found in Figure 2. These results, together with the 1055 statements of the families that were collected from the interviews, will be described below with regard to feasibility, acceptability and potential effectiveness. Also, the statements about possible improvements will be described. Due to the richness of the data, only the three most mentioned themes for feasibility, acceptability, potential effectiveness and improvements are presented here. More details about other themes that emerged can be found in Table 3 (for feasibility, acceptability and potential effectiveness) and Table 4 (for improvements).

FIGURE 2

Acceptability, feasibility and potential effectiveness of Mr.V as reported by the families. The ratings are ordered from high to low



Note. The themes are ordered from most statements to least statements.

TABLE 3Interview statements ($n = 932$) about acceptability, feasibility and potential effectiveness of Mr.V

Themes	Statements (n)
<u>Acceptability</u>	240
Acceptable	190
Liked the functions or interactions or design	102
Positive associations with the tool	48
Purpose was understandable	40
Less acceptable	5
Functions or interactions or design could be improved	50
<u>Feasibility</u>	421
Feasible	379
How they used the tool	86
Appropriate for all family members and others involved	85
Types or amount of surprises they made	60
Appropriate in home context or sensitive setting or hospital	49
Openness in how to use or control the tool	38
Strategies to make surprises or rules about the content	33
Easy to incorporate into family routines or during difficult times	28
Less feasible	42
Situations when the tool was overwhelming or less feasible to use	26
Less appropriate features of the tool	16
<u>Potential effectiveness</u>	271
Potentially effective	264
Provided a positive, fun or exciting experience	94
Valuable for improving family cohesion or interaction	49
Wanted to use it longer for longer lasting effects	37
Involvement of siblings	33
Buddy for children	26
Supportive for parents	25
Potentially less effective	7

Acceptability

According to the questionnaire ratings, almost all families agree or strongly agree that Mr.V provides the surprises in a positive way. Around three-quarter of the families also agree or strongly agree that Mr.V is nice or friendly and looks attractive. A minority of the families agrees or strongly agrees that Mr.V feels as a buddy or friend. During the interviews, 240 statements were made by family member about acceptability. Most of these statements (79.2%) indicated that the families thought Mr.V was very acceptable. Families talked most about how they liked functions or interactions or design of Mr.V, the positive associations they had with Mr.V, and how the purpose of Mr.V was

understandable. Some illustrative examples of some of these statements were: “I liked most of the sounds, they were a bit sparkling, a bit fairytale-like, magic-like”; “It looks nice, it is funny, it is comparable to a gumball machine that we used to have in the past, everyone wanted those”; “It is a sort of a reward system so to say [...], there are balls inside with some nice assignments or compliments and once in a while a ball drops”. Some statements (20.8%) were made about features of Mr.V that demonstrated lower acceptability. These statements were mostly on how the functions or interactions with Mr.V could be improved, and on how the design could be improved. Some illustrative examples were: “Only the drawer was not working smoothly, it got stuck a few times”; “I think it can be smaller and made of plastic, it feels a bit heavy now”.

TABLE 4 Interview statements ($n = 123$) about improvements of Mr.V	
Themes	Statements (n)
<u>Acceptability</u>	37
More controllable	25
Frequency surprises	9
Parental control	7
Content surprises	5
Fitting family schedule	4
More family-centered	12
More inclusive for siblings and older children	9
More child appropriate	3
<u>Feasibility</u>	46
Better interaction	28
Add humanoid voice with feedback	12
Add more possibilities for interaction	10
Add sound switch/timer	6
Better looks	18
Possibility to customize appearance	11
More colors	7
<u>Potential effectiveness</u>	40
In other environments	27
During treatment	14
In the hospital	10
In other environments	3
More focus on purpose	13
Suggestions for best practice to use	7
More guidance for surprises content	4
Purpose more understandable for children	2

Note. The themes are ordered from most statements to least statements.

Feasibility

According to the questionnaire ratings, almost all families agree or strongly agree that Mr.V is easy to use and can be used by children between 4 and 12 years of age. More than three-quarter of the families agree or strongly agree that Mr.V is part of their daily routine, and more than half of the families agree or strongly agree that they can use Mr.V the way they want to, and if they want to. In the interviews, the families made 421 statements about the feasibility of Mr.V. The majority of these statements (90.0%) indicated that the families thought it was very feasible to use Mr.V. Families mostly explained how they used Mr.V, how the machine was appropriate for all family members and others involved, and the types or amount of surprises they made. Some illustrative examples of some of these statements were: “Most of the times, me and my husband wrote the surprises and then [the child] and his brother, and my daughter opened them”; “Everybody liked it, the youngest two found it most exciting, the oldest one mainly made the assignments, she liked to do that”; “We provided them with some rules like you can ask some presents, but think about more fun things to do, I think that was the goal, how can you do things with the family”. A few statements (10.0%) were made about less feasible features of Mr.V. These statements included situations when Mr.V was overwhelming or less appropriate to use, and features of Mr.V that were sometimes less appropriate. Some illustrative examples were: “I think that Mr.V is a lot of fun, but the frequency of balls, when you would have it for a longer time at home, should not be two surprises per day, that is not doable. Of course, it depends on what kind of surprises you write down, but it is almost not possible to immediately do the things that we had written down”; “Well, I really missed a volume button, the sound was too loud”.

Potential effectiveness

According to the questionnaire ratings, almost all families agree or strongly agree that Mr.V was fun, inclusive for the whole family, and helped to do more things together. Around three-quarter of the families also agree or strongly agree that Mr.V was as much fun the last day as it was the first day. In the interviews, the families made 271 statements about the potential effectiveness of Mr.V. Almost all of these statements (97.4%) indicated that the families thought Mr.V could be very effective for them. Families mostly explained how Mr.V provided them with a positive and fun experience, how Mr.V was valuable for improving family cohesion or interaction, and

how they wanted to use Mr.V for a longer period of time. Some illustrative examples of some of these statements were: “What comes out [of Mr.V] is always a bit of a surprise, so it is really exciting over and over again and that makes it fun”; “[Mr.V] ‘forces’ you a bit to think about what you can do with the family”; “It remains fun, because the surprises are different every day”. Few statements (2.6%) were made about why Mr.V was potentially less effective. For example: “It disturbs sometimes, that is a point of discussion, on the one hand you want to activate to do family things, but on the other hand I have a 60/70 hours job”.

Improvements for the tool

In the interviews, families made 123 statements about possibilities to improve Mr.V. Families suggested that the acceptability of Mr.V would be higher if Mr.V would be more controllable, and even more family-centered. The feasibility to use Mr.V could be improved in terms of the interaction with the tool, and by giving Mr.V better looks. The potential effectiveness could be enlarged by also using Mr.V in other environments, and by putting more focus on its purpose. Examples of this were: “It would be nice if I was able to change the setting of when Mr.V goes to sleep”; “When it would maybe become available in the shops, I would like to choose my own color”; “I think it is nice to provide the parents with some tips about what to write on the notes”; “I certainly see the potential for the market and for schools, people who work with rewarding systems or want to connect, team-building kind of things”.

DISCUSSION

The objective of this pilot study was to describe the experiences of families with a newly developed tool called Mr.V, and to evaluate the potential of this tool to support family functioning and normal family life at home during cancer treatment by promoting family activities. We found that all families used Mr.V for multiple days, regardless of differences in family composition, the diagnosis of the child or the child’s age. There were many variations noticeable between families in how they used the machine. More specifically, in how they prepared the surprises, how much they let Mr.V act on its own, and how intensively they used the functions of the tool. Therefore, we speculate that families were able to use Mr.V in their own way, and adapt it to their own preferences and routines, providing evidence of its universal applicability.

In their evaluation of Mr.V, families were overall very satisfied with the tool. In line with responses to another healthcare tool to promote coping and decrease distress in children undergoing cancer treatment [12], we found that Mr.V was easy and fun to use, well designed, and provided a relevant and positive experience. We also found that Mr.V was inclusive and appropriate for the whole family, helped families to do more things together, and improved family cohesion and interaction. However, Mr.V was not considered as a buddy or friend. Families proposed to make Mr.V more interactive (e.g., add a voice and make it more responsive), which is in line with research on social robots in healthcare that have these qualities and are considered as companions [15]. Families also suggested to not only or exclusively use Mr.V at home, but also in other environments, such as the hospital.

Clinical implications

The development of Mr.V would not have been possible without the valuable collaboration with design researchers. This collaboration is an example of how design can contribute to innovations in healthcare. Design researchers are able to translate needs and ideas of families into directions where it is possible to intervene and to shape new ways of care [16]. They are able to design and develop new technologies and medical devices that promote health in new, different, more appealing and playful ways [17].

Limitations and future research

Mr.V was tested by families during a relatively short period of time, and it would be interesting to find out how the tool would be used and could promote family activities throughout the entire period of cancer treatment. Mr.V should also be tested more, to establish its effectiveness in supporting families during childhood cancer treatment. Measures on feelings of normality, feelings of support, empowerment, resilience, and feelings of distress could help to evaluate how meaningful Mr.V is for families.

Even though we designed Mr.V as a preventative tool to generally support families, it may also be useful as an intervention for specific families that are at elevated risk for distress by providing therapeutic messages. The advantages of using Mr.V for this, is that the assignments are provided in a fun and more appealing way (i.e., makes it feel less therapeutic), and that families can be reminded of the assignments throughout the week in a playful way. Likewise, it could be investigated whether Mr.V would also be

applicable to families dealing with other kinds of illnesses or distress, or for children with special needs.

It is important to realize that further financial support is needed to re-design Mr.V into a more advanced version, following the suggestions provided by families. This new version of Mr.V should resemble a commercial product, should be easy to program according to the needs of each family and should be more responsive in line with the new trends of social robots for children [18]. However, next to financial support for re-designing, there will be costs involved for hospitals to purchase the tool. Although the tool is not very complex and should therefore be affordable to produce, hospitals could also select specific families who will benefit more from Mr.V to reduce the number of purchases. Additionally, hospitals will need to develop a service system to distribute the tool, which could be in collaboration with for example family organizations that are connected to the hospital.

Conclusion

Mr.V is a promising family-centered tool for families dealing with childhood cancer that provides supportive care at home in addition to standard care that is available at the hospital. Mr.V is an acceptable and feasible tool that can be implemented by families independently at home, regardless of their level of need for support. Mr.V promotes family activities, and therefore has the potential to support family functioning and normal family life at home. However, more research on the effectiveness of Mr.V is needed.

REFERENCES

1. Kaspers, G.J.L.; Benoit, Y.; Pieters, R. Inleiding in de kinderoncologie. In *Leerboek kinderoncologie*, Kaspers, G.J.L., Dors, N., Luijpers, W., Benoit, Y., Eds.; De Tijdstroom: Utrecht, the Netherlands, **2019**.
2. Price, J.; Kassam-Adams, N.; Alderfer, M.A.; Christofferson, J.; Kazak, A.E. Systematic Review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2016**, *41*, 86-97, <http://doi.org/10.1093/jpepsy/jsv074>.
3. Long, K.A.; Marsland, A.L. Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Review* **2011**, *14*, 57-88, <http://doi.org/10.1007/s10567-010-0082-z>.
4. Pai, A.L.; Greenley, R.N.; Lewandowski, A.; Drotar, D.; Youngstrom, E.; Peterson, C.C. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology* **2007**, *21*, 407-415, <http://doi.org/10.1037/0893-3200.21.3.407>.
5. Van Schoors, M.; Caes, L.; Verhofstadt, L.L.; Goubert, L.; Alderfer, M.A. Systematic review: Family resilience after pediatric cancer diagnosis. *Journal of Pediatric Psychology* **2015**, *40*, 856-868, <http://doi.org/10.1093/jpepsy/jsv055>.
6. Alderfer, M.A.; Long, K.A.; Lown, E.A.; Marsland, A.L.; Ostrowski, N.L.; Hock, J.M.; Ewing, L.J. Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology* **2010**, *19*, 789-805, <http://doi.org/10.1002/pon.1638>.
7. Patterson, J.M.; Holm, K.E.; Gurney, J.G. The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology* **2004**, *13*, 390-407, <http://doi.org/10.1002/pon.761>.
8. Kazak, A.E. Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health* **2006**, *24*, 381-395, <http://doi.org/10.1037/1091-7527.24.4.381>.
9. Huisman, J.; De Ridder-Sluite, J.G. Ontwikkelingsgerichte zorg. In *Leerboek kinderoncologie*, Kaspers, G.J.L., Dors, N., Luijpers, W., Benoit, Y., Eds.; De Tijdstroom: Utrecht, the Netherlands, **2019**.
10. Zabriskie, R.B.; McCormick, B.P. The influences of family leisure patterns on perceptions of family functioning. *Family Relations* **2001**, *50*, 281-289, <http://doi.org/10.1111/j.1741-3729.2001.00281.x>.
11. Nijhof, S.L.; Vinkers, C.H.; Van Geelen, S.M.; Duijff, S.N.; Achterberg, E.J.M.; Van der Net, J.; Veltkamp, R.C.; Grootenhuis, M.A.; Van de Putte, E.M.; Hillegers, M.H.J.; et al. Healthy play, better coping: The importance of play for the development of children in health and disease. *Neuroscience & Biobehavioral Reviews* **2018**, *95*, 421-429, <http://doi.org/10.1016/j.neubiorev.2018.09.024>.
12. Marsac, M.L.; Hildenbrand, A.K.; Clawson, K.; Jackson, L.; Kohser, K.; Barakat, L.; Kassam-Adams, N.; Aplenc, R.; Vinsel, A.; Alderfer, M.A. Acceptability and feasibility of family use of The Cellie Cancer Coping Kit. *Supportive Care in Cancer* **2012**, *20*, 3315-3324, <http://doi.org/10.1007/s00520-012-1475-y>.
13. D'Olivo, P.; Van Bindsbergen, K.L.A.; Huisman, J.; Grootenhuis, M.A.; Rozendaal, M.C. Designing tactful objects for sensitive settings: A Case Study on Families Dealing with Childhood Cancer. *International Journal of Design* **2020**, *14*, 103-124.

14. Saldaña, J. *The Coding Manual for Qualitative Researchers*, 3rd ed.; SAGE Publications Ltd: **2015**.
15. Kahn, P.H.; Gary, H.E.; Shen, S. Children's social relationships with current and near-future robots. *Child Development Perspectives* **2013**, *7*, 32-37, <http://doi.org/10.1111/cdep.12011>.
16. Caprari, E., Porsius, J. T., D'Olive, P., Bloem, R. M., Vehmeijer, S. B. W., Stolk, N., & Melles, M. Dynamics of an orthopaedic team: Insights to improve teamwork through a design thinking approach. *Work* **2018**, *61*, 21-39.
17. Groeneveld, B., Dekkers, T., Boon, B., & D'Olive, P. Challenges for design researchers in healthcare. *Design for Health* **2018**, *2*, 305-326.
18. Dawe, J., Sutherland, C., Barco, A., & Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2018**, *0*, e000371.

7

General discussion

The general objective of this thesis was to develop and investigate the introduction of innovative and interactive interventions into pediatric oncology care to support children with cancer and their families during treatment both at the hospital and at home. This final chapter provides a summary of the main findings and reflections on these findings while answering our three research questions about the feasibility, the experiences, and the preliminary effectiveness of the interventions. Furthermore, project reflections, methodological considerations, clinical implications and future directions are discussed, and overall conclusions are drawn.

MAIN FINDINGS

Table 1 shows an overview of all studies and outcomes that were presented in this thesis.

Part I – Support for children at the hospital: Exploration and investigation of a social robot in pediatric oncology care

We started in **Chapter 2** by assessing the opinions of almost three hundred health care providers working in pediatric oncology around the world regarding social robots. We found that health care providers were mostly positive about social robots. They considered hospitalization and medical procedures to be the most valuable scenarios for a social robot, and sleep to be the least valuable scenario. They found distraction to be the most valuable function to use the robot for, and education to be the least valuable function. Most health care providers were willing to use a social robot in their work, even though they also expected technical difficulties with this type of innovation. Psychosocial staff members seemed generally more reluctant towards social robots compared to nurses and medical staff.

In **Chapter 3** we introduced a social robot, which was named Hero, as a buddy to 20 children undergoing cancer treatment. Children were able to interact with Hero twice while being hospitalized, and a third time while undergoing a medical procedure. We found that children were very interested to participate in the study and that they reported positive experiences. They found the robot to be age-appropriate, and they reported to feel better on average after the interactions. Almost all children appreciated the support of the robot during a medical procedure, and parents were positive about a robot as a buddy for their child. Children perceived consistently high levels of bonding over the three interactions. Yet, some technical difficulties were encountered during the interactions that need improvement.

TABLE 1
Summary of studies in this thesis and main findings

TABLE 1 Summary of studies in this thesis and main findings					
Part I – Support for children at the hospital: Exploration and investigation of a social robot in pediatric oncology care					
Chapter	Short title	Aims	Study sample	Measurement	Main findings
2	Opinions of health care providers on social robots	Describe opinions of health care providers in pediatric oncology regarding social robots and examine difference in their opinions based on their background characteristics	Health care providers working in pediatric oncology globally ($n = 286$)	<ul style="list-style-type: none">Questionnaire with multiple choice and open questions	<ul style="list-style-type: none">Health care providers were mostly positive about social robots, and therefore this innovation could be a promising addition to pediatric oncology carePsychosocial staff members seemed more reluctant than other health care providersImportant potential barriers were defined that should be addressed upon implementation
3	A social robot as a buddy in pediatric oncology care	Explore the introduction of a social robot as a buddy into pediatric oncology care regarding feasibility, experiences of families, and bonding of children over multiple interactions	Children (4-12 years) hospitalized at the stem cell transplant unit or solid tumor department ($n = 20$)	<ul style="list-style-type: none">Logbook and observation forms (feasibility)Questionnaire in interview form (experiences)Questionnaire <i>Closeness, Trust, and Perceived social support</i> (bonding)	<ul style="list-style-type: none">Children were very interested to participate, reported positive experiences, and perceived high levels of bonding over multiple interactionsA social robot as a buddy could be a beneficial addition to psychosocial care at the hospitalSome challenges need to be overcome to improve feasibility in the hospital context and technical functioning
4	Sleep education by a social robot at the outpatient clinic	Evaluate interactive education by a social robot on sleep hygiene at the pediatric oncology outpatient clinic regarding feasibility, experiences of families, and preliminary effectiveness	Children (8-12 years) receiving anti-cancer treatment and visiting the outpatient clinic with their parents ($n = 28$) and parents filling out a questionnaire two weeks later ($n = 24$)	<ul style="list-style-type: none">Observation forms (feasibility)Semi-structured interviews (experiences)Questionnaire <i>Children's Sleep Hygiene Scale</i> (sleep hygiene)	<ul style="list-style-type: none">Providing education about sleep hygiene in an interactive way using a social robot at the outpatient clinic seemed feasible, and families were generally positiveThere is preliminary evidence that the sleep hygiene of children improved

TABLE 1
Continued

TABLE 1 Continued					
Part II – Support for families at home: Development and investigation of two interactive tools					
Chapter	Short title	Aims	Study sample	Measurement	Main findings
5	Designing tactful objects for sensitive settings	Explore the concept of tactfulness by designing two interactive tools addressing the needs of families dealing with childhood cancer	Families with a child with cancer (6-16 years) in active cancer treatment who were not hospitalized (i.e., at home) for a week (<i>n</i> = 8)	<ul style="list-style-type: none">• Diary (use and experiences)• Pictures and videos (use)• Semi-structured family interviews (experiences and potential effectiveness)• Questionnaire (experiences and potential effectiveness)	<ul style="list-style-type: none">• The development of two interactive tools called AscoltaMe and Mr.V as <i>Tactful Objects</i> was described• Families found the tools easy to use, and had mostly positive experiences with Mr.V• Mr.V seemed to fulfill its purpose and therefore to be potentially effective
6	Support for families at home during childhood cancer treatment	Test a newly developed tool called Mr.V the Spaceman and describe how families used and evaluated the tool, and how it could be further improved	Families with a child with cancer (5-9 years) in active cancer treatment who were not hospitalized (i.e., at home) for a week (<i>n</i> = 10)	<ul style="list-style-type: none">• Machine data (use)• Semi-structured family interviews (experiences and potential effectiveness)• Questionnaire (experiences and potential effectiveness)	<ul style="list-style-type: none">• Mr.V was further developed and redesigned into Mr.V the Spaceman• Families found Mr.V the Spaceman an acceptable and feasible tool that was implemented independently by families at home, regardless of their level of need for support• Mr.V the Spaceman promoted family activities and therefore has the potential to support family functioning and normal family life at home

In **Chapter 4** we used a social robot to provide sleep hygiene education to 28 children with cancer and their parents at the outpatient clinic. We found that the execution of the education at the outpatient clinic was feasible, and all children were able to complete the education without technical issues. Families were mostly positive about their experiences, and the setting with a social robot was inclusive, as several children with (developmental) comorbidities were able to participate as well. Most families reported to have followed up on the sleeping suggestions from the robot and to have applied the recommendations at home. Preliminary effectiveness was found to be promising, as we measured an improvement in sleep hygiene two weeks after the interactive educational session.

Part II – Support for families at home: Development and investigation of two interactive tools

In **Chapter 5** two interactive tools (tactful objects) were developed and described: AscoltaMe to enhance communication between family members, and Mr.V to stimulate social activities in families. The tools were pilot-tested by 8 families dealing with childhood cancer treatment while being at home. We found that families experienced both tools to be enjoyable and playful, and to be a distraction from the child's illness. Mr.V fulfilled its purpose, and reminded families to engage in quality time together. AscoltaMe was used differently than expected as it was not used as much, nor were thoughts or emotions shared. The tools were easy to use but required some creativity to find a suitable way to use them. Families appreciated the looks of the tools, the associations with the designs, the interactions with the tools, the physical presence at home, the fact that they were shared with all family members, and how they blended in with family routines.

In **Chapter 6** Mr.V was redesigned into a spaceman. The spaceman was pilot-tested by 10 families with a child with cancer under active treatment while being at home. We found that all families used Mr.V for multiple days and in a way that suited them. Almost all families evaluated Mr.V as acceptable, feasible to use, and potentially effective for them. Mr.V promoted family activities and therefore has the potential to support family functioning and normal family life at home. Families also provided feedback on possible ways to further improve the tool.

REFLECTIONS ON MAIN FINDINGS

Feasibility

Pilot and feasibility studies are an essential part of planning complex or new interventions. They provide the opportunity to evaluate and explore the setting in which the intervention is introduced, and which barriers and facilitators are encountered while implementing the process in the context. We examined different types of feasibility in our studies, such as the usability of the tools, the study designs, and the context in which they were deployed.

Usability

For our social robot studies, interaction patterns were developed (i.e., new software) and implemented in a NAO robot (existing hardware) by our collaborators. This enabled our robot to interact with the children autonomously and to provide personalized responses whereby also using earlier answers of the child (i.e., it had a memory). A major benefit of these efforts is that the robot was easy to use and did not require much training or involvement from staff (i.e., only turning on the robot and laptop, and starting the interaction). This contributed positively to the feasibility of employing a social robot in our clinical setting. However, the interactivity and adaptivity of the robot also resulted in higher risks for technical problems. In our first study, when the robot was used as a buddy, we encountered a substantial number of technical difficulties (in 33% of the interactions, with 10% uncompleted interactions). Therefore, we adjusted the design of the interactions for our second study where the robot was used to provide sleep hygiene education. First, the repair mechanism (i.e., the alternative way of responding to the robot in case speech recognition failed) did not work adequately enough, and together with our technical partners, a different repair mechanism was implemented. A tablet was added to the set-up, whereby children could select an answer from multiple options on the tablet in case the speech recognition software failed. This made the interactions run more smoothly. Additionally, the tablet also could be used in the education to provide visual support and exercises to children.

Second, we decreased the complexity of the interactions. In the first study, the robot asked many semi-open questions to children, such as favorite color, pet type, and holiday destination, where unexpected answers were given that did not fit the expected interactions that were programmed (such as “all colors of the rainbow” and “pastel colors”), while in the second study the questions could be mostly answered with yes,

no, and maybe or sometimes. These adaptations to the design of the interactions resulted in three times less technical problems in our second study (in 11% of the interactions, with all interactions completed), and thus better usability. The age of the children could have contributed to this improved feasibility as well, as the sleep education was implemented with somewhat older children compared to the robot buddy. Older children may be better at adapting their behavior towards the robot when difficulties in the interaction occur, resulting in less challenging behavior for the robot to process.

AscoltaMe and Mr.V were designed to have simple interactions (such as shuffling balls and making sounds, and recording or playing voice messages), and did not require an internet connection or any advanced software. In the further development and redesign of Mr.V to a spaceman, an additional function was developed to provide families with more control over the tool. A rotary knob was added with which families could set a preferred time zone in which the surprises could be dropped, to provide them with more control over the timing of the surprises. The tools were feasible to use, as families were able to implement them independently at home without support from researchers or staff from the hospital, and without technical difficulties. Therefore, the feasibility of using these tools at home was high.

Study designs

The interventions had different set-ups and were introduced and (pilot-)tested in different settings, which had different impacts on the feasibility. The social robot was used at the inpatient and outpatient care at the hospital. During inpatient care, multiple interactions were planned with the robot as a buddy, with an overall drop-out rate of 30%. This drop-out rate was largely explained (83%) by the inability to plan multiple meetings because of changes in the medical journey of children. Therefore, having multiple interactions during inpatient care did not seem feasible, and implementing multiple interactions that build on each other (i.e., that input from the child in one session is needed for the next session) is not recommended in a clinical inpatient setting. On the contrary, at the outpatient care at the hospital all sessions with the robot were completed. The outpatient clinic was much more structured and predictable. Families usually had one appointment and felt that there was some space to interact with the robot before or after their appointment or they filled the time in-between appointments if they had multiple subsequent appointments. AscoltaMe and

Mr.V were used in the home setting by families for usually a week. Families were able to use the tools in a way and at time points that worked for them, which resulted in high feasibility of this set-up.

Context

The interventions were developed for and applied to the specific context of pediatric oncology patients. During our study at the inpatient care, we experienced that multiple children preferred to respond to the robot using the buttons on its feet instead of responding verbally. This could be a specific finding for our context, as we did not see this in our studies with children from the general population [1,2]. This finding could be explained by the fact that the children in our study were hospitalized and often quite ill. Answering via buttons was probably less intensive than answering by speech in a loud and timely matter. This is something to consider when developing interactive interventions that are feasible to use for sick children: They should not be too demanding.

Experiences

The experiences of children, their families and health care providers with the interventions are of critical importance to the successfulness of the interventions. Making sure that children and their families feel comfortable using the interventions, and that health care providers are supportive of the interventions, are essential elements for realizing effectiveness. Therefore, the results of this section are closely related to the potential effectiveness as described in the next section.

Children and parents

Children and their families were generally enthusiastic and interested in the interactive nature of the interventions. In all studies, participation rates were high, with a remarkable 91% in our social robot study where it was used as a buddy. These findings support the fundamental concept that interactive, playful tools are an attractive and suitable form for interventions for children [3]. Also, ratings from children and their families on their experiences with the social robot and Mr.V were high. They wanted to interact with the social robot more often and wanted to have Mr.V at home again or keep it for a longer period of time. The fact that Mr.V was inclusive for all family members was especially appreciated by families. Considering

the strong recommendation that siblings of children with cancer should be provided with psychosocial services as well [4], it is worthwhile to further explore the potential effectiveness of Mr.V for this.

The ratings of children and their families regarding their experiences with AscoltaMe, however, were lower than with the social robot and Mr.V. This is why this intervention was not further developed. Even though children and their families experienced AscoltaMe as enjoyable and fun, they reported that they did not use the tool for the intended purpose of discussing thoughts or emotions, and that it felt somewhat unnatural to use. Literature on families in the general population shows that parents and children are users of various modern media, and that despite that, opportunities for communication are not always taken and that there is a less than desired exchange of expressive and affective messages [5]. An intervention called *Family Circles* was developed, which is a messaging system that represents a technological form of leaving spoken messages on tokens at home throughout the house. Their trial field study suggested that the tool can support expressive, informal communication. Therefore, this tool could be further explored for the use in the health care setting.

Health care providers

The opinions of health care providers that were collected in our survey study, indicated that they expected social robots to be most valuable during hospitalization and medical procedures, and that distraction would be the most valuable function. This is in line with the results from our robot buddy study. However, health care providers expected little value from sleep or education, while – even the combination of the two – was found to be very promising in our setting. A potential explanation could be the way the opinions of health care providers were asked. The questionnaire did not specify how the robot would be used in the context of sleep and it may have been difficult for health care providers to envision the contribution of a social robot in a clinical setting when they had no or limited experiences with them. Furthermore, psychosocial staff members seemed more reluctant towards social robots. This is something we experienced in our robot buddy study as well. Even though our team of child life specialists was of great help in including the children in our study, we were unable to include the child life specialists themselves in our study. Either they were not present during the medical procedures or they did not respond to the questionnaire about their experiences. This is something that warrants further attention (see Future directions).

Preliminary effectiveness

In all our studies, an important overarching question was: Do children and their families benefit from the interactions with the tools? Considering that our interventions were all newly developed, most of our studies were exploratory (pilot-)studies to examine the feasibility of using the interventions and to evaluate the experiences of children, their families and health care providers with the interventions. Yet, we were able to look at indications of preliminary effectiveness of our interventions regarding stress and anxiety, bonding of children with the social robot, and sleep hygiene.

Stress and anxiety

As outlined in the introduction of this thesis, one of our aims was to change the subjective experience of children of potentially traumatic events to reduce levels of, or completely prevent, medical traumatic stress [6]. As part of our robot buddy study, the robot accompanied children during a medical procedure at the treatment room where it told a story in an animated fashion that was personalized and partially self-composed by children. Children and parents reported to have experienced less stress and anxiety, and sometimes less pain during the medical procedures when the robot accompanied them, compared to previous procedures. However, children and parents also noted that the level of stress of the child was usually not that high, which can be a result of the interventions from our child life specialists. For children that experienced high levels of stress and anxiety, the robot did not seem to meet their support needs, and children were too stressed to pay attention to the robot. Therefore, a buddy may not be sufficient for these children, and different content is needed that includes more active distraction, as was done in other social robot studies with promising results [7-10]. During hospitalization, when children interacted with the robot buddy in their patient room, they reported on average to feel better after the interactions than before the interactions. Therefore, the role of a robot buddy in overall stress and anxiety reduction at the hospital should be further examined.

Bonding

Children experienced high levels of bonding with the robot buddy over multiple interactions and also reported to consider the robot to be a buddy or a friend. In our study among health care providers, we found that they believe that it important that children are familiar or have bonded with the robot before using it during treatment.

The results from our robot buddy study showed that bonding scores were already high upon a first encounter, which is in line with findings from earlier research in which the bonding questionnaire was validated [11]. Therefore, even though it is appropriate to first introduce a social robot to children and teach them how to use it, children do not seem to need much more bonding to feel comfortable around a robot. Considering that the bonding scores in our study remained persistently high over time, the robot could be meaningful when it comes to overall stress and anxiety reduction for children in the hospital. This confirms the findings described before and was also concluded in several reviews on the use of social robots in health care [12-14].

Sleep hygiene

In our sleep education study with the social robot, we were able to measure sleep hygiene behaviors in children before and after the intervention, and found promising results: The sleep hygiene behaviors of children were statistically significantly improved two weeks after the education. This finding is particularly hopeful, as a review concluded that most sleep education programs (without social robots) in children from the general population are not necessarily associated with changes in sleep behavior such as sleep hygiene [15]. Therefore, a social robot could be of added value in education to children, which could be attributed to its interactive, and playful nature. Other educational interventions that were provided via social robots to children in the health care context showed positive results as well [16-18].

PROJECT REFLECTIONS

While setting up and conducting the projects in this thesis, we experienced some specific barriers and facilitators related to their innovative, technological, and multidisciplinary nature. These lessons learned are important to share, since technological intervention research for children in the health care setting is growing, and these kinds of reflections can be educational and are rarely published.

Scenarios

At the start of our social robot project, we carefully considered different scenarios for the robot. We originally explored if the robot could be beneficial in situations where parents could not be with their child, with the purpose to reduce stress and anxiety. Scenarios we examined, were: (1) Diagnostic imaging (i.e., PET/CT-scan), (2) radiation therapy (i.e.,

brachytherapy, AMORE therapy and MIBG therapy), (3) hospitalization, and (4) sleeping at the hospital. These scenarios were well discussed with children and their parents, as well as with child life specialists and other health care providers with expertise in the specific areas, such as nuclear medicine. In almost all scenarios several barriers were identified, which are summarized in Table 2. After careful considerations, the first two scenarios were canceled, and the third and fourth scenario were adapted. For the third scenario, a step-by-step introduction of the robot to children was added (starting with getting acquainted in their own patient room), as well as the scenario of distraction during a medical procedure in the treatment room (e.g., subcutaneous port access), resulting in the robot buddy study (Chapter 3). For the fourth scenario, we integrated our scientific knowledge on sleep problems in childhood cancer [19-21], and responded to the lack of, and need for, sleep education in children with cancer. This resulted in our robot sleep education study (Chapter 4). The expertise of health care providers at our pediatric hospitals, as well as their input in our international survey study, were important facilitators in selecting and reflecting on the different scenarios. This resulted in a balanced selection of scenarios that we considered to have the most potential.

Content

After selecting the scenarios, we developed the content for the robot in these scenarios. First, we focused on selecting behaviors for the robot that would contribute to the desired outcomes while also making optimal use of the robot. Second, it was important to design content that would be feasible to develop within the timeframe of the project. These efforts resulted in a software framework and robot behaviors that were more advanced than existing software. The robot in our project was able to act autonomously (i.e., was not operated by health care providers) and to have personalized conversations with children (i.e., respond differently and more suitable based on the response of the child), whereby also using earlier answers of the child (i.e., it had a memory). Even though this development came with more risks of technological complications when using the robot, we deemed it more important to create a robot that required minimal effort from health care providers (i.e., for better future implementation) and a better experience for children (i.e., more durable relationship and longer-term interest). We pilot-tested the technical functioning of the robot outside the hospital context first with children from the general population [1,2] to avoid unnecessary burden for children with cancer. This approach contributed importantly to the usefulness and successfulness of the robot in our clinical setting.

TABLE 2
Scenarios and considerations for application of a social robot during pediatric oncology treatment in our project

Scenario	Considerations	Conclusion
A) Diagnostic imaging When parents cannot be with their child during imaging (due to radiation risk), a social robot as a buddy could accompany the child to reduce the child's distress	<ul style="list-style-type: none"> • In contrast to what we expected, parents are able to stay with their child if necessary during diagnostic imaging • Many other facilities are available to distract or support children (e.g., music, reading by parents) • The procedure is very time sensitive, and the robot could delay • The procedure requires children to rest (i.e., to move as little as possible) and the environment to be silent (i.e., low-stimulus) • Procedure not used often, cost-effectiveness of development questionable • Good scan results and staff • Protection for the robot needs to be developed or the robot cannot be used for days after radiation exposure 	Not desirable
B) Radiation therapy When parents cannot be with their child during therapy (due to radiation risk), a social robot as a buddy could accompany the child to reduce the child's distress	<ul style="list-style-type: none"> • Most children are too young to interact with a robot (i.e., mostly 2-3 year olds) • Difficult scenario for initial feasibility testing: If something goes wrong, not possible to interfere due to radiation exposure • Depending on age, children may not be able to move (i.e., no freedom to play or interact with robot or even see it) • Robot needs protection (not existing) or cannot be used for days after radiation exposure 	Not feasible

TABLE 2 Continued		
Scenario	Considerations	Conclusion
C) Hospitalization When a child is hospitalized (for long periods of time) and separated from peers and family members, a social robot could be a companion to support the child's well-being	<ul style="list-style-type: none">• Difficult to define outcomes of success• Unclear whether a robot companion during hospitalization would be worth the initial developmental efforts (i.e., creating a toy)	Adapted based on: 1) The outcomes of our health care providers study; • Using a social robot in the treatment room was considered the most valuable scenario • Safe bonding of children with the robot was stressed to be important 2) The literature; • Showed a need for design of longer-term interactions between children and robots, fitting with our context where children are treated for a longer period of time → Resulted in Chapter 3: A social robot as a buddy
D) Sleeping at the hospital When a child is hospitalized and needs to sleep at the hospital, a social robot could accompany the child during the night to reduce stress and improve sleep	<p>Children sleeping at the hospital alone does not occur (especially at the Princess Máxima Center where all patients room have an attached parent room)</p> <p>Presence of a robot during the night can be disruptive to sleep or can arouse children</p> <p>The robot makes quite some noise, especially when it moves</p> <p>The voice of the robot is not soothing to be used for example for relaxation exercises and there are many alternatives (i.e., white noise machines and stuffed animals, relaxation exercise via apps or online)</p>	Adapted based on the literature: • Showed significant sleep problems in children with cancer • Showed no sleep (hygiene) education program available for children (with cancer or other illnesses) → Resulted in Chapter 4: A social robot for sleep hygiene education

Designers made important contributions to the content of AscoltaMe and Mr.V, most evidently with regard to their creativity. The development of the content of AscoltaMe and Mr.V was carried out by our collaborating partner based on our defined aims for the tools, and their deepening into our pediatric oncology context. The designers were able to create tools that were attractive to families, and their creativity was especially visible in the further development and redesign of Mr.V from a gumball machine into a spaceman. They also created a tool-kit around the interventions, such as a box that came with the interventions, including related attributes and for example a background story about Mr.V the Spaceman. One of the designers also created the illustrations for the robot sleep education study (i.e., the material for the visual support and exercises on the tablet), and for the magnet with sleeping suggestions that children received to take home. In the robot buddy study, there were creative aspects as well, such as that the robot used information that children shared with the robot to personalize the conversations, and children were able to create a story together with the robot, including movements, light shows and sound recordings. Also Wintertuin, one of our project partners, contributed significantly to the content of the robot by writing interactive stories specifically suitable for the robot to tell children. All these creative additions were important contributions to the projects.

Collaboration

In both projects, the development of the interventions required cooperation between multiple parties that worked in different fields. At the hospital, there was expertise with the clinical setting and knowledge on the requirements of psychosocial interventions, while the technical parties were able to develop hardware and software. To establish the envisioned interventions, this needed to be combined while communication was often challenged by differences in approaches, jargon, research experiences (methods), scientific output (publications and literature), interests or perceived benefit, and potential implementation success. Therefore, expectation management was an important part of the projects, and the process of shaping the interventions was labor intensive. Despite these complexities, the collaborations paid off and lead to new, innovative interventions which would not have been possible to realize without.

Organization

Both projects were designed for children with cancer and initiated before the centralization of care for these children to the Princess Máxima Center for pediatric

oncology in May 2018. The *Meedoen=Groeien!?* project (with AscoltaMe and Mr.V) started in 2015 in the early start-up stage of the Princess Máxima Center when it was located within the Wilhelmina Children's Hospital of the University Medical Center Utrecht (UMC Utrecht). The social robot project started in 2016 at the Emma Children's Hospital of the Amsterdam University Medical Centers (Amsterdam UMC) and moved to the Princess Máxima Center in 2018. This relocation had an impact on the project, as it was not feasible to set up and start a study at the Emma Children's Hospital, and to collect the data before the patients moved. Once the Princess Máxima Center opened for all patients in 2018, there were understandably other priorities, and there was a temporarily hold on new studies. Also specifically our robot project, that needed lots of support from the organization (such as IT and legal services), was a bit too early for this new organization. Regulations were not always clear yet, for example regarding the use of the camera and microphone of the robot, safe storage of patient data, and hygiene of the robot. Analyses were needed to map potential risks when using the robot (vulnerability assessment) and the developed software needed to be verified. It was also unclear whether the robot needed to be classified as a medical device, which had an impact on the regulations that apply for the robot and the research that we were allowed to do. Fortunately, with the efforts of many colleagues from the Princess Máxima Center that supported our projects, we were able to implement the interventions into the pediatric oncology setting, and with the centralized care of the Princess Máxima Center the studies could be introduced to many children.

METHODOLOGICAL CONSIDERATIONS

The findings of this thesis must be considered in light of some overall limitations.

Sample

Although smaller sample sizes are not unusual in this type of research, it should be mentioned that all evaluations with children and their families were limited in numbers. Most of our studies with patients and their families were explorative studies to test feasibility and obtain experience. We first needed to establish that the interventions worked (technically), were acceptable to children and their families, and fitted regulations, before setting up a large study. We also see this in other studies with interactive interventions for families in the general population [5,22,23] and pediatric patients [24,25], and in social robots studies in children with diabetes [18] and cancer

[8,26,27]. The evaluations among health care providers were based on a convenience sample, which may have affected the representation of this group. Moreover, we were unable to include child life specialists in our robot buddy study, so their experiences could not be compared to the findings of the survey study.

Measures

Even though we usually applied three or more different methods for our evaluation (e.g., observations, questionnaires, interviews), most of these measures were developed by us. There were no appropriate and validated ways to measure for example stress and anxiety in children during medical procedures, to assess experiences of children and their families with interactive tools, or to estimate the impact or effects of the tools. Only for sleep hygiene and bonding validated questionnaires were available [11,28], although it must be noted that the bonding questionnaire was not suitable for the youngest children in our study, and that sleep hygiene was only evaluated using parent reports. To measure stress and anxiety, we translated and tested the Procedural Behavior Rating Scale (PBRS) [29] and the modified Yale Preoperative Anxiety Scale (mYPAS-SF) [30]. Unfortunately, neither scale worked to our satisfaction as the scores from these measures did not match with the observed behaviors in children (i.e., the measures were not sensitive or distinctive enough for children experiencing low or moderate stress and anxiety). Moreover, the (effects of the) behavior of parents or health care providers could not be taken into account, nor could coping behaviors that occurred.

Privacy

In our social robot studies, Automated Speech Recognition (ASR) software was used to understand what the child was saying. We used the cloud-based ASR system by Google, called Dialogflow. This system showed to give the best performance for child-robot speech interaction with the NAO robot that we used [31]. Research also showed that it is important that the robot understands the child for an effective intervention [1,32], and that children feel less comfortable in the interaction with the robot when speech recognition fails [33]. Therefore, we decided to use the best available software instead of developing this software ourselves. Using this software, however, limited us in the design of our interactions and studies, because the answers of children that were recorded by the robot were sent to Google's Dialogflow where they were stored in audio form and text form. Considering that this data could contain personal or

sensitive information from children, and we did not want any private information to leave the hospital, we adapted the conversational scripts. Consequently, the robot was unable to ask children for their name, age, or illness (although we were able to add the name of the child in a way that the robot could use it, and it would not be shared with Google).

CLINICAL IMPLICATIONS AND FUTURE DIRECTIONS

With the research described in this thesis, we hope to have made some important contributions to the field of innovative interventions for the use in pediatric oncology. We were able to develop a robot that autonomously processed the responses of children, and then selected appropriate, personalized responses using also earlier answers of the child (i.e., memory-based). With this, we created a “smart” social robot that was able to function independently at the hospital, without the need of an operator (i.e., health care provider). The need for this independency in the field of health care is becoming more evident, and it is something other new projects are aiming for as well [34]. For the home setting, we were able to create interactive tools that functioned technically well and that could be used by families independently without any additional support from researchers or health care staff as well. This independent use, not burdening health care providers, is an important clinical implication regarding the feasibility of implementing these interventions in the clinical health care setting.

More research

A next step would be to study the effectiveness of our interventions in a larger study design, including validated measures. This is in agreement with conclusions and recommendations from other review studies regarding social robots in health care [14,17]. As outlined in our Project reflections, several barriers need to be overcome, and preliminary experience is needed before it is possible to start a large (randomized controlled) study. Therefore, more publications about developmental considerations, and barriers and facilitators in performing studies with technological health care tools, as was done by researchers in the United States [35], are needed to accelerate the process. Also, sharing conversational scripts or software would make it easier to translate work to other settings and for other purposes. Furthermore, considering the lengthy treatment of pediatric cancer, more research on how to keep the interactions interesting to children and their families long-term, as well as how to safeguard long-

term use (i.e., continued availability of the tools) is important. Fortunately, some first steps in this direction seem to have been made with an increase in human-robot interaction literature on how long-term interaction should be designed [36,37].

Further technical development

It is important to stress that all tools that were created in this thesis were prototypes. Before any of these interventions can be further researched for effectiveness or in the future be implemented into care, further technical development is needed. For the social robot, a next step would be to develop native ASR software. This would resolve privacy issues (i.e., data of patients will not be shared with external parties), as well as a large part of our technical issues (i.e., no internet connection problems). As a result, the robot would be able to talk with children about more personal topics, such as their illness or how they are feeling. Another next step would be to add adaptive mechanisms, such that when the interaction is not going smoothly (i.e., the robot does not understand the child multiple times in a row), the robot resorts to simpler interactions (i.e., yes-no questions). This would also contribute to the age-appropriateness of the robot, making the interactions more accessible for younger children. Also, emotion recognition software would be a valuable contribution for future robots interacting with sick children. If a robot would be able to recognize the facial expressions of children or be able to detect subtle changes in their faces or voices (i.e., recognize common displays of emotions), the robot would be even more suitable to be used in the sensitive context of sick children. In our project, we attempted to develop this software, but we were unable to implement it yet. Other researchers are working on emotion recognition software in adults [38,39] and children with autism [40]. Mr.V the Spaceman could be further developed into a more advanced version following suggestions provided by families in our last study. This feedback mostly concerned additional options for families to program the device according to their needs (i.e., number of surprises) and to make the device more interactive (i.e., talk, e.g., more like a robot). It is important to note that all the mentioned developments will require lots of financial support and time.

Including child life specialists

Child life specialists play an important role in supporting patients and their families during treatment. The tools as they were developed and researched in this thesis,

would be an additional resource to their work. However, as we have seen in two of our studies, child life specialists in our center did not seem eager to incorporate a robot into their practice. Other researchers have reflected upon experiences of child life specialists working with social robots [41], and upon reflections of child life specialists on the process of implementation [42]. Especially the first paper explains the different kind of barriers that child life specialists experienced in using a social robot: From fear of operating the robot, and fear of the robot not working in front of children, to not knowing how it could be used with children, and generally refusing to use it. Fortunately, the study also found that this resistance declined over time with trial and error, and after child life specialists experienced the impact of the robot on children. It is likely that the fears that were described in the research above, are experienced by child life specialists in our center as well. Also, our study among health care providers showed reluctance among child life specialists towards social robots and a fear to be replaced. Therefore, it is important to include child life specialists at an early stage of the project where their thoughts and preferences can be included in the design of the robot and possible concerns can be taken away. They could be part of the data collection process as well, to gain experience with using the robot.

Additional settings

The educational intervention that was developed for the robot, focused on sleep hygiene. Yet, there are various other topics that would be suitable for interactive education with a social robot as well. In our set-up, the robot tested the knowledge of children with quiz-like questions, and provided tailored information based on the responses of children. Other topics that seem suitable for this format, are for example pain education, which is a significant component of (non-pharmacological) pain interventions [43-45], and education about difficult topics such as predisposition syndromes [46] or nutrition [47,48] which can be repeated by the robot several times. Looking at the literature, the results of a meta-analysis on coping and adjustment in children with cancer showed different needs related to the time since diagnosis and type of stressor [49]. Teaching children different coping strategies at different moments, paired with medical procedures and specific treatments, could enhance the ability of children to cope and adjust. Here, a social robot could be of additional value by providing tailored education at multiple moments. Also, a cognitive and problem solving training was developed for children with cancer to address the late effects of neurocognitive sequelae [50]. This intervention struggled with a low participation rate,

raising concerns about the acceptance of the program. A social robot could provide solutions here in making the intervention more appealing and interactive for children, comparable to another pediatric oncology study where the robot was successfully used as a therapy assistant [26] or educational games as was done in children with diabetes [18]. Another study used a social robot to provide information about anesthesia and surgery in the waiting room, which could be an appropriate location [51].

Mr.V was developed to be used by families at home. However, multiple families pointed out that Mr.V could be an addition at the hospital as well, for example during (long) hospital stays to have dedicated moments of family time together or to motivate children to go outside the patient room when they are feeling more sick. Another way to support family functioning could be to develop an additional digital Mr.V to connect family members at the hospital with family members at home, where the surprise can be shared with all family members even though they are not physically together. Additionally, Mr.V could be used more clinically as an intervention by psychologists or other health care providers at the hospital, to provide specific assignments to families in a playful and accessible way. More generally, a standard set of surprises (i.e., activities or assignments) could be developed to use Mr.V more therapeutically, or family members could be asked to share their worries, fears, or happy moments, also facilitating intra family communication.

Conclusion

In this thesis, four technological interactive interventions were developed and scientifically evaluated with the aim of reducing medical traumatic stress and supporting families in coping with childhood cancer treatment. Most of the interventions were found to be feasible to use, to provide fun and positive experiences to children and their families, and to be potentially effective. Further technological development is needed to improve (the functioning of) the interventions, as well as more research on their effectiveness and generalizability to other settings. Also the involvement of child life specialists in any further steps is needed. We hope that the project reflections in this thesis are helpful to future innovative, technological projects, and that our research efforts as described in this thesis have contributed to the field of innovative interventions in pediatric oncology care and to the future psychosocial care for children with cancer during treatment at the hospital and at home.

REFERENCES

1. Ligthart, M.E.U.; Fernhout, T.; Neerincx, M.A.; Van Bindsbergen, K.L.A.; Grootenhuis, M.A.; Hindriks, K.V. A child and a robot getting acquainted - Interaction design for eliciting self-disclosure. In Proceedings of the 18th International Conference on Autonomous Agents and MultiAgent Systems (AAMAS), Montreal, Canada, **2019**; pp. 61-70.
2. Ligthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Co-creation as a facilitator for co-regulation in child-robot interaction. In Proceedings of the Companion of the ACM/IEEE International Conference on Human-Robot Interaction (HRI), Boulder, CO, USA, **2021**; pp. 298-302.
3. Nijhof, S.L.; Vinkers, C.H.; Van Geelen, S.M.; Duijff, S.N.; Achterberg, E.J.M.; Van der Net, J.; Veltkamp, R.C.; Grootenhuis, M.A.; Van de Putte, E.M.; Hillegers, M.H.J.; et al. Healthy play, better coping: The importance of play for the development of children in health and disease. *Neuroscience & Biobehavioral Reviews* **2018**, *95*, 421-429, <http://doi.org/10.1016/j.neubiorev.2018.09.024>.
4. Gerhardt, C.A.; Lehmann, V.; Long, K.A.; Alderfer, M.A. Supporting siblings as a standard of care in pediatric oncology. *Pediatric Blood & Cancer* **2015**, *62*, S750-804, <http://doi.org/10.1002/pbc.25821>.
5. Schatorjé, R.; Markopoulos, P. Intra-family messaging with Family Circles. In *Connecting families: The impact of new communication technologies on domestic life*, Neustaedter, C., Harrison, S., Sellen, A., Eds.; Springer: Berlin, Germany, **2013**; pp. 57-74.
6. Kazak, A.E.; Kassam-Adams, N.; Schneider, S.; Zelikovsky, N.; Alderfer, M.A.; Rourke, M. An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology* **2006**, *31*, 343-355, <http://doi.org/10.1093/jpepsy/jsj054>.
7. Farrier, C.E.; Pearson, J.D.R.; Beran, T.N. Children's fear and pain during medical procedures: A quality improvement study with a humanoid robot. *Canadian Journal of Nursing Research* **2020**, *52*, 328-334, <http://doi.org/10.1177/0844562119862742>.
8. Jibb, L.A.; Birnie, K.A.; Nathan, P.C.; Beran, T.N.; Hum, V.; Victor, J.C.; Stinson, J.N. Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial. *Pediatric Blood & Cancer* **2018**, *65*, e27242, <http://doi.org/10.1002/pbc.27242>.
9. Rossi, S.; Larafa, M.; Ruocco, M. Emotional and behavioural distraction by a social robot for children anxiety reduction during vaccination. *International Journal of Social Robotics* **2020**, *12*, 765-777, <http://doi.org/10.1007/s12369-019-00616-w>.
10. Smakman, M.H.J.; Smit, K.; Buser, L.; Monshouwer, T.; Van Putten, N.; Trip, T.; Schoof, C.; Preciado, D.F.; Konijn, E.A.; Van der Roest, E.M. Mitigating children's pain and anxiety during blood draw using social robots. *Electronics* **2021**, *10*, 1211, <http://doi.org/10.3390/electronics10101211>.
11. Van Straten, C.L.; Kühne, R.; Peter, J.; De Jong, C.; Barco, A. Closeness, trust, and perceived social support in child-robot relationship formation. Development and validation of three self-report scales. *Interaction Studies* **2020**, *21*, 57-84, <http://doi.org/10.1075/is.18052.str>.
12. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatrics Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.

13. Lopez-Rodriguez, M.M.; Fernandez-Millan, A.; Ruiz-Fernandez, M.D.; Dobarrío-Sanz, I.; Fernandez-Medina, I.M. New technologies to improve pain, anxiety and depression in children and adolescents with cancer: A systematic review. *International Journal of Environmental Research and Public Health* **2020**, *17*, <http://doi.org/10.3390/ijerph17103563>.
14. Moerman, C.J.; Van der Heide, L.; Heerink, M. Social robots to support children's well-being under medical treatment: A systematic state-of-the-art review. *Journal of Child Health Care* **2019**, *23*, 596-612, <http://doi.org/10.1177/1367493518803031>.
15. Bluden, S.L.; Chapman, J.D.; Rigney, G.A. Are sleep education programs successful? The case for improved and consistent research efforts. *Sleep Medicine Reviews* **2012**, *16*, 355-370, <http://doi.org/10.1016/j.smr.2011.08.002>.
16. Belpaeme, T.; Kennedy, J.; Ramachandran, A.; Scassellati, B.; Tanaka, F. Social robots for education: A review. *Science Robotics* **2018**, *3*, <http://doi.org/10.1126/scirobotics.aat5954>.
17. Dawe, J.; Sutherland, C.; Barco, A.; Broadbent, E. Can social robots help children in healthcare contexts? A scoping review. *BMJ Paediatr Open* **2019**, *3*, e000371, <http://doi.org/10.1136/bmjpo-2018-000371>.
18. Blanson Henkemans, O.A.; Bierman, B.P.B.; Janssen, J.; Looije, R.; Neerincx, M.A.; Van Dooren, M.M.M.; De Vries, J.L.E.; Van der Burg, G.J.; Huisman, S.D. Design and evaluation of a personal robot playing a self-management education game with children with diabetes type 1. *International Journal of Human-Computer Studies* **2017**, *106*, 63-76, <http://doi.org/10.1016/j.ijhcs.2013.04.012>.
19. Steur, L.M.H.; Grootenhuis, M.A.; Van Someren, E.J.W.; Van Eijkelenburg, N.K.A.; Van der Sluis, I.M.; Dors, N.; Van den Bos, C.; Tissing, W.J.E.; Kaspers, G.J.L.; Van Litsenburg, R.R.L. High prevalence of parent-reported sleep problems in pediatric patients with acute lymphoblastic leukemia after induction therapy. *Pediatric Blood & Cancer* **2020**, *67*, e28165, <http://doi.org/10.1002/pbc.28165>.
20. Steur, L.M.H.; Kaspers, G.J.L.; Van Someren, E.J.W.; Van Eijkelenburg, N.K.A.; Van der Sluis, I.M.; Dors, N.; Van den Bos, C.; Tissing, W.J.E.; Grootenhuis, M.A.; Van Litsenburg, R.R.L. The impact of maintenance therapy on sleep-wake rhythms and cancer-related fatigue in pediatric acute lymphoblastic leukemia. *Supportive Care in Cancer* **2020**, *28*, 5983-5993, <http://doi.org/10.1007/s00520-020-05444-7>.
21. Steur, L.M.H.; Kolk, R.H.E.; Mooij, F.; De Vries, R.; Grootenhuis, M.A.; Kaspers, G.J.L.; Van Litsenburg, R.R.L. The prevalence and risk factors of sleep problems in pediatric oncology: Its effect on quality of life during and after cancer treatment. *Expert Review of Quality of Life in Cancer Care* **2016**, *1*, 153-171, <http://doi.org/10.1080/23809000.2016.1168265>.
22. Chatting, D.; Yurman, P.; Green, D.P.; Bichard, J.-A.; Kirk, D.S. Ritual machine V: Where are you. In Proceedings of the 3rd Conference on Biennial Research Through Design, London, UK, **2017**; pp. 131-147.
23. Helmes, J.; Hummels, C.; Seilen, A. The other brother: Re-experiencing spontaneous moments from domestic life. In Proceedings of the 3rd International Conference on Tangible and Embedded Interaction (TEI), Cambridge, UK, **2009**; pp. 233-240.
24. Marsac, M.L.; Hildenbrand, A.K.; Clawson, K.; Jackson, L.; Kohser, K.; Barakat, L.; Kassam-Adams, N.; Aplenc, R.; Vinsel, A.; Alderfer, M.A. Acceptability and feasibility of family use of The Cellie Cancer Coping Kit. *Supportive Care in Cancer* **2012**, *20*, 3315-3324, <http://doi.org/10.1007/s00520-012-1475-y>.

25. Marsac, M.L.; Klingbeil, O.G.; Hildenbrand, A.K.; Alderfer, M.A.; Kassam-Adams, N.; Smith-Whitley, K.; Barakat, L.P. The Cellie Coping Kit for sickle cell disease: Initial acceptability and feasibility. *Clinical Practice in Pediatric Psychology* **2014**, *4*, 389-399, <http://doi.org/10.1037/cpp0000062>.
26. Alemi, M.; Ghanbarzadeh, A.; Meghdari, A.; Moghadam, L.J. Clinical application of a humanoid robot in pediatric cancer interventions. *International Journal of Social Robotics* **2016**, *8*, 743-759, <http://doi.org/10.1007/s12369-016-0382-7>.
27. Meghdari, A.; Shariati, A.; Alemi, M.; Vossoughi, G.R.; Eydi, A.; Ahmadi, E.; Mozafari, B.; Amoozandeh Nobaveh, A.; Tahami, R. Arash: A social robot buddy to support children with cancer in a hospital environment. *Proceedings of the Institution of Mechanical Engineers* **2018**, *232*, 605-618, <http://doi.org/10.1177/0954411918777520>.
28. Harsh, J.R.; Easley, A.; LeBourgeois, M.K. A measure of children's sleep hygiene. *Sleep* **2002**, *25*, A316.
29. Katz, E.R.; Kellerman, J.; Siegel, S.E. Behavioral distress in children with cancer undergoing medical procedures: developmental considerations. *Journal of Consulting and Clinical Psychology* **1980**, *48*, 356-365, <http://doi.org/10.1037//0022-006x.48.3.356>.
30. Jenkins, B.N.; Fortier, M.A.; Kaplan, S.H.; Mayes, L.C.; Kain, Z.N. Development of a short version of the modified Yale Preoperative Anxiety Scale. *Anesthesia & Analgesia* **2014**, *119*, 643-650, <http://doi.org/10.1213/ANE.0000000000000350>.
31. Kennedy, J.; Lemaignan, S.; Montassier, C.; Lavalade, P.; Irfan, B.; Papadopoulos, F.; Senft, E.; Belpaeme, T. Child speech recognition in human-robot interaction: Evaluations and recommendations. In Proceedings of the ACM/IEEE International Conference on Human-Robot Interaction (HRI), Vienna, Austria, **2017**; pp. 82-90.
32. Lighthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Design patterns for an interactive storytelling robot to support children's engagement and agency. In Proceedings of AMC/IEEE International Conference on Human-Robot Interaction (HRI), Cambridge, UK, **2020**; pp. 409-418.
33. Lighthart, M.E.U.; Neerincx, M.A.; Hindriks, K.V. Getting acquainted for a long-term child-robot interaction. In Proceedings of the Social Robotics: 11th International Conference (ICSR), Madrid, Spain, **2019**; pp. 423-433.
34. Foster, M.E.; Ali, S.; Litwin, S.; Parker, J.; Petrick, R.; Smith, D.H.; Stinson, J.; Zeller, F. Using AI-enhanced social robots to improve children's healthcare experiences. In Proceedings of the Social Robotics: 12th International Conference (ICSR), Golden, CO, USA, **2020**; pp. 542-553. https://doi.org/10.1007/978-3-030-62056-1_45
35. Mott, T.; Lovelace, J.; Steward, B. Design considerations for child-robot interaction in pediatric contexts. In Proceedings of the Companion of the ACM/IEEE International Conference on Human-Robot Interaction (HRI), Boulder, CO, USA, **2021**; pp. 252-256.
36. Kanda, T.; Sato, R.; Saiwaki, N.; Ishiguro, H. A two-month field trial in an elementary school for long-term human-robot interaction. *IEEE Transactions on Robotics* **2007**, *23*, 962-971.
37. Ahmad, M.I.; Mubin, O.; Orlando, J. Adaptive social robot for sustaining social engagement during long-term children-robot interaction. *International Journal of Human-Computer Interaction* **2017**, *33*, 943-962.
38. Webb, N.; Ruiz-Garcia, A.; Elshaw, M.; Palade, V. Emotion recognition from face images in an unconstrained environment for usage on social robots. In Proceedings of the International Joint Conference on Neural Networks (IJCNN), Glasgow, UK, **2020**; pp. 1-8.

39. Sun, J. Emotion recognition and expression in therapeutic social robot design. In Proceedings of the 2nd International Conference on Human-Agent Interaction (HAI), Tsukuba, Japan, **2014**; pp. 197-200.
40. Leo, M.; Del Coco, M.; Carcagni, P.; Distanto, C.; Bernava, M.; Pioggia, G.; Palestra, G. Automatic emotion recognition in robot-children interaction for ASD treatment. In Proceedings of the the IEEE International Conference on Computer Vision Workshop (ICCVW), Santiago, Chile, **2015**; pp. 145-153.
41. Beran, T.; Pearson, J.R.; Lashewicz, B.; Baggott, S. Perspectives of child life specialists after many years of working with a humanoid robot in a pediatric hospital: Narrative design. *Journal of Medical Internet Research* **2020**, *22*, e23496.
42. Beran, T.N.; Pearson, J.R.; Lashewicz, B. Implementation of a humanoid robot as an innovative approach to child life interventions in a children's hospital: Lofty goal or tangible reality? *Frontiers in Psychology* **2021**, *12*, 639394.
43. Davidson, F.; Snow, S.; Hayden, J.A.; Chorney, J. Psychological interventions in managing postoperative pain in children: A systematic review. *PAIN* **2016**, *157*, 1872-1886, <http://doi.org/10.1097/j.pain.0000000000000636>.
44. Hockenberry, M.J.; McCarthy, K.; Taylor, O.; Scarberry, M.; Franklin, Q.; Louis, C.U.; Torres, L. Managing painful procedures in children with cancer. *Journal of Pediatric Hematology/Oncology* **2011**, *33*, 119-127, <http://doi.org/10.1097/MPH.0b013e3181f46a65>.
45. El Geziry, A.; Toble, Y.; Al Kadhi, F.; Pervaiz, M.; Al Nobani, M. Non-pharmacological pain management. In *Pain management in special circumstances*, Shallik, N.A., Ed.; IntechOpen: **2018**; pp. 1-14.
46. Schlub, G.M.; Crook, A.; Barlow-Stewart, K.; Fleming, J.; Kirk, J.; Tucker, K.; Greening, S. Helping young children understand inherited cancer predisposition syndromes using bibliotherapy. *Journal of Genetic Counseling* **2021**, *30*, 1119-1132, <http://doi.org/10.1002/jgc4.1396>.
47. Tripodi, S.I.; Bergami, E.; Panigari, A.; Caissutti, V.; Brovia, C.; De Cicco, M.; Cereda, E.; Caccialanza, R.; Zecca, M. The role of nutrition in children with cancer. *Tumori Journal* **2023**, *109*, 19-27, <http://doi.org/10.1177/03008916221084740>.
48. Barr, R.D.; Stevens, M.C.G. The influence of nutrition on clinical outcomes in children with cancer. *Pediatric Blood & Cancer* **2020**, *67*, e28117, <http://doi.org/10.1002/pbc.28117>.
49. Aldridge, A.A.; Roesch, S.C. Coping and adjustment in children with cancer: a meta-analytic study. *Journal of Behavioral Medicine* **2007**, *30*, 115-129, <http://doi.org/10.1007/s10865-006-9087-y>.
50. Patel, S.K.; Katz, E.R.; Richardson, R.; Rimmer, M.; Kilian, S. Cognitive and problem solving training in children with cancer: A pilot project. *Journal of Pediatric Hematology/Oncology* **2009**, *31*, 670-677, <http://doi.org/10.1097/MPH.0b013e3181b25a1d>.
51. Bronnert, R.; Nicolleau, C.; Bouhours, G.; Butrulle, C.; Rineau, E.; Lasocki, S. Impact of the presence of a humanoid robot in the anesthesia visit waiting room on patient's satisfaction. The PEPPER before-after study. *Minerva Anestesiologica* **2022**.

A

Addendum

SUMMARY

When a child is diagnosed with cancer, it has a major impact on both the child and the family. Cancer treatment causes a certain level of medical traumatic stress, and the family is disrupted. Coping with this stress is important to reduce the psychosocial impact of the disease and its treatment. Advances in technology have offered new opportunities, especially interactive tools, for psychosocial interventions for children and their families during treatment, both at the hospital and at home. This thesis is about several interactive tools that we developed and scientifically evaluated for this purpose.

Part I – Psychosocial support for children at the hospital: Exploration and investigation of a social robot in pediatric oncology care

In the first part of this thesis, we explored the introduction of a social robot into pediatric oncology care. Social robots are being developed and tested more and more in the context of pediatric health care, yet limited in pediatric oncology. We used multiple methods, including logbooks, observations, questionnaires and interviews to examine: (1) The feasibility of using a social robot in the pediatric oncology setting, (2) the experiences of children, families and health care providers with the social robot, and (3) the potential effectiveness of the social robot. Three prospective clinical studies were conducted about or with a social robot.

Study 1: Opinions of health care providers about social robots

We assessed the opinions of health care providers working in pediatric oncology regarding social robots and we looked at differences in their opinions based on their background characteristics. Almost three hundred health care providers from around the world participated in this cross-sectional online survey study. Health care providers were mostly positive about social robots and were willing to use them in their work, even though the majority also expected technical difficulties with this type of innovation. They considered hospitalization and medical procedures to be the most valuable scenarios for a social robot, and distraction to be the most valuable function to use the robot for. Psychosocial staff members seemed more reluctant towards social robots compared to nurses and medical staff members. Overall, social robots seem promising for the use in pediatric oncology care, but potential technical barriers should be addressed upon implementation.

Hero

The social robot that we developed was called Hero (a name that was chosen by the children at the Princess Máxima Center for pediatric oncology). For this social robot, we used existing hardware, namely the NAO⁶ robot from SoftBank Robotics ©. This robot has human features in appearance (i.e., it is a humanoid robot), and any of its parts, including its head, arms, legs, and fingers, can move. The software was developed in close collaboration with multiple external partners, which allowed us to realize an advanced social robot that was able to interact with children autonomously (i.e., without the help of a human controlling the robot via a laptop) and attuned (i.e., personalized) to the responses of children, whereby also using earlier answers of the child (i.e., it had a memory). Hero was developed with two different functionalities: A getting acquainted conversation followed by co-creating a story and storytelling, and sleep education. The software was pilot-tested in children from the general population at schools.

Study 2: A social robot as a buddy

We introduced Hero as a buddy to twenty children (6-12 years old) during cancer treatment, and completed 51 interactions. Children were able to interact with Hero three times: Two times while being hospitalized and a third time while undergoing a medical procedure. We found that children were very interested to participate in the study and that they reported positive experiences. They found the robot to be age-appropriate, and they reported to feel better on average after the interactions with the robot. Almost all children appreciated the support from the robot during a medical procedure, and parents were positive about a robot as a buddy for their child. Children perceived consistently high levels of bonding with the robot over the three interactions. Further software development is needed to improve the technical functioning of the robot, yet the concept of a social robot buddy at multiple moments during childhood cancer treatment holds promise as an addition to existing psychosocial care.

Study 3: A social robot for sleep hygiene education

We used Hero to provide sleep hygiene education to 28 children with cancer (8-12 years old) and their parents at the outpatient clinic. We found that the execution of the education at the outpatient clinic was feasible, and all children were able to

complete the education without technical issues. Families were mostly positive about their experiences, and the setting with a social robot was inclusive, as several children with (developmental) comorbidity were able to participate as well. Most families reported to have followed up on the sleeping suggestions from the robot and applied the recommendations at home. Considering that we also measured an improvement in sleep hygiene two weeks after the educational session with the robot, preliminary effectiveness was found to be promising. Therefore, we recommend that the use of a social robot for educational purposes in pediatric oncology should be further explored.

Part II – Psychosocial support for families at home: Development and investigation of two interactive tools

In the second part of this thesis, we explored the use of two interactive tools for families with a child with cancer in the home context. To date, limited coping tools seem to be available for psychosocial supportive care for families at home during childhood cancer treatment. Therefore, in another close collaboration with an external partner, two completely new and innovative tools were developed to contribute to this gap. Two prospective clinical studies were conducted with these tools in the pediatric oncology setting. Multiple methods were used, including machine data, family diaries, pictures and videos, questionnaires and interviews to examine: (1) The feasibility and acceptability of families with a child with cancer of using the interactive tools at home, (2) the experiences of children and families with the interactive tools, and (3) the potential effectiveness of the interactive tools.

AscoltaMe

The first tool that we developed (hardware and software) was called AscoltaMe (Italian for 'listen to me') and was aimed at enhancing communication in the family. The tool was designed based on the tin-can-telephone game whereby family members could leave voice messages for each other. AscoltaMe was intended to be used casually and to be left around the house to encourage families under stressful circumstances to stay connected with each other and to motivate them to keep communicating.

Mr.V

The second tool that we developed (hardware and software) was called Mr.V (short from *Verrassing*, Dutch for ‘surprise’) and was aimed at enhancing family functioning. The tool was designed based on a gumball vending machine whereby the machine was filled by family members themselves with activities and messages. These surprises were then provided to families by the machine at random moments. Mr.V was intended to be placed in a common area of the house and to include all family members to stimulate them to do more things together and to continue normal, everyday family life. During the project, Mr.V was further developed and redesigned into Mr.V the Spaceman.

Study 4: The design and a pilot-test of AscoltaMe and Mr.V

We described the development of the two interactive tools as tactful objects: A design perspective that empowers people in sensitive settings. Next we described how the tools were used by eight families with a child with cancer (6-16 years old) in the home setting. We found that the tools were easy to use, and that families experienced the tools to be enjoyable and playful. Mr.V fulfilled its purpose, and reminded families to engage in quality time together. AscoltaMe was used differently than expected: It was not used as much, nor were thoughts or emotions shared. The fact that Mr.V was shared with all family members, and blended in with family routines, indicated potential effectiveness of the tool and further development and exploration of the tool would be worthwhile.

Study 5: Mr.V the Spaceman

We redesigned Mr.V into a spaceman to support family functioning and safeguard normal family life. The spaceman was tested by ten families with a child (5-9 years old) under cancer treatment while being at home. We found that all families used Mr.V for multiple days and in a way that suited them. Almost all families evaluated Mr.V as acceptable, feasible to use, and potentially effective for them. Mr.V promoted family activities and therefore holds the potential to support family functioning and normal family life at home. Families provided feedback on how to further improve the tool, which should be incorporated in the further development of the intervention before it can be examined for effectiveness.

Conclusion

For this thesis, we were able to develop four technological interactive interventions with the aim of reducing medical traumatic stress and supporting families in coping with childhood cancer treatment. These tools were scientifically evaluated, and most of the interventions were found to be feasible to use, to provide fun and positive experiences to children and their families, and to be potentially effective. With this work, we hope to have made some important contributions to the field of innovative interventions in pediatric oncology care. However, more research and further technological development are needed to improve (the functioning of) the interventions, as well as involvement of child life specialists in any further steps. We assume that our research efforts as described in this thesis will contribute to future psychosocial care for children with cancer during treatment at the hospital and at home, in which these types of technological innovations will undoubtedly play a role.

NEDERLANDSE SAMENVATTING

Wanneer bij een kind kanker wordt vastgesteld, heeft dit grote gevolgen voor zowel het kind als het gezin. De behandeling van kanker veroorzaakt een bepaalde mate van medisch traumatische stress, en het gezin wordt ontwricht. Omgaan met deze stress is belangrijk om de psychosociale gevolgen van de ziekte en de behandeling te verminderen. Nieuwe technologische ontwikkelingen bieden nieuwe mogelijkheden, in het bijzonder interactieve hulpmiddelen, voor psychosociale interventies voor kinderen en hun gezinnen tijdens de behandeling, zowel in het ziekenhuis als thuis. Dit proefschrift gaat over meerdere interactieve hulpmiddelen die we hiervoor hebben ontwikkeld en wetenschappelijk onderzocht.

Deel I – Psychosociale steun voor kinderen in het ziekenhuis: verkenning en onderzoek van een sociale robot in de kinderoncologische zorg

In het eerste deel van dit proefschrift hebben we de introductie van een sociale robot in de kinderoncologische zorg onderzocht. Sociale robots worden steeds meer ontwikkeld en getest in de context van de kindergeneeskunde, maar dit is nog beperkt in de kinderoncologie. We hebben meerdere methoden gebruikt, waaronder logboeken, observaties, vragenlijsten en interviews, om onderzoek te doen naar: (1) de haalbaarheid van het gebruik van een sociale robot in de kinderoncologische zorg, (2) de ervaringen van kinderen, hun gezinnen en zorgverleners met de sociale robot, en (3) de potentiële effectiviteit van de sociale robot. Drie prospectieve klinische studies zijn uitgevoerd over of met een sociale robot.

Studie 1: meningen van zorgverleners over sociale robots

We hebben de meningen van zorgverleners werkzaam in de kinderoncologie over sociale robots onderzocht en we hebben gekeken naar verschillen in hun meningen op basis van hun achtergrondkenmerken. Bijna driehonderd zorgverleners wereldwijd hebben deelgenomen aan dit cross-sectionele online onderzoek. De meeste zorgverleners stonden positief tegenover sociale robots en waren bereid deze te gebruiken in hun werk, hoewel de meerderheid ook technische problemen verwachtte bij het gebruik van deze innovatie. Zorgverleners beschouwden ziekenhuisopnames en medische procedures als de meest waardevolle scenario's voor een sociale robot en afleiding als de meest waardevolle functie om de robot voor in te zetten. Psychosociale zorgverleners waren terughoudender tegenover sociale robots dan verpleegkundigen

en medisch personeel. Concluderend lijken sociale robots veelbelovend voor het gebruik in de kinderoncologische zorg, maar mogelijke technische belemmeringen moeten bij de implementatie worden aangepakt.

Hero

De sociale robot die we hebben ontwikkeld heette Hero (een naam die was gekozen door kinderen van het Prinses Máxima Centrum voor kinderoncologie). Voor deze sociale robot gebruikten we bestaande hardware, namelijk de NAO⁶ robot van SoftBank Robotics ©. Deze robot heeft menselijke kenmerken qua uiterlijk (genaamd humanoïde robot), en elk van zijn onderdelen, waaronder zijn hoofd, armen, benen en vingers, kan bewegen. De software is ontwikkeld in nauwe samenwerking met meerdere externe partners, waardoor we een geavanceerde sociale robot hebben kunnen realiseren die autonoom (d.w.z. zonder de hulp van een persoon die de robot bestuurt, bv. via een laptop) en afgestemd (d.w.z. gepersonaliseerd) op antwoorden van kinderen kan reageren, waarbij de robot ook gebruik maakt van eerdere antwoorden die kinderen hebben gegeven (d.w.z. de robot had een geheugen). Hero was ontwikkeld met twee verschillende functionaliteiten: een kennismakingsgesprek gevolgd door het samen creëren van een verhaal en storytelling, en slaapeducatie. De software is eerst getest op scholen bij kinderen uit de algemene bevolking.

Studie 2: een sociale robot als maatje

We hebben Hero geïntroduceerd als maatje bij twintig kinderen (6-12 jaar) die behandeld werden voor kanker. Kinderen konden drie keer iets met Hero doen: twee keer tijdens een ziekenhuisopname en een derde keer tijdens het ondergaan van een medische ingreep. De kinderen bleken zeer geïnteresseerd in deelname aan het onderzoek en ze rapporteerden positieve ervaringen. Ze vonden de robot geschikt voor hun leeftijd en ze gaven aan dat ze zich gemiddeld beter voelden na de interacties met de robot. Bijna alle kinderen waardeerden de ondersteuning van de robot tijdens de medische ingreep, en ouders waren positief over een robot als maatje voor hun kind. Kinderen ervaarden consistent hoge niveaus van verbondenheid met de robot gedurende de drie interacties. Verdere ontwikkeling van de software is nodig om de technische werking van de robot te verbeteren, maar het concept van een sociaal

robotmaatje voor kinderen op meerdere momenten tijdens hun kankerbehandeling is een veelbelovende aanvulling op de bestaande psychosociale zorg.

Studie 3: een sociale robot voor slaaphygiënevoorlichting

We hebben Hero gebruikt om educatie te geven over slaaphygiëne aan 28 kinderen met kanker (8-12 jaar) en hun ouders op de polikliniek. We vonden dat de uitvoering van de educatie op de polikliniek haalbaar was, en alle kinderen konden de voorlichting zonder technische problemen afronden. De gezinnen waren overwegend positief over hun ervaringen, en de setting met een sociale robot was inclusief, aangezien kinderen met een ontwikkelingsachterstand of andere aandoening (comorbiditeit) ook konden deelnemen. De meeste gezinnen gaven aan de slaapsuggesties van de robot te hebben opgevolgd en de aanbevelingen thuis te hebben toegepast. Aangezien we ook een verbetering in slaaphygiëne hebben gemeten twee weken na de educatieve sessie met de robot, lijkt de effectiviteit vooralsnog veelbelovend. Daarom bevelen we aan om het gebruik van een sociale robot voor educatieve doeleinden in de kinderoncologie verder te onderzoeken.

Deel II – Psychosociale steun voor gezinnen thuis: ontwikkeling en onderzoek van twee interactieve hulpmiddelen

A

In het tweede deel van dit proefschrift hebben we het gebruik van twee interactieve hulpmiddelen voor gezinnen met een kind met kanker in de thuiscontext onderzocht. Tot op heden lijken er beperkte hulpmiddelen beschikbaar te zijn voor psychosociale steun aan gezinnen thuis tijdens de behandeling van kanker bij kinderen. Daarom werden in nauwe samenwerking met een externe partner twee volledig nieuwe en innovatieve hulpmiddelen ontwikkeld om dit tekort te adresseren. Met deze hulpmiddelen werden twee prospectieve klinische studies uitgevoerd in de kinderoncologie setting. Meerdere methoden werden gebruikt, waaronder systeem gegevens uit de hulpmiddelen, gezinsdagboeken, foto's en video's, vragenlijsten en interviews, om onderzoek te doen naar: (1) de haalbaarheid en aanvaardbaarheid voor gezinnen met een kind met kanker om de interactieve hulpmiddelen thuis te gebruiken, (2) de ervaringen van kinderen en hun gezinnen met de interactieve hulpmiddelen, en (3) de potentiële effectiviteit van de interactieve hulpmiddelen.

AscoltaMe

Het eerste hulpmiddel dat wij hebben ontwikkeld (hardware en software) heette AscoltaMe (Italiaans voor 'luister naar mij') en was bedoeld om de communicatie in het gezin te verbeteren. Het hulpmiddel is ontworpen op basis van het bliktelefoon spel waarbij gezinsleden spraakberichten voor elkaar konden achterlaten. AscoltaMe was bedoeld om terloops te worden gebruikt en in huis te laten liggen om gezinnen in stressvolle omstandigheden aan te moedigen met elkaar in contact te blijven alsook hen te motiveren om te blijven communiceren.

Mr.V

Het tweede instrument dat we hebben ontwikkeld (hardware en software) heette Mr.V (afkorting van Verrassing) en was bedoeld om het gezinsfunctioneren te verbeteren. Het hulpmiddel is ontworpen op basis van een kauwgomballenautomaat waarbij de automaat gevuld werd door gezinsleden zelf met opdrachten en berichtjes. Deze verrassingen werden dan op willekeurige momenten door de machine verstrekt. Mr.V was bedoeld om in een gemeenschappelijke ruimte van het huis te worden geplaatst om zo alle gezinsleden te stimuleren meer dingen samen te doen en het normale, dagelijkse gezinsleven voort te zetten. Tijdens het project is Mr.V doorontwikkeld tot Mr.V de Astronaut.

Studie 4: het ontwerp en de pilot-test van AscoltaMe en Mr.V

We hebben de ontwikkeling van de twee interactieve hulpmiddelen als tactvolle objecten beschreven: een ontwerpperspectief dat mensen in moeilijke omstandigheden versterkt. Vervolgens hebben we beschreven hoe de hulpmiddelen werden gebruikt door acht gezinnen met een kind met kanker (6-16 jaar) in de thuissituatie. De gezinnen vonden dat de hulpmiddelen gemakkelijk te gebruiken waren en dat de gezinnen de hulpmiddelen als plezierig en speels hebben ervaren. Mr.V voldeed aan zijn doel, en herinnerde gezinnen eraan om quality time met elkaar door te brengen. AscoltaMe werd anders gebruikt dan verwacht: het werd niet zo vaak gebruikt, noch werden gedachten of emoties gedeeld. Het feit dat Mr.V door alle gezinsleden werd gebruikt, en werd ingepast in de routines van het gezin, wijst op de potentiële effectiviteit van dit hulpmiddel en verdere ontwikkeling en verkenning van dit hulpmiddel zou de moeite waard zijn.

Studie 5: Mr.V de Astronaut

We hebben Mr.V doorontwikkeld tot een astronaut om het gezinsfunctioneren te ondersteunen en het normale gezinsleven te waarborgen. De astronaut is getest door tien gezinnen met een kind (5-9 jaar) dat behandeld werd voor kanker in de thuissituatie. We hebben vastgesteld dat alle gezinnen Mr.V meerdere dagen hebben gebruikt en op een manier die bij hen paste. Bijna alle gezinnen beoordeelden Mr.V als aanvaardbaar, makkelijk te gebruiken en potentieel effectief voor hen. Mr.V bevorderde gezinsactiviteiten en heeft daarom het potentieel om het gezinsfunctioneren en het normale gezinsleven thuis te ondersteunen. De gezinnen hebben tips gegeven over hoe het hulpmiddel verder verbeterd kan worden. Deze tips moeten worden meegenomen in de verdere ontwikkeling van de interventie voordat deze op effectiviteit kan worden onderzocht.

Conclusie

Voor dit proefschrift hebben we vier technologische interactieve interventies ontwikkeld met als doel medische traumatische stress te verminderen en gezinnen te ondersteunen bij het omgaan met de behandeling van kanker bij kinderen. Deze hulpmiddelen werden wetenschappelijk onderzocht, en de meeste interventies bleken haalbaar om te gebruiken, bezorgden kinderen en hun gezinnen leuke en positieve ervaringen, en zijn potentieel effectief bevonden. Met deze onderzoeken hopen we een aantal belangrijke bijdragen te hebben geleverd op het gebied van innovatieve interventies in de kinderoncologie. Er is echter meer onderzoek en verdere technologische ontwikkeling nodig om (de werking van) de interventies te verbeteren, evenals meer betrokkenheid van pedagogisch medewerkers bij verdere stappen. We gaan er vanuit dat onze onderzoeksinspanningen zoals beschreven in dit proefschrift zullen bijdragen aan de toekomstige psychosociale zorg voor kinderen met kanker tijdens de behandeling in het ziekenhuis en thuis, waarin dit soort technologische innovaties ongetwijfeld een rol zullen gaan spelen.

LIST OF PUBLICATIONS

International peer-reviewed publications

Van Bindsbergen, K.L.A., Van Gorp, M., Ligthart, M.E.U., Hindriks K.V., Neerincx, M.A., Alderliesten, T., Bosman, P.A.N., Grootenhuis, M.A., & Merks, J.H.M. Introducing a social robot as a buddy into pediatric oncology care: Feasibility, experiences, and bonding of children with the robot over multiple interactions. *Submitted*.

Van Bindsbergen, K.L.A., Van der Hoek, H., Van Gorp, M., Ligthart, M.E.U., Hindriks K.V., Neerincx, M.A., Alderliesten, T., Bosman, P.A.N., Merks, J.H.M., Grootenhuis, M.A., & Van Litsenburg, R.R.L. (2022). Interactive education on sleep hygiene with a social robot at a pediatric oncology outpatient clinic: Feasibility, experiences, and preliminary effectiveness. *Cancers*, 14, 3792. doi:10.3390/cancers14153792

Van Bindsbergen, K.L.A., Van Gorp, M., Thomassen, B.W., Merks, J.H.M., & Grootenhuis, M.A. (2022). Social robots in pediatric oncology: Opinions of health care providers. *Journal of Psychosocial Oncology Research and Practice*, 4, e073. doi:10.1097/OR9.0000000000000073

Van Bindsbergen, K.L.A., D'Olive, P., Rozendaal, M.C., Merks, J.H.M., & Grootenhuis, M.A. (2021). Support for families at home during childhood cancer treatment: A pilot study with Mr.V the Spaceman, a family-based activities tool. *Supportive Care in Cancer*, 29, 4875-4884. doi:10.1007/s00520-021-05995-3

D'Olive, P., Van Bindsbergen, K.L.A., Huisman, J., Grootenhuis, M.A., & Rozendaal, M.C. (2020). Designing tactful objects for sensitive settings: A case study on families dealing with childhood cancer. *International Journal of Design*, 14, 103-124.

Bult, M.K., Van Bindsbergen, K.L.A., Schepers, S.A., De Ridder-Sluiters, H.G., Verhaak, C.M., Van Litsenburg, R.R.L., Merks, J.H.M., Van Noesel, M.M., & Grootenhuis, M.A. (2019). Health-related quality of life of adolescents with cancer during the first year of treatment. *Journal of Adolescent and Young Adult Oncology*, 8, 616-622. doi:10.1089/jayao.2019.0017

International conference proceeding

Ligthart, M., Fernhout, T., Neerincx, M.A., Van Bindsbergen, K.L.A., Grootenhuis, M.A., & Hindriks, K.V. (2019). A child and a robot getting acquainted – Interaction design for eliciting self-disclosure. In *Proceedings of the 18th International Conference on Autonomous Agents and MultiAgent Systems* (pp. 61-70).

Thesis chapter

D'Olive, P., Van Bindsbergen, K.L.A., Huisman, J., Grootenhuis, M.A., & Rozendaal, M.C. From tactful objects to tactful intelligence. In *Designing Tactful Objects for Sensitive Settings* (p. 129-151). Dissertation P. D'Olive (2021). doi:10.4233/uuid:f85769e2-c1ff-4404-a59f-552773ddb7b4

Dutch publication

Van Bindsbergen, K.L.A. (2021). Nieuw in het Máxima: Robotmaatje Hero. *Attent*, 1, 8.

Media

Feature at *Jeugdjournaal* aired on public service channel NPO3 under the title “Steeds meer robots helpen kinderen in het ziekenhuis” (July, 2018).

<https://jeugdjournaal.nl/artikel/2243104-steeds-meer-robots-helpen-kinderen-in-het-ziekenhuis.html>

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Chapter 2: Social robots in pediatric oncology: Opinions of health care providers

Kelly L.A. van Bindsbergen: Conception and design of the study; data acquisition; data preparation and analysis; data interpretation; writing first draft of manuscript; critical revision of manuscript for intellectual content; approved final version. Marloes van Gorp: Data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Brigitte W. Thomassen: Critical revision of manuscript for intellectual content; approved final version. Johannes H.M. Merks: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version.

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Chapter 3: Introducing a social robot as a buddy into pediatric oncology care: Feasibility, experiences, and bonding of children with the robot over multiple interactions

Kelly L.A. van Bindsbergen: Conception and design of the study; data acquisition; data preparation and analysis; data interpretation; writing first draft of manuscript; critical revision of manuscript for intellectual content; approved final version. Marloes van Gorp: Supervision of data acquisition; data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Mike E.U. Ligthart: Resources and software; critical revision of manuscript for intellectual content; approved final version. Koen V. Hindriks: Resources and software; critical revision of manuscript for intellectual content; approved final version. Mark A. Neerincx: Critical revision of manuscript for intellectual content; approved final version. Tanja Alderliesten: Critical revision of manuscript for intellectual content; approved final version. Peter A.N. Bosman: Critical revision of manuscript for intellectual content; approved final version. Martha A. Grootenhuis: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Johannes H.M. Merks: Conception and design of the

study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version.

Chapter 4: Interactive education on sleep hygiene with a social robot at a pediatric oncology outpatient clinic: Feasibility, experiences, and preliminary effectiveness

Kelly L.A. van Bindsbergen: Conception and design of the study; data acquisition; data preparation and analysis; data interpretation; writing first draft of manuscript; critical revision of manuscript for intellectual content; approved final version. Hinke van der Hoek: Data acquisition; data preparation and analysis; data interpretation; writing first draft of manuscript; critical revision of manuscript for intellectual content; approved final version. Marloes van Gorp: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Mike E.U. Ligthart: Resources and software; critical revision of manuscript for intellectual content; approved final version. Koen V. Hindriks: Resources and software; critical revision of manuscript for intellectual content; approved final version. Mark A. Neerincx: Critical revision of manuscript for intellectual content; approved final version. Tanja Alderliesten: Critical revision of manuscript for intellectual content; approved final version. Peter A.N. Bosman: Critical revision of manuscript for intellectual content; approved final version. Johannes H.M. Merks: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Martha A. Grootenhuys: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Raphaële R.L. van Litsenburg: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version.

Chapter 5: Designing tactful objects for sensitive settings: A case study on families dealing with childhood cancer

Patrizia d'Oliveo: Conception and design of the study; resources and hardware; data acquisition; data preparation and analysis; data interpretation; writing first draft of

manuscript; critical revision of manuscript for intellectual content; approved final version. Kelly L.A. van Bindsbergen: Conception and design of the study; data acquisition; data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Jaap Huisman: Conception and design of the study; supervision of data acquisition; critical revision of manuscript for intellectual content; approved final version. Martha A. Grootenhuys: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Marco C. Rozendaal: Conception and design of the study; resources and hardware; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version.

Chapter 6: Support for families at home during childhood cancer treatment: A pilot study with Mr.V the Spaceman, a family-based activities tool

Kelly L.A. van Bindsbergen: Conception and design of the study; data acquisition; data preparation and analysis; data interpretation; writing first draft of manuscript; critical revision of manuscript for intellectual content; approved final version. Patrizia d'Olive: Conception and design of the study; resources and hardware; data acquisition; data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Marco C. Rozendaal: Conception and design of the study; resources and hardware; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version. Johannes H.M. Merks: Critical revision of manuscript for intellectual content; approved final version. Martha A. Grootenhuys: Conception and design of the study; supervision of data acquisition; supervision of data preparation and analysis; data interpretation; critical revision of manuscript for intellectual content; approved final version.

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PHD PORTFOLIO

Name: Kelly L.A. van Bindsbergen
 PhD period: October 2017- June 2022
 Promotores: Prof. dr. Martha A. Grootenhuys
 Prof. dr. Johannes H.M. Merks
 Co-promotores: Prof. dr. Mark A. Neerincx
 Prof. dr. Peter A.N. Bosman
 Department: Child and Adolescent Psychiatry & Psychosocial Care
 Emma Children's Hospital, Amsterdam UMC

1. PhD training	Year	Workload (ECTS)
Courses		
<u>Clinical skills</u>		
Communication with patients	2018	0.3
Medical hypnosis for children	2020	1.5
<u>Research skills</u>		
Research data management	2018	0.7
Medical literature: EndNote	2018	0.1
Medical literature: Searching for a systematic review	2018	0.1
Scientific writing in English for publication	2019	1.5
Project management	2019	0.6
Basic course legislation and organization for clinical researchers (e-BROK)	2019	1.0
Writing patient information forms	2019	0.3
Seminars, workshops and master classes		
Two-weekly research meeting <i>Psychosocial department, Emma Children's Hospital</i>	2017-2018	0.2
One-weekly research seminars <i>Princess Máxima Center for pediatric oncology</i>	2017-2022	1.5
One-weekly research meetings <i>Princess Máxima Center for pediatric oncology</i>	2018-2022	1.5
One-monthly psycho-oncology care and research meetings <i>Psychosocial department, Princess Máxima Center for pediatric oncology</i>	2017-2022	1.5
One-weekly psycho-oncology research meetings <i>Psychosocial research group, Princess Máxima Center for pediatric oncology</i>	2017-2022	3.0
TULIPS 2-years PhD-curriculum (Training Upcoming Leaders in Pediatric Science)	2019-2021	2.8
Princess Máxima Center (PhD) workshops	2019-2022	0.8
Princess Máxima Center 2-days research retreat	2017, 2019, 2021	1.5

Psycho-oncology research groups 2-days research retreat	2022	0.5
TULIPS young investigators day (Training Upcoming Leaders in Pediatric Sciences)	2017, 2018, 2019, 2020	1.0
ECRN (Early Career Research Network) researcher day of the NVPO (Dutch Association for Psychosocial Oncology)	2018, 2019	0.5
ECRN (Early Career Research Network) practitioners day of the NVPO (Dutch Association for Psychosocial Oncology)	2019	0.3
KWF (Dutch Cancer Society) psychosocial oncology working community meetings	2017, 2019, 2021	0.3
Oral presentations		
Obot: Onze oranje oncologie (r)Obot voor kinderen en ouders <i>Health Valley Bridge, Nijmegen</i>	2020	0.5
Social robots in pediatric oncology: Opinions of health care providers <i>SIOP (International Society of Pediatric Oncology), online</i>	2021	0.5
Interactive education on sleep hygiene with a social robot at a pediatric oncology outpatient clinic <i>SIOP (International Society of Pediatric Oncology), Barcelona, Spain</i>	2022	0.5
Poster presentations		
Health related quality of life of adolescents with cancer during the first year of treatment <i>SIOP (International Society of Pediatric Oncology), Washington DC, United States of America</i>	2017	0.5
Support for families at home during childhood cancer treatment: A pilot study with Mr.V the Astronaut <i>SIOP (International Society of Pediatric Oncology), Lyon, France</i>	2019	0.5
Robotmaatje: kinderen met kanker ondersteunen tijdens hun behandeling, <i>Princess Máxima Center of pediatric oncology, Utrecht, the Netherlands</i>	2020	0.5
(Inter)national conferences		
49th Congress of the International Society of Pediatric Oncology (SIOP) <i>Washington DC, United States</i>	2017	1.0
Medical Psychology Amsterdam <i>Amsterdam, the Netherlands</i>	2017	0.3
Amsterdam Kinder Symposium (AKS) <i>Amsterdam, the Netherlands</i>	2018	0.3
Child Health symposium, Training Upcoming Leaders in Pediatric Sciences (TULIPS) <i>Noordwijk, the Netherlands</i>	2018	0.5
Meedoen=Groeien!? symposium <i>Maarsse, the Netherlands</i>	2018	0.3
PAL 4 Future Health symposium <i>Amersfoort, the Netherlands</i>	2019	0.3
Amsterdam Kinder Symposium (AKS) <i>Amsterdam, the Netherlands</i>	2019	0.3
Child Health symposium, Training Upcoming Leaders in Pediatric Sciences (TULIPS) <i>Rotterdam, the Netherlands</i>	2019	0.5

Addendum

ISOQOL-NL symposium <i>Amsterdam, the Netherlands</i>	2019	0.3
Child Health symposium <i>Utrecht, the Netherlands</i>	2019	0.3
51st Congress of the International Society of Pediatric Oncology (SIOP) <i>Lyon, France</i>	2019	1.0
IMPACT symposium <i>Delft, the Netherlands</i>	2019	0.3
Educational symposium, Princess Máxima Center for pediatric oncology <i>Utrecht, the Netherlands</i>	2020	0.3
Child Health symposium <i>Utrecht, the Netherlands</i>	2021	0.1
Quality of Life symposium, Dutch Childhood Cancer Society (SKION) <i>Utrecht, the Netherlands</i>	2021	0.3
Child Health symposium, Training Upcoming Leaders in Pediatric Sciences (TULIPS) <i>Egmond aan Zee, the Netherlands</i>	2021	0.5
53st Congress of the International Society of Pediatric Oncology (SIOP) <i>Online</i>	2021	1.0
2. Teaching		
Lecturing		
N/A		
Supervising		
Co-supervising applied science student	2019	0.3
Supervising applied science student	2021-2022	1.3
3. Parameters of esteem		
Grants		
N/A		
Awards and prizes		
Nominated Health Valley Bridge price	2020	
Selected for the two-year PhD curriculum Training Upcoming Leaders in Pediatric Science (TULIPS)	2019-2021	
Other		
Editorial board member of the journal of the Dutch Society for Psychosocial Oncology (NVPO)	2018-2021	4.5
Member of the Pain and Anxiety Reduction working group of the Princess Máxima Center for pediatric oncology	2018-2019	0.3
Secretary of the International Society of Pediatric Oncology (SIOP) Pediatric Psycho-Oncology (PPO) committee	2018-2022	6.8
Organizing and participating at the Weekend of Science at Utrecht	2018, 2021	0.6
Invited jury member National Social Robotics Contest	2022	0.3

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ABOUT THE AUTHOR

Kelly L.A. van Bindsbergen was born on November 2nd 1993 in Zevenaar, the Netherlands. She grew up in Babberich with her parents and two younger sisters. She attended high school (Liemers College in Zevenaar) where she finished *Voortgezet Wetenschappelijk Onderwijs* in 2011.



In 2014 Kelly obtained her Bachelor's degree in *Pedagogische Wetenschappen* (at Utrecht University), including an honors program, a voluntary research internship and an additional thesis in *Neuroscience*. In 2016 she obtained her Research Master's degree in *Development and Socialization in Childhood and Adolescence* (also at Utrecht University), including an additional internship. While studying, she had several part-time jobs as a research assistant on different projects.

Following her ambitions in research, Kelly started as a junior researcher at the Princess Máxima Center for pediatric oncology in the psychosocial research group of Prof. dr. Martha Grootenhuis in 2016. In 2017, she continued working at the Princess Máxima Center as a PhD student under the supervision of Prof. dr. Martha A. Grootenhuis, Prof. dr. Johannes H.M. Merks, Prof. dr. Peter A.N. Bosman and Prof. dr. Mark A. Neerincx. During her time as a PhD student, she attended and presented at several (international) conferences, and she was selected for the 2-year TULIPS PhD curriculum (Training Upcoming Leaders in Pediatric Science). She was also the secretary of the SIOP-PPO committee (International Society of Pediatric Oncology – Pediatric Psycho-Oncology) and editorial board member of the journal of the NVPO (Dutch Association for Psychosocial Oncology).

Kelly is currently working as a research coordinator at the PROM Core Facility of the Princess Máxima Center, which is facilitated by the research group of Prof. dr. Martha A. Grootenhuis. She provides advice and support to all researchers at the Princess Máxima Center who use PROMs (Patient Reported Outcome Measures, i.e., questionnaires) in their research.

Kelly lives together with her husband and son in Zeist.

