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**A case study on families dealing with childhood cancer**

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# Designing Tactful Objects for Sensitive Settings: A Case Study on Families Dealing with Childhood Cancer

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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.

**Keywords** – Tactful Objects, Tactfulness, Sensitive Settings, Families, Childhood Cancer, Human-Computer Interaction.

**Relevance to Design Practice** – In this paper, we introduce *Tactful Objects* as a design perspective on interactive artifacts that empower people in sensitive settings. By investigating the concept of *tactfulness* in the context of childhood cancer, we have articulated the design qualities of such objects and highlighted their value when designing for sensitive settings.

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## Introduction

Childhood cancer is an example of a disruptive life event (Massimi et al., 2012), such that the everyday life of families dealing with childhood cancer becomes a sensitive setting to design for (Davis & Waycott, 2015). Childhood cancer generates social, physical and emotional challenges that significantly impact the development of the child (Li et al., 2013) and put stress on interpersonal family relationships (Dixon-Woods et al., 2001). 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 (Haverman et al., 2011; Marsac et al., 2012; Moerman et al., 2019; Nijhof et al., 2018). In addition, studies in Design and “Sensitive” HCI (Waycott et al., 2015), have reported how interactive artifacts can be helpful in moments of crisis (Liu et al., 2015) because they can facilitate activities, support everyday routines or encourage new ones (D'Alessandro & Dosa, 2001; Kehr et al., 2012). While stimulating changes (Ryan & Deci, 2000) such artifacts may help in re-establish the *normality* that got impacted by disruptive life events (Patterson et al., 2004). In other words, they can help families to recreate the combination of spaces, habits, memories (Orth et al., 2018) that support their lifestyle (Massimi et al., 2012).

Developing interactive artifacts for people dealing with crises requires tact in order to account for vulnerabilities and to avoid overwhelming the users (Cheverst et al., 2001; Crabtree et al., 2003; Massimi et al., 2010; Mori et al., 2013; Vines et al., 2014). 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 (D'Olivo et al., 2017) the material qualities (Wiberg, 2018) and temporal form (Vallgård et al., 2015) 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.

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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 (Bronfenbrenner & Morris, 1998; Canning, 2007; Goldstein, 2012; Nijhof et al., 2018). These proximal stimuli are described in Bronfenbrenner and Ceci's *bio-ecological* model (1994). In this model, the family is understood as an interdependent system where each member influences the other (Minuchin, 1988). As such, the family is the most critical proximal social context influencing the optimal development of the child (Ashiabi & O'Neal, 2015; Saarni, 2011) especially in case of stressful and disruptive conditions.

**Patrizia D'Olivo** holds a MSc degree in Design & Engineering from Politecnico di Milano. She was trained as a product designer and material selection specialist. As a PhD candidate in Industrial Design at the Delft University of Technology, she uses a Research Through Design approach to explore how interactive objects and technologies can be tactfully attuned to the needs of users in sensitive settings; and designed to empower them in dealing with disruptive life events.

**Kelly L. A. van Bindsbergen** holds a MSc degree in research in Developmental Psychology from Utrecht University. She was trained as a researcher in the field of child development. As a PhD candidate at the Emma Children's Hospital and the Princess Máxima Center for Pediatric Oncology, she focuses on reducing medical traumatic stress in children with cancer during their treatment by using new technologies.

**Jaap Huisman** is a Doctor in Clinical Psychology and until 2019 was head of the department of Psychological and Psychosocial Care at the Princess Máxima Center for Pediatric Oncology in Utrecht, the national center for pediatric oncology in the Netherlands. Besides his clinical work, he has published research in the field of pediatric oncology, child endocrinology, and neonatology.

**Martha A. Grootenhuis** is a Professor, head of the department of Psycho-Oncology and group leader on psychosocial research at the Princess Máxima Center for Pediatric Oncology in Utrecht, the Netherlands. She works on studies in order to identify psychosocial problems at an early age and stage, and interventions to improve psychosocial functioning and quality of life for children with cancer, chronic disease, their parents and other family members. Her research is relying on web-based applications, such as the KLIK method ([www.hetklickt.nu](http://www.hetklickt.nu)), designed to systematically track the quality of life of children.

**Marco C. Rozendaal** is an Assistant Professor of Interaction Design at Delft University of Technology. He has a background in media technology and the arts. His work explores new interaction design paradigms engendered by emerging technologies to understand their social opportunities and ethical implications. Marco is currently investigating new interaction styles and paradigms in relation to smart networked products.

Challenges in life, which generate stress and trigger profound changes, are described as disruptive life events (Massimi et al., 2012). 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 (Massimi et al., 2012). Childhood cancer can be considered a disruptive life event because it significantly changes a family's *normal interactions and structures* (Cox & Paley, 1997). Despite the support provided by professionals and healthcare institutions, families describe it as a long and lonely process (Patterson et al., 2004) that creates stress on relationships (Folkman et al., 1986), and generates a surreal experience (Patterson et al., 2004). 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 (Nijhof et al., 2018). Social robots have been introduced in the hospital environment to distract and interact with the children during distressing procedures (Breazeal, 2011; Dawe et al., 2019; Moerman et al., 2019). 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 (Marsac et al., 2012). Other examples implement user friendly web-based platforms to let children, sibling and parents communicate with the medical staff throughout the trajectory of treatment (Haverman et al., 2011).

Research in design (Diefenbach et al. 2017; Petermans & Cain, 2019) as well as in clinical studies (Halliday et al., 2017) 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 (Dorrestijn & Verbeek, 2013; Kaptelinin & Nardi, 2006; Kehr et al., 2012; Laschke et al., 2011; Verbeek, 2005; Waelbers, 2011). 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 (Huisman et al., 2012; Kirk et al., 2016; Odom et al., 2014; Schatorjé & Markopoulos, 2013). Many of the activities, relationships and values in this context are idiosyncratic and highly personal (Gaver et al., 2007). A tactful approach is even more warranted when families are faced with disruptive life events and are hereby likely to become vulnerable users (Vines et al., 2014).

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

(Marsac et al., 2012). 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 (2012) 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 (2017) 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* (Helmes et al., 2009) 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* (Schatorjé & Markopoulos, 2013) 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 cylindrical 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 (D'Olivo et al., 2017). RtD is a research approach in which design activities are an inherent part of doing research (Stappers & Giaccardi, 2017). 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 (D'Olivo et al., 2018) 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* (Patterson et al., 2004) generated by the profound stress caused by the illness and treatment, and the inability to talk openly about one's feelings, worries and hopes (Stiefel & Stiefel, 2006). 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.

### 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.



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. Copyright © Patrizia D'Olivo.

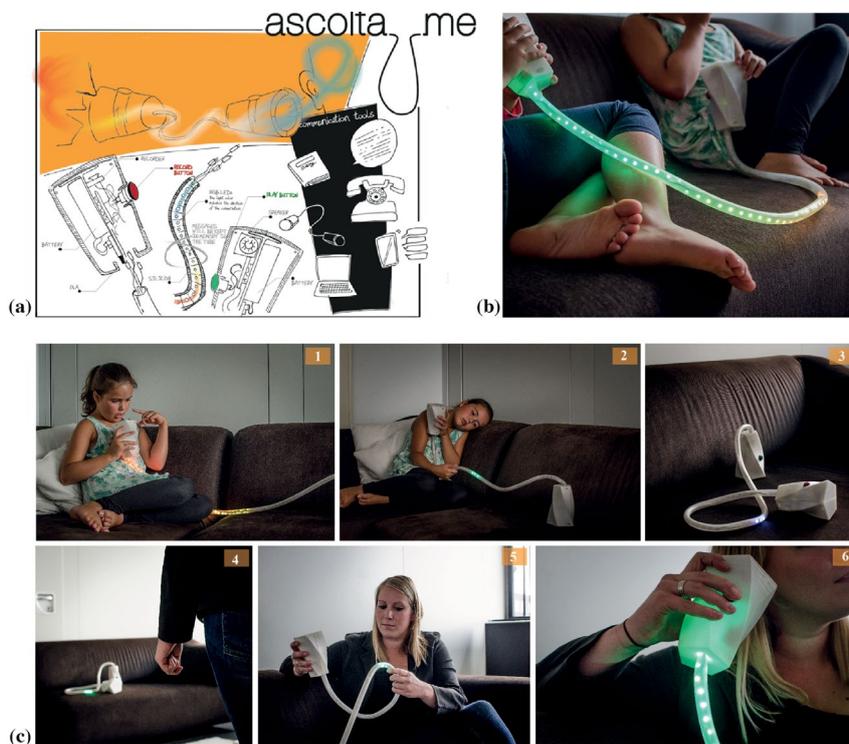


Figure 2. AscoltaMe, an object that aims at stimulating communication between family members: (a) concept sketches, (b) prototype, (c) scenario of use. The sequence of actions is indicated in numerical order. Copyright © Patrizia D'Olivo.

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 a surprise is dispensed, Mr.V makes a funny sound to signal to the family that their surprise is waiting. These effects were carefully orchestrated to be clear in their meaning and emotional tone, and to be noticeable without being disturbing. For AscoltaMe, voice messages are materialized as light. When speaking, the light begins to fill the tube and stops in the middle of the tube, where it lingers and pulsates. The temporal quality of the light effect was carefully designed to represent a voice message as an *entity* that flows elegantly from the recording side to the speaker-side; and being synchronized with the pressing of the recording or the listening button. AscoltaMe expresses that it wants to be listened to by the light being *stuck* within the tube, drawing attention in subtle ways.

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<sup>1</sup>.

## 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 ( $N = 33$ ;  $n_{children} = 8$ ,  $n_{siblings} = 9$ ,  $n_{parents} = 16$ ). 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 1. Participant descriptions ( $N = 33$ ).**

	Child (patient)		Siblings	Parents
	Age	Gender		
<i>Mr.V</i>	$(n = 4)$		$(n = 5)$	$(n = 8)$
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
<i>AscoltaMe</i>	$(n = 4)$		$(n = 4)$	$(n = 8)$
Rachel's family	6	female	2	2
Simon's family <sup>a</sup>	10	male	0	2
Monica's family <sup>b</sup>	7	female	1	2
Leon's family	8	male	1	2

Note: Names are fictional.

<sup>a</sup> Simon stopped, but shared data through the diary.

<sup>b</sup> 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.

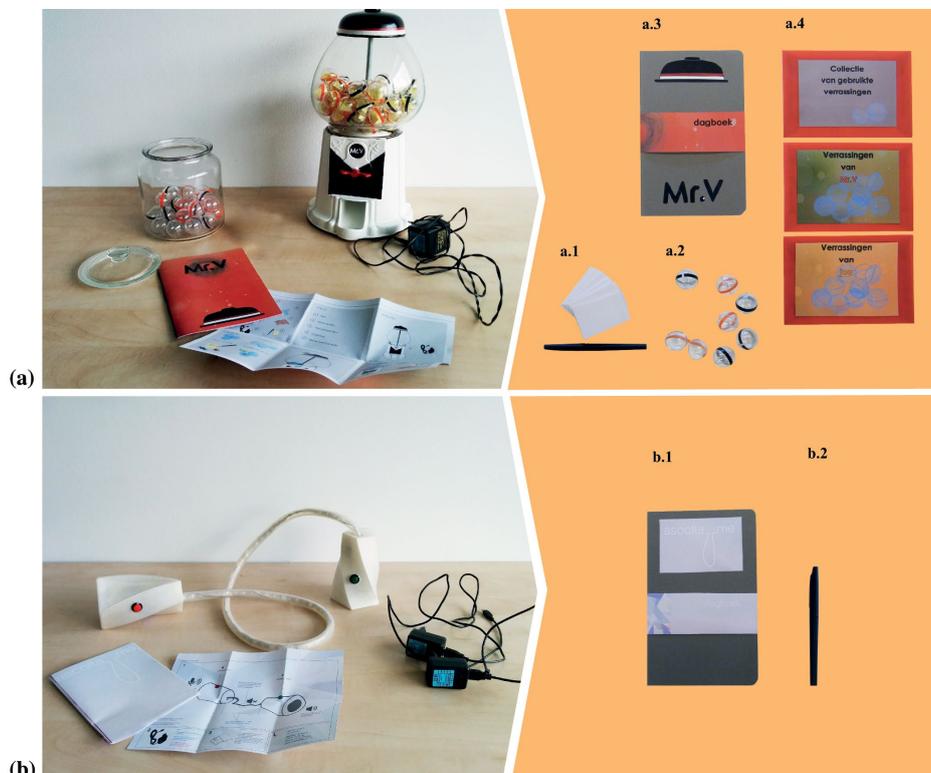
## Measures

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.

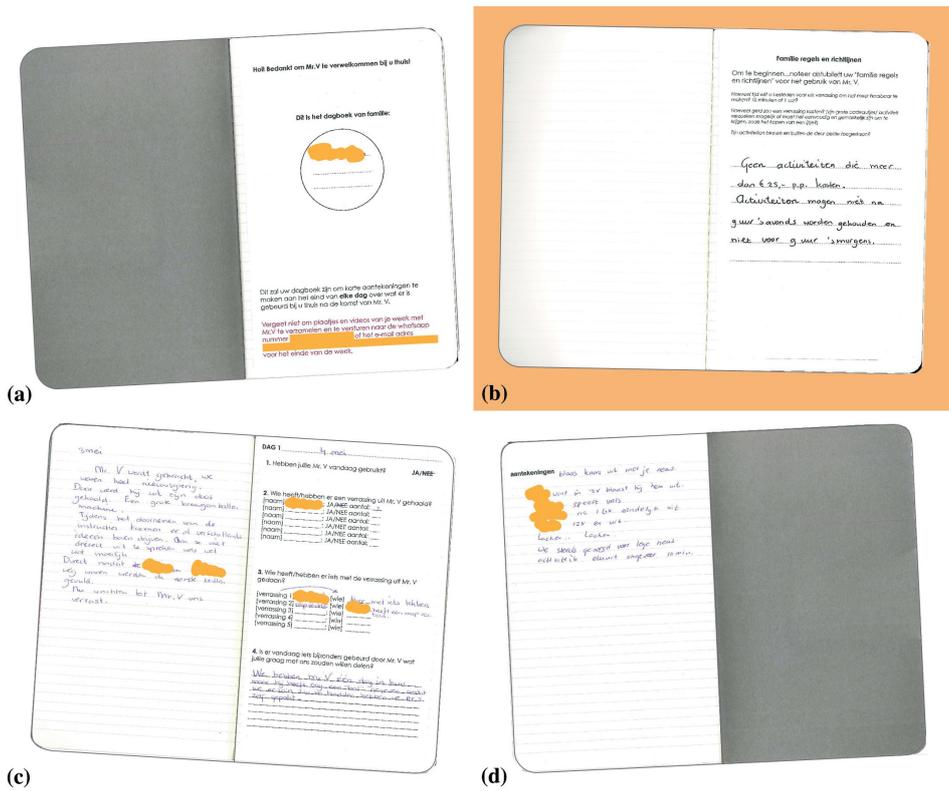
## Data Collection, Processing and Analysis

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* (Sanders & Stappers, 2012) was used to organize the quotes in statements cards, cluster themes



**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). Copyright © Patrizia D'Olivo.



**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, and (d) extra space for notes. Copyright © Patrizia D'Olivo.

and subdivide the clusters in knowledge levels (Ackoff, 1989). Collected pictures and videos were inserted in the statement cards as well as linked to an interpretation following the dual coding approach (Clark & Paivio, 1991) (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 the, 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



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.

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. Copyright © Patrizia D'Olivo.

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.

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

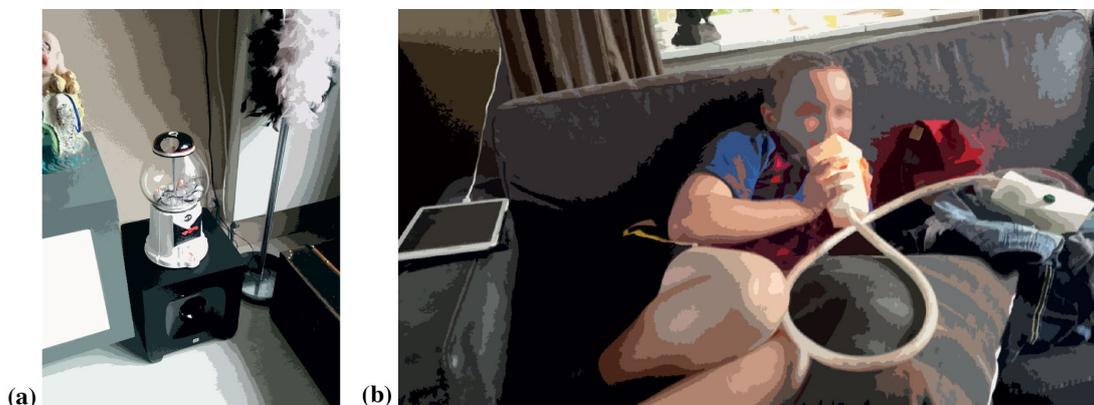
day whenever possible, while for Mary’s family the *preferred time was afternoons between 3 and 5*. John’s parents expressed disappointment about Mr.V because *some surprises came out when John was not at home or he did not receive anything once back at home*. Particularly, family stressed that they 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.



**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. Copyright © Patrizia D’Olivo.



**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”.** Copyright © Patrizia D’Olivo.

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 unfishy 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 (Folkman et al., 1986; Grootenhuis et al., 2012). 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 (Woodgate, 2006). Furthermore, as observed for the Cellie Cancer Coping kit (Marsac et al., 2012), which was also tested later with sickle-cell disease patients (Marsac et al., 2014), 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 (Breazeal, 2011; Jibb et al., 2018; Moerman et al., 2019). Furthermore, Tactful Objects could be proposed during medical treatment to engage adolescents, that are considered to be difficult target users (Christiansen et al., 2015) 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. (Massimi et al., 2010, 2012; Talhouk et al., 2018). 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 (Thieme et al., 2014), to address people's and researcher's vulnerabilities (Groeneveld et al., 2018; Vines et al., 2014) and to carefully manage the impact of any form of intervention (McNaney & Vines, 2015). 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 (Janlert & Stolterman, 1997; Verbeek, 2005). 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 (Kaptelinin & Nardi, 2006; Kuijer & Giaccardi, 2018; Kuutti & Bannon, 2014); and to the understanding of how metaphors can trigger *emotional values* by embodying personally significant associations (Orth et al., 2018).

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 (Rozendaal, 2016) and result into different behavior change strategies (Tromp et al., 2011). For instance, a design like the *Connected Stones* (Nicenboim et al., 2018) 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 (Van Boheemen, 2016). 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 (Chatting et al., 2017; Kirk et al., 2016) 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 (Schatorjé & Markopoulos, 2013). In this regard, AscoltaMe embedded an interesting childhood metaphor, but it did not allow for an idiosyncratic appropriation and didn't 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 (Rozendaal et al., 2019) 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 (Vermeeren et al., 2010). 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 (Jorgensen, 2015; Vines et al., 2013). 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 (Rozendaal et al., 2018), or by allowing the objects themselves to collect use information in real-time (Cila et al., 2017; Giaccardi et al., 2016a) in an ethical and transparent manner (Gaver et al., 2007).

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 (Odom et al., 2016) 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 (Karapanos, 2013). 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* (Gaver et al., 2007). 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 (Vines et al., 2013, 2014).

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 (Giaccardi et al., 2016b; Rozendaal et al., 2019) capable to sense people's needs and vulnerabilities (Vines et al., 2013, 2014), and to mediate complex interactions among group of users in sensitive settings (Kirk et al., 2016; Schatorjé & Markopoulos, 2013). 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.

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## Endnotes

1. For the sake of clarity, *second*, *third* and *fourth* author enabled and facilitated the recruitment process of the families in treatment within the pediatric oncology center of reference. *First* and *second* author conducted the fieldwork. *First* and *last* author dealt with the data analysis, and *second* author validated the analysis. *Third*, *fourth* and *last* author supported in theoretically frame the research respectively within the healthcare and design domains. *First* and *last* author have a background in product and interaction design respectively. *Second*, *third* and *fourth* author have a background in child development and psychology respectively

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## Appendix

### Appendix 1. Examples of surprises provided to the families testing mr.V to facilitate the ideation of the 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 e-mail address \*\*\*\*\* before the end of the week*

### Mr.V diary: Example of daily page

DAY # \_\_\_\_\_

**1. Have you used Mr.V today?** Yes/No

**2. Who has/have taken a surprise from Mr.V?**  
 [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?**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### 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? (is the surpris a big gifts/activity or should it be simple and easy?)*

*Is the surprise concerning something indoor or outdoor or both?*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### AscoltaMe diary: Example of daily page

DAY # \_\_\_\_\_

**1. Have you used AscoltaMe today?** Yes/No

**2. Who has / have recorded something in AscoltaMe?**  
 [name] \_\_\_\_\_ : yes/no n. times: \_\_\_\_  
 [name] \_\_\_\_\_ : yes/no n. times: \_\_\_\_

**3. Who has / have listened to a message in it AscoltaMe?**  
 [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 AscoltaMe that you would like to share with us?**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### Appendix 3. Examples semi-structured interview questions for Mr.V.

#### Sections (N=5)

List questions (N=56):

#### Main questions (n=7)

- Sub-questions (n=31)
  - Related Questions (n=18)

#### Usage

#### 1. What was it like to have Mr. V at home for a week? (Initial reaction / warming up)

- Was it fun?
- Did everyone use it?
  - Did everyone add a surprise in Mr.V?
  - Did everyone collected and opened a surprise from Mr. V?
- Who used Mr. V the most?
  - Who put most of the surprises in Mr. V?
  - Who collected and opened most of the surprises from Mr. V?

#### 2. Would you like to describe one of the times you have used Mr.V ?

- Who took the surprises?
  - 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?
  - 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?
  - What did you do with the surprises? What happened?

#### 3. How did you used Mr.V?

##### In practice

- Where was Mr.V positioned in your house?
  - Why there?
  - Did Mr.V ever moved from that position?
- How much did you used Mr.V?
  - How many surprises (approximately) did you add in Mr.V?  
(One person every day, or each day a different person?)
  - How many surprises were delivered (approximately) by Mr. V?  
(One, two, three every day?)
  - 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?  
(Time of day, together or alone?)

- About how long have you been busy with the surprises from Mr.V? (Per surprise / per day?)

##### Content

- What kind of surprises did you add in Mr.V?
  - 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? (Examples?)

#### Technology and Design

#### 4. What did you think of the product itself?

- Did you understand how to use it? Was it easy to use?
- 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

#### 5. Did you notice something different this week because you used Mr.V? (Has Mr.V added anything to the atmosphere or activities in the house?)

- Have you done different or new things?
- Have you done more things together?
- Which is your greatest memory?

#### 6. How would you rate Mr.V?

- 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

#### 7. Do you have any improvements or good ideas to ameliorate Mr.V?

- 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 questionnaire.**



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.**

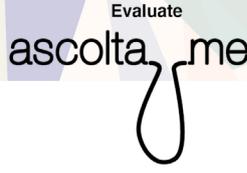
ABSOLUTELY INAPPROPRIATE 1 2 3 4 5 6 7 8 9 10 REALLY APPROPRIATE

**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



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. Examples of the statement cards generated during the analysis according to the typology of data.**

**STATEMENT CARD INTERVIEW DATA**

BACKGROUND COLOR CODING PER FAMILY

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

00:00:33.14 MOTHER N.8 MARY'S FAMILY MR.V

**TENTATIVE LABEL AND RESEARCHER COLOR ID**

EFFECT OF USING MR.V

**PARAPHRASE**

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.

**QUOTE**

"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..."

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

PHOTO MARY N.20 MARY'S FAMILY MR.V

**TENTATIVE LABEL AND RESEARCHER COLOR ID**

FAMILY RITUAL DURING TREATMENT

**IMAGE**



**DESCRIPTION**

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.

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

DIARY page 3 MOTHER SIMON'S FAMILY ASCOLTAME

**TENTATIVE LABEL AND RESEARCHER COLOR ID**

PROTOTYPE WEAKNESS

**PARAPHRASE**

The sound quality is poor

**DIARY SEGMENT**

Opname afspeld kwaliteit is best slecht te horen.

REFERENCE (photo data, family, object)

PHOTO JOHN'S FAMILY MR.V

**TENTATIVE LABEL AND RESEARCHER COLOR ID**

TYPE OF SURPRISES

**CONTENT**

1. Don't eat at the dining table but in front of the TV;
2. Hang a piece of cloth in the garden and throw paint on it;
3. Blow a candle with your nose;
4. Take another ball;
5. Do a funny dance;
6. Imitate someone;
7. Say the alphabet inverted;
8. Hug a tree and make a photo;
9. Make a portrait of your neighbor;
10. Stay one minute 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 spread 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. Bake a super tasty pie;
20. Make sure that mom and dad laugh;
21. Walk or cycle for at least 30 minutes;
22. Take a picture of the garden;
23. Take a picture of yourself licking your big toe and send it to five different people;

**PHOTO NOTES**



## Appendix 6. A list of surprises collected in each of the four families testing Mr.V.

### Family (N=4)

List of surprises (N=88)

#### Kevin's family (n=15)

1. Choose a game and play together.
2. Watch together a family movie and eat chips/snacks.
3. Bake cookies.
4. Let's do a BBQ together.
5. Organize a high tea.
6. Let's go to watch the Pandas in Rhenen.
7. Mom and dad will receive breakfast in bed thus they don't have to make it for us.
8. Bake brownies.
9. Let's have a day together in the wood.
10. Have a cozy lunch/dinner somewhere.
11. Eat a home-made pizza.
12. Watch together a movie on TV.
13. Have a cozy day out.
14. Have a coffee/tea with some tasty snacks.
15. Bake puff pastry sausages.

#### John's family (n=23)

16. Don't eat at the dining table but in front of the TV.
17. Hang a piece of cloth in the garden and throw paint on it.
18. Blow a candle with your nose.
19. Take another ball.
20. Do a funny dance.
21. Imitate someone.
22. Say the alphabet inverted.
23. Hug a tree and make a photo.
24. Make a portrait of your neighbor.
25. Stay one minute on one leg.
26. Sing a song.
27. Do a dance.
28. Make a drawing all together.
29. Give each other a compliment.
30. Eat a slice of bread spread with Nutella without using your hands.
31. Give each other a hug.
32. Make funny faces for 2 minutes.
33. Make a cup of tea.
34. Bake a super tasty pie.
35. Make sure that mom and dad laugh.
36. Walk or cycle for at least 30 minutes.
37. Take a picture of the garden.
38. Take a picture of yourself licking your big toe and send it to five different people.

#### Mary's family (n=23)

39. Call grandma and greet her.

40. What are we going to eat tonight for dessert?
41. Today I treat! (Mom).
42. I will read a story to Mary tonight (Mom).
43. Let's buy the tickets for the parade!
44. Make a smoothie and drink it together.
45. Look together at the photo album from 2012.
46. Go and eat an ice-cream at Jacco.
47. Give 1 liter of water to the banana plant.
48. Give a kiss to your dad!
49. Go outside hand in hand with someone else, walk with your eyes close ...which bird do you heard?
50. Fancy go to the swimming pool?
51. Pump the wheels of the bikes.
52. Go and collect the little beans in the garden.
53. Eat an ice cream at Jacco as dessert (Mary).
54. Have a walk in Goudplevier.
55. I love you!
56. Walk with me to the garden and look at the grapes and vegetables.
57. Let's look together at the photos from Peru'.
58. Give a kiss to mom.
59. Say good morning to the neighbor.
60. Sing together two tunes from 'Vader Jacob'.
61. Call your aunt and say hello.

#### Sammy's family (n=27)

62. Go to the zoo if it is nice weather.
63. Sammy's sister buys a small present for Sammy (under 5 euros).
64. Mom buys a small present for dad (under 5 euros).
65. Sammy's sister cooks tonight.
66. Bake a pie.
67. Startle someone.
68. Watch a movie.
69. Look at old pictures.
70. Eat an ice cream.
71. Make a face-mask.
72. Choose a bag of candies/cookies from the store.
73. Play together with the Wii.
74. Have a walk.
75. Dad buys a small present for mom (under 5 euros).
76. Sammy buys a small present for her sister (under 5 euros).
77. Get 20 McChickens from the McDonald.
78. Sammy cooks tonight.
79. Let's go and do the grocery by bike.
80. Play tennis with your sister.
81. Play tennis all together.
82. Give a treat to the pet.
83. Play a game.
84. Bake cupcakes.
85. Go out to eat pizza tonight.
86. Go downtown.
87. Let's eat together out. Sammy's sister and Sammy will pay.
88. Play tennis with your sister.