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Designing Tactful Objects for Sensitive Settings

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DESIGNING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

Patrizia D'Olivo

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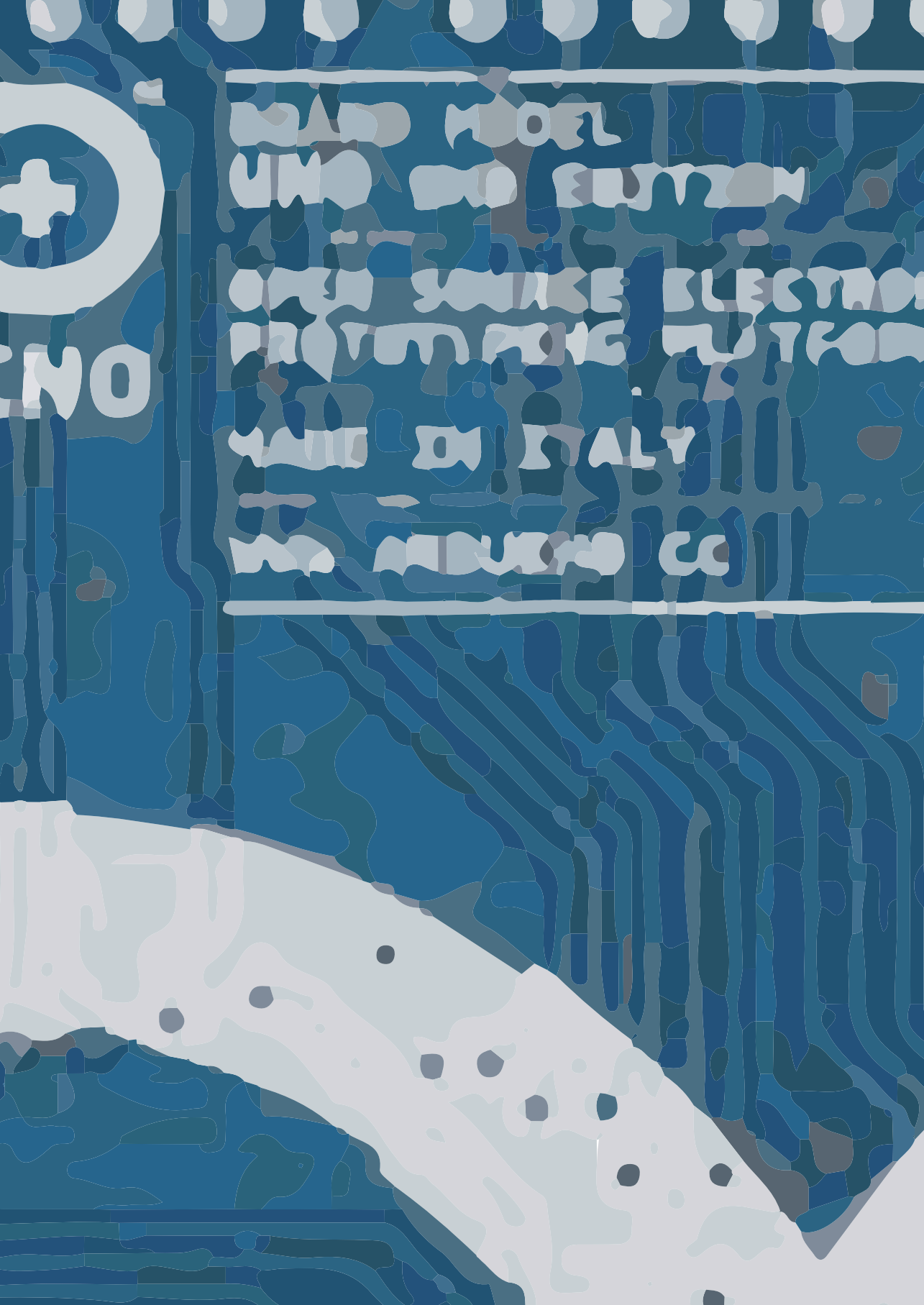

DESIGNING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

DISSERTATION

for the purpose of obtaining the degree of doctor
at Delft University of Technology
by the authority of the Rector Magnificus Prof.dr.ir. T.H.J.J. van der Hagen,
Chair of the Board for Doctorates
to be defended publicly on
Wednesday 9 June 2021 at 15:00 o'clock

by

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Festeggeremo la fine della chemio fianco a fianco su quel palco

For my mom.

E starai bene sai e finirà anche il buio, tante cose cambieranno

I tuoi capelli lunghi, quelli cresceranno di un colore che è un incanto

E se non cresceranno allora sai, ti dico, allora starai meglio senza…

E quando parlerai alla gente girerà la testa, alcuni sverranno

E si potrà capire quello che è importante, quel che vale veramente

Insieme rideremo e non ricorderemo, non ricorderemo niente

Ricostruiranno tutto ormai si fa anche quello, dopo un sogno che si è infranto…

Festeggeremo la fine della chemio fianco a fianco su quel palco

E starai bene sai e finirà anche il buio, tante cose cambieranno

E rimarranno i segni ma sembrerai più bella, il tuo sorriso ha vinto

E le paure quelle, quelle qualche volta, quelle ancora torneranno

E si potrà capire… Finché il sole si alza

Si potrà capire perché… Finché il sole si alza

Non si muore, non si muore

Finché il sole si alza… Si potrà capire perché

Finché il sole si alza… Non si muore, non si muore

Sick Tamburo, La Fine Della Chemio

DESIGNING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

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Preface

"I remember it as if it were yesterday, the sense of responsibility I felt in taking the challenge of conducting this research project. Learning about the life of people dealing with disruptive life events, like being diagnosed with cancer or having beloved ones being diagnosed with cancer has been life-changing.

I felt sadness in reading and watching the stories that patients and families of patients were sharing through blogs, documentaries, and books, to give a glimpse of what it feels like being sick or dealing with a chronic condition. At the same time, a sense of empowerment was shining through those testimonies, giving proof of the resourcefulness of people in finding ways to cope with the situation and their willingness to help others in understanding it.

I wondered if I was able to conduct my work sensitively, and find a way to meaningfully use design to build upon this resourcefulness without imposing my ideas.

One evening I ended up watching a movie that was on my list for a while called 50/50.[1] It was a movie inspired by a true story, centred on the experience of Adam, a 27-year-old radio programme writer who is diagnosed with cancer. It then focuses on his subsequent struggle to beat the disease.

The dialogues between Adam and the therapist assigned to him during the treatment caught my attention. In most of the sessions, Adam's concern was helped in interpreting how the behaviour of his family and friends changed. The revelation of the therapist was that loved ones feel just as stress as the patient and knowing that they cannot change the situation, the only thing they can change is how they choose to deal with it to maintain a sense of normality.

Here my journey starts, focusing on exploring how design can tactfully empower people in finding meaningful ways to adapt to a new normal in sensitive settings."

Patrizia - Delft, 6 January 2021

Footnote

1. 50/50 is a 2011 American black comedy-drama film directed by Jonathan Levine, written by Will Reiser, and starring Joseph Gordon-Levitt, Seth Rogen, Anna Kendrick, Bryce Dallas Howard, and Anjelica Huston.

1
INTRODUCTION

The work described in this dissertation is based on the collaborative project 'Meedoen=Groeien!' (Participating=Growing!) between Delft University of Technology (TU Delft), HandicapNL and the Princess Máxima Center for Pediatric Oncology, funded by the Dutch Friends Lottery (Dutch: 'VriendenLoterij'). The project aims at generating design solutions for children with chronic and life-threatening illnesses in order to stimulate their development and provide guidelines for the implementation of such solutions. The project builds on the innovative Developmental-Oriented-Care programme (Aarsen et al., 2012) ideated by the founders of the Princess Máxima Center for Pediatric Oncology in Utrecht (the Netherlands). In this holistic form of care, children and their families are considered as a whole in order to provide the best treatment and nurture their resources to overcome the disruption brought by the life-threatening illness. Two doctoral design researchers were involved in exploring possibilities in using design to support the development of a child during the childhood cancer treatment with two different focuses. The focus of the research project presented in this thesis is centred on assisting the child in his/her psychosocial development during treatment.

1.1 Rationale

This dissertation focuses on investigating the potential of design in empowering vulnerable users dealing with disruptive life events in sensitive settings to adapt to a New Normal (Massimi et al., 2012). The personal anecdote shared in the opening and the overall programme on which the project builds on, illustrate how addressing the dynamics that occur in a sensitive setting in the presence of a disruptive life event such as a chronic disease or childhood cancer is complex. Therefore, it requires a systemic approach where patients and their close family and friends are considered as a unit. Addressing the disruption caused by disruptive life events also means intervening in the context where complex dynamics occur and where people have less support such as in their everyday life. This dissertation explores how to design tactful forms of support to empower people in preserving normality in sensitive settings. The thesis takes childhood cancer as a sensitive setting of reference.

Supporting the psychosocial development of children means catering for their psychological and emotional well-being. Development is a complex process of systematic and successive changes over time and family is one of the contexts where proximal processes (i.e., interactions) happen to be extremely important in influencing these changes (Ashiabi & O'Neal, 2015). Childhood cancer and other chronic diseases can generate high levels of stress and anxiety capable of hindering the development of the child but can also turn into a traumatic event for the entire family (Last & Grootenhuis, 1998). How can a child's development be addressed while considering the family as a whole? How can we integrate design into the life of families to empower and support all family members throughout the treatment trajectory, and how can we develop and introduce design solutions in a sensitive way in such contexts?

This dissertation attempts to address these questions by tackling two specific challenges of families dealing with childhood cancer (i.e., preserving space for quality time for the family as a whole and communication between family members) through the iterative development and implementation of interactive artefacts in their home context. The introduction of such artefacts in this context is aimed at exploring *tactfulness* as an expressive design quality for the design of *tactful objects* namely, interactive artefacts capable of attuning to the needs of people in sensitive settings. Such artefacts are further evaluated in the field in order to define *principles of tactfulness* to inform researchers and practitioners working in sensitive settings on how to develop interactive artefacts and future intelligent objects capable of tactfully mediating relations with people.

1.2 Problem Description

Disruptive life events, are unique events that have a significant impact on the normal everyday life of people because they share the characteristics of being *"invisible, stigmatising and generating long-lasting disruption"* (Massimi et al., 2012). Childhood cancer is considered a disruptive life event. The severity of the illness, pain, medical procedures, and invasive or frightening treatment are capable of generating high levels of stress and anxiety in a child (Kazak et al., 2006). However, childhood cancer pervades also in the daily activities of the child's family, disrupting them, and has effects on how family members feel by exerting pressure on their relationships and carrying considerable uncertainty about the future, creating an almost surreal experience (Patterson et al., 2004). Medical literature describes how it is important to develop coping strategies (Kazak, 1989) that support a family in such a situation with their adjustment to a given disruptive event (Shing et al., 2016). Such coping strategies are described as balanced reactions to stress that enable them to tolerate, minimise, accept, and/or ignore what cannot be mastered (Lazarus & Folkman, 1984).

Since the stress caused by this condition and the necessity in coping with the life-threatening

nature of the child's disease (Kazak et al., 2006; Stuber et al., 1998) extends also to the family (Hocking et al., 2014), all family members must be considered to better understand how to limit the effects of the disruption caused by childhood cancer at the same time. To look at this complexity holistically, a systematic *bio-ecological model* based on Bronfenbrenner's Ecological Systems Theory has been developed (1977). The two elements of 'Nature' and 'Nurture' were described by Bronfenbrenner & Ceci (1994) to interact dynamically, fuse, and together contribute to the development of the child. Namely, the genetic characteristics of the child and the proximal processes (i.e., the mechanisms through which developmental potential is actualised) are both considered factors capable of impacting the development of the child. Proximal processes can take the form of people, objects, activities, and the interactions with those have to have regularity, and be free from interruptions since they have more influence on developmental outcomes than contextual factors (i.e., their environment) (Ashiabi & O'Neal, 2015). Therefore, focusing on the family is extremely important, as it allows caregivers and professionals in the paediatric field a means to design and implement interventions that contribute to the development of the child in an effective way.

Focusing on the family as a whole also provides an indication on ways, moments and contexts where it is possible to intervene through design intervention. The family works as a complex interdependent system (Minuchin, 1988) where each member influences one another (Ambert, 2001; Cox & Paley, 1997; Erickson et al., 1992; Knafo & Galansky, 2008). The members themselves play a key role in promoting successful adaptation (Sroufe, 1990) and cope with a threatening situation by developing resiliency, in other words the capacity to quickly recover after stress (Last & Grootenhuis, 1998) . Thus, the work presented in this thesis aims to empower the family members by helping them safeguard space for quality time and social interaction and maintain interpersonal communication in the occurrence of a disruptive life event.

Current approaches in clinical research are introducing creative tools and technologies to empathise with patients and family members, and to investigate therapeutic outcomes (Haverman et al., 2011; Wiener et al., 2012, 2020). For example, Marsac and colleagues (2012, 2014) have used toy puppets and card-sets to ask patients to evaluate how they perceive their illness and related treatment. Similarly, Nygren and colleagues (2017) have used Participatory Design approaches to ideate interventions that promote children's health by closely involving parents, caregivers and other stakeholders. Most of the applied methodologies and techniques are primarily aimed at addressing the child's medical condition or the other family members' needs by looking at them individually, and are used within the hospital environment. Interestingly, the home context has received only little attention. However, during the long and intensive treatment phase, if conditions allow for it, the child spends most of his/her time at home with his/her other family members (Li et al., 2013; Ward et al., 2014). Furthermore, as a recent medical study reports, this is the context where the family is *"more secure in having difficult discussions and practicing new skills"* (Salem et al., 2020: 7). This tendency generates an increasing demand for innovative and tactful ways of supporting families when the child is not under direct professional observation at home.

Most of the recent work on *design for families* has been directed towards the design, development and deployment of objects and technologies for the home/domestic context to support people in better managing everyday life and home rituals (Kirk et al., 2016). This contributes to the development of a new understanding on the role that objects and technologies have in enhancing and mediating experiences in domestic contexts. Everyday objects have often been discussed in the literature as being useful in the creation of identity or ways of structuring, representing and disclosing people's relationships with their environment (Kirk & Banks, 2008; Verbeek, 2005). Their physicality is fundamental not just to invoke memories but also to perform social functions within the environment (Kirk & Sellen, 2010). This is in line with the focus of the work presented in this thesis of creating design

solutions that could 'live' with disrupted families at home and be capable of *sensitively and tactfully encouraging interaction and communication in the home context.*

When artefacts become interactive through the addition of computation, they turn into resources that can complement the abilities and skills that people already put in action to address everyday challenges (Giaccardi, Kuijer, et al., 2016). According to Hallnas and Redström (2002), when interactive artefacts enter people's lives, their presence becomes meaningful because they become bearers of meaningful expressions. The interaction with interactive artefacts and their expressions generate specific experiences and those experiences retain specific qualities (Löwgren, 2009) that can positively impact people's life over time. This can help in integrating technology in healthcare in a way that is more centred on people and experiences rather than the medical condition (Jenkins et al., 2019). Hence, following this interest, the project explores how interactive artefacts can generate positive experiences and tactfully empower vulnerable users (e.g., families dealing with childhood cancer challenged in their interaction and communication), by translating *tactfulness* into an expressive quality for designing interactive artefacts for sensitive settings.

1.3 Research Objectives and Research Questions

The research presented in this thesis aims at (i) **investigating tactfulness as a design quality to develop interactive objects with the purpose of empowering people in sensitive settings;** and (ii) **providing resources to researchers and practitioners working in sensitive settings on how to design such objects.** The research aim is complemented with a design goal **to provide implementable solutions to empower families dealing with the disruptive life event of childhood cancer in their home context.**

In relation to the design goal, the thesis focuses on the case of families with children in treatment between five and 16 years old and engages them in their private home context by introducing interactive artefacts designed to sensitively blend into their everyday routines, and playfully support shared activities and daily communication without turning into a new clinical ritual. This process led to the introduction of the **design perspective of Tactful Objects**, interactive artefacts attuned to the needs of vulnerable users in sensitive settings.

In relation to the aforementioned research objectives and design goal, the work was conducted to address the overarching research question: **'How can vulnerable users be empowered by design in sensitive settings?**'. The dissertation then develops following three research sub-questions:

Rsub-Q1	Rsub-Q2	Rsub-Q3
How can families with children with cancer be empowered to adapt to a New Normal during life disrupting events?	How can tactfulness be used as an expressive design quality to develop interactive artefacts for the sensitive setting of families dealing with childhood cancer?	How does computational intelligence allow interactive artefacts to become more tactful and attuned to the needs of families dealing with childhood cancer?

These research sub-questions are addressed according to the steps described in the methodology.

1.4 Research-through-Design Methodology

The research approach used in this thesis is Research-through-Design (**RtD**). This is an approach where design actions play a formative role in knowledge generation (Stappers & Giaccardi, 2017). In simple terms, it takes a problem outside design and uses design to

address it. The knowledge developed is then embodied in the artefacts that are aimed at helping understand and act upon the phenomenon under analysis (Frayling, 2015).

According to this approach, concepts and prototypes are developed and deployed in field studies. The deployment of prototypes enables interactions that are observable through design and this allows for the research into the interdependence between designed artefacts and the practices they encourage and support (Gaver & Bowers, 2012). According to the aim of the work described here, hypotheses on how to use *tactfulness* to provide support to people in sensitive settings were then formulated and materialised into two interactive artefacts. This approach has helped in engaging the families throughout the project without forcing them into sustained group participation or generating stressful situations.

Due to the interdisciplinary nature of this RtD project the design researcher needed to engage with different stakeholders, such as a project steering committee, research supervisors and technical support from both the design and healthcare fields. Stakeholders involved in the research from the design field included: a promotor (Prof. dr. Elisa Giaccardi) and a co-promotor (Dr. ing. Marco C. Rozendaal) and engineers from the idStudioLab (TU Delft). Stakeholders involved in the research from the healthcare field included: a promotor (Prof. dr. Martha A. Grootenhuis), an external advisor in clinical psychology (Dr. Jaap Huisman) and a doctoral medical researcher in Child Development (MSc. Kelly L.A. van Bindsbergen) from the Psychological and Psychosocial Care Department at the Princess Máxima Center for Pediatric Oncology. To better understand the experience of being confronted with childhood cancer, the design researcher initially immersed herself in the topic by exploring existing literature, talking with healthcare professionals and engaging alone with cancer survivors in a first field study during a cancer survivors' meeting. Successively, to structure and conduct two field studies with the families and the patients in treatment, the design researcher was supported by the medical researcher, Kelly L.A. van Bindsbergen. This collaboration facilitated the design activities with patients undergoing treatment, but also in structuring the project according to medical ethical protocols and integrating theories and approaches coming from both the design and healthcare fields.

To communicate the knowledge gathered through the development and deployment of the prototypes, the design researcher made use of 'thingly forms' (Pierce, 2014) of reporting research such as pictorials (Bardzell et al., 2016; Jenkins et al., 2016) throughout the project. Two of the chapters (Chapter 4 and 6) in this thesis are structured as design annotations (Löwgren, 2013) and intended to demonstrate what was learned from the prototypes themselves as intermediary forms of knowledge (Höök et al., 2014) from which the project developed. The knowledge developed in the thesis moves from particular artefacts as *instances of tactfulness*, into detailing the *design quality of tactfulness* and giving shape to *design principles for the development of tactful objects* (Höök & Löwgren, 2012). These intermediate forms of knowledge contribute to the broader design research programme of Objects with Intent (**OwI**) for the design of smart objects for one's every day (Rozendaal, 2016; Rozendaal et al., 2019).

1.5 Contribution

The contribution of this thesis is to extend knowledge on how to design for sensitive settings. Overall, the thesis makes a contribution to three areas:

The **primary contribution** is the d*evelopment of the Tactful Objects perspective* (see Chapters 3, 4, 5, 6 and 7). This design perspective entails defining the design quality of *tactfulness*, generating four actionable *tactfulness principles* for designing in sensitive settings, developing examples of *tactful objects*, and envisioning how computational intelligence can be designed tactfully.

The **secondary contribution** is the *exploration of a tactful approach to conduct design and design research in sensitive settings* (see Chapter 2). The work investigated how RtD could turn into a tactful approach to build scientific knowledge for design in sensitive settings; tactfully address sensitive settings; and provide design students, practitioners and researcher with guidelines and examples for conducting design work in sensitive settings.

The **third contribution** regards *innovation in healthcare* (see Chapter 8). This contribution describes the opportunities that this project highlights for psychosocial cancer care in paediatric oncology. Here a reflection is proposed on how future collaborations between the design and the healthcare fields may improve based on a shift in mindset and approach.

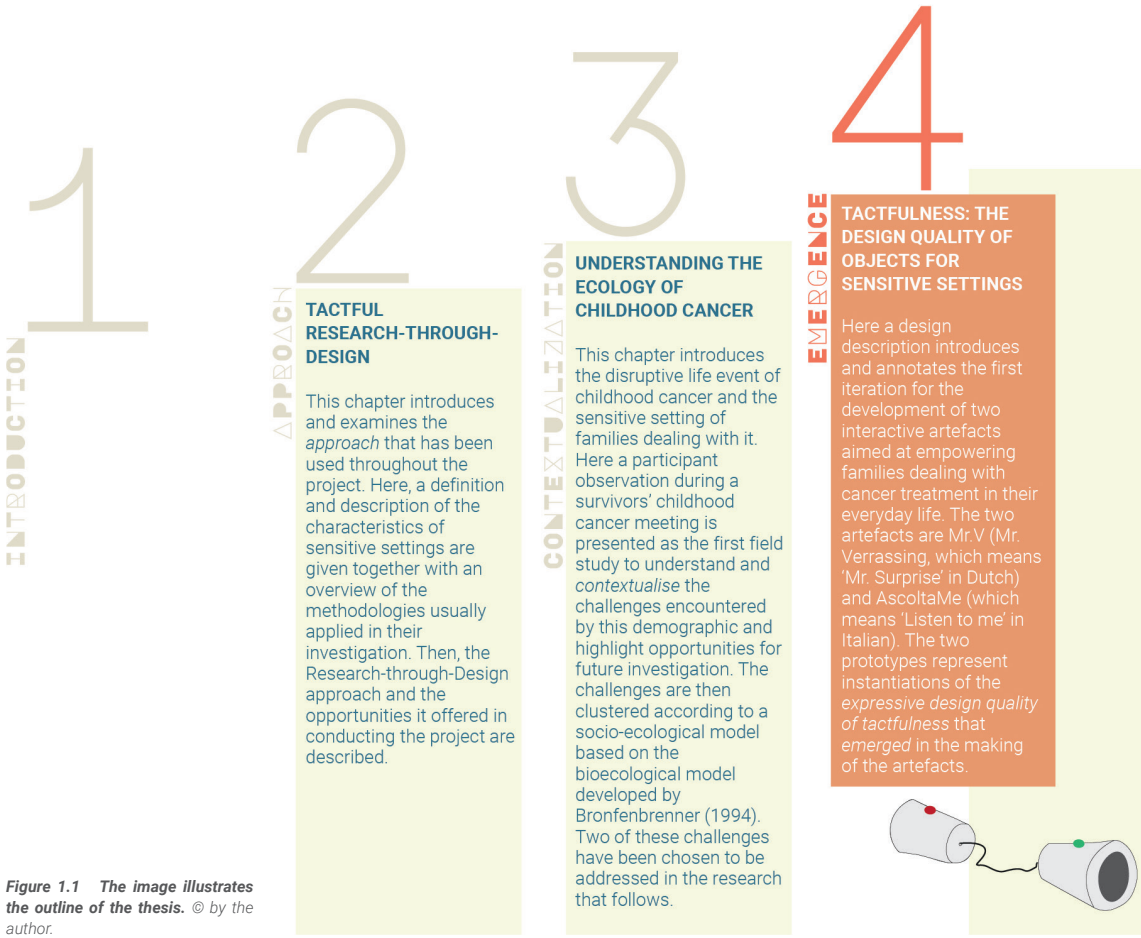


Figure 1.1 The image illustrates the outline of the thesis. *© by the author.*

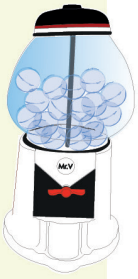
1.6 Thesis Outline

The thesis contains eight chapters. A specific label highlights the purpose of the content of each chapter, namely *introduction, approach, contextualisation, emergence, definition, application, evaluation/envisioning* and *contribution*. **Chapter 4** and **Chapter 6** consist of design descriptions, where the prototypes developed throughout the project are illustrated with the use of annotations and illustrations. **Chapter 3,4,5,6,** and **7** are paper-based (i.e., have been submitted/accepted to academic journals and conferences) and only minor adaptations were made to the content as it appears in this thesis. ***Figure 1.1*** visually displays the structure of the thesis.

5
DEFINITION

DESIGNING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

In this chapter a second field study is presented. Mr.V and AscoltaMe are introduced as *tactful objects* in the home context of eight families with a child undergoing treatment for cancer. Families were asked to assess and describe how the artefacts had impacted on their everyday life and which objects' characteristics triggered that. Four specific aspects ascribing *tactfulness* were clearly *defined*.



6
APPLICATION

MAKING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

In this chapter a new design description is used to annotate a second iteration where the prototype of Mr.V was selected and re-designed as a data-enabled object named Mr.V the Spaceman. In order to develop Mr.V the Spaceman, the four aspects identified in the previous field study were *applied as tactfulness design principles*. The description focuses on detailing the changes implemented in the prototype's expressivity. This is aimes at further investigating the relation that the object needs to establish with people to be tactful and understand how data could support that.

7
EVALUATION / ENVISIONING

FROM TACTFUL OBJECTS TO TACTFUL INTELLIGENCE

In this chapter the last field study is introduced. Here a field exploration with 10 families with children undergoing treatment for cancer was conducted to *evaluate* Mr.V the Spaceman. The study aims at further enriching the description of the four *tactfulness principles* and based on these results *envisioning* how to integrate computational intelligence to develop *future intelligent tactful objects* capable of better attuning to the needs of people in sensitive settings.



8
CONTRIBUTION

SUMMARY OF CONTRIBUTIONS & CONCLUSIONS

This chapter concludes with a general reflection on the *contribution* of the presented work in relation to the definition of the *Tactful Object perspective*, the *design quality of tactfulness* and the *tactfulness design principles* as *intermediate-knowledge levels* for design in sensitive settings. The thesis moves then, on describing the contribution of the work to *Interaction Design, design education*, and the *healthcare field. Limitations, clinical implications and recommendations for clinical implementation* are also discussed. Furthermore, a brief speculation on *opportunities for future research* are presented.

2
TACTFUL RESEARCH-THROUGH-DESIGN

2.1 Introduction

This chapter introduces the methodology that has been used to address the challenges faced by children undergoing cancer treatment and their families through design. It starts by elaborating on what a sensitive setting is, what its attributes are and what methodologies are normally used to investigate it. Then it moves onto elaborating on the Research-through-Design (**RtD**) methodology applied throughout this specific project, and articulates a series of design actions that were engaged in to answer particular research questions. The chapter then continues with describing how the implementation of the RtD approach has transformed the sensitive setting under analysis into a 'space' to design for. To conclude, the chapter highlights four aspects through which the RtD approach enabled the design researcher to engage in and address the specific attributes of a sensitive setting.

2.2 Sensitive Settings

Sensitive settings are by definition settings where the nature of the topics under study are normally considered as intimate or incriminating and connected to disruptive-life events. Research in social sciences and health assist this together with research focused on for instance death, grief, violence, etc. (Dickson-Swift et al., 2008). Childhood cancer is considered a disruptive life event that extends from the hospital and becomes continuously present in one's everyday life (Hassling et al., 2005). It turns a family's every day into a sensitive setting to design for.

2.2.1 Characteristics of Sensitive Settings

Three main attributes characterise sensitive settings: (i) the presence of vulnerable users, (ii) the ethical entanglements in relation to vulnerable users, healthcare environments and the use of technology, and finally (iii) being conscious of the researcher's self-protection.

2.2.1.1 Vulnerable Users

Vulnerability is a term used for groups of people who lack the capacity of self-protection or the ability to develop resilience or effective coping strategies (Aldridge, 2016). People encountered in sensitive settings can be individually, uniquely and innately vulnerable themselves or because of their circumstances, the environment or as a result of structural factors or influences (Larkin, 2009) like in the case of families dealing with childhood cancer. Research conducted with vulnerable people is aimed at helping them in identify strategies to alleviate or prevent vulnerability in the long term (Dickson-Swift et al., 2008).

2.2.1.2 Ethical Entanglements

Ethical entanglements are another aspect that can have potential consequences or implications for the people (or for the class of individuals) involved in the research conducted in sensitive settings. This is because the research conducted could potentially pose a substantial threat to those who are or have been involved in it (Dickson-Swift, James, & Liamputtong 2008). There are numerous, and often complex, ethical issues which must be managed and negotiated by researchers in interacting with vulnerable users. This can happen because for instance, the research concerns areas of *"intrusive threat"* for people, because the research is conducted in private contexts or because the users are already dealing with a stressful situation (Dickson-Swift, James, & Liamputtong 2008). In relation to the work presented in this thesis, the ethical entanglements emerge due to the presence of vulnerable users such as families dealing with cancer but also due to the involvement of healthcare professionals and public/private environments. Conducting research with patients undergoing treatment entails adhering to a full medical protocol screening before initiating a study, anticipating the potential psychological and physical risks in patients' participation and evaluating how those could interfere with the treatment (Cheverst et al., 2001). Furthermore, a requirement is careful adherence to medical ethical procedures that might be different from the ones used in design research. For example, the informed consent should be approved by a medical ethical committee linked to a specific healthcare institute, safety procedures should be more strict (e.g., prototypes used in the study should be easily cleanable and have CE certification, etc.), and the use of technology should be closely monitored by the healthcare professionals not to generate psychological or physical risks (Roeser, 2016) in the patients under treatment.

2.2.1.3 Researchers' Self-Protection

What is also emphasised by researchers working in sensitive settings is that ethical and moral issues also emerge for the researchers themselves (McNaney & Vines, 2015). Several studies have reported how researchers working in particular sensitive settings can experience feelings of guilt when the relationship with the participants comes to an end (Dickson-Swift et al., 2008) or when participants with whom they establish rapport with pass away or cannot participate in the research anymore (Groeneveld et al., 2018). Very few researchers can predict the personal experience that the research will entail in advance or be prepared to remove themselves from relationships, and even fewer report on this when they describe their projects.

2.3 Research Approaches to Sensitive Settings

Research on a sensitive topic that examines the experiences of people is generally more likely to be undertaken using qualitative methodologies and feminist approaches (Cheverst et al., 2001), because those are capable of advocating for reciprocity and collaboration including answering questions based on personal experiences, some level of self-disclosure and the formation of friendships with research participants (Aldridge, 2014). Due to this, ethnographic methods are often chosen to strategise collection of data while participatory approaches have been used in order to engage and give a voice to the individuals represented in the study.

Ethnography is one of the social science research methods used to investigate, observe and learn about social behaviour and human culture within sensitive settings. In an ethnographic approach, data collection is conducted by using qualitative research practices such as interviews, note taking, video, and photography to discover patterns within discourses, and by mapping data to categories of theoretical interest to the study. There has been a significant shift towards using Ethnography in design (Crabtree et al., 2012) because it can provide novel ways of understanding how people relate to and think about technologies as cultural artefacts (Kjeldskov et al., 2004; Vetere et al., 2005). Ethnography has become a significant resource for design (Nova, 2014). It has been implemented in clinical settings to capture real-life activity and everyday behaviour, and often to enable the designer to understand what people do in a setting and how they plan their activities (Crabtree et al., 2009). However, collecting data through this approach can sometimes be a very difficult task, because researchers find themselves asking sensitive questions (Dickson-Swift et al., 2008). Surveys, in-depth interviews and in-situ observation can often become stressful for both the researcher and the interviewee, or not feasible, creating awkwardness and an uncomfortable atmosphere (Thieme et al., 2016).

To facilitate the data collection through ethnographic work and involve the users of a system in its design, Gaver and colleagues introduced Cultural Probes (1999). Cultural Probes is a design analytic method capable of making *"the ordinary visible"* (Graham & Rouncefield, 2008) because it is used to 'reflect' the culture of participants and collect responses while allowing them to participate in an accessible way and encourage dialogue (Crabtree et al., 2003). Design probes are intriguing small objects used to pose questions through a gentle, provocative, creative means while generating empathic engagement (Wallace, McCarthy, Wright, & Olivier, 2013: 3441). Probes[2] have been used in design with and for families (Horst et al., 2004; Kirk et al., 2016), design with and for children (Giaccardi, Paredes, Diaz, & Alvarado, 2012; Wyeth & Diercke, 2006), design for hospitalised children (Riekhoff & Markopoulos, 2008) and design for people with chronic diseases (Hassling et al., 2005). This allowed individuals to engage in sensitive settings while conversing about emotional topics (Ayers et al., 2017), and was also informative for stakeholders connected to these individuals.

Recently in the attempt to promote a more holistic way of understanding relationships between people, objects and their everyday environments in which practices take shape

(Giaccardi et al., 2016b), a new way of conducting Ethnography is advancing. This new wave proposes to broaden the scope of enquiry and go beyond human centredness (Bødker, 2015; Bødker & Christiansen, 2004; Crabtree et al., 2013). The new methodological and theoretical developments build on: ontology theories seeking to redefine the treatment of humans, objects and their relations with people (Harman, 2012), contemporary ethnography practices (Anderson et al., 2009; Giaccardi et al., 2016b; Giaccardi, 2019a), more-than-human design for conducting work in the wild (Hutchinson et al., 2003; Odom et al., 2016) and ethical implications of the contextual issue of data collection (Crabtree et al., 2018; Giaccardi & Redström, 2020). This shift introduced perspectives such as Entangled Ethnography (Murray-Rust et al., 2019) and Thing-Ethnography (Giaccardi, 2019b). By equipping objects with sensors, it is possible to access new perspectives of a given every day that would otherwise not be feasible to obtain through traditional Ethnography and see people, artefacts, algorithms and data coming together to provide different viewpoints about this reality.

With the post-design shift towards 'experiences', some User-Centred Design approaches started to focus on involving users to gain information on latent needs that cannot be easily expressed in words (Sanders, 2002). Empathic Design stemmed as a branch of User-Centred Design to support design teams in gaining an authentic perspective of people and their everyday lives through dialogue over time (e.g., Elizabeth & Dandavate, 1999; Koskinen et al., 2003; Suri, 2003). This approach evolved as a response to Design for User Experience (Hassenzahl, 2013; Hassenzahl et al., 2010) by focusing on 'empathy' as the ability to understand and share another person's feelings and situation (Wright & McCarthy, 2008). In Kouprie & Visser (2009) this engagement is described through four phases: discovery, immersion, connection, and detachment. Empathic Design includes first-person methods (e.g., simulating the users' impairments), Participatory Design, Inclusive Design, and Ethnography (Mattelmäki, 2006, 2008). An example of research conducted to support empathic engagement with how disabled people might feel is the work from Wilde (2011) where props and embodied design techniques are proposed to simulate the reduced freedom of movement.

In order to give a 'voice' to individuals who are normally marginalised or excluded (Aldridge, 2016; Vines et al., 2014), participatory approaches (Postma et al., 2012; Sanders & Stappers, 2008) were introduced into sensitive settings. Participatory Design approaches emerged about 50 years ago (Sanders & Stappers, 2008) and are rooted in the Scandinavian approach to systems design, or 'Cooperative Design' (Halskov & Brodersen Hansen, 2015). In these practices the *"role of the designer and the researcher blur and the user becomes a critical component of the process"* (Sanders, 2002: 1). The Participatory Design process is deemed as a collective empowering process capable of eliciting multiple perspectives and experiential knowledge from people with a deep understanding of the field under analysis (Granath, Lindahl & Rehal, 1996; Saad-Sulonen et al., 2018). It usually evolves through workshops or group sessions (Vines, Clarke, et al., 2013) where participants are helped in sharing feedback on a product or service through the use of several tools (e.g., collages, mapping, mock-ups) (Sanders et al., 2010). There are many ways in which participatory practices have been used in the wild in Human-Computer Interaction (**HCI**) and design studies to involve participants as active parties in research. Participatory Design approaches have been adopted in design practices such as Co-Design and Co-Creation where designers and people not trained in design, work together in the design development process (Sanders & Stappers, 2008) and in hands-on activities (Brewster et al., 2020).

However, Sanders & Westerlund (2011) identified several issues in participatory processes. Too much time is spent on one early idea instead of exploring other possibilities. It can be difficult to motivate participants to be creative because they may be unable or unwilling to engage with creative methods that put them at the heart of the process, or to recall and relate their experiences in narrative ways through visuals and text. Nevertheless, researchers

should take participants' cognitive abilities into account, as well as their literacy and motor skills, and also whether they have been given the necessary educational opportunities in order to describe, write about or translate their experiences in the ways that are requested. When the focus moves onto using participatory approaches in sensitive settings, the necessity to identify aspects of best practice is even more evident (Vines, Clarke, et al., 2013). The presence of vulnerable users and ethical entanglements requires developing and managing long-term relationships and engagement with participants starting from the sensitising phase before the study, throughout the study, and after the study (Thieme et al., 2014). This can help in collecting rich and deep data but also in actively engaging the participants so that they understand the value of their help for the duration of the project (Vines, Clarke, et al., 2013).

The past decade has seen a shift that brought design researchers closer to vulnerable users to collaborate together in the development of products, services and interventions to promote the quality of life and well-being of individuals in sensitive settings (Hemmings et al., 2002; Petermans & Cain, 2019; Thieme et al., 2012). However, despite the quantity and quality of participatory approaches and their contribution to sensitive settings in encouraging engagement, openness and giving a voice to vulnerable users, they seem to fall short of providing the means to conduct sensitive research in the private context of the demographic under study in this thesis. This is caused by the potential intrusiveness of data collection techniques and the stressful active participation requested in collective sessions. Furthermore, the design goal of the project described in this thesis is to confront users with solutions that could be immediately embedded and tested in everyday situations rather than discussing opportunities or initial concepts. Hence, an opportunity has been recognised in using the practice-based approach of RtD to turn sensitive settings into a space for design action and confront users with 'tangible' ideas to converse easily without tapping into uncomfortable topics.

2.4 Turning Sensitive Settings into a Design Space

In this thesis, sensitive settings have been considered as a landscape for design opportunities (Dove et al., 2016) to address the needs of vulnerable users. In HCI, a landscape of design opportunities is a metaphorical but also physical space (Löwgren, 2013) where design activities (Sanders & Westerlund, 2011) and future speculations (Odom et al., 2012) occur; or the context where physical artefacts to address a certain need are developed, introduced or used (Gaver, 2011; Sengers & Gaver, 2006).

The use of design actions as instantiation to explore opportunities in a design space to generate impact and produce new knowledge ascribe to the RtD approach. The design action of creating artefacts can have different intentions including the one related to the aim of this thesis, that is to improve the well-being of people dealing with disruptive life events by focusing on future possibilities. In an interesting provocation presented at the 2015 edition of the RtD conference in Cambridge, UK (Durrant et al., 2017), Christopher Frayling framed RtD as an approach that originates from Practice-Based Design Research (Vaughan, 2017). By taking the work of Read (1948) on Education Through Art as an example, Frayling explains RtD as: *"A research approach based on experiments where things are learned through the medium of studying design. RtD takes a problem outside design and uses design as a way of addressing it. In this way the knowledge is embodied in artefacts that assist in understanding certain things which exist outside design."* (Frayling, 2015). It is an approach in continuous development (Stappers & Giaccardi, 2017) where design leads the process of inquiry and generates new research.

Design actions generate tangible experiments that become the propositions within the research programme to investigate the context. As clearly explained by Stappers & Giaccardi

(2017: 11), these tangible experiments represent what in traditional research terms is defined as *"pieces of controlled research, in which variables are isolated and controlled and hypotheses are validated or rejected"*. In RtD, experiments are a way to *"try something out to see if it works"* (Stappers & Giaccardi, 2017: 11), and fulfil the scope of the inquiry, fit in a research programme (Redström, 2011) or as part of an action oriented intervention (Halse et al., 2010). The creation of tangible experiments in the form of prototypes to be used in field trials allows users to participate in the inquiry by experiencing and testing the research hypotheses in several iterations. In this way researchers test if the designed things are appropriate/accepted or not while the end users can still discover unanticipated uses (Redström, 2017). Thus, this approach gives a new role to prototyping, because it uses tangible artefacts as a 'designerly' way to investigate the context of analysis and produce knowledge (Storni, 2015). The prototypes preserve openness in the possibility of being tested (Lim et al., 2008) and act as filters capable of 'highlighting' particular regions of the design space (Cross, 2006) proposing a response to a situated question in a specific context (Löwgren, 2013).

In summary, the RtD approach seems particularly relevant to address the context investigated in this thesis. It is a methodology that allows a vision to be 'humbly' embodied through tangible solutions that can be gently introduced and taken on board by people. Also, by keeping the prototypes in the centre of the investigation, the context can be explored differently by tiptoeing away from sensitive situations and by offering a new way of 'listening' where people can react to what they have used and interact with it in their every day.

2.5 Doing Research-through-Design in Sensitive Settings: the Four Elements of a Tactful Approach

This section will focus on examining four specific elements in relation to phases of the work described in this thesis (***Figure 2.1***) and how the RtD approach offered an appropriate way to address these entanglements. Two of the elements (i.e., the prototypes and people) intertwined in the process during specific phases of the work, while another two elements (i.e., the infrastructure and the researcher's well-being) have consistently been part of the process.

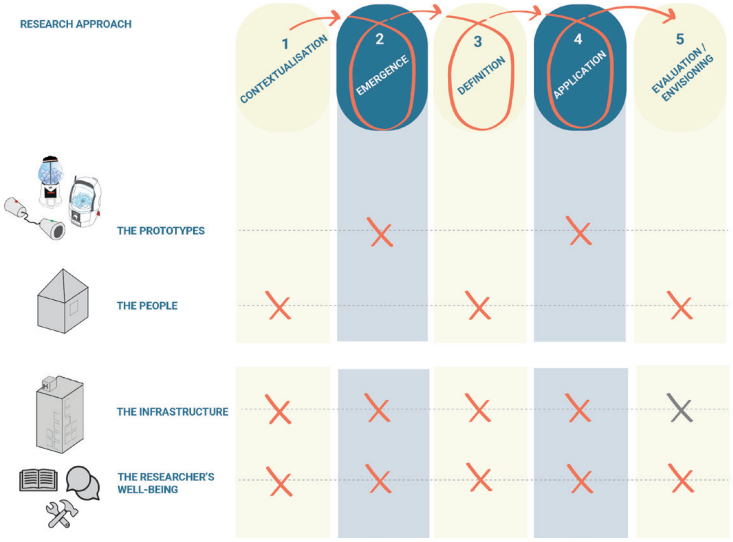


Figure 2.1 The picture presents an overview of the research methodology and the four elements that alternate and appear in relation to the five phases of the project. The Prototypes and People intertwined in the process in separate phases, in the making phase and in the field studies phase respectively. Infrastructure and the Researcher's well-being instead were constant elements that shaped the project's process. *© by the author.*

2.5.1 The Prototypes

The first element concerns developing and using prototypes as instantiations of hypotheses that facilitated the research process in the sensitive setting. As described by Redström (2017) and Brandt and Binder (2007), an RtD project can be modelled in the same way as a design project where a client formulates an assignment for a professional designer. Prototypes are identified as experiments because they are examinations of questions, and in this way they provide directions to follow within the design process (Bang et al., 2012). Therefore, prototypes turn into 'exemplars' of knowledge to test the limitations and suggest possible changes (Bang & Eriksen, 2014; Brandt, 2006; Brandt & Binder, 2007; Redström, 2017) and shifts while unintended insights are gained (Krogh & Koskinen, 2020).

The prototypes' development in this thesis is discussed with the description of Mr.V, AscoltaMe and Mr.V the Spaceman. In the making of the prototypes, the design quality of *tactfulness* **emerged** (Chapter 4) and successively the knowledge that was needed to express the *tactfulness* quality was **applied** (Chapter 6). Mr.V and AscoltaMe are the result of the first RtD iteration. Here, hypotheses on how to tackle the challenges of families dealing with childhood cancer using *tactfulness* as an expressive design quality were represented in a tangible way. Mr.V the Spaceman is the result of the second RtD iteration. Here, four *principles of tactfulness* that emerged during the first iteration were applied in the design of a data-enabled object for families dealing with childhood cancer. The development of the prototypes allowed the RtD approach in tactfully addressing the sensitive setting because:

It allowed the design space to be explored by building knowledge towards design theory;
The knowledge produced from the use of the prototypes is modest and accounts only for the situated aspects related to the specific setting in which they have been used, such as the everyday environment of families dealing with cancer. However, the value of the knowledge they produce is bidirectional: (a) it gives other researchers and practitioners the possibility to build on what has been developed later on to ask better questions, propose new ideas, and produce better design for the same setting (Storni, 2015); and (b) it allows basic definitions to describe complex or abstract concepts like the one of *tactfulness* be formulated. By looking at the particular knowledge that is produced from the process instead of the designed objects (Storni, 2015), it emerges that Mr.V and AscoltaMe are instantiations of the design quality of *tactfulness* in its expressive sense, while Mr.V the Spaceman ascribes a different kind of knowledge that moves towards the definition of *principles* for the design of *tactful objects* for sensitive settings (Höök & Löwgren, 2012) (***Figure 2.2***).

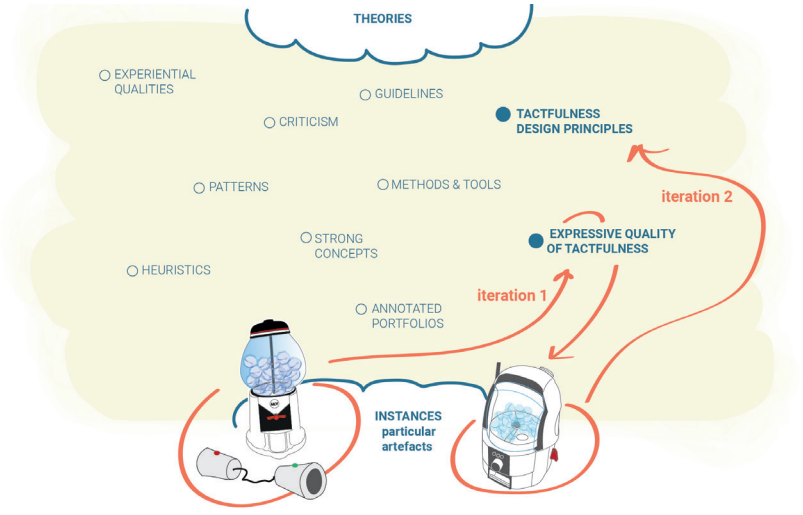


Figure 2.2 Adaptation of model from Höök & Löwgren (2012) that highlights the type of intermediate levels of knowledge developed in this project. *© by the author.*

In this way, the prototypes of Mr.V, AscoltaMe, and Mr.V the Spaceman are materialisation of ongoing *experiments* (Hobye et al., 2013) to define which hypothesised aspects in the design of interactive artefacts for the every day of people in sensitive settings work best. This definition fits and supports a bigger theoretical 'research programme' (Redström, 2017) being the 'Objects with Intent' (**Owl**), paradigm envisioning smart everyday things as collaborative partners (Rozendaal, 2016; Rozendaal et al., 2019).

It facilitated the integration of sources of inspiration such as examples of design for the domestic environment of families and for empowering people in everyday situations;
The initial prototypes of Mr.V and AscoltaMe were inspired by different lines of work presented in the literature such as Transformational Products and Pleasurable Troublemakers (Kehr et al., 2012; Laschke et al., 2011). Here, the definition of design solutions has been conducted with the purpose of gently influencing the user towards a particular behaviour resulting in a particular benefit. In the project described in this thesis, besides reaching the goal by stimulating a change in the families' behaviour, deploying a prototype catered for investigating which interactions/new practices were visible in the families' contexts.

Considering the unfinished nature of the prototypes, they provided opportunities for the users to rediscover internal resources that are already owned (Giaccardi et al., 2016) and use this awareness to overcome challenges and build strategies for new practices, often more than providing solutions. This aligns with the concept of empowering users by leveraging on their knowledge and resources (Ladner, 2015; Van Dijk & Verhoeven, 2016).

Nevertheless, the necessity to stimulate 'change' and 'awareness' through time in the everyday life of families dealing with a stressful situation, also requires considering a temporal dimension. This calls for a perspective in the prototype's development that takes slow technology into consideration (Kirk et al., 2016; Odom et al., 2018). Thus, users will have the time to establish interaction with the object and become conscious of its presence in their everyday life allowing the object to evolve into its 'mediator' role through its foreground and background presence (Hauser et al., 2018).

It allowed technology to be tactfully introduced into the sensitive setting;
The prototypes developed for the families needed to be integrated in the home context and left there for several days. Also, they needed to work autonomously and act in a way that was understandable, appropriate and controllable by the families without causing stress. Therefore, the implementation of autonomy in the objects required an approach different to that of the 'Wizard of Oz'[3] and simulation techniques. The different iterations of the prototypes allowed the level of complexity and intelligence of the object to slowly increase and calibrate in a way that was appropriate and respectful for the context. This also helped in reflecting on the ethical implications and risks of introducing technology in a private and sensitive setting (Roeser, 2016).

It allowed users and stakeholders to tactfully engage in a generative dialogue;
Developing and using prototypes to conduct research offers a way to easily communicate ideas to both vulnerable users and stakeholders involved in the project. Prototypes are by definition in development, and they do not cover all the possible features that are represented in a final design. However, for the researcher they function as filters (Koskinen & Frens, 2017) and manifestations of abstract concepts (Lim et al., 2008; Wensveen & Matthews, 2015).

In this work, prototypes became the focus of interest in involving family members and allowing them to express opinions while also sharing some personal experiences and life anecdotes without feeling under pressure. Furthermore, space was given to the participants to comment on several iterations of the same design, indirectly consenting them to examine, consider and reflect on the data they produced previously.

For healthcare professionals (e.g., nurses, psychologists, child life specialists, oncologists), the presence of 'materialised ideas' in the form of prototypes generated rich conversations during regular meetings and brainstorming sessions organised in the hospital. This gave them the chance to reflect on how to address the families in their everyday context in ways that they would not normally consider in professional practice.

It allowed data to be collected sensitively;
By asking the family members to give visual examples of how the prototypes are integrated into their home context, they also indirectly provided information regarding everyday activities and rituals. This resulted in collecting rich data that the design researcher could not acquire in person for privacy reasons. Furthermore, in the second iteration, turning a simple interactive prototype (Mr.V) into a data-enabled one (Mr.V the Spaceman) offered a way to collect data on patterns and preferences in a subtle way without distracting the family. Infact, data-enabled prototypes can perform in situ Ethnography (Giaccardi, et al., 2016b) by recording data from a point of view that users would not be able to record or do not consider relevant, and that instead can provide a different and interesting perspective on the problem under analysis.

2.5.2 The People (Children and their Families)

By highlighting the element of 'people', the reflection focuses on how using an RtD approach facilitated the involvement and engagement of vulnerable users. The description of who are the vulnerable users that are addressed in this project and how they engaged is discussed in detail in the three field studies. Here, the necessity to explore *tactfulness* to approach and support vulnerable users in sensitive settings is first **contextualised** (Chapter 3), then **defined** (Chapter 5) and finally **evaluated** (Chapter 7). The RtD approach was tactful because:

It facilitated the engagement and the (collective and equal) involvement of vulnerable users;
All three studies conducted during the project were designed as qualitative studies in line with the approaches used in sensitive settings. The first field study aimed at sensitising the design researcher with the demographic under analysis, a participant observation of childhood cancer survivors at a large support group conference was conducted. The second and third study were conducted as empirical studies to understand how to design a tactful support for families dealing with childhood cancer. This involved eight and 10 families with a child undergoing cancer treatment, respectively.

In this first study, the design researcher by introducing herself in the context with the aim of finding design inspiration, sparked the interest of the participants and their willingness to disclose personal experiences. In the second and third study, the use of an RtD approach proved to be efficient in engaging the families as a whole, while at the same time gave all the members the chance to contribute at the same level in providing rich and personal perspectives on the impact of the objects. Furthermore, each family was given the chance to share their own experiences individually without participating in co-design sessions together with other families at the same time. Thus, in the collected data, the nuances related to each family's identity (value, rituals, routines) (Wiener et al., 2012) and privacy were preserved (Giaccardi & Redström, 2020; Hors-Fraile et al., 2016; Jenkins et al., 2019; Murray-Rust et al., 2019; Wiener et al., 2012)

It built trust and confidence;
The opportunity for the families to provide comments and share reflections, knowing that the design researcher was willing to learn from their experience, made them understand that their perspective was considered valuable. This instilled confidence, so that they felt less scared or reluctant in proposing ideas on how to improve the artefacts without having to come up with a new design by themselves.

2.5.3 The Infrastructure

In the description of the infrastructure, the reflection focuses on how the use of an RtD approach facilitated the design researcher in handling the organisational aspect of the project such as interacting with stakeholders, following protocols and rules and aligning stakeholders' expectations. This aspect emerges in all of the chapters. The RtD approach facilitated the design researcher in tackling the 'infrastructure challenges' in the sensitive setting because it:

Overcomes the setting's limitations;
The two studies conducted with families with a child undergoing treatment described in the thesis were designed, approved and conducted in accordance with the regulations of the Medical Ethical Committee of the University Medical Center Utrecht in the Netherlands. What facilitated the acceptance of the studies was the fact that they concerned the testing of playful products for the home context of families

with children in treatment which were not labelled as medical devices. This meant that the objects would not interfere with the daily activities in the hospital and did not have to respect high hygienic standards to be used by the families as it happens for objects used in the hospital.

The obligation imposed by the Medical Ethical Committee to monitor the experiences of the families also in their home context through healthcare supervision, triggered the establishment of a mutual collaboration in the field work between the design researcher and healthcare professionals. This step, facilitated the recruitment of the participants while protecting their patient-profiles. Furthermore, a medical researcher was also involved during the field studies due to her professional knowledge in how to approach the children and families in treatment and her capability in recognising potential risks for the patients. This, interestingly allowed the design researcher to observe and learn how to establish the correct rapport with the vulnerable group, not to grow attached, and eventually handle negative developments in the condition of the patients and eventual loss.

Found a common research ground on approaches to collect, analyse and communicate the data;
RtD is not based on standards and is not yet a formalised approach. This creates challenges in terms of documenting the knowledge, replicability, validity of the data and generalisability of the findings (Storni, 2015); when they need to be communicated and discussed in fields based on traditional methodologies and strict protocols such as medicine. However, conducting the research according to this approach allowed theories and the model coming from different fields other than design to be easily integrated and used to analyse the collected data. An example is the bio-ecological model (Bronfenbrenner & Ceci, 1994) based on Bronfenbrenner's Ecological Systems Theory (see Chapter 3) that was used to organise the data on the challenges encountered by the families while dealing with childhood cancer collected during the first field study.

This intertwined approach also invited the revisitation of data collection methods that differentiated the design field from healthcare. During sessions with patients, healthcare professionals do not often make use of recording means, only minor notes are taken. Therefore, conducting an ethnographic investigation can become quite difficult since it can be perceived as intrusive, as most parents do not feel at ease with sharing pictures of their own children during treatment. The approach used in the project stimulated reflection in finding an ideal way to collect data while remaining respectful of the families.

In the first study, the design researcher immersed herself in the field, observing and noting down anecdotes and opinions; rather than doing interviews, proposing questionnaires or organising co-design sessions. In this way she established limits when interacting with the group of participants while letting them share their feelings without any judgment nor interruption. In the second field study, attention has been given in the way the prototypes were introduced in the context not to make families think that they had a specific problem to solve. Furthermore, a diary was given to the families to note down their comments, suggestions and daily interaction with the prototype since they could not be observed by the researcher 'at that moment'. Moreover, since photos are an important form of data in design but can be perceived as intrusive in a private context; families were asked to autonomously take pictures to keep track of their interaction with the prototypes and shared them with the researcher in an encrypted WhatsApp™ online chat. Hence, this put them in charge of deciding which moments were important that needed to be reported to the researcher. Then semi-structured interviews were conducted in which multiple family members participated together. Questionnaires were used to rate the artefacts. The third study followed a similar structure but the diary was removed since the research prototype turned into a data-enabled product capable of autonomously collecting non-sensitive data.

Finally, the data was analysed in ways that could enhance collaboration between professionals from different backgrounds. In the first study, the data was analysed following a narrative inquiry approach to avoid the use of personal quotes from the participants (McAdams, 2012) and preserve sensitivity. This approach (used also in developmental theory) was suitable for the context of investigation because it was capable of capturing the emotion of the moments described, conveying the meaning communicated by the participants and clearly summarising the ways in which individuals planned and derived meaning from the events (Smith, 2000). In the second and third study, content analysis of diaries, online chats and interviews were analysed respectively through manual coding (Sanders & Stappers, 2012) and coding software (Atlas.ti™). Collected pictures and videos and exchange results were also allowed for inclusion where researchers sought patterns and validation. The questionnaires and the data sensed by the prototypes were instead input into statistical software (IBM SPSS 27.0™) enabling quantitative analysis by means of descriptive and frequency statistics.

2.5.4 The Researcher's Well-being

The researcher's well-being element focuses on how the use of an RtD approach also facilitated the design researcher in preserving her own self-protection while conducting the research activities. This aspect emerges in all chapters. The RtD approach supported the researcher's well-being because:

It generated a positive distraction during the research process;
The use of an RtD approach gave the design researcher the possibility to shift the focus of attention in several intertwined activities that provided distraction from the emotional topic under analysis. The continuous contact with healthcare professionals and collaborators helped in externalising challenging thoughts, worries and struggles that otherwise would have had a negative impact on the overall research (Groeneveld et al., 2018). Developing tangible and playful artefacts to support children and family members in stressful situations in parallel with conducting scientific research, also generated a sense of purpose and achievement. Finally, building design solutions in several iterations increased the confidence in the design researcher to have found a way to sensitively increase the complexity of the technology introduced in the every day of these families, without creating overwhelming situations.

It supported the design researcher in bridging perspectives between different disciplines and integrate knowledge;
The various tangible activities conducted in the field also helped in overcoming initial alignment struggles with healthcare professionals and in slowly growing a strong and fruitful connection with them. This helped in speeding up the research process that was already challenged by medical protocols and setting constraints. Furthermore, it also gave a possibility to healthcare professionals to understand the added value in addressing sensitive settings with different approaches than traditional ones, and facilitated the integration of ideas and knowledge as an act of design.

Chapter's Takeaways

Sensitive settings present specific characteristics that differentiate them from other research settings and therefore research in such settings require sensitive approaches;

Research through Design (RtD) is deemed as an ideal approach to investigate such settings because it allows vulnerable users to engage in a tactful way, while involving them in the evaluation of implementable bespoke solutions for their context and sensitively collecting research insights;

Four specific elements of the RtD approach are considered in line with the idea of a tactful approach to sensitive settings. These elements are: (i) the presence of tangible prototypes that behave as research products and have impact on people's lives, (ii) establishing a relation with participants that allows them to behave as experts without putting them under the spotlight, (iii) the possibility to align expectations and ways of working with the bigger collaborative project's infrastructure and (iv) the protection of the researcher's well-being when dealing with sensitive topics and sustained interactions with stakeholders.

Endnotes

2. Some of the variation of cultural probes found in literature are: Informational Probes, Technology Probes and Mobile Probes (Hutchinson et al., 2003); Empathy Probes (Mattelmäki, 2002); Domestic Probes and Urban Probes (Graham & Rouncefield, 2008); Playful probes (Bernhaupt et al., 2007).

3 . In the HCI field, a Wizard of Oz experiment constitutes a research experiment in which users interact with an interactive/computational system that users believe to be autonomous, but which is being operated/partially operated by an unseen person.

3
UNDERSTANDING THE ECOLOGY OF CHILDHOOD CANCER

Based on published journal article: D'Olivo, P., Rozendaal, M. C., Giaccardi, E., Grootenhuis, M. A., & Huisman, J. (2018). Reconfiguring a New Normal: A Socio-Ecological Perspective for Design Innovation in Sensitive Settings. *She Ji: The Journal of Design, Economics, and Innovation, 4(4), 392-406.*

3.1 Introduction

Disruptive life events, such as a serious illness, can significantly change a family's everyday routine and put stress on relationships among family members (Massimi et al., 2012: 723). Childhood cancer, for example, confronts families with an uncontrollable situation which carries with it considerable uncertainty about the future (Marsland, Ewing, & Thompson, 2006: 237). This chapter looks at childhood cancer as a disruptive life event capable of generating high levels of stress and anxiety during hospitalisation and at home, and therefore being a hindrance on a family's existing routines and relationships (Shing et al., 2016: 1290). The severity of the illness, pain, medical procedures, and the spectre of invasive or frightening treatment elicit stress and anxiety (Kazak et al., 2006: 343-44). Childhood cancer can be traumatic for the entire family (Hocking et al., 2014: 1287). Immediately after being diagnosed, the family unit faces an onslaught of bewildering and often frightening demands they must learn to manage. Not only do parents have to attend to the child's physical well-being, but also to his or her fears regarding invasive medical procedures that can generate significant distress (even after treatment) and also possibly try to alleviate the fears and concerns of their other children. The situation may lead to posttraumatic stress symptoms (PTSS) (Stuber, Kazak, Meeske, & Barakat, 1998: 169-82) including intrusive thoughts, arousal, and hypervigilance in any family member (Kazak et al., 2006: 343). Therefore, reducing medical traumatic stress experienced by sick children and their families during and after treatment is vital in ensuring the success of the medical treatment, reducing adverse psychological reactions caused by the overall experience of the illness, and boosting self-esteem and trust in the future (Shing et al., 2016: 1287-90).

If we truly wish to understand how to address the disruption caused by cancer, all family members must be part of the discussion (Minuchin, 1988: 8). Family-centred perspectives that have emerged in the field of developmental psychology see families as interdependent, self-regulating systems (Cox & Paley, 1997: 250-57) where each member influences one another (Knafo & Galansky, 2008: 1148-49). These multiple, reciprocal, proximal influences have been studied using a developmental systems approach, notably through the lens of Bronfenbrenner and Ceci's bioecological model, which was inspired by Bronfenbrenner's Ecological Systems Theory (1994). The model aims at improving the understanding of the conditions and processes that influence human development, by showing how a child's inherent qualities and the characteristics of external environments and proximal processes interact and influence his or her life over time (Ashiabi & O'Neal, 2015: 1-14; Bronfenbrenner, 1977: 513). The model depicts this complex environment as a series of five nested interactive systems (Bronfenbrenner, 1979) (***Figure 3.1*** *see p.28*). The child sits at the centre of the model, including his or her biological and psychosocial characteristics. Moving from that which is closest to the child to that furthest away, the following were identified 1) the interpersonal level, which includes the child's interactions with people close to them such as family members, classmates, teachers and caregivers; 2) the organisational level, including the interrelations between the microsystems that the developing child finds him or herself in, such as family, school, hospital; 3) the community level, which includes interrelationships within the wider social system the child is embedded in and any social factors influencing their interaction; and 4) the sociocultural level, which represents the cultural values, customs, and laws governing inhabitants in the child's immediate geographical context; and, lastly, 5) the time level, the temporal dimension representing change and consistency in the characteristics of both the child and the child's environment (Bronfenbrenner & Evans, 2000). Despite its widespread prominence, only a handful of clinical research projects—in cancer support (Kazak, 1989: 25-30); cancer education (Centers for Disease Control and Prevention, 2015), violence prevention (Centers for Disease Control and Prevention, 2017); health promotion (McLeroy, Bibeau, Steckler, & Glanz, 1988: 351-77); childhood food and nutrition education, policy, and management (Gregson et al., 2001: 4-15; Hirsch, Lim, & Otten, 2016; Lynch & Batal, 2011: 185-203); and childhood chronic illness product development (Jeong & Arriaga, 2009: 1-4) —have opted to utilise this model.

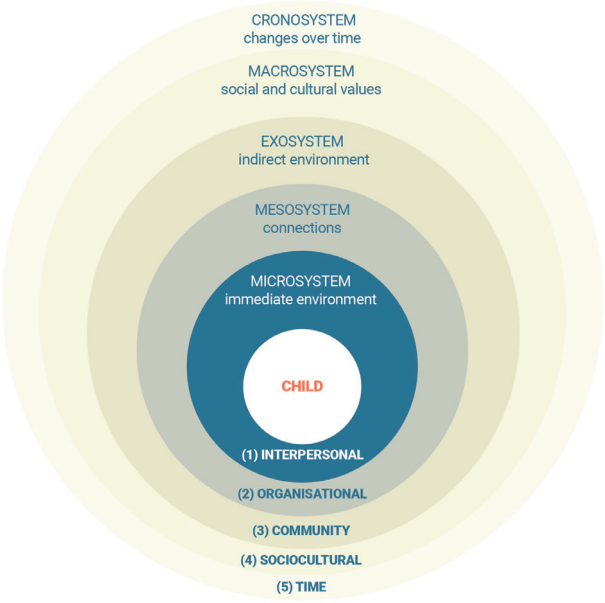


Figure 3.1 Bronfenbrenner and Ceci's bioecological model (1994). *© by the author.*

When disruptive life events occur, they greatly affect the interactions between these nested systems (Cox & Paley, 1997: 254-55). Family members—part of the closest system layer—can play a crucial role in promoting adaptation to the change in circumstances and, together, can enable all concerned to cope more easily (Kazak, 1989: 25-28). Technologists and designers Massimi, Dimond, and Le Dantec call these efforts to adapt to and cope with uncontrollable events *"finding a new normal"* (2012: 723). Their fieldwork led them to conclude that individuals and families affected by life disruptions tend to seek a *"reconfigured lifestyle"* by constructively making use of *"tenuous and emerging social groups and resources"* (Massimi et al., 2012: 723). There is some existing work by design researchers seeking to support adapting to a changed lifestyle in an innovative way, for instance in the case of a loved one's death. One set of proposals seeks to enable those in mourning to quietly communicate with others, share their grief discreetly, and commemorate the deceased's life and passing, and also presents approaches to creating technology-based heirlooms (den Hoven et al., 2008; Kirk & Banks, 2008; Massimi, Odom, Kirk, & Banks, 2010: 4477-80). Other researchers have explored how design can help families to better deal with navigating divorce by facilitating communication between family members. Others have explored how technology can help women re-establish intimacy in relationships and rebuild their lives after domestic violence by using photography as a tool to express and represent ongoing tension (Clarke, Wright, Balaam, & McCarthy, 2013: 2517-26; Odom, Zimmerman, & Forlizzi, 2010: 151-160; Vetere et al., 2005: 471-80).

Validated models and studies from the field of psychology (Last & Grootenhuis, 1998: 175-76) can help designers gather insights from the field, frame their data, and generate design ideas that will engage users in innovative, strategic, and tactful ways (Koukourikos, Tzeha, Pantelidou, & Tsaloglidou, 2015: 438-41). Bronfenbrenner and Ceci's model (1994) can help designers describe, analyse, and deepen their understanding of the roles and interdependencies of routines and relationships in family life. By applying this understanding to the life disruption design process, designers are more likely to grasp how to turn everyday products into enablers of whatever new normal the users are adjusting to.

This chapter presents the findings gathered during the participant observation of the 6th

European Childhood Cancer Survivor (CCI, 2016) meeting. This explorative work was conducted to gather first-hand insights into the experiences of childhood cancer survivors and their family members and the challenges they face. The results section, describes and organises the findings using Bronfenbrenner and Ceci's model (1994) and the emerging coping strategies that occur at different systemic levels. Based on these results, the adoption of a socio-ecological approach to design innovation in sensitive settings is argued. This approach emphasises the social aspects that emerge from context analysis using Bronfenbrenner and Ceci's model (1994) and derives opportunities for design that address not only the child in his or her biological and psychosocial aspects, but also the whole family as a system of social relations. Benefits and limitations of this contribution to the literature will also be proposed and analysed. In conclusion, avenues for future research and design recommendations for innovation in the context of childhood cancer will be presented.

3.2 Childhood Cancer and Psychosocial Cancer Care

The term childhood cancer refers to diagnoses of cancer in individuals between the ages of zero and 18. Common types of cancer in this age range are leukaemia and brain tumours (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014: 84). When families are confronted with the possibility of childhood cancer, the medical aspect of the diagnosis typically consists of five phases: the pre-diagnosis, diagnosis, treatment, follow-up, and the late-effects screening phase. This section will briefly sketch out some of the stressors families encounter and the changes they are likely to make in their everyday routines as they adapt to each phase.

The pre-diagnosis phase is a short or long period of concern and insecurity about the child's health. The diagnosis phase includes the stressful and frightening medical examinations and emotional shock of cancer diagnosis (Li, Lopez, Chung, Ho, & Chiu, 2013: 214-15). From that moment on, concerns related to the diagnosis permeate every aspect of the family's existence. They must develop a realistic understanding of the considerable implications—for both child and parents—arising from both diagnosis and treatment (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001: 673). The whole family feels powerless and anxious, and stress creates tensions between family members. Parents have to find some way to explain what is happening to the child or deal with their child's mix of anger and sadness if he or she is old enough to understand the impact of the illness. They will also have to divide their attention between the sick child and his or her siblings to avoid them feeling neglected or becoming jealous (Woodgate, 2006: 408-12), while also dealing with the stressor of making decisions about beginning treatment, and even possibly considering taking part in study randomisation for new treatments (Bond & Pritchard, 2006: 150).

Entering the treatment phase generates a big change in a family's everyday routines. At this stage, learning to deal with the effects of medical treatment is a significant source of stress. Chemotherapy usually starts shortly after diagnosis. The child rapidly comes to terms with what cancer treatment is about—painful medical procedures, sickness from chemotherapeutic agents, possible fatigue from radiotherapy, and side effects such as hair loss (Verschuur & Zwaan, 2012: 54). Parents have to organise regular hospital visits and make them fit in with their work schedules. They also need to find the time to take care of domestic tasks, and in the case of larger families, care for the other children. Treatment also disrupts the sick child's and siblings' school attendance and engagement in hobbies and sports (Last & Grootenhuis, 1998: 170-72). Beyond such practical issues, chemotherapy can lead to mood swings, feelings of isolation, and difficulty communicating with family (Phipps, 2006: 75-99). Sick children find it difficult to share their worries with their parents, and their parents do not want to show any form of weakness to their children.

There is a tremendous transition in the care provided when treatment ends, and this can be very stressful. Children and parents receive a lot of support from multidisciplinary teams over the length of the treatment phase. However, once treatment ends this guidance

lessens, and families find themselves with the urge to regain control of their lives (Stam, Grootenhuis, Brons, Caron, & Last, 2006: 312). The main challenges associated with this follow-up and the late-effects of the screening phase are handling the uncertainty about the future and considering life after cancer (Earle, Clarke, Eiser, & Sheppard, 2007: 156-58). Families need to move on and look to the future but are faced with the threat of a possible relapse (Kupst & Bingen, 2006: 35-52). Sick children go back to school—where they have probably fallen behind—or, if older, must return to preparing for their future careers. Medical check-ups become less frequent, and life slowly gets back to normal. At this stage, survivors fully realise how they have changed, and must learn to accept the effects generated on their bodies by the treatment. Almost all children and adolescents who have been successfully treated for cancer have to deal with negative health outcomes (Geenen et al., 2007: 2705-15). They may develop health problems as result of the treatment; being diagnosed with cancer for the second time, cardiac conditions, brain tissue degeneration, endocrine problems, and infertility, for example—but also suffer from cognitive and/or social disadvantages in terms of academic achievement, finding a job, a partner, and finding health insurance coverage (Grootenhuis et al., 2012: 111-17).

Since many of the sources of stress that develop during this long journey cannot be controlled (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986: 992-1003), coping strategies play an important role in supporting the emotional adjustment of everyone concerned (Shing et al., 2016: 1291). Coping strategies are balanced reactions to stress that enable families to tolerate, minimise, accept, and/or ignore what cannot be mastered (Lazarus & Folkman, 1984: 140). Emotion-focused coping strategies are directed towards regulating effects surrounding a stressful experience, and problem-focused coping strategies seek to tackle the problem causing the distress (Last & Grootenhuis, 1998: 172). Patients or families who show the ability to adapt to stress and cope with a threatening situation, develop resiliency (Last & Grootenhuis, 1998: 170) , the capacity to quickly recover after stress. Understanding the emotional and behavioural reactions and coping strategies of families in the throes of disruptive life events will help designers create more appropriate and beneficial products and services, ones that support the family's emotional adjustment and strengthen its resiliency.

3.3 Method: Participant Observation of Childhood Cancer Survivors

Researchers have used different research methodologies in the context of childhood cancer and chronic diseases. Researchers typically carry out data collection and analysis of how children with cancer and their families deal with their condition via questionnaires, semi-structured interviews, focus groups with parents and caregivers, and direct patient participation on online platforms. Another method, based on the change management approach called Appreciative Inquiry, involves interviewing other stakeholders who may be involved—for example, people who educate families on how to deal with challenging situations (Carter et al., 2016: 141; Hocking et al., 2014: 1287-94; Schepers, 2017). In the field of design, probes, inclusive strategies, and elicitation methods including co-realisation have been introduced to investigate and describe sensitive contexts and vulnerable people (Crabtree et al., 2003: 4; Jeong, Park, & Zimmerman, 2008: 3227; Vines, McNaney, Lindsay, Wallace, & McCarthy, 2014: 44-46; Wyeth & Diercke, 2006: 385). In these cases, design researchers develop and manage long-term relationships and engagement with participants starting from the sensitising phase before the study, to throughout the study, to after the study (Thieme et al., 2014: 139-42). This enables them to collect deeper and richer data, and also to actively engage the participants so that they understand the value of their help throughout the life of the project (Vines, Clarke, Wright, McCarthy, & Olivier, 2013: 429-38). New approaches in clinical research apply creative techniques and sensitive tools that help researchers to empathise with patients while investigating the therapeutic outcomes. For example, Marsac and colleagues used toy puppets and decks of cards to ask patients to evaluate how they perceive their disease and treatment (2014: 392-93). Similarly, Nygren and colleagues used participatory design approaches to develop a model that can guide

interventions aimed at promoting children's health by involving patients, parents, caregivers and other stakeholders directly (2017: e19).

Given the work that has been already developed in the field and the approaches that already exist, here the topic of childhood cancer is explored by looking at how families with children in treatment can be tactfully supported outside of clinical contexts. The findings are based on the participant observation of 28 childhood cancer survivors at a large support group conference with 99 participants from 23 countries. The design researcher carried out data collection by immersing herself alone in the context to observe and note down observations, anecdotes, and participants' opinions, rather than conducting interviews, proposing questionnaires, or organising co-design sessions. By maintaining a moderate distance, she expanded her understanding of the context and learned how to interact with the participants without the risk of overwhelming them (Dickson-Swift, James, Kippen, & Liamputtong, 2007: 330). Her supervisors collaborated on the data analysis, and helped the design researcher to theoretically frame the research within the context of childhood cancer. In this chapter, for the sake of consistency, 'design researcher' will be used when discussing the fieldwork conducted by the doctoral researcher (Tong, Sainsbury, & Craig, 2007: 349-57).

3.3.1 Procedure

3.3.1.1 Establishing Rapport and Addressing Ethical Concerns

During an international three-day conference, the design researcher carried out participant observations with childhood cancer survivors and their families. The annual Childhood Cancer International Europe Regional Meeting (CCI, 2016) is a conference that promotes mutual learning and information exchange among representatives from European cancer survivor groups and parental associations. The decision to participate in this event was motivated by a need to document how families and children coping with childhood cancer openly describe the main difficulties and obstacles they face. 99 people from 23 countries participated in the CCI meeting (CCI, 2016). The assembly was primarily comprised of survivors, parents, healthcare professionals, and cancer associations. The conference was attended by 28 cancer survivors in total, which included male and female participants from 12 to 35 years old. Some of them already knew each other, and others were new. English was the common language used over the course of the event.

The demographic of interest for the present research was children undergoing treatment for cancer between the ages of zero to 18 years old and their family members. Some parents joined the event, but the survivors' group differed from the demographic of interest regarding the age range of the attendees and the phase of their cancer condition. However, most of them had been cured of cancer during their childhood. The event provided the design researcher with the chance to get acquainted with different perspectives on the topic, an opportunity that would otherwise have been considerably more difficult to arrange with families undergoing treatment. Therefore, given the scope created by such a public event, the design researcher's supervisors agreed that it was a valuable resource for preliminary data observation.

To obtain consent to conduct the observation, the design researcher got in contact with one of the childhood cancer parental associations participating in the conference. This association was also involved as a partner in the overall research project After introducing the aim and protocol of the research, the design researcher was invited to join the event by a member of the parental association. Before the conference started, the design researcher received written consent from the organisers to conduct her observations at the conference. Later on, at the plenary opening of the meeting, the design researcher introduced herself to the audience, explained the purpose of her presence, and explained that she would be observing conference events by taking brief notes. One of the event organisers addressed the entire audience asking if everyone consented to having the design researcher at the conference and if anyone wanted to be included in the observations. The design researcher obtained verbal consent and agreement from all the audience members. At the end of the event, she was also granted permission to use the materials produced by the conference organisers, including photos, videos, and presentations, but only for the purposes of analysis.

3.3.1.2 The Researcher's Participation

During the conference, the design researcher maintained a discreet presence. She joined the

presentation sessions and a survivors' workshop. Besides attending the formal events, she also shared coffee breaks and meals with the participants, engaging in informal conversations. On day three, the conference organisers planned a workshop for the survivors. The workshop revolved around three topics: helping survivors recognise the late effects and changes after treatment; providing information to hospitals and caregivers about how to organise follow-up clinics and keep track of a patient's history after his or her treatment has been undergone; and defining future guidelines for associations to connect survivors from different countries and identifying strategies to get them involved. Before the workshop session, the organisers asked the 28 cancer survivors if the design researcher was allowed to join them again and if they wanted to be included in her observation notes. After a private consultation among the organisers and survivors, she was welcomed into the room where the workshop took place, and they gave their verbal consent once more. The activities alternated between discussions, brainstorming, and outlining key action points. The design researcher sat close to the group to observe but did not intervene. During the warm-up session, the participants introduced themselves by describing their character and favourite hobbies, and by giving details about their cancer experience. After that, the participants were invited to choose one of the three topics of the workshop and to brainstorm possible opportunities associated with them. The conference facilitators recorded testimonies from the 28 survivors on video during and after the workshop, giving them the opportunity to share their impressions and experiences. The videos were screened at the closing event of the conference to the entire audience.

3.3.1.3 Data Collection, Narrative Analysis, and Analysis Validation

The design researcher immersed herself in the environment with the group of participants for the entire three days of the conference. She noted down behaviour, emotions, and thoughts in context and at the moment when individuals experienced them (Jorgensen, 2015). She paid particular attention to respecting participants' limits and used a sensitive approach that enabled them to share their feelings without judgment or interruption (Dickson-Swift et al., 2007: 330; Dickson-Swift, James, & Liamputtong, 2008). Showing empathy, especially during the sharing of details surrounding participants' personal lives, was central to the design researcher, enhancing her connection with the participants. She carefully documented the experiences shared by parents and survivors, details of events that happened during the conference, summaries of each formal presentation, and informal conversations. Given the sensitive nature of the context, she chose not to use an audio recording device. She transcribed and eventually anonymised the notes she took during and after the conference for use later during the analysis. The conference organisers took pictures during the final presentations at the workshop. In addition to the data produced by the design researcher, and the video documentation produced by the conference organisation, other analysis materials included: a conference newsletter published after the conference summarising the meeting's key insights, photos and conference presentations published on the event website, and four video clips where one of the survivors participating in the conference together with another three young patients treated in the same hospital, creatively portrayed their vision of their cancer experience.

The design researcher analysed the aggregated data gathered from her notes using a narrative inquiry approach, thus this chapter will not present actual quotes from the participants (McAdams, 2012: 15-17). This approach seemed suitable for the context of this investigation because it can capture the emotion in the moments described, convey the meaning communicated by the participants, and clearly summarises the ways individuals organise and derive meaning from events (Smith, 2000: 313-35). The design researcher organised the data and removed irrelevant and redundant elements. The content was then listed and divided into themes (Miles & Huberman, 1985). Her supervisors then reviewed and discussed each theme. To clarify the essence of each theme and reach an agreement, the themes were defined as a description of a specific challenge faced by the participants. This included a general definition of the challenge, information about the context and the stakeholders involved, the effect and complications the challenge generates, and the emerging coping strategies as results of that effect (Labov, 1972: 97-120; Last & Grootenhuis, 1998: 169-79). Afterwards, the themes were synchronically arranged according to the levels in Bronfenbrenner and Ceci's model (1994). When the analysis was concluded, the design researcher shared the results with the conference parental association members who had invited her to the conference and one of the workshop facilitators. She also invited them to provide feedback to support the analysis. feedback to support the analysis.

3.4 Results: Learning from the Shared Testimonies of Cancer Survivors

Based on the results of the observations and informal talks conducted at the CCI meeting (CCI, 2016), five themes illustrating the experiences and coping strategies that cancer survivors and

their families adopted during and after treatment emerged: accepting the transformation of one's body; learning to avoid avoidance, which can paralyse a family; maintaining interest in social activities, to reignite a sense of hope and optimism; retaining a sense of belonging to one's social networks, an important resource whose role and use can change dramatically during a life disruption; and dealing with the social stigma surrounding cancer, which can hinder survivors from engaging with normal, everyday life (***Figure 3.2***). Each theme reveals specific features representative of the coping strategies adopted at each level of Bronfenbrenner and Ceci's model (1994), starting from the centre where the child is positioned (***Figure 3.3***). The time dimension is intertwined with the other levels, and therefore no theme relates to it specifically. The themes together represent an overall summary of the main concepts mentioned by survivors, parents, and healthcare professionals present at the conference.

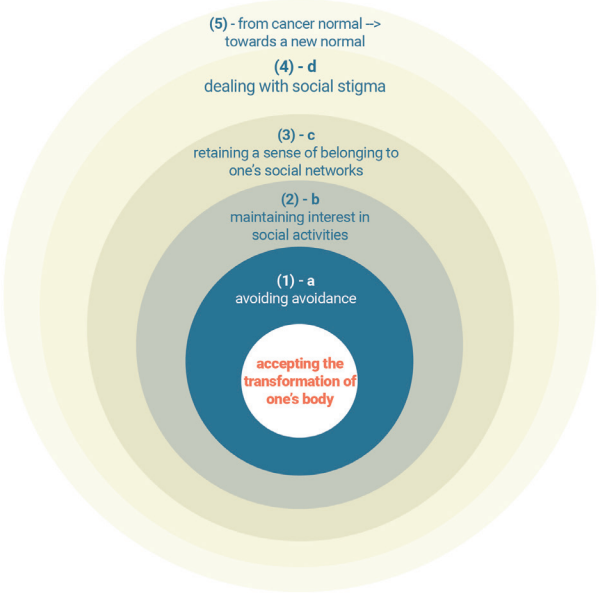


Figure 3.2 Synchronic overview of the themes and Bronfenbrenner and Ceci's (1994) model levels. *© by the author.*

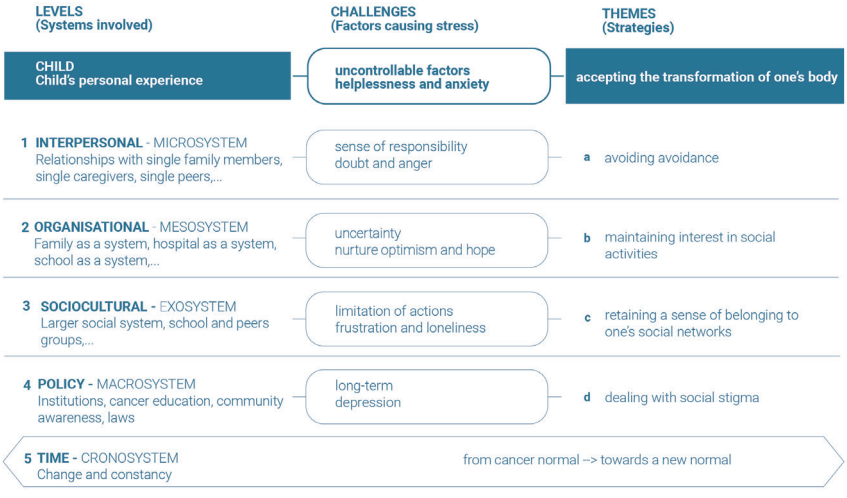


Figure 3.3 Bronfenbrenner and Ceci's model (1994) levels, challenges, and coping strategies. *© by the author.*

3.4.1 Themes and Coping Strategies

3.4.1.1 The Individual Level: Accepting the Transformation of One's Body

Being treated for childhood cancer causes bodily changes that children, and especially adolescents, have to learn to accept. Some of these changes are temporary, such as hair loss and weight gain, but sometimes the damage caused by the cancer itself can be permanent—an amputated limb as a result of a bone tumour or hearing loss and attention deficit as a late effect of cancer treatment. According to some of the survivors, these bodily changes can be severely detrimental to a person's self-confidence. During and after treatment, patients must re-evaluate their strengths and learn to see themselves in a new light. In the literature, bodily changes are classified as uncontrollable factors that, if not taken seriously, can lead to feelings of *"helplessness and anxiety"* (Last & Grootenhuis, 1998: 175).

The experiences shared during the conference highlighted that, working on one's self-esteem during cancer treatment can help strengthen a sense of confidence in the patients. Survivors explained how important it was to work on accepting limitations to their mobility due to muscle weakness and bone fragility caused by treatment and also learned to control their diet and regimen to regain energy. Healthcare professionals who attended the conference pointed out that teenage patients in particular need to learn to re-evaluate their bodies in relation to their peers. This should be done in a healthy manner, so they have the confidence to approach others and start new relationships. They may also need to be informed about the consequences that the treatment will have on their ability to become parents. All the participants said it was important to encourage children in treatment as well as survivors to reflect on their bodies, feelings, and emotions to help them create awareness of themselves in the world, find the motivation they need to pursue their goals, and establish healthy relationships with others more effectively.

3.4.1.2 The Interpersonal Level: Avoiding Avoidance

When a child is diagnosed with cancer, his or her family members can also experience feelings of vulnerability and powerlessness. As reported by parents during the conference, dealing with the unexpected is frightening, and being faced with the possibility that the child might suffer or even die is extremely stressful. According to the literature, family members share a sense of responsibility towards each other, and not being able to control that sensation can generate feelings of self-doubt and self-anger (Last & Grootenhuis, 1998: 175). The parents and survivors said that although sharing feelings with each other is difficult, sharing helps everyone to cope with the stressful emotions they've experienced and creates a constructive family environment where everybody has an equal right to ask for help. Children have the right to express their pain and sadness, and parents have the right to show and talk about their insecurities and fears. Therefore, finding ways to support communication going forward seems vital for families in this context.

The experiences shared during the conference highlighted that families need support if they are to avoid avoidance—they need help dealing with difficult topics and emotions. The conference participants talked about how social media helped them share their feelings with family members. When direct, face-to-face communication felt daunting, indirect and mediated communication via screens and text messages seemed to make it easier for family members to talk. The survivors and parents agreed that there are many ways to help family members talk about difficult issues and that, in general, they preferred to use the same communication channels that people use in everyday life. During the course of the event, they intimated and sometimes expressed a need to find ways of sparking conversation even when the situation involved difficult topics.

3.4.1.3 The Organisational Level: Maintaining Interest in Social Activities

Childhood cancer can seriously inflict on hope and optimism as the situation deepens in severity and becomes possibly life threatening. The conference participants explained that when they feel well, they take pleasure in what they are doing; what they are interested in and in what way they are motivated by life in general. They engage in leisure activities and hobbies and do fun things together with family and friends. According to the participants, these kinds of activities can help them bolster their sense of hope and optimism (Last & Grootenhuis, 1998: 175). They said laughter and engaging in fun activities were effective ways for survivors and family members to overcome feelings of uncertainty in particular (Last & Grootenhuis, 1998: 175). For instance, the survivors joked about the severity of their cancer by debating which type of cancer was the 'coolest.' Organisers of the childhood cancer parental organisation reported that a high number of families joined summer camp initiatives to foster motivation in their children, help them bond with new friends, and involve their siblings more directly.

The experiences shared during the conference highlighted that engaging in social activities, reinforcing family bonds, seeing how other people are dealing with the same problem, and keeping spirits up is important for families to instil hope and to better cope with the emotional challenges accompanying childhood cancer. Cancer treatment can last a long time—anywhere from months to years— and participants appeared to truly benefit from focusing on the present and enjoying simple daily experiences together. Gently being reminded about the small, positive things in life might be a way to prevent defensive behaviour creeping in and the feeling of being neglected.

3.4.1.4 The Community Level: Retaining a Sense of Belonging to One's Social Networks

During cancer treatment, the social landscape surrounding the family changes. The psychological impact of cancer and the resources it demands intensify family bonds and heightens the search for fresh sources of input. The participants confessed that it was harder to maintain contact with friends and everyday life events because of frequent hospital visits and their friends' difficulty comprehending the situation. Some parents and survivors explained that their friends or close relatives just wanted to forget or avoid talking about the experience. The uneasiness that the children and their family members feel when trying to broach the topic of what is happening limits their actions, and the disconnection leads to feelings of frustration and loneliness (Last & Grootenhuis, 1998: 175).

However, during the conference, the participants did highlight two ways their social networks were expanding or becoming more consolidated. Some explained that their network had begun to include not only doctors, nurses, and fellow patients facing the same problems, but also new institutions, environments, and associations offering a safe space throughout a person's cancer journey. They suggested creating a group chat that could unite new friends together during hospitalisation, for example, to enable people sharing a similar trajectory in life and to keep in contact. Other participants noted that social media helped families to challenge the limitation of mobility associated with cancer and to also re-establish contact with old friends. Parents and teenage survivors presented blogs they used to keep their friends outside the hospital up-to-date during their cancer treatment and shared their experiences with children in treatment and their families in other countries.

3.4.1.5 The Sociocultural Level: Dealing with Social Stigma

The participants stated that, for most people, cancer still carries a social stigma. In spite of the medical information available on the topic and the increasing positive clinical outcomes, they explained that some parts of society find it difficult to perceive cancer as curable—or even as a viable topic of conversation. Some people still have difficulty saying the word 'tumour' or 'cancer' out loud. According to the survivors and their parents, people do not know how to broach the topic of severe illness diagnosis, a treatment for which the final outcome is uncertain, and in cases where long-term effects may emerge. The uneasiness coupled with the long-lasting condition often pushes people away (Armstrong, 2006: 23; Last & Grootenhuis, 1998: 175), frightens them, creates misunderstandings, and elicits pity, effectively isolating the sick child and his or her family. All the participants agreed that people generally harbour misconceptions about cancer and are not accurately informed about the disease. Even after treatment, when patients have been cured, people may still perceive them as needing special attention in certain contexts—at school or work, or at sports practice for example. For instance, one conference participant working as an English teacher in an elementary school revealed how important it is for professionals working in educational contexts to learn how to communicate with children in treatment while they are in school, and explain to their classmates what is happening in a careful, respectful, and understandable way.

The survivors communicated that once cured, they just wanted to go back to their normal lives. However, social stigma can inhibit them when they get back to normality, and in the long run, that limitation can lead to depression (Last & Grootenhuis, 1998: 175). In line with that need to express themselves and be treated as cancer-free, the survivors used photos, videos, and visualisations to express and visualise what they were going through during the conference. One of the facilitators, who was also a member of the survivors' community, proudly introduced her way of reinventing herself and her position in society including a website and fashion blog she developed to start her career as a youth influencer. In her presentation; she demonstrated how the experience of cancer did not stop her from reaching her career goals, cultivating her interests, and showing society how normal life can be after cancer. These examples show that it is possible to educate others about cancer, break down the stigma surrounding it, and enable survivors and their families to re-adapt to their lives in any way they wish.

3.5 Discussion: Strategies Towards Socio-Ecologically Informed Design for Sensitive Settings

The results reveal that cancer, a truly disruptive life event, has a contemporaneous impact on several levels—personal, interpersonal, familial, and societal. This section discusses how design practice in sensitive settings can be informed and enriched by applying insights from the healthcare field, exploring opportunities that emerge from this collaboration, and considering the benefit of introducing design as a lever for innovation in healthcare.

3.5.1 A Socio-Ecological Perspective to Introducing Design Practice in Sensitive Settings

The conference participants shed light on the emotional burden they carried and the struggles of living through changes that had altered their sense of normal life and attested to the importance of re-establishing this normality (Patterson, Holm, & Gurney, 2004: 390-407). The findings reveal that, apart from advanced medical treatment and psychosocial support, families and children who are experiencing (or have experienced) childhood cancer are looking for everyday ways of tactfully leveraging their internal resources (Steele, Mullins, Mullins, & Muriel, 2015: S585). Supporting families' internal resources means supporting relationships and social interactions among family members (Cox & Paley, 1997: 243-67).

To inspire designers' and design researchers' thinking about potential forms of support for family relationships and social interaction in light of the insights provided by Bronfenbrenner and Ceci's model (1994), this work suggests to look at the context from a broader, socio-ecological perspective that brings these social dynamics to the forefront. Design cannot influence a child's biological condition or the physical side effects generated by the treatment, but it can work on the proximal social elements that influence his or her development by supporting and nurturing the resilience of the entire family. Focusing on the family as a whole means creating opportunities to support the personal growth of each family member—by empowering them to be more supportive of themselves and one another when needed; finding ways to keep relationships alive and sustaining them; and raising their awareness about their strengths so they can harness these as resources for the future (Alderfer & Kazak, 2006: 56).

3.5.2 Socio-Ecologically Informed Design Opportunities

Interesting design concepts can potentially address family needs at different systemic levels (D'Olivo, Rozendaal, & Giaccardi, 2017: 943-55). However, for a solution to be effective in the short term and have a direct impact on the family's well-being, it should be designed to work within the child's immediate environment at the levels of self and family (in Bronfenbrenner and Ceci's model (1994), these are levels 1 and 2). The design should encourage and inspire family members in a tactful, personal, and attentive way. According to the findings, children with cancer and their family members use social engagement and communication as coping mechanisms to help them relax and remain optimistic (Christiansen et al., 2015: S726; Grootenhuis & Last, 2001: 74-75). To shape designs capable of appropriately facilitating these coping processes and carefully inviting and enabling families to develop the skills they need to recreate a normal family life, designers should introduce these coping mechanisms into their design solutions (Massimi et al., 2012: 723).

First of all, to re-establish normality requires any design initiative fostering positive thinking, which is an important element in cognitive behavioural interventions (Phipps, 2006: 93). Moreover, communication keeps a person apprised of what others are doing and at the same time offers a way of bonding (Grootenhuis & Last, 2001: 74). It follows that interactive product designs may be a sensitive way to encourage family members to openly talk to each other. Finally, simple everyday interactions and rituals can be a distraction for the family and can also stimulate a child's development and curiosity (Santos, Crespo, Canavarro, & Kazak, 2015: 664). Sharing special moments together is key to maintaining healthy connections

among family members, because family life is based on shared routines and habits. Therefore, bespoke products could be a means of gently helping those families to continue doing things together (Kirk, Chatting, Yurman, & Bichard, 2016: 2474-86).

3.5.3 Design as a Lever for Healthcare Sector Innovation

Knowledge from the field of developmental psychology was used, in particular Bronfenbrenner and Ceci's model (1994), to expand on the scope of the research into the childhood cancer experience and help in better organising the complexity it presents (Kazak & Noll, 2015: 149-51). Moreover, as design research can benefit from knowledge coming from the healthcare field, psychosocial cancer care—and healthcare research and practice more broadly speaking—can benefit from these findings too. By detailing opportunities for action in the field and introducing alternative approaches to establishing rapport with vulnerable populations, design research can provide valuable alternatives for actors in sensitive contexts (Thieme, Balaam, Wallace, Coyle, & Lindley, 2012: 789-90; Vines et al., 2014: 44-46). Design can support novel ways of conducting research and intervention projects (Thieme et al., 2014: 139-42). Design can also work as a lens through which experts from multiple fields can look at the same context and understand each other (Liu, Inkpen, & Pratt, 2015: 1530-36). Design can pinpoint areas of intervention for people experiencing life disruptions by seeking out their opinions in less standardised ways (Jeong et al., 2008: 3227-29). Finally, designers can create interactive products that can also be used to help researchers from different disciplines and healthcare professionals engage and empathise differently with children and their family members (Liu, 2014: 258-59; Liu et al., 2015: 1534).

3.5.4 Benefits and Limitations

Although the observation process was quite challenging for the design researcher, the experience enabled her to gather compelling and detailed real-world data that would have been difficult to obtain otherwise. After becoming better acquainted with the topic by reading the literature and holding meetings with clinical experts, she gained first-hand experience with the overwhelming nature of the context (Dickson-Swift et al., 2008: 33-54). At first, she felt as though she was invading what appeared to be a close-knit, private network. The community seemed to have its own rules and dynamic. For instance, most of the survivors were used to introducing themselves with their name followed by the type of cancer they had. This way of identifying themselves demonstrated how differently they engaged in any form of conversation with strangers at the event. Internal dynamics such as these, indirectly impacted the design researcher's conversational sensitivity over the course of the event. In fact, she was indirectly reminded of how challenging the everyday life experience of the survivors was compared to her own with every interaction she had with them. Therefore, even if the participants felt comfortable talking about their conditions, she painstakingly chose her words during every single conversation to avoid sounding impolite or intrusive.

Involving more researchers, and researchers with different backgrounds, to perform the data collection could have had both positive and negative outcomes. On one hand, the data collection would have been performed by multiple subjects and therefore objectively validated in the field. Furthermore, multiple researchers could have supported each other in overcoming personal inhibitions due to the sensitive topic. For instance, the presence of researchers with a background in psychology would have been supportive for a researcher with a design background which could perhaps be less professionally equipped for when emotional or stressful situations arose. On the other hand, the presence of more researchers at the same event could have been perceived as overwhelming and intrusive and could have also inflicted on the participants' engagement and comfort level during the conversations. The participants would have needed to build trust and learn to feel at ease with an entire group of new people external to the cancer community, and continuously adapt to a different level of sensitivity and empathy in each interaction with the different researchers.

This event was a valuable opportunity to gather information about childhood cancer experiences that was beyond the clinical data provided by experts or found in the literature. This approach did not place families and their children under the focus group spotlight or ask them to undergo long personal interview sessions. Instead, the design researcher stepped out of her comfort zone, and in doing so demonstrated her willingness to earn acceptance into their tight community (Dickson-Swift et al., 2008: 40-41). To gain their trust, she had to clarify and explain her purpose and be completely transparent about herself. Knowing that the survivors' perceptions and responses may very well have been different with another person, the conference parental association members and workshop facilitators were asked for feedback regarding the analysis. In this way, the hope was to acknowledge any potential bias and further validate the findings.

Finally, it is important to note that this exploratory work was conducted among survivors of childhood cancer, including family members, volunteers, and healthcare professionals. The design researcher and her supervisors are aware that this population does not necessarily reflect the demands of children currently undergoing treatment, and the unmet needs of their families in general. In fact, it was found that cancer survivors and their parents had quite different recollections of how they experienced coping with cancer. This implies the necessity of considering the individual characteristics and behaviour of survivors and their families to help interpret their past experiences. Future research would benefit from the participation of families that currently have a child undergoing treatment for childhood cancer and of children in the age range of interest.

3.6 Contribution and Future Work

This research was based on qualitative data collected by observing and engaging with childhood cancer survivors and their families at a large support group conference. In this chapter, the experiences participants shared were categorised into five challenges that together create a picture of the complex personal and familial challenges of coping with childhood cancer: accepting the transformation of one's body, avoiding avoidance, maintaining interest in social activities, retaining a sense of belonging to one's social networks, and dealing with social stigma. The five themes also describe coping strategies that emerge when people deal with stressful disruptive life events (Last & Grootenhuis, 1998: 175). The themes were matched to the levels of a model adopted from developmental psychology to better articulate their interdependencies and associations with levels of individual, familial, and social experience. Although medical studies on psychosocial support in childhood cancer have used this model before, to the best of the researcher and the researcher's supervisors' knowledge, no other study has used this model to explore design opportunities for novel and sensitive forms of support that both address the population's unspoken needs in a tactful way and address the family collectively. The main contribution is an understanding of how insights from developmental psychology can help to simplify and disentangle the complexity of a sensitive context. This preliminary inquiry also serves to frame a new perspective from which to identify design opportunities that can profoundly and effectively address the needs of the family system in its parts and as a unit.

It is expected that the field of design can add to the support and sense of empowerment felt by these families and, more generally, provide a lever for innovation in sensitive settings. With these initial reflections in mind, the hope is to see designers developing designs capable of nurturing the family as a whole and also involving families directly in the design feedback loop. The optimism that is wished to be promoted with this work can be stimulated by introducing playful yet tactful products that capture the interest of different family members and spur their interactions with each other. Future work in line with the socio-ecological perspective explored here can be relevant and broadly applicable to other contexts where disruptive life events cause dysfunction within families. New opportunities for innovation

can spring from the way that sick and vulnerable users are engaged in research. Interaction design can be used to tackle disruption through approaches that ask different disciplines to collaborate. In terms of paediatric oncology, for example, such methods will enable design and technology experts to better understand how best to strengthen family ties and empower families to explore and create their new normal. In light of the findings and these conclusions, the design researcher has already begun to design interventions for families dealing with childhood cancer.

Chapter's Takeaways

Childhood cancer is a disruptive life event that has effects on the family as a whole;

Bronfenbrener & Ceci (1994) bio-ecological model used in Developmental Psychology is a valuable tool to map out the biological and social complexity and the systemic interrelations influencing children's development during childhood;

When families are confronted with childhood cancer, the medical aspect of the diagnosis typically consists of five phases (i.e., the pre-diagnosis, diagnosis, treatment, follow-up, and the late-effects screening phase). During this process, the families need to develop coping strategies and resilience to deal with several stressors and changes in their everyday routines;

From the first field study it emerged that: (i) working on self-esteem helps cancer patients in strengthening a sense of confidence; (ii) communication is vital, patients and family members need to share their emotions, (iii) engaging in activities with close social networks instil hope and relaxation (iv) during cancer treatment, the social network of reference for the family changes, and (v) society must be educated about cancer to reduce the stigmatisation of cancer survivors;

Implementable design solutions, capable of offering support to children and family members and influence the child's development during cancer treatment, could focus on tactfully preserving space for quality time and communication when the family is at home.

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4
TACTFULNESS: THE DESIGN QUALITY OF OBJECTS FOR SENSITIVE SETTINGS

Partially based on published conference pictorial: D'Olivo, P., Rozendaal, M. C., & Giaccardi, E. (2017, June). AscoltaMe: Retracing the Computational Expressivity of a Tactful Object for Sensitive Settings. In *Proceedings of the 2017 Conference on Designing Interactive Systems (pp. 943-955).*

Introduction

The power of objects lie in their quality of being, as Latour notes, *"matters of concern"* around which people gather (Latour, 2008). By being part of our daily lives, objects gain a certain role (Desjardins & Wakkary, 2013) and adapt to being incorporated into our everyday routines (Giaccardi, 2015). If computation is then used to imbue objects with intent, they turn into entities capable of steering unhealthy habits towards healthy ones, or daringly propose new perspectives on ourselves and the life we live (Cila et al., 2017; Marenko & Van Allen, 2016; Rozendaal, 2016). This chapter considers the expressivity of objects with intent in sensitive settings and retraces the process and rationale behind the material qualities and temporal form of Mr.V and AscoltaMe, two objects designed to trigger interaction and open up communication in families dealing with childhood cancer. In doing so, the chapter introduces and visually outlines *tactfulness* as the fundamental characteristic that enables objects designed for sensitive settings to be considered objects with intent in ways that are appropriate and sensitive to the situation (Crabtree et al., 2003; Vines et al., 2014).

Motivation and Contribution

When designing an object, its embodiment always needs to be carefully articulated (Gaver, 2002). Objects are assessed and integrate into our lives on the basis of how useful and valuable they are, and this is often a matter of functionality and style. However, when objects gain autonomy, intention and inner life through computation (Rozendaal, 2016), the way their expressive features are materialised significantly influences the way in which the objects are accepted and interacted with—in other words, how they engage with the user. Here, *tactfulness* is proposed as a fundamental characteristic of how an object designed for sensitive settings expresses consideration for the specific context and situation users are dealing with. Designing for *tactfulness* means crafting the features of the object so that it is discreet rather than pervasive (Turkle, 2007), diplomatic in ways that offer possibilities to discern and build trust (Donovan & Gunn, 2012), and consistent in the way it helps maintain a sense of 'normality' and continuity in everyday life (Massimi et al., 2012). This chapter examines how *tactfulness* is embodied and expressed, which determines how the object will likely integrate into the user's context and play a role in his or her daily routines (Jung & Stolterman, 2012; Löwgren, 2016)— thus, how it accomplishes its intent. Understanding how to design for *tactfulness* offers new opportunities for both Human-Computer Interaction (**HCI**) researchers working in sensitive settings (Crabtree et al., 2003; McNaney et al., 2013; Thieme et al., 2014; Vines et al., 2014) and interaction designers interested in objects with intent (Cila et al., 2017; Marenko & Van Allen, 2016; Rozendaal, 2016).

Visual Strategy

The visual narrative of this chapter focuses on the vision, development and choices of material qualities and temporal form that led to designing Mr.V and AscoltaMe. This research into *tactfulness* is introduced by visuals on initial experiments and the first versions of the devices, and then articulated to the design choices that specifically led to the embodiment and computational expressivity of Mr.V and AscoltaMe. This chapter does not account for interaction qualities; these have been left intentionally under-designed and will be integrated in the tactful design of the two objects after the field study presented in Chapter 5. All the design choices made are articulated according to the 'Materials Experience framework' (Giaccardi & Karana, 2015) and 'temporal form' (Vallgårda et al., 2015) for computational objects. Through this visual strategy the intent is to illustrate how *tactfulness* has been embodied in Mr.V and AscoltaMe and speculate how the materiality and expressivity of these *tactful objects* may contribute to their intent in sensitive settings which require empathy and care.

Facilitating Interaction and Communication in Families Dealing with Childhood Cancer

The term interaction, in this work, is a reference extending to the collective shared activities and rituals that as a *"symbolic form of communication"*, contribute to the family members' experience of everyday life. Essentially rituals are characterised by their repetition, acted out in a systematic fashion over time (Kirk et al., 2016). According to the literature, rituals and leisure activities, help family members in preserving a sense of normality and control in everyday life by preserving healthy behaviour in particular, and providing distraction and cohesion (Zabriskie & McCormick, 2001). During disruptive life events such as illness or divorce, new obligations and changes regarding living situations can generate difficulties and challenges disrupting the

normality which preceded it. In these situations, objects can play an important role (Kirk & Sellen, 2010), as they might trigger and remind family members to preserve interest in family rituals in a playful and *tactful* way.

While talking about communication, it is not defined as simply as the transmission of information from a sender to a receiver. Communication is considered rather as a collaborative sense-making activity that is vital in maintaining social relationships (Liu et al., 2015; Vetere et al., 2005). Communication is critical for healthy relationships particularly within families. This in turn translates into healthy routines and lifestyles (Minuchin, 1988). However, during disruptive life events, an overload of emotions and vulnerabilities can generate communication barriers that significantly disrupt normal family life. Also, in these situations, computational objects can play an important role, as they may open up new ways of communicating that are less confronting and more *tactful*.

The design of *tactful objects* in this context aims at providing an appropriate, sensitive, and discreet means for reconnecting people in close relationships when these get disrupted by uncontrollable events (Massimi et al., 2012)

Designing Tactfulness

The objects that are presented in this chapter are inspired by work on everyday computational objects like 'Ritual Machines' (Chatting et al., 2017; Kirk et al., 2016), and 'Transformational Products' (Kehr et al., 2012; Laschke et al., 2011), and on artefacts tangibly exploring the concept of slow technology such as 'Photobox' (Odom et al., 2014) and 'Slow Game' (Odom et al., 2018) (***some examples of such artefacts are presented in this overview***). These are all interesting and playful research prototypes developed for domestic and/or family everyday contexts. Through their computation, these objects are capable of triggering awareness, connection and humour; therefore, becoming interesting references to develop designs for the needs of families dealing with stressful events (such as families with a child diagnosed with cancer).

Ritual Machines

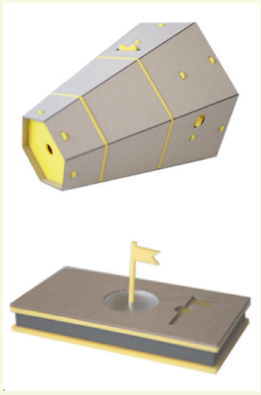


(credits: Yurman et al., 2015: 2, Fig.4)

RITUAL MACHINE IV
'A message in a Jam'

'A Message in a Jam' is a bespoke machine, that extends from an existing ritual of gift giving through the delivery of audio messages when family members are physically separated.

The object consists of two components: a jam container and a portable speaker bag. A 'Message in a Jam' allows the family at home to leave messages for the mother who is used to travel frequently for work in her lorry. Messages are spoken into a jam jar by removing the lid and played remotely in the mother's lorry cabin through a connected speaker but only when she is 'stuck in a traffic jam' (Yurman et al., 2015).



(credits: Chatting et al., 2017: 441, Fig.6)

RITUAL MACHINE V
'Where are you?'

'Where are you?' is a bespoke machine that creates a ritual of location sharing and reflective discussion for parents frequently separated from their children.

The machine is a telescope that allows the child to explore an illustrated world map in search of the flag which their parents have placed somewhere on their travels. By moving the telescope in different directions and by zooming in and out with a wheel, the whole map can be explored. Inside the child sees an illustrated world showing towns, cities and landmarks. When parents go away they take a second device that allows them to plant a flag wherever they go - as a digital totem. This flag will appear in its correct place in the telescope world (Chatting et al., 2017).

Transformational Products



(credits: Kehr et al., 2012; www.pleasurabletroublemakers.com/#/the-chocolate-machine/)

‘Chocolate Machine’

The ‘Chocolate Machine’ continuously confronts its user with temptations.

The ‘Chocolate Machine’ is a slender container, which is filled with wrapped chocolate balls. It is based on a theory called ‘Ego Depletion’ focused on self-control and willpower. This machine is positioned on a desktop and releases a chocolate every hour. The person can either eat the chocolate ball or put it back into the container. A counter registers the number of times the chocolate is put back (Kehr et al., 2012).



(credits: Laschke et al., 2011; www.pleasurabletroublemakers.com/#/keymoment/)

‘Keymoment’

‘Keymoment’ translates the concept of ‘choice’ in a tangible way.

It is a minimalistic key holder for the family home based on the ‘Aesthetic of Friction’. The object holds both car keys and bike keys. If the bike keys are taken nothing happens. In the case that the car keys are taken, the object throws the bike keys to the ground. The bike keys can always be put back on the hook. Once a decision has been made, the object ‘accepts’ it and holds the bike keys again if they are not being used, until a key is removed from the keyholder again (Laschke et al., 2011).

Slow Technology

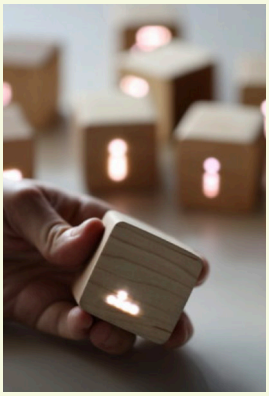


(credits: Odom et al., 2014; willodom.com/portfolio/portfolio/field-study-of-photobox/)

‘Photobox’

The ‘Photobox’ project explores how slowing down digital photography could create an interactive pace that encourages anticipation, reflection, and long-term interaction.

‘Photobox’ is a domestic technology embodied in the form of a networked oak chest that autonomously prints selected photos from its owner’s Flickr collection randomly each month, without any control from the owner (Odom et al., 2014).



(credits: Odom et al., 2018; willodom.com/portfolio/portfolio/slow-game/)

‘Slow Game’

The ‘Slow Game’ project helps in ‘grappling’ with the concept of slowness and temporality.

The game consists of a set of small 5cm cubes, with a low resolution display consisting of 64 tiny white lights. The game is based on the video game ‘snake’, where the player manoeuvres a line which grows in length around a screen with the line itself being a primary obstacle. The game is based on the game of playing Chess with a remote opponent. Here, the game is played by physically rotating the cube, which turns the direction in which the snake slowly moves (Odom et al., 2018).

The Making of Mr.V

Mr.V (Mr. Verrassing which means 'Mr. Surprise' in Dutch), is an object with the purpose of being introduced into the common spaces of a house as a little family companion. It is imbued with the intent of stimulating and triggering disrupted families in doing more things together. It resembles a 'gumball vending machine' but the large transparent head is used to collect little containers with notes for everyday activities instead of sweets. Other elements such as the frontal lever and the top part are used as decoration to provide character to the object, presenting Mr.V with a little bow tie and a bowler hat. The notes in the containers are personally written by each family member, and describe activities and compliments that they want to share together. The containers are then added manually to the object from the hole in its 'hat'. Mr.V comprises of an internal clock which randomly decides when to share the surprise containers with the family during the week. When Mr.V 'thinks' that it is time for a bit of distraction it will start shuffling the containers with the notes and making sounds to invite the family to check which surprise is waiting for them. A small button on the back of the object offers the possibility of activating the device and receiving a surprise at that given moment also.





To visualise the *tactfulness* of Mr.V, the next pages provide an overview of the prototype development, a scenario of use and finally five main design features. The modalities of embodiment and expressivity of each feature are explained with reference to the 'Materials Experience framework' (Giaccardi & Karana, 2015) and 'temporal form' (Vallgårda et al., 2015) for computational objects. Each of these features represents a decision point in the design process concerning material qualities and temporal form.

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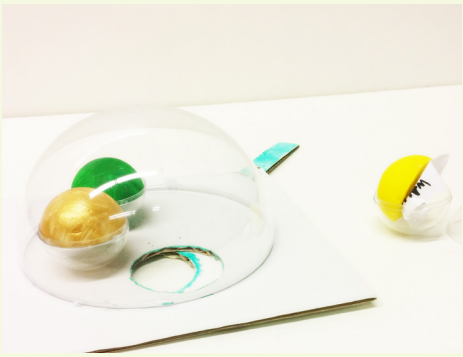
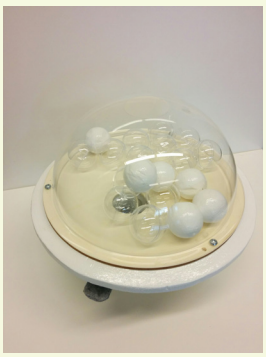
Kanjerketting by VOKK (credits: www.kanjerketting.nl/)

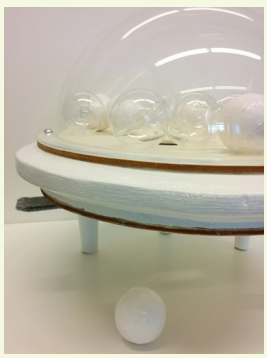


Chemo-Kasper by VOKK (credits: vokk.nl/)

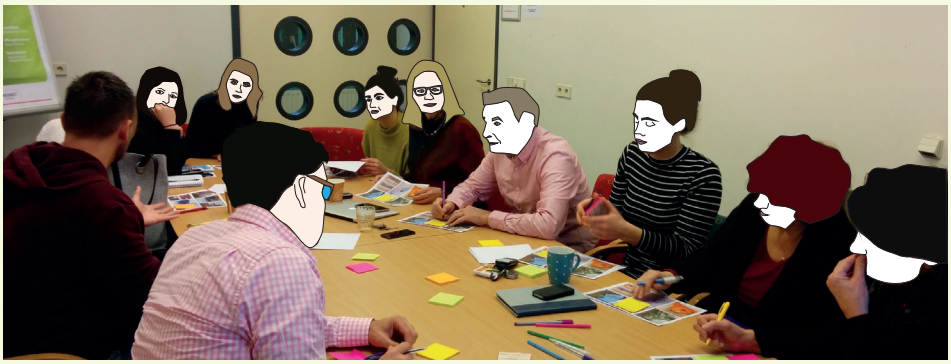


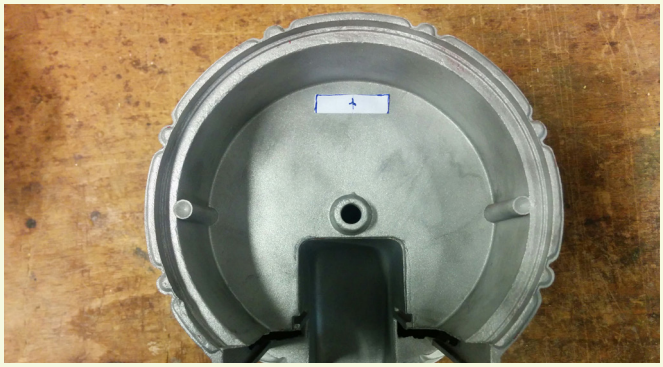
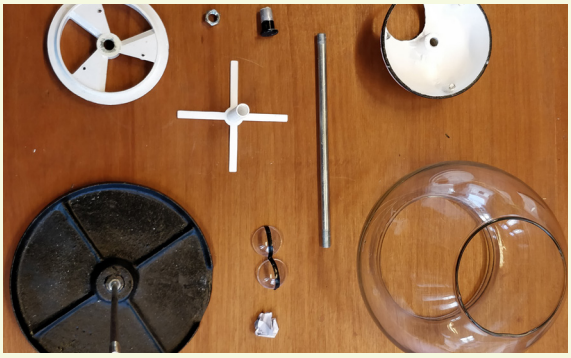
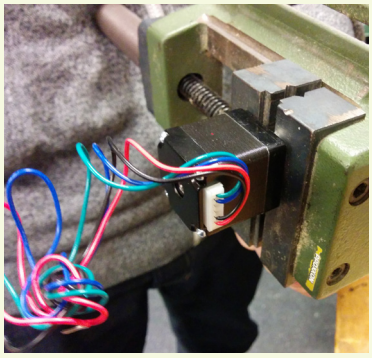




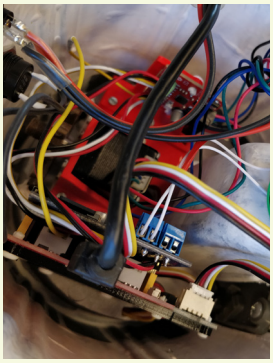
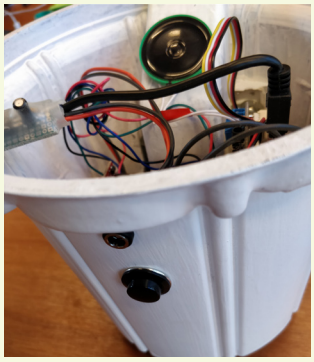






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in de stad






EDITION LIMITEE






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Affective Level

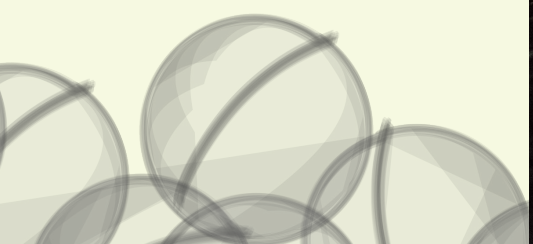
HOW DOES TACTFULNESS MAKE ONE FEEL?



A Childhood Memory

Mr.V was designed and built by hacking a real 'gumball vending machine'. The explicit aesthetic of Mr.V resembling the iconic container where a little knob when turned drops a small surprise or sweet, was chosen as a tangible representation of the concept of surprise. By using this metaphor, the object tactfully intends to capture the interest of family members of different ages and encourages them to engage as it sparks their curiosity (e.g., in sick children and their siblings) or because it taps into memories of the past (e.g., in parents).

The sense of curiosity and childhood memories that are embodied and visually expressed by the look of the object are the affective features through which the object tactfully intends to capture the interest of the various family members and find a space in their everyday rituals.





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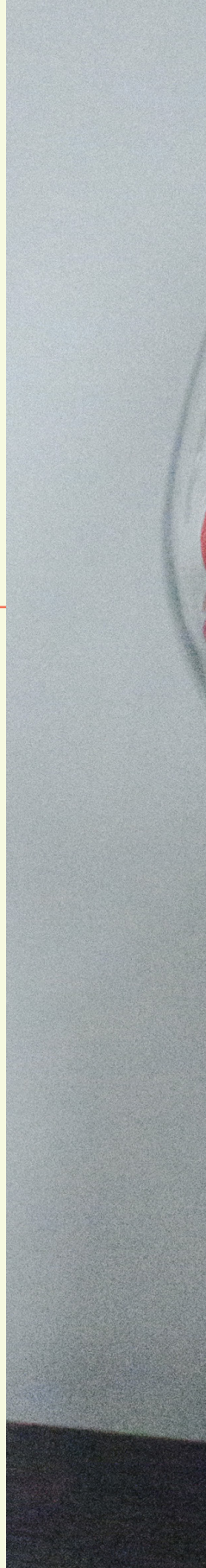
Sensorial Level

WHAT DOES TACTFULNESS FEEL LIKE?

Traditional Materials and Details Conveying Character

The object consists of a robust and stable metal structure which is easy to create space for on a table or a piece of furniture. The upper part of the object body is made of glass and is anchored to the metal part at the bottom with a metal cap held together by a central screw. The metal cap is opened at the top to insert the plastic containers holding the surprise notes. The humanoid shape (i.e., head and body) and the details of the object (i.e., the frontal knob turned into a little bow, the metal cap turned into a bowler hat) have the purpose of conveying character. The strong and stable materials of which the object is made have the purpose of conveying trust in a sensorial manner, while the humanoid shape and details enable Mr.V to tactfully turn into a little family companion.

The see-through head here is the way in which Mr.V wants to 'transparently' provide information to families about what they can expect from him, metaphorically speaking. Impalpable ideas and rituals that are part of a family's routine, are 'tangibly captured' so they are not forgotten and visibly presented to families in their private space. By turning notes and activities into playful surprises in containers, the burden of taking care of such important parts of family life is tactfully facilitated in a light and positive way. These activities which are normally scheduled in a calendar and adapted to fit into one's daily routine 'only when it is possible' are catered for in this way.





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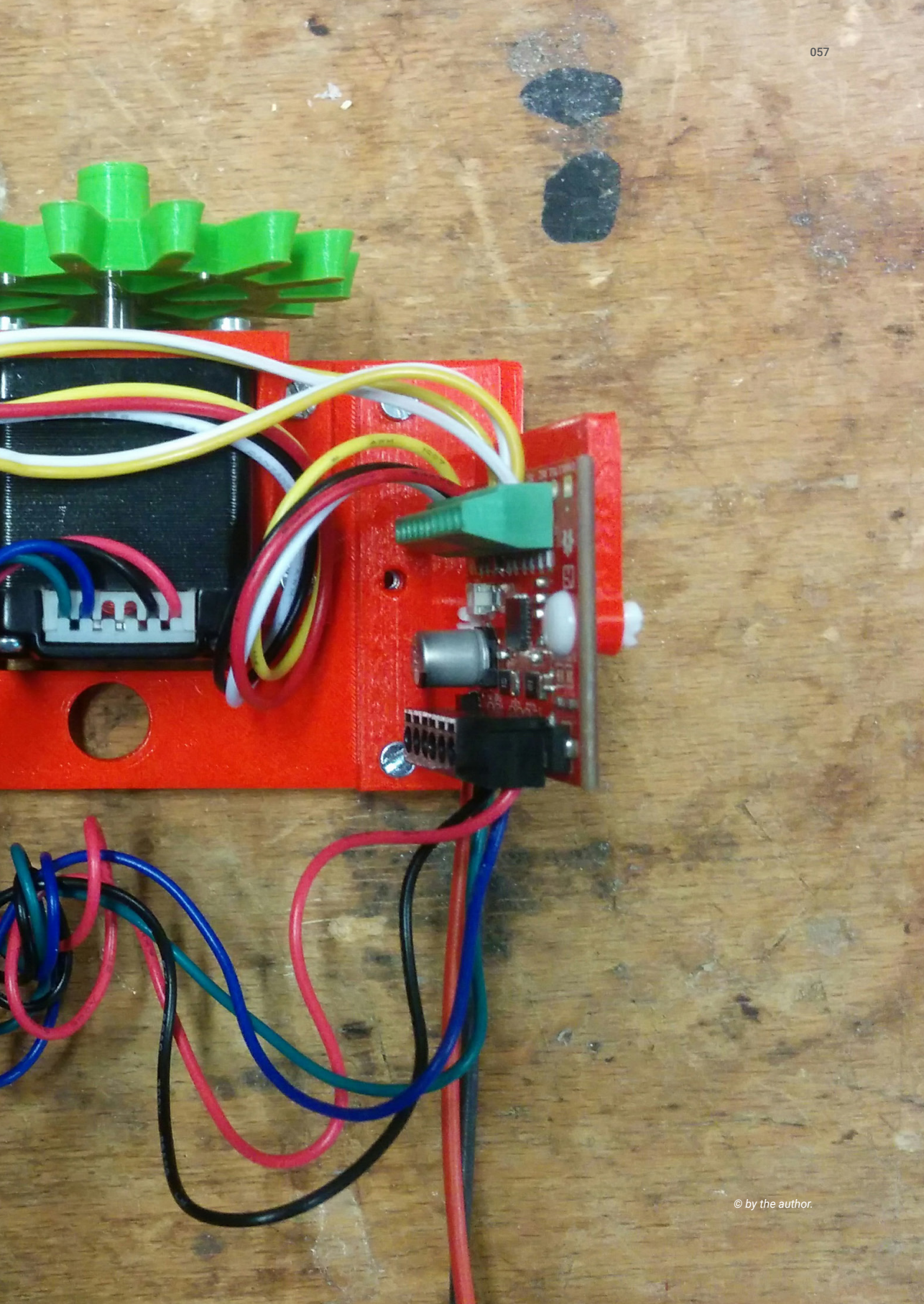
Interpretive Level

HOW DOES TACTFULNESS SPEAK TO US?

Sparkling Lights and Cheerful Sounds

The object functions given Arduino boards comprising of a timer, a loudspeaker, LED lights and a mechanical wheel. As soon as the machine is plugged into the socket, the timer activates the 'surprises schedule' and the containers get dropped randomly during the week. When the machine is about to drop a container it starts to shuffle the plate where the containers are lying. When the moment is right, the wheel turns to drop a surprise, colourful lights start to sparkle and a funny sound is emitted to indicate that the surprise has dropped and is ready to be collected and opened.

Once plugged in, the device becomes alive and ready to accommodate the family in a cheerful way. The family's attention is tactfully captured through visual and sound outputs. Mr.V tactfully expresses the presence of a new activity that is awaiting the family, but it leaves the family free to accept it or discard it according to their preferences without creating any further stress.



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Performative Level

WHAT DOES TACTFULNESS MAKE ONE DO?

A Little Companion Providing Gifts

The object finds its place in one's home. It is designed to fit into the common spaces of a house where it can be seen and used by different family members at the same time. Its playful appearance stands out in the environment as if another member of the family were physically there as company in the background, while triggering attention through sound and lights when necessary. Its appearance is not too childish or too serious in order to respond to the preference of all family members. By blending into a family's environment Mr.V helps in maintaining a sense of continuity and normality in a family's everyday environment.

The peculiar identity of Mr.V as a companion that provides gifts to the family, enables family members to feel the need to physically wait and it builds up excitement while waiting for the next surprise. This helps maintain a sense of continuity and normalcy in the interaction of family members because the family is tactfully stimulated in being there and participating in activities together.





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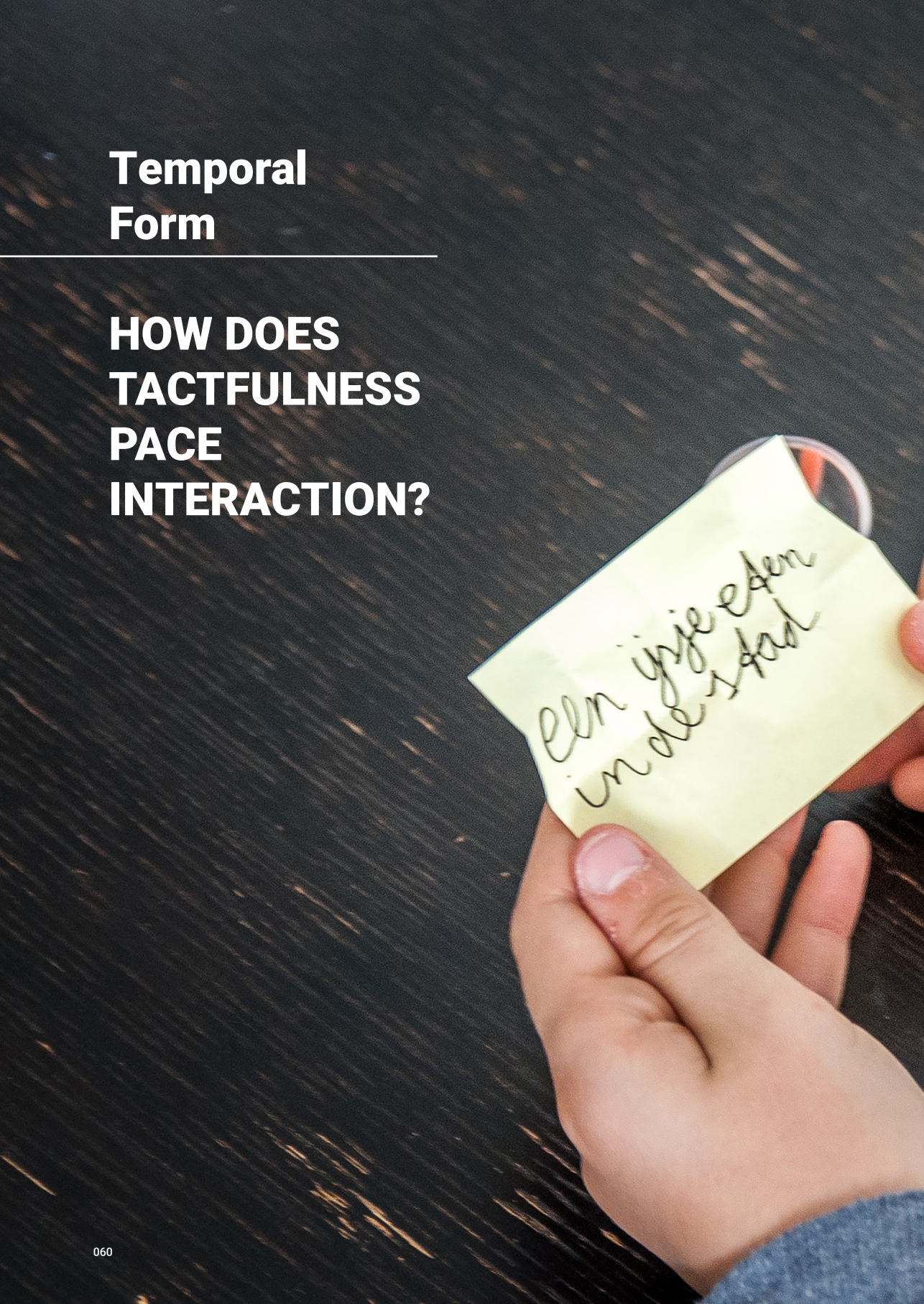
Temporal Form

HOW DOES TACTFULNESS PACE INTERACTION?



Timely ‘Ideas in a Ball’

The object’s scheduled behaviour turns into a gentle reminder for the family to cherish their quality time together. Mr.V uses an internal clock to provide surprises in a timely manner when the family does not expect it and this gives them a sense of motivation every day. Mr.V acts in the background and moves to the foreground only when it is time to trigger the family’s attention without causing stress.

This daily ritual of actions are sounded and are visually striking given sound-light-dropping mimics, a combination of a schedule in a calendar and the alert of a clock in a playful way. The users can then tactfully connect the ‘gift’ provided by Mr.V to the reminder that it is important to be conscious of spending time together and share joyful moments especially in difficult and stressful times.



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The Making of AscoltaMe





AscoltaMe (translated from Italian as 'listen to me') is an object with the purpose of being casually held, taken along with you and left around the house. It is imbued with the intent of encouraging disrupted families to talk about their feelings, worries and hopes. Its translucent body presents two elements: a microphone and a loudspeaker connected via a flexible silicon tube. The microphone captures messages that family members want to share and 'holds' them in the tube. These messages linger in the tube until someone decides to listen to them. Voice messages are made visual as light. While speaking, the light begins to fill the tube. Once a message has been sent, the light remains in the tube. The light lingers and pulsates, indicating that AscoltaMe is patiently waiting to share its message with others. 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 released and listened to, the light and the message will return back into the tube and will remain there until the message is listened to in full.

To visualise the *tactfulness* of AscoltaMe, the next pages provide an overview of the prototype development, a scenario of use and finally five main design features. The modalities of embodiment and expressivity of each feature are explained with reference to the 'Materials Experience framework' (Giaccardi & Karana, 2015) and 'temporal form' (Vallgårda et al., 2015) for computational objects. Each of these features represents a decision point in the design process concerning the material qualities and temporal form.

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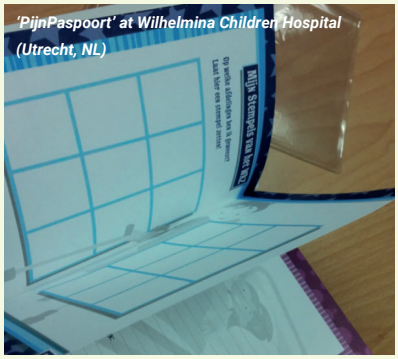
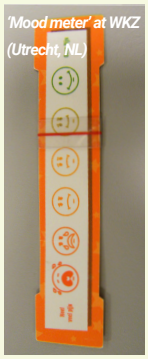
'Wishes wall' at Emma Children Hospital (Amsterdam, NL)

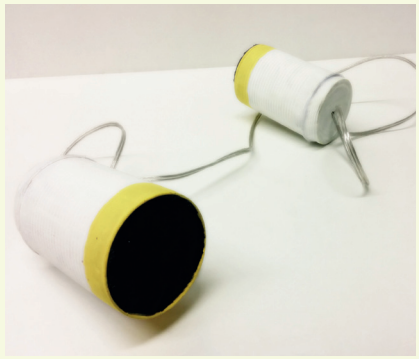


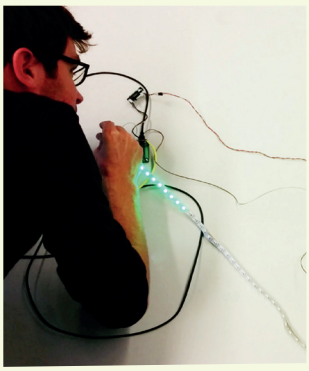
'PijnPaspoort' at Wilhelmina Children Hospital (Utrecht, NL)

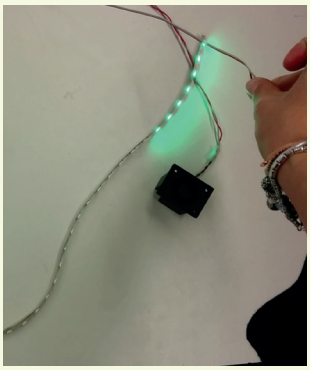


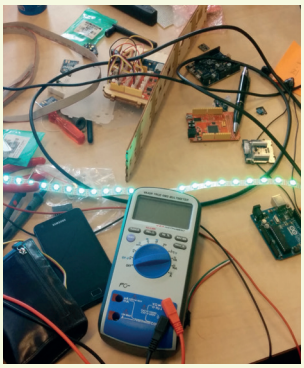
'Mood meter' at WKZ (Utrecht, NL)

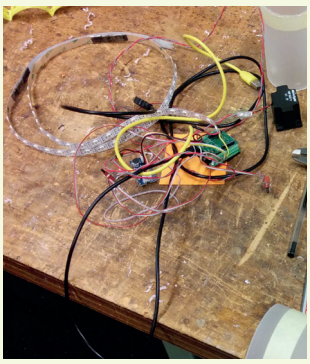


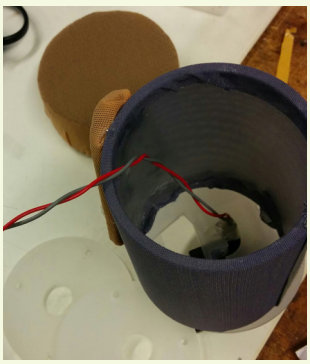


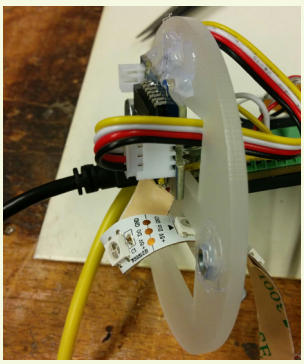


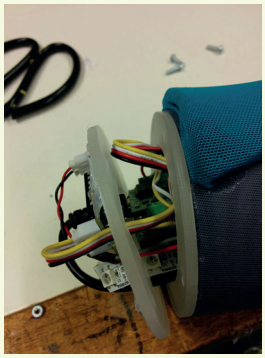




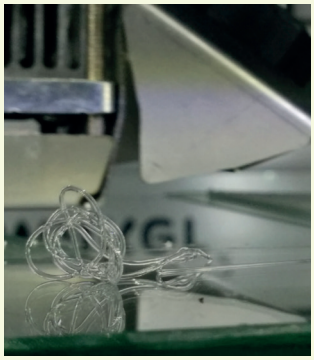
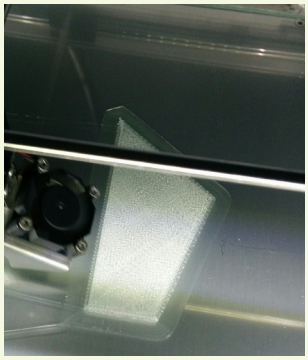
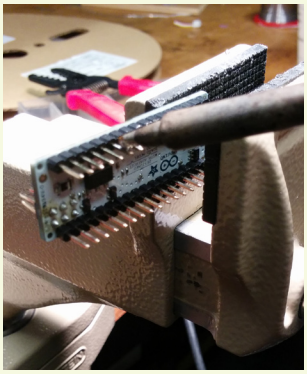
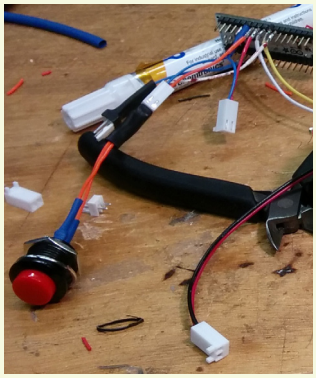
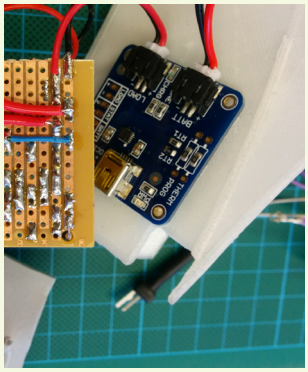
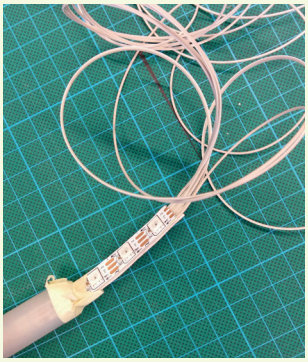
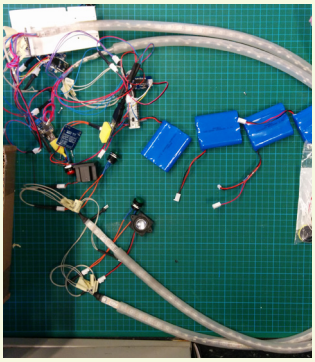
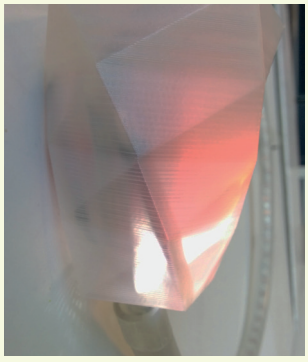










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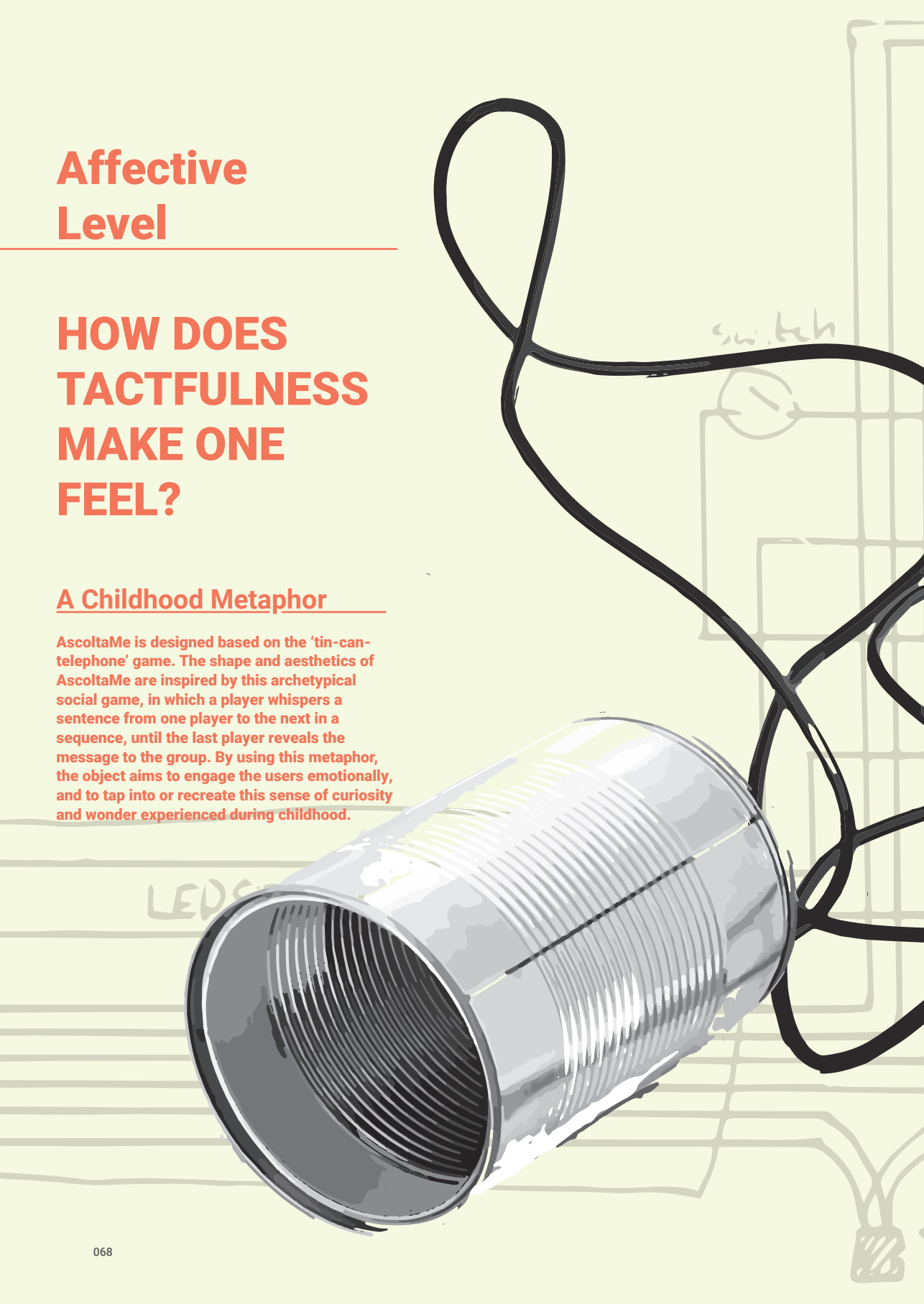
Affective Level

HOW DOES TACTFULNESS MAKE ONE FEEL?

A Childhood Metaphor

AscoltaMe is designed based on the 'tin-can-telephone' game. The shape and aesthetics of AscoltaMe are inspired by this archetypical social game, in which a player whispers a sentence from one player to the next in a sequence, until the last player reveals the message to the group. By using this metaphor, the object aims to engage the users emotionally, and to tap into or recreate this sense of curiosity and wonder experienced during childhood.



The gentle sense of curiosity and childish wonder that is embodied and metaphorically expressed by the way the object looks, are the affective features through which the object tactfully intends to capture the interest of different family members and encourage them to engage.





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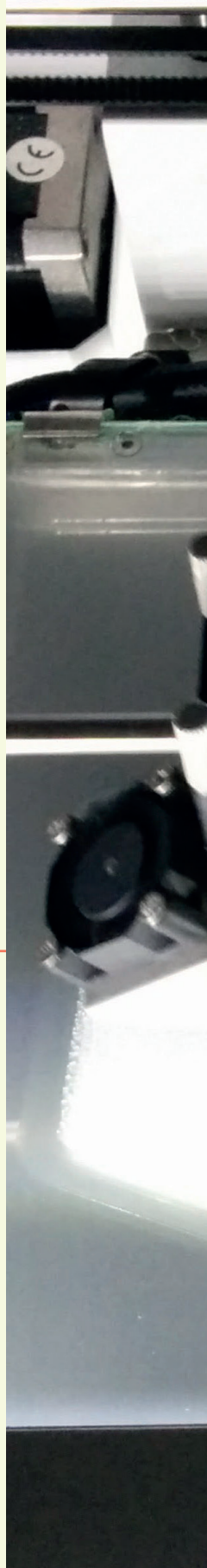
Sensorial Level

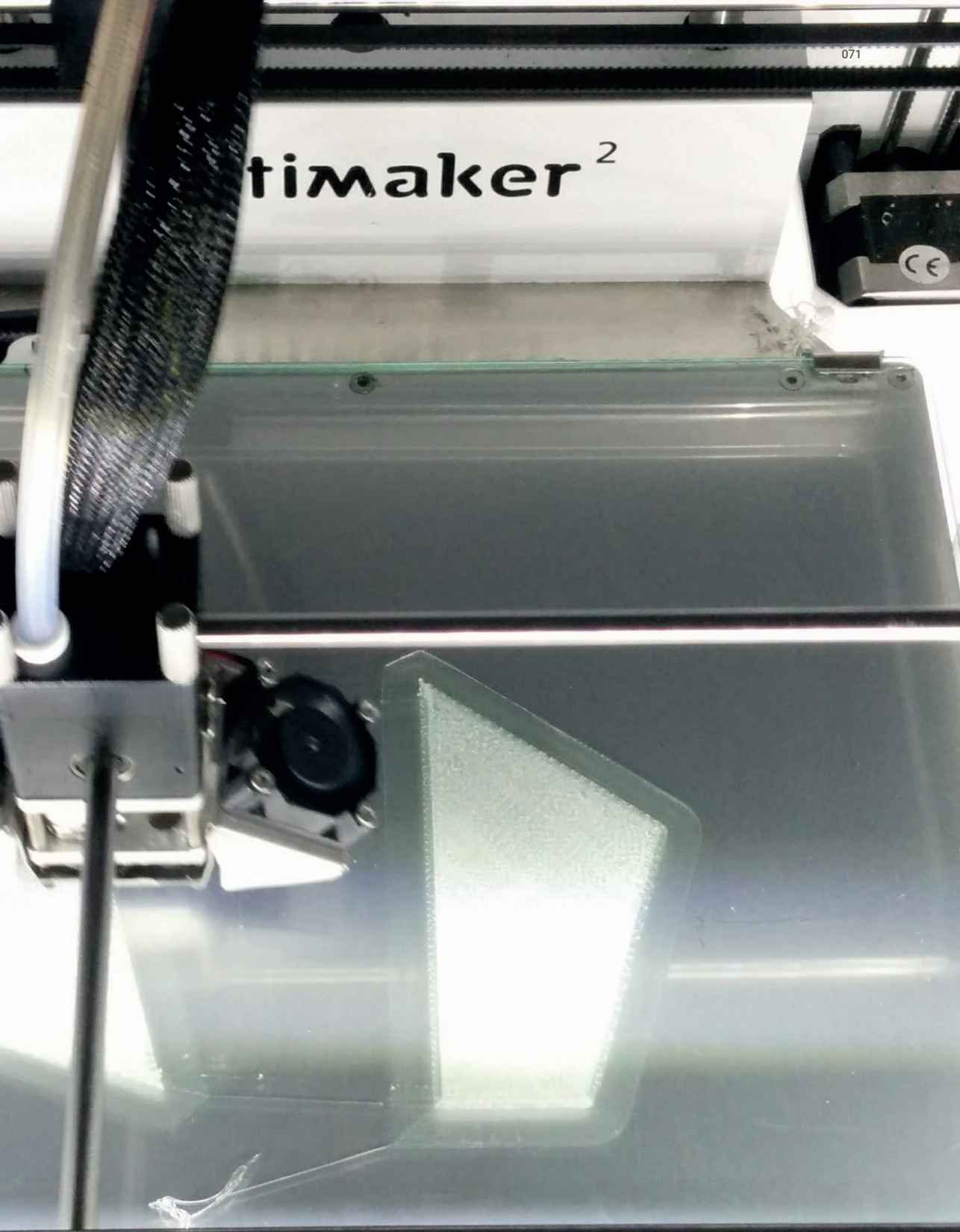
WHAT DOES TACTFULNESS FEEL LIKE?

3D Printed Translucency

AscoltaMe is made of a solid and flexible body designed to be easy to hold and take along with you around the house. The body of the object is divided into two main elements: the delicate 'shells' casted via 3D printing, and the 'connector' consisting of a sanded silicon tube. Through these translucent material elements, the object communicates trust in a sensorial manner, neither masking nor showing off its electronic core.

The translucency of the object (mimicking transparency in communication) purposely gives AscoltaMe the expression of an open yet trustable character. This designed transparency allows one to capture and tactfully materialise traces of impalpable words and thoughts. By turning them into light, their heaviness and difficulty is diminished and pondered upon in a different way.





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Interpretive Level

HOW DOES TACTFULNESS SPEAK TO US?



Sensitive Bits

Arduino™ boards, batteries, a loudspeaker and a microphone make up the circuitry that brings AscoltaMe to life. When the red RECORD button is pressed, a message is recorded. The red light indicates that the recording is in process. As the light moves towards the centre, the red light turns into a brighter white light, expressing the absence of sound because the message is 'lodged in the tube' but safely contained. When the message is 'lodged', AscoltaMe continues breathing patiently, expressed by a slowly pulsating light, like a heartbeat. When the green PLAY button is pressed, the white light turns into a green light to indicate that a channel of communication has been opened.

Through a subtle expression of its functionality, AscoltaMe tactfully expresses the presence of words and thoughts that are waiting to be listened to, sensitive not to cause inappropriate distress in an environment which is already tense.

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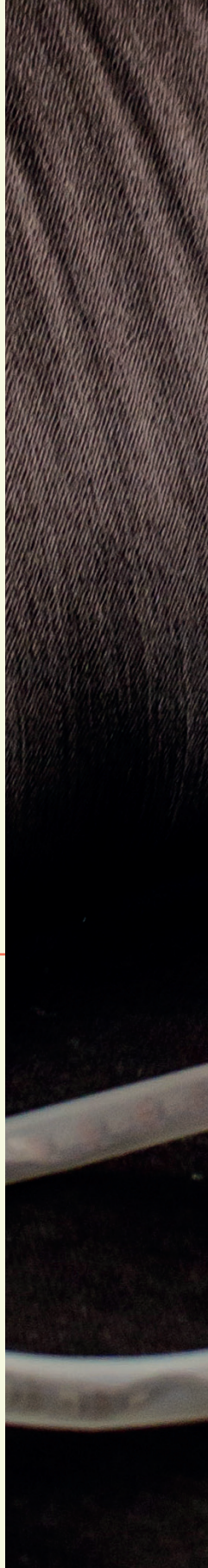
Performative Level

WHAT DOES TACTFULNESS MAKE ONE DO?

A Familiar yet Mysterious Object

AscoltaMe finds its place in one's home. It can be placed anywhere and is ambiguous enough to adapt to different contexts. Playful ambiguity is embodied here through the flexibility of its materials. The flexible materiality of AscoltaMe allows it to easily become part of the family environment where other toys may be laying around or where comfy spaces are ready to welcome it. The flexibility of the silicon tube accommodates fidgeting and encourages exploration and play with this familiar yet mysterious object.

The flexibility of the materials enables AscoltaMe to adapt to different, everyday contexts of its users. This in turn helps maintain a sense of continuity and normality in communication, as family members explore the tactful affordance and performance of the object.





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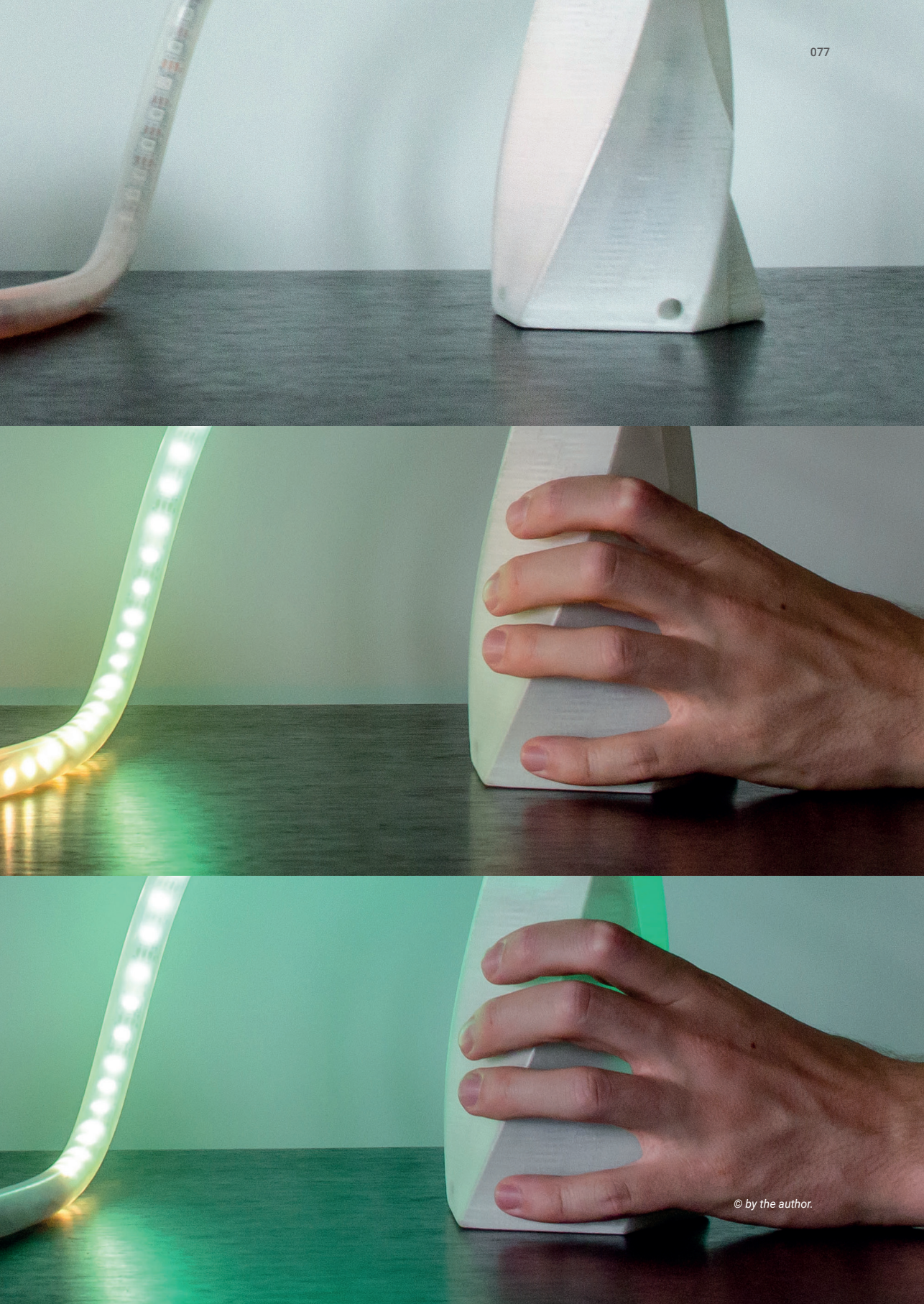
Temporal Form

HOW DOES TACTFULNESS PACE CONVERSATION?

Words in Motion

The movement generated by the light inside the tube visually expresses the flow of communication, of impalpable words and thoughts traveling in and out of AscoltaMe. When a person stops recording a voice message, this flow is interrupted; it is still visible but contained and lodged inside the object. When a voice message is listened to (but not completely) the object intentionally 'resists' this interrupted action, and the message travels back through the tube in the form of light to its mute status.

The sinuous movement of the light mimics the rhythm of the conversation between people. The message enters and pauses, restarts and exits in correspondence to changes in colour and the movement of the light. Users can then tactfully experience how light and words come to correspond with each other and to different states in their communication.



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Conclusions and Future Work

This visual chapter illustrates the exploration of the material qualities and temporal form of two *tactful objects*: Mr.V and AscoltaMe. This example shows how qualities of *tactfulness* have been embodied and expressed in two objects designed with the intent of helping families overcome the emotional barriers that may hinder interaction and communication during disruptive life events such a childhood cancer. In doing so, how the embodiment and computational expressivity of these *tactful objects* may contribute to their intent in sensitive settings was proposed.

In future work, Mr.V and AscoltaMe will be taken to families dealing with childhood cancer to learn how their *tactfulness* helps integrate the intent of these objects in disrupted everyday lives. This step will provide insights on the tactful qualities of the objects as well as indications regarding how to develop interaction features accordingly.

This initial exploration of the notion of *tactfulness* may contribute to shedding light on new opportunities for both HCI researchers working in sensitive settings (Crabtree et al., 2003; McNaney et al., 2013; Thieme et al., 2014; Vines et al., 2014) and interaction designers interested in objects with intent (Cila et al., 2017; Marenko & Van Allen, 2016; Rozendaal, 2016).

Chapter's Takeaways

Design solutions to everyday challenges in sensitive settings can take the form of interactive objects;

Tactfulness can be embedded as an expressive quality to design interactive objects attuned to the needs of people in sensitive settings;

The exploration of how such quality can be embedded in the design of interactive objects can be done through prototyping activities. This allows interactive objects to be developed that can be directly introduced in the home context of the vulnerable users and be experienced through daily interactions;

Research design frameworks such as the 'Materials Experience framework' (Giaccardi & Karana, 2015) and the 'temporal form' (Vallgårda et al., 2015) can provide support in identifying and detailing tactfulness through these objects' material qualities and behavioural expressions.

Acknowledgements

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5
DESIGNING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

Based on published journal article: D'Olivo, 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(2), 103-124.*

5.1 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 paediatric 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 with reducing distress (Haverman et al., 2011; Marsac et al., 2012; Moerman et al., 2018; Nijhof et al., 2018). In addition, studies in Design and 'Sensitive' Human-Computer Interaction (Sensitive **HCI**) (Waycott et al., 2015), have reported how interactive artefacts can be helpful in moments of crisis (Liu et al., 2015) because they can facilitate activities, support everyday routines and/or encourage new ones (D'alessandro & Dosa, 2001; Kehr et al., 2012). While inducing changes (Ryan & Deci, 2000) such artefacts may help in re-establishing the *normality* that was impacted by disruptive life events (Patterson et al., 2004). In other words, they can help families to recreate a combination of space, habits, and memories (Orth et al., 2018) that support their lifestyle (Massimi et al., 2012).

Developing interactive artefacts for people dealing with crises requires tact in order to account for vulnerabilities and to avoid overwhelming users (Cheverst et al., 2001; Crabtree et al., 2003; Massimi et al., 2010; Mori et al., 2013; Vines et al., 2014). Here, *tactfulness* is advanced as a design quality to attune the objects' meaning, expressivity and embodiment to the needs of people in sensitive settings. This quality has been explored in the context of childhood cancer to help shape (D'Olivo et al., 2017) the material qualities (Giaccardi & Karana, 2015; Wiberg, 2018) and 'temporal form' (Vallgårda et al., 2015) of two interactive artefacts that were designed in appropriate and sensitive ways. Therefore, *tactfulness* was found to be useful in form-giving practices for interaction design. However, in order to apply this to a broader design perspective, understanding how tactfully designed interactive artefacts perform in sensitive settings and how they provide empowering experiences is vital. This is what this study aims to achieve.

The format of the chapter will be outlined in the following paragraphs. The Related Work section, elaborates on childhood cancer as a sensitive setting and presents some of the current supportive tools in cancer supportive care. Designing examples that illustrate tactful approaches when designing for well-being are also presented. The rationale that resulted in the development of two interactive artefacts for families dealing with childhood cancer in tactful ways is also explained. Following this, the chapter reports on a study conducted with eight families with a child undergoing treatment for cancer, who were willing to experiment with one of these artefacts in their homes. The chapter describes the families' experiences and reflects on how these insights helped in articulating the qualities of *tactful objects*. Discussion on the contribution of the work to research in healthcare and reflections on the value of *tactful objects* when designing for other sensitive settings are also presented. The chapter concludes with the limitations of the study and provides direction for future work.

5.2 Related Work

In the field of developmental psychology, the growth of a child is described as a process where genetic factors that govern the biological development of the child 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 one another (Minuchin, 1988). Therefore, the family is the most critical proximal social context influencing the development

of the child (Ashiabi & O'Neal, 2015; Saarni, 2011) especially in the case of stressful and disruptive conditions.

Challenges in life, which generate stress and trigger significant 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 an individual and on a family as a whole. For instance, the well-being of each family member can be affected by any influences on relationships and family coherence (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 healthcare 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 creates a surreal experience (Patterson et al., 2004). Therefore, childhood cancer is a disruptive life event that becomes a sensitive setting to design for, involving the family as a whole.

Much of the attention on psychosocial supportive care in paediatric oncology is allocated 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., 2018). 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 encourage communication between children, family members and caregivers, which assists coping with the situation and reducing distress (Marsac et al., 2012). Other examples implement user friendly web-based platforms to allow children, siblings and parents to communicate with healthcare staff throughout the trajectory of a child's 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) identifies how our feelings of well-being and happiness depend upon the activities we engage in. Artefacts and technologies are considered 'mediators' that shape the behaviour of their users and the activities they engage in, are a stimulus for reflection and awareness, and offer support in one's 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 regarding their rituals and routines (Huisman et al., 2012; Kirk et al., 2016; Odom et al., 2014; Schatorjé & Markopoulos, 2013). Many of the activities, relationships and values are idiosyncratic and highly personal in this context (Gaver et al., 2007). A tactful approach is even more warranted when families are faced with disruptive life events and are thereby likely to become vulnerable users (Vines et al., 2014).

Inspiration was drawn from some design examples that illustrate tactful approaches when designing for well-being. The 'Cellie Cancer Coping Kit', mentioned previously, is a good example of how to design for children with cancer as vulnerable users (Marsac et al., 2012). The friendly appearance of the puppet, suitable for children to hold and cuddle with is considered tactful, acting as a companion to the child during medical procedures. Another example is 'Chocolate Machine' by Kehr and colleagues (2012) which is tactfully designed as a behaviour 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. 'Ritual Machine V' by Chatting and colleagues (2017) then, is an example of how artefacts can be tactful when they are designed with sensitivity towards 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 routines of the particular family for which the object is designed. Additionally, 'Other Brother' (Helmes et al., 2009) is an example of an object 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, which takes pictures and records sounds of spontaneous social events taking place in its environment, triggered by directional sound cues. It is tactfully designed to be seen as an intelligent character which feels like part of the family. Finally, 'Family Circle' (Schatorjé & Markopoulos, 2013) as another example, demonstrates an interesting concept of being a portable voice messaging solution system supporting transitory indirect messaging in the household for working parents and teenage 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 its use around the house and in communicating secondary information. Families can play with the colour and brightness of the tokens' integrated lights to convey visual information about the sender, intended receiver, or the nature or urgency of the message.

5.3 Design Cases

Here the description will consider how *tactfulness* was explored when designing interactive artefacts 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, first an observation of a cancer survivor's meeting (D'Olivo et al., 2018) was conducted and healthcare professionals working in paediatric oncology were interviewed. Two recurrent challenges encountered by children with cancer and families during treatment were identified as a reduced amount of *quality time* (Patterson et al., 2004) generated by the great deal of stress caused by the illness and treatment, and the *inability to talk openly* about one's feelings, worries and hopes (Stiefel, 2006). To address these challenges, two prototypes were developed in consultation with psychologists, child life specialists, and social workers of the participating paediatric oncology centre. First the two prototypes (i.e., Mr.V and AscoltaMe) will be explained and then reflections on their tactful qualities will be presented.

5.3.1 Mr.V

Family life is based on shared routines and collective activities. In difficult times these should be preserved to give a sense of continuity and motivation. Social activities often get hampered by the distress and the demotivation generated by the long and intensive cancer treatment. Mr.V aims at encouraging social activities that the family can engage in together (***Figure 5.1*** *see p.86*). 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 which provides ideas for family activities instead of gum. The ideas are notes written by family members and contain various activities which 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 starts 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 to the back of Mr.V.



Figure 5.1 Mr.V, an object that aims at encouraging social activities within the family: concept sketches and prototype.
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5.3.2 AscoltaMe

Sharing personal thoughts but also worries is important in order to maintain healthy connections between family members and reduce the burden of carrying something in one's 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 5.2***). Its translucent body presents two elements, a microphone and a loudspeaker connected via a flexible silicone tube. The microphone captures messages that family members want to share and 'holds' them in the tube. Voice messages are visualised as light, which begin to fill the tube. The light then lingers in the tube and pulsates, notifying users that there is a message waiting to be listened to. A red button positioned on one end of the object allows a message to be recorded and a green button positioned on the other end allows the message to be listened to. 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, demonstrating that the message is still available.



Figure 5.2 AscoltaMe, an object that aims at encouraging communication between family members: concept sketches and prototype. *© by the author.*

5.4 Tactful Qualities

Tactfulness has been the leitmotif in the design of Mr.V and AscoltaMe as a means to designing these artefacts to be appropriate and sensitive. Although the notion of *tactful objects* had not been defined fully at this stage, *tactfulness* was intuitively applied in crafting both artefacts.

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

The *expressiveness* of the objects was designed to communicate their intent clearly but

subtly. Mr.V shows that it will drop a surprise by shuffling the containers around, accompanied by light effects coming from within the machine. When a surprise is dispensed, Mr.V makes a funny sound to alert 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 disruptive. For AscoltaMe, voice messages are made visual 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 listener-side; and is operated by the pressing of the recording or the listening button. AscoltaMe expresses that it wants to be listened to by the light 'lodged' within the tube, drawing attention to it subtly.

The *embodiment* of the objects was designed to be appropriate in the family home setting considering their aesthetics and robustness. As such, both objects were designed as interactive tangible artefacts with an eye to detail, use of colour 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 with human clothing. The front lever was designed as a bow-tie and the top opening to add the containers to the machine, as a hat. Its metal and glass materials felt sturdy and safe. AscoltaMe was designed as a mysterious yet familiar-looking object with the purpose of finding its place in the home as an electronic toy. Its white translucent embodiment meant the embedded Arduino™ technology was on display and allowed 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.

5.5 Field Study

An empirical study was conducted to understand how families dealing with childhood cancer experienced these interactive artefacts in their homes. The study was designed, approved and conducted in accordance with the regulations of the Medical Ethical Committee of the University Medical Center Utrecht in the Netherlands. In consultation with the paediatric oncology centre, it was decided to limit the prototype testing for each family to one week in order to avoid generating stressful and overwhelming experiences. It was also decided to avoid making use of design research techniques that might be experienced as intrusive (e.g., videotaping the interviews, etc.), and it was proposed to conduct participant recruitment and fieldwork under healthcare professional supervision. This chapter acknowledges the collaborative effort of all researchers from both the design and healthcare field, in framing, conducting and discussing the research.[4]

5.5.1 Participants

11 families with a child with cancer were approached to participate in this study. The inclusion criteria were that the child was undergoing active treatment for cancer; not hospitalised; between six and 16 years of age (10 to 16 years old for Mr. V, and six to 10 years old 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 their 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). Each family that participated in the study's demographic is shown in ***Table 5.1*** by artefact.

	Child (patient)		Siblings	Parents
	age	gender		
Mr.V		**(*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
AscoltaMe		**(*n*=4)**	**(*n*=4)**	**(*n*=8)**
Rachel's Family	6	female	2	2
Simon's Family [a]	10	male	0	2
Monica's Family [b]	7	female	1	2
Leon's Family	8	male	1	2

Table 5.1 Participant Descriptions (N = 33).
Note: Names are fictional; (a) Simon stopped participating in the study, but shared data through the diary; (b) Monica stopped participating in the study (no data).

5.5.2 Procedure

The study consisted of three phases. In the *introduction phase*, Mr.V or AscoltaMe, the given artefact, was presented to the families at their home or at the hospital. Instructions about the main functions of the artefacts were given, as well as a user manual and a diary (***Figure 5.3***). Families were invited to try them out and ask questions, which took approximately 15-30 minutes. Then during the *use phase,* families were asked to keep the artefacts in their homes for at least one week, and to take notes in a diary about their use of the artefact on a daily basis. In the concluding *evaluation phase,* families were interviewed either at home or at the hospital and filled out a questionnaire. This last phase took approximately 60-75 minutes.

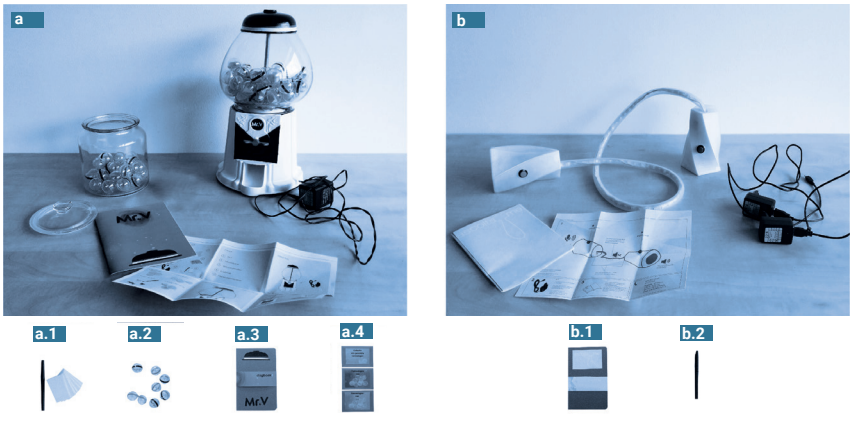

Figure 5.3 Overview of the materials provided to the participants: (a) Mr.V with surprise-containers, power cable and user manual (a.1 note paper and marker; a.2 plastic containers; a.3 diary; a.4 envelopes to collect used surprises, surprises suggested by Mr.V – see examples in* Appendix 5.1-** *and blank note paper), (b) AscoltaMe with power cable and user manual (b.1 diary; b.2 marker). *© by the author.*

5.5.3 Measures

Different types of measures were used. Families were given a *diary* (***Figure 5.4***) in which they could take notes of what happened each day when using the artefact (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 were considering (e.g., rules concerning the location, duration, and costs of the activities) (see ***Appendix 5.2*** for details). Secondly, families were invited to take pictures and/or videos when using the artefacts, and shared them with the researchers through an encrypted instant messaging chat on WhatsApp™. Thirdly, a semi-structured interview was conducted after the testing week, asking participants to detail their experiences. It was asked how/if they felt the objects made an impact on their family life, the ways in which they used and appreciated the objects, and how they perceived the objects to embed them into their home (see ***Appendix 5.3*** for details). The interviews were organised as group interviews in which multiple family members participated in the interview together. In total, 18 family members were interviewed (N = 18; $n_{children}$ = 6, $n_{siblings}$ = 3, $n_{parents}$ = 9). Lastly, a questionnaire consisting of five statements to rate the artefacts on a scale from one (strongly disagree) to 10 (strongly agree) was presented (see ***Appendix 5.4*** for details). In total, 24 family members filled out the questionnaires (N = 24; $n_{children}$ = 6, $n_{siblings}$ = 7, $n_{parents}$ = 11). Initially, the intention was to use this quantitative data to corroborate the results from the qualitative analysis. However, due to the limited contribution of these quantitative findings, it was decided to exclude this data from the analysis.

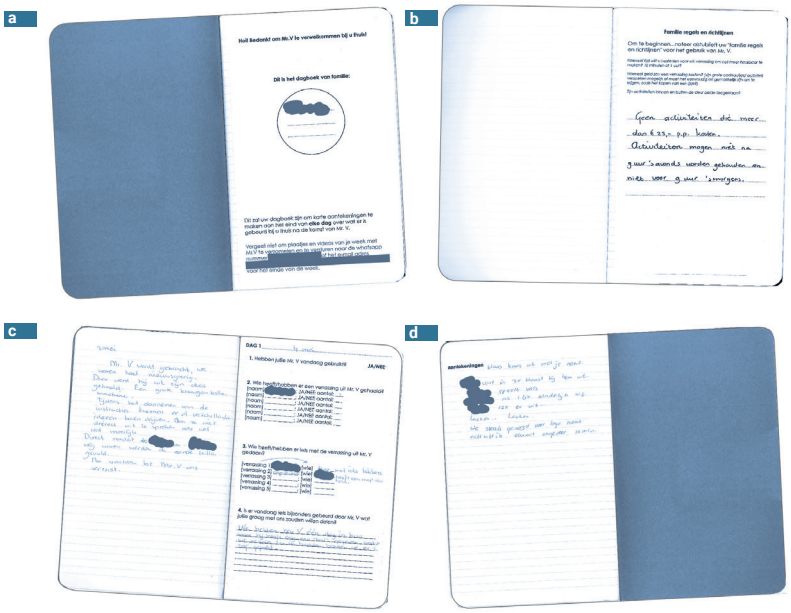

Figure 5.4 Diary structure: (a) introductory page with family's name, (b) rules page available only for families using Mr.V, (c) example of one of the seven daily-pages with questions for the family, and (d) extra space for notes. *© by the author.*

5.5.4 Data Collection, Processing and Analysis

The data was collected by the design researcher and other assistant researchers (K.L.A.vB. and R.G.V.). The interviews were transcribed verbatim by two other assistant researchers (M.R. and J.P.), anonymised by the design researcher and translated into English by a professional translation agency. The translated interviews were analysed according to each interview question that addressed different levels of the experience. The 'mapping on the

wall technique' (Sanders & Stappers, 2012) was used to organise the quotes on statements cards, cluster themes and subdivide the clusters into knowledge levels (Ackoff, 1989). Statement cards were also created by using the collected photos and prints of videoframes, following the dual coding approach (Clark & Paivio, 1991) (see ***Appendix 5.5*** for examples). 421 statements were collected in total. The statement cards were clustered following a thematic analysis approach in order to examine and record patterns within the data. The design researcher that conducted the field study and the interviews, and a supervisor, who was not involved in the fieldwork, collaborated on the interpretation of the data. The assistant medical researcher, who co-conducted the fieldwork and interviews, cross-checked the interpretation of the findings and the clustering.

5.6 Results

The results of the data analysis will be reported on by summarising the themes that emerged according to the different questions (i.e., the impact on family life, ways of using the objects, the appreciation of the objects, and the embedding of the objects in the home). Participants' quotes are presented in ***italics***.

5.6.1 The 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 relieved them 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 us to do things that we were not doing often: things and activities that normally would come second place due to our busy schedule at 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 was shared within the family and no references to the disease were made.*** She also explained how, together with her partner, they played an active role in starting a conversation through AscoltaMe because the children would not have 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.

Nevertheless, both artefacts 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 a child is sick but still manages to do their usual activities, the child looks healthy.*** Siblings mentioned that Mr.V brought ***great fun and motivation*** and ***something to look forward to*** during treatment; since their ill siblings were often really tired, Mr.V stimulated them to do something. The funny messages, jokes and social games initiated by AscoltaMe, even if only briefly, generated light-hearted moments for parents, children and siblings.

5.6.2 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 artefacts as being easy to use but requiring some creativity, that being creating activities for Mr.V or deciding 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 were written down on 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 at a particular moment of the treatment (***Figure 5.5***) (see ***Appendix 5.6*** 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 ***going for 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 always makes someone happy.*** Every family had a personal way of using Mr.V, expressing the freedom in choosing what to do and what not to do. For instance, John's father said that ***all the surprises dropped, were opened, but not all of them were acted upon.***

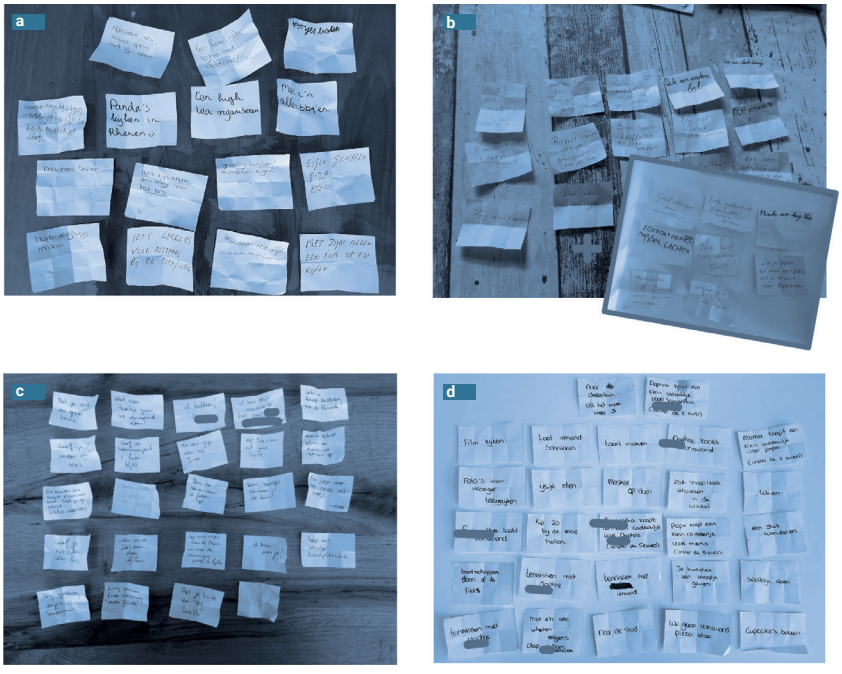

Figure 5.5 Impression of the collections of surprises: (a) Kevin's Family, (b) John's Family, (c) Mary's Family, (d) Sammy's Family. *© by the author.*

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 sounds while playing a kind of ***hide and seek*** game 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 being asynchronous and the 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.***

5.6.3 Object 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 artefacts' embodiment.

The two artefacts were described in relation to the associations they elicited. Families used different ways to describe them, as ***devices, familiar artefacts*** 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 ***peanut 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 character.

Concerning the behaviour of the artefacts, 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 with the button*** since a ***predictable schedule is sometimes reassuring***. For AscoltaMe, parents mostly felt 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 5.6***).



Figure 5.6 Rachel's mother demonstrates how she used AscoltaMe. *© by the author.*

When reflecting on their embodiment, Mary's mother appreciated the ***vintage look*** of Mr.V and the details, and Kevin's father described it as ***well-crafted*** and ***precious***. However, the sound that Mr.V made when a ball was dropped, was 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 artefact was for them. Kevin's father pointed out that Mr.V's ***glass did not 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 the ***children found the lights attractive*** too but that its white translucent embodiment ***looked unfinished***. Furthermore, they were not entirely satisfied with the sound emitted by the artefact, which was described as being of a ***low and poor*** quality by Simon's mother. Leon's mother mentioned that she felt hesitant to give it to her child to play with outside and/or to bring it to day care since ***it did not look 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 held in [the] hands is quite heavy for smaller and/or weaker children, and even a little awkward.***

5.6.4 The Embedding of the Objects in the Context of a Home

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

Most parents mentioned that these artefacts fitted into their homes nicely. 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 5.7a***). 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 in particular mentioned that it was necessary to have a spot close to a power socket in order to use Mr.V, 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 that would be an ideal place to suddenly attract their attention when Mr.V started ***producing sounds and displaying lights.*** AscoltaMe was often placed on the couch and mostly remained there. Rachel's mother noted 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 5.7b***) 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.

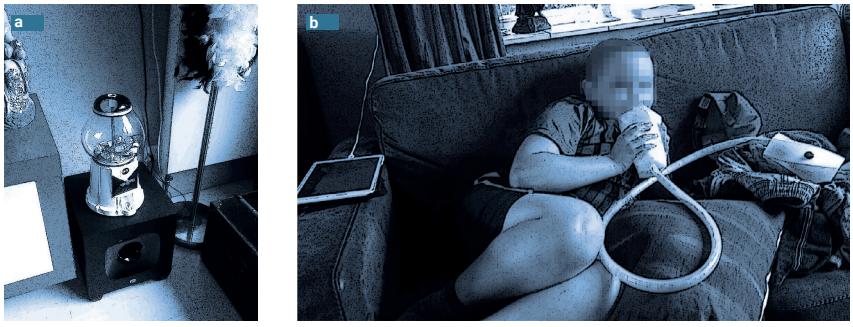

Figure 5.7 Objects inside the families' houses: (a) Mr.V in the living room of John's Family, (b) AscoltaMe on the couch with Leon. *© by the author.*

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 neighbour added some surprises*** (***Figure 5.8***). In Kevin's family, the use of Mr.V was coordinated in a specific way. The child was encouraged to open most of the surprises, and Kevin's father admitted to having ***secretly opened the surprises and then put them back into the slot to let 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 5.8 Screenshots of the video shared by John's Family with a funny challenge proposed by their neighbour using Mr.V: "Blowing a candle with your nose.". *© by the author.*

Since the use of Mr.V was quite elaborate (i.e., requiring different steps such as creating, receiving, and participating in 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 15:00 and 17:00***. John's parents expressed disappointment in Mr.V because ***some surprises came out when John was not at home or he did not receive anything once back at home.*** Families 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.

5.7 Discussion

This section discusses how the results of the field work have helped in articulating the qualities of tactful objects and account for what can hinder their tactfulness. The section will continue by discussing the contribution of tactful objects to research in the healthcare field and other sensitive settings.

5.7.1 Articulating Tactful Objects

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

Tactful objects make an impact by *establishing partnerships* that are empowering by providing support in ways that leverage people's *intrinsic motivations* and that *channel 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. In spite of not performing

according to the intentions set out in the initial design in encouraging family members to talk about their feelings, worries and hopes, AscoltaMe was found to provide new forms of short-term play. By reflecting on these results, it was concluded that AscoltaMe could not form a partnership to the extent that Mr.V did. This could have been caused by two reasons. First, AscoltaMe might have felt patronising, 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.

As mentioned earlier, *tactful objects* establish partnerships through *collaboration*. It was observed how interactions that struck a balance between *steering* users toward desired forms of behaviour, yet allowing them *freedom*, were considered to be empowering. For example, Mr.V proactively dropped a ball containing a surprise 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. It was up to the families themselves to decide this based on their own needs and circumstances. Their interaction with AscoltaMe seemed to be less collaborative. 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 participate in and when to carry them out). However, this pulsating light effect might not have been dominant enough to spark 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 being interactive.

It was understood that *tactful objects* should be *inviting* to use. People's willingness to use an object can be considered a prerequisite for *tactful objects* in becoming 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 sparked 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 proactive behaviour 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, which 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 were 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 at stimulating. It was noticed how the use of the objects was 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 was also a stimulus for social play. Families also talked about the particular moments in which they used the objects based on their schedules and availability, 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 was followed, *tactfulness* was intuitively explored in crafting Mr.V and AscoltaMe. Thus, it can be asked 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 response of the associations and feelings that were anticipated. The *expressiveness* of both the objects designed to be both clear and subtle led to different observations. For AscoltaMe, the translation of a voice message into light might have been difficult to grasp conceptually (i.e., due to a lack of clarity) and it might not have had enough provocative power in encouraging families to have conversations over time (i.e., the artefact being too subtle). The *embodiment* of the objects had an impact on their perceived appropriateness and invitingness. The aesthetics and robustness of the objects were 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 plastic was considered less fit to be used as a toy and looked unfinished as a decorative object.

In summary, *tactful objects* are articulated as objects that enable people to act with respect to their vulnerabilities and circumstances by establishing *partnerships* and *collaboration* 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 requires 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 being patronising. When *tactful objects* reflect this participatory approach through their appearance, form and interactivity, these objects can tactfully mediate behaviour and activities within specific contexts of use.

5.7.2 The Contribution of Tactful Objects

Tactful objects could be an interesting point of departure for design interventions to support engagement and the ways families cope in this specific healthcare area (Folkman et al., 1986; Grootenhuis et al., 2012). Research in the psychosocial and developmental area for cancer care can look at this exploration as a way of understanding how meaningfully making use of those objects can be by implementing them in standard interventions to support coping, resilience and family cohesion. Healthcare professionals can also consider using *tactful objects* to help families in hospital or at home, to plan playful activities that feel less stigmatising or therapeutic, to connect in a more indirect way with patients or involve neglected siblings (Woodgate, 2006b). Furthermore, as observed with 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 kinds of illnesses. For instance, *tactful objects* could offer support to users dealing with illnesses that require undergoing stressful medical procedures and where the patients should be reassured and distracted (Breazeal, 2011; Jibb et al., 2018; Moerman et al., 2018). Furthermore, *tactful objects* could be proposed during medical treatment to engage adolescents, that are considered to be difficult target users (Christiansen et al., 2015) in comparison to children or adults.

Tactful objects highlighted features that can potentially support other groups of users in crisis. Uncertainty, emotional distress, and the 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 *tactfulness* and *tactful objects* could be considered 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 researchers' 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 was presented in this chapter, the result is an articulation of *tactful*

objects as an outline or an initial design approach that takes these considerations into account. The discussion will continue by reflecting on the qualities of *tactful objects* that were articulated in the context of childhood cancer and how they can be generalised to other kinds of sensitive settings.

Embodying an appropriate metaphor in a *tactful object* helps in sparking users' interests 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 in interpersonal communication) in a way that appealed to curiosity and wonder, and that could intrinsically motivate. Hence, choosing an appropriate metaphor for *tactful objects* for any sensitive setting must be consistent 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 connects objects and activities as being ones that are continuously evolving and influenced by culture (Kaptelinin & Nardi, 2006; Kuijer & Giaccardi, 2018; Kuutti & Bannon, 2014). It also extends to the understanding of how metaphors can establish *emotional values* by embodying personal associations (Orth et al., 2018).

It was also noticed how enabling collaboration with *tactful objects* involved carefully balancing the behaviour of the object in alignment with the support that is expected of the object. For example, the objects that were designed could gently trigger a response from families to act while the families themselves had the freedom to decide when and how to act in response to the objects' behaviour. Thus, the interplay between humans and objects can be described to involve freedom and effort. This *freedom* and *effort* can be composed (and balanced) differently for the type of support that is required (Rozendaal, 2016) and result in different behaviour 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 their 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 of 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 behaviour, but rather provide gentle suggestions by glowing. 'Diem', then, is a design example that illustrates how this freedom and effort might be balanced differently and can change over time. Diem is a bedside lamp that lulls a person to sleep by dimming the light as the evening progresses (Van Boheemen, 2016). The person is allowed to increase the brightness of the lamp (i.e., allowing for freedom in action) but this will require more physical effort, the later at night it gets. The longer the user postpones going to sleep, the more assertive the lamp becomes in its demands, dimming sooner than it would have earlier in the evening, for example. These examples, show how the collaboration with *tactful objects* might be approached as ongoing negotiations that require an understanding of how people may respond to, follow, or wish to overrule the behaviour of an object, thus balancing freedom and effort in different ways.

Finally, it is important 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 is embedded in the home context; requires understanding the needs of the family members, their everyday routines and the characteristics of the setting. This leads to the question of whether *tactful objects* should be considered 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 behaviour to be built *"with encoded elements of the family character and values within"* so that the objects fit into the family's 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 a family's own idiosyncratic ways of communicating, and that the benefits that it brings to the family should be clear compared to their existing ways of communicating (Schatorjé & Markopoulos, 2013). In this regard, AscoltaMe embedded an interesting childhood metaphor into the family context, but it did not allow for idiosyncrasy and did not fulfil 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.

5.8 Limitations and Future Work

The findings have been constrained to people's recollections of their behaviour. Only using participants' recollections might have resulted in the loss of some detail and aspects of the experience (Vermeeren et al., 2010). It was noticed how the participants were hesitant to interact with the researchers regularly during the study by writing notes on a day-to-day basis in the diary and taking photographs while using the objects. The 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, Clarke, et al., 2013). Therefore, in future studies other ways in which insights can be obtained without burdening participants in their difficult circumstances should be considered. For example, it could be useful to introduce 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 useful information in real time (Cila et al., 2017; Giaccardi, Cila, et al., 2016) in an ethical and transparent manner (Gaver et al., 2007).

The results were also influenced by the two prototypes that were developed. For AscoltaMe, the use of the standard Arduino™ based electronic components did not allow it to be as light and small as 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 behaviour of objects in one's 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 the form of 'research products', which Odom and colleagues (2016) describe as products used in longitudinal research carefully fine-tuned regarding their appearance, behaviour and interactivity before actually being deployed in the field.

This work acknowledges that the one-week deployment of the prototypes in families' homes limits any generalisations about the long-term embedding of *tactful objects*. To measure the long-term impacts of the intervention on one's well-being and the 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, limitations were encountered that needed to be respected. Nevertheless, the results report more than just initial excitement from the families about the objects that were deployed and exceeded the 'trajectory of novelty' (Gaver et al., 2007). For example, it was observed how people's impressions of the artefacts were constructed after multiple use-episodes, and how people coordinated

their use of the artefact within the complex daily schedules of the family. Despite these limitations, this study allowed *tactful objects* intended for a vulnerable group of people who are often difficult to engage with and approach be investigated (Vines et al., 2014; Vines, McNaney, et al., 2013).

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 users about the embodiment and expressive capabilities of the artefacts), 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, Cila, et al., 2016; Rozendaal et al., 2019) capable of sensing people's needs and vulnerabilities (Vines et al., 2014; Vines, McNaney, et al., 2013), and mediating complex interactions among groups of users in sensitive settings (Kirk et al., 2016; Schatorjé & Markopoulos, 2013). Therefore, the next step will be to look into expanding the sensing capabilities of *tactful objects*. This will allow for the understanding of how they might attune to and adapt to the needs of people and the demands of a given situation in a semi-autonomous fashion. The interest now is in expanding the understanding of *tactful objects*, as this will ultimately help designers in creating interactive artefacts that are sensitive, supportive, and respectful for people in challenging life circumstances.

5.9 Conclusions

This chapter introduced *Tactful Objects* as a *design perspective* on interactive artefacts that empower people in sensitive settings. It explained how childhood cancer is a disruptive life event that affects children and their families as a whole by causing uncertainty, emotional distress, and changes to their family routines, which becomes a sensitive setting to design for. It presented two interactive artefacts that were designed to empower families dealing with childhood cancer in tactful ways. The first, Mr.V, is an interactive dispenser to initiate social activities within the family. The second, AscoltaMe, is a kind of walkie-talkie to enhance communication between family members. The chapter further describes how these two interactive artefacts were evaluated during a one-week field study with eight families with a child undergoing treatment for childhood cancer. The results provided insights into how families experienced these artefacts concerning their impact, use, and appreciation embedded in the context of the home. Based on these findings, it can be concluded that *tactful objects* enable people to act with respect for their vulnerabilities and circumstances by establishing partnerships and collaboration that are inviting and that are appropriate for the setting in which they are embedded. Reflections on the possible contribution of *tactful objects* to research in healthcare and in design in other sensitive settings are also presented.

Chapter's Takeaways

Interactive objects can work as mediators in sensitive settings by supporting people in dealing with daily challenges and motivate them in using intrinsic resources;

Prototyping activities have helped in embodying tactfulness in two interactive objects, named Mr.V and AscoltaMe designed to support quality time and communication in the home context of families with a child dealing with childhood cancer;

Data collection tools such as a diary, questionnaires, online chats and interviews allowed insights to be retrieved without becoming invasive;

From the second field study it emerged that interactive objects are tactful when: (i) they behave like partners, (ii) collaborate and do not impose strict rules to follow, (iii) are inviting and pleasant to interact with, (iv) act appropriately in the context.

Endnote

4. For the sake of clarity, a research assistant and two supervisors from the healthcare field enabled and facilitated the recruitment process of the families in treatment within the paediatric oncology centre of reference. The design researcher and the medical researcher conducted the fieldwork. The design researcher and another supervisor worked on the data analysis, and the medical researcher validated the analysis. The two supervisors from the healthcare field and the supervisor from the design field supported the theoretical frame of the research within the healthcare and design fields respectively. The design researcher and supervisor from the design field have a background in product and interaction design respectively. The medical researcher and the two supervisors from the healthcare field have a background in child development and psychology respectively.

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6 MAKING TACTFUL OBJECTS FOR SENSITIVE SETTINGS

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Introduction

Disruptive life events such as sickness, divorce, or relocation may unexpectedly occur and significantly impact everyday life (Massimi et al., 2012). When affected by disruptive life events, people become vulnerable (Aldridge, 2016) and find it difficult to engage in 'normal' interactions and routines (Patterson et al., 2004). Designing for sensitive settings calls for more than emphatic sensitivity in the research process (Dickson-Swift et al., 2008; Munteanu et al., 2014; Vines et al., 2014). It requires a sensitive and thoughtful approach also in defining the design qualities and role that the research artefact and technology introduced in may have (Davis & Waycott, 2015). The question however is how designers can imbue qualities of *tactfulness* in artefacts and technologies designed for sensitive settings.

This chapter describes the Research-through-Design (**RtD**) process (Stappers & Giaccardi, 2017) behind the design of Mr.V, a *tactful object* for families dealing with childhood cancer. By analysing insights in the field and examining changes to the original artefact over a period of three years, '*tactfulness*' was conceptualised and articulated through annotations of the design. The four design principles that emerged from the process are key to the design of such *tactful objects* and their expressive interactive qualities (Redström, 2008). Based on these principles, the chapter defines *tactful objects* as everyday objects which express their intent and act in a respectful way towards people's vulnerabilities and circumstances, providing support that is not seen to be stigmatising or patronising.

Research-through-Design Process

The work was carried out in collaboration with the largest paediatric oncology institute in the Netherlands, with the intention of exploring how design could aid in the psychosocial development of children in treatment. The design researcher familiarised herself initially with Child Developmental Theory (Ashiabi & O'Neal, 2015), research and activities conducted at the institute, and participated in a cancer survivor meeting to better understand the needs and concerns of children and their family members. Details of this study and a description of the emerging needs of cancer survivors were thoroughly described in Chapter 3 (D'Olivo et al., 2018).

The preliminary sensitisation process showed that a child's development during treatment is strongly influenced by how the family manage to preserve a sense of 'normality' in everyday interactions, communication and routines and that this has influence on relaxation, family cohesion and resilience (Alderfer & Kazak, 2006; Santos et al., 2015). However, supportive and preventative interventions in paediatric cancer care focus mainly on the child's medical condition or other family members' needs by looking at them individually, and are developed for use within the hospital environment (Haverman et al., 2011; Marsac et al., 2012). The home context has received only little attention. However, during the treatment phase, if conditions allow for it, the child spends most of his/her time at home (Li et al., 2013; Ward et al., 2014) with his/her other family members. This is also the context where the family feel *"more secure in having difficult discussions and practicing new skills"* (Salem et al., 2020: 7). Following this, some initial artefacts were developed (see Chapter 4) (D'Olivo et al., 2017) and were deployed as part of a primary field study with families dealing with childhood cancer (see Chapter 5) (D'Olivo, van Bindsbergen, et al., 2020) . The aim was to investigate how a particular type of interactive artefact, namely an 'Object with Intent' (**OwI**) (Rozendaal, 2016), could be used to support the daily interactions and communication of families of children with cancer in their home context during stressful times. A detailed description of this first iteration can be found in Chapter 5 (D'Olivo, van Bindsbergen, et al., 2020). In this chapter, the focus will be on the one artefact to which families responded more positively to and which was then further developed, Mr.V.

Inspired by work on everyday computational objects and slow technology such as 'Ritual Machines' (Kirk et al., 2016), 'Transformational Products' (Laschke et al., 2011), 'Photobox' and 'Slow Game' (Odom et al., 2018; Odom et al., 2014), a playful object was envisioned that would encourage family interaction at home, creating distraction and promoting relaxation. The object invites each family member to think about activities they would like to share with their loved ones, write down those ideas, and feed them into the object. The object then dispenses the notes randomly as surprises, encouraging family members to engage in fun activities that would turn everyday moments into special ones. Informed by this initial design vision, the first

working prototype of Mr.V was developed. The artefact resembles a vintage vending machine for chewing gum. An Arduino™ controlled rotating pierced disc automatically drops small plastic balls containing the note-surprises at set times (D'Olivo, van Bindsbergen, et al., 2020).

To deploy the prototype, a study was designed that was approved and conducted in accordance with the regulations of the Medical Ethical Committee of the University Medical Center Utrecht in the Netherlands. Mr.V was introduced in the home context of four families in treatment for a limited period of one week per family together with one of the medical researchers involved in the project. Successively, with the collaboration of the same medical researcher, field observations were conducted where impressions on how Mr.V was received, how it was used daily and where it was placed in the home were collected. The data collection was conducted through the use of different means such as: family diaries, WhatsApp™ encrypted chats where families shared pictures and videos with the researchers, semi-structured group interviews in each family home, and a questionnaire to rate multiple aspects of Mr.V. A detailed description of methods, analysis processes and findings was presented previously in Chapter 5 (D'Olivo, van Bindsbergen, et al., 2020).

Four main themes emerged during the analysis, which account for the characteristics of *tactful objects* as a specific category of Owl's (Rozendaal, 2016). Through the rich descriptions and visual references of this contribution, the aim is to annotate the features of the designs created during the RtD process and empirical findings of this first deployment, and in particular the changes made to the original artefact that led to the final prototype of Mr.V the Spaceman. Mr.V the Spaceman was designed for a second deployment phase in the home context of 10 new families with children undergoing cancer treatment (reported in Chapter 7 and Van Bindsbergen et al., 2021) The complex and entangled process of making *tactful objects* is illustrated in this chapter by a rich and scrupulous account of the artisanal craft and technological research that led from the original Mr.V prototype to the final prototype of Mr.V the Spaceman.

Mr.V



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Mr.V the Spaceman



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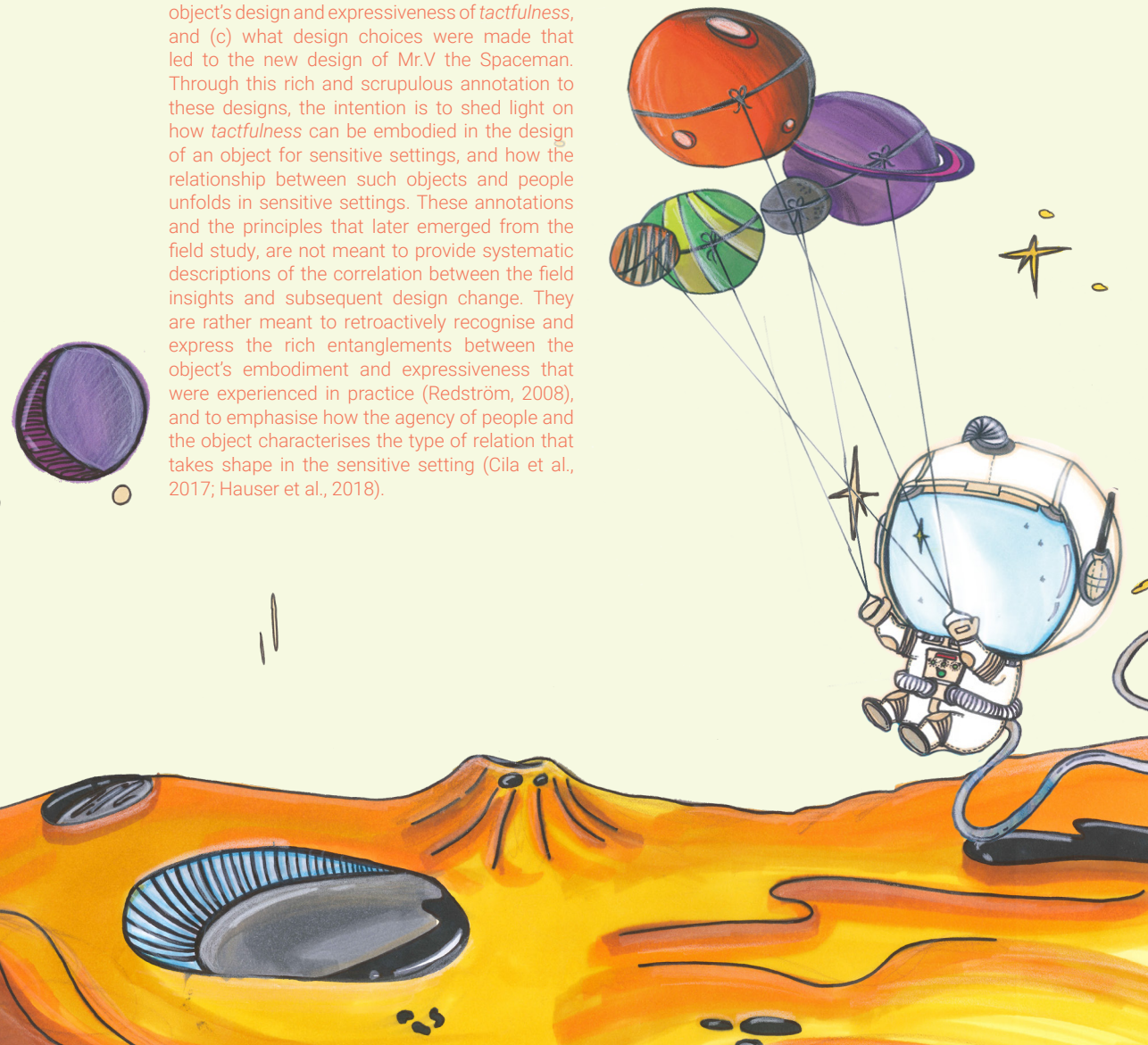
Contextualising Entanglements of Artisanal Craft and Technological Exploration

This section describes and visually illustrates the entanglement of the artisanal craft and technological exploration of affordances and interactional elements that have characterised this RtD process. The chapter is structured according to four design principles. These principles emerged from the field study (D'Olivo, van Bindsbergen, et al., 2020) as a *key to the design of tactful objects, that is, to the type of relation that these objects need to establish with people in order to be perceived as tactful in sensitive settings.* For each principle, the text and correlated images annotate: (a) how the first prototype was designed, (b) what insights were generated by the field study in relation to the object's design and expressiveness of *tactfulness*, and (c) what design choices were made that led to the new design of Mr.V the Spaceman. Through this rich and scrupulous annotation to these designs, the intention is to shed light on how *tactfulness* can be embodied in the design of an object for sensitive settings, and how the relationship between such objects and people unfolds in sensitive settings. These annotations and the principles that later emerged from the field study, are not meant to provide systematic descriptions of the correlation between the field insights and subsequent design change. They are rather meant to retroactively recognise and express the rich entanglements between the object's embodiment and expressiveness that were experienced in practice (Redström, 2008), and to emphasise how the agency of people and the object characterises the type of relation that takes shape in the sensitive setting (Cila et al., 2017; Hauser et al., 2018).



Sensitive Partnership



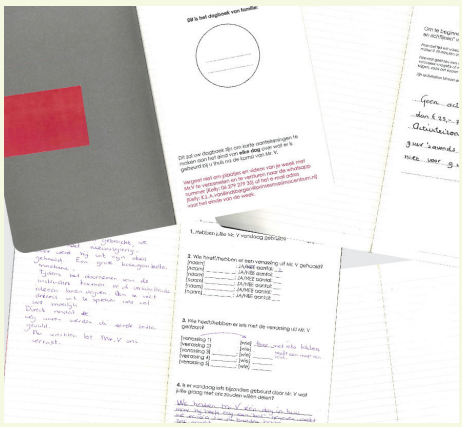
The first prototype of Mr.V was designed to encourage family interaction at home by randomly and playfully dispensing notes containing activities as surprises. Mr.V had the purpose of sensitively fulfilling a supportive function by leveraging the family members' intrinsic motivation and channelling their strengths and capabilities.

Mr.V



Participants explained that they saw Mr.V as a member of the family and that it reminded them to do things together in a playful way, and that they appreciated how its proactive behaviour helped them to plan these activities. By dispensing surprises as a means of suggesting family activities, the participants felt that Mr.V provided support without forcing them to accept it.

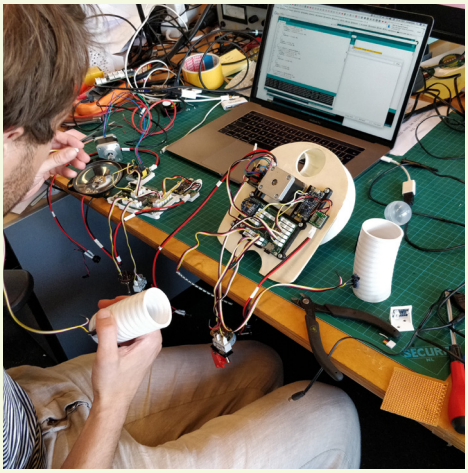
Families' diary notes on Mr.V



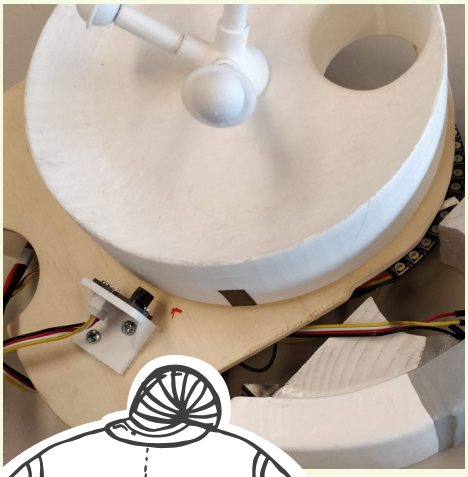
In the new prototype, Mr.V the Spaceman's role and simple behaviour did not change. However, for the second deployment, the opportunity to collect non-sensitive data through the object with the goal to help improve and better attune the support given to the families was considered. Mr.V was thus upgraded to a data-enabled RtD artefact (Giaccardi, 2019b) and equipped with optic and pressure sensors to record data about its daily interactions in a logfile (i.e., how many times Mr.V was used, at what time families preferred to receive the surprises, and when the surprises were requested at one's own will). This addition provided the *tactful object* with the sensing capabilities needed to become autonomous in its behaviour and more tactfully responsive to changing needs and circumstances (Wooldridge & Jennings, 1995).

Through the field study (D'Olivo, van Bindsbergen, et al., 2020), it was understood that objects in sensitive settings are considered tactful and capable of support well-being (Petermans & Cain, 2019) when they establish partnership with humans (Giaccardi, 2019a) in a positive and non-stigmatising way. Data-enabled, the new Mr.V the Spaceman should continue to empower family members by leveraging on their skills (i.e., knowing their individual preferences and being creative) (Giaccardi, Kuijer, Neven, & others, 2016). Embodying playful strategies (i.e., activities with a sense of surprise) (Kehr et al., 2012) and providing a tangible representation of what is needed to fulfil the family's needs (i.e., delivering surprises as a way to prompt an opportunity for quality time together) are other ways this object empowers a family (Ihde, 1990).

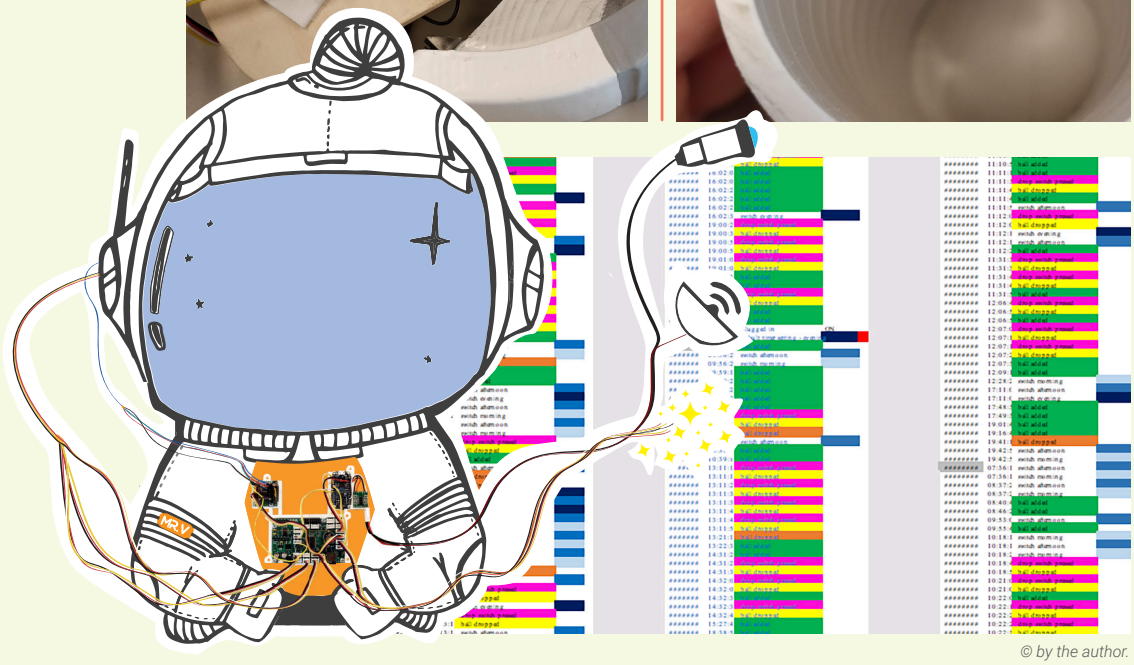
Mr.V the Spaceman: sensors implementation and example of logbook with the data collected by the object.











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Balanced Collaboration











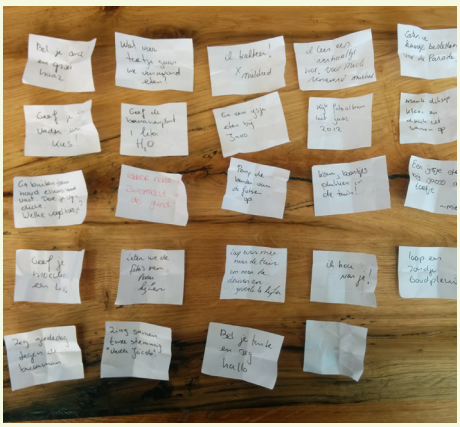

The first prototype of Mr.V reminded families to think about things and activities they like to do together, write them down as notes, enclose them in small round containers and place them into the device. These containers were then randomly dispensed by Mr.V.

Components given to interact with Mr.V.



Families noted that Mr.V provided a lot of openness, and this became slightly overwhelming when there were more than 60 containers to fill. Families felt pressured to come up with new ideas, but they tried to overcome the challenge by categorising the content of the notes. Later, the analysis of those categories provided information about the resources available and preferences of the families involved. At the same time, Mr.V also presented some limitations because the surprises were dropped at pre-defined moments not chosen by the families. Families noted that they would have liked to control Mr.V's surprise schedule but that they did not want to lose the element of surprise.

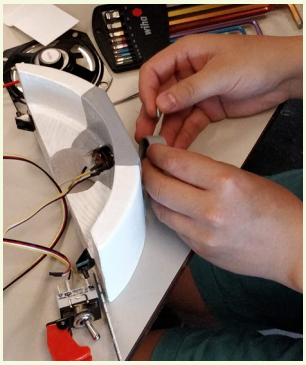
Collection of family's activities introduced in Mr.V.



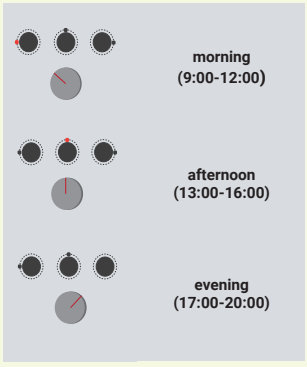
Improvements were made to simplify the process of creating the activities in Mr.V the Spaceman. The number of containers decreased from 60 to 16, and a personal family booklet was added. The booklet contains a series of colored pages (four pages per colour) with pre-cut strips that family members can tear-off and use to write the surprises. The choice of using coloured paper is a subtle hint to facilitate the ideation phase and support the families in differentiating activities, for instance, the content/category of the surprises. To address the balance between the element of surprise and controlling the surprises mentioned by the families, an interface was created regarding the dropping moment. The interface lets the family decide the timeframe in which they want to receive the surprise, yet it allows some unpredictability in when exactly Mr.V will drop one. The frontal knob controls a timer and allows the user to choose a small range of hours between 'morning', 'afternoon', and 'evening'. Families can choose to receive a maximum of two automatically dispensed surprises a day. However, an 'emergency button' is available if they feel like they want to receive more surprises. This button looks like a toggle switch with a safety cover that is positioned on the side of the machine, and if pressed, provides a surprise immediately.

Through the field study (D'Olivo, van Bindsbergen, et al., 2020), it was understood that *tactful objects* should be designed to collaborate with people (Rozendaal et al., 2019) by balancing the ways in which they steer towards desired forms of behaviour (Jelsma, 2000) while also allowing freedom in appropriation and openness in use (Boon et al., 2018). The collaboration between Mr.V the Spaceman and the families should be designed to evolve towards a form of co-performance (Kuijer & Giaccardi, 2018) in which the object learns to perform practices alongside family members, and becomes more tactful and aware of what they need 'at that moment' day after day.

Mr.V the Spaceman: implementation of control interface, manual button, selected containers and booklet.









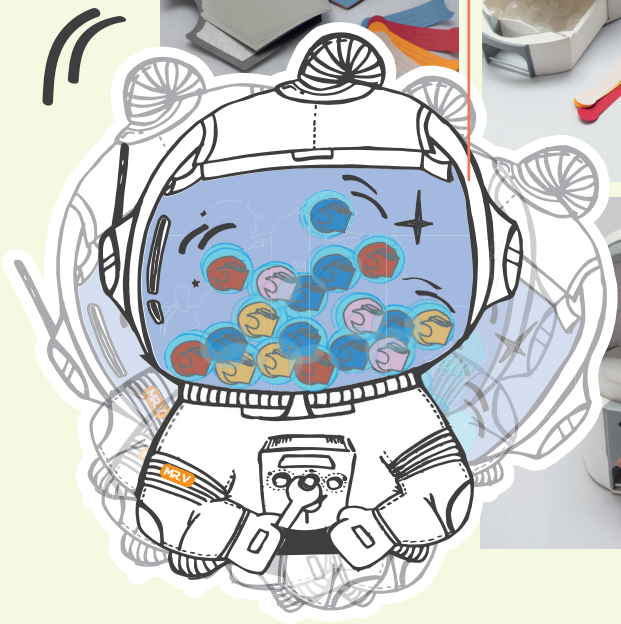
















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Familiar Character





The appearance of the first Mr.V was designed to trigger positive childhood memories by using the metaphor of a 'chewing gum vending machine'. This was also appealing as a form of interaction and use that people were familiar with (Janlert & Stolterman, 1997). The character of a machine-like dispenser was mingled with human-like features created by the addition of two ornamental elements resembling a 'bow tie' and 'hat'.

Mr.V and its bow tie.



In the field study (D'Olivo, van Bindsbergen, et al., 2020), families appreciated Mr.V as being detailed, nicely crafted, appealing to both boys and girls, and to people of different ages. Participants described Mr.V as a 'new family member' or as a friendly and supportive 'co-parent'. However, parents tended to restrict its use to the child with cancer and only the minor involvement of siblings.

A participant rating Mr.V given a questionnaire.



Therefore, it was decided to work on the object's appearance by leveraging on its anthropomorphic aspects to improve the meaningful and emphatic connection between the given family and the object, but also on the overall family-centred experience, facilitating the inclusion of all family members.

The re-design of the character of Mr.V the Spaceman, capitalises on its anthropomorphism by using the metaphor of a 'spaceman' without losing the machine dispenser's familiar connotation. The human-like quality is created by its embodiment as a 'little chubby spaceman' that still remains mysterious because it lacks facial features. An aesthetic was created that is not too childish in order to gauge the interest of parents and older siblings also. Its human-like quality is further strengthened by the possibility of assigning it a name and writing this name down on a little patch-tag that can be attached to its right 'arm' with Velcro®. The new Mr.V was also designed as an integrated activity kit that avoids clutter and provides other elements to the object. For instance, Mr.V's 'antenna' is a marker that can be used to write the surprises. The 'feet' of Mr.V prevent the dropped containers from rolling away and at the same time are the handles of a drawer used to store unused containers and the booklet. Everything was designed to provide a consistent experience linked to the 'spaceman' theme: Mr.V is packaged in a white box with a translucent cover that can be closed with a safety belt. The package is accompanied with a letter that tells the story of Mr.V 'coming from space' to bring surprises collected during its travels to the whole family.

Through the field study (D'Olivo, van Bindsbergen, et al., 2020), it was understood that designing *tactful objects* for sensitive settings means to design objects capable of establishing meaningful and emphatic connections with people (Orth et al., 2018) by looking familiar, by functioning in a trustworthy way, and by fitting within an overall narrative (Desmet & Hekkert, 2007). The new design of Mr.V the Spaceman tries to balance the 'hybrid' (Rozendaal et al., 2019) activity kit/spaceman aspect so that its humanoid appearance can possibly be a stimulus for a form of 'quasi-other' relation (Ihde, 1990) between the family and the object; and enhance the possibility of experiencing it as a human-thing that adapts its character according to the family members it is interacting with.

Mr.V the Spaceman: character details and packaging.











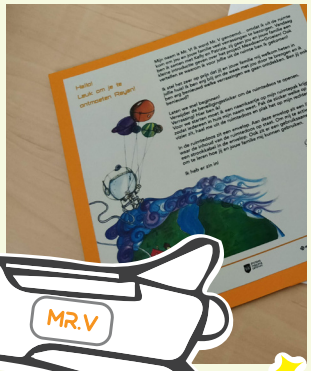




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Discreet Presence





The previous Mr.V had a sustained presence in the home context of the families who tried out the object and was always placed in the living room. However, it was understood from the families that the sound produced by the object when a ball was dispensed did not feel consistent with the object's cheerfulness and playfulness. Furthermore, it was not possible to control the activity of the object and the families expressed some concern about being afraid to have to wake up during the night because of it.

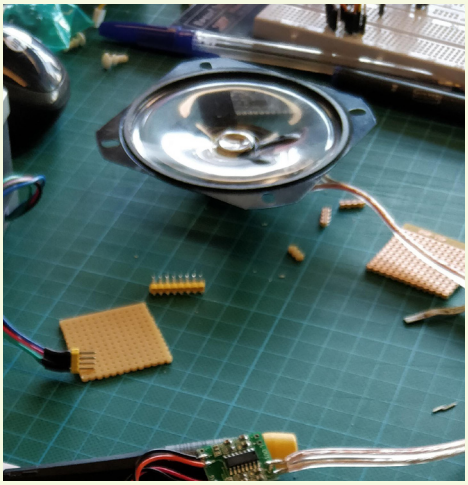
Mr.V in one of the families' living rooms.

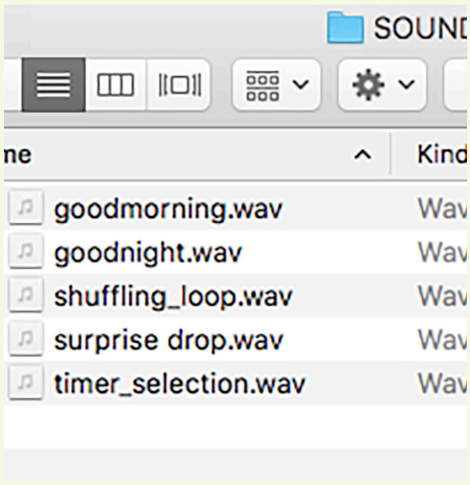


To make the new Mr.V the Spaceman better attuned to the home context, the way it communicates through sound and light was redesigned. To spark attention and excitement, Mr.V emits a radar-like sound 10 minutes before dropping a surprise within the chosen timeframe (i.e., morning, afternoon or evening). This event is accompanied by the flickering of white lights coming from within Mr.V and the shaking of the filled containers caused by the actuation of the base-plate on which they rest. During these 10 minutes, the flickering white lights slowly increase in intensity and frequency until the container is actually dropped. The moment a ball is dropped, a sparkling sound is emitted. Furthermore, a new set of sounds was added to express that Mr.V 'wakes up' and 'goes to sleep' at 9:00 in the morning and at 20:00 in the evening respectively. These sounds have the purpose of strengthening the perception of Mr.V 'behaving' according to the scheduled rituals of the family and also to assure that the object remains inactive throughout the night.

Through the field study (D'Olivo, van Bindsbergen, et al., 2020), it was understood that in order to tactfully communicate intent, spark attention, and blend a given object into its environment, objects should carefully orchestrate different behaviour and expressiveness (Redström, 2008). The reason behind this is to avoid discomfort and misunderstanding (Gaver et al., 2007), but also, generate interest and create serendipity (Helmes et al., 2009). The expressiveness of the new Mr.V the Spaceman should be able to accommodate its contextual state and allow a tactful presence that moves the foreground and background (Ihde, 1990) according to the daily situation of the family (e.g., a good day, bad day, sudden crisis, school routine, holiday routine, etc.).

Mr.V the Spaceman: implementation of new expressive features, prototype ready to be deployed and demo (-scan QRcode to visualise-)











FLOWCODE

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Conclusions and Future Work

This chapter described the RtD iterations that led to the design of Mr.V the Spaceman as a *tactful object*. The rich descriptions of results illustrate how principles of *tactfulness* were embodied and expressed in the physical and digital crafting of an object, designed with the intent to empower families of children with cancer to maintain a healthy family life during stressful times at home. Particular attention was placed on how the making process connected empirical findings and design exploration. Attention was also placed on how it contributed to the categorisation of the type of relations that an interactive object should establish with people and be tactful in sensitive settings. These relations are encapsulated into the four principles that were used in the chapter for retrospectively organising the entanglements of artisanal craft and technological exploration that characterised this long three-years RtD process:

Sensitive partnership: *Tactful objects should be respectful of people's circumstances and vulnerabilities, and act as sensitive partners without stigmatising or patronising;*

Balanced collaboration: *Tactful objects should balance people's intentions and their own intention, and be collaborative;*

Familiar character: *Tactful objects should establish a meaningful familiar connection to people, and be inviting;*

Discreet presence: *Tactful objects should position themselves with discretion within the setting in which they are embedded.*

Through these principles, *tactful objects* were identified as an Owl's category (Rozendaal, 2016), specifically designed with the purpose of establishing tactful and sensitive relationships with people in sensitive settings. A new and longer cycle of deployment (described in Chapter 7) saw Mr.V the Spaceman in the home of another 10 families with a child undergoing treatment. New insights have been collected on how to further develop Mr.V as a *tactful object* (Van Bindsbergen et al., 2021), but also on how to implement autonomous behaviour in sensitive settings (Waycott et al., 2015) as well as in everyday contexts (Rozendaal et al., 2019) in a tactful way.

The conceptualisation and exploration of *tactful objects* given in this chapter contributes to shedding light on new opportunities for both Human-Computer Interaction (**HCI**) researchers and practitioners interested in designing interactive artefacts for sensitive settings and healthcare (Massimi et al., 2010; Thieme et al., 2014; Wallbaum et al., 2015). It also instigates a more general reflection on how the sensing potential, interface complexity and agency of interactive artefacts should be developed without becoming intrusive and losing legibility and trust (Borgmann, 1987; Dorrestijn & Verbeek, 2013; Giaccardi & Redström, 2020).



Chapter's Takeaways

By highlighting specific characteristics of the interactive objects that were introduced in the field, the families accounted for the meaning of tactfulness as an embedded expressive quality;

The four concepts of partnership, collaboration, invitingness and appropriateness defined in what a 'tactful object' consists of has been used as 'principles' for a new design iteration resulting in the creation of Mr.V the Spaceman;

The willingness to create an object more sensitive to its surroundings and capable of providing more information on family patterns led towards the creation of a data-enabled object capable of recording non-sensitive data;

In the new design, the addition of sensing capabilities has the purpose of enabling the object to establish a more sensitive partnership with the users. The introduction of new elements to structure the interaction in a subtle way prepares the object in entertaining a more balanced collaboration with the families and offers more tangible support. The integration of several meaningful associations in the object's appearance has the purpose of transforming the object into a more familiar character. Finally, re-designing the object's interactive features is to help the object in expressing its intentions better and in preserving a discreet presence in the home context over time.

Acknowledgements

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7
FROM TACTFUL OBJECTS TO TACTFUL INTELLIGENCE

Based on journal article currently under review: D'Olivo, P., van Bindsbergen, K.L.A., Huisman, J., Grootenhuis, M.A., Rozendaal, M.C. (n.d.) From Tactful Objects to Tactful Intelligence. Under review with the *AI & Society: Journal of Knowledge, Culture and Communication* **(not for sharing).**

A medical perspective on part of this study is also reported in: Van Bindsbergen, K.L.A., D'Olivo, P., Rozendaal, M.C., Merks, J.H.M., and 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. https://doi.org/doi:10.1007/s00520- 021-05995-3.*

7.1 Introduction

Interactive artefacts (Giaccardi, 2015) have evolved from relatively simple computational objects to increasingly intelligent ones, capable of sensing, reacting, autonomously making judgment, and creating connection with other objects (Rozendaal et al., 2019). While interactive artefacts were considered utilitarian tools controlled by people, now with objects that show signs of increasing intelligence, the agency is shared between people and objects (Giaccardi & Redström, 2020; Kuijer & Giaccardi, 2018). In this new scenario, intelligent artefacts become blends of tools and agents (Rozendaal et al., 2020), and the interaction between people and artefacts transforms into collaboration, fostering a human-computer symbiosis (Mueller et al., 2020). This also introduces new methodological challenges and ethical issues (Giaccardi, 2019a; Murray-Rust et al., 2019; Van de Poel, 2020). Many scholars are currently focusing on how to design with intelligence from an interaction design perspective. In their research they explore how to work with intelligence as a design material (Holmquist, 2017; Rozendaal et al., 2018), how to make intelligence expressive and understandable (Chabot, 2019; Redström, 2008), and how to make intelligence useful in people's everyday lives (Cila et al., 2017; Rozendaal et al., 2019).

Research conducted in sensitive settings (Davis & Waycott, 2015), where vulnerable groups of people (Vines et al., 2014) (e.g., children, elderlies) deal with disruptive-life events (Massimi et al., 2012) (e.g., sickness, divorce), investigates the empowering role of interactive and intelligent artefacts in promoting quality of life and well-being (Moerman et al., 2018; Waycott et al., 2015). The design of such artefacts and their intelligence have implications on how people understand them and relate to them, especially in sensitive settings (Jenkins et al., 2019; Rozendaal, 2016). Based on this, in previous work (D'Olivo, van Bindsbergen, et al., 2020; D'Olivo et al., 2017) *tactfulness* was researched as an expressive quality for the design of interactive artefacts that can empower people in stressful situations and promote change and well-being in a sensitive way (Petermans & Cain, 2019; Thieme et al., 2012).
In light of this point of interest, the aim of this chapter is to assess if (i) a data-enabled *tactful object* designed according to the *principles of tactfulness* is experienced as a supportive psychosocial tool for families with children in treatment for cancer, and (ii) how this can contribute in envisioning *tactful intelligence* as a future development for *tactful objects*.

The chapter starts by introducing *Tactful Objects as a design perspective*, and how it came to being in relation to an investigation conducted in the home context of families dealing with childhood cancer. The chapter then moves on to describe how *tactfulness* has been applied in designing *Mr.V the Spaceman*. Then, the chapter continues with the description of a field study conducted in the homes of 10 families with a child with cancer who is undergoing treatment. The chapter then discusses how the object was experienced to be tactful—and how these insights in combination with the data it sensed—helped in envisioning how *computational intelligence* can help *tactful objects* to promptly attune to people's varying needs and circumstances. The chapter concludes by highlighting the contribution of the work to research in Human-Computer Interaction (**HCI**), Interaction Design, and Healthcare.

7.2 Tactful Objects

In previous work (D'Olivo, van Bindsbergen, et al., 2020), *Tactful Objects* were introduced as a perspective to define the design qualities of interactive artefacts functioning in sensitive settings. This notion took shape in the context of a research project aimed at using design to assist in the psychosocial development of children with cancer and was conducted in collaboration with the largest paediatric oncology centre in the Netherlands. The every day of families dealing with a disruptive-life event (Massimi et al., 2012) like childhood cancer is a sensitive setting where the illness affects not only the child's health and ability to cope with

the long and intensive treatment (Kupst & Bingen, 2006), but also causes a loss of normality in the family's everyday routines putting stress on the relationships among family members (Folkman et al., 1986; Patterson et al., 2004). Therefore, in parallel to the treatment, supporting the psychosocial development of the child and family members, means encouraging their involvement in collective activities to stimulate distraction, optimism and cohesion (Santos et al., 2015), and helping them in preserving a good level of communication regarding their emotions and feelings (Grootenhuis et al., 2012). It was found that preventative healthcare interventions involving technology and alternative playful approaches, addressed primarily the emotional well-being of the child or the other family members looking at them individually (Marsac et al., 2012; Nijhof et al., 2018), and were strictly linked to the hospital environment (Haverman et al., 2011; Wildevuur & van Dijk, 2011) and treatment adherence (Wiener et al., 2020). Less opportunities have been explored to address the family members as a system in their everyday life at home, where instead, as reported by a recent work from Salem and colleagues families feel *"more secure in having difficult discussions and practicing new skills"* (2020: 7).

To develop the *perspective of Tactful Objects* and explore opportunities for the home context of these families, two artefacts were created following a Research-through-Design (**RtD**) approach (Stappers & Giaccardi, 2017), which consists of multiple design and test iterations. During this first iteration, tactfulness emerged 'in the making' as an expressive design quality that implicitly guided the design process (D'Olivo et al., 2017). From the deployment of these two artefacts in the field, the design *perspective of Tactful Objects* established four tactfulness principles (D'Olivo, van Bindsbergen, et al., 2020). *Tactful objects* are objects that display tactful behaviour because they allow people to act with respect towards their individual vulnerabilities and circumstances following four principles based on the level of understanding of the experience the *tactful objects* enhance (i.e., the intended impact, the ways of interaction, the appearance and the embedding in context). According to the four principles, *tactful objects* (i) establish *sensitive partnerships* with people, they (ii) *collaborate* with people in a way that is *balanced* considering the extent people and the object contributed in the collaboration, they are inviting because they (iii) resemble a *familiar character*, and (iv) maintain a *discreet presence* by acting appropriately in the setting in which they are embedded.

7.3 Mr.V the Spaceman

Here, the result of the second iteration in which the four *tactfulness principles* were applied in the design of a new *tactful object*, named 'Mr.V the Spaceman' (***Figure 7.1***), are described. Mr.V the Spaceman was a character designed to sensitively encourage family members to interact at home during stressful times (D'Olivo, Rozendaal, et al., 2020). Mr.V the Spaceman worked as a gumball dispensing machine, but it dispensed balls containing activities instead of gumballs. The interaction with the object was designed to be simple. Family members were invited to think about activities they liked to do with their beloved ones and wrote these down on notes (e.g., play a board game, watch a movie, etc.). They could then place the notes into plastic ball containers and manually insert them into Mr.V the Spaceman. During the day, Mr.V the Spaceman dropped the balls, containing the notes in the form of surprises at unexpected moments to let the family members share in the activities together throughout the day.



Figure 7.1 Mr.V the Spaceman and the interaction steps: i) writing the note and folding the paper; ii) opening the ball container and filling it with the note; and iii) closing the ball container and inserting it into Mr.V the Spaceman. *© by the author.*

Mr.V the Spaceman was also equipped with sensors. This was done in order to understand the role of data in helping obtain a better understanding of people's interactions with the object, and to further use these insights as a starting point to reflect on the possibility of introducing intelligence in the future development of *tactful objects*. An *optic sensor* was placed on the rotating pierced disc from where the ball containers dropped. When the disc rotated, the optic sensor recorded the movement of the dropping ball containers (***Figure 7.2a*** *see p.134*). A *pressure sensor* was placed in the 'oxygen hose' on top of the 'head' of Mr.V the Spaceman from where the filled ball containers were inserted. When ball containers slid against the sensor, they were recorded (***Figure 7.2b*** *see p.134*). Mr.V the Spaceman also recorded when the 'time-knob' was turned and in which position it was set. An internal clock kept the object updated with the correct time during the day. An Arduino™ board controlled both sensors and the internal clock, and held a removable SD card (***Figure 7.2c*** *see p.134*) where all the data was automatically stored in a logbook. The logbook consisted of a text file where each event was reported with a date, time and name (i.e., '08/08/2018; 17:05:16; plugged in') (***Figure 7.2d*** *see p.134*). The section continues by describing how Mr.V the Spaceman was designed according to the four *tactfulness principles*.

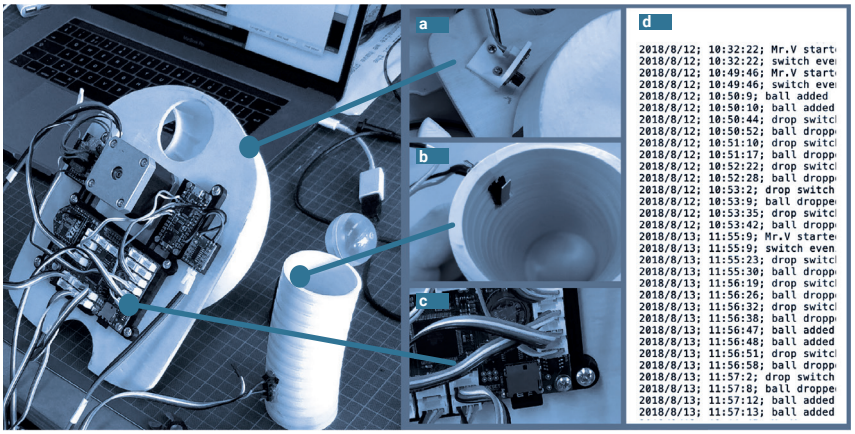

Figure 7.2 Artefact's sensing features: a) optic sensor; b) pressure sensor; c) removable SD card; and d) example of logbook. *© by the author.*

7.3.1 Principle 1: Sensitive Partnership

According to the first principle, a *tactful object* should show sensitivity towards people's circumstances and vulnerabilities by acting as a partner that supports them in a positive and non-stigmatising way (D'Olivo, Rozendaal, et al., 2020). Mr.V the Spaceman was designed to provide support by approaching changing family routines as something fun and exciting, and by channelling a family's strengths and capabilities in making such as change. An example of this was introducing Mr.V the Spaceman to families as a surprise machine to help them engage in quality time as being playful and not having any clinical or therapeutic connotations. Furthermore, asking family members themselves to think about interesting activities to do, and use this as an intrinsic aspect of the machine's interaction and function, taps into people's own creativity and is respectful towards their resources and preferences. The agency of Mr.V the Spaceman was the continuous awareness triggered by its presence in the home context and its prompts when a surprise was about to come out. This was created by carefully thinking about what the object could and should do without taking over the responsibility or decisions of what the family could still do and would like to do.

7.3.2 Principle 2: Balance Collaboration

The second principle focuses on the way a *tactful object* engages with people in a collaborative way by thoughtfully dividing tasks between Mr.V the Spaceman and the families. Families were given the task to ideate and create activities, and were given the responsibility to carry them out. Mr.V the Spaceman was designed with the task of reminding and encouraging families to carry out the activities by turning the creation and the dispensing of these activities into a positive surprising everyday experience. Creating such interaction with Mr.V the Spaceman, required thoughtfully balancing the guidance it provided. This was done by allowing people to creatively use and appropriate Mr.V the Spaceman and to balance the level of control required to enjoy its unpredictability. For example, Mr.V the Spaceman was given to families with a total of 16 empty ball containers and a complementing booklet with pages of four different colours in which the families could write down activities to insert into Mr.V the Spaceman. The pages' colours offered a way for the families to distinguish the notes' content without providing strict guidelines as to how to use the colours (***Figure 7.3a***). To control Mr.V the Spaceman's unpredictability, families could decide if they wanted a surprise dispensed in the morning, afternoon, or evening by turning a timer knob in three corresponding positions (***Figure 7.3b***). To preserve the surprise effect, balls containing

activities were still randomly dispensed within the selected timeframe. As an ultimate control element, the prototype also presented an 'emergency button' that when pressed allowed surprises be received immediately (***Figure 7.3c***).

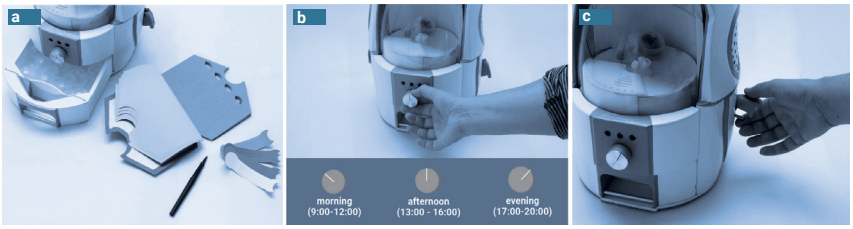

Figure 7.3 Artefact's interactive features: a) selected number of ball containers and booklet with pre-cut paper strips; b) time-knob and pre-set timeframe slots; and c) emergency button. *© by the author.*

7.3.3 Principle 3: Familiar Character

The third principle describes how a *tactful object* establishes a meaningful connection with people because it behaves and looks familiar (D'Olivo, Rozendaal, et al., 2020). In creating Mr.V the Spaceman as a familiar character, three aspects needed to be integrated: a *metaphor* to allow people to understand how to interact with Mr.V the Spaceman as an interactive artefact; *anthropomorphic cues* to help people make sense of its agency, and *aesthetically integrated* functional elements to support playful experimentation with the device. Mr.V the Spaceman worked according to the intuitive mechanism of the gumball dispensing machine that provided known ways of interaction for many people with pleasant childhood memories attached to it. Furthermore, its appearance capitalised on the anthropomorphic concept of a 'spaceman' with a chubby body and a plastic screen mimicking a space helmet. Mr.V the Spaceman was introduced given a short story as a character that came from space to bring surprises for all the family (***Figure 7.4a***), and could be given a name by placing a patch-tag with Velcro® on its right 'arm' (***Figure 7.4b***). This feature supported the notion of a partnership in terms of a sentient character that provided an animistic frame of reference to relate to the object's presence in the home context and its (limited) autonomous behaviour. The aesthetics of Mr.V the Spaceman was designed to express an identity of being an integrated activity kit with a toy-like appeal to promote playful exploration. For instance, the antenna on the side of the helmet was a marker that could be used to write the notes. The feet functioned as a handle to open a drawer where the empty ball containers and booklet were stored (***Figure 7.4c***).



Figure 7.4 Artefact's aesthetic features: a) the spaceman character; b) the patch-tag to label the object; and a) dispensing machine/ integrated activity-kit. *© by the author.*

7.3.4 Principle 4: Discreet Presence

The fourth principle explains that a *tactful object* has a discreet presence within a sensitive setting because its expressiveness is designed to be both clear and subtle (D'Olivo, Rozendaal, et al., 2020). To integrate into the home context, the object needs to invite the families in initiating collective and pleasant activities without imposing itself or becoming disruptive itself. Only when necessary the family's attention needed to be triggered by the object through recognisable, clear and enjoyable prompts. In order to induce a sense of anticipation among the family members, Mr.V the Spaceman was designed to emit a radar-like sound 10 minutes before dispensing the surprise. The sound was accompanied by a flickering white light and a wiggling movement of the rotating plate where the ball containers were resting. The dispensing event was signalled by a sparkler-like sound and a flickering white light which increased in intensity until the ball container dropped. At 09:00 in the morning, Mr.V the Spaceman 'woke up' emitting an energy-like sound, and at 20:00 in the evening, Mr.V the Spaceman's 'bedtime' was signalled by a swoosh-like sound; thus, the family was not disturbed during the night.

7.4 Field Study

A study was set up with the aims to (i) assess if a *data-enabled tactful object* designed according to the principles of tactfulness was experienced as a supportive psychosocial tool for families with children in treatment for cancer, and to (ii) learn how this can help *envisioning tactful intelligence as a future development for tactful objects.* A field study was conducted where Mr.V the Spaceman was introduced in the homes of 10 families with children undergoing treatment for cancer. The study was designed, approved and conducted in accordance with the regulations of the Medical Ethical Committee of the University Medical Center Utrecht in the Netherlands. In consultation with the paediatric oncology centre involved in the project, it was decided to limit prototype testing for each family to one week.

7.4.1 Participants

18 families that met the inclusion criteria were selected and approached by child life specialists and paediatric oncologists with an information letter. Inclusion criteria were: being in active treatment for cancer, not being hospitalised, and being between five and 15 years of age. The families were contacted by telephone by the medical researcher from the psychosocial department of the hospital a week later about their participation. Eight families declined to participate because: the child got hospitalised (n = 3), they did not see value in trying out the object (n = 2), or they thought it would be too demanding (n = 3). In total, 10 families (55.6%) with a child undergoing treatment at the paediatric oncology centre were included in the study were included, and written consent was obtained from all family members (N = 47, $n_{children}$ = 10, $n_{siblings}$ =16, $n_{parents}$ = 21). The families' characteristics are shown in ***Table 7.1***. Fictional names were used to safeguard anonymity.

Families *				
	Child (patient)		Siblings	Parents
	age	gender		
	(*n*=10)		(*n*=16)	(*n*=21)
Robert's Family	5	male	2	2
Sean's Family	8	male	1	2
Thomas' Family	7	male	1	2
Jack's Family	7	male	1	2
Aaron's Family	7	male	1	2
Rachel's Family	7	female	2	2
Simon's Family	7	male	1	2
David's Family	5	male	1	2
Lenny's Family	9	male	1	2
Lana's Family	5	female	5	3

Table 7.1 Families' Characteristics (N = 47).
** In Van Bindsbergen and colleagues (2021) provides a medical perspective on this study and the participating families are reported with numbers from one to 10 respectively.*

7.4.2 Procedures and Measures

The study consisted of three steps. First, Mr.V the Spaceman was introduced to the families at their home or at the hospital through the use of a short story. It was preferable for the story to be read aloud by the child together with the researchers or the parents. An explanation about the object followed. Families were also informed that Mr.V the Spaceman recorded data and were invited to try the object out and ask questions. This took about 15 to 30 minutes. Second, families were asked to use the object at home for one week. Third, at the end of the week, follow-up sessions were conducted where the families were interviewed and filled-out a questionnaire. This took about 60 minutes.

Different types of measures were used. The families were invited to take photos and/or videos during the week and share them with the researchers through an encrypted chat on WhatsApp™. Some of the families also used a booklet as a diary to take notes. Group interviews were conducted with each family. The interview consisted of four open questions on the use of Mr.V the Spaceman, a questionnaire with 13 statements to rate several aspects of the object on a five-point Likert-scale ranging from one (strongly disagree) to five (strongly agree) and seven open questions on current malfunctions, possible improvements, overall impressions and an assessment scale to rate the object from one (worst) to 10 (best) (see ***Appendix 7.1***). Machine data was downloaded from the embedded processor as .txt documents. All the collected data was anonymised and safely stored on the online platform SURFdrive™. SURFdrive™ is provided by Dutch Universities as a service to store sensitive data online with a privacy warranty. The anonymised data is stored for a duration of 15 years and after that will be destroyed according to the law.

7.4.3 Data Collection, Processing and Analyses

In total, 31 family members were interviewed ($n_{children}$ = 10, $n_{siblings}$ = 6, $n_{parents}$ = 15). The design researcher, the medical researcher and another two assistant researchers from the healthcare and the design field respectively (G.D. and M.S.) collaborated in the data collection. The interviews together with the booklet notes were transcribed verbatim, anonymised and translated by another two assistant researchers from the design field (R.V. and M.S.). The design researcher, the medical researcher and one of the supervisors analysed and interpreted the data in several iterations, cross-checking the findings for validation. Photos and videos collected were also anonymised. The materials were then analysed through Atlas.ti™, qualitative analysis software. In order to build on the research previously conducted (D'Olivo, van Bindsbergen, et al., 2020), an elaborative coding approach was applied (Saldaña, 2014: 54, 229) in multiple iterations. Quotes describing the experience of Mr.V the Spaceman were grouped into four levels of analysis (i.e., the impact experienced on one's social life, the use of the object, its appreciation, and embedding it into the context), which corresponded to the four *tactfulness principles*, and allowed for assessing if and how Mr.V the Spaceman was experienced to be tactful or not. In total, 1076 quotes were clustered into 48 codes.

In total 35 family members filled-out the questionnaire ($n_{children}$ = 10, $n_{siblings}$ = 9, $n_{parents}$ = 16). The questionnaire focused on assessing acceptability, feasibility and the potential effectiveness of Mr.V the Spaceman as a supportive psychosocial tool for families with children in treatment. It was decided to exclude the questionnaire results from this chapter since they did not specifically address the investigation on designing *tactful computational intelligence*. Analyses on these specific results can be found in the work of Van Bindsbergen and colleagues (2021). Furthermore, a total of 10 logbooks ($n_{families}$ = 10) were collected, organised in an Excel™ file and used to complement the interview findings. The specific type of data recorded in the logbook, is presented in ***Table 7.2***. The logbook data was colour coded (i.e., each event was assigned the same colour) and counted. To compliment this overview, two other types of data were added: the ***n. of days of Mr.V at home*** (i.e., count of the number of days between Mr.V the Spaceman being dropped-off and the interview), and the ***n. of notes written*** (i.e., count of the number of paper strips removed from the booklet). Quantitative descriptive and frequency analyses were conducted with the Statistical Package for Social Sciences software (IBM SPSS 27.0). A list of the data, frequencies and statistics are reported in ***Table 7.3***.

Type of data	Data description
n. days of use of Mr.V	Count of the number of days between the first timestamp and the last timestamp recorded.
n. balls added	Count of the total ball containers added by the family.
n. balls added on the first day	Count of the ball containers added on the first day.
n. balls added on later days	Count of the ball containers added throughout the week.
n. times time-knob was turned	Count of the time-knob rotations throughout the week.
n. times time-knob was set in the morning	Count of the times in which the time-knob was set to the left.
n. times time-knob was set in the afternoon	Count of the times in which the time-knob was set to the centre.
n. times time-knob was set in the evening	Count of the times in which the time-knob was set to the right.
n. automatic surprises dropped	Count of the ball containers dropped automatically throughout the week.
n. times manual-button was pressed	Count of the times the manual-button was pressed.
n. times Mr.V was unplugged	Count of the times Mr.V the Spaceman was unplugged-plugged.

Table 7.2 Type of Data Recorded in the Logbook and Description of the Data.

	Families*										Statistics		
	Robert's Family	Sean's Family	Thomas' Family	Jack's Family	Aaron's Family	Rachel's Family	Simon's Family	David's Family	Lenny's Family	Lana's Family			
	n	*n*	*n*	*n*	*n*	*n*	*n*	*n*	*n*	*n*	*M*	*SD*	*range*
n. days of Mr.V at home	10	8	21	29	11	12	9	7	7	7	12.1	7.3	[7-29]
n. days of use of Mr.V	4	7	13	15	8	10	8	7	6	4	8.2	3.6	[4-15]
n. notes written	10	18	11	8	17	24	36	15	9	20	16.8	8.5	[8-36]
n. balls added	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]
On later days	3	16	18	23	1	80	52	0	2	13	20.8	26.0	[0-80]
n. times time-knob was turned	2	12	51	57	44	10	63	12	16	16	28.3	22.7	[2-63]
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]
n. automatic surprises dropped	2	6	14	15	13	10	11	10	8	4	9.3	4.3	[2-15]
n. times manual-button pressed	4	37	34	15	18	87	51	4	12	10	27.2	26.1	[4-87]
n. times Mr.V was unplugged	3	4	8	7	1	1	0	1	1	4	3.0	2.8	[0-8]

Table 7.3 Descriptive Statistics and Frequencies of the Logbook Data Provided by Mr.V the Spaceman (N = 10).

** In Van Bindsbergen and colleagues (2021) provides a medical perspective on this study and the participating families are reported with numbers from one to 10 respectively.*

7.5 Findings

The families' descriptions contributed to enriching the understanding of each *tactfulness principle*. By comparing data from the logbook and interviews, it was deduced also how the object could collect details on families' behaviour useful in informing how to design a *tactful intelligent object*. Each sub-section starts with a brief summary of the findings and follows with a selection of the logbook data and the participants' original quotes (in ***italics***) supporting the description.

7.5.1 Partnering with Families by Leaving Room for Self-Direction, Creativity and Meaning-Making

According to the first principle, a *tactful object* should show sensitivity towards people's circumstances and vulnerabilities by acting as a partner that supports them in a positive and non-stigmatising way. Results showed how Mr.V the Spaceman helped family members to participate in activities together in a way that was experienced as positive also during difficult days caused by the treatment. An example of such a difficult day could be when the use of certain medication made the children undergoing treatment aggressive and easily irritable in interacting with people, or too nauseous and tired to be engaged. Unexpectedly, it was found that parents appropriated Mr.V the Spaceman to adjust its purpose according to their parenting needs, for instance by creatively using Mr.V the Spaceman to propose chores and easily include siblings in the activities. These findings support the expectation that fostering *sensitive partnerships* means introducing objects capable of leaving room for people's self-direction, creativity and meaning-making while achieving intended behavioural outcomes (i.e., engaging in quality time together).

Reminding and Actualising Activities

According to the data recorded, Mr.V the Spaceman spent on average 12.1 days at home with each family (*SD* = 7.3) and was used on average 8.2 days (*SD* = 3.6). During this timeframe, results showed how Mr.V the Spaceman helped families to be reminded of doing activities together and even helped them to actually do them. Rachel's father expressed how he felt that Mr.V the Spaceman helped bring the family together: ***"What I liked especially was that it was an activity for the whole family. By having Mr.V at home, you are forced to do things together every day, that was nice."***. David's mother recognised that the presence of Mr.V the Spaceman made her more aware of her children' needs: ***"[…] we dealt with these things more consciously and were more aware of the things that the children like to do and to do those things together."***. Mr.V the Spaceman was found to act in a light and playful way, as mentioned by Thomas' father: ***"It is a lot of fun! The nicest part was the awareness of Thomas, like: 'Oh! There are more surprises coming soon!' "***. It also succeeded in engaging families during critical days, as Aaron's father mentioned: ***"[…] he*** [Aaron] ***received treatment and the first four/five days he was exhausted, he did not feel well […]. We used it*** [Mr.V] ***also when he was feeling not so well […]. It was good. So, the feeling of excitement remains"*** (**Figure 7.5a, b, c**).

Parenting Role

Contrary to the expectations of the study, it was found, that in four families, parents used Mr.V the Spaceman to facilitate their parenting role by proposing activities that are not normally pleasant, in a playful way. Aaron's father explained that with the help of the object, the family turned 'boring' chores into something fun: ***"[…] we wanted it to remain exciting […]. It can also be used for other goals, clean your room so to speak."***. In Sean's family they wrote a lot of surprises concerning the preparation of healthy meals, which was one of the most annoying things for Sean during his long treatment, since he was often craving comfort food.

Involving Siblings

Families mentioned different ways in which they coordinated their interactions with Mr.V the Spaceman depending on their interests and skills. With most of the families, parents and children were equally in charge of defining the surprises' content and collecting the surprises that were dropped. Sometimes, like in Lana's case, parents helped in writing the notes because the child did not know how to write yet. The object also became a resource to easily include siblings of different ages. Three families mentioned how siblings worked together when using and playing with Mr.V the Spaceman. For instance, Rachel's mother explained that her three daughters approached Mr.V the Spaceman differently: ***"[…] the youngest***

two found it the most exciting, the oldest one mainly liked to write the assignments.". Sean's mother, mentioned that Sean's brother Paul, who was not yet capable of reading, was in charge of collecting and opening the surprises, while Sean was in charge of reading the content: *"[…] Paul pulled the ball out of Mr. V and then he opened the ball and then Sean read it to us […]. They did a good job together!"* (***Figure 7.5d***).



Figure 7.5 Partnering with Families: a) Simon and his sister participating in one of the challenges proposed by Mr.V the Spaceman; b) Simon's family members had a walk in the park, suggested by Mr.V the Spaceman; c) Sean's grandfather got involved in one of the outdoor activities proposed by Mr.V the Spaceman; and d) David and his brother organising the content of the activities together. *© by the author.*

7.5.2 Balancing Task Division in a Collaborative Way

The second principle focused on the way a *tactful object* engages with people in a collaborative way by thoughtfully dividing tasks between Mr.V the Spaceman and the families. It was noticed how the interaction with Mr.V the Spaceman had unfolded itself as had been imagined. Families were able to successfully create activities that were appropriate for their own family context by using the materials provided by Mr.V the Spaceman, and used the time-knob and emergency-button to make Mr.V the Spaceman's behaviour fit to their own preferences and schedules. Surprisingly, it was also found that families demonstrated even more creativity in the appropriation of Mr.V the Spaceman than had been expected, and further learned about how families were in need of even more control over Mr.V the Spaceman's behaviour.

Giving Subtle Guidance

Families creatively thought about 16.8 activities on average (*SD* = 8.5) and it was observed how the number of ball containers, the coloured notes, and the rules page (***Figure 7.6a*** *see p.142*) helped them as scaffolding tools. Two of the families distributed the ball containers according to the number of family members. Rachel's mother explained: ***"We divided the balls, there are five of us and we all wrote notes in three, or four*** [surprises]***."***. David's mother explained: ***"We divided the balls equally amongst everyone."***. In two other families, the colour of the notes was used to differentiate the content of the surprises. In Simon's family, each colour was associated with a topic: ***"Indoor surprises were blue, outdoor surprises were pink, personal surprises were yellow, and food related surprises were red."***. Sean's family drew up a list of surprises first and then the colours were used to identify and equally distribute the content, as they explained: ***"[…] we made a list, and eventually we discussed it together […]" "we created categories, the blue ones were five euros, and then the yellow was till 20 euros and the red ones were the extreme ones […]."***. Unexpectedly, two families also added white paper strips that were not included in the booklet to note down their activities, thus giving a different example of appropriation and way of structuring their task (***Figure 7.6b*** *see p.142*). The booklet's 'rules page' was used to help guide families in creating the surprises (***Figure 7.6c*** *see p.142*). In the case of David's family, his mother set one main rule: ***"[…] we agreed that it needed to be something for the whole family."***. In Sean's family, they set a list of rules such as: ***"Not buying toys, four balls per family member, of the four balls: two surprises less than five euros, one surprise less than 25 euros […]."***.

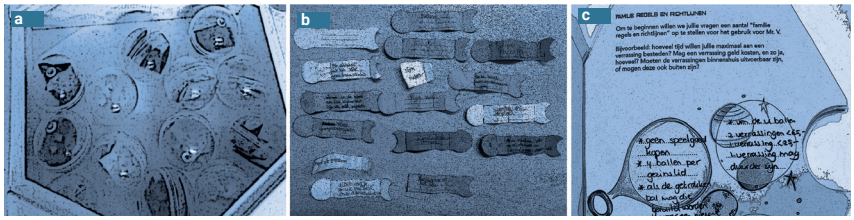

Figure 7.6 Balancing Tasks Division: a) distribution of content in the ball containers provided in David's family; b) in Rachel's family white strips of paper were added to the colourful paper strips provided in the booklet; and c) rules page used by Sean's parents to establish the type of content allowed in the surprises. *© by the author.*

Giving Opportunity for Family Coordination

Families dealt differently with the distribution of the surprises during the week. The logbook data showed that on average, families added 14.2 ball containers on the first day they used Mr.V the Spaceman at home (*SD* = 9.2) and 20.8 ball containers later during the week (*SD* = 26.0). Only one of the families did not add any other ball containers during the week. Jack's mother mentioned that on the first day they made enough surprises for one week and then when the surprises were opened and the activities completed, the father placed the ball containers with the same notes back in Mr.V the Spaceman: ***"We thought about something for six or seven days. And after a while, my husband put all the balls back so some of the activities were participated in twice!".*** Lenny's mother decided to select the number of ball containers inside Mr.V the Spaceman over time and every evening she added the notes that were to be dropped the day after: ***"[…] often in the evening we thought about things for the following day or if we came home in the evening we put something in quickly." "[…] I thought 'I want to steer a bit when a ball comes out' and if you put them all inside, you do not know what is coming out.".***

Adjusting to Preferences

Concerning the control of Mr.V the Spaceman's unpredictability, all families used the time-knob to set the dropping time of the automatic surprises according to their preference. The logbook data reported that on average families received 9.3 automatic surprises (*SD* = 4.3) throughout the week. On average, 3.6 automatic surprises (*SD* = 3.6) dropped in the morning, 3.8 automatic surprises (*SD*=2.6) dropped in the afternoon and only 1.9 automatic surprises (*SD* = 2.6) dropped in the evening; showing a preference for the morning and afternoon. Sean's mother explained that her family often choose the morning setting to be able to do the activities during the same day: ***"When you want to go canoeing, you will not go in the evening, so that is why we preferred to receive and open the balls in the morning and the rest of the day we were able to do the given activities.".*** Rachel's family chose the ***afternoon*** or ***evening*** in order to receive the surprises when everybody was at home: ***"Yes, because it was for the family, we set it on in the evening and afternoon, then everyone could keep track.".***

Giving Means for Ultimate Control to Family Members

Family members did use the emergency button as a means of an ultimate control. The logbook data showed how the emergency button was pressed 37.2 times on average (*SD* = 26.1) during the week. Parents explained that they used it in case they wanted a surprise immediately and also mentioned how often children played with it because it was easy and fun. Sean's mother explained: ***"If there was no ball yet, one of us was allowed to pull the handle […].".*** Rachel's father mentioned that it was easy to get surprises using the emergency button: ***"You can press the manual button infinitely, so you can get an infinite amount of balls.".*** Thomas' father confirmed that his child played a lot with it: ***"He*** [Thomas] ***wanted to show everyone, how Mr.V worked, so he used the button on the side regularly to show how a ball rolled out.".***

Leaving Room for Future Improvements

The families were also heard considering the need to have more control over Mr.V the Spaceman, specifically on: the predicted dropping time, on the type of surprise selected by the object, and on the children's accessibility to the object. First, children and parents in one family mentioned how the timeframe of three hours was too large. Mixed feelings of excitement and frustration emerged as Sean's mother explained: ***"[…] we were really waiting for the ball to drop, because the preference was between 09:00 and 12:00 in the morning, that was the setting; and then you see that the ball rolls out at 11:55.".*** Second, two families noted that it was sometimes not possible to engage in the type of activity

proposed by Mr.V the Spaceman immediately, as Rachel's father explained: ***"[…] it is complicated if you have to play Frisbee outside in the evening, in the dark."***. Third, the parents of two of the families noted that children often played with Mr.V the Spaceman and they would have liked to have had a way to limit their access to it, as Simon's father pointed out: ***"[…] we put it on in the 'morning' and then the children moved it to 'evening' […]. So I would say, make sure that parents can decide the settings and that they have more control over it […]. I think it would be better when it can be controlled a bit less by the children."***. Fourth, the parents of two of the families noted that Mr.V the Spaceman provided at least one surprise every day and they would have preferred to control the activation of the object and distribute the surprises during the week differently, as Aaron's father mentioned: ***"Parents should be able to decide themselves, there should be a balance […], have more control on that, distribute the balls over, four or three weeks."***.

7.5.3 Integrating Familiar Metaphors, Anthropomorphic Cues and Aesthetically Functional Elements

The third principle described how a *tactful object* establishes a meaningful connection with people because it behaves and looks familiar, and how this involved integrating a *familiar metaphor, anthropomorphic cues* and *aesthetically functional elements*. The results provided a description on how families experience these different facets of Mr.V the Spaceman's overall character and how they appreciated it. However, it was noticed how interesting insights emerged on the interpretation of the object as a character. For instance, the 'spaceman' humanoid association made people see the object as something to converse with (such as with a social robot). Moreover, families expressed the desire to associate meaning, character and aesthetics freely to the object to make it more their own.

The Dispensing Machine and the Activity Kit

Both parents and children understood Mr.V the Spaceman's functionality by referring to the working principle of the object as a gumball dispensing machine dropping surprises. Jack's mother explained that Jack and his brother knew how to use it without her help: ***"[…] they have seen a lot of them at Intertoys[5] […], so they have played with some machines like this when they were younger, so they know how it works […]. The machine at home works the same, but then with the little notes with activities, instead of presents."***. The integrated activity kit concept where each component can be removed and interacted with was also easy to understand and according to Simon's father contributed to encouraging exploration: ***"There is something here and there, and the balls and the drawer, it was immediately a thing that you could explore. Yes, that created an experience for the children."***.

The Humanoid Character

The humanoid character made the participants treat Mr.V the Spaceman as part of the family and encouraged them to communicate with it. During the interview with Sean's family, they mentioned that one evening someone said: ***"Goodnight Mr. V!"*** and Sean's little brother shouted: ***"That was me!"*** and Sean's mother confirmed the children saw Mr.V the Spaceman as a buddy. Due to its looks and expressive features, children and parents assumed a certain level of intelligence and expected some feedback. Jack's mother mentioned that her child tried to communicate with it: ***"Now he*** [Jack] ***is talking to Mr.V, but the machine is not replying."***. In line with the same concept, Rachel's father proposed the possibility of having a more responsive object: ***"That it can talk to you. A bit like Siri, so to say. That you can have more contact with it, like asking it how much time do we need to wait or something. Or if people press it two times very fast that it reacts like 'Hey!'. That it gives some feedback."***.

Openness to Free Association

To add to the perception of Mr.V the Spaceman as something they liked, some parents proposed to focus on allowing the families to choose which character they associate with the object freely. Jack's mother explained: ***"It is neutral at the moment."*** and ***"If it fit my child better, he would really love it […]. So, I think that if Jack got a robot in the shape of a Pikachu[6], he would go crazy for it, he would be really happy!"***. Aaron's family also speculated on alternative characters they would have enjoyed: ***"A Gandalf[7] or something?. I imagine a wizard, that holds a stick and when it moves the stick, a ball comes out […], because the balls come out in a magical way […], like crystal balls […], it is a mystery that comes out."***.

7.5.4 Using Subtle but Clear Expressivity to Preserve a Discreet Presence in The Home Context

The fourth principle states that a *tactful object* has a discreet presence within a sensitive setting because its expressiveness is designed to be both clear and subtle. Results showed how Mr.V the Spaceman could easily fit in family's homes (and in one case in the hospital room). It was understood that the object could express itself clearly (e.g., dropping a surprise, going to bed) but could sometimes lead to annoyance caused by some of the sounds it produced, and this made the families turn off Mr.V the Spaceman by unplugging it.

Fitting into the Environment

Mr.V the Spaceman was described to fit the home context. As Simon's father said: ***"[…] because it is so neutral, you can place it anywhere in your house."***. Most of the families positioned it in the living room so that everybody had access to it and the power connection was easy to reach. Sean's parents specified: ***"Well, it is a central spot in the house, and close to a power socket."***. Rachel's parents clarified: ***"We have our living room and there is a sort of corner to play on the carpet […]. We placed it there and from a practical point of view there was an electricity socket there"*** (***Figure 7.7a, b, c***). One family also used Mr.V the Spaceman in the hospital after the child was suddenly hospitalised. When Lana's family was interviewed they demonstrated that they positioned the object in a corner of the hospital bedroom over a bin close to the electric sockets (***Figure 7.7d***). Lana's mother commented: ***"We have not had any problem in having Mr.V at the hospital […], and because the nurses were not familiar with it, we explained it to them."***.

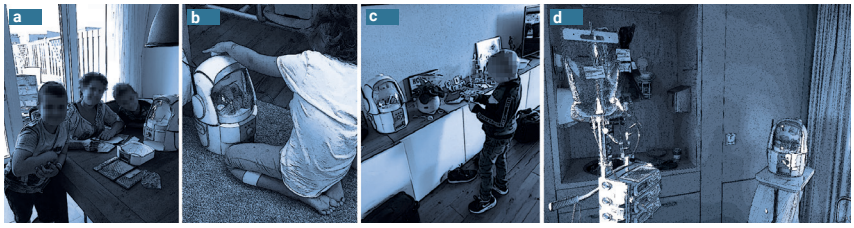

Figure 7.7 Discreet Presence in Context: a) Sean's family placed Mr.V the Spaceman on the living room table; b) Rachel's family placed Mr.V the Spaceman on the carpet in the children corner of the living room; c) Simon's family placed Mr.V the Spaceman in the hall near the living room; and d) Lana decided to bring Mr.V the Spaceman to her hospital room and placed it close to the electric sockets. *© by the author.*

Fitting into the Families' Routines

All the families were found to understand the object's expressivity. For instance, Lenny's mother recognised that Mr.V the Spaceman had a rhythm and she explained that to a friend visiting her house: ***"Yesterday there was a friend of mine here and at 20:00 in the evening, PING! My friend shouted: 'Aaah what is that?' I said: 'Mr.V is going to sleep.' And my friend asked: 'Who?' and I said: 'Well you have that when you have a robot at home'."***. She also noted that her son understood when Mr.V the Spaceman signalled anticipation before the surprise was dropped: ***"[…] on the first day it signalled that there was something coming […]. Then Lenny suddenly heard the thing and then he said 'Oooh! Something is coming in 10 minutes'."***. According to some of the parents these expressive features created an exciting routine, as Thomas's father explained while describing his child's reaction every morning: ***"When waking up, the first thing that he*** [Thomas] ***does is run towards it*** [Mr.V] ***[…], it is something you look forward to."***.

Missing a Sound Control Interface

However, the object data and the interviews revealed that families unplugged Mr.V the Spaceman from time to time because the sound level could not be controlled and produced a loud noise at times when the children were already in bed. The logbook showed that the object was on average unplugged at least three times during the week (*SD* = 2.75); with the exception of one family that did not unplug it at all. Sean's father explained that they unplugged Mr.V the Spaceman because they wanted to have complete control over the sounds in the house during specific moments of the day: ***"We had past difficulties with falling asleep […], sometimes we dismiss every factor in the house in order to provide a nice sleeping environment […], and then if you cannot influence Mr.V, then it is a little hard, and then you are inclined to remove the power plug […]."***. While Jack's mother unplugged the device in the evening to adjust the

schedule of the object according to the children's one: *"[…] Mr.V has some kind of bedtime too, he goes to sleep […]. They* [Jack and his brother] *need to go to bed at exactly 20:00 in the evening […], so I pulled the plug then."*.

Leaving Room for Future Improvements

To address this specific limitation, parents provided suggestions on how to adjust the object's expressivity to meet their needs and routines. David's mother suggested adapting the sound level: *"You know that it turns off at 20:00 in the evening, but it still scared us every time and then we laughed really hard because it also scared the cat. I would have liked it if the volume were a bit lower."*. She also mentioned to add more flexibility in the object's morning schedule to match the children's rhythm during school time: *"It turns on at 09:00 in the morning but on weekdays they* [David and his brother] *are at school at 09:00. So, it would be better if it turned on at 08:00 in the morning […], because now they miss that moment because they are not at home."*. Jack's mother focused on adjusting the evening schedule to match her children's bedtime during the school period: *"[…] because they* [Jack and his brother] *are sleeping at 20:00 in the evening. So, it is an unexpected sound during their bedtime upstairs […], it would have been nice if I was able to change the setting of when Mr.V goes to sleep."*.

7.6 Discussion

In this section, it is discussed how the findings deepened an understanding of *tactfulness,* and prompted reflections on how to make the object more *tactful as an intelligent object.* Successively, the ethical implications connected to that will be reflected on. The theoretical and methodological contribution of the work to different fields will be further highlighted, ending with the limitations of the study and briefly outlining suggestions for future work.

7.6.1 Envisioning Tactful Intelligence

Considering the insights collected throughout the study, the question now focuses on understanding how it is possible to envision *tactful intelligence* accordingly. Different approaches can be taken in developing intelligent objects (Chabot, 2019; Rozendaal et al., 2018). In top-down approaches, like the one used with Fizzy, a robotic ball for hospitalised children (Rozendaal et al., 2019), the object's intelligence was enacted by the researcher through puppeteering in a Wizard of Oz-like setup. Here, the object's intelligent behaviour can be engineered by formalising (and scaling down) the human intuitions the researcher had in controlling the object to obtain particular effects (in terms of cues and responses). The approach that was used with Mr.V the Spaceman in this study involved a bottom-up process that started by implementing a simple form of autonomy (e.g., dropping surprises at random times) and equipping the object with an array of sensors (D'Olivo, van Bindsbergen, et al., 2020), as a form of *data-enabled RtD* (Giaccardi, 2019b). Data-enabled RtD opens uncharted territories for how RtD practitioners might engage with computational things due to the completely new forms of interaction and relations between people and other connected things that arise. Within this framing, artefacts shift from simple things to partners and the exchange of data creates continued opportunities for co-creation in use while putting value on the process instead of the artefact itself (Giaccardi, 2019b). In relation to the work described in this chapter, the data collected by Mr.V the Spaceman via these sensors can provide insights into the use of patterns of the families, and when combined with experience-data, inspired the envisioning of a future intelligent Mr.V that is more aware of how to support families in sensitive settings. Below, these insights are reflected on by speculating ways to make Mr.V the Spaceman more intelligent as a *tactful object* and reflect on the ethical considerations when doing so.

Mr.V the Spaceman can became a more *sensitive partner* by being more attuned to individual needs and circumstances concerning its use and application. It was seen by counting the ***n. days of use*** between the first and the last timestamp, that the object was used effectively by the families throughout the week. A more intelligent Mr.V the Spaceman could use this data to make an assessment of people's engagement over time and strategise how to keep

their interest alive. For example, Mr.V the Spaceman could vary the way it expresses itself through particular sound and light patterns as a function of its frequency of use, detected by the sensors. Also the ***n. of surprises added on the first day*** and on ***later days*** can give Mr.V the Spaceman a sense of how particular families come up with new activities over time. An intelligent Mr.V the Spaceman could use this data to activate the creativity of the family more often in the case that the number of surprises decreased. With this in mind, it was speculated how Mr.V the Spaceman could suggest new activities based on previous activities that the families had engaged in throughout the week, or based on activities made by other families using other Mr.Vs. This requires Mr.V the Spaceman knowing what kind of activities are written down on notes, and eventually sharing these with other Mr.Vs in a connected network. This can eventually lead to ethical implications that will be discussed later. Finally, the analysis of the use-patterns over time along with the cancer treatment protocols assigned to each family by the hospital might even lead to Mr.V the Spaceman becoming aware of the child's illness trajectory.

User data collected by Mr.V the Spaceman will help the object in intelligently *balancing the collaboration* with the families through a sort of shared control that shifts more towards co-performance (Kuijer & Giaccardi, 2018) where uniquely human and uniquely artificial capabilities are integrated together. With the data on the amount of times the ***time-knob was set on in the morning, afternoon or evening***—along with data that indicates if the ***emergency-button*** had been pressed—Mr.V the Spaceman could assess what the most convenient moments are for families to receive surprises and engage in activities together. For example, by comparing the information on the number of ***automatic surprises*** received during the week with the number of surprises that were manually requested, an intelligent Mr.V the Spaceman could interpret whether the number of automatic surprises was suitable or not, and eventually present some extra ones to the families during the week. Mr.V the Spaceman could also use this data to dynamically change the window of opportunity without overburdening families with complex control options. For instance, recording that the emergency-button was often pressed after the automatic dropping of a surprise could prompt the intelligent Mr.V the Spaceman that the families did not receive a surprise, or on the contrary, if pressed sooner, maybe did not want to wait any longer. These insights can then be used by Mr.V the Spaceman to set up the time-knob autonomously or finetune the time-window position and length to gain more specificity as desired by the families.

Making Mr.V the Spaceman context-aware can improve its *discreetness* in the home. Recording a lot of ***unplugging*** could be recognised by the intelligent object as an indication that during specific moments, it is not necessary to be powered on or that its presence should subtler. Therefore, an intelligent version of Mr.V the Spaceman would recognise in which room of the house it is placed, what is happening in its surroundings, adjust its sound level according to the time of the day it is or the level of noise in the house, automatically go into stand-by or night mode or even substitute the sound with a subtle pulsating light. The results further highlighted the necessity for Mr.V the Spaceman to know who is using it and allow access to different functionalities for different users. For example, if the manual button is pressed randomly and often, an intelligent Mr.V the Spaceman might be able to identify who is using it. The object could then recognise that children are playing with it and react by making funny jokes and use the children's favourite cartoon sounds to initiate a playful interaction, but also to lock particular features (i.e., child-safety mode) not to let children modify the structure created by the parents based on their family schedule.

With these speculations, particular concerns emerge when computational intelligence is incorporated into *tactful objects*. As emphasised in recent work, there are several socio-ethical implications in using computational intelligence that concern privacy and confidentiality data issues (Hors-Fraile et al., 2016; Murray-Rust et al., 2019; Reddy et al., 2020). For instance, applying intelligence to personalised interaction involves *user-profiling and data sharing* which both have ethical implications. User-profiles is normative (Rossi et al.,

2017), and can be vulnerable to stereotyping and stigmatisation (Vincent, 2016). Regarding the data sharing, who is responsible for the security of the data? What if the data exchange between a connected network of Mr.Vs creates a breach of sensitive information between one family and another (or perhaps with care-givers)? When thinking about computational intelligence that increases the autonomous functioning and decision making of people it collaborates with, the *transparency (of control) and agency confusion* are critical issues. When it is not transparent how control is shared exactly (Abbink et al., 2012; Spagnolli et al., 2017), how the objects reasoning takes place, confusion can arise about how, what and who is responsible when things go wrong (Haselager, 2013); like in the case in which the object interprets the requests of the family members in a wrong way. Obviously, *context aware systems* are prone to privacy issues and legal clarity (Asaro, 2011), which require defining what exactly needs to be monitored by sensors, how much of the environment and people's situations should be visible, and how to deal with this aggregated data, as described earlier. In developing *intelligent tactful objects*, design practitioners and researchers should be trained to be responsible (Roeser, 2012) and prepared to anticipate and raise these kinds of ethical questions during the design process, and new approaches, methodologies and norms should be developed to support them (Van de Poel, 2020). For instance, in a future iteration, the *tactfulness principles* used in this work should be implemented with questions and keywords related to the ethical implications of capturing data. In this way they can turn into a valuable support for researchers and designers in also considering these aspects while designing a new *tactful object*. Moreover, a new intelligent Mr.V the Spaceman will be envisioned with the capability of *clearly communicating* which data it collects from families and how it intends to use it, or explain to the families how to access the data that was recorded to monitor it. However, as with some artificial intelligence systems (Markoff & Paul, 2015), the communication with the object can be easily influenced by anthropomorphising and 'Otherware' social metaphor association (Hassenzahl et al., 2020), and instead the generation of such emotional dependency in the user should be avoided.

7.6.2 Theoretical Contribution to Human-Computer Interaction and Interaction Design

The work described in this chapter contributes to research in Human-Computer Interaction (**HCI**) and Interaction Design by extending knowledge on: the empowerment of complex socio-technical systems such as families, interplay and learning between humans and objects, challenges on designing for the ambiguity of smart objects and the embodiment of multiple human-technology relationships.

Empowerment

Mr.V was designed as a *sensitive partner* with the intent of empowering family members in maintaining healthy behaviour in interacting with each other also during difficult times. In HCI and Interaction Design, *empowerment* is described as complex and most often used in the context of people with disabilities (Ladner, 2015) where assistive technologies in the form of physical-digital hybrids have the purpose of *"enabling people to be and become most fully who they are"* (Van Dijk & Verhoeven, 2016). Using design to empower people (Fogg, 2002) without imposing directionality, but motivating them in a positive way (Desmet & Pohlmeyer, 2013; Hassenzahl et al., 2013), allows for *behavioural change* to be achieved (Jelsma, 2000; Kehr et al., 2012; Lockton et al., 2010). This is in line with what is presented in the Resourceful Ageing project (Giaccardi & Nicenboim, 2018) where empowerment is achieved by tapping into internal resources and using data/intelligence to create opportunities for improvising and co-performing instead of monitoring and persuading. However, in this work it has been learned that designing a sensitive partner that empowers and encourages the behavioural change of a whole family, also calls for a perspective that is *family-centred* (Han et al., 2018) and in line with approaches also used in psychosocial support in cancer care (Ashiabi & O'Neal, 2015; Salem et al., 2020; Santos et al., 2015; Zabriskie & McCormick, 2001). Mr.V the Spaceman empowered the whole family as a 'collective action', providing support and attention to each individual family member.

Co-performance

The work conducted contributed in providing illustrations on how a future tactful intelligent Mr.V the Spaceman will learn how to better attune to a context and family's needs by interacting with family

members. The definition of this type of object's agency that derives from a process of embodied learning from people's actions in the context, corresponds to the notion of *co-performance* (Kuijer & Giaccardi, 2018). The object is capable of learning and consequently performing or re-interpreting the family's practices (e.g., proposing new activities) together with the family members in the context. This helps in augmenting the abilities and skills of people to improve their well-being at the same time. The interaction between families and Mr.V the Spaceman evolved as a situated and sustained *interplay between humans and objects* (Desjardins & Wakkary, 2013). In the 'creation' of the surprises, the object had a prominent role by providing a tangible means for interaction and delicately guiding the families. In receiving the surprises, the role of the object and the families were equally balanced as the families selected the timeframe for delivery, and the object surprised the families with unknown content within the timeframe. Finally, during the moment set aside for the activity, the family had a prominent role in deciding when and how the activities would take place, and how the object moved in the background. The *agency of the object* (Rozendaal et al., 2020; Verbeek, 2005) balances with the agency of the families and this contributes to maintaining active interaction over time. This acknowledges the uniquely human and uniquely artificial capabilities and how these can be integrated in the context of performing/carrying out everyday practices, generating a *balanced collaboration* where both humans and objects can internalise new competencies and skills over time (Giaccardi, Kuijer, et al., 2016).

Hybridity

In the, literature, *hybridity* (Rozendaal et al., 2019, 2020) is described as the characteristic of smart objects given their ontological ambiguity as being both tools and agents. The work described here contributes to this notion by providing an illustration about the hybrid nature of the object and its merit (Dörrenbächer et al., 2020). For instance, Mr.V the Spaceman was designed and experienced as an *interactive toy-like dispensing-machine with the anthropomorphic connotation of a spaceman*. Blending together these different metaphors while designing the object is challenging but necessary in guaranteeing that the object's purpose and agency is understood. According to Dörrenbächer and colleagues (2020), this represents the strategy for designing domestic partners capable of better adjusting to the needs of users. Thanks to their hybridity, they remain flexible to interpretation and this facilitates their acceptance in the context and gives opportunity for new relationships to arise. If one of these metaphors becomes more prominent then, an understanding of these objects might be lost. For instance, if the machine-likeness becomes more prominent in the appearance of Mr.V the Spaceman, people might not empathise with it anymore, as an intentional creature or buddy. Alternatively, if the humanoid character metaphor becomes more prominent, people will interact with it as a human (Dörrenbächer et al., 2020), expecting the object to be more authoritative rather than an equal partner in their everyday life. This reflection aligns also with, what is according to Hassenzahl and colleagues (2020), the next grand challenge in HCI concerning the way people live and design this new class of technology in the foreseeable future.

Human-technology relations

This work illustrated how Mr.V the Spaceman could embody *multiple human-technology relations* as described in Don Idhe's post-phenomenology (1990; Verbeek, 2005). According to Idhe's description of human-technology relations, technology can assume different roles in our daily lives such as: mediating our experiences, generating alterity relations where it behaves as another, and shaping our experiences in the background while not remaining experienced in a conscious sense. These relations can exist simultaneously and alternate over time. Although these human-technology relations were not designed intentionally, they were seen to emerge. For instance, families used the materials provided by Mr.V the Spaceman in an *embodiment-relation* to create, store and receive activities as surprises but they also started to speak to Mr.V the Spaceman as if it were human, suggesting an *alterity-relation.* The mere presence of Mr.V the Spaceman in the home, reminded families of the importance of enjoying quality time together (i.e., a *hermeneutic relation*), but it also blended into the interior of the home as a manifestation of Idhe's *background-relation* (Rosenberger & Verbeek, 2015). Therefore, this work contributes to research on human-technology relations by giving illustrations on how an object also designed to address a specific health related challenge can go beyond the utilitarian scope of the e-health tool/device. Furthermore, this work contributes in reflecting how to design an object's discreetness and 'non-use' (e.g., foreground presence) when introduced into a context.

7.6.3 Methodological Contribution to Research in Design and Healthcare

Using a data-enabled RtD approach (Giaccardi, 2019b) to conduct field research with families dealing with childhood cancer, offered an opportunity to engage with a vulnerable group of

people dealing with stressful circumstances (Munteanu et al., 2014; Vines et al., 2014; Vines, Clarke, et al., 2013) and also helped to overcome contextual limitations (Dickson-Swift et al., 2007; Thieme et al., 2014; Waycott et al., 2015). For the family members, Mr.V the Spaceman became a 'tangible conversation piece' (Stappers et al., 2015). By describing how they used it and what they thought about it, the families also shared personal life anecdotes with the researchers. The object functioned as a sort of sensitive probe (Crabtree et al., 2003; Gaver et al., 1999) allowing the researchers to dive deeper into the families' habits, routines and culture without being invasive. However, Mr.V the Spaceman looked and worked as a real product 'ready to use', at the same time (Odom et al., 2016).

The object was designed to retrieve non-sensitive data in a subtle way without distracting the family (Giaccardi, Cila, et al., 2016), and without imposing sustained participation from the family members in filling in diaries or attending co-design sessions with other families (Aldridge, 2016). Using a prototype equipped with sensors made it easier to overcome the challenge of conducting observations in sensitive (and private) settings (Gaver et al., 2007). It would have been impossible for the researcher, and not sensitive, to remain in close contact with the families in such a private context over the entire week of the study (Munteanu et al., 2014). Mr.V the Spaceman became an 'extension' of the researchers and physically spent time with the families, sharing in their everyday life. The prototype could perform a form of ethnography (Giaccardi, Cila, et al., 2016) by recording data in situ from the point of view that users would not be able to record nor consider relevant, and that could provide a complementary and possibly more holistic perspective on the problem under analysis. For instance, details of the specific repetitive patterns and strategy that were implemented by families when filling Mr.V the Spaceman with ball throughout the week would have not been easily captured through the interviews alone.

This contribution is also the result of a fruitful and structured collaboration between the design and healthcare field. By interacting with healthcare professionals, design researchers gained knowledge on how to appropriately structure the design study in line with medical ethical requirements (Munteanu et al., 2015), diving into the field with more confidence (Groeneveld et al., 2018) and getting the chance to meet patients undergoing cancer treatment. By following design researchers in their field exploration, healthcare professionals obtained a different perspective on their patients' life outside the hospital, and what new meanings and possibilities were brought by design (and *tactful objects*) in caring for their patients. Furthermore, they were able to experience the possibility of using design to address the family as a whole (D'Olivo et al., 2018) and collect research data (Giaccardi, Cila, et al., 2016).

7.6.5 Limitations and Future Work

The concept of *tactfulness* through the example of Mr.V the Spaceman was discussed and elaborated on. This work should also be applied in other sensitive settings to generalise the understanding of *tactfulness* as an interactive quality for design in sensitive settings.

The sensitive context and the necessity in obtaining permission from the Medical Ethical Committee to conduct the study at families' homes, created limitations within the study design. The one-week deployment of the prototype constrained any generalisations about the long-term effect of the *tactful object* developed, and a longitudinal study should be considered (Karapanos, 2013). However, the work built on a previous study conducted in the same context where families already gave positive feedback on the impact of an earlier version of Mr.V the Spaceman (D'Olivo, van Bindsbergen, et al., 2020), providing insights that go beyond the *'trajectory of novelty'* (Gaver et al., 2007) regarding the use of the object.

Diving into the field allowed the researchers to learn more about the complex dynamics that are present in the surroundings of families dealing with childhood cancer (Patterson et al.,

2004). The children's medical condition can rapidly change (Woodgate, 2006a) and with that the routines of the family members also living with them (Alderfer & Kazak, 2006). Mr.V the Spaceman was evaluated with some of the families while the child received treatment or was suddenly hospitalised. This already provided a different perspective compared to the use of the object in a stable situation. However, the object was not used during different moments in the treatment trajectory, which could have provided new and different results to reflect on. Additionally, the implementation of Mr.V the Spaceman in hospital was not studied, which could also be a relevant environment to consider.

The reflections on the implementation of computational intelligence in sensitive settings are instrumental in thinking about future work. In line with studies on the agency of objects in people's everyday life (Cila et al., 2017; Giaccardi, 2019a; Rozendaal et al., 2019, 2020), it was deemed important to look into the risk and ethical implications in developing *intelligent tactful objects* and introducing artificial intelligence in sensitive settings (Giaccardi, 2019b; McNaney & Vines, 2015; Murray-Rust et al., 2019). Further analysis of the data obtained by the sensors and collected by the objects in the field will help select essential information needed to adjust their behaviour in an appropriate way and establish boundaries (Jenkins et al., 2019) not to invade the user's privacy and hinder the object's tactfulness.

7.7 Conclusions

This chapter described how tactfulness was used as a design quality in developing a *tactful object* for sensitive settings and to further speculate on how to imagine the design of *intelligence in a tactful form*. For this purpose, Mr.V the Spaceman was designed whereby applying four *tactfulness principles*, namely: *sensitive partnership, balanced collaboration, familiar character and discreet presence.* Mr.V the Spaceman is a tactful object with the purpose of empowering families dealing with the disruptive life-event of childhood cancer by maintaining healthy interactions during stressful times at home and is also equipped with sensing capabilities to record user patterns. The work enriched the definition of each of the four principles and allowed for reflections on how interactive objects could be made more tactful as intelligent objects. Critical aspects such as security and privacy in data sharing, carefulness in user-profiling, and safeguarding the transparency of intelligence and control need to be considered in such a responsible design approach. Contributions of this work to research in HCI, Interaction Design and Healthcare were discussed to highlight the value of developing objects that use their intelligence to better adjust to the needs of people in sensitive settings and augment their skills and abilities to enhance people's well-being.

Chapter's Takeaways

The introduction of computational intelligence in tactful objects for sensitive settings allows for the envisioning of interesting opportunities to make objects more sensitive and supportive in the environment in which they are introduced. Therefore, it is important to understand how exactly computational intelligence can bring benefit in such settings;

Insights from the third study indicate that a data-enabled object designed for families with children in treatment for cancer: (i) could help parents in their parenting role, in facilitating the involvement of the siblings and maintaining awareness on the importance of spending time together; (ii) should be able to balance the delegation of tasks within the family in a collaborative way so that both the object and family members have their own role and learn to co-perform together over time, (iii) should be built as a hybrid combination of familiar metaphors, anthropomorphic cues and functional elements that facilitate emphatic connection and interest; (iv) should use subtle but clear expressivity to fit into the context and the routines of the families, to better perform according to what is necessary and act only when is needed;

'**T**actful intelligence' is an interesting and challenging opportunity for future research in sensitive settings.

Endnotes

5. Dutch toy store for children.
6. Pikachu is a fictional creature that appears in video games, animated television shows and movies, trading card games, and comic books licensed by The Pokémon Company.
7. Gandalf is a protagonist in J. R. R. Tolkien's novels The Hobbit and The Lord of the Rings

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8 SUMMARY OF CONTRIBUTIONS & CONCLUSIONS

8.1 Introduction

This final chapter is dedicated to reflections on the project's research and design contribution and in explaining how the main research question of this thesis, namely, **how can vulnerable users be empowered by design in sensitive settings?** was addressed. In order to do that, answers to the three research sub-questions will be provided first. Second, the contribution of the work to the field of Interaction Design and design education will be highlighted. Third, the societal contribution of the work to the Healthcare field (specifically psychosocial cancer care in paediatric oncology) will be explained. The chapter concludes with describing the implications, limitations and recommendation for the clinical implementation of the results of the project and proposes opportunity for future research.

The research contribution of this thesis was to extend knowledge on design for sensitive settings. Overall, the thesis addressed research in three areas: **(i) the development of tactful objects for sensitive settings, (ii) the exploration of a tactful approach to conduct design and design research in sensitive settings, (iii) the contribution with regards to innovation in healthcare.**

Three research sub-questions were formulated to address the *development of tactful objects for sensitive settings* by focusing on the specific context of families dealing with childhood cancer. The design *perspective of Tactful Objects* used throughout the project comprehends: the definition of the design quality of '*tactfulness*', the generation of four actionable *tactfulness principles* for practitioners and researchers working in sensitive settings, the tangible development of *tactful objects*, and the speculation on how to introduce computational intelligence in a tactful way in sensitive settings.

1: How can families with children with cancer be empowered to adapt to a New Normal during life disrupting events?

The first research activity put into action to address this first sub-question was an initial field study conducted by observing participants at a survivors' childhood cancer meeting. This exploration highlighted several challenges caused by childhood cancer. To organise these insights, a model was developed and used in the healthcare field to describe the systemic complexity of child development, namely, the Bronfenbrenner and Ceci's bioecological model (1994). Overall, it was understood that the temporal shift between *normal family life* with specific routines and habits before cancer, to a *cancer normal* divided between home and hospital and then again, a *new normal* having undergone the treatment, profoundly affects the child. It also affects the family members who are the proximal system that strongly support his/her development. Home is the environment where the child and his/her family members struggle the most to autonomously find resources to preserve and maintain normality through this time.

There are different challenges caused by childhood cancer (described in Chapter 3). It was found that to empower families with children with cancer to adapt to a New Normal, it is necessary to focus on the child and the first two levels of the Bronfenbrenner and Ceci's model (1994) comprehensive also of the family members (i.e., interpersonal level, organisational level). What this means is to act on the interaction and communication between the child with each individual family member but also within the family as a whole. These discoveries represent the starting point from which the project developed with the intention of designing a form of support that could tactfully integrate into the family context while being able to sensitively empower family members and continuously adapt to the changes that their context requires.

2: How can tactfulness be used as an expressive design quality to develop interactive artefacts for the sensitive setting of families dealing with childhood cancer?

To address this second sub-question, the inquiry focused on the sensitive setting of families dealing with childhood cancer as a design space, and consequently explore how *tactfulness* could be embodied as an expressive quality in interactive artefacts to help families deal with childhood cancer. Two artefacts were developed and described in Chapter 4, namely Mr.V and AscoltaMe. The articulation of *tactfulness* through the character of the technological materials used in the design of the interactive artefacts (Redström, 2005) and the experiences that they have the purpose of enhancing, was carried out following the 'Materials Experience framework' developed by Giaccardi & Karana (2015) and the notion of 'temporal form' by Vallgårda and colleagues (2015). The design quality of *tactfulness* was expressed in the designs examining how the artefacts influenced the human sensory system regarding their proximity (i.e., the sensorial level), the association and meanings they carried (i.e., the interpretive level), the emotions they triggered (i.e., the affective level), the practices they mediated (i.e., the performative level) and the temporality of the input and output signals they used in the context to communicate and interact with people (i.e., the temporal level).

Successively, the deployment of these artefacts in the field (addressed in Chapter 5) contributed to framing the *perspective* of Tactful Objects. These are interactive artefacts which express *tactfulness*, and that gives them the capability of empowering people in sensitive settings. The field work provided the opportunity to observe how families understood and appreciated these artefacts, and the type of family behaviour and changes that they triggered in the family's everyday context. The family members' descriptions highlighted that the way in which *tactfulness* was embodied helped the artefacts to be perceived as partners aiming at being supportive in a positive way, in transforming the interaction between artefacts and people interacting together. The *tactfulness* also provided the artefacts with an inviting appearance, easy to empathise with, and made the artefacts behave appropriately for the context in which they were introduced. Therefore, it was understood that *tactfulness* could be used to design objects capable of enabling people by acting with respect for their vulnerabilities and circumstances through the establishment of partnerships and collaborations. This was carried out in an inviting way that was appropriate for the setting in which they are embedded.

The project was iteratively developed to more clearly define what constitutes *tactfulness* and how it could be used to articulate the expressiveness of interactive artefacts for the sensitive setting of families dealing with childhood cancer.These insights on *tactfulness* were further articulated as design principles and used to design a new artefact named Mr.V the Spaceman (presented in Chapter 6). Mr.V the Spaceman was designed to be perceived as a *sensitive partner* addressing the family's needs, by establishing a *balanced collaboration* with the family, and by tangibly embodying a *familiar character* that could maintain a *discreet presence* in the family home context. The interactive artefact was also equipped with sensors in order to collect user-related data.

3: How does computational intelligence allow interactive artefacts to become more tactful and attuned to the needs of families dealing with childhood cancer?

To address this last sub-question, the new research activity conducted was a third field study (presented in Chapter 7). Here, the data-enabled Mr.V the Spaceman was used. This study helped in establishing the four *tactfulness principles* and the data collected by the artefact provided insights on the behaviour, preferences and desires of the families involved in the study. This data in combination with the users' experiences foregrounded the opportunity to envision a form of tactful computational intelligence that could allow *tactful objects* in better adapting to the needs of people in sensitive settings and behave even more tactfully.

Computational intelligence can increase the capabilities of interactive artefacts so that they become able to learn how to best support the families as a *sensitive partner* while at the same time keeping their behaviour open to new interpretations (Boon et al., 2018) according to the desires of the families. It can also bring the artefacts to *collaborate* with families in a more *balanced* way by learning about that family's practices and rituals and use this knowledge to further support each family member while allowing them to remain independent and in control (Kuijer & Giaccardi, 2018). It can also have positive effects in balancing the several aspects that contribute in perceiving the object as a *familiar character* by embodying meaningful metaphors, being the stimulus for specific experiences and adopting recognisable user cues (Rozendaal et al., 2019, 2020) Finally, computational intelligence has the ability to calibrate the artefacts' interactive features to help them maintain a discreet presence, such as understanding what the clearest and most sensitive ways of communicating intentions with people are, and adjusting the foreground and the background presence according to the needs at the time.

8.2 Contribution to Interaction Design and Design Education

This contribution concerns the *exploration of a tactful approach to conduct design research in sensitive settings*. To achieve this, the work investigated how Research-through-Design (**RtD**) (see Chapter 2) could turn into a tactful approach to build scientific knowledge for design in sensitive settings, engage vulnerable users in sensitive settings in an appropriate way and provide strategies for research and practice in collaborative projects between the design and healthcare fields.

8.2.1 Contribution to Interaction Design by Developing an Intermediate Level of Knowledge for Design

As briefly introduced in Chapter 2, by building upon the framework proposed by Hook & Löwgren (2012), AscoltaMe, Mr.V and Mr.V the Spaceman prototypes turned into the instantiation of the *Tactful Objects perspective* and helped in building different levels of research knowledge at different levels of abstraction (***Figure 8.1*** *see p.158*). AscoltaMe, Mr.V and Mr.V the Spaceman became 'filters' to highlight the needs and opportunities of specific areas of the sensitive setting of families dealing with childhood cancer. Translating design activities into prototypes allowed them to tangibly embody the hypotheses that emerged to address the three research questions presented previously while also generating implementable solutions in the field.

Defining the expressive design quality of *tactfulness* further through such artefacts allowed design principles to emerge. Such principles are meaningful in providing ways to make effective design decisions in developing interactive artefacts that will behave tactfully in the sensitive setting in which they are introduced. At the same time, they also provide a starting point to reflect on how to develop a form of computational intelligence that while increasing in complexity and capabilities, remains tactful and attuned to the needs of people in sensitive settings. These principles are not guidelines or standard rules, but suggestions to be borne in mind by researchers and practitioners developing interactive artefacts for such settings. These guidelines can also assist in anticipating ethical challenges and the societal implications of the implementation of these interactive artefacts in sensitive settings. The *principles* ascribe to a more general level of knowledge than *expressive qualities* and contribute to supporting the envisioning of a *perspective* and consequently *future theorisation*.

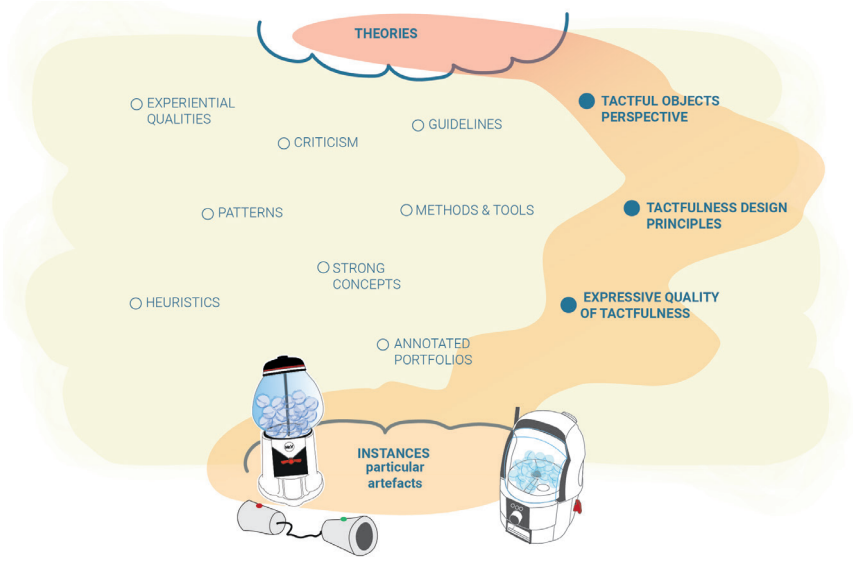

Figure 8.1 Adaptation of model from Höök & Löwgren (2012) that highlights the type of intermediate levels of knowledge developed in this project: the expressive quality of tactfulness, tactfulness design principles and Tactful Objects perspective. *© by the author.*

The *perspective of Tactful Objects* described in this thesis and the *Playscapes perspective* described by Boon (2020) for the creation of space for young children's physical activity and play in the hospital developed within the same 'Meedoen=Groeien!' project, together also offer insights into the implementation of computational intelligence in everyday settings. The design of Mr.V the Spaceman (in Tactful Objects) and Fizzy the Robotic ball (in Playscapes) become meaningfully connected with the broader research programme of 'Objects with Intent' (**Owl**) developed by Rozendaal (2016). The Owl research programme consists of what Redström (2017) defines as a 'larger effort' of programmatically developing smart everyday objects with the intent of empowering their users (***Figure 8.2***). Programmes are complex socio-material assemblages capable of 'collecting' isolated statements addressing specific cases in the design space, unifying definitions, and creating traces for future development by being transitional and fluid. The Owl research programme expresses 'the difference it can make if' the goal of some of the objects developed for the sensitive setting of families with a child dealing with cancer such as Mr.V the Spaceman and Fizzy would be used in everyday contexts instead. The objects mentioned here were designed to make two different contributions and address two different challenges such as the one in supporting the psychosocial and physical development of children with cancer respectively. However, even if they function as isolated statements, they can turn into 'fragments' populating and contributing to the articulation of a more fundamental level of knowledge as the one generated by Owl. Successively, such a research programme provides knowledge to the theoretical foundations for the development and introduction of agentic partners in the everyday life of people together with other research programmes such as the Resourceful Aging research programme, for instance (Giaccardi, Kuijer, et al., 2016; Giaccardi & Nicenboim, 2018).

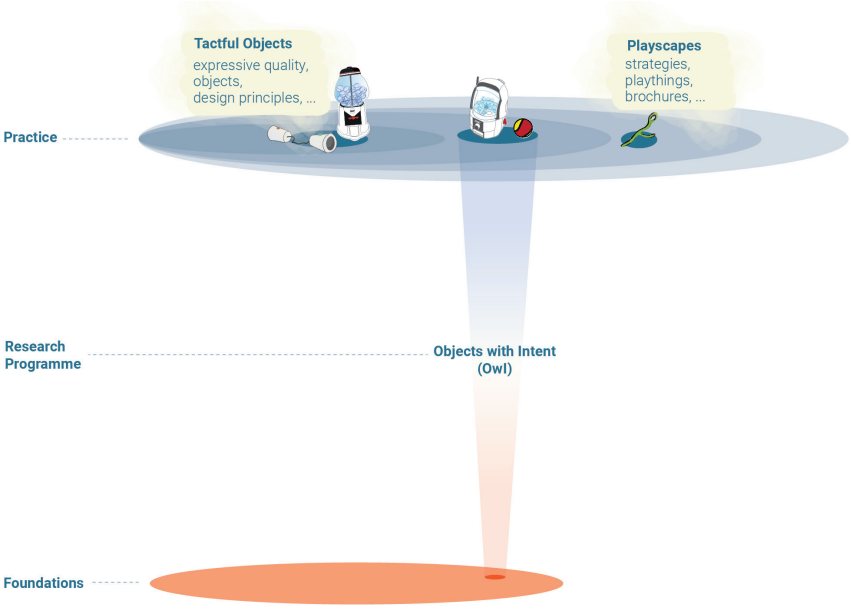

Figure 8.2 Adaptation of figure 5.6 from Rëdstrom (2017: 95) on the link between the type of knowledge developed here and in Boon's thesis (2020) , and its contribution to the broader research programme of Owl (Rozendaal, 2016; Rozendaal et al., 2019). *© by the author.*

8.2.2 Contribution to Interaction Design by Showing the Potential of Research-through-Design in Sensitive Settings

This project contributes to interaction design by also offering an example on how a RtD approach could be implemented to address sensitive settings and facilitate the collaboration between the design and the healthcare field. This approach allowed different theoretical models and approaches from both the design and healthcare field (e.g., the Developmental Theory, Ethnography, Participatory Design, etc.) to meet and use prototypes to go beyond the mere scope to initiate or discuss potential concepts and generate scientific knowledge while offering implementable solutions.

The RtD approach was particularly relevant to address the context investigated in this thesis. This methodology allowed a vision through tangible solutions to be 'humbly' embodied, which were gently introduced and taken on board in order to collect data in a sensitive way. By keeping the prototypes in the centre of the investigation, the context was explored differently by tiptoeing away from sensitive situations and by offering a new way of 'listening' where people could react to what they had used and interact with it in their every day.

The 'completeness' of the research prototypes developed for this project was determined by the need to fulfil requirements related to hygiene and sturdiness for their employment in the field with the families who participated in the study. The 'completeness' of the design was also developed to this level as it was needed to discuss research opportunities and insights with professionals from the healthcare field and fulfil their expectations. The prototypes became statements talking to the families and to the healthcare professionals for the design researcher. When asked to reflect on the conclusion of the 'Meedoen=Groeien!' project, ***Pieter Jan Stappers***, professor of Design Techniques and Director of Research of the Design School at the Faculty of Industrial Design, Delft University of Technology, and promotor of

the second doctoral design researcher focusing on addressing the physical development of the children in treatment in the same 'Meedoen=Groeien!' project, provided a comment that indeed highlighted the meaningfulness of the prototypes in communicating the research results with the parties involved in the project:

> *"Through the use of prototypes, all participating parties understand the possibilities in the project better and then other spin-off activities come around. While these activities are invisible, prototypes are very reassuring signs or markings on the landscape that help people navigate. In this specific project, they showed the existing possibilities between design and healthcare.".*
> *(meeting at Delft University of Technology, Delft, 14 January 2019)*

Furthermore, the use of advance research prototypes also provides a starting point to sensitively tackle the complexity of the setting while strategically introducing and reflecting on the potential of interactive and intelligent agents in adapting to the continuous changes in time that such settings experience. When asked to reflect on the conclusion of the 'Meedoen=Groeien!' project, ***Huib De Ridder***, professor of Information Ergonomics at the Faculty of Industrial Design, Delft University of Technology, a member of the steering committee that initiated the conversation between Delft University of Technology and Hanneke De Ridder (one of the project's ambassadors) to set up the project's goal and structure, shared a reflection that aligns with the contribution here described:

> *"Dealing with child development means that you cannot focus on one moment in time, you need to design things that become dynamic and change. This change is the complexity that should be tackled.".*
> *(meeting at Delft University of Technology, Delft, 17 January 2019)*

8.2.3 Contribution to Interaction Design by Supporting Design Students, Researchers and Practitioners Working in Sensitive Settings

The *tactfulness design principles* and the *Tactful Objects perspective* can provide general guidance and inspiration to design students, future researchers and practitioners in generating solutions for several sensitive settings other than the one analysed in this thesis. They can also offer a way to initiate reflection on the risk and ethical implications in implementing technology in sensitive settings (Roeser, 2012).

Final year master students of the faculty of Industrial Design Engineering at Delft University of Technology used the *tactfulness principles* in their thesis to envision and design other *tactful objects* to support people in other sensitive settings. One student, ***Marieke De Paauw*** focused on using the *tactfulness principles* to design an interactive object aimed at tactfully giving structure to parents of children with mild intellectual disabilities during their eating routines by increasing parents' self-efficacy and making children feel more independent. The project resulted in ***Luna***, an interactive table light that can be placed on a dining table which uses expressive features (i.e., wall projections and light) to work as a partner in the house and remind those parents of regularly preparing meals for themselves and their children, while leaving them a sense of autonomy and control in choosing when and what to prepare for their children (de Paauw, 2019). Another example, was the project developed by ***Rubi Vermeulen*** focused on using the *tactfulness principles* to support women with severe sleep deprivation in their sleeping hygiene (Vermeulen, 2018). The student developed ***Maya***, a tactful home interactive system aimed at gently guiding women affected by sleep deprivation in following a consistent weekly routine before going to bed. The system collaborates by tactfully triggering women's awareness and motivation in interrupting activities that can be disruptive for their sleeping hygiene (e.g., using screens in bed, going to bed too late). This integrated home system generates a 'relaxing journey' by means of different interactive sceneries (e.g., with sound, lights) within the house over the two-three hours before bedtime to help the user in focusing on the transition from being awake to falling asleep.

Furthermore, 18 Students from the Master's of the faculty of Industrial Design Engineering (Delft University of Technology) participating in the ***Capita Selecta***, an elective course presenting and discussing design challenges and research topics in the healthcare field, joined a workshop aimed at observing how design students apply the *tactfulness principles* to develop new designs for people in sensitive settings. At the conclusion of the workshop, they shared that the *tactfulness design principles* were easy to understand and provided further suggestions on their application according to the design process timeline. At the ***beginning of the design process,*** the *tactfulness design principles* represent a great starting point that can help in finding direction. The students also found them useful in boosting creativity during the ideation phase, as they function as a sort of checklist. Some of the students noted that using the guidelines in the ***middle of the process***, helped them in bringing the focus back especially when they were overwhelmed by the amount of insights collected about the sensitive context they were investigating. The guidelines offered a way to keep track of the progress along the process. For some of the students the guidelines were also useful ***at the end of the design process*** when the concept was finalised to evaluate if all the *tactfulness* aspects were in place.

The students further expressed the importance in expanding these principles by adding some examples and a detailed explanation of how the principles have been applied in different case studies with visualisations of the outcomes, details of the process, relevant keywords, and pointers towards ethical implications for the introduction of technology in the context under analysis. Hence, this small-scale evaluation highlighted the necessity and the value in expanding the principles not only to clarify and enrich them but also to create a stimulus for students and future researchers/practitioners in reflecting and deliberating on the benefit and risk of using technology in sensitive settings (Roeser, 2012).

8.3 Contribution to Healthcare

This contribution reflects the broader impact that such work had in relation to the fields of design and healthcare involved, as a form of *tactful innovation in healthcare*. This contribution concerns how the future collaboration between these two fields may improve based on a mindset and approach shift.

8.3.1 Contribution to Healthcare by Supporting the Developmental-Oriented-Care Programme and Family-Centred Approaches for Psychosocial Cancer Care in Paediatric Oncology

One of the project's contributions was also providing an illustration of how to conduct design research by addressing a group of users (i.e., family) instead of a single user, in line with the Developmental-Oriented-Care programme (Aarsen et al., 2012) and Family-Centred approaches currently used in paediatric cancer care (Salem et al., 2020; Santos et al., 2015; Zabriskie & McCormick, 2001)

The work demonstrated how it is possible to collectively engage all family members, including siblings, and how it is possible to fulfil family needs through simple interventions aiming at normalising things in the context instead of enforcing new practices. When asked to reflect on the conclusion of the 'Meedoen=Groeien!' project, ***Mechteld van den Beld,*** former director of the Revalidatie Fonds (now HandicapNL), linked to the Dutch Friends Lottery (Dutch: 'VriendenLoterij') that funded the project, and one of the project initiators and members of the project steering committee together with Hanneke de Ridder, provided a statement that highlighted the value of this collaborative work:

> *"I think that there is a need for design in several realities for example also rehabilitation to rethink how to engage patients differently but also rethink existing tools, in a way that they become capable of normalising patients' conditions and motivating them […]. In this way new*

products can integrate into a story that fits the patient's exact needs.".
(meeting in Utrecht, 3 January 2019).

The designed objects addressed the emotional and the social aspects of the development of the child, in a playful way that kept the child and family members active and distracted within their own home context. At a closing event organised for the conclusion of the 'Meedoen=Groeien!' project, one of the participants, ***Elfi de Jong***, a coach and counsellor specialised in the Healthcare Sciences, Movement Science, and Healthcare Management, working specifically on the reintegration of people with chronic diseases and that was herself diagnosed with MS (Multiple Sclerosis) at the age of 36, shared her impressions on the value of the tangible results that were obtained:

> *"I think it is necessary to communicate face to face among family members, but it is extremely important to find ways to do it in an easy way. Using objects like AscoltaMe and Mr.V can offer stimuli to communicate with each other in the family not to talk about the disease all the time, as a sort of distraction.".*
> *(meeting in Utrecht, 12 December 2018)*

Furthermore, the reflections shared by the families throughout the study demonstrated that they did not perceive the objects as being strictly connected to the hospital environment or to cancer treatment. Already in the studies, parents advanced the possibility to use the objects also with families with children dealing with other chronic conditions or dealing with other disruptive life events; but also, in contexts such as school classes to stimulate interaction and communication in group activities. When asked about her impressions of the results of the 'Meedoen=Groeien!' project, ***Jannie Diekstra***, a designer working at the Princess Máxima Center as a project leader in the 'Mijn Máxima Plan' from 2016 to 2019 for the development of a supportive tool for parents of children in treatment for cancer, involved in the 'Meedoen=Groeien!' project as an expert in the steering committee and parent of a child treated for cancer, shared a similar perspective while speaking of the value of Mr.V:

> *"Mr.V does not only focus on being here in hospital and being ill but instead it focuses on imagining and acting on what is possible to do while going through this tough process as a family. Even if developed for this setting, such an object can be implemented outside the context of child oncology.".*
> *(meeting at Wilhelmina KinderZiekenhuis, Utrecht, 28 February 2019)*

Finally, according to the families, the designs could have also been introduced into the hospital environment to entertain the children in their room, and involve visiting family members in small and fun activities, or also be provided to children when they need to be completely isolated during the treatment and parents cannot be physically there to distract them. Families and healthcare professionals proposed that the designs could also be used by healthcare staff as suggestions for play activities that could motivate the child to get out of bed or during bad days in the hospital, and perhaps be integrated into the hospital in connection with other interactive objects such as Fizzy, the robotic ball (Boon, 2020) by suggesting activities that the child could do with the ball. When asked about her impressions of the results of the 'Meedoen=Groeien!' project, ***Guus W.F. Dekkers***, a psychologist that worked at the Princess Máxima Center and joined the project to help in the participant recruitment and in conducting part of the third study, agreed on the possibility of Mr.V supporting the interaction between the psychologist and the patient between being in hospital and at home.

> *"I would use it in my own practice. I could give it to the patient and together we could make some cards to use at home in the same way it was used by the families that participated in the studies, or use it to put words in to select subjects to talk about and then see what comes out.".*
> *(meeting at the Princess Máxima Center, Utrecht, 12 December 2018)*

8.3.2 Contribution to Healthcare by Supporting Collaborative Projects with the Field of Design

This project also provides a significant contribution to the healthcare field by addressing points of attention that were previously identified in the literature on challenges of conducting

design work in healthcare (Groeneveld et al., 2018; Thieme et al., 2016) and on how to think up possible sustained collaboration between designers and healthcare professionals (Wallace et al., 2012; Wallace, Wright, et al., 2013).

To bring innovation to healthcare and understand how to better structure future collaboration where patients undergoing treatment should be involved; a mindset shift between the stakeholders is needed. This project contributed to this point by giving an example of how knowledge, theories and models from different fields can be used together to frame and better detail research questions and address a common challenge. ***Dr. Jaap Huisman***, a clinical psychologist that was the former head of the psychosocial department at the Princess Máxima Center, and got involved in the 'Meedoen=Groeien!' project and specifically on the work described in this thesis as an external advisor and supported the study protocol development, recognised this contribution:

> *"You cannot do this without the input of professionals from different fields. I am a psychologist and I am used to thinking about concepts of social science, but I learned a lot from this project as I realised that by looking at the same problem and context with different scope you can produce very different solutions […]. For me as a psychologist the value of design is that it produces different ways to look at problems and research questions. It broadens your scope while it allows you confront two different scientific fields.".*
> *(phone meeting at Delft University of Technology, Delft, 14 December 2018)*

The role of design researchers in such complex projects is to be able to identify a design space within which the parties involved can navigate and innovate more freely without the constraints imposed by traditional healthcare procedures. The work presented in this thesis demonstrates how using prototypes to embody a vision and a narrative of an experience can help healthcare professionals in having a better understanding of the design potential. It also enables them in supporting the design researcher in finding interesting and meaningful opportunities to introduce design into the sensitive setting. ***Dr. Netteke A.Y. Schouten-van Meeteren***, a paediatric oncologist working at the Princess Máxima Center, which supported the 'Meedoen=Groeien!' project and the work described in this thesis by recruiting study participants, explained that after understanding how Mr.V worked, it was possible to start visualising how to introduce the artefact in her daily practice and address her struggle in giving more voice and autonomy to the children undergoing treatment:

> *"I have the opinion that Mr.V could also help in the dynamics between the child, healthcare professionals and parents during procedures […]. It is difficult for parents but also for healthcare professionals to step aside and allow the child to express what he/she is thinking […]. I think that having something which the child can use to prepare, something that people are really obliged to listen to, would be really important and put the child in a very valuable position in being autonomous to communicate himself/herself […]. I would introduce Mr.V in this context in the role of being the spokesman for the child.".*
> *(meeting at the Princess Máxima Center, Utrecht, 15 January 2019).*

For healthcare professionals, it is important to evaluate the potential benefits and risks of less conventional proposals before introducing them into their field. For this to happen this project also aimed at generating scientific evidence for the future of healthcare to make an impact while thinking outside the box. ***Hanneke de Ridder,*** a child psychologist and director of the Developmental-Oriented-Care programme at the Princess Máxima Center, who was also one of the ambassadors for the development of the centre as an institution focusing on bringing forward the Developmental-Oriented-Care programme and from which the 'Meedoen=Groeien!' project originated, focused specifically on the importance of examples of work like the one described in this contribution:

> *"In projects like this one you must have trust in each other and became a little bit of a family from both sides. This will help to implement a scientific way of working. This for people in healthcare is important. Because healthcare is a really structured way of working, with protocols, labs, conformed to criteria and to an end result, working outside the box is not their way of working. They have learned to work in accordance with this structure and that is*

exactly the opposite way of working as a designer. As a designer you can use creativity and that is what you give to each other.".
(meeting at the Princess Máxima Center, Utrecht, 10 January 2019)

To address the previous point, it is therefore important to dedicate time on aligning perspectives. This project contributes to that by showing how common ways of disseminating scientific knowledge to make innovation visible and understandable were found through shared publications both in the design and paediatric psychosocial care in cancer communities. This was possible because a common effort was put in place by identifying the research questions to address during the field studies conducted and come to a common understanding of what goals were feasible and achievable within the timeframe of the project. Also, ***Prof. dr. Martha A. Grootenhuis,*** the current head of the psychosocial department at the Princess Máxima Center, and second promotor in this research project has highlighted specifically that:

"In academic terms, design and healthcare are different […]. In a complex project like this one, it is sometimes easy to take what is happening in the scientific field of the other person you are working with for granted but this should not be the case. I think the collaboration improved when what we wanted to study got clearer […]. At the beginning, we were maybe too focused on evaluating the effectiveness of the design interventions, but we understood that real effectiveness is really hard to study, so we also collaboratively re-designed our research question. We understood that what would have been already important also in clinical terms was to see how children and families could react and feel about the products.".
(meeting at the Princess Máxima Center, Utrecht, 8 January 2019).

It is also important to identify an intermediary person, with the key role of facilitating the research on-site. This person should be open to maintaining personal commitment towards the new perspective brought by the design side and at the same time should have professional skills required in the healthcare field. In this way, healthcare professionals feel much more at ease in discussing opportunities and build trust towards the project instead of been exposed to a totally new field without having the time to prepare for it. Nevertheless, when this facilitator is present, flexibility is necessary to make the collaboration work. This project contributed to this point because it showed how by remaining flexible to adapt and being responsive to the requests in the field, challenges and obstacles that arise along the process can be overcome. ***Kelly L.A. van Bindsbergen***, is the medical researcher that took on the facilitator role in part of the 'Meedoen=Groeien!' project described in this thesis in recruiting participants and conducting a second and third field study together with the design researcher. She works as a doctoral researcher in Developmental Psychology at the Princess Máxima Center and commented on this experience:

"What we have established with this project is something really new, there are not that many projects like that […]. It has been a real rocky road […], like to get to know the whole hospital system and meet the Medical Ethical Committee's demands […]. If you want to design something for the hospital environment and for healthcare you should be prepared to be flexible to change plan to fit in here, and from our side [healthcare professionals] we need to be open to go out of our comfort zone and try out new products and be more creative in the ways we conduct our work. If both parties have that openness and flexibility, we can do amazing things otherwise the collaboration is going to be hard […].".
(meeting at the Princess Máxima Center, Utrecht, 15 January 2019).

Lastly, it is also important to find a way to 'safely' introduce any form of innovation in healthcare. This project contributed to this by highlighting how innovation should be introduced by clearly explaining and demonstrating how it could fit within the existing healthcare culture, without overloading or creating misunderstanding and stressful situations also for healthcare professionals. ***Marianne Naafs-Wilstra***, former director of the childhood cancer parental organisation in the Netherlands called VOKK (VOKK, n.d.) that has been involved in the 'Meedoen=Groeien!' project as part of the steering committee, and facilitated the contact between the design researcher and the organisers of the Childhood Cancer International meeting (CCI, 2016) reflected on this point by sharing her experience:

"In general, in every field, it is easy to get stuck in the same frame, so it is important to move away from that way of thinking. For instance, when as a parenting association we introduced the KanjerKetting (a bead reward-system for children undergoing treatment) […], at that moment not all healthcare professionals immediately saw that it was really valuable and meaningful for children and parents. Like in this example, it is really important to have people from outside the field to look at a certain problem because this person will come in with different ideas and solutions and will also be able to listen to the unexpressed needs of children and families surrounding the treatment.".
(meeting at the Princess Máxima Center , Utrecht, 12 December 2018).

8.4 Implications, Limitations, and Recommendations for Clinical Implementation

This section looks at the clinical implications of the work and the limitations of the studies that have been conducted. It also provides suggestions on possible implementations of Mr.V the Spaceman as a commercial product.

In the first field study, the testimonies of cancer survivors were used to map out challenges and coping strategies of children with cancer and their families. However, the insights collected could have been richer if they were gained from interviewing families with children undergoing treatment directly. Furthermore, it would have been interesting to also look into other psychosocial models addressing family cohesion, family functioning and quality of life to further inform the design choices made later (Santos et al., 2015; Zabriskie & McCormick, 2001). In the second field study, the age and gender of the children, and family compositions were representative of the demographic of interest (i.e., two different age groups per prototype). However, two of the families included left the study before its conclusion and this reduced the amount of insights collected on one of the prototypes. This influenced the possibility to use the questionnaires' results because not enough answers were collected. It also became clear that the use of the daily diary was too demanding for the families. This called for new strategies in conducting data collection in the third study. In the third field study, thanks to remote data collected and the higher amount of insights, it was possible to understand that the families used Mr.V for multiple days regardless of the family composition and child's age. The panel of participants was sufficient for such a qualitative design study and representative of the demographic of interest. However, the higher number of male patients could have influenced the judgment of the children over certain features of the object such as its appearance. The evaluation of the object through questionnaires provided positive feedback regarding feasibility, acceptability and the potential effectiveness of the object (reported in: Van Bindsbergen et al., 2021). The added measure of the online encrypted chat facilitated the families in sharing images and notes with the researchers. For this study, Mr.V the Spaceman was not yet built as an intelligent object and the speculations on the possibility to design intelligent tactful objects has not been evaluated further.

It would have been interesting to explore the families' home context further in addition to their routine and habits but this proved challenging because of the private nature of the setting and the presence of patients in treatment. Furthemore, AscoltaMe, Mr.V and Mr.V the Spaceman were tested for a short period of time. It would be important to set up a longitudinal study with a larger demographic (differentiated by the children's age and cancer diagnosis) to understand how Mr.V the Spaceman could be used to promote family interaction throughout the entire cancer treatment (e.g., beginning phase, hospitalisation, heavy treatments), and 'measure' such impact. This implies to validate Mr.V the Spaceman also in the hospital to make clinical routines and monitor improvement during those phases in a more appealing and fun way. Nevertheless, it could be interesting to evaluate if Mr.V the Spaceman is capable of playfully supporting the clinical routines of other demographics such as the families at elevated risk for distress or with chronically ill children which deal with similar challenges. For instance, this work could be applied in a similar way to the approach used by Marsac and colleagues' both in the childhood cancer and sickle-cell disease contexts (Marsac et al., 2012, 2014).

Finally, families found that some improvements are needed to control the object and to make it be more responsive and thus turn it into a 'real product'. To produce an object like Mr.V the Spaceman, mechanical and software aspects should be engineered further, and new materials should be selected to ensure robustness. The integrated sensors could be possibly connected to an interface reporting data to the healthcare professionals to monitor the family's activity during the child's treatment. All these changes would require the definition of a plan to obtain financial support by healthcare institutions, crowdfunding initiatives or private sponsors from industry or the insurance sector. Next to the financial support, a strategy should be defined to distribute the product. If the product was to be used in the hospital, specific quantities of Mr.Vs would need to be distributed per hospital and/or hospital areas (e.g., child room, therapy room, common areas). If the product was to be given to the families for their home, a renting service should be created in collaboration with parental associations linked to the hospital to let the families take it out on loan. Turning the tangible object into a digital application could reduce the production cost, make it accessible remotely through a screen interface and perhaps make it more appealing also to teenagers. However, this would detach the final product from its initial concept of being a 'partner' with the purpose of working for and with people in the sensitive setting, functioning as a visual reminder accessible to everyone at the same time and bringing the family members physically together. Furthermore, young children may not have access to electronic devices and this would imply that the access to the application would be administered only under the control of the parents and so it would be easy to ignore or postpone notifications.

8.5 Opportunities for Future Research

Literature in healthcare highlights that technology based tools such as e-health systems have the potential *"to address disparities and increase the accessibility of psychosocial care for patients and family members"* so that for instance, people that might be unable to visit the hospital regularly can be reached out to, supported or monitored (Wiener et al., 2020: 6). This reflection contributes to highlighting the valuable role that technology can play in sensitive settings like the one the families met during the studies here presented. However, systems and artefacts augmented by computational intelligence can also modify their behaviour on the basis of external inputs and interactions and adapt to unexpected circumstances or new contexts in order to help realise the goal for which they are designed (Van de Poel, 2020). They acquire many of their features during their operation and due to the way they evolve rather than via their initial design. In healthcare, this brings new challenges such as feeding back information from the devices to healthcare professionals or from the devices to patients (Jenkins et al., 2019); sustaining the family/patients' engagement (Wiener et al., 2020), engaging with compassion and care (Roeser, 2017); and legal and ethical concerns related to the risk of misinformation and maintaining privacy, and confidentiality (Hors-Fraile et al., 2016). This means that it is crucial to monitor the behaviour of the artefacts augmented by computational intelligence when introduced in sensitive settings.

In this project, computational intelligence has only been proposed but not evaluated as a potential resource working in partnership with people (Giaccardi & Redström, 2020; Thieme et al., 2020), to help their agency, extend their skills or develop new ones and in this way 'taking care of people' in a more 'humane' way (Jenkins et al., 2019; Natashah Hitti, 2020). However, it is evident that in the shift towards the development of more intelligent objects/systems of objects and services, new challenges emerge (Fritsch et al., 2018). Unintended outcomes should be prevented or monitored and resolved in the shortest time possible. However, it is also necessary to make sure that the data created and shared by computational intelligence is interpretable and can be used by people to strengthen them or assist them in making more knowledgeable decisions than they could make before (Jenkins et al., 2019).

Computational intelligence can also help design researchers and practitioners to evaluate human behaviour easily in relation to everyday smart products by investigating the field from a totally different perspective and remotely collect data that would be difficult to obtain

otherwise. However, this implies that the design practice should become 'anticipatory', with the ability to craft desirable relations between people and emerging technologies, so that intelligent objects can be part of people's everyday life while remining understandable, relatable, and readable yet not persuading people into doing anything (Berdichevsky & Neuenschwander, 1999). This requires educating design researchers and practitioners in understanding agency in design (Giaccardi & Redström, 2020), listing technical norms regulating the agency of computational intelligence (Van de Poel, 2020) and sharing this knowledge through an approachable means such as manifestos and guidelines (Robbins & Giaccardi, 2019).

8.6 Conclusions

In conclusion, to respond to the main research question, **'to empower vulnerable users by design in sensitive settings'**, it is necessary to deliver design solutions capable of addressing a **tactful experience**. Designing for sensitive settings requires an approach that is different from non-sensitive settings. The utilitarian aspect of technology in supporting people in addressing everyday challenges needs to be linked to a layer of sensitivity to communicate and trigger tactful interactions, providing opportunities of action for people and preventing them from losing their independence. This means that future *tactful intelligent objects* could address the existing challenges in the field by remaining open and allowing people take control. Not becoming normative will allow the artefacts establish collaboration with people that will help them become aware of their potential and internal resources including difficult circumstances. The **perspective of Tactful Objects** and the **tactfulness principles** can help in create new designs for sensitive settings that are not judgmental and adapt continuously to the users' needs while remaining familiar, supportive and allowing people to build confidence towards the future. Such a perspective can also help to create a common understanding between design research and healthcare research while looking together at the same challenges.

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SUMMARY

Supporting the psychosocial development of a child means to guarantee the child's psychological and emotional well-being. Children's development is a complex process of systematic and successive changes over time and the family context is one of the primary contexts that influences these changes. Childhood cancer and chronic diseases generate high levels of stress and anxiety capable of hindering the development of the child but also negatively impacting on the everyday life of parents and siblings, turning childhood cancer into a potentially traumatic event for the entire family. Most of the recent interventions proposed in healthcare have the purpose of primarily addressing the child's medical condition or the other family members' needs by looking at them individually, and are mainly used within the hospital environment. The family as a system and the home context have received only little attention. However, during the long and intensive treatment phase, if the conditions allow it, the child spends most of his/her time at home with his/her family members. Furthermore, as explained by Salem and colleagues (2020: 7) home is the context where families feel *"more secure in having difficult discussions and practicing new skills"*. This has given rise to an increasing demand for innovative ways of supporting families when they are not under direct professional observation.

The work described in this dissertation is based on the collaborative project 'Meedoen=Groeien!' (Participating=Growing!) between Delft University of Technology (TU Delft), HandicapNL and the Princess Máxima Center for Pediatric Oncology, funded by the Dutch Friends Lottery (Dutch: 'VriendenLoterij'). The project aims to generate design solutions for stimulating the development of children with chronic and life-threatening illnesses, such as childhood cancer, and to provide guidelines for the implementation of such solutions. The project builds on the innovative Developmental-Oriented-Care programme (Aarsen et al., 2012) initiated by the founders of the Princess Máxima Center for Pediatric Oncology in Utrecht, in the Netherlands. In this holistic form of care, children and their families are considered as a whole in order to provide the best treatment and nurture their resources to overcome the disruption brought by the life-threatening illness. The research project presented in this thesis is centred on supporting the child in his/her psychosocial development during treatment. The work conducted focuses specifically on families with children between five and 16 years old undergoing treatment for cancer. It engages them in their home context by introducing objects designed to sensitively blend into their everyday routines. These objects are proposed to support the children and their families in preserving a normal domestic life without turning into a new clinical ritual. In the research project, design actions were central to knowledge generation (i.e., 'Research-through-Design' (**RtD**); (Stappers & Giaccardi, 2017). Various stakeholders were involved in the project, including research supervisors, a steering committee and support staff, with disciplinary backgrounds in design, healthcare and engineering.

The thesis contains eight chapters. A specific label highlights the purpose of the content of each chapter, namely *introduction* (Chapter 1), *approach* (Chapter 2), *contextualisation* (Chapter 3), *emergence* (Chapter 4), *definition* (Chapter 5), *application* (Chapter 6), *evaluation/ envisioning* (Chapter 7) and *contribution* (Chapter 8). Chapter 4 and Chapter 6 consist of design descriptions, where prototypes developed throughout the project are illustrated with the use of annotations. Chapter 3, 5 and 7 report on field studies conducted to explore the context under analysis and introduce the developed prototypes into the field to generate knowledge.

The thesis' introduction (**Chapter 1**) provides a detailed problem description and further explains that the aim of the work presented is to address a general research question that consists in understanding **'how can vulnerable users be empowered by design in sensitive settings?'.** This goal is addressed in the thesis with the introduction of the design *perspective of Tactful Objects*, namely, interactive artefacts attuned to the needs of vulnerable users in sensitive settings. The development of the perspective is based on an iterative RtD approach that follows three sub-research questions:

1: How can families with children with cancer be empowered to adapt to a New Normal during life disrupting events?

2: How can tactfulness be used as an expressive design quality to develop interactive artefacts for the sensitive setting of families dealing with childhood cancer?

3: How does computational intelligence allow interactive artefacts to become more tactful and attuned to the needs of families dealing with childhood cancer?

In **Chapter 2**, the RtD approach is described, consisting of iterative design activities and knowledge development. This chapter briefly explains what sensitive settings are, what their characteristics are and what methodologies are normally used to investigate them. Then it moves onto elaborating on how the RtD approach has been articulated through a series of design actions to answer particular research questions. The chapter then continues with describing how the implementation of the RtD approach has transformed the sensitive setting under analysis into a 'design space'. By summarising four elements that emerged as relevant for the development of the project (i.e., the prototypes, the people, the infrastructure and the researcher's well-being), the chapter serves as a prelude for the reader to know what will be extensively described in the chapters that follow.

Chapter 3 addresses *sub-question n.1*. Here, the ecology of childhood cancer is detailed, and a first exploratory field study is introduced to clarify which specific challenges for families dealing with childhood cancer will be considered. This first step also helps in clarifying for which reasons design should be seen as a valid alternative and contribution in the context of families dealing with cancer. Childhood cancer is introduced and identified as a disruptive-life event; an event capable of disrupting the normal routine of complex systems of people such as families. The chapter also presents known stressors impacting the psychosocial development of children during cancer treatment. It shifts then into detailing the Bronfenbrenner and Ceci's bio-ecological model (1994) to explain how those stressors also impact on the family of the child. This introductory part is then concluded with a description of the medical interventions that are currently provided within the hospital context to encourage the family's resilience. In the second part, a participant observation during a three-day childhood cancer meeting is reported. The chapter elaborates on this observation to understand the struggles encountered by children and their family members during cancer treatment. Those challenges are then clustered systematically according to Bronfenbrenner and Ceci's model (1994). Two challenges in particular appear to have a strong impact on the whole family and constantly arise in the everyday home context. These challenges, related to social interaction and communication were then selected as relevant opportunities to be addressed by designing **tactful supportive solutions** for the home context of those families.

Chapter 4 describes two design solutions. Here, two hypotheses on how to stimulate social interaction and communication in families dealing with childhood cancer in a tactful way are described. Those two hypotheses are translated into tangible prototypes in line with the RtD approach. Mr.V (Mr.Verrassing, 'Mr. Surprise' in Dutch) is introduced as a playful companion to foster social engagement and relaxation when the families spend time together at home and AscoltaMe (translated as 'listen to me' from Italian) is introduced as a new interactive device with the purpose of supporting communication. The design choices aimed at defining the expressive features of these new objects are documented here and reported in visual and textual form following an annotated portfolio format. This format facilitates the graphical organisation of the elements to reveal how the design researcher has interpreted the expressive **quality of tactfulness.** Through the annotated portfolio, the process and rationale behind the design features of Mr.V and AscoltaMe are described.

These are computational objects imbued with the intent of helping families overcome the emotional barriers they may experience during a disruptive life event, as they attempt to maintain space for quality time together and communication. With a focus on the objects' material qualities (Giaccardi & Karana, 2015) and temporal form (Vallgårda et al., 2015), the chapter introduces and visually outlines *tactfulness* as the fundamental characteristic that enables objects for sensitive settings to be appropriate and sensitive.

In **Chapter 5**, research ***sub-question n.2*** is addressed by describing how the hypotheses highlighted in Chapter 4 were evaluated. In order to understand how families interpreted the expressive quality of *tactfulness* and the role of the designs in their everyday life, a field study was conducted. Mr.V and AscoltaMe were introduced as **tactful objects, namely – interactive artefacts attuned to the need of people in sensitive settings**. The first part of the chapter reports on the setup of the study, in which eight families with children undergoing treatment for cancer were selected and were involved in the evaluation of the prototypes. Following the study setup, the selected families were divided according to the age of the children. Mr.V was introduced to families with children between 10 and 16 years old and AscoltaMe was introduced to families with children between six and 10 years old. The families used the prototypes in their home for at least one week, and then they were interviewed. The interview helped in collecting the collective opinions of all family members about the prototypes and their interaction with them. As result of the study, a set of points emerged as relevant for the families in relation to the *perspective of Tactful Objects:*

--- To have a **positive impact** in sensitive settings, *tactful objects* should **behave like partners;**

--- The **interaction** between *tactful objects* and people should be **shaped as a collaboration;**

--- *Tactful objects* should be **inviting;**

--- *Tactful objects* should **act appropriately** when **embedded in sensitive settings.**

From the study it also emerged that the prototype of Mr.V was the one that offered a type of support that families were looking for.

Chapter 6 consists of a design description to illustrate how the insights of the second field study were used 'as principles' to review the concept of Mr.V. Furthermore, this chapter describes a new design iteration that resulted in *Mr.V the Spaceman.* Mr.V the Spaceman is presented as a tactful object with the purpose of supporting families of children with cancer in maintaining space for quality time during stressful times. The chapter recounts insights from the second field study and changes to the original artefact of Mr.V and shed light on how an understanding of tactfulness has emerged and developed into a key design quality for this work. This complex and entangled process of making Mr.V the Spaceman is described and illustrated by rich and scrupulous visual and textual annotations. The format graphically organises how the aesthetic and interactive features of the new prototype were modified according to **four tactfulness principles**, namely **sensitive partnership, balanced collaboration, familiar character and discreet presence.** Furthermore, sensors were embedded in the prototype to capture user-data, transforming Mr.V the Spaceman into a data-enabled object.

Chapter 7 takes Mr.V the Spaceman and introduces it in a third field study to answer research ***sub-question n.3.*** This chapter aims at expanding on the definition of the *tactfulness design principles* but also reflects on how to develop future intelligent objects capable of being even more tactful. The chapter starts by detailing how the *four tactfulness principles* have been applied to the design of Mr.V the Spaceman as a *tactful data-enabled object* with the purpose of stimulating interaction at home in families dealing with childhood cancer. The chapter proceeds with reporting on a field study with 10 families with children in treatment between

five and 15 years old that tried Mr.V the Spaceman at home for a week, providing insights on how they experienced the object in their everyday life as being tactful. The chapter explains how the findings (and the object-data that were sensed remotely), enriched the definition of each of the four *tactfulness principles*. Furthermore, it speculates on the opportunity (and ethical implications) of using **computational intelligence to develop future intelligent tactful objects** capable of:

--- **Establish a more sensitive partnership** with their users;

--- **Collaborate with people** in a more **balanced way**;

--- **Integrate familiar character aspects**;

--- **Act appropriately** by maintaining a **discreet presence**.

Finally, **Chapter 8** looks back at the project as a whole and describes the responses to the main research question and sub-questions, and it elucidates the contribution of the thesis to Interaction Design, design education, and the healthcare field. Implications, limitations and recommendations for clinical implementation are also discussed. Furthermore, a brief speculation on opportunities for future research are presented. These opportunities concern the introduction of computational intelligence in sensitive settings, the related ethical implications and the necessity to prepare researchers and practitioners in design and healthcare for monitoring such complexity.

In conclusion, design can empower vulnerable users in sensitive settings by delivering design solutions capable of generating a tactful experience. Interactive objects can offer such support if designed to embed tactfulness and address the challenges encountered by people in the sensitive setting where they live. This thesis explains how four principles can be followed to embody tactfulness in the design process. **Designing tactful objects for sensitive settings means to design objects that behave like sensitive partners, establish a balanced collaboration with people, resemble familiar characters and maintain a discreet presence in the context where they are introduced.**

The qualitative design studies reported in this thesis are limited to the sensitive setting of families with children with cancer. Future research could consist of a longitudinal study with a wider demographic (differentiated per children' age range and diagnosis) including also families with chronically ill children. These families could equally benefit from the introduction of tactful interventions as they share similar challenges in their everyday life.

Future clinical development could also include an evaluation of the potential of *tactful objects* inside the hospital setting. The *tactful object* of Mr.V the Spaceman was positively evaluated and accepted by the families involved in the last field study. To facilitate its future clinical implementation, investments should be put in place to assure feasibility and robustness, together with a plan to involve interested healthcare institutions and associations that are open to integrating innovative tools throughout the treatment of their patients. This would contribute to stressing the importance of projects like the one of 'Meedoen=Groeien!', which sets a powerful example of how collaboration between design and healthcare professionals can tangibly contribute to Developmental-Oriented-Care.

SAMENVATTING

(Translation by ***Kars Jansen***; editing by ***Boudewijn Boon***)

Zorgdragen voor de psychosociale ontwikkeling van een kind betekent het waarborgen van het psychologisch en emotioneel welzijn van het kind. De ontwikkeling van een kind is een complex proces van systematische en achtereenvolgende veranderingen in de loop der tijd en het gezinsverband is een van de voornaamste contexten welke invloed heeft op deze veranderingen. Kinderkanker en andere chronische ziekten bij kinderen generen een hoog niveau van stress en angst welke een gezonde ontwikkeling van het kind in de weg zitten. Daarnaast heeft het ook een negatieve impact hebben op het alledaagse leven van het gezin, wat mogelijk kan leiden tot een traumatische gebeurtenis voor het hele gezin. Veel voorgestelde hulp in de zorg richten zich met name op het aanpakken van de ziekte van het kind of de behoeften van de andere individuele gezinsleden, welke veelal binnen de ziekenhuisomgeving plaatsvindt. De thuissituatie en het gezin-systeem hebben relatief weinig aandacht gekregen, ondanks dat, gedurende de lange en intensieve behandelfase, het kind veel van zijn/haar tijd thuis doorbrengt met zijn/haar gezinsleden (zolang de omstandigheden dit toelaten). Zoals uitgelegd door Salem en collega's (2020: 7) is de thuis context waar gezinnen zich *"meer veilig voelen in het voeren van moeilijke discussies en oefenen van nieuwe vaardigheden"*. Hierdoor is een toenemende vraag ontstaan naar innovatieve manieren om gezinnen te ondersteunen wanneer zij niet onder directe professionele observatie staan.

Het werk beschreven in dit proefschrift is onderdeel van het samenwerkingsproject 'Meedoen=Groeien!' tussen Technische Universiteit Delft (TU Delft), HandicapNL en het Prinses Máxima Centrum voor kinderoncologie in Utrecht (Nederland). Dit samenwerkingsproject is gefinancierd door de 'VriendenLoterij'. Het project richt op het genereren van ontwerpoplossingen die de ontwikkeling stimuleren van kinderen met chronische en levensbedreigende ziektes, zoals kinderkanker, en op het geven van richtlijnen omtrent de implementatie van zulke oplossingen. Het project bouwt voort op het innovatieve Ontwikkelingsgerichte Zorg programma (Aarsen et al., 2012), opgezet door de oprichters van het Prinses Máxima Centrum voor kinderoncologie. Binnen deze holistische vorm van zorg worden kinderen en hun gezin zien als een geheel, met als doel om de beste behandeling te geven en de voorziene middelen te koesteren voor een normale ontwikkeling van het kind welke een levensbedreigende ziekte ervaart. Het onderzoekproject in dit proefschrift richt zich op het ondersteunen van het kind in zijn/haar psychosociale ontwikkeling gedurende de behandeling. De focus van het onderzoek ligt op gezinnen met kinderen in de leeftijd van vijf tot 16 jaar welke een behandeling tegen kanker ondergaan. Het houdt de gezinnen in hun thuis context bezig met objecten welke ontworpen zijn voor het subtiel mengen in hun alledaagse routine. Deze objecten zijn voorgesteld om de kinderen en hun gezinnen te assisteren in het behouden van een normaal huiselijk leven zonder dat deze een nieuwe klinische routine worden. In dit onderzoeksproject stonden de ontwerphandelingen centraal voor kennisontwikkeling (d.w.z. 'Research-through-Design' (**RtD**); Stappers & Giaccardi, 2017). Verschillende belanghebbenden waren betrokken bij het project, inclusief onderzoeksbegeleiders, een projectcomité en technische ondersteuning. Allen met een disciplinaire achtergrond in ontwerp, gezondheidszorg of techniek.

Het proefschrift bestaat uit acht hoofdstukken. Een specifiek label markeert het doel van elk hoofdstuk, namelijk *introductie* (Hoofdstuk 1), *benadering* (Hoofdstuk 2), *contextualisering* (Hoofdstuk 3), *verschijning* (Hoofdstuk 4), *definitie* (Hoofdstuk 5), *toepassing* (Hoofdstuk 6), *evaluatie/voorstelling* (Hoofdstuk 7) en *bijdrage* (Hoofdstuk 8). Hoofdstuk 4 en Hoofdstuk 6 bestaan uit de beschrijving van het ontwerp, waarbij ontwikkelde prototypes worden geïllustreerd met gebruik van annotaties. Hoofdstuk 3, 5 en 7 rapporteren uitgevoerde veldonderzoeken om de context te verkennen met behulp van analyses en het introduceren van de ontwikkelde prototypes om kennis te vergaren.

Hoofdstuk 1 introduceert het onderzoek en geeft een gedetailleerde probleembeschrijving. Het geeft aan dat dit proefschrift als doel heeft een antwoord te geven op de onderzoeksvraag: **'Hoe kan ontwerp kwetsbare gebruikers in gevoelige contexten aanmoedigen?'.** Dit doel

wordt in het proefschrift benaderd met de introductie van het ontwerp *perspectief van Tactful Objects*. Tactful Objects zijn interactieve voorwerpen aangepast aan de behoeften van kwetsbare gebruikers in gevoelige contexten. De ontwikkeling van het perspectief is gebaseerd op een iteratieve RtD benadering waaruit 3 sub-onderzoeksvragen volgen:

> **1: Hoe kunnen gezinnen met kinderen met kanker in staat gesteld worden zich aan te passen aan een Nieuw Normaal gedurende levensontwrichtende evenementen?**
>
> **2: Hoe kan 'tactfulness' gebruikt worden als een expressieve ontwerpkwaliteit voor het ontwikkelen van interactieve voorwerpen voor gezinnen in gevoelige context welke te maken hebben met kinderkanker?**
>
> **3: Hoe kan computationele intelligentie ervoor zorgen dat interactieve objecten meer tactvol en afgestemd zijn naar de behoefte van gezinnen welke te maken hebben met kinderkanker?**

Hoofdstuk 2 introduceert de RtD benadering die in het project gebruikt wordt, welke in het kader staat van iteratieve ontwerphandelingen en kennisontwikkeling. Dit hoofdstuk legt in het kort uit wat gevoelige contexten zijn, wat de kenmerken hiervan zijn en welke methodologieën normaal worden gebruikt om ze te onderzoeken. Daarna wordt er dieper ingegaan op hoe de RtD benadering is toegepast in dit specifieke project om een serie van ontwerp activiteiten uit te leggen voor het beantwoorden van specifieke onderzoeksvragen. Vervolgens beschrijft het hoofdstuk hoe de RtD benadering gebruikt is om de geanalyseerde gevoelige context om te vormen naar een 'ontwerpruimte'. Door het benoemen van 4 elementen (de prototypen, de mensen, de infrastructuur en het welzijn van de onderzoeker) welke belangrijk blijken te zijn voor de ontwikkeling van het project, dient Hoofdstuk 2 als inleiding voor wat er uitgebreid beschreven staat in de volgende hoofdstukken.

Hoofdstuk 3 gaat in op *sub-onderzoeksvraag n.1*. Hier wordt de ecologie van kinderkanker beschreven en een eerste verkenningsonderzoek is geïntroduceerd om te verklaren welke specifieke uitdagingen gezinnen met kinderkanker hebben. Kinderkanker wordt geïntroduceerd en geïdentificeerd als een gebeurtenis die het leven ontwricht; een gebeurtenis die ervoor zorgt dat de normale routine van complexe systemen van mensen, zoals gezinnen, verstoord wordt. Het hoofdstuk presenteert ook bekende stress factoren die invloed hebben op de psychosociale ontwikkeling van kinderen gedurende de behandeling tegen kanker. Vervolgens worden de details van Bronfenbrenner and Ceci's bio-ecologie model (1994) beschreven, om uit te leggen hoe stressfactoren een impact hebben op het gezin en het kind. Dit introducerende deel wordt beëindigd met een beschrijving van de medische interventies welke momenteel beschikbaar zijn in een ziekenhuis om de veerkracht van het gezin te bevorderen. Het tweede deel van dit hoofdstuk beschrijft een verkennende observatie gedurende een drie-daagse kinderkanker bijeenkomst. Het hoofdstuk werkt deze observatie uit om de uitdagingen van de kinderen en hun gezinnen gedurende de behandeling in kaart te brengen. Deze uitdagingen zijn vervolgens systematisch geclusterd volgens het Bronfenbrenner and Ceci's model (1994). Twee specifieke uitdagingen blijken een sterke impact te hebben op het hele gezin en zijn constant aanwezig in de alledaagse thuis context. Deze uitdagingen, gerelateerd aan sociale interactie en communicatie, zijn geselecteerd als relevante kansen om aangepakt te worden doorr middel van het ontwerpen van **tactvolle ondersteunende oplossingen** te ontwikkelen voor de thuis context van deze gezinnen.

Hoofdstuk 4 beschrijft twee ontwerp oplossingen. Hier worden twee hypotheses beschreven over hoe communicatie en sociale interactie te stimuleren binnen gezinnen die te maken hebben met kinderkanker. Deze hypotheses zijn vertaald naar tastbare prototypes, in overeenstemming met de gekozen RtD benadering. Mr.V wordt geïntroduceerd als een speels 'maatje' dat zorg draagt voor ontspanning en sociale verbindingen wanneer het gezin

samen thuis is. AscoltaMe wordt geïntroduceerd als een nieuw interactief toestel met het doel om te helpen bij het communiceren. De keuzes gericht op expressieve kenmerken van deze nieuwe objecten worden gedocumenteerd en gerapporteerd in visuele en tekstuele vorm volgens het 'geannoteerde portfolio' format. Dit format faciliteert de grafische organisatie van de elementen om te onthullen hoe de ontwerponderzoeker de expressieve kwaliteit van **tactfulness** heeft geïmplementeerd. Door het geannoteerde portfolio wordt het proces en het grondgedachte achter de kenmerken van het ontwerp van Mr.V (Mr. Verrassing) en AscoltaMe (vertaald als 'luister naar me' uit het Italiaans) beschreven. Mr. V en AscoltaMe zijn computationele objecten doordrongen van de intentie om gezinnen te helpen de emotionele barrières die ervaren worden tijdens een levensontwrichtende gebeurtenis te doorbreken. De ontwerpen pogen om ruimte te bewaren voor gezamenlijke quality time en communicatie. Met een focus op de kwaliteit van de materialen van de objecten (Giaccardi & Karana, 2015) en 'temporal form' (Vallgårda et al., 2015), wordt tactfulness geïntroduceerd en visueel geïllustreerd als een fundamentele eigenschap die objecten passend en sensitief maakt voor gevoelige contexten.

In **Hoofdstuk 5** wordt het tweede veldonderzoek met als doel om de hypotheses, beschreven in Hoofdstuk 4, te evalueren en om een antwoord te bieden op ***sub-onderzoeksvraag n.2***. Het veldonderzoek werd uitgevoerd om te begrijpen hoe gezinnen de expressieve kwaliteit van tactfulness interpreteren en wat de rol is van de ontwerpen in het alledaagse leven. Mr.V en AscoltaMe worden geïntroduceerd als **tactful objects** – **interactieve voorwerpen aangepast naar de benodigdheden van mensen in gevoelige contexten.** Het eerste deel van het hoofdstuk gaat over de opzet van de studie, waarin acht gezinnen zijn betrokken in de evaluatie van de prototypes. In alle gezinnen was er een kind onder behandeling voor kanker. De geselecteerde gezinnen zijn verdeeld naar de leeftijd van de kinderen: Mr.V werd geïntroduceerd bij gezinnen met kinderen tussen de 10 en 16 jaar oud en AscoltaMe werd geïntroduceerd bij gezinnen met kinderen tussen zes en 10 jaar oud. De gezinnen gebruikten de prototypes voor minimaal één week in hun thuisomgeving, waarna ze werden geïnterviewd. Het interview heeft geholpen met het inwinnen van gedeelde meningen onder alle gezinsleden over de prototypes en de interactie ermee. Als resultaat van de studie kwamen een aantal punten naar voren welke relevant zijn voor de gezinnen in relatie naar het *perspectief van Tactful Objects:*

--- Om een **positieve impact** te hebben in gevoelige contexten, zouden *tactful objects* zich moeten gedragen als een **partner**;

--- De **interactie** tussen *tactful objects* en mensen zou moeten gevormd worden als een **samenwerking**;

--- *Tactful objects* zouden **uitnodigend moeten zijn**;

--- *Tactful objects* zouden zich **correct moeten gedragen** binnen een **gevoelige context**.

Vanuit de studie komt ook naar voren dat het prototype van Mr.V het object was welke een vorm van ondersteuning gaf waar gezinnen naar zochten.

Hoofdstuk 6 bestaat uit een ontwerpbeschrijving om te illustreren hoe de inzichten van de tweede veldstudie gebruikt zijn 'als principes' voor het evalueren van het concept Mr.V. Ook beschrijft dit hoofdstuk een nieuwe ontwerpiteratie, met als resultaat Mr.V the Spaceman. *Mr.V the Spaceman* wordt gepresenteerd als een *tactful object* met het doel om gezinnen met kinderkanker te ondersteunen om ruimte te behouden voor communicatie en quality time tijdens stressvolle periodes. Het hoofdstuk herhaalt de inzichten vanuit de tweede veldstudie en de veranderingen naar het originele voorwerp van Mr.V (Hoofdstuk 5), en werpt licht op hoe een begrip van *tactfulness* zich heeft ontwikkeld in een belangrijke ontwerpkwaliteit voor dit werk. Het complexe en ingewikkelde proces van het maken van Mr.V the Spaceman

is beschreven en geïllustreerd door vele nauwgezette visuele en tekstuele annotaties. Dit format organiseert op grafische wijze hoe de esthetiek en interactiemogelijkheden van het nieuwe prototype zijn aangepast volgens de **vier tactfulness principes**, namelijk **sensitieve partnerschap, gebalanceerde samenwerking, vertrouwd karakter en discrete aanwezigheid.** Verder zijn er ook sensoren geïntegreerd in het prototype voor het vastleggen van gebruikersdata, wat Mr.V the Spaceman verandert in een data-enabled object.

Hoofdstuk 7 implementeert Mr.V the Spaceman in een derde veldonderzoek om antwoord te geven aan ***sub-onderzoeksvraag n.3***. Dit hoofdstuk gaat dieper in op de definitie van de *tactfulness design principes* maar reflecteert ook op de ontwikkeling van toekomstige intelligente objecten zodat deze meer tactvol kunnen zijn. Het hoofdstuk start met het beschrijven van hoe de vier tactfulness design principes zijn toegepast in het ontwerp van Mr.V. the Spaceman als *tactful data-enabled object* met als doel om interacties te stimuleren thuis bij gezinnen welke met kinderkanker te maken hebben. Het hoofdstuk doet vervolgens verslag van een veldstudie onder 10 gezinnen met kinderen tussen de vijf en 15 jaar oud, welke op dat moment een behandeling voor kanker ondergingen. Alle gezinnen hebben Mr.V the Spaceman voor één week thuis uitgeprobeerd. Deze veldstudie resulteerde in inzichten over hoe gezinnen het object als tactvol ervaarden in het alledaagse leven. Het hoofdstuk legt uit hoe de bevindingen (en de object-data die op afstand gewonnen waren) de definities verrijkte van alle vier de tactfulness design principes. Verder speculeert het hoofdstuk over de kansen (en ethische implicatie) van het gebruik van computationele intelligentie voor het ontwikkelen van toekomstige **intelligente tactful objects** welke capabel zijn in:

--- Een meer **sensitief partnerschap** met zijn gebruikers **te ontwikkelen**;

--- Een meer **gebalanceerde samenwerking me**t mensen aan **te gaan**;

--- **Aspecten integreren** van een **vertrouwd karakter**;

--- Gepast te handelen door een **discrete aanwezigheid** aan **te houden**.

Tenslotte kijkt **Hoofdstuk 8** terug naar het gehele project en beschrijft de reacties op de onderzoeksvraag en sub-onderzoeksvragen. De bijdrage van het proefschrift aan Interaction Design en ontwerpeducatie wordt toegelicht, alsmede de maatschappelijke bijdrage aan de gezondheidszorg. Implicaties, beperkingen en aanbevelingen voor klinische toepassingen worden ook besproken. Ook wordt een korte speculatie over de kansen voor toekomstige onderzoek gepresenteerd. Deze kansen hebben betrekking op de introductie van computationele intelligentie in gevoelige contexten, de bijkomstige ethische implicaties en de noodzakelijkheid om onderzoekers en professionals in ontwerp en de gezondheidszorg voor te bereiden op het monitoren van zulke complexiteit.

De conclusie wordt getrokken dat interactieve objecten kwetsbare gebruikers in gevoelige contexten in hun kracht kunnen zetten, door middel van het creëren van *tactvolle ervaringen*. Interactieve objecten kunnen zulke ondersteuning bieden als ze zijn ontworpen met het oog op *tactfulness* en gericht zijn op de uitdagingen die mensen ondervinden in de gevoelige context waarin zij leven. Dit proefschrift legt uit hoe 4 principes in acht genomen kunnen worden om *tactfulness* in te bedden in het ontwerpproces. **Het ontwerpen van tactful objects voor gevoelige contexten betekent het ontwerpen van objecten welke zich gedragen als sensitieve partners, zorgen voor een gebalanceerde samenwerking met mensen, overkomen als vertrouwde karakters en welke een discrete aanwezigheid zijn in de context waarin zij zijn geïntroduceerd.**

De kwalitatieve studies in dit proefschrift zijn beperkt tot de gevoelige context van gezinnen met kinderen met kanker. Toekomstig klinisch onderzoek kan zich richten op een longitudinale studie met een bredere inclusie (gedifferentieerd naar leeftijd van de kinderen en diagnoses),

waarin ook gezinnen met kinderen met andere ziektebeelden worden meegenomen. Deze gezinnen kunnen evenzeer profiteren van de introductie van tactvolle interventies, gezien de soortgelijke uitdagingen die deze gezinnen tegenkomen in hun alledaagse leven.

Toekomstige klinische onderzoek kan ook een evaluatie bevatten over de potentie van *tactful objects* binnen de ziekenhuisomgeving. Het tactful object Mr.V. the Spaceman werd bij het laatste veldonderzoek door de betrokken gezinnen positief geëvalueerd en geaccepteerd. Om in de toekomst klinische implementatie te faciliteren zijn investeringen nodig voor het verzekeren van haalbaarheid en de robuustheid, tesamen met een plan om geïnteresseerde gezondheidszorginstellingen en verenigingen te betrekken welke open staan voor het integreren van innovatieve hulpmiddelen gedurende de behandeling van hun patiënten. Dit zou bijdragen aan het benadrukken van het belang van projecten zoals 'Meedoen=Groeien!', welke een krachtig voorbeeld geeft van hoe samenwerking tussen ontwerp en gezondheidszorg tastbaar kan bijdragen aan Ontwikkelingsgerichte Zorg.

SOMMARIO

(Editing by ***Alessandra Onnembo***)

Lo sviluppo psicosociale dei bambini è un processo complesso che implica diversi cambiamenti nel corso del tempo. Favorire questo sviluppo significa garantire il benessere psicologico ed emotivo del bambino, e la famiglia rappresenta uno dei contesti in grado di influenzare questi cambiamenti.

Il cancro infantile e le malattie croniche infantili possono generare alti livelli di stress e ansia in grado di ostacolare il regolare sviluppo del bambino, ma possono anche avere un impatto negativo e potenzialmente traumatico sulla vita quotidiana dell'intera famiglia. La maggior parte degli interventi e delle forme di sostegno utilizzati in ambito medico per limitare gli effetti negativi del cancro infantile e delle malattie croniche infantili sono generalmente proposti solo all'interno del contesto ospedaliero: essi sono dedicati principalmente al trattamento della condizione medica del bambino, oppure alle esigenze degli altri membri della famiglia.

Durante il lungo e intenso periodo di trattamento, se le condizioni lo consentono, il bambino può trascorrere la maggior parte del tempo a casa con i familiari; nonostante questo la famiglia ed il contesto domestico hanno ricevuto poca attenzione in letteratura. Come spiegano Salem e colleghi (2020: 7), la casa è il contesto in cui le famiglie si sentono "*più sicure nel discutere tematiche difficili e adattarsi ad una nuova routine*"; questa riflessione funge da stimolo per la creazione di nuove iniziative volte a sostenere le famiglie con bambini in trattamento, in particolar modo quando questi non sono sotto diretta osservazione medica.

Il lavoro di ricerca svolto si basa sul progetto 'Meedoen = Groeien!' (Partecipare = Crescere!), una collaborazione tra la Delft University of Technology (TU Delft), HandicapNL e il centro di oncologia pediatrica Princess Máxima, finanziato dalla Dutch Friends Lottery (in Olandese: 'VriendenLoterij'). Il progetto mira ad introdurre soluzioni progettuali (*di design*) per supportare lo sviluppo di bambini con malattie croniche e potenzialmente letali, come il cancro infantile, ed a fornire linee guida al fine di implementare tali soluzioni. Il progetto si basa sull'innovativo programma Developmental-Oriented-Care (Cura orientata allo sviluppo) (Aarsen et al., 2012) avviato dai fondatori del centro di oncologia pediatrica Princess Máxima di Utrecht, nei Paesi Bassi. Questa forma di cura olistica, concentrata su vari aspetti dello sviluppo (psicosociale, fisico, cognitivo e religioso), considera i bambini e le loro famiglie come un'unica unità, e mira a ideare nuove risorse e migliori trattamenti con lo scopo di superare gli ostacoli causati da questo tipo di malattie.

Il progetto presentato in questa tesi pone l'attenzione sul sostegno del bambino nel suo sviluppo psicosociale durante il trattamento. In particolare, lo studio si sviluppa nel contesto domestico di famiglie con bambini tra i cinque e i 16 anni malati di cancro, e prevede il confronto con oggetti progettati appositamente per adattarsi con ***'delicatezza'*** (**tactfulness**) alla loro routine quotidiana. Questi oggetti sono stati pensati per aiutare i bambini e le loro famiglie a mantenere una vita domestica il più 'normale' possibile, senza introdurre una routine di tipo clinico.

Nel progetto di ricerca, la progettazione è stata il nodo fondamentale attraverso cui è stato possibile concepire un nuovo contributo scientifico nell'ambito del Design applicato in ***contesti sociali sensibili*** (**sensitive settings**), secondo un preciso metodo definito come 'Research-through-Design' o **RtD** (Ricerca-attraverso-Progettazione) (Stappers & Giaccardi, 2017). Tale contributo è stato possibile anche grazie al coinvolgimento nel progetto di diverse figure professionali con background disciplinari in Design, Medicina e Ingegneria, tra cui figurano supervisori di ricerca, un comitato direttivo e diversi membri del personale ospedaliero.

La tesi è strutturata in otto capitoli. Ogni capitolo è stato associato ad una parola chiave che ne indica l'obiettivo preposto: *introduzione* (Capitolo 1), *approccio* (Capitolo 2), *contestualizzazione* (Capitolo 3), *identificazione* (Capitolo 4), *definizione* (Capitolo 5),

applicazione (Capitolo 6), *valutazione/previsione* (Capitolo 7) e *contributo* (Capitolo 8). I Capitoli 4 e 6 illustrano le soluzioni progettuali sviluppate nella forma di prototipi. I Capitoli 3, 5 e 7 descrivono tre casi studio volti a indagare il contesto domestico delle famiglie, al fine di introdurre i prototipi sviluppati da cui dedurre nozioni utili a sostenere il contributo scientifico della tesi.

L'introduzione della tesi (**Capitolo 1**) fornisce una descrizione dettagliata del problema in esame e illustra lo scopo generale del lavoro, ovvero quello di **scoprire in che modo è possibile supportare al meglio utenti vulnerabili in contesti sociali sensibili attraverso il Design.** Nella tesi questo obiettivo è stato raggiunto con la definizione di una **prospettiva progettuale** chiamata **'Tactful Objects**', ovvero **oggetti interattivi capaci di entrare in sintonia con le esigenze di utenti vulnerabili in contesti sociali sensibili con un approccio *'delicato'*** (**tactful**). Questa prospettiva si è sviluppata in maniera interattiva secondo il metodo RtD seguendo tre domande:

> **1: In che modo è possibile supportare famiglie con bambini malati di cancro nell'adattamento a una 'Nuova Normalità' durante il periodo di trattamento?**
>
> **2: In che modo è possibile tradurre concretamente il concetto di *delicatezza* in qualità espressiva degli oggetti interattivi da introdurre nell'ambiente domestico di famiglie con bambini malati di cancro?**
>
> **3: In che modo l'introduzione di capacità computazionali ed intelligenza artificiale nella progettazione di questi oggetti può consentire agli stessi di approcciarsi in maniera ancora più delicata ed appropriata in sintonia con i bisogni di tale utenza?**

Il **Capitolo 2** descrive il metodo RtD, un metodo basato su una serie di attività progettuali tangibili ed interattive mirate al progresso della conoscenza scientifica. Il capitolo definisce brevemente cosa s'intende per contesti sociali sensibili, quali sono le loro caratteristiche e quali metodologie di ricerca vengono tradizionalmente utilizzate in questi ambiti che prevedono la presenza di *utenti vulnerabili*. Il capitolo spiega inoltre il motivo per cui il metodo RtD sia stato preso in considerazione come valida alternativa per mettere in pratica una serie di azioni progettuali che rispondono a specifiche domande di ricerca, difficili da affrontare con altri approcci metodologici. Il capitolo descrive successivamente come con questo tipo di metodo sia stato possibile trasformare il contesto in analisi in un vero e proprio 'spazio di progettazione'. Nella conclusione del capitolo vengono descritti i quattro fattori principali che hanno influenzato lo sviluppo del progetto: i prototipi (*prototypes*), gli utenti (*people*), l'infrastruttura (*infrastructure*) e la necessità di preservare il benessere del ricercatore (*researcher's well-being*). Il capitolo è una sorta di guida al lettore che fornisce gli strumenti per capire cosa sarà ampiamente descritto nei capitoli successivi.

Il **Capitolo 3** affronta e risponde alla *domanda n. 1*. Qui viene discussa l' 'ecologia del cancro infantile' (*ecology of childhood cancer*) e viene illustrato un primo caso di studio esplorativo, al fine di comprendere quali sono le sfide che le famiglie con bambini malati di cancro devono affrontare. Questo primo passo mira a capire le ragioni per le quali il Design potrebbe contribuire positivamente nel contesto delle famiglie che affrontano questa situazione. Nel capitolo si definisce il cancro infantile come un 'evento dirompente' (*life-disruptive event*), in grado di compromettere la normale routine e l'equilibrio delle relazioni tra i membri di una famiglia; successivamente vengono presentati i fattori di stress che possono influire sullo sviluppo psicosociale dei bambini durante il trattamento. Questa panoramica viene presentata tramite il modello 'bioecologico' (*bioecological model*) sviluppato da Bronfenbrenner e Ceci (1994). La parte introduttiva si conclude con una descrizione delle proposte fornite attualmente in ambito medico e ospedaliero per incentivare la resilienza della famiglia. Nella seconda parte del capitolo viene riportato l'incontro con pazienti guariti

o lungoviventi (***survivors***) ad una conferenza internazionale sul cancro infantile (***Childhood Cancer International-CCI***), dove sono emerse tematiche che aiutano a comprendere quali sono gli aspetti più difficili da affrontare per i bambini e i loro familiari durante il periodo di trattamento del cancro. Queste tematiche vengono poi raggruppate in modo sistematico e poste in relazione con il modello bioecologico di Bronfenbrenner e Ceci (1994). In questo quadro due aspetti sembrano influenzare maggiormente il contesto domestico delle famiglie in trattamento: la necessità di mantenere livelli salutari di interazione e di comunicazione tra tutti i membri della famiglia. Questi due aspetti sono stati fondamentali per la **progettazione di soluzioni in grado di supportare con delicatezza queste famiglie nel loro contesto domestico.**

Il **Capitolo 4** introduce il concetto di *delicatezza* e spiega come questa possa essere tradotta concretamente in un oggetto interattivo adeguato ad operare in contesti sociali sensibili. Il capitolo propone una descrizione della prima fase di interazione-progettuale, dove vengono ideate due soluzioni per supportare l'interazione e la comunicazione delle famiglie, introdotte come due distinte ipotesi di ricerca. Le due ipotesi sono state rese tangibili in prototipi secondo il metodo RtD: la prima consiste in ***Mr.V*** (Mr. Verrassing, 'Mr. Sorpresa' in olandese) un 'compagno di giochi' per stimolare l'interazione, la coesione e la condivisione del tempo libero tra i membri della famiglia. Il secondo, ***AscoltaMe*** (dall'italiano, ascoltami), è un dispositivo progettato con lo scopo di invitare il bambino e i membri della famiglia a comunicare in maniera alternativa e superare le barriere emotive che possono erigersi durante la malattia. Le scelte progettuali che caratterizzano questi due oggetti sono documentate e riportate sotto forma di immagini e annotazioni in un format simile ad un portfolio; esso descrive il processo e la logica alla base delle scelte fatte nell'ideare Mr.V e AscoltaMe. Questo formato è ideale per spiegare come la ricercatrice ha interpretato e tradotto creativamente il concetto di ***delicatezza* per trasformarla in una qualità espressiva**: in particolare si focalizza sulla combinazione di specifiche scelte materico-esperienziali (***materials experience***) (Giaccardi & Karana, 2015) e di espressione della 'ritmicità' computazionale (***temporal form***) (Vallgårda et al., 2015) dei due oggetti.

Il **Capitolo 5**, risponde alla ***domanda n.2***. Il capitolo descrive come le famiglie hanno valutato i prototipi descritti precedentemente. Questo secondo caso studio mira infatti a comprendere come le famiglie interpretano la qualità espressiva di *delicatezza* e come percepiscono il contributo che i *Tactful Objects* possono avere nella loro vita quotidiana.
La prima parte del capitolo illustra come è stato strutturato il caso studio. Mr.V è stato presentato a otto famiglie con bambini di età compresa tra 10 e 16 anni ed AscoltaMe è stato presentato a famiglie con bambini di età compresa tra sei e 10 anni. Le famiglie hanno potuto utilizzare i prototipi per minimo una settimana; successivamente sono state intervistate ed hanno condiviso annotazioni personali sull'esperienza. L'intervista ha raccolto le opinioni di tutti i membri della famiglia e informazioni importanti riguardanti le modalità di interazione quotidiana con gli oggetti presentati. I risultati dello studio hanno condotto a definire i *Tactful Objects* come *oggetti interattivi capaci di entrare in sintonia con i bisogni di utenti vulnerabili in contesti sociali sensibili.* In particolare, le famiglie hanno suggerito che:

--- *Tactful Objects* dovrebbero **comportarsi come dei partners** per essere accettati ed avere un **impatto positivo** in contesti sociali sensibili;

--- *Tactful Objects* dovrebbero **interagire in collaborazione con gli utenti vulnerabili** e non essere interpretati come strumenti medicali;

--- *Tactful Objects* dovrebbero essere **invitanti e piacevoli da utilizzare**;

--- *Tactful Objects* dovrebbero essere in grado di **agire in modo appropriato a questo specifico contesto**.

Dallo studio è emerso inoltre che il prototipo di Mr.V si è rivelato come il tipo di supporto più adatto per le famiglie partecipanti.

Il **Capitolo 6** descrive la seconda fase di interazione-progettuale. In questo caso sono stati utilizzati i risultati raccolti durante il secondo caso studio con le famiglie. Le riflessioni su cosa sono i *Tactful Objects* e quali sono le caratteristiche che dovrebbero presentare per essere percepiti come *delicati* sono state convertite in linee guida/principi (**tactfulness principles**) per riprogettare Mr.V e creare ***Mr.V the Spaceman*** ('Mr.V l'Astronauta'). Il capitolo spiega quindi come i risultati dello studio svolto in precedenza abbiano portato a ridefinire attraverso quali aspetti la qualità espressiva di *delicatezza* possa essere concretizzata in un oggetto interattivo. Il processo creativo è presentato utilizzando annotazioni visive e testuali secondo un format simile ad un portfolio. Il capitolo illustra graficamente il modo in cui le caratteristiche del nuovo prototipo siano state modificate secondo **quattro principi**: (i) la possibilità di stabilire una forma di partnership *delicata* e attenta tra utente e oggetto (**sensitive partnership**), (ii) la volontà di instaurare un tipo di interazione intesa come collaborazione bilanciata tra utente e oggetto (**balanced collaboration**), (iii) la creazione di un oggetto a cui l'utente possa associare un significato e con cui nasca un legame affettivo e cognitivo (**familiar character**), (iv) la possibilità di far percepire all'utente un oggetto come adeguato perché capace di mantenere una presenza discreta nel contesto in cui è introdotto (**discreet presence**). Per raggiungere questo obiettivo le capacità del prototipo sono state migliorate tramite l'utilizzo di sensori, trasformando cosi Mr.V the Spaceman in un oggetto interattivo, abilitato alla raccolta autonoma di dati (**data-enabled object**) sui pattern di utilizzo da parte degli utenti.

Il **Capitolo 7** descrive come Mr.V the Spaceman sia stato introdotto nuovamente nel contesto domestico delle famiglie per rispondere alla ***domanda n.3***. Attraverso questo terzo caso studio, il capitolo mira a ampliare le linee guida per la progettazione dei *Tactful Objects* definite in precedenza e riflette su un potenziale futuro sviluppo dei **Tactful Intelligent Objects** (*Tactful Objects Intelligenti*), oggetti capaci di sfruttare elevate capacità computazionali per potersi comportare in maniera ancora più appropriata e delicata con gli utenti in base alle necessità del momento. Il capitolo spiega brevemente come i quattro principi sono stati utilizzati nella progettazione di Mr.V the Spaceman e come l'oggetto sia in grado di raccogliere autonomamente i dati. Il capitolo prosegue con la descrizione del terzo caso studio, che ha previsto il coinvolgimento di 10 famiglie con bambini in trattamento di età compresa tra i cinque e i 15 anni. Le famiglie hanno testato il prototipo a casa per una settimana, e hanno condiviso quotidianamente con la ricercatrice le loro attività tramite una online-chat criptata. Le famiglie sono state poi intervistate e hanno compilato un questionario. Il capitolo spiega inoltre come le esperienze descritte dalle famiglie e i dati rilevati autonomamente dall'oggetto, abbiano arricchito la definizione dei quattro principi sui cui basare lo sviluppo dei *Tactful Objects*. Infine, propone alcune importanti riflessioni sulle opportunità e implicazioni etiche riguardo all'utilizzo dell' intelligenza artificiale in contesti sociali sensibili. Lo scopo di questa discussione ha la finalità di proporre linee guida per sviluppare **oggetti intelligenti e senzienti, in grado di adattarsi *delicatamente* e in modo sensibile ai bisogni dell'utente** perché:

--- capaci di **utilizzare la loro intelligenza per stabilire un tipo di partnership sensibile**, dove utente e oggetto si aiutano reciprocamente per affrontare difficoltà e **migliorarsi nel tempo**;

--- capaci di **utilizzare la loro intelligenza per collaborare con le persone in modo equilibrato, bilanciando libertà di azione e senso di controllo/guida**;

--- capaci di **utilizzare la loro intelligenza per comprende quali aspetti e espressioni possono risultare rilevanti per l'utente** al fine di legare **emotivamente e cognitivamente** con l'oggetto;

--- capaci di **utilizzare la loro intelligenza per agire sempre in modo appropriato e mantenere una presenza discreta senza imporsi** nel contesto quotidiano dell'utente.

Infine, il **Capitolo 8** ripercorre il progetto nel suo insieme e chiarisce il contributo della tesi al Design dell'Interazione, alla disciplina del Design e al settore medico. Vengono poi discusse le implicazioni, i limiti della ricerca svolta e i suggerimenti per lo sviluppo in ambito clinico di Mr.V the Spaceman. Infine, il capitolo presentata una breve riflessione sulle opportunità di ricerca futura. Queste opportunità riguardano l'introduzione dell'intelligenza artificiale in contesti sociali sensibili, le relative questioni etiche e la necessità di preparare alla complessità della materia ricercatori, professionisti della progettazione e dell'ambito medico.

Il design può supportare gli utenti vulnerabili fornendo soluzioni in grado di generare un'esperienza che sia *delicata* e attenta alle loro necessità senza imporsi e forzare cambiamenti in queste situazioni stressanti. Questi oggetti interattivi possono di fatto essere in grado di offrire il tipo di supporto adeguato per affrontare alcuni tipi di sfide che gli utenti possono incontrare, se vengono progettati per raggiungere l'obiettivo con *delicatezza*. Questa tesi spiega come è possibile introdurre tale qualità espressiva nel processo di progettazione seguendo quattro principi. **Progettare *Tactful Objects* per contesti sociali sensibili significa quindi progettare oggetti che si comportano come partner sensibili, capaci di stabilire una relazione equilibrata con utenti vulnerabili, e sono in grado di utilizzare la loro espressività e personalità per generare empatia, mantenendo una presenza discreta nel contesto in cui vengono introdotti.**

I tre casi studio riportati in questa tesi sono limitati al contesto di famiglie con bambini malati di cancro. La ricerca futura potrebbe potenzialmente applicarsi nella definizione di uno studio longitudinale con un gruppo demografico più ampio, differenziato per fascia di età, diagnosi dei bambini, coinvolgendo anche famiglie con bambini afflitti da malattie croniche. Queste famiglie potrebbero ugualmente trarre vantaggio dall'introduzione di questi oggetti poiché affrontano sfide quotidiane simili a quelle di famiglie con bambini malati di cancro.

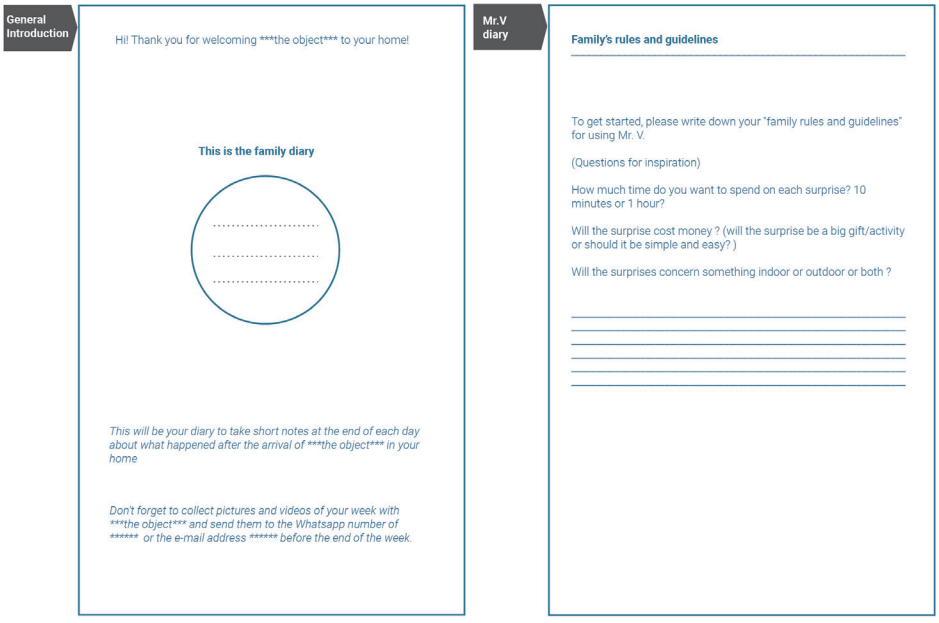
In futuro sarebbe importante valutare anche l'introduzione dei *Tactful Objects* e nello specifico di Mr.V the Spaceman anche all'interno dell'ambiente ospedaliero. Mr.V the Spaceman è stato valutato positivamente da tutte famiglie coinvolte e pertanto sarebbe interessante pianificare come facilitarne la futura implementazione clinica. Questo richiede una scrupolosa valutazione della fattibilità e robustezza dell'oggetto, insieme alla definizione di un business plan per coinvolgere le istituzioni e le associazioni sanitarie aperte ad investire in strumenti innovativi durante il trattamento dei loro pazienti. Questo contribuirebbe inoltre ad evidenziare l'importanza di progetti come 'Meedoen = Groeien!', un valido esempio di come la collaborazione tra Design e settore medico possano contribuire in modo concreto alla ricerca riguardante lo sviluppo dei bambini malati e il supporto delle loro famiglie.

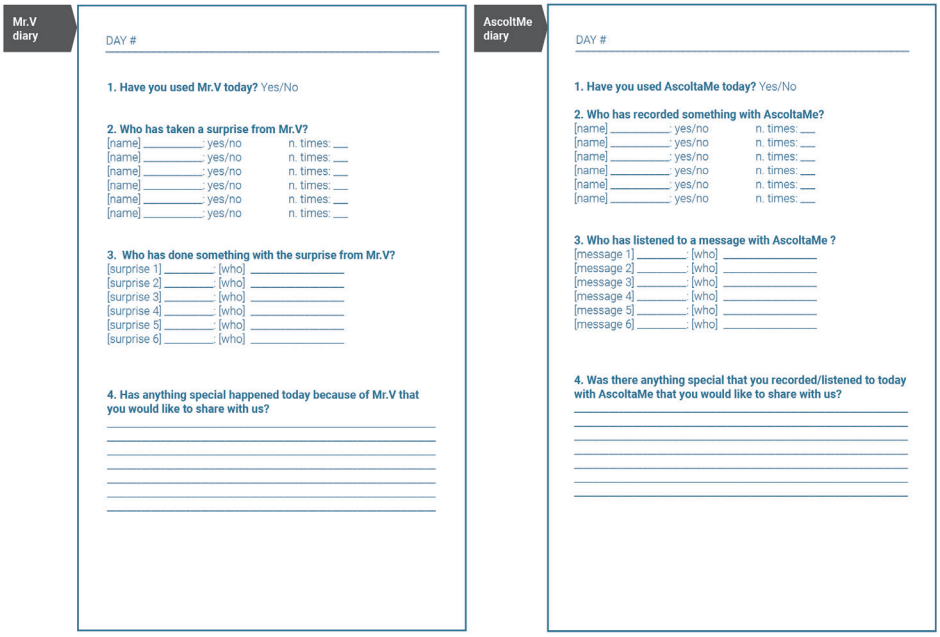
APPENDIX

Appendix 5.1: Examples of Surprises Provided to the Families who Trialled Mr.V to Facilitate the Ideation of the Activities (Translated in English from Dutch).

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 it time for food ... shall we sit at the table together and have a nice chat about what we did today?
Shall we have an ice cream ?
What's on the menu today? Let's prepare something together!
What's the weather like today? Shall we go for a walk outside or watch a nice movie together in the living room?
Who is the best artist 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 make something today? Pizza or cake?
Give each other a compliment!
It is hug day! Who would you like to give a hug to first?
Let's dance!!!

Appendix 5.2: Diary Structure (Translated in English from Dutch).





Appendix 5.3: Example of Semi-Structured Interview Questions for Mr.V (Translated in English from Dutch).

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

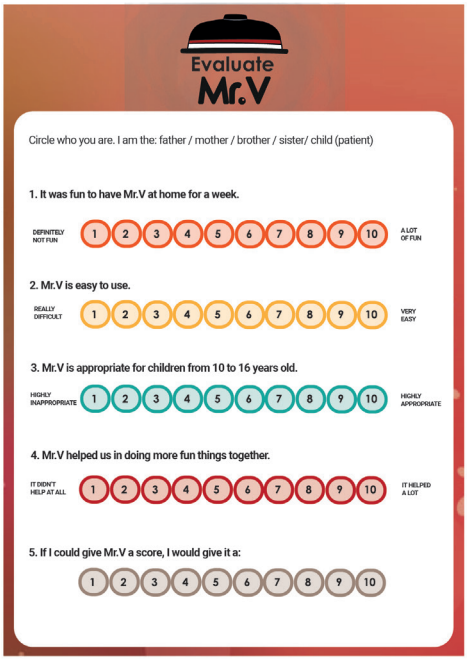
1. What was it like to have Mr. V at home for a week? (Initial reaction / warming up)
- Was it fun?
- Did everyone use it?
  - *Did everyone add a surprise to Mr.V?*
  - *Did everyone collect and open a surprise from Mr. V?*
- Who used Mr. V the most?
  - *Who put most of the surprises in Mr. V?*
  - *Who collected and opened most of the surprises from Mr. V?*

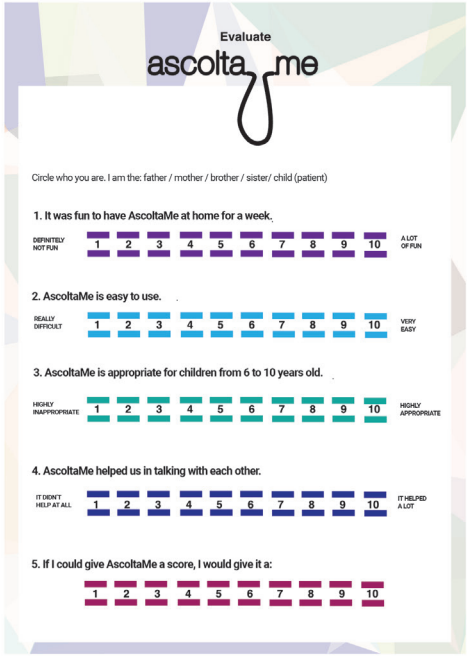
2. Would you like to describe one of the times you used Mr.V ?
- Who took the surprises?
  - *Who took the initiative?*
  - *Who participated?*
- When was this? (In the morning, after school, in the evening)
- Location: where did you use Mr.V in the house and where did you read the surprises?
- What was the content of the surprises?
  - *What did you do with the surprises? What happened?*
  - *How long were you 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 use Mr.V?
(In practice)
- Where was Mr.V positioned in your house?
  - *Why there?*
  - *Did Mr.V ever move from that position?*
- How much did you use Mr.V?
  - How many surprises (approximately) did you add to Mr.V?
  - (Did one person add a surprise everyday or was it a different person everyday?)
  - How many surprises were given (approximately) by Mr.V?
  - (One, two, three a day/per day?)
  - Did you press the button on Mr.V to get more surprises?
  - Did you open all of the surprises from Mr.V? How many did you not?
  - Were the surprises opened immediately (or did the containers pile up during the week)?
- When and with whom did you open the surprises from Mr.V?
  (At what time of the day did this generally happen and was it together or alone?)
- How long were you busy with the surprises from Mr.V? How much time would you spend per surprise everyday?
  (Per surprise / per day?)

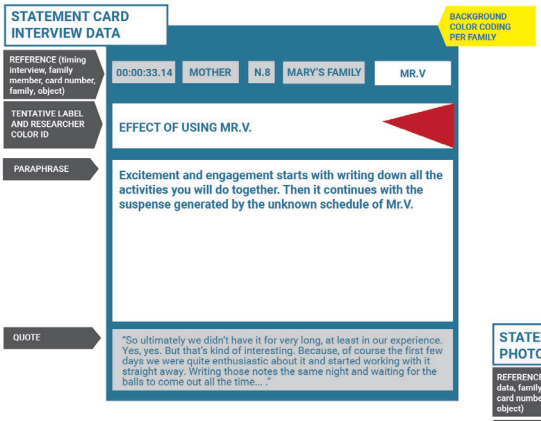
	(Content) What kind of surprises did you add to Mr.V? What kind of surprises did you prefer to repeatedly put into the containers? What kind of surprises did you put in the containers only once? Did the kind of surprises you put in the containers change during the week? Were the surprises related to illness or not? Did you do something because of Mr.V which you normally wouldn't do? (Give examples)
Technology & Design	**4. What did you think of the product itself?** Did you understand how to use it? Was it easy to use? Or is it too difficult or childish? 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 did you think about the shape, colour, 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 things differently or done new things? Have you done more things together? What is your greatest memory? **6. How would you rate Mr.V?** Would you like to keep Mr.V for 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 see any improvements or good ideas to improve Mr.V?** Is there something you feel that's missing about the product? Is there anything that you think would make it even more fun?
Other comments ...	

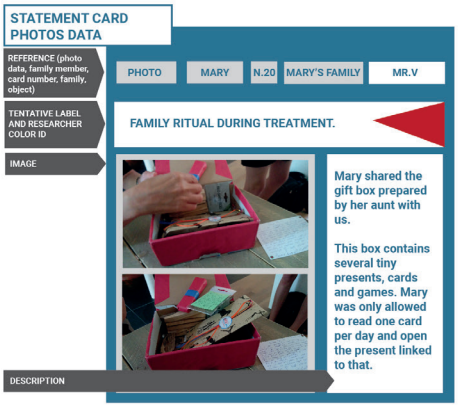
Appendix 5.4: Evaluation Questionnaire (Translated in English from Dutch).

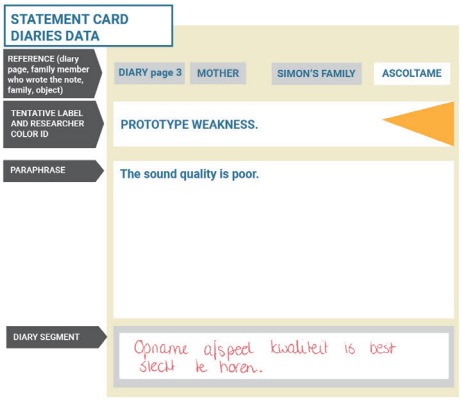


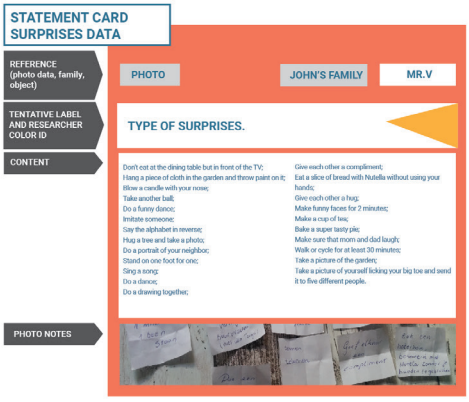


Appendix 5.5: Example of the Statement Cards Generated during the Analysis (Quotes, Diary segments and Surprises content translated in English from Dutch).





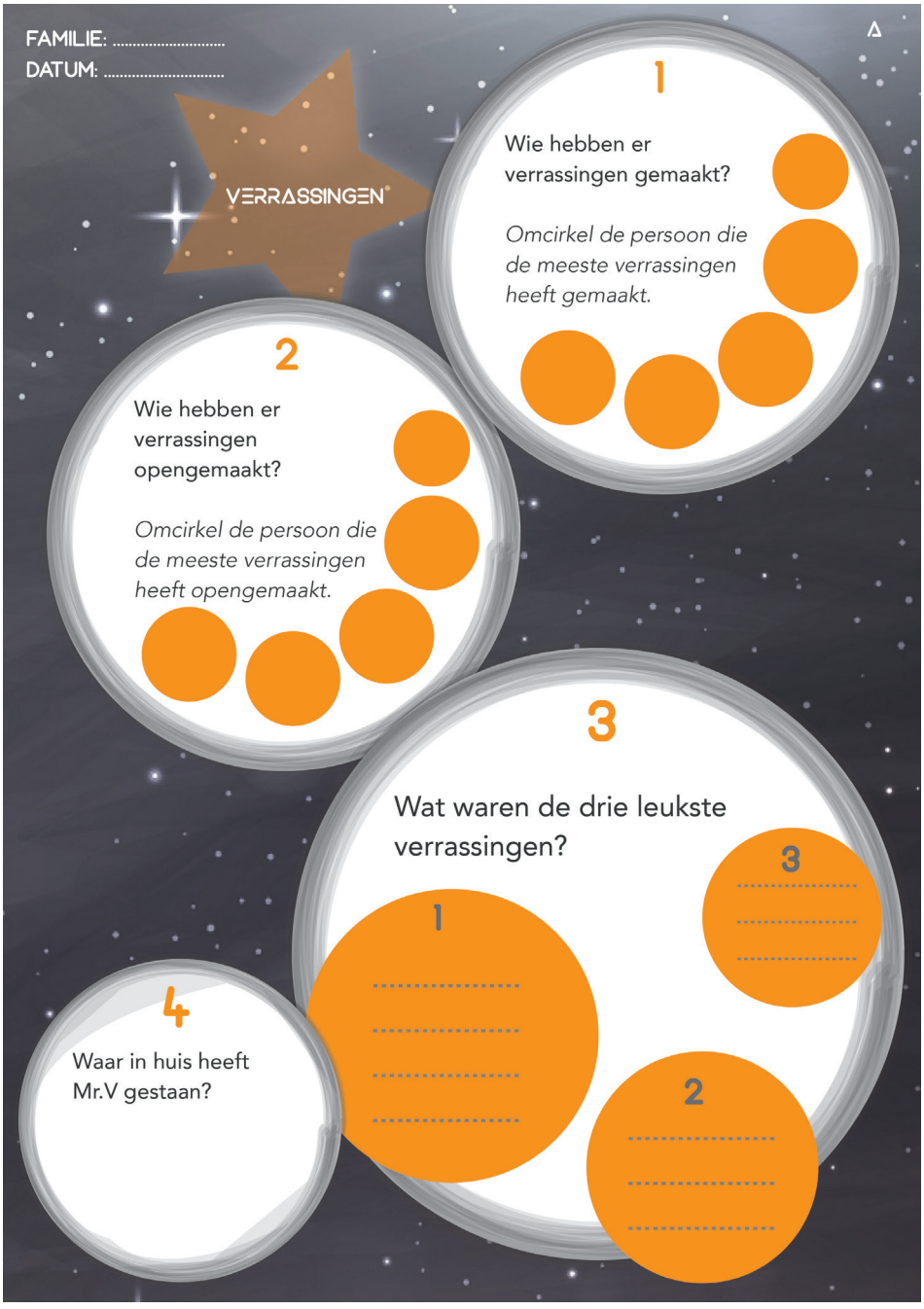




Appendix 5.6: List of Surprises Collected in each of the four Families Trialling Mr.V (Translated in English from Dutch).

Family (N = 4)	List of surprises (N = 88)	Surprises per family
Kevin's family	Choose a game and play together; Watch a family movie together and eat crisps/snacks; Bake cookies; Let's have a BBQ together; Organise a high tea; Let's go to watch the pandas in Rhenen; Mom and Dad will get breakfast in bed and don't have to make it for us; Bake brownies; Let's have a day together in the woods; Have lunch/dinner out; Make a homemade pizza; Watch a movie together on TV; Have a day out; Have coffee/tea with some tasty snacks; Make sausage rolls;	(*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 in reverse; Hug a tree and take a photo; Do a portrait of your neighbor; Stand on one foot for one minute; Sing a song; Do a dance; Do a drawing together; Give each other a compliment; Eat a slice of bread 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)
Mary's family	Call grandma and say hi; What are we going to eat tonight for dessert?; Today I treat you! (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; Have a look at the photo album from 2012 together; Go and have ice-cream at Jacco; Give 1 litre of water to the banana plant; Give a kiss to your dad!; Go outside hand in hand with someone else, walk with your eyes closed ...What birds do you hear?; Fancy going 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 at the photos from Peru' together; Give a kiss to mom; Say good morning to the neighbours; Sing two tunes by 'Vader Jacob' together; Call your aunt and say hello;	(*n* = 23)
Sammy's family	Go to the zoo if the weather is nice; Sammy's sister will buy a small present for Sammy (under 5 euros); Mom will buy a small present for dad (under 5 euros); Sammy's sister will cook 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 sweets/cookies from the store; Play Wii together; Go for a walk; Dad will buy a small present for mom (under 5 euros); Sammy will buy a small present for her sister (under 5 euros); Get 20 McChickens from McDonalds; Sammy will cook tonight; Let's go and do the groceries by bike; Play tennis with your sister; Play tennis all together; Give a treat to the pet; Play a game; Bake cupcakes; Go out for pizza tonight; Go to the city centre; Lets eat out together. Sammy's sister and Sammy will pay; Play tennis with your sister;	(*n* = 27)

Appendix 7.1: Example of Semi-Structured Interview Questions and Questionnaire for Mr.V the Spaceman.



B

OVER MR.V

Omcirkel wie jij bent, ik ben:

- VADER
- MOEDER
- BROER (LEEFTIJD: ....)
- ZUS (LEEFTIJD: ....)
- KIND (patiënt)
- .....

MR.V IS LEUK OM THUIS TE HEBBEN.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR.V IS GESCHIKT VOOR KINDEREN VAN 4 TOT 12 JAAR.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR.V IS AARDIG/VRIENDELIJK.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR. V IS LEUK OM TE GEBRUIKEN MET HET HELE GEZIN.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR.V VOELT ALS EEN MAATJE/VRIENDJE.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR.V HELPT OM MEER LEUKE DINGEN MET ELKAAR TE DOEN.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

ALS IK ER ZIN IN HEB, KAN IK MR. V GEBRUIKEN.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR. V WAS ONDERDEEL VAN ONZE DAGELIJKSE ROUTINE.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

IK KAN MR. V GEBRUIKEN ZOALS IK DAT WIL.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

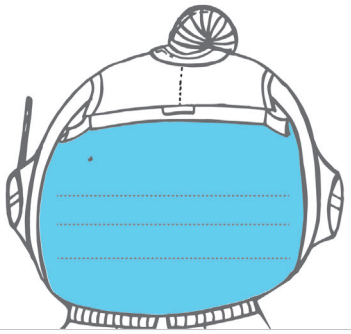
MR. V WAS DE LAATSTE DAG NOG NET ZO LEUK ALS DE EERSTE DAG.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR.V IS MAKKELIJK TE GEBRUIKEN.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MIJN LEUKSTE HERINNERING AAN MR. V IS:



MR.V ZIET ER AANTREKKELIJK UIT.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg

MR. V GAF DE VERRASSINGEN OP EEN POSITIEVE/LEUKE MANIER.

Helemaal niet | Een beetje | Neutraal | Erg | Heel erg


C
VERBETERPUNTEN
1
Heb je (technische) problemen gehad met Mr. V?
Ja, namelijk:.....
.....
.....
.....
Nee
2
Heb je iets gemist aan Mr. V?
Ja, namelijk: .....
.....
.....
.....
Nee
BEOORDELING
1
Zou je Mr. V nog langer thuis willen hebben?
Ja
Nee, omdat: .....
.....
.....
.....
2
Zou je Mr. V aan andere gezinnen aanraden?
Ja
Nee, omdat: .....
.....
.....
.....
3
Zou Mr. V een meerwaarde kunnen zijn om thuis te hebben tijdens het behandeltraject in het ziekenhuis?
Ja, want: .....
.....
.....
.....
Nee
5
Als ik Mr. V een totaal cijfer zou moeten geven, dan geef ik een:
1 2 3 4 5 6 7 8 9 10
4
Zou je Mr. V kopen als hij in de winkel te krijgen zou zijn?
Ja
Nee, omdat: .....
.....
.....
.....

ANTWOORDEN E

MR.V IS LEUK OM THUIS TE HEBBEN.

MR.V IS GESCHIKT VOOR KINDEREN VAN 4 TOT 12 JAAR.

MR.V IS AARDIG/VRIENDELIJK.

MR. V IS LEUK OM TE GEBRUIKEN MET HET HELE GEZIN.

MR.V VOELT ALS EEN MAATJE/VRIENDJE.

MR.V HELPT OM MEER LEUKE DINGEN MET ELKAAR TE DOEN.

ALS IK ER ZIN IN HEB, KAN IK MR. V GEBRUIKEN.

MR. V WAS ONDERDEEL VAN ONZE DAGELIJKSE ROUTINE.

IK KAN MR. V GEBRUIKEN ZOALS IK DAT WIL.

MR. V WAS DE LAATSTE DAG NOG NET ZO LEUK ALS DE EERSTE DAG.

MR.V IS MAKKELIJK TE GEBRUIKEN.

MIJN LEUKSTE HERINNERING AAN MR. V IS:

MR.V ZIET ER AANTREKKELIJK UIT.

MR. V GAF DE VERRASSINGEN OP EEN POSITIEVE/LEUKE MANIER.

THANKS TO...

"credo che il design abbia significato se comunica conoscenza."
(Enzo Mari. 25 modi per piantare un chiodo, p.123)

I would like to start my acknowledgements with a quote from my favourite (and the 'most punk') Italian designer ever *Enzo Mari*. The quote translates as *"I believe that design has meaning if it communicates knowledge"*. I think that this sentence contains the essence of what has been the joy and the struggle of this important journey for me, which is a journey that started already since the first time I entered a Design school. Now that the cycle is complete I would like to thank some of the people that have contributed tremendously in helping me reach this achievement.

I would like to dedicate these first lines to my supervisors, to thank them for the constant support that went beyond the purpose of the project. ***Marco***, thank you for choosing me for this project and helping me to build trust and confidence in myself as a design researcher. You have been a friendly mentor, a positive motivator and a curious 'agent' in my PhD path. I am so grateful to be able to continue the collaboration with you even now. ***Elisa***, you are such an inspiration, but I am sure that I am not the first one telling you this! I am grateful I had the chance to meet you and experience the way you work and think. Your academic creativity and the ability to carefully articulate each meaningful thought helped me more than once to clarify what was still 'messy' in my head. ***Martha***, thank you for your trust. Our paths crossed suddenly and I am so grateful for that moment. A big part of what became possible in my project happened because of your support. Despite the initial 'disciplinary distance', I have found in you a person that is capable to read between the lines and see always opportunities and value.

I think that together with my supervisors a deserved thank you goes also to Jaap and Kelly. ***Jaap***, thank you for being an important advisor and supporter of my work and my creativity since the beginning of the project. Your friendliness and calm character have always been welcoming to me, making me feel at ease in my research context. (Soon-to-be doctor) ***Kelly***, I am glad I had the chance to meet you! We made a great team together and our work relation shifted nicely into a dear friendship. I admire your rigour in working and writing in your field and I am so glad that we have managed to create an impact together while having fun too. I also would like to thank all the members of the ***Poppi group*** of the Princess Máxima Center (with special thanks to ***Guus*** for her support in the last study and for sharing with me her reflections). Thank you for giving me the chance to be 'one of you' for a little while. I would like to thank also: ***Marie*** for her help in the patients' recruitment during the second field study, ***Netteke*** for her openness in sharing her precious reflections on the opportunities brought by design in paediatric oncology, and ***Charlotte*** for her invaluable help in preparing me for my first Medical Ethical Committee encounter. A final thanks to all the medical staff that introduced me to the world of paediatric oncology, and all the ***families and children*** that shared a little bit of their precious time to support me in making this project meaningful.

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to me by sharing your personal experiences, and for trusting my work. You are a great example for all of us.

Thanks to my project buddy ***Boudewijn***. Our roads have crossed and separated several times throughout these years and I can say that I am so glad you were there with me! I told you already and I will keep on repeating that: you are a great researcher and I admire you so much!. I envy your ability to articulate your wise thoughts with such clarity and rigour and stand for your ideas. I feel that our connection has grown with time and now that the project is ended, we have finally the mental space to reconnect again, share a genuine laugh, and enjoy 'wondering chats' about the beauty of nature. The office is a bit empty without you around now, but I will keep on 'bugging you with some bugs' so you will not forget about me.

Thanks to my dear wonder-paranymphs ***Chen*** and ***Lyé***. You are my support and my safe shore. So many things have happened throughout these years, and I am glad we have managed to solidify our friendships -through and outside- research. Our doubts and struggles are always around the corner but we know exactly how to fix the situation: a good coffee break together or even better... a nice Chinese-Japanese-Italian fusion meal. We have so much in common and many things still to share. Of course, I also want to thank your other half ***Jiaji*** and ***Alex*** for their help and friendship, and your other half-half ***Anya, Yuki*** and ***Kenta*** for bringing so much joy and magical anecdotes to your lives.

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Thanks also to two great women who are the trigger behind my presence here today. ***Elvin***, my link with you started since I was a master student trying to 'absorb knowledge' from your foundational research work and it continues till today. I am so glad I had the chance to work together with you and learn so much from you! ***Valentina*** 'thank you 1000'! Tutto è iniziato per 'colpa' tua e te ne sono grata! Con il tuo lavoro e la tua passione per la ricerca e il Design hai aperto la mia mente quando ero ancora un' acerba studente al Polimi. Ancora adesso, nonostante gli impegni e i Km di distanza, sono contenta di averti prima di tutto come amica e poi come collega. Sei la prof. che tutti gli studenti dovrebbero aver almeno una volta nella vita!

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A thanks goes also to the lovely secretaries ***Joost***, ***Daphne***, ***Denise***, ***Charleyne***, ***Amanda***, ***Jolanda***, and ***Sara*** for your availability and patience when I came to ask the same question more than once.

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Lieve ***Kars***, 'il mio principe in bicicletta'! (Cit. TARM). You know already that the little bit of 'confidence and proudness' that shines through the pages of this thesis is your merit. You are my 'sparring partner' on the ring and in life, and now I hope to repay you for all the patience and care you put up for me every single day since I met you. Are you ready for thesis-free weekends?!

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Patrizia - Delft, 9 May 2021

About the Author & List of Publications



Patrizia D'Olivo was born in Pordenone, Italy. Patrizia started her PhD in August 2014 at Delft University of Technology in the Connected Everyday Lab at the Department of Human-Centred-Design (Delft University of Technology, the Netherlands). In her work she discusses *tactfulness* as a critical expressive design quality of interactive objects for sensitive settings, as well as the methodological implications of conducting Research-through-Design in such settings. After the conclusion of her doctoral project, she started her position as PostDoc researcher. She collaborated with the Material Experience Lab at the Department of Sustainable-Design-Engineering (Delft University of Technology, the Netherlands) combining her interest for interactive systems, innovative materials and people in a project focused on framing the identity of biomaterials from living organisms to enhance their acceptability in society. Currently she has joined the Expressive Intelligence Lab at the Department of Human-Centred Design (Delft University of Technology, the Netherlands) and in collaboration with the the Rijndam revalidatiecentrum and Erasmus MC in Rotterdam she is focusing on developing agentic objects as motivational devices for people to do home-based rehabilitation exercises after a stroke (*ArmCoach4Stroke* project).

Prior to starting her PhD, Patrizia explored the connection between materiality and technology by working as a research assistant at Delft University of Technology (the Netherlands) on the topic of 'materiality of connectedness' with Prof. dr. Elisa Giaccardi and Prof. dr. Elvin Karana. Earlier, after the conclusion of a research internship at Ecole Nationale Supérieure des Mines de Saint Etienne (France) for her master thesis on 'Sensory Metrology' (awarded the Targa Giovani Prize in the *ADI Design Index 2013*), she worked as a research and teaching assistant in the Department of Chemistry, Materials, and Chemical Engineering 'Giulio Natta' at Politecnico di Milano (Italy) with Prof. dr. Barbara Del Curto. She obtained her bachelor's degree cum laude in Product Design (BSc) and her master's degree in Design & Engineering (MSc) from Politecnico di Milano (Italy).

(Illustration by ***Catarina Gonzáles Gonzáles***)

Journal Articles (submitted)

D'Olivo, P., van Bindsbergen, K.L.A., Huisman, J., Grootenhuis, M.A., Rozendaal, M.C. (n.d.) From Tactful Objects to Tactful Intelligence. Under review with *AI & Society: Journal of Knowledge, Culture and Communication*

D'Olivo, P., Karana, E. (*Forthcoming*) Materials Framing: A Case Study of Biodesign Companies' Web Communications. *She Ji: The Journal of Design, Economics, and Innovation.*

Journal Articles (published)

D'Olivo, 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(2), 103-124.*

D'Olivo, P., Rozendaal, M.C., Giaccardi, E., Grootenhuis, M.A., & Huisman, J. (2018). Reconfiguring a New Normal: A Socio-Ecological Perspective for Design Innovation in Sensitive Settings. *She Ji: The Journal of Design, Economics, and Innovation, 4(4), 392-406.*

Van Bindsbergen, K.L.A., **D'Olivo, P**., Rozendaal, M.C., Merks, J.H.M., and 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. https://doi.org/doi:10.1007/s00520- 021-05995-3*

Groeneveld, B., Dekkers, T., Boon, B., & **D'Olivo, P.** (2018). Challenges for design researchers in healthcare. *Design for Health, 2(2), 305-326.* **(shared first authorship)**

Caprari, E., Porsius, J.T., **D'Olivo, P**., Bloem, R.M., Vehmeijer, S.B.W., Stolk, N., & Melles, M. (2018). Dynamics of an orthopaedic team: Insights to improve teamwork through a design thinking approach. *Work, 61(1), 21-39.*

Robbins, H., Giaccardi, E., Karana, E., & **D'Olivo, P.** (2015). Understanding and Designing with (and for) Material Traces. *Studies in Material Thinking, 13(1), 1-24.*

Conference Papers

D'Olivo, P., Rozendaal, M.C., Giaccardi, E. (2020). Making Tactful Objects for Sensitive Settings: A Research through Design Process. In *Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society (NordiCHI '20), October 25-29, 2020, Tallinn, Estonia.* ACM, New York, NY, USA, https://doi.org/10.1145/3419249.3420140

D'Olivo, P., Rozendaal, M.C., & Giaccardi, E. (2017, June). AscoltaMe: Retracing the Computational Expressivity of a Tactful Object for Sensitive Settings. In *Proceedings of the 2017 Conference on Designing Interactive Systems (pp. 943-955).*

D'Olivo, P., Del Curto, B., Faucheu, J., Lafon, D., Bassereau, J. F., Lê, S., & Delafosse, D. (2013). Sensory Metrology: when emotions and experiences contribute to Design. In *DS 75-7: Proceedings of the 19th International Conference on Engineering Design (ICED13), Design for Harmonies, Vol. 7: Human Behaviour in Design, Seoul, Korea, 19-22.08. 2013.*

D'Olivo, P., Del Curto, B., Faucheu, J., Lafon, D., Bassereau, J. F., & Delafosse, D. (2013). Education and Research: when design and engineering perform new links with the industrial world. In *7th INTED 2013 (International Technology, Education and Development Conference)*

(pp. 0935-0945). L. Gómez Chova, A. López Martínez, I. Candel Torres-International Association of Technology, Education and Development (IATED).

Giaccardi, E., Karana, E., Robbins, H., & **D'Olivo, P.** (2014, June). Growing traces on objects of daily use: a product design perspective for HCI. In *Proceedings of the 2014 conference on Designing interactive systems (pp. 473-482)*.

Workshop Paper & Posters

D'Olivo, P., Rozendaal, M.C., Giaccardi, E. (2015). "Fostering Psychosocial Development and Well-being for Teenagers with Cancer through Playful Experiences". *Conference: CHI2015 (Computer Human Interaction) - workshop: Supporting Children to Engage in Play for Wellbeing, Seul (South Korea)*.

D'Olivo, P., Del Curto, B., Delafosse, D., Faucheu, J., Lafon, D., & Bassereau, J. F. (2013). Design texture and design finish surface treatment to achieve the user's preferences. In *5TH INTERNATIONAL MATERIALS EDUCATION SYMPOSIUM (pp. 63-63)*. Granta Design.

Van Bindsbergen, K.L.A., **D'Olivo, P.**, Rozendaal, M.C., Huisman, J., & Grootenhuis, M.A. (2019, December). Working Together with Designers to Support Families at Home During Childhood Cancer Treatment: A Pilot Study. In *Pediatric Blood & Cancer* (Vol. 66, pp. S481-S481). 111 River St, Hoboken 07030-5774, NJ Usa: Wiley.

Accepted Conferences & Public Talks

D'Olivo, P., Ormellese, M., Garbagnoli, P., Marra, F., Pulci, G., Sarasini, F., & Del Curto, B. (2013). Smart Design: When the Application of Intelligent Materials Give its Contribution to the Industrial Design Development. In *Euro Intelligent Materials 2013* (pp. 58-58). www. siblog. de

D'Olivo, P., Mr.V brings 'Verrassing'. In *This Happened #13. 2019*. Rotterdam, Netherlands. www.youtube.com/watch?v=UV6PevGnNl0&t=182s

Presentation and workshop contribution, (Groeneveld, B., Dekkers, T., Boon, B., & **D'Olivo, P.**, 'Common Ground in Healthcare Research: Bridging Perspectives Between Healthcare and Design Research', DRS2016), in *PhD by Design - Instant Journal #3 - Exploring what the future holds for practice-based PhDs (2016)*.

Exhibition participation

DDW 2017, in the 'DDW Arena' with Break!, in collaboration with Minon Rosier

EXCEED2017, with AscoltaMe

MEDICA2017, in the 'Holland Pavilion' with 'Meedoen=Groeien!' in collaboration with Boudewijn Boon and Marco C. Rozendaal

INNOVATION FOR HEALTH EXPO 2017, with 'Designing the New Normal'

DDW 2016, at 'Mind the Step' with 'Meedoen=Groeien!' in collaboration with Boudewijn Boon and Marco C. Rozendaal



Childhood cancer is a disruptive life event that creates high levels of stress and anxiety in families. It turns everyday routines up-side-down, and can block the child's psychosocial development when families have difficulties to emotionally cope with this potentially traumatic event. D'Olivo developed three interactive objects aimed at preserving space for quality time and stimulate interpersonal communication between family members. These objects were deployed in the homes of children who are receiving cancer treatment in order to better understand how families responded to them, and whether they were appropriate to support their situation.

The broader question addressed by the work is **'how can vulnerable users be empowered by design in sensitive settings?'**. Tactfulness was found to be a critical expressive design quality of such objects, leading to the idea of Tactful Objects as a design perspective on interactive artefacts that function in sensitive settings. According to this perspective, designing tactful objects for sensitive settings means to design objects that **behave like sensitive partners**, **establish a balanced collaboration with people**, **resemble familiar characters** and **maintain a discreet presence in the context where they are introduced**. The thesis discusses the practical value of Tactful Objects in healthcare as well as the methodological implications of conducting Research-through-Design in sensitive settings.