PARTICIPATORY DESIGN IMPROVING THE QUALITY OF LIFE IN INPATIENT CHILDREN WITH CANCER

A Thesis Submitted to
the Graduate School of Engineering and Science of
İzmir Institute of Technology
in Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE

in Industrial Design

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June, 2019
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ACKNOWLEDGMENTS

I would like to extend my sincere thanks to my thesis advisor Asst. Prof. Dr. Ayça TUNÇ COX for her encouragement and guidance throughout this thesis. I would also like to express my deep gratitude to my thesis co-advisor Prof. Dr. Deniz HASIRCI for her invaluable support and time that have helped to shape my thoughts. This thesis would not have been possible without their support.

I would also like to thank Asst. Prof. Dr. Gökhan MURA, Assoc. Prof. Dr. Naz A.G.Z. BÖREKÇİ and Assoc. Prof. Dr. Burcu Gülay TAŞÇI, for their support as members of my thesis committee.

I am thankful to Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital for giving me the chance to conduct this study. I am deeply grateful to all children for participating in this study and broadening my horizons with their perspectives. I am thankful to caregivers of the children for always being enthusiastic towards this study. I should thank the nurse Ayşe ÖREL and doctors Prof. Dr. Dilek İNCE, Prof. Dr. Şebnem YILMAZ and Prof. Dr. Hatice Nur OLGUN for guiding me in the hospital. Thanks to Prof. Dr. Kamer MUTAFOĞLU for encouraging my idea to conduct this study in the preliminary stages of the study.

I would like to thank all of my professors in the Department of Industrial Design, İzmir University of Economics, especially to Asst. Prof. Dr. A. Can ÖZCAN for being understanding, tolerant and supportive, Dr. Deniz SAYAR for our long conversations regarding my thesis and Dr. Elif KOCABIYIK SAVASTA for sharing her insights with me. I am thankful to all of my research assistant colleagues, especially Ece KÜRELİ GÜLPINAR, Elif TEKCAN and Adnan Alper DEMİRCİ, who helped me. Special thanks are extended to Ersan ÇELİKTAŞ for his help in photography.

I owe a deep sense of gratitude to my family, Tansel, Seval and Tuğçe ÖRNEKOĞLU for their endless support and immeasurable love. I should also thank Argun TANRIVERDİ for listening to my endless talks about this study and being supportive. I am grateful to Nurcan DOĞAN for her unshakable faith in me. Finally yet importantly, I would like to thank my husband Kaan SELÇUK for sharing my happiness, stress and excitement through this journey and the unconditional love he brings to my life.

ABSTRACT

PARTICIPATORY DESIGN IMPROVING THE QUALITY OF LIFE IN INPATIENT CHILDREN WITH CANCER

The diagnosis of cancer influences the lives of children in many ways. Instead of maintaining daily activities, children often visit hospitals or stay there for an uncertain period. Due to the disease and treatment, children experience suffering and pain, their school and play activities are interrupted and they become separated from social and familiar environments. This may cause several problems in their development and quality of life (QOL).

QOL is the state of well-being in terms of physical, psychological and social aspects. According to surveys that investigate the negative effects of cancer on children's QOL, "the loss of normalcy" and inability to play, do sports, spend time with family and friends are considered by children to be worse than the physical symptoms and side effects of the treatment. Children with cancer need play during hospitalization in order to pursue their development and to feel normal.

A case study was conducted in Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital in order to understand the needs of children with cancer, provide a design suggestion for their play area, and especially investigate the effects of the participatory design process on QOL of children. A participatory design study was carried out in order to achieve more responsive results to participants' needs by involving users in the design process. It was found out that the process contributes to the improvement of QOL of children by making them feel that their ideas matter as well as distracting them from negative thoughts regarding cancer.

Keywords: Participatory design, generative techniques, design with/for children, quality of life (QOL), children with cancer, hospitalization, play area design

ÖZET

KANSERLE MÜCADELE EDEN ÇOCUKLARIN HAYAT KALİTESİNİ ARTTIRMAK İÇİN KATILIMCI TASARIM

Kanser teşhisi, çocukların yaşamını birçok açıdan etkiler. Ayrıca çocukların "normal hayatlarına" olumsuz yönde bir etki gösterir. Çocuklar, günlük hayatlarını sürdürmek yerine sıklıkla hastaneye giderler ve tam olarak belirli olmayan bir süre boyunca hastanede kalırlar. Hastalık ve tedavi yöntemleri sebebiyle hayatlarında ani bir değişim meydana gelir. Bu süreçte çocuklar acı çekmeyi, okul ve günlük hayatlarındaki kesintileri, sosyal ve aile ortamlarından ayrı kalmayı ve oyunun eksikliğini tecrübe ederler. Bunun çocukların gelişim sürecinde ve yaşam kalitesinde sorunlara neden olabileceği bilinmektedir.

Yaşam kalitesi, insanların fiziksel, zihinsel ve sosyal koşullar bakımından iyi olma halidir. Kanserin çocukların yaşam kalitesi üzerindeki olumsuz etkilerini araştıran çalışmaların sonuçlarına göre "normallik kaybı" ve oyun oynayamama, spor yapamama, aile ve arkadaşlar ile vakit geçirememe; çocuklar tarafından bu hastalığın fiziksel belirtilerinden ve yan etkilerinden daha kötü olarak tanımlanmıştır. Çocukların hastanede yattıkları süre boyunca fiziksel, zihinsel ve duygusal gelişimlerini sürdürebilmeleri ve normal hissetmeleri için oyuna ihtiyaçları vardır.

Dokuz Eylül Üniversitesi Nevvar ve Salih İşgören Çocuk Hastanesi'nde kanserle mücadele eden çocukların ihtiyaçlarını anlamak, oyun alanları için bir tasarım önerisi sağlamak ve özellikle bu katılımcı tasarım sürecinin çocukların yaşam kalitesi üzerine etkilerini araştırmak için bir alan çalışması yürütülmüştür. Katılımcıları tasarım sürecine dâhil ederek katılımcıların ihtiyaçlarına daha iyi yanıt verebilmek için katılımcı tasarım çalışması yapılmıştır. Bu sürecin, çocukların fikirlerinin önemli olduğunu hissetmelerini sağlayarak ve onları kanserle ilgili olumsuz düşüncelerden uzaklaştırarak çocukların yaşam kalitesini iyileştirmelerine katkıda bulunduğu saptanmıştır.

Anahtar Kelimeler: Katılımcı tasarım, üretici teknikler, çocuklar için/ile tasarım, yaşam kalitesi, kanserle mücadele eden çocuklar, hastanede yatış, oyun alanı tasarımı

To the memory of my beloved grandmother,

Meral KARAGÖZ,

who lost her life to cancer

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CHAPTER 1

INTRODUCTION

1.1. Problem Definition

Cancer is a disease that can be described based on its most common denominator: uncontrollable and continuous growth of cells. Cancer can start in lungs, brain, breast, colon or blood, almost everywhere in the body. This situation creates health problems (American Cancer Society 2019a). Cancer can be seen both in adults and children. Childhood cancer is a considerably important life threatening illness as the leading cause of death except accidents (American Cancer Society 2019b). Besides, according to researchers, one of the biggest problems that negatively affects the quality of life of children with cancer is the disease with its treatment process (Hilda, et al. 2015, p.246). Children with cancer cannot enjoy their daily lives as much as healthy children do. The side effects of the treatment, being apart from their families and friends, the uncertainty of the illness and its treatment, interrupted daily routine, and lack of play cause a sudden decrease in their quality of life (Favara-Scacco, et al. 2001, Roddenberry and Renk 2008, Silva, Cabral and Christoffel 2010). Moreover, generally their ideas are not asked regarding the treatment and they lose the sense of control over their lives (Evan 2014, p.127). The loss of sense of control also leads to poor quality of life in children. So far, miscellaneous intervention techniques have been applied to children in order to improve their quality of life such as art therapy (Carboni 1995), music therapy (Nguyen, et al. 2010), exercise therapy (Kruijsen-Jaarsma, et al. 2013), yoga (Thygeson, et al. 2010), play therapy (Mohammadi, Mehraban and Damavandi 2017) and the like.

Participatory design is briefly defined as a mindset that gives users a chance to contribute and have a voice in the design process. The philosophy of participatory design is based on democracy. It advocates the participation of especially marginalized people in the society (Spinuzzi 2005, p.164, Skivenes and Strandbu 2006, Sanoff 2007, p.213, Hussain 2010, Simonsen and Robertson 2013, p.1). Children with cancer are included in one of these groups. Moreover, there are many participatory design studies conducted in order to meet the needs of children with cancer by the help of design

(Ruland, Starrren and Vatne 2008, Lindberg 2013b, Mateus-Berr, et al. 2015). However, these studies do not focus on the effect of the process on children, but the end product.

Departing from the existing corpus in the field, this participatory design study focuses on the process, instead of the design outcome of the study. The importance of the design outcome is undeniable. However, in this case, it is expected that the process itself might be at least as powerful as the result in improving life quality of children with cancer. So far, several studies investigated the impact of participatory design process (McElligott and Van Leeuwen 2004, Hourcade, Beitler, et al. 2008, Guha, Druin ve Fails 2010, Könings, Seidel and van Merriënboer 2014). However, there is a gap in the literature. The prospective effects of participatory design process on improving quality of life of children with cancer have not been investigated yet.

> "We know that children involved in design processes are helping to create better technology for tomorrow. It's time to ensure as a community that we are also helping them to live a better today." (Guha, Druin and Fails 2010, p.201)

1.2. The Purpose of the Study

The main purpose of this thesis is to investigate the role of the participatory design process in improving quality of life (QOL) of children with cancer. In order to achieve this, a participatory design research was conducted with children with cancer. The outcome was expected to be beneficial for the children's QOL. Besides, this study focuses especially on the effect of the participatory design process itself and whether it contributes to the children's QOL by giving them a voice, making them feel that their ideas are important by asking their opinions and distracting them from their negative thoughts regarding cancer and its side effects.

1.3. The Research Questions

The main research questions of this study are as follows:

- What is the role of participatory design in improving the quality of life of children with cancer?
  - How can the participatory design process itself contribute to improving the quality of life of children with cancer?

- Can the participatory design process be considered as an intervention method for children with cancer? If so, how?

1.4. The Methodology of the Thesis

As pointed out by researchers in the field (Hanington 2010, Sanders and Stappers 2012), Do, Say and Make techniques should be used together in order to achieve the best result in a participatory design research. Accordingly, this thesis is carried out via three main methodological strands: 1) Observation; 2) Questionnaires and Interviews; and 3) Design sessions.

Observation was the first method, which was applied in the preliminary stage of the research process. The children with cancer, their caregivers and the doctors of the Hematology and Oncology Service were observed by the researcher in order to have more insight into their daily routine and play preferences.

Following this process, the children with cancer, their caregivers and two doctors, one of them is oncologist and other one hematologist, and a head nurse were asked to fill in a questionnaire to gain deeper understanding into children’s preferences, lifestyle and of their illness, as well as the effects of their illness on their quality of life. These answers are supported with the data elicited from the interviews with them. In addition, a specific questionnaire, The PedsQL 4.0 Generic Core Scales, was applied to children and their caregivers before the process started and at the end.

The final method was the Participatory Design Sessions organized in three stages: In order to prepare children for the design sessions, they were given sensitizing workbooks. After they completed the activities in the workbook, participatory design sessions were conducted with children with cancer. At the final stage, participants received a Certificate of Participation. Their opinions and feelings were also asked about the process with a final questionnaire in order to collect further information about the process itself.

1.5. Structure of the Study

This thesis contains five chapters. The first chapter is the introduction whereby the aim of the study, research questions, hypotheses as well as the method are described.

The second chapter strives to explain the aspects of the quality of life of children with cancer. It provides a background regarding cancer; quality of life and health related quality of life. It explains the intervention techniques that are used in order to improve QOL of children with cancer by emphasizing the importance of play in this case. It also discusses the importance of measuring the quality of life of children with cancer and the reasons to select The Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales for this study.

The third chapter describes the participatory design and its principles. It emphasizes children's rights to participate in the decision-making processes, who are traditionally excluded from these. Various participatory design techniques and tools are described in detail in this chapter. Moreover, cognitive development stages of children are explained in order to determine the suitable age group for this study. It also explains important points that should be taken into account while conducting a participatory design research with children.

The fourth chapter introduces the case study conducted in Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital. The setting, participants and the method of the study are explained and findings are discussed in this chapter.

Finally, in the conclusion chapter, research questions are revisited and an overview of the study is provided. The limitations and strengths of the study are discussed and recommendations for further studies are presented.

CHAPTER 2

QUALITY OF LIFE OF CHILDREN WITH CANCER

2.1. The Definition of Cancer

Cancer covers a group of diseases and the common feature of them is the cells that continue growing out of control. It can start in lungs, brain, breast, colon or blood, almost everywhere in the body and it leads to problems there. The cancer cells can spread to other body parts, as well (American Cancer Society 2019a). In childhood, cancer is a life threatening disease, which is the leading cause of death except accidents (American Cancer Society 2019b). Cancer and its treatment process affect the quality of life of children in a negative way (Hilda, et al. 2015, p.246).

2.2. Quality of Life of Children with Cancer

World Health Organization describes quality of life (QOL) as how individuals comprehend their situation in life in terms of their cultural structure and value system (WHO 1998). It is also defined as being able to accomplish daily tasks (Donald 2001). This is related to aims, hopes, standards and interests of individuals as well (WHO 1998). In other words, QOL is the state of well-being in terms of physical, psychological and social circumstances of human beings (Evan 2014). Their freedom degree, personal principles and their reaction to noticeable characteristics of their environments affect it (WHO 1998).

Health-related quality of life (HRQOL) is particularly about the effect created by health or chronic illnesses on the well-being of human beings with regard to their physical, psychological and social state, and on their capability to function ordinary tasks (Donald 2001, Vogels, et al. 2004). HRQOL is also described as a source that reflects how individuals perceive their circumstances from their points of view (Calman 1984, Theunissen, et al. 1998, Donald 2001).

The diagnosis of cancer influences the life of children in multiple aspects. It negatively affects their “normal lives”. Instead of maintaining their daily activities, they often visit hospitals or they stay there for an uncertain period (Silva, Cabral and Christoffel 2010, p.335, Kirch, Wolfe and Lord 2014, p.1). Due to the disease and the treatment, a sudden shift occurs in children's daily lives. During this process, children experience suffering and pain, their school activities and daily routine get interrupted, and they suffer from separation from the social and familiar environments and lack of play (Favara-Scacco, et al. 2001, Silva, Cabral and Christoffel 2010). This may cause several problems about their physical, psychological, and social development. The very first reason is that children stay apart from the most basic aspects that influence their development; such as their parents, friends, school, and play (Carvalho e Sousa, et al. 2015). Consequently, the disease and treatment of cancer negatively affect the QOL of children in several aspects.

Due to the procedures such as chemotherapy and radiation therapy, children experience physical, psychological, social and educational difficulties (De Bolle, et al. 2008, Canter, et al. 2015). As referred by Roddenberry and Renk (2008), side effects of these procedures may unintentionally lead to poor QOL. Therefore, it might be beneficial to examine QOL of especially children with cancer as emphasized by many researchers (Calman 1984, Roddenberry and Renk 2008). HRQOL measures are important in this case in order to determine if the treatment is suitable or which one is the best. They may also contribute to the decision-making process about "end-of-life" option and to stop treatment if HRQOL is unsatisfactory.

Anthony, et al. (2013), prepared a model that includes the most important aspects that influence the QOL/HRQOL of children with cancer by reviewing existing assessment tools. This demonstrates that in general, the tools designed for assessing the QOL level of pediatric cancer patients focus on the four fundamental domains as physical, psychological, social and general health[1]. First of all, the aspects that may negatively affect physical life quality of children cover problems in terms of physical development, lack of physical activity, inability to speak, hair loss, nausea and the like. Secondly, children's problems with their personal appearance, self-esteem, behaviour and emotional distress may affect their psychological QOL. Thirdly, children's relationship with their family, friends, teachers, and their school life may influence their social QOL. Lastly, children's perception regarding their past, present and future health may influence their general QOL.

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[1] Please see Figure 2.1. for the schema of QOL domains adapted from Anthony, et al. (2013).

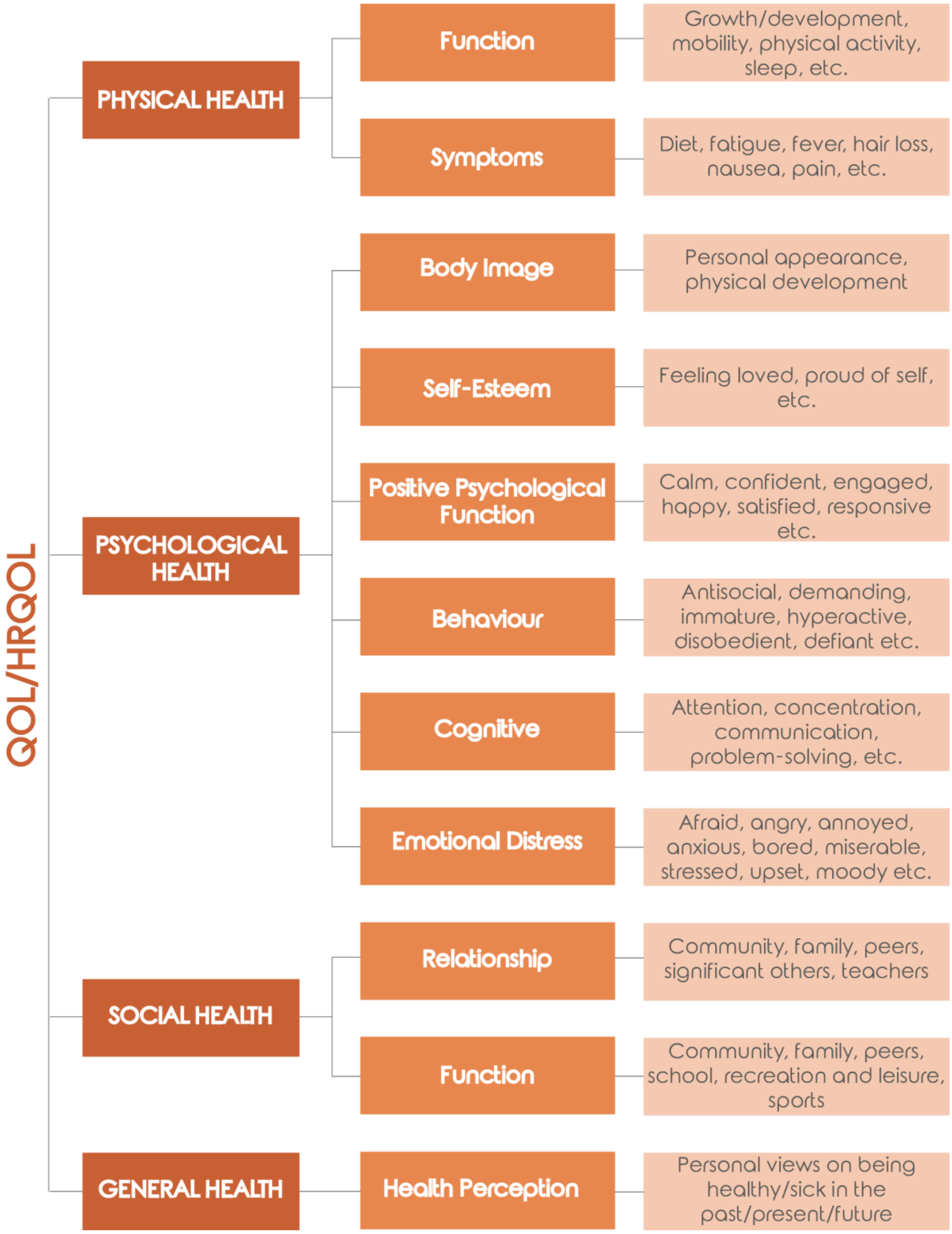


Figure 2.1. QOL/HRQOL domains, subdomains and concepts adapted from Anthony, et al. (2013)

2.2.1. Interventions to Improve QOL of Children with Cancer

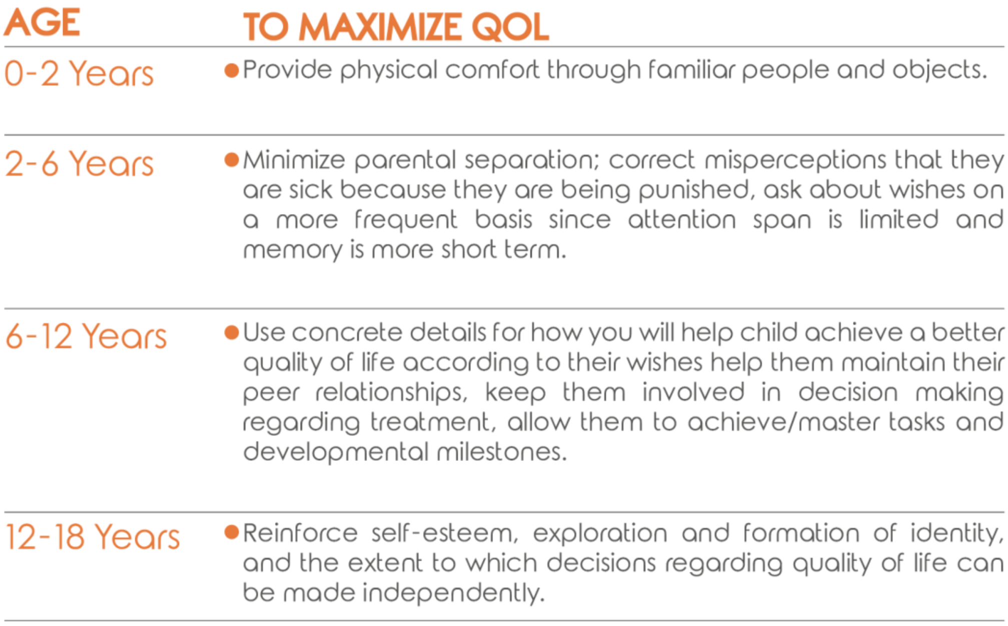
Pediatric palliative care focuses on QOL of children in physical, social, and psychological aspects. It aims to meet the needs of children with cancer and their families. In general, pediatric palliative care team is multidisciplinary and consists of doctors, nurses, psychologists, child life specialists and others who are specialized in relieving the pain and stress that come along with the symptoms and treatments of cancer (Kirch, Wolfe and Lord 2014, p.2). Even if it is applied when there is no possibility to cure the cancer (NHS 2005, p.81), ideally, it is recommended to start the palliative care when the child is diagnosed with cancer. Due to the fact that it provides an additional support to chemotherapy and radiotherapy, it is beneficial to apply it throughout the treatment (Kirch, Wolfe and Lord 2014, p.2). Hinds (2010, p.19) also supports that considering the QOL in pediatric oncology not only in end of life situations of children but also just after the diagnosis gained importance.

There are non-pharmacological interventions that focus on improving the QOL of children with cancer. The intervention techniques such as art therapy (Carboni 1995), music therapy (Nguyen, et al. 2010), exercise therapy (Kruijsen-Jaarsma, et al. 2013), yoga (Thygeson, et al. 2010), and play therapy (Mohammadi, Mehraban and Damavandi 2017) are used in order to provide a relief from the symptoms of the disease and its treatment such as pain, anxiety and the like. For instance, Nguyen, et al. (2010, p.153) conducted a study in order to investigate if there is an influence of music on reducing pain and anxiety level of children with leukemia who underwent lumbar puncture procedure. As a result of this study, it was found out that listening to music with earphones decreased the pain and anxiety scores of children. Consequently, it improved their QOL.

As stated by Evan (2014, p.125), due to the severe treatment conditions and staying away from family, friends, and school life for a long period, sometimes “helping these kids to be just kids” may be prior to treatment. According to the results of several surveys that investigate the negative effects of cancer on children’s QOL, “the loss of normalcy” and inability to play, do sports, spend time with family and friends are considered by children to be worse than the physical symptoms and side effects of the treatment. Evan (2014, p.128) states that in order to improve the QOL of children in terms of their emotions and psychological condition, it is crucial to provide them with the sense of normalcy.

Himelstein, et al. (2004, p.1756) explained the factors to maximize the QOL of children in a table by considering their development stages[2]. According to their explanation, especially adolescents (12-18 years) can have difficulties regarding their self-esteem and identity formation. Evan (2014, p.130) states that when they lose their hair or gain weight because of the treatment procedures or when they miss an opportunity to socialize due to their disease, their self-esteem can be influenced negatively. On the other hand, giving them a chance to improve their QOL by themselves has a great importance. For instance, when a teenager notices that she becomes happier when she plays cards with other teenagers this can give her a sense of control, since she feels like she has found a new coping strategy and a way to improve her QOL. Sense of control is essential for children with cancer, due to the fact that this illness itself is uncontrollable (Evan 2014, p.127).

Table 2.1. Aspects to take into consideration in order to maximize QOL of children according to their developmental stages adapted from Himelstein, et al. (2004, p.1756) and Evan (2014, p.126).



AGE	TO MAXIMIZE QOL
0-2 Years	● Provide physical comfort through familiar people and objects.
2-6 Years	● Minimize parental separation; correct misperceptions that they are sick because they are being punished, ask about wishes on a more frequent basis since attention span is limited and memory is more short term.
6-12 Years	● Use concrete details for how you will help child achieve a better quality of life according to their wishes help them maintain their peer relationships, keep them involved in decision making regarding treatment, allow them to achieve/master tasks and developmental milestones.
12-18 Years	● Reinforce self-esteem, exploration and formation of identity, and the extent to which decisions regarding quality of life can be made independently.

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[2] Please see Table 2.1.

One of the factors that has a huge impact on children's QOL is play. The United Nations High Commission for Human Rights introduces play as every child's right (Ginsburg 2007). Play is defined by Garvey (1977, p.4) as voluntary activities that are inherently motivated and related to delight and joy. Brown and Vaughan (2009) state that people's need to play is biologically driven and as normal as their desire for food, sleep and the like. Besio (2018, p.4) explains the most important features of play. First of all, the feeling of freedom is one of the main aspects in relation with play. The ones who play intensely feel that and it can be seen by the observers, as well. Secondly, pleasure and fun is also related to play. They are described as indispensable properties of play. Thirdly, play involves concentration and momentousness. For instance, it is not easy to interrupt children who play a game, since to play is deeply engaging. Lastly, children show their never-ending eagerness towards play. This can be associated with intrinsic motivation, curiosity, surprises and challenges.

Table 2.2. Cognitive dimensions of play adapted from Besio (2018, p.7)

COGNITIVE DIMENSION	Practice Play	● First type of play ● Related to body actions ● Experimenting objects visually and tactilely ● Repetition
	Symbolic Play	● Symbolic use of body and objects ● Pretending and make-believe ● Simulation of the action with the body ● Role playing
	Constructive Play	● Gathering, combining, arranging and fitting elements to form a whole, achieve a goal ● Combining abilities gained through practice and symbolic play
	Play with Rules	● Play and games based on a specific code and rules accepted and followed by players ● Challenging ● Board games, sport activities

According to Besio (2018, p.8), types of play can be classified under two main topics as cognitive[3] and social[4] dimensions. These types of play take place at a certain time period in children's lives.

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[3] Please see Table 2.2.for cognitive dimensions of play

[4] Please see Table 2.3. for social dimensions of play

Table 2.3. Social dimensions of play adapted from Besio (2018, p.8)

SOCIAL DIMENSION	Solitary Play	● Playing alone and independently
	Parallel Play	● Playing independently with the same activity, at the same time, in the same place with others also engaged in play ● Playing without joining each other
	Associative Play	● Focusing on a separate activity with respect to his/her peers ● Considerable amount of sharing, lending, taking turns among children
	Cooperative Play	● Joining others in sustained engegement in activities with toys, objects, games with a shared goal ● Organizing their play cooperatively with a common goal

Carvalho e Sousa (2015) states that play has an important role during children's hospital stay. This provides a maintenance in development of children and is also good for coping with stress, which is caused by the unfamiliarity of the healthcare environment which affects their QOL. Groves and Weaver (2007, p.71) state that to experience the hospital environment may be challenging, frightening and traumatic for children. Apart from the benefits that play activities provide to all children, these activities are particularly beneficial for hospitalized children for they provide a linkage to home, a sense of normalcy, ability to express feelings, a sense of control and the like. These are related to improving QOL of children as well.

Play has a huge impact on physical, social, and psychological QOL of children (Silva, Cabral and Christoffel 2010, p.335). It is also crucial for children's development with regard to all of these aspects (Vygotsky 1978, Ginsburg 2007, p.182, Groves and Weaver 2007, p.71). Ginsburg (2007) explains that it is significant for the healthy development of the brain. With the play, children improve their skills and confidence, which they will need to cope with future challenges. As opposite of the early understanding of considering play as a pointless activity that causes waste of time, Piaget (1999b) believed that play is essential for cognitive development of children. It helps children to practice and enhance their abilities. As explained by Groves and Weaver (2007, p.71), play provides children an opportunity to learn, since they are exposed to new information during a play activity.

Table 2.4. The functions of play in hospital environments adapted from Groves and Weaver (2007, p.71)

THE FUNCTIONS OF PLAY IN HOSPITAL ENVIRONMENTS

- To link the home
- To provide a sense of normalcy
- To express feelings
- To reduce stress and anxiety
- To regain confidence and self-esteem
- To teach procedures in an enjoyable way
- To encourage involvement of families and siblings
- To facilitate communication for all children regardless of their age, development stage, language or ability
- To minimise regression
- To provide fun

2.2.2. Measuring QOL of Children with Cancer

In the 1970s, analysing QOL gained prominence because it became important to measure the effect of various circumstances on the lives of individuals. Measuring HRQOL became popular as an essential source of knowledge about health (Varni, Burwinkle, et al. 2002). It is also essential to measure HRQOL of individuals in order to give them information about possible impacts of treatments. Measuring HRQOL may also help to control the benefits of treatments from the patient's point of view, and to decide if it is necessary to support treatments regarding social, psychological and physical conditions (Donald 2001).

In order to measure HRQOL, several studies have been conducted so far. There are numerous instruments for eliciting data about life quality of adults (Sneeuw, et al. 1999, Vogels, et al. 2004). However, the inventories prepared especially for children are limited. According to some researchers, there might be difficulties while applying HRQOL instruments to children. Children may have problems in expressing themselves due to their lack of language knowledge, limited cognitive abilities to interpret the questions and they may just take a short-term perspective instead of a long-term one on their life circumstances (Theunissen, et al. 1998, Vogels, et al. 2004, De Bolle, et al. 2008). Hence, some inventories try to measure HRQOL of children by asking questions only to parents of children as proxy raters.

On the other hand, some researchers argue that the parent proxy report alone does not provide reliable information at all and children's opinions with a self-report should also be taken into account in order to reach complete results. Nonetheless, proxy raters complement the information gathered from self-reports and therefore, a thorough assessment should include both of them (Eiser and Morse 2001, Varni, Burwinkle, et al. 2002). Child self-reports are also essential for providing patient’s perspective about impacts of treatment or circumstances and accounts for one of the major strengths of QOL instruments (Donald 2001, Ergin, et al. 2015, Varni, Burwinkle, et al. 2002). Roddenberry and Renk (2008) add that because of the subjective nature of QOL, children’s own opinions about their own QOL may be a valuable source of information about their own treatment experience.

So far, several studies focused on conducting HRQOL research with children cancer survivors (De Clercq, et al. 2004, Landolt, et al. 2006, De Bolle, et al. 2008, Weiss, et al. 2018), but children with advanced cancer were rarely the focus of the studies.

Until now, numerous studies investigated other factors that may affect HRQOL. The effect of attitudes toward illness (Canter, et al. 2015), illness uncertainty (Fortier, et al. 2013), hearing loss (Weiss, et al. 2018) on QOL of children with cancer have been researched. However, the effects of participatory design process on QOL of children with cancer have not been investigated yet. Here is how this study is expected to contribute to the existing literature.

There are various HRQOL instruments. Several factors must be taken into consideration to select one of them for application in a study. First of all, the instrument should be multidimensional and include physical, psychological and social dimensions as defined by World Health Organization (Vance, et al. 2001, Varni, Burwinkle, et al. 2002). There are other important factors whilst applying the instrument to children. According to Varni (2002), sometimes imperfect concordance occurs between self-report and parent proxy report in especially internalizing problems rather than externalizing ones. This demonstrates that a child self-report instrument should provide the widest age range options. Furthermore, it should be sensitive to cognitive development stages of children (Varni, Burwinkle, et al. 2002, Ergin, et al. 2015). There are HRQOL instruments like;

- PedsQL (The Pediatric Quality of Life Inventory) (Varni, Burwinkle, et al. 2002)

- PAC-QOL (Pediatric Advanced Care Quality of Life Scale) (Cataudella, et al. 2014)
- KINDL (Bullinger and Ravens-Sieberer 1998)
- TNO-AZL Questionnaires for Children's HRQOL (or TACQOL) (Vogels, et al. 2004)
- DISABKIDS (Disabled Children's Quality of Life Measure) (Chaplin, et al. 2012)
- QOLS (The Quality of Life Scale) (Burckhardt and Anderson 2003)
- PAQLQ (Pediatric Asthma Quality of Life Questionnaire) (Poachanukoon, et al. 2006)
- PediQUEST (Pediatric Quality of Life and Evaluations of Symptoms Technology) (Rosenberg, et al. 2016)
- WHOQOL-BRFF (WHO 1998)
- COOP-WONCA (Sneeuw, et al. 1999)

The Pediatric Quality of Life Inventory (PedsQL) is an inventory, which is prepared for measuring HRQOL of children (Varni, Burwinkle, et al. 2002). There are disease specific modules of PedsQL which include asthma, brain tumor, cancer, cardiac, cerebral palsy, diabetes, epilepsy and the like (Varni 2018). The PedsQL 3.0 Cancer Module is an instrument that focuses on specific procedures of the cancer. The PedsQL 4.0 Generic Core Scales includes 23 items in total and four dimensions; physical functioning with eight items, psychological functioning with five items, social functioning with five items and school functioning with five items. Both child self-report and parent proxy report are available. It also provides options appropriate to group of ages. Child self-reports start with 5-7 year-old (young child) and continue with 8-12 year-old (child), 13-18 year old (adolescents). For parent proxy reports, 2-4 year-old (toddler) is available. The self-report does not exist for them because of the developmental limitations. Answers are given on a 5-point Likert scale (0: never a problem, 1: almost never a problem, 2: sometimes a problem, 3: often a problem, 4: a lot of a problem). The scale is different only for children 5-7 year-old . It is shortened to a 3-point Likert scale (0: not at all a problem, 2: sometimes a problem, 4: a lot of problem) and smiling, middle and frowning faces are used to make them express themselves easily. The answers are reverse-scored as 0=100, 1=75, 2=50, 3=25, 4=0. Thus, lower PedsQL score demonstrates lower HRQOL (Varni, Burwinkle, et al. 2002).

Various studies are conducted so far in order to determine the validity and reliability of The PedsQL 4.0 Generic Core Scales in Turkey (Tanir and Kuguoglu 2011, Kabak, et al. 2016), in Brazil (Scarpelli, et al. 2008) in China (Ye, et al. 2016), in San Diego (Felder-Puig, et al. 2004) and in Texas (Robert, et al. 2012). According to these studies, Cronbach's coefficient alpha is generally higher than the minimum standard of 0.70, which means these instruments can be used as a measure in pediatric cancer units. PedsQL is selected for this study to apply to children with cancer and their caregivers at Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital for several reasons. First of all, it has been validated in several age groups, languages and cultures. As referred by Donald (2001) HRQOL instruments may require changes depending on the culture. Thus, it is important to consider relevance to culture when selecting a suitable instrument for the study and Turkish version of The PedsQL 4.0 Generic Core Scales was available online for free for non-funded academic research. It also provides age appropriate options that consider cognitive development stage of children (Varni, Burwinkle, et al. 2002, Ergin, et al. 2015). For example, for children 5-7 year-old there is a simplified 3-point Likert scale instead of 5-point and happy to sad faces are used to increase children's understanding. Moreover, in general, this thesis advocates participation of children in the areas that directly concerns them[5]. The PedsQL 4.0 Generic Core Scales provides a child self-report instrument unlike some similar instruments that include only parent proxy reports.

This chapter has defined cancer, QOL and HRQOL. It has explained the effects of the illness on QOL of children with cancer and introduced The PedsQL 4.0 Generic Core Scales to be used in the case study. The following chapter aims at describing participatory design with children with cancer.

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[5] Please refer to Section 3.1. for detailed explanation regarding Participatory Design.

CHAPTER 3

PARTICIPATORY DESIGN WITH CHILDREN WITH CANCER

Sanders and Stappers (2012) define design research as research that aims to provide information and inspiration for the design process. It focuses on investigating people as users of products, services and environments. They explain the landscape of design research approaches and methods by using a map[6].

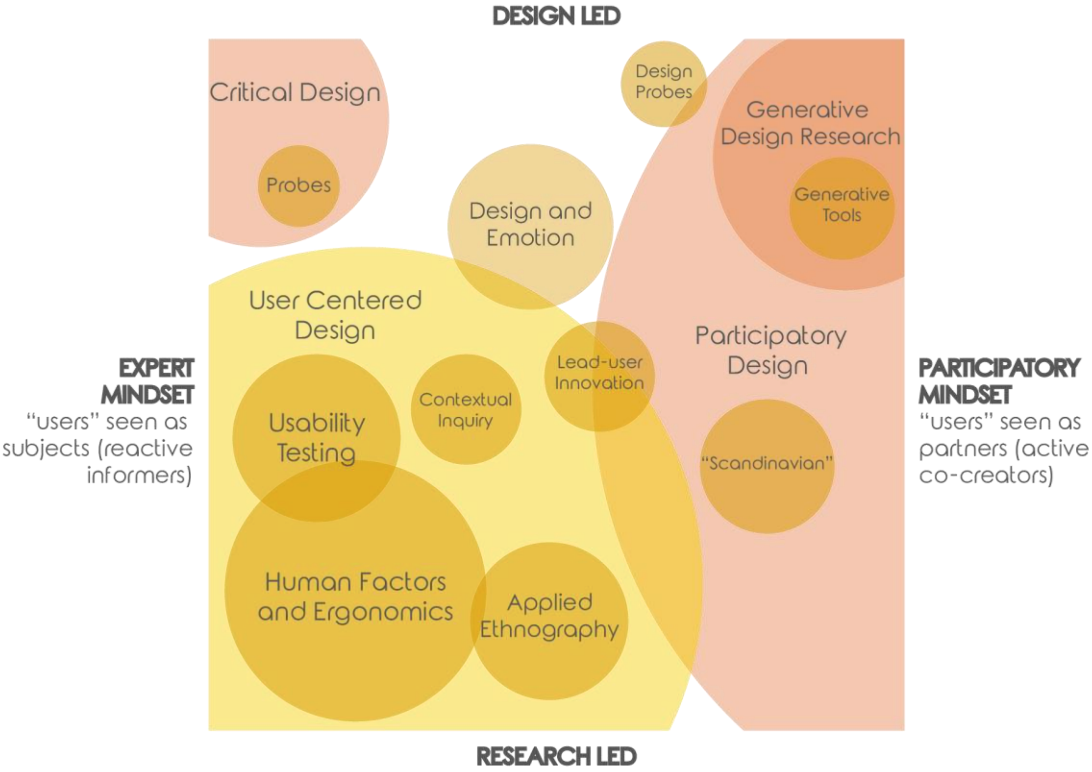

Figure 3.1. The emerging landscape of design research approaches and methods adapted from Sanders and Stappers (2012, p.19)

According to Sanders (2008), this map consists of two intersecting extents; one of them illustrates approach and the other mindset. Design research approaches are divided into two as 1) research-led; and 2) design-led viewpoints. The research-led

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[6] Please see Figure 3.1. for the map of design research approaches adapted from Sanders and Stappers (2012)

viewpoint has been used by applied psychologists, anthropologists, sociologists and engineers. This perspective dates back to older times. Design-led viewpoint came into the picture not long ago (Sanders 2008, Sanders and Stappers 2012).

The expert and participatory mindsets are located on the right and left side of the map that demonstrates the opposition. On the left side of the map, design researchers design *for* people by accepting themselves as experts. They entitle people as ‘users’, ‘subjects’ or ‘consumers’. In contrast, on the right side of the map, design researchers design *with* people by considering people as true experts of their experiences. The participatory mindset makes design researchers accept people as co-creators in the design process and willingly include people in the design process by sharing power with them (Sanders and Stappers 2012, Sanders 2008).

Sanders (2006) explains that the map consists of four zones with the clusters and bubbles inside of them. The biggest zone is user-centered design, which is research-led and conducted with expert mindset. According to Sanders and Stappers (2012), the ones that use this approach focus on making products meet the needs and demands of users. However, they use tools and methods for evaluating prototypes or concepts. It includes four bubbles; usability testing, human factors and ergonomics, applied ethnography and contextual inquiry that derive from applied social and behavioral sciences and engineering.

From another point of view, Hanington (2003) divides design research methods into three as traditional, adapted and innovative methods[7]. According to him, traditional methods such as interviews, questionnaires, and focus groups are open to question. The main reason is that they count on what people say and accept them as truth. However, he points out that these methods are good at validating already known information but not at discovering knowledge. Traditional research methods fall short of providing information regarding prospective future experiences (Sanders 1992, Visser, Van der Lugt and Sanders 2005, Preece, Rogers and Sharp 2015). They give access only to present and past experiences of people (Visser, Van der Lugt and Sanders 2005).

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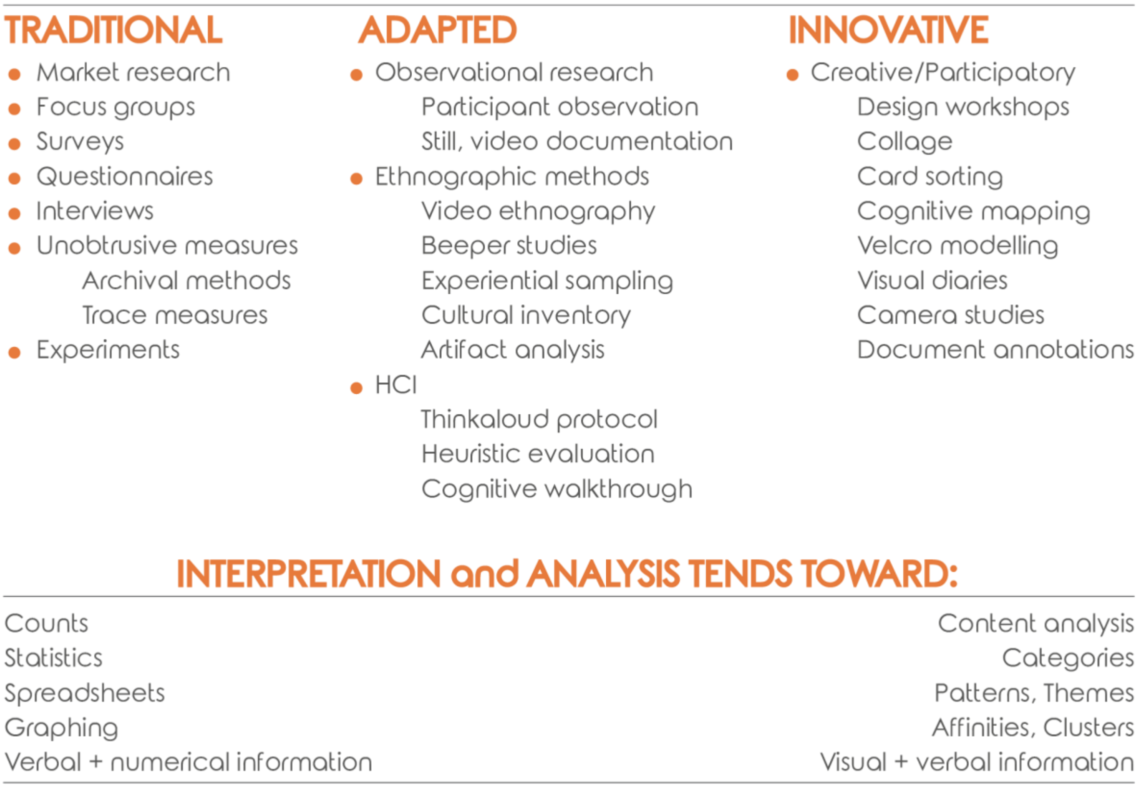
[7] Please see Table 3.1. for design research methods adapted from Hannington (2003)

Table 3.1. Design research methods adapted from Hanington (2003)



TRADITIONAL	ADAPTED	INNOVATIVE
● Market research	● Observational research	● Creative/Participatory
● Focus groups	Participant observation	Design workshops
● Surveys	Still, video documentation	Collage
● Questionnaires	● Ethnographic methods	Card sorting
● Interviews	Video ethnography	Cognitive mapping
● Unobtrusive measures	Beeper studies	Velcro modelling
Archival methods	Experiential sampling	Visual diaries
Trace measures	Cultural inventory	Camera studies
● Experiments	Artifact analysis	Document annotations
	● HCI	
	Thinkaloud protocol	
	Heuristic evaluation	
	Cognitive walkthrough	

INTERPRETATION and ANALYSIS TENDS TOWARD:

Counts	Content analysis
Statistics	Categories
Spreadsheets	Patterns, Themes
Graphing	Affinities, Clusters
Verbal + numerical information	Visual + verbal information

On the other hand, adapted methods are the ones that are borrowed from other disciplines but adapted in order to fit better to the requirements of design research. For instance, observation is borrowed from psychology and is still in use by the field of design (Hanington 2003). As explained by Levitt and Richards (2010), methods of the field of ethnography such as observation, questionnaire and interview provide a great amount of information in users' current situation, ideas, attitude and point of view. However, these methods fail to satisfy the needs of design research, which requires an understanding of what people *think*, *do* and *feel*. Although they cover the *think* and *do* parts, they fall short of providing insight about the *feel* part.

Lastly, innovative methods are the ones that are used for generative research. Hanington (2003) defines it as a research that is conducted in the preliminary stages of the design process. This is in contrast with evaluative research, which is conducted at the end-stage of design process. Mattelmäki (2006, p.31) states that in order to gain insight about people's feelings, values and dreams it is needed to use innovative methods at the early stage of a design process. In addition, Levitt and Richards (2010) supports that the information collected by applying these methods provides design concepts that are more in line with users' needs and desires. As emphasized also by

Hanington (2003) innovative methods are beneficial especially for designers. Because of their background in creativity and visual activity, it is more reasonable for them to use research methods that provide data about users in a creative way. Moreover, from the participants' point of view, participating in a generative session might be more preferable than filling out a questionnaire or being interviewed. The tools that facilitate users to express their needs are also needed in generative sessions (Hanington 2003). Otherwise, participants may not be able to contribute to the design process if they are not provided with substances different than words such as two-dimensional images or three dimensional forms (Sanders 1992, Visser, Van der Lugt and Sanders 2005).

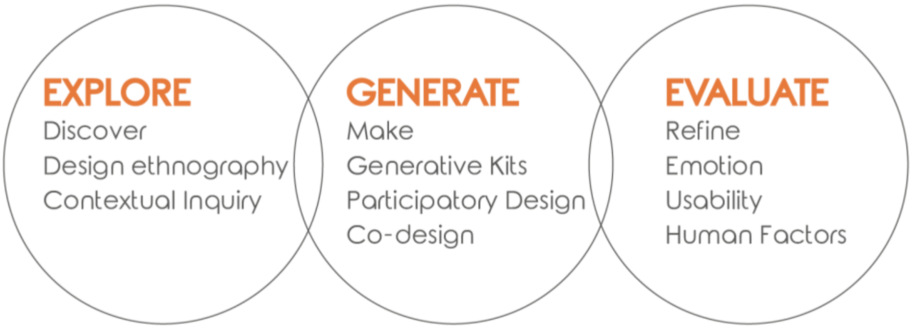


Figure 3.2. Approaches relate across phases of design research adapted from Hanington (2010)

According to Hanington (2003), generative research, which takes place in the preliminary stages of a design process, is in contradiction with evaluative research that is used generally at the last stages. As stated by Gielen (2008), earlier in the industrial design profession, users were involved only in the testing and evaluating steps of the design process after the product was already designed by the designer. Therefore, in these times, users were only evaluating prototypes or finished products (Hanington 2003). However, at this step, changing the product regarding users' feedback is very costly and not feasible. It is much more meaningful to include users as active participants in the preliminary stages of a design process instead of including them as passive testers at the last stages (Gielen 2008).

Sanders and Stappers (2012) define participatory design as an approach that involves end users in the design process in order to make sure of that the designed product supplies the needs of users.

Generative tools are defined by Sanders (2006) as a recently added design-led bubble of participatory design zone in the map[8]. These tools enable designers and non-designers to share a design language for communication in a visual and a direct way. As the name implies, generative tools help expressing countless ideas that cover their dreams, insights, opportunities etc. (Sanders and Stappers 2012). Sanders (2006) points out that generative toolkits are constructed by the help of ethnographic information that provides solid understanding of the context of use. Thus, it is not completely design-led.

3.1. Participatory Design

In the earlier times, the industrial design profession was known substantially about producing a variety of goods by mass production methods (Heskett 1987). In these times, it was more product-centered than human-centered. As the time went by, designing products according to needs and preferences of individuals gained more importance and a shift occurred from a product centered approach to a human centered one (Gielen 2008, Turhan and Doğan 2017). Progressively, learning how individuals interact with products became necessary for designers so as to be able to design products that will be suitable to the lives of users (Visser, Van der Lugt and Sanders 2005).

User-centered design is focused on producing easy to use and more understandable products for users (Norman 1988). Involving the users who will be directly affected by the outcomes in the design process is based on the philosophy of user-centered design. The degree of involvement varies, however the fundamental part of the user-centered design is the involvement of users (Fails, Guha and Druin 2013). According to Sanders (1992), participatory design can be considered as user-centered design raised to another level. Lately, user-centered design approach, which takes user as a subject was altered to participatory design approach, which takes user as a partner (Dell'Era and Landoni 2014).

In northern Europe, participatory design originated in Scandinavia in the early 1970s. The motivation behind this was empowering workers and promoting democracy in the workplace. In fact, this was an answer to the transforming workplace due to the

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[8] Please see Figure 3.1. for the map of design research approaches adapted from Sanders and Stappers (2012)

introduction of computers. Computer professionals and union leaders provided workers with an opportunity to have a say regarding the new technologies introduced in their workplace (Spinuzzi 2005, p.164, Sanoff 2007, p.213, Simonsen and Robertson 2013, p.1).

In the United States, in the 1960s, the idea of participatory design came to light with the civil rights movement to describe a process involving end users. Volunteer citizen participation is still one of the most significant concepts in American society. According to views of some historians, Americans have always wanted to be involved in the decision-making process for the aspects that have an affect on their lives (Sanoff 2007, p.213).

The Americans' freedom and right to be involved in the decision-making process is a fundamental force that shaped democracy, in other words, the rights of people to participate (Sanoff 2007, p.213). As also explained by Ehn (1992, p.42), individuals should be provided with the right to participate in an equal way in decision-making processes that are related to their lives. Therefore, the roots of participatory design lie in the participatory democracy that enables a collective decision-making process for all individuals (Sanoff 2007, p.213).

Participatory design, as a democratic and humanistic approach, advocates the inclusion of minority groups such as people with disabilities, refugees, elderly people, and children in a society by giving them a right to participate in decision-making processes (Skivenes and Strandbu 2006, Hussain 2010, Merter and Hasırcı 2016).

Sanoff (2007, p.213) explains that participatory design is used by practitioners from multiple disciplines. However, they have the same ideology. In participatory design processes, each participant, whose voice needs to be heard, is considered as experts in their field. The participants have different backgrounds and they collaborate in order to create a design idea. The practitioners of participatory design do not test their participants in a laboratory environment. Instead, they share experiences of users in their own environments.

Participatory design gives the end users, who will be affected by the outcome of a design process, a chance to have a voice in the design of products, services, environments and businesses (Robertson and Simonsen 2012, p.3). The aim is to ensure that the outcome of the design process will meet their needs (Dell'Era and Landoni 2014, p.143). This method has been used in several fields such as architecture, city planning, urban design, computer science, education, geography and the like (Sanoff 2008, Dell'Era and Landoni 2014, Luck 2018). For instance, in architecture, architects worked in collaboration with residents, so as to provide the residents a chance to influence the design process (Gielen 2008).

In industrial design, participatory design approaches gained significance later in order to meet the users' unsatisfied needs (Gielen 2008). On the other hand, in the field of design, there is a shift in the responsibilities of designers from creating a finished and unalterable product to considering the participation of users (Sanoff 1988, p.29). Moreover, according to the researchers, people tend to overvalue the self-assembled products more than ready-made products, which is defined as IKEA effect (Norton, Mochon and Ariely 2012, p.453). This example points out the importance of participation even in the assembly of a product. The participation provides a sense of control to participants.

> "Participation is a matter of control over decisions by the participants." (Sanoff 1990, p.i)

Due to the proliferated terminology used in the literature, there are many similar approaches that have a different name but more or less the same ideology with participatory design. There are a variety of design methods that include children's participation. According to Saure Hagen et al. (2012), these are inspired from each other and continue developing step by step just like that participatory design is derived from user-centered design.

One of the design approaches mindful of children is Bonded Design, which is developed by Allison Druin. Primarily, Bonded Design method is based on Vygotsky's Zone of Proximal Development[9] (Fails, Guha and Druin 2013). Bonded Design includes the participation of children in an intense short period of time. During these meetings, they participate in design activities with using techniques such as brainstorming, analyzing and criticising the existing design, drawing and sketching to show the ideas (Fails, Guha and Druin 2013).

Contextmapping, which is developed at Delft University of Technology, is also a form of participatory design that may be conducted with children, since it supports user involvement in an intense amount in order to understand the contexts of using

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[9] Please see Section 3.3.1. for detailed information regarding Zone of Proximal Development.

products (Visser, Van der Lugt and Sanders 2005). It is started in design education in the beginning of the 2000s (Sanders and Stappers 2012). This is also beneficial for designers to understand users in a better way and using these insights in the design process.

> Participatory Design is not defined by formulas, rules and strict definitions but by a commitment to core principles of participation in design. These, in turn, are informed by a rich heritage of projects, methods, tools and techniques that we can bring to bear on each specific design context in which we participate. (Simonsen and Robertson 2013, p.3)

On the other hand, according to Luck (2018, p.3), participatory design is not a single method. Sanders (2003, p.18) also explains that, participatory design should not be considered as a method, but a mindset and the attitude towards people. The people who have the participatory mindset believe that all individuals have a say in the design process. If they were provided with the suitable tools to express their ideas, they can become creative. What kinds of tools and techniques could be used then in participatory design? The following section tries to answer this question.

3.2. Classification of Tools and Techniques

> Skeptics of co-design still cite the famous Henry Ford quote—if you asked users what they wanted, it would not have been a car but "a faster horse"—as evidence that participation in design should be limited to a narrow set of professionals. But more are now realizing that facilitating the participation of users and other stakeholders involves far more effort than merely asking them "what they want". (Sanders and Stappers 2014)

In the early 1990s, more than a half of the new products fell by the wayside just after being introduced in the market. As explained by Sanders (1992), the reason of this issue was that designers were not aware of the needs and demands of users of the products. The deficiency in information and the unreliability in assumptions lead to a recession in the market. In Sanders' (1992) opinion, the problem was the traditional research techniques used. For example, usability tests provided neither efficient information nor solutions to the problems. They were good at determining and defining problems but not beneficial for uncovering users' needs. This is the fundamental reason that she proposed a new approach that includes exploring users' needs. Her approach by introducing generative techniques brings about an alteration in users' role from passive informant to active participant.

Sanders (1992) states that 'need' is a complex term that can be examined in several levels. The theory of Maslow (1954), Hierarchy of Needs, consists of seven levels of needs. The fundamental one is physiological needs such as hunger and thirst. Unless these needs are satisfied, other levels of need cannot become important. He declares that, the needs at the higher levels can become essential only if the needs at the lower levels are completely or at least to a certain degree satisfied.

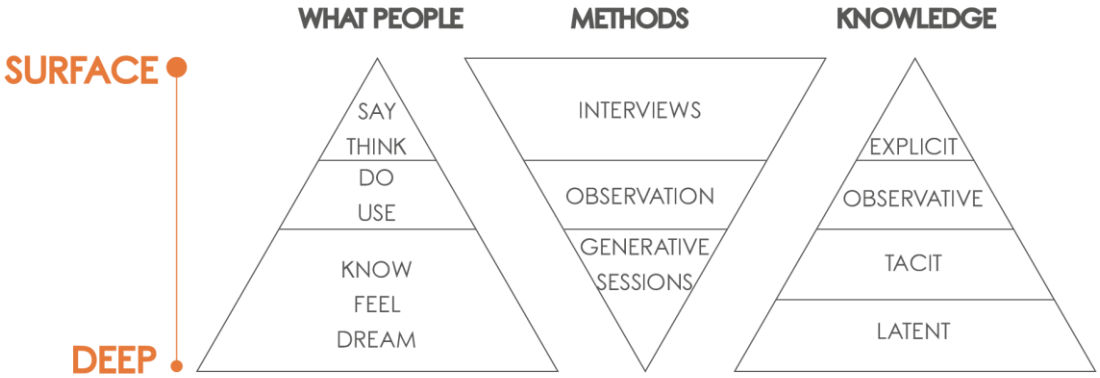

Figure 3.3. The emerging landscape of design research approaches and methods adapted from Sanders and Stappers (2012)

Industrial designers should consider all levels of needs since users may need a product in order to satisfy their needs at each level (Sanders 1992). Dell'Era and Landoni (2014, p.143) also state that the triangulation of what people do, say and make is important to address needs of individual. However, users may have problems in expressing what they need. Sanders (1992) divides expression of needs into four levels as explicit, observable, tacit, and latent needs[10]. When users' needs are latent, they are subconscious and passive. Thus, they do not even know them. Sanders and Stappers (2012) explain tacit knowledge with an example; even if people are able to use their phones to call someone it would be harder for them to explain how to do it to someone else by using words. When needs of people are tacit, they know them but they may have difficulty in expressing them in words.

> "Have you ever noticed how, at times, it is hard to put your thoughts, feelings or ideas into words? You are not alone." (Levitt and Richards 2010, p.25)

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[10] Please see Figure 3.3.

Therefore, the issue of user needs should not be analyzed only in the surface level (Sanders 1992). Visser et al. (2005) state that generative techniques are introduced by Sanders (1992) so that one may elicit knowledge regarding what people know, feel or dream. These generative techniques are also known as being projective. As the name suggests, they project needs of people even if they are not aware of them, which is hard to elicit by using traditional techniques (Hanington 2003).

According to Hanington (2012), in a participatory design research different approaches combine each other. He suggests that in order to fully understand the needs of users, converging perspectives of ethnography, social science and design is required. He emphasizes that[11] exploratory phase (questionnaires, surveys, observation etc.) helps to construct the generative kits (generative phase) for participatory design sessions and later inform the development of products that will be tested (evaluative phase) in terms of usability and human factors (Hanington 2010, Hanington 2012).

According to Sanders and Stappers (2012, p.66), there exist dozens of techniques and hundreds of tools to use. They state that there are several ways of grouping the tools and techniques. However, they prefer to classify tools and techniques by focusing on the activities as Say, Do and Make techniques.

In spite of the fact that Make tools and techniques are emphasized by Sanders and Stappers (2012, p.66), according to them they should not be used by isolating others, since all three of Say, Do and Make tools and techniques are complementary in a generative design research[12]. They explain it with an example: When a researcher is carrying out a generative design research regarding future kitchen experiences of people, the researcher firstly observes what they *do* in their kitchen as habits and preferences. Secondly, he/she asks them some questions and listens to what they *say*, by interviewing them about the details of their use of kitchen. These help people to recall their past kitchen experiences. After this stage, s/he finally studies what they *make* by providing them with an ideal kitchen experience construction toolkit. This reveals data for future experience of people.

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[11] Please see Figure 3.2.

[12] Please see Figure 3.4.

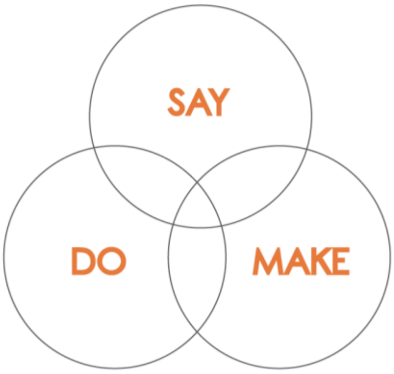


Figure 3.4. Say, Do and Make tools and techniques complement and reinforce each other adapted from Sanders and Stappers (2012)

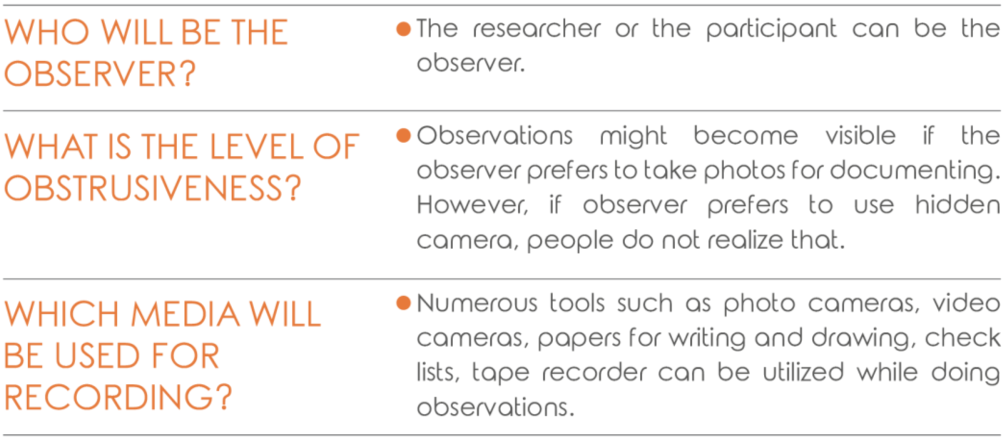
3.2.1. Do Techniques

As can be inferred from the example, **Do** techniques refers to observation of people and their activities in detail. Observation is one of the mostly preferred tool that is used for collecting data from people (Kellett 2011, p.16). The importance of Do techniques can be explained concisely with this quote (Sanders and Stappers 2012, p.67):

> Looking around someone’s living room for fifteen minutes can give you a more reliable impression of that person’s character than spending a day with the person him- or herself. (Gosling and colleagues 2002; cited in Gladwell, 2005)

As listed by Sanders and Stappers (2012, p.67,68), before starting to use **Do** techniques there are three essential aspects to consider:

Table 3.2. Considerations while using **Do** techniques (Sanders and Stappers 2012, p.68)



WHO WILL BE THE OBSERVER?	● The researcher or the participant can be the observer.
WHAT IS THE LEVEL OF OBSTRUSIVENESS?	● Observations might become visible if the observer prefers to take photos for documenting. However, if observer prefers to use hidden camera, people do not realize that.
WHICH MEDIA WILL BE USED FOR RECORDING?	● Numerous tools such as photo cameras, video cameras, papers for writing and drawing, check lists, tape recorder can be utilized while doing observations.

3.2.2. Say Techniques

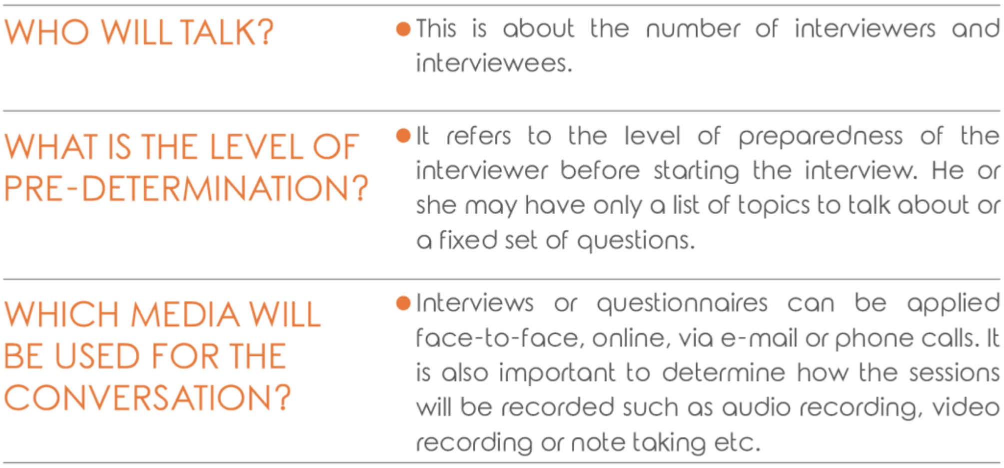
Say techniques include interviews and questionnaires, since they provide responses from people by addressing questions. These are beneficial for using quantitative statistics. Objectiveness level can vary in **Say** techniques, as well. Questionnaires can provide only a limited possibility to the participant while giving answers to these questions. They may want to answer the question in a different way but this type of questions constrains them. In this sense, interviews provide more freedom to the participants by giving them a chance to control the direction of their answers. Even if interviews can also be prepared in a closed form, their structures allow more freedom than closed-form questionnaires. By the help of this, the researcher may reach valuable data from unexpected directions (Sanders and Stappers 2012, p.68).

There is a fundamental ethical principle while conducting interviews with people. As explained by Oppenheim (1992, p.83), they should not cause harm for participants. If the interviewee feels upset because of the questions in an interview, then the interview should be ended.

> Once I was asked a questionnaire but I did not understand the questions so I just said “yes” and “no” where I thought I should! (Young person aged 13) (Tisdall, Davis and Gallagher 2008, p.2)

As illustrated by Sanders and Stappers (2012, p.69) before starting to use **Say** techniques there are three essential aspects to consider:

Table 3.3. Considerations while using **Say** techniques (Sanders and Stappers 2012, p.69)



WHO WILL TALK?	● This is about the number of interviewers and interviewees.
WHAT IS THE LEVEL OF PRE-DETERMINATION?	● It refers to the level of preparedness of the interviewer before starting the interview. He or she may have only a list of topics to talk about or a fixed set of questions.
WHICH MEDIA WILL BE USED FOR THE CONVERSATION?	● Interviews or questionnaires can be applied face-to-face, online, via e-mail or phone calls. It is also important to determine how the sessions will be recorded such as audio recording, video recording or note taking etc.

3.2.3. Make Techniques

After completing the data elicitation with Say and Do techniques, **Make** techniques can be employed and people can express their ideas and feelings by making things (Sanders and Stappers 2012, p.70). The Make tools that were introduced by Sanders (1992) provide a “design language” that facilitates the communication between users and designers. Brandt et al. (2012, p.155) also state that even the non-designers can embody and externalize their ideas by using the Make tools and they create artifacts from their thoughts. For instance, in a participatory design study with children, Vaajakallio, Mattelmäki and Lee (2010, p.27) observed that children started generating ideas with Make tools by touching and building them. Only one of these children drew his ideas before building. Due to the projective nature of these tools, it is advised to use them in the generative stage of a design development process. In this stage, the Make tools help to elicit tacit and latent needs of users in order to find a way to meet the unfulfilled user needs[13] (Sanders and Dandavate 1999).

Toolkits are essential for these generative techniques. A toolkit is prepared by the researcher in relevance with the topic of the study. Thus, a toolkit cannot be generalized for using in all studies (Sanders and Dandavate 1999, Sanders and Stappers 2012). Preparing the toolkit suitable to the study is at upmost importance for success. A toolkit may consist of countless sorts of tools both two and three dimensional such as words, photos, symbolic shapes, dummies, Lego, velcro-covered 3D forms and the like. It depends on the participant to use which elements in a toolkit (Sanders and Stappers 2012, p.70). For instance, Turhan and Doğan (2017) used Make toolkits in their study that is conducted with design students. For this study, the researchers prepared a toolkit with two and three-dimensional forms, colored pens, paper tapes, play-dough and several kinds of papers for the participants to facilitate the expression of specific needs (Turhan and Doğan 2017, p.35).

There are also several types of Make toolkits. For instance, participants create artifacts like collages and diaries that demonstrate their stories or dreams. After creating it, they are asked to explain the story to the researcher for eliciting more information (Sanders and Dandavate 1999).

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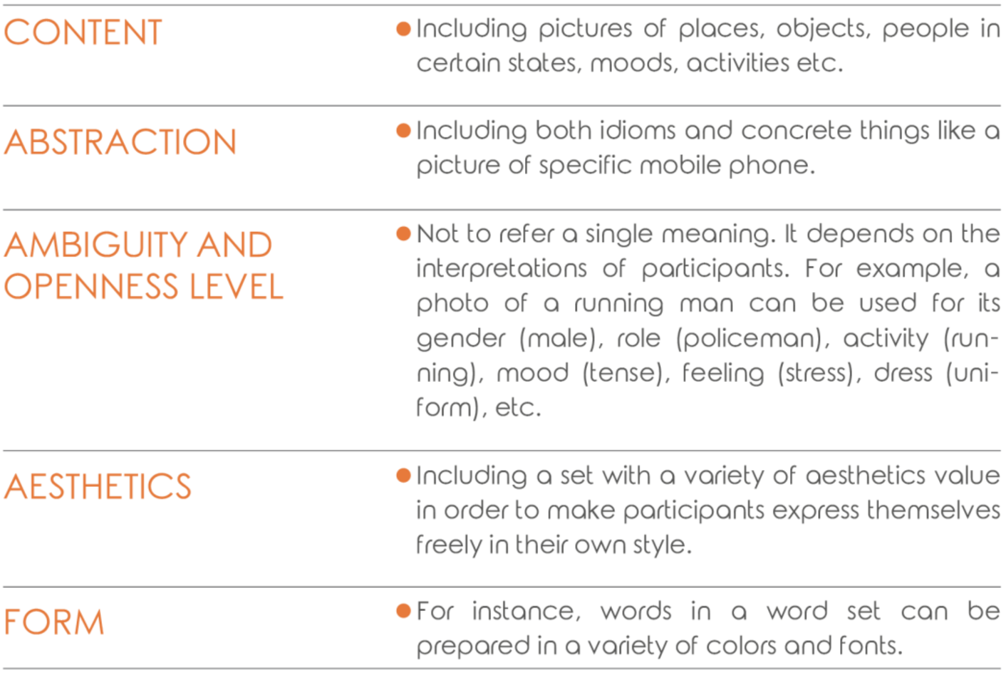
[13] Please see Figure 3.3. for the schema that shows the relationship between tacit and latent knowledge and Make tools.

As illustrated by Sanders and Stappers (2012, p.72), before starting to use **Make** techniques there are five essential aspects to consider:

Table 3.4. Considerations while using **Make** techniques (Sanders and Stappers 2012, p.72)



CONTENT	● Including pictures of places, objects, people in certain states, moods, activities etc.
ABSTRACTION	● Including both idioms and concrete things like a picture of specific mobile phone.
AMBIGUITY AND OPENNESS LEVEL	● Not to refer a single meaning. It depends on the interpretations of participants. For example, a photo of a running man can be used for its gender (male), role (policeman), activity (running), mood (tense), feeling (stress), dress (uniform), etc.
AESTHETICS	● Including a set with a variety of aesthetics value in order to make participants express themselves freely in their own style.
FORM	● For instance, words in a word set can be prepared in a variety of colors and fonts.

A background is also provided by the researcher in the making process. A variety of backgrounds can be used. For example, it can be blank or pre-structured for guiding the participants (Sanders and Stappers 2012, p.72). In addition, the size of the toolkit should be taken into account as well. It is recommended not to include too many items in order to avoid confusing the participants (Sanders and Stappers 2012, p.73).

Stappers and Visser (2007) used sensitizing toolkit in their contextmapping study. The study was about providing a deeper understanding of the users of the shoe care product company Kiwi. The sensitizing package was a set to help people express their experiences about footwear that includes items such as a workbook and a Polaroid camera. The workbook included assignments spared as long as a week. Each day the user was asked to answer questions related to the topic. Since the topic was footwear, the questions were related to the number of shoes of users, their preferences in where to collect them and how their feet feel during the day. By the help of this exercise, participants became more aware of their preferences, habits and feelings regarding footwear. This exercise was helpful to continue with generative sessions since they were sensitized with their experiences, they expressed them more easily during these sessions.

3.3. Participatory Design with Children

Childhood was not seen as a particular and significant period of life in medieval times. Children were accepted as similar to adults. Consequently, there were no clothes or toys designed especially for children. However, in the early 1800s, the Industrial Revolution led to serious changes in people's lives and a shift occurred to viewing childhood as an important stage of life and development (Stolarz-Fantino, et al. 2009, p.3).

A similar shift occurred regarding the perception of children in terms of involvement in a participatory design process. Historically, participation has been associated with active involvement (Arnstein 1969). Nonetheless, this is not applied to the works conducted with child participants. They mostly used more passive methods such as listening and consulting, which does not fit with active involvement processes. It was common to involve children in data collection but not in the design process (Kellett 2009). It is also stated by another researcher that historically, children have not been allowed to make decisions even about the issues that have an impact on their lives. They were considered as inadequate, unskillful and unsophisticated to make decisions that make sense (Cunningham 1998). Moreover, traditional research methods[14] provide limited involvement of children. For example, observation technique does not require direct involvement of children (Barker and Weller 2003). Listening to children's ideas does not equal to the sharing decision-making process with them (Morrow 2009). It is claimed that these techniques are not conducted *with* but *on* children (Barker and Weller 2003).

Over time, children's participation gained more importance even in legislation and political programs throughout the world (Chawla and Heft 2002, Skivenes and Strandbu 2006, Kellett 2009). Today, children are seen as social actors and facilitating them in meaningful participation advocates this position (Kellett 2009). This helps to change their objectified position from 'human becomings' to 'human beings' (Skivenes

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[14] Please see Table 3.1. for design research methods adapted from Hannington (2003)

and Strandbu 2006, Kellett 2009,). This might be related to modernization of democratic societies both in cultural and political aspects, since children's right to make a contribution and be a participant in the decision-making processes is a sign of their involvement in a democratic society (Skivenes and Strandbu 2006). Kirby and Gibbs (2006) also support that idea and add that enhancing participation of children is based on improving democracy and creating a more inclusive society.

After a controversial process, the discourse of children's participation appeared in the *Article 12* of UNCRC (United Nations Convention on the Rights of the Child). The article states that rights of children involve expressing their ideas and participating in decision-making processes that may affect their lives (Skivenes and Strandbu 2006, p.12). This Article declares that children have the right of participation in matters that concerns them. The recognition of children as social actors and users of products and services and further attention given to children's rights has been created an alteration towards active involvement of children in decision-making processes (Kirby, Lanyon, et al. 2003, Coad and Lewis 2004, Cairns and Brannen 2005, Davies, et al. 2006, Kellett 2009).

> Article 12, no. 1:
> 1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (CRC 2009).

Hart's (1992), 'Ladder of children's participation' was the first endeavor to provide a meaningful practice to the articles of UNCRC (Kellett 2009). According to Hart (1992), it is possible to measure to which extent children are involved in the process. The lowest three rungs; manipulation, decoration, and tokenism are defined as non-participation. Other four rungs; assigned but informed, consulted and informed, adult initiated shared decisions with children, child-initiated and directed and lastly child-initiated shared decisions with adults are aligned according to the degree of children's participation in the process (Hart 1992). However, according to Phil Treseder's model, on the other hand, he argues that children need empowerment in order to be capable of participating (Morgan, Davies and Wood 2012). His model includes top five rungs of Hart's ladder. Whereas, these are arranged in a circular order as forms of right participation. This means that although they differ from each other they are equal (Kellett 2009).

Shier's model concentrates on adult's roles. This model is based on five stages of participation from the first level 'Children are listened to' to the last level 'Children share power and responsibility for decision-making' (Kellett 2009). This model asks a question at each step of each level in the frames of openings, opportunities, and obligations. Answers help to define their situation and what can be done for widening children's participation (Shier 2001). According to Kellett (2009), Shier's model is focusing more on adult-child collaborations for more effective participation. This approach is very close to Vygotsky's (1978) approach, which he defined as Zone of Proximal Development[15]. It refers to the difference between children's actual performance without any help from adults and potential performance with a guidance from adults.

Apart from these, Kirby and Gibbs (2006) state that there cannot be a single level of participation. Since the decision-making power continually changes from children to adults depending on the projects and tasks.

Saure Hagen et al. (2012) compare three main models (Druin 2002, Large et al. 2006, Hussain 2010) which show different point of views on the level of involvement of children.

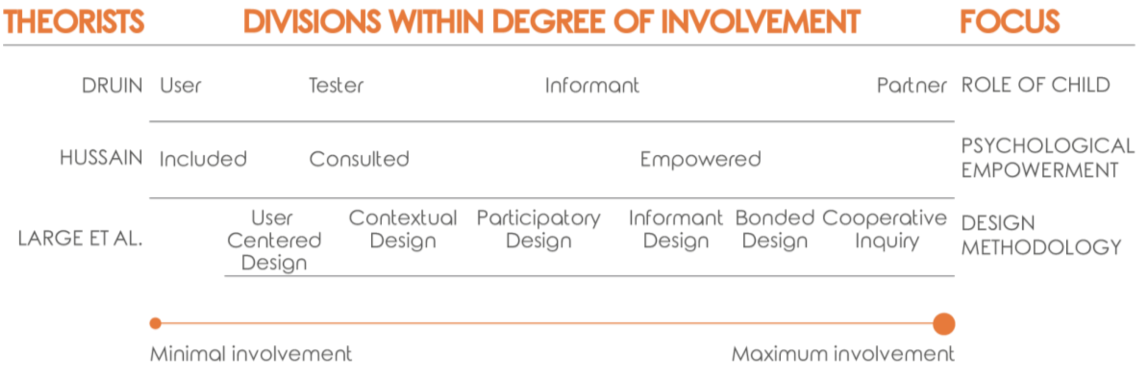

Figure 3.5. Combination of theoretical approaches that describe different degrees of child user involvement adapted from Saure Hagen et al. (2012)

Overall, children's active involvement in the design process is valuable because of two main reasons. Firstly, it provides more ideas in quantity and variety. Secondly, giving a voice to marginalized groups is a strongly supported idea and children are

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[15] Please refer to Section 3.3.1. for detailed information regarding Zone of Proximal Development.

among one of these groups. On the other hand, several researchers advocate that participatory design process gives an opportunity to children’s voice and empowers children as researchers (Guha, Druin and Fails 2013, Kellett 2009).

3.3.1. Determining the Age Range of Children

Before starting to conduct a participatory design study with children it is substantial to understand children’s development stages (Gelderblom and Kotzé 2009). Children perceive the world in a totally different way when compared to adults (Saure Hagen, et al. 2012). They differ from adults in terms of their cognitive, motor, social, emotional, and communication capabilities. These differences should be examined before conducting a participatory design research with children. The cognitive development stage of a child may require more concrete or actual explanations of abstract concepts in a participatory design process. Furthermore, development stages of children vary according to age groups. Hence, it is critical to consider age differences while conducting a participatory design research (Fails, Guha and Druin 2013, p.105).

The suitable age range of the children should be determined by considering their development stage. This thesis investigates the participatory design process with children and design is a problem solving process (Heary and Hennessy 2002, Fails, Guha and Druin 2013). Problem solving and decision making are two essential elements of cognitive development (Ahmad, et al. 2016). For this reason, this study focuses specifically on the cognitive development stages of children.

Development is explained by Shaffer and Kipp (2010, p.2) as the orderly or patterned alterations and continuities that happen to individuals between their conception and death. As emphasized by many researchers (Shayer 2003, Shaffer and Kipp 2010, Lourenço 2012), in the field of developmental psychology, the most famous developmentalists are Jean Piaget and Lev Vygotsky with their theories in child development. Their positions regarding child development are nearly equal (Shayer 2003). Lourenço (2012) explains the most obvious difference between them: Piaget’s theory is based on individuality, but Vygotsky’s is collectivity.

On the one hand, Lev Vygotsky (1896-1934) advocates collectivity with his sociocultural theory in cognitive development (Shaffer and Kipp 2010, p.281). According to Vygotsky (1978), at least two developmental levels should be determined.

One of them is actual developmental level. This level can be determined by using tests. In these tests, only the works that children accomplished on their own are considered as indicators of their developmental levels. Vygotsky (1978) emphasizes that when children are working in a group or under teacher guidance to solve a problem, it reveals another developmental level: zone of proximal development. For example, if a ten-year-old child solves a problem alone, it may show that s/he is eight years old in terms of mental development. However, if a ten-year-old child solves a problem in collaboration with a group of children or under adult guidance his/her problem-solving skills might match with a twelve-year-old's level. The difference between eight and twelve is called zone of proximal development. This is the zone between an actual developmental level, which is determined by individual problem solving and prospective developmental level, which is determined under adult supervision or in a collaborative work with other children (Vygotsky 1978, 86). This theory supports the participatory design processes conducted by adults with children[16]. In these processes, adults are facilitators who help children to explain their needs and ideas.

On the other hand, Jean Piaget (1896-1980) developed a theory, which supports individuality (Lourenço 2012). Piaget is the first psychologist to make a systematic study on cognitive development and a huge contribution to our understanding of children's thinking and the field of developmental psychology with his constructivist theory (Hourcade, Interaction Design and Children 2007, Shaffer and Kipp 2010). Constructivism refers to the idea that children construct their knowledge structures actively in accordance with their experiences and interactions with the world. According to Jean Piaget's constructivist theory, children build their knowledge about the world based on their individual experiences (Stolarz-Fantino, et al. 2009, Shaffer and Kipp 2010, p.54).

While Piaget was working on testing mental ability of people, he found that children of the same age group were giving the same sort of wrong answers. After elaborating on this issue, he realized that being older does not make people more intelligent than younger ones but the children process their thoughts in a totally different way. In order to determine how the way children think progressed from one stage to another, he established his own laboratory and spent sixty years working on this issue (Shaffer and Kipp 2010, p.53). He classifies cognitive development of children into

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[16] Please refer to Section 3.1. for detailed explanation about Participatory Design.

four: 1) the sensorimotor stage, 2) preoperational stage, 3) concrete operations stage and 4) formal operations stage (Piaget 1995).

3.3.1.1. Sensorimotor Stage (0-2 Years)

According to Shaffer and Kipp (2010, p.253) in sensorimotor stage (0-2 years) infants learn to coordinate **reflexes**. In two years, they learn about themselves at a tremendous rate and transform from reflexive creatures to planful problem solvers. Infants start to understand the consequences of their actions in the first years of their lives. When they touch something and hear a voice, they repeat the action. Stolarz-Fantino, et al. (2009, p.65) state that repeating the actions such as sucking their fingers and waving their hands are named as **primary circular reactions,** which are considered to be the initial sign of cognitive development.

At the end of this stage, infants begin to solve problems at a **symbolic level**. Piaget (1952, p.335) explains it with an example based on the observation of his own son, Laurent. While Laurent was sitting at a table, Piaget put a piece of bread at an unreachable location and a stick to the right. Firstly, Laurent attempted to reach but when he could not reach, he gave up. However, when he noticed the stick, he used it as an extension of his arm in order to reach the bread. Shaffer and Kipp (2010, p.255) state that this is an example of symbolic problem solving or inner experimentation.

Shaffer and Kipp (2010, p.256) mention another important aspect, **object permanence**, the understanding that objects maintain existing even if they are not seen or perceived through other senses. However, according to Piaget (1999a, p.51), when objects disappear, infants believe that they do not exist anymore. Throughout the sensorimotor stage, they develop it progressively (Stolarz-Fantino, et al. 2009, p.83). At the end of this stage, they become aware of invisible displacements and they totally comprehend the object permanence (Shaffer and Kipp 2010, p.256).

3.3.1.2. Preoperational Stage (2-7 Years)

Shaffer and Kipp (2010, p.261) state that in the preoperational stage (2-7 years), **symbolic function** gains importance. This is explained as the ability to use an object or a word as a representation of another one. At this stage, symbolic play is also one of the most essential aspects. Children pretend that they are someone else like a mother, superhero and the like. During this sort of play, they also use some objects in order to symbolize others. For instance, they may use a box that represents a bed.

According to Piaget, at this age children are **egocentric** and they see the world only from their own perspective (Stolarz-Fantino, et al. 2009, p.132). Children have a problem with understanding what others see from a different viewpoint. Even if someone is looking at something from a different vantage point, children assume that they see this in the same way they do (Shaffer and Kipp 2010, p.264). Piaget and Inhelder (1997, p.232) devised the “Three mountain problem” in order to detect if children are thinking in a egocentric way or not. This test also indicates if the children are at the preoperational or concrete operational stage.

As explained by Stolarz Fantino et al. (2009, p.133) at this stage, children are confused about **cause-effect relationship**. For instance, preschool-aged children may think that graveyards are the reason of death for people and if people stay away from graveyards they can escape from death. In this case, apparently the cause-effect relationship is misunderstood by the children.

Similarly, since preschoolers tend to focus on only one aspect they have a difficulty in **differentiating appearance from reality**. For example, when they see a certain animal wearing a mask of another type of animal they have a tendency to believe that the animal has transformed into another one (Shaffer and Kipp 2010, p.264).

3.3.1.3. Concrete Operational Stage (7-11 Years)

In the stage that Piaget called concrete operational (7-11 years) there is a transition from early childhood to middle childhood. Children start to undergo mental activities, which help them to find out solutions for problems in a **logical** attitude (Stolarz-Fantino, et al. 2009, p.186).

Concrete operational stage can be considered as a stage that includes improvements corresponding to the limitations of preoperational stage. For example, with regard to egocentrism, unlike preoperational stage, children in this stage become aware that diverging perspectives exist. For this reason, children approach situations by considering other people’s ideas and viewpoints (Shaffer and Kipp 2010, p.272).

Moreover, concrete-operational children also become good at solving Piaget’s **conservation** problems (Shaffer and Kipp 2010, p.272). Conservation refers to an ability of logical thinking that even if some changes occur in apperance of an object, some properties of it may remain the same (Piaget and Inhelder 1958, p.32). For instance, conservation of volume tasks are for determining the children’s ability of understanding that the amount of a liquid remains unchanged even if it is shown them in cups that have different forms (Stolarz-Fantino, et al. 2009, p.186).

As explained by Piaget and Inhelder (1958, p.16), in this stage children also acquire the ability of mental seriation. They become capable of **classifying** objects, as well. For instance, they understand the relation between classes (e.g. mammals) and subclasses (e.g. dogs and cats). It helps to understand why children start collecting some objects like Pokemon cards (Stolarz-Fantino, et al. 2009, p.186).

Shaffer and Kipp (2010, p.273) state that the age of 7 is the most appropriate age to start formal education in several countries. This can be explained with the acquisition of many skills in this stage that helps children to understand calculations, language and classifications.

The biggest limitation of this stage is that children can think logically only about **concrete** situations. They have difficulties in abstract concepts (Stolarz-Fantino, et al. 2009, p.187).

3.3.1.4. Formal Operational Stage (11+)

Formal operational stage (11+) is the final stage of cognitive development. As explained by Piaget, in this stage children are able to think in an **abstract** way (Stolarz-Fantino, et al. 2009, p.245). This ability is one of the most important characteristics of this stage that differentiates it from the previous stages. Since concrete operational children can use their operational schemas only when thinking about real objects or events that physically exist (Shaffer and Kipp 2010, p.273). In contrast, formal operational children become able to think in a logical way about the situations that do not have any relation with the reality (Shaffer and Kipp 2010, p.274). An assignment applied to children by Piaget clearly shows the difference between these two stages. Piaget asked the children to imagine and draw a third eye wherever they want to put on their body and explain why. As a result, while concrete operational children place the third eye next to their eyes, formal operational children gave more creative answers. For instance, one of them placed the third eye on the hand in order to become capable of seeing what is in a cookie jar. These answer shows the evidence of improved hypothetical thinking (Piaget 1970).

Due to the fact that adolescents start to think about hypothetical possibilities of current situations, they may also start questioning their environment. They may put the blame on their parents or the government for discrepancies or unreasonable situations (Shaffer and Kipp 2010, p.276). Piaget explains this as a result of their newly acquired ability of abstract reasoning (Piaget 1970).

In this stage, children start to think **systematically**. This is another characteristic that demonstrates its difference from concrete operational stage (Stolarz-Fantino, et al. 2009, p.245). Piaget and Inhelder (1958, p.108) explains that generally in order to determine the formal operational logic, the “combination of liquids problem” is applied. While concrete operational children try to solve this problem in an unsystematical way, formal operational children try all possible combinations in a systematical way in order to find out which combination of liquids creates one specific color.

By bearing in mind the development stages of Piaget, it was found that to conduct this study with children who are at the sensorimotor (0-2 years) and preoperational (2-7 years) stages is not feasible. Apparently, children at sensorimotor stage are too young to express themselves. It is possible to conduct this study with children at preoperational stage. Yet, they are generally confused about cause-effect relationship and they have a difficulty in differentiating appearance from reality.

As also explained by several researchers[17] who conducted participatory design research with children, for these studies the most appropriate development stages of children are the concrete operational (7-11 years) and formal operational stages (11+ years). Since children at concrete operational stage are not egocentric, they start finding logical solutions to problems and they also become able to classify objects. The only problem with this stage is that they cannot think logically about abstract concepts. For this reason, it is recommended to use concrete objects while working with them in a participatory design study. At formal operational stage, children can think logically even in an abstract and systematic way. For these reasons, the age range of children to conduct this study with was determined as 7-17.

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[17] Please refer to Section 3.4.2. for detailed information regarding considerations about age while conducting participatory design research with children.

3.3.2. Participatory Design with Children with Cancer

Participatory design, as a democratic and humanistic approach, advocates the inclusion of minority groups such as people with disabilities, refugees, elderly people, and children in a society by giving them a right to participate in decision-making processes (Skivenes and Strandbu 2006, Hussain 2010, Merter and Hasırcı 2016). Children with cancer is another minority in society that needs to be given voice in order to better understand their needs, and thus, to improve their QOL.

There are only a few participatory design studies conducted with children in the field of industrial design (Gielen 2008, Merter and Hasırcı 2016, Umulu and Korkut 2018). The participatory design studies with children were conducted mostly in the field of human computer interaction (Taxen, et al. 2001, Druin, Bederson and Hourcade, et al. 2001, Large, bowler, et al. 2007), engineering (Hussain 2010, Arnold, Lee and Yip 2016, Alves-Oliveira, et al. 2017), and occupational therapy (Gellis 2009).

So far, only limited number of participatory design studies was conducted with children with cancer. Ruland, Starrren and Vatne (2008), from the fields of medicine and biomedical informatics, conducted a participatory design study in order to develop software system called SISOM. According to their statement (Ruland, Starren and Vatne 2008, p.625), the aim was to help children with cancer to express their symptoms and problems. However, they did not work with children with cancer during the design process. Due to the challenges of involving seriously ill children in a design process, they worked with healthy children. Instead of design sessions, they interviewed children with cancer in order to test their understanding of SISOM.

Mateus-Berr et al. (2015) conducted a participatory design study with children with cancer in the scope of a national research project in the field of applied arts. The aim of the project was to develop a health game for pediatric patients after cancer treatment with HSCT (hematopoietic stem cell transplantation). Since these children become tired easily, they could not participate in the whole participatory design study but they attended the testing stage (Mateus-Berr, et al. 2015, p.1397).

As another example of a participatory design study with children, Lindberg (2013b) worked with children who have or had leukemia in order to develop an online peer support to promote mental health of children in the field of human computer interaction. Conducting participatory design sessions with the target users in health related contexts is preferred in the cases that the well-being of children is not put into jeopardy (Ruland, Starren and Vatne 2008).

However, this thesis emphasizes the importance of including end-users of products in a design process and thus, it is conducted with children with cancer. It is seen from the literature review that in the field of industrial design, participatory design studies with children with cancer have not been conducted yet. For these reasons, it was expected that this study may contribute to the existing literature.

3.4. Considerations

As children are experts at being children, an adult user cannot compensate a child user during a design process of a product for children. Adults cannot properly remember their childhood memories enough to put themselves in children's place. Even if they remember, they are not children anymore. Moreover, childhood is changing and will change. Thus, it is not the same to be a child 20 years ago and today. This demonstrates the importance of including the children in the design process instead of adult proxies. The products designed for children require their expertise (Druin 1996).

Participatory design approaches are advantageous for several reasons while designing with children (Druin 2002). However, it is essential to modify them in order to conduct these methods in a more appropriate and child-friendly way. Due to the difference between children and adults in terms of their cognitive, physical, social, emotional and communication capabilities, there are considerations that should be taken into account during design sessions with children (Fails, Guha and Druin 2013, p.105).

In spite of the fact that participatory design methods with adults and children have similarities, some points should be taken into consideration during a participatory design process with children. As a similarity between participatory design with adults and children, both are capable of brainstorming, prototyping or evaluating. In addition, both provide an expertise on a specific issue (Druin 1996).

In reality, children's participation is not simple (Kellett 2009). Children perceive their surroundings unlike adults. It is not only associated with their smallness in size but also linked to that their cognitive, social, emotional and physical development level is different than adults (Saure Hagen, et al. 2012). As explained in detail by Skivenes and Strandbu (2006), there are several challenges of children's participation. According to them, three main obstacles are; 1) children’s communication skills, 2) their differentiated needs and capabilities and 3) desire of adults to protect children.

First, it is essential for adults to consider children’s ability in linguistics and forming easy to understand and short sentences while speaking with them. On the other hand, as claimed by Johansson (2003) (Skivenes and Strandbu 2006), communication does not only include linguistics, but also attitude, body language and facial expressions.

Secondly, children have different backgrounds. Thus, it cannot be expected from them to have same needs and capacities, even if they are at the same age. This may lead to disparate features in children in terms of physical and emotional strength. Considering children and adults may have dissimilar experiences and upbringing, it might be a challenge for adults to understand them (Skivenes and Strandbu 2006).

Third obstacle is that a major part of adults have a tendency to protect children, since childhood is seen as an immature and sensitive period of human life. So-called ‘child savers’ make decisions instead of the children to protect them. However, when an adult does something in order to prevent a problem to protect a child, it may cause more problems in the child’s point of view. In this case, children’s opinions should also be taken into consideration (Skivenes and Strandbu 2006).

3.4.1. Do & Say Techniques with Children

In earlier times, because of inadequate cognitive, communicative and social skills of children it was not expected for them to provide good quality answers to questions of questionnaires. Conducting questionnaires with children themselves, instead of conducting them only with adults who are their parents or teachers, gained importance in the last 20 years. This is also important to express their modern western perception as social and economic actors of their own lives with their own perspectives (Bell 2007, p.461). However, while using these techniques for children there are several aspects that should be taken into account (Bell 2007, p.463).

In general, the problem with Say techniques is that sometimes participants may tell what the researcher wants to hear. Either, they may want to seem better than they already are. This is called say/do dilemma when what participants say is not the same with what they do (Sanders and Stappers 2012, p.69). Bell (2007, p.462) explains this situation as ‘satisficing’ (Vaillancourt 1973). A number of reasons can lead to this problem, especially when conducting research with children. First, when complex words are used in a sentence, the question is called ’poorly-designed’, which possibly causes satisficing. Secondly, the cognitive capacity level of children should be taken into account in order to prevent this. Finally, the questions should be meaningful and interesting for children in order to avoid making them feel bored or uninterested.

Cognitive development level of children[18] plays an important role in gathering good quality data from them with a questionnaire or interview (Borgers, de Leeuw and Hox 2000, Bell 2007). For instance, the children who are younger than age of four cannot be respondents. Only observations or parent proxy reports can be applied. Due to the very limited language skills, the children who are between 4-7 years of age are not very suitable either. However, after the age of eight, semi-structured and structured interviews can be conducted with children, since their linguistic skills are developed enough at this age (Borgers, de Leeuw and Hox 2000, p.71).

Simplicity is the most essential aspect while designing the instruments for children (Bell 2007, p.463). Moreover, they should not include ambiguous statements (Borgers, de Leeuw and Hox 2000, Bell 2007). Because especially young children only understand the literal meaning of words, it may lead to misunderstanding. Correspondingly, it is required to make questions in a direct and specific way (De Leeuw 2011, Bell 2007).

As explained by Bell (2007), the number of response options should not be excessive. Otherwise, it can be confusing for children. Even if it is suitable to include four or five options for children older than eleven years of age, for younger children it is advised to have three or four options and even to prefer ‘yes/no’ questions instead (Borgers and Hox 2001).

In addition, providing visual stimuli and response cards are suggested, since they contribute to make interview more interesting and fun for children (Borgers, de Leeuw and Hox 2000, p.72). For example, scaled responses that ask how strongly they agree or disagree with a statement can be symbolized by using smiley faces (Bell 2007, p.465). Furthermore, use of art-based activities in interviews is highly recommended, since they enable children to express their views and experiences in a creative way (Gibson, et al. 2018, p.117). For instance, in a study that includes art-based activities in interviews

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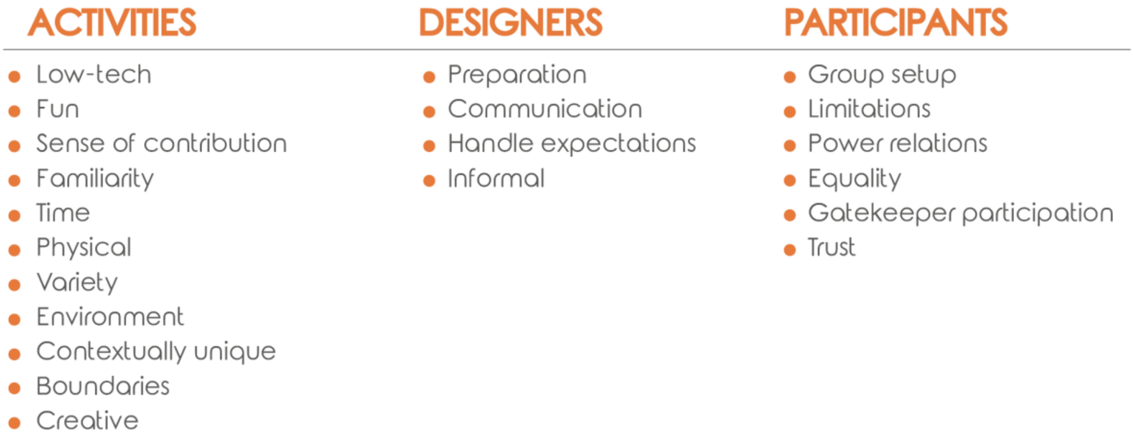
[18] Please refer to Section 3.3.1.1. for Piaget’s cognitive development stages

with children with learning disabilities, a card sorting activity is conducted in order to elicit their feelings about being in hospital. Hospital environment based symbol cards were prepared by the researcher and the children were asked to put them in the 'likes' or 'dislikes' box (Gibson, et al. 2018, p.115).

3.4.2. Participatory Design Sessions with Children

Table 3.5. Properties of design methods with children adapted from Lindberg (2013b)



ACTIVITIES	DESIGNERS	PARTICIPANTS
● Low-tech	● Preparation	● Group setup
● Fun	● Communication	● Limitations
● Sense of contribution	● Handle expectations	● Power relations
● Familiarity	● Informal	● Equality
● Time		● Gatekeeper participation
● Physical		● Trust
● Variety		
● Environment		
● Contextually unique		
● Boundaries		
● Creative		

Lindberg (2013b) provides a list of common properties of participatory design research with children. She divides the properties into three groups as the *activities* that take place, the *designers* who are responsible for preparation and leadership of these activities and the *participants* of them. The following aspects should be taken into consderation while conducting participatory design research with children.

Creativity: When comparing **Say**[19], **Do**[20] and **Make**[21] techniques that are classified by Sanders and Stappers (2012), Say techniques may not work well with children, due to the fact that children have a deficiency in explaining themselves verbally. Do techniques may not be the best option either, since they require interpretation of researcher and it is likely to misinterpret the children's action from an adult perspective (Grundy, Pemberton and Morris 2012). According to Boyden and Ennew (1997, p.37), research methods with children should be applied in a manner that helps children express what they think and perceive in their own way by avoiding any misrepresentation or obstruction that can be caused by the way adults think and talk. In

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[19] Please refer to Section 3.2.2. for detailed information regarding Say techniques
[20] Please refer to Section 3.2.1. for detailed information regarding Do techniques
[21] Please refer to Section 3.2.3. for detailed information regarding Make techniques

this sense, it is necessary to use techniques that do not depend on words (Boyden and Ennew 1997, p.37). For this reason, **Make** techniques appear to be more suitable for children. Thanks to the creative activities that require less linguistic skills, these techniques work well with children (Grundy, Pemberton and Morris 2012, p.181). From another point of view, using innovative techniques instead of traditional ones[22] to collect data from children is preferred because their linguistic skills may not represent their cognitive skills (Bryant 1974). Vaajakallio, Lee and Mattelmäki (2009, p.249) also explain that creative activities capture children's imagination. **Make** techniques do not restrict children. On the contrary, by providing easy configurations and ambiguous shapes, these techniques help children to interpret them in a variety of different creative ways (Giaccardi, et al. 2012, Lindberg 2013b).

Fun: According to Mazzone et al. (2010, p.115), fun is a substantial issue when working with children. This idea is supported by numerous researchers (Frauenberger, Good and Alcorn 2012b, Giaccardi, et al. 2012, Grundy, Pemberton and Morris 2012). Thus, activities should be fun in order to engage children in the design sessions and attract their attention. Even if being fun is considered as a subjective issue, as stated by Lindberg (2013b) mostly low-tech (e.g. drawing) and creative activities are generally described as fun.

Familiarity: Familiarity is an important aspect of the activities that are conducted with children. It encourages children to express themselves in a spontaneous and collaborative way. This is another reason to use low-tech tools like drawings since children are familiar with that (Horstman, et al. 2008, Giaccardi, et al. 2012). Using comics in a design session with children too is an example of including familiar concepts. These are appropriate because they are created by the help of a low tech tool, drawing, by children. In addition, most children are familiar with this concept since they read comic books (Lindberg 2013a, p.333). From another perspective, Sanders and Stappers (2012, p.103) state that it is always better to conduct the research with people where they are familiar with. Thus, a place that children are familiar with should also be arranged for participatory design sessions.

Boundaries: It is explained by several researchers that in order to increase the contribution of children, boundaries are required (Moraveji, et al. 2007, Guha, Druin and Chipman, et al. 2005). For instance, during brainstorming sessions it is

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[22] See Table 3.1. for the schema that shows traditional, adapted and innovative techniques adapted from Hannington (2003)

recommended to provide more structure to children (Guha, Druin and Chipman, et al. 2005, p.42)

Power Relations: Boyden and Ennew (1997, p.37) emphasize that the power imbalance between adults and childen should be eliminated in the design process. For this reason, Fails, Guha and Druin (2013) explain that during design sessions, children and adults are accepted equal. Adults may be experts in design but children are experts in being children. This equality should be applied in every stage of the process. For example, they use only first names while calling each other, children do not raise their hands to speak (Large, bowler, et al. 2007, p.70) in order not to create a student-teacher relationship. This is because the time they spent is not reserved for education, nor the adults who they work together are their instructors, they are researchers (Fails, Guha and Druin 2013, p.127).

Informal: In order to eliminate the borders between adults and children, both should wear casual clothes, they sit and communicate at the same eye-level and use informal language. Only in this sense children are given a voice in the design process, they share their ideas in a better way and this leads to better design outputs (Fails, Guha and Druin 2013, p.127).

Reinforcement: Children may need positive reinforcement during design sessions as a social and emotional support (Fails, Guha and Druin 2013, p.106). The intervention by the researcher may also be required when children get off the point in order to make them more focused on the aim of the activity (Mazzone and Read 2005, p.3).

Communication: Communication is considered as the key in every stage of participatory design process (Horstman, et al. 2008, Fails, Guha and Druin 2013, Lindberg 2013b). According to Kellett (2009), adults should also pay attention to use the correct language and attitude in order to prevent exclusion of children. To introduce the main aim of the project and why there is a need for the participants’ contribution in a way that children can understand is essential before starting. During design activities, tasks should be explained to children by using an easy to comprehend language. If it is possible, using concrete or visual examples would make it more understandable than using words or abstract concepts for children (Mazzone and Read 2005, p.3). Using drawing or painting as a tool to communicate is possible. For instance, Hasırcı (2008, p.245) who conducts an international participatory project with Greek and Turkish children states that even if the children do not speak the same language they communicated by painting. Moreover, checking what children say, write or draw with the children themselves is very important in order to prevent any misunderstanding by a researcher. Checking their drawings and notes with children, reveals their intended meaning (Horstman, et al. 2008, p.1004).

Sense of contribution: It is quite valuable to provide children with a sense of contribution. For example, it may motivate children to be more engaged if they know that their contribution may have an influence on children who are under the same circumstances. The researcher should make children be sure that their opinions are very valuable (Horstman, et al. 2008, p.1004). One of the recommendations for achieving this is to have a session for showing children how their opinions are applied to the new design (Thomas and O'Kane 1998, p.345). At the end of the participatory design research, children can present their output. Researchers give them encouraging feedbacks and congratulate them on their great success (Mazzone and Read 2005, p.3).

Gifts: It is also important to consider to thank children warmly for contributing to the study (Mazzone and Read 2005, p.3). Gielen (2008, p.180) also states that it is important to reward the children for their help by giving compliments or small gifts. Researchers may prepare a certificate of achievement for children in recognition of their contribution (Carter and Ford 2013, p.101). Alternatively, they can send a card or gift to children that shows how valuable their participation was (Horstman, et al. 2008, p.1004). Fails, Guha, and Druin (2013) too recommend to present children with small gifts and express gratitude for their participation in a verbal and written way.

Age: Another important point is to consider the age of children in a participatory design research (Fails, Guha and Druin 2013, p.105). So far, most of the children who have participated in design processes are between the ages of 7 and 11. Druin (1996) states that children between the ages of 7 to 10 are the most suitable ones for a co-design process, since this age is adequate enough for verbal expressions and self-reflection. This period corresponds to Piaget’s concrete operational stage (children between the ages of 6 to 12) (Piaget 1995). According to him, in this stage children are able to think in a logical way with concrete information. However, it is not easy for them to think with abstract concepts. Because of this reason, several techniques include concrete objects to link their thinking. Since adolescents (13 to 18 year-olds) and children differ from each other in terms of their development, the techniques, which will be applied in a participatory design process with teenagers should be examined independently from children (Fails, Guha, and Druin 2013).

Time: Conducting participatory design sessions with children requires more breaks since their attention spans are shorter than adults (Fails, Guha and Druin 2013, p.105). Furthermore, it can take more time to process data and give an answer for children when compared with adults. For this reason, it is important to wait for their responses and give them more time if they need it (Horstman, et al. 2008).

Pilot study: To conduct a pilot study is recommended by several researchers (Sanders and Stappers 2012, Mazzone and Read 2005). Mazzone and Read (2005, p.3) state that while working with children it always helps to obtain better results to apply a pilot study with a small sample of children. Moreover, according to Kistemaker, it is very important to provide a toolkit that fits the participants and the first try generally needs fixing. Conducting a pilot study also creates a positive perception by making participants feel that the researcher takes them seriously and makes some adjustments for them (Sanders and Stappers 2012, p.188).

3.4.3. Participatory Design Sessions with Children with Cancer

There are not many studies that focus on participatory design sessions with children with cancer, especially in the discipline of Industrial Design[23]. In this case, because of the limited number of pertinent research, considerations while conducting participatory design sessions not especially in an oncology or hematology service but in a health related context were taken into account, too.

In addition to the considerations explained in the previous part, conducting participatory design sessions in a health related context requires more different considerations. However, as explained by Lindberg (2013b), studies that provide a guideline for how to design with children in a health related context is limited. Therefore, it is important to determine the common features of participatory design methods in a health related topic.

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[23] Please refer to Section 3.3.2. for the examples of participatory design studies conducted in the Industrial Design discipline.

Table 3.6. Properties of design methods with children in a health related context adapted from Lindberg (2013b)

ACTIVITIES	DESIGNERS	PARTICIPANTS
● Low-tech	● Communication	● Power relations
● Familiarity	● Personal	● Informed consent
● Proxy	● Flexible	
	● Ask questions Patience	

Proxy: As explained by Grundy, Pemberton and Morris (2012, p.181), using proxies can be advantageous in a sensitive context. Health related context is considered as one of them. According to the psychologists, using proxies like teddy bears or baby dolls may help children express themselves about an upsetting situation in a non-verbal way when they cannot explain it by using words. Moreover, speaking in the third person may make them talk about the sensitive topic in an easier way and makes it less traumatic for them (Grundy, Pemberton and Morris 2012, p.181). Comicboarding also includes characters and these can be used as proxies (Moraveji, et al. 2007, Lindberg 2013c).

Group setup: According to some studies it is possible conduct the sessions with large groups such as the entire students in a class (Frauenberger, Good and Keay-Bright, et al. 2012a). Yet, Lindberg (2013b, p.162) explains that in a sensitive context, it is recommended to conduct the sessions in a ‘one researcher – one child’ setup. There are various reasons for that. First of all, it helps the researcher to be more focused on one child and recognize if any change occurs in his/her mood. In this case, researcher can more easily realize and stop the session if something disturbs or upsets the child, since it is essential to be sure that participation of children will not cause any negative effects on them. According to Horstman et al. (2008, p.1004), especially when conducting sessions with sick or vulnerable children, the capability of researcher to recognize increased anxiety or stress level of child is crucial. Secondly, this one-to-one setup contributes to sessions in another way that all children can express their ideas in an equal manner (Lindberg 2013b, p.162). In some group settings, more dominant children may block more silent children from expressing their ideas (Vaajakallio, Lee and

Mattelmäki 2009, p.248). Lastly, in this way it requires less effort from the researcher to keep the child focused during the activity (Lindberg 2013b, p.162).

Feeling valued as an individual: Horstman (2008) strongly recommends spending time with children in order to get to know them and understand what they value, because this makes the child feel valued as an individual. Generally, hospitalized children may have a toy, book, or a photograph they care about deeply and the conversation may be about them. It also works as an icebreaker activity (Horstman, et al. 2008, p.1003). In some cases, to play a game with children before starting the sessions can be a good icebreaker activity (Carter and Ford 2013, p.101).

Personal: The way researchers behave during sessions also has a huge influence on children. It is better to conduct the sessions in a friendly manner, by introducing themselves to children with their first names (Horstman and Bradding 2002). Sometimes it may be needed to ask personal questions to children. In this case, researchers should also share their own personal information with children in order to reduce the hierarchy and build trust in their relationship with them (Horstman, et al. 2008, p.1003). For example, if the activity is taking photographs for children, the researcher should also share some of the photographs that s/he took (Carter and Ford 2013, p.101). Otherwise, it creates an inequality and power imbalance between the researcher and the child, which is not desired[24] (Lindberg 2013b, p.159).

Patience: It has a huge importance for a researcher to be patient with participants (Horstman, et al. 2008). For example, some questions may take much more time for participants to answer. Especially in a sensitive context, participants may remain silent for a long time. If one of these situations occur, researchers should wait in patience by not rushing them (Elmir, et al. 2011, p.14).

Infection: As explained by Carter and Ford (2013, p.101) when conducting participatory design sessions with children in a health related context, it is important to consider the issues like cross-infection. For example, each children may be provided with a personal pen for using in the design sessions instead of sharing a pen among each other.

Material choice/Antibacterial: Moreover, the selection of materials is an important point to consider when working with children in a health related context. For example, providing children with a pen covered with a felt that smells like a strawberry or other

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[24] See Section 3.4.2. for detailed information about power relations between children and adults.

fruits may not be good for hospitalized children for some of the children may be allergetic to them or become nauseated because of the smell (Carter and Ford 2013, p.101).

Healthcare Needs: Considering healthcare related needs of children is crucial while preparing activities for hospitalized children. For example, if children suffer from a lack of strength in their fingers, the researcher should not force them to use their fingers (Carter and Ford 2013, p.101).

Ethics: Th**e** participation of children need to be completely voluntary (Scally 2014, p.204), for conducting an ethically appropriate research. There are other requirements such as obtaining informed consent and child assent. The researcher explains the procedures and respond to the questions of the participants, both parents and children. The researcher needs to be aware of the fact that participants have a right to withdraw from the study whenever they feel uncomfortable. Participants should be informed about this as well (Diekema 2006, p.S8). Child assent is different than consent obtained from the parents of children. However, it has a huge importance, since it gives children a sense of control and makes the children partner in the decision-making process (Diekema 2006, p.S10). In line with the purposes of this thesis, it has a crucial significance to promote participation of children in areas that are directly related to them[25]. Hence, asking their opinions regarding participating in this study was inevitable. Confidentiality is another important point that should be considered when conducting research with children (Kirk 2007, p.1252). Accordingly, Tinson (2009, p.22) also states that using pseudonyms instead of real names of children is strongly recommended in order to protect their personal identities.

The factors above have been investigated in order to conduct this case study in a way that will not cause harm to children with cancer and elicit more information about their needs. The design sessions (Make toolkit and senstizing workbook) were prepared to encourage **creativity** and **fun**, and to give a sense of **familiarity**. The study was conducted in an **informal** language and clothing in order to eliminate the **power imbalance** between the researcher and children. Children were **reinforced** during the design sessions to trust themselves and do their best. To reach an effective **communication** with children, mostly visual elements were used instead of using words or abstract concepts by the researcher. Each child was presented a Certificate of

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[25] Please see Section 3.1. for the detailed information regarding participatory design.

Participation and a small **gift** in order to make them feel the **sense of contribution**. The instruments were prepared according to **age** differences of children. A wooden mannequin **proxy** was used in order to make children feel more comfortable while sharing their opinions in this sensitive context. In terms of **group setup**, the study was conducted one-on-one with each child for an in-depth investigation. The researcher spent time with children and played games with them for making them **feel valued as an individual**. During the study, the researher also shared **personal** information about herself to reduce the hierarchy between the researcher and children. The Make toolkit was cleaned by using sanitizer in order to prevent **infection** issues. Lastly, **ethical** approval and informed consent form were obtained, and pseudonyms were used rather than names of children. The following chapter explains the details of the case study.

CHAPTER 4

CASE STUDY

4.1. Setting

The aim of this study is to investigate whether the participatory design process itself would contribute to the QOL of children with cancer in a positive way. For this reason, a case study was conducted at inpatient Hematology and Oncology Service of Dokuz Eylül University Nevvar and Salih İşgören Children’s Hospital. This hospital provides an outpatient clinic for children as well. It is located in Balçova, İzmir, Turkey. This hospital was chosen for the case study for various reasons. First, Dokuz Eylül University Hospital is an established university research and application hospital in Turkey. Nevvar and Salih İşgören Children’s Hospital is a part of this hospital, especially created for children. Secondly, there were inpatient children with cancer who are at the suitable age[26] (7-17 year-olds) for the participatory design sessions. Lastly, it has an indoor play area specifically for the inpatient children with cancer. By bearing in mind the importance of play for children with cancer, the topic of the participatory design sessions was to find a better solution to meet the needs of all children in the Hematology and Oncology Service. Thus, to select a hospital that has a special play area for this specific user group was essential.

Figure 4.1. Indoor play area at Dokuz Eylül University Nevvar and Salih İşgören Children’s Hospital photographed by the researcher

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[26] Please refer to Section 3.3.1.1. for the explanations of reasons to conduct this study with this age group.

Figure 4.2. Indoor play area at Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital photographed by the researcher

In this hospital, the age of inpatient children in the Oncology and Hematology Service varies between 0-17. The indoor play area in the Hematology and Oncology Service is created by the help of donations[27]. The play area is open to all children. However, in the preliminary research it was found out that this area does not meet the needs of all children in different ages.

As explained by researchers (Guha, Druin and Fails 2010), even when the focus of the study is the effect of the process, it is not advised to conduct the study only for this aim. That is why an actual participatory design study brief was prepared by the researcher. Considering the importance of play for children with cancer, the aim of the participatory design study was to suggest modular furniture for the play area that meets the needs of all children.

4.2. Participants

In total, there were 13 participants in this study. Five inpatient children with cancer, five caregivers of these children, two doctors (one of them is oncologist and other one hematologist) and the head nurse of the Hematology and Oncology Service participated in different phases of the study.

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[27] Donations were collected by KAÇUV (Kanserli Çocuklara Umut Vakfı / Hope for Children with Cancer Foundation) and ÇOYAG (Nehir'in Çocukça Yaşam Gönüllüleri / Nehir's Childish Life Volunteers). This area is called "Nehir'in Oyun Odası (Nehir's Play Area)" in order to honour the memory of Nehir, the girl who lost her life to cancer at the age of 3,5.

4.2.1. Doctors and the Nurse

Two doctors, an oncologist and a hematologist, guided the researcher throughout the study with regard to determining the available inpatient children who will participate in the study according to the conditions of their treatment, health condition and choosing harmless materials for the design sessions. They checked each step of the study in order to control and warn the researcher if there is any possible inconvenience.

At the beginning of the study, the researcher carried out negotiations with these doctors in order to get approval and advices from them regarding the schedule of the study. It was also important to be introduced to children and their caregivers who are in such a sensitive context by someone they know and trust, like the doctors. After determining the participants by considering the age range and health conditions, the doctors introduced the researcher to the children and their caregivers.

Furthermore, in the questionnaire and interview, they answered individual questions regarding each child and general questions regarding all children with cancer, as well. The questions related to QOL, daily routine and play habits of children were asked individually for each child. On the other hand, the questions related to play area and further suggestions were asked generally, since the answers of these questions cover all children with cancer in general.

The head nurse of the Hematology and Oncology Service answered the same questions with the doctors. Due to the fact that nurses have been spending a great extent of time with the children when compared to doctors, they may have noticed different important points with regard to the QOL, daily habits, treatment of children and the use of play area.

4.2.2. Children with Cancer

Totally, five children participated in this study. The age of the children varies between 8 and 17. While determining the participant children, the treatment and health condition of children was one of the key criterions. For instance, one of the inpatient children had an infection and she was not able to speak. Not to disturb or ruin the treatment of children was the fundamental consideration of the study. Thus, she was not considered as a potential participant.

Another key criterion while determining the participant children was the age of the children. According to literature review[28], the most appropriate development stages of children are the concrete operational (7-11 years) and formal operational stages (11+ years).

The gender of the children was not a criterion while determining the participant children. Four boys and a girl participated in the study.

After determining potential participants, the researcher explained the study to seven children and their caregivers. The details of the study were explained to them both verbally as well as in writing. However, two of them did not pursue their participation. One of the children changed his mind and did not sign the informed consent form. It was essential to conduct this study with volunteer children. They were informed that they could withdraw from the study whenever they want. The child was a 17-year-old boy and he said that he was not comfortable with the idea of participating. On the other hand, his father was insisting on him to participate, since he believed that his child is not attending any activity and this study would distract him from his negative thoughts. However, the opinion of the child was important and he did not participate in the study. Another child and his caregiver assigned the informed consent form and they filled out the The PedsQL 4.0 Generic Core Scales. Nevertheless, they did not show up again in the hospital and thus could not participate in the study.

Due to the severity of the illness, it was not easy to find available inpatient children participants for this study. Because the study was anticipated to take approximately three months with each child, the doctors kindly warned the researcher that it may not be possible to see the same child again throughout the study because of the uncertainty of the illness. For this reason, the number of children who could participate in the study has been rather limited and the study was completed in a month with each child.

The participant children were dealing with cancer that differs from each other in terms of type and severity. Therefore, their treatment processes were different in regard to duration and beginning-ending date of the hospital stay. However, they follow the same routine. The treatments consist of a number of chemotherapy cycles. They come to the hospital and if their blood test results are good enough to cope with side effects of the treatment, they stay in the hospital and have chemotherapy. After staying in the

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[28] Please see Section 3.3.1.1. for the features of each development stage.

hospital for a certain period based on the requirements of their treatment, they go back to home for rest. Then, the cycles repeat.

The following part individually introduces five participant children under the themes of diagnosis, educational, physical, social, psychological[29], family life and play preferences.

4.2.2.1 Child 1

Diagnosis: He is an 8-year-old boy. He was diagnosed with cancer in May 2018. On his face there is a congenital beauty spot. Cancer developed out of this beauty spot. He does not know about his illness. His parents do not want to tell this to him, because he can get upset if he learns.

Educational: He is homeschooled and he is in the first grade. This year, he learned how to read and write. His teacher comes to his home when he is not staying at hospital. His teacher gives him homework and he practices reading and writing.

Physical: Physically, he is very energetic. He likes doing exercises, as well. He does not like to lie down on his bed in the hospital.

Social: He is not a very social child. He does not have many friends in the hospital. He feels bored in there.

Psychological: He easily gets angry. In the hospital, sometimes he rejects the treatment procedures like establishing vascular access for the chemotherapy. He knows that chemotherapy serum has a yellow color. When he sees it, he realizes that it will cause many side effects and he gets angry.

Family: He has two sisters. He is the youngest child in his family. His mother stays with him as his caregiver in the hospital.

Play: Mostly, he plays with his phone. He prefers to play games like Minecraft. Moreover, he likes painting and drawing very much. There are many drawings and paintings hanged on the walls of the play area that belongs to him.

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[29] See Table 2.1. for the domains of QOL. Main domains that affect QOL are classified as physical, psychological and social health.

4.2.2.2. Child 2

Diagnosis: He is a 10-year-old boy. He was diagnosed with cancer in 2012, when he was 3 years old. He was living in the eastern part of Turkey. However, after his diagnosis his mother and siblings moved to İzmir for his treatment at Dokuz Eylül University Nevvar and Salih İşgören Children's Hospital. He is aware of his illness and he knows all the treatment process, since for the third time the cancer relapsed, and he is living with it since 2012. He knows about chemotherapy and its side effects.

Educational: Last year, he was home schooled. However, this year he gave his education a break because of his psychological condition. This year, he told his parents that he will not be able to take the responsibility of his school works during his treatment, since it became very tiring for him.

Physical: Physically, he is an active child. He rarely gets tired and he is very energetic.

Social: He is extremely active in terms of social life, as well. He is still in touch with his classmates in his hometown. They came all together in the class and sent him a video whereby they said they miss him, and they send best wishes about his treatment. He gets along well with the nurses, too. He even makes jokes on them. He has an Instagram account and he spends so much time on social media. He wants to become a Youtuber when he grows up. He has a favorite Turkish TV series and he contacted the lead actor by sending messages to him on Instagram. He is extrovert, confident and talkative. He talked with the researcher and shared his opinions about one of his games, even in the day when they first met.

Psychological: He is a sensitive child. Once, when he was walking around by the seaside with his mother, a man did not allow his child to talk with him. The man was believing that cancer is contagious. As his mother said, he felt very bad when he heard these words and he could not stop crying for a while.

Family: He has two siblings. One of them is 15 months old. The other one is 14 years old. He gets along well with his siblings. His mother is staying with him when he stays in the hospital.

Play: In terms of play preferences, he likes to play with toy guns. Moreover, he likes to do puzzles. Frequently, he prefers to spend his time in the play area when he stays in the hospital. Volunteer students often come to the hospital for doing some fun activities such as drawing and painting with these inpatient children. He likes to play with these volunteers in the play area. His computer is indispensable for him and he takes it with him during his hospital stay. He likes to play games on computer. He also likes to play with his cousins. He is a fanatic football lover. His favorite team is Galatasaray.

4.2.2.3. Child 3

Diagnosis: He is a 12-year-old boy. He was diagnosed with cancer in 2018. He has leukemia. His treatment requires a longer continued hospital stay when compared to other participant children.

Educational: His hometown is not İzmir. He came to this city for hospitalization. He was going to school in his hometown. However, this year he gave it a break because of his illness.

Physical: He used to play football regularly. However, now he cannot play outside although he is energetic.

Social: He is a very social child. He gets along well with interns, doctors, and nurses in the hospital. Generally he stays in the single room, thus he does not know other inpatient children.

Psychological: Sometimes he gets sensitive about his illness. When his friends from school sent him letters, he could not stop crying. When it rains, he likes to watch it from his window.

Family: His mother is staying with him when he stays in the hospital. His father also comes to the hospital frequently.

Play: His favorite play is chess. He takes it with him when he stays in the hospital. He is very good at this game. Because his mother is not as good as he is, sometimes he plays chess on his phone.

4.2.2.4. Child 4

Diagnosis: She is a 16-year-old girl. She was diagnosed with cancer in 2017. Firstly, her parents preferred only the alternative medicine methods and she underwent a cure with herbs. When they understand it did not work, she was almost unable to breathe. Then they ended up taking her to the hospital. She is not from İzmir, either. Her family moved to İzmir for her hospitalization. They cannot afford to live in the city center because their economic situation is not good enough. They live in a district far away from the hospital. They come to the hospital by bus. She is aware of the fact that she is dealing with cancer.

Educational: So far she has been going to school, but this year she had a break because of her illness.

Physical: When she started her treatment in this hospital, a tracheostomy was performed in order to solve her breathing problem. She was not under good physical circumstances. However, she got better and there were no physical obstacles for her. She feels energetic but she is not physically active and she does not do exercise. She prefers to lounge.

Social: She is a social child. She makes friends easily in the hospital. She has a boyfriend and she talks with him in the hospital over the phone, since he is not in İzmir. She gets along well with nurses. She stays calm and let the nurses do their jobs even in the hardest and the most painful procedures.

Psychological: She is a sensitive child. She likes to listen to emotional music. On the other hand, she is very strong. She consoles her parents when they get worried about her illness.

Family: She has a large family. She has 5 siblings and her mother is pregnant. Her mother is not able to stay with her when she stays in the hospital because of this. For this reason, sometimes her cousin stays with her. Her father also comes with his daughter to the hospital.

Play: She is fond of music. She wants to learn to play the guitar, too. In her spare times, she listens to music by using her phone. She likes to play chess although she believes that she is not good at it. She tries to improve her skills. She also enjoys putting make up on her spare times. She thinks that it makes her feel psychologically better.

4.2.2.5. Child 5

Diagnosis: He is a 17-year-old boy. He was diagnosed with cancer in 2018. When he had pain on his shoulder he went to many doctors but they did not realize that he had cancer in his bones. Finally, when he was diagnosed with cancer, it was 1,5 years late. He knows about his illness and he fights against it. He is not living in İzmir. For this reason, he stays in his aunt’s house in İzmir when he does not stay in the hospital.

Educational: So far he had been going to school, but this year he had a break because of his illness.

Physical: He has cancer in his bones on his shoulder and had a surgery for this reason. Normally, he used to do sports regularly. However, after his diagnosis and surgery he thinks that he cannot do sports anymore. He became more passive.

Social: He is an easygoing child. He mostly stays in triple room in the hospital. He makes friends there. He gets along well with the hospital staff as well. He did not keep in touch with his school friends.

Psychological: He is very strong and mature. He gets sensitive sometimes, but normally he stays strong. His biggest problem is that he had to have a break from his education in his last year in the high school. It makes him feel worried about his future. On the other hand, he gets upset when he cannot do what he needs to do on his own because of the limitations of his illness and surgery.

Family: Generally his brother stays with him when he stays in the hospital. Sometimes, his grandmother comes to the hospital as well. When his grandmother stays with him, she cannot help him at all, because she is old and illiterate. However, he understands what is needed to be done and he directs his grandmother. He does not have a good relationship with his mother.

Play: He does not like to play games in the play area. Since he thinks that it is for younger children and there is nothing useful for him. He spends most of his time in his room with his tablet and phone. He watches some series. Normally, he likes to play playstation. Although in the play area there is a playstation, the games are too childish for him.

4.2.3. Caregivers of the Children

In this text, the term “caregiver” refers to the companions of children who stay with them in the hospital and look after them. All children have at least one caregiver who stays with them in the hospital. Each caregiver had a familial relation to the child for which they cared.

Caregivers of the children participated in several stages of the study. Mostly, the communication between the researcher and the children was established by the help of caregivers. The researcher was in contact with the caregivers of children in order to arrange the next meeting. Two oldest children were in direct contact with the researcher. The role of the caregivers was more passive in their cases.

4.3. Method

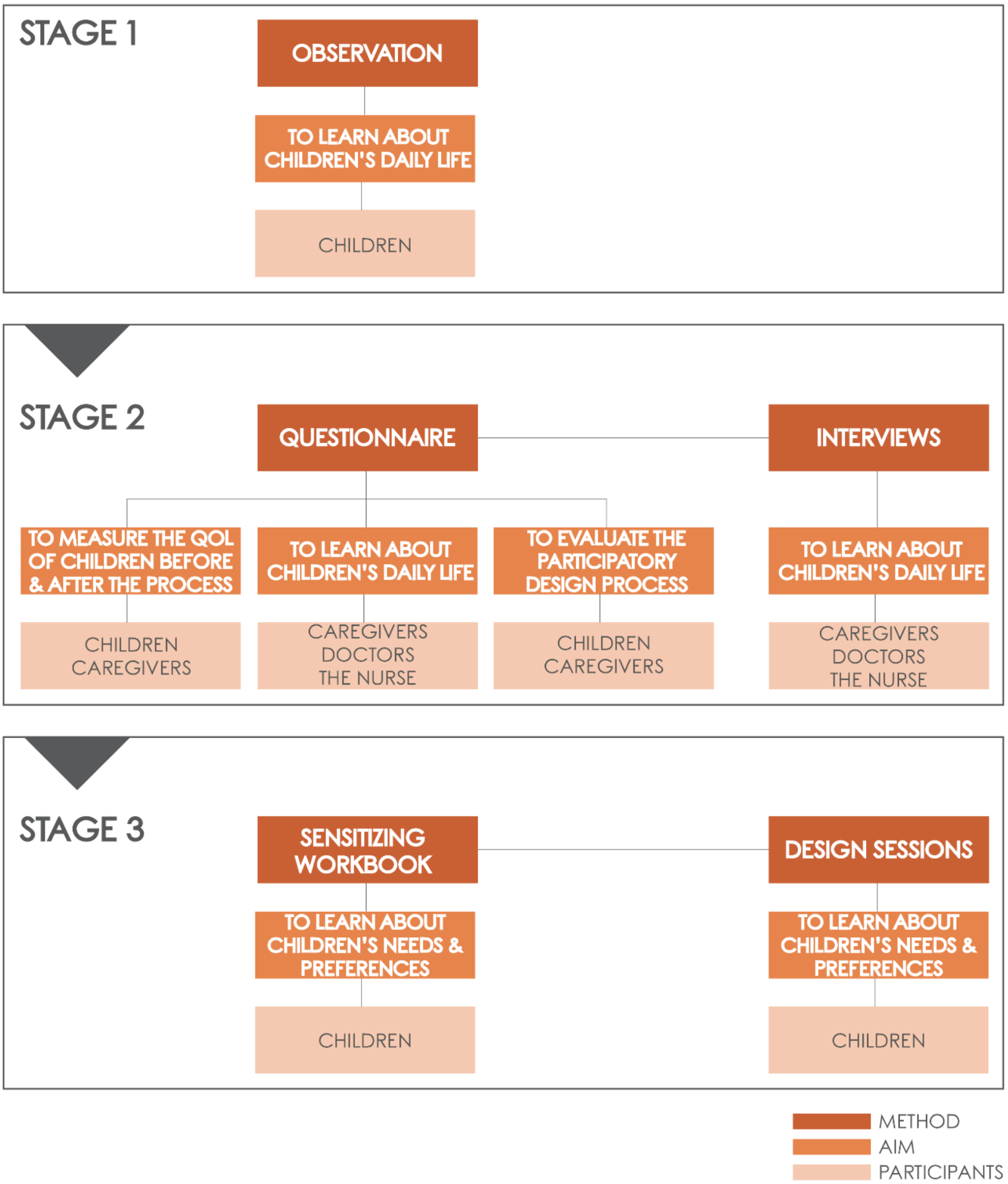

Figure 4.3. The main stages of the study

The case study includes seven steps: 1) meeting with participants and application of The PedsQL 4.0 Generic Core Scales to children and their caregivers, 2) observation of the play area, 3) interviews and questionnaire with doctors and the nurse,

4) application of questionnaire to caregivers of children, 5) sensitizing workbook activity with children, 6) design sessions with children, 7) application of The PedsQL 4.0 Generic Core Scales and evaluation questionnaire, and presentation of the Certificate of Participation to children and their caregivers as well as small gifts for children.

Ethical approval was obtained from the Ethics Committee of İzmir University of Economics (B.30.2.İEÜ.0.05.05-020.20)[30] and Noninvasive Research Ethics Board of Dokuz Eylül University (2019/06-57)[31] to conduct this study.

A time schedule was prepared before starting the case study. In the schedule, the estimated time for each stage of the study was shown. The schedule was also shared and discussed with the involved doctors. They shared their ideas and it contributed to the improvement of the schedule. For instance, the doctors mentioned that children are not available in the morning times, since doctors and interns make their rounds at these times. Thus, they recommended to the researcher to visit them in the afternoon.

4.3.1. The PedsQL 4.0 Generic Core Scales

The ones who accepted to participate, both children and their caregivers, signed an informed consent form. The PedsQL 4.0 Generic Core Scales[32] is filled out by the children and their caregivers before the study starts.

At the end of the process, each child and their caregivers filled out The PedsQL 4.0 Generic Core Scales for the second time.[33] The purpose was to compare the data that was gathered at the beginning of the study with this one and understand whether the participatory design study has an impact on children’s QOL or not.

4.3.2. Observations

Second stage was the observation stage. The researcher observed the play area while some inpatient children were using it. It was aimed to see which objects are used mostly by the children.

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[30] Please refer to Appendix P for the full document.

[31] Please refer to Appendix P for the full document.

[32] See Section 2.2.2.1. for detailed information regarding The PedsQL 4.0 Generic Core Scales as well as the reasons to select it for this case study.

[33] See Figure 4.9 for the timeline.

The problems with the observations were that neither the play area was used by children regularly nor were there a schedule for the use of it. The caregivers of the children were worried that their children may catch an infection in the play area. Thus, most of them did not let their child spend much time in the play area. Consequently, the play area was generally empty.

According to the observations, it was discovered that this area has both advantages and disadvantages. Firstly, considering the significance of play, especially for children with cancer, it is a chance for these children to be provided with an indoor play area. There are many hospitals that do not have an indoor play area in Turkey. Besides, the biggest advantage was that it has large windows that allow the daylight in and provide a view of mountains. Most of the children and their caregivers enjoy this view when they come to the play area. According to many researchers, it is good to have a connection with the nature in this context for improving well-being and healing. Moreover, the play area provides children more than one activity. There are one long table and six chairs around it that are generally used for group works. An area that promotes group works is advantageous for children, since it can foster socialization. In addition, there are two smaller tables for younger children and four smaller chairs around each table. It is an advantage that these smaller chairs are very light and most of the children can move them by themselves when they want to sit or stand up.

On the other hand, there were many disadvantages, as well. First of all, the corners of the long table were not rounded. Bearing in mind that this area is used by younger children too, it might be dangerous. They may hit their heads and have accidents. When young children freely walk around in this area, their caregivers cannot be comfortable and they follow their children to prevent any damage. Secondly, the sockets were not covered. This too might pose a threat for young children.

There is not a regular schedule for that but sometimes volunteer students visit the children in the hospital. They play games, do fun activities, paint, and draw together. There are also volunteers from KAÇUV who occasionally spend time with children and bring games or toys with them.

4.3.3. Interviews and Questionnaires

Following the observation stage, the doctors, one of them is oncologist, other one hematologist, and the head nurse were interviewed and asked to fill out a questionnaire. The aim of the interview and questionnaire was to obtain more information about the children who will participate in the study. The doctors and the nurse were asked questions regarding the QOL, daily habits and treatment of these children. There were also questions related to the evaluation of the current play area and suggestions for improving it.

Afterwards, caregivers of children were interviewed, and questionnaires were conducted under the same topics with the doctors and the nurse. In addition, for the caregivers there were questions concerning past play habits of their children, as well.

At the end of the study, children and their caregivers filled out a questionnaire about the evaluation of the participatory design process. It was expected that these data would provide information about the ideas and feelings of the participants regarding the effects of the process, which is the focus of this study.

4.3.4. Sensitizing Workbook

In order to obtain further information about the children's needs, play habits and preferences, a sensitizing workbook was given to each child. Another purpose of this workbook was to sensitize the children to the topic before the design sessions. In this way, children started thinking more about the play area. Children took this workbook to their home and completed the exercises until the next meeting for the design sessions. When the researcher met with each child after they completed the activities in the sensitizing workbook, children verbally explained all of their answers on the workbook. This provided deeper information about children's needs and preferences.

The sensitizing workbook includes five questions in total. In the first and second questions, photographs of the play area were given to the children with “plus” and “minus” stickers. They were asked to paste “plus” stickers on the items that they like and “minus” stickers on the items that they do not like in this play area. The third question was more detailed. Close up photographs of the furniture or play equipment were given to the children. They were asked to use “plus” and “minus” stickers to express what they like or dislike in this play area. With the help of these three questions it was expected to learn about their opinions and preferences in this play area. For the fourth question the page was divided into two as good memories and bad memories. For this question, children were given a sticker sheet that contains 91 images from different concepts. They were asked to paste the images on the either right (bad memories) or left (good memories) side of the workbook. In the fifth question children were given a blank page and they were asked to write or draw their wishes or dreams about the play area. It was expected that children's answers to the fourth and fifth questions would provide information about their needs in the play area.

In the literature review, it was recommended by several researchers to change some properties accordingly when the children's ages were varied[34]. Especially, adolescents may require to be treated differently than younger children. For this reason, the sensitizing workbook was prepared as two different templates, but with the same contents. One of the templates was more colorful and dynamic (more playful, informal)[35] to attract the attention of younger children. On the other hand, the other one was more simple and linear (more formal)[36] in order not to make the adolescents think that they are being treated as children. Consequently, four children (Child 1-2-3-4) were given the sensitizing workbook with the colorful template. Only one of the children, the 17 year old (Child 5), was given the workbook with the simple template, as he acted very mature and complained about being treated as a child in the hospital. In this case, an exception was made. Child 4 who was 16 years old was given the workbook with the colorful template in spite of the fact that she was an adolescent also. The reason for that was because she was very childlike in her behavior that was more like the behavior of the younger children rather than that of the child who was 18 years old.

4.3.5. Design Sessions

After children completed their workbooks, design sessions were conducted with children in the play area whenever possible. The design sessions were conducted one-on-one with each child by the researcher. Due to the diverging treatment processes of

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[34] See Section 3.4. for detailed explanation regarding considerations while conducting participatory design research with children.

[35] Please see Appendix S for the English version of this sensitizing workbook.

[36] Please see Appendix R for the English version of this sensitizing workbook.

children, it was not possible to conduct these sessions all together as group sessions. They were not available at the same period of time. Moreover, due to their health concerns, caregivers were not comfortable with the idea of group sessions.

A Make toolkit[37] was prepared by the researcher that consists of modules made of felt, wooden sticks at varying lengths, 1/8 scale model of the play area made of corrugated cardboard and wooden mannequins.

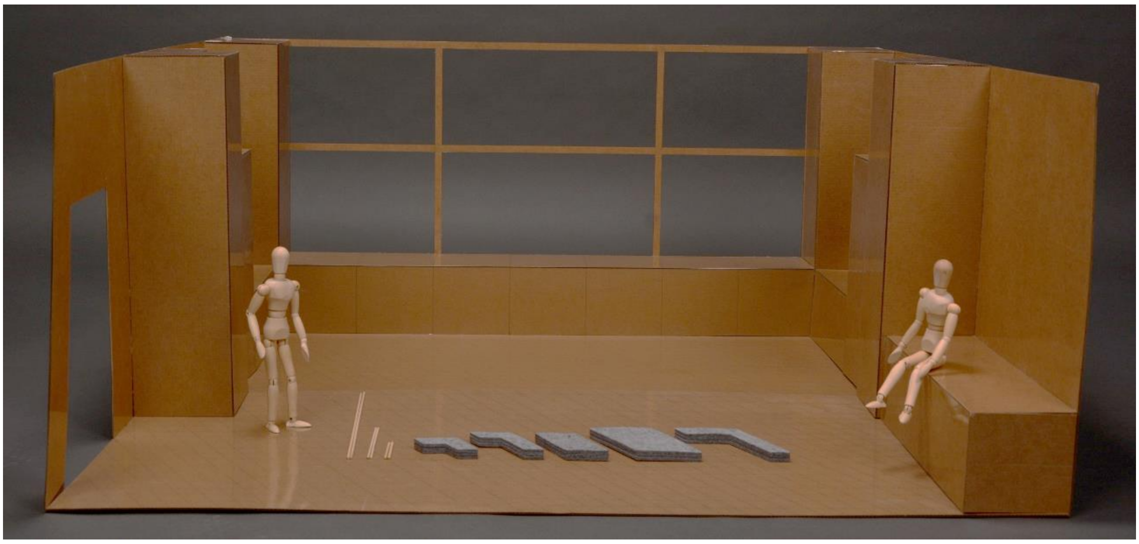

Figure 4.4. The toolkit (prepared and photographed by the researcher)

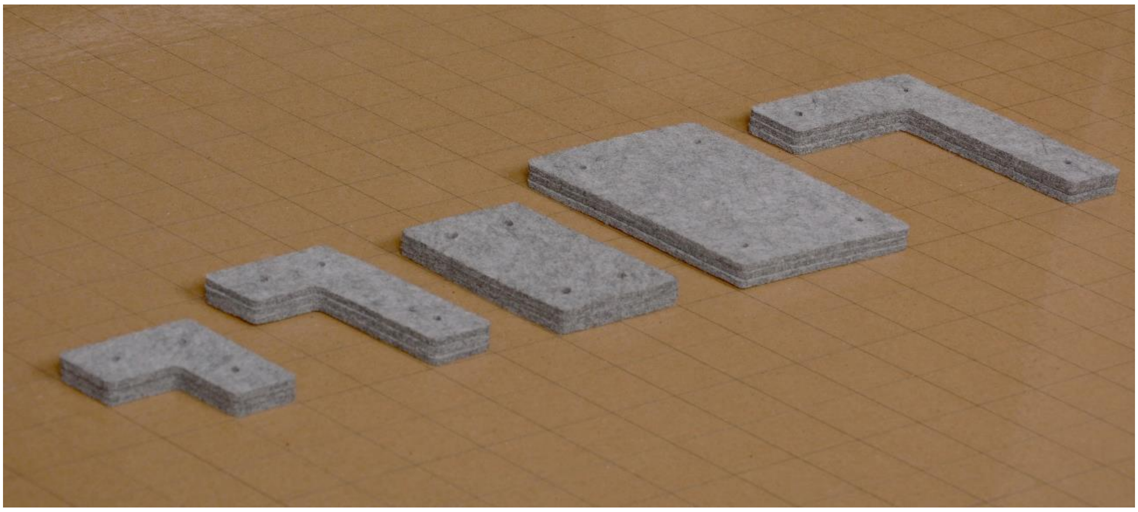

Figure 4.5. The modules made of felt (prepared and photographed by the researcher)

The material selection for the toolkit was an important issue considering that the children who would work with them are dealing with a serious disease. Hygiene is one of the most crucial aspects to take into consideration when working with children with

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[37] Please see Figure 4.4. for the toolkit prepared for using with children with cancer during the case study. For further information about Make tools please see Section 3.2.3.

cancer. Furthermore, these children were more vulnerable towards infection. Similarly, the form of the modules should not be harmful to health.

Figure 4.6. The initial ideas for modules made of plexiglass (prepared and photographed by the researcher)

Figure 4.7. Assembly of initial ideas for modules by using two-sided tapes (photographed by Ersan Çeliktaş)

At first, basic geometric forms such as circles, rectangles, squares, and triangles were prepared out of plexiglass by using laser-cutting machine. However, its edges were sharp, which could prove to be dangerous for children to handle. In addition, it was not feasible to connect these parts by using two-sided tapes. When it is pasted, it was not easy to separate the connected pieces from each other. This might have caused some difficulties because of the fact that children might not reach what they want on the first try. They may want to assemble and reassemble. Thus, the joint detail should be flexible to these changes.

For these reasons, the material and the form of the modules were revised. Since felt is a lighter and softer material compared to Plexiglas, it is preferred as the material of the modules. The modules were prepared by using laser-cutting machine. Thanks to the material, there were no sharp edges. Five different forms[38] were prepared that may help children to design their own furniture for the play area. In order to solve the joint detail problem, the modules were created with a hole cut on the each corner. By using wooden sticks, these modules can be connected to each other to create a 3D form[39]. In this way, it was easier to assemble and reassemble the 3D forms as needed. The form of the modules was determined by the researcher after trying to use basic geometric forms such as circle, rectangle, square, triangle etc. It was expected that 60 degrees of angle will provide more opportunities to the children when they are designing their furniture. Thus, a rhomboid shaped basic unit is prepared and all five forms created by multiplying this unit. In order to prevent any infection issues among children, these modules were used individually by each child. Separate sets of modules (20 pieces for each different form) were prepared for each of them.

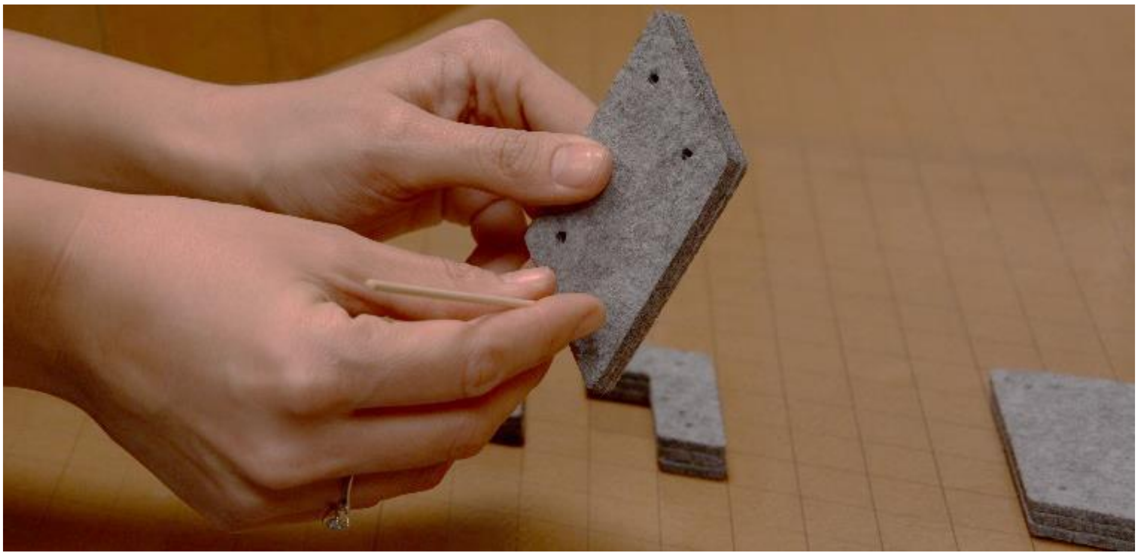

Figure 4.8. Connecting the modules with wooden sticks (photographed by Ersan Çeliktaş)

A 1/8 scale model of the play area made of corrugated cardboard was prepared, including only the fixed furniture, floor and walls. It was not reasonable to produce it

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[38] Please see Figure 4.4.

[39] Please see Figure 4.5.

five times for each child. However, the children could become infected because of their contact with the same objects. For this reason, the model was coated with a transparent sticker sheet and the surface was cleaned with a sanitizer before and after each design session.

The model of the play area was larger than expected and it was not easy to carry it. The size of the model is determined by considering the height of wooden mannequins. The scale was 1/8, since the suitable height was 20cm, and the average height of children was 1.60cm.

Children were also provided with wooden mannequins (height: 20cm) during the design sessions for two main reasons. Firstly, with the help of these wooden mannequins, human-furniture-space relationship became more concrete for the children. Secondly, these wooden mannequins were used as child proxies. Since the study was conducted in a sensitive context, it was recommended to use a proxy in order to enable children to express themselves more easily. During the design sessions, children designed furniture for these mannequins and it created a distance between them and their personal life.

In order to elicit more information and to better understand their intention, they were asked detailed questions throughout the design session. They also explained what they did verbally.

Initially, the plan was to arrange a final presentation day with all participants at the conclusion of design sessions. However, it could not be arranged due to the different treatment schedules of these children. Thus, the last stage which would have included presentation of ideas and feedback from all the participants could not be accomplished.

Finally, children and their caregivers were presented a Certificate of Participation[40] prepared by the researcher. In addition, a small, magnetic version of either chess or parcheesi was given to the children as small gifts to express the researcher’s gratitude towards them for their efforts during the process. The certificates were prepared as two templates, one was visually more playful, and the other one was more formal, just as the sensitizing workbooks. While selecting the small gifts, the interests of children were taken into consideration.

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[40] Please see Appendix H for the English version of Certificates of Participation.

4.4. Findings and Discussion

Each stage of the study was conducted one-on-one with children because of their diverging treatment processes. The time schedule of the study is given in the next sections for each child separately.

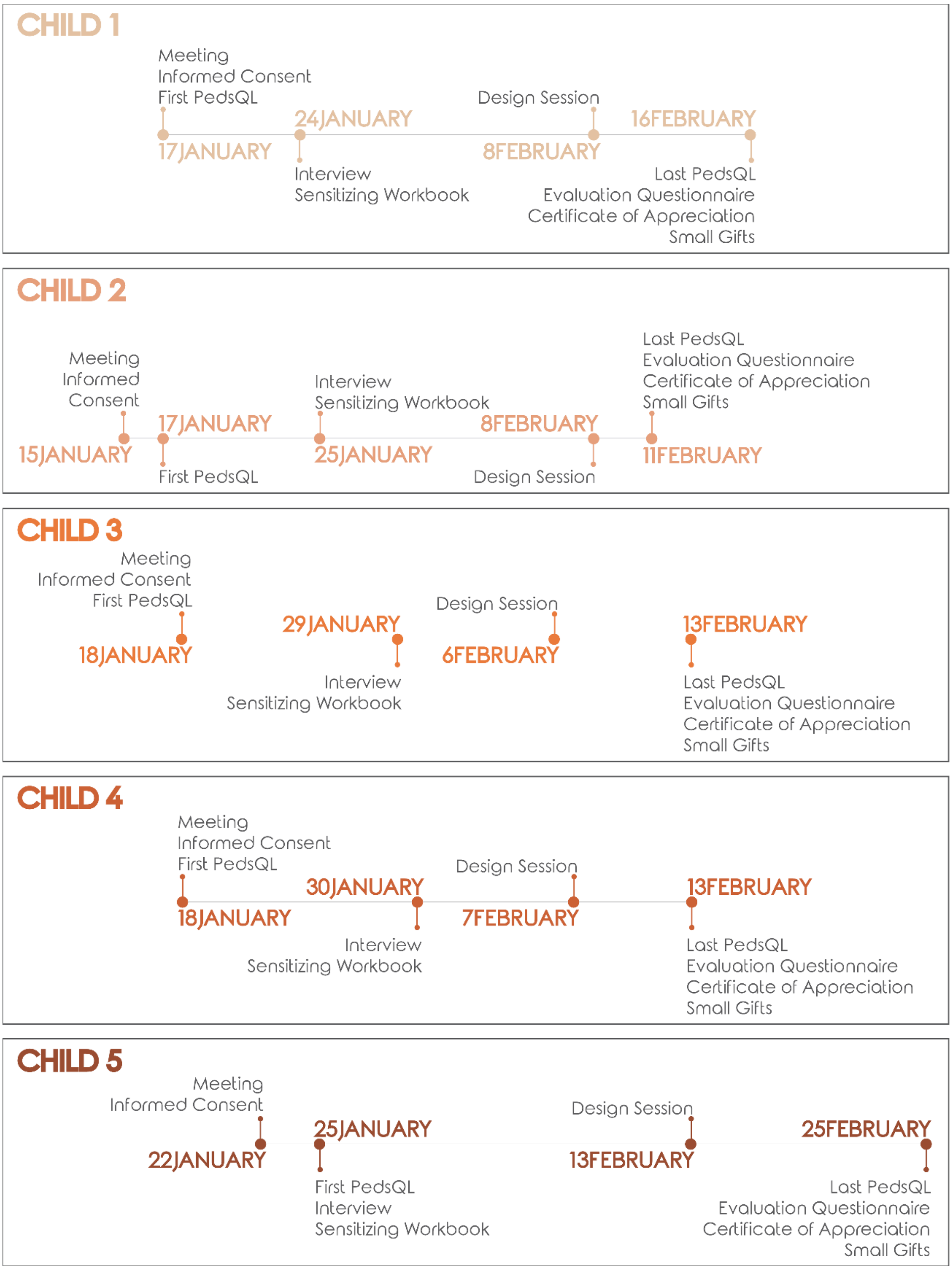

Figure 4.9. Time schedule of the study with all children

4.4.1. Individual Cases

The data gathered from the case study is analyzed by examining children one by one. First, the purpose of the study is to investigate the effect of the participatory design sessions on the QOL of children with cancer. For this reason, it was essential to interpret the differences between the first and last The PedsQL 4.0 Generic Core Scales results of each child. Secondly, it is seen that each stage is related with the next one. For relating them, the data is analyzed by providing in depth information for each case respectively.

4.4.1.1. The Case of Child 1 (Age 8)

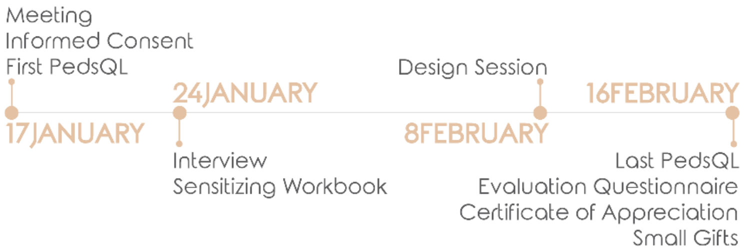

Figure 4.10. Time schedule of the study with Child 1

Meeting 1 (17 January)

Child 1 and the researcher came together four times throughout the study. In the first meeting, the researcher was introduced by the doctor to Child 1 and his mother in his patient room. He was in a triple-patient room. After they accepted to participate and signed the informed consent form, they answered the questions of PedsQL in the same day.

Meeting 2 (24 January)

At the second meeting, they were at the outpatient service of the hospital. Child 1 was there for blood tests. While they were waiting for the results of the blood tests, they met with the researcher at the cafeteria of the hospital. The sensitizing workbook was given to Child 1 by the researcher. He started to complete the activities in the workbook there. It did not work well, since, he was afraid of the dog in the cafeteria. Simultaneously, the interview was conducted with the mother. However, she felt nervous and slightly answered only some of the questions. She was worried that her son would hear about these and feel upset because Child 1 was not aware of the severity of his illness.

Meeting 3 (8 February)

In the third meeting, the design session took place in the play area of the Oncology and Hematology Service. Child 1 was more relaxed and happy there in comparison with the previous meeting for he had more control over the environment. The environment was more familiar to him. He explained all of his answers on the sensitizing workbook. For instance, he stated that he put a minus on chairs in the play area, because they are too rough for him.

Figure 4.11. Answers of Child 1 for the first question of the sensitizing workbook (photographed by the researcher)

The last question, which is about their future wishes and needs for the play area was left blank by the Child 1. He said that nothing came to his mind related to this question.

During the design session, he generated two design ideas. One of them was focused on drawing since he loves it. He wanted to design furniture that provides him a rotatable tabletop connected to the seating unit.

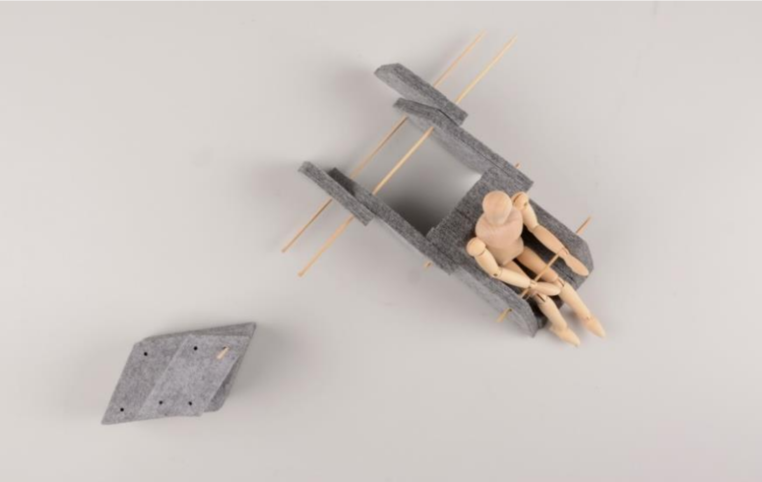

Figure 4.12. Top view of the design session outcomes with Child 1 (photographed by Ersan Çeliktaş)

Figure 4.13. Perspective view of the design session outcomes with Child 1 (photographed by Ersan Çeliktaş)

After the conversation between the researcher, Child 1 and his mother, he started to draw the trees and mountains on the sensitizing workbook[41].

> Researcher: Where would you like to put this furniture that you designed for drawing?
> Child 1: I would put it in the corner near the window.
> R: Why is that?
> C1: Cause I love to see what is going on outside and I like to draw what I see there.

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[41] Please see Figure 4.14.

R: Really? Do you draw these trees? It is a very good idea!
Mother of Child 1: Yes, he draws them very well. Honey, you did not fill in the last question. Do you want to draw these trees there?
R: That would be great! Can you show me how do you draw?
C1: Okay, I can.

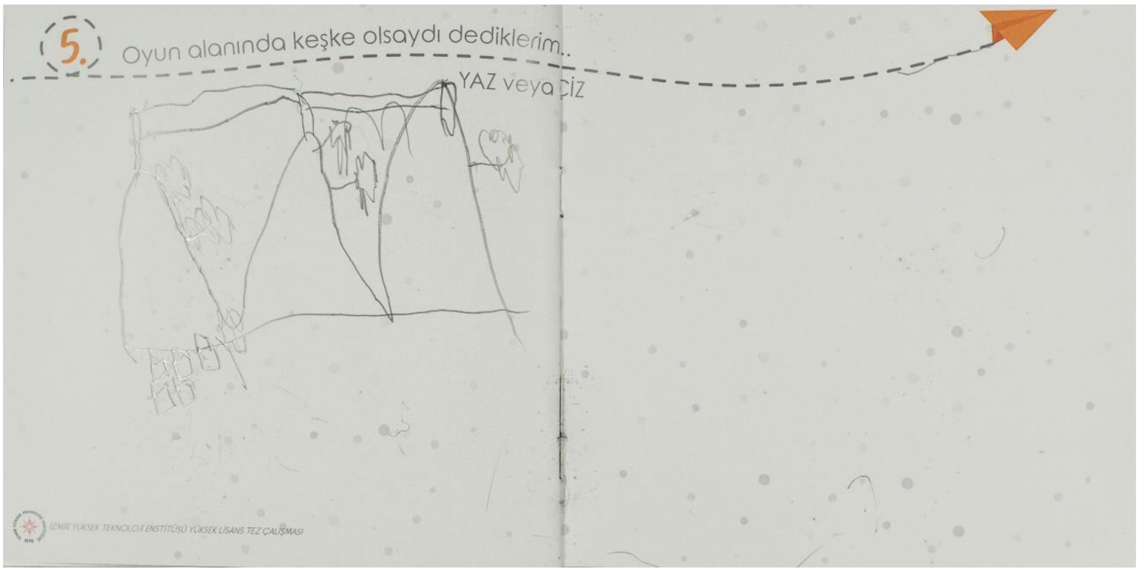

Figure 4.14. Answers of Child 1 for the last question of the sensitizing workbook (photographed by the researcher)

Throughout the design session, the mother of Child 1 was there. She also commented on his ideas and helped to elicit more information from him. To have her in this session was beneficial for the efficiency of the design session, because he was feeling more comfortable with her.

He liked the wooden mannequin very much. He played with that by trying to put it in a self-standing position. Its rotatable joints were also interesting for him. The mannequin facilitated the session by attracting the attention of the Child 1.

He also designed another furniture. In this case, rather than providing a function like the previous one, his other idea was based on his imagination. He called what he designed as a car. This demonstrates that these modules do not have to be used only to provide a function like drawing, sitting etc. but they can be also used in order to create an imaginary world by children.

Meeting 4 (16 February)

For the last meeting, they could not meet with the researcher in the hospital. He could not stay in the hospital for the next chemotherapy cycle, since his blood test results were not good enough. Thus, the researcher visited them at their home. Especially, the mother of Child 1 was very contented to have a guest at their home. It was not a problem for her, because she was in direct contact with the researcher until that time. In this meeting, they answered the questions of PedsQL for the second time. They filled out the evaluation questionnaire[42], too.

Lastly, the Certificate of Appreciation was presented to them. As a small gift, a small version of magnetic chess was presented to the Child 1, as well.

Results

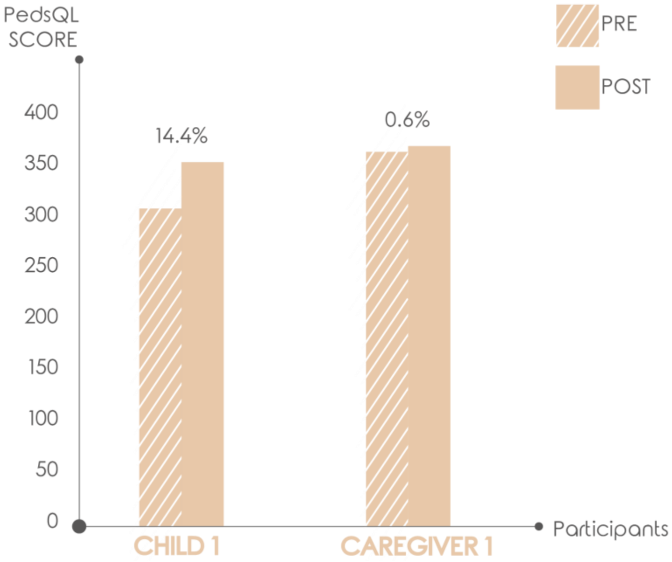

Figure 4.15. PedsQL scores and change ratio (%) of Child 1 and Caregiver 1

According to answers of Child 1 on the questionnaires, it is found that there is a positive effect of the participatory design process on his QOL. Whilst the PedsQL score was 291 before the study, after the study it went up to 333, with a considerable increase of 14.4%. His answers on the evaluation questionnaire also stand behind this increase. He mentioned that he totally felt better during the study when compared with the past (Question 1).

In the evaluation questionnaire, it was also requested from the children to prioritize the stages of the study (Question 3). His answer shows that the design session

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[42] See Appendix F and G for the full questionnaire.

was the most enjoyable part for him. As also cited earlier[43], it was expected that the design session will be more fun for children, since it provides more useful tools for children to express themselves in comparison with questionnaires. However, his answers show that he did not enjoy the sensitizing workbook activity. It was expected to be more fun for children, since it includes visuals more than words.

Furthermore, it is found that Child 1 enjoyed this study, because being able to design a product for himself and his friends contributed to improvement of his self-confidence (Question 4).

On the other hand, PedsQL scores of his mother slightly changed from 344 to 346 by an increase of 0.6%. Moreover, her answers on the evaluation questionnaire indicate that there is a positive effect of this study in terms of well-being of her child (Question 1). She also stated that during the study her child was feeling more valuable as a human being because his ideas were asked (Question 6).

4.1.1.2. The Case of Child 2 (Age 10)

Figure 4.16. Time schedule of the study with Child 2

Meeting 1 (15 January)

Child 2 and the researcher met five times during the study. In the first meeting, the doctor introduced the researcher to him and his mother. They met in the patient room of Child 2. He was staying in a single-patient room. Both the child and his mother accepted to participate and signed the informed consent form.

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[43] See Section 3.4.2. for further information regarding the discussion on suitability of Make tools for children.

Meeting 2 (17 January)

In the second meeting, the researcher visited them in his patient room again. His mother and he were asked to fill out PedsQL. The researcher read and explained the questions to them. There were no problems in this stage.

Meeting 3 (25 January)

In the third meeting, they met in the waiting room of the hospital. Child 2 was given the sensitizing workbook by the researcher. The questions and activities in the workbook were explained. Normally, the researcher gave all children the same pencil for filling in some parts of the workbook. However, he said that he did not want this because the colors of the pencil reminded him of the colors of the opposing football team. Thus, the pencil was replaced with an orange pencil, since orange is his favorite color.

By bearing in mind the previous interview session with the mother of Child 1, his mother was not interviewed when the Child 2 was with them. It was found that it is better to conduct the interview one-on-one with the caregivers of the children, since their caregivers may feel stressed and afraid of saying something that may upset their children. After answering his questions about the workbook, his mother took him home. She came back for taking the results of blood test. She was interviewed while waiting for the results in the waiting room.

Meeting 4 (8 February)

In the fourth meeting, the design session was conducted in the play area of the Oncology and Hematology Service. The session started with discussing his answers in the sensitizing workbook. He explained what each image in the workbook reminds him of.

In order to create an equal and trustworthy atmosphere, the researcher also shared some personal information with him. During the session, his mother was also there and she shared information about him, as well. This was beneficial for reaching more data for the study. She contributed to eliciting information regarding needs and preferences of him.

> Researcher: What do you think about playing in a tent? For example, when I was little, my sister and I were setting up a tent for us in our home. It is still a very cozy memory for me.
> Mother of Child 2: He also does that and spends time there with his sisters. Darling, do you remember that we were putting pillows on top of each other?
> Child 2: Yes, I love to play there with my sister!

In this case, the mother of Child 2 built a bridge between the researcher and the child. She understood what the researcher meant and explained it to the child by using words familiar to him.

Child 2 was very enthusiastic about participating in this study. Even if the vascular access was established on his hand, he did not hesitate to start generating ideas by using the toolkit with his hands[44]. During the session, it was aimed to find only one idea. However, he enjoyed the activity very much and he did not want to stop generating ideas. As a result, four design ideas were generated.

Figure 4.17. Child 2 is designing furniture in the design session (photographed by the researcher)

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[44] Please see Figure 4.17.

In the first idea on the left[45], he focused on having a swing in the play area. He mentioned that he likes swings while discussing his answers on the sensitizing workbook. However, as emphasized by doctors and the nurse, it is not good for him to use the swings in the outdoor play areas because he may acquire an infection. In this situation, it would be good for him to have this opportunity in an indoor play area.

After explaining his responses to the sensitizing workbook and the contributions of his mother, he also decided to design furniture to hide underneath. In the idea on the right, he created a hole for hiding, just like a tent.

His other ideas were to design a TV couch. He offered two size options. The differences between sizes reflect the differences between older and younger children in terms of size. He was aware of the fact that this play area was for a wide age range of children.

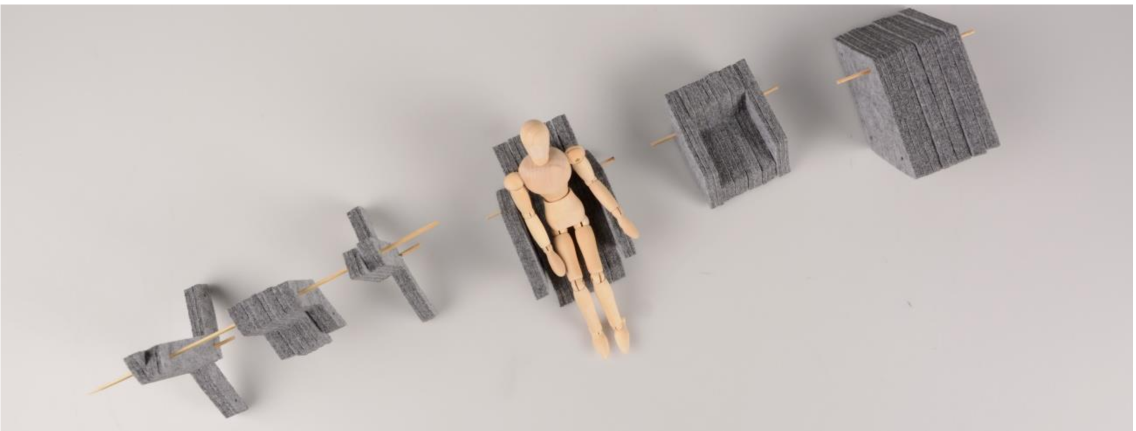

Figure 4.18. Top view of the design session outcomes of Child 2 (photographed by Ersan Çeliktaş)

Figure 4.19. Perspective view of the design session outcomes of Child 2 (photographed by Ersan Çeliktaş)

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[45] Please see Figure 4.19.

Meeting 5 (11 February)

In the last meeting, the researcher met with Child 2 and his mother in the patient room of Child 2. They filled out the PedsQL for the second time. They filled out the evaluation questionnaire, as well. The Certificate of Participation was presented to them. As a small gift, a small version of magnetic parcheesi was presented to Child 2. This gift was different from the gifts of other participant children. There is a reason behind this decision. During one of the meetings with Child 2, the researcher observed that someone donated some toys, games, clothes etc. to the children of the Hematology and Oncology Service. While caregivers of children were sharing these donations, his mother took parcheesi for him. However, she lost the checkers and Child 2 felt very upset. By remembering this incident, the researcher decided to give him parcheesi. After presenting him this small gift, Child 2, his mother and the researcher played that game together.

Results

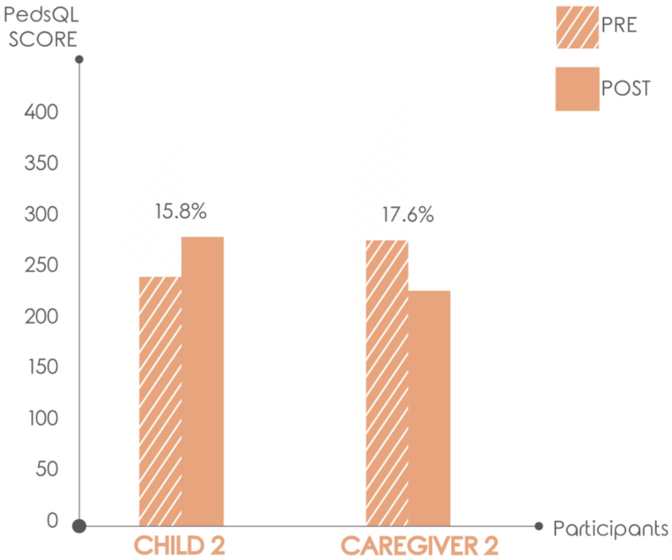

Figure 4.20. PedsQL scores and change ratio (%) of Child 2 and Caregiver 2

The answers of Child 2 on the questionnaires revealed a positive effect of the participatory design process on his QOL. While the PedsQL score was 228 before the study, after the study it reached to 264, revealing a notable increase by approximately 15.8%. This is also supported by his answers on the evaluation questionnaire, which show he completely believes that he was feeling better during the study than prior to it (Question 1).

In the evaluation questionnaire, it was requested from the children to prioritize the stages of the study (Question 3). Child 2 stated that he enjoyed the design process the most, followed by the sensitizing workbook activity. The least enjoyable activity was filling out the questionnaire from his point of view. It was also mentioned before[46], participating in a generative session might be preferable to filling out a questionnaire or being interviewed for the participants. As explained earlier[47], using words to explain themselves does not always work for children. Instead, they can more freely express their ideas by using generative tools. His answer to this question supports this.

Furthermore, it is also revealed that Child 2 enjoyed this study because his ideas were asked regarding a topic that concerns him (Question 4). As explained earlier[48], children are generally not given the opportunity to contribute to the decision making process even in a topic that relates to them. However, his answer shows that this is an important aspect that makes Child 2 feel better during the study.

On the other hand, according to the answers of his mother, there is a noticeable decrease by approximately 17.6% in the PedsQL results. The score was 264 before the study and it fell off to 215 after the study. This might be explained by the fact that while his mother was filling out the first PedsQL, Child 2 was with her in the patient room. He was wondering about and carefully listening to the answers of his mother. This might have made her give positive answers to the questions in order not to sadden Child 2 with her negative answers. At the beginning, the score of his mother (261) was even higher than Child 2 (228). However, in the last PedsQL, Child 2 was sleeping while his mother filled out the PedsQL. In contrast to the decrease in the PedsQL results, her answers on the evaluation questionnaire show that she completely believes that Child 2 felt better during the study (Question 1). She also stated that the study provided her child an escape from boredom in the hospital (Question 6).

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[46] Please see Section 3.2. for further discussion regarding traditional and generative techniques.

[47] See also Section 3.4.2. for more information about considerations regarding communication between children and adults.

[48] See Section 3.3. for detailed explanation of children's right to participate.

4.1.1.3. The Case of Child 3 (Age 12)

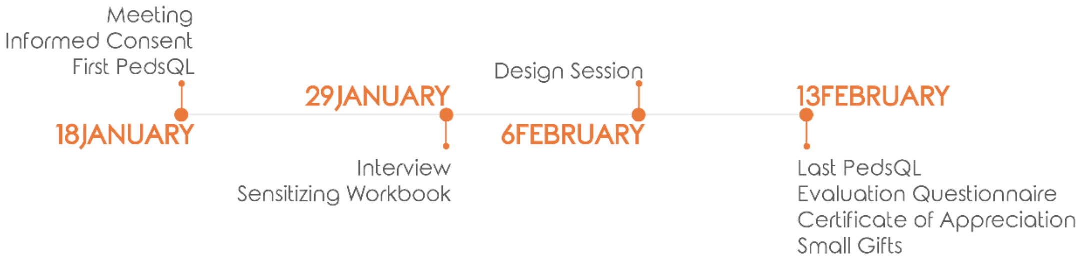

Figure 4.21. Time schedule of the study with Child 3

Meeting 1 (18 January)

Child 3 and the researcher met four times during the study. In the first one, the researcher was introduced by the doctor to Child 3 and his mother in the patient room of him. He was staying in a single-patient room. His mother wanted to ask the opinion of his father, too. After a while, they accepted to participate and signed the informed consent form. They answered the questions of PedsQL in the same day.

Meeting 2 (29 January)

In the second meeting, he was given the sensitizing workbook in his patient room. After explaining the details to him, the researcher interviewed his mother in the play area of the hospital. Intentionally, the interview was conducted one-on-one with his mother when Child 3 was at his patient room.

Meeting 3 (6 February)

In the third meeting, Child 3 had a swelling on his arm, which is caused by an infection. Therefore, he could not go to the play area. Thus, the researcher came to his patient room and the design session was conducted on an available bed there.

First, the researcher and Child 3 discussed his answers on the sensitizing workbook. He left the first three questions blanks. He explained that he could not figure out how to use the minus and plus stickers. After that, he completed the first three activity with the help of the researcher. He also explained why he likes or dislikes them.

Figure 4.22. The researcher and Child 3 completed the first three questions together in the beginning of design session (photographed by the researcher)

> Child 3: I did not understand how to do this one.
> Researcher: Okay, let's do it together! Let's think about the play area, what do we have there? What do you see in this photo that makes you feel better?
> C3: For example, what is this one? I could not see it, it is too small. (He points at the oven toy.)
> R: This is the oven toy. Do you love it? (She shows him the zoomed photo of it in the third question of the sensitizing workbook.)
> C3: Yes, I love it.
> R: Okay, let's put a plus on it!
> C3: How can we take it from there?
> R: It's easy; you'll just pull it from the corner.

Figure 4.23. The researcher and Child 3 are playing chess during the break in the design session (photographed by the researcher)

Throughout the design session, Child 3 focused on playing chess in the play area. Together with the researcher, they designed the furniture for this activity. By request of Child 3, they gave a break to the session. On this break, the researcher played chess with him in order to experience this and understand the needs of this activity in a better way[49]. As explained earlier, it was advised to play games with children as icebreaking activities. In this case, there was an additional benefit of playing with children during the design session. While playing chess, Child 3 realized that he had a backache, since he was not leaning back on the couch. After having this experience, a backrest was added to the furniture.

Figure 4.24. Top view of the design session outcomes of Child 3 (photographed by Ersan Çeliktaş)

Figure 4.25. Perspective view of the design session outcomes of Child 3 (photographed by Ersan Çeliktaş)

During the design session, he was very happy and he thought that time past very quickly during this process. On the other hand, he was wondering about the other children who participated in this study. It was clear that he would love to meet them. Participating in a group session would be fun for him. He is a social and easygoing child. Because of his infection, he was not spending much time with other children in general. In fact, a group design session would be a socializing activity for him.

> Child 3: Did other children wanted to participate in this design study?
> Researcher: Yes, they did. There are four children apart from you. Let's see. We are all working on designing furniture for the play area.
> C3: Are they boys or girls?

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[49] Please see Figure 4.23.

R: There are both boys and girls.

Furthermore, Child 3 was thinking that he is explaining himself better by "making". He believed that instead of trying to find an idea by thinking, by making he was able to generate ideas in a better way.

> "Actually, you should not think about it. Just focus on making. While you are making, the idea comes up." (Child 3, 12 years old)

In this session, his father and mother were also in the same room. They did not contribute to the design but they asked some questions related to the health conditions and comfort of their child. For instance, his father was worried about the swelling on his arm.

> Father of Child 3: Can he move his arm easily?
> Researcher: Yes, he can.
> Father of Child 3: Today, he had pain on his arm.
> R: Does it hurt? If you want we can stop the session now. Please, don't push yourself.
> C3: No, it doesn't hurt at all.

Meeting 4 (13 February)

In the fourth meeting, they met in his single-patient room. They answered the questions of PedsQL for the second time. They filled out the evaluation questionnaire, as well. The Certificate of Appreciation was presented to them by the researcher. As a small gift, a small version of magnetic chess was presented to Child 3. After that, Child 3 played this game with the researcher. He said that it is good to have a small one. In this way, they can carry it everywhere with them.

Figure 4.26. The researcher and Child 3 are playing magnetic chess at the end of the study.

Results

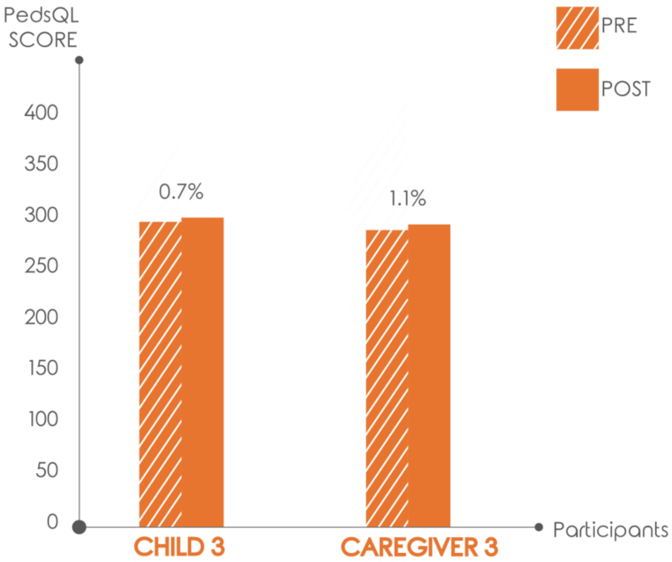

Figure 4.27. PedsQL scores and change ratio (%) of Child 3 and Caregiver 3

The first PedsQL score of Child 3 was 280 and it slightly increased to 282 by an increase of 0.7%. This shows that there is a positive effect of the participatory design study on his QOL. The process also proved to be beneficial for his QOL according to his answers on the evaluation questionnaire. He stated that he was feeling better when compared with the past (Question 1).

In the evaluation questionnaire it was requested from the children to prioritize the stages of the study (Question 3). His top priority regarding this study was the design sessions. He also stated that the sessions made him very happy. Additionally, according to him, to be able to design a product for himself and his friends was the most enjoyable feature of the study (Question 4).

According to the answers of his mother on PedsQL, the first score was 273 and it barely increased (approximately 1.1%) to 276. Moreover, her answers on the evaluation questionnaire support the idea that this study has a positive impact on her child’s QOL (Question 1). She also mentioned that this participatory design study cheered her child up (Question 6).

4.1.1.4. The Case of Child 4 (Age 16)

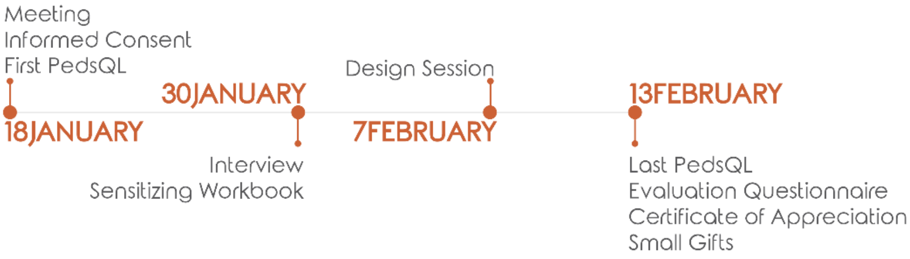

Figure 4.28. Time schedule of the study with Child 4

Meeting 1 (18 January)

The researcher met with the Child 4 five times during the study. She was in a double-patient room. The doctor introduced the researcher to the Child 4 and her cousin. Her cousin was her companion at that time. The researcher explained the study verbally and gave the informed consent form that provides written explanation to them. After that, when her father came to the hospital, the researcher explained the study to him, as well. Then, they signed the informed consent form and answered the questions of PedsQL in the same day.

Meeting 3 (30 January)

In their third meeting, they met in the cafeteria of the hospital while they were waiting for the blood test results. She was given the sensitizing workbook there. All activities in the workbook were also explained to her by the researcher. Since the cafeteria was not very crowded and she was aware of her illness, the father of Child 4 was interviewed there. Hence, answering the questions was not hard for him. Occasionally, she commented on some questions, as well.

Meeting 4 (7 February)

In their fourth meeting, they met in the play area for the design session. She was supposed to bring the sensitizing workbook with her. However, she said that she forgot it at home. Since she is living far away from the hospital, it was not easy to go back and take it. Thus, the design session was conducted without the workbook. As can be seen in the other children's cases, discussing the answers of children on the workbook before starting the design session was useful for the efficiency of the session. For this reason, she was asked about her answers on the workbook as much as she could remember.

She focused on listening to music in the play area while enjoying the view. She also mentioned that she wanted to be alone sometimes, but it was not possible in the hospital. Bearing these in mind, she designed a seating unit that can be enclosed so she could stay alone while listening to music there. During the design session, they listened to her favorite songs.

> "I like listening to music very much especially when I am making something. For example, when I make scarfs, I always listen to music." (Child 4, 16 years old)

Figure 4.29. Top view of the design session outcomes of Child 4 (photographed by Ersan Çeliktaş)

Figure 4.30. Perspective view of the design session outcomes of Child 4 (photographed by Ersan Çeliktaş)

During the design session, his father was not always in the play area. However, he came there sometimes in order to control if his daughter is fine. He asked whether she was hungry or not.

Furthermore, she talked on the phone with her mother during the design session. She mentioned that she is playing in the play area. This demonstrates that she perceives this design session as a playful activity.

Figure 4.31. Answers of Child 4 for the fourth question of the sensitizing workbook (photographed by the researcher)

She brought the sensitizing workbook to the last meeting but the activities were not done accurately. First pages were left blank or completed with a pen. However, children were supposed to use the minus and plus stickers to show what they like and dislike. The stickers were pasted on other stickers that belong to the next activity and they were pasted on the pages of the sensitizing workbook randomly[50].

Meeting 5 (13 February)

In the last meeting, they met in the waiting room of the hospital. They answered the questions of PedsQL for the second time. They filled out the evaluation questionnaire, as well. The Certificate of Appreciation was presented to them by the

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[50] See Figure 4.31.

researcher. As a small gift, a small version of magnetic chess was presented to Child 4. She wanted to play with the researcher but could not because she was feeling nauseous.

Results

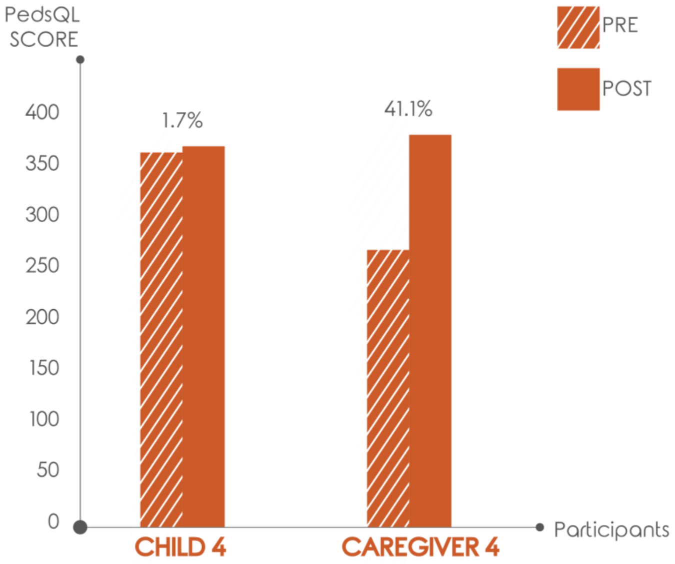

Figure 4.32. PedsQL scores and change ratio (%) of Child 4 and Caregiver 4

The answers of Child 4 on the questionnaires indicate that there is a positive effect of the participatory design process on her QOL. While the PedsQL score was 343 before the study, after the study it went up to 349, revealing a marginal increase by approximately 2%. This is also supported by her answers on the evaluation questionnaire that show she totally believes in that he was feeling better during the study when compared to the past (Question 1).

In the evaluation questionnaire, it was requested from the children to prioritize the stages of the study (Question 3). From the point of view of Child 4, the most enjoyable stage of the study was filling out the PedsQL. Design session follows that as the second most enjoyable activity. Considering the information given in the literature review, it was not expected[51]. According to her, the least enjoyable one is the sensitizing workbook. This was expected since she understood neither the instructions nor the aim of the activity. In this case, not to enjoy during this activity is normal. However, as a

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[51] Please see Section 3.2. for further discussion regarding traditional and generative techniques.

written comment on the evaluation questionnaire, she mentioned that she liked each part of the study very much and they did well for her (Question 6).

In addition, it is also evident that Child 4 enjoyed during this study because it provided her distraction from her negative thoughts by keeping her mind busy with this study (Question 4).

According to the answers of her father, there is a dramatical increase by approximately 41.1% in the PedsQL results. The score was 253 before the study and it rose to 357 after the study. He believes that Child 4 was feeling better during the study when compared to past (Question 1). He also stated that it was good to keep his child's mind busy in order to stay away from negative thoughts and this is the best feature of this study (Question 4).

4.1.1.5. The Case of Child 5 (Age 17)

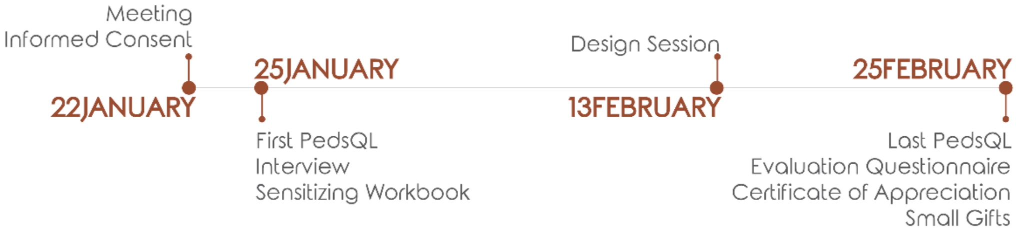

Figure 4.33. Time schedule of the study with Child 5

Meeting 1 (22 January)

Child 5 and the researcher met four times throughout the study. In the first one, the researcher was introduced by the doctor to Child 5 and his grandmother in the patient room. He was staying in a triple-patient room. His grandmother did not want to participate in this study, since she was illiterate. However, his brother accepted to participate. They signed the informed consent form.

Meeting 2 (25 January)

In the second meeting, they answered the questions of PedsQL. The brother of Child 5 was interviewed in the patient room. Child 5 was a witness to this interview but it did not affect him in a bad way, since he was aware of his illness and handling this situation with a mature attitude, he did not feel upset during the interview. Like Child 4, he commented on some questions. In this meeting, he was also given the sensitizing workbook. His workbook was different from other children’s workbooks not in terms of the content but the visuals. The visual template of his workbook was more formal. Since he was older than other children and very close to adulthood it was better to differentiate him from other children. His conversation with the researcher also supports this idea.

> I feel like this play area is not suitable for me. If you ask me, there should be products that address everyone. However, it is not like that here. So, I always stay in my bed. I have never been in the play area. (Child 5, 17 years old)

Meeting 3 (13 February)

For the third meeting, they could not meet in the hospital in two weeks, since his blood test results were not suitable for having the next chemotherapy cycle. For this reason, the researcher offered to visit him in his home. However, he was living with his aunt and the researcher never met her. His aunt did not allow this offer and it made Child 5 feel upset.

Figure 4.34. Answers of Child 5 for the third question of the sensitizing workbook (photographed by the researcher)

Two weeks after the second meeting, they had a chance to meet in the play area of the Hematology and Oncology Service for the design session. They started with discussing his answers on the workbook. His dissatisfaction of the play area was clearly seen in the third question. He explained that there are only two factors that he likes in the play area. One of them is TV and the other one is lounge chair. According to his explanation they like them for the opportunity of playing Playstation. However, he also mentioned that the Playstation CDs for younger children. He found them very childish. As also written in his sensitizing workbook, his concentration was on the Playstation tournaments that can be organized in the play area. His design suggestion was related to this topic. He designed two armchairs for the tournaments. He also designed a pouf for the other children who will wait by sitting there for their turn.

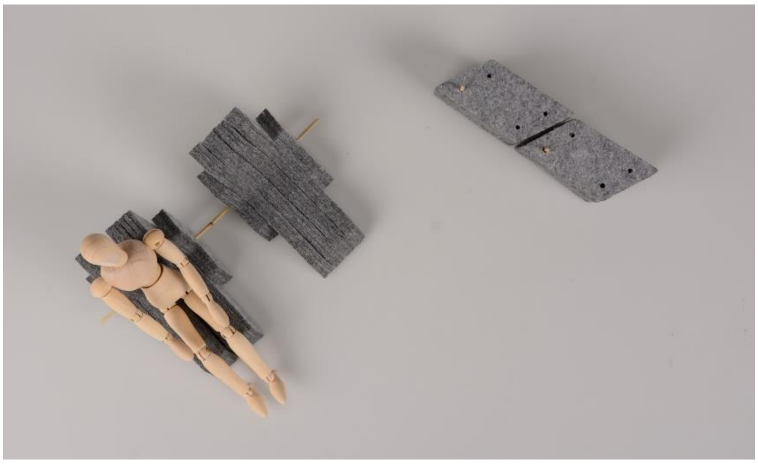

Figure 4.35. Top view of the design session outcomes with Child 5 (photographed by Ersan Çeliktaş)

Figure 4.36. Perspective view of the design session outcomes with Child 5 (photographed by Ersan Çeliktaş)

Meeting 4 (25 February)

In the last meeting, they met in the patient room of the Child 5. He and his brother answered the questions of PedsQL. They filled out the evaluation questionnaire, as well. The Certificate of Appreciation was presented to them by the researcher. As a small gift, a small version of magnetic chess was presented to Child 5.

Results

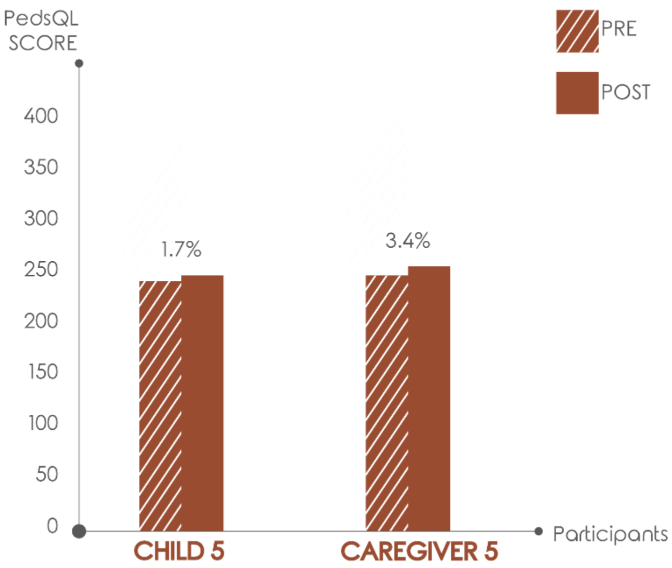

Figure 4.37. PedsQL scores and change ratio (%) of Child 5 and Caregiver 5

The answers of Child 5 on the questionnaires indicate that there is a positive effect of the participatory design process on his QOL. While the PedsQL score was 229 before the study, after the study it slightly increased (approximately %2) to 233. His answers on the evaluation questionnaire also reinforce that he was totally feeling better during the study when compared to the past (Question 1).

In the evaluation questionnaire it was requested from the children to prioritize the stages of the study. From the point of view of Child 5, the most interesting stage of the study was the design session (Question 3). Filling out PedsQL comes before the sensitizing workbook activity.

Besides, appears that according to his point of view the best feature of this participatory design study was being asked about a topic that relates to him (Question

4). As explained in the literature review[52], children feel better when their ideas are asked about a topic that concerns them. Moreover, he added that now he is hopeful about the play area and he feels that it will be a good place to spend time (Question 6).

Likewise, his brother expressed that there is a positive impact of this participatory design study on Child 5's QOL. The PedsQL score was 233 before the study and after the study, it reached to 241, with a slight increase of approximately 4%.

4.4.2. Overall Results

In this section, overall results in the PedsQL scores of children and their caregivers[53] and evaluation questionnaire are explained. Moreover, furniture design ideas that are offered by children during the design sessions are divided into relevant themes.

According to PedsQL child-report scores of all children[54], the QOL of 5 out of 5 children increased. In spite of the fact that some of them only slightly increased, none of the children's QOL showed a decrease. Child 2 showed the greatest (approximately 15.8%), Child 3 showed the smallest increase ratio (0.7%) among all children.

Moreover, according to average child-report PedsQL scores of all children[55], it can be stated that QOL of children increased in three of the four sections in the PedsQL. The graph demonstrates that there is an increase in physical (4.5%), psychological (15.6%) and social (8.4%) QOL of children. Only the educational QOL of children slightly decreased by 3.5%. It is known that their school activities are interrupted due to the side effects of the illness and its treatment. As time passes by they may become more dissatisfied with this interruption. Thus, this might not be related to the participatory design study conducted with children. Furthermore, the graph shows that psychological QOL has the largest increase ratio (15.6%). The participatory design study might have affected their mood and emotions such as anger, worry and fear in a positive way. Considering that it provides distraction from negative thoughts related to cancer and its treatment process, it might have contributed to improving psychological QOL of children.

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[52] Please see Section 3.3. for the explanation regarding the benefits of participatory design with children

[53] Please see Table 3.7. for detailed information about PedsQL scores of children and their caregivers.

[54] Please see Figure 4.38.

[55] Please see Figure 4.39.

Table 3.7. PedsQL scores of all children and their caregivers

		PHYSICAL									PSYCHOLOGICAL						SOCIAL						SCHOOL							CHANGE
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	AVE	Q1	Q2	Q3	Q4	Q5	AVE	Q1	Q2	Q3	Q4	Q5	AVE	Q1	Q2	Q3	Q4	Q5	AVE	TOTAL	RATIO %
CHILD 1	PRE	100	100	0	50	0	75	100	100	**66**	50	100	100	0	100	**70**	100	100	100	100	100	**100**	100	50	25	50	50	**55**	**291**	
	POST	100	100	100	25	100	100	100	0	**78**	100	50	100	100	100	**90**	100	100	100	100	100	**100**	100	100	50	75	0	**65**	**333**	**14.4**
CAREGIVER 1	PRE	100	75	100	100	0	100	100	100	**84**	100	75	50	100	100	**85**	100	100	100	100	100	**100**	100	100	50	100	25	**75**	**344**	
	POST	100	100	100	75	25	100	100	50	**81**	75	100	50	100	100	**85**	100	100	100	100	100	**100**	100	100	75	100	25	**80**	**346**	**0.6**
CHILD 2	PRE	50	75	100	50	0	50	75	100	**63**	0	50	75	0	100	**45**	50	100	25	100	100	**75**	50	50	25	100	0	**45**	**228**	
	POST	50	100	50	50	0	50	75	100	**59**	50	100	25	0	100	**55**	100	75	75	100	100	**90**	100	50	50	100	0	**60**	**264**	**15.8**
CAREGIVER 2	PRE	50	50	25	25	25	0	50	100	**41**	50	100	25	50	75	**60**	100	100	50	100	100	**90**	100	100	50	100	0	**70**	**261**	
	POST	50	25	50	50	0	75	50	100	**50**	25	75	25	0	25	**30**	100	100	50	50	100	**80**	100	50	25	100	0	**55**	**215**	**-17.6**
CHILD 3	PRE	100	75	100	50	50	25	100	100	**75**	100	50	25	100	100	**75**	50	50	50	100	50	**60**	100	50	100	50	50	**70**	**280**	
	POST	50	100	50	50	100	100	75	50	**72**	100	50	50	100	100	**80**	100	50	100	100	100	**90**	50	50	100	0	0	**40**	**282**	**0.7**
CAREGIVER 3	PRE	50	50	75	50	25	100	50	100	**63**	0	0	100	100	50	**50**	100	100	100	50	100	**90**	100	50	100	50	50	**70**	**273**	
	POST	100	50	100	0	0	100	75	100	**66**	50	50	50	100	50	**60**	100	100	100	50	100	**90**	50	50	100	50	50	**60**	**276**	**1.1**
CHILD 4	PRE	50	100	100	100	100	100	50	100	**88**	100	100	100	100	100	**100**	100	100	100	100	100	**100**	100	50	100	25	0	**55**	**343**	
	POST	100	100	100	100	100	100	50	100	**94**	100	100	100	50	100	**90**	100	100	100	100	100	**100**	100	100	0	25	100	**65**	**349**	**1.7**
CAREGIVER 4	PRE	100	75	50	75	0	0	100	100	**63**	50	100	25	75	100	**70**	50	100	100	100	25	**75**	25	100	0	100	0	**45**	**253**	
	POST	75	100	100	100	100	100	100	100	**97**	100	100	100	50	100	**90**	100	100	100	100	100	**100**	50	100	100	100	0	**70**	**357**	**41.1**
CHILD 5	PRE	100	25	0	25	100	75	100	50	**59**	50	50	0	50	0	**30**	50	100	100	50	100	**80**	100	100	100	0	0	**60**	**229**	
	POST	100	50	0	50	100	50	100	50	**63**	75	50	50	50	50	**55**	50	100	100	50	50	**70**	50	75	100	0	0	**45**	**233**	**1.7**
CAREGIVER 5	PRE	100	50	50	25	100	0	75	25	**53**	100	75	0	0	100	**55**	50	100	100	100	100	**90**	50	25	100	0	0	**35**	**233**	
	POST	100	0	0	50	100	50	100	50	**56**	50	50	0	0	50	**30**	100	100	100	50	100	**90**	100	25	100	50	50	**65**	**241**	**3.4**

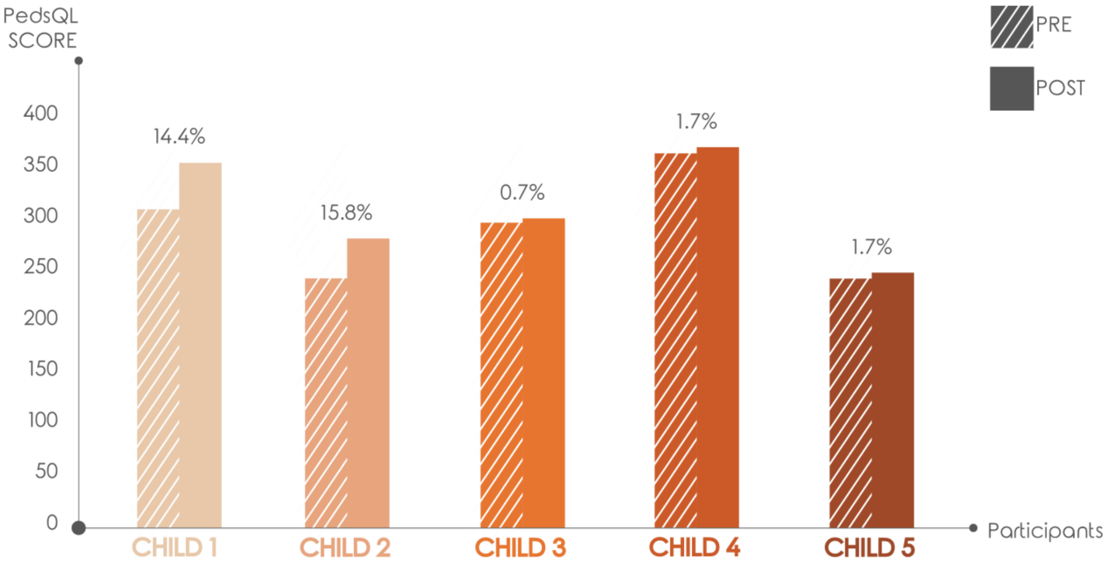

Figure 4.38. PedsQL scores and change ratio (%) of all child participants

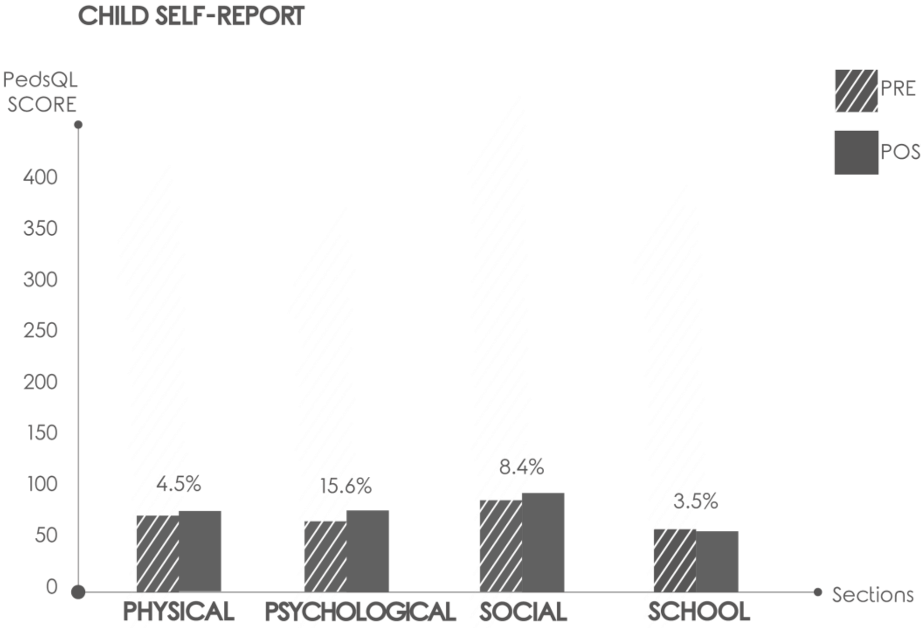

Figure 4.39. Average child self-report scores in four main sections

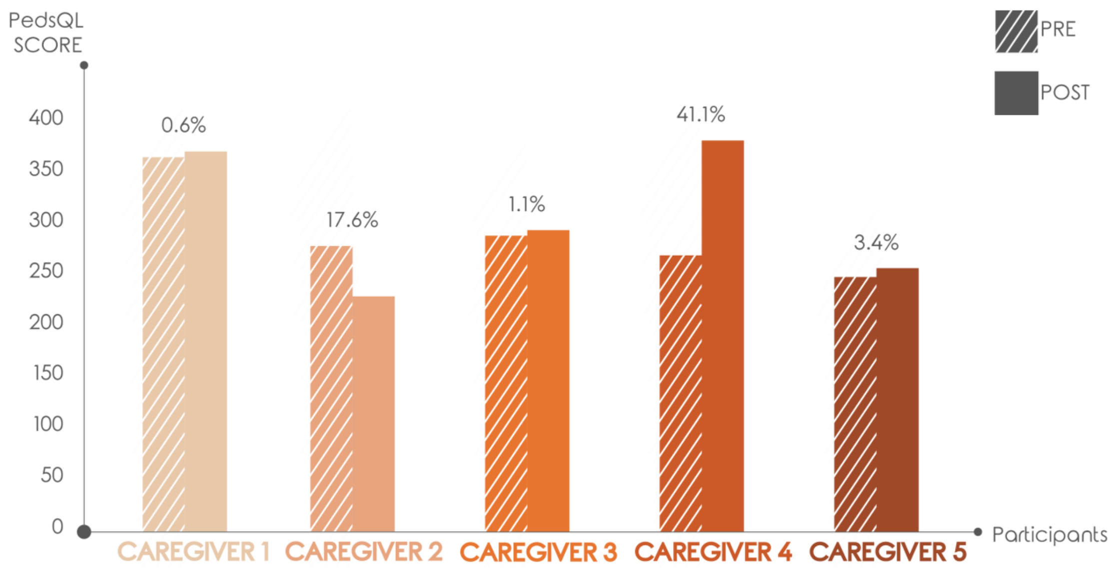

Figure 4.40. PedsQL scores and change ratio (%) of all caregiver participants

On the other hand, PedsQL scores of proxy reports show that QOL of 4 out of 5 children has increased. Only the QOL of Child 2 decreased by approximately 17.6%. In accordance with his father's report, QOL of Child 4 showed the greatest increase ratio (approximately 41.1%) among all caregivers. On the other hand, the proxy report of Child 1 showed the smallest increase ratio among all caregivers by 0.6%.

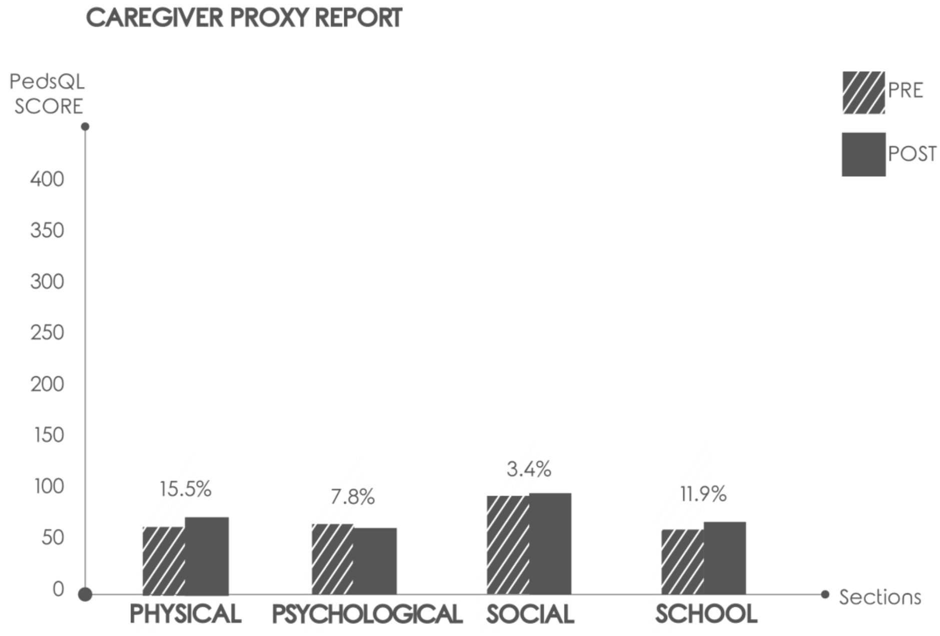

Figure 4.41. Average caregiver proxy-report scores in four main sections

The average proxy report PedsQL scores of all children indicate that QOL of children increased in three of the four sections in the PedsQL. The graph demonstrates that there is an increase in physical (15.5%), social (3.4%) and educational (11.9%) QOL of children. Only the psychological QOL of children decreased by 7.8%. One reason for this decline might be the fact that psychological QOL is an internal aspect whilst the other sections (physical, social and school functioning) are external aspects. In other words, psychological QOL is more subjective and might be misunderstood from an external perspective. Furthermore, it is seen in the graph that physical QOL of children showed the largest increase ratio (15.5%) according to opinions of caregivers. During the interviews, some of the caregivers stated that their children are not physically active and they spend most of their time in their beds. However, doctors mentioned that children should attend physical activities in order to prevent the loss of strength in their muscles. Thus, lack of physical activity was a concern for caregivers. While designing products with the Make toolkit during the study, the children were physically active. This might have affected the perception of their children's physical QOL.

Considering the answers of children on the evaluation questionnaire[56], 4 out of 5 children chose the "definitely agreed" option in Question 1, stating they were feeling better during the participatory design study when compared with the past. Only one of them chose the option "agreed". For the Question 2, 3 out of 5 children stated "very good", and two of them "good" for their general mood and attitude during the study. It shows that the process has a positive impact on children's well-being and their perception of their own well-being.

Thirdly, 4 out of 5 children stated that design session was "the most enjoyable" stage of the study (Question 3). The design sessions were seen by children as a playful activity. In this respect, it might have contributed to their QOL by meeting their needs in terms of play activities. 3 out of 5 children considered sensitizing workbook as "the least enjoyable" stage of the study. Filling out PedsQL is found more enjoyable by children. 1 out of 5 children even defined it as the most enjoyable stage. This shows that there is a problem with the appropriateness of the sensitizing workbook. While designing it, various factors including the age differences were taken into account. Nevertheless, it appears to have been still complicated for the children. As explained by

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[56] See Appendix L and M for the full questionnaire.

several researchers, generative techniques would be more appropriate for children to express themselves. Children may prefer to express themselves visually instead of by using words. For instance, two of the participant children completed some parts of the sensitizing workbook with the guidance of the researcher in the design session and one of them completed it at home in a way that was not expected. These incidents underline the fact that the sensitizing workbook should be revised and the number of questions could be less. Moreover, it would be better to conduct the sensitizing activity with children instead of letting them do it when they are at home.

This activity was expected to be more fun than filling out the PedsQL. However, PedsQL was asking their opinions about themselves and the researcher was with them asking the questions. In other words, it was fostering the socialization. Throughout the study, the children were socializing with the researcher. It is known that socialization is one of the most important needs of children that affect their QOL. They had chats with the researcher during each stage of the study except the sensitizing workbook activity. This might be another reason for why the sensitizing workbook was not more enjoyable for them than the PedsQL.

Besides, conducting this study demonstrated that the caregivers should not be interviewed when their children were around and listening to them. Since this affects the content of their answers. During the interviews, one of the caregivers gave only short answers to some questions. She thought that her child will be upset if he hears about the details of his illness.

The caregivers of the children were worried about their child’s well-being even if the sessions were conducted one-on-one with children. They were asking questions about the health conditions of their children during the design sessions to be sure that they are fine. In this case, group sessions would not be easy to conduct.

The interviews conducted with the caregivers revealed that they were mostly not satisfied with the hygiene rules in the indoor play area even though there are certain regulations for maintaining the hygiene in the play area. For example, it is cleaned every day, if some parts of the toys fall into the floor, it is forbidden to continue to play with it etc. There is a sanitizer to clean every object in the play area before and after usage. Notwithstanding, they still hope to have better hygiene standards for their children. Their demands include people taking off their shoes before entering the play area.

As stated during the interviews, the location of the play area was not appropriate. Especially, for children who may have nausea due to the side effects of the treatment, it is not beneficial to locate the play area near the kitchen. In the kitchen, caregivers of children cook their children's favorite meals, which is expected to help children feel better. However, the smell in the kitchen directly reaches to the play area, causing a concern.

Moreover, the furniture design ideas that these children offered during the design sessions show their needs in some particular issues. For instance, according to the furniture designed by Child 1, who is the youngest child among the participants, it appears that he might need to express himself by using his imagination. Child 2 generated multiple design ideas by considering the age differences between the inpatient children in the hospital. It might show that he needs the feeling of togetherness. Not wanting to be alone might be the reason of creating furniture not only for himself but also for others. Child 3 and Child 5 designed furniture that provides effective communication and socialization with the activities such as playing chess and Playstation. It indicates their need for socializing. For the case of Child 4, it is clear that she needs privacy in this hospital. Therefore, the needs of children can be categorized under four main themes as following;

- Imagination (Child 1),
- Togetherness (Child 2),
- Socialization (Child 3 and Child 5),
- Privacy (Child 4).

Lastly, it is revealed that all of the children would participate in a participatory design study if it would be arranged again (Question 5 of the evaluation questionnaire)[57]. The study also demonstrated that even before reaching the design outcome as a real product in the play area, the participatory design process contributed to improvement of QOL of children with cancer.

4.4.3. Design Outcome

The modular furniture system was one of the outcomes of the study. However, it was not the focus of the study. This design outcome was not evaluated by the children at

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[57] See Appendix L and M for the full questionnaire.

the end of the study as a product, since the emphasis was on the participatory design process and its effects on QOL of children. The process itself was seen as the ultimate “product” of the study, and thus, participants were asked to evaluate the process at the end of the study.

Yet, even though the modular furniture was not the focus point, it was expected that if it is actually produced it would be beneficial for the children’s QOL. It provides the flexibility that is required in order to meet the needs of all children in the play area. It is observed that in its current condition this play area cannot meet the needs of older children. Because the play area is not very large, it is not easy to include all equipment for all age ranges. Deployment of modular furniture that can be arranged in various forms for various purposes allows all children to have what they need in the play area.

Besides, the children use these modules to build their own furniture based on their needs in different occasions. It is also expected that this modular furniture will provide them a sense of control, which is considered essential especially for adolescents[58]. The children with cancer experience an uncontrollable illness. Hospitalization also leads to an aggravated lack of control, since they cannot make decisions on their own. For this reason, providing a sense of control, the outcome of the participatory design study may contribute to the improvement of QOL of children with cancer as well.

In addition, building their own furniture makes this furniture more valuable compared to ready-made one for the children just like in the IKEA effect. According to IKEA effect people value what they make by themselves more than the ready-made products[59]. Moreover, as can be used for building furniture, these modules can also be used as larger Lego modules and boost the creativity of children, especially for those at younger ages. They do not have to build only functional products, but they can also build an imaginary world for themselves.

Lastly, when they stay in the hospital, they see the same play area every day. They cannot spend time outside and they get bored to be exposed to the same environment in the hospital building. Hence, to have the modular furniture and thus the potential to change the environment according to their needs would provide an escape from the monotony of their daily routines.

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[58] Please see Section 2.2.1. for more information about importance of sense of control for adolescent.

[59] Please refer to Section 3.1. for further information regarding the relationship between participatory design and IKEA effect.

CHAPTER 5

CONCLUSION

Cancer is an uncontrollable disease that affects lives of children in a negative way and leads to poor QOL. This study proposes participatory design as a tool to increase the QOL of these children. Children with cancer are among the special groups and generally their opinions are not asked in decision-making processes. Their parents, doctors or teachers make decisions on behalf of them at almost every stage of their lives. Participatory design, which has its roots in democracy and humanism, advocates the inclusion of marginalized groups such as people with disabilities, refugees, elderly people, and children in a society by providing them with a right to participate in decision-making processes and have a control over decisions (Sanoff 1990, Skivenes and Strandbu 2006, Hussain 2010, Merter and Hasırcı 2016).

Several researchers (Sanoff 1990, Evyapan 2002, Simonsen and Robertson 2013, Mateus-Berr, et al. 2015, Luck 2018) explained that a product designed with the inclusion of users has the probability that it would be more beneficial for them on various levels. This study differs from others in the field in the sense that it is focused on the process, rather than the product. In addition, the participatory design process has never before been associated with QOL. To this end, this study especially investigated the effect of the participatory design process itself. It was expected that the participatory design process itself would contribute to QOL of children. Although some participatory design studies have been conducted with healthy children while designing for children with cancer due to the sensitivity and difficulties of the context, participatory design advocates the involvement of real users in the decision-making process. In this thesis the importance of involving end-users of products in a design process is pointed out. Hence, it is conducted with children with different types and stages of cancer. Before conducting this study various factors that should be taken into consideration are investigated in order not to cause any harm to children and ruin their treatment process. These factors also helped to elicit more information from children.

As a result, this study has proven that participatory design process positively affects the QOL of children with cancer. There might be various reasons that show why it contributed to the QOL of children. First, participatory design gives the users a voice

(Sanoff 2007, Robertson and Simonsen 2012, Dell'Era and Landoni 2014). Thus, they have an opportunity to take part in the decision-making process. Due to the nature of the illness and the fact that children with cancer spend most of their time in the hospital environment, they experience a sense of lack of control (Evan 2014, p.127). However, when their ideas are asked regarding an issue that is related to them, they feel a sense of control (Sanoff 1990, p.i). This might be one of the reasons why their QOL has increased during the study. Secondly, it might be beneficial for their self-confidence, which is considered one of the aspects that has an impact on their QOL (Anthony, et al. 2013). Generally, their opinions and ideas are not asked and when they are asked during the participatory design sessions, they might feel more important as a human being and more confident. In order to have a chance to design a product for themselves and their friends might also have a positive impact on their confidence and accordingly on their QOL. Moreover, the participatory design process provides children with a way of socialization, which is a significant aspect for the QOL of children (Anthony, et al. 2013). The importance of socialization can be supported with their personal comments during the sessions. Lastly, the participatory design process might have distracted them from their negative thoughts regarding cancer and its side effects.

Even though this study does not claim to be exhaustive or conclusive, considering the positive impact of participatory design sessions on QOL of children, it might be considered, albeit tentatively, as an intervention technique. As explained in the literature review, there are many intervention techniques used for improving QOL of children with cancer. So far, art therapy (Carboni 1995), music therapy (Nguyen, et al. 2010), exercise therapy (Kruijsen-Jaarsma, et al. 2013), yoga (Thygeson, et al. 2010), and play therapy (Mohammadi, Mehraban and Damavandi 2017) have been offered. Participatory design process as appropriated in this study has a common denominator with the main aim of said intervention techniques: contribution to the improvement of QOL. Still there should be more research done on the topic to offer participatory design as an intervention technique unreservedly.

Due to the uncertainty and severity of the illness, it was not easy to access children with cancer in the hospital. Their available times were different from each other. Moreover, their caregivers were worried about infections. For these reasons, the study was conducted one-on-one with each child. Because it was more time consuming than group sessions, more children could not be included in the study. If the time span were longer, more children could participate in this study. For further studies, it is recommended to conduct participatory design sessions with children with cancer in a larger span of time with more participants to improve the generalizability of the findings. In the context of this study it was aimed to discuss the physical, psychological, social functioning of children with cancer instead of the disease related symptoms. For this reason, in this study only The PedsQL 4.0 Generic Core Scales is applied. More comprehensive studies may also examine cancer related symptoms such as nausea, pain, anxiety and the like with physical, psychological, social functioning of children by using both of the instruments. Due to time constraints, the researcher designed the Make toolkit modules and a pilot study was not conducted. In a larger span of time children with cancer can be also involved in designing the modules in the Make toolkit that were used in the design sessions in order to increase the involvement of the children. Moreover, it is recommended to conduct a pilot study to help prepare more suitable tools for children such as the sensitizing workbook and toolkit.

In spite of the fact that there are other factors that have not been included in the scope of this thesis, this study still has shown that there are positive effects of participatory design processes on QOL of children with cancer. Bearing in mind the fruitful findings of the thesis, it is hoped that this thesis will trigger and inspire researchers to investigate and consider the benefits of not only the end product but also the participatory design process on QOL of children with cancer.

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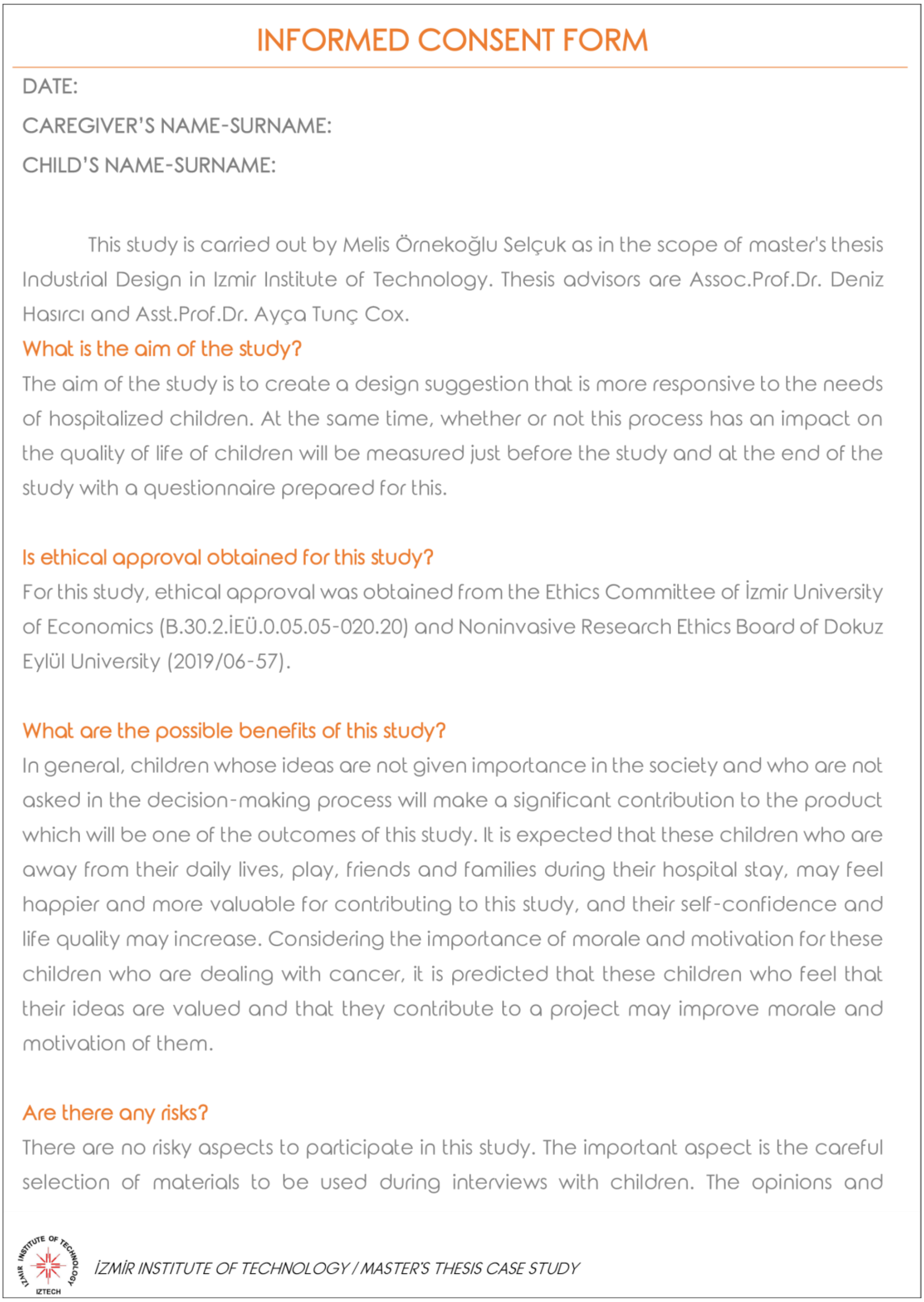
APPENDIX A

INFORMED CONSENT FORM



INFORMED CONSENT FORM

DATE:

CAREGIVER'S NAME-SURNAME:

CHILD'S NAME-SURNAME:

This study is carried out by Melis Örnekoğlu Selçuk as in the scope of master's thesis Industrial Design in Izmir Institute of Technology. Thesis advisors are Assoc.Prof.Dr. Deniz Hasırcı and Asst.Prof.Dr. Ayça Tunç Cox.

What is the aim of the study?

The aim of the study is to create a design suggestion that is more responsive to the needs of hospitalized children. At the same time, whether or not this process has an impact on the quality of life of children will be measured just before the study and at the end of the study with a questionnaire prepared for this.

Is ethical approval obtained for this study?

For this study, ethical approval was obtained from the Ethics Committee of İzmir University of Economics (B.30.2.İEÜ.0.05.05-020.20) and Noninvasive Research Ethics Board of Dokuz Eylül University (2019/06-57).

What are the possible benefits of this study?

In general, children whose ideas are not given importance in the society and who are not asked in the decision-making process will make a significant contribution to the product which will be one of the outcomes of this study. It is expected that these children who are away from their daily lives, play, friends and families during their hospital stay, may feel happier and more valuable for contributing to this study, and their self-confidence and life quality may increase. Considering the importance of morale and motivation for these children who are dealing with cancer, it is predicted that these children who feel that their ideas are valued and that they contribute to a project may improve morale and motivation of them.

Are there any risks?

There are no risky aspects to participate in this study. The important aspect is the careful selection of materials to be used during interviews with children. The opinions and

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Figure A.1. The first page of informed consent form

suggestions of doctors (Prof. Dr. Dilek İnce and Prof. Dr. Şebnem Yılmaz) will be adhered to in this regard. It will be conducted without disturbing the children and in their treatment processes. All activities are planned to be completed within 1 month.

Will the participants pay for this research?

No financial support was received in this study. All materials used to work with children will be provided by the researcher. Participants will not be charged.

Do participants have the right to withdraw?

Participants are completely free to participate in the research. Although the participants are agreed to participate in the research, he/she has the right to withdraw from the study without having to specify a reason.

Will the information of the participants be kept confidential?

The information of the participants will be kept confidential. The data will be used in scientific studies such as articles, conferences and thesis. In these publications, the names of the participants will be kept confidential and pseudonyms will be used instead of real names of children.

The details of this study will be explained to the participants verbally and their questions will be answered. However, if you have any question, please do not hesitate to contact the researcher.

Res. Assist. Melis ÖRNEKOĞLU SELÇUK,

Department of Industrial Design,
Faculty of Fine Arts and Design,
Izmir University of Economics,
Balçova 35330, İzmir, Turkey
+90 232 488 54 11

I have read and comprehended the information above about the research. I understand. I fully agree to participate in this research.

Signature:	Signature:
Name-Surname:	Name-Surname:
Phone Number:	Phone Number:
Date:…./…./……	Date:…./…./……

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Figure A.2. The second page of informed consent form

APPENDIX B

INFORMED CONSENT FORM (TURKISH VERSION)

KATILIMCI BİLGİLENDİRME ve ONAY FORMU

TARİH:

VELİNİN ADI-SOYADI:

ÇOCUĞUN ADI-SOYADI:

Bu araştırma İzmir Yüksek Teknoloji Enstitüsü, Endüstriyel Tasarım yüksek lisans tez çalışması kapsamında Melis Örnekoğlu tarafından yürütülmektedir. Tez danışmanları Doç.Dr. Deniz Hasırcı ve Dr. Öğretim Üyesi Ayça Tunç Cox'dur.

Araştırmanın amacı nedir?

Çalışmanın amacı hastanede yatan çocukların **oyun alanı** için ve onlarla birlikte, onların ihtiyaçlarına daha fazla yanıt veren bir **ürün tasarımı** önerebilmektir. Aynı zamanda bu sürecin kendisinin çocukların **hayat kalitesi** üzerinde etkisi olup olmadığı çalışmaya başlamadan hemen önce ve çalışma bittikten sonra uygulanacak anket çalışmaları ile ölçülecektir.

Araştırma için gerekli izinler alındı mı?

Bu çalışmanın yürütülmesinde **etik açıdan uygun** olduğuna dair İzmir Ekonomi Üniversitesi, Mühendislik ve Fen Bilimleri Etik Kurulu'ndan (05.11.2018 tarihinde alınan B.30.2.İEÜ.0.05.05-020-20 sayılı etik kurul onayı) ve Dokuz Eylül Üniversitesi Girişimsel Olmayan Araştırmalar Etik Kurulu'ndan onay alınmıştır.

Araştırmanın öngörülen yararı nedir?

Genellikle toplumda fikirlerine önem verilmeyen ve tasarım kararı alırken görüşlerine başvurulmayan çocuklara aslında fikirlerinin önemli olduğu ve bu çalışmanın sonucunda ortaya çıkacak üründe büyük bir katkıları olacağı hissettirilecektir. Hastanede kaldıkları süre boyunca günlük hayatlarından, oyundan, arkadaşlarından ve ailelerinden uzak kalan bu çocukların bir çalışmaya katkı sağlamaktan dolayı kendilerini mutlu ve değerli hissedecekleri, özgüvenlerinin ve hayat kaltelerinin artacağı düşünülmektedir. Kanser ile mücadele eden bu çocuklar için moral ve motivasyonun önemini göz önünde bulundurursak, **fikirlerine değer verildiğini** ve bir projeye katkı sağladıklarını hisseden bu çocukların moral ve motivasyonunda **olumlu** gelişmeler olacağı öngörülmektedir.

Araştırmanın riskli bir yanı var mı?

Bu çalışmaya katılmanın herhangi **riskli bir yanı bulunmamaktadır**. Önemli olan husus, çocuklarla yapılan görüşmeler sırasında kullanılacak malzemelerin özenle seçilmesidir. Bu konuda doktorların (**Prof. Dr. Dilek İnce** ve **Prof. Dr. Şebnem Yılmaz**) görüş ve önerilerine

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.3. The first page of informed consent form in Turkish

sadık kalınacaktır. Uygulamanın çocukları yormadan, onların **tedavi süreçlerine uyumlu zamanlarda** yapılması önemlidir. Buna doktorlarıyla yapılan görüşmeler sonucunda karar verilecektir. Tüm aktivitelerin **1 ay** içinde tamamlanması planlanmaktadır.

Araştırmanın masrafı olacak mı?

Bu çalışmada mali destek alınmamıştır. Çocuklarla çalışmak için kullanılacak tüm malzemeler araştırmacının kendisi tarafından temin edilecektir. Katılımcılardan herhangi bir **ücret talep edilmeyecektir**.

Katılımcının araştırmadan çıkma hakkı var mı?

Katılımcılar araştırmaya katılıp katılmamak konusunda tamamen **özgürdür**. Bu konuda **gönüllülük** esastır. Katılımcı araştırmaya katılmayı kabul etmiş olsa da bir neden belirtmek zorunda olmaksızın araştırmadan **çekilme hakkına sahiptir**. Araştırmadan çekilmiş olması, günlük hayatını veya tedavi sürecini hiçbir şekilde etkileyemez.

Katılımcıların bilgileri gizli tutulacak mı?

Katılımcıların bilgilerinin **gizliliğine önem verilmektedir**. Katılımcı tasarım çalışmalarından ortaya çıkan verilen yüksek lisans tezinde veya ileride makale, konferans gibi **bilimsel yayınlarda** kullanılacaktır. Bu yayınlarda **katılımcıların isimleri gizli tutulacak** ve kendilerinden bahsederken 'Katılımcı 1, Katılımcı 2,..' gibi rumuzlar kullanılacaktır.

Katılımcılara bu çalışmanın detayları sözlü olarak da açıklanacak ve soruları cevaplanacaktır. Fakat aklınıza takılan bir soru olduğunda lütfen araştırmacılarla iletişime geçiniz.

Araş. Gör. Melis ÖRNEKOĞLU SELÇUK,

Endüstriyel Tasarım Bölümü,
Güzel Sanatlar ve Tasarım Fakültesi,
İzmir Ekonomi Üniversitesi,
Balçova 35330, İzmir, Türkiye
+90 232 488 54 11
+90 555 596 72 43

Araştırma ile ilgili bilgilendirme yazısını okudum, anladım. Bu araştırmaya katılmayı tamamen gönüllü olarak kabul ediyorum.

İmza:
İsim-Soyisim:
Telefon No:
Tarih:…./…./……

İmza:
İsim-Soyisim:
Telefon No:
Tarih:…./…./……

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.4. The second page of informed consent form in Turkish

APPENDIX C

INTERVIEW FORM FOR CAREGIVERS

CAREGIVER - INTERVIEW (INFORMATION)

DATE:

NAME-SURNAME:

CHILD'S NAME-SURNAME:

A. DAILY ROUTINE AND NEEDS OF CHILDREN

1. Could you please explain daily routine of your child?
2. What does your child like here?
3. What does your child dislike here?
4. Are there any objects that your child carries with him/her all the time?
5. What is the object that your children interacts with mostly in his/her daily life?
6. What is the biggest problem of your child in his/her daily life?

B. QUALITY OF LIFE OF CHILDREN

1. How is the physical health situation of your child?
2. How is the psychological health situation of your child?
3. How is the social health situation of your child?

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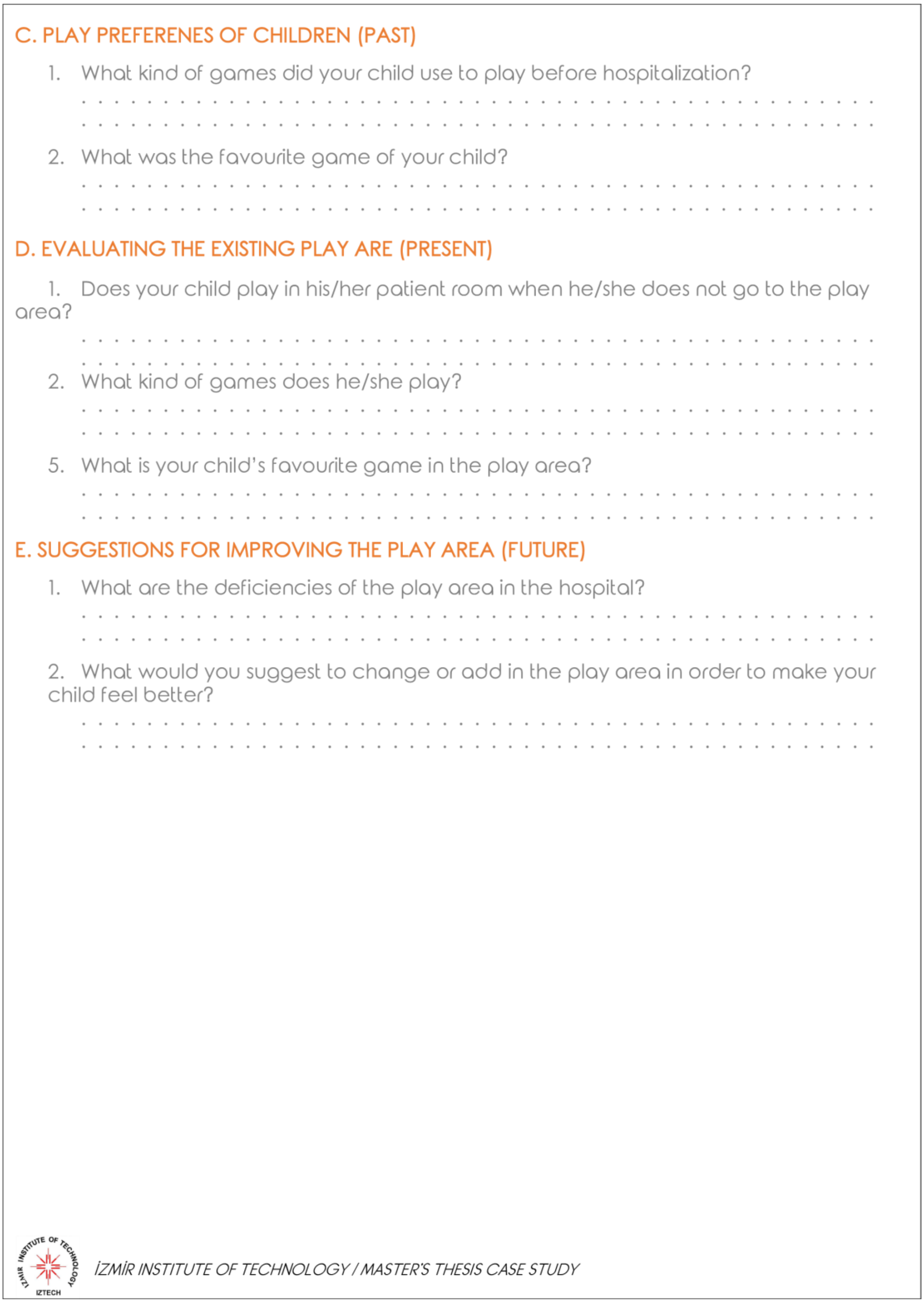
Figure A.5.The first page of interview form for caregivers



C. PLAY PREFERENES OF CHILDREN (PAST)

1. What kind of games did your child use to play before hospitalization?

. . . .

. . . .

2. What was the favourite game of your child?

. . . .

. . . .

D. EVALUATING THE EXISTING PLAY ARE (PRESENT)

1. Does your child play in his/her patient room when he/she does not go to the play area?

. . . .

. . . .

2. What kind of games does he/she play?

. . . .

. . . .

5. What is your child's favourite game in the play area?

. . . .

. . . .

E. SUGGESTIONS FOR IMPROVING THE PLAY AREA (FUTURE)

1. What are the deficiencies of the play area in the hospital?

. . . .

. . . .

2. What would you suggest to change or add in the play area in order to make your child feel better?

. . . .

. . . .

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Figure A.6. The second page of interview form for caregivers

APPENDIX D

INTERVIEW FORM FOR CAREGIVERS (TURKISH)

VELİ RÖPORTAJ FORMU (Bilgi Toplama)

TARİH:

VELİNİN ADI-SOYADI:

ÇOCUĞUN ADI-SOYADI:

A. ÇOCUKLARIN GÜNLÜK RUTİNLERİ VE İHTİYAÇLARI

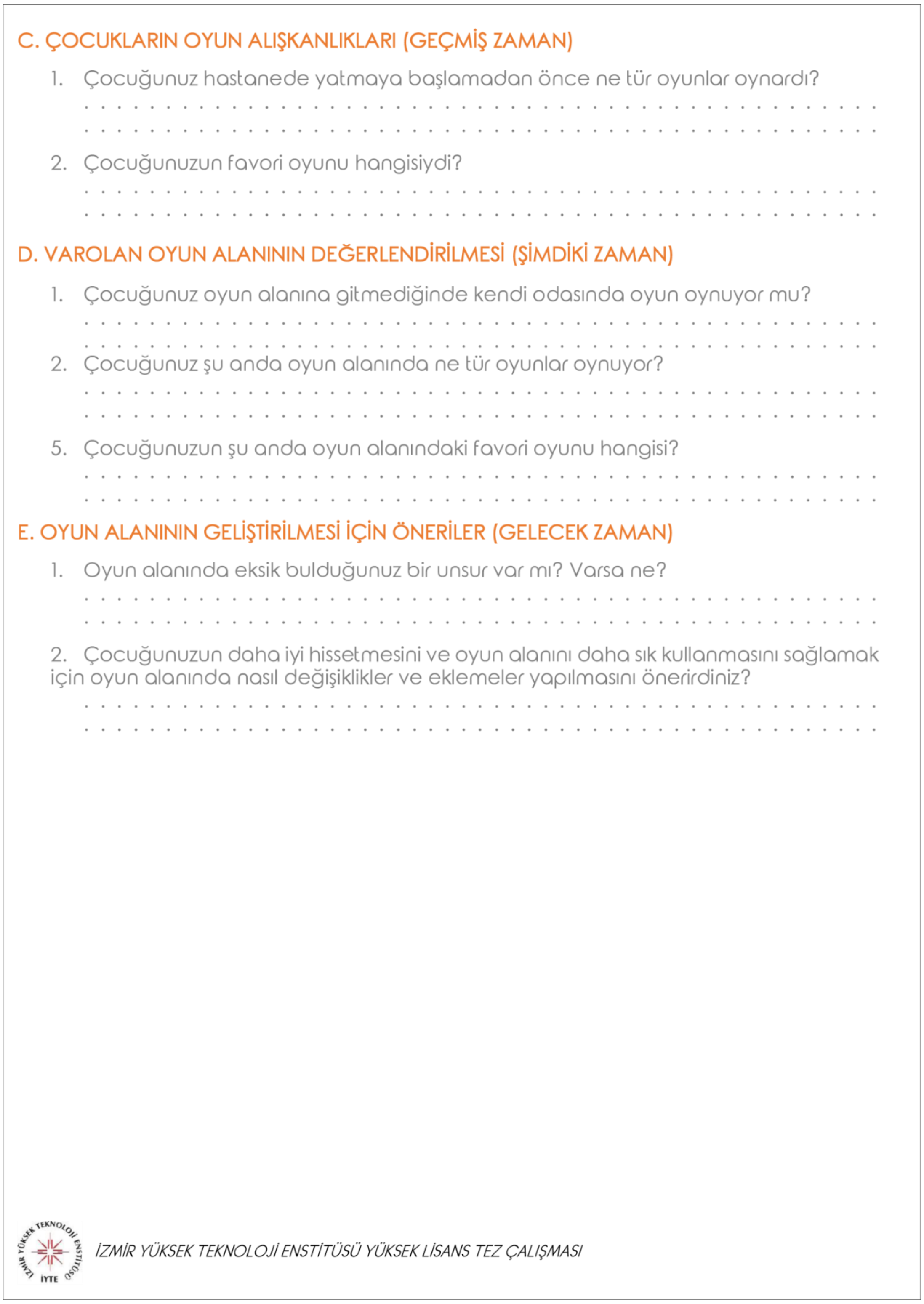
1. Çocuğunuzun günlük rutininden bahseder misiniz?
2. Çocuğunuzun burada sevdiği ne gibi unsurlar var?
3. Çocuğunuzun burada sevmediği ne gibi unsurlar var?
4. Çocuğunuzun sevdiği ve hep yanında taşıdığı bir obje/oyuncak var mı? Varsa ne?
5. Çocuğunuzun günlük hayatında en çok kullandığı ürün nedir?
6. Çocuğunuzun günlük hayatında karşılaştığı en büyük sorun nedir?

B. ÇOCUKLARIN HAYAT KALİTESİ

1. Çocuğunuzun fiziksel durumundan bahseder misiniz?
2. Çocuğunuzun psikolojik durumundan bahseder misiniz?
3. Çocuğunuzun sosyal durumundan bahseder misiniz?

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.7. The first page of interview form for caregivers in Turkish



C. ÇOCUKLARIN OYUN ALIŞKANLIKLARI (GEÇMİŞ ZAMAN)

1. Çocuğunuz hastanede yatmaya başlamadan önce ne tür oyunlar oynardı?

. . . .

. . . .

2. Çocuğunuzun favori oyunu hangisiydi?

. . . .

. . . .

D. VAROLAN OYUN ALANININ DEĞERLENDİRİLMESİ (ŞİMDİKİ ZAMAN)

1. Çocuğunuz oyun alanına gitmediğinde kendi odasında oyun oynuyor mu?

. . . .

. . . .

2. Çocuğunuz şu anda oyun alanında ne tür oyunlar oynuyor?

. . . .

. . . .

5. Çocuğunuzun şu anda oyun alanındaki favori oyunu hangisi?

. . . .

. . . .

E. OYUN ALANININ GELİŞTİRİLMESİ İÇİN ÖNERİLER (GELECEK ZAMAN)

1. Oyun alanında eksik bulduğunuz bir unsur var mı? Varsa ne?

. . . .

. . . .

2. Çocuğunuzun daha iyi hissetmesini ve oyun alanını daha sık kullanmasını sağlamak için oyun alanında nasıl değişiklikler ve eklemeler yapılmasını önerirdiniz?

. . . .

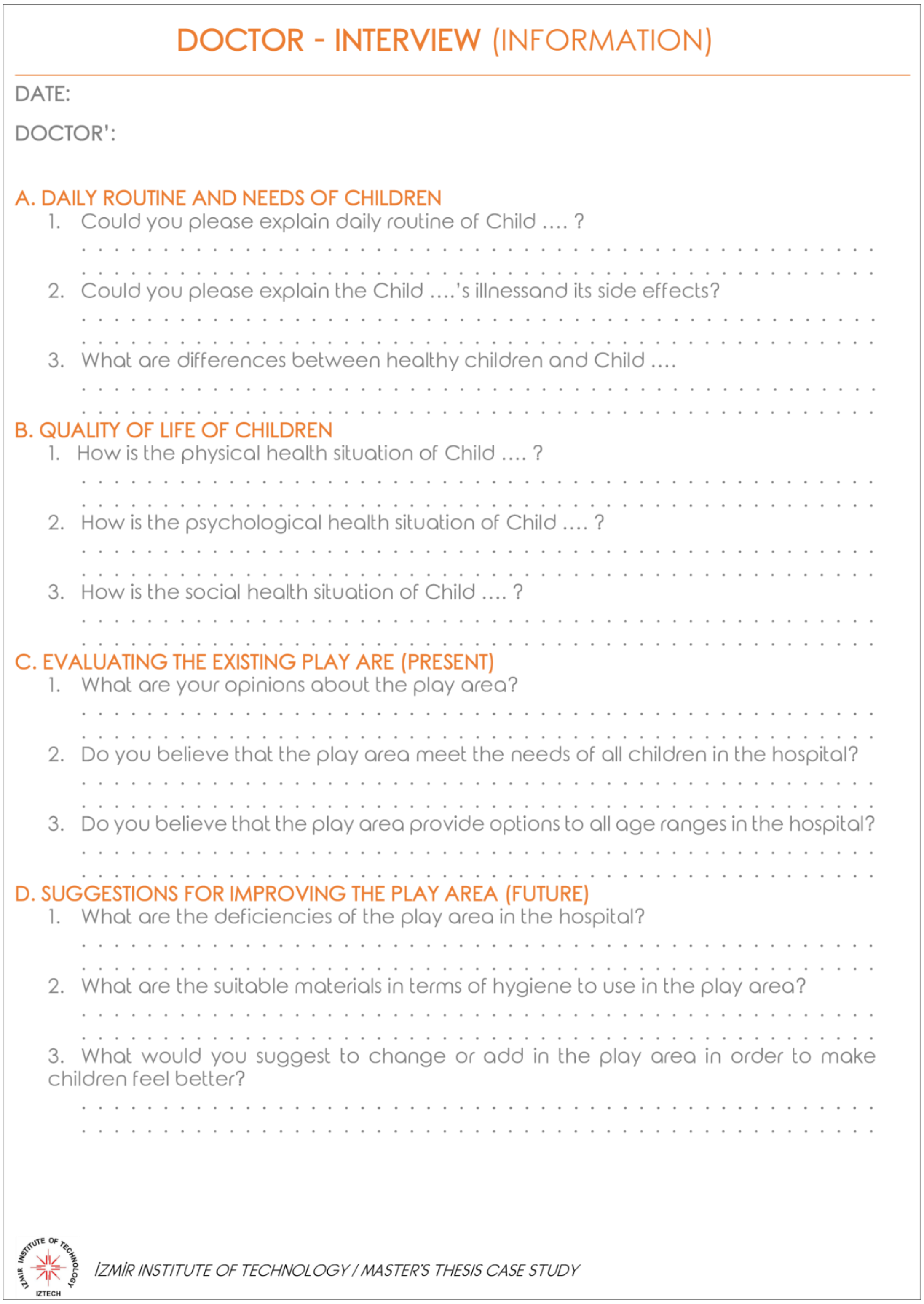
. . . .

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.8. The second page of interview form for caregivers in Turkish

APPENDIX E

INTERVIEW FORM FOR DOCTORS



DOCTOR - INTERVIEW (INFORMATION)

DATE:

DOCTOR':

A. DAILY ROUTINE AND NEEDS OF CHILDREN

1. Could you please explain daily routine of Child .... ?

. . . .

. . . .

2. Could you please explain the Child ....'s illnessand its side effects?

. . . .

. . . .

3. What are differences between healthy children and Child ....

. . . .

. . . .

B. QUALITY OF LIFE OF CHILDREN

1. How is the physical health situation of Child .... ?

. . . .

. . . .

2. How is the psychological health situation of Child .... ?

. . . .

. . . .

3. How is the social health situation of Child .... ?

. . . .

. . . .

C. EVALUATING THE EXISTING PLAY ARE (PRESENT)

1. What are your opinions about the play area?

. . . .

. . . .

2. Do you believe that the play area meet the needs of all children in the hospital?

. . . .

. . . .

3. Do you believe that the play area provide options to all age ranges in the hospital?

. . . .

. . . .

D. SUGGESTIONS FOR IMPROVING THE PLAY AREA (FUTURE)

1. What are the deficiencies of the play area in the hospital?

. . . .

. . . .

2. What are the suitable materials in terms of hygiene to use in the play area?

. . . .

. . . .

3. What would you suggest to change or add in the play area in order to make children feel better?

. . . .

. . . .

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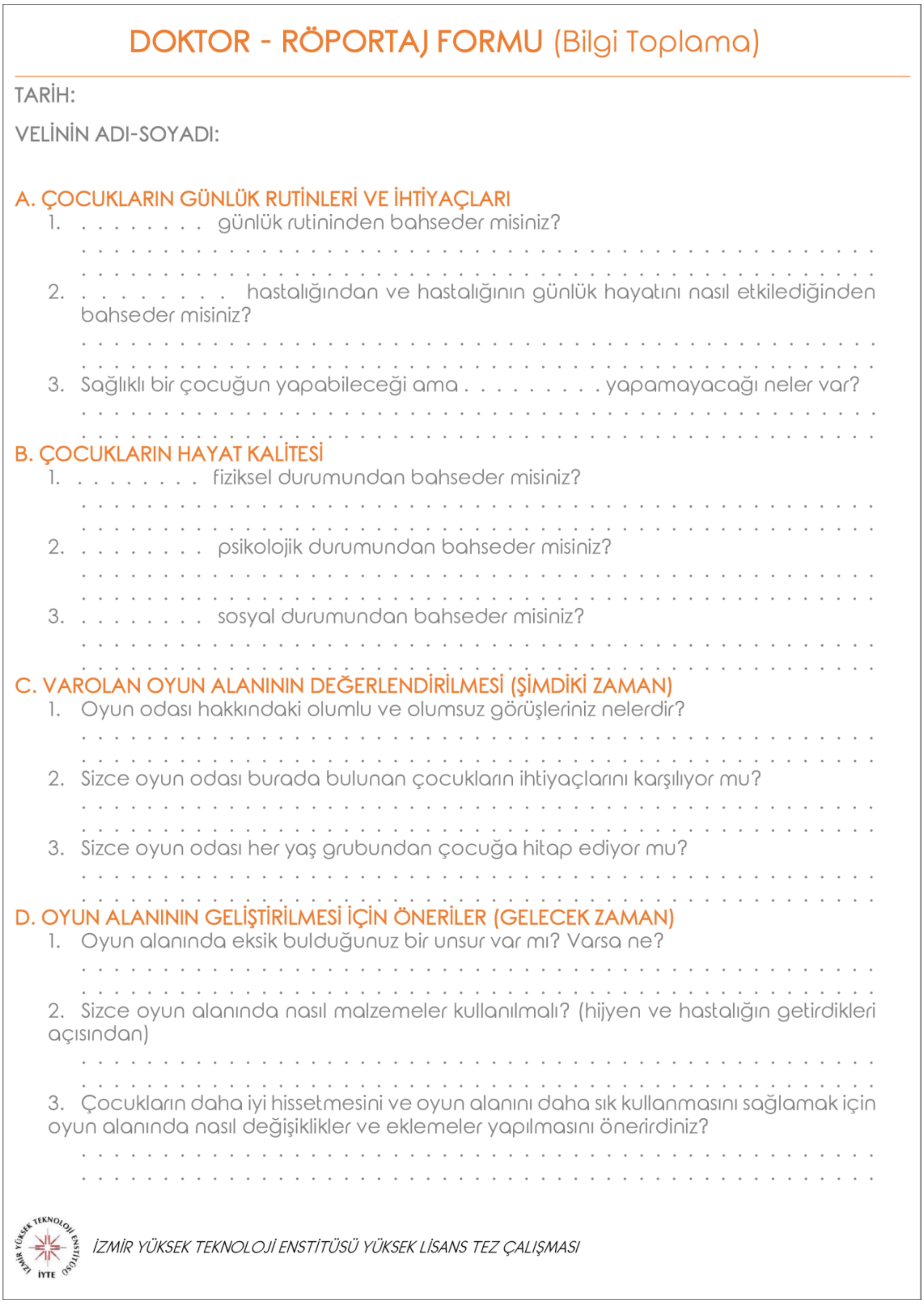
Figure A.9. The interview form for doctors

APPENDIX F

INTERVIEW FORM FOR DOCTORS (TURKISH)



DOKTOR - RÖPORTAJ FORMU (Bilgi Toplama)

TARİH:

VELİNİN ADI-SOYADI:

A. ÇOCUKLARIN GÜNLÜK RUTİNLERİ VE İHTİYAÇLARI

1. . . . . günlük rutininden bahseder misiniz?

   . . . .

   . . . .

2. . . . . hastalığından ve hastalığının günlük hayatını nasıl etkilediğinden bahseder misiniz?

   . . . .

   . . . .

3. Sağlıklı bir çocuğun yapabileceği ama . . . . yapamayacağı neler var?

   . . . .

   . . . .

B. ÇOCUKLARIN HAYAT KALİTESİ

1. . . . . fiziksel durumundan bahseder misiniz?

   . . . .

   . . . .

2. . . . . psikolojik durumundan bahseder misiniz?

   . . . .

   . . . .

3. . . . . sosyal durumundan bahseder misiniz?

   . . . .

   . . . .

C. VAROLAN OYUN ALANININ DEĞERLENDİRİLMESİ (ŞİMDİKİ ZAMAN)

1. Oyun odası hakkındaki olumlu ve olumsuz görüşleriniz nelerdir?

   . . . .

   . . . .

2. Sizce oyun odası burada bulunan çocukların ihtiyaçlarını karşılıyor mu?

   . . . .

   . . . .

3. Sizce oyun odası her yaş grubundan çocuğa hitap ediyor mu?

   . . . .

   . . . .

D. OYUN ALANININ GELİŞTİRİLMESİ İÇİN ÖNERİLER (GELECEK ZAMAN)

1. Oyun alanında eksik bulduğunuz bir unsur var mı? Varsa ne?

   . . . .

   . . . .

2. Sizce oyun alanında nasıl malzemeler kullanılmalı? (hijyen ve hastalığın getirdikleri açısından)

   . . . .

   . . . .

3. Çocukların daha iyi hissetmesini ve oyun alanını daha sık kullanmasını sağlamak için oyun alanında nasıl değişiklikler ve eklemeler yapılmasını önerirdiniz?

   . . . .

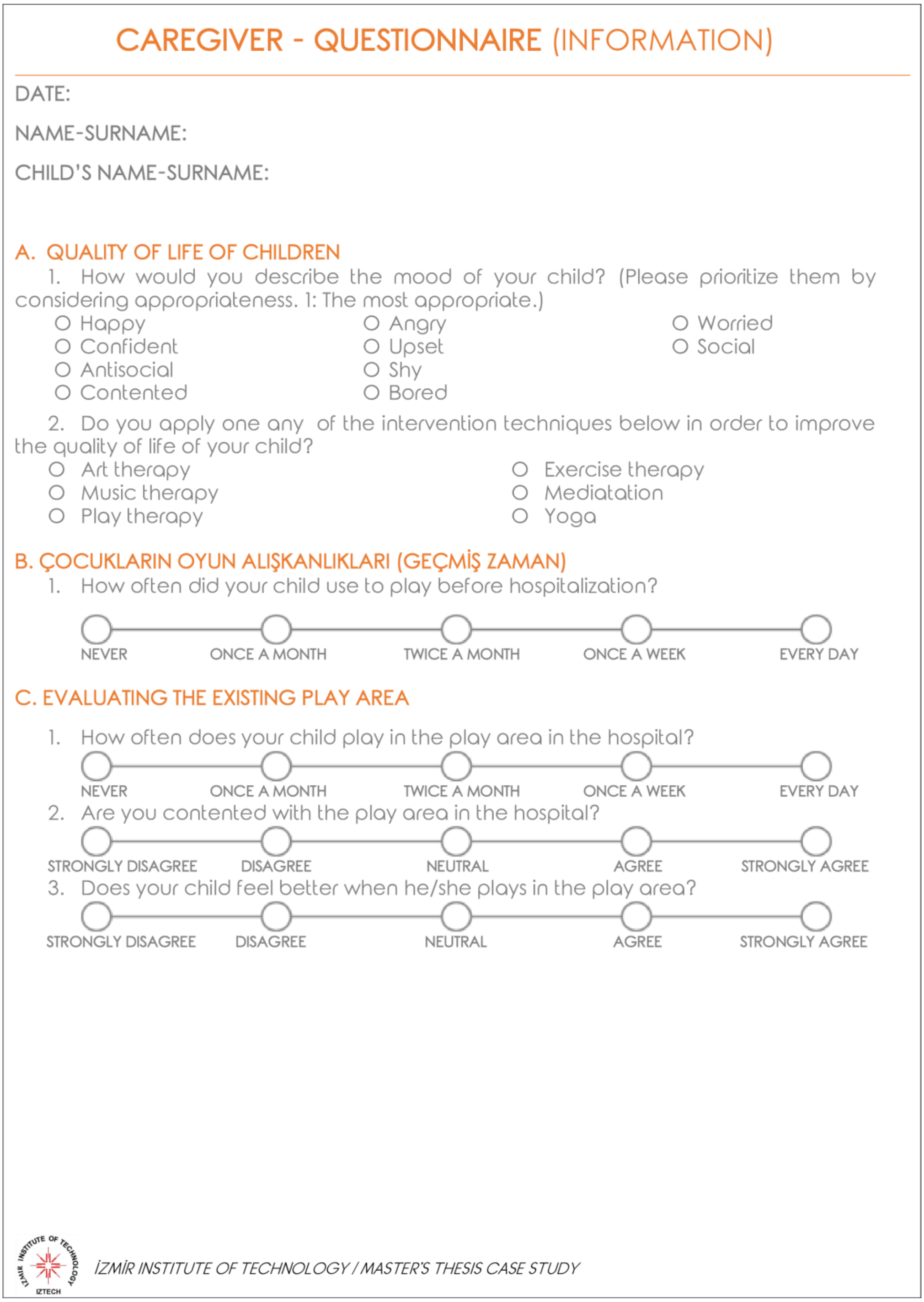
   . . . .

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.10. The interview form for doctors in Turkish

APPENDIX G

QUESTIONNAIRE FORM FOR CAREGIVERS



CAREGIVER - QUESTIONNAIRE (INFORMATION)

DATE:

NAME-SURNAME:

CHILD'S NAME-SURNAME:

A. QUALITY OF LIFE OF CHILDREN

1. How would you describe the mood of your child? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ Happy
○ Confident
○ Antisocial
○ Contented
○ Angry
○ Upset
○ Shy
○ Bored
○ Worried
○ Social

2. Do you apply one any of the intervention techniques below in order to improve the quality of life of your child?

○ Art therapy
○ Music therapy
○ Play therapy
○ Exercise therapy
○ Mediatation
○ Yoga

B. ÇOCUKLARIN OYUN ALIŞKANLIKLARI (GEÇMİŞ ZAMAN)

1. How often did your child use to play before hospitalization?

○ NEVER ○ ONCE A MONTH ○ TWICE A MONTH ○ ONCE A WEEK ○ EVERY DAY

C. EVALUATING THE EXISTING PLAY AREA

1. How often does your child play in the play area in the hospital?

○ NEVER ○ ONCE A MONTH ○ TWICE A MONTH ○ ONCE A WEEK ○ EVERY DAY

2. Are you contented with the play area in the hospital?

○ STRONGLY DISAGREE ○ DISAGREE ○ NEUTRAL ○ AGREE ○ STRONGLY AGREE

3. Does your child feel better when he/she plays in the play area?

○ STRONGLY DISAGREE ○ DISAGREE ○ NEUTRAL ○ AGREE ○ STRONGLY AGREE

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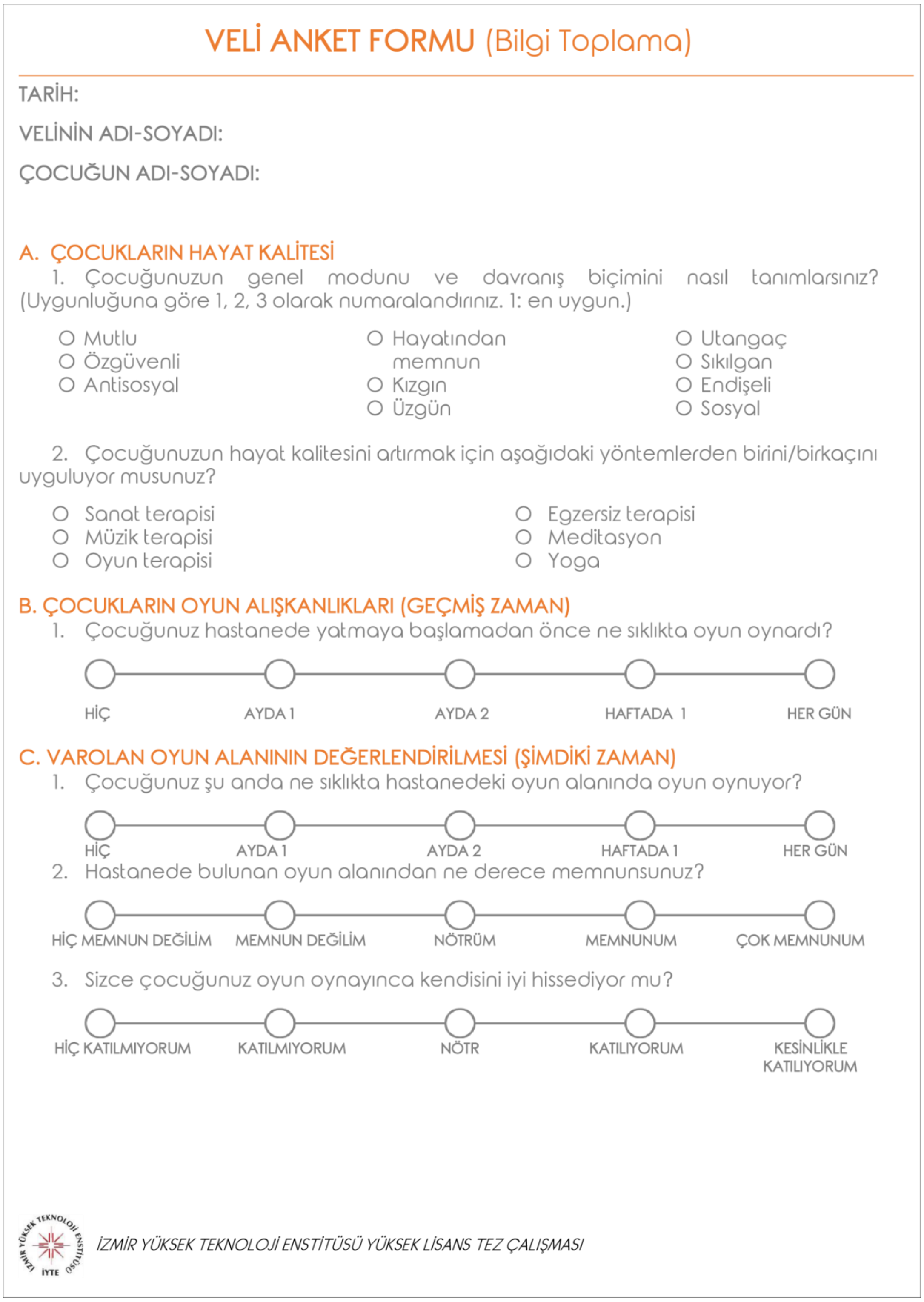
Figure A.11. The questionnaire form for caregivers

APPENDIX H

QUESTIONNAIRE FORM FOR CAREGIVERS (TURKISH)



VELİ ANKET FORMU (Bilgi Toplama)

TARİH:

VELİNİN ADI-SOYADI:

ÇOCUĞUN ADI-SOYADI:

A. ÇOCUKLARIN HAYAT KALİTESİ

1. Çocuğunuzun genel modunu ve davranış biçimini nasıl tanımlarsınız? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

○ Mutlu
○ Özgüvenli
○ Antisosyal
○ Hayatından memnun
○ Kızgın
○ Üzgün
○ Utangaç
○ Sıkılgan
○ Endişeli
○ Sosyal

2. Çocuğunuzun hayat kalitesini artırmak için aşağıdaki yöntemlerden birini/birkaçını uyguluyor musunuz?

○ Sanat terapisi
○ Müzik terapisi
○ Oyun terapisi
○ Egzersiz terapisi
○ Meditasyon
○ Yoga

B. ÇOCUKLARIN OYUN ALIŞKANLIKLARI (GEÇMİŞ ZAMAN)

1. Çocuğunuz hastanede yatmaya başlamadan önce ne sıklıkta oyun oynardı?

○ HİÇ ○ AYDA 1 ○ AYDA 2 ○ HAFTADA 1 ○ HER GÜN

C. VAROLAN OYUN ALANININ DEĞERLENDİRİLMESİ (ŞİMDİKİ ZAMAN)

1. Çocuğunuz şu anda ne sıklıkta hastanedeki oyun alanında oyun oynuyor?

○ HİÇ ○ AYDA 1 ○ AYDA 2 ○ HAFTADA 1 ○ HER GÜN

2. Hastanede bulunan oyun alanından ne derece memnunsunuz?

○ HİÇ MEMNUN DEĞİLİM ○ MEMNUN DEĞİLİM ○ NÖTRÜM ○ MEMNUNUM ○ ÇOK MEMNUNUM

3. Sizce çocuğunuz oyun oynayınca kendisini iyi hissediyor mu?

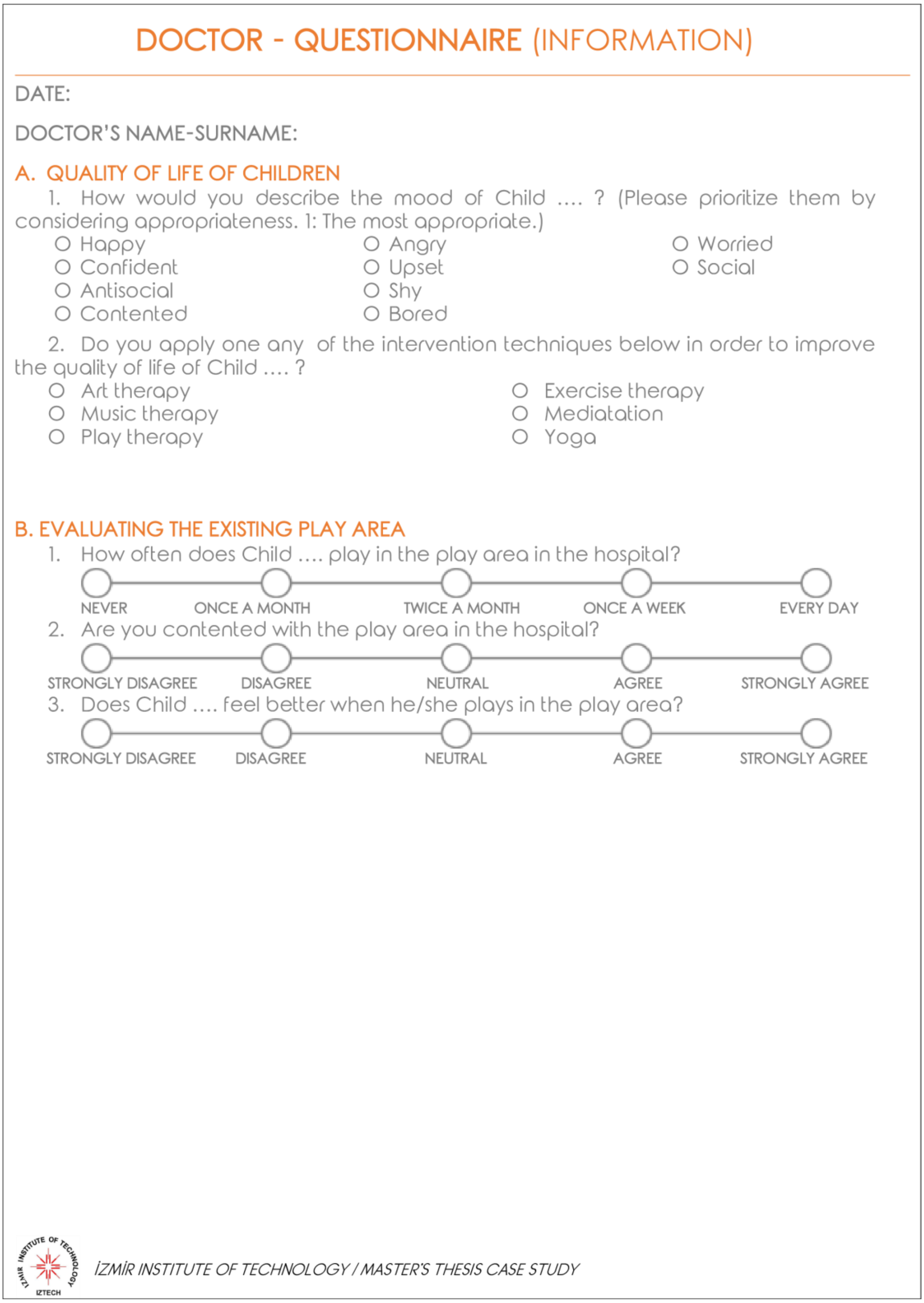
○ HİÇ KATILMIYORUM ○ KATILMIYORUM ○ NÖTR ○ KATILIYORUM ○ KESİNLİKLE KATILIYORUM

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.12. The questionnaire form for caregivers in Turkish

APPENDIX I

QUESTIONNAIRE FORM FOR DOCTORS



DOCTOR - QUESTIONNAIRE (INFORMATION)

DATE:

DOCTOR'S NAME-SURNAME:

A. QUALITY OF LIFE OF CHILDREN

1. How would you describe the mood of Child .... ? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ Happy
○ Confident
○ Antisocial
○ Contented
○ Angry
○ Upset
○ Shy
○ Bored
○ Worried
○ Social

2. Do you apply one any of the intervention techniques below in order to improve the quality of life of Child .... ?

○ Art therapy
○ Music therapy
○ Play therapy
○ Exercise therapy
○ Mediatation
○ Yoga

B. EVALUATING THE EXISTING PLAY AREA

1. How often does Child .... play in the play area in the hospital?

○	○	○	○	○
NEVER	ONCE A MONTH	TWICE A MONTH	ONCE A WEEK	EVERY DAY

2. Are you contented with the play area in the hospital?

○	○	○	○	○
STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE

3. Does Child .... feel better when he/she plays in the play area?

○	○	○	○	○
STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE

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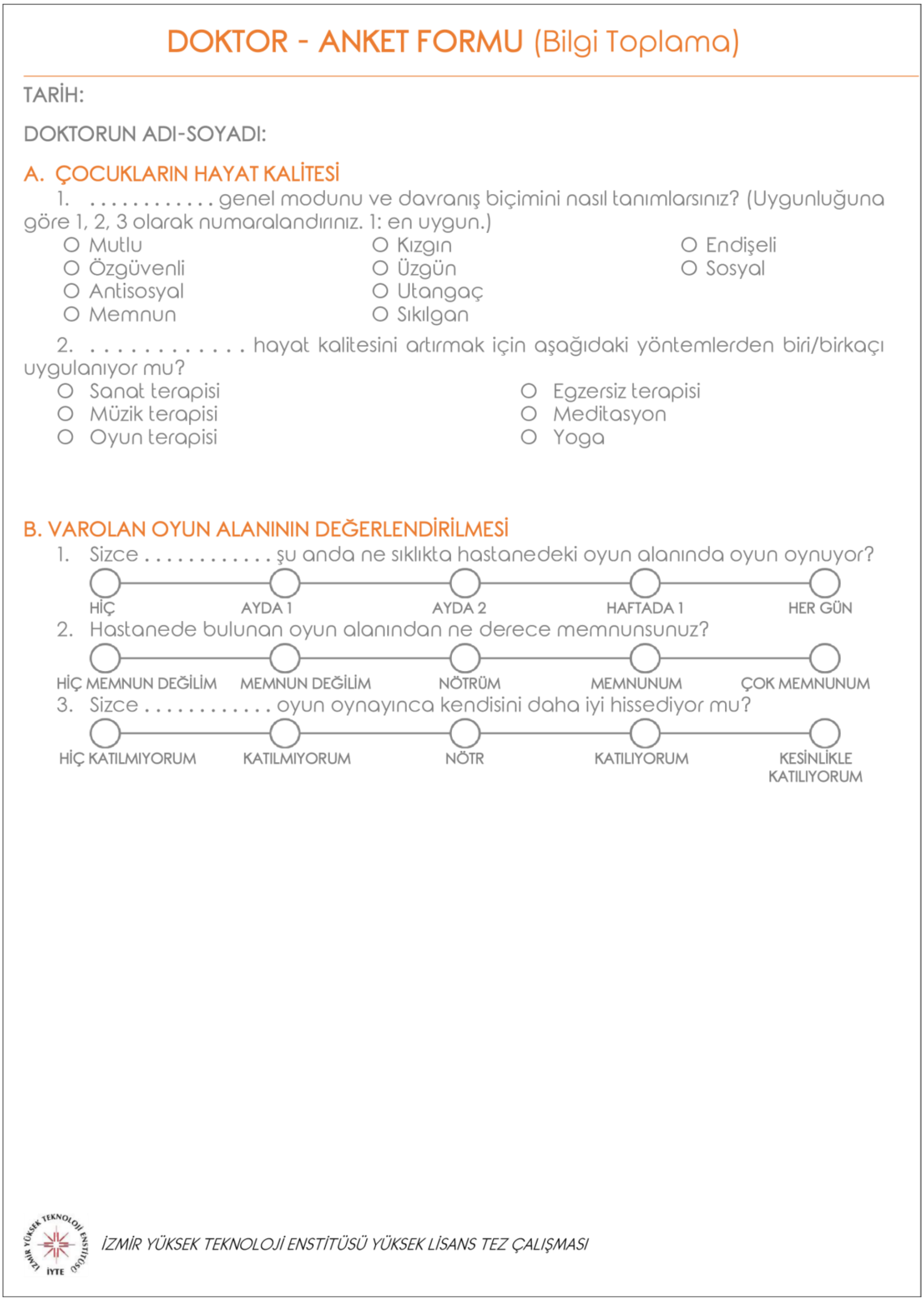
Figure A.13. The questionnaire form for doctors

APPENDIX J

QUESTIONNAIRE FORM FOR DOCTORS (TURKISH)



DOKTOR - ANKET FORMU (Bilgi Toplama)

TARİH:

DOKTORUN ADI-SOYADI:

A. ÇOCUKLARIN HAYAT KALİTESİ

1. .... genel modunu ve davranış biçimini nasıl tanımlarsınız? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

- ○ Mutlu
- ○ Özgüvenli
- ○ Antisosyal
- ○ Memnun
- ○ Kızgın
- ○ Üzgün
- ○ Utangaç
- ○ Sıkılgan
- ○ Endişeli
- ○ Sosyal

2. .... hayat kalitesini artırmak için aşağıdaki yöntemlerden biri/birkaçı uygulanıyor mu?

- ○ Sanat terapisi
- ○ Müzik terapisi
- ○ Oyun terapisi
- ○ Egzersiz terapisi
- ○ Meditasyon
- ○ Yoga

B. VAROLAN OYUN ALANININ DEĞERLENDİRİLMESİ

1. Sizce .... şu anda ne sıklıkta hastanedeki oyun alanında oyun oynuyor?

○ HİÇ ○ AYDA 1 ○ AYDA 2 ○ HAFTADA 1 ○ HER GÜN

2. Hastanede bulunan oyun alanından ne derece memnunsunuz?

○ HİÇ MEMNUN DEĞİLİM ○ MEMNUN DEĞİLİM ○ NÖTRÜM ○ MEMNUNUM ○ ÇOK MEMNUNUM

3. Sizce .... oyun oynayınca kendisini daha iyi hissediyor mu?

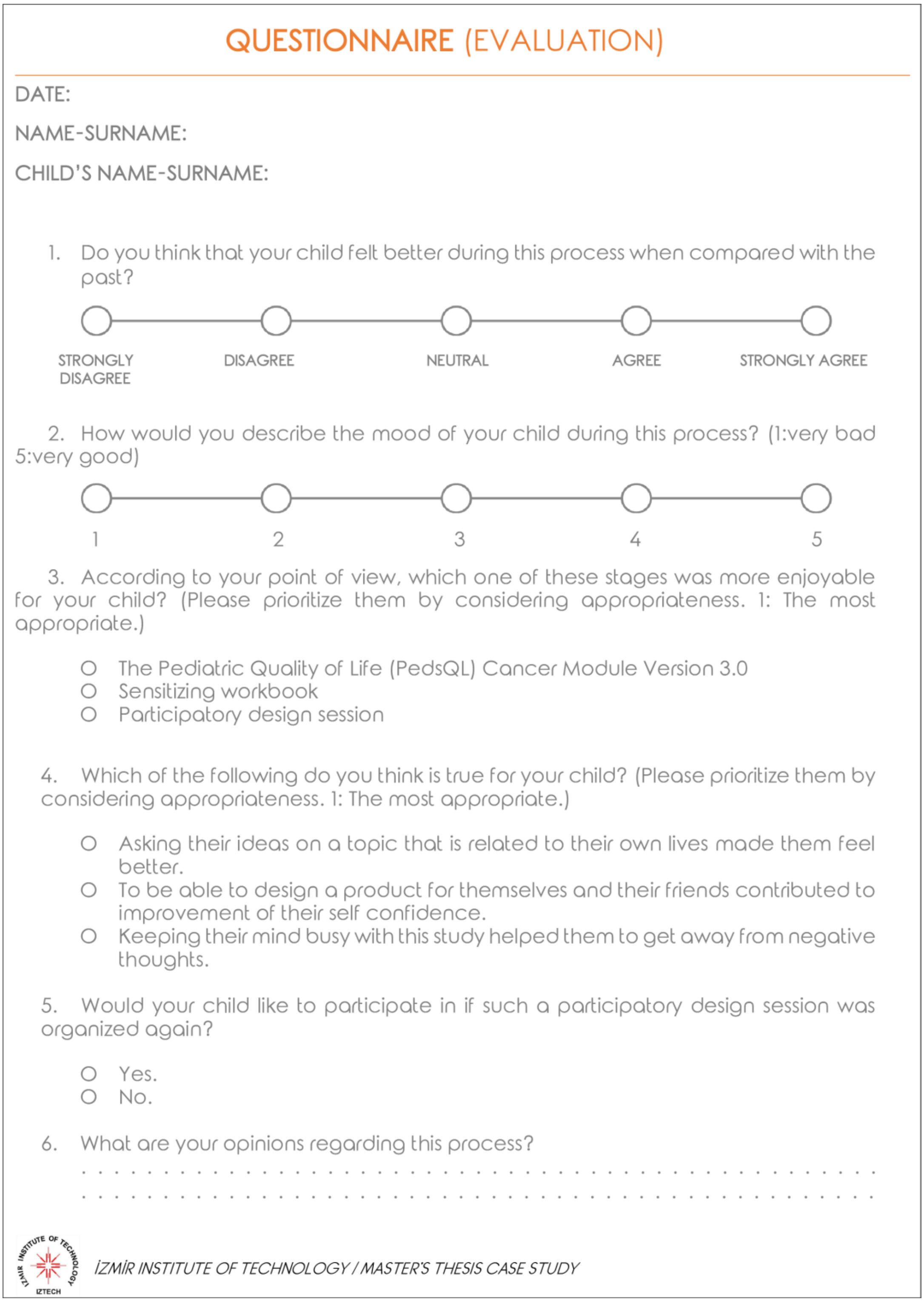
○ HİÇ KATILMIYORUM ○ KATILMIYORUM ○ NÖTR ○ KATILIYORUM ○ KESİNLİKLE KATILIYORUM

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.14. The questionnaire form for doctors in Turkish

APPENDIX K

EVALUATION QUESTIONNAIRE FORM 1



QUESTIONNAIRE (EVALUATION)

DATE:

NAME-SURNAME:

CHILD'S NAME-SURNAME:

1. Do you think that your child felt better during this process when compared with the past?

○	○	○	○	○
STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE

2. How would you describe the mood of your child during this process? (1:very bad 5:very good)

○	○	○	○	○
1	2	3	4	5

3. According to your point of view, which one of these stages was more enjoyable for your child? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ The Pediatric Quality of Life (PedsQL) Cancer Module Version 3.0
○ Sensitizing workbook
○ Participatory design session

4. Which of the following do you think is true for your child? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ Asking their ideas on a topic that is related to their own lives made them feel better.
○ To be able to design a product for themselves and their friends contributed to improvement of their self confidence.
○ Keeping their mind busy with this study helped them to get away from negative thoughts.

5. Would your child like to participate in if such a participatory design session was organized again?

○ Yes.
○ No.

6. What are your opinions regarding this process?

. . . .
. . . .

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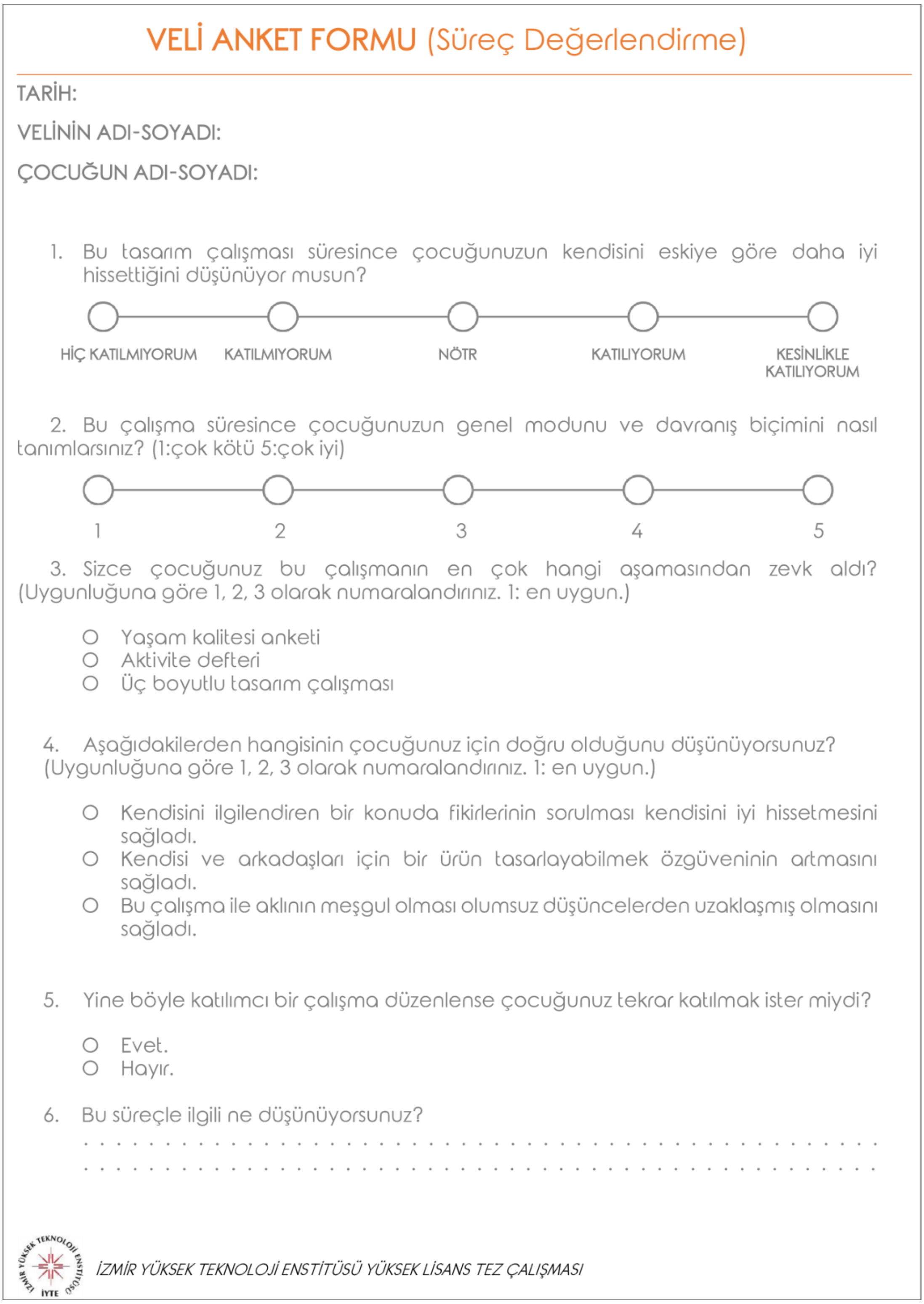
Figure A.15. The evaluation questionnaire form for caregivers

APPENDIX L

EVALUATION QUESTIONNAIRE FORM 1 (TURKISH)



VELİ ANKET FORMU (Süreç Değerlendirme)

TARİH:

VELİNİN ADI-SOYADI:

ÇOCUĞUN ADI-SOYADI:

1. Bu tasarım çalışması süresince çocuğunuzun kendisini eskiye göre daha iyi hissettiğini düşünüyor musun?

○	○	○	○	○
HİÇ KATILMIYORUM	KATILMIYORUM	NÖTR	KATILIYORUM	KESİNLİKLE KATILIYORUM

2. Bu çalışma süresince çocuğunuzun genel modunu ve davranış biçimini nasıl tanımlarsınız? (1:çok kötü 5:çok iyi)

○	○	○	○	○
1	2	3	4	5

3. Sizce çocuğunuz bu çalışmanın en çok hangi aşamasından zevk aldı? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

○ Yaşam kalitesi anketi
○ Aktivite defteri
○ Üç boyutlu tasarım çalışması

4. Aşağıdakilerden hangisinin çocuğunuz için doğru olduğunu düşünüyorsunuz? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

○ Kendisini ilgilendiren bir konuda fikirlerinin sorulması kendisini iyi hissetmesini sağladı.
○ Kendisi ve arkadaşları için bir ürün tasarlayabilmek özgüveninin artmasını sağladı.
○ Bu çalışma ile aklının meşgul olması olumsuz düşüncelerden uzaklaşmış olmasını sağladı.

5. Yine böyle katılımcı bir çalışma düzenlense çocuğunuz tekrar katılmak ister miydi?

○ Evet.
○ Hayır.

6. Bu süreçle ilgili ne düşünüyorsunuz?

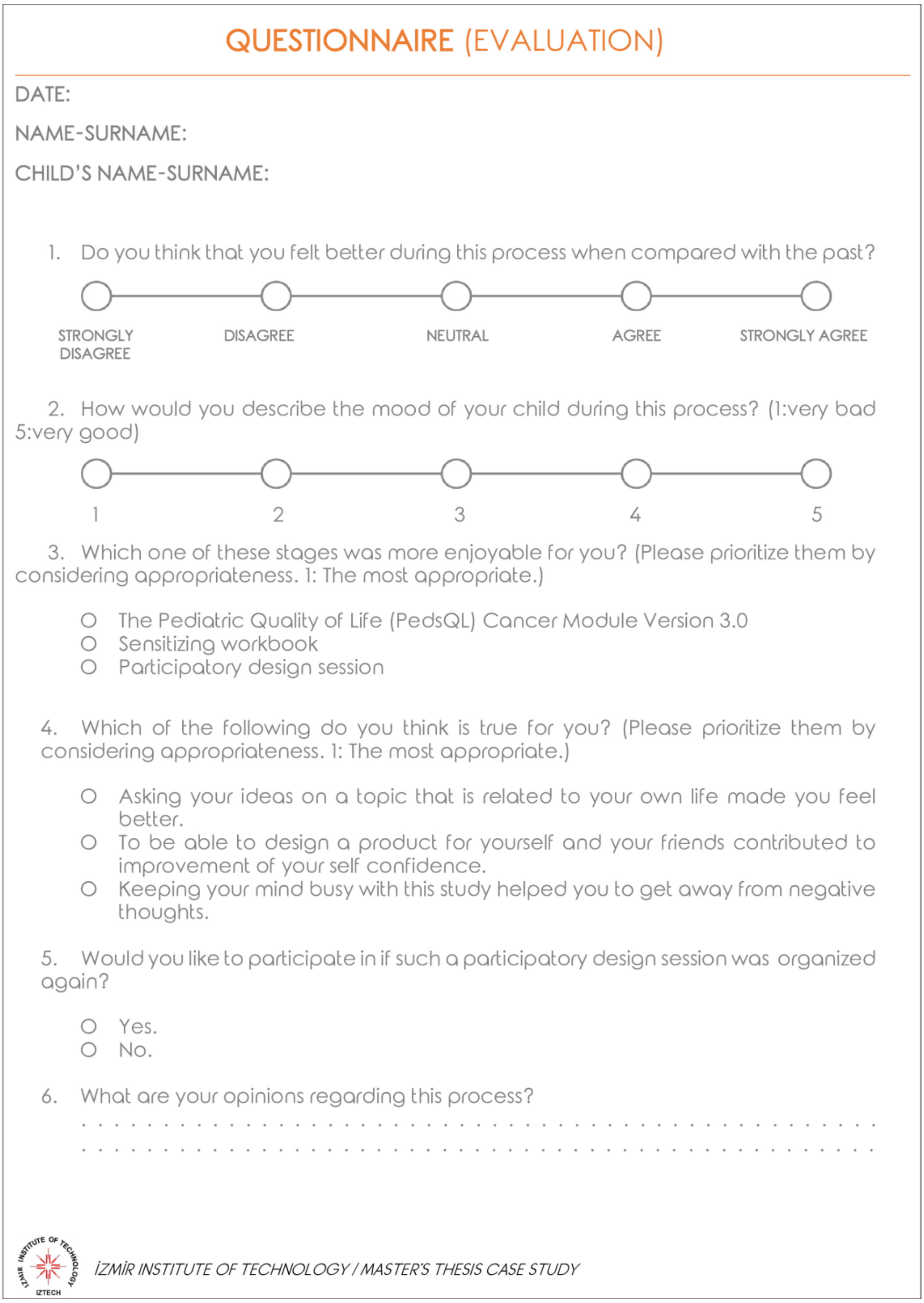
. . . .
. . . .

İZMİR YÜKSEK TEKNOLOJİ ENSTİTÜSÜ YÜKSEK LİSANS TEZ ÇALIŞMASI

Figure A.16. The evaluation questionnaire form for caregivers in Turkish

APPENDIX M

EVALUATION QUESTIONNAIRE FORM 2



QUESTIONNAIRE (EVALUATION)

DATE:

NAME-SURNAME:

CHILD'S NAME-SURNAME:

1. Do you think that you felt better during this process when compared with the past?

○	○	○	○	○
STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE

2. How would you describe the mood of your child during this process? (1:very bad 5:very good)

○	○	○	○	○
1	2	3	4	5

3. Which one of these stages was more enjoyable for you? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ The Pediatric Quality of Life (PedsQL) Cancer Module Version 3.0
○ Sensitizing workbook
○ Participatory design session

4. Which of the following do you think is true for you? (Please prioritize them by considering appropriateness. 1: The most appropriate.)

○ Asking your ideas on a topic that is related to your own life made you feel better.
○ To be able to design a product for yourself and your friends contributed to improvement of your self confidence.
○ Keeping your mind busy with this study helped you to get away from negative thoughts.

5. Would you like to participate in if such a participatory design session was organized again?

○ Yes.
○ No.

6. What are your opinions regarding this process?

. . . .
. . . .

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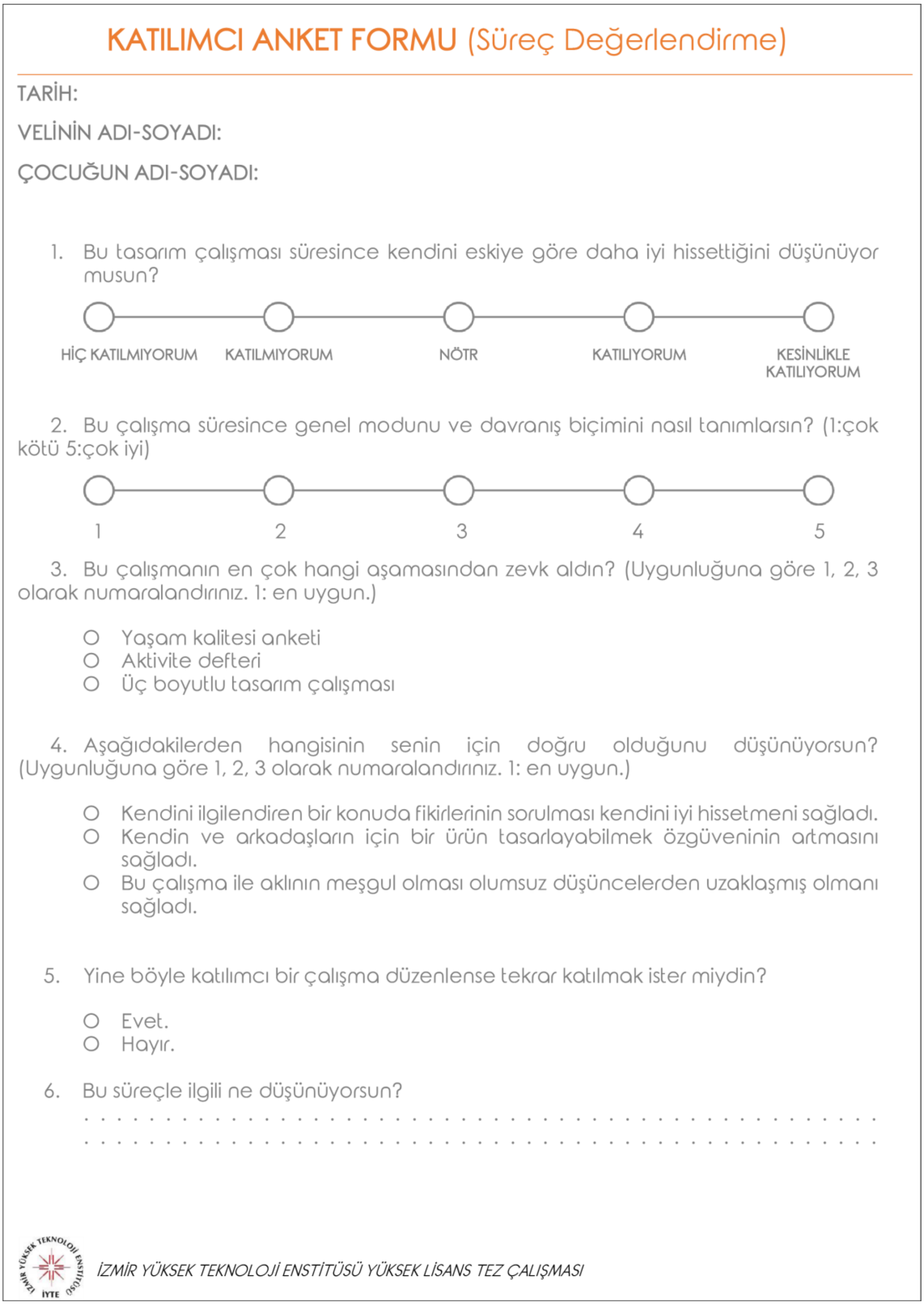
Figure A.17. The evaluation questionnaire form for children

APPENDIX N

EVALUATION QUESTIONNAIRE FORM 2 (TURKISH)



KATILIMCI ANKET FORMU (Süreç Değerlendirme)

TARİH:

VELİNİN ADI-SOYADI:

ÇOCUĞUN ADI-SOYADI:

1. Bu tasarım çalışması süresince kendini eskiye göre daha iyi hissettiğini düşünüyor musun?

○	○	○	○	○
HİÇ KATILMIYORUM	KATILMIYORUM	NÖTR	KATILIYORUM	KESİNLİKLE KATILIYORUM

2. Bu çalışma süresince genel modunu ve davranış biçimini nasıl tanımlarsın? (1:çok kötü 5:çok iyi)

○	○	○	○	○
1	2	3	4	5

3. Bu çalışmanın en çok hangi aşamasından zevk aldın? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

○ Yaşam kalitesi anketi
○ Aktivite defteri
○ Üç boyutlu tasarım çalışması

4. Aşağıdakilerden hangisinin senin için doğru olduğunu düşünüyorsun? (Uygunluğuna göre 1, 2, 3 olarak numaralandırınız. 1: en uygun.)

○ Kendini ilgilendiren bir konuda fikirlerinin sorulması kendini iyi hissetmeni sağladı.
○ Kendin ve arkadaşların için bir ürün tasarlayabilmek özgüveninin artmasını sağladı.
○ Bu çalışma ile aklının meşgul olması olumsuz düşüncelerden uzaklaşmış olmanı sağladı.

5. Yine böyle katılımcı bir çalışma düzenlense tekrar katılmak ister miydin?

○ Evet.
○ Hayır.

6. Bu süreçle ilgili ne düşünüyorsun?

. . . .
. . . .

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Figure A.18. The evaluation questionnaire form for children in Turkish

APPENDIX O

CERTIFICATE OF PARTICIPATION (INFORMAL & FORMAL)

Dear ....;

Between January-February 2019, you also participated in my case study in Dokuz Eylül University Nevvar & Salih İşgören Children's Hospital.

During this process, we have done very well with you. I learned a lot from you. Now, I will try to make actual the designs we have made for those children who have the same needs for both the play area here and at other hospitals. Your contribution is great in this design, which can be useful for both you and your friends. I congratulate you for that!

Thank you so much!

Melis Örnekoğlu

İZMİR INSTITUTE OF TECHNOLOGY / MASTER'S THESIS CASE STUDY

Dear ....;

Between January-February 2019, you also participated in my case study in Dokuz Eylül University Nevvar & Salih İşgören Children's Hospital.

During this process, we have done very well with you. I learned a lot from you. Now, I will try to make actual the designs we have made for those children who have the same needs for both the play area here and at other hospitals. Your contribution is great in this design, which can be useful for both you and your friends. I congratulate you for that!

Thank you so much!

Melis Örnekoğlu

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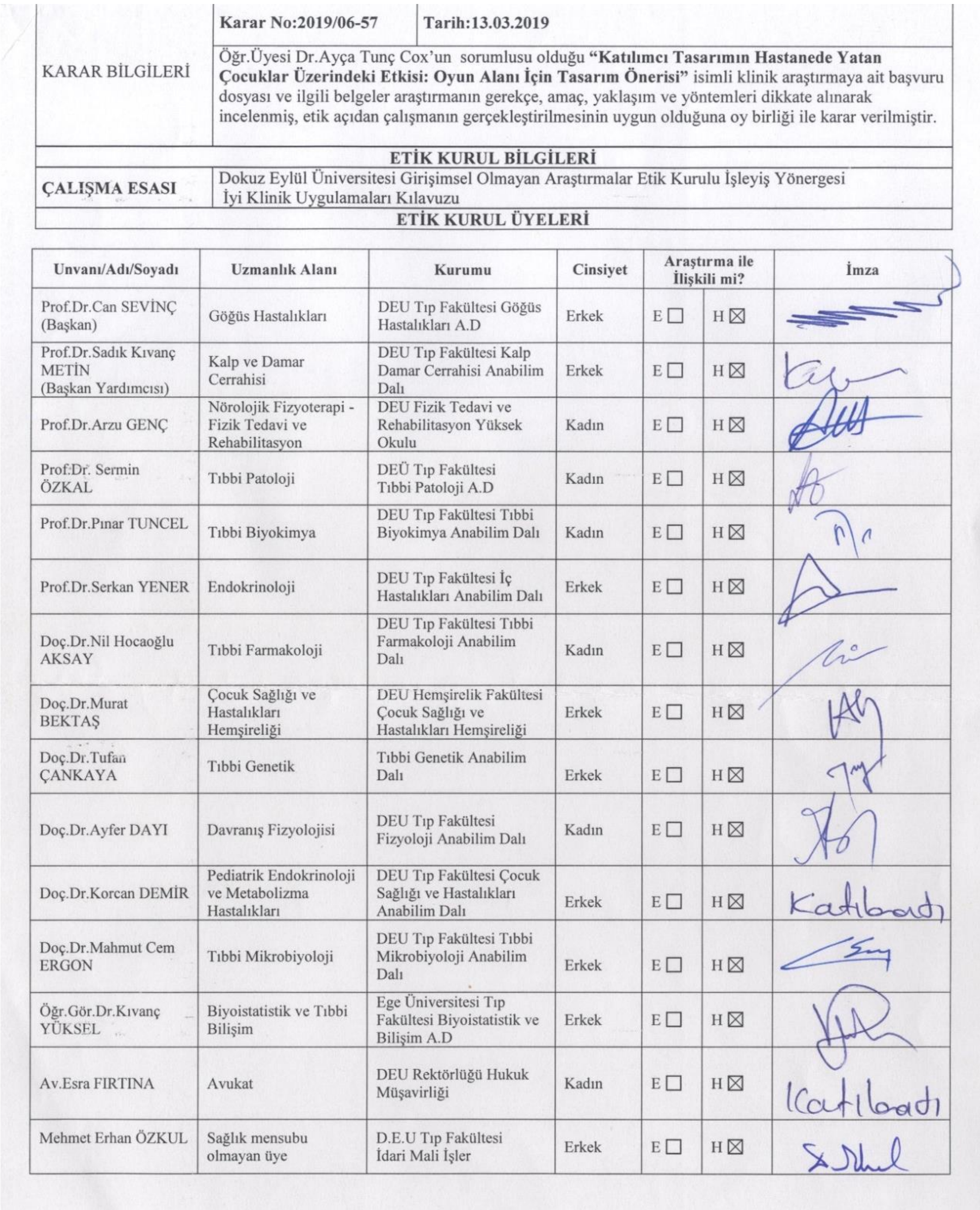
Figure A.19. The certificate of participation (formal and informal version respectively)

APPENDIX P

APPROVALS OF ETHICAL COMMITTEES

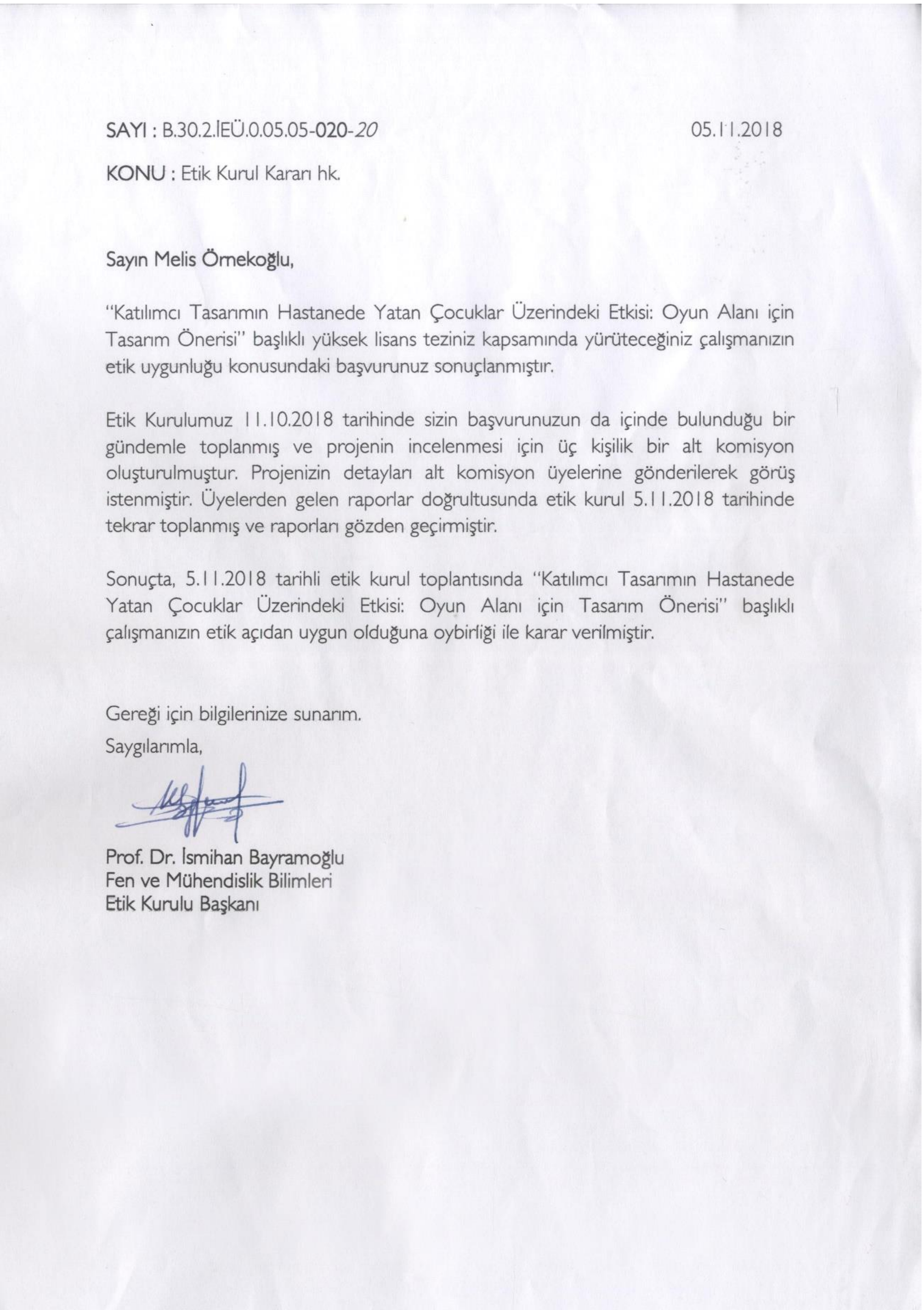


KARAR BİLGİLERİ	**Karar No:2019/06-57**	**Tarih:13.03.2019**
	Öğr.Üyesi Dr.Ayça Tunç Cox'un sorumlusu olduğu **"Katılımcı Tasarımın Hastanede Yatan Çocuklar Üzerindeki Etkisi: Oyun Alanı İçin Tasarım Önerisi"** isimli klinik araştırmaya ait başvuru dosyası ve ilgili belgeler araştırmanın gerekçe, amaç, yaklaşım ve yöntemleri dikkate alınarak incelenmiş, etik açıdan çalışmanın gerçekleştirilmesinin uygun olduğuna oy birliği ile karar verilmiştir.	
ETİK KURUL BİLGİLERİ		
ÇALIŞMA ESASI	Dokuz Eylül Üniversitesi Girişimsel Olmayan Araştırmalar Etik Kurulu İşleyiş Yönergesi İyi Klinik Uygulamaları Kılavuzu	
ETİK KURUL ÜYELERİ		

Unvanı/Adı/Soyadı	**Uzmanlık Alanı**	**Kurumu**	**Cinsiyet**	**Araştırma ile İlişkili mi?**		**İmza**
Prof.Dr.Can SEVİNÇ (Başkan)	Göğüs Hastalıkları	DEU Tıp Fakültesi Göğüs Hastalıkları A.D	Erkek	E ☐	H ☒	
Prof.Dr.Sadık Kıvanç METİN (Başkan Yardımcısı)	Kalp ve Damar Cerrahisi	DEU Tıp Fakültesi Kalp Damar Cerrahisi Anabilim Dalı	Erkek	E ☐	H ☒	
Prof.Dr.Arzu GENÇ	Nörolojik Fizyoterapi - Fizik Tedavi ve Rehabilitasyon	DEU Fizik Tedavi ve Rehabilitasyon Yüksek Okulu	Kadın	E ☐	H ☒	
Prof.Dr. Sermin ÖZKAL	Tıbbi Patoloji	DEÜ Tıp Fakültesi Tıbbi Patoloji A.D	Kadın	E ☐	H ☒	
Prof.Dr.Pınar TUNCEL	Tıbbi Biyokimya	DEU Tıp Fakültesi Tıbbi Biyokimya Anabilim Dalı	Kadın	E ☐	H ☒	
Prof.Dr.Serkan YENER	Endokrinoloji	DEU Tıp Fakültesi İç Hastalıkları Anabilim Dalı	Erkek	E ☐	H ☒	
Doç.Dr.Nil Hocaoğlu AKSAY	Tıbbi Farmakoloji	DEU Tıp Fakültesi Tıbbi Farmakoloji Anabilim Dalı	Kadın	E ☐	H ☒	
Doç.Dr.Murat BEKTAŞ	Çocuk Sağlığı ve Hastalıkları Hemşireliği	DEU Hemşirelik Fakültesi Çocuk Sağlığı ve Hastalıkları Hemşireliği	Erkek	E ☐	H ☒	
Doç.Dr.Tufan ÇANKAYA	Tıbbi Genetik	Tıbbi Genetik Anabilim Dalı	Erkek	E ☐	H ☒	
Doç.Dr.Ayfer DAYI	Davranış Fizyolojisi	DEU Tıp Fakültesi Fizyoloji Anabilim Dalı	Kadın	E ☐	H ☒	
Doç.Dr.Korcan DEMİR	Pediatrik Endokrinoloji ve Metabolizma Hastalıkları	DEU Tıp Fakültesi Çocuk Sağlığı ve Hastalıkları Anabilim Dalı	Erkek	E ☐	H ☒	Katılmadı
Doç.Dr.Mahmut Cem ERGON	Tıbbi Mikrobiyoloji	DEU Tıp Fakültesi Tıbbi Mikrobiyoloji Anabilim Dalı	Erkek	E ☐	H ☒	
Öğr.Gör.Dr.Kıvanç YÜKSEL	Biyoistatistik ve Tıbbi Bilişim	Ege Üniversitesi Tıp Fakültesi Biyoistatistik ve Bilişim A.D	Erkek	E ☐	H ☒	
Av.Esra FIRTINA	Avukat	DEU Rektörlüğü Hukuk Müşavirliği	Kadın	E ☐	H ☒	Katılmadı
Mehmet Erhan ÖZKUL	Sağlık mensubu olmayan üye	D.E.U Tıp Fakültesi İdari Mali İşler	Erkek	E ☐	H ☒	

Dokuz Eylül Üniversitesi Girişimsel Olmayan Araştırmalar Etik Kurulu Karar Formu

Figure A.20. Approval from Noninvasive Research Ethics Board of Dokuz Eylül University



SAYI : B.30.2.İEÜ.0.05.05-**020**-*20* 05.11.2018

KONU : Etik Kurul Kararı hk.

Sayın Melis Örnekoğlu,

"Katılımcı Tasarımın Hastanede Yatan Çocuklar Üzerindeki Etkisi: Oyun Alanı için Tasarım Önerisi" başlıklı yüksek lisans teziniz kapsamında yürüteceğiniz çalışmanızın etik uygunluğu konusundaki başvurunuz sonuçlanmıştır.

Etik Kurulumuz 11.10.2018 tarihinde sizin başvurunuzun da içinde bulunduğu bir gündemle toplanmış ve projenin incelenmesi için üç kişilik bir alt komisyon oluşturulmuştur. Projenizin detayları alt komisyon üyelerine gönderilerek görüş istenmiştir. Üyelerden gelen raporlar doğrultusunda etik kurul 5.11.2018 tarihinde tekrar toplanmış ve raporları gözden geçirmiştir.

Sonuçta, 5.11.2018 tarihli etik kurul toplantısında "Katılımcı Tasarımın Hastanede Yatan Çocuklar Üzerindeki Etkisi: Oyun Alanı için Tasarım Önerisi" başlıklı çalışmanızın etik açıdan uygun olduğuna oybirliği ile karar verilmiştir.

Gereği için bilgilerinize sunarım.

Saygılarımla,

Prof. Dr. İsmihan Bayramoğlu
Fen ve Mühendislik Bilimleri
Etik Kurulu Başkanı

Figure A.21. Approval from the Ethics Committee of İzmir University of Economics

APPENDIX R

SENSITIZING WORKBOOK (FORMAL)

activity workbook

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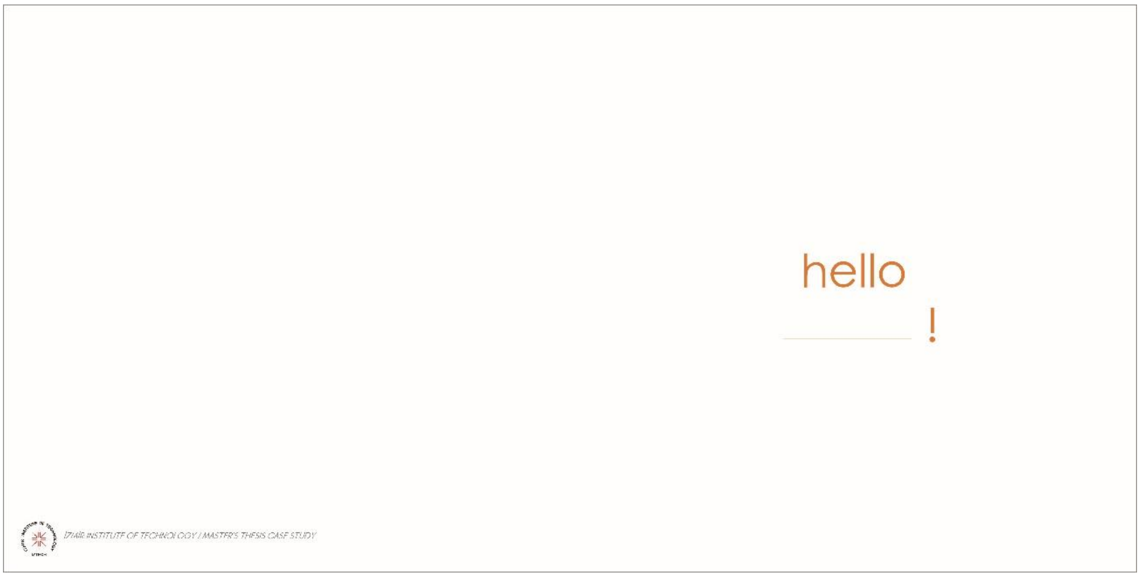
Figure A.22. The cover page of the sensitizing workbook (formal)



hello

!

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Figure A.23. The first page of the sensitizing workbook (formal)

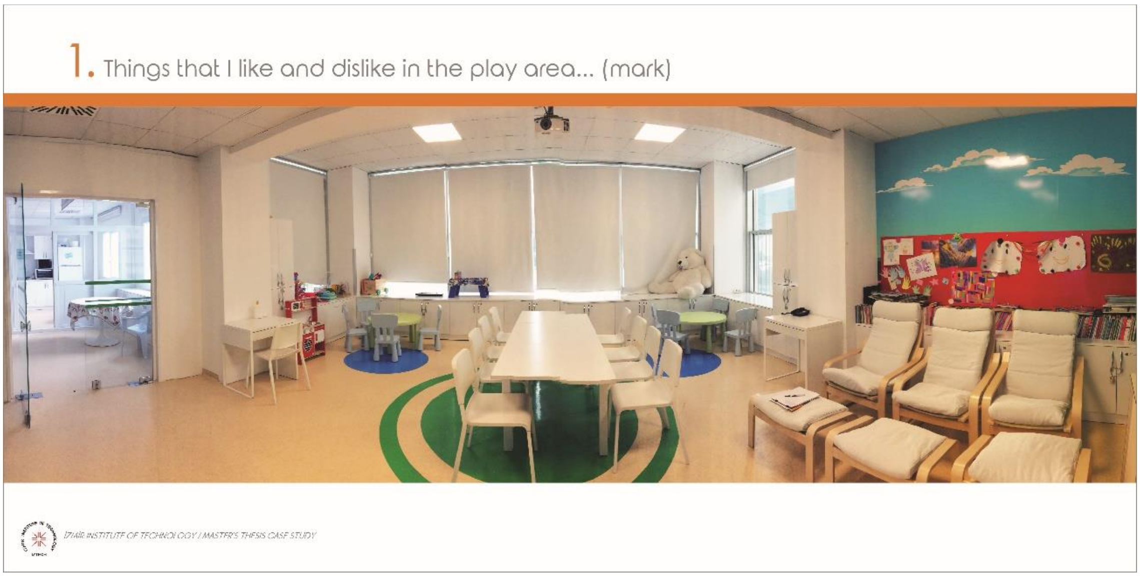
1. Things that I like and dislike in the play area... (mark)

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Figure A.24. The first activity in the sensitizing workbook (formal)

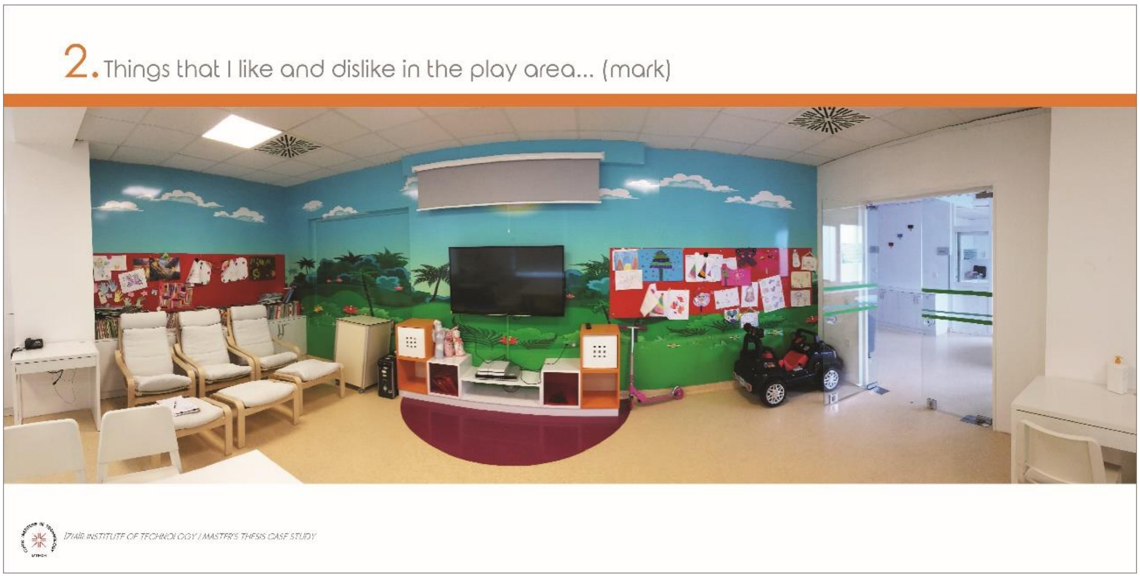
2. Things that I like and dislike in the play area... (mark)

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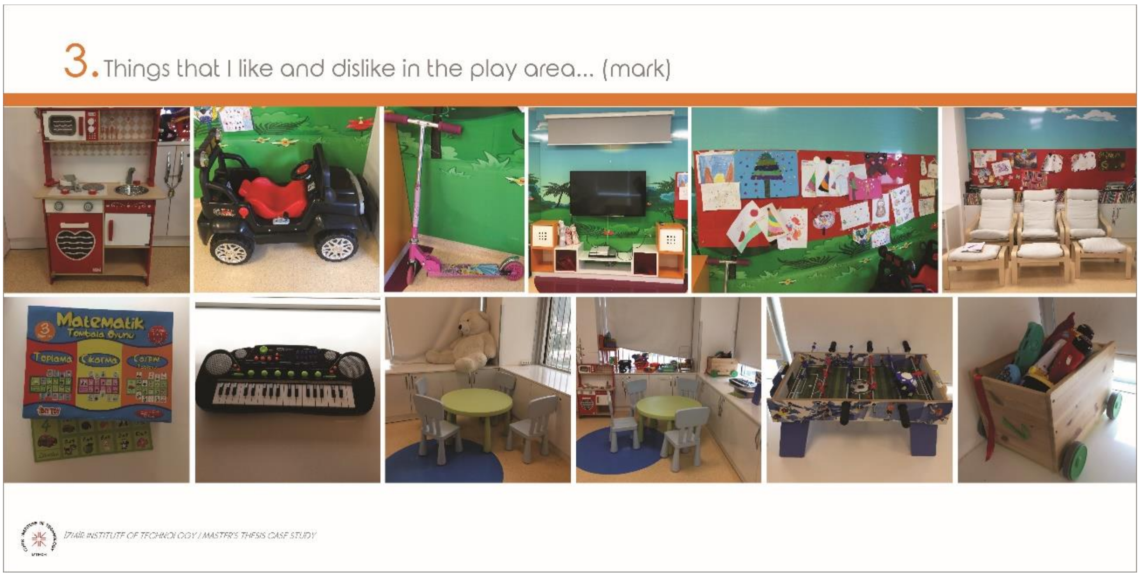
Figure A.25. The second activity in the sensitizing workbook (formal)



3. Things that I like and dislike in the play area... (mark)

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Figure A.26. The third activity in the sensitizing workbook (formal)

4. Good memories... Bad memories...

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Figure A.27. The fourth activity in the sensitizing workbook (formal)

5. I wish it would be in the play area... (write or draw)

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Figure A.28. The fifth activity in the sensitizing workbook (formal)

thank you

!

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Figure A.29. The last page of the sensitizing workbook (formal)

APPENDIX S

SENSITIZING WORKBOOK (INFORMAL)

Figure A.30. The cover page of the sensitizing workbook (informal)

Figure A.31. The first page of the sensitizing workbook (informal)

Figure A.32. The first activity in the sensitizing workbook (informal)

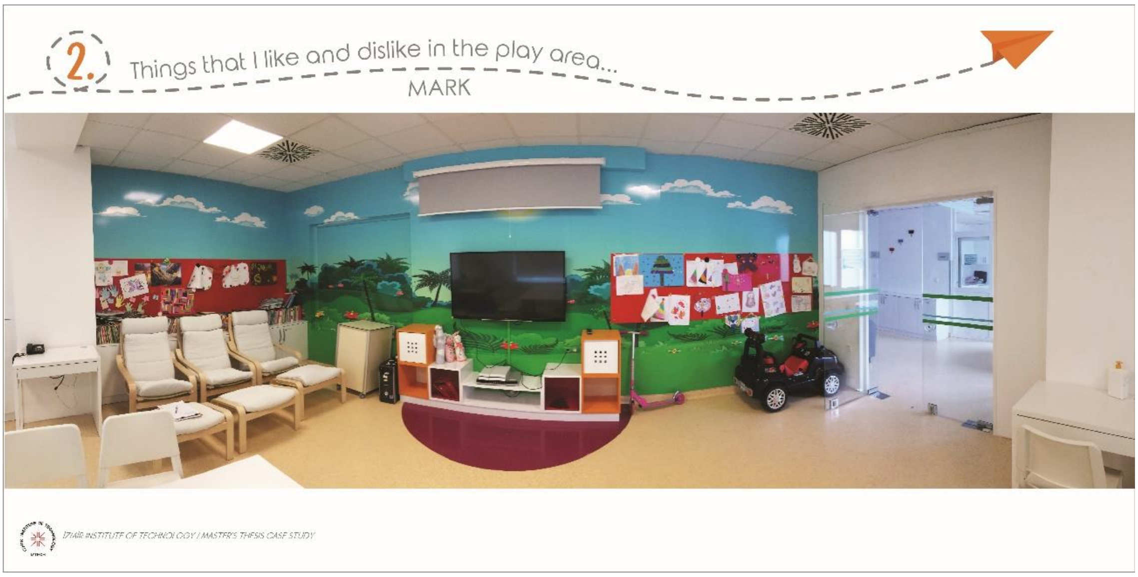

Figure A.33. The first activity in the sensitizing workbook (informal)

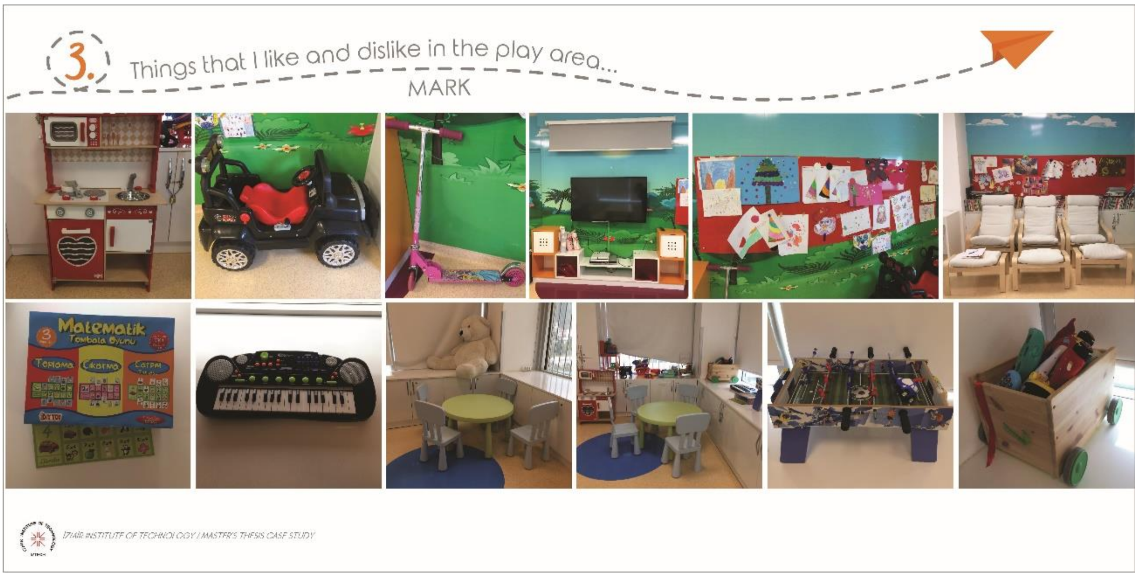

Figure A.34. The third activity in the sensitizing workbook (informal)

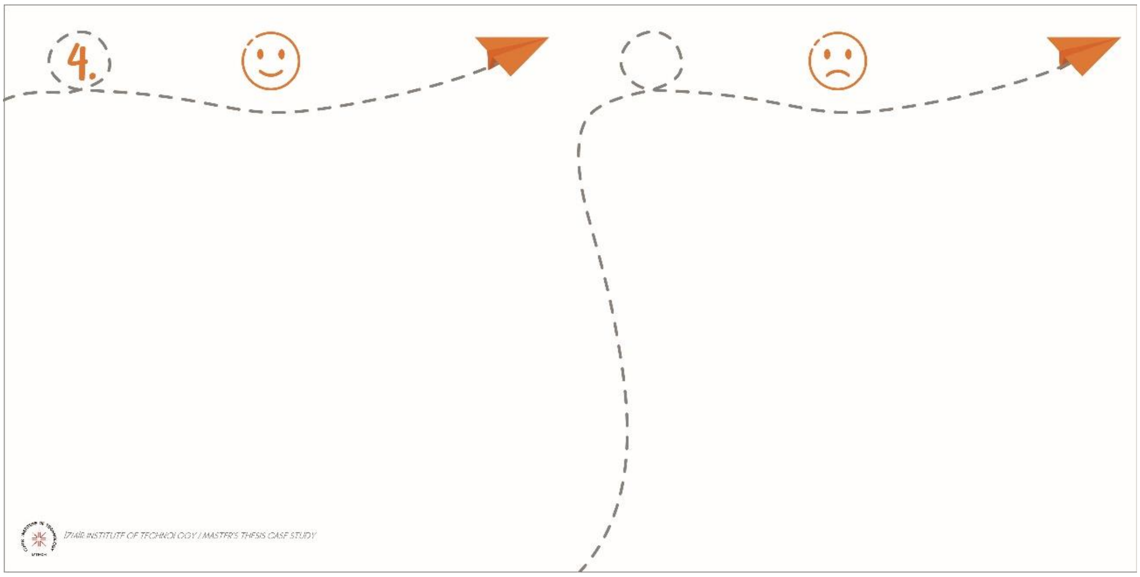

Figure A.35. The fourth activity in the sensitizing workbook (informal)

5. I wish it would be in the play area...

WRITE or DRAW

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Figure A.36. The fifth activity in the sensitizing workbook (informal)

thank you

------ !

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Figure A.37. The last page of the sensitizing workbook (informal)

APPENDIX T

STICKERS FOR SENSITIZING WORKBOOK

Figure A.38. The sticker sheets for the sensitizing workbooks