

## CO-DESIGN WITH CHILDREN WITH CANCER: INSIGHTS FROM WHAT THEY SAY, MAKE, AND DO (1)

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1. This article is derived from the corresponding author's master's thesis, supervised by; Assoc. Prof. Dr. Ayça Tunç-Cox and Prof. Dr. Deniz Hasirci. In the scope of the thesis, another paper (Örnekoğlu-Selçuk et al., 2022) gives more detailed information regarding the importance of communication during co-design with children with cancer. The aforementioned conference paper was presented at the 5th National Design Research Conference UTAK 2022. This article complements that work with its focus on the design recommendations, suggestions for facilitators and the link between QOL and co-design sessions.

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### INTRODUCTION

Despite attempts to change children's objectified position from 'human becoming' to 'human being,' they are often marginalized in society (Skivenes and Strandbu, 2006; Kellett, 2009). Generally, children are not directly asked to express their ideas or needs in many situations that affect them, instead, adults decide on their behalf. Children diagnosed with cancer become even more marginalized and their quality of life (QOL) decreases due to their lack of control and the severity of their illness and treatment (Hilda et al., 2015).

Playing has a vital role in children's QOL for maintaining the development of children and coping with stress caused by hospital unfamiliarity (Carvalho e Sousa et al., 2015). Play activities are particularly beneficial for hospitalized children since they provide a linkage to home, a sense of normalcy and control, and the ability to express feelings (Weaver & Groves, 2007). This indicates the importance of a play area for children with cancer and the need to provide well-designed play area in hospitals so as to contribute to their QOL.

To this end, scrutinizing the needs of children with cancer regarding play areas in hospitals is crucial. Conducting co-design sessions with them might be helpful since this approach advocates an active involvement of users in the design process (Skivenes and Strandbu, 2006; Mattelmäki and Visser, 2011). Thanks to co-design sessions, children's design ideas concerning a play area in a hospital might yield recommendations that are more responsive to their needs, thereby, increasing their QOL.

Starting from this premise, this study reports on a co-design process conducted with children with cancer at a hospital in Izmir, Turkey; to generate furniture design ideas for the play area located at the Hematology and Oncology Service. It strives to provide recommendations to designers – who are deemed as facilitators of co-design sessions with children

with cancer – and a reference for further studies. Ultimately, this study promotes the active involvement of children with cancer in co-design processes, underlining the possible connections between their participation in co-designing and their QOL.

### **Quality of Life (QOL) of Children with Cancer**

QOL is the state of well-being in terms of physical, psychological and social circumstances of human beings (Evan, 2014). Cancer diagnosis produces undesired consequences in the lives and QOL of children (Hilda et al., 2015). The side effects – illness and treatment uncertainty, interrupted daily routine and lack of play – cause a dramatic decrease in their QOL (Favara-Scacco et al., 2001).

To improve the QOL of children with cancer, non-pharmacological intervention techniques have been applied so far. Hendriks et al. (2016) have associated participatory design with perceived QOL; claiming that not just the end result but also the process itself might be beneficial for participants' QOL. Accordingly, the role of the co-design process in contributing to the QOL of children with cancer has been investigated in this study.

### **Co-designing with Children with Cancer**

In today's world, the transition from user-centered design to participatory design (which is a collaborative approach) has led to a shift in the role of users as well as designers (Johnson et al., 2017). *Co-design* has its roots in participatory design (Steen, 2013), which gives the users that will be affected by the outcome of a design process a chance to have a voice in the design of products, services and environments (Robertson and Simonsen, 2012). Accordingly, co-design can be defined as a process in which designers are involved as facilitators as well, rather than experts, to help people with lived experience express themselves in a better way and influence the final design outcome as active participants (Mattelmäki and Visser, 2011). Sanders' (1992) approach by introducing generative techniques brings about this alteration in the role of users from passive informants to active participants. This is also in line with *generative design research* defined by Sanders and Stappers (2012) as an approach that promotes changing the role of the people from testers to design partners so as to better meet their needs.

A similar shift is noticeable in the perception of children's involvement in a design process. Previously, more passive methods (e.g. listening and consulting) were used with child participants. Hanington (2003) explained that traditional research methods like observations and interviews provide limited involvement of children. The claim is that these techniques are not conducted *with* but *on* children (Barker and Weller, 2003). Over time, children's participation gained more importance, thus, facilitating their fruitful participation in design processes became essential (Kellett, 2009).

However, the number of co-design studies with children with cancer is still limited (Ruland et al., 2008; Lindberg, 2013a; Mateus-Berr et al., 2015). Children's involvement in these studies is mostly reduced to testing (Boon et al., 2016; Warren, 2019). Particularly in industrial design, it is difficult to find studies that report on a co-design process conducted with children with cancer, not for/on them. Bearing in mind the significance of meaningful and active involvement, this study differs from the existing ones by enabling children with cancer to actively participate in the design

process and not only in tests, observations or interviews. Therefore, it is expected to contribute to existing literature. Nah and Lee (2015) emphasize the importance of actualizing children's participation by considering their rights and creating an inclusive co-design environment. Accordingly, as elaborated in section 2.2.4. Considerations, various factors have been investigated to conduct this study in a "youth-friendly" way, so that the children would not be harmed (Lindberg, 2013b).

## THE CASE STUDY

This case study was conducted at the play area of the Hematology and Oncology Service of a children's hospital in Turkey. The said play area was intended to make children's hospitalization period more bearable, however, it seems not to be in active use by children. Preliminary observation of the children's daily routines and their usage of the play area was conducted to define the problem and prepare the brief for the co-design sessions. During the interviews, the hospital staff and caregivers stated that the furniture in the play area does not cater to the needs of all children, perhaps because children were not involved in its design process. Further observations later proved the significance of furniture design in the play area. This testified to the necessity for a better understanding of the needs and wishes of children with cancer regarding the play area in the hospital. Consequently, co-design sessions were conducted with them by one of the authors – who will be referred to as 'researcher' throughout the text.

### Participants

In total, thirteen participants – five inpatient children with cancer, five caregivers of these children, two doctors and the head nurse – of the Hematology and Oncology Service were involved at different stages of the co-design process.

#### Doctors and the Nurse

First, the researcher negotiated with two doctors, an oncologist and a hematologist, for approval and advice. They guided the researcher while determining available inpatient children with cancer as participants based on their illness and treatment conditions. They aided the researcher in selecting harmless materials for the Make toolkit. Lastly, the doctors and head nurse took part in the questionnaires and interviews regarding the children's illnesses as well as the play area in the hospital.

#### Children with Cancer

This study was conducted with inpatient children with cancer who stay in the hospital. Unlike outpatient children, the inpatient children follow a routine that consists of several chemotherapy cycles. If their blood test results are good enough to cope with the side effects of the treatment, they stay in the hospital for chemotherapy. At the end of their required period of stay, they return home to rest.

The key criteria while determining the participants were the treatment, health condition and age of the children. This study aimed to co-design furniture with these children which could make the play area more responsive to the needs of all inpatient children. Diversity in age groups was intended to understand their varied needs. Thus, the participants were between the ages of 7 and 17.

The researcher informed potential participants and their caregivers about the study both verbally and in writing. Due to the severity of the illness, the number of participants was rather limited and the study had to be completed in a month with each child.

#### Caregivers of the Children

Caregivers – who are the companions of children, participated at several stages of the study. At least one caregiver with a familial relation to the children stays with them while on admission in the hospital. The researcher contacted such caregivers to arrange meetings.

#### Method

Generative design research was conducted in the study to facilitate the active participation of the children by using a combination of ‘Say’ (e.g., interviews), ‘Do’ (e.g., observations) and ‘Make’ (e.g., Make toolkits) tools and techniques since all three are complementary (Hanington, 2010; Sanders and Stappers, 2012). In other words, *triangulation* was used by combining different kinds of data to increase the scope and depth of this study (Flick, 2018).

#### Do Techniques: Observations

Observation was the first method that was applied in the preliminary stages. During the observation process, open-ended notes were taken on an observation log about four aspects: (1) the interior design of the play area (2) activities provided in the play area (3) children’s frequency of using the play area, and (4) children’s mood in the play area.

#### Say Techniques: Interviews and Questionnaires

Interviews were conducted with caregivers of children, two doctors and a head nurse. They were administered a questionnaire to gain insight into the children’s preferences, lifestyle, illness and QOL.

The Pediatric Quality of Life Inventory (PedsQL) is an inventory prepared for measuring QOL of children (Varni et al., 2002). PedsQL is applied to children with cancer and their caregivers before and after the co-design process to see if there will be noticeable difference in children’s QOL. PedsQL has been validated in several age groups, languages and cultures (Felder-Puig et al., 2004; Kabak et al., 2016). It also provides age-appropriate options that consider the cognitive development stage of children (Varni et al., 2002). To support PedsQL results, children and their caregivers completed a questionnaire where they were asked to evaluate the co-design process and its relation to children’s QOL. The Turkish version of the PedsQL 4.0 Generic Core Scales was available for use online.

#### Make Techniques: Co-design Sessions

Say techniques might not work well alone when it comes to the active involvement of children. For instance, young children might not be able to fully articulate what they need and want only through Say techniques because of their limited linguistic skills. Still, their linguistic skills might not necessarily represent their cognitive skills (Bryant, 1974). Do techniques on their own may not be the best option either since it is likely to misinterpret the children’s actions from an adult’s perspective (Grundy et al., 2012). Hence, using either one of these methods in isolation might limit the active involvement of children in the design process. Therefore, Make toolkits that may consist of countless sorts of 2D or 3D tools such as

words, photos, dummies and Legos (Sanders and Stappers, 2012) might be more inclusive for children as familiar and creative tools. Providing easy configurations and ambiguous shapes, they help children to interpret them differently in a variety of range creative ways (Lindberg, 2013b). Children can create models, collages or drawings to express themselves (Grundy et al., 2012; Lindberg, 2013b). Of course, it is still advisable to talk with them about what they created through the Make techniques to prevent any misinterpretation; this is how Say and Make techniques complement each other (Horstman et al., 2008).

Through Make techniques, the co-design sessions were conducted only with children with cancer as the main users of the play area. As a preparation for the sessions, children were given sensitizing workbooks to help them become more conscious of their experiences. After completing the activities in the workbook, participants brought them to the one-on-one co-design sessions.

#### Sensitizing Workbook

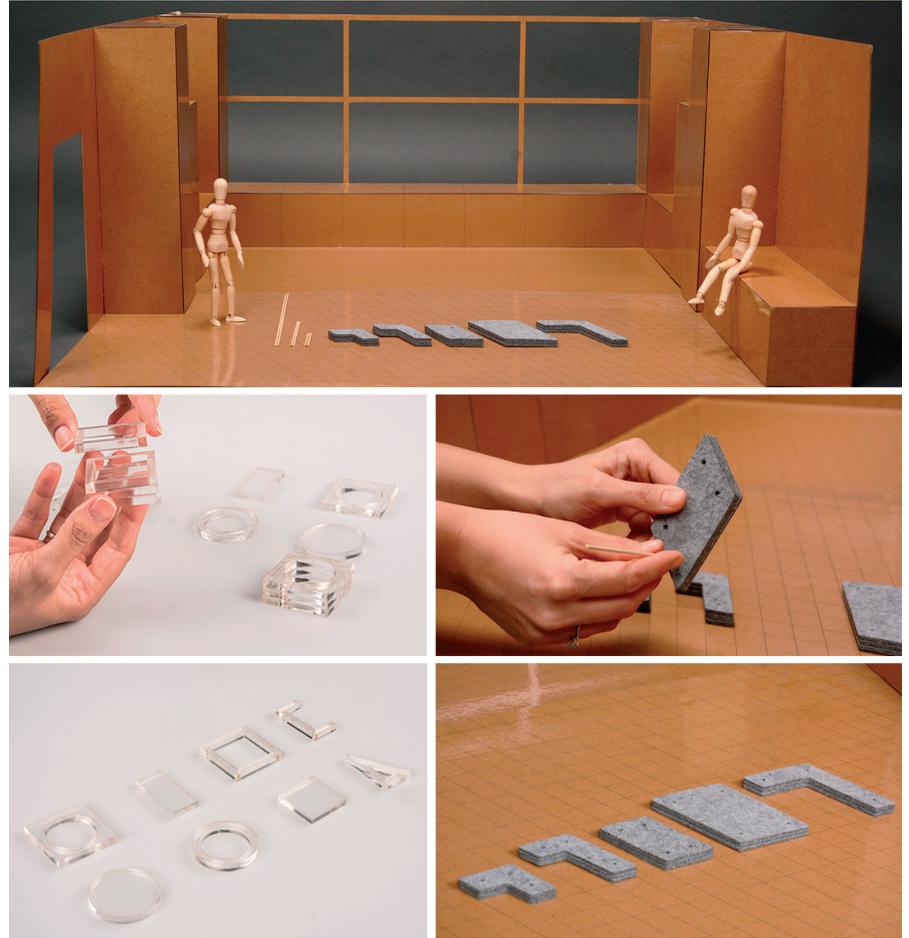
The sensitizing workbook included five questions in total. The first three questions were designed to gain insight on children's opinions and preferences of the existing play area. Thus, they were provided with photographs of the play area as well as "plus" (for furniture they like) and "minus" (for furniture they dislike) stickers. For question four, the page was divided into two columns – good and bad memories, and the children were given a sticker sheet that contained 91 images about different concepts. They were asked to paste them either on the right (bad memories) or left (good memories) side. In question five, children were asked to write or draw their dreams about the play area on a blank page. The last two questions were to understand their needs in and wishes for the play area.

#### Make Toolkit

A Make toolkit (**Figure 1**) was prepared for designing furniture for the play area to help children express themselves easily. It consisted of modules made of felt, wooden sticks of varying lengths, a 1/8 scale model of the play area made of corrugated cardboard and wooden mannequins. To make the children engage better, Lego-like plexiglas modules were prepared for the toolkit. However, felt was preferred in the end for its lightness and softness. Five different forms were prepared with 60 degrees of angle for more options while designing furniture.

#### Considerations

Before conducting the co-design sessions – and in light of the literature review and the analysis of observations, interviews and questionnaire results – various factors were taken into consideration to avoid any harm to children or ruin their treatment (Lindberg, 2013a). Furthermore, the factors also helped to elicit more information from children. The factors include: (1) To provide them with the necessary tools for facilitating their active participation, it is important to pay attention to their skills of expressing themselves easily (Spiel et al., 2018) taking cognizance of their age range (Fails et al., 2013) especially when conducting co-design sessions with marginalized children. Children between the ages of 7 and 10 (Piaget's (1995) concrete operational stage) can think in a logical way with concrete information, however, abstract thinking is not easy for them. Therefore, using concrete objects is recommended while conducting research with them (Lerner, 2002; Fails et al., 2013). Accordingly, a Make toolkit was



**Figure 1.** The Make toolkit designed by the researcher (top), the initial ideas for modules of the Make toolkit made of plexiglas (left bottom) and the final ideas for modules of the Make toolkit made of felt (right bottom) (Photography: Ersan Çelikaş)

designed to enable especially younger children who might not fully express themselves verbally to use their making skills to complement their verbal skills and communicate through design language. (2) Without changing the content, two visually different templates were prepared for the sensitizing workbooks and the Certificate of Participation for younger and older children. (3) A wooden mannequin proxy (Grundy et al., 2012) was used to make children feel more comfortable while sharing their opinions. (4) So as not to overwhelm the children, the co-design sessions were arranged to be a maximum of one hour long. (5) Co-design sessions were conducted one-on-one (Horstman et al., 2008) with each child for an in-depth investigation. (6) The researcher played games with the children and shared personal information (Horstman et al., 2008) about herself to bridge the sense of hierarchy. (7) Before and after each co-design session, the Make toolkit was cleaned with sanitizers to prevent infection. (8) At the end of the sessions, each child was presented with a Certificate of Participation and a small gift to give them a sense of feeling for contributing to the study. (9) Lastly, ethical approval was obtained from the Ethics Committee of Izmir University of Economics (B.30.2.İEÜ.0.05.05-020.20) and Non-invasive Research Ethics Board of Dokuz Eylül University (2019/06-57) before conducting this study. Additionally, all participants signed an informed consent form and pseudonyms were used for confidentiality (Kirk, 2007).

### Data Analysis

The data collected through observations of the play area was analyzed through content analysis and created the base for the study. In addition, interviews and questionnaires with caregivers, doctors and the nurse provided rich data, especially with regards to information that could not be gathered through observation (e.g., illness, QOL, daily routine, children's play preferences). The results of the analysis helped to design the Make toolkit and sensitizing workbook according to the needs of children. Moreover, the co-design processes with each child were shaped in light of the data collected through observation, interviews and questionnaires. For instance, co-design sessions were conducted one-on-one with each child having learnt more about the sensitivity of their illness and the concerns of their caregivers about infection risks. The co-design sessions were recorded, photographed and transcribed for thematic analysis. The data triangulation helped to analyze the case of each child separately according to their personal needs and backgrounds (Flick, 2018).

### FINDINGS

This section presents the individual insights gained from the observations and interviews during the children's one-on-one co-design processes with the researcher in relation to their backgrounds and profiles. Moreover, according to the evaluation of the questionnaire responses and PedsQL results, the children's opinions about the co-design process and its possible impact on their QOL were explained.

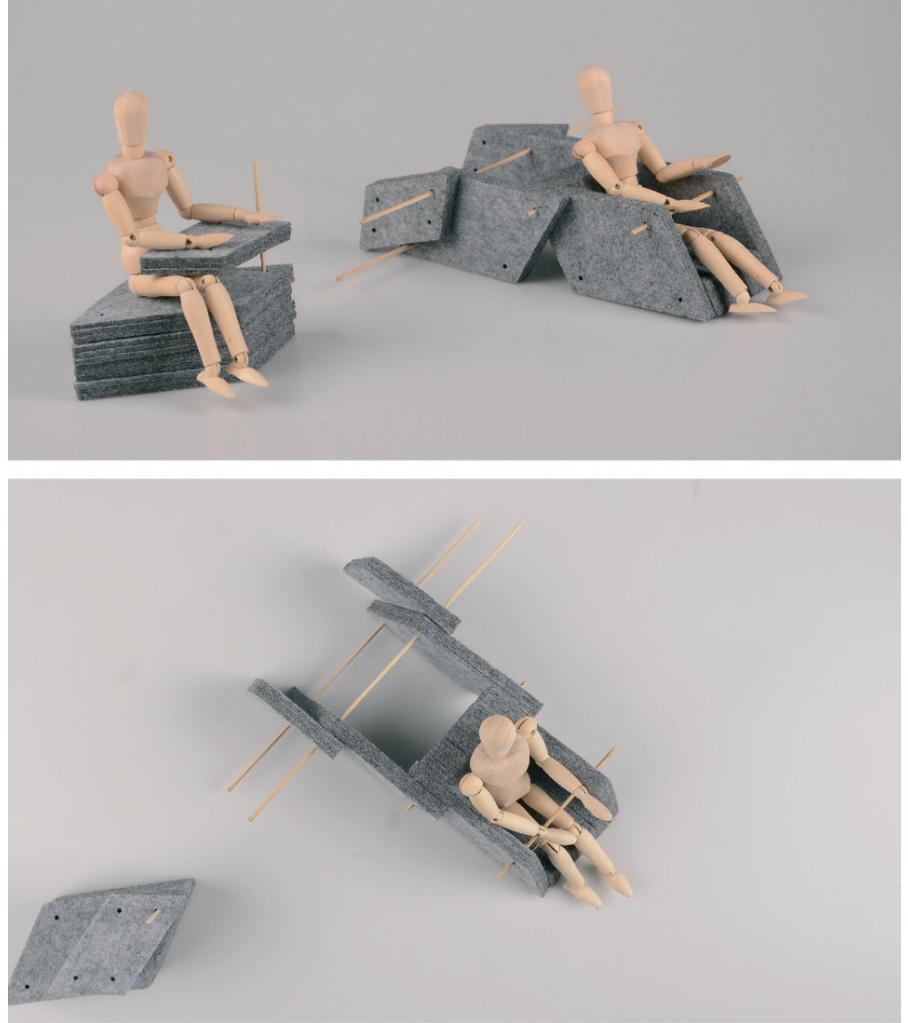
#### **Insights gained during the co-design process**

##### Co-design with Child 1

Child 1 is an 8-year-old boy diagnosed with skin cancer in May 2018. Cancer developed out of a beauty spot on his face. Since his parents keep it a secret, he is unknowing of the severity of his illness. He homeschools and has just learned how to read and write. Physically, he is energetic albeit mostly bored in the hospital for lack of friends. He is the youngest child in his family – with two older sisters. He mostly plays games on his phone and he is also keen on drawing.

He was given the sensitizing workbook in the hospital's cafeteria. His mother (caregiver) was simultaneously interviewed, too. However, during the course of the interview, she was uneasy for fear that her son might hear her. Likewise, Child 1 was also not comfortable because of the presence of a dog in the cafeteria. Thus, the venue for the next meeting shifted to the hospital's play area. He was more relaxed in the play area since he had more control over this environment. Just like the other children, Child 1 also explained all his answers on the sensitizing workbook before the commencement of the co-design session. Throughout the session, his mother commented on his ideas and helped to elicit more information from him. On top of this, the mannequin included in the Make toolkit facilitated the co-design session by attracting the attention of Child 1. During the session, he generated two furniture design ideas: a drawing chair with a rotatable part and an imaginary car (**Figure 2**).

For the last meeting, Child 1 and his mother had to meet the researcher outside the premise of the hospital. According to the child's blood test results he was not ready for the next chemotherapy session. Hence, the meeting with the researcher had to take place in the child's home. They



**Figure 2.** Furniture design ideas (top: a drawing chair with a rotatable part, bottom: an imaginary car) generated by Child 1 during the co-design session (Photography: Ersan Çeliktaş)

were glad of this development since the researcher had formed close bond with them. In the meeting, they filled out the evaluation questionnaire. Child 1 and his mother were individually presented with a Certificate of Participation and a small magnetic chess as a gift.

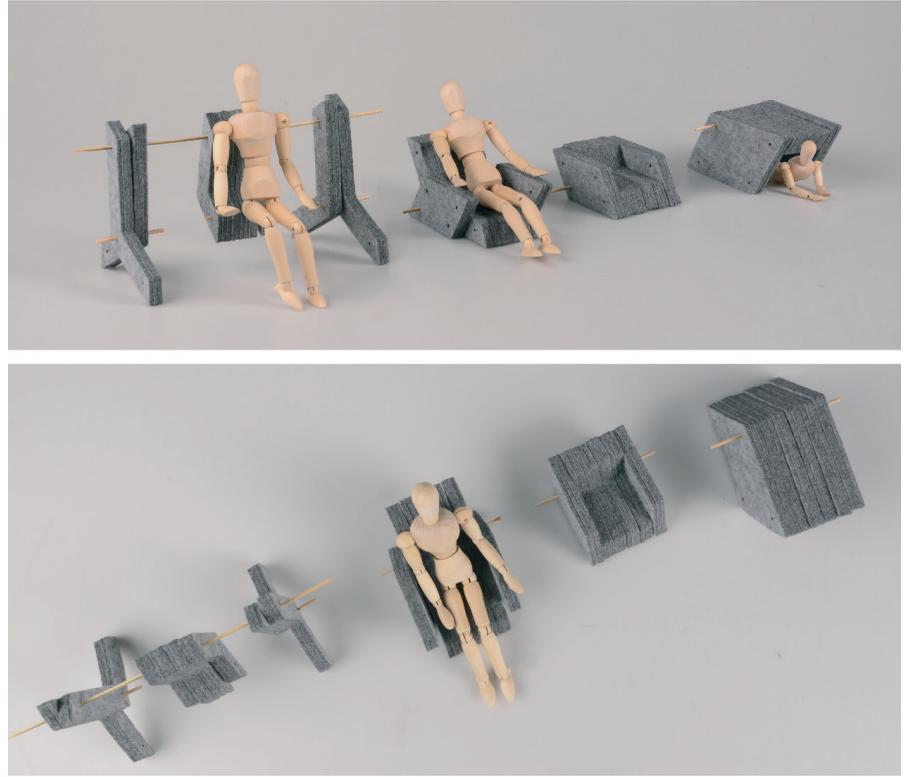
#### Co-design with Child 2

Child 2 is a 10-year-old boy diagnosed with cancer when he was 3. After his diagnosis, his mother and siblings moved to Izmir for his treatment. He is aware of his illness; knows the treatment process and its side effects since he has been living with it for 7 years. His treatment made education a tiring endeavor for him. He is quite an active child in physical and social activities. He gets along well with the nurses; even exchanging jokes with them. He spends a considerable amount of time on social media, Instagram more precisely. From the day they met, his relationship with the researcher was quite smooth. For example, on the first day of meeting, while the researcher acquainted herself with him, he shared his opinions about games and further pointed out that his most preferred is puzzles. He admitted his fondness to spend time in the play area. His attachment to his computer was obvious from how indispensable it was to him and how he brings it to the hospital to play always.

Child 2 was given the sensitizing workbook and the questions were explained in the waiting room of the hospital. He did not want the pencil given by the researcher because the colors of the pencil reminded him of the opposing football team. Thus, the pencil was replaced with an orange (his favorite color) pencil. Child 2's mother was interviewed alone and it was more efficient. In the fourth meeting, the co-design session began by discussing his answers in the sensitizing workbook as usual. During the session, his mother played a key role by bridging whatever communication gap that arose between the researcher and the child. She helped to shed more light on what the researcher said to the child by using words that were familiar to him. Even though a vascular access was affixed to his hand, he did not hesitate to use his hands to generate ideas (**Figure 3**). The session aimed to generate only one idea but because he enjoyed the activity, the child offered four different design ideas (**Figure 4**). He was very enthusiastic.



**Figure 3.** Child 2 enjoyed the co-design session and generating ideas with the Make toolkit (photographed by the researcher)



**Figure 4.** Furniture design ideas generated by Child 2 during the co-design session (Photography: Ersan Çeliktaş)

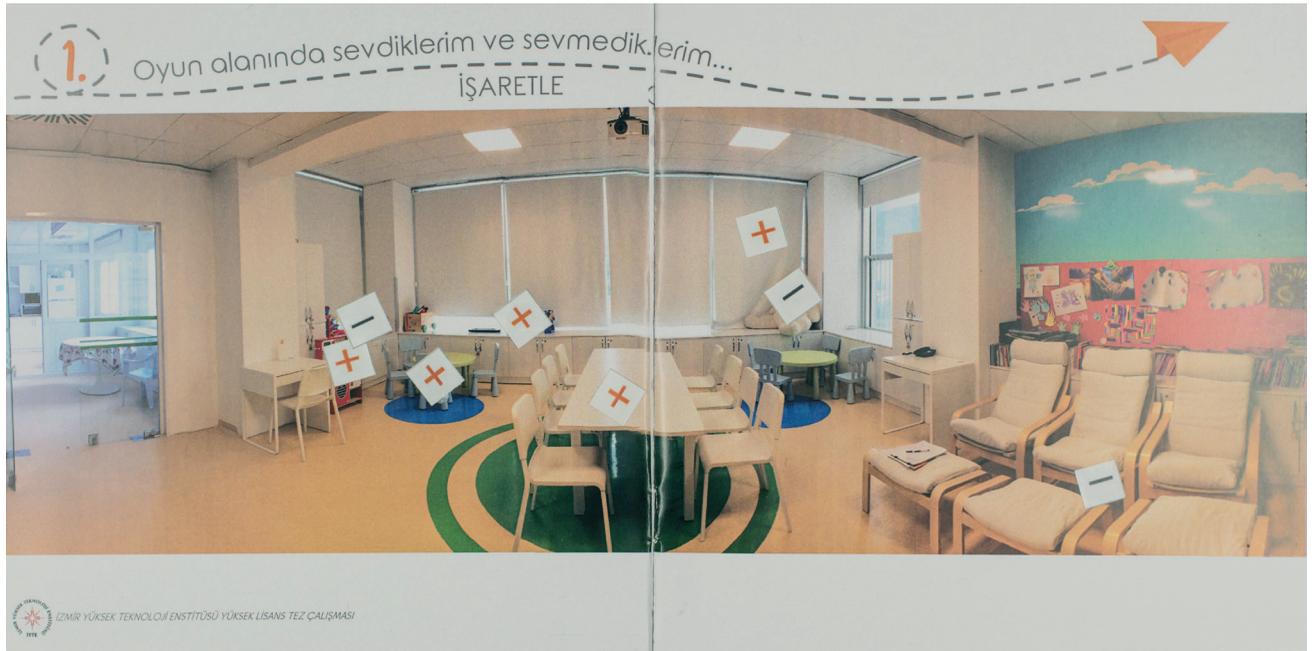
Of the four ideas offered by Child 2, the first was a swing: he mentioned his interest in swings in the sensitizing workbook. He also designed TV couches of different sizes for both himself and other younger children in/at the hospital. His last design was a hollow box with front and/or back openings where children can hide underneath while playing with their friends. In his sensitizing workbook, he mentioned a similar kind of playing activity with his sisters.

In the last meeting, Child 2 and his mother filled out the questionnaires in his patient room. A Certificate of Participation was presented to each of them. Additionally, the child was presented with a small gift – a small version of magnetic Parcheesi. The choice of gift was informed by the child's passion for the game during one of the meetings with the researcher.

#### Co-design with Child 3

Child 3 is a 12-year-old boy diagnosed with leukemia in 2018. He is on break from schooling and in Izmir for hospitalization. He reports well with doctors and nurses but does not have many friends. Playing football was his favorite activity alas, for risk of infection, he is no longer allowed to play outside. As a result, he takes his chess set with him when he stays in the hospital.

He was given the sensitizing workbook in his room and his mother was interviewed there. The third meeting – the co-design session – was scheduled to take place in the play area of the hospital to better help him remember his needs. However, due to a swelling on the child's arm, this session was conducted in his single-patient room. As usual, the session began with the child elaborating on his answers in the sensitizing workbook. Since he did not understand how to use the stickers, together



**Figure 5.** A page from Child 3's sensitizing workbook that was filled in with the help of the researcher at the beginning of the co-design session (photographed by the researcher)

with the researcher, they completed that part (**Figure 5**). Child 3 like other children also explained why he [dis]likes the furniture in the play area.

Child 3's idea throughout the co-design session was focused on designing furniture for playing chess in the play area (**Figure 6**). During one of the quick breaks, the child played chess with the researcher. While playing chess, he realized that a backrest was needed to prevent backache. He was also curious about other participants of this study: he fancied the opportunity to meet them. Child 3 was happy and said that time went by speedily during the co-design process. Furthermore, he disclosed that he was able to express himself better by "making" with the help of the Make toolkit.

The last meeting was held in his single-patient room. After filling out the questionnaires, a Certificate of Participation and a small magnetic chess set were given to him. Later, he played chess with the researcher (**Figure 7**). During the course of the game, he mentioned that it was convenient to have a small chess set to carry everywhere with him.

#### Co-design with Child 4

She is a 16-year-old girl diagnosed with cancer in 2017. They moved to Izmir for treatment but could not afford to live there. She has five siblings and her mother is pregnant. She is aware of the nature of her illness. Up until this year when she took a break, she had been going to school. Even though she felt energetic, she was not physically active. Her easygoing nature was evinced in how easily she makes friends in the hospital and how good her relations are, with nurses. Her sensitive nature makes her fond of emotional music. To feel better, she likes putting on make-up.

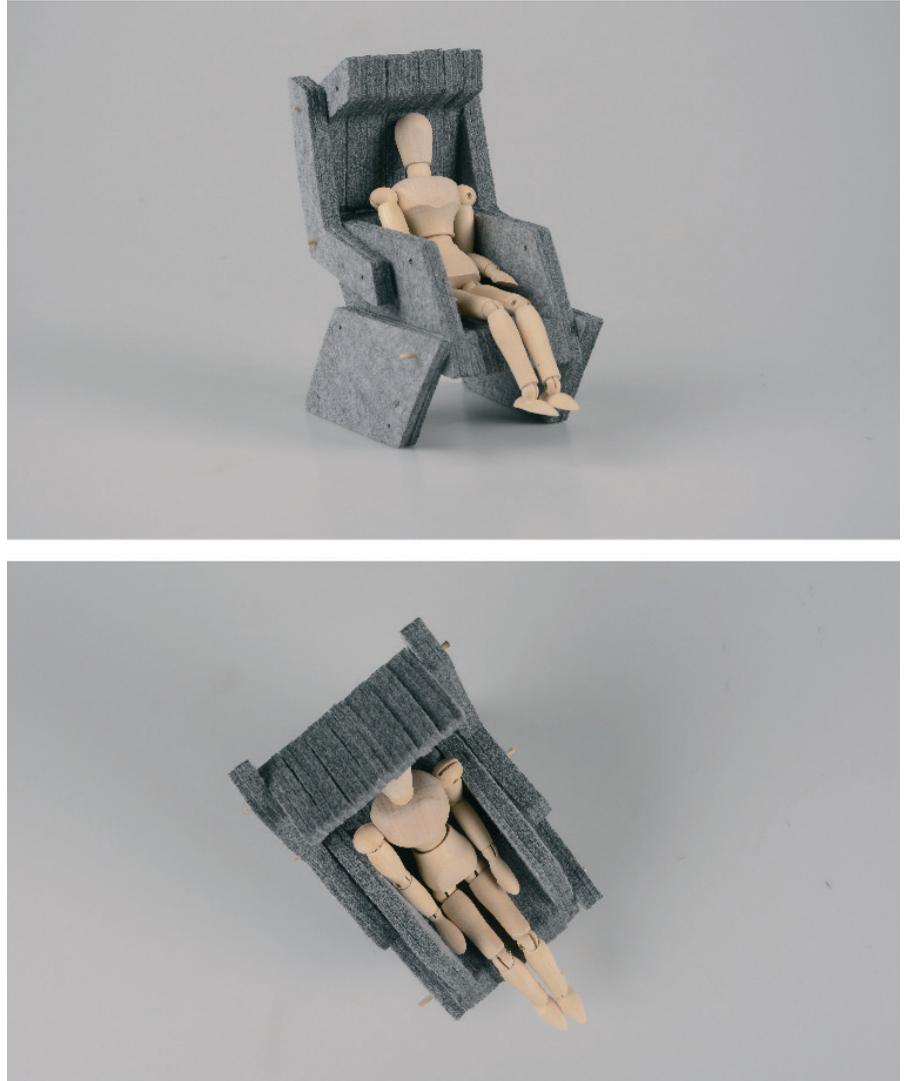
Although she was an adolescent her playful persona made the researcher give her the informal sensitizing workbook. She seems to have appreciated this more. With the consciousness of her illness in mind, her father was interviewed in the cafeteria since it was not very crowded. During the interview with her father, she offered a series of comments on some



**Figure 6.** Furniture design idea for playing chess generated by Child 3 during the co-design session (Photography: Ersan Çeliktaş)



**Figure 7.** The small magnetic chess set was presented to Child 3 and they played chess with the researcher



**Figure 8.** Furniture design idea generated by Child 4 during the co-design session(Photography: Ersan Çeliktaş)

questions. For the co-design session, she came to the play area together with her father but while coming, she forgot to bring the workbook. Her furniture design idea for the play area was a seating unit (**Figure 8**) that can be enclosed to guarantee privacy while listening to music. She also noted that she likes to be alone sometimes but that was impossible to achieve in the hospital and its environs. To smother any tension and make the child comfortable during the co-design session, they listened to her favorite songs. While the session was on, she received and spoke on the phone informing the other party that she was playing in the play area. In the last meeting, they filled out the questionnaire. Child 4 and her father were presented with the Certificate of Participation and a small magnetic chess.

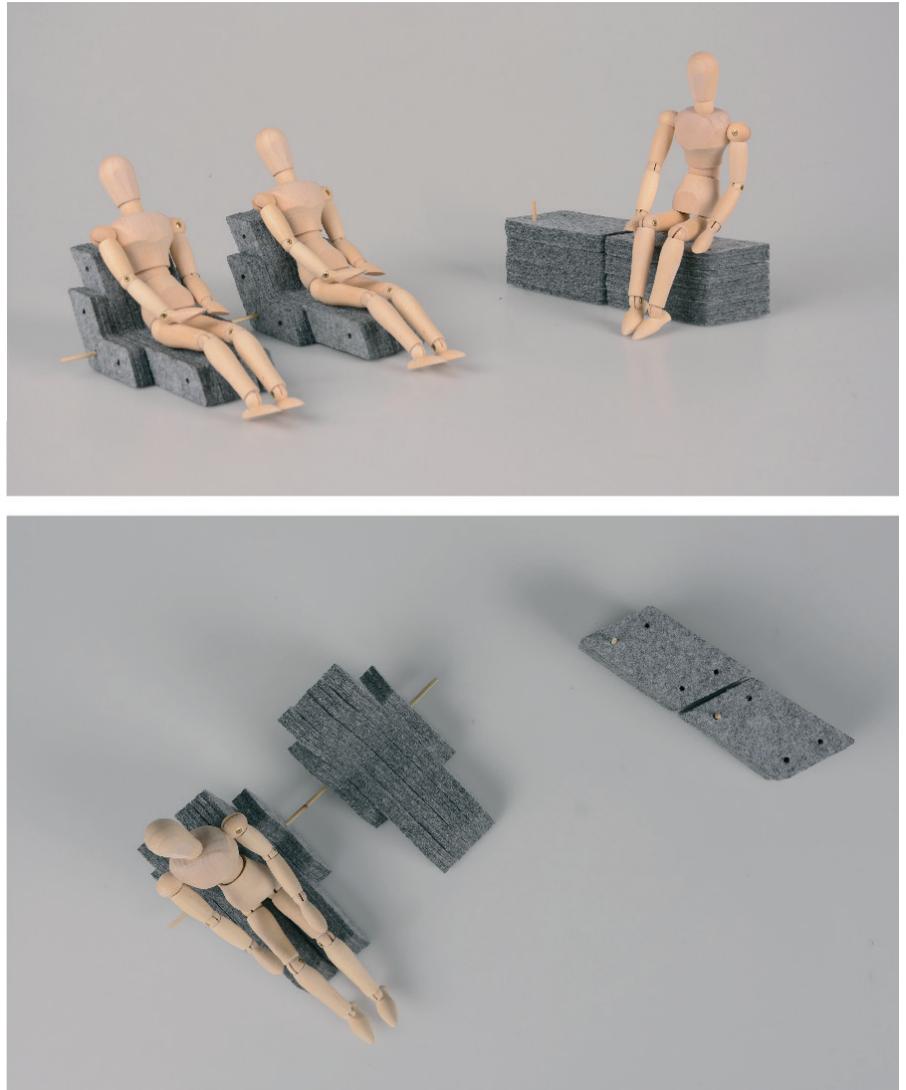
#### Co-design with Child 5

Child 5 is a 17-year-old boy diagnosed with cancer in the bones located in his shoulder, in 2018. He does not hail from Izmir so when he is not hospitalized, he lives with his aunt. The severity of his illness necessitated that he puts on hold his education for now and this makes him worried about his future. Although he used to do sports regularly, now he thinks his active sport days are behind him due to the surgery he had. He feels

upset when he is unable to take care of himself. His sociability helps him to make friends easily in the hospital. He is convinced that the play area at the hospital is only useful for younger children but not for him. As a result, he spends all of his time in the hospital on his phone. Unlike the other children, he finds the games in the play area too childish and prefers PlayStation.

Since he is a teenager aware of his illness, he opted to sit-in during the interview with his brother; he did and occasionally offered comments. His age made the researcher prepare and present to him a more 'formal' version of the sensitizing workbook with the same content.

Due to his blood test results, the next chemotherapy cycle was postponed so he had to stay with his aunt. In the meantime, the researcher offered to visit him at home but his aunt rejected for lack of familiarity with the researcher. The Child was upset by this. However, after two weeks, the co-design session was organized in the play area. Elaborating his answers on the sensitizing workbook revealed that he would like to organize PlayStation tournaments in the play area. Consequently, his furniture design idea consisted of two armchairs for the players and a pouf for other



**Figure 9.** Furniture design ideas generated by Child 5 during the co-design session (Photography: Ersan Çeliktaş)

children while they await their turn (Figure 9). Lastly, after filling out the questionnaires, he received the Certificate of Participation and a small gift of a magnetic chess set.

**Evaluation of the Co-design Process**

From the questionnaires evaluated, four out of the five children chose “definitely agreed” and only one chose “agreed” as a response for Question 1 (Q1: Do you think that you felt better during this process when compared with the past?). Three out of the five children expressed that their general mood and attitude during the study was “very good” while only two opted for the “good” response to Question 2 (Q2: How would you describe your mood during the co-design process? Options: 1;very bad to 5;very good). It shows that the process has had a positive impact on children’s well-being and their perception of it. When asked to rank the activities they participated in (PedsQL, sensitizing workbook, co-design session) from the most to least enjoyable, four out of the five children revealed that the co-design session was “the most enjoyable” and playful stage. Three out of the five children considered the sensitizing workbook as “the least enjoyable” stage in the study. This addresses a need to redesign the sensitizing workbook (Q3: Which one of these stages was more enjoyable for you? (Please prioritize them). Lastly, results from the questionnaire revealed that all the children would participate in a co-design process if it was to be arranged again (Q4: Would you like to participate if a co-design session was

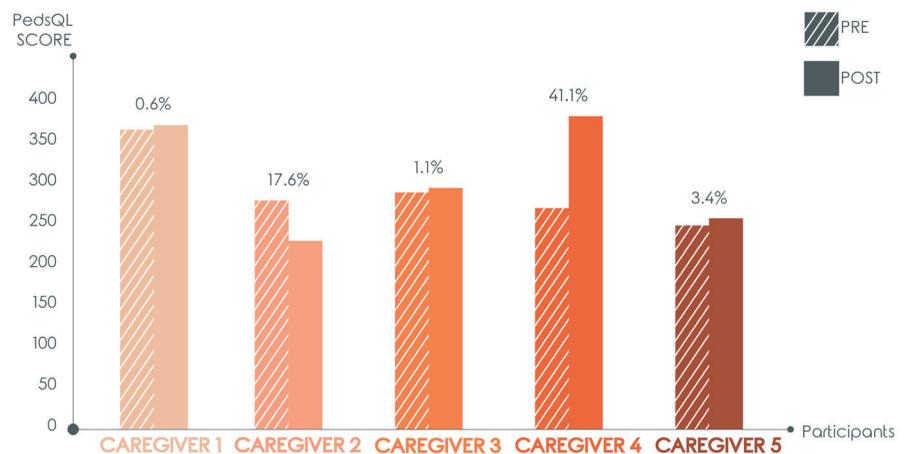
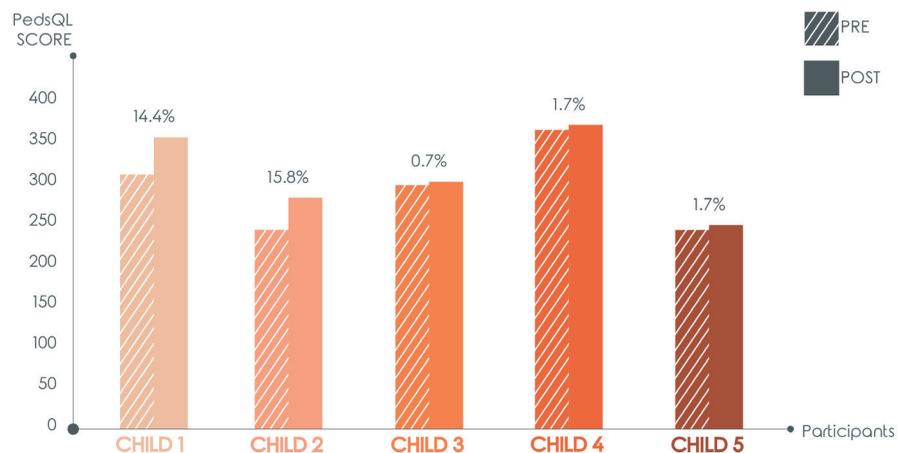


Figure 10. PedsQL pre-post comparison according to child reports (top) and proxy reports (bottom)

*organized again?*). In addition to the qualitative data gathered, quantitative data was also collected through the PedsQL questionnaires completed by the children and their caregivers both before and after the co-design process. Even though a caregiver indicated a decrease in their child's QOL (proxy report), the change ratio between pre and post PedsQL child reports showed that the QOL of all the children increased (**Figure 10**).

## DISCUSSION AND CONCLUSION

The results of this study are divided into three: design recommendations for play areas for children with cancer in the hospital; recommendations for facilitators of the co-design sessions with children with cancer; and the possible positive impact of co-design sessions on the QOL of children with cancer.

This study has demonstrated that the indoor play area at the Oncology and Hematology Service of the hospital plays a crucial role in the lives of visiting children. The fact that most of the children are prevented from playing outside for the risk of infection underlines the importance of providing inpatient children with a play area that meets their needs.

Findings from the field suggest that design ideas generated by children can be associated with their needs, personalities and backgrounds (Table 1). The need of Child 1 conformed to his personal interests and hobbies. Moreover, he expressed his need to have access to nature in the play area. Additionally, using his ingenuity to create an imaginary world can otherwise be included among his needs. The TV couches of different sizes designed by Child 2 represent his personality as a social child. Furthermore, his tent design idea was obviously a portrayal of him trying to replicate in the play area of the hospital the feeling of warmth he derives from playing 'together' with his sisters. The furniture for playing chess design idea of Child 3 corresponds to his interests and demonstrates his need to socialize in the play area. Child 4's design idea – an enclosed seating unit that guarantees seclusion to listen to music – indicates her need for privacy at the hospital. Lastly, the seating unit designed by Child 5 might be linked to his needs for socialization and activities associated with older children.

The results of the co-design sessions showed that all the furniture design ideas generated by the children during the sessions varied and were based on subjective needs. The modules made of felt involved in the Make toolkit enabled them to create what they intend to see in the play area. From observation, the children enjoyed the design process with little modules to create furniture ideas. If they can create that furniture by assembling bigger modules in the play area, they can use them there and continue to be the design partners of an ever-changing play area altogether. Accordingly, designers of these spaces can consider using flexible, adaptable or modular furniture which can increase children's participation and satisfaction while designing a hospital play area. A modular furniture system may provide flexible opportunities for a wide age range thereby sidestepping the problem of age rigidity emphasized by the children during the co-design process. Children can use these modules on their own to create furniture for their specific needs. Since children often feel a lack of control ensuant from the uncertainty of their illness and unfamiliarity with hospital environments researchers (for example, Hilda et al., 2015) pointed out that adopting such creative possibilities might give the children some sense

Child	Age	Design Ideas Generated During the Co-design Sessions	Quotes	Keywords
1	7	A drawing chair with a rotatable part and an imaginary car (Figure 2)	"I would put this drawing chair in the corner near the window... I love to see what is going on outside and I like to draw what I see there."	*Imagination *Access to nature/ life outside
2	10	A swing, TV couches at different sizes, a tent to hide inside while playing (Figure 4)	"I love to play with my sister, putting pillows on top of each other and hiding under them."	*Togetherness
3	10	Furniture for playing chess (Figure 6)	"Actually, you should not think about it. Just focus on making. While you are making, the idea comes up."	*Socialization
4	16	A seating unit that provides privacy (Figure 8)	"I like listening to music very much especially when I am making something. For example, when I make scarves, I always listen to music."	*Privacy
5	17	Two armchairs for PlayStation tournament players and a seating unit for children waiting their turn (Figure 9)	"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 to the play area."	*Socialization *Activities meant for older children

**Table 1.** Design ideas generated during the co-design sessions by the children and keywords extracted from the process in relation to the children's needs in the play area in the hospital

of control while in the hospital. "IKEA effect" (Norton et al., 2012) lends credence to the stance by explaining that children may value these products more than the ready-made ones since they invest their effort in creating and customizing them according to their needs and taste. Moreover, a modular furniture system in the play area can provide the children with an escape from monotony.

This study also provides suggestions to the facilitators of the co-design sessions with children with cancer. First, the observations and interviews were quite helpful in having more efficient co-design sessions with children. They allowed the researcher to get to know the children better and create activities accordingly. For instance, although the color of a pencil might seem like a trivial detail, it matters to some children. Moreover, the pre-meetings with children proved useful in improving children's familiarity with the researcher, thus contributing to the effectiveness of co-design. Also, it might be better to conduct one-on-one interviews with caregivers of the children since they may feel stressed by the presence of their children. In part, this also depends on other parameters such as the child's personality, knowledge of their illness and maturity. As far as the generative tools are concerned, the Make toolkit and the sensitizing workbook seemed to contribute to the process. Children expressed their needs in an easier way through making activities. However, for some children, the activities in the sensitizing workbook were not clear enough. For better clarity, it is advisable to co-design the generative tools including the sensitizing workbook and the Make toolkit with children. To achieve a higher level of communication with the children, it is advisable for facilitators to consider their age differences and interests. The role of caregivers during co-design cannot be overemphasized. Direct conversations between the researcher and caregivers enhanced communication during the process as such their support was constructive in the co-design process. To this end, it is strongly recommended that facilitators of co-design processes have a close communication with family members of the participating children to increase the effectiveness of the sessions and avoid situations that might lead to unintended problems like disagreements between children and their family members. Actively

involving caregivers in co-design sessions was also beneficial for the efficiency of the session. Even when they were not too active, the children felt more comfortable in their presence. Their contribution was valuable as they reflected their point of view and opened new conversations with children. It was learned that children might need to be given the freedom to tailor the co-design session according to their tastes and this requires flexibility/adaptability by the facilitator. For instance, listening to music during the session – if they find it more enjoyable and comfortable – can only increase the efficiency and effectiveness of idea generation. This means that not only the outcome of the co-design session but also the process itself can be co-designed with the participants.

Furthermore, the study found that involving children with cancer in co-design processes might contribute to their QOL for several reasons. First, as a democratizing activity, the co-design processes might help children with cancer experience a sense of accomplishment and control over their environment (Robertson and Simonsen, 2012). Pertinent literature underscores that children often feel in control when their ideas are sought regarding an issue that concerns them (Sanoff, 1988). Correspondingly, the participating children in this study appreciated that their ideas were sought throughout. Second, during the co-design sessions, children can socialize with the facilitator and other stakeholders. As clearly stated by the children during the co-design processes, one of the most fundamental needs of children with cancer concerns socialization issues. Third, the co-design sessions might provide a distraction from illness-related negative thoughts. For instance, it was seen that children perceive the co-design sessions as a playful activity. Furthermore, according to the observations and interviews with the children, their caregivers, doctors and nurse, children with cancer generally spend most of their time in their hospital beds. With the Make toolkit, children can create models themselves thereby becoming more physically active. Moreover, results from the questionnaires and PedsQL evaluated addressed a link between the QOL of children and the co-design process. However, due to the limited number of participants – a slight increase in most cases (child report) and a decrease in one case (proxy report) – the results cannot be seen as concrete evidence. Nonetheless, this study hopes that this might imply the potential health-related benefits of the co-design sessions and therefore inspire researchers to conduct comprehensive studies on that in a larger time span and with more participants.

In conclusion, even though this study does not claim to be exhaustive insights into the needs of children with cancer regarding the design of play areas in hospitals to aid healthcare workers were provided. Moreover, a link between QOL and the co-design processes has been presented. With suggestions provided for facilitators of co-design sessions, this study hopes it functions as a reference and also encourages more researchers to actively involve children with cancer in co-design processes rather than merely designing for them.

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**Anahtar Sözcükler:** Kanserle mücadele eden çocuklar; katılımcı tasarım süreci; çocuk hastanesi; oyun alanı; modülerlik

### **KANSERLE MÜCADELE EDEN ÇOCUKLARLA KATILIMCI TASARIM: SÖYLEDİKLERİNDEN, ÜRETTİKLERİNDEN VE YAPTIKLARINDAN İÇGÖRÜLER**

Kanser teşhisi çocuklar için travmatik ve hayatlarını değiştiren bir olay olabilmektedir. Bu hastalığın teşhisi ve tedavi süreci çocukların acıyı deneyimlemesine, okul ve oyun aktivitelerinin kesintiye uğramasına, sosyalleştikleri ve alışkın oldukları ortamlardan ayrı düşmelerine neden olmaktadır. Tüm bunlar çocukların hayat kalitesini olumsuz yönde etkilemektedir. Bu makale, kanserle mücadele eden çocukların yaşam kalitelerini iyileştirebilecek tasarım önerileri sunabilmek için hastanedeki oyun alanı mobilyaları ile ilgili ihtiyaçlarına ışık tutmak adına onlarla yürütülen bir katılımcı tasarım sürecini konu almaktadır. Sonuçlar,

çocuklar tarafından kişiselleştirilebilen modüler bir mobilya sisteminin, çeşitli yaş gruplarının ihtiyaçlarına uyarlanabilmesi sayesinde çocukların yaşam kalitelerine katkıda bulunabileceğini önermektedir. Ayrıca, katılımcı tasarım oturumları ile artan kontrol duygusu, sosyalleşme ve fiziksel etkinlikler aracılığıyla çocukların iyi olma hali arasında olası bir bağlantı vardır. Çocuklarla katılımcı tasarım oturumlarının kolaylaştırıcısı olan tasarımcılara, aile bireylerini katılımcı tasarım süreçlerine aktif olarak dahil etmeleri, üretici araçları ve süreci katılımcılarla birlikte tasarlamaları ve katılımcı tasarım oturumlarını şekillendirirken gözlemler ile sözlü görüşmeler yürütmeleri tavsiye edilmektedir. Bu çalışmanın bulgularının tasarımcılar, katılımcı tasarım süreç yürütücüleri ve sağlık çalışanları için faydalı olacağı beklenmektedir.

### **CO-DESIGN WITH CHILDREN WITH CANCER: INSIGHTS FROM WHAT THEY SAY, MAKE, AND DO**

Being diagnosed with cancer is traumatic and life-changing for children. Due to the disease and treatment, children experience suffering, pain, interruption in school and playful activities, and separation from social and familiar environments. These negatively affect their quality of life (QOL). This article reports a co-design process conducted with children with cancer to shed light on their needs with regard to the play area furniture at the hospital to recommend design ideas that might improve children's QOL. The results have shown that a modular furniture system that can be customizable by children might contribute to their QOL – thanks to its adaptability to the needs of a wide range of age groups. In addition, there is a possible link between co-design sessions and children's well-being in terms of an increased sense of control, socialization and physical activities. For designers– who are the facilitators of co-design sessions with children– actively involving caregivers in co-design processes, co-designing the generative tools and the process with participants, and conducting observations and interviews to shape and complement the co-design sessions are advised. The findings of this study are expected to assist designers, co-design practitioners and healthcare members.

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