The Contribution of the Pediatric Oncology Healthcare Spaces to the Psychosocial Wellbeing of Mothers in the Egyptian Context

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The Contribution of the Pediatric Oncology Healthcare Spaces to the Psychosocial Wellbeing of Mothers in the Egyptian Context

A Thesis Submitted by
Yara Ashraf Adly

To the
Masters of Science in Architecture Program

4th of February, 2023

Under the Supervision of:
Dr. Ahmed Sherif, Department of Architecture, The American University in Cairo
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in partial fulfillment of the requirements for the degree of
Masters of Science in Architecture Program
Declaration of Authorship

I, Yara Ashraf Adly, declare that this thesis titled, “The Contribution of the Pediatric Oncology Healthcare Spaces to the Psychosocial Wellbeing of Mothers in the Egyptian Context” and the work presented in it are my own. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University.
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated.
- Where I have consulted the published work of others, this is always clearly attributed.
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
- I have acknowledged all main sources of help.
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself.

Signed: Yara Ashraf Adly

Date: 4th of February 2023
Abstract

This study sheds light on the significant contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers in the Egyptian context. The research focuses on understanding the experiences of mothers in the different encountered stages during the hospitalization of their children to identify their psychosocial needs and wants. The complexity of healthcare facilities drives the designers to give the humane aspects such as the psychological and social wellbeing second priority. Despite the significant parental role in promoting their children’s health and wellbeing, only few studies explored the contribution of the built environment in response to the parental experiences and needs during their children’s hospitalization process. This study aims to draw attention to the importance of considering the psychosocial needs of the mothers while designing the spaces of the pediatric oncology healthcare settings. It proceeds with the core question: What is the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers who accompany their children during their hospitalization journey in the Egyptian context? Ulrich’s (1991) theory of supportive design along with its associated stress inducing factors were used to guide the process.

A descriptive phenomenological approach was adopted where participant observation, including physical and behavioral mapping, was conducted across two Egyptian pediatric oncology healthcare settings. These were followed by in depth interviews (n = 46) with the mothers. This approach addressed the differing psychosocial needs and experiences of mothers during three stages of hospitalization of their children; ‘adjusting to the unknown’, ‘accommodating to the status quo’, and ‘weaving through the ordinary life’, which were studied in three different spatial layouts; Single inpatient rooms, double inpatient rooms, outpatient chemotherapy units. Key questions addressed mothers’ mundane experiences, utilization of spaces, and the contribution of the studied spaces to the psychosocial needs and wellbeing of mothers. Results disclosed common psychosocial needs and demands yet with different intensities across the three hospitalization stages. The dominating factors influencing the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers include issues such as privacy and perceived control, territoriality and personalization, the quality of mother-child relationship, access to social support, and access to restorative resources. Overall, as perceived by mothers, the studied spaces promote differing intensities of contributions to the psychosocial wellbeing of mothers in the Egyptian pediatric healthcare settings. Moreover, mothers’ cultural values, behaviors, and traditions play an essential role in the discussion of the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers.

Keywords: Pediatric oncology healthcare spaces, Psychosocial wellbeing, Psychosocial needs, Mothers, Pediatric healthcare facilities, Phenomenology, Ethnographic field tools, Egyptian culture
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Chapter 1

Introduction

Pediatric chronic diseases represent a central event that creates a major challenge to all family members. The diagnosis of childhood cancer is one of the most serious and devastating experiences that mothers can endure. It usually presents itself unexpectedly, giving mothers little opportunity to prepare for the demands of caring for their newly diagnosed child. Even with a good prognosis, the process of diagnosis, treatment, and hospitalization affects the quality of life of the entire family (Han et al., 2009). Children with cancer are usually hospitalized during the diagnosis and treatment phases. In one-third of the cases, hospitalization can last several weeks and even months due to the treatment’s complications (Allareddy et al., 2012; Mairuhu et al., 2021; Price et al., 2009). Children are commonly exposed to serious challenges during the hospitalization process. These challenges include separation from family, changes in familiar routines, deprivation of social relationships, exposure to medically necessary but frightening procedures, and obstruction of independent activities (Carnevale, et al., 2006; Henderson et al., 2017; Oxley, 2015). For children of all ages, hospital environments provoke a wealth of emotions such as fear, anxiety, sadness, anger, loneliness, and homesickness. All of which impact adversely on children’s physical and psychosocial wellbeing (Birch et al., 2007; Carney at al., 2003; Coyne, 2006; Forsner et al., 2009; Norton, 2012).

Parents play a significant role in promoting their children’s health and wellbeing during hospitalization. Mothers are considered to be the primary caregiver and source of support for their child (Holm et al., 2003). Their involvement in children’s health care is generally associated with positive outcomes for both parents and children (Letourneau &Elliott, 1996; Rosenbaum et al., 1998; Woodside et al., 2001). Moreover, the parental adjustment and engagement in their child’s care directly affects their child’s treatment effectiveness and well-being (Holm et al., 2003). With regard to pediatric cancer, the parental distraction of their children during medical procedures has been shown to be associated with high child coping behavior and lower distress (Manne et al., 1992). Parents have been included as nurses’ assistants during the cancer-related medical procedure to reduce pain, anxiety, and distress. Studies of the efficacy of the parents’ interventions indicate that they play a significant role in reducing child pain, anxiety, and distress (Barrera, 2000; Broome et al., 1998; Manne et al., 1992; Powers et al., 1993; Smith et al., 1996).

Hospitalization constitutes a major crisis for parents, especially mothers, to the extent that it can have a traumatizing effect on their physical, psychological, & social well being. Studies indicate that many parents experience high levels of anxiety, depression, and uncertainty when their children are seriously ill (Franck et al., 2015; Wray et al., 2011). Moreover, studies disclosed the mothers’ struggle and tension between caring for their hospitalized child and meeting the demands of life and family outside the hospital (Foster et al., 2017). The role of healthcare facilities as physical environments is essential in promoting parents' wellbeing. During the hospitalization
process, the patients and their parents seek not only a cure but a holistic healing experience that provides much-needed support in these stressful times. Accordingly, providing spaces that consider the psychological/social constructs and the needs of the mothers while designing is essential for less stressful and traumatic experiences. (Chaudhury et al., 2009; Dijkstra et al., 2006; Ulrich et al., 2004).

1.1 Problem Statement

Due to the various user needs and functional requirements, the complexity of the healthcare facilities drive the designers to give the humane aspects such as the psychological and social wellbeing (known to be psychosocial wellbeing) second priority. Despite the significant parental role in promoting their children’s health and wellbeing, only few studies explored the contribution of the built environment in response to the parental experiences and needs during their children’s hospitalization process (Patterson et al., 2010; Marsac et al., 2011; Alisic et al., 2014). Correspondingly, there is a subsequent lack of data that informs the design of spaces to meet the psychosocial needs of parents, especially the mothers, to improve their overall wellbeing and outcomes during the hospitalization of their children. Franck and colleagues (2015) disclosed the need to better understand parents’ needs and preferences while rooming-in with their children during hospitalization. In this regard, this research addresses the mundane experiences and spatial utilization (behavioral mappings) of the mothers in two Egyptian pediatric oncology healthcare settings to identify the contribution of the spaces to the psychosocial wellbeing of the mothers.

‘What is the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers who accompany their children during their hospitalization journey in the Egyptian context?’ This question marks the starting point of the present study. It is thoroughly examined through exploring how the ‘spaces’ that should provide ‘psychosocial support’ are inhabited and to what extent the ‘pediatric oncology healthcare spaces’ contribute to accomplishing the psychosocial needs and wellbeing of mothers during their children’s hospitalization journey. The information and analysis offered in this study provide a useful guide to ‘the contribution of spaces’ that are ‘culturally sensitive’ to the psychosocial needs of the ‘Egyptian’ mothers. Also, there is a need to draw attention to the importance of considering the psychosocial needs of the mothers while designing the spaces where psychosocial support is essential in pediatric oncology healthcare settings.

1.2 Research Questions

What is the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers who accompany their children during their hospitalization journey in the Egyptian context?

A. What are the mothers’ psychosocial needs?
B. What are the different stages that mothers encounter during their children’s
hospitalization journey?
C. How do mothers inhabit the selected pediatric oncology healthcare spaces?
D. What are the spatial qualities that inhibit or promote the fulfillment of mothers’ needs?

1.3 Research Objectives

A. Understand the experiences of mothers during the different hospitalization stages.
   a. Identify the different stages that mothers go through.
B. Document the utilization of the selected pediatric oncology healthcare spaces.
   a. Behavioral mapping for the activities
C. Understand the contribution of the studied spaces.
   a. Explore the spatial qualities that ‘promote’ or ‘inhibit’ the fulfillment of needs.

1.4 Research Hypotheses

A. The pediatric oncology healthcare spaces can contribute significantly to the psychosocial wellbeing and needs of the mothers during their children’s hospitalization journey.
B. The mothers’ psychosocial needs vary during the different stages of hospitalization of their children in the pediatric oncology healthcare spaces.
C. The Egyptian ‘socio-cultural’ habits, traditions, and behaviors contribute to the uniqueness of the experiences and psychosocial needs of the mothers in the Egyptian pediatric oncology healthcare settings.

1.5 Research Aim & Scope

This research draws attention to the importance of considering the psychosocial needs of the mothers while designing the spaces of the pediatric oncology healthcare settings. It aims to identify mothers’ essential needs and wants to improve their experiences and psychosocial wellbeing during the different stages of their children’s hospitalization to better contribute to the healthcare outcomes. The scope of the research covers the mothers’ mundane experiences and utilization of the spaces during their children’s hospitalization journey. It addresses the differing psychosocial needs and experiences in three different spatial layouts: single inpatient rooms, double inpatient rooms, outpatient chemotherapy units, which corresponds to the three stages that mothers encountered during the hospitalization of their children: "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life."
1.6 Research Methodology

The investigation process of this qualitative research approach starts by providing a review of the existing literature on the humanistic approaches needed in pediatric healthcare facilities. It highlights the experiences and the needs of parents who accompany their cancer diagnosed children during hospitalization. It focuses on understanding how individuals perceive healthcare settings as psychosocially supportive environments. This is followed by a review of Ulrich’s theory of supportive design (1991) and its associated stress inducing factors that highlight the role of the built environment in promoting the individuals’ psychosocial wellbeing. Based on both the literature review and fieldwork observations, five issues were identified as the guiding themes for the understanding the parental needs and the contribution of the pediatric oncology healthcare spaces to mothers’ psychosocial wellbeing. The themes include privacy & perceived control, territoriality and personalization, the quality of mother-child relationship, access to social support, and access to restorative resources and positive distraction. These set the foundation for this research’s approach to better understand the parental experiences and needs within the Egyptian pediatric oncology healthcare settings.

Mothers’ mundane experiences and utilization of spaces of the Egyptian pediatric oncology healthcare settings were fundamentally examined through a descriptive phenomenological approach. Corresponding to Al Gamal and Long (2010)’s disclosure on the process of ‘anticipatory grief’ among parents living with a child with cancer, the study incorporated three stages that mothers go through during their children's hospitalization journey: "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life." These stages were labeled in respect of the encountered experiences of the mothers within three different spatial layouts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units, representing the spaces where psychosocial support is essential. Participant observation and semi-structured interviews with the mothers were used as the two main ethnographic fieldwork techniques. Systematic field visits and detailed behavioral mapping were undertaken to document the behavioral activities and physical patterns used in relation to the study settings and their supportive facilities. Interviews with the mothers were used to probe for the details of activity patterns during the different stages within the various spatial layouts. The documented data was later coded using manual thematic analysis. During the coding process, common patterns emerged across the two study contexts highlighting certain psychosocial needs and desires in respect to the Egyptian culture. They were later discussed in relation to the literature review, overarching research question, and the aforementioned hypotheses.

1.7 Research Structure

This dissertation layout is composed of six chapters: introduction, literature review, methodology, results and analysis, discussion, and conclusion. It starts with an introduction chapter that addresses the role of the parents in promoting their children’s wellbeing during the hospitalization process. It highlights the traumatizing effect of the children’s hospitalization journey on parents’ physical, psychological, and social wellbeing. Moreover, it reveals the
subsequent lack of data that informs the design of spaces to meet the psychosocial needs of parents, especially the mothers. The literature review chapter (Chapter 2) then focuses on providing an understanding for the psychosocial wellbeing and quality of care approaches in pediatric healthcare settings. Correspondingly, Ulrich’s (1991) theory of supportive design and its associated stress inducing factors are set to be the framework for understanding the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers in Egyptian context. The following chapter (chapter 3) details the methodological approach and sets the scope of the research. The scope entails three stages that mothers encounter during their children’s hospitalization journey: "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life". These were studied in three different spatial layouts in the Egyptian contexts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units, corresponding to the above stages. Moreover, Chapter 3 details the analytical method and tactics conducted by the researcher. This study used fieldnotes, physical mappings, behavioral mappings, and photographs to document physical and behavior observations. While audio-recording, transcription, and note taking were used to document the interviews that were later coded using manual thematic analysis. Succeedingly, Chapter 4 presents the field studies and the documentations of the disclosed mothers’ experiences and utilization of the selected pediatric oncology healthcare spaces (physical and behavioral mapping) across the two Egyptian pediatric oncology healthcare settings. Observation results were further elaborated through the interview findings that provide a deeper understanding for the captured needs and experiences of mothers during their children’s hospitalization process. Findings from the various data collection methods and the results of the different study areas are overlaid and discussed in Chapter 5. Finally, Chapter 6 highlights the main findings of the two Egyptian pediatric healthcare contexts. It discusses the study challenges and limitations, and presents recommendations and final remarks.

1.8 Research Significance

Mothers play an important role in promoting their children’s health and wellbeing during hospitalization. As they accompany their children throughout the whole process, their mundane experiences and utilization of the different spatial layouts need to be identified and taken into consideration. This research provides designers of pediatric oncology healthcare facilities with an in-depth understanding to the mothers’ needs so that they can design spaces to promote the psychosocial wellbeing of mothers. This research identifies the varying needs of mothers during the different stages of hospitalization of their children; thus, allowing the designers to better serve their needs. This research will also attract attention to the suffering that is currently experienced by mothers due to the lack of consideration of their needs in the current pediatric oncology healthcare facilities. Moreover, it provides suggestions on how to alleviate this suffering in future designs.
Figure 1. Flow Diagram for Research Process
Chapter 2

Literature Review

2.1 Introduction

Health is a basic human necessity. In various cultures, we were all raised believing that health is the absence of disease; however, there is a whole lot more to approach holistic health since holistic health by nature is considered as an approach not a concept by itself. According to the Zhuangzi (c. 369-286 BCE), the holistic approach is subjected to flexible patterns, not simply mechanical assemblages of self-sufficient elements. When single components such as the physical, psychological, and social states of individuals are put together to produce a large functional unit, a holistic quality develops not only depending on the behaviors or the functions of the components all together; but also stemming from the individual components’ capacities and state. Therefore, it is essential to promote the wellbeing of the physical, psychological, and social state of individuals.

Healthcare facilities are considered to be multifunctional environments that cater for the needs of several stakeholders, including patients, informal caregivers (parents), healthcare personnelles, and visitors. The design of healthcare facilities is complex by nature since it is not only about designing a space to accommodate the ill, but also about creating a healing environment that supports both patients and their families to cope with stress induced from the traumatic and psychosocial effects of trauma, sickness, and hospitalization. However, in many cases, the complexity of healthcare facilities’ design drives designers to disregard the humane aspects such as the psychological and social wellbeing, known to be psychosocial wellbeing. This has led many healthcare facilities to become dehumanized and inhospitable institutions (Alvaro et al., 2016; Bates, 2018).

Only recently, the need to define the factors for creating a ‘humane’ healthcare environment (known to be the humanization of healthcare settings) has been stressed upon in literature (Alvaro et al., 2016; Bosia et al., 2016; Carmel & Portillo, 2016; Zumba, 2017; Bates, 2018). In pediatric healthcare settings, especially in oncology departments, implementation of a humanistic approach wouldn’t only be serving children as patients, but would also be serving parents as they accompany their children throughout the whole hospitalization process. Parents play a significant role in promoting their children’s health and wellbeing during hospitalization. Their experiences and needs should be identified and taken into consideration while designing pediatric healthcare facilities. However, only few studies explored the role of the built environment in response to parents’ experiences and needs throughout their children’s hospitalization (Patterson et al., 2010; Marsac et al., 2011; Alisic et al., 2014).
This chapter aims to provide a review of existing literature on the humanistic approaches needed in pediatric healthcare facilities. It highlights the experiences and needs of parents who accompany cancer diagnosed children during hospitalization. In particular, this chapter focuses on understanding the psychosocial wellbeing and care approaches used to enhance the quality of care for parents, especially mothers. Moreover, it focuses on understanding how individuals perceive healthcare settings as psychosocially supportive environments. The final part of this chapter explores Ulrich’s theory of supportive design (1991) and its associated stress inducing factors, highlighting the role of the physical environment in providing individuals’ psychosocial wellbeing. It includes parental coping with stress strategies: privacy and perceived control, territoriality and personalization, access to social support, and finally access to positive distraction. This review sets theoretical foundation for the research approach and framework for understanding parental experiences and needs within the Egyptian pediatric oncology healthcare context, which seem to be different from those explained in the literature of western countries due to socio-cultural differences.

2.2 Humanization of the Pediatric Healthcare Facilities

By nature, healthcare facilities are identified as complex environments with a variety of functional needs and user requirements. The rapid evolution of technology in the medical field resulted in promoting the notions of flexibility and efficiency while adhering to hospital design guidelines, codes, and detailed regulations (Samimi, 2012). In many cases, such complexity in healthcare facilities led the designers to disregard various humane aspects known as psychosocial wellbeing. This leads the healthcare facilities to become dehumanized and uncomfortable institutions, which could negatively impact their main hospitalization mission (Alvaro et al., 2016; Bates, 2018). Moreover, ensuring a strategic financial investment in healthcare facilities might be an additional reason behind dehumanization. It leads to cutting expanses that target creating ‘humane’ environments since hospitals are considered not only as healthcare providers but also as investment resources (Alvaro et al., 2016). On the other hand, recent literature suggests that adding a ‘humane’ layer at the core of the design would in fact mediate all those requirements while creating the appropriate healing that would not only suit children as patients but also suit their parents (Bates, 2018).

In recent decades, literature regarding healthcare facilities has paid increasing attention to the apparent need for creating ‘humane’ environments in healthcare facilities. Over the post-war period, calls towards hospital humanization were indeed increasing and were also part of wider international trends (Bardon, 1981). References to the notion of humanizing healthcare facilities were made in a range of social, economical, and political contexts across the globe, which resulted in raising questions regarding the meaning behind the term (Bates, 2018). The multiple meanings and ideological foundations of humanistic design are worthy of detailed attention in their own right as they enable a better understanding of trends in humanistic healthcare design in practice (Alvaro et al., 2016). As a multi-layered concept, humanization doesn’t only relate to the physical aspects of space, but also to the psychological, social, and operational aspects (Bosia et al., 2016). Nowadays, the international guidelines for hospital design acknowledge the aspect of
humanization in health facilities as a basic factor on medical outcomes, as well as the adaptation in the environmental quality of space organization and hospital design (Zumba, 2017).

The understanding of psychosocial and physical needs of the users is considered to be the key to a humane design of healthcare institutions (Carmel-Gilfilen & Portillo, 2016). While there is an excessive amount of information regarding health and safety constraints, little information is available to designers about their principal concern, the individual human being (Samimi, 2012). Only by fully understanding the relationship between individual’s behavior, culture, social, and physical environment, the experience of spaces within healthcare environments can evolve into an interactive and inclusive healing journey (Deasy & Lasswell, 1990). In literature, several approaches were introduced; however, the cultural perception of humanistic design varied. The use of scale and natural materials were considered as essential features of humanistic design that can decrease the institutional feeling of a hospital (Bates, 2018). Moreover, home-like healthcare environments were also introduced as humanistic, as they could decrease the stress resulting from the unfamiliarity with space (Risse, 2003).

In pediatric healthcare settings, the implementation of the humanistic approach wouldn’t only be serving children as patients, but would also be serving parents as they accompany their children throughout the whole hospitalization process. Considering that pediatric hospitals must consider the needs and preferences of both patients and families, recent studies highlighted the necessary elements such as interactions between patient, family and health multi-professional staff to be implemented to humanize pediatrics healthcare settings (Ribeiro, 2014). Moreover, notions such as access to information and emotional support, communication, and user integration are considered the key elements for humanization in pediatric facilities (Zumba, 2017). The use of the architecture was also highlighted as a way to promote both child and family wellbeing in order to facilitate the development of the work process of health professionals (Carmel-Gilfilen & Portillo, 2016).

2.2.1 Parental Role and Distress during hospitalization

During the first decades of the 20th century, it was common practice for hospitalized children to be separated from their families and allowed only limited contact with their parents (Connell & Bradley, 2000; Davies, 2010). Healthcare providers intentionally maintained strict professional boundaries which resulted in having psychologically distant and emotionally disengaged relationships with children. Moreover, children were not given information regarding their illness or medical treatment with the intention to prevent unnecessary anxiety or distress (Davies, 2010; Hunt, 1974). In such environments, one can imagine the excessive fear and altered behavior that children not only experienced during hospitalization, but also persisted following discharge from hospital (Jolley, 2007). In response to the recognition of the damaging effects of hospitalization on children’s development and emotional well-being, contemporary approaches to pediatric psychosocial care emerged. Increased awareness of these negative responses to hospitalization gradually led to changes in the psychological approach to caring for children during their inpatient stays (van der Horst & van der Veer, 2009).
Parents became involved in the hospitalization process and acted as partners to their children’s hospitalization journey. The involvement of parents in children’s health care is generally associated with positive outcomes for both parents and children (Letourneau & Elliott, 1996; Rosenbaum et al., 1998; Woodside et al., 2001). The parental adjustment and engagement in their child’s care directly affects their child’s treatment effectiveness and well-being (Holm et al., 2003).

With regard to pediatric cancer, the parental distraction of their children during medical procedures has been shown to be associated with high child coping behavior and lower distress (Manne et al., 1992). Parents have been included as nurses’ assistants during the cancer-related medical procedure to reduce pain, anxiety, and distress. Studies of the efficacy of the parents’ interventions indicate that they play a significant role in reducing child pain, anxiety, and distress (Barrera, 2000; Broome, Rehwaldt, & Fogg, 1998; Manne et al., 1992; Powers et al., 1993; Smith et al., 1996).

However, parents started to report stress associated with the hospitalization of their children. During the diagnosis phase, parents tend to experience extreme levels of anxiety that sometimes reach a panic level, then anxiety levels reduce on subsequent days. Miles & Carter (1983) suggest that parents’ responses throughout their children's hospitalization phases are the results of the interactions between situational variables, personal characteristics, and environmental stressors. Studies indicate that many parents experience high levels of anxiety, depression, and uncertainty when their children are seriously ill (Franck et al., 2015; Wray et al., 2011). Experiences such as changes in their parental role, feelings of helplessness, lack of support, and financial burdens are considered to be primary factors causing parental distress (Nabors et al., 2018; Tallon et al., 2015). High parental distress is considered to be a barrier to the effective participation in child care and can adversely affect the hospitalized child, influencing children’s experiences and their ability to cope with their own distress (Power et al., 2008). Indeed, a review of the literature suggested parents’ anxiety prior to medical intervention was a consistent predictor of children’s anxiety. In addition, parental distress has been associated with negative long-term adjustment for parents and children (Dunn et al., 2012; Kassam-Adams et al., 2009; Nugent et al., 2007). Moreover, environmental stressors are considered to be factors that arise from the physical and psychosocial aspects of the pediatric oncology environment, where parental stress in response to a child’s illness is considered to be a normal and inevitable response.

2.3 Psychosocial Wellbeing and Care

2.3.1 ‘What’: Defining Psychosocial Wellbeing

When dealing with distressed parents, it is essential to concentrate on the development of psychological and social well being, known to be the psychosocial wellbeing, since it caters for positive relationships with other individuals in the surrounding environments. The term quality of life is usually interchangeable with the term psychosocial well-being since it involves similar components. Moreover, it is often used in healthcare research to specify how the individual’s well-being may be impacted over time by a medical condition (Guyatt, 1993). As a matter of fact, psychosocial well-being is considered to be a multidimensional construct that
consists of psychological, social, and subjective components; all of which influence the overall functionality of individuals in achieving their true potential as members of the society (Kumar, 2020). It incorporates the physical, economic, social, mental, emotional, cultural, and spiritual components of health. According to Segen's Medical Dictionary (2012), psychosocial refers to a person’s psychological development in, and interaction with, a social environment, while for the Gale Encyclopedia of Medicine (2008), psychosocial refers to the mind’s ability to consciously or unconsciously adjust and relate the body to its social environment. Although both definitions are not complex in themselves, these definitions disclose a state of well-being that motivates the development of life skills. This enables individuals, families, or communities to understand and engage with their surrounding environment (East African Community, 2019). The term psychosocial denotes the inter-connection between psychological sub-components and social sub-components; where the psychological sub-components include emotions, thoughts, behaviors, in addition to coping strategies, and the social sub-components include interpersonal relationships, social roles, norms, values, traditions and community life. All of which contribute to individuals’ overall wellbeing (OED, 2003). Accordingly, it reflects to the dialectic relationship between the individual’s emotional, psychological, perceptual, and social realms with its cultural and traditional dimensions.

2.3.2 ‘Why’: The need for Psychosocial Wellbeing in Pediatric Facilities

2.3.2.1 ‘Anticipatory Grief’ - Among Parents living with Cancer Diagnosed Children

Pediatric chronic diseases represent a central event that creates a major challenge to all family members. Pediatric cancer is now viewed as a chronic life-threatening illness rather than an incurable disease (Wong & Chan, 2006). This means that parents have to live with the threat of relapse or death for years. Accordingly, the pediatric cancer diagnosis and its therapy process is an essential stress trigger for both children and their parents. Families with a cancer diagnosed child undergo stressful experiences such as frequent hospitalization of the child which often leads to psychosocial problems, isolation, and reduced recreational activities (Shamsi et al., 2016; Zokae Ashtiani et al., 2017). Al Gamal and Long (2010) disclosed the process of ‘anticipatory grief’ among parents living with a child with cancer. When parents go through a long period of uncertainty, with the possibility of permanent damage or death of their child, anticipatory grief occurs. Anticipatory grief is defined as the phenomenon that involves the process of mourning, coping, adapting, accommodating, and accepting change that begins and stimulates in response to an imminent loss (Rando, 2000). Moreover, Worden (2003) defined anticipatory grief as an active process of grieving in response to different types of loss, which is the loss of a child’s health in this case. Correspondingly, the conceptual analysis of anticipatory grief indicates that it is a multidimensional phenomenon including various stages and coping approaches (Al Gamal and Long, 2010; Fulton & Gottesman, 1980; Rando 2000). Thus, understanding the different stages the parents go through during their children’s hospitalization is essential. It acts as an alert for professionals to the need for supportive interventions to preserve parents’ psychosocial wellbeing.
2.3.2.2 Care Burden and Parents’ Psychosocial Wellbeing

Although both parents may get involved in caregiving, women are traditionally expected to provide care, nurturing, and help with the role of caregiver particularly in developing countries (Santo et al., 2011; Adelman et al., 2014; Sulkers et al., 2015). Studies show that mothers, as the primary caregivers, usually carry huge care burdens that result in several painful experiences such as avoidance of social interaction, reduced social relationships, unwillingness to talk, and decline in the quality of life (Khanjari et al., 2013; Cal et al., 2017). Moreover, mothers tend to always feel that it is their full responsibility to be caring for children with cancer during the hospitalization process which puts excessive physical and psychological burden on them (Nemati et al., 2018). Accordingly, mothers are considered to be more vulnerable to the issue of care burden. Thus, it is essential to understand the causes of the care burden to be able to provide appropriate strategies to reduce it.

Care burden is one of the most common psychosocial wellbeing problems (Shokri et al., 2020). It is defined to be the extent to which caregivers perceive caregiving’s adverse effects on their emotional, social, physical, and spiritual functioning (Zarit et al., 1986). Other authors defined it to be a multidimensional response to the surrounding environments’ stressors that are associated with the caregiving experiences (Kasuya et al., 2000). Lack of information about the course of the disease, feelings of inadequacy, and disorganized family life are considered to be the most common causes for care burden (Ahmadi et al., 2018; Ahmadi et al., 2019). However, there are multiple factors that can alleviate the care burden for the caregivers of the cancer diagnosed children. Social support is one resource that can affect care burden since it has a buffering effect, especially among mothers (Burnette et al., 2017; Wang et al., 2017). Feeling supported enhances mothers’ sense of self-efficacy in dealing with her child. It can reduce mothers’ emotional burden as mothers benefit from open and frequent communication about children’s disease, which has a great impact on their psychosocial and physical well-being (Zhang et al., 2014; Shiba et al., 2016). Mothers’ care burden is not only limited to care giving of the hospitalized child, but it also includes caregiving of the husband and their other children (Barlow & Ellard, 2006).

2.3.3 The role of Pediatric Psychosocial Care (PPC)

Contemporary approaches to Pediatric Psychosocial Care (PPC) emerged during the first decades of the 1900s. It grew as a response to the recognition of the damaging effects of hospitalization on children’s and parents’ psychological, social, and emotional wellbeing. PPC is defined as the culturally sensitive provision of psychological, social, and spiritual care (Legg, 2011). It includes developing rapport, empathy and support, enabling patients along with their families to feel comfortable and safe, and providing communication between healthcare personnel and families and clear medical information (Curtis et al., 2016; Legg, 2011). One of the primary goals of PPC is to promote parent and families’ resilience and adaptive responses within the challenging medical context (Humphreys & LeBlanc, 2016; Beickert & Mora, 2017). The early assessment of the family’s strengths, vulnerabilities, and psychosocial resources can help the...
PPC professionals to **anticipate the adjustments** needed and **allow for efficient provision of psychosocial care** based on their needs (Wiener & Alderfer, 2011; Wiener et al., 2010). The availability of group support, individual and family counseling for caregivers can be also useful in addressing feelings of **anxiety, adaptation, coping styles, and communication patterns** (Wiener & Pao, 2012). Accordingly, psychosocial care does not encourage dependence on the medical team, but rather encourages development of effective coping strategies.

Psychosocial care professionals have a fundamental role in determining whether the medical information is clearly communicated and understood by the family. Assessing each family member’s **coping and learning techniques** is an essential component of helping a family at this critical time (Moss et al., 2019). Accordingly, the work of PPC professionals addresses a range of issues related to **physical, psychological, and social development** among parents. Moreover, it should be undertaken with an understanding of the importance of the relationships among individuals’ psychosocial wellbeing and healing environments (Doha International Family Institute, 2018). Accordingly, it is necessary for the PPC professionals to **promote quality of care approaches** within the surrounding supportive environments, especially in pediatric healthcare settings, to **reduce care burden and parental stress**, and **maintain the psychosocial wellbeing** of both parents and children during the hospitalization process.

### 2.4 Enhancing Quality of PPC

As the family was increasingly acknowledged as being critically important in the emotional, developmental, and medical care of the hospitalized child, both **family-centered care (FCC) and Trauma Informed Care (TIC)** emerged as approaches for enhancing the quality of care for both children and their parents during pediatric hospitalization and medical encounters (Auerbach et al., 2021). The main aim behind implementing such approaches is to emphasize respect for family perspectives and encourage family participation in care and decision making (Davidson et al., 2007). Moreover, implementation of such approaches would help in providing health care in a way that **minimizes the potential for current or ongoing psychological trauma or posttraumatic stress** throughout hospitalization experiences (Marsac et al., 2016). Accordingly, FCC and TIC are complementary concepts as each concept is associated with **improved health outcomes and better patient and family experience**.

#### 2.4.1 Family Centered Care

Family-centered care (FCC) is a philosophical approach that is guided by a set of principles that provides a pathway to **engage not only with children but also with their parents and families during their hospitalization experience** (Mooney-Doyle et al., 2020). It is defined as an **approach of caring for children and their guardians** within pediatric healthcare settings, ensuring that care is planned around the whole family, not just the individual patient, by which all the family members are recognized as care recipients (Shields et al., 2006). It seeks to **establish and maintain mutually beneficial partnerships among patients, families, and healthcare professionals** to make informed decisions about the medical care and support services needed.
for both the patient and family (Pettoello-Mantovani et al., 2009; Richards et al., 2017). Moreover, FCC promotes orientating care to support and involve the family with the goal of improving quality, psychological well-being, clinical outcomes, and the overall patient and parents experience. Therefore, FCC is considered to be a platform to inquire about, understand, and attend to the child and family response to the overall hospitalization experience.

2.4.1.1 Background

As a concept, Family-centered care has initially developed in the economically advantaged countries as a result of an increased social awareness. Such social awareness focused on the importance of meeting the psychosocial and developmental needs of both children and parents, highlighting the role of families in promoting the health and wellbeing of their children (Haller JA, 1967; Skipper et al., 1968; Hardgrove at al., 1972; Hennemen et al., 2002; Thompson RH, 1985). Historically, family-centered care has evolved from the concept of Medical Home, which was neither a house nor a hospital, but rather an approach through which comprehensive primary care was provided. The concept of a medical home is defined as an accessible, coordinated, and culturally effective primary care in which a pediatric clinician works in partnership with the family and patient to assure that all of the medical and non-medical needs are met (Neff et al., 2003). Through this partnership, the pediatric clinician can help the family and patient to access specialty care and family support, and other public and private community services that are important to the overall health of the child and his family (American Academy of Pediatrics, 2002).

Before the 1950s, hospitals used to be provoking a wealth of emotions for children such as fear, anxiety, loneliness and homesickness (Birch et al., 2007; Carney at al., 2003; Coyne, 2006). It was believed that having parents visiting their children constantly would obstruct effective care and cause more anxiety to children once their parents leave when the allowed visiting time is over (Nethercott, 1993; Shields, 1998; Johnson B, 1990), while on the other hand, researchers reported that children whose parents didn’t visit them at all suffered acute trauma (Bowlby J, 1971; Bowlby J, 1973). Accordingly, the Platt Report (Platt H, 1959) recommended that visiting should be unrestricted, and mothers shall stay with their children during the hospitalization phase, humanizing the pediatric healthcare settings. However, the movement towards the implementation in hospitals and health systems has been slow since the degree to which family-centered care is implemented varies across institutions, countries and regions (Palmer S, 1993; Coyne I et al., 2007).

Nowadays, general consensus on the importance of family involvement in high quality care for hospitalized children has been reached (Committee on Hospital Care & Institute for Patient and Family Centered Care, 2012; Johnson et al., 2008). The American Academy of Pediatrics (AAP; 2012) asserts that all pediatric health care professionals should adhere to patient-centered and family-centered care paradigm to ensure children and their families are well-informed about diagnoses and procedures in addition to empowering them to be involved and make decisions in all aspects of care (Claridge et al., 2020). In fact, FCC can be considered as an extension of the
Patient-focused care, which promoted delivering care based on patients’ needs while abandoning the traditional approach by which delivering care was based on the organizational perspective. In other words, FCC takes the patient-focused care to the next step by expanding the loop of care delivery to include parents whose wellbeing is recognized as equally important as the patient's life (Neff et al., 2003).

2.4.1.2 Core Principles of FCC

During the last decades, family-centered care has been promoted as the philosophies and practices that put the family at the heart of services, identifying parents as the driving force (Katz et al., 2002). In partnership with the Association for the Care of Children’s Health, the Institute for Patient- and Family-Centered Care (IPFCC) proposed five key elements that characterize family-centered care perspective: recognizing family as a constant in child life, facilitating communication between family members and healthcare providers, understand children and parents’ needs and integrate them within healthcare systems, recognizing parental strengths and coping strategies, and finally encouraging and facilitating parent-to-parent support. Those five key elements were later grouped into three main clusters: Family as a constant, Supporting family individuality, and Culture/Social Responsiveness since some of the previously mentioned key elements rely on the existence of one other (Watt et al., 2013; Foster et al., 2015; Doha International Family Institute, 2018). For instance, recognizing parent as a constant in child life, which is considered to be the main key element in FCC, can be demonstrated through recognizing parental strengths, facilitating communication between family members and healthcare providers with the aim of reducing parental distress, understanding parental needs and integrate them within healthcare systems, and providing flexibility within health care settings. While for the supporting family individuality cluster, it can be demonstrated through respecting families’ coping methods, in addition to providing emotional support and family-to-family support (Pettoello-Mantovani et al. 2009). As a concept, FCC finds its true meaning in the social context where it has occurred, honoring the difference from one culture to another. Therefore, FCC is a context-based concept that should be addressing the perspectives of communities from which parents and children are coming in order to provide a comprehensive and responsive environment that corresponds to their needs (Mooney-Doyle et al., 2020)

2.4.1.3 FCC in Pediatric Oncology

In pediatric oncology, the implementation of the family-centered perspective requires a dynamic and evolving approach since the nature of pediatric cancer as a disease and its treatment phases are in constant change thus evolving the needs of hospitalized children and their parents (Mooney-Doyle et al., 2020). In order to address such evolution, the examination of care of children is to be nested within the care of parents who are coming from various socioeconomic and cultural contexts. Indeed FCC acknowledges that children and their parents are much more greater than the sum of their needs, thus its goal is to incorporate a multi layered focus on their experiences and needs as individuals with an overarching aim to improve their wellbeing as
a family unit (Woodgate et al., 2011; Ångström-Brännström., 2018). As pediatric psychosocial care professionals, the incorporation of FCC’s core tenets of collaboration, flexibility, customization of care, and respect for family difference coincides with their vision of customizing the care for patients and families based on systematically identified needs and experiences that are elicited from the children and families themselves while putting into consideration the environmental and lifestyle factors (Mooney-Doyle et al., 2020). Accordingly, family-centered care in pediatric oncology is be considered as a framework to guide engagement with and care for children with cancer and their parents. Moreover, FCC allows pediatric psychosocial care professionals to view the care of children with cancer and their families through a lens of multidimensional, overlapping factors that influence the family’s experience of the illness and its effects on the family as a whole and on its members as individuals (Smith W, 2018; Mikkelsen, 2011).

2.4.2 Trauma Informed Care

In conjunction with family-centered practices, trauma-informed approaches are used to enhance quality of care for patients and their families, as well as the wellbeing of medical care providers (Marsac et al., 2016). Trauma-informed (TIC) is a psychosocial care framework focused primarily on the hospital context, incorporating an understanding of posttraumatic stress developed through the hospitalization experiences for children and their families (Kassam-Adams et al., 2015). According to the Substance Abuse and Mental Health Services Administration’s (SAMHSA), trauma-informed care is defined as a strengths-based delivery approach that emphasizes physical, psychological, and emotional safety for both providers and survivors, while creating opportunities for survivors to rebuild a sense of control and empowerment. This definition is considered to be among the most comprehensive and widely employed and thus can be used in guiding the application of trauma-informed care in pediatric healthcare networks (SAMHSA, 2014).

The implementation of TIC requires adjusting the healthcare network’s organizational culture to incorporate an understanding of trauma into routine care and treatment processes with the goal of decreasing the effect of the potentially traumatic events on both patients and their parents (Ko et al., 2008; Stuber et al., 2006). Changing such practices reflects the core principles of a trauma-informed approach that are categorized as essential in the healthcare setting, including patient empowerment, choice, collaboration, safety. And trustworthiness (Harris et al., 2001). Moreover, trauma-informed care incorporates additional key elements including addressing distress and providing emotional support for the family, encouraging coping resources, and providing anticipatory guidance regarding recovery (Kazak et al., 2006; SAMHSA, 2014). Accordingly, TIC must involve both organizational and clinical practices that recognize the complex impact trauma has on both patients and providers (Menschner et al., 2016). Such a process is often complex since it requires assessing the willingness and capacity of healthcare providers to design an innovative approach that allows health care systems to transform into TIC systems and adopt TIC approaches.
In settings that employ a family-centered approach to care, the addition of a trauma-informed approach is natural and offers several advantages. As illustrated in Figure 2, family-centered and trauma-informed care approaches are complementary but offer unique contributions to promoting high quality pediatric healthcare. Each approach emphasizes involving the entire family in care, ensuring cultural competence in care delivery, promoting collaboration among care providers and continuity of care, and engaging in self-care for providers (Kazak et al., 2006; SAMHSA, 2014; Committee On Hospital Care, 2012). In other words, both approaches highlight the importance of creating supportive environments that cater for psychological and social wellbeing of both children and parents.

2.5 Psychosocial Supportive Environment

The role of physical environments of the healthcare facilities is essential in promoting all stakeholders’ wellbeing. During the hospitalization process, the patients and their families seek not only a cure but a holistic healing experience that provides much-needed support in stressful times. Accordingly, providing a well-designed and a supportive physical setting is essential for a less stressful and traumatic experience. Moreover, taking into consideration the psychological and social constructs and needs while designing is necessary to enable families along with patients to adapt and cope well, improving the overall hospitalization process (Chaudhury et al., 2009; Dijkstra et al., 2006; Ulrich et al., 2004).
2.5.1 A Multidimensional Construct of the Environment

For architects, environments are basically the spaces and shelters where individuals interact and execute various functions; however, this is not the ultimate definition for the term environment as it is just one of many other perspectives that are defined from various disciplines. Lockie (2015) defined the environment as the totality of conditions that surround individuals in a particular space and time, interacting with the physical, biological and cultural elements that are originally interlinked to individuals. Accordingly, environments here are not physically tangible constructs for sociologists nor for anthropologists; it is about human interaction and interpretation of context that exert some sort of an influence on individuals. Moreover, Moser (2003) defined the environment as a setting that is neither neutral nor value free, but rather a culture bound that constantly conveys meanings and messages that is essential for human functioning and is integral to human action. Accordingly, after investigating the various definitions, one can realize that the environment is a multidimensional construct that consist of various dimensions. It is no longer a simple physical and tangible element that can promote individuals' well-being. It consists of social and cultural dimensions that provide a better construct to human perceptions, attitudes, and behaviors which must be directed to promote wellness.

2.5.2 Healthcare Facilities as Social and Cultural Environments

Hospitals are ultimately liminal spaces, where people are removed from their everyday lives, taken to the in-between space of being diagnosed, treated, operated upon, and medicated. For many people, hospitals are places in which their previous identities are stripped bare and new identities are forged. Therefore, interest for medical anthropologists to study people inside hospitals emerged, revealing the socio-cultural dimensions of healthcare settings. Contrary to a commonly held notion that hospitals are identical clones of the global biomedical model; anthropologists describe and interpret the variations in hospital cultures in different countries (Dilger & Hadolt, 2015). In fact, hospitals are domains where core values and beliefs of a culture come into view. In situations and processes of illness and recovery, people’s ‘true’ values, convictions and moral systems become most clearly visible (Fainzang, 2001). Along the same lines, Lock (1986) notes that the study of health, illness, and medicine provides us with one of the most revealing mirrors of the relationship between individuals, society, and culture. Accordingly, the element of ‘life’ must be added in hospitals. The extant studies of hospital life suggest that it is a world apart, a culture which is altogether different from the ‘real’ world or even a reversal of normal life. Although some ethnographers considered hospital wards as ‘a tight little island’ (Coser, 1962), others contend that life in the hospital should not be regarded in contrast with life outside the hospital, the ‘real’ world, but that it is shaped by everyday society (Van Der Geest, et al., 2004). Therefore, we can say that a hospital is not a separate island but an important part, if not the capital of the ‘mainland’.
2.5.3 ‘What’: Psychosocial Supportive Environment

The term ‘supportive’ generally means to **strengthen the position of a person**, or community, and having the quality of supporting and sustaining one’s assistance or adherence (OED, 2003). Ulrich (2001) described the term ‘supportive’ as an environmental characteristic that **supports or facilitates coping and restoration with respect to stress** that accompanies illness and hospitalization. With these definitions, the term **psychosocial supportiveness** can refer to the **quality of the built environment**, which strengthens or sustains the ability of an individual to perform. Moreover, Dilani (2000) highlighted that psychosocially supportive environments **enhance people’s capability to better cope with stress** (Dilani, 2000). He proposed features for a psychosocially supportive environment: such as **integrating the hospital into the city and its social structure**. Therefore, the previous statements suggest that psychosocial is not about designing for an unconscious psychological process. It’s about **providing spaces that maximize opportunities for patients to access social support from within the hospital**, from both members and other patients.

The relationship between individuals and environment is identified mainly by the **individual’s perception and conscious experience of objects** within the surrounding environment (Mazumdar, 2000). According to Brunswik’s **probabilistic model on environmental perception** and understanding of individual learning differences, the perceptual process is described as analogous to a lens, wherein stimuli from the environment become focused and perceived through the perceptual efforts (Brunswik, 1956). Moreover, Gifford et al. (2000) elaborated on the lens model framework with its consequential stages. It first **responds to particular objective features of the physical environment**, then it **integrates these reactions into emotional impressions**, and finally **translates them into evaluations of the built environment**. Accordingly, this probabilistic model may include **psychosocial supportiveness** as a **filter in the perception of physical cues**.

2.5.4 Ulrich’s Theory of Supportive Design

In healthcare settings, literature highlights the existence of a relationship between the supportive environments and stress theory (Chaudhury et al., 2009; Dijkstra et al., 2006; Ulrich et al., 2004). **Ulrich’s Theory of Supportive Design** conceptualizes how the **physical environment can impact individuals’ psychosocial wellbeing**, where the healthcare’s physical-social environment reduces the hospitalization induced stress not only for patients, but also for
parents and healthcare personnel (Molzahn, 2013; Ulrich et al., 2004). Ulrich advocated that physical and social healthcare environments, as healing environments, should be designed to promote wellbeing by providing a sense of control, access to social support, and access to positive distractions in the physical surroundings (Ulrich et al., 1991). This theory is often used to describe and interpret individuals' needs during hospitalization and suggests strategies for achieving supportive design. Using such approaches within healthcare facilities, especially in pediatric healthcare settings, would allow physical environments to cater for all stakeholders' (patients, parents, healthcare personnel, social workers, etc.) wellness and promote the integrating of healing environments in individuals' surrounding buildings. Despite the use of the theory of supportive design in cross cultural research in developed countries, limited research on this theory was identified in developing countries (Andrade & Devlin, 2015).

2.6 Parental Coping with Stress within Pediatric Facilities

2.6.1 Coping with Stress Mechanisms

Although the definitions vary, coping has traditionally been defined as thoughts and behaviors that are used to manage the internal and external demands of situations that are appraised as stressful (Lazarus & Folkman, 1984). Coping is considered to be a dynamic process that changes in response to the ongoing demands of the stressor. The specifications of the structure of coping responses have been one of the major challenges in coping related research. Due to the nature of coping itself, it is not based on a specific behavior, but rather a broad organizational construct that includes a large spectrum of behaviors that individuals use to manage their stressful and traumatic experiences (Skinner et al., 2003). Accordingly, the construct of coping has been subcategorized in a variety of ways. Compas, Connor-Smith, and Saltzman (2001) proposed that coping responses can be depicted along two broad dimensions: Voluntary versus involuntary and engagement versus disengagement. A decade later, Compas et al., (2012) proposed a more detailed model representing coping responses whereby people use three primary coping mechanisms to cope with a childhood illness including active coping, passive coping, and accommodative coping. Active coping, also known as positive coping, refers to the cognitive and behavioral attempts to deal directly with problems and their effects (Choi et al., 2012). It includes strategies that measure problem solving and communication. On the other hand, passive coping, also known as avoidant coping, refers to cognitive attempts to avoid confronting problems and behaviors as an attempt to indirectly reduce emotional tension (Choi et al., 2012). It includes strategies such as withdrawal from sources of stress and social interactions, disengagement, distraction, and other forms of avoidance. Whereas accommodative coping includes coping efforts to adapt to stress through reappraisal, positive thinking, acceptance, and seeking social support (Stoppelbein et al., 2013). Research suggests that accommodative coping is related to better emotional adjustment, whereas passive coping is related to poor adjustment after a child is diagnosed with an illness (Compas et al., 2012). Accordingly, coping can also be considered a multi-dimensional phenomenon as it includes a variety of facets defining the intensity of engagement (Lerwick, 2016). Although the previously mentioned coping theories focus on the children’s coping, Compas et al. (2012) suggested that this coping
model can be conceptualized within the context of the family’s coping skills.

2.6.2 Parental Coping Strategies

When examining parental coping mechanisms during the hospitalization process, parents of pediatric cancer patients reported to be using mostly accommodative and active coping strategies interchangeably (Stoppelbein et al., 2013). Through an extensive qualitative investigation, (McGrath et al., 2004; McGrath et al., 2005) found that accommodative coping is associated with parents seeking social support. Parents tend to report that interaction with other parents experiencing similar situations and having support from friends and extended family members made it easier for families to cope with childhood cancer. Moreover, parents of children with leukemia reported that the accommodative coping strategies aimed at maintaining family strength and an optimistic outlook were perceived as being the most helpful (Patistea, 2005). Communication is often mentioned in the literature as a coping strategy used by parents of children with cancer (Vollmer et al., 2017). Apart from open communication about the illness with the child (Landolt et al, 2003; Chaney et al., 2016), communicating with professionals about parents' emotional experiences throughout the hospitalization period (Hall, 1987) in addition to communicating with the healthcare personnel to understand children’s medical situation are essential factors for coping with such traumatic experiences and stressful events. Accordingly, parental active coping has been conceptualized as a willingness to encounter information through being available during the doctors’ daily checkup visits and advocating questions asking the healthcare personnel during or after the process (Doupnik, 2017; Peterson, 1989). Parents cited that information-seeking as a coping strategy is associated with feelings of empowerment. For parents, accompanying their children throughout the hospitalization process and being able to look after their children while taking the chemotherapy sessions decreases the issue of parental role alteration (Stoppelbein et al., 2013), and increases the perceived amount of control parents have over their children’s hospitalization process, which is considered to be an important active coping mechanism (Vollmer et al., 2021).

2.7 The Quality of Parent-Child Relationship

Children are dependent on their families, especially their parents, to meet their physical, emotional, and social needs; therefore, the quality of the parent–child relationship plays a crucial role in the psychological development of children (Lamb et al., 2011; Pinquart, 2013). Mothers are considered to be the primary caregivers and the best pediatrician to the child; accordingly, research highlighted the importance of mother's presence throughout the hospitalization process. Their existence doesn't only increase the quality of medical attention as, but also keeps child-parent affection relationships (Barrera et al., 2007). According to different theories, the emotional bond between the parent and child is considered the most important dimension (Lamb et al., 2011; Pinquart, 2013; Clark et al., 2000). Furthermore, it is a natural desire of parents to participate in their child’s care and emotional and practical support (Power et al., 2008). If parents of a critically injured child have reduced capacity to meet their child’s needs there is a negative impact on the physical and psychological adjustment of their injured child.
(Gonçalves et al., 2008; Ruth et al., 2020) and the well-being of the entire family unit can be threatened (Skinner 2007). The only intrapersonal coping resource the young children require is the ability to contribute to a secure and productive attachment to a caregiver (Goldsmith & Alansky, 1987).

### 2.7.1 The Attachment Theory

The influence of caregiver behavior is identified as the key factor in the quality of the parent-child relationship (Bowlby, 1973). The quality of care provided by the parent primarily functions to influence the child’s confidence in the availability of the parent and the quality of the parent-child relationship. Moreover, the attachment theory addresses the parent-child relationship relative to the emotional wellbeing of the hospitalized child (Van der Horst & van der Veer, 2009). The formation of a secure attachment pattern is a critical milestone of early development that provides the foundation for positive psychological and health-related outcomes throughout the lifespan (Puig et al., 2013; Sroufe, 2005). In pediatric healthcare settings, attachment patterns develop within the context of young children’s interactions with mothers (Ainsworth et al., 1978). Mothers who are available to their children and provide consistent, appropriate, and sensitive responses to children’s emotions and behaviors facilitate the development of a secure attachment relationship. In contrast, an insecure attachment relationship is likely to develop when there is a disruption in the communication between infants and their caregivers. Such disruption is characterized by inconsistent or non responsive interactions and caregiver unavailability (Turner, 2005). Accordingly, attachment theory provides a useful framework for understanding both family and child responses to the stressful healthcare experiences and for guiding care practices. Consistency, comfort and predictability are desirable features for pediatric healthcare settings. These conditions are essential to sustain a secure attachment relationship between the parent and the child during hospitalization.

### 2.7.2 Architectural Determinants for the Quality of Parent-Child Relationship

<table>
<thead>
<tr>
<th>Type of Contact</th>
<th>Bodily Contact</th>
<th>Non Physical Contact</th>
<th>No Contact</th>
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<tbody>
<tr>
<td>Environmental impact</td>
<td>No distance between Parent &amp; Child</td>
<td>Increased usage of space for interaction</td>
<td>Increased use of withdrawal possibilities</td>
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Figure 4. One of the Architectural Determinant for Parent-Child Interaction - Proximity between parent and child (Vollmer et al., 2021)

Within the pediatric healthcare setting, the physical environment is an essential component of the care provided in children’s health care settings and plays an important role in supporting the quality of child-parent relationship and interactions (Henriksen et al., 2007). Literature proposes approaches by which hospital environments influence the amount and degree of
interaction that occurs (Shepley et al., 2008). Based on a qualitative fieldwork, four architectural determinants were captured highlighting the quality of child-parent relationship and interactions. The architectural determinants include the function and place of interaction, proximity between parent and child, used space for interaction, and availability of possible spaces for parental withdrawal (Vollmer et al., 2021). In Figure 4, the proximity between parent and child is highlighted since such determinants highlight the different activities and interactions conducted in each mode and their impact on the overall parent-child relationship. Accordingly, architectural supportive interventions for hospitalized children and their caregivers should strive to facilitate children’s sense of protection and safety, while maintaining proximity between the child and his primary attachment figure (Krauss et al., 2016).

2.8 Privacy and Perceived Control

Literature on the design of healthcare facilities illustrates many approaches by which the design can provide opportunities for patients’ privacy and social interaction, while upholding principles of family-centered care that helps in fulfilling parents’ request to accompany their children throughout the hospitalization period. However, opportunities for supporting parents’ in finding relaxation, privacy, control, and withdrawal are yet missing (Vollmer et al., 2021). Despite the call for the various quality of care approaches that encourage parents to take an active part in the care of their hospitalized child, there is little evidence on finding the suitable approaches to best accommodate parents, enabling them to be effective and healthy participants in their child’s treatment and recovery (Franck et al., 2015). In the majority of societies, privacy is conceived as a fundamental social need; however, there are significant variations in the perception of privacy for individuals due to the influence and variance of culture and traditions (Buchman, 2004).

2.8.1 The Perception and Levels of Privacy Across Cultures

Privacy has always been considered as a public endeavor that has controlled variables such as gender, culture, age, and personality (Hall 1966, Altman and Chemers 1980). According to Edward Hall, an American anthropologist and cross-cultural researcher, cultural differences affect how people utilize and interpret space. Hall classified the cultures into 2 main classes; contact group represented by the spatial behavior of Mediterranean culture, and non-contact group represented by the spatial behavior of European culture. For the Mediterranean societies, they are known for their proximate interactive distance, while for the Northern European societies, they prefer the extensive one. According to Hall, differences in interpersonal distances are not only limited to cultural contact and non-contact groupings, but also encompass subcultures. Across cultures, the desire for privacy varies since some cultures need more privacy in comparison with others (Altman and Chemers, 1980). Accordingly, Irwin Altman (1975), developed his privacy regulation model, in which levels of privacy were classified into desired, achieved, and optimum levels. The balance between levels of privacy is crucial as the ultimate goal is always reaching the optimal level of privacy. However, when such balance is not achieved, many conditions can occur affecting the psychological wellbeing of individuals.
When the optimum level of privacy is exceeded, the individual feels isolation, social solitude, and boredom. On the other hand, when the achieved level is lower than the desired level, it can be concluded that the person’s surveillance in social behavior is not proper and the individual suffers from crowding. Accordingly, consistent with Altman’s studies, the design of pediatric oncology healthcare facilities should cater for reaching the optimal levels of privacy for both patients and their families.

2.8.2 Perceived Control: Interplay between Privacy and Social Interactions

In healthcare facilities, privacy is directly related to the notion of perceived control. Accordingly, privacy can be defined as the selective control of social interactions (Altman, 1975; Mulhall et al., 2004). Parents and children want to control to whom they are accessible. Such ability to control interactions is so important to the extent that it could be even more important than the process of interaction itself. (Shepley, 2005). Research has shown that the results in the stress coping abilities of parents who feel they have some control over their children’s situation is better than that of those who feel a lack of control (Ulrich et al., 2003; Uwajeh & Ikenna, 2019). Accordingly, control is seen as a protective cognitive factor that extends beyond controlling the physical environment. It has been linked to the emotional well-being of parents, patients, and healthcare personnel (Page, 2009). A sense of control is related to opportunities to modify or alter aspects of the environment (Huang et al., 2004). In hospitals, the established routine renders parents helpless. In the outdated patient rooms, parents experience a loss of control related to almost every aspect of their daily lives: what and when to eat and when to receive visitors. They have little opportunity to leave the ward or patient room, are limited in their range of activities in addition to the amount of control over their surrounding physical environment (Allen et al., 1980; Huang et al., 2004; Vollmer et al., 2021).

Environmental control is the degree to which people perceive they can control and impact characteristics of their physical environment (Devlin & Andrade, 2017). Room occupancy is also associated with privacy and access control. In fact, room occupancy reveals the interplay between privacy and social interactions that occurs within pediatric oncology patient wards. Single occupancy rooms can enhance control, as occupants have full command over how to adjust the environmental conditions to suit their own needs and preferences; however, social isolation results due to the absence of direct social interaction (Devlin et al., 2016). While in multioccupancy rooms, patients along with their parents might stress over the possibility of private conversations being overheard, the noise, the feeling that they are being looked at in their patient room by passers-by, and the frustration that there are no facilities for parents to be alone with their children (Pinson, 2013). However, regardless of the room type, basic environmental features that permit patients, some level of control should be provided. Accordingly, supportive design environments should cater for aspects such as territoriality, flexibility, & personalization to balance the interplay between privacy and social interaction and also enhance parents’ sense of control within the physical settings.
2.9 Territoriality and Personalization

As individuals enter into relations with their physical environments, they impart to the world and structure it spatially, which represents a certain degree of organization. The spatial structure of such an environment then is formed and marked out by physical barriers and boundaries such as fences, walls, doors, gates, etc. Individual dwelling units, for example, have always constituted a peculiar system of barriers that gives structure to a specific part of space, demarcated mainly by “external” and “internal” terms that indicate a complex system of different places and zones within and around it. However, such structuring of the surrounding environment takes place only at the levels of consciousness; it doesn’t presume an active input into the environment (Heidmets, 1994). Accordingly, there is a second class of structuring that consists of forms that entail a more or less marked practical transformation of the environment to give it a physical form suited to man. Studies of environmental psychology highlighted the phenomena of territoriality and personalization as the most essential “psychological determinants” of the actual structure of any inhabited environment (healthcare, residential, commercial facilities) (Heidmets, 1994).

2.9.1 The phenomenon of Territoriality

Human territoriality has recently been brought to the public attention as a significant aspect of everyday socio-environmental life. Territoriality itself is a complex concept with a variety of definitions through which the emphasis is based on active defense, exclusiveness of use, and control of space (Altman, 1975). Generally speaking, territoriality can be characterized as a set of behaviors that are displayed by an individual in relation to a physical environment, informing others that such an object is “under his/her control” and is used exclusively over a specific period of time (Edney, 1974). It is defined as a mechanism that is used to regulate the boundaries between individual and others using personalization and perceived control to satisfy individuals social and physical needs (Altman, 1975; Blumberg & Devlin, 2006). Accordingly, territory is not a possession of a specific element, but rather it can be considered as the designation of a particular place to a particular subject, through which specific behavioral norms, attitudes, and other factors occur. Moreover, empirical studies of human territoriality have shown it to be related to social hierarchy (Sundstrom and Altman, 1974)

2.9.1.1 Types of Territorialities

Synthesizing on human territoriality, Altman (1975) has suggested that there are three basic types of territories: primary, secondary and public territories. Primary territories are those controlled and used exclusively by a single entity for an extended period of time. It is considered to be the integral to oneself’s daily activities and is perceived as an indispensable part of oneself. Secondary territories represent locations that are not necessarily used exclusively by a single entity; yet provide wide area coverage and are periodical controlled. Public territories, on the other hand, are areas where everyone shares equivalent rights and nothing is allocated to individuals. In the pediatric inpatient department, the child's designated room is considered to
be the most prevalent depiction of a primary territory for both parents and children (Blumberg & Devlin, 2006). According to Proshansky and colleagues (Proshansky, Itelson & Rivlin, 1970), individuals thrive on organizing their physical surroundings to set detectable boundaries and maximize their freedom of choice. In this regard, the various territorial boundaries are symbolic and usually identified by personal belongings or possessions (Veitch & Arkkelin, 1995). Moreover, the boundaries and divisioning of a certain territory is a way to pursue freedom of choice. When a territory is closer to the individual, he can act freely within its boundaries. Accordingly, flexibility and customizability can promote the feeling of owning territory where parents can personalize and make their children’s assigned room home-like and better adjusted to their personal needs (Gashoot, 2012).

2.9.1.2 Privacy and Territoriality

Recent literature highlights the importance of studying the relationship between the two phenomena, territoriality and privacy (Namazian & Mehdipour, 2013). On an intuitive level both phenomena appear to overlap substantially. Individuals seeking to preserve their privacy or territory are in both cases defending their own right not to be invaded by others, and the behavior of those whose privacy has been violated is similar to that of those whose territory has been invaded (Edney & Buda, 1976). In fact, some writers have drawn the two concepts very closely. Proshansky (1970) suggests that individuals’ determinant of territorial behavior is one’s desire to maintain or achieve privacy as it affords a sense of autonomy and emotional release. Moreover, Altman (1975) suggests that the phenomenon of territoriality is related to and can be subsumed under privacy because it is one of the ways available to man of achieving privacy. In situations when privacy and its associated mechanisms are ignored and the different levels of personal space and territory are not recognized, people will have to struggle coping with the surrounding environment’s stressors and achieving what they consider to be appropriate levels of interaction. Accordingly, designers should take into account the dynamics of privacy as a changing process in which people open and close themselves to others and to different levels as different times, using personal space, territorial behavior, and other mechanisms to achieve a desired degree of privacy (Namazian & Mehdipour, 2013).

2.9.2 The Phenomenon of Personalization:

The phenomenon of personalization of the environment is closely linked to the phenomenon of territoriality. Altman (1975) defined personalization as an aspect of territoriality. According to Bartholomew (1974), personalization can be defined as a way of changing the environment and transforming it according to individuals’ own needs and uses. Fitzhugh & Anderson (1980) measure personalization through changes exhibited in the surrounding environment. While territoriality views the environment as an object that can be governed, personalization considers the environment as a way to materialize one’s individuality and distinctiveness (Heidmets, 1994). Studies categorized the phenomenon of personalization under two courses, where one focuses on different means for personalizing the environment, while the other examines the effects that these circumstances have on the individual. Despite the fact that the majority of
studies conducted on the issues of personalized environments in healthcare settings reported that there is a lack of adequate means of personalization, Cláudia and Ann (2015) highlighted that **personalization is not only an aspect of territoriality, but also an aspect of individuals’ perception of control.** They defined perception of control over the physical environment as the feeling that individuals can change, modify or transform the environment according to their needs. Individuals feel control when they feel they can personalize a space, changing its environmental characteristics. Accordingly, Heidmets (1994)’s reviews on the purposes and role of environmental personalization proves that individuals gain assurance, safety, and a sensation of ownership through the act of personalization, projecting of the individual’s self into the surroundings. Moreover, the capacity to bring part of their home within the hospitalization phase results in easier coping and adaptation to the surrounding traumatic and stressful factors for both patients and parents. Thus, personalization is also a key factor that contributes to parents coping with stress within new settings.

2.10 Access to Social Support

Social support is reported to be one of the most well-documented psychosocial factors influencing individuals’ wellbeing (Uchino, 2009). Establishing **social connectedness** to others, surrounding environments, and even the self is considered to be a primary concern in human nature (Hagerty et al., 1996). While the hospitalization process includes many emotional, social, and physical stressors, research suggests that **social support** can **reduce the amount of stress**, **reduce depression**, and **positively influence health outcomes** among patients and their parents (Bolger & Amarel, 2007; Frasure-Smith et al., 2000; Uchino, 2009). In fact, social support can be facilitated through **opportunities for social interaction, social integration** and an **enhanced connection to community** (Kim & Kaplan, 2004). **Social integration** is a multidimensional construct that includes a behavioral component, where **active engagement** in a wide range of social relationships, and a cognitive component, where a **sense of communality** and identification with one’s social roles (Brissette et al., 2000). Recent studies have documented a link between a sense of community and subjective well-being (Young et al., 2004). **Sense of belonging** is an important concept for mental health social functioning, and physical health outcomes (Hagerty et al., 1996). Accordingly, in developed countries designers for healthcare facilities concentrate on providing access to social support for parents along with their hospitalized children since the focus of the current research highlights the positive relationship between quality of care design approaches, such as Family Centered Care, and **users’ psychosocial well-being** (Alvaro et al., 2016).

2.10.1 Types of Social Support

Studies focusing on types of social support are usually associated with an individuals’ needs during stressful and traumatic experiences. Accordingly, if stress is defined in terms of the absence of social relationships, then social support is defined in terms of resources that allow for access to social relationships, by which individuals’ needs are met (Jacobson, 1986). Caplan (1979) describes **social support systems** as formal and informal relationships through which an
individual receives the **emotional**, cognitive, and material support **necessary to cope with stressful experiences**. Cited as the most needed type of social support, **emotional support** refers basically to an individual's behavior that fosters **feelings of comfort**, in addition to surrounding others’ behaviors that fosters **feelings of caring and security** (Jacobson, 1986). Lazarus and Folkman (1984) argued that coping with stress is a process that involves different types of social support at different times. Moreover, coping with stress reflects the continuous development of appraisals and reappraisals of the shifting relationship between an individual and the changing demands throughout the stressful experience. Accordingly, it is necessary to consider social support in its **temporal dimension**, since parental social support needs differ from one stage to another throughout the hospitalization process.

### 2.10.1.1 Parental Peer to Peer Support

One of the most **efficient types of social support cited by parents** is the ‘**Peer to Peer Support**’ (Shepley, 2005). Studies indicate that contact with peers results in significant benefit in social and communication skills (Fels et al., 2001; Said et al., 2018). Moreover, **interactions with other parents sharing similar experiences** seems to have a positive impact on parental psychological wellbeing (Ahmann, 1999). Parent-to-parent support provides parents with information, emotional support, and sense of being understood (Dunst, et al., 2003). Parents have cited support from other parents as an **essential factor** in helping them **cope successfully with the stress** of a hospital experience (Johnson, 1992). Moreover, parents who are supported are better able to help their child with cancer to cope with the stress of illness, treatment, and hospitalization. Support from other parents is more likely to be accepted than formal support (Hockenberry et al., 2006). However, **in early stages of hospitalization**, formal support is cited to be more preferred than peer to peer support (Vollmer et al., 2021). Foster and colleagues (2017) found that **spatial configurations** within hospital wards, specifically single rooms or shared rooms, had a significant impact on relationships and interactions among children, parents, and nurses. Parents in shared rooms appreciated the peer support, and social interaction that are afforded by the **shared spatial configuration**, while parents in single rooms experienced more isolation and less interaction (Foster et al., 2017). Accordingly, the notion of increasing the provision of single rooms within the inpatient department is therefore likely to directly affect family-centered care application in practice. However, parents in single-patient rooms described enhanced parent-child interaction due to the lack of interactions with others.

### 2.10.2 Role of Physical Environment in providing Access to Social Support

Healthcare facilities’ physical environments are an essential component of the care provided in pediatric healthcare settings; in addition, they play an important role in supporting the practice of family-centered care (Henriksen et al, 2007). While considering the psychosocial impact of Family-centered care on the family unit, pediatric oncology nursing research examined the impact of the **physical environment** and the **structure of individuals’ relationships** (Mooney-Doyle et al., 2020). Evidence exists that the hospital environment can influence the amount and degree of interaction that occurs (Shepley, 2005). Verwey et al. (2008) found that fulfilling a
parent's physical needs was an important component in reducing stress. Ensuring aspects such as comfortable sleeping arrangements within the inpatient room and flexible seating arrangements within the outpatient department, made a family’s experience a more positive one (Watt et al., 2013). Moreover, creating withdrawal spaces that allow for relaxation away from the inpatient area, in addition to peer interaction could be preferable. Evidence has shown that providing family lounges, day rooms, outdoor gardens, and waiting rooms with flexible furniture can promote social support. In addition, providing a family meeting area for visitors can encourage positive feelings and promote family relatives and friends to visit the patient and their parents in the hospital (Pinson, 2013). Accordingly, a thoughtfully designed hospital environment can support parents and children psychosocially by providing greater control, protecting privacy, and facilitating communication and participation in care (Joseph at al., 2008).

2.11 Positive Distraction

In healthcare facilities, the notion of distraction is mainly used to divert patients’ attention from the surrounding stressful environment and the stress-inducing thoughts (Campagnol & Shepley, 2014; Pati & Nanda, 2011). Since the 1970s, healthcare-related environmental research has shifted its focus from reducing the negative effects of the physical environment to creating restorative environments that reinforce positive experiences (Shepley, 2006). Ulrich (1991) defined positive distraction as environmental features that have been shown to reduce stress. It evokes positive feelings, holds attention and interest, and eventually fosters beneficial psychological changes (Ulrich et al., 1991). The overarching goal of positive distractions is to provide low levels of distraction without reaching overstimulation (Blumberg & Devlin, 2006). In pediatric healthcare settings, incorporating positive distractions could offer comfort and a positive perception of the supportive environment for both patients and their parents (Ulrich, 1997). Various types of positive distractions, such as access to external view, nature, color, and artwork have been identified as being effective in general healthcare environments (Cusack et al., 2010). Social interaction has been also considered as a form of positive distraction not only for patients, but also for their families (Campagnol & Shepley, 2014). However, access to nature has been highlighted as the most efficient therapeutic device that can soothe and encourage coping with stress, change occupants mood, and relieve their perceived level of pain, anxiety, and depression in various healthcare situations (Pinson, 2013). Moreover, research has demonstrated that natural window views (Ulrich 1984) and accessible gardens (Whitehouse et al. 2001) can enhance people’s health and well-being in healthcare settings.

2.11.1 Defining Restorative Environments

Since its origins in the 1960s, research on restorative environments has increasingly become organized around Ulrich’s (1991) theory of supportive design, which concerns stress reduction. Hartig (2004) defined the term restorative to be the renewal or recovery of adaptive resources or capabilities that have become consumed in meeting the demands of everyday life. As such, restoration is seen as a general process through which particular consumed resources become
restored. Over their life course, many people spend a substantial amount of time in healthcare settings, either as a patient, companion, or even a visitor. As people use physical, psychological and social resources on an everyday basis, the need for restoration arises regularly. Therefore, restoration is an important process, as new demands will come along and resources will have to be renewed to face them.

2.11.2 Windows as Restorative Resources

Windows are more than openings in an exterior wall and must be considered for their size and proportion (Shepley, 2006). They offer a special kind of connection between life outside and the inside. While people are contained inside, windows provide some sort of interactions with the exterior surrounding spaces whether streets or landscapes. In a comparison of window and windowless hospital rooms, Verderber (1986) found that windows that are very small, distant or high, were not thought of as windows at all. The presence of windows is an extension of the concept of access to nature (Shepley, 2006). Following stressful or demanding experiences, a visual exposure to nature can reduce stress by eliciting positive emotions, such as pleasantness and calmness; sustaining non-vigilant attention and positive interest; and reducing negative thoughts (Ulrich et al., 1993; Ulrich et al., 1991). People do not need to be outdoors to realize restorative benefits while engaging with natural features surrounding the facilities (Masoudinejad & Hartig, 2020). A substantial amount of evidence indicates that a view of vegetation through a window is evaluated more favorably and preferred over a view of built environments (Balling & Falk, 1982; Butler & Stuerwald, 1991; Kaplan, 1993). Moreover, natural environments have more restorative potential than built environments (Kaplan, 1995).

The restorative quality that the sky, vegetation, and other contents impart to a window view can be framed in terms of Attention Restoration Theory, ART (R. Kaplan & Kaplan, 1989; Kaplan, 1995). ART suggests the ability to concentrate may be restored by exposure to external view (Heather et al., 2016). It refers to restoration as a process in which effortless attention goes to interesting and pleasant aspects of the environment (R. Kaplan & Kaplan, 1989; Kaplan, 1995). The components of restorative experience can be treated as mediators of relationships between physical environmental attributes and psychological restoration. They allow individuals a “get away” ticket from the everyday stresses, experience “expansive” contexts, engage in activities that are “compatible” with one’s intrinsic motivations, and finally critically experience stimuli that are “softly fascinating” (Kaplan, 1995). Such a combination of factors encourages the involuntary attention and enables individuals’ directed attention capacities to recover and restore (Kaplan 1995; Staats 2012). Accordingly, the aspect of having effortless engagement of attention by the environment, is the key component in restorative experience in ART.

2.12 Conclusion

Literature has well established the impact of the dehumanization of healthcare facilities on parents’ psychosocial wellbeing (Ulrich et al., 1991; Franck et al., 2015; Wray et al., 2011; Nabors et al., 2018; Tallon et al., 2015). The implementation Family-centered and Trauma informed Care
approaches doesn't only offer unique contributions to promoting high quality of care, but also highlight the importance of creating supportive environments that cater for the psychosocial wellbeing of both children and parents (Kazak et al., 2006; SAMHSA, 2014; Committee On Hospital Care, 2012). Ulrich’s (1991) theory of supportive design along with its associated stress inducing factors highlighted the role of the built environment in addressing the individuals’ psychosocial wellbeing. Despite the use of Ulrich’s (1991) theory in cross cultural research in developed countries, limited research adopting this theory was conducted in developing countries (Andrade & Devlin, 2015). There is a lack of literature which relies on parents as firsthand users expressing their own preferences and needs. Moreover, there is a lack of design solutions which provide ‘culturally responsive experiences’ for parents during their children’s hospitalization period. Accordingly, there is a need for a research investigation on the provision of psychosocially supportive environments which correspond to parents’ psychosocial needs and experiences (Foster et al., 2017; Patterson et al., 2010; Marsac et al., 2011). As the built environment plays a great role in parental coping with stress, it is expected that using Ulrich’s (1991) theory of supportive design along with its associated stress inducing factors: privacy and perceived control, territoriality and personalization, the quality of parent-child relationship, access to social support, and access to restorative resources and positive distraction would provide a better understanding for parents' experiences and psychosocial needs during the hospitalization of their children. As highlighted in Table 1, this chapter helps introducing some of the parental needs and the associated environmental qualities that may appear during the different stages that mothers go through in children’s hospitalization journey. In this regard, the next chapter discusses the implemented research design and the conducted fieldwork in Egyptian pediatric oncology healthcare settings.
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<td>- Provide access to different outdoor play areas.</td>
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<td>Educational Support</td>
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Chapter 3

Methodology

3.1 Research Design

It is the most natural - but yet forgotten- fact in architecture that studying people is a must, especially when designing for people. Designers should carefully pay attention to the users’ needs for the space. This is only possible through "observing," or as Deasy and Lasswell (1985) in their book "Designing places for people" call it, "playing the people-watching game." Deasy and Lasswell highlight the availability of so little information for designers about their principal concern, the human client. At the same time, so much information is available to deal with the other building concerns of technology, health, and safety. The study of the relationship between the environment and behavior is essential. It is imperative while designing healthcare facilities if we intend to design "healing spaces" (Samimi, 2012). In this regard, this research uses 'Husserl's descriptive phenomenology' (see Penner & McClement, 2008; Reiners, 2012; and Shorey et al., 2022) as the key approach to understanding the experiences of mothers within pediatric healthcare spaces as unfolded in the introduction and literature review chapters. In a broad sense, the purpose of phenomenology is to describe particular phenomena as lived experiences (Speziale & Carpenter, 2007). Using a phenomenological analysis, this study's aim is to clarify the meanings of phenomena from lived experiences. As such, phenomenology offers a critical shift from a positivist cause-effect focus to one of human subjectivity and discovering the meaning of actions (Giorgi, 2005). Accordingly, the phenomenology practiced within a human science perspective can result in valuable knowledge about individuals' experiences. Given the aims underlying major phenomenological approaches, a descriptive phenomenological approach is better suited for examining the experiences of cancer patients’ mothers in the different spaces where psychosocial support is needed. It will help identify their psychosocial needs during their children’s hospitalization journey. This approach is especially appropriate considering the need for more local research examining this particular group of caregivers and the need for a fundamental understanding of their lived experience.

In order to achieve the research objectives and understand the experiences of mothers with an overarching goal of identifying mothers’ psychosocial needs within the two local healthcare contexts, ethnographic fieldwork techniques were conducted. These include participant observation with its various stances and strategies, behavioral observations, and semi-structured interviews with the mothers. Data collection was completed between late January-late March 2022 and mid-September-late November 2022. Participant observations were first conducted on a selected pediatric healthcare space (outpatient chemotherapy daycare units). This was to examine and document the prevalent physical and behavioral mapping in one local
healthcare facility (Children's Cancer Hospital Egypt 57357) before proceeding with the interviewing the mothers.

Corresponding to Al Gamal and Long (2010)’s disclosure on the process of ‘anticipatory grief’ among parents living with a child with cancer, interviews with mothers in the sample revealed three stages that mothers go through during their children's hospitalization journey. These are: "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life", which are labeled in respect of the experiences of the mothers. Accordingly, the research scope was adjusted to cover the mothers' experiences throughout the journey. It addressed the differing psychosocial needs and experiences of mothers across the three stages. These are studied in three different spatial layouts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units, that correspond to the above stages and represent the spaces where psychosocial support is needed.

Systematic field visits and detailed behavioral mapping were undertaken to document the variable behavioral activities and physical patterns used in relation to the study settings and their support facilities. Interviews with the mothers followed. The interviews were to gain a deeper understanding of the reasons behind the different observations and assumptions. Moreover, they are used to probe for the details of activity patterns during the different stages in the selected spatial layouts. The research relies on primary data collected from fieldwork. The data was collected through field notes, sketches, behavioral mappings, photographs, and transcriptions ((see Appendix A).

Finally, the researcher completed an IRB training course prior to conducting this research. It was a thesis requirement set by The American University in Cairo. The research title, aim, purpose, scope, duration, a sample of interview questions, and consent form were all submitted and approved by the Institutional Review Board (IRB) at AUC to ensure confidentiality and privacy for all interlocutors (see Appendix B). Since all interviews were conducted face-to-face, a consent form was handed to the interlocutors while the topic was explained. The mothers were given an Arabic version of the informed consent form to sign before conducting any interviews. These consent forms included the research title, aim, duration, and procedure (see Appendix C). For illiterate interlocutors, the form was read out to them, and the topic was explained to them before recording. The faces of mothers and children were masked in all photos to maintain confidentiality since consent was not possible during fieldwork observation in large spaces.

3.1.1 Study Areas

This research selected two different healthcare facilities that represent two of the most common pediatric healthcare environments available to the majority of the Egyptian population. Both hospitals provide services at low cost or free of charge and primarily serve low to middle-income populations. Since access to healthcare facility users is limited due to privacy and medical restrictions, the studied healthcare facilities were selected based on their willingness to host the researcher for administering the study. The comparison between the spatial layouts for the
mentioned stages at the two pediatric healthcare settings is found to be insightful. This comparison supports identifying mothers’ psychosocial needs within the inpatient and outpatient departments and seeing if parallels may arise. It provides an understanding of the mothers’ experiences, different uses and needs, spatial appropriations, and different ‘modes of inhabiting spaces’ during hospitalization stages. Moreover, it provides insights on ‘how’ and ‘why’ some design features in both settings underwent adaptations by mothers to match their needs.

3.1.1.1 Case Study 1 - Ain Shams University Children’s Hospital (ASUCH)

Figure 5. ASUCH - New building - South East elevation
(https://commons.wikimedia.org/File:Ain_Shams_New_Pediatrics_hospital.jpg)

Figure 6. ASUCH - Pin Location
The first case study area is Ain Shams University Children's Hospital (ASUCH) (Figure 5). It is a teaching hospital in the Demerdash Hospitals Complex located in Abbassia, Cairo, Egypt (Figure 6). The original El-Demerdash Hospital was established in the late 1920s by a generous grant from El-Demerdash Pasha, his wife, and their daughter. It was built on 12,400 square meters and had only 90 beds. Decades later, El-Demerdash Hospital became the Demerdash Hospitals Complex, affiliated with the Faculty of Medicine of Ain Shams University, and funded by the Ministry of Higher Education (Ministry of Health and Population/Egypt, El-Zanaty Associates, & ORC Macro, 2003). ASUCH consists of three main buildings: an old pediatric hospital (A), a new inpatient building (B), and the outpatient building(C) (Figure 7) The old building was constructed in the 1940s with a current capacity of 198 beds (Ain Shams University Hospitals, 2022). The new building began operation in 2018 with a capacity of 194 beds. Both hospitals are connected by a bridge, while the outpatient building is stand-alone due to the nature of the outpatient clinics and heavy traffic and circulation. Within the new inpatient building, the inpatient medium care units (Figure 8), located on the first floor, and the oncology unit on the fourth floor (Figure 9), were used for conducting the fieldwork. They were considered potential spaces of psychosocial support, as they host the "adjusting to the unknown" and "accommodating to the status quo" stages of children’s hospitalization. In the outpatient building, the outpatient chemotherapy unit and its waiting area (Figure 10), located on the 4th floor, were used for conducting the fieldwork as they were considered potential spaces of psychosocial support, hosting the "weaving through the ordinary life" stage of children’s hospitalization.

Figure 7. ASUCH - Pediatric Hospital Buildings

<table>
<thead>
<tr>
<th>KEY LEGEND:</th>
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<tbody>
<tr>
<td>A</td>
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<tr>
<td>B</td>
</tr>
<tr>
<td>C</td>
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</table>
Figure 8. ASUCH - Inpatient Medium Care Unit

Figure 9. ASUCH - Inpatient Double Unit

Figure 10. Outpatient Chemotherapy Unit & Waiting Area
The second case study area is the Children’s Cancer Hospital Egypt 57357 (CCHE) (Figure 11). It is a leading research hospital specializing in pediatric oncology in Zeinhom, El Sayeda Zeinab, Cairo, Egypt (Figure 12). It is widely known as Hospital 57357, with its unique healthcare institution that is constructed with donations. It was established in 2007 with the mission of providing the best comprehensive family-centered quality care, integrating the family as primary users through providing them with sufficient amenities and a chance for a cure to all children with cancer seeking its free-of-charge services (Children’s Cancer Hospital Foundation, 2022). The current hospital capacity is 345 beds and is expected to be increased after completion of the extension. Unlike ASUCH’s pediatric hospital buildings, CCHE’s consists of one main building that includes both the inpatient and outpatient departments. The inpatient unit, located on the third floor, was used for conducting the fieldwork. It is composed of single (Figure 13) and double-patient rooms (Figure 14) with various family support areas. These were considered potential spaces of psychosocial support, hosting the “adjusting to the unknown” and “accommodating to the status quo” stages of the children’s hospitalization. While for the outpatient department, located on the first floor, the daycare outpatient wards and their waiting areas were used for conducting the fieldwork (Figure 15). These represented potential spaces of psychosocial support, hosting the “weaving through the ordinary life” stage.
Figure 13 CCHE - Single Inpatient Room (CCHE media center)

Figure 14. CCHE - Double Inpatient Room (CCHE media center)

Figure 15. CCHE - Daycare Unit Sample (CCHE media center)
3.1.2 Data Collection Tools

3.1.2.1 Participant Observation

According to Zelditch (1962), participant observers actually employ three methods, not only one, including participant observation, informal interviews, and sampling. Since this research is tackling a social phenomenon which requires direct interaction with the users for data gathering, using participant observation as a research method can help in understanding the complex social relationship between the mothers and their surrounding others, and the environment. In fact, participant observation, as a method, is considered especially relevant to the types of research that are related to the understanding of experiences and types of relationships along with their impact on individuals. This is because it can redress many of the limitations of the other qualitative methods. The different strategies of participant observation are considered as flexible, less intrusive, and draw on multiple sources of data, such as non-verbal communication and activities (Greene and Hogan, 2005).

The first stage data collection was to thoroughly document the physical attributes of the different spatial layouts and study their relation to the experiences of mothers across the two selected contexts. That was done through Physical mapping for the inpatient and outpatient departments. The architectural floor plans for the inpatient departments of ASUCH and CCHE were provided by the hospitals’ engineering departments after obtaining consent from the hospital’s directors. While sketches were used for the outpatient department as they were not provided by the hospitals’ engineering departments. Photographs were recorded for the traces of mothers’ utilization of physical elements within the different spatial layouts to give better illustrations for the information provided by the physical mapping (e.g., fully Solid doors, use of window knobs for laundry hanging, etc.) during the extensive field visits. Moreover, photographs were used to illustrate the external view of the different spatial layouts whenever needed. The gathered visual data turned into key evidence highlighting the contribution of the pediatric oncology healthcare spaces to mothers’ needs and wants, which were later discussed in the interviews.

The intensity of the researcher's participation in the culture of the context studied determines the quality, validity, and amount of data gathered. According to Gold (1958), four main theoretical stances act as a spectrum for researchers conducting field observation: complete participation, participant as an observer, observer as a participant, and complete observer. To begin with, at one extreme is the complete participant in which the researcher is considered an active group member and conducts his/her fieldwork without disrupting normal activities. The main disadvantage regarding this stance is the high possibility of lacking objectivity because of the researcher's fear that the group members might feel deceived and distrustful when the research role is revealed. Moreover, the ethics of the overall situation becomes questionable. For the second stance, which is the participant as an observer, the researcher is considered an aware group member. One conducts the fieldwork by observing others more than participating without clearly revealing his/her research role. Although the researcher is still a participant with the group members, the tradeoff between the depth of the data revealed to the researcher and
the level of confidentiality provided for the data collection is jeopardized and is a main disadvantage. While for the third stance, observer as a participant, it enables the researcher to participate in the group activities. However, the researcher's role is revealed to all group members, and his main role is limited to collecting as accurate data as possible from observations within the context. According to Merriam (1998), one of the main disadvantages of this stance is that the group members control the level of information revealed. On the other hand, Adler (1994) highlights the 'peripheral membership role' approach that enables the researcher to observe and interact closely enough without participating in activities that constitute the core of group membership. Accordingly, the researcher would be able to gather as accurate data as possible without total immersion with group members. Finally, for the fourth and final stance, the opposite extreme from complete participation, comprehensive observation hides the researcher from context. The researcher is placed in a public setting for observations, while the group members are unaware that they are being studied. Here ethical issues are highlighted, such as members' consent; however, it allows the group member to act naturally without the pressure that they are being observed and studied. The researcher's stances during the different stages of hospitalization are discussed in the coming section.

3.1.2.2 Behavioral Observation

The second stage data collection was to document the behavioral patterns observed in the selected spaces of pediatric healthcare. The aim was to understand mothers' experiences during the different stages that mothers go through in the two selected contexts. Behavioral mapping was undertaken to document mothers' activities in both the inpatient and outpatient departments, which hosted the different stages within the selected spatial layouts. For this research, the stances of participation were determined based on the mothers' state during each stage and the spatial layout of the selected spaces of pediatric healthcare. Within the "adjusting to the unknown" and "accommodating to the status quo" stages, participant as an observer stance was used as mothers' approval and cooperation were needed to enter the single patient rooms (private) and double shared rooms (semi-private) prototypes. Moreover, their consent was needed to document the physical and behavioral observations (e.g., sketches, behavioral mappings, and images). The first visits were quite awkward and stressful for both mothers and the researcher; accordingly, building rapport was a must to ensure a thorough and accurate data collection. In fact, two mothers from the "adjusting to the unknown" stage and one mother from the "accommodating to the status quo" stage refused to participate in the study. They expressed being stressed and frightened due to their child's unstable condition, thus refusing the request to enter their rooms for observation. While within the "weaving through the ordinary life" stage, a complete observation stance was used as the ward layout -with its crowdedness- allowed the researcher to be seated near the nurse station, observing the mothers' natural and spontaneous behavior patterns without feeling the pressure of being observed or studied.

To capture mothers' mundane experiences and spatial utilization patterns, fieldwork visits were conducted weekly during February, March, September, October, and early November 2022. On average, 2-3 visits were conducted weekly, lasting 4-5 hours each. The fieldwork took place
during different hours of the day to document the everyday experiences observed within the
different spatial layouts in both contexts. The Children's Cancer Hospital Egypt 57357 granted
limited access to the inpatient departments. Only two visits were allowed on weekdays, and a
representative from the hospital team accompanied the researcher at all times. While for the
outpatient departments, full access was granted from 9:00 am to 8:00 pm on weekdays with an
unlimited number of visits. At the Ain Shams University Children's Hospital, full access was
granted to all the requested spaces. An unlimited number of visits was conducted to document
the physical and behavioral observations at different times of day/night on weekdays. As a
female researcher, access to the inpatient department hosting mothers and their sick children was
easily granted.

Moreover, being a female researcher facilitated extensive field visits with long durations since
having an emotional connection and building rapport with the mothers (same gender) did not
require a complicated process; it was quite simple. The data gathered in this phase included
photographs, field notes, and sketches. Toward the end of the data collection stage, the
documented activities were reviewed, and the interview protocol was started. Every context was
given around two months (sometimes overlapped), and the interviewing process began towards
the end of every hospitalization stage for each studied spatial layout in both contexts.

3.1.2.3 Sampling and Interviews with Mothers

To go beyond the physical and visual data, 46 stories and conversations were collected from the
two study contexts: 26 from the Ain Shams University Children's Hospital and 20 from the
Children's Cancer Hospital Egypt 57357. All the interviewees were the mothers who were
available within the studied spatial layouts. As there are three stages that mothers go through in
both contexts, 10 interviews were conducted within the "adjusting to the unknown" stage, 22
within the "accommodating to the status quo" stage, and 14 within the "weaving through the
ordinary life" stage (refer to tables below). The mothers' socioeconomic status in both contexts
included a range of literacy levels (illiterate to intermediate education), residence locations (Cities
and villages), and age (mid 20's to late '50s) with an ordinary combination of middle to low-
income sub-cultural groups. Mothers within the different spatial layouts during different stages
in both contexts were asked about the activities conducted on their typical day, the quality of the
parent-child relationship, and the approaches used for maintaining privacy and control. The
questions also included the types of spaces used for social support (informational/emotional),
their "go to" place whenever they are stressed, the different mechanisms used for coping with
stress, the role of windows and external view, and finally, the preferred seating modes within the
different spatial layout prototypes in relation to their needs. All the questions were originally
deduced from the parents' needs and wants along with the extracted themes that were discussed
previously in the literature review chapter (Chapter 2). The questions were developed and
modified in parallel with the fieldwork process. Since most of the activities conducted within the
different stages of hospitalization needed further elaboration (hunting for the 'why' perspective),
it was important to use the interviews for probing for details of both the "observed" and "unseen"
activity patterns which took place at different times of the day (see Appendix D).
3.1.3 Data Analysis

This study used field notes, sketches, behavioral mappings, and photographs to document physical and behavioral data. While audio recording, transcription, and note-taking were used to document the interviews. All the data was later coded using manual thematic analysis. Thematic analysis is a method for analyzing qualitative data that entails searching across a data set to identify, analyze, and report repeated patterns (Braun & Clarke, 2006). Some scholars have described thematic analysis as falling within the realm of ethnography, particularly suited to phenomenology; where the experiences of individuals are analyzed to extract common or shared meanings (Aronson, 1995; Joffe, 2011). During the coding process, common patterns emerged across the three hospitalization stages, highlighting specific psychosocial needs and desires with respect to the Egyptian culture. In this regard, selecting three different spatial layouts within the two different contexts was beneficial to overlay the narratives and findings, and to identify prevalent commonalities and conclusions related to the hypothesized themes from the literature review chapter. Moreover, a codebook for each stage within each context was designed to associate the different themes (see Appendix E).
<table>
<thead>
<tr>
<th>Stage 1: “Adjusting to the unknown”: Inpatient Medium Care Units (S1-ASUCH)</th>
<th>Age</th>
<th>Child's Age</th>
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<tbody>
<tr>
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</tr>
<tr>
<td>Om Moustafa</td>
<td>S1-ASUCH-3</td>
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</tr>
<tr>
<td>Om Mohamed</td>
<td>S1-ASUCH-4</td>
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<td>Om Moaz</td>
<td>S1-ASUCH-5</td>
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<th>Stage 2: “Accommodating to the Status Quo”: Inpatient Double Rooms (S2-ASUCH)</th>
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<td>Om Hussein</td>
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<tr>
<td>Om Nour</td>
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<tr>
<td>Om Gaffar</td>
<td>S2-ASUCH-3</td>
<td>43</td>
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<tr>
<td>Om Mohamed</td>
<td>S2-ASUCH-4</td>
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</tr>
<tr>
<td>Om Radwa</td>
<td>S2-ASUCH-5</td>
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<td>Om Kareem</td>
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<td>Om Habiba</td>
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<td>Om Karima</td>
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<tr>
<td>Om Adham</td>
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<td>Om Saeed</td>
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<td>Om Abbar</td>
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<td>Om Mahmoud</td>
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<tr>
<td>Om Mohamed</td>
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<table>
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<th>Stage 3: “Weaving through the Ordinary Life”: Outpatient Chemotherapy Department (S3-ASUCH)</th>
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<th>Child's Age</th>
</tr>
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<tr>
<td>Om Badr</td>
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<td>Om Hassan</td>
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<td>Om Anas</td>
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Table 2. Interlocutors and the stages that mothers go through within the different spatial layouts in Ain Shams University Children’s Hospital (CCHE)
<table>
<thead>
<tr>
<th>Children's Cancer Hospital Egypt 57357 - CCHE Interlocutors</th>
<th>Age</th>
<th>Child's Age</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1 - “Adjusting to the unknown”:</strong> Inpatient Single Rooms (S1-CCHE)</td>
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<td></td>
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<td>Om Youssef</td>
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<tr>
<td>Om Islam</td>
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<td>8</td>
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<tr>
<td>Om Joumana</td>
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<td>9</td>
</tr>
<tr>
<td>Om Esraa</td>
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</tr>
<tr>
<td>**Stage 2 - “Accommodating to the Status Quo”: Inpatient Double Rooms (S2-CCHE)</td>
<td></td>
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</tr>
<tr>
<td>Om Yassin</td>
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<td>9</td>
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<tr>
<td>Om Abdallah</td>
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<tr>
<td>Om Yasmine</td>
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<td>Om Nashwa</td>
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<td>Om Noura</td>
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<td>Om Iman</td>
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<tr>
<td>**Stage 3 - “Weaving through the Ordinary Life”: Outpatient Chemotherapy Department (S3-CCHE)</td>
<td></td>
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<tr>
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</tbody>
</table>

Table 3. Interlocutors and the Stages that mothers go through within the different spatial layouts in Children’s Cancer Hospital Egypt 57357 (CCHE)
Chapter 4

Analysis and Results

4.1 Introduction

This chapter presents the data gathered from the fieldwork conducted in the studied spaces in two local hospitals in Egypt: Ain Shams University’s Children Hospital and Children’s Cancer Hospital Egypt 57357. First, the two study contexts were thoroughly analyzed in terms of physical observations of the different spatial layouts, which corresponds to the three hospitalization stages, using physical descriptions and mappings. This was followed up by behavioral observations and mapping which studied the mothers’ utilization patterns in the different spatial layouts. Observation results were further elaborated through the interview findings, discussed in section 4.4. These provided a deeper understanding of the mothers’ experiences, and the captured needs within the different spatial layouts during the three hospitalization stages. The overlay of these two data sources was intended so that they can inform and complement one another, and thus build a comprehensive understanding of the mothers’ needs and wants.

As mentioned earlier in Chapter 3 (section 3.1), the results correspond to Al Gamal and Long (2010)’s disclosure on the process of ‘anticipatory grief’ among parents living with a child with cancer. The study incorporated three stages that mothers encounter during their children's hospitalization journey within three different spatial layouts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units within the two selected contexts' inpatient and outpatient departments. As the first stage in children’s hospitalization journey, "adjusting to the unknown" is the mothers’ most stressful and frightful stage compared to the rest of the stages. Due to the severity of their children’s health status, mothers spend almost 1-3 months inside the inpatient department with minimal social interactions and movement outside the department’s boundaries. During this stage, mothers were still trying to navigate through the crisis of their children’s diagnosis while slowly adjusting to its unknown status. While during the "accommodating to the status quo" stage, mothers visited the hospitals biweekly and stays for approximately 7-10 days per visit. As they watch their children's immunity systems improve day after day, their anxiety and overthinking regarding their children's health status decreased. Accordingly, mothers were accommodating to their children's improved health status, working on fulfilling their needs and preferences and leaving behind the anxiety and overthinking status. As parents reach the final hospitalization stage, "weaving through the ordinary life," through which they visit the hospital occasionally (once every 3-4 weeks), parents weave their children's chemotherapy sessions into their life routine to the extent that it becomes one of their weekly or monthly chores.
4.2 Ain Shams University Children’s Hospital (ASUCH)

4.2.1 Stage 1- “Adjusting to the unknown”: Inpatient Medium Care Units

4.2.1.1 Physical Observations:

Due to the longitudinal rectangular layout of the new pediatric hospital, referred to as building B in Chapter 3, wayfinding within the hospital was relatively easy. The vertical circulation core divides the building into 2 wings, allowing parents to easily access the different floors. On the first floor, the inpatient medium care department is located on the right-hand side of the vertical circulation core (Figure 16). In this department, a central nurse station is located. It serves 7 inpatient rooms, with the 8th room transformed into a nurses’ lounge and the room’s toilet transformed into a storage area. Due to the centrality of the nurse station and the department’s small size, easy access to all rooms was guaranteed. However, there is no direct visual access from the central nurse station into the inside of the rooms due to the “fully Solid doors”. These are mainly used for patients’ and the parents’ privacy and safety concerns. As a result, whenever the mothers had to leave the room (to submit documents to the administration or pick up clean clothes and sheets dropped off by their husbands), they first had to report to the nurse in order to avoid leaving their children alone without supervision.
As shown in Unit A (Figure 16), the design of the department follows a **double loaded corridor arrangement**, where the northern inpatient rooms have **visual access to the hospital's garden and Ramses street**, while the southern inpatient rooms have **visual access to the main entrance and the old pediatric hospital building**. For the northern inpatient rooms, the **garden acts as a buffer zone** decreasing noise significantly, thus **allowing windows to be opened more often**. While for the southern inpatient rooms, noise level varied throughout the day. During daytime, the **lively status of the overall pediatric complex generated background noises**, while during nighttime, **noise from outside** was unnoticeable. The only **support facility** that exists within the department is the **nurses’ lounge**. It is located on the northern side of the department along with some inpatient rooms, having **visual access to the hospital garden and Ramses Street** (Figure 17). There is an **evident absence of social support spaces, such as family/visitors’ zones** as mothers are strictly prohibited to be in contact with others due to the severity of their children’s health status.

Within the inpatient room, one can find three different zones: **patient zone, parent zone, and common zone**. The patient zone includes the patient bed, bedside cabinet, and adjustable overbed table, while the parent zone includes the companion recliner, and the common zone is where the TV, refrigerator, and the storage cabinet are located (Figure 18). The parent’s recliner is usually placed away from the healthcare personnel’s direct pathway so that they can easily reach the patient. Therefore, in this case, it is placed near the window, allowing both the patient and the parent to enjoy the view. In fact, the **large sized 2x2m window** with its **metal guard rail** (Figure 17).
19) portrays an *enclosed balcony* experience for users. Moreover, it allows for a sufficient amount of solar radiation needed for their laundry, hung on the doorknobs and window knobs, to naturally dry (Figure 20).

Figure 18. Medium Care Inpatient Room - Zoning with Areas Analysis

Figure 19. Enclosed balcony experience
4.2.1.2 Behavioral Observations: Usage Patterns and Categories

In the medium care inpatient room spaces, mothers’ behavioral patterns reflected the need for more home-like and amendable aspects that should be integrated within such rigid spaces. The activities observed in this stage were identified through the active presence of users. The patterns observed in this stage highlight issues such as parent-child relationship, privacy and perceived control, personalization, and positive distraction. During this stage, mothers were still trying to navigate through the crisis of their children’s diagnosis. Their children’s safety was their top priority, putting aside all their other needs and preferences. During this stage, the child’s immunity system usually becomes very weak. The mother limits her movement outside the room, isolating herself from any “unnecessary contact” with her peers who may cause infection transmission to her child. She usually spends this whole stage mainly with her child, developing a very strong and unique mother-child bond (Figure 21). The mother-child bond was observed to include non-physical contact through which the mother keeps some distance between her child and herself. Mothers tend to be sharing their daily routines and activities with their child during the whole stage. In the afternoon hours (2-4pm), the mother and child were seen to be producing drawings, paintings, studying, and even reciting Quran together. While later in the day (7-9pm), they were seen reading and watching movies together.

Om Cherolos, a 32-year-old mother whose eldest child (Cherolos, 11 years old) was diagnosed with Leukemia, portrayed the most common modes of parent-child bond. She was always seen having bodily contact with her child reflecting intensities of mother-child interactions throughout the day. During the long hours of injecting the treatment dosage to her child, she was seen giving him comfort and emotional support by sitting on the inpatient bed facing Cherolos and holding his hands. While during nap hours and sleeping time, she holds him between her arms until they both fall asleep. On a similar note, Om Moustafa, a 36-year-old mother whose middle eldest child (Moustafa, 11 years old) was diagnosed with leukemia, highlighted the
strengthened bond between Moustafa and herself which was developed throughout this hospitalization stage. Before Moustafa’s diagnosis, Om Moustafa used to be a working mother who barely spent any quality time with her children during her workdays. However, during this stage, they were found sharing activities, watching movies, and getting to understand each other on a deeper level. They were seen reciting movie jokes together during their movie nights and observing cars from the window while making racing bets.

Figure 21. Medium Care Inpatient Room - Mother-Child Interaction Modes
Untangling mothers’ experiences throughout this stage was not only limited to understanding parent-child relationships. **Mothers’ daily routine with their children represented the notions of privacy, perceived control, and personalization.** Due to the nature of the medium care inpatient unit, the **single room layout** allowed the mother to have **full control over the room’s temperature, lighting system, TV, and access to the window** (Figure 22). This helped her cope with the stress. Moreover, the existence of the **Anteroom as a “lobby”** played a very important role in having a balance between providing privacy for mothers and giving them some sense of control. Throughout the behavioral observations, nurses’ and doctors’ knocking on the **Anteroom’s door** was highlighted as an “alarm” for the mother to be ready for their entrance. Even though the mother was always wearing suitable clothes and ready for any sudden nurse’ visits, she used to exploit the minutes during which the doctor and the nurse wore the gown in the Anteroom to **sit upright and tidy the room** before knocking on the room’s door and entering. Moreover, the **“fully Solid doors”** with no inspection glass openings **provided more privacy for mothers** (Figure 23). During nighttime, the external **window with its one way tinted reflective glass** became a primary source of exposing mother-child activities to the passers-by downstairs due to the lack of curtains. Accordingly, the mother tended to **“hang a piece of white cloth”** for her privacy during the night time and remove it in the early hours of the morning to enjoy the warm sun rays and morning breeze.

![Figure 22. Medium Care Inpatient Room - Mothers' Perceived Control](image-url)
Since both the mother and the child were trying to find comfort and calmness during their journey, the mother tried to develop a **daily routine** within the inpatient room’s environment, mimicking their home environment and routine. To do so, the mother personalized the inpatient room’s zoning to serve her needs (Figure 24). The mother’s routine with her child starts at around 8-9 am when they both wake up and eat breakfast. **They usually have their breakfast while sitting on the companion recliner.** While the child searches for a TV channel to watch while eating, the mother used the inpatient adjustable overbed table as her “**small kitchenette countertop**”. She used it to prepare her sandwiches and store her child’s already made breakfast that is provided by the hospital. Once the mother was done with preparing the breakfast, she used the companion recliner’s extension piece as their dining table for their breakfast. Due to the lack of another seating element, she tended to sit on the floor while eating. In fact, this cycle was not only limited to breakfast time, but it was also repeated during lunch and dinner times (2pm & 7pm). When breakfast time was over, the mother used to help her child to get seated on the bed while she tidied the room, getting ready for the doctors’ checkup followed by the treatment dosages. Typically, the mother and her child tended to use the inpatient’s bed only during sleep hours, doctors’ checkup times, and during the treatment dosages. During the afternoon hours (2-4pm), the mother along with her child started their shared activities routine. The extension piece was not only used as a dining table, but also as a **support element for the mother-child’s shared activities**. They used it while drawing, painting, and writing. Moreover, the extension piece was also used as a **quick and non-permanent storage space**.
Due to the lack of social interactions with peers, the mother was observed to utilize several positive distraction activities within the room and the department’s boundaries to better help her cope with the stress induced. As the mother limited her movement outside the room, contacting people outside the hospital was considered to be her only connection medium with the “outer world”. Moreover, due to the lack of any designated family visiting areas, Om Ereny, a 30-year-old mother whose 5-year-old girl (Ereny) was diagnosed with Leukemia, demonstrated the essentiality of having her phone throughout Ereny’s hospitalization stages (Figure 25). Since Ereny was not a single child, Om Ereny had to be in contact with her other 2-year-old daughter whom she left with her sister in the countryside.
**Windows** were considered to be the *mother’s restorative resource*. Using *passive observation*, the mother tended to sit during different hours of the day observing either the building’s main entrance and the old pediatric hospital context, or the hospital’s garden and passersby in Ramses Street. This depended on the inpatient room’s view. In the early hours of the morning, Om Cherolos was observed **going to the nurses’ lounge to enjoy the garden view with its morning breeze** since her child’s room was **overlooking the back of the old pediatric hospital building with its boring view** (Figure 26). On the other hand, during the sunset hour, Om Moustafa was observed opening the window, rotating the companion recliner to be fully facing the window, while reciting **“evening prayers”**. She was observed **wandering** with the car horns, buses, and passersby in the busy Ramses Street and its mid-rise residential building; **escaping from the confined inpatient room limits with its boring calmness**, hoping that one day **Moustafa and herself will be with those passersby** who were trying to go back home to their families and friends after a hectic workday.
Figure 26. Medium Care Inpatient Unit - Using Nurses' Lounge and Windows as Restorative Resources.
4.2.2 Stage 2- “Accommodating to the Status Quo”: Inpatient Double Rooms

4.2.2.1 Physical Observations:

Similar to the design of the medium care department, the design of the oncology inpatient unit (Unit B) is highlighted through a **double loaded corridor**, where the northern inpatient rooms have **visual access to the hospital’s garden and Ramses Street**, while the southern inpatient rooms have **visual access to the building’s main entrance and the old pediatric hospital building**. However, unlike the design of the medium care department, the design of the double oncology department **lacks a centralized nurse station**. A remote **nurses’ room** is found to be replacing one of the southern inpatient rooms. It acts as both a decentralized nurse station and a nurses’ lounge (Figure 27). It is considered as the only support facility that is located within the department, while there is an **evident lack of social support spaces**, such as the **playing room** for children and **family/visitors’ zones** for mothers.

![Diagram of Unit B Double Inpatient Unit - Zoning and Circulation Analysis](image)

**Figure 27. Unit B- Double Inpatient Unit - Zoning and Circulation Analysis**
In contrast with the medium care inpatient room, the double patient room lacks the provision of a "dedicated zone for parents" (Figure 28). As there is inconsistency in providing the "sufficient" support amenities within the room, some rooms are found with a single companion chair, while the others with 2-seater metal benches. However, storage cabinets provided for each patient within the room is considered to be sufficient. Within inpatient rooms that lack the provision of a companion chair for each mother, the single companion chair is observed unused by mothers, placed in-between the invisible patient zones (no man's land). While in the other rooms, benches are used for multiple activities such as eating, socialization, window observation, and hanging laundry.

The design of the inpatient double rooms reflects aspects such as privacy, safety, and territoriality. The use of the "fully Solid doors" provides mothers with some privacy as it allows for no direct visual access. Moreover, the location of the inboard toilet and the use of inpatient beds' curtains allow for some visual privacy for both mothers and children within the inpatient room. For beds placed away from the window side, the location of the inboard toilet allows for visual privacy. Figure 29). While for beds placed near the window side, the use of the inpatient beds’ curtains allows for visual privacy. The use of the inpatient beds’ curtains is not only limited to the provision of privacy for both parents and children. They allow for “defining mothers’ personal space” within the inpatient room. Due to the lack of shading elements covering windows, the
inpatient beds’ curtains placed near the windows are used as a shading element during the day (Figure 30). Similar to the design of the medium care inpatient rooms, the double inpatient rooms include large sized (2x2m) windows with metal guard rails. As the oncology inpatient unit is located on the 4th floor, metal bars were added, covering the window as a safety measure for both children and mothers. While the laundry was observed hanging on the added metal bars, its placement on one side of the window reflects aspects of territoriality (Figure 31). As the curtains for beds cover half of the window’s size, the use of the window along with its metal bars is divided among mothers sharing the same room (Figure 32).

Figure 29. The role of inboard toilet and bed curtains in providing visual privacy
Figure 30. The use of bed curtains as shading element

Figure 31. Laundry reflecting aspects of territoriality
4.2.2.2 Behavioral Observations: Usage Patterns and Categories

Moving away from the social isolation and self-independent behaviors, mothers’ behavioral patterns throughout the “accommodating to the status quo” stage represented the collaborative, active, and interconnectivity that should be integrated within such functional and rigid spaces. The active presence of mothers along with their conducted activities throughout this stage highlighted aspects such as access to social support, parent-child relationship, and access to positive distraction. As mothers watch their children’s immunity system improving day after day, mothers’ anxiety and overthinking regarding their children’s health status decreases. Indeed, their children’s safety is still their top priority; yet they start taking into consideration their needs and preferences and work on fulfilling them.

One of the most common notions that was highlighted throughout this stage is access to social support. Having unknown company within the room seemed to be difficult for some mothers at first. During the first couple of days, the mother is observed to be zoning out, limiting her contact to be only with her child and the healthcare personnel. However, once the mother gets used to having company within the same room, both mothers are observed to be interacting and socializing with each other. They even ask about each other in the following visits and become friends. One of the most observed notions of social support among peers is the emotional support provided by one another (Figure 33). Emotional support is not only limited to getting to know more about their children’s health status, it includes talking about their other kids, family relatives, friends, and even taking advice from each other regarding any marital problem.
Om Gaffar, a 43-year-old mother whose 7-year-old (Gaffer) is diagnosed with Lymphoma, reflects the “intimate relationship” that a mother can have with her roommate. Due to her introvert character, Om Gaffar wasn’t comfortable at all sharing the room with someone. At first, she used to have limited conversations with Om Mohamed, who, on the other hand, was an extroverted social individual. Couple of visits later, Om Gaffar was noticed to have an altercation with her husband over the phone. As Om Mohamed approached her to make sure that she’s okay, Om Gaffar started crying and venting out to “her friend”. As a participant observer, Om Gaffar’s transition from being socially isolated, to venting out a marital problem was quite shocking. However, noticing Om Mohamed emotionally supporting Om Gaffar through her breakdown and proposing solutions highlighted the emotional support provided by mothers rooming in a shared room.

Access to social support was not only limited to social interactions and activities among peers, but mothers were also observed meeting their husbands and family relatives in front of the main entrance of the hospital (Figure 34). Due to the lack of dedicated space for visitors within the hospital, husbands and family relatives are observed downstairs waiting to meet the mothers. During day hours, they are observed sitting on the stairs, pavement, and ramp sideways. Some family relatives were observed even praying on cardboards spread on the floor (Figure 35). Since mothers are not allowed to leave their children alone in the room, peers depend on one another to take care of their child while they are gone. They alternate turns so that both peers sharing the same room can go downstairs to meet visitors (Figure 36).

Om Nour, a 26-year-old mother whose child (Nour, 4 years old) is diagnosed with Leukemia, and Om Hussein, a 28-year-old mother whose youngest child (Hussein, 6 years old) is diagnosed with Lymphoma, reflect the “interdependency among peers” and “familial social interactions”
developed throughout this hospitalization stage. After one of the doctor’s check up rounds, Om Nour was asked by the nurses to find someone who can bring her daughter “Platelets” (cell fragments that reduce blood clotting) from a blood bank outside the hospital. As Om Nour used to live in El Fayoum, she knows no one in Cairo to ask for such a favor. While Om Nour had to go herself, Om Hussein was observed reassuring Nour and taking care of her until her mom came back.

On a similar note, Om Hussein was observed to be asking Om Nour, her roommate, to take care of Hussein until she goes downstairs to meet up with her husband (Abou Hussein) and her daughter (Malak). Since healthy children are not allowed to accompany their mothers throughout their siblings’ hospitalization journey, Om Hussein left Malak, her 10-year-old girl, with her sister (Wafaa) since Abou Hussein’s working hours won’t allow him to fully take care of her. As Om Hussein is strongly attached to Malak, Abou Hussein tends to bring Malak with him whenever he visits. During one of the field visits, Om Hussein was observed sitting on the pavement right in front of the hospital’s main entrance, socializing with Abou Hussein while watching Malak vibrantly playing and running around. As a complete observer, one can sense the family warmth that is needed yet missing throughout Hussein’s hospitalization journey.

Figure 34. Outdoor ‘Family gathering space’ - In front of the Inpatient Building’s main entrance
Mothers are observed to be having *different intensities of social interaction at different times of the day* (Figure 37). In the *early mornings*, mothers are observed having *minimal social interaction* as they become busy getting their child ready before the doctors' checkup at 10 am.
Once the checkup is over, mothers eat their breakfast together while asking each other about the doctor’s feedback regarding the children’s health status. During the afternoon hours (1-2pm) some mothers are observed to be withdrawing from any social interaction as their children are having a midday nap due to the severity of the in-progress chemotherapy session. They tend to close the bed curtains and the lighting above the bed so that whoever enters the room knows that it is the “withdrawal hour” (Figure 38).
Social interaction among peers is not only limited inside the room, it extends to be within the whole department (Figure 39). At noon, mothers are observed to be standing on the doorstep of the inpatient room, having casual conversations across the corridor. As nurses limit mothers’ movement across the inpatient rooms, mothers work around it and check up on their peers across the corridor. Moreover, during different hours of the day (8-9am) & (3-4pm), mothers are observed to place the companion chair in the doorway to keep the inpatient’s door open, having a glimpse of whatever is happening around the department (Figure 40). Due to the fully solid doors, mothers feel the tendency of finding a way to have this “sense of connectivity” with life within the department. They are observed to open the windows while having the door opened to allow for some proper air flow to pass throughout the inpatient room. At night, mothers exploit the fact that the nurses have limited circulation across the department, so they tend to visit each other across the patient rooms. Moreover, they are observed to be socializing in the staff circulation’s corridor, located at the end of the oncology inpatient wing, to avoid getting caught by the nurses.
Figure 39. Unit B - Mothers’ Social Interaction Map

Figure 40. Use of chair to keep door opened
Parent-child relationship within the inpatient double room is reflected through mothers' seating zones inside the room. Within inpatient rooms that lack the existence of both companion chairs, mothers are observed to be sitting on the bed along with her children most of the day, leaving that one non-designated companion chair with no use. Even though the size of the inpatient bed is not suitable for accommodating both the child and the mother throughout the day, such “close proximity” between the mother and her child reflects the different modes of the mother-child bond (Figure 41). During chemotherapy sessions, mothers are observed doing three different scenarios. Some mothers are seen lying on bed, having their children sleeping on their laps. While others are seen sitting on bed beside their children with minimal physical bonding, either distracting the children from the pain induced from the treatment by playing together with their children’s toys or distracting both themselves along with their children through playing with their mobile phones.

Figure 41. Double Inpatient Room - Different modes of the ‘Mother-Child Bond’
Mothers’ **seating zones** within the inpatient rooms didn’t only reflect the modes of mother-child bond, it also highlighted the **interplay between privacy and access to windows as a restorative resource** that was captured through mothers’ behavioral observations. It was observed that mothers who are **wearing niqab** tend to be using the **inpatient bed curtains** more frequently than other mothers. They were observed to be **closing the curtains** at different times of the day. Om Adham, a 49-year-old mother whose youngest child (Adham, 9 years old) is diagnosed with Lymphoma, and Om Saeed, 34-year-old niqabi mother whose only child (Saeed, 6 years old) is diagnosed with Lymphoma, reflect notions of “**adaptability & compromises**” developed among mothers while sharing the same room. As Om Saeed is **seated near the window**, she feels that she is **visually exposed to whoever steps inside the room**. Accordingly, she is observed to be **closing the curtains** whenever she takes off the niqab; during **sleeping hours**, while **eating**, and even while just **lying down on the bed with her child**. On the other hand, **closing the beds’ curtains** directly affects Om Adham since it **obstructs the visual accessibility to the window** from her bed. However, Om Adham is observed to be **working around** this issue by either **sitting on the 2 seater metal bench**, located away from the bed curtains and has visual access to the window, or **standing in front of the window**, enjoying the external view whenever she wants (Figure 42).

**Figure 42.** Double Inpatient Room - The use of 2 seater metal bench for maximum exposure to external view for mothers seated away from window
4.2.3 Stage 3- “Weaving through the Ordinary Life”: Outpatient Chemotherapy Department

4.2.3.1 Physical Observations:

Due to the nature of the outpatient clinics and their heavy circulation, pediatric outpatient departments are located in a separate four storey building that is close to the inpatient building within the pediatric healthcare complex. As highlighted in Unit C (Figure 43), the outpatient chemotherapy department (which is located on the 4th floor) consists of: one chemotherapy room, a waiting area, examination rooms, and supporting facilities. However, there is no dedicated space for the nurses, such as a nurse’s station or room. The waiting area was always crowded with limited seating and hence, standing mothers and children. The waiting area also acted as the main access node for the department, the main pathway for circulation for all users (doctors, nurses, mothers, and children). Parents along with their children were often observed sitting on the stairs’ landings as an extension to the department’s waiting area. Accordingly, the size of the waiting room was insufficient compared to the number of users visiting. The small sized chemotherapy room was also crowded during the departments’ working hours (10am till 2pm), accommodating 8 patients within a (2mx3m) compact room. Elevated cupboards were placed above the children’s chemotherapy chairs as storage space within the department. While an operable large sized window was located on the wall opposite to the room’s entry node, allowing for natural sun lighting and ventilation (Figure 44).

![Diagram](image)

Figure 43. Unit C- Outpatient Chemotherapy Unit - Zoning and Circulation Analysis
4.2.3.2 Behavioral Observations: Usage Patterns and Categories

The behavior of Mothers within the chemotherapy outpatient department was quite different from those within the inpatient department. During the previous stages, mothers were trying to accept their children’s illness, adapt and adjust their needs throughout their stay with their children at the hospital. However, for this stage, mothers were considering their monthly visits as their final destination for their children’s hospitalization journey. Both parents were allowed to stay within the department. Mothers and fathers were observed to be accompanying their children during their chemotherapy sessions; however, the percentage of mothers accompanying their children was higher than that of the fathers by 80%.

In the chemotherapy room, the mothers’ behavior reflected access to social support, territoriality, and control issues. Mothers were doing several activities including socializing with peers, sleeping during sessions, eating, and having phone calls. Due to the lack of storage areas, mothers were storing their personal belongings underneath the chairs. Personal belongings were also sometimes found hanging on the windows’ knobs as a shading device (Figure 45). Due to the lack of provision of dedicated zones and amenities for parents, the majority of mothers were sitting on their children’s’ dedicated chairs with their children on their laps. Some parents were observed standing right next to their children’s chairs, while others were observed sitting on empty children’s chairs whenever possible. When all the chairs were occupied by children, some mothers sat on the wooden bench in the waiting area with a very close proximity to the room. Since mothers needed to keep an eye on the treatments’ side effects, they were going back and forth between the room and the waiting area checking up on their children (Figure 46).
Figure 45. Outpatient Chemotherapy Room - Issues of crowdedness, territoriality, and control

Figure 46. Outpatient Chemotherapy Room - Mother-Child Seating Modes & Peer Interaction Modes
Om Anas, a 45-year-old mother whose youngest child (Anas, 13 years old) was diagnosed with Leukemia, reflected on the “struggle of finding a zone” that mothers went through while accompanying their children during their chemotherapy sessions. She arrived with her child at 9 am. They first took a turn for the doctor's checkup, who would determine the dose and duration of the session. They then waited for their turn in the waiting area. During her waiting time, Om Anas socialized with other mothers, who were also waiting for their children’s’ turns for a checkup. At the beginning of the session (11:30 am), Om Anas was sitting on an empty chair right next to Anas since there were multiple empty chairs in the room. She ate her breakfast while scrolling on Facebook, watching videos. This was the main source of noise in the room. As the room began to get crowded with children taking turns for their sessions and their mothers standing right in front of them; Om Anas stood outside next to the door, maintaining visual access by standing right next to the room’s door. Half an hour later, she was found sitting on the wooden bench located right next to the door, with no visual access to the room due to her back pain. The frustrations that were captured through Om Anas’ facial expressions and her constant trips inside and outside of the room highlighted the need for dedicating a parent zone along with its basic amenities for mothers within the chemotherapy room.

Figure 47. Unit C - Parents’ utilization of the Waiting Area
4.3 Children's Cancer Hospital Egypt 57357 (CCHE)

In contrast with ASUCH’s longitudinal rectangular layout, CCHE inpatient department has a radial layout, which in turn results in a much more complex circulation and wayfinding system. Upon arriving at the inpatient department, parents follow a color-coded wayfinding system (Figure 48). The identity of each inpatient floor is clearly noted in a dominant accent color throughout the unit and inside patients’ rooms. The inpatient department was divided into a hierarchy of controlled access nodes. The information desk is located right next to the elevator area, separating the public zone (including the elevator’s lobby, stairs, and visitors’ waiting area) and the semi-private and private zones. The central nurse station (Figure 49) connects the single rooms and double room’s domes together, providing a limited and controlled access to the department’s most private zone. Those are the zones where patients and their parents were placed. Moreover, the central nurse station acts as an additional information desk for parents and families. In addition to the hierarchy of controlled access nodes, the design of the inpatient department allows for a hierarchy of social spaces and waiting areas. Within the public zone, the general waiting area (Figure 50), located right in front of the visitors’ lobby, provides a sheltered space for visitors that is accessible to all users (visitors, parents and healthcare personnel). There are also additional smaller waiting areas within each inpatient dome (Figure 51). The access to the smaller waiting areas is controlled by the dome’s nurse station.
Within the inpatient department (Figure 52), there are three inpatient domes, two of which consist of single patient rooms. While the third dome consists of double patient rooms. In general, each inpatient dome has a **central nurse station** serving **eight inpatient rooms**, and a **one isolation room**. Moreover, it includes support amenities such as a **family zone**, located behind the nurse station, and a **nourishment zone**, serving both nurses and parents. The **radial layout of the inpatient domes** allows the **central nurse station** to have **controlled access**, **direct visual access**, along with **easy access** and **equitable distance** to all inpatient rooms. Moreover, it allows the patient rooms, even those located within the same dome, to have **access to different external views**.
4.3.1 Stage 1 - “Adjusting to the unknown”: Inpatient Single Room

4.3.1.1 Physical Observations:

The design of the single inpatient room reflects the aspects of **territoriality**, **privacy**, and **access to positive distraction**. In an inpatient room, there are four different zones: **patient zone**, **parent zone**, **visitors’ zone**, and **common zone**. The patient zone consists of an inpatient bed, bedside cabinet, and adjustable overbed table. While the parent zone has a companion recliner, extra companion chair, and side table. The visitors’ zone includes a chair similar to the parents’ companion chair. While the common zone is where a TV, refrigerator and the storage cabinet were located (Figure 53). Similar to ASUCH’s’ medium care isolation rooms, a **parent’s recliner** is usually placed away from the medical personnel’s direct pathway to allow the personnel to quickly reach the patient. Therefore, in this case, it was placed near the window wall allowing both the patient and the parent to enjoy the view. Due to its **small size** and **lightweight**, the extra
companion chair has no fixed location inside the room. Sometimes it was placed next to the curtain wall. While other times it was placed near the toilet’s wall facing the patient bed. Depending on the number of visitors’, the extra companion chair was sometimes used as a visitors’ chair. To avoid having the visitors’ zone interfering within the patient’s and the parent’s zones, the visitors’ chair is usually placed in front of the inpatient’s room lobby, to be visible from the inpatient’s room entrance.

The radial design of the inpatient room along with the location of the inboard toilet played a significant role in providing privacy for both children and parents. The location of the inboard toilet created a small lobby in front of the rooms’ entry node that allowed for some visual privacy (Figure 54). In addition, the radial layout maximized the area of the “blind spot” in which the inpatient’s bed and the companion recliner were placed. Therefore, the mother was provided with some visual privacy while resting on the inpatient bed or sitting on the recliner. The implementation of a curtain wall reflected the openness, exposure, and integration with the outside experiences. Moreover, it provided maximum access to the external view within the room. This helped with reducing mothers’ stress induced from the hospitalization stage. Accordingly, the curtain wall played a major role in providing access to positive distraction for both mothers and their children. However, the use of the curtain wall invaded the users’ privacy, mostly at night. Accordingly shading curtains were installed, acting as a privacy element at night and a shading element during the day. (Figure 55).
4.3.1.2 Behavioral Observations: Usage Patterns and Categories

In addition to the functional and efficient design of CCHE’s single inpatient rooms; mothers’ behavioral patterns within the spaces reflected the flexible and home-like aspects that are integrated within the rooms. As the first stage in a child’s hospitalization journey, “adjusting to the unknown” was usually a mother’s most stressful and frightful stage. During this stage, mothers were still trying to navigate through the crisis of their children’s diagnosis, while slowly adjusting to its unknown status. Mothers spent the majority of their time inside the inpatient room, untacking their daily experiences within the space. Hence, the participant as an observer stance was essential. This behavior of mothers in this stage highlighted issues such as parent-child relationship, perceived control, personalization, and positive distraction.

Due to the nature of the single inpatient room, a mother and child spent tremendous amounts of
time together with minimal interference from the healthcare providers. The care providers only accessed the room during the checkup rounds and the chemotherapy sessions. During this stage, mothers developed a very strong and unique mother-child bond. The mothers’ behavior reflected the intensities of mother-child interactions. The mothers had frequent bodily contact with their children as a comforting gesture. During nap hours, the mothers shared the inpatient bed with their children, “holding the children between their arms”. While during the “child in pain” moments, they calmed their children down by “holding their hands”. In addition to bodily contact, mothers also had some moments of non-physical contact with their children while still maintaining some level of interaction. During different hours of the day, they performed activities with their children such as eating, playing, drawing, and reading. After the chemotherapy sessions, the children would fall asleep, while the mothers rested on the companion recliner, keeping an eye on the children for any chemotherapy side effects. This state is an example of when a mother had non-physical contact while maintaining “close proximity” with her child.

Om Hassan, a 45-year-old mother whose child (Hassan, 13 years old) was diagnosed with Leukemia, represented the compassionate side of the parent-child bond within the single inpatient room. Throughout the day, Om Hassan always had bodily contact with her child with various intensities. During the chemotherapy session, she was comforting her child, giving him the emotional support needed at that time. Whenever her child seemed to be in pain, Om Hassan was sitting on the inpatient bed, holding her child between her arms. As she desperately tried to reduce his pain, Om Hassan gently touched his hand, kissing him on his forehead, while reciting verses of the Holy Quran in a very low voice until he rested his head on her shoulder and fell asleep. Such a comforting and spiritual gesture reflected the unique bond that Om Hassan had developed with her child.

While sharing her daily routines and activities together with her child, a mother was also personalizing her utilization of the space with full control over the room’s flexible furniture’s layout, temperature, lighting system, TV, and storage space. Similar to mothers’ behavior observed within ASUCH’s medium care inpatient rooms; a mother’s activities in CCHE’s single patient rooms reflected the home-like environment created through the mother-child daily routine. Due to the large room area, flexible and sufficient amenities provided, mothers had more zoning options and much more control. All of which better served their needs when compared to the efficient yet static options within ASUCH’s medium care inpatient rooms. While eating meals throughout the day, mothers along with their children used the parent’s extra companion chair, visitors’ chair, and the side table. They were placed then near the window for the mother to enjoy the view, yet facing the common zone for the child to enjoy watching television. For shared activities such as reading, drawing, or watching TV, mothers followed one of the following scenarios. When reading, the mother shared the same companion recliner with her child. Other times, she left the companion chair for her child, and sat on the bedside or on the extra companion chair while facing her child to have a full interactive mode with her child. During sleeping or nap times, the mother either shared the inpatient bed with her child or rested alone on the companion recliner (Figure 56).
Due to the social isolation that mothers tend to experience during this stage, they had several positive distraction activities within the room boundaries to better help them cope with the stress induced. At different times of the day, mothers called family members and friends who are checking up on her child’s health status. Moreover, they sat near the window throughout the day, whether conducting activities or just resting. For a mother, the window was considered to be her connection medium with the “outer world”. The curtain wall did not only allow for maximum exposure to external view, but also compensated for the departments’ removal of the windows’ knob, prohibiting a mother from opening the window as an approach to ensure the safety of both the mother and her child. However, the curtain wall with non-reflective glass became a primary source of exposing mother-child activities to the passersby in the street, especially at night. Therefore, it reflected an interplay between privacy and access to windows as restorative resources.

Om Youssef, a 35-year-old mother whose youngest child (Youssef, 8 years old) was diagnosed with Leukemia, reflected on the “practical use of curtains” that mothers adopted to maintain privacy while having access to the external view. Since there were foldable curtains installed for the curtain wall, Om Youssef utilized each to fulfill her needs within different hours of the day. During early hours of the morning, Om Youssef had “fully opened” curtains, enjoying the diffused morning sun rays while eating breakfast. In the afternoon hours, she “partially” opened the curtains. To maintain some privacy during her resting hour, she closed only the curtains next to her companion’s recline, while leaving the other curtains open to passively observe the...
passersby downstairs and the children playing in the hospital’s renewed landscape. However, at night, she “fully closed” the curtains for maximum privacy during sleeping hours.

Figure 57. Hospital’s Renewed Landscape

4.3.2 Stage 2- “Accommodating to the Status Quo”: Inpatient Double Rooms

4.3.2.1 Physical Observations:

The design of the double inpatient rooms reflects the aspects of territoriality, privacy, and access to positive distraction. Similar to the design of the single inpatient room, the double inpatient room consists of three different zones: patient zone, parent zone, and common zone. However, the common zone is not only shared by the child and his mother, it is shared by their roommates as well. The inpatient bed, bedside cabinet, and adjustable overbed table defines the patient zone, while the companion recliner and extra companion chair define the parent zone. For the common zone, it is highlighted by containing the TV set, refrigerator, and storage cabinets. In addition, the extra companion chair’s side table is included within the common zone since only one table is located and it is found to be shared by peer parents (Figure 58). Due to the nature of the double patient rooms, direct access to the curtain wall is not inclusively provided for all peer mothers as one is seated near the window while the other is seated away from the window side. Accordingly, the existence of the small-sized and lightweight extra companion chair provides the “flexibility” needed for mothers who are seated away from the window to move their chair near the window and enjoy the external view without intruding into the peer mothers’ territory.
Similar to the design of the single inpatient rooms, the radial design of the double patient room along with the location of the inboard toilet plays a significant role in providing privacy for both children and their parents. Despite the increased area for the double patient room in relation to the single inpatient room, the location of the inboard toilet for both room designs allow for maximization of the “blind spot” area in which the inpatient bed and the companion recliner are placed (Figure 59). Thus, allowing the mother some visual privacy while resting on either type of furniture. Moreover, the installation of bed curtains allows for visual privacy for both the child and the parent within the room as well as demarcate each individual peer’s zone (Figure 60). Windows, as parents’ restorative resources, are found to play a major role in reducing mothers’ induced stress. The implementation of a curtain wall provides maximum visual access to the external view with implemented safety measures for both parents and children within the room. However, the use of curtain wall usually invades users’ privacy, especially at night. Thus, the implementation of foldable curtains provides a layer of visual privacy for mothers and children during resting and sleeping hours as well as sun shading during the day.
4.3.2.2 Behavioral Observations: Usage Patterns and Categories

As mothers roam around and share their hospitalization journey with their peers, their behavioral patterns are observed to be gradually shifting from “self-independent” patterns to more “interactive” patterns. Due to the hybrid nature of the double inpatient dome, mothers’ behavioral observations highlighted access to social support as one of the most common behavioral traits among mothers. Moreover, the active presence of mothers along with their conducted activities highlights other behavioral aspects such as parent-child relationship and territoriality. During this stage, mothers are observed to be accommodating to ensure their
children’s’ improved health status; thus, working on fulfilling their needs and preferences and leaving behind the anxiety and overthinking state of mind.

Within the inpatient rooms, peer mothers were observed interacting, socializing, and even depending on one another to take care of their children. Similar to mother’s behavioral observations at ASUCH, mothers within CCHE’s double patient rooms are observed to be having different intensities of social interaction at different times of the day. During early hours of the morning, minimal social interactions are observed as each mother gets occupied performing their motherly duties with her child; either by washing up, feeding them their breakfast, and getting ready for the day. Moreover, during the chemotherapy session, mothers are observed to be close the bed curtains, withdrawing from any social interaction as their children are having a midday nap due to the severity of the in-progress chemotherapy session. However, during the doctors’ checkup round, peer mothers are observed to be checking on each other’s child, providing emotional support for one another. In fact, the aspect of emotional support plays a very important role in developing intimate and strong friendships amongst peer mothers. Moreover, it is not only provided through peer support, access granted to family members is considered to be an essential factor for the provision of emotional support for mothers. As family visits are allowed within the inpatient department, some mothers were observed introducing them to their peers, socializing all together throughout the visit.

Om Yassin, a 32-year-old mother whose only child (Yassin, 9 years old) is diagnosed with Leukemia, was once observed meeting her sister in the General Waiting Area during the visiting hours (Figure 61). While both were socializing and interacting, Om Abdallah, a 32-year-old mother whose child (Abdallah, 7 years old) is diagnosed with Lymphoma, was observed approaching Om Yassin in the lobby. She sat right next to them and started socializing with Om Yassin’s sister. From the perspective of an observer, one can consider Om Abdallah’s attitude to be quite intrusive; however, the “sincere” and “easygoing” aspects of their conversations reflect “informal” and “friendly” aspects that define the nature of their relationship. Accordingly, one can detect the intimate relationship developed between mothers during this stage. Expanding its nature from being peers sharing the same room during a certain stage, to being friends checking in on one another throughout the hospitalization journey.
On the other hand, Om Yasmine, a 33-year-old mother whose youngest child (Yasmine, 11 years old) is diagnosed with Leukemia, reflects the *interplay between having access to social support and maintaining privacy*. Due to the nature of the shared rooms, Om Yasmine’s privacy within the room is mostly unattainable. Despite the existence of the bed curtains that allow for some visual privacy, *acoustical privacy is not yet achieved*. Accordingly, Om Yasmine is observed to be *leaving the room while taking a phone call*. During one of the field visits, she is observed to be *having an extended phone call* in the *children’s playing room*.

Social interactions among peers are not only limited inside the room, it extends to be *the bounds of the whole department*. Due to the central location of the nurse station, nurses’ control parental access from one dome to the other; accordingly, mothers are rarely observed socializing across domes. Despite the provision of a dedicated seating zone for parents, which are located behind the nurse station, mothers are observed to be using the whole space as their socializing zone. Their behavioral observations reflect *different modes of social interactions*. For *long conversations*, mothers are observed to use the *dedicated seating zone* for this purpose, in which they interact not only with mothers but also with nurses. While for *casual conversations*, mothers are observed to socialize with one another *in front of the room doors*, so that they would be *within relatively close proximity to their children*. As for the *quick and unintended conversations*, mothers are observed to be using the *nourishment zone*, where they quickly meet while preparing their hot beverages (Figure 62). While for the *intimate and private conversations*, mothers are observed to be using the *children's playing area* due to its location, away from the inpatient domes’ zone (Figure 63).
Figure 62. Double Inpatient Dome- Mothers’ Social Interaction Map
Figure 63. Inpatient Department - Children Playing Area for intimate & private conversations

Similar to the parent-child observations at ASUCH, parent-child relationship within CCHE’s inpatient double room is reflected on the mothers’ seating zones within the room. Due to the availability of sufficient area and multiple seating choices, mothers are observed with “various seating proximities” in relation to their children, reflecting the different modes of the mother-child bond. Some mothers who are seen lying on the bed while having their children sleeping on their laps reflects a physical close-proximity bond. Other mothers who are observed sitting on their extra companion chair while distracting their children from pain by sharing activities reflects a non-physical close-proximity bond. While mothers who are observed sitting on their companion recliner withdrawing from any child-parent interaction reflects an absence of any physical contact (Figure 64)
The radial layout of the inpatient department and the lightweight flexible seatings allow mothers to have constant visual access to external views. Mothers who are seated next to the window are observed to be using mainly the companion recliner while passively observing people downstairs. While mothers who are seated away from the window are observed to be using mainly the lightweight chair to have direct access to the external view. As their peers use their bed curtains, obstructing the view from their companion recliners, mothers are observed to move the lightweight chairs near the window (Figure 65). Moreover, the radial layout of the inpatient department allows peer mothers to have shared control over the windows’ foldable curtains. Om Noura, a 30-year-old mother whose only child (Noura, 5 years old) is diagnosed with
Leukemia, and Om Iman, a 26-year-old mother whose only child (Iman, 4 years old) is diagnosed with Lymphoma, reflect the notion of territoriality through their access to the curtain wall along with its accompanied zone. Placed near the window, Om Noura is observed to have control over her territorial zone where her companion recliner and extra companion chair are placed. Furthermore, she is observed to be controlling the foldable curtains placed within her territorial zone. While placed away from the window, Om Iman is observed to have control over her territorial zone placed between the common zone and Om Noura’s territorial zone. Additionally, she is observed to be controlling the foldable curtains that gives her visual access from her extra companion chair. Accordingly, one can say that peer mothers have shared access to the window, foldable curtains, and their attached zone based on mother’s seating with reference to the window and her visual angle/exposure to the external view (Figure 66).

Figure 65. Double Inpatient Room - The use of lightweight companion chair for maximum exposure to external view for mothers seated away from window

KEY LEGEND:
- Bed Curtains, Blocking Exposure to External View
- Lightweight Chair, Allowing Exposure to External View
Figure 66. Double Inpatient Room - Peer Parents Territorial Zones

4.3.3 Stage 3- “Weaving through the Ordinary Life”: Outpatient Daycare Department

4.3.3.1 Physical Observations:

In contrast with ASUCH’s Outpatient Department, CCHE’s Outpatient clinics are located within the same building as the inpatient department; however, vertical separation is provided. The outpatient services are located on the ground and first floors, while the inpatient departments are located from the second till the sixth floors. As highlighted in Figure 67, the outpatient chemotherapy department, which is located on the first floor, consists of 5 types of day care units that were mainly classified based on the type and duration of the treatment. Moreover, it includes one waiting area that acts as the main access node for the department and the main information center for parents. To begin with, the symmetrical design of the waiting area, the central location of the information desk, and the entry node divides the area into 2 main zones. The circulation/traffic zone allowed for direct access to the information desk, and the seating zones (A&B) allowed for the distribution of the noise and crowdedness across the whole waiting area. However, the asymmetrical location of the waiting area and access to the daycares overlapped the heavy users’ traffic with seating zone A (Figure 68). Moreover, it acted as a source of noise, crowdedness, and disturbance surrounding the information desk.
Figure 67. CCHE - Outpatient Daycare Department - Zoning & Circulation Analysis
For the daycare units, several spatial qualities such as the unit's layout, unit's access node, location of the nurse station, unit's proximity to the waiting area, and access to external view were used to highlight the architectural variations within each daycare unit. The design of daycare units 1&2 is basically one big ward layout. These units are exposed to natural lighting through the curtain wall that covers units’ northern facade and overlooks the admin building. However, due to the need for some patients to have oxygen treatments for the chemotherapy sessions’ side effects, a wall partition was implemented. This wall divides the ward into 2 zones/units. The ward layout of Daycare Unit 1 (Figure 69) is used to host children’s chemotherapy sessions that last from 6 to 11 hours. It includes 15 chemotherapy recliners along with an equivalent number of companion chairs, and one main nurse station. The nurse station is located right next to the unit’s access node. It provides the treatments for sessions and monitors the overall status of the ward. Moreover, it includes two remote nurse zones to maintain visual access and easy access for all patients and covers the whole unit. In order to access daycare unit 1, one has to go through daycare unit 3 which is located between daycare unit 1 and the waiting area. Moreover, a secondary access node through daycare unit 2 is provided due to uncontrollable circulation between daycare units 1 & 2.

Daycare Unit 2 (Figure 70) is used to host children’s chemotherapy sessions that last from 4 to 6 hours. Its’ ward layout includes 13 chemotherapy recliners along with an equivalent number of companion chairs, one central nurse station, and a stretcher’s zone used for emergencies and chemotherapy’s complications. The location of the central nurse station within the ward...
provides **visual access to the whole unit**. However, a **remote nurse desk** is found located behind the central nurse station, allowing for **visual access to the recliners placed in the central nurse station’s “blind spot”**. The stretcher’s zone consists of 4 areas separated by curtains, where **visual privacy for each stretcher** is provided. In order to access daycare unit 2, one has to either **go through daycare units 1 & 3**, highlighting the **far proximity** from the waiting area or go through the **service corridor**, which includes the entrance for daycare 5 and the toilet areas that serve daycares 2,4,&5.

![Diagram](image)

**Figure 70. Outpatient Daycare Department - Daycare Unit 2- Zoning Analysis**

Similar to Daycare Units 1 & 2, the ward layout for **Daycare Unit 3** (Figure 71) is used to host children’s chemotherapy sessions with duration that range from 10 minutes to 4 hours. It includes **10 chemotherapy recliners** along with an **equivalent number of companion chairs**, **one central nurse station**, and a **storage room**. Due to the units’ location within the department, **neither access to external view nor natural lighting are provided**. Despite its location within a **close proximity to the waiting area**, it is found to be **crowded** and **noisy** since it acts as the **main circulation node** connecting the waiting area to the daycare unit 1. Moreover, this circulation node divides the unit to 2 zones, **obstructing the visual exposure from the central nurse station** and **causing lack of privacy for Zone B**.
Due to the increasing number of outpatient users within the hospital, some admin offices, which were initially placed in the first floor, are being relocated to the basement floor. This allowed for the extension of the outpatient chemotherapy department. Accordingly, Daycare Unit 4 (Figure 72), which was initially an admin office, is located within a close proximity to the department, hosting antibiotic and blood transfers sessions. The ward layout of Daycare Unit 4 is quite different from the layout of the previously mentioned daycare units. It is divided into 3 main zones, nurse station zone, treatment zone, and nurses’ lounge. The nurse station zone is located in an enclosed area that actually obstructs direct visual access to all recliners. The treatment zone includes 10 chemotherapy recliners with a non-equivalent number of companion chairs. While the nurses’ lounge zone includes remote desks, a recliner for nurses to rest, and a storage room. In fact, the location of the structural columns contributed to the division of the unit’s layout into zones. Moreover, the longitudinal design of the unit predetermined the location of the nurse station; thus, it is located right next to the treatment zone. Due to the units’ location within the department, neither access to external view nor natural lighting was provided. Moreover, the use of the main corridor as the primary and only access node for the unit was considered to be the source for noise and lack of privacy for some chemotherapy recliners along with their companion chairs.
In contrast with the layout for Daycare Units 1, 2, & 3, the design of the Daycare Unit 5 (Figure 73) is found to be individual cubicles that were used to host children’s chemotherapy sessions that last more than 12 hours. It includes 10 enclosed cubicles with a central nurse station that provides direct visual access to all cubicles. Moreover, the location of the central nurse station allows for controlled access to the unit. Due to the units’ location within the department, neither access to external view nor natural lighting is provided. Moreover, the units’ access nodes are provided through the service corridor that acts as the primary source of noise due to its heavy traffic throughout the day. Within each cubicle, one shall find an inpatient stretcher and an adjustable overbed table for patient, companion chair for parent, and TV for entertainment (Figure 74). Each cubicle has a small inspection window overlooking the unit’s entry nodes and central nurse station, allowing for some visual connection with life outside the cubicle (Figure 75). However, for parents and children’s privacy, foldable curtains were installed.
Figure 73. Outpatient Daycare Department - Daycare Unit 5 - Zoning Analysis

Figure 74. Outpatient Daycare Department - Daycare Unit 5 - Individual Cubicle - Zoning Analysis
4.3.3.2 Behavioral Observations: Usage Patterns and Categories

As parents reach the final hospitalization phase through which they only visit the hospital occasionally, parents weave their children’s chemotherapy sessions into their life routine to the extent that it becomes one of their weekly/monthly chores. Throughout this stage, parents’ behavioral observations within the different daycare units highlighted aspects such as parent-child relationship and access to social support along with issues of territoriality, privacy, and perceived control. Since the waiting area was considered to be an essential part in the “weaving through the ordinary life” hospitalization stage, conducting parent’s behavioral observations at different times of the day was necessary. In fact, parents were observed to be using the waiting area not only while waiting for their child’s turn, but also in between the chemotherapy sessions. As children sometimes had to take multiple sessions a day, parents tended to accompany their children in the waiting area during the break time in between the sessions. Throughout their waiting time, parents were observed to be conducting several activities within the space. Some mothers were observed sitting on the seating bench while holding their children between their arms, having a strong bodily contact with their children. While other mothers are observed sitting next to their children with no physical contact yet keeping an eye on their children. Other parents were observed having social interactions with their peers while sitting on benches, or even seated on the floors in the waiting areas’ corners. While other parents were observed withdrawing from any type of interactions through watching TV, having phone calls, scrolling over their mobile, and sleeping on the bench (Figure 76).
Within the daycare units 1&2, parents along with their children were found to be provided with a “personal space/zone” that included the child’s chemotherapy recliner, companion chair, and an adjustable overbed table (Figure 77). While in daycare units 3&4, children and parents’ “personal space/zone” included only chemotherapy recliner and a companion chair, with no table as the short duration of the sessions didn’t necessarily include provision of food (Figure 78). Due to the limited personal area for each child along with his companion, there was a lack of dedicated storage space within the ward layouts. Mothers were found to be using the adjustable overbed table, empty companion chairs, and their children’s wheelchairs for storing their personal belongings. Moreover, mothers were observed to be using the surrounding area as a storage space for their personal belongings. In Daycare Units 1&2, mothers who are placed near the curtain wall were observed to be using the clearance area behind the child’s recliner for storage. While in other daycares, mothers were observed to be using the area underneath their companion chair for storage (Figure 79). In fact, the use of the adjustable overbed table was not only limited to storing personal belongings, mothers were observed to be using it to define “their territory” during different times of the day. In daycare units 1 & 2, mothers who were placed within the units’ cross circulation nodes were found to be using the table as a buffer zone only.
during visiting times and eating hours, avoiding the heavy traffic’s inference with their personal zone (Figure 80). However, in daycare unit 3, due to the lack of providing adjustable overbed tables, mothers who were placed within the units’ cross circulation pathway were found struggling to identify their territoriality. Their personal space was interfered with the continuous heavy traffic and the main circulation pathway provided within the daycare unit (Figure 81).

Figure 77. Daycare Units 1&2 - Mothers’ Personal Space/Zone

Figure 78. Daycare Units 3&4 - Mothers' Personal Space/Zone

Figure 79. Storage Areas within the Daycare Units
Figure 80. Daycare Units 1&2 - Use of Adjustable Overbed Tables to regulate 'Territorial Boundaries'

Figure 81. Daycare Unit 3 - Lack of 'Regulated Territorial Boundaries'
Mothers’ behavioral observations within the different daycare units’ layouts highlighted the **modes of child-parent relationship** developed during the chemotherapy sessions. Similar to the design of the single patient room, the nature of the **enclosed cubicles** (Daycare unit 5) allowed the parent along with his child to develop a **strong parent-child bond** since both spent quality time together during the chemotherapy session with minimal interference from the healthcare providers. However, for the other daycare units with ward layout, aspects such as **parents’ seating modes** along with their **visits’ routine** and **shared activities** were observed to be the **key factors** that differentiate between the child-parent interaction modes (Figure 82). Based on the child’s age, some mothers were found to be **sitting on the children’s recliner while having their children sitting on their laps** throughout the session, maintaining a **strong bodily contact** along with their children. During such a state, mothers were observed to be either **playing with their children** trying to entertain them and distract them from the pain induced from the chemotherapy session. Mothers were also found **calming their children down** until they fall asleep, allowing mothers to also get some rest and take a nap. However, the majority of parents are found to be **using their companion chairs** during their children’s session, yet highlighting **different intensities of the non-physical contact** developed between parents and their children. In fact, the **location of the companion chair in respect to the child’s recliner** reflects modes of the non-physical child-parent interactions. For **maximum interaction**, a parent was found to be moving the companion chair and placing it **right in front of the recliner**, maintaining a **constant eye to eye contact** that helps in reducing the stress for both the child and the parent. For **maintaining a balance between child-parent interactions and surroundings’ observations**, parents were found to be **tilting the companion chair** to be facing the child’s recliner yet maintain a visual access to the surrounding environment. During such a state, parents were observed to be either **playing with their children** or **helping them to eat**. While for **increasing possibilities for withdrawal from child-parent interaction**, parents were observed to be placing their companion chair **in parallel to the child’s recliner** allowing for **direct visual contact** with the surrounding environment and **minimal interaction with children** (Figure 83).
Figure 82. Daycare Units - Mother-Child Interaction modes

**Strong Bodily Contact**
Mothers sitting on the children’s recliner while having their children sitting on their laps

**Non Physical Interactive Mode**
Mother sitting on her companion chair while interacting and keeping an eye on her child

**Withdrawal Mode**
- Mother sitting on the children’s recliner while observing the surrounding
- Child playing with Volunteer

**Withdrawal Mode**
- Father sitting on the companion chair while playing with his phone.
- Child sleeping on the recliner

**KEY LEGEND:**
- Mother
- Child
Within daycare units 1, 2, 3, & 4, mothers' behavioral observations reflect the **lack of privacy and perceived control** that was highlighted throughout this stage due to the nature of the ward layout design. Due to the nature of the ward layout, parents were observed to be **lacking control** over the **location of their assigned seating for the sessions, lighting system, TV, natural ventilation as the windows’ knobs were removed, and noise**. During several sessions, it was observed that **sources of noise** were usually **nurse stations, parents’ phone calls, and children playing games or watching videos with loud noises**. However, parents’ behavioral observations reflected that the just mentioned **sources of noise** were actually parents’ sources of entertainment, serving as the **positive distraction modes** for parents during the chemotherapy sessions. Parents were observed to be in control of the **foldable shading curtains** that are implemented for the curtain wall’s facade. For parents who were seated near the curtain wall, each parent had full control over the foldable curtain located within his personal zone. Parents were observed to be using the foldable curtains during different times of the day. In early hours of the day, parents were observed to be enjoying the light sunrays, leaving the foldable curtains open. However, starting from 3 pm till sunset hours, some parents were observed **semi closing** the foldable curtains, while others were observed to **fully close** them. While after sunset hours, some parents were observed leaving the **semi-closed and fully closed** curtains as is for privacy purposes, while others were observed to be opening the foldable curtains, not caring much about the visual privacy obstructed by the passersby in side streets (Figure 84).

Figure 84. Daycare Units 1&2 - Use of Foldable Shading Curtains throughout the day
As the daycare units lack architectural elements such as curtains surrounding each personal zone or foldable partitions that allow for some sort of visual privacy, parents, especially mothers who are wearing hijab or niqab, were found to be the most affected as they are always exposed to the surrounding others. Om Laila, a 29-year-old mother whose eldest child (Laila, 5 years old) was diagnosed with Leukemia, reflects the “struggle of finding privacy” that a niqabi mothers go through during her child’s chemotherapy session. As Laila’s chemotherapy session can last up to 8 hours, she was placed in daycare unit 1. During several chemotherapy sessions, Om Laila was observed to be using her companion chair to provide herself some sort of visual privacy. Whenever she wants to eat or take a nap, she was observed to be rotating the companion chair to be facing the wall while giving her back to the whole unit.

The outpatient daycare units are found to be lacking controlled access; thus, reflecting the issues of privacy for both patients and parents. During the hospitals’ working hours (9am-4pm) the units are found overly crowded with patients along with their companions, patients’ young siblings, parents checking for available seats, nurses, doctors, staff cleaning the area and providing meals in specific hours, volunteers, and visitors. Within daycare units 1&2, parents who were placed surrounding the partition wall, dividing the large ward layout to units 1 & 2, were observed to be relocating their companion chairs from being placed right next to the recliners to be facing the recliner due to the heavy traffic connecting units 1&2 (Figure 85). While other parents who were placed near the entry nodes within daycare units 2 & 3 were observed to be moving their chair to the other side of the children’s recliners, away from the units’ main access nodes. Moreover, allowing mixed gender companions within the outpatient day care units along with providing minimal distance between the patients’ dedicated personal zones are considered as factors for the lack of privacy found within the outpatient daycare department. As highlighted in Figure 86, the minimal distance provided between Abou Mahmoud’s and Om Joudi’s companion chairs within daycare unit 1, reflects the lack of privacy that was highly needed between opposite genders in Egyptian culture.
On a Thursday chemotherapy session within daycare unit 2, Om Osama, a 38-year-old mother whose eldest son (Osama, 14 years old) was diagnosed with leukemia. She was observed to be “profoundly disturbed” during the visiting hour, in which visitors distribute toys and gifts for the children. As Om Osama was placed near the service corridor, which acts as the primary access node for the daycare unit. She was observed to be relocating her companion chair away from the heavy traffic circulation pathway. Moving away from the visitors’ gathering point, which was located in front of the medical storage cabinets, right next to the unit’s access node. It’s found that her relocation of the companion chair on the other side of the recliner chair was actually blocking the entrance for one of the stretcher’s zones; however, it was observed that such a space was usually used as a prayer area, while other spaces within the same zone were used during emergencies.

On a similar note, Abou Abdallah, a 40-year-old father whose youngest child (Abadallah, 8 years old) was diagnosed with lymphoma, reflects the “interplay between privacy, territoriality, and perceived control” that was directly related to the seating location within the unit. As Abou Abdallah was placed right in front of the stretcher’s zone, access from and to the stretcher’s zone interferes with his personal zone. Moreover, due to the lack of architectural elements that could provide enclosure, Abou Abdallah was found to be struggling to have control over “his personal space” as parents, patients, visitors, and nurses were all interfering within his zone. During the visiting hours, visitors were observed to be using the area in front of Abou Abdallah’s seating zone as a gathering space; thus, creating crowdedness and noise in front of his personal space. Accordingly, Abou Abdallah was observed to be using the adjustable overbed tables along with his personal belongings whenever possible to “physically” highlight his territory, creating a “semi-buffered zone” between the units’ circulation pathways and his own territory.
Similar to mothers’ experiences in the double inpatient dome, parents’ behavioral observations within the ward layout daycare units highlighted access to social support as one of the most common behavioral aspects among parents. Due to the hybrid and accessible nature of the ward layouts, parents were observed socializing, interacting, and sometimes depending on each other to take care of their children. Within the different ward layouts, it is observed that the location of the companion chair in respect to the child’s recliner within each parent’s “territorial zone” reflects the non-physical peer-to-peer interaction. Originally, the arrangement of the recliners and companion chairs within the ward layouts were mainly targeting the patient’s along with his companion’s privacy. Thus, the companion chair was used to be surrounded by two child’s recliners from both sides, ensuring that neither child recliners nor companion chairs are placed right next to each other. However, during the field visits, companion chairs were mostly found placed right next to other companion chairs, increasing parents’ access to direct peer-to-peer interactions (Figure 88 & Figure 89). The minimal distance that was usually found between the companion chair results in an interplay between parents’ privacy and access to social interactions.
Figure 88. Modified companion chairs’ location promoting peer interactions

Figure 89. Daycare Units - Peer to Peer Interactions within the daycare units
4.4 Interview Results (with mothers)

After conducting the physical and behavioral mappings (macro-micro perspective), interviews with mothers who are encountering different hospitalization stages (micro-macro perspective) were conducted to provide a deeper understanding of the qualitative participatory observation results across the two case studies. It was essential to conduct the semi-structured interviews with mothers to hunt for justifications of the observed behaviors and experiences, and to understand mothers’ need in regard to the different spatial layouts provided for the different hospitalization stages. In total, 46 interviews were conducted in both case studies: 26 in ASUCH and 20 in CCHE. All the interviewees were the mothers who were available within the spatial layouts. As mentioned earlier in section 3.1, there are three stages that mothers encounter in both contexts. 10 interviews were conducted during the first stage: “adjusting to the unknown” stage, 22 during the second stage: “accommodating to the status quo” stage, and 14 during the third stage: “weaving through the ordinary life” stage.

As mentioned in the research methodology (Chapter 3), the interviews were audio recorded, transcribed, and coded using manual thematic analysis. During the coding process, some patterns began to emerge across the two study settings highlighting mothers’ experiences and needs, relating to the five key themes that set the framework of this research: privacy and perceived control, access to social interaction, access to positive distraction, parental coping with stress, and territoriality and personalization. The fieldwork observations, field notes and the stories collected from interviews helped in the synthesis of data, where the findings were coordinated and compiled based on different means of data gathering. The data presented in the following section is based on interviews with mothers in both case studies simultaneously. Data are presented in themes through which the mothers’ differing needs and wants during the three stages of hospitalization of their children were addressed in each theme.

4.4.1 Privacy and Perceived Control

The first theme represents the issues of privacy and perceived control that highly concerns mothers during the children’s hospitalization process. Interviews with mothers highlighted a variety of intensities regarding mothers’ needs for privacy and perceived control through each of the different stages of hospitalization. In the coding process, this theme was greatly emphasized in conversations with mothers who were going through first stage: “adjusting to the unknown”. At the first stage through their children’s hospitalization process, mothers expressed their preference for rooming in with their children in a single patient room as they would feel “safe, private, in control, and more comfortable”. (Om Youssef, Code. S1-CCHE-1; Om Mohamed, Code. S1-ASUCH-4). Despite mothers’ awareness that constant access for healthcare personnel to the room will always invade their privacy within the single patient room, they expressed having an optimum level of privacy during different times of the day. While the assumption was that bed curtains wouldn’t be needed in the single inpatient room, Om Hassan (S1-CCHE-1) and Om Esraa (S1-CCHE-5) highlighted the role of the bed curtains, implemented within CCHE’s single inpatient units, in the provision of an added layer of privacy during their sleeping and nap
“As you see, I never take off my hijab during the entire day, and even during sleeping hours. I’m always expecting nurses to access the room at different times of the day. However, I still feel uncomfortable with their random visits. I tend to use the bed curtains while Hassan and myself take a midday nap after his chemotherapy session, and I also use them while sleeping at night. One would never know who might enter the room, a male/female nurse; therefore, using the bed curtains during sleeping hours seems to be more convenient and appropriate.” (Om Hassan, S1-CCHE-1)

“As Esraa’s health is still not stable, we spend our entire day in bed. Due to the severity of the chemotherapy treatment, she sleeps in between and after the sessions. As she only falls asleep while holding her between my arms, I squeeze myself right next to her on bed. During such hours, I close the bed curtains as the healthcare personnel, who are responsible for delivering the meals, bring her dinner meals. To be honest, I don’t see it appropriate for a stranger to see me laying on bed, I don’t feel comfortable at all. Thus, I only use the bed curtains for such situations.” Om Esraa (S1-CCHE-5)

Nonetheless, the privacy and perceived control theme was notably present in some of the conversations with mothers who were going through the second stage: “accommodating to the status quo”. However, it was not as highly emphasized as by mothers who were going through “adjusting to the unknown” stage. Some mothers highlighted their need for privacy and control within the double rooms. They expressed their need for visual privacy with respect to the healthcare personnel, with a constant intensity throughout the stage. Moreover, mothers expressed their need for privacy with respect to the peer mothers with a temporal dimension, that is directly related to their duration of stay, as they get used to the concept of sharing their room with other peers. Om Hussein (S2-ASUCH-1), Om Noura (S2-CCHE-5), and Om Adham (S2-ASUCH-9) highlighted the role of the bed curtains, implemented within the double inpatient units, in the provision of privacy and control in the different phases during the “accommodating to the status quo” stage.

“Despite the fact that 3 months duration have passed since our first stay in the double patient rooms, I still remember the discomfort I felt during the first couple of days on our first visit. Having unknown company within the same room who is literally living with my daily interactions, activities, phone calls, and having a full update on my child’s health status was very disturbing and irritating. I remember that I used to close the bed curtains most of the day just to have some sense of privacy even if it is just visual. Now, as I got used to sharing the room with different peer mothers, whom I befriended with, I only use the bed curtains during nap hour in the day and during the sleeping hours at night just to have visual privacy from the healthcare personnel who have unlimited access to the room during different hours of the day.” (Om Hussein, S2-ASUCH-1)

“Having bed curtains installed in the room which I can use whenever I want is very practical and satisfying for me. I usually use the bed curtains while sleeping, changing clothes, reading, and withdrawing from the surrounding stress. It is the only tangible element that can provide me with some sort of control over my personal space. Due to the nature of the shared room, one has limited control over the noise that results from the peer’s activities. One can consider Om Iman’s daily phone calls as the primary source of noise
within the room.” (Om Noura, S2-CCHE-5)

“Since this is still my first week in the double patient rooms, I’m finding difficulties accommodating this notion of sharing the room with a complete stranger. As an introvert person, I don’t usually enjoy company. I feel uncomfortable sharing my daily routine with a stranger.” (Om Adham, S2-ASUCH-9)

Mothers expressed the role of spatial qualities of the single and double rooms in fulfilling their need for privacy. Mothers highlighted the role of the Anteroom [الطرقة] in the medium care inpatient units at ASUCH, in the provision of privacy during their sleeping and nap times. Om Mohamed (S1-ASUCH-4) and (Om Ereny, S1-ASUCH-2) expressed their exploitation for the couple of minutes that the healthcare personnel take, to wear the gown and the mask, before knocking on the room’s door and entering. Moreover, they correlated the Anteroom’s experience with their daily routines and experiences at home.

“The existence of a connecting lobby for the inpatient room is actually very beneficial for my privacy as a mother. Despite the fact that I’m always wearing my hijab and ready for any sudden visits from the healthcare personnel, I sometimes sit comfortably [نأخذ راحتني في القاعدة] and take a nap using the recliner or on bed. In our countryside, it is not acceptable for a stranger to see a women other than her husband [غير واجب] sitting comfortably in such position. Accordingly, I tend to exploit the couple of minutes, in which whoever is passing through the connecting lobby, to sit properly before allowing him/her to enter the room… In fact, I used to behave in the same routine at home when my mother-in-law is visiting. Once I hear her passing by in the corridor leading to the living room, I quickly sit properly as a sign of respect.” (Om Mohamed, S1-ASUCH-4)

“During our sleeping hours, I highly depend on the existence of the lobby between the inpatient room and the nurses’ station to alarm me whenever anyone is entering the room. In the early hours of the morning, healthcare personnel, who are responsible for delivering the daily meals, usually bring in the breakfast meal for Ereny. Despite the fact that I’m always wearing non transparent clothes [الجلابة الثقيلة] to make sure that it won’t be lifted while sleeping, I don’t feel comfortable at all for a stranger to enter the room while I’m sleeping on the bed. Accordingly, I tend to depend on the sound of the corridor’s door when it is shutting to wake me up, exploiting the couple of minutes that the healthcare personnel take to wear the gown and the mask, to sit upright before they knock on the room’s door asking for permission to enter…. In fact, I’m used to waking up to the sound of the door when it is shut even before our experience here. Due to the nature of Abou Ereny’s work, as a day laborer, he has no fixed working hours. Most of the time he returns home in very late hours when we are all asleep. Thus, once I hear the room’s door shut, I quickly wake up, take out his clean clothes, and heat the lunch’s leftovers while he takes his shower…..” (Om Ereny, S1-ASUCH-2)

Correspondingly, mothers during “accommodating to the status quo” stage highlighted the role of the inboard toilet, as it helps in providing privacy for the beds located near the toilet’s wall, within the double inpatient units at both ASUCH and CCHE. Om Yassin (S2-CCHE-1) and Om Noura (S2-CCHE-3) expressed their preference to be seated near the inboard toilet’s wall as it acts as a visual barrier from the passersby or the ones standing at the room’s entry node (see Figure 29). Moreover, Om Radwa (S2-ASUCH-5) and Om Yasmine (S2-CCHE-3) further
elaborated on choosing to be seated near the inboard toilet’s wall as their preference.

“As we prefer to leave the room’s door open most of the day, allowing for the wind to flow within the room, the zone near the window wall becomes visually exposed to whoever is passing through the corridor. Therefore I prefer to be sitting near the toilet’s wall to be able to take my niqab off during different times of the day without being visually exposed to passersby.” (Om Radwa, S2-ASUCH-5)

“Due to the loud noise in the room that results from children crying, T’s loud sound, or my peer’s non-stoppable phone calls, sometimes I don’t hear the nurses when they knock. As I’m placed on the side near the toilet wall, my location allows me to use the couple of seconds that the nurse takes while walking through the lobby in front of the toilet to sit upright if I’m laying down the bed or on the recliner.” (Om Yasmine, S2-CCHE-3)

In addition, other mothers in the double patient rooms at ASUCH highlighted their use of bed curtains and inboard toilet’s door during different times of the day, providing them privacy and control at their window sided seats. Om Kareem (S2-ASUCH-6), Om Hamza (S2-ASUCH-11), and other mothers expressed their preference to be seated near the window since their location, along with the provision of bed curtains, provides them both privacy and control (see Figure 29). Moreover, Om Hussein (S2-ASUCH-1) along with other mothers expressed their exploitation to the fact that the inboard toilet’s door opens outwards as a safety measure for patients. She reported that they leave the toilet’s door open during their sleeping hours as a privacy screen, adding an extra layer of visual privacy (Figure 90). Moreover, they use the toilet’s door to control access to the room during their sleeping hours. She reported leaving the toilet’s door open so when the room’s door opens, it would hit the toilet’s door and the clashing noise would wake them up.

![Figure 90. The role of the inboard toilet and the use of open toilet door in providing visual privacy](image-url)
“As I prefer to be seated near the window to get distracted by whatever is happening outside, my location allows people to see me sitting on bed while they are walking in the department’s corridor or just standing in front of the room’s door, especially that my roommate and myself prefer to leave the room’s door open most of the day allowing for the wind flow to refresh the room. In fact it doesn’t bother me a lot since I’m always wearing my scarf and my non transparent clothes [الجلابية الثقيلة]. However, I tend to use the bed curtains while taking my midday nap and during sleeping hours at night, allowing me some sort of visual privacy while sleeping and a sense of control over my personal zone.”

(Om Kareem, S2-ASUCH-6)

“I remember during one of my previous stays, my roommate (Amal) used to keep the toilet door open during sleeping time. At that time, I was still in my first week in a shared room so I tended to avoid asking unnecessary questions. I remember waking up one night to a heavy clashing sound, resulting from the clash of the room’s door with the toilet’s door. Despite the panic that we all had, I found this hack to be a very beneficial idea during the night, and I actually began applying it in the following visits with different roommates.” (Om Hussein, S2-ASUCH-1)

“As I’m seated near the window, I heavily depend on using the toilet’s door hack during the night. It is a well known hack by the way, I know several mothers who are also using it. I don’t really like closing the bed curtains for several hours as it makes me feel more suffocated, as if our confinement within the room is not enough [بتخنقني أكثر.. على أساس إن حبستنا في الغرفة لوحدها مش كافية]”

(Om Hamza, S2-ASUCH-11)

Throughout the different stages, mothers highlighted “windows” as a primary source for invading their privacy within the inpatient and outpatient units. In both contexts, mothers, especially in low floor units, expressed their discomfort regarding the glazes of passersby and people sitting downstairs in the hospital complex. In the medium care inpatient units at ASUCH, mothers within rooms overlooking the back of the old pediatric hospital expressed their frustration due to the lack of windows’ curtains. Moreover, due to the large sized window along with its one way tinted reflective glass, mothers expressed their need for windows’ curtains, especially at night. Since the companion recliner is located near the windows, the mothers feel that they are exposed to the passersby downstairs.

“As my room is overlooking the entrance of the hospital and the back of the old pediatric hospital building, family members of other inpatient peers are always waiting downstairs during different hours of the day. It becomes quite disturbing at night since they entertain themselves by looking upstairs observing people within their rooms. As the window's glass is reflective by nature and there are no curtains installed, people downstairs can see whatever activities I conduct on the companion recliner all night long.” (Om Cherolos, S1-ASUCH-1)

“After sunset hour, all the activities that I conduct whether alone or with Moustafa on the companion recliner are exposed by the passersby downstairs since the window’s glass is reflective at night and there are no curtains installed to be used for the windows. Accordingly, I asked Abou Moustafa to grab us some extra bed sheets to hang during night hours so that no one would see us down the street, and I remove it in the early hours of the morning since the window’s glass is not reflective during the day.” (Om Moustafa,
While at CCHE, mothers in single and double inpatient units expressed their frustration of the curtain walls’ reflective glass. Some mothers in the single units’ dome, that is partially overlooking the hospital extension construction site, expressed their discomfort about being exposed to the site workers. Despite the existence of the large scaled “ship sail” shading device (Figure 91) separating the facade from the construction site, mothers reported a sense of being exposed. In this regard, mothers repeatedly expressed their dependence on using the foldable curtains in different room layouts at different times of the day.

"The curtain wall is very beneficial during the day since it provides us with warm sun exposure while I enjoy observing people downstairs. However, during the night, I feel that all people around are watching us. It doesn’t feel comfortable at all knowing that other people have the opportunity to observe and watch all your activities within the room. That’s why I close the curtains during the night..” (Om Iman, S2-CCHE-6)

“As my room is overlooking the hospital’s extension building, which is still under construction, I always have this fear of being exposed by the site workers. Accordingly you would always find me closing the curtains that are located right next to the companion recliner, while leaving the rest of the curtains open during the day and closed during the night.” (Om Islam, S1-CCHD-3)

During stage 3: “weaving through the ordinary life” in the Outpatient Daycare Department at CCHE, interviewees highlighted the invasion of privacy and lack of control that results from the overcrowded ward layouts. Mothers, especially ones wearing niqab, emphasized their frustration and discomfort of being “seen” throughout their children’s chemotherapy session. While other
mothers expressed their discomfort about the mixed gender spatial layout, especially that the area between companion chairs is compact.

“As Abdallah’s chemotherapy session can last up to 8 hours, it is very difficult for me to be sitting properly all day long without eating, drinking, resting, or even taking a nap. I feel uncomfortable eating or drinking underneath the niqab as the surrounding people (staff, peers, visitors, etc) keep watching the whole process, which is somehow frustrating. Moreover, I don’t find it appropriate to be sitting comfortably on the companion chair while there are men and women around. During every visit, I just hope that time flies so I can go back home.” (Om Abdallah, S3-CCHE-4)

“Laila’s bi-weekly 8-hour chemotherapy sessions are quite traumatizing not only for Laila, but also for myself. I actually spend these 8 hours doing absolutely nothing. As I’m wearing the niqab, it is very challenging for me to eat or drink throughout the visit. However, I tend to take multiple naps until she is done with her session. As I don’t feel comfortable napping while facing the whole unit, I usually rotate my chair to be facing the curtain wall, giving my back to the whole unit and falling asleep. (Om Laila, S3-CCHE-1)

“As you can see, the distance between the companion chairs is very compact. There is no personal space at all between the two companion chairs, so whenever I need to go to the toilet, grab a coffee, or even just stand up and stretch my body, I have to disturb the parent sitting next to me and ask him/her to move a bit so that I can walk away. It even becomes more frustrating when a father is sitting on the companion chair next to me. Don’t get me wrong, all parents here are very decent and polite; however, I don’t feel comfortable at all having a very close proximity to a stranger man/woman with neither space nor barrier in between…” (Om Khadiga, S3-CCHE-3)

In this regard, there was an overriding preference for corner seatings, column-wall sided seating, and behind nurse station seating over other seating modes. Mothers repeatedly expressed their discomfort about not being able to have some visual privacy during their children’s chemotherapy sessions (Figure 92).

“If I would choose, I would prefer to be seated in the corner, where the noise level is low, the location of the nurses station and the visitor’s gathering nodes are relatively far, surrounded by a peer from one side, and away from the people’s central observation nodes.” (Om Kajmen, S3-CCHE-6)

“During the visits in which we are seated beside a column, I feel more comfortable and secure as the combination of the column and curtain wall which provides some sense of enclosure and reduces this continuous feeling of being exposed…” (Om Jana, S3-CCHE-7)

“Despite the noise coming from the central nurse station, I would prefer to be seated right behind it in which I would be comfortably eating and drinking underneath the niqab.” (Om Abdallah, S3-CCHE-4)
The second theme was an emphasized phenomenon documented during the behavioral observations (discussed in previous sections), the issue of territoriality and personalization. Accordingly, various changes are conducted within the spatial layout of the different hospitalization stages to fulfill the basic and everyday needs of users. During the “adjusting to the unknown” stage in both contexts, mothers expressed the phenomenon of personalization by ‘spatial adaptation’ in the inpatient room as an approach to reflect their daily routine back home. Mothers reported changing the primary use of some of the available amenities (rooms’ furniture and their own personal belongings) within the single inpatient room to create a home-like environment. In ASUCH, Om Moustafa (S1-ASUCH-3) and Om Mohamed (S1-ASUCH-4) expressed conducting some activities within specific zones that they’ve personalized to mimic their daily routines back home. They reported their use of the inpatient bed only during their children’s chemotherapy session or sleeping hours, resembling their use of the “bedroom” back home. While their use of the companion recliner along with its extension piece for conducting their shared activities resembles their use of the “living room and dining area” back home. And finally, their use of the inpatient adjustable overbed table for preparing quick meals and storing the leftovers resembles their use of the “kitchen’s countertop” back home (see Figure 24).

“Since our first day here at the hospital, I’ve been trying to create a stable and familiar environment for Moustafa so that his hospitalization stage would be less painful and stressful. I’m trying to mimic our
daily routine that we used to do back home here at the hospital, by utilizing the available amenities within the room. So when we both wake up, we try as much as possible to use the bed only for chemotherapy sessions and nap hours. That’s what we actually do back home, we only use the bedrooms during sleeping hours, spending the rest of the day in the living room watching TV, eating, studying, and resting. Here, Moustafa and myself use the companion recliner as our living room space to conduct all our shared activities together. I sometimes use the bed’s table to prepare a sandwich while Moustafa’s meal is prepared by the hospital. We tend to eat all our meals together on the companion recliner and use its extension piece as our dining table.” (Om Moustafa, S1-ASUCH-3)

“Similar to our daily routine back home, we only use the bed at night to sleep. I try as much as possible to make Mohamed feel comfortable by creating different zones and experiences within the room that are quite similar to our spaces back home. We are a very simple family with a very humble home. The only rooms we have back home are two bedrooms and one toilet that opens up on a big hall where the kitchen and the living space are placed together. That’s why Mohamed and myself spend the whole day away from the bed, similar to our routine back home. We conduct all our daily activities on the companion recliner with its extended piece. While Mohamed sits on the recliner and uses the extended piece as his table, I sit on the floor, I’m already used to it so I actually feel comfortable doing so.”

(Om Mohamed, S1-ASUCH-4)

Correspondingly, in CCHE, Om Hassan (S1-CCHE-1) and Om Islam (S1-CCHE-3) expressed their comfort within the large sized single inpatient room with its flexible and sufficient amenities. Similar to mothers at ASUCH’s medium care inpatient rooms, Om Hassan and Om Islam expressed conducting some activities within specific zones that they’ve personalized to mimic their daily outlines back home. As there are more than one companion chair, they reported creating a “dining zone” within the inpatient room using the two light weighted chairs and the side table, placing it near the window to enjoy the natural lighting along with the view. They also reported conducting their shared activities within the same zone; thus having a vibrant and active zone, resembling the “living room and dining area” back home. While their use for the companion chair and the inpatient bed during their withdrawal hours, children’s chemotherapy sessions, and sleeping hours, resembling the “quiet zone/bedroom” back home (see Figure 56).

“The room here is very large in my opinion. I enjoy doing multiple activities within the same space yet in different zones, and that’s is challenge!.. For Hassan’s stability and comfort, I try to create a home-like routine that is quite similar to our routine back home. Once we wake up, we eat our breakfast. I quickly prepare a sandwich for myself while Hassan goes to sit on the light weighted chair and search for his cartoon channel. We both sit on those light weighted chairs next to the curtain wall. I enjoy watching people sitting downstairs in the hospital’s renewed landscape, while Hassan watches his cartoon shows. Actually this created corner is quite similar to our experience in the living room back home.It reminds me of our morning routine, in which as a family we used to eat our breakfast in the living room while watching TV.” (Om Hassan, S1-CCHE-1)

“Our daily routine is quite similar to the one we used to do back home. Islam only uses the bed while sleeping or while taking the chemotherapy session. I’ve actually created small zones within the room so that Islam wouldn’t get depressed from the isolation that we are experiencing during our stay. For breakfast
and lunch, Islam uses the recliner while I use the light weighted chair to sit, using a side table that exists here in the room as our small dining table. Since the recliner is already placed near the curtain wall, I entertain myself by watching people downstairs in the side street while Islam watches cartoon shows. For dinner, we move the 2 light weighted chairs and the side table away from the window, near the toilet’s wall so that people downstairs wouldn’t see us.”

(Om Islam, S1-CCHE-3)

During the “accommodating to the status quo” stage, the phenomenon of personalization by space adaptation was neither highlighted nor expressed by mothers in the double inpatient rooms at both contexts. However, the phenomenon of territoriality was thoroughly observed and was later expressed by mothers in the interviews. Om Mohamed (S2-ASUCH-16) and Om Yasmine (S2-CCHE-3) expressed their mutual agreement and cooperation to fulfill their need for "defining each peer’s personal space" within the room. They reported their use of the inpatient bed curtains to define their parent/child zone. Moreover, they reported their use of personal belongings (laundry) in regulating their territorial boundaries for windows and metal benches that are situated in the common/shared zone (see Figure 32 & Figure 66).

“My roommate is a decent woman; we respect each other’s personal space…. It never goes by a defined agreement; we share everything in the room together. As you can see for example, I hang the laundry only on the metal bars that are away from my peer’s bed. It is not appropriate of course to interfere in her space that is defined by her bed curtains to hang my laundry. When I need extra space, I hang the rest of the laundry on one of the metal bench’s seat…” (Om Mohamed, S2-ASUCH-16)

While during the “weaving through the ordinary life” stage, especially at CCHE, mothers repeatedly emphasized the issue of territoriality during their children’s chemotherapy sessions in the daycare units. Mothers expressed their concern and discomfort regarding the overcrowdedness and the lack of identified personal space within certain locations in the different ward layout daycare units. Om Sama (S3-CCHE-5), Om Jana (S3-CCHE-7), and Om Osama (S3-CCHE-8) reported mothers’ dependence on the adjustable overbed table to highlight their territory within the daycare units 1 and 2. While Om Kajmen (S3-CCHE-6) expressed changing her companion chair’s location and using the adjustable overbed table, creating a buffer zone for her territoriality.

“Whenever I’m placed near the aisles connecting daycare units 1 & 2, I tend to feel that whoever is passing is invading my personal space. I usually put the table in front of my seat as a visible barrier between my personal space and the circulating aisle. It is very disturbing and very uncomfortable!” (Om Sama, S3-CCHE-5, Daycare unit 1) (see Figure 80)

“This location in daycare 2 is by far the worst location we’ve been seated since our journey within the outpatient daycare department. As you can see, people coming in from the service corridor usually stand right next to me while checking the unit. It’s very disturbing. Also people who are walking in the unit sometimes knock my personal belongings that I place on the floor since there are no other storage areas. I do use the table to create a barrier between my personal zone and their pathways, but in this case one table is not enough. I actually need two, one as a barrier between my personal zone and people’s pathways
towards the unit while the other as a barrier right next to me separating my personal zone from the ones coming from the service corridor…”
(Om Osama, S3-CCHE-8, Daycare unit 2) (see Figure 87)

“As you can see, there is no visible distance between my chair and the other one right next to me. Originally, our chairs should be the ones placed on the aisle connecting daycare units 1& 2 but we tend to move them towards the inside as everyone who is passing knocks my seat by mistake. However, when the child on his recliner is placed on the exterior side, people do take care while passing.
(Om Kajmen, S3-CCHE-6, In front of the wall separating Daycare units 1&2) (see Figure 85)

Moreover, within daycare units 3 and 4, Om Yassin (S3-CCHE-2), and Om Khadiga (S3-CCHE-3) expressed their annoyance and discomfort about the interconnectivity between their seats’ locations and the circulation pathways, invading their personal space. They greatly emphasized their struggle to identify their territory within the daycare unit; thus, they reported using their personal belongings as a buffer zone.

“Whenever I’m placed here (right next to the pathways connecting the waiting area with daycare unit 1), all the passersby whether from the waiting area, daycare unit 1, or even this daycare unit are watching me to get entertained. They can even see what I’m doing over my phone. There’s no sense of enclosure or privacy whatsoever, as if I’m sitting right in the middle of crossroads...I usually put Yassin’s essential backpack on the floor as a desperate approach of creating some distance between people passing by and my chair, but it doesn’t work quite well as people dodge walking over it yet still invading my personal space (Om Yassin, S3-CCHE-2, Daycare unit 3) (see Figure 81)

“ As you can see, the distance between the companion chairs is very compact, there is no personal space at all between the two companion chairs...It even becomes more frustrating when a father is sitting on the companion chair next to me...I don’t feel comfortable at all having a very close proximity to a stranger man with neither space nor barrier in between...(Om Khadiga, S3-CCHE-3, Daycare unit 4) (Figure 93)
Parental coping with stress represents the overarching theme that guides and touches upon all the other themes: privacy and perceived control, territoriality and personalization, access to social support, and access to positive distraction. As all themes are considered to be harmonizing forces that guide parents to go through a better hospitalization journey with their children. Interview responses exhibited great emphasis on the quality of mother-child relationship as their key factor for navigating through the various stages of their children’s hospitalization process. Throughout the interviews, mothers highlighted the interconnection between the quality of the developed mother-child relationship during the “adjusting to the unknown” and “accommodating to the status quo” stages, and mothers’ coping with stress mechanisms. The majority of the mothers explicitly emphasized the provision of “comfort” and “reassurance” through having both bodily and physical contact with their children. Om Islam (Code. S1-CCHE-3) and Om Habiba (S2-ASUCH-7), identified their relationship with their children as “one of a kind with a spiritual nature”. They emphasized their preference of being within a very close proximity with their children as they consider it the main source of comfort and reassurance. As beautifully expressed by Om Moustafa, a 36-year-old mother during her “adjusting to the unknown” stage at ASUCH:

“سبحان الله، في رابط غريب بين الأم والطفل محدش عمره يفهمه. أنا بس بشم رائحة ابني وهو في حضني يبطل أفكار في أي حاجة مقلقة ولا مرض ولا مستنشفي ولا أي حاجة.. بحس بطامانية غريبية سبحان الله” (Om Moustafa, S1-ASUCH-3)

Moreover, mothers expressed the “spiritual” aspect of the developed mother-child bond. They emphasized it as an “essential procedure” provided for their children whenever they are in pain. Om Hassan (S1-CCHE-1) and Om Joumana (S1-CCHE-4) highlighted their frustration while observing their children in pain, and their use of comforting and spiritual gestures as an approach to reducing their children’s pain induced during the chemotherapy sessions.

“There is nothing more difficult than seeing your son in pain while you stand with your hands folded. However, I always believe in the “power of prayers” and turning to God in such situations. As you’ve observed, you would tend to find me sitting on the bed, holding Hassan between my arms, gently comforting him while reciting verses of the Holy Quran until the pain reduces and he falls asleep. Only then, I can breathe once again..” (Om Hassan, S1-CCHE-1)

“Whenever I sense that Joumana is in pain, I tend to hold her hands gently yet firmly, close my eyes, recite verses of the Holy Quran trying to pull away the pain from her. As naive as it may sound, this desperate procedure actually soothes Joumana and myself. For me, following such an approach is way much better than standing with my hands folded, doing nothing” (Om Joumana, S1-CCHE-4)

Although interview responses highlighted the parent-child bond as a source of comfort and reassurance. However, mothers also emphasized the provision of “safety” and “security” through having bodily contact with their children. Om Radwa (S2-ASUCH-5), and Om Esraa (S1-CCHE-5), emphasized that the act of sleeping on the same bed while holding their children...
between their arms provides them a quick recognition of any side effects from the chemotherapy treatment.

“Regardless of the bed’s size, which is only sufficient for one person, I prefer to be sleeping right next to Radwa all night. While holding her between my arms, I can sense any change that is happening to her. Just by taking her breath, I can sense if she is tired or not. Whenever she is shivering, I can easily tell whether her body temperature is high or is it just because the room’s temperature is low. Having physical contact with Radwa while sleeping can easily provide me with an update to her status.”
(Om Radwa, S2-ASUCH-5)

“As Esraa just got diagnosed a couple of weeks ago, she tends to have a high temperature that is usually followed by vomiting every now and then. Before our inpatient stay, I used to sleep in her bed holding her between my arms so that she would feel safe and comfortable to be able to sleep. Accordingly, when we came here, I tended to follow our routine so that she would still feel safe and secure. Also, I found out during our first week here that actually by holding her between my arms during night, I can sense whenever her temperature gets high, and right before she starts vomiting, I take her quickly to the toilet. Despite the insufficient bed size, I found that sleeping right next to her is practically beneficial…”
(Om Esraa, S1-CCHE-5)

In fact, the mother-child bond doesn’t necessarily benefit one side over the other. Throughout the interviews, mothers highlighted the “mutually beneficial relationship” that results from mother-child’s bodily and physical contact since close proximity doesn’t only provide safety and security for both children and mothers, but also helps in reassigning mothers as the primary caregivers for their children. Om Adham (S2-ASUCH-9), Om Cherolos (S1-ASUCH-1), and Om Nashwa (S2-CCHE-4) emphasized the increased child-parent attachment during such circumstances as children always perceive their mothers as their source of safety, comfort, and security. While Om Moaz (S1-ASUCH-5) Om Erey (S1-ASUCH-2), and Om Kareem (S2-ASUCH-6) emphasized mothers’ need to fulfill their duties as their children’s primary caregivers and attachment figure for their very young children. This helps them to better contribute to their children’s overall healthcare outcomes.

“Since Adham knew of his illness, he became dependent and attached to me more than ever before. He lacked this sense of safety that used to flood the house. He no longer sees anyone other than me as his source of safety and comfort; accordingly, he can’t lose sight of me…. In the first couple of days, I was always anxious, frightened, and depressed. The only de-stressing moments are always when I take Adham between my arms. The same thing goes along with Adham. As a 9 years old boy, going through such a traumatizing experience is not easy at all. He can only sleep when I take him between my arms…” (Om Adham, S2-ASUCH-9)

“In general, children consider their mothers to be the icon that resembles safety and security for them. While being in a frightening and alienated environment, one can imagine how traumatized the children are. For Cherolos, the hospital resembles fear and pain; accordingly, being attached and dependent on me is not surprising at all. On the contrary, I feel that we are both dependent on each other. I provide him safety and security, while being with him constantly, provides me comfort and safety. We can call it a mutually beneficial relationship..” (Om Cherolos, S1-ASUCH-1)
“It comes as no surprise that the mother-child relationship between Moaz and myself is unbreakable. As a 6 months old, Moaz never feels safe and comfortable except while holding him between my arms. Having my scent around is enough for him to feel reassured. I know this might sound a bit selfish, but I’m actually satisfied with the fact that no one else can better help nor understand Moaz as myself. In hospitals, it is known that nurses take the mothers’ duties as the primary caregiver within the inpatient room; however, due to Moaz’s very young age, the nurse actually depends on me to help her out while doing any medical procedure. He needs to be held steadily so that she can proceed, and I’m actually the only one who can do so.” (Om Moaz, S1-ASUCH-5) 

“.... In fact, when I observe the nurses helping out Ereny during the medical procedures and whenever she is in pain, I sometimes feel upset… Of course I truly understand the fact that the nurse is more capable of handling Ereny’s health status during such a stage; however, an inner selfish voice tends to tell me that I’m the one who is supposed to take care of her. Thus, I tend to critically observe the nurse while helping out Ereny, hoping to be assisting the nurse very soon. Moreover, during doctor’s check up routine, I seek to understand Ereny’s health status as much as I can by asking doctors some followup questions …” (Om Ereny, S1-ASUCH-2) 

The quality of the developed mother-child relationship was not only highlighted during the “adjusting to the unknown” and “accommodating to the status quo” stage, it was highlighted during “weaving through the ordinary life” stage at the outpatient chemotherapy daycare units. Mothers’ behavioral observations within CCHE’s different daycare units’ layouts in both contexts reflected different modes of mother-child relationship. Moreover, mothers’ behavioral observations within ASUCH’s outpatient chemotherapy room revealed the existence of bodily and nonphysical modes of interactions, while the assumption was that the lack of dedicated parent zone would result in having weak and shallow mother-child interaction modes. However, mothers didn’t furtherly elaborate on the developed quality of mother-child bond/relationship during the interviews in both contexts. 

4.4.4 Access to Social Support 

This represents one of the most important themes emphasized through all the interviews, and also prominently documented in the behavioral mapping across both contexts, the issue of access to social support. As their children’s immunity system becomes better day after day, mothers expressed their realization of their own social needs and preferences that they usually work on to fulfill. Interview responses exhibited great emphasis on the need to maintain social interaction with peers and family relatives throughout different hospitalization stages. Mothers expressed their preference for having peer-to-peer support especially during the second stage “accommodating to the status quo” and third stage “weaving through the ordinary life”. Within the double patient rooms, Om Radwa (S2-ASUCH-5), Om Abdallah (S2-CCHE-2), Om Iman (S2-CCHE-6), Om Nashwa (S2-CCHE-4), Om Hussein (S2-ASUCH-1), Om Kareem (S2-ASUCH-6), Om Habiba (S2-ASUCH-7), and many other mothers highlighted the role of the peer interactions as a primary coping mechanism. Some expressed the emotional support that their peers provide
during their weak moments, while others expressed it as a source of safety, and a sense of belonging. Moreover, it reduces their sense of loneliness and isolation.

“I remember during my first period here in the fourth floor (double rooms), I had continuous nervous breakdowns. I was struggling to adapt with Radwa’s status quo. I used to break down every once in a while, to the point that one of Radwa’s doctors warned me that if I continued to break down like this, they would escort me and ask for another companion instead. At that time, Om Haitham was my roommate, may God bless her. She helped me to stay strong, and accommodate to the status quo. Only then I was able to take good care of Radwa.” (Om Radwa, S2-ASUCH-5)

“At first, I thought that I would not be enjoying sharing a room with a stranger. However, during each hospitalization stay, I realize that I’m not only having social interaction with my peers to make time pass, they are actually one of the main reasons that makes the stay in each visit bearable. You know, knowing that you are not facing this alone, and there are other people who would care about you and help you whenever you need, boosts you with a great certainty that everything will fall into place one day.” (Om Iman, S2-CCHE-6)

“Sharing a room with a peer makes your confinement in the room bearable. [أحساسك بالونس لما يكون معناك حد] في الغرفة يهون عليكي الحبسة التي احنا محسوسناها دي” (Om Hussein, S2-ASUCH-1)

“We tend to spend the whole day facing each other [وشنا في وش بعد], with no activities to be done whatsoever, so you would always find us talking about many things. We sometimes even talk about personal stuff such as our kids, husbands, and family relatives. I have known Om Radwa for a long time now, it is not our first time to stay together in one room, so I think we’ve reached a stage where we can be sharing a lot about our personal life easily. I consider her as a friend.” (Om Kareem, S2-ASUCH-6)

Correspondingly, within the outpatient chemotherapy departments, Om Badr (S3-ASUCH-3), Om Yassin (S3-ASUCH-2), Om Khadiga (S3-CCHE-3), Om Laila (S3-CCHE-1), Om Jana (S3-CCHE-7), and many other mothers repeatedly expressed their peer interactions to be a source of entertainment. During the sessions, mothers get to share their different struggles that they went through until they’ve reached the outpatient stage. They expressed socialization with peers in general to be the main source of making the time spent in the daycare pass quickly.

“Whether in this phase or in previous ones, interaction with peers is always the bearable factor by which the long hours I stay here pass quickly [يهون عليكي فترة الفصول هنا]. The small distance between the companion chairs here makes it easier for us to interact together and have extended conversations that ends up turning into a source of entertainment during the visits.” (Om Khadiga, S3-CCHE-3)

“I’m an extrovert by nature, I enjoy having conversations with different people even if I don’t know them at all. I entertain myself by listening to their stories, and about their children’s health status. I really do like narrating Badr’s journey throughout the different hospitalization phases since we are now in our final visits. I believe that narrating his story would inspire others and give them hope as other peers did with me when Badr was still in earlier stages.” (Om Badr, S3-CCHE-3)
“I think one of the best things about the shared daycare units is the access to peer interactions. As Jana is 14 years old, she doesn’t need me to be constantly seated beside her during the whole session. I sometimes walk within the daycare unit in which Jana is seated, and also around the daycare units trying to make the duration of the sessions pass quickly. I really do like to socialize a lot, it is my only source of entertainment here during Jana’s sessions. As I speak with other peers, I get to know more about the nature of the disease itself. From what I hear I can easily say that Elhamdullah Jana didn’t suffer a lot during her journey, compared to other cases. Thus, listening to others’ hospitalizations phases is actually beneficial as it makes one realize that your child case is not a severe one when compared to the other cases. [الي يشوف بلاوي الناس] (Om Jana, S3-CCHE-7)

During the “accommodating to the status quo” and “weaving through the ordinary life” stages, mothers in both contexts repeatedly highlighted their dependence on each other to take care of their children while they are not available in the room. Within the double patient rooms in both contexts, mothers reported their need to move around to finish administrative paper work, buy medical supplies, and quickly breathe in some fresh air while walking in surrounding streets. Om Yasmine (S2-CCHE-3), Om Karima (S2-ASUCH-8), Om Abrar (S2-ASUCH-12), Om Nour (S2-ASUCH-2), Om Abdallah (S2-CCHE-2), and Om Hussein (S2-ASUCH-1) expressed their dependence on their peers mainly during family visiting hours, long extended phone calls, private conversation with healthcare personnel, or quickly meeting their demands outside the hospital. They reported their comfort and trust about their peers’ provision of full support to take care of their children while they are away for a limited time meeting other demands.

“Whenever I have an extended phone call with my close family relatives, whether my husband, my sister, or my mother, I go outside the room to have more privacy. I usually have my phone calls outside the patient dome to avoid making noise near the nurse station. I use the children’s playing room since it is empty during the majority of the day. I ask Om Nashwa to take care of Yasmine until I come back. To be honest, Om Nashwa is a very kind hearted person, I no longer need to ask her to take care of her. I remember that I once returned back to the room to find her helping Yasmine to go to the toilet as she was no longer able to wait for me to come back. She didn’t even try to call me to come back and check on my daughter. Yes! There are still people who are as pure and kind hearted as Om Nahswa.” (Om Yasmine, S2-CCHE-3)

“Whenever I need to stamp papers for Abrar’s medications downstairs in the social affairs office, I heavily depend on my peer to take care of Abrar until I quickly come back. I usually do this during the working hours of the hospital.” (Om Abrar, S2-ASUCH-12)

“Every now and then, I go downstairs, outside the hospital, to breathe in some fresh air and also pick up a proper meal for myself and my roommate. We usually take turns in doing so to break from this boring routine that one has inside the patient room. One takes care of the children while the other goes downstairs for a walk, picks up food and other demands if needed and comes back.” (Om Karima, S2-ASUCH-8)

“The last time you visited, I don’t know if you remember or not, but while you were interviewing Om Hussein, one of the nurses came and asked me to find a family relative who can bring Nour “Platelets”,

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cell fragments that reduce blood clotting, from a blood bank located outside the hospital. I’m originally from El Fayoum, so all my family relatives are living there, no one is available nearby to ask him such a favor. I was a bit afraid since I don’t know where or how to go. Om Hussein then, may God bless her, told me exactly what to do and where to go. She even reassured me that she will take care of Nour until I come back. Between you and me, I thanked God that I have such a decent peer as Om Hussein.”

(Om Nour, S2-ASUCH-2)

“The past couple of days, Hussein began to vomit a lot as a side effect of the chemotherapy sessions. I can’t leave him for a long span of time, but when Abou Hussein comes to visit with my 10-year-old daughter Malak, I tend to depend on Om Nour to take care of Hussein until I go downstairs, sit with Malak a bit and come back again. It is very difficult being torn between my 2 children like this..”

(Om Hussein, S2-ASUCH-1)

While in the outpatient chemotherapy departments Om Sama (S3-CCHE-5), Om Aesha (S3-CCHE-9) and Om Hassan (S3-ASUCH-4) expressed their dependence on the surrounding peers whenever they go to get something to eat or drink from the cafeteria downstairs, or go to the toilet. As the children are not allowed to walk around with their chemotherapy device, mothers ask their peers to make sure that their children are kept on their recliner until they quickly go and come back. Moreover, mothers at ASUCH expressed their severe annoyance about the lack of dedicated companion chairs within the outpatient chemotherapy room. Some mothers reported their cooperation with peers in using the limited available resources. They reported sharing roles with peers whose children are at a young age and are able to sit on the recliner while having their children sitting on their lap. They relied on their peers to watch out for their children while they are waiting outside or gone for a while.

“Sama’s therapy session can extend till 8 or 9 hours. Of course I can’t stay seated for that long. I sometimes go downstairs to buy us something to drink. I usually ask the peers surrounding me to take care of Sama while I’m downstairs. I even offer to bring them something with me so that they would be sure that I’m not lying to have a walk downstairs, leaving my daughter alone as many other peers do.” (Om Sama, S3-CCHE-5)

“Whenever I need to go to the toilet, I wait till Aesha falls asleep. This is my only opportunity in which I can leave without her crying out. I usually ask the peer sitting right next to me to just take care of her until I come back. I usually give them heads up that she might start crying if she woke up and didn’t find me so that they would calm her down until I come back.” (Om Aesha, S3-CCHE-9)

“The chemotherapy room is so compact to endure 8 children along with their parents standing next to them as there are no dedicated chairs for parents to sit down. I usually take Hassan on my lap until the room becomes overly crowded, then I ask the peer sitting right next to me to monitor Hassan’s chemotherapy dose until I go take my breath outside for a bit and come back. I’m not a fan of the overcrowded places, I easily feel suffocated, especially because of wearing the niqab. I can’t bear to sit the whole session in such an overcrowded compact room.” (Om Hassan, S3-ASUCH-4)
Interviews with mothers within the CCHE reflected their admiration for the hierarchy of social spaces dedicated for the parents. Mothers expressed their preference for using the family zone to have social interactions with peers whom they are not sharing their rooms with (see Figure 62). Om Noura (S2-CCHE-5) expressed her use of the space for having information support from nurses, while Om Nashwa (S2-CCHE-4) highlighted using it for having short termed phone calls within a close proximity to the room. Moreover, Om Iman (S2-CCHE-6) and Om Yasmine (S2-CCHE-3) highlighted their use of children’s playing rooms as a semi-private social zone in which they gather with other mothers or have their extended phone calls (see Figure 63). While Om Yassin (S2-CCHE-1) and Om Abdallah (S2-CCHE-1) highlighted their use of the elevators’ lobby waiting area as their public family zone in which they meet with their visitors who are mainly close family relatives (see Figure 61).

“I really like the variety of spaces that the hospital provided for each inpatient floor. This variation makes us feel that we do have a choice. I usually prefer having social interactions with other peer mothers within the seats located behind the nurse station. They are very close to Noura’s room so I get to sit there as much as I want without feeling guilty that I’m fully away from Noura. I even sometimes use this zone to have small conversations with nurses, in which I get to know more about my daughter’s case. You know, talking with nurses in fact makes you feel more calm and secure as you get to know details about the different cases, and understand more about your child’s stage.”

(Om Noura, S2-CCHE-5)

“During sleeping hours, Abou Nashwa sometimes calls after work to check up on Nashwa and myself. I then go outside the room to avoid having anyone waking up because of my conversation over the phone. I usually use the seats behind the nurse station to conduct such phone calls. Their close proximity to the room makes me feel comfortable. If Nashwa woke up and called me I would hear her while sitting on those seats.”

(Om Nashwa, S2-CCHE-4)

“While our kids are drawing in the children’s playing room, we tend to have small conversations within the room. I sometimes use it if I want a private place for my long phone calls with my sister.”

(Om Iman, S2-CCHE-6)

“Whenever I have an extended phone call with my close family relatives, whether my husband, my sister, or my mother, I usually go outside the room to have more privacy. I usually have my phone calls outside the patient dome to avoid making noise near the nurse station. I use the children’s playing room since it is empty during the majority of the day…”

(Om Yasmine, S2-CCHE-3)

On the contrary, interviews with mothers within ASUCH reflected their common discomfort and concerns about the lack of dedicated spaces for social support. Mothers repeatedly expressed their severe annoyance about the lack of dedicated spaces for family visits. Om Radwa (S2-ASUCH-5), Om Hamza (S2-ASUCH-11), and Om Mohamed (S2-ASUCH-16) highlighted their experience while meeting their family relatives downstairs as an “inappropriate” and “unsuitable” experience (see Figure 34 & Figure 35).
“It doesn’t make any sense for me to be honest. How should I be sitting with my husband on the pavement when all the surrounding people can hear our conversation. It is very inappropriate and uncomfortable..” (Om Radwa, S2-ASUCH-5)

“In our countryside, women are not allowed to sit outdoors while all the people are watching her sitting on the pavement. I’m not used to this..” (Om Hamza, S2-ASUCH-11)

“It is very uncomfortable to be sitting in front of the building’s main entrance, all the passersby are observing you sitting on the pavement [فرجة لللي رايح واللي راجع]” (Om Mohamed, S2-ASUCH-16)

Moreover, within the double patient rooms, mothers repeatedly expressed their need for a social gathering space in which they could gather during the different times of the day. Om Habiba (S2-ASUCH-7), Om Gaffar (S2-ASUCH-3), and Om Mohamed (S2-ASUCH-15) reported mothers’ use of the **staff corridor as a compensation for the lack of social gathering space**, in which mothers meet at night to socialize, eat together, and spend some time outside their rooms a bit (see Figure 39). They furtherly elaborated on their use of the gathering space and **correlated such experience with some of their routines with family relatives back home**.

“Sometimes, as a group of peer mothers, we decide to get food from outside the hospital and eat all together. Usually 2 of us go to pick up the order and we hide the food in several rooms so that the nurses wouldn’t find out about our plan and ruin it. At night, while the nurses are all chilling in their nurses’ room, we meet in the staff corridor, which has no surveillance camera, sit on the floor [نفرش على الأرض] and start eating all together…. Yes it actually reminds me of the time when I had a gathering with my female cousins. We sit on the floor and use the low table [الطبلية] and eat all together. [ما هو الأكل يحب اللمة بردو]..” (Om Habiba, S2-ASUCH-7)

“During this week’s visit, I was so happy to attend the food gathering that some peer mothers organized. It reminded me of our Ramadan’s family gatherings where all my family relatives would sit, eat, and spend the whole night all together. I hope Mohamed’s condition will be stable by Ramadan inshallah to organize our yearly gathering night..” (Om Mohamed, S2-ASUCH-15)

While Om Radwa (S2-ASUCH-5), Om Kareem (S2-ASUCH-6), Om Hussein (S2-ASUCH-1), and Om Nour (S2-ASUCH-2) reported their use of the companion chair in the doorway to keep the inpatient’s door open, as their approach to have a glimpse of whatever is happening around the department (see Figure 40). They expressed their need for a sense of connectivity with life within the department; through **correlating the overall door opening experience with their daily routines and interactions with neighbors at home**.

“What is comforting about this visit’s shared room is that Om Radwa and myself share many of our habits. Both of us enjoy opening the window and the room’s door to allow the air to flow within the room. Leaving the door actually entertains us, as we get to see whoever is passing through the corridor while sitting on the metal seated bench…. I actually do a similar routine back home. Once I wake up and my husband goes to work, my neighbors and myself open our apartments’ doors while only leaving the door shutter [شراعة] so that the wind can flow inside the house, without having cats entering inside the apartment. I’m
also able to observe whoever is passing as my apartment’s door overlooks the buildings’ entrance and start socializing.” (Om Kareem, S2-ASUCH-6)

“As you’ve seen, I like to leave the room’s door open to be able to observe whatever is happening outside, while seated on my seat. I used to do something similar back home. I usually open the apartment’s door during the sunset hour [ساعة الصحراء], leaving only the aluminum sheet door [بسبب الصلبة الالمنيوم] to enjoy the summer breeze and have small conversation with Om Sabah, my neighbor, who also opens her door all day long until her husband gets back home.” (Om Hussein, S2-ASUCH-1)

However, during the “adjusting to the unknown” stage, mothers expressed their preference for social isolation. As their children’s safety is their top priority, mothers reported preventing themselves from any “unnecessary contact” with any other peer that might cause infection transmission to her child. Moreover, they highlighted that the overall situation is not appropriate for having social interactions with peers and getting to know them.

“Whenever I go outside the room to prepare a warm drink for Mustafa or myself and find another peer mother, I usually have a very short conversation [كلامنا على الواقفة]. Each one of us asks the other about her child’s status, and that’s it.” (Om Moustafa, S1-ASUCH-3)

“As I do enjoy the garden’s view that the nurses’ lounge overlooks, I tend to sit there for a bit drinking my afternoon tea, while Cherolos is asleep. Sometimes I meet other mothers while they are using the kettle to prepare a hot drink, but I usually have a very short conversation [اقتصر في الكلام] to avoid catching any microbe or a virus that would worsen Cherolos’s immunity system.” (Om Cherolos, S1-ASUCH-1)

“As I told you before, Esraa’s health is still not stable so I can’t really risk her immunity status and go outside the room to chit chat with other peer mothers.” (Om Esraa, S1-CCHE-5)

“I’m here just for my child’s safety, I’m not here to make any friends...” (Om Joumana, S1-CCHE-5)

Nonetheless, some mothers expressed their need for social support but only from close family relatives and friends. As the majority of the mothers have other children outside the hospital, they reported their need to maintain contact with their family relatives, “balancing their duties” (Om Islam, S1-CCHE-3; Om Moustafa, S1-ASUCH-3). Based on their children’ status, Om Cherolos (S1-ASUCH-1), Om Ereny (S1-ASUCH-2), and other mothers expressed their dependence on phone calls, which act as their connection medium with the “outer world”. While Om Esraa (S1-CCHD-5), Om Islam (S1-CCHE-3), and other mothers at CCHE expressed their dependence on both phone calls and the one hour family visits that the hospital allows within their rooms.

“It’s been 3 weeks since the last time I saw my other kids. We are originally from Fayoum, we don’t have a house here. I’ve left Cherolos’ younger siblings with their grandmother as their father won’t be able to take care of them. He is not living with them, he works here in Orascom during the week and returns back to Fayoum on weekends. I usually use my phone on a daily basis to check up on them. I make sure that they
are studying well, eating well, and most importantly that they are not bothering or messing out with their grandmother. Abou Cherolos also phone calls us every day to check up on Cherolos. Whenever we need anything during the weekdays, he brings it for us; however, no one is allowed to access the room except for me and the nurses, so I quickly go downstairs, pick up the things, and go upstairs again.” (Om Cherolos, S1-ASUCH-1)

“Ereny has a younger sister, 2 years old, who has heart problems [ثقب في القلب]. Since they didn’t allow me to bring her with me to take care of her, I had to leave her with my sister in our countryside [في بلدنا] in El Menia. As you came and saw me, I’m always on the phone with my sister making sure that the young girl is fine and that she is giving her all the medications. Because of her status, my young girl won’t be able to bear the long transportation [مكان هتدور تستحمل بهدلة المواصلات] to come. In addition, there are no dedicated spaces for visitors downstairs. I see people meeting their family members in front of the hospital entrance, sitting on the sidewalks. Of course my daughter won’t be able to endure all of this.” (Om Ereny, S1-ASUCH-2)

“Esraa has a younger sister whom I had to leave with her grandmother as they didn’t allow me to have here with us. She is only 2 years old, she is so young to be left all this time away from me. Everyday, I have a morning and an evening phone call with my mother, making sure that Mariam is all good and she’s not bothering her. I also call my neighbor every once in a while to make sure that things are all good in our apartment. We are originally from Suez and as my husband works here, he just goes back to Suez to visit our daughter and spend the day with her then come back to Cairo again. He used to come and visit us during the visiting hours, but because of Esraa’s unstable condition, the one hour visits that is allowed to everyone here is not allowed for us to maintain Esraa’s immunity system.” (Om Esraa, S1-CCHE-5)

“I sometimes feel guilty towards Islam’s younger sisters. They are still at a very young age to have this instability in their lives. I had to leave them with my younger sister and my mother to take care of them. I know it has only been one and half months, but this is our first time as a family to be separated that way. So I heavily depend on my daily phone calls with my sister to know all about their updates. As for my husband, he comes and visits us every once in a while. I really do like that they are allowing us a one hour visit without the need to go outside the room. Elhamdulillah, Islam’s status is stable and there is no danger on his immunity system from his father’s visits. I wish the hospital would allow my daughters to come and visit us to be able to see them… It doesn’t allow anyone less than 18 years old to come and visit.” (Om Islam, S1-CCHE-3)

4.4.5 Positive Distraction

In addition to the access to social support, access to positive distraction represents one of the most important themes emphasized through all the conversations in both contexts. Interview responses exhibited great emphasis on the need to have access to different withdrawal activities in the various hospitalization stages. Mothers emphasized escaping from the surrounding stress factors at different times of the day as an approach to easily cope with whatever stress factors they are facing. Through all the conversations, mothers repeatedly emphasized the role of the window along with its external view as one of their mostly used indoors withdrawal activities.
Mothers who were going through the “adjusting to the unknown” in both contexts expressed their duration of stay within the single isolated patient room as “solitary confinements”, while their use of the windows as their one and only “gateway”. Mothers expressed their full boredom inside the room, as they limit their movement outside to avoid catching an infection, and transmitting it to their children. Thus reporting their use of the large sized windows and curtain walls with their external views inside the single patient rooms as their “restorative resource”. Interview responses highlighted mothers’ overriding preference for overlooking garden views.

Om Cherolos (S1-ASUCH-1), Om Moaz (S1-ASUCH-6) and Om Youssef (S1-CCHE-2) expressed the feelings of “calmness” and “serenity” that the garden view provides. Moreover, Om Ereny (S1-ASUCH-2) and Om Joumana (S1-CCHE-4) correlated their preference for having a garden view with their experiences back home. While Om Islam (S1-CCHE-3) and Om Cherolos (S1-ASUCH-1) highlighted their preference for the garden view to act as a buffer zone for their privacy.

“In the very early hours of the day, I usually go to the nurses’ lounge to enjoy the garden view with its morning breeze. Whenever I sit there I feel calm and peaceful. In fact, such a view could be considered as my energy booster for the day..” (Om Cherolos, S1-ASUCH-1)

“As you can see, my room is overlooking the entrance of the hospital and the back of the old pediatric hospital building.. It is a very boring view compared to the other side which overlooks the garden and Ramsis Street. I really wish to have a view that overlooks a very large garden, where I can breathe the fresh air in the early mornings and enjoy the serene view of the greenery. In such traumatic experience, having a garden view is a must to calm your nerves.” (Om Moaz, S1-ASUCH-5)

“At first, I had sessions with the psychosocial specialist as I had no idea how to cope with such stress within an alienated environment. I used to have regular breakdowns every now and then. But now, I’m actually using this peaceful and serene view to calm my nerves. During the early hours of the day, even before Youssef wakes up, I sit and enjoy watching the hospital’s renewed landscape. It’s the thing that actually makes staying here bearable.” (Om Youssef, S1-CCHE-2)

“Back home, on Fridays, I used to open the house’s windows to enjoy the early morning’s fresh breeze before friday’s prayer while sitting in the lounge overlooking the farmland where my husband works. In early hours of the morning, I usually find our neighbors’ kids playing and fooling around between the bushes in the surrounding farmlands. Just overlooking such a view gives you peaceful yet energizing vibes..” (Om Ereny, S1-ASUCH-2)

“Back home, we are used to opening the windows during day time and filling the rooms with some fresh and clean air. We are not used to sitting within a non natural ventilated room, relying on the air coming out of the air conditioner. We do believe that such air is the reason behind staying sick, fresh air cleans you inside-out.” (Om Joumana, S1-CCHE-4)

“If I were to choose, I prefer to have a room overlooking a garden view. In fact, the garden view would be working as a serene and peaceful view to calm down my nerves and a buffer zone that would provide me
with more privacy that I already lack within this room, as it overlooks the hospital’s extension building, which gives me the vibes of being exposed by the site workers.” (Om Islam, S1-CCHD-3)

“My current view is actually causing me some stress as I always feel that whatever I’m doing inside the room is fully exposed by those people sitting downstairs near the hospital’s entrance. I think that the garden view would provide some privacy since people would not be allowed to sit inside it.” (Om Cherolos, S1-ASUCH-1)

Nonetheless, Om Moustafa (S1-ASUCH-3) and Om Esraa (S1-CCHE-5) expressed their preference for having their windows overlooking main street views. They highlighted the pivotal role of the street view within the single patient room, since it “resembles hope” that one day, they will be on the other side of this window view.

“During the sunset hour, I usually rotate my chair and open the window, wandering with the car horns, buses, and passersby in the busy Ramsis street with its mid-rise residential building. I try to escape from the confined and suffocated inpatient room with its boring calmness. I just think about the day where Moustafa and myself will be on the other side of the window with the passersby trying to go back home to our families and friends.” (Om Moustafa, S1-ASUCH-3)

“As I have rarely left the room since Esraa got diagnosed, observing people, cars, buses, and busy streets outside from the window is my only connection to the outside world. It makes me realize that life does move on and never stops, which gives me hope that one day Esraa will be better and we will be with those people and passersby that I regularly observe from here.” (Om Esraa, S1-CCHE-5)

Moving on to the “accommodating to the status quo” stage, mothers in both contexts expressed their experience within the double patient room as “prisons”, while their use of the windows as their sources of “withdrawal” and “distraction”. Mothers reported feeling “imprisoned” due to the implementation of the metal bars and the ship sail-like shading device on the exterior facade at ASUCH and CCHE respectively (Figure 94). Om Radwa (S2-ASUCH-5) and Om Noura (S2-CCHE-5) expressed their severe annoyance as such implementations fully obstruct their view from their preferred seats, which are located away from the window.
“Staying here in the room makes me feel that I’m imprisoned. There is no place in the hospital where one can go and take a break. The addition of the metal bars covering the whole windows makes the overall situation intolerable! It makes me feel officially that I’m imprisoned in Abu Zaabal….” (Om Radwa, S2-ASUCH-5)

“This ship’s sail-like shading element obstructs my overall view! I feel that I’m imprisoned between 4 walls despite the implementation of a glass facade. I can’t see anything from my seat. If I want to know what is happening downstairs, I have to go and check myself by standing near the glass wall.”

(Om Noura, S2-CCHE-5)

Interview responses highlighted mothers’ overriding preference for having their windows overlooking street views. Om Nour (S2-ASUCH-2), Om Habiba (S2-ASUCH-7), Om Yassin (S2-CCHE-1) and Om Yasmine (S2-CCHE-3) expressed their preference for having street view as a distraction resource during the day hours. They reported nurses’ limiting their movement outside the room during the hospital’s working hours (9am-4pm), during which doctors usually pass for checkups so mothers have to be with their children to know the updates. Om Mohamed (S2-ASUCH-4) and Om Radwa (S2-ASUCH-5) furtherly elaborated on using the window as a distraction resource. They expressed their use of the activities conducted downstairs as a background distracting factor.

“Om Gaffar is a quiet and non-talkative person. She only talks when she is fully stressed and can’t handle it anymore. Most of the time I try to open up conversations with her just to let the time pass, yet her replies are always limited to the question. The conversation never goes on. I would prefer to have windows overlooking the street. Car horns, talkative passersby walking downstairs can actually distract me from such a silent and boring atmosphere.” (Om Mohamed, S2-ASUCH-4)
“During Radwa’s chemotherapy hours, I usually prefer to get distracted from seeing her in pain. Having daily conversations with Om Kareem is beneficial, but I would prefer to have other distracting activities that I could choose from. The current room view, overlooking the back of the old pediatric hospital, makes me feel more imprisoned. It is not helping at all. There are no activities conducted downstairs to get distracted by their noise. I prefer to have a window overlooking the street view. Standing near the window and watching passersby downstairs from my peers’ rooms is actually a beneficial distraction resource.” (Om Radwa, S2-ASUCH-5)

Although Om Hussein (S2-ASUCH-1), Om Gaffar (S2-ASUCH-3), Om Saeed (S2-ASUCH-10), Om Nashwa (S2-CCHE-1), and Om Iman (S2-CCHE-5) expressed their use of the windows as a withdrawal resource during different times of the day. However, Om Abdallah (S2-CCHE-2) and Om Kareem (S2-ASUCH-6) expressed their need to zone out from the social dynamics within the room, wandering with people walking downstairs in the streets who resemble the continuation of ordinary life.

“Om Yassin and myself spend the whole day talking and interacting with each other and with other peer mothers to entertain ourselves, since there are not many activities to be done within the room. But sometimes, I need some break time. I usually use the window with its side street view to withdraw from the noise that is existing inside the room. Observing people walking downstairs, leaving their work and heading back home after their long and hectic day, increases my patience level for the remaining days to go back home.” (Om Abdallah, S2-CCHE-2)

“As I’ve told you before, Om Radwa and myself spend the whole day facing each other [وشا في وش بعد], with no activities to be done whatsoever. So we tend to interact most of the day. However, there comes times where I need to withdraw from any stress or social interactions with other peers. During such hours, I use the window with its view as my withdrawal resource, yet this visit’s current view, overlooking the back of the old pediatric hospital, is not helping at all. I would prefer to have the other side’s rooms where the windows are overlooking the street view. I enjoy observing people in the fully crowded Ramsis street, wandering with those waiting for a microbus to go back home, and others who are walking down the street with their friends talking and laughing. All of which proves that life goes on and never waits for anyone. Such a view gives me hope and patience for the remaining days after which we would be on the other side of the window with the ones going back home.” (Om Kareem, S2-ASUCH-6)

On the contrary, interviews with mothers during the “weaving through the ordinary life” stage expressed the neutral role of the windows’ view within outpatient chemotherapy departments. Mothers repeatedly expressed the essential role of the windows within the chemotherapy bays and the waiting area in providing natural lighting and ventilation, yet stating that the view is not as equally important.

“Within the outpatient chemotherapy room, having a window is a must. We can usually detect the amount of time we spend here from the sunlight penetrating the units. However, having a view is not necessary at all. It is an add on, if it exists then I would be pleased otherwise it doesn’t matter at all. For the view
area, I do believe that having a window is necessary. It can act as a distraction resource during waiting time.” (Om Badr, S3-ASUCH-3)

“I don’t think that having a view is a must for us as parents. We usually give our back to the curtain wall that exists in daycare units 1 & 2. However, the existence of a window is of course necessary. One can realize the difference when you compare units 1 & 2 with other units that have no windows overlooking the exterior side of the hospital. Units that lack windows make me feel suffocated.” (Om Aesha, S3-CCHE-9)

In addition to having the window as their main restorative resource in various hospitalization stages, mothers at the ASUCH expressed their preference for having an accessible balcony, especially within the single inpatient rooms. They expressed the addition of a balcony within the room as the incorporation of a new dimension to their access to external view. Om Moustafa (S1-ASUCH-3) and Om Cherolos (S1-ASUCH-1) expressed their access to a balcony as an upgrade from the 2D flat screened experience that the window provides to a 3D coherent experience; through which they would feel intertwined with the external atmosphere, with no buffer zone separating them from such experience. While mothers at CCHE didn’t express with great emphasis the need for adding balconies, as they are satisfied with the curtain wall’s exposure to external view.

“I wonder if they can really add a balcony for the single inpatient rooms. Such a solitary confinement experience needs to be lessened by the addition of the balcony. The size of the window is sufficient for me. It provides me with a sufficient exposure to the external view, yet it limits my enjoyment of the external environment. I still feel confined within the room. The addition of the balcony would intensify such exposure to the external environment. By going outside to the balcony, I would feel that I had an actual chance to escape from being locked inside this room.” (Om Moustafa, S1-ASUCH-3)

Interviews with mothers within CCHE reflected their admiration with the new recreational center that is located on the third floor. Some mothers expressed their use of the recreational center as their “go to” space where they can find peacefulness and calmness. Om Islam (S1-CCHE-3), Om Nashwa (S2-CCHE-4), and Om Yasmine (S2-CCHE-3) furtherly elaborated on their experience at the recreational center with their children.

“Since Islam’s condition is getting better day after day, the doctor allows him to visit the recreational center to free himself a bit from the room’s confined environment [يفك عن نفسه من حبسة الغرفة ]. I do also enjoy spending some time at the recreational center. I sit in the central atrium that overlooks the classrooms, keeping an eye on Islam while he is in the music or the drawing classrooms. The atrium is exposed to the natural sunlight from the glass roof. I really like the fact that I get to feel relaxed while observing Islam from the classroom’s curtain wall that overlooks the central atrium.” (Om Islam, S1-CCHE-3)

“This recreational center on the third floor is a new addition to the hospital. Since its opening, it became my go to space whenever I needed to withdraw from the whole inpatient floor. I usually take Nashwa with me since it is originally serving the children. While Nashwa is drawing in one of the classrooms, I wait for
her at the entry hall. In fact, I really enjoy sitting in this spacious entrance. The glass roof allows sun to penetrate inside the hall adding life and warmth to its beautifully painted walls. Whenever I sit there, I feel calm and relaxed, zoning outside the whole hospitalization journey, recharging my energy...” (Om Nashwa, S2-CCHE-4)

“As Yasmine and Noura share their room together, they do like to share their drawing classes together in the recreational center. While Yasmine is having her drawing class, I usually have my one-on-one sessions with my therapist that help me better cope with the stress induced from Yasmine’s hospitalization journey. One of the best support facilities provided here at the hospital is the psychosocial department. They offer help not only for the children but also for their parents. There are dedicated one-on-one therapy rooms inside the recreational center.” (Om Yasmine, S2-CCHE-3)

Figure 95. Recreational Center’s Main Waiting Area, Central Atrium, & Window overlooking the classroom from the Central Atrium

Moreover, other mothers expressed their preference for using the renewed landscape seating as their “go to” space where they can escape the hospital’s confined environment, get exposed to the natural sun rays, and breathe fresh air, while enjoying the hospital’s garden as their main view with no buffer zone in between. Om Yassin (S2-CCHE-1) and Om Iman (S2-CCHE-6) furtherly elaborated on their withdrawal experience at the renewed landscape, overlooking the garden.

“Spending some time downstairs in the renewed landscape gives me some sense of freedom that is missing within the confined shared room. It helps me withdraw from the overall stressful experience Yassin and myself face at the hospital. There are even some moments in which I close my eyes, forget all about the stress and Yassin’s sickness, breathe in some fresh air, hoping that this would end once I reopen my eyes again.” (Om Yassin, S2-CCHE-1)

“The renewed landscape is quite interesting and entertaining. The newly designed seating area with its colorful shading elements and non traditional playful and dynamic seatings actually encourages me to be spending more time downstairs. After the Hospital’s working hours, the landscape becomes quieter, relaxing and a much calmer space. I really enjoy observing the garden peacefully until the Maghrib prayer. I then take Iman upstairs after spending some quality time downstairs.” (Om Iman, S2-CCHE-6)
4.4.6 Conclusive Insights

Through the conducted interviews, mothers emphasized their different needs, experiences, and preferences that reflect their psychosocial state at each stage of hospitalization. Interestingly, the interviews responses highlighted the dominance of some themes over the others in different hospitalization stages. Interview responses showed great emphasis on the need for privacy with various intensities during the different hospitalization stages. However, when mothers were asked to choose between privacy and other themes, mothers’ responses varied across the different stages. When mothers were asked: If you were to choose, would you prefer sitting in a private setting with no social interaction or would you prefer sitting in a shared setting with minimal privacy? 90% of respondents during the “adjusting to the unknown” stage expressed their preference for privacy over social interaction, while 86% of respondents during the “accommodating to the status quo” and “weaving through the ordinary life” stages expressed their preference for social interaction over privacy. During the “adjusting to the unknown” stage, mothers expressed their child’s safety and comfort as their top priority at the moment, putting aside all their needs and preferences. While during the “accommodating to the status quo” stage, mothers highlighted the role of peer interactions as a primary coping mechanism. During the “weaving through the ordinary life” stage, mothers expressed their peer interactions to be a source of entertainment. All of which, highlight the role of the different spatial settings in providing an interplay between privacy and access to social support.

“Of course I would choose to be sitting in this single inpatient room over the double patient rooms located on the 4th floor. Ereny’s safety is the most important aspect at the moment, I don’t really care about my own social needs. I don’t mind feeling socially isolated which is totally opposite to my extroverted character. What is important now is my child’s health…” (Om Ereny, S1-ASUCH-2)

“In this phase, I would choose to be sitting in a shared room where I can interact with other mothers. When you listen to other’s hospitalization journeys, you feel that you are no longer going through this alone. You sometimes even hear cases that their status is way worse than your child’s, so you begin thanking God for your child’s situation and get to know that you are going through a blessing. [الي يشاهد الناس تهنئ عليه ]” (Om Abdallah, S2-CCHE-2)

“Whether in this phase or in previous phases, interaction with peers is always the bearable factor by which the long hours I stay here pass quickly [ يهنئ عليكم فترة الفاصلة هنا ]” (Om Khadiga, S3-CCHE-3)

Correspondingly, during the “accommodating to the status quo” stage, when mothers were asked: If you were to choose, would you prefer being seated right next to the toilet’s wall to maintain your privacy or would you prefer being seated near the window to have access to external view? 88% of respondents at ASUCH expressed their preference to be located near the window to have maximum exposure to the external view from their seats, while 67% of respondents at CCHE expressed their preference to be located near the toilet’s wall since the curtain wall provides them with partial access to external view from their privately secured seats. Thus, highlighting
the role of the spatial setting in providing an interplay between privacy and access to positive distraction.

“In my opinion, privacy is essential throughout the various stages of hospitalization; however, if I would choose between being seated near the toilet’s bed for privacy measure or being seated near the window for access from the bed to the external view, I would choose being seated near the external view with minimal provision of privacy that bed curtains provide, to enjoy the view which would be distracting me from this stressful experience”  (Om Abrar, S2-ASUCH-12)

“As I’m now seated near the window viewing the hospital’s garden and the busy and lively Ramses street, I think I would choose access to an external view over privacy since I have partial control on when to be seen using the bed curtains.” (Om Mahmoud, S2-ASUCH-13)

“For me, I would choose to be seated next to the toilet’s wall as the curtain wall allows me to see whatever is happening outside from my seat and the toilet wall allows me to be partially hidden, not seen from the room’s door.” (Om Yasmine, S2-CCHE-3)

“I think the seats near the toilet wall would be more functional as it hides whoever is sitting on bed and at the same time give access to the beautiful garden view that has been renewed very soon without being seen and observed by people who are sitting in the landscape downstairs.” (Om Abdallah, S2-CCHE-2)

Moreover, during the “weaving through the ordinary life” stage, when mothers were asked: If you were to choose, would you prefer adding curtains for the individual’s personal space that would define your territoriality, and provide you with some visual privacy, or would you prefer having a minimal personal space within a crowded setting, yet maintain their visual access to your surroundings? 93% of the respondents expressed their preference for having minimal personal space to maintain their visual access to the surrounding peers who entertain them. However, mothers expressed their need for having flexible and customized regulated territorial boundaries; that are similar to the adjustable overbed table used by mothers at CCHE daycare units. Thus, highlighting the interplay between privacy, territoriality, and personal space within the daycare outpatient chemotherapy units.

“I think that by adding curtains I would feel more suffocated within this minimal area. In order to add curtains, there must be sufficient space to surround, and this would mean wasting some space. Let’s be realistic, I know that it is impossible to have more personal space within the daycare unit. I can’t be asking for more space at the expense of another child’s chemotherapy recliner. All I’m asking for, is to have an object that is similar to this table yet covers more area to physically define my territory, and separate it from the surroundings, whether this surrounding is another peer’s personal zone, circulation aisles/pathways, or even the visitors’ gathering nodes.” (Om Sama, S3-CCHE-5, Daycare unit 1)

“I think a more flexible object that surrounds my zone and creates some distance between myself and the other peer would be sufficient.” (Om Aesha, S3-CCHE-9)
“I don’t commend this idea of installing curtains inside the daycare units. This would result in having each peer closing the curtains in different times of the day, which means that we would feel isolated during the whole chemotherapy sessions that could extend up till 7-8 hours”
(Om Aesha, S3-CCHE-9, Daycare unit 1)

To sum up, the behavioral observations conducted in both fields along with the interview responses from mothers during the various hospitalization stages reflects the interplay between privacy and perceived control, access to social support, access to positive distractions, and territoriality and personalization. All of which shall work together to better serve the overarching theme ‘parental coping with induced stress’ throughout their children’s hospitalization journey.

4.5 Conclusion

As disclosed from the physical observations, the behavioral mappings, and the conducted interviews with mothers, the studied pediatric oncology healthcare spatial layouts reflect different intensities of psychosocial needs across the different stages that mothers encounter during their children's hospitalization. The issues of privacy and perceived control, territoriality and personalization, the quality of the mother-child relationship, access to social support, and access to restorative resources and positive distraction were found to be the dominating factors that influence the contribution of the studied pediatric oncology healthcare spaces to the psychosocial well-being of mothers in both context (Table 4). This table represents the individual themes in relation to the three stages that mothers encounter during their children's hospitalization journey; "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life." within three different spatial layouts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units.
Table 4. The Contribution of Pediatric Oncology Healthcare Spaces to Mothers’ Psychosocial Needs and Wellbeing

<table>
<thead>
<tr>
<th>Contribution of Pediatric Oncology Healthcare Spaces</th>
<th>Psychosocial Needs and Wellbeing</th>
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<tbody>
<tr>
<td>Access to Information and Support Services</td>
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<tr>
<td>Caregiver Support and Resources</td>
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<tr>
<td>Emotional Support and Counseling</td>
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<td>Social and Supportive Activities</td>
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<tr>
<td>Peer Support and Community Programs</td>
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<td>Financial Assistance and Resource Access</td>
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Note: This table outlines the various ways in which pediatric oncology healthcare spaces contribute to mothers’ psychosocial needs and wellbeing. Each contribution is linked to specific psychosocial needs and wellbeing outcomes.
Chapter 5

Discussion

The above findings reflect the socio-cultural factors that influence the psychosocial needs of mothers. The analysis of the fieldwork observations and interviews with mothers reveal five fundamental themes concerning the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers: privacy and perceived control, territoriality and personalization, the quality of the mother-child relationship, access to social support, and access to restorative resources and positive distraction. Accordingly, this chapter discusses the individual themes in light of the literature review and the fundamental research question on the contribution of the pediatric oncology healthcare spaces to the psychosocial well-being of mothers in Egyptian context. The study analyzes the extent to which mothers’ needs vary during the three stages of hospitalization of their children in relation to the five fundamental themes.

5.1 The Contribution of the Pediatric Oncology Healthcare Spaces in relation to ‘Privacy’ and ‘Perceived Control’

In most societies, privacy is a fundamental social need (Buchman, 2004). Touman & Al-Ajmi (2017) have demonstrated the importance of privacy to the whole Arab society, particularly to the Egyptians. Indeed, the behavioral observations and interview responses revealed the mothers’ need for privacy and control during their hospitalization journey with their children. However, the intensity of a mother’s need for privacy and control varies according to their hospitalization stage. Alan Westin’s (1976) definition of privacy highlighted the individuals’ differing needs for privacy. He went on to define privacy as the claim of individuals to control when, how, and to what extent information about them is communicated to others. He viewed privacy as the voluntary and temporary withdrawal of a person from the general society through physical or psychological means. Moreover, Devlin & Andrade (2017) further elaborated on the direct relationship between privacy and perceived control. They highlighted room occupancy as the ‘physical parameter’ within the healthcare settings that reveals the interrelation between privacy and perceived control. Correspondingly, mothers going through the “adjusting to the unknown” stage greatly emphasize their preference for rooming in with their children in a single patient room as they, along with their children, become very vulnerable during the first stages of hospitalization. They expressed their need for complete control over their surrounding environment and maximum withdrawal from unnecessary physical contact with others; to avoid visual exposure to others in such a state. While the assumption was that mothers would be expressing their discomfort and concern about their invasion of privacy in the shared layouts, mothers going through the “accommodating to the status quo” and “weaving through the ordinary life” stages did not greatly emphasize their need for privacy. The behavioral observations and interview responses highlighted their need for controlled visual privacy only.
while conducting specific activities throughout their stay. During the “accommodating to the status quo” stage, mothers expressed their need for visual privacy when it comes to the healthcare personnel only during their sleeping and napping hours. While during the “weaving through the ordinary life” stage, mothers, especially those wearing niqab, expressed their need for visual privacy from the opposite gender (adult patients, fathers, and healthcare personnel) only during eating and resting hours.

In fact, mothers’ repeated expressions on the issue of visual privacy revealed the crucial role that the spaces play in providing privacy. In line with Altman’s (1975) privacy regulation model, in which levels of privacy were classified into desired, achieved, and optimum levels, the pediatric oncology healthcare spaces should cater to reaching a certain balance. The ultimate goal is to reach the optimal level of privacy by balancing all levels. Indeed, during the “adjusting to the unknown” stage, mothers perceived an optimum level of privacy and control during their stay. Despite mothers’ awareness that constant access for healthcare personnel to the room will always invade their privacy, they highlighted the Anteroom and bed curtains’ role in providing privacy within the single patient rooms. The Anteroom, a vestibule permanently attached to an isolation room, prevents the movement of infectious diseases toward or away from the patient's room (Andalib et al., 2022). Accordingly, doors for both Anteroom and the inpatient rooms are solid, with no openings for the privacy and safety needed for both patient and his/her parents. Correspondingly, mothers at ASUCH expressed their exploitation of a couple of minutes that the healthcare personnel take while wearing the gown and the mask before entering to dress up if needed. Moreover, they expressed the crucial role of the "fully Solid doors" in providing visual privacy and safety for both their children and themselves. At the same time, mothers at CCHE expressed their dependence on using the bed curtains as an "over shield," providing more visual privacy, due to the lack of the Anteroom since the single patient room is not considered an isolation room.

During the "accommodating to the status quo" stage, mothers highlighted perceiving a balance between the achieved and desired levels of privacy. Despite their preference for leaving the room's door open, which causes a partial invasion of privacy, mothers highlighted the role of the inboard toilet in providing visual privacy for the beds near the inboard toilet's wall within the double inpatient units. They expressed the role of the inboard toilet in minimizing the invasive visual corridor and obstructing the notion of "being seen" by the passersby or the ones standing at the room's entry node. Moreover, mothers furtherly highlighted the role of the bed curtains in providing visual privacy for the beds located away from the inboard toilet wall within the double inpatient units.

On the other hand, mothers, especially ones wearing the niqab, during the “weaving through the ordinary life,” expressed their perceived invasion of privacy and lack of control resulting from crowdedness within the outpatient chemotherapy ward layouts. Altman’s (1975) privacy regulation model discussed the impact of unbalanced levels of privacy on individuals’ psychosocial well-being. He stated that when the optimum level of privacy is exceeded, the individual feels isolation, social solitude, and boredom. When the achieved level of privacy is
lower than the desired level, it can be concluded that the person’s social behavior surveillance is improper, and the individual suffers from crowding. Correspondingly, mothers during the “weaving through the ordinary life” expressed their overriding preference for corner seatings as they are located away from the wards’ crowdedness. Moreover, such seats have physical barriers, such as walls and columns, that could provide them with visual privacy when they rotate the chair to face such barriers.

Mothers’ behavioral mapping and interview responses discussed in the previous chapter not only highlighted mothers’ needs for privacy but also identified several measures conducted by mothers to make up for the lack of visual privacy. Mothers had to adjust the original use of some elements within the studied pediatric oncology healthcare spaces to provide them with the needed visual privacy. The instantaneous reaction of mothers within the different pediatric oncology healthcare spaces is to use some physical barriers or, in Altman’s (1975) terms, “physical privacy regulating mechanisms” to obstruct undesired visual exposure by others. Within double patient rooms, mothers re-invented the Anteroom setting with its double doors separating their private zone (inpatient room) from the public zone (nurse station and circulation area). They used the inboard toilet’s door to secure them a warning for an unplanned entrance without being seen by nurses during the sleeping and nap hours. The alarming sound created by the clash of the room’s door with the inboard toilet door allows mothers to close the bed curtains before getting exposed to the nurses entering the room. Moreover, such re-invention gives mothers some control over nurses’ access to the patient rooms during their private hours. Mothers’ behavioral mapping also reflected their adaptation of the bed curtains from initially providing visual privacy from other individuals within the building to windows’ shading elements securing them from strangers’ gaze in the street during different times of the day. Since the studied pediatric oncology healthcare spaces within the ASUCH lack shading devices for windows, mothers seated near the windows expressed their discomfort regarding the uncontrolled issue of “being seen” by the passersby downstairs in the street.

Cultural values certainly play a role when discussing mothers’ privacy preferences and conducted behaviors. As one of the fundamental individuals needs in Egyptian culture, privacy is also affected by ‘sociological customs and habits’ and ‘sociological traditions.’ The mothers correlated their experiences within the studied spaces and their daily routines and experiences back home, such as: "Sitting properly while a family relative is at home," and "wearing heavy, nontransparent clothes to ensure it will not lift while sleeping." As well as the "Constant wear of the veil during the whole duration of stay" reflects their inheritable cultural traditions. Moreover, their reported frustrations and discomfort due to the lack of windows' shading elements and the lack of family gathering space, emphasizing the issue of "being seen" by strangers, certainly highlights their cultural inheritable behaviors and traditions. Such traditions constantly introduce regulations and widely recognized behavioral patterns that govern a particular culture to a certain extent (Touman & Al-Ajmi, 2017). Accordingly, understanding the cultural dimension is essential in understanding the ‘why’ dimension behind mothers’ need for privacy and control.
In this sense, this study's findings reveal privacy and control as multifaceted themes. Mothers repeatedly associated privacy and control with other themes such as social interaction, territoriality, and access to positive distraction. Interestingly, interview responses highlighted the dominance of some themes over the notion of privacy and control in different hospitalization stages. Accordingly, pediatric oncology healthcare spaces should cater to fulfill mothers' visual privacy and control needs during the three hospitalization stages. Moreover, the design of studied spatial layouts (single inpatient room, double patient room, chemotherapy ward layouts) should include the measures conducted by mothers to compensate for the lack of visual privacy previously mentioned in Chapter 4.

5.2 The Contribution of the Pediatric Oncology Healthcare Spaces in relation to ‘Territoriality and Personalization’

Environmental psychology studies highlighted territoriality and personalization as the most essential "psychological determinants" of the actual structure of any inhabited environment (Heidmets, 1994). However, the nature and function of the different inhabited environments (healthcare, residential, commercial, etc.) allow for multiple definitions and perspectives regarding such phenomena. In healthcare settings, Blumberg & Devlin (2006) defined territoriality as a mechanism used to regulate the boundaries between individuals and others, using personalization and perceived control to satisfy individuals' social and physical needs. Thus, the territory is no longer a possession of a specific element. However, it can be considered the "designation of a particular place to a particular subject" through which specific behavioral norms, attitudes, and other factors occur (Altman, 1975; Blumberg & Devlin, 2006). In this study, mothers' behavioral observations and interview responses highlighted their constant need for personal space, 'their own territory' within the studied pediatric oncology healthcare spaces during the different hospitalization stages.

Altman (1975) expressed his conception of three types of territories; the studied pediatric oncology healthcare spaces can be considered primary and secondary territories within the chosen pediatric healthcare contexts. As the primary territories are those controlled and used exclusively by a single entity, the single patient rooms are considered the most prevalent depiction of a primary territory for parents and children. Mothers expressed their preference for rooming in with their children in the single inpatient room as it provides them with complete control and exclusive accommodation they seek during their "adjusting to the unknown" stage. Moreover, their behavioral observations emphasized their use of the room's boundaries as their regulated territorial boundaries in which they perform their daily activities and personalize their use of the space accordingly.

On the other hand, the double patient rooms and the outpatient daycare units are models of a secondary territory for both parents and children due to their shared nature which provides mothers with periodical control and limited personal space. While the assumption was that mothers within both the double patient rooms and outpatient daycare wards would be expressing their concerns regarding issues of territoriality, only mothers in the daycare wards expressed the
lack of regulated territorial boundaries. In the double patient rooms, mothers' behavioral observations revealed their use of the inpatient bed curtains and personal belongings in defining their territorial boundaries when needed. Their use of the inpatient beds' curtains is not limited to providing privacy for both parents and children; it also allows for "defining mothers' personal space" within the inpatient room. Moreover, the act of laundry hanging on the added metal bars and the placement of it on only one side of the window reflects the regulated territorial boundaries set by mothers, which they further elaborated on during the interviews. While within the outpatient daycare wards, the behavioral observations and interview responses revealed mothers' use of the adjustable overbed table as their "only available physical buffer boundary" to reduce others' invasion of their personal space. According to Proshansky and colleagues (Proshansky et al., 1970), individuals thrive on organizing their physical surroundings to set detectable boundaries to maximize their freedom of choice. In some daycare units, mothers placed within the units' cross circulation nodes and visitors' meeting nodes used the table as a buffer zone, avoiding the heavy traffic inference with their personal zone. However, in other daycare units, mothers struggled to identify their territoriality due to the lack of an adjustable overbed table and the insufficient use of personal belongings as their only territorial boundary. Accordingly, pediatric oncology healthcare spaces shall always provide mothers with flexible and adaptable physical elements that can promote their feeling of owning territory and maximize their control over their personal zone in different seat locations within various spatial layouts.

As recent literature highlights the importance of studying the relationship between the two phenomena, territoriality and privacy (Namazian & Mehdipour, 2013), mothers' behavioral observations and interview responses within the secondary territories reveal the interplay between privacy and territoriality. Interview responses of mothers in the outpatient daycare units emphasized that mothers who reported their need to preserve their privacy also reported their need to maintain a territory. In both cases, they are trying to defend their right not to be invaded by others. Furthermore, as expressed through Proshansky's (1970) conception, individuals' territorial behavior determinants are their desire to maintain or achieve privacy. Correspondingly, mothers within the double patient rooms reported using the inpatient beds' curtains to achieve that, as mentioned above. In this regard, the design of psychosocial spaces should consider the inter-relationship between mothers' need for privacy and territorial boundaries during the different hospitalization stages.

Despite the lack of adequate means of personalization in most studies on the issues of personalized environments in healthcare settings, Cláudia and Ann (2015) defined personalization not only as an aspect of territoriality but also as an aspect of individuals' perception of control. They defined the perception of control over the physical environment as the feeling that individuals can change, modify, or transform the environmental characteristics fulfilling their needs. Likewise, only mothers in the single inpatient rooms could modify their use of "their primary territory" as they have exclusive use and complete control over the space. As mothers seek privacy, assurance, and safety during the “adjusting to the unknown” stage, they change the primary use of some available amenities within the single inpatient room to
create a home-like environment. Mothers relayed dedicating different zones for specific activities to resemble their apartments’ different zones back home. Based on the behavioral observations and interview responses, the inpatient bed resembles the bedroom, the companion chairs, the side table, and light weighted visitors’ chair resemble the living and dining areas, and the adjustable overbed table and the mini refrigerator resemble the kitchen. According to Heidmets (1994), individuals’ capacity to recreate ‘part of their home’ to the place where the process of hospitalization occurs results in easier coping and adaptation to the surrounding traumatic and stressful factors for both patients and parents. In this regard, the design of the pediatric oncology healthcare spaces during the early stages of hospitalization should include flexibility and customizability to promote “home-like experiences” in which parents can personalize their children’s assigned rooms to fit their personal needs and daily routines better.

5.3 The Contribution of the Pediatric Oncology Healthcare Spaces in relation to ‘The Quality of Mother-Child Relationship’

As Henriksen and colleagues (2007) described, the physical environment is essential to the care provided in pediatric healthcare settings. It plays a vital role in supporting the quality of the parent-child relationship. Based on Vollmer and colleagues’ (2021) qualitative fieldwork, four architectural determinants highlight the quality of the child-parent relationship and different modes of interaction. Those determinants include the function of interaction, proximity between parent and child, used space for interaction, and availability of possible spaces for parental withdrawal. In this study, the pediatric oncology healthcare spaces revealed three proximity modes (bodily contact, non-physical contact, no contact) that reflect different intensities of mother-child interactions during the different stages. As mothers have complete control and exclusive accommodation in the single inpatient room, they tend to develop a very strong and unique mother-child bond. As they have flexible and sufficient amenities, their behavioral patterns reflect the various intensities of mother-child interactions during different times of the day. For example, mothers have bodily contact while sharing the inpatient bed with their children during sleeping and nap hours. On the other hand, they have non-physical yet close proximity contact using companion chairs and side tables to conduct their shared activities with their children. While increasing possibilities for withdrawal from interaction, mothers were observed to be using the window as their primary restorative source, as mentioned in Chapter 4.

While the assumption was that limited intensities of mother-child interactions would result from the over crowdedness and the lack of identified personal space, various intensities of mother-child interactions occur within the outpatient daycare units of CCHE. As mothers have control only over the provided personal zone, which includes the child’s chemotherapy recliner, companion chair, and an adjustable overbed table, the location of the companion chair to the child’s recliner was used to reflect modes of non-physical contact. For maximum interaction, mothers place the companion chair right in front of the recliner, maintaining constant eye contact that helps reduce stress for both the child and the parent. Typically, mothers were either
playing with their children or helping them eat during such a state. While increasing possibilities for withdrawal from interaction, mothers were observed placing their companion chair in parallel to the child's recliner. Such a state allows for direct visual contact with the surrounding environment and minimal interaction with children.

On the other hand, due to the lack of companion chairs in double patient rooms and the outpatient chemotherapy unit at ASUCH, mothers share the inpatient beds and children's recliners, respectively, during mother-child interactions. As mothers do not get other seating modes, their behavioral observations reflect limited intensities of mother-child interactions; however, the interview responses emphasized the role of bodily contact in building a solid and unique mother-child relationship. Mothers explicitly emphasized the "comfort," "reassurance," "safety," and "security" of holding their children between their arms. They reported that maintaining proximity with their children allows them to quickly recognize any side effects from the chemotherapy treatment. Accordingly, most mothers shared the inpatient bed with their children in the inpatient department, even when the companion chairs were available. While in the outpatient chemotherapy, based on the child's age, some mothers were found sitting on the children's recliner, having their children on their laps. Such a phenomenon reflects the role of the mother-child relationship in reducing mothers' induced stress and reveals the "inseparable proximity" needed for young children to develop a secure and productive attachment to a caregiver (Goldsmith & Alansky, 1987). In this sense, mothers' behavioral observations and interview responses highlight the "mutually beneficial" quality of the mother-child relationship developed within the studied pediatric oncology healthcare spaces.

5.4 The Contribution of the Pediatric Oncology Healthcare Spaces in relation to ‘Access to Social Support’

During stressful situations and experiences, individuals cited their tendency to seek consultation and assurance, especially from their loved ones (Taylor et al., 2007). This form of support is an effective and valuable way to reduce stress levels (Devlin & Andrade, 2017; Devlin et al., 2016). According to Ulchino (2009), social support is considered one of the most documented psychosocial factors influencing individuals' well-being. Moreover, it creates therapeutic and family-centered care environments (Ulchino, 2009; Alvaro et al., 2016). The behavioral observations and interview responses show that mothers thrive on social interactions from different sources during their hospitalization journey with their children. However, the extensive fieldwork on social support's temporal dimension (Lazarus and Folkman, 1984) reveals mothers' different dynamics of social interactions and social support systems during the different stages of hospitalization. Caplan (1979) classified social support systems into formal and informal relationships through which an individual receives the emotional, cognitive, and material support necessary to cope with stressful experiences. While the assumption was that mothers would be expressing loneliness and isolation due to the lack of social interactions directly related to the nature of the medium care isolation rooms, mothers who are going through the "adjusting to the unknown" stage emphasized their preference for social isolation. Due to the unstable
conditions of their children's health status, most mothers felt that the overall situation is inappropriate for creating a social community: "I'm here just for my child's safety; I'm not here to make any friends....". However, observing the mothers revealed their reliance on having formal relationships with nurses through which they receive the informational support needed that helps in reducing stress and practical support whenever they need to leave their children alone in the room. Thus, coinciding with Vollmer and his colleagues (2021) hypothesis, individuals prefer formal social support more than informal social support during the early stages of hospitalization.

Mothers going through the "accommodating to the status quo" and "weaving through the ordinary life" stages significantly emphasize their preference for having and maintaining informal relationships with peers, known as peer-to-peer support. During the "accommodating to the status quo" stage, mothers featured peer support as their primary coping mechanism. In contrast, during the "weaving through the ordinary life" stage, mothers characterized peer support as their source of entertainment. However, they all expressed the role of peer support in providing emotional support, increasing their sense of safety, belonging, and being understood while reducing their sense of loneliness and imprisonment. Finally, they talked about the practical support through which mothers help one another, share responsibilities and resources, and form a sort of association that tends to defend one another in case of conflict with other peers.

As documented during the fieldwork and interviews, the design of healthcare facilities can directly influence the amount and degree of user interaction (Shepley, 2005). Foster and colleagues (2017) found that spatial configurations within hospital inpatient and outpatient departments significantly impacted the relationships and interactions between different users. To start, within the single inpatient departments, hosting the "adjusting to the unknown" stage, the central location of nurse stations allows easy access to all patient rooms, reassuring that help is near whenever needed. While within CCHE's inpatient department, hosting the "accommodating to the status quo" stage, the hierarchy of social spaces increases the opportunities and modes of social interactions with peers, family visitors, and other healthcare personnel. Thus, providing mothers with diverse spaces for conducting different activities allows for forming social communities within the hospital environment. Moreover, the use of frosted glass paneled doors allows for a connection between the inpatient rooms and the interactions within the unit's corridor and nurse station. Accordingly, mothers' behavioral observations and interview responses show their use of the family zone, nourish area, and children's playing area for short termed/unintended, long-term/intended, semi-private, and familial social interactions. Lastly, within the outpatient departments, hosting the "weaving through the ordinary life" stage, the nature of the ward layout, with its crowdedness and minimal personal spaces, allows mothers maximum exposure to social interactions with peers yet with the minimal provision of territoriality and privacy.

On the other hand, within ASUCH's double inpatient department, hosting the "accommodating to the status quo" stage, mothers had to take measures to compensate for the lack of social
gathering spaces, giving up on some of their privacy needs. Upon observation and interview, they expressed their dependence on using their supposedly "semi-private inpatient room" as their primary social gathering space. Mothers used the companion chair in the doorway to keep the inpatient's door open to the staff corridor as compensation for the lack of social gathering spaces. The interview responses revealed this phenomenon as a reflection of the mothers' socio-cultural community, highlighting the essential role of cultural values in this discussion of mothers' thriving need for social interactions and peer support. In light of the urban fabric of the low-middle income Egyptian dwelling units, the intimate units' proximity and the lack of privacy is a primary constituent of the 'family-structured' neighborhood (Moustafa, 2004). Similarly, mothers adapted the pediatric oncology healthcare spaces to fulfill some needs with their daily routines and experiences back home: "we sit on the floor and use the low table [الطبلية] and eat all together, [ما هو الأكل يحب اللمة بردو]", and "my neighbors and myself open our apartments' doors while only leaving the door shutter [شراعة الباب] to observe whoever is passing as my apartment's door overlooks the buildings' entrance and start socializing." Depicting their "neighborly relations and communication" and the importance of the notion of "togetherness." This finding coincides with Edward Hall's (1966) cultural classifications for privacy, revealing the Egyptian mothers with their spatial behavior in the shared layouts as contact groups known for their proximate interactive distance (Hall; 1966, Altman and Chemers, 1980). 86% of mothers during the "accommodating to the status quo" and "weaving through the ordinary life" stages who expressed their preference for social interaction over privacy reflect their thriving need for social interactions and peer support. Moreover, mothers' repeated emphasis on their discomfort regarding the minimal distances between the mixed-gendered seating within the outpatients' ward layouts echoes the socio-cultural inheritable traditions. Accordingly, understanding the cultural dimension is essential in grasping the full picture behind mothers' need for social support throughout their children's hospitalization journey.

5.5 The Contribution of the Pediatric Oncology Healthcare Spaces in relation to ‘Access to Restorative Resources and Positive Distraction’

Since the 1970s, healthcare-related environmental research has shifted its focus from reducing the adverse effects of the physical environment to creating restorative environments that reinforce positive experiences (Shepley, 2006). People tend to use physical, psychological, and social resources daily, so the need for regular restoration arises (Hartig, 2017). Hartig (2004) defined the term restorative as the renewal or recovery of adaptive resources or capabilities that have become consumed in meeting the demands of everyday life. As new demands will come, Hartig (2017) expressed the essential role of different restorative resources that replenish depleted resources. Correspondingly, through behavioral observation and interviews, the mothers emphasized their need to access different restoration resources to better cope with the stress inflicted through the different hospitalization stages. As mothers tend to spend most of their time within the confined hospital environment, they repeatedly mentioned the window’s role and its external view as one of their most used indoor restoration resources during the interviews.
During the "adjusting to the unknown" and "accommodating to the status quo" stages, mothers expressed windows as more than openings in an exterior wall of a certain size and proportion. They expressed the unique "connection with the outside" that windows provide during their stay. Mothers who were going through the "adjusting to the unknown" stage in both contexts identified windows as their one and only "gateway" within their "solitary confined" single inpatient rooms. Similarly, mothers who are going through the "accommodating to the status quo" stage in both contexts identified windows as their sources of "withdrawal" and "distraction" within the "prison-like" double patient room. In both contexts, they all expressed their appreciation for the large-sized windows. However, some mothers in the double patient rooms expressed their severe annoyance with the implementation of the metal bars and the ship sail-like shading device on the exterior facades. To them, those elements fully obstruct their view from their preferred seats which are typically far from the window. Despite their full awareness of the safety and privacy reasons behind such implementations, they still expressed their preferences for removing them to have maximum exposure to the external view and full connection to the "life outside." However, they remain adamant about their need to maintain visual privacy; thus, they suggested using window curtains as a flexible and adaptable element that can be controlled and used whenever needed.

In terms of Kaplan & Kaplan (1989;1995) Attention Restoration Theory (ART), the window's restorative aspect relies on its external view's quality. The quality of an external view is determined by the effortless attention that goes to interesting and pleasant aspects of the environment: the "getaway" ticket from the everyday stresses, experiencing "expansive" contexts, engaging in activities that are "compatible" with one’s intrinsic motivations, and finally critically experience stimuli that are "softly fascinating," Kaplan (1995). Likewise, mothers' perspective for their preferred external view was included to understand the qualities of the external view required to accommodate their need for restoration resources. While the assumption was that mothers would always prefer the natural view with its pleasantness and calmness, which would help reduce the induced stress, this study revealed mothers' different external view preferences. Through this, they escape the surrounding stress factors during the different stages of hospitalization.

As mothers who are going through the "adjusting to the unknown" stage are still trying to navigate through the stressful and traumatic crisis of their children's diagnosis, they expressed their preference for having access to nature. Their repeated emphasis on their need for "calmness" and "serenity": "تشمى هوى ربيا النظيف"، [منظر الطبيعة التي كله سكون وهواء وراحة بال] [عشقني تهدى أعماليك : "In early hours of a Friday morning, I usually find our neighbors' kids playing and fooling around between the bushes in the surrounding farmlands. Just overlooking such a view gives a person peaceful yet energizing vibes." This highlights the use of natural views as a restorative resource. Moreover, it coincides with Ulrich's (1991) study on the role of biophilia, biophilic, and natural landscape in reducing stress by eliciting positive emotions, sustaining non-vigilant attention, and reducing negative thoughts. However, mothers' overriding preference to view nature is not only for having a distressing restorative resource but also for maintaining visual privacy. As mentioned in section 5.1,
mothers greatly emphasized their need for visual privacy at such a stage; thus, they reported their need for a serene view to act as a buffer zone between the inpatient room and the passersby downstairs.

On the other hand, mothers going through the "accommodating to the status quo" stage expressed their overriding preference for having access to street/urban views. They repeatedly emphasized their use of the activities conducted downstairs as a background distracting source, a fact that aligns with Shepley (2006) ’s claim that white noise has a potential stress-reducing impact. Moreover, their commonly shared pleasure of watching the movement in the streets stems from their socio-cultural "neighborly relations" and the "family "structured neighborhood (Moustafa, 2004), as previously mentioned in section 5.4. The mothers are used to intimate units and proximity in their neighborhoods with windows and balconies overlooking the lively narrow streets. They wander with people passing by, cars moving, and shops opening and closing; it is no surprise that they are now showing their aspiration and overriding preference for lively street scenes rather than a still, frozen nature view.

In addition to windows, healthcare facilities shall provide diverse restorative resources for mothers within the confined hospital environment. After observation of the mothers in the double patient units and conducting interviews, usage of the doorway as a source of connection between the inpatient rooms and the unit's corridor seems prevalent. In the interviews, mothers reported that keeping the inpatient's door open and frosted glass paneled doors connects to life outside the room. This acts as a factor of social support and positive distraction that helps mothers shift their attention away from stressful experiences to a much more exciting and pleasant environment. The aspect of having the effortless engagement of attention by the environment, according to Kaplan (1995), is a key component of restorative experience. Thus, using the doorway and frosted glass paneled doors as a micro-scaled "inside-outside" form of communication can be considered a restorative resource.

This study's findings reveal that access to restorative resources and a positive distraction are environmental features. Based on the interviews, the mothers associate access to restorative resources and positive distraction with access to social support. Moreover, the responses foreshadow the interplay between privacy and access to positive distraction. Accordingly, the design of the pediatric oncology healthcare spaces should provide diverse restorative resources that cater to the mothers' different restoration preferences during different hospitalization stages. Furthermore, pediatric healthcare facilities should provide a variety of restorative spaces within and beyond the confined hospital environment, similar to CCHE's provision of the hierarchy of social spaces, recreational centers, and accessible landscapes previously mentioned in Chapter 4.
Chapter 6

Conclusion

6.1 Summary

This study sheds light on the significant contribution of the pediatric oncology healthcare spaces to mothers' psychosocial well-being in Egyptian context. The research focuses on understanding mothers' experiences during the different stages that they encounter during their children's hospitalization to identify their psychosocial needs and wants. It proceeds with the core question, "What is the contribution of the pediatric oncology healthcare spaces to the psychosocial well-being of mothers in the Egyptian context?". The investigation comprised subsequent follow-up questions; What are the mothers' psychosocial needs? What are the stages that mothers go through during their children's hospitalization journey?, "How do mothers inhabit the selected pediatric oncology healthcare spaces? What are the spatial qualities that inhibit or promote the fulfillment of mothers' needs?". Finally, "As perceived by mothers, what are the environmental preferences that would improve their psychosocial well-being?". In this regard, Ulrich's (1991) theory of supportive design and its associated stress-inducing factors were used to guide the process of understanding mothers' experiences and psychosocial needs during their children's hospitalization period. Corresponding to Al Gamal and Long (2010)'s disclosure on the process of 'anticipatory grief' among parents living with a child with cancer, the study incorporated three stages that mothers go through during their children's hospitalization journey; "adjusting to the unknown," "accommodating to the status quo", and "weaving through the ordinary life." These stages were labeled in respect of the encountered experiences of the mothers within three different spatial layouts: Single inpatient rooms, double inpatient rooms, and outpatient chemotherapy units. Participant observations and interviews with mothers across the study areas situated in two Egyptian pediatric oncology healthcare settings. As disclosed from the fieldwork and Interview results, mothers across the study areas share common psychosocial needs and demands. However, different intensities of psychosocial needs were found across the different stages that mothers encounter during their children's hospitalization. It was found that the dominating factors influencing the contribution of spaces design to the psychosocial well-being of mothers include issues of privacy and perceived control, territoriality and personalization, the quality of the mother-child relationship, access to social support, and access to restorative resources and positive distraction.

Providing a maximum level of privacy and perceived control is essential during the first stage of children's hospitalization, the "adjusting to the unknown" stage. As mothers feel vulnerable while trying to adapt to their children's unknown state, they spend the whole stage inside the room boundaries, avoiding 'unnecessary contact' with strangers. They limit their contact to only be with their sick children and the healthcare personnel. The nature of the single patient room contributes to fulfilling mothers' maximal need for privacy and control. The role of the Anteroom...
and the bed curtains included in the single patient room contributes to fulfilling mothers' visual privacy needs. Despite the immense need for privacy and control in other stages of children's hospitalization, mothers expressed the need for visual privacy in the shared room layouts. This was especially the case for the niqabi mothers (covering their faces) in the double patient rooms. They preferred sitting near the inboard toilet's wall as it provides a sense of visual privacy. In contrast, other mothers preferred sitting near the window for maximal exposure to the external view. To maintain visual privacy, they used bed curtains during mid-day sleeping and nap times. Due to the lack of window curtains in one of the studied contexts, the mothers used the bed curtains to cover the window to inhibit getting exposed by passers-by downstairs. Moreover, the inboard toilet doors were used during the night to create a sense of visual privacy and provide mothers with some level of control over visual access to the room. In the outpatient daycare settings others expressed an overriding preference for corner seating, column-wall-sided seating, and behind-nurse station seating in search of some privacy. The niqabi mothers strived the most for visual privacy within the outpatient ward layouts.

Territoriality and personalization influenced the contribution of space to mothers' psychosocial well-being. Providing mothers with a sense of territoriality is essential in outpatient daycare units. Mothers seemed to struggle to define their regulated territorial boundaries. The seats near the units' cross circulation nodes, visitors meeting nodes, units' entry nodes, and nurse stations were perceived as unsatisfying since the activities of these spaces interfere with the mothers' zone/territory. Moreover, they found mixed-gender side-to-side seats uncomfortable due to the minimal distance between them. The use of the adjustable overbed table was found to be the only available physical buffer boundary. Accordingly, the mothers preferred the corner and column-wall seats to complement the adjustable table and create a defined and enclosed territory. Despite the contribution of the outpatient units in inhibiting territoriality, the studied spaces in the inpatient departments were, in fact, providing the needed level of territoriality. The spatial layout of the double patient rooms defined a personal zone for each mother. That, along with bed curtains, personal belongings, and laundry hanging on dedicated sides of the windows' metal bars and the two-seater benches, further identified the peers' 'own territory.' Finally, the spatial layout of the single inpatient room promoted a sense of territoriality and personalization. Mothers perceive the room as their 'private territory,' expressing a sense of safety, security, and exclusive control over the environment. Changing the primary use of some of the available amenities helped them create their own 'home-like experiences.' By personalizing their room's zoning, they could dedicate zones for activities resembling their home life.

The study's findings also highlighted the essential need for strong mother-child relationships during all stages of the children's hospitalization. The studied pediatric oncology healthcare spaces at CCHE and the single patient rooms at ASUCH revealed the three proximity modes (bodily contact, non-physical contact, no contact) that resemble different intensities of mother-child interactions. As the mothers find flexible and sufficient amenities, their behavioral patterns reflect their use of the patient zone, parent zone, and common zones to promote maximum, balanced, and withdrawal modes of interactions.
On the other hand, due to the lack of companion chairs in double patient rooms and outpatient chemotherapy rooms at ASUCH, mothers’ were found to experience limited intensities of mother-child interactions. Mothers shared the inpatient beds and children’s recliners as their only available seating mode for mother-child interactions. Nonetheless, all studied pediatric oncology healthcare spaces promoted bodily contact that reflects a strong and unique mother-child relationship through sharing the inpatient bed and children’s recliners within the inpatient and outpatient units, respectively. Finally, the mother-child relationship proved to be a 'mutually beneficial quality' essential for children's and mothers' psychosocial well-being.

Interviews with mothers highlighted access to social support as an effective and valuable means of reducing mothers' stress levels. Social support is one of the most documented psychosocial needs that directly influence the mothers' psychosocial well-being. However, different types of social support were found across the hospitalization stages. The spatial layouts of the single inpatient departments promote the contribution of the space to mothers' psychosocial well-being. The easy access provided by the central location of the nurse station to all rooms promotes mothers' sense of security and reassurance. Mothers' behavioral observations revealed the formal relationship that mothers develop with nurses, through which they have access to informational and practical support. At CCHE, the spatial layout of the single inpatient room promotes family visits which are the only informal support needed during the 'adjusting to the unknown' stage. On a similar note, the outpatient units' spatial layout and the ward layout allow for maximum exposure to social interactions. Due to its crowdedness and minimal personal spaces, there is a higher chance for social interaction but a minimal sense of territoriality and privacy. This, in turn, results in the informal relationships that mothers have developed with peers. As for the double-patient units, the hierarchy of social spaces promotes opportunities and modes of social interactions with peers, family visitors, and other healthcare personnel. It provides mothers with various spaces for conducting different activities and allows for forming informal relationships and social communities within the hospital environment. On the other hand, the lack of social gathering spaces and family visits areas at ASUCH inhibit the contribution of the space to mothers' psychosocial well-being. As mothers strive for social interactions, the double inpatient rooms are used as their primary social gathering spaces, forcing them to partially give up on their visual privacy needs. Their use of the doorway and the staff corridor compensate for the need for more social gathering spaces.

Windows as a restorative resource promotes the contribution of spaces to the mothers’ psychosocial well-being. As mothers who are going through the "adjusting to the unknown" stage navigate through the stressful and traumatic crisis of their children's diagnosis, access to nature with its serenity and calmness was the overriding preference. On the other hand, access to lively and constantly changing street scenes was the overriding preference for the mothers going through the "accommodating to the status quo" stage. They used noisy and lively street scenes as distracting and withdrawal sources. In addition to windows, mothers found balconies to be another potential restorative resource within the single inpatient rooms. During the "adjusting to the unknown," mothers preferred having an accessible balcony at ASUCH. They revealed the incorporation of a new dimension that promotes a coherent experience with
maximum exposure to the external environment with no physical separation. For the mothers who are going through the "weaving through the ordinary life," access to social support was revealed as their restorative and positive distraction resource. In addition to windows, balconies, and social support, the use of the frosted glass paneled doors at CCHE and the use of the companion chair at the doorway to keep the inpatient's door open at ASUCH reveals mothers' strive to maintain a connection between life within the room and life outside the room. Finally, the availability of a hierarchy of social spaces, a new recreational center, and an accessible landscape at CCHE shows that different restorative resources can be provided within and beyond the confined hospital environment to promote mothers' psychosocial well-being.

6.2 Conclusive Remarks

Overall, as perceived by mothers' behavioral observations in the Egyptian pediatric oncology healthcare settings, the design of the different spatial layouts promotes differing intensities of contributions to the psychosocial wellbeing of mothers. During the “adjusting to the unknown” stage, mothers expressed their need for optimum privacy, exclusive control, seclusion, intimacy, reassurance, and exposure to serene views. The design of the inpatient single and medium care units was found to be contributing to significant privacy, control, intimate mother-child relationship, territorial, and restorative roles. However, they were found hindering ‘discrete personalization’ roles. While during the “accommodating to the status quo” stage, mothers expressed their need for balanced visual privacy, social integration, mother-child interaction modes, territoriality, and exposure to active views. The design of the double inpatient units was found contributing to privacy, control, access to social support, intimate mother-child relationship, and restorative roles. However, the design of ASUCH’s double inpatient unit was found to be obstructing the dedication of the parental zone and limiting the mother-child interaction modes. Lastly, during the “weaving through the ordinary”, mothers expressed their need for minimal visual privacy, defined territorial boundaries, and their use of social interactions as their restorative resource. The design of the outpatient daycare units was found contributing to access to social support, moderate mother child relationship, and restorative roles. However, they were found hindering privacy, control, and territoriality roles.

Beyond the dominating factors discussed, mothers' cultural values, behaviors, and traditions play an essential role in discussing the contribution of pediatric oncology healthcare spaces to mothers' psychosocial wellbeing. The Egyptian mothers' need for visual privacy, territoriality, social interactions, peer support, and exposure to serene or active views as a restorative resource reveals the layers of socio-cultural customs, habits, and inheritable traditions. Moreover, the behavioral observations conducted in both fields and the interview responses during the various hospitalization stages reflect the interplay between privacy and perceived control, territoriality and personalization, access to social support, access to restorative resources, and positive distractions. All of these shall work together to better serve the overarching theme of 'parents coping with induced stress' throughout their children's hospitalization journey and cater to the mothers' differing psychosocial needs.
Accordingly, this research provides the designers of the pediatric oncology healthcare settings with an in-depth understanding of the needs and wants of the small segmented Egyptian mothers. Using mothers' mundane experiences, reported needs, and their ‘minutus’ spatial adaptations, the designers can promote the psychosocial wellbeing of the mothers while designing the Egyptian pediatric oncology healthcare settings. Moreover, this research seems to be useful for the operators of the pediatric oncology healthcare settings. It reveals the differing psychosocial needs of the mothers during the encountered stages that should be accommodated both programmatically and spatially. Finally, fellow researchers can benefit from this qualitative research’s methodological approach, investigation forms, and concluded data for future studies.

6.3 Challenges

Since this study was based on the qualitative research approach (fieldwork observations, behavioral mappings, and interviews), the most prominent and expected challenge was accessibility to the subjects. Accessibility is typically limited to healthcare facilities' users due to privacy and medical restrictions; the studied healthcare facilities were predominantly selected based on their willingness to host the researcher for administering the study. At ASUCH, full access was granted by the authority. That included access to all the requested spaces, with unlimited visits allowed during different times of the day/night on weekdays. Conducting multiple visits with long durations disclosed mothers' mundane experiences and spatial utilization. During the first visits, some mothers were particularly sensitive about their daily routine, wants, and adopting measures for the lack of specific amenities. They were concerned about possibly being dismissed from their children's treatment program. However, after gaining their confidence, more detailed information was obtained.

Building trust with the mothers was another major challenge. As a female researcher, establishing an informal relationship with the mothers helped induce emotional connection and build rapport. The semi-structured interviews were turned into casual conversations while introducing some questions in between the talk instead of pursuing a formal interview narrative. This helped better understand the mothers' views and make them comfortable with the chat. On the other hand, at CCHE, limited access was granted for accessing the inpatient departments, with a hospital representative administering the whole process. In this regard, building rapport with the mothers in CCHE's inpatient units was challenging. I was allowed to conduct only two field visits with limited durations, following a formal one-to-one question-answer format.

Undoubtedly, language was another critical challenge. To the extent possible, I made the most accurate translation of the dialogues from Arabic to English. However, sometimes, the strength of the meaning of certain expressions was diluted in the translation process; this was especially common with responses to the intriguing 'why' questions behind conducting certain behaviors. The most expressive insights emerged when mothers tried to express the quality of the developed mother-child bond, the role of access to social support, and how they perceived their preferred external view preferences as a restorative resource. Accordingly, sometimes I put the Arabic expressions between two square brackets right after the translated sentence to keep the
expression's original depth intact. Finally, using a descriptive phenomenological approach was a bit challenging; extensive fieldwork and detailed gathering process was required to provide a solid understanding of the mothers’ lived experiences during their children’s hospitalization process.

6.4 Recommendations

The recommendations offered in this section are based on extensive literature review and findings of this research. It predominantly aims to support the psychosocial wellbeing of mothers and improve the contribution of pediatric oncology healthcare spaces to fulfilling mothers’ psychosocial needs in the Egyptian context.

- **Visual Privacy & defined territories** are an essential need for the Egyptian mothers; accordingly, promoting a sense of enclosure through flexible physical boundaries such as curtains could be useful in all shared layouts during the different stages of hospitalization.

- **Inboard toilets** play a crucial role in the provision of visual privacy and access control in the inpatient rooms. Having an entry zone where people are identified first before visually exposing the mothers seemed to be essential in the inpatient departments.

- **Flexibility** and **Adaptability** should be integrated in the design of the different spatial layouts, allowing mothers more freedom while personalizing the space to better suit their differing needs.

- Creating social gathering zones/opportunities for mothers inside the unit through creating alcoves in the corridors where mothers can meet and socialize can help the development of the informal support community.

- Similarly, the provision of meeting facilities/venues for other family members during the inpatient hospitalization period seems to be essential.

- **Central Nurse Stations** seemed to be essential only during the critical hospitalization stages.

- Whenever possible, access to serene views during the most stressful and frightful hospitalization stages is preferred for mothers, while access to lively street scenes with some change and motion should lead over a still, frozen view during other hospitalization stages.

- **Home-like and culturally sensitive features** should be introduced to the pediatric oncology healthcare settings to decrease the stress resulting from the unfamiliarity with space.
6.4 Limitations and Future Studies

Finally, the topic of the contribution of the pediatric oncology healthcare spaces to the psychosocial wellbeing of mothers is limited in time and space. The analysis of the spaces is limited to the certain room types and layouts presented in this research. It didn’t include the intensive care units and outpatient clinics; thus, it is important to note that the results may vary across other prototypes. The research is only limited to the public pediatric oncology healthcare settings. The facilities studied and the mothers interviewed were all within this small segment of public pediatric oncology hospitals. These findings may not apply to private pediatric oncology healthcare environments. Moreover, the results are not fully representative of the rest of the healthcare industry. Accordingly, it would be interesting for future studies to examine the contribution of spaces of a private pediatric oncology healthcare setting. Furthermore, the results and analysis are limited to the stages of hospitalization disclosed from the experiences of mothers with an ordinary combination of middle to low-income sub-cultural groups. Thus, the concluded differing psychosocial needs and wants may differ from those of other sub-cultural groups. It would be interesting for future studies to explore different socio-economic backgrounds and different cultures.
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Appendix A: Sample Field Notes
Appendix B: IRB Approval

To: Yara Adly
CC: Ahmed Sherif
     Samar Ashour
From: Heba Kotb Chair of the IRB
Date: 7th December, 2021
Re: IRB approval

This is to inform you that I reviewed your revised research proposal entitled

“Parents’ Psychosocial Wellbeing: The contribution of spaces of
psychosocial support within Egyptian Pediatrics Healthcare Settings”

It required consultation with the IRB under the “expedited” category. As you are aware, there were minor revisions to the original proposal, but your new version addresses these concerns successfully. Your proposal used appropriate procedures to minimize risks to human subjects and that adequate provision was made for confidentiality and data anonymity of participants in any published record. I believe you will also make adequate provision for obtaining informed consent of the participants.

This approval letter was issued under the assumption that you have not started data collection for your research project. Any data collected before receiving this letter could not be used since this is a violation of the IRB policy.

Please note that IRB approval does not automatically ensure approval by CAPMAS, an Egyptian government agency responsible for approving some types of off-campus research. CAPMAS issues are handled at AUC by the office of the University Counsellor, Dr. Ashraf Hatem. The IRB is not in a position to offer any opinion on CAPMAS issues, and takes no responsibility for obtaining CAPMAS approval.

This approval is valid for only one year. In case you have not finished data collection within a year, you need to apply for an extension.

Thank you and good luck.

Heba Kotb
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Institutional Review Board
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Appendix C: Consent Form

الجامعة الأمريكية بالقاهرة

استمارة موافقة مسبقة للمشاركة في دراسة بحثية

عنوان البحث: ال nhịطارات النفسية للأمراض

ساهمة التصميم المعماري في الصحة النفسية والاجتماعية للأمراض داخل مستشفيات أورام الأطفال

الباحث الرئيسي: يارا أشرف علوي، مهندسة معمارية وباحثة في الجامعة الأمريكية بالقاهرة

البريد الإلكتروني: adly@aucegypt.edu

الهاتف: 01226732127

انت مدعو للمشاركة في دراسة بحثية عن الحصول على فهم شامل لمساهمة ال nhịطارات المعمارية في الدعم النفسي والاجتماعي للأطفال بالكثرة.

هدف الدراسة هو تحسين الصحة النفسية والاجتماعية للأطفال خلال مرحلة الاستجابة لأطفالهم من خلال التحقق في تقارب أمور التحديات النفسية والاجتماعية، وفهم سلوك ال نيبات النفسي الاجتماعي في صحة الأطفال بشكل عام.

نتيجة البحث ستستغرق مدة متخصصة ومؤثر على

المدة الموقعة للمشاركة في هذه البحث هي فترة بسيطة لعدة 1 شهر

إجراءات الدراسة تم التحقق في حالة النفسية والاجتماعية للرجال وعلاقتيهم بالإمبراطورية الموجودة في مستشفيات أورام الأطفال المصرية. باستخدام تقنيات العمل الميداني الاستطلاعي، تتضمن مرحلة جمع البيانات مراقبة المشاركة من من قرب بطريقة بحثية مع استجاباتها التي يمكن أن تعزز في فهم الرابط القربي بين الأطفال والرضيع بالإضافة إلى علاقة الرعاية بين الوالدين والمراضات والعلاقات الوالدين ببعضهم البعض. على ذلك، فإن استخدام البيانات سوف يوفر فيما عمقلي للمؤسسات التي تم جمعها في مرحلة المراقبة.

المخاطر الموقعة من المشاركة في هذه الدراسة لا يوجد

الاستجابة الموقعة للمشاركة في البحث: سوف يوفر هذا البحث لمصممي مستشفيات أورام الأطفال فيما عمقلي

لاستجابة الأمراض حتى يتمكنوا من تصميم مساحات تعزز الصحة النفسية والاجتماعية للأمراض خلال مرحلة

الاستجابة للأطفال في المستشفيات السرية والإحترام الخصوصية: المعلومات التي ستستغرق بها في هذا البحث سوف تكون سرية

أي استقالة متعلقة بهذه الدراسة أو حقوق المشاركة فيها عند حدوث أي اصابات ناجحة عن هذه المشاركة يجب أن توجه إلى: يارا أشرف علوي، 01226732127

إن المشاركة في هذه الدراسة ما هي إلا عمل تطوعي حيث أن الإنتاج عن المشاركة لا يتضمن أي عقوبات أو

فقدان أي مزايا تجاه تلك ولمكن أيضًا الوقف عن المشاركة في أي وقت من دون عقوبة أو فقدان لهذه المزايا.

اسم männها: ________________________________

التاريخ: ________________________________
Appendix D: Interview Questions

1. How do you navigate your child’s illness during the hospitalization period?
   ○ How long have you been visiting the hospital?
   ○ What is the type of your child's cancer?
     ■ What are the different stages of hospitalization that you went/go through?
     ■ What is the expected duration for your child’s hospitalization period?

2. How do you balance between caring for your hospitalized child and meeting demands of life and family outside the hospital?
   ○ Are there any provided spaces where you can meet other family members?
   ○ Does your husband provide help in taking care of your hospitalized child?

3. What is your typical day at the hospital?
   ○ What are the types of spaces used throughout your day?
     ■ How do you perceive the spaces used throughout your day?
       ● Ex: spacious, bright, noisy, open, comfortable, crowded, etc
       ● Why?
     ■ What are the activities conducted in each space throughout your visit?
       ● How do you spend your time throughout your visit?

4. How do you maintain your privacy within the space?
   ○ Are there specific seatings/zones where you can feel that your privacy is maintained?
   ○ What are the possible ways by which you can maintain your privacy?
   ○ When do you feel maintaining your privacy is needed the most?

5. Do you have any sense of control over the accessible environments?
   ○ Do you believe that you should have control over such environments? Why?

6. Do you have any personal space inside the space?
   ○ Are you satisfied with the provided territory/space?
   ○ What changes do you usually make in your personal space?
     ■ Ex: move the chair near the window? in front of the TV? Away or near peers?
   ○ Do you have adequate space for storing your personal belongings?
     ■ Where do you usually store your personal belongings?

7. How does the spatial layout affect the quality of relationship/bond/interactions with your child?

8. Are there any spaces where you can socialize and have parents’ informal support meetings?
   ○ Do you prefer having peer support? Why or why not?
In your opinion, what are the types of spaces that promote social interactions?

9. Do you have access to windows inside the units? Waiting Areas?
   ○ What is it overlooking?
     ■ Do you prefer it to overlook a main street, a side street, hospital’s access nodes, or garden? Why?
   ○ Would you prefer having an accessible balcony or would a window be sufficient?
   ○ Would you prefer sitting in a zone with a window/view or not?
   ○ Which areas where you feel access to windows/balconies is needed the most?
     ■ Would a ‘preferred’ view differ in each space/stage?

10. Do you have a ‘go to’ place inside the hospital whenever you need time for yourself?
   ○ If yes, where? Why do you choose this specific space? How do you feel while using it?
   ○ If not, what type of spaces/spatial qualities are needed?

11. Do you prefer a specific zone/seat within the space? Why?
   ○ Additional Questions for ward layouts:
     ■ Do you prefer sitting next to/facing the nurse station, window, etc? Why?
     ■ Do you prefer sitting next to another parent or next to another child? Why?
     ■ Do you sit and observe people? When and Why?
       ● Would ‘observing other people’ be a category based on which you would choose your seat?
     ■ Does the different timing of the day affect your seating preference?
       ● How and Why?

12. If you were to choose, would you prefer sitting in a private setting with no social interaction or would you prefer sitting in a shared setting with minimal privacy?

13. If you were to choose, would you prefer being seated right next to the toilet’s wall to maintain your privacy or would you prefer being seated near the window to have access to an external view?

14. If you were to choose, would you prefer adding curtains for the individual’s personal space that would define your territoriality and provide you with some visual privacy or would you prefer having a minimal personal space within a crowded setting yet maintain their visual access to your surroundings?
Appendix E: Sample Codebook