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UNDERSTANDING THE ROLE OF HOSPITAL DESIGN ON THE PSYCHOLOGICAL TRAUMA OF HOSPITALIZATION FOR CHILDREN

REPORT FROM THE PILOT STUDY

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ABSTRACT

The Ann & Robert H. Lurie Children's Hospital of Chicago (formerly, Children's Memorial Hospital) has gone through many transformations since its founding in a small North Side cottage 130 years ago. Lurie Children's recently executed one of the most significant transformations in its history. It moved into a replacement facility, leaving its historic home in the Lincoln Park neighborhood of Chicago and moving near its academic partner, Northwestern Memorial Hospital, in the Streeterville neighborhood. The move to the new hospital offers an excellent opportunity to study the effect of hospital design on patient and family experiences during hospitalization.

This study lays a foundation for understanding the link between hospital design and child and family stress with more precision. It pilots measures of parental and child anxiety and stress during and after hospitalization, with the goal of developing a sound method for exploring the role of hospital design features in mitigating them. Once the methods are refined, they will be used in tandem to evaluate the design of the new Lurie Children's Hospital.

The initial findings reveal that the chosen psychometric measures identified children with elevated anxiety during and after hospitalization and parent stress during and after hospitalization. Consistent with many of the hypotheses going into the study, descriptive data (such as whether the child had experienced previous hospitalizations or been admitted through the emergency department) measured covariates of anxiety, stress, and other sequelae (such as separation anxiety, general anxiety, and nightmares). Through the interview and the photo questionnaire, children's and parents' emotional responses to specific design features were measured and correlated with the child's social and mental capacity and anxiety levels. Parent stress was strongly associated with parents' reported satisfaction both with staff performance and with the accommodations available to families.



Table of Contents

Acknowledgements	i
Abstract	ii
Introduction	1
Review of Literature	3
Research Methodology	6
Findings	10
The Study Participants and Their Hospitalization Experiences	10
Measuring Anxiety, Stress, and Sequelae	15
Conclusions	29
References	31
Appendices	34
Appendix A: Summary and Photos of Hospital Facilities	34
Appendix B: Hospitalization Experience Study Survey Map	38
Appendix C: Hospitalization Experience Survey (Parent Pretest)	39
Appendix D: Hospitalization Experience Survey (Adolescent)	45
Appendix E: Photo Activity (Child)	52
Appendix F: Photo Activity (Adolescent)	55

INTRODUCTION

The Ann & Robert H. Lurie Children's Hospital of Chicago (formerly Children's Memorial Hospital (CMH)) has gone through many transformations since its founding in a small North Side cottage 130 years ago. Today, Lurie Children's is the leading specialty pediatric hospital in the region and consistently ranks as one of the top pediatric hospitals in the nation. Lurie Children's has also been a steadfast leader in assuring that the hospitalization experience for children is child-centered. Some of the earliest research on hospitalization and traumatic psychological sequelae was conducted at Lurie Children's in the 1960s (Sipowicz & Vernon, 1965; Vernon, Schulman, & Foley, 1966).

Lurie Children's recently completed one of the most significant transformations in its history—a comprehensive move to an entirely new replacement facility—leaving its historic home in the Lincoln Park neighborhood of Chicago and moving near its academic partner, Northwestern Memorial Hospital, in the city's Streeterville community. The new hospital offers an exciting opportunity to expand on efforts to make the hospitalization experience even more child-centered and family friendly. The design of the new hospital takes advantage of Lurie Children's long history in Chicago and noteworthy commitment to the community. The design team partnered with a wide range of cultural institutions and philanthropists in Chicago to design spaces and units oriented around the world of children and youth. For example, as a result of Lurie Children's partnership with the Shedd Aquarium, two major design features of the new Emergency Department are a 5,000-gallon aquarium in the waiting area and two life-sized whale models placed at the entrance that now greet every visitor to Lurie Children's.

The move to the new hospital also offers an excellent opportunity to study the effect of hospital design on patient and family experiences during hospitalization. The hospital's former building was erected in the 1950s, but by 2012 it offered limited space and structural capacity to meet advancing healthcare needs and create a more modern and truly child-centered experience for patients and families. Today, while the new hospital is able to offer the same high-level care and services for children and

families as the old one, the design of the new hospital is significantly geared to better meet the human needs of families.

To better understand the impact of hospital design on patient outcomes, researchers at the hospital are conducting a number of focused studies. This report details findings from a pretest study conducted in the previous hospital facility. The study team first developed and piloted the means to accurately measure the impact of design features on child and parent stress and anxiety. These tools were then used to gather pretest data in the previous facility. A post-test will be conducted at the new hospital to assess changes in the child and parent hospitalization experience as a result of the move and the new child-centered design features. The study used two assessment methods—an Inpatient and Follow-Up Survey completed by parents and a Health Design Photo Questionnaire completed by children during their stay in the former hospital.

REVIEW OF LITERATURE

Since the mid-1960s, the research literature has recognized that hospitalization can be psychologically traumatic for children. After being hospitalized, children may show signs of posttraumatic stress disorder, heightened aggression, sleep disruption, general anxiety, and separation anxiety (Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002; Sipowicz & Vernon, 1965; Vernon, Schulman, & Foley, 1966)—all manifestations of traumatic psychological sequelae stemming from the hospitalization. Efforts to prevent emotional trauma promise to aid in the healing process and help children avoid psychological sequelae stemming from the hospitalization experience itself (Koller, 2008).

Children's hospitals have attempted to reduce the traumatic experience of hospitalization by (a) providing support services to the child and the family before and during hospitalization, (b) expanding opportunities for therapeutic play and similar activities during hospitalization, and (c) increasing the capacity for parents to sleep in the patient room and be present during medical procedures. The Child Life movement, which supports the provision of normal childhood experiences and activities (such as play and schoolwork) into the hospitalization experience, has been at the core of much of this work since the 1970s.

Meanwhile, efforts to study the impact of hospital design on hospitalized children have been somewhat limited (see Table 1) (Ulrich et al., 2008). To date, most studies have only been conducted with adult patients, and only some of the findings from these studies may be applicable to pediatric patients (Sadler & Joseph, 2008). Findings from studies that have related design features to psychological sequelae have concluded the following:

- Sleep space for parents of pediatric patients can reduce parental and child stress (Smith & Hefley, 2007).
- Children's experiences of design elements vary by age, stress level, and gender (Adams, Theodore, Goldenberg, McLaren, & McKeever, 2009).

- Children who experience repeated hospitalizations are able to find ways to use the hospital environment to improve their ability to cope (Boyd & Hunsberger, 1998).
- Children and parents who use a common garden area in a hospital setting find the experience to be restorative and healing (Whitehouse & Varni, 2001).
- Children and families can experience positive emotional meaning from art within healthcare settings (Belver & Ullan, 2010).
- When pediatric inpatient environments are family-friendly (e.g., where families can be private together and have adequate furniture in the room to rest and relax), as well as child-friendly (Varni et al., 2004), parent satisfaction increases (and presumably stress decreases).
- Children experience a profound loss of control when they are hospitalized, which can significantly increase their post hospitalization psychological response (Rennick et al., 2002). Design innovations may help overcome some of this sense of powerlessness by making mobility easier for children or by giving children play spaces in the hospital where they can exercise control.

Table 1 Current Evidence of the Impact of Health Design on Adult and Pediatric Patient Experiences						
Design element	Mechanism studied					
	Improved sleep	Privacy	Stress	Social support	Depression	Reduced pain
PATIENT ROOM						
Private room	AP	A	A	A		
Appropriate lighting	AP		A		A	A
Access to daylight	A		A		A	A
Family zone in room		A	A	A	A	
Views of nature			A		A	A
Noise reduction	AP	A	A			A

Note: A=research conducted with adult patients; P=research conducted with pediatric patients. From “A Review of the Literature on Evidence-Based Healthcare Design,” R. Ulrich, C. Zimring, X. Xhu, J. DeBoase, H. Seo, Y. Choi, et al., 2008, *Health Environments Research & Design Journal*,1(3), p. 61-125.

While no studies have examined a direct link between the psychological sequelae of hospitalization and specific hospital design features, it is generally held that healthcare environments that are appropriate for children (a) allow children to function at the peak of their abilities in many domains (such as making adaptive technologies available to do schoolwork) and (b) provide opportunities for social and

emotional support for both children and parents (like private hospital rooms or easily accessible family meeting areas) (Olsen, Hutchings, & Ehrenkrantz, 2000; Sadler & Joseph, 2008).

This study lays a foundation for understanding the link between hospital design and child and family stress with more precision. It pilots measures of parental and child anxiety and stress during and after hospitalization, with the goal of developing a sound method for exploring the role of hospital design features in mitigating them.

Objectives of study: Develop valid and reliable psychometric and behavioral measures that:

1. Would assess the stress and anxiety for children during hospitalization;
2. Would predict the likelihood of post hospitalization psychological sequelae for children;
3. Indicate the extent to which parents are able to adequately support their child during their child's illness or injury; and
4. Correlate with the child's and family's capacity to avoid potential psychological sequelae of hospitalization.

RESEARCH METHODOLOGY

The goal of this study was to develop, critically assess, and refine two methods for studying the role of hospital design in mitigating the presence and extent of psychological sequelae after hospitalization. Now that the methods have been refined, they will be used in tandem to evaluate the design of the new Lurie Children's Hospital. The two methods are briefly described below and later explored in depth.

Method 1: Inpatient and Follow-Up Survey. An inpatient survey instrument was completed by parents (with hospitalized children age 3 or older) and hospitalized adolescents, ages 12 to 17. The survey was conducted in person during the 3rd to 5th day of hospitalization, and the same survey was completed by phone 6 weeks following discharge. The survey includes items to assess parent and child stress levels, capacity to cope, use of respite services in the hospital, exposure to hospital design features, and other relevant domains.

Method 2: Health Design Photo Questionnaire. Photo questionnaires focused on assessing children's experience of hospital design features were completed by hospitalized children, ages 5 to 17. Photo-taking by the children was typically conducted as a family activity, although research assistants offered to facilitate. Children were asked to describe their reactions to their hospital room, the Brown Family Life Center (a medical-free play zone for inpatient children and adolescents), and their bedtime experience.

Method 1: Inpatient and Follow-Up Survey of Parents and Hospitalized Children

Previous research indicates that the kind and level of stress and emotional turmoil experienced by children during hospitalization is different than that experienced after discharge (Rennick et al., 2002). Where the experience during admission is dominated by the uncertainty surrounding their medical condition, separation anxiety, and fears about the novelty of the hospitalization experience, upon discharge, children are adapting to a new normal, resituating themselves into their home and school environment, and reflecting on the experience of being hospitalized. Thus, the current study analyzes a survey for parents completed during

the child’s inpatient stay and again 6 weeks following the discharge. Conducting the survey at these two points assured that changes were measured over time and that the presence of psychological sequelae were identified.

The Inpatient and Follow-Up Survey queried parents about their families’ experiences in the hospital. Adolescents (12 years and older) who preferred not to participate in the photo part of the project were asked to complete a survey about their experiences in the hospital, in addition to the parent completing the Inpatient and Follow-Up Survey. Table 2 summarizes the elements that are part of the survey and indicates which elements are elements of the parent, adolescent, and follow-up surveys. Parents were asked to report for their child (regardless of their child’s age) as well as for themselves. The survey collected information about the family, hospital facility, and design feature exposure (use of private room, child-centered spaces in the hospital) and behaviors during hospitalization (sleep patterns, eating patterns, and behaviors that express fear and anxiety). Psychometric measures included survey-based scales that explore stress and anxiety (discussed in the section titled “Measuring Anxiety, Stress, and Sequelae”).

Table 2: Outline of Parent and Youth Surveys

Survey element	Domain	Parent survey	Youth survey
STUDY VARIABLES:			
Hospital design feature use	Hospital design feature use and elicitations	I	I
Columbia Impairment Scale	Child/youth social behaviors	IF	I
Emotional Functioning Scale	Depressive and anxious feelings	IF	I
Parental stress	Parent coping and efficacy	IF	----
Sleep disruption	Hours of sleep and sleep disruptions for child	IF	I
Restorative experience scores	Positive adjectives circled for each of six hospital features (Brown Family Life Center, Siragusa Lobby, hallways, art, chapel, cafeteria)	I	I
CONTROL VARIABLES:			
Family demographics	Age, race, gender, language spoken at home	I	----
Experience with prior hospitalizations	Repeat hospital exposure	I	----
Satisfaction with service quality	Communication with staff; staff availability, approachability; satisfaction with and confidence in services	I	I
Sense of privacy	Whether the room was private; perception of privacy in family conversations and conversations with staff	I	I
Hospitalization facts	Sedation/use of sleep aids, length of stay, mobility, etc.	I	----

I=Inpatient Survey; F=Follow-Up Survey

Surveys were conducted in person by a research assistant on the 3rd, 4th, or 5th day of admission (after the family had the opportunity to be exposed to the hospital and its features). The Follow-Up Survey was conducted approximately six weeks after discharge over the phone, although a portion of the sample experienced an admission subsequent to the one under study before and hence had their Follow-Up Survey delayed.

Method 2: Health Design Photo Questionnaires Completed by Hospitalized Children

A subset of families who agreed to participate in the Inpatient and Follow-Up Survey were also asked to participate in a photo questionnaire. Often referred to as photo journaling, photo voice, and photo elicitation, the use of photos has been widely used in studies that seek to explore participant responses to their physical environment (Hurworth, 2003; Stedman, Beckley, Wallace, & Ambard, 2004). The photo questionnaire was structured around three activities: describing the hospital room, describing the Brown Family Life Center, and describing their bedtime routines. Children were asked to take pictures of things in both settings that scared them, made them feel happy, etc. For the bedtime activity, children were invited to take pictures of aspects of their bedtime routine that were different from home.

Children were asked to complete the questionnaire if they were 5 years of age or older. In general, adolescents chose to complete the written survey rather than the photo project.

Research assistants briefed the families on the photo activities, showed them how to use the camera and complete the questionnaire, and offered to help conduct the activities. All participating families chose to work on the questionnaire independently. The research assistant returned the next day to check on the families' progress and typically collected the completed questionnaires two days after recruiting the family into the study.

Sample and response rates: Table 3 specifies the final sample sizes for all of the data collection efforts. During the pilot phase, we learned that adolescents had a high rate of refusing participation in the photo activities; these were offered a survey that they could complete on their own. This resulted in a combined youth participation rate of 53.6%, slightly higher than our original goal of 50%. In addition, because the new Lurie Children's Hospital only has private rooms, an effort was made to oversample

families who were assigned a semi-private room at CMH but did not need to share it. This allowed the project team to pilot the instruments in a private room setting.

Table 3 Sample Sizes (n = 100)				
Method	Parent Surveys	Adolescent Survey (ages 12-17)	Photo activity	Follow-up Survey
Inpatient and Follow-Up Survey	99	16	27	68
Family using a shared room	22	3	10	17
Family using nonshared room	41	5	11	24
Family used both a shared and a nonshared room during their stay	37	8	6	27
Participation rate	99.0%	26.3%	27.3%	68.7%



FINDINGS

The Study Participants and Their Hospitalization Experiences

The study participants represent a wide range of ages and racial/ethnic groups. Families with children under 3 years of age were not recruited into the study. About 40% of the families in the study had a child under age 10, and about 60% had a child age 10 or older (Table 4). The sample was fairly well-split between boys and girls, with both representing about half of the sample. Slightly more than half of the participants indicated that they were White, 16% reported being African American, and 19% reported being Hispanic. About 14% of respondents reported speaking a language besides English at home.

Table 4 Demographics of Study Participants (n = 100)

	Percent
Age	
3 to 6 years old	22.0
6 to 9 years old	17.0
10 to 13 years old	27.0
14 to 16 years old	17.0
17 years old and over	17.0
Gender	
Male	54.0
Female	46.0
Language spoken at home	
English	86.0
Spanish	9.0
Other	5.0
Race/ethnic group	
White	54.0
African American	16.0
Hispanic	19.0
Asian	3.0
Other/mixed	8.0

Prior hospitalization experience was expected to affect the anxiety created by hospitalization. Thus, an attempt was made to have about half of the sample reserved for children who had not been hospitalized since their first birthday. Given the complexity of the patients cared for at the hospital, this was a difficult goal to achieve—only 34% of the final sample had not experienced hospitalization before (Table 5). All but one child had a parent who stayed overnight in the hospital with him/her, and most children were able to play at least a little by the time the survey was conducted. Because the new hospital only has private rooms and because it is expected that the lack of private rooms in the old hospital building would substantially impact the experience of hospitalization, data were collected about the room type in the previous hospital. About 40% of participants only had a private room; 27% had both a private and a shared room; and 22% only had a shared room (Table 5).

Table 5 Elements of Hospitalization Experience (n = 100)

	Percent
Sharing a room	
Yes	22.0
No	41.0
Both, yes and no	37.0
Yes responses	
Previous hospitalizations after age 1?	66.0
First admission to CMH?	
Parent staying overnight?	99.0
Child is able to play at least a little?	75.0
Child is able to leave his/her room to play?	64.0

The capacity to get sleep in the hospital was expected to be related to stress and anxiety for both the child and the parent; ability to get sleep is considered an outcome, at least partly, of good design. Table 6 reports parents' experiences of sleep length and disturbances. Parents reported that at home they get on average 7.2 hours of sleep per night. In the hospital, they got on average 4.6 hours. In addition, they reported being awoken an average of 4.5 times each night. Parents reported that on average

Table 6 Family Experiences During Hospitalization (n = 100)

Means	Mean
Parent typical night sleep (hours)	7.2
Parent typical night in hospital (hours)	4.6
Number of times parent is woken up	4.5
Child typical night at home (hours)	7.9
Number of times child wakes up	1.8
Parent was awoken at night because	
	Percent
The nurse came in the room	81.4
The parent's bed was uncomfortable	70.1
There was too much noise	50.5
Child was restless	42.3
The parent was worried	36.1
The room was too hot or too cold	35.1
The parent was restless	30.9
The room was not dark enough	16.5

their child sleeps 7.9 hours per night at home and was awoken 1.8 times each night at the hospital. (Parents were not asked about the number of hours their children slept at the hospital because they would not be able to report on it accurately.)

Parents reported being awoken at night for a long list of reasons. The most frequently cited reason for waking at night was that the nurse came in (81.4%). Over 70% reported waking because their own bed was uncomfortable. About half reported that there was too much noise; 42.3% reported that they woke because the child was restless. Fewer parents noted that there was too much light (16.5%) or that the temperature was not right (35.1%), which are often cited as sources of awakening for adult patients.

Finally, several questions were asked to get a general sense of how the family was adapting to the hospitalization experience (not shown in a table). Just under two-thirds (63.6%) reported that the family was able to eat adequately during the hospitalization. About 60% of parents reported that that had adequate privacy to discuss their child's care and needs. And fewer than 40% (39.4%) reported that the family could have relaxed family time during the hospitalization.

Table 7 shows the spaces and features of the hospital that the parents and children reported using, along with their respective restorative experience scores (explained in detail in the section titled "Measuring Anxiety, Stress, and Sequelae"). Of the six spaces/features assessed, the most frequently used were: the hospital hallways, art hanging in the hospital (could be anywhere), the Siragusa Lobby, and the Brown Family Life Center (Figure 1). Regardless of the frequency of use, the Brown Family Life Center and the chapel achieved the highest restorative experience scores; the cafeteria and the hallways received the lowest restorative experience scores. Hospital art and the Siragusa Lobby achieved middle-level restorative experience scores. Like the Brown Family Life Center, the Siragusa Lobby has many activities for children to engage in.

Finally, the survey asked the participants to rate the hospital and its staff on a wide range of services and capacities that would affect parents' overall perception of whether their child received high-quality care. These items were taken from a survey that the hospital regularly administers after discharge for quality assurance purposes. These survey items are listed in Table 8.

In general, parents gave staff higher ratings than they did the physical accommodations.

The highest frequency given for staff items was in response to *staff interacted with my child in a kid-friendly way* (75.8%); the lowest frequency given for staff items was in relation to degree to *which the hospital staff addressed your emotional needs* (43.4%).

The two highest rated accommodation items had to do with *information provided about facilities for families in the hospital* (52.0% rated as very good) and *how well things worked in the room* (47.0% rated as very good).

The lowest rated items were the *temperature of the room* (16.0% rated as very good) and the *comfort of overnight facilities for parents* (14.0% rated as very good).

Table 7 Percent of Parents and Children Exposed to Different Hospital Features		
	% visiting	Mean restorative experience score
Hallways		
Parent	93.8	1.4
Child	71.6	1.4
Hospital art		
Parent	73.7	2.2
Child	51.5	2.0
Siragusa Lobby		
Parent	75.0	1.6
Child	35.0	2.3
Brown Family Life Center		
Parent	66.0	3.7
Child	58.0	4.6
Cafeteria		
Parent	80.0	1.0
Child	15.0	0.9
Chapel		
Parent	16.0	3.1
Child	6.0	3.3

FIGURE 1
Brown Family Life Center



Table 8: Parents' Very Good Ratings of Staff and Accommodations (n = 100)	
Staff quality	Percent
Staff interacted with my child in a kid-friendly way	75.8
Staff's approachability, friendliness with questions and concerns	73.7
Staff efforts to include you in decisions about your child's treatment	66.0
Safety and security at the hospital	64.6
Degree to which staff respected your knowledge of your own child	62.6
How well your child's pain was controlled	60.4
Staff concern to put your child at ease	59.6
Responses to concerns/complaints made during your stay	51.6
Staff concern for your child's and your family's privacy	50.0
Staff concern to make your child's stay as restful as possible	50.0
Degree to which the hospital staff addressed your emotional needs	43.4
Accommodations	Percent
Information about available facilities for family members	52.0
How well things worked in the room	47.0
Lighting of your child's room	31.0
Room cleanliness	27.6
Accommodations and comfort for visitors	27.3
Appearance of room	23.0
Temperature of your child's room	16.0
Comfort of overnight facilities for parents	14.0

MEASURING ANXIETY, STRESS, AND SEQUELAE

Objective 1: Develop valid and reliable psychometric and behavioral measures that would assess the stress and anxiety for children during hospitalization.

The stresses related to hospitalization are most likely to surface as anxiety, and perhaps, separation anxiety. This study included a measure reported by parents used to indicate the extent to which children experienced stress and anxiety during hospitalization—the Emotional Functioning Scale. The Emotional Functioning Scale is a brief tool that has been shown to be a useful initial screen for depression and anxiety (including separation anxiety); it is part of the Child Symptom Inventory (Gadow & Sprafkin, 2002), a widely used screening tool for eight different psychiatric conditions. The items included in the full emotional functioning scale were factor-analyzed to determine the extent to which the items worked together as a scale for the individuals in this study. As a result, two depression items were dropped because they did not work well for this sample (they did not load on any factor), while the rest of the items worked together well as a single measure of general anxious feelings. The remaining items in the Emotional Functioning Scale (now termed the Anxious Feelings Scale) had factor loadings over .5. Table 9 displays a sample item and the results from the reliability analysis. The scale had a Cronbach alpha of .873, well over the over .7 threshold generally considered acceptable.

Table 9 Description and Psychometric Properties of Scales

Name of scale	Sample item	Subject	Number of items	Low/high score	Reliability (Cronbach's alpha)
Anxious feelings	How often does your child feel restless or edgy?	Child	11	0/44	0.873
Columbia impairment, abbreviated	How much of a problem would you say your child has with getting into trouble?	Child	11	0/44	0.870

The Columbia Impairment Scale (CIS) (Bird et al., 1993) was also included in our survey to measure general social and mental functioning, which might be degraded as a result of chronic illness and multiple hospitalizations, and, thereby, might mediate the child's experience of anxiety and their perception of hospital facilities. Although the CIS includes

multiple domains focused on interpersonal relationships, academic functioning, leisure time functioning, and general psychopathology, it is often used to measure a single underlying domain of general mental and social functioning (Winters, Collett, & Myers, 2005). It is also able to reflect a variety of issues (such as history of trauma) that might be relevant to our sample and that might moderate a child’s perception of the hospital experience.

Two items from the CIS were dropped prior to fielding because of their limited applicability to children who are under school age or who are not in a regular classroom (as may be the case for children who experience multiple hospitalizations). All of the 11 CIS items had factor loadings over 0.5 for this sample, and only one factor had any continuity among the scale items (i.e., the four subscales did not surface in the factor analysis). Reliability testing resulted in a Cronbach’s alpha of 0.870, higher than the 0.7 threshold that is generally considered acceptable.

To gain a deeper understanding of how the participants’ anxiety level differed during their inpatient experience from their typical anxiety level, parents were asked to answer the Emotional Functioning Scale items twice—once considering their child’s state during hospitalization and a second time considering their child’s state *on a typical day*. The two scales were totaled. The *during hospitalization* score was subtracted from the *typical day* score to compute an anxiety difference score. This process was repeated for the follow-up interview. Parents were asked to report on their children after hospitalization, and that score was subtracted from the *typical day* score to determine the extent to which they continued to experience a heightened anxiety level after hospitalization.

To initially compare the *in hospital* to the *follow-up* anxiety difference scores, the scores were collapsed into three categories: Same or less anxiety than is typical, slightly more anxiety than is typical (a score difference of up to 7 points), and more anxious than typical (a score difference of 8 or more points, ranging to 27 points over the typical score). Table 10 reports the frequencies for the anxiety difference scores during hospitalization and at follow-up. These data suggest that the anxious feeling scale is able to reliably measure anxiety caused by the hospitalization and the sequelae of hospitalization.

Table 10 Anxiety Difference Score

Categories	In the hospital (n = 91)	At follow-up (n = 63)
Same or less anxious	27 (29.7%)	27 (42.9%)
Slightly more anxious	34 (37.4%)	29 (46.0%)
More anxious	30 (33.0%)	7 (6.9%)

Both of the anxiety difference scores correlated highly with the CIS, as expected, meaning that children with more social/mental impairment experienced a higher level of anxiety in the hospital and at follow-up, relative to their typical anxiety level (Table 11).

Table 11 Bivariate Correlations for Anxiety Difference Scores (Pearson Correlations)

Name of score	Columbia impairment	Parent stress
Anxiety difference score in the hospital (n = 91)	0.245*	-0.165
Anxiety difference score at home (n = 63)	0.524**	0.554**

* p < 0.05; ** p < 0.01

Finally, Table 12 shows the mean anxiety difference scores in the hospital by demographic elements and characteristics of the child’s hospitalization. Children experienced higher levels of anxiety (relative to their typical levels of anxiety) if they were younger, unable to eat adequately, required pain medication, and if the hospital staff was not perceived to be concerned about putting the child at ease.

Table 12 Anxiety Difference Scores in the Hospital by Characteristics of the Child and Hospitalization (n = 91)

	Mean anxiety difference score (in the hospital)		Mean anxiety difference score (in the hospital)
Gender		Able to play at least a little	
Male	5.4	Yes	6.1
Female	6.5	No	5.8
Age		Able to leave room	
Under age 6	9.0*	Yes	6.0
Age 6 or older	5.1	No	5.8
Race		Able to eat adequately	
White	5.2	Yes	3.1*
African American	7.1	No	7.0
Hispanic/other	6.4		
Child had previous hospitalization(s)		Family has adequate privacy to discuss child’s needs	
Yes	5.4	Yes	5.8
No	6.9	No	6.1
Admitted through the emergency department		Family can have relaxed family time	
Yes	6.9	Yes	4.3#
No	5.2	No	7.0
Child had surgery during admission		Staff concerned to put child at ease	
Yes	7.3	Yes	4.3*
No	4.8	No	7.9
Had pain medication		Had pain medication	
Yes	6.5*	Yes	6.5*
No	3.2	No	3.2
Had medication to help sleep		Had medication to help sleep	
Yes	7.3	Yes	7.3
No	5.7	No	5.7

p < .10 (marginal);* p < .05; ** p < .01

Objective 2: Develop valid and reliable psychometric and behavioral measures that would predict the likelihood of post hospitalization psychological sequelae for children.

To explore the relationship between the experience of heightened anxiety in the hospital and psychological sequelae after hospitalization, a simple cross-tabulation is presented in Table 13. The results are unclear. On one hand, children who had a higher anxiety level during hospitalization were the most likely to have a heightened anxiety level at follow-up, as we would expect. On the other hand, half of the children who did not have heightened anxiety during hospitalization did have heightened anxiety at follow-up. When anxiety difference at follow-up is regressed by several in-hospital variables (anxiety difference in the hospital, CIS, and parent stress level in the hospital; see Table 14), the regression coefficients suggests that there is a connection between heightened anxiety in the hospital and heightened anxiety at follow-up that may be mediated by other aspects of the child’s and the parents’ capacity (such as the number of children in the household or the social support received by the child at school).

Table 13 Comparison of Anxiety Difference Scores in the Hospital and at Home (n = 61)

Anxiety difference in the hospital	Anxiety difference at follow-up		
	Same or less anxious	Slightly more anxious	More anxious
Same or less anxious	50.0%	38.9%	11.1%
Slightly more anxious	50.0%	45.0%	5.0%
More anxious	30.4%	56.5%	13.0%

Table 14 Regression for Psychological Sequelae after Hospitalization

Dependent variable: Anxiety difference at follow-up	Standardized beta coefficient
Anxiety difference in the hospital	0.316*
Columbia Impairment Scale (typical day)	-0.218
Parent stress in the hospital	0.315*
R square	0.175**

* p < 0.05; ** p < 0.01

Beyond the mediating effects of child impairment and parent stress, during the follow-up interviews, research assistants observed a great deal of anecdotal evidence showing that families varied greatly in their adjustment back to normal life. For example, some families experienced additional hospitalizations that made the transition to home life more challenging or delayed. To explore this in more depth,

we cross-tabulated the anxiety difference scores at follow-up by two items from the survey that asked parents about the readjustment at home (Table 15). In both cases, a child’s anxiety difference score at follow-up was significantly higher if the parent reported that the family’s adjustment in returning back to normal (whatever normal means for the family) was not complete.

Table 15 Anxiety Difference at Follow-up by Family Adjustment Variables (Chi Square Analysis) (n = 61)

Adjustment to normal home life	Anxiety difference at follow-up		
	Same or less anxious	Slightly more anxious	More anxious
Do you feel that your family’s routine has returned to normal?*			
Yes	54.8%	35.7%	9.4%
Sometimes/no	19.0%	66.7%	14.3%
Do you feel that your family can have relaxed family time on most days?*			
Yes	50.0%	40.4%	9.6%
Sometimes/no	9.1%	72.7%	18.2%

* p < 0.05; ** p < 0.01

Thus, while there appears to be a relationship between the anxiety children experience in the hospital and the residual anxiety that they experience after hospitalization, this relationship also appears to be mediated by the level of normal functioning that the family is able to achieve after hospitalization. And, while the data are not able to take the issue of family functioning further, it is presumed that the level of normal functioning (again, whatever that means for the family) is strongly associated with subsequent health problems that the child might have as well as the family’s capacity to manage the family life during and after hospitalization.

Finally, Table 16 reports the means of the anxiety difference scores at follow-up by the child's demographics and characteristics of the hospitalization. In our study, children were more likely to experience psychological sequelae if they were non-White, did not have any previous hospitalizations, and if the child was admitted through the emergency department; the latter two factors being associations that were expected.

Table 16 Mean Anxiety Difference Scores at Follow-up by Characteristics of the Child and Hospitalization (n = 91)

	Mean anxiety difference score (at follow up)		Mean anxiety difference score (at follow up)
Gender		Able to play at least a little	
Male	1.6	Yes	1.9
Female	2.6	No	3.1
Age		Able to leave room	
Under age 6	2.2	Yes	2.8#
Age 6 or older	2.1	No	0.9
Race		Able to eat adequately	
White	0.9**	Yes	1.8
African American	1.9	No	2.4
Hispanic/other	5.1		
Child had previous hospitalization(s)		Family has adequate privacy to discuss child's needs	
Yes	1.5#	Yes	2.9
No	3.4	No	1.7
Admitted through the emergency department		Family can have relaxed family time	
Yes	3.7	Yes	1.8
No	1.4	No	2.3
Child had surgery during admission		Staff concerned to put child at ease	
Yes	2.4	Yes	2.3
No	2.3	No	1.8
Had pain medication		Child's pain was controlled	
Yes	2.4	Yes	
No	0.3	No	
Had medication to help child sleep			
Yes	3.1		
No	2.0		

p < 0.10 (marginal); * p < 0.05; ** p < 0.01

Objective 3: Develop valid and reliable psychometric measures that indicate the extent to which parents are able to adequately support their child during their child's illness or injury.

The Parent Stress Scale was developed from the MacKay Anxiety/Frustration Scale (MacKay, 1978). This scale was reduced considerably in length for our study and reshaped to be applicable to the inpatient environment. The factor analysis indicated that seven items reflecting worry and stress loaded on the same factor at 0.5 or higher. Reliability analysis for these seven items resulted in a Cronbach's alpha of 0.811 (Table 17).

Table 17 Description and Psychometric Properties of Scales

Name of scale	Sample item	Subject	number of items	low/high score	reliability (Cronbach's alpha)
Parent stress	Since your child was admitted to the hospital, how often have you felt fearful?	Parent	7	0/28	0.811

Parent stress during hospitalization was strongly associated with the child having anxious feelings in the hospital and with the parent's stress score at follow-up (Table 18); it was not associated with the child's anxiety difference score in the hospital or CIS score. To examine whether the level of parent stress was related to the experience in the hospital, the mean parent stress score was computed for a number of items from the survey that measured the parents' perception of staff and service quality (Table 19 on the next page). Parents who reported less stress also reported a higher satisfaction with staff and with the accommodations for the child and family in the hospital. Within these factors, perception of staff quality had a higher association with parent stress than did perception of the accommodations.

Table 18 Bivariate Correlations of Subset of Scales (Pearson Correlations)

Name of scale	Anxious feelings (in the hospital)	Anxiety difference	Columbia impairment (typical day)	Parent stress (at follow-up)
Parent stress (in hospital)	0.353**	-0.165	0.173	0.244*

* p < 0.05; ** p < 0.01

Table 19 Mean Parent Stress Scores by Parent Ratings of Staff and Accommodations (n = 100)

	Very good	Good, fair, poor, very poor	Sig.
Staff quality:			
Staff interacted with my child in a kid-friendly way	8.2	11.7	**
Staff's approachability, friendliness with questions and concerns	8.4	11.1	**
Staff efforts to include you in decisions about your child's treatment	8.3	10.5	*
Safety and security at the hospital	8.3	10.3	*
Degree to which staff respected your knowledge of your own child	7.8	11.1	**
How well your child's pain was controlled	8.2	10.3	*
Staff concern to put your child at ease	7.9	10.9	**
Responses to concerns/complaints made during your stay	7.6	10.2	**
Staff concern for your child's and your family's privacy	8.3	9.8	
Staff concern to make your child's stay as restful as possible	7.7	10.4	**
Degree to which the hospital staff addressed your emotional needs	7.8	10.0	*
Accommodations:			
Information about available facilities for family members	8.3	9.7	
How well things worked in the room	8.1	9.9	*
Lighting of your child's room	7.2	9.9	**
Room cleanliness	6.8	9.8	**
Accommodations and comfort for visitors	7.6	9.6	
Appearance of room	6.7	9.7	**
Temperature of your child's room	6.5	9.5	*
Comfort of overnight facilities for parents	7.9	9.3	

* p < 0.05; ** p < 0.01

FIGURE 2
Siragusa Lobby



Objective 4: Develop valid and reliable means of measuring specific hospital design features that correlate with the child’s and family’s capacity to avoid potential psychological sequelae of hospitalization.

Reactions to specific design features in the hospital were collected in two ways—parent interviews and photo questionnaires. The interview asked parents about which of the six specific features/spaces they and/or their child have visited. The spaces include: the Brown Family Life Center, the Siragusa Lobby (shown in Figure 2), the cafeteria, the chapel, the hallways, and hospital art. Parents were then asked to circle any of 20 adjectives (10 positive adjectives, 10 negative adjectives) that reflected their own and their child’s emotional responses to each feature/space. One point was given for each circled positive adjective, with a total possible score of 10 (Table 20). Very few respondents circled any of the negative adjectives, making negative responses unscorable.

Table 20 Description and Psychometric Properties of Scales

Name of scale	Sample item	Subject	Number of items	Low/high score	Reliability (Cronbach’s alpha)
Restorative experience	Please circle words that describe how [the space/object] made you feel: Relaxed, relieved, calmed, etc.	Parent	10	0/10	0.645
Restorative experience	Please circle words that describe how [the space/object] made your child feel: Relaxed, relieved, calmed, etc.	Child	10	0/10	0.764

Table 21 Bivariate Correlations between Disposition Scales and Restorative Experience Scale

Name of scale	Anxious feelings (in the hospital)	Anxiety difference (in the hospital)	Columbia impairment	Parent stress#
Brown Family Life Center	0.191	-0.132	0.277*	0.019
Hallway	-0.006	-0.018	-0.072	-0.114
Lobby	0.168	-0.094	0.079	-0.185
Viewing art	0.118	-0.040	0.354*	-0.058
Cafeteria	Insufficient data			0.057

* $p < 0.05$; ** $p < 0.01$

Correlations are with the parents' report of their own experience in the space or observing the object.

Restorative experience scores were generally not associated with child anxiety, child anxiety difference score, or parent stress (Table 21). However, there was a correlation between the CIS and the child's restorative experience scores for the Brown Family Life Center and the art in the hospital. This association suggests that the more mental/social impairment a child is reported to have, the more the Brown Family Life Center and hospital art provide a restorative experience for a child.

Finally, mean restorative experience scores for each child were computed using the child's demographics and characteristics of the child's hospitalization (Tables 22 and 23). In general, boys were more likely to find features/spaces to be more restorative than girls; children who were able to play at least a little by the time of the interview had more restorative experiences reported by their parents than those who could not yet play; and children experienced more restorative experiences if their parents reported that the staff was concerned about putting their child at ease, and if the parent reported that the child's pain was adequately controlled.

Table 22 Mean Restorative Scores by Characteristics of the Child (n = 91)

	Brown Family Life Center (n = 58)	Art (n = 52)	Hallways (n = 100)	Lobby (n = 35)
Gender				
Male	4.7	3.0*	1.3	3.1*
Female	4.6	1.7	0.8	1.6
Age				
Under age 6	5.7*	2.7	1.5	2.8
Age 6 or older	4.1	2.2	1.0	2.1
Race				
White	4.9	2.3	1.0	2.6
African American	3.9	1.4	0.9	1.4
Hispanic/other	5.6	2.8	1.3	2.0

$p < 0.10$ (marginal); * $p < 0.05$; ** $p < 0.01$

Table 23 Mean Restorative Scores by Characteristics of the Hospitalization (n = 91)

	Brown Family Life Center (n = 58)	Art (n = 52)	Hallways (n = 100)	Lobby (n = 35)
Child had previous hospitalizations				
Yes	4.9	2.3	0.9	2.2
No	4.1	2.3	1.4	2.9
Admitted through the emergency department				
Yes	4.4	2.9	1.2	2.2
No	4.8	2.0	1.0	2.4
Child had surgery during admission				
Yes	4.7	2.3	1.2	3.1
No	4.6	2.4	1.0	1.8
Had pain medication				
Yes	4.7	2.4	1.1	2.5
No	3.9	1.9	0.9	1.6
Had medication to help child sleep				
Yes	4.9	2.8	1.5	3.0
No	4.6	2.2	1.0	2.2
Able to play at least a little				
Yes	4.9*	2.6*	1.3#	2.4
No	2.4	1.0	0.5	2.0
Able to leave room				
Yes	4.5	2.3	1.4*	2.2
No	5.1	2.4	0.6	2.7
Able to eat adequately				
Yes	4.6	2.9	1.6	2.7
No	4.8	2.0	0.9	2.2
Family has adequate privacy to discuss child's needs				
Yes	5.1	2.3	1.2	2.5
No	4.0	2.3	1.0	2.3
Family can have relaxed family time				
Yes	5.1	2.8	1.8**	2.8
No	4.3	1.9	0.6	2.1
Staff concerned to put child at ease				
Yes	5.1#	2.6#	1.6**	2.4
No	3.8	1.6	0.4	2.2
Child's pain was controlled				
Yes	5.3*	2.5	1.3#	2.6
No	3.6	1.9	0.6	2.0

p < 0.10 (marginal);* p < 0.05; ** p < 0.01

The second way that we assessed how children responded to specific hospital features was through the photo questionnaire. Children ages 5 and older were offered the opportunity to participate in the study by photographing features of their room (a typical patient room is shown in Figure 3) and the Brown Family Life Center that elicited different emotions, their favorite things and their least favorite things.

FIGURE 3
Patient Room



In the Brown Family Life Center, art was the most photographed favorite thing followed by activities and the *space* (these were photos of a section of the whole room or the signs at the entryway).

Children were most likely to photograph medical equipment and medical equipment attached to their bodies (like IVs) as their least favorite things in their room. Next, children photographed the space (photos of large sections of the room, corners with family coats and supplies piled up, or other broad features that reflected the general space, as opposed to specific features). In the Brown Family Life Center, children were quite unlikely to report that using medical equipment was a least favorite thing (even though many children bring their IVs to the center). A minority of children reported not liking the space or the activities that could be done in the space.

Both of the items photographed in the patients' rooms and the Brown Family Life Center that were considered *favorite* and *least favorite* were consistent with expectations about how children perceive the hospital environment, and they suggest that the photo questionnaire approach provides specific direction when exploring design elements more specifically for the full study.

Figures 4 and 5 provide a very brief overview of the findings from the photo questionnaire. Children photographed a wide range of objects in their rooms that they identified as their favorite things. The most frequently photographed things were activities (like playing cards with a family member, doing art projects, or playing a video game). The second most frequently photographed favorite thing was the TV, followed by objects brought from home (blankets, stuffed animals).

FIGURE 4
Children's Photos of
Least Favorite Things

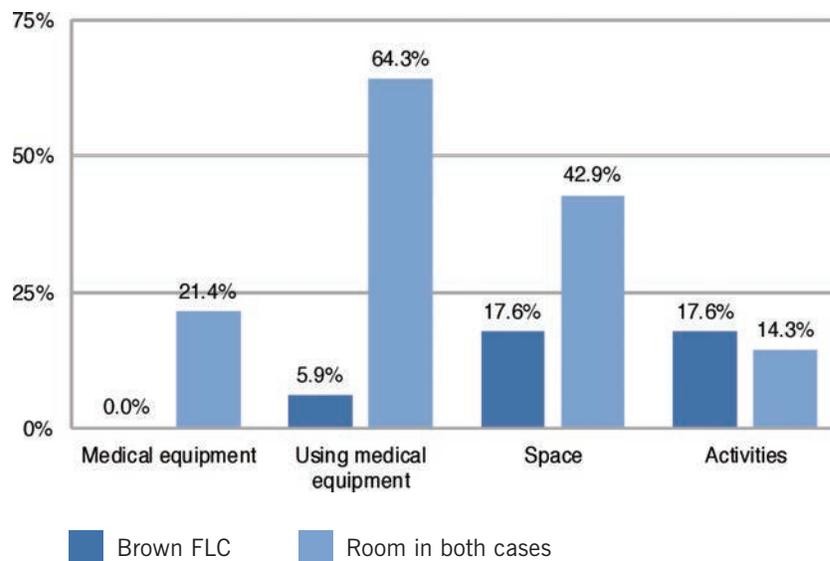
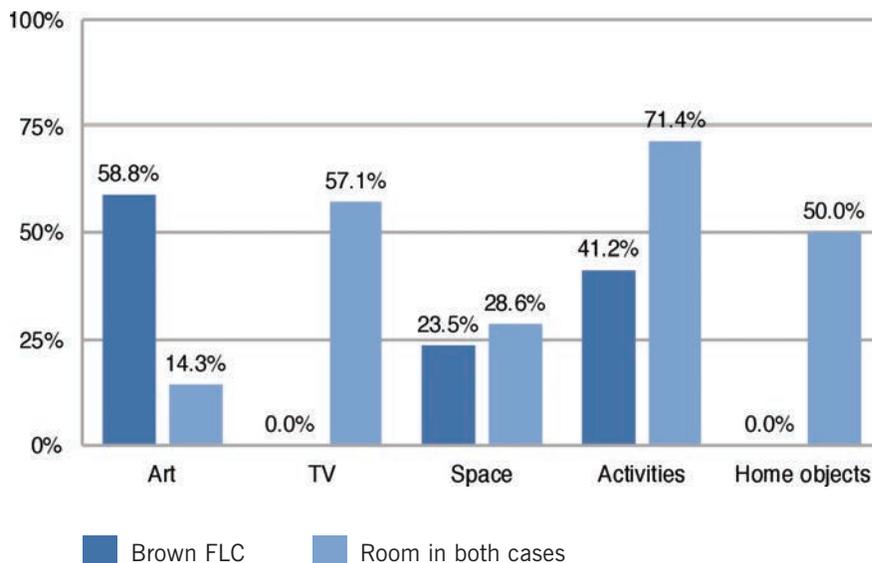


FIGURE 5
Children's Photos of
Favorite Things



CONCLUSIONS

The goal of this study was to develop the capacity to measure children's and parents' experiences of hospitalization, their emotional responses to hospital design features, and the relationship between their experiences and response to stress and anxiety during and following hospitalization. In general, the approach taken by this pilot study was successful.

- The chosen psychometric measures identified children with elevated anxiety during and after hospitalization and parent stress during and after hospitalization.
- Consistent with many of the hypotheses going into the study, descriptive data (such as whether the child had experienced previous hospitalizations or been admitted through the emergency department) measured covariates of anxiety, stress, and sequelae.
- Through the survey interview and the photo questionnaire, children's and parents' emotional responses to specific design features were measured and correlated, to some extent, with the child's social and mental capacity (as measured by the CIS).
- Parent stress was strongly associated with parents' reported satisfaction both with staff performance and with the accommodations available to families.

This pilot study sets a strong foundation for the second and final part of the study that will take place in the new hospital. This study tested and refined the study methods, and revealed critical gaps in the analysis of the pilot data. Several additions to the methods used in this pilot study will offer surer conclusions from the full study.

First, the factors used to determine the extent of psychological sequelae are quite varied (especially for children with medical complexity, which the sample was dominated by), and the pilot study did not fully capture them. The pilot study measured the presence of sequelae, its association with parent stress and general mental and social

impairment, and its association with very minimal measures of family functioning after hospitalization. The fact that race was found to be one of the most important factors driving psychological sequelae indicates that the full study would benefit from a broader assessment of socioeconomic status, social resources at home, family functioning, and parents' capacity to manage their child's complex medical condition.

Secondly, the fact that many children who did not show heightened anxiety during the hospitalization did demonstrate some level of sequelae afterward suggests the importance of considering that expressed anxiety may take on different forms under the pressure of hospitalization and after, once the child is at home and presumably the crisis has ended. It is not clear whether this issue raises a challenge to the choice of measurement or to the timing of the measurement (that is, clarifying expectations about when and how anxiety surfaces throughout the course of hospitalization and convalescence for children).

Thirdly, the previous hospital building did not include respite spaces for parents and other family members, while the current hospital includes a number of these. The new hospital was designed with family great rooms on several floors (where families can cook meals together, play board games, or watch a movie together), an indoor garden, spa services, a more easily accessed chapel, and other amenities that parents may use independently of their children. These features were designed with the hope that they will help parents restore their energy and reduce their stress. Reducing parents' stress, as hypothesized by the designers of the new hospital, may expand the capacity for parents to be effective co-caregivers during their child's hospitalization. The published research literature includes very little information about parents' capacity to cope with their child's hospitalization or their use of respite services and spaces. Thus, the full study would benefit from expanding the range of data collected from parents to include information about what they do for their own respite and their use of the hospital's spaces and amenities for this purpose.

Adding these elements to the full study will assure that the findings make a substantial contribution to the current understanding of the hospitalization experience for children and their parents, the stresses and anxieties stirred up by hospitalization, and the role of hospital design in alleviating them. It will further add to the relevant literature aimed at exploring how hospitals can support better health outcomes for children and families through thoughtful design choices.

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APPENDIX A: SUMMARY AND PHOTOS OF HOSPITAL FACILITIES

Family-focused features	Children's Memorial Hospital (through June 9, 2012)	Ann & Robert H. Lurie Children's Hospital of Chicago (opened June 9, 2012)
Inpatient units		
Patient rooms	270 beds in semiprivate rooms	288 beds in private rooms
Parent sleep accommodations	Lounge chairs	Sleeper-sofa
Family great rooms	No	In most inpatient units
Family shower facilities	No	Yes
Interactive areas	No	Each elevator lobby on inpatient floors; throughout hallways
Play areas	No	Most units
Common areas:		
Family Life Center	Yes	Yes, more space and more amenities
Play/interactive areas	Lobby	Throughout public spaces
Garden	Exterior, can be viewed through lobby window	Interior, fully accessible
Cafeteria	Yes, basement	Yes, next to garden, city view
Chapel	Yes	Yes
Coffee shop	Yes	Yes
Gift shop	Yes	Yes
Family learning center	No	Yes
Family spa	No	Yes
Pharmacy	Yes	Yes, with a snack bar
Family sleep suites	No	Yes

Children's Memorial Hospital
(through June 9, 2012)



Typical patient room

Ann & Robert H. Lurie Children's Hospital of Chicago
(opened June 9, 2012)



Typical patient room



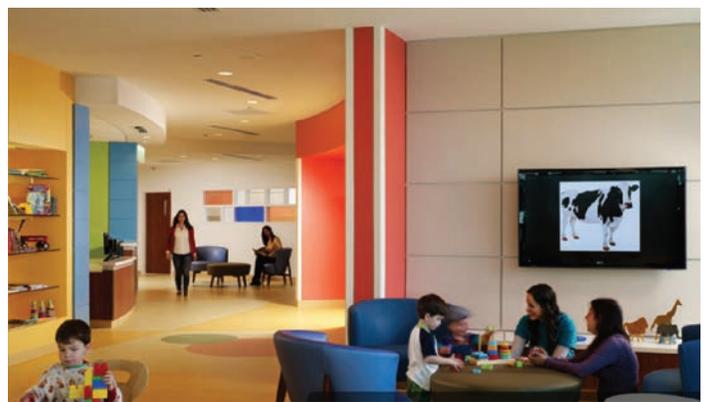
NICU pod



NICU room



Brown Family Life Center



Family Life Center

Children's Memorial Hospital
(through June 9, 2012)



Fish tank (entrance to Brown Family Life Center)



Interior entrance



Lobby

Ann & Robert H. Lurie Children's Hospital of Chicago
(opened June 9, 2012)



Fish tank (entrance to Emergency Department)



Interior entrance



Lobby/garden/cafe area

Children's Memorial Hospital
(through June 9, 2012)



Hallway

Ann & Robert H. Lurie Children's Hospital of Chicago
(opened June 9, 2012)



Hallway



Chapel



Chapel

APPENDIX B: HOSPITALIZATION EXPERIENCE STUDY SURVEY MAP

Domain	Parent survey in hospital		Parent survey after discharge		Teen survey (in hospital)	
	Section	Description	Section	Description	Section	Description
Demographics	Part 1	Child's age, race, language, gender, zip code, parents' marital status	-----	-----	Part 1	Gender, age, grade
Previous hospitalizations	Part 1	At CMH, all together	Part 1	Additional hospitalizations since discharge	-----	-----
Current hospitalization facts	Part 2	Sharing room, expected length of stay, surgery, medication, capacity to move out of room	Part 2	Discharge date, continuing medical care, return to school	-----	-----
Child's level of anxiety/depression	Part 3	Child Emotional Functioning Scale (asterisked items); in hospital vs. typical day	Part 3	Child Emotional Functioning Scale (asterisked items); on a typical day currently	Part 3	Child Emotional Functioning Scale (adolescent self-administered version); in hospital vs. typical day
Child's global functioning	Part 4	Columbia Impairment Scale	Part 4	Columbia Impairment Scale	-----	-----
Family sleeping and eating in the hospital	Part 5	Hours of sleep for child, parent; reasons for lack of sleep; sense of privacy; eating; relaxed family time	Part 5	Hours of sleep for child, parent; reasons for lack of sleep; sense of privacy; eating; relaxed family time	Part 2	Sleep, privacy, friends visiting, sharing a room, eating, school work
Parent stress	Part 6	MacKay Scale (modified); stress/anxiety/frustration	Part 6	MacKay scale (modified); stress/anxiety/frustration	-----	-----
Service quality	Part 7	Selected items from CMH inpatient patient satisfaction survey	Part 7	Selected items from CMH inpatient patient satisfaction survey	Part 4	Selected items (fewer than parent) from CMH inpatient patient satisfaction survey
Use and response to facilities	Part 8	Frequency of parent and child use of selected facilities; emotional responses	-----	-----	Part 5	Frequency of use of selected facilities; emotional responses
Overall atmosphere of hospital	Part 8	Rating of 1-10	-----	-----	Part 6	Rating of 1-10
Overall impressions of hospitalization	-----	-----	Part 8	Open ended: experience of hospitalization, facilities, ways we could make things easier	Part 6	Open ended: experience of hospitalization, facilities, ways we could make things easier

APPENDIX C: HOSPITALIZATION EXPERIENCE SURVEY (PARENT PRETEST)

Hospitalization Experience Survey

[This survey is to be conducted through an in-person interview during a child's 3rd or 4th day of hospitalization (when the hospitalization is expected to last 6 or more days total). The interview will be conducted in the patient's room at a time that is convenient to the parent.]

Interviewer: "You are being asked to complete this survey because you agreed to participate in a research study focusing on the experience of hospitalization for children and their parents. This study is being conducted so that we can better understand how children and families cope with hospitalization and what services and facilities we can offer to help them cope better. We ask that you answer these questions as honestly as you can."

Part I: About your child and family

Parent Name:	
Parent Gender:	<input type="radio"/> Male <input type="radio"/> Female
Parent's Age:	
Parents' Marital Status:	<input type="radio"/> Married <input type="radio"/> Living as Married <input type="radio"/> Widowed <input type="radio"/> Single/Never Married <input type="radio"/> Divorced/Separated
Child's Name:	
Child's Gender:	<input type="radio"/> Male <input type="radio"/> Female
Child's Date of Birth : (MM/DD/YYYY)	
Zip code of residence:	
Number of adults living in house:	
Number of children living in house:	
Language spoken at home:	<input type="radio"/> English <input type="radio"/> Spanish <input type="radio"/> Other
With which race or ethnic group does your child identify:	<input type="radio"/> White/Non-Hispanic <input type="radio"/> African American <input type="radio"/> Hispanic <input type="radio"/> Asian <input type="radio"/> Other: _____
Is this your child's first admission at Children's Memorial?	<input type="radio"/> Yes <input type="radio"/> No
Has your child had previous hospitalizations (do not include 1 st year of life)?	<input type="radio"/> Yes <input type="radio"/> No

Sharing a room? <input type="radio"/> Yes <input type="radio"/> No
--

Part II: Your child's current hospitalization

Admission Date:	
Expected length of stay:	
Reason for hospital stay:	
Any underlying, chronic or additional health problems:	
Child's Room Number:	
Was your child admitted through the Emergency Department?	<input type="radio"/> Yes <input type="radio"/> No
Has a parent or guardian stayed overnight?	<input type="radio"/> Yes <input type="radio"/> No
Is your child having surgery while admitted?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Do Not Know Yet
Has your child had medication to alleviate his or her pain or calm him or her while admitted?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Do Not Know Yet
If yes, for how many days?	
Has your child had sleeping medication while admitted?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Do Not Know Yet
Has your child been able to play even a little in his or her room since being admitted?	<input type="radio"/> Yes <input type="radio"/> No
Has your child been able to leave his or her room to go to playgroups, visit the Brown Family Life Center, or other such activities?	<input type="radio"/> Yes <input type="radio"/> No

Part III. How your child is doing

Interviewer: "Now I would like to ask you some questions about how your child is handling being in the hospital. I'll ask you to compare his/her behavior to a typical day when he/she is not in the hospital. Please select the correct answer from this answer card for each question."

In your opinion:	Never	Rarely	Sometimes	Often	Most of the Time
Does your child eat well?					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child play?					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often has your child had a low energy level or been tired for no apparent reason?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child show little interest in (or enjoyment of) pleasurable activities?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child act restless or edgy?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often is your child worried that you or your spouse will be hurt or leave home and not come back?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child have difficulties controlling worries?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child laugh or joke around?					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often is your child irritable most of the day?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
When your child is put in an uncomfortable social situation how often does he/she cry, freeze or withdraw from interacting?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child have nightmares?					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often is your child depressed or sad for most of the day?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often is your child worried that some disaster will separate him/her from his/her parents/caregivers?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often has your child been very upset when he/she expects to be separated from his/her home or parents/caregivers?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				

	Never	Rarely	Sometimes	Often	Most of the Time
How often is your child excessively shy with peers?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
Would you describe your child as talkative?					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often is your child extremely tense or unable to relax?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
How often does your child have little confidence or is very self-conscious?*					
In hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				

Part IV. How would you describe your child?

Interviewer: Please answer the following questions using a zero to four scale. Zero means that something is ‘No Problem’ and 4 means that the behavior is ‘A Very Big Problem.’”

	Zero	1	2	3	4
In general, how much of a problem do you think your child has with:					
Getting into trouble?	<input type="radio"/>				
Getting along with his/her mother or his/her female caregiver?	<input type="radio"/>				
Getting along with his/her father or his/her male caregiver?	<input type="radio"/>				
Feeling unhappy or sad?	<input type="radio"/>				
How much of a problem would you say he/she has:					
With his/her behavior at school?	<input type="radio"/>				
With having fun?	<input type="radio"/>				
With feeling nervous or worried?	<input type="radio"/>				
Getting along with his/her brother(s)/sisters(s)?	<input type="radio"/>				
Getting along with other kids his/her age?	<input type="radio"/>				
How much of a problem would you say he/she has:					
With his/her schoolwork (doing his/her job)?	<input type="radio"/>				
With his/her behavior at home?	<input type="radio"/>				

Part V. You and your family

Interviewer: “These questions ask about sleeping and eating in the hospital.”

How many hours of sleep do you typically get in a normal night at home?	_____ Hours
Have you slept overnight at the hospital?	<input type="radio"/> Yes <input type="radio"/> No
If yes, how many hours of sleep did you typically get the nights you stayed at the hospital?	_____ Hours
How many times did you typically wake up during the night at the hospital?	_____ Times
What were the reasons for you waking up throughout the night? (Check all that apply)	
<input type="radio"/> Child was restless	<input type="radio"/> I was restless
<input type="radio"/> Too much noise	<input type="radio"/> Not dark enough
<input type="radio"/> Too hot or too cold	<input type="radio"/> I was worried
	<input type="radio"/> Bed was uncomfortable
	<input type="radio"/> Nurse/other came in room
	<input type="radio"/> Other _____
How many hours of sleep did your child typically get in a night?	_____ Hours <input type="radio"/> DK
How many times did your child typically wake up during the night?	_____ Times <input type="radio"/> DK
Do you feel that your family has had adequate privacy to discuss your child’s care and needs?	Yes <input type="radio"/> Sometimes <input type="radio"/> No <input type="radio"/>

Do you feel that your family can have relaxed family time during the hospitalization?	Yes <input type="radio"/>	Sometimes <input type="radio"/>	No <input type="radio"/>
Is your family able to eat adequately during the hospitalization?	Yes <input type="radio"/>	Sometimes <input type="radio"/>	No <input type="radio"/>

Part VI. How would you describe yourself?

Interviewer: "The next set of questions focus on you and how you have felt during the hospitalization. Please use the answer card if you need to. Since your child was admitted to the hospital, how often have you felt:"

	Never	Rarely	Sometimes	Often	Most of the Time
Fearful	<input type="radio"/>				
Optimistic	<input type="radio"/>				
Well-rested	<input type="radio"/>				
Anxious	<input type="radio"/>				
Scared	<input type="radio"/>				
Angry	<input type="radio"/>				
Unable to sleep	<input type="radio"/>				
Irritable	<input type="radio"/>				
Able to handle things	<input type="radio"/>				
Confused	<input type="radio"/>				
Able to help your child	<input type="radio"/>				
Frustrated	<input type="radio"/>				
Relieved	<input type="radio"/>				
Hopeful	<input type="radio"/>				

Part VII. Your view of hospital staff

Interviewer: "Please rate the following services and supports here at the hospital during this hospitalization as Very Poor, Poor, Fair, Good, Very Good."

	Very Poor	Poor	Fair	Good	Very Good
Staff concern for your child's and your family's privacy	<input type="radio"/>				
Staff concern to make your child's stay as restful as possible	<input type="radio"/>				
Staff efforts to include you in decisions about your child's treatment	<input type="radio"/>				
Degree to which the hospital staff addressed your emotional needs	<input type="radio"/>				
Degree to which staff respected your knowledge of your own child	<input type="radio"/>				
Response to concerns/complaints made during your stay	<input type="radio"/>				
Staff concern to put your child at ease	<input type="radio"/>				
How well your child's pain was controlled	<input type="radio"/>				
Safety and security of the hospital	<input type="radio"/>				
Information provided about available facilities for family members (e.g., places to sleep, eat, shower, talk, etc.)	<input type="radio"/>				
Accommodations and comfort for visitors	<input type="radio"/>				
Comfort of overnight facilities for parents	<input type="radio"/>				
Room cleanliness	<input type="radio"/>				
How well things worked in the room (e.g., TV, call button, lights, bed, etc.)	<input type="radio"/>				
Appearance of room	<input type="radio"/>				
Lighting of your child's room	<input type="radio"/>				
Temperature of your child's room	<input type="radio"/>				
Staff's approachability, friendliness with questions and concerns	<input type="radio"/>				
Staff's interacted with my child in a kid-friendly way	<input type="radio"/>				

Part VIII. Hospital facility use

Interviewer: “In this last section, I will ask you if you or your child has used five different facilities or places at the hospital. We would like your feedback about each one. The responses on this sheet represent different ways the facility or space could have made you or your child feel. Please indicate as many as you like.”

Brown Family Life Center:

Have you or your child used the Brown Family Life Center or Morton Teen Lounge? <input type="radio"/> Parent <input type="radio"/> Child <input type="radio"/> Neither					If yes, how many times? Parent _____ Child _____				
Please circle the words that describe how the use of this facility made YOU feel:					Please circle words that describe how the use of these facilities made YOUR CHILD feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed	Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed	Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content	Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged	Soothed	Tense	Lonely	Playful	Engaged

Cafeteria:

Have you or your child used the hospital cafeteria? <input type="radio"/> Parent <input type="radio"/> Child <input type="radio"/> Neither					If yes, how many times? Parent _____ Child _____				
Please circle the words that describe how the use of this facility made YOU feel:					Please circle words that describe how the use of this facility made YOUR CHILD feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed	Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed	Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content	Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged	Soothed	Tense	Lonely	Playful	Engaged

Lobby:

Have you or your child visited the Lobby? <input type="radio"/> Parent <input type="radio"/> Child <input type="radio"/> Neither					If yes, how many times? Parent _____ Child _____				
Please circle words that describe how the use of this facility made YOU feel:					Please circle words that describe how the use of this facility made YOUR CHILD feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed	Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed	Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content	Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged	Soothed	Tense	Lonely	Playful	Engaged

Chapel:

Have you or your child visited the Chapel? <input type="radio"/> Parent <input type="radio"/> Child <input type="radio"/> Neither					If yes, how many times? Parent _____ Child _____				
Please circle words that describe how the use of this facility made YOU feel:					Please circle words that describe how the use of this facility made YOUR CHILD feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed	Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed	Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content	Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged	Soothed	Tense	Lonely	Playful	Engaged

Understanding the Role of Hospital Design on the Psychological Trauma of Hospitalization for Children

Hospital Art:

Have you or your child stopped and looked at the art pieces or displays throughout the hospital? <input type="radio"/> Parent <input type="radio"/> Child <input type="radio"/> Neither	If yes, how many times? Parent : <input type="radio"/> Everyday <input type="radio"/> Most Days <input type="radio"/> Some Days Child: <input type="radio"/> Everyday <input type="radio"/> Most Days <input type="radio"/> Some Days
If yes, what items? Parent: _____	Child: _____
Please circle words that describe how viewing this artwork made YOU feel:	Please circle words that describe how viewing this artwork made YOUR CHILD feel:
Relaxed Anxious Relieved Uneasy Calmed Interested Bored Happy Delighted Stressed Confused Frustrated Exhausted Worried Content Soothed Tense Lonely Playful Engaged	Relaxed Anxious Relieved Uneasy Calmed Interested Bored Happy Delighted Stressed Confused Frustrated Exhausted Worried Content Soothed Tense Lonely Playful Engaged

Overall:

Were there any other spaces you and your family enjoyed during your time at the hospital? <input type="radio"/> Yes <input type="radio"/> No	If yes, please list:
Do you have any suggestions for other facilities that would have been nice to have access to during your time here?	How would you rate the overall atmosphere of the hospital, with one being the worst possible place and ten being the best possible place? _____ (rating 1-10)
Please circle words that describe your overall impression of Children’s Memorial Hospital facilities.	
Kid-Friendly Safe Happy Unfriendly Uneasy Cheerful Institutional Cold Calm Crowded Clean Comfortable Hurried Organized Neat Sterile Confusing Chaotic Scary Efficient	

Interviewer: “Thank you for your help. We appreciate your time. I would like to schedule/confirm the time to come back and work with your child on the photo project.”

APPENDIX D: HOSPITALIZATION EXPERIENCE SURVEY (ADOLESCENT)

Hospital Experience Survey for Teens

You are being asked to complete this survey because you agreed to take part in a research study about being in the hospital. We are doing the study to help us understand what it's like to be in the hospital and what we can do to make it a better experience. We ask that you answer these questions as honestly as you can.

Part I:

Name:	Gender: <input type="radio"/> Male <input type="radio"/> Female
Age:	Grade:

How many hours of sleep do you typically get in a night at home?	_____ Hours
How many hours of sleep have you typically gotten while sleeping at the hospital?	_____ Hours
How many times do you typically wake up during the night at the hospital?	_____ Times
What were the reasons for you waking up at night? (Check all that apply)	
<input type="radio"/> I was restless <input type="radio"/> Bed was uncomfortable <input type="radio"/> Nurse came in room <input type="radio"/> Too much noise <input type="radio"/> Not dark enough <input type="radio"/> I was uncomfortable or in pain <input type="radio"/> Too hot or too cold <input type="radio"/> I was worried <input type="radio"/> Had to go to the bathroom <input type="radio"/> Other _____	
Does a parent or relative stay overnight with you at the hospital?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Sometimes
Have your friends been able to visit you during your stay?	<input type="radio"/> Yes <input type="radio"/> No
If yes, how many times did they visit?	_____
Do you share a room?	<input type="radio"/> Yes <input type="radio"/> No
If yes, has sharing a room been difficult or nice for you?	<input type="radio"/> Difficult <input type="radio"/> Nice
Why?	
Do you feel you have been able to eat well during your hospitalization?	<input type="radio"/> Yes <input type="radio"/> No

Part II:

Tell us what describes you best. There is no right or wrong answer.

Statement	Never	Rarely	Sometimes	Often	Most of the Time
I ask for help when I need it					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
I get along well with my parents					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
When I have a problem, I talk with others about it					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
I get along with my brothers and sisters					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
When good things happen to me, I tell others					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
I am nice to others					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
I have a close friend I can talk to when I need to					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				

Part III:

How do you feel in the hospital compared to a typical day at home or school? There is no right or wrong answer.

How often do...	Never	Rarely	Sometimes	Often	Most of the Time
You eat well?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You have a low energy level or are tired for no apparent reason?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You have little interest in (or enjoyment of) pleasurable activities?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You act restless or edgy?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You worry that your parents and/or caregivers will be hurt or leave home and not come back?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You have difficulties controlling your worries?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You feel irritable for most of the day?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You cry, freeze or withdraw from interacting when put in an uncomfortable social situation?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You feel depressed or sad for most of the day?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You worry Some disaster will separate you from your parents/caregivers?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You get very upset when you expect to be separated from your home or parents/caregivers?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				

Part III: (Continued)	Never	Rarely	Sometimes	Often	Most of the Time
You feel excessively shy with your peers?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				
You feel extremely tense or unable to relax?					
In the hospital	<input type="radio"/>				
Typical day	<input type="radio"/>				

Part IV:

In this section we ask you rate the services and supports here at the hospital. By “staff” we mean any one working at the hospital- nurses, aides, doctors etc. There is no right or wrong answer.

	Very Poor	Poor	Fair	Good	Very Good
Staff concern for you and your family’s privacy	<input type="radio"/>				
Staff concern to make your stay as restful as possible	<input type="radio"/>				
Response to concerns/complaints made during your stay	<input type="radio"/>				
Staff’s approachability, friendliness with your questions and concerns	<input type="radio"/>				
Staff concern to put you at ease	<input type="radio"/>				
How well your pain was controlled	<input type="radio"/>				
How well things worked in the room (e.g., TV, call button, lights, bed, etc.)	<input type="radio"/>				
Appearance of room	<input type="radio"/>				
Lighting of your room	<input type="radio"/>				
Temperature of your room	<input type="radio"/>				
The quality of the food served in the room	<input type="radio"/>				
The amount of the food served in the room	<input type="radio"/>				
Quality of the internet access available in the room	<input type="radio"/>				
Overall comfort of the room	<input type="radio"/>				

	Never	Rarely	Sometimes	Often	Most of the time	N/A
The hospital staff welcomes my friends who come to visit me	<input type="radio"/>					
My friends feel comfortable when they come to visit me	<input type="radio"/>					
My friends like visiting me at the hospital	<input type="radio"/>					

Have you been able to keep up with your school since being in the hospital?	<input type="radio"/> Yes <input type="radio"/> No
Have you gotten help with school work from a hospital staff member?	<input type="radio"/> Yes <input type="radio"/> No
Have you used the internet at the hospital for homework?	<input type="radio"/> Yes <input type="radio"/> No

Part V:

This last section will focus on five different places or things in the hospital. We would like to know if you used these spaces and how they made you feel. Please indicate as many as you like.

Brown Family Life Center:

Have you used the Brown Family Life Center or Morton Teen Lounge?				
<input type="radio"/> Yes	<input type="radio"/> No	Number of times visited _____		
If not, why?				
<input type="radio"/> Was not able to/Too Sick	<input type="radio"/> Was not able to (other reason)	<input type="radio"/> Not interested		
<input type="radio"/> Did not know about it	<input type="radio"/> Other, explain _____			
Please circle the words that describe how the use of this facility made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Cafeteria:

Have you used the hospital cafeteria?				
<input type="radio"/> Yes	<input type="radio"/> No	Number of times visited _____		
If not, why?				
<input type="radio"/> Was not able to/Too Sick	<input type="radio"/> Was not able to (other reason)	<input type="radio"/> Not interested		
<input type="radio"/> Did not know about it	<input type="radio"/> Other, explain _____			
Please circle the words that describe how the use of this facility made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Lobby:

Have you visited the Lobby?				
<input type="radio"/> Yes		<input type="radio"/> No		Number of times visited _____
If not, why?				
<input type="radio"/> Was not able to/Too Sick		<input type="radio"/> Was not able to (other reason)		<input type="radio"/> Not interested
<input type="radio"/> Did not know about it		<input type="radio"/> Other, explain _____		
Please circle words that describe how the use of this facility made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Hallways:

Have you walked through the hallways?				
<input type="radio"/> Yes		<input type="radio"/> No		
If yes, how often?		<input type="radio"/> Everyday	<input type="radio"/> Most Days	<input type="radio"/> Some Days
If not, why?				
<input type="radio"/> Was not able to/Too Sick		<input type="radio"/> Was not able to (other reason)		<input type="radio"/> Not interested
<input type="radio"/> Did not know about it		<input type="radio"/> Other, explain _____		
Please circle words that describe how the use of this facility made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Chapel:

Have you visited the Chapel?				
<input type="radio"/> Yes		<input type="radio"/> No		Number of times visited _____
If not, why?				
<input type="radio"/> Was not able to/Too Sick		<input type="radio"/> Was not able to (other reason)		<input type="radio"/> Not interested
<input type="radio"/> Did not know about it		<input type="radio"/> Other, explain _____		
Please circle words that describe how the use of this facility made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Hospital Art:

Have you stopped and looked at the art pieces or displays throughout the hospital?				
<input type="radio"/> Yes <input type="radio"/> No If yes, how often? <input type="radio"/> Everyday <input type="radio"/> Most Days <input type="radio"/> Some Days				
If yes, what items:				
If not, why?				
<input type="radio"/> Was not able to/Too Sick <input type="radio"/> Was not able to (other reason) <input type="radio"/> Not interested <input type="radio"/> Did not know about it <input type="radio"/> Other, explain _____				
Please circle words that describe how viewing this artwork made YOU feel:				
Relaxed	Anxious	Relieved	Uneasy	Calmed
Interested	Bored	Happy	Delighted	Stressed
Confused	Frustrated	Exhausted	Worried	Content
Soothed	Tense	Lonely	Playful	Engaged

Part VI:

Were there any other spaces you and your family enjoyed during your time at the hospital?										
<input type="radio"/> Yes <input type="radio"/> No										
If yes, please list:										
How would you rate the overall atmosphere of the hospital, with one being the worst possible place and ten being the best possible place?										
1 2 3 4 5 6 7 8 9 10										
Why did you choose this rating?										
Please circle words that describe the overall environment of Children’s Memorial Hospital facilities.										
Kid-Friendly	Safe	Happy	Unfriendly	Uneasy						
Cheerful	Institutional	Cold	Calm	Crowded						
Clean	Comfortable	Hurried	Organized	Neat						
Sterile	Confusing	Chaotic	Scary	Efficient						
Do you have any suggestions for other facilities or activities that would have been nice to have access to during your time here?										
Is there anything you would have liked to have or do, that you could not do here?										

Thank you for your help. We appreciate your time.

APPENDIX E: PHOTO ACTIVITY (CHILD)

Room Activity

Patient Name _____ Date _____ Time _____ to _____



Picture something that makes you feel;

Happy (Check when completed) This picture is of _____

Silly (Check when completed) This picture is of _____

Sad (Check when completed).This picture is of _____

Playful (Check when completed) This picture is of _____

Grumpy (Check when completed) This picture is of _____

Talkative (Check when completed) This picture is of _____

Angry (Check when completed) This picture is of _____

Bored (Check when completed) This picture is of _____

Scared (Check when completed) This picture is of _____

Other (Something that stood out to you or that was important to you during your stay

This picture is of _____



One thing in my room I like (Check when completed)

This picture is of _____



One thing in my room I DON'T like (Check when completed)

This picture is of _____



My favorite thing in my room is (Check when completed)

This picture is of _____

Common Room Activity

Patient Name _____ Date _____ Time _____ to _____



Take pictures things that are;

Fun (Check when completed) This picture is of _____

Boring (Check when completed) This picture is of _____

Pretty (Check when completed). This picture is of _____

Ugly (Check when completed) This picture is of _____

Helpful (Check when completed) This picture is of _____

Difficult (Check when completed) This picture is of _____

Relaxing (Check when completed) This picture is of _____

Exciting (Check when completed) This picture is of _____

Other (Something that stood out to you or that was important to you during your stay)

This picture is of _____



My favorite thing to do here (Check when completed)

This picture is of _____



One thing I DON'T like to do here (Check when completed)

This picture is of _____



The best thing about this place (Check when completed)

This picture is of _____



Bed Time Activity



Please help you child complete this activity at night, if possible, an hour to thirty minutes before he/she goes to sleep.

Tonight's bed time is _____pm

3 words that described what it is like to go to bed at the hospital are;

1. _____ 2. _____ 3. _____

Pick words from below or make up your own!

Relaxed Frustrating Scary Uncomfortable Public Angry Happy Restless
Funny Unable to sleep Tense Worried Cold Depressing Hopeful Sleepy
Lonely Hot Different Grumpy Content Stressed Noisy Private Boring



Take a picture that represents each of the three words you picked!

Picture of word 1 (Check when completed). This picture is of _____

Picture of word 2 (Check when completed). This picture is of _____

Picture of word 3 (Check when completed). This picture is of _____



Take two pictures of two things you did to get ready for bed

Picture of activity 1 (Check when completed). This picture is of _____

Picture of activity 2 (Check when completed). This picture is of _____



Take a picture of something that is the SAME during bedtime in hospital and bedtime at home. Now, take a picture of something that is DIFFERENT.

Same Picture (Check when completed). This picture is of _____

Different Picture (Check when completed). This picture is of _____

Thanks you again for participating in our research study and completing the bed time activity!



APPENDIX F: PHOTO ACTIVITY (ADOLESCENT)

Patient Room Pictures

Date _____ Time _____



Please take pictures of architecture, design and/or decorating features that you like.

Description of pictures _____



Please take pictures of architecture, design and/or decorating features that you DON't like.

Description of pictures _____



Please take pictures of things that cause you stress.

Description of pictures _____



Please take pictures of things that help to relieve stress.

Description of pictures _____



Please take pictures of things that cause your parent/s and family members stress.

Description of pictures _____



Please take pictures of things that help to relieve your parents stress.

Description of pictures _____

Sleeping at the Hospital



Please take pictures of things that prevent you from sleeping well.

Description of the pictures _____



Please take pictures of things that help you sleep better.

Description of the pictures _____



Please take pictures of things that cause anxiety and/or stress during the night at the hospital.

Description of the pictures _____



Please take pictures of things that help you relax during the night at the hospital.

Description of the pictures _____

If you would like to take picture of your family and friends, feel free to do so. We will print these pictures for you and include them in your photo book. No personal photos will be used for research purposes.

Common Area Pictures

Date _____ Time _____



Please take pictures of architecture, design and/or decorating features that you like.

Description of pictures _____



Please take pictures of architecture, design and/or decorating features that you DON't like.

Description of pictures _____



Please take pictures of things that cause you stress.

Description of pictures _____



Please take pictures of things that help to relieve stress.

Description of pictures _____



Please take pictures of things that cause your parent/s and family members stress.

Description of pictures _____



Please take pictures of things that help to relieve your parents stress.

Description of pictures _____

If you would like to take picture of your family and friends, feel free to do so. We will print these pictures for you and include them in your photo book. No personal photos will be used for research purposes.

During your interview, we are going to ask you the following questions about your photos

1. What do you see here?
2. How does it relate to your hospital experience?
3. Why does this object, situation, concern or strength exist?
4. What can we do about it?