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Children's Thoughts and Feelings Regarding Their Treatment
Environment: Stresspoints and Coping in a Pediatric
Hematology/Oncology Clinic

By

William N. Yeaple

A dissertation submitted to the Graduate Faculty in Psychology in
partial fulfillment of the requirements for the degree of Doctor of
Philosophy, The City University of New York.

1998

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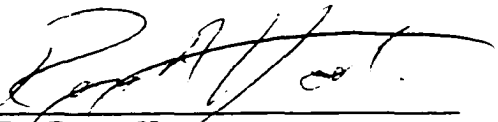
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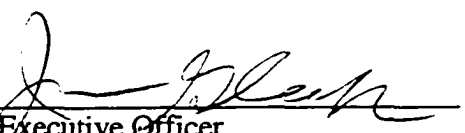
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William N. Yeaple
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This manuscript has been read and accepted by the Graduate Faculty in Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

August 31st, 1998.
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Abstract

Children's Thoughts and Feelings Regarding Their Treatment Environment: Stresspoints and Coping in a Pediatric Hematology/Oncology Clinic

By

William N. Yeaple

Advisor: Professor Roger Hart

Within the past forty years health professionals and architects have come to acknowledge and alleviate some of the distress and anxiety that children and teenagers experience while they are in a hospital. This new sensitivity has resulted in significant changes in the layout, function and even the appearance of pediatric healthcare facilities. While major strides have been taken to eliminate the most obvious sources of stress and anxiety, the voice of pediatric patients themselves is often missing from discussions on the subject. This research was designed to investigate children's thoughts and feeling about one kind of hospital setting where there are many causes of stress and anxiety: a pediatric hematology/oncology outpatient clinic.

The author spent nine months at a pediatric hematology/oncology clinic as a participant observer in the playroom. Forty-five patients ranging in age from 5 to 22 were interviewed. Content analysis led to the concept of stresspoints, around which the findings are reported. Stresspoints were differentiated from one another by changes in: time, location, the people involved (usually medical staff), activities (usually procedures), and the psychological and/or physical well-being of the patient. Six stresspoints were identified: entering the clinic, waiting in the Playroom, the transition between the Playroom and the screening or examination rooms, waiting to see a nurse or doctor in a screening or examination room, undergoing procedures, and when the staff had to communicate important information to the patients and their families.

The major conclusion from the research is that in order to create life-affirming environments for pediatric patients all of the actors involved should pay particular attention to the spatial and temporal stresspoints where patients and their families have to cope with extraordinary and sometimes overwhelming amounts of stress.

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When children are being treated they need a place where they can feel safe. Elsa Pelier, the Child Life Specialist provides that place, which is both physical and psychological, in the Playroom. I hope she knows how much the patients appreciate what she does. It was a privilege to work with her in the Playroom.

I was very fortunate in having a Dissertation Committee: Roger Hart (Chair), Gary Winkel, and David Bearison that allowed me to proceed with research that was very exploratory, while providing me with insights and guidance that helped the dissertation enormously. Roger Hart deserves special mention because he has also been very generous, allowing me to stay in his house for several months when I returned to New York. Without his support, it would have been much more difficult for me to have finished the dissertation.

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Lee Rivlin read the final draft of the dissertation, and her comments only reinforced my opinion of her as a person of enormous intellect and insight coupled with a deep concern for the human condition. It was my good fortune to be able to study with her and to have her as an Outside Reader.

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1. INTRODUCTION

Based on my belief in the philosophy of science which instructs us to use research to solve problems,¹ the purpose of this study was to gather information from pediatric hematology/oncology patients that could be used by Architects and Interior Designers when they are designing a pediatric hematology/oncology Clinic. The emphasis, therefore, has been on describing and analyzing aspects of children's and teenagers' experience that should be acknowledged while designing such facilities. To this end, a case study site was studied in depth, enabling a full account of the patients' perceptions, thoughts and feelings about their treatment environment; what their time in the Clinic was like; what the transactions and interactions were between the patients and their socio/physical environment; what they liked and disliked about the existing facility; and what their "ideal" Clinic would be like. The intent was not to provide all the information necessary to write a comprehensive architectural space program for a new Clinic but rather to focus on the relationship between the patients' psychological and physical needs, and the physical and social environment.

It is generally acknowledged that hospitalization or, even a visit to a doctor, can be a stressful experience and within the past forty years health professionals and architects have come to acknowledge and alleviate some of the distress and anxiety that children experience while they are in the hospital. This new sensitivity has resulted in significant changes to the layout and function of pediatric units in hospitals. Children's emotional and developmental needs are taken into account. Almost universally, accommodations are provided for parents- playrooms, school programs and classrooms are on site. While major strides have been taken to eliminate the most obvious sources of distress and anxiety,

¹ Popper (1968)

what has not been acknowledged or appreciated is that the entire experience is not stressful. One of the patients in the study made the point that "every visit for every child is different." While this is apparently an accurate description of the patients' experience, nevertheless, there are identifiable sources of stress, anxiety and pain; what I have termed stresspoints, that the patients experienced during their visits to the clinics.

Not only does this stresspoint concept enable the research findings to be organized around the stresses, including environmental stressors, that the children had to cope with, it also allows an account of how the physical and social environment can facilitate or obstruct the coping strategies of patients. In essence the stresspoint concept makes a connection between the patients' psychological and physical well-being and aspects of the environment.

An additional benefit to this approach, which will become apparent when reading the patients' suggestions for improvements, is that an environment that considers and accommodates the patient's needs when they are under stress is also an environment that is in general more pleasant and enjoyable to be in for the patients when they are not under stress, as well as for their parents and the staff. For instance, adding artwork to the walls of halls, screening rooms, and examination rooms not only can help patients cope with their anxiety, artwork also creates a more visually appealing environment.

While pediatric patients' with hematological and oncological diseases have special needs, specific findings from this study, such as the need to for activities while waiting and sources of distraction during procedures, are relevant for other types of outpatient clinics designed for children. More generally, the concept of stresspoints can be used during the design of other types of pediatric healthcare environments as well as hospitals for the general population to address the patients' psychological and physiological needs.

2. LITERATURE REVIEW

When patients visit a pediatric hematology/oncology clinic they have been and will be subjected to a number of different stressors; forces or events from the environment that threaten their well-being or even existence (Baum, Singer, & Baum, 1982). In order to have some understanding about their experience at the various stresspoints discussed in the findings chapters of this study, the following literature review addresses the major stresses to which they are subjected. The first topics covered will be the effects of illness and the stressors associated with hospitalization, such as separation from everyday social and physical environments, loss of autonomy and control, and fear of bodily harm. For many patients, the pain associated with diagnostic treatment related techniques that they are subjected to while they are in the clinic, such as venipunctures, bone marrow aspirations, and lumbar punctures is a major source of stress, and this literature is reviewed as well as literature about pain as a multidimensional phenomena. Of special interest is the gate control theory of pain (Melzack and Wall, 1965) which posits that while the level of pain can be increased by psychological factors such as anticipatory anxiety; the level of pain can be reduced by coping mechanisms such as distraction techniques, hypnosis, and imagery and relaxation techniques. This literature is especially relevant for this study because it suggests that environmental factors can have both a negative and a positive effect on the level of pain patients experience.

Patients may also be subjected to stressors directly related to the institutional quality of the social/physical environment of the hospital and this literature is reviewed, as well as literature concerning privacy. The issue of privacy demands special attention because when patients visit a clinic their need for privacy may be accentuated and lack of privacy can be especially stressful.

Next reviewed is literature specifically written about children's health care environments. This literature does not appear to be theory driven nor has any author developed a conceptual framework that brings together theoretical perspectives from both the medical field; specifically a theoretical model that addresses coping in a medical setting; and a model that addresses environmental issues. In the final section of the literature review, the work of several authors is combined to create just such a model.

2.1. Children's Experience of Illness and Hospitalization

2.1.1. Illness

In the literature there is some disagreement about how illness can affect children's development. While a serious illness can strike to the core of a person's being because of the feelings of anxiety, pain, dread, despair, genuine angst and fear associated with it, children who successfully master the ongoing stress of illness and hospitalization can develop a sense of pride and confidence, increasing their sense of self esteem (Mattsson, 1972; Winklestein, 1989).

When illness is life threatening there is also a continuous uncertainty that cannot be relieved due to the fear of dissolution (van Eys, 1983). There is a challenge to children's psycho social adaptation (Mattsson, 1972) because they may be deprived of experiences essential to their development (Butler, 1983). Young children are especially susceptible to the threats of serious and chronic illness because they are relatively new to the world and their cognitive powers and coping skills are not fully developed. Chronic illness can impede their emotional and behavioral and development (Eiser, 1990). Throughout childhood, children struggle to become free and autonomous by emancipating themselves from their parents and other adults. At the same time there is a small part of themselves that wishes to be young and cared for (Ack, 1983). During chronic illness there can be a

backward pull to dependency (Mattson, 1972; Ack, 1983) and a disintegration of recently acquired complex physiological, psychological, and social functions (Coppolillo, 1983). Coppolillo (1983) more specifically attributed the destructive forces of development to assaults on the child's integration of the sense of self. There is according to Coppolillo a process of disintegration where "not only the processes by which more recently acquired complex functions are fragmented into their more primitive components, but also those instances in which integration is impeded or distorted by illness" (p. 55). Regressive behaviors may be manifested "when the child's ability to function in any of the developmental domains - psychomotor, cognitive, language, psycho social is disrupted" (Vessey, Farley, & Risom, 1991, p. 230). Children's personalities may be negatively affected because of poor body image, poor self concept, lack of motivation and lack of faith in their abilities (Selekman, 1991). The physiological, psychological and social aspects of chronic disease include: acute and chronic pain, compliance problems, developmental delay due to reduced interaction with the environment, hyperactivity, feelings of anger, helplessness, and low self-esteem which may be manifested in behavior such as regression, withdrawal, uncertainty, apathy, academic difficulties, and eating disorders. to name only a partial sample. (Burbach & Peterson, 1988; Butler, 1983; LeBaron & Zeltzer, 1985)

The disintegrative aspects of childhood chronic disease are not well understood (Eiser, 1990) nor are the negative effects of illness universally acknowledged. Fritz, Williams, and Amylou (1988) assessed the psychosocial status of fifty-two survivors of childhood cancer and determined that most were functioning well and that serious psychosocial disorders such as depression and academic or social malfunctioning were relatively uncommon. A cancer victim stated:

leukemia did not hurt as much as it helped me. I not only developed a close relationship with a lot of people, but I got to know myself pretty well. I also made a lot of new friends... I feel the whole experience was very enriching for me. (Kelley, 1983, p. 25)

There is also, according to Mattson (1972), the possibility that children will feel a sense of pride and confidence in mastering the stress of illness. This is not to say that all children adjust to chronic illness equally well. Rather it has been recognized that it is important to plan psychosocial interventions based upon individual response styles as well as the severity and symptomatology of the illness, the treatment course, pain levels, etc. Individual and family coping styles and skills must be identified. There are: intrapersonal factors such as the severity of the illness or handicap, functional independence, and temperament and coping style; and interpersonal factors such as, temperament and coping style of the mother; and social-ecological factors such as marital and family functioning, socioeconomic status, and family size and utilization (Eiser, 1990), that affect children's adjustment or maladjustment to chronic illness.

2.1.2. Hospitalization

Just as there is disagreement about the long-term effects of illness, there is also some disagreement about the negative effects of hospitalization. Haller (1967) made a distinction between long hospitalizations and short stays. In long hospitalizations, children are subject to what he called problems of omissions: lack of attention and lack of affection. Children who are in the hospital for a short stay in contrast suffer from problems of commission. Haller stated that, "The child is almost simultaneously committed to a strange environment, forced to undergo an uncomfortable operation, and required to relate to many strange people" (p. 22).

Ack (1983) stated that there "is psychological upset both during and after hospitalization" (p. 132) ... and that the "most common sequelae of hospitalization is psychiatric rather than medical" (p. 133). Vessey et al. (1991) discussed the iatrogenic

insults that children suffer while they are in pediatric intensive care that may cause psychological and developmental problems.

This viewpoint is disputed by several authors. According to Brown (1979), only a few children manifest signs of distress or fretfulness during a brief hospitalization and only a minority of children show signs of longer term upset after they had been discharged. McClowry and McCleod (1990), and Mabe, Treiber, and Riley (1991) believed that an inaccurate impression of the effect that hospitalization had on children was being maintained by perpetuating the impression that the negative effects of hospitalization were widespread. Mabe et al. (1991) discovered that the depressive and anxious symptoms that some hospitalized children experienced could be attributed to parental distress and the enduring symptoms of the illness, not prior hospitalizations or the frequency of medical procedures. They hypothesized that the "hospital veterans" had habituated and become accustomed to the hospitalization experience and that "some studies suggest that most of the variance in effects of hospitalization may be due primarily to illness" (p. 167). Spinetta and Maloney (1975) found that as the number of visits to the hospital or clinic increased, the anxiety that children with chronic illness felt, decreased (cited in Bearison and Pacifi, 1989).

In contrast to this view is one put forth by Oremland and Oremland (1973) who felt that the child who had been repeatedly hospitalized and gone through painful treatments also needed adequate preparation because he "still suffers pain, separation from his family, and worst of all, the anticipation of previously experienced and inevitably repeated discomforts" (p. 49).

McClowry and McCleod (1990) felt that an over-generalization about the negative effects of hospitalization ignored the tremendous changes that had occurred in the hospital environment since the 1950's following Prugh, Staub, Sands, Kirschbaum, and Lenihans'

(1953) work in which they demonstrated that enhanced psychosocial care such as parental involvement, psychological preparation, early ambulation, and play therapy reduced the behavioral stress that hospitalized children experienced. This is not to say that the stressful situations that children encounter during hospitalization are being denied; the wide range of psychosocial interventions (Fosson, Martin, & Haley, 1990; Gottlieb, 1990) that have been instituted acknowledge and preclude any such denial. In fact there are many factors and situations that have to be considered when talking about the stress of hospitalization, even though "a sizable majority of children with chronic disease cope effectively with both the disease and demands of treatment (Eiser, 1990, p. 90). The focus of research now is not to determine whether or not hospitalization is stressful, but rather to identify "which children are at risk for adverse responses to hospitalization and what conditions affect children's adjustments to hospitalization ..." (Mabe et al., 1991, p. 162).

Some children experience what Cooke (1967) called "a very heavy load of difficult hospital experiences" (p. 5) and should therefore receive concentrated attention and effort to help them carry through. One group of "hospital veterans" who bear a heavy load are children with leukemia. The fear of dying, painful medical procedures, and the side effects of chemotherapy and radiation regimens conspire to make these patients more anxious with succeeding visits to the hospital or clinic. Spinetta and Maloney (1975) stated that, "... for the leukemic children, the longer the duration of the illness, the higher the anxiety" (p. 1036, cited in Bearison & Pacifi, 1984, p. 267). More generally, preschoolers and adolescents appear to be hit hardest by their hospitalization, while schoolage children seem to be less susceptible to the stressors that they have to deal with.

A number of sources of stress create psychological upset during hospitalization that patients have to adjust to. There are nonspecific changes, i.e., those not unique for hospitalization, such as separation from things; toys, furnishings, and the home and

separation from activities such as school and play, as well as separation from people such as the mother and father, siblings and friends. The stress associated with these separations is complicated by the introduction to new things, new activities and new people. Children going away to summer camp often are very anxious due to these type kinds of separation problems. But children who are being hospitalized are faced with these types of changes, often with little or no notice. They may be in a weakened condition due to their illness. They may fear bodily harm or death. They are exposed to an often unfamiliar and frightening hospital environment complete with terrifying equipment and health specialists who perform medical procedures that can be both frightening and painful. They experience a loss of autonomy and control and are subjected to regimented hospital activities, procedures, and routines (Mabe et al., 1991; Wojtasik & Sanborn, 1991).

How well children adjust to these stressful factors and situations depends upon exogenous and endogenous factors (Cooke, 1967). The exogenous factors include the attitudes of the parents. Are they anxious and distressed? Children pick up on their parents anxiety. How well the family functions is also a factor. Was there maladjustment in the child or family before the hospitalization? Were there many life changes before the hospitalization? Had the child been hospitalized before? How often? How long was the hospitalization and what was the quality of the hospitalization experience? Endogenous factors that affect children's ability to cope include their physical and personality characteristics, such as their age, intelligence, the nature and degree of the illness and their resilience.

The patients' attitude towards hospitalization is also a factor. This may be affected by interventions designed to prepare the child for the hospitalization. Of special interest to this study are interventions developed by Wolfer and Visintainer (Visintainer & Wolfer, 1975; Wolfer & Visintainer, 1975; Wolfer & Visintainer, 1979) to help prepare children

and their parents for minor surgery. They developed what they called stress-point nursing care which provided information and supportive care at pre- and postoperative stressful points: "admissions, shortly before the blood test, late in the afternoon the day before the operation, shortly before the preoperative medications, before transport to the operating room, and upon return from the recovery room" (Wolfer & Visintainer, 1975, p. 161). In the first two studies, patients who received stress-point nursing care showed less upset behavior, were more cooperative while they were in the hospital and had fewer adjustment problems after they left the hospital than those patients who received standard nursing care or other treatment conditions. Interestingly, in the third study (Wolfer & Visintainer, 1979), preparatory materials, based on information that the nurses told the children and parents at each stress-point in the previous studies, given to patients and their parents at home, were found to be as effective as in-hospital stress-point preparation. As in much of the literature written by medical professionals, Wolfer and Visintainer do not address the environment in their experiments. Nevertheless, their work demonstrates the need to systematically examine a patient's tenure in a medical setting with regard to conditions that are especially stressful, and work to make those conditions less disturbing.

Hospitalization is a very trying experience for many children but it need not represent only trauma, it can also develop pride and confidence as a result of mastering both psychic and physiological injury. Rather than thinking only about how painful and distressing the experience can be, it might be more useful to think of it as a life crisis which could be successfully conquered (Oremland & Oremland, 1973), affording growth and success for children who can be amazingly resilient (Wojtasik & Sanborn, 1991) and fostering attitudes toward health care which are positive (Wolfer & Visintainer, 1979).

The brief synopsis of illness and hospitalization above was meant to provide an overview of the breadth of factors and stressful situations children have to cope with when

they are hospitalized. In the following review of the literature, I will focus on those stressful situations that lend themselves to interventions through design, i.e., sources of stress that an environmental psychologist could study in order to provide information that designers could use to create environments that could successfully master the stress of hospitalization or at the very least reduce the stress in those situations.

2.2. Sources of Stress During Hospitalization

The first source of stress and anxiety that I will discuss is the anxiety that children experience when they are separated from familiar people, activities, places and objects. This will be followed by a discussion on the loss of autonomy and control patients experience when they are hospitalized. Finally the stress caused by the fear of bodily harm due to operations will be looked at.

2.2.1. Disruption of Social/Physical Experience

For a number of years the anxiety, distress and iatrogenic insults that children suffered when they were hospitalized was attributed to separation anxiety, the separation of children from their parents, particularly their mothers, what Brown (1979) called the "maternal-deprivation model."

Before the work of early researchers such as Bowlby (1960), Robertson (1959), and Prugh (1953) when children were hospitalized they were subjected to two major sources of disturbances. There was threat of hospitalization itself and there was what Fosson et al. (1990) called "life's greatest stress- the disruption of attachment relations" (p. 326) Bowlby thought that children could handle brief separations from their mothers but longer separations could adversely affect their personalities. For the younger children especially, "when peek-a-boo is still a game of learning to trust, perceived abandonment is a near overwhelming emotion" (van Eys, 1987, p. 202). Older children may realize that

they are not being abandoned but at the same time the most powerful coping device and perhaps the only one that they have when they are faced with an overwhelming stressful situation such as hospitalization with all its perceived threats, is the support of their parents. Parents represent security and familiarity and help buffer children from their greatest fears. Even much older children, those in their teens, may still need to have their parents with them when they are in life threatening situations. This can create a problem for families if they do not understand the nature of cancer. The patients may think that minor symptoms of discomfort may be life threatening and fear even the briefest separations. This type of separation anxiety can result in the discontinuation of a child's normal activities.

Following the publication of the Platt Report (1959) which was greatly influenced by the writing and thoughts of Bowlby (1960) and Robertson (1959), many hospitals began to take steps to remove one major source of disturbance, the separation of children from their parents, especially their mothers. Brown (1979) stated that "one of the principal recommendations of the Platt Report was the advocacy of facilities in children's wards for the mothers of under 5's to remain with their children throughout their stay" (p. 22). Hospitals began to institutionalize 24 hour parental visitation rights and as of 1991 98% of the general pediatric units had those visitation hours (Vessey et al., 1991). Along with the visitation rights many hospitals provide some facilities to accommodate the parents, such as cots or chairs that fold out into beds. These measures are especially beneficial for children between the ages of six months and four years (Fosson et al., 1990). The importance of maintaining this relationship which represents security (Nierenberg & Janovic, 1978) and familiarity (Cooke, 1967) has been generally acknowledged but recently a more ecological approach has been put forth.

Brown (1979) believed that although separation was an important factor in explaining some of the problems children have in the hospital, it was by no means the only

factor. Brown recognized that separation was stressful and he acknowledged and applauded the important changes in hospitals that had been instituted based on the maternal-deprivation or attachment model put forth by Bowlby and others in the 1950's but he stated that:

what evidence there is tends not to support the attachment model... what emerges from studies in hospitals is that separation from a single loving mother-figure, is, on its own, neither sufficient antecedent of longer-term psychological upset, nor distress, rather, where disturbance is found, there is frequently also found the most severe example of disruption of social experience in a more general sense. (Brown, 1979, p. 22)

He proposed instead a discontinuity model which gave equal importance to the disruption of other social relationships, including those with other family members and friends. These ideas have apparently been accepted to some degree by the medical establishment. Recently Eiser (1990) stated that there had been a move away from the focus on mother-child interactions to an appreciation for the reciprocal relationships between all the members of the family in order to help the entire family adjust to the child's illness. The alternative model that Brown (1979) proposed replaced the focus on the disruption of the mother and child bond and focused instead on the disruption of children's social life when they are taken away from their family and friends. Part of this model has been recognized by the Association for the Care of Children's Health (ACCH) which in its mission statement for the year 2000 emphasized family centered care. This emphasis on maintaining family relationships is reflected in the ACCH'S mission and vision for child care when they stated that:

- *family centered, psychologically sound, developmentally supportive care will be the standard for all children
- *coordination of care, with families a part of the health care team, will occur within and across agencies
- *the design of health care facilities will promote the practice of family-centered and developmentally supportive care (Tucker & Roberts, 1990, p. 198).

This organization envisions a time when health care facilities will be designed to provide psychologically and developmentally sound, supportive family centered care. Families will then become part of the health care team (Tucker & Roberts, 1990).

This ecological approach, which strives to preserve a family's dynamics in order to help them adjust to their children's illness, does not acknowledge the other part of children's social lives, their friends, who become increasingly important as children approach adolescence.

Children need social intercourse to grow and develop socially (Auerbach, 1989); social intercourse that is dependent upon friendships. One of the normal tasks of childhood, establishing friendships, is frequently disrupted by frequent or lengthy hospitalizations (Gottlieb, 1990). Not only are friendships important for normal growth and development but they can also lend social support and act as a buffer to the stress of chronic illness and hospitalization (Auerbach, 1989). Kelley (1983) stated that:

My "real" friends were the first people outside of my immediate family to come to my aid... I was really in the pits... suddenly my friends showed up with some presents. This gave me a lift that cannot be described. (p. 22)

Not only can friends provide a "lift" they can also have a direct effect on how children weather their illness. In the case of cancer survivors, both Fritz, Williams, and Amylou (1988) and O'Malley, Foster, Koocher, and Slavin (1980, cited in Bearison & Pacifi, 1984, p. 269) found that a critical factor which affected how well the survivors of pediatric cancer adjusted was their ability to maintain social relationships while they were ill. Fritz et al. (1988) found that communication patterns and the availability of peer support during treatment especially salient.

Another critical relationship is the one between patient and staff. When children are in the hospital they are placed under a great deal of stress simply by the tremendous numbers of new people that they have to interact with and different procedures that they are

subjected to. Nierenberg and Janovic (1978) citing the American Journal of Nursing¹, stated that in the first 24 hours after being admitted a child will have come in contact, on average, with 54 people. Having to deal with so many new people in such a short period of time only exacerbates the anxiety they already feel due to their medical condition. Haller (1967) stated that "there is no worse time to relate to new people and new surroundings than immediately following an injury" (p.19). One of the major themes in the psychological preparation of the child involves creating a relationship of trust and confidence with the staff (Weir, 1983). Having the continuity of care which can only be provided by an ongoing personal relationship with one physician is critical in helping families and therefore children to cope (Sitarz, 1987). The family and staff can then help children to cope with their illness and hospitalization, creating an "environment that will be conducive to the child's mastery of upcoming events" (Weir, 1983, p. 270).

2.2.2. Loss of Autonomy and Control

One of the results of hospitalization and illness is that children lose most of their autonomy. When they enter a hospital, they are forced to give up their right to privacy and become dependent on the staff for most of their needs. This situation is particularly harmful to children who are chronically ill because they are not given the opportunity to learn independence (Selekman, 1991). Throughout childhood, children struggle to emancipate themselves, first from their parents and then from other adults. During a childhood unimpeded by serious illness, children develop less fear and more of a sense of control as they actively construct the world in order to understand it and thereby cope with it (Perrin & Gerrity, 1981). As a child develops a sense of self and becomes more competent during the process of integration he or she becomes more autonomous and less dependent upon

¹ Complete reference not given.

adults (Coppollillo, 1983). Children struggle to understand the world around them, reducing the fear of the unknown and gaining a sense of control of their lives. When illness strikes it brings with it not only physiological trauma but also psychic trauma as the relatively certain world of a healthy childhood is suddenly disrupted. Children's fear of being at the mercy of an illness can be acknowledged and addressed, increasing their sense of control over their lives. A major threat to children's sense of control and autonomy occurs when their activities levels are restricted. Having their mobility restricted is especially disturbing to children because they "rely on freedom of movement to discharge tension, to express dissatisfaction and aggression, and to explore and master the environment" (Mattson, 1972, p. 803).

This struggle for autonomy and emancipation can be obstructed by chronic illness forcing children, especially younger children, to be rely on their parents, creating the possibility that they might regress to a more dependent state (Ack, 1983). Cancer, because of its life threatening nature, even erodes the autonomy of teenagers, forcing them to depend on parents for emotional support and even transportation to the hospital or clinic. Zeltzer, Kellerman, Ellenberg, Dash, and Rigler (1980) related the story of a seventeen-year-old young man who was devastated when he had to depend on his mother to drive him to the clinic because chemotherapy associated vomiting prohibited him from riding his motorcycle to the clinic.

Recently there have been moves towards allowing children and their families to become more responsible for the children's care. This enabling and empowering process allows families to become competent in the care of their children; strengthening the integrity of the family and providing the potential for turning the negative experience of illness into a positive growth experience for both the child and the family. Nissim and Stem (1991) discussed the benefits of empowering the parents with their ventilator-assisted child's care

as strengthening the integrity of the family, turning the negative experience of illness to a positive growth experience for both the child and family, and freeing health care professionals so that they can take care of other patients. Illness and hospitalization are especially fearful events but children can be prepared psychologically to deal with these stressful situations if they are given information at their developmental level (Bibace & Walsh, 1980; Weir, 1983).

2.2.3. Fear of Bodily Harm

Perhaps the most anxiety producing experience that children have to deal with while hospitalized is the fear of bodily harm. Haller (1967) asked "what does an operation mean to a child" and answered himself ... "an operation means an injury... basically it constitutes both psychological and physiological trauma" (p.19). An operation that is a surprise is even more traumatic because "there is perhaps no more trying emotional experience than sudden, unexpected trauma" (p. 19). The trauma of an operation is even more upsetting because as Haller (1967) stated:

there is no worse time to relate to new people and new surroundings than immediately following an injury. Yet in the strange environment of a hospital, we are asking a child to undergo such trauma and at the same time to adjust to ancillary features" (p.19).

For a number of years, children's response to the fear of bodily harm has been examined through a psychoanalytic lens using such concepts as fear, anger, anxiety, withdrawal and depression. Preschoolers often request Band-aids for minor cuts that are often almost too small to see. Adolescents, who are preoccupied with their appearance, dread any type of disfigurement. They are victims of what Mattson (1972) called "universal fears of bodily mutilation and disfigurement" (p. 803). According to Coppolillo (1983) the body is experienced as a cherished object and when a part of that body is lost or damaged that loss must be mastered through a grieving process. Preschool children in

particular can be upset by these medical procedures because they do not understand why they are being hurt, equating pain with punishment for either imagined or real misdeeds (Butler, 1983).

One of the ways that medical professionals have begun help children cope with their emotional upset is to allow greater parental involvement. Over the past two decades, parents have been allowed to become more involved in preparing their children for medical procedures and also being with them while they are being treated. In most cases parental participation is of great benefit to children. Parents can lend their strength and reduce the fear of the upcoming procedures by explaining to their children in language that they can understand what is going to happen and why (Oremland & Oremland, 1973). While friends and other family members are important to children, many, if not most, children go to their parents for comfort.

While nobody can allay children's fears better than their parents, the opposite is also true. Parents can either be of great benefit to their children while they are anticipating or going through a painful medical procedure or they can exacerbate their children's anxiety through a process of emotional contagion (Bush, Melamed, Sheras & Greenbaum, 1988). Children, who are "endowed with amazing sensitivity to the cues and signals that the world conveys" (Coppolillo, 1983, p. 57), observe the anxiety that their parents are experiencing. This compounds whatever feelings of anxiety that the children may already be having. This can then make the parents more anxious, which in turn makes the child more anxious and so on. Coppolillo stated that "on the morning of the surgery, most surgeons don't want parents near the child... because their overwhelming stress is transmitted to the child... you can see how the perplexity and anguish of the child's parents compound the malaise the illness has already produced" (Ibid., p. 57). The question seems to be, which came first- children's anxiety which triggered the mothers', or mothers' anxiety which

triggered the children's? Mabe (1991) found that children who were having trouble adjusting to hospitalization were more likely to have mothers who were also experiencing some emotional difficulties. Fosson et al. (1990) also found that in three of the four observation periods a significant proportion of the children's anxiety could be attributed to the parents'. They concluded that "thus in an unfamiliar and perhaps novel environment, children's feelings were cued by parental feelings to a significant degree" (p. 326). Oremland and Oremland (1973) agreed that in some circumstances parents should be kept away when the child would pick up on the overwhelming stress but, on the other hand, they state that "most parents, however, can be enabled to be a source of strength to their frightened child," because "who, after all, knows their child better than anyone... parents can be helpful in transmitting information in a way their child can comprehend, reducing the fear of the unknown" (p. 56). At this point I would have to agree with Gottlieb (1990) who thought that "the interaction of child and parental anxiety needs to be better understood so more precisely directed interventions can be offered" (p. 328).

2.3. Diagnostic and Treatment Related Pain and Coping Strategies

The focus of this review will be on pain caused by treatment or diagnostic procedures that the patients are subjected to when they come to clinic, and the coping strategies that researchers in the field have developed to help the patients cope with those procedures. It is beyond the scope of this dissertation to review critically all of the research done in this area, particularly in terms of the relative merits of the different coping strategies and mechanisms that have been developed. For a more comprehensive review please see Rudolph, Dennig, and Weisz (1995) and Peterson (1989). Instead, I have examined the literature from the viewpoint of an environmental psychologist who would like to provide information to architects and designers so that they may design environments that help the

patients cope during stressful medical procedures. In this regard, many of my comments about the studies and the literature will be to note the lack of information and discussion about the context/environmental conditions, especially the physical environment.

Before I begin, however, I would like to make a general comment about the literature that I reviewed. As a newcomer to the body of literature written about pain and coping with painful procedures, there were numerous concepts that I was not familiar with. The difficulty of the task of trying to make sense of the literature was exacerbated because, I found, as did Rudolph, et al. (1995), "marked inconsistency in researchers' definitions and means of operationalizing various components of the coping process" (p. 329). This problem was also noted by another reviewer.

One of the biggest problems with this body of research is that it continues to be fragmentary and piecemeal. There are hundreds of individual studies, but they are not comparable in terms of variables studied, measures, design, subjects, or time frame, even when people share the same conceptual orientation. It sometimes looks as if we are all conducting isolated studies on totally unique and unrelated phenomena. (Kupst, Mudd, & Schulman, 1991, p. 20)

The piecemeal and isolated character of the research and/or conceptual orientation is best demonstrated by the fact that many of the researchers do not cite Melzack and Wall's (Melzack & Wall, 1965; Melzack, 1986; Melzack & Wall, 1991) gate control theory of pain, which joins the neurophysiological and psychological aspects of pain perception (see below for a more detailed explanation). This omission is especially disconcerting when a major review article that considers pain a "multifaceted phenomenon" composed of physiological, cognitive, behavioral, sensory, and affective components (Rudolph, et al., 1995) does not make reference to the gate control theory. (Incidentally, these were the same authors cited above who thought there was a lack of consistency in the field.)

The lack of conceptual clarity was especially apparent to me when I tried to compare the different distraction coping responses/strategies/interventions the various researchers

used. I was particularly interested in distraction because, compared to the other interventions, elements of the physical environment can have a powerful impact on distraction interventions. The elements of the physical environment therefore lend themselves to study by environmental psychologists and manipulation by designers.

2.3.1. Treatment Related Pain

During the course of their illness most, if not all, of the children and teenagers who are diagnosed with a hematological or oncological disease experience pain at one time or another as a result of their illness, and/or diagnostic procedures or treatment modalities. The primary source of pain for patients when they visit clinics are diagnostic procedures: venipunctures, which were administered to oncology patients and hematology patients, and bone marrow aspirations (BMA's) and lumbar punctures (LP's) which were specific to the oncology patients. For many patients, pain caused by procedures is the most disturbing and fearful aspect of their illness and treatment, with more children complaining about the pain from their procedures than the pain from their illness (Miser, 1993). It is not unusual for patients to have to go through several years of these procedures and many of them do not become inured to the pain.

BMA's are the most invasive procedures and have been described as "one of the most traumatic and aversive medical procedures administered to children," (Jay, Elliot, Katz & Siegel, 1987, p. 860) which cause "documented extreme and virtually ubiquitous distress in children..." (Jay, Elliot, Fitzgibbons, Woody & Siegel, 1995, p. 3). Ubiquitous is perhaps too strong a word because McGrath, Hsu, Capelli, Luke, Goodman, and Dunn-Grier (1990) reported that in a survey of 77 patients "only" 73% indicated that their last BMA's caused them moderate to severe pain. In other words one-quarter of the patients surveyed did not experience severe pain even though this procedure involves:

... the insertion of a large needle into the child's hip bone (posterior iliac crest), followed by the suctioning-out of marrow with a syringe ... Often, only a local injection of lidocaine is administered which anesthetizes the skin surface and the bone but does not lessen the pain associated with the suctioning of the marrow... (Jay et al., 1995, p. 3)

In the study by McGrath and et al. (1990) cited above, 62% of the patients thought their last lumbar puncture, which is a routine diagnostic procedure "in which a long needle is inserted into either the bone or spinal column and fluid is withdrawn," (Jay, Elliot, & Varni, 1986, p. 601) and chemotherapy is injected, were moderately to severely painful.

Even venipunctures can cause a great deal of distress especially when they are repeated frequently (as many as 300 venipunctures during a course of treatment), because then the veins become less accessible. In one setting, up to one third of the three to nine year olds had to be restrained while the needle was inserted. (Manne, Redd, Jacobsen, Gorfinkle, & Schorr, 1990, p. 565)

The noxious stimulant caused by these procedures very frequently causes acute pain which can be intensified and exacerbated by "children's uncertainty, lack of control, and the probability of future painful treatments and disabilities" (McGrath, 1993, p. 50). But as noted above, the level of pain children experience for similar procedures can vary significantly even though "the majority of people, regardless of cultural background, have a uniform sensation threshold" (Melzack & Wall, 1991, p. 17). The same procedure can be experienced very differently by different people or even by the same person at different times because there is not a one to one correspondence between a noxious stimulus and the level of pain experienced. These differences could not have been explained by older models of pain which assumed a "direct correspondence between sensory stimulation and pain representations" (McCaul & Malott, 1984, p. 517). It was assumed that there were hard wired connections between specific pain receptors that relayed pain signals between the skin or viscera and the brain. No modulation of the signal was possible in these models so

that the intensity of the pain experienced was in direct proportion to the amount of tissue damage (Zeltzer, 1990; Melzack, 1986). In 1965, Melzack and Wall proposed what they called the gate control theory of pain which acknowledged the psychological factors involved in pain perception, the topic of the next section.

2.3.2. Gate Control Theory of Pain

The gate control theory of pain has recently been called the "most widely accepted and most productive model of pain" (Matthews, McGrath & Pigeon, 1993, p. 97), and "the current and most complete framework from which to understand the human experience of pain" (Johnston, 1993, p. 65). It has "demonstrated the highly complex nature of pain perception and response, and has led to our appreciation of the interactive variables in the pain experience" (Hinnant, 1994, p. 18). Basically, this theory posits that stimuli that arise from a noxious event can be "radically modified and even blocked at the earliest stages of transmission in the nervous system" (Melzack & Wall, 1991, preface). The reason for this is that those stimuli have to pass through a "gate" in the spinal cord before they can be relayed to the spinal cord cells in the central nervous system which project to areas in the brain which are responsible for the pain experience. The theory posits that there is a perception of pain "when the number of nerve impulses that arrive at these areas exceeds a critical level" (Melzack, 1986, p. 3). The theory proposes that gates, which are extremely fast acting, are in the dorsal horns of the spinal cord and are comprised of neural mechanisms that modulate the flow of nociceptive² impulses that are generated when tissue

² "Nociception is the initial physiological signal that alerts the central nervous system to the introduction of an aversive stimulus." Fordyce (1988) cited in Rudolph et al. 1995, p. 329

" 'Nociception' or 'nociceptive processing' refers to the detection of a noxious stimulus and the transduction and transmission of information about the presence and the quality of that stimulus from the site of stimulation to the brain. 'Nociception' is not synonymous with 'pain.' Pain is a psychological experience, the human perception; nociception is the activity in the nervous system that may lead to pain." (McGrath, 1990, p. 94)

is damaged. These gates are controlled by the input of small and large fibres from the peripheral nervous system. In general, the input from the small fibers opens the gates and allows the noxious signals to pass through, while large fibre inputs tend to close the gate and restrict the flow (Hinnant, 1994; Melzack, 1986; Park and Fulton, 1991).

In addition, and this is critical in understanding the "interface between psychological and physiological aspects of pain (Mathews, McGrath, & Pigeon, 1993, p. 97), descending controls or fibers from the brain have a powerful inhibitory influence on the gate. These descending fibers comprise a pain-inhibitory system and are activated by numerous psychological factors and environmental factors, which thereby "exert a profound impact on children's pain (McGrath, 1993, p. 40). Pain therefore is not simply the final result of a sensory system that merely passes along information about tissue damage to the brain. Rather there is a "dynamic process that involves continuous interaction among complex ascending and descending systems," (Melzack, 1986, p. 1) that modulate the nociceptive signals. Pain is therefore a multidimensional experience that is affected by numerous psychological factors. These factors will be discussed next.

2.3.3. Pain as a Multidimensional Phenomena

Numerous authors have noted that the level of pain perception a person experiences is a very complex and uniquely personal phenomenon (Anderson, Zeltzer, & Fanurik, 1993; Covelman, Scott, Buchanan, & Rosman 1990; Rudolph et al., 1995; Blount, Powers, Cotter, Swan, & Free, 1994; Hinnant, 1994; McGrath, 1990; Melzack & Wall, 1991; Melzack, 1986; Varni & Katz, 1990). Each pain experience can be characterized along a number of sensory, affective, and evaluative dimensions. (Melzack & Wall, 1991) During an invasive medical procedure, such as a BMA, there are many factors that influence how the pain will be characterized. There are the physiologic and sensory dimensions of the tissue damage, such as: location, duration, intensity, quality, but while

the "nociceptive afferent input" which results is "proportional to the intensity of the noxious stimulus, the pain produced by an injury is modified by many factors..." (McGrath, 1990, p. 209). According to McGrath there are the relatively stable influencing factors which are characteristic of patients; their: sex, age, cognitive level, previous pains, family learning, and culture; and profoundly influential psychological factors: situational factors, behavioral factors, and emotional factors. Situational factors include the children's understanding of the source of the pain, expectations about the duration of the pain, their ability to use simple coping strategies, and the amount of perceived control they have during the procedure. Behavioral factors include both the patients' overt distress behaviors and the parents' and staffs' responses. Emotional factors such as the amount of fear, anger, frustration, anxiety, and sadness can influence and modify pain perception (McGrath, 1993).

Although they categorize them differently, other authors Hinnant (1994), and (Anderson et al. (1993) identified the nociceptive modifying influence of many of the same factors as McGrath. What is missing, however, from all of these authors' analysis of the "context-specific factors" which "exert a profound impact on children's pain," (McGrath, 1993, p. 1404) is recognition of how the physical environment can influence children's state of mind, or act as a setting for interpersonal interactions. This oversight is to a certain extent addressed by Covelman et al. (1990) who stated that, "A child's response to pain, whether acute or chronic, is a complex interaction between individual and transactional context" (p. 225). Their model uses many of the same factors as the authors mentioned above, but in addition they included nonsocial environmental factors such as:

elements of the setting that can have an impact on the child because of their strangeness, novelty, or other characteristics that might influence the child's emotional state. (Covelman, et al., 1990, p. 226)

Unfortunately this was the end of the discussion on nonsocial environmental features. They did not discuss how, what, or why environmental elements might affect the

emotional state of their patients in any greater detail, either in the discussion of their model, or in their method section where they discussed relaxation techniques. I would have liked to have known what the environment was like where they relaxation techniques were taught. Were those environments designed to enhance the relaxation session? I also have questions about the treatment rooms. Were any modifications made to them to positively influence the children's emotional state? Granted their primary focus was on the family, and the chapter they wrote was quite brief, nevertheless it is disappointing not to have gained a greater insight on environmental variables.

2.3.4. Anticipatory Anxiety

Although there are many psychological factors that exacerbate the level of pain a patient experiences during a painful procedure, one factor, anticipatory anxiety and the associated distress, are particularly insalubrious (Anderson et al., 1993; Jay et al., 1985; Jay et al., 1986; Kellerman, Zeltzer, Ellenberg, & Dash, 1983; McGrath, 1993; Varni, 1990). Anticipatory anxiety can "amplify the perceived pain caused by actual tissue insult." (Jay et al., 1986, p. 601) and "in general the more fearful and anxious the child is, the stronger and more unpleasant the pain" (McGrath, 1994, p. 1404). Children and teenagers with cancer are particularly vulnerable to what McGrath (1990) called an anxiety-pain-anxiety, or a pain-emotional distress-pain cycle that can increase in amplitude because during the course of their treatment they will be subject to many and repeated invasive procedures. In other words, the more fear and anxiety a patient feels about a procedure, the more pain and distress they will feel during the procedure. This more intense pain perception will then create more anxiety about the next procedure, which leads to a higher level of pain, and so on. This heightened anxiety can cause patients to "lose their appetites, develop sleeping difficulties, have nightmares, act aggressively towards peers and siblings, .. require physical restraints despite sedation and analgesic medication" (McGrath, 1990, p.

438), or "become anxious and vomit as they approach the clinic building on the day of an anticipated bone marrow aspiration" (Kellerman et al., 1983, p. 85).

Fortunately there are a number of options available to reduce the amount of anticipatory anxiety patients feel, as well as the strength or intensity of pain during procedures, even procedures that cause considerable tissue damage. These include pharmacological (which I will not discuss) and non-pharmacological interventions. Particularly important are the coping skills children and teenagers can learn that "contribute to a sense of mastery and confident outlook toward coping with a future procedure" (Anderson et al., 1993, p. 438).

Unfortunately the powerful effect the sociophysical environment can have on reducing the amount of anticipatory anxiety the patients feel has not been addressed in a thoughtful and comprehensive manner except immediately before the procedure.

2.3.5. Coping with Painful Medical Procedures

As I noted earlier, I found it difficult to review the literature written about how pediatric patients cope with painful medical procedures. A major problem that I discovered is that, based upon the literature I reviewed, there are two major camps. One camp examines coping in terms of the typologies children use to cope such as: information seeking versus information avoiding, problem focused versus emotion focused, approach versus avoidance, etc. This literature is excellently reviewed by Rudolph, et al. (1995) The other camp discusses coping in terms of interventions which McGrath (1990) and Anderson et al. (1993) categorize as physical, behavioral, or cognitive. Surgical techniques, pressure, massage, or acupuncture are some of the coping interventions which are physical. Behavioral techniques include but are not limited to: exercise, operant conditioning, relaxation, and biofeedback. Distraction, attention, imagery, and hypnosis are some of the cognitive methods (McGrath, 1990). However, the categories are not

mutually exclusive because "most non pharmacological methods vary in the particular combination of physical, behavioral and cognitive modulation that is involved" (McGrath, 1990, p. 133), and this makes the literature difficult to interpret. In fact, several authors use the term "cognitive-behavioral" (McGrath, 1994; Jay et al. 1995; Berde, 1995; Varni, 1990) to characterize their or other authors' methods.

A weakness of both camps is that the researchers become advocates for either a particular typology or a particular intervention, thereby limiting the number of coping strategies available to their patients. This is not in the patients' best interest since the effectiveness of one therapy by itself is limited because only one pain-suppressing mechanism is activated. Instead, if several different types of interventions, i.e., multiple convergent therapy, are used during one session such as: relaxation, hypnosis, distraction, more pain modulating systems are apt to be activated cumulatively. This increases the possibility for greater pain reduction (Melzack & Wall, 1991).

Restricting the coping strategies is also in contrast to a process and context oriented concept of coping, which assumes that a person may or may not use the same coping strategy at different times (Lazarus, 1984) or stage of the stressor (Folkman & Lazarus, 1988). It is important to recognize the stage or phase; anticipation, confrontation, post confrontation (Folkman & Lazarus, 1988) or appraisal, encounter, and recovery (Peterson, 1989; Peterson, Harbeck, Chaney, Farmer, & Thomas, 1990), in which a stressor occurs because at each stage, "the demands placed on the child, the types of coping responses elicited, and the likely efficacy of various responses" (Rudolph, et., 1995, p. 343) may be different. In terms of coping with a medical procedure, this means that the way patients cope with the procedure may be very different than the way they cope with their anxiety before the procedure (Blount, Sturges, & Powers, 1990; Broome, 1990; Peterson, 1989; Peterson et al., 1990). Blount et al. (1990) found that children undergoing bone marrow

aspirations and lumbar punctures used phase specific coping mechanisms, such as humor and nonprocedural talk during the non-painful phases and audible deep breathing during the painful phases. They concluded that "phase characteristics should be considered when designing therapeutic intervention programs" (p. 44).

While understanding the characteristics of the different phases is important, some coping strategies or interventions are more effective for some children than for others (Anderson et al., 1993; Melzack & Wall, 1991), or for the same patient at different ages (Smith, Ackerson, Blotcky, & Berkow, 1991). McGrath (1993) posited that:

Further research will probably continue to elucidate that a child's pain relief during medical procedures is not primarily the result of a unique non pharmacological intervention (e.g. hypnosis, distraction), but the result of how effectively the intervention altered relevant situational, behavioral, and emotional factors. (p. 51)

As noted earlier, McGrath did not, nor did many other researchers, address the elements in the physical environment that might have an effect on the situational, behavioral, and emotional factors that modulate patient's perception of pain. I think that this is a serious oversight, and therefore I will concentrate the rest of this review on interventional studies and examine them specifically in terms of whether or not they addressed the effect the physical environment had on the intervention.

2.3.5.1. Distraction Coping Methods

Distraction coping strategies, as do other cognitive coping techniques, such as imagery and hypnosis, have a principal goal: to have the patients focus their attention away from the painful procedure so intently that the pain perception is lessened (McGrath, 1990). Previously distraction was thought to be effective based on a cognitive model of pain that assumed that pain perception depended upon the brain attending to and processing painful signals. The mechanism underlying the effectiveness of distractional techniques were thought to be their ability to consume some degree of a person's attentional capacity

because it is difficult for us to focus on more than one stimulus at a time, which would otherwise be focused on the noxious stimuli. Within this model distractors interrupt the painful sensation processing (McCaul & Malott, 1984; Redd, Jacobsen, Die-Trill, Dermatis, McEvoy, & Holland, 1987). Recently the theoretical underpinning of this model has been questioned. According to McGrath (1990):

Distraction has been incorrectly perceived as a simple diversionary tactic in which a child is passively placed in a situation where he/she does not attend to the presence of pain. The implication is that the pain is still there but the child is momentarily focused elsewhere. (p. 160)

An alternative model postulates that distraction is an active process that is effective because it may "directly attenuate the neuronal impulses invoked by a noxious stimulus" by activating "endogenous opoid and nonopoid pain-suppressing systems," (McGrath, 1990, p. 160) or by activating "the descending systems of the brainstem so that inputs are modulated at spinal levels (Melzack & Wall, 1991, p. 260). Distraction, and other cognitive techniques, in this model, do not simply allow the children to ignore their pain. but actually reduce the transmission of neural events that precipitate a painful experience before they reach the brain.

Interestingly, even though there is disagreement on the mechanisms underlying distraction's ability to alter pain perception, there is agreement about the relationship between the distractor and the level of pain. McCaul and Malott (1984) stated that "distraction techniques that require more attentional capacity will be more effective" (p. 516), and McGrath (1990) declared that "the more absorbed they (children undergoing an invasive medical procedure) are by an event, the more their pain will be reduced" (p. 160).

It is apparent from the previous statements that distraction techniques differ in their ability to command a patient's attention. Even though what may be very distracting to one patient may not be distracting to another, or to the same person at a different time, I was

surprised while reviewing the literature, as were McCaul and Malott (1984) more than ten years ago, by the "absence of experiments comparing distraction strategies that vary in quantified attentional requirements" (p. 521). Apparently, little or no attempt has been made to try to define the distractors in terms of what McCaul and Malott (1984) called stimulus intensity. This is of interest not only to academic researchers, but also to clinicians because the more attentional capacity a task demands, the greater its pain reducing capacity (McCaul & Malot, 1984; McGrath, 1990).

This is not to say that researchers have not addressed the issue of "attentional requirements." Some have, but they have not done so in a rigorous or analytical manner. Anderson et al. (1990) mentioned a number of what they called cognitive tasks: singing, counting, playing games such as checkers or video games, drawing the patient's attention to objects in the room, etc., that can be used to distract patients during medical procedures. However, neither the attention demanding properties of those tasks that made them effective distractors, nor the relative efficacy of those tasks were addressed. Similarly, Varni and Katz (1988) made no distinction between what they called "behavioral interventions... which distract" (p. 109) such as guided imagery, video games, or interpersonal interactions that could help patients cope with their chemotherapy treatments.

Other studies demonstrate why it is important not only for academic purposes, but more importantly why it is crucial in the clinical setting to develop measures to quantify and compare different distraction tasks. In one study by Jacobsen, Manne, Gorfinkle, and Schorr (1990), parental behaviors during their children's venipunctures were observed. They found that the parent's use of distractive techniques such as saying "Look at the drawing," or "Look at Mommy" made no difference in terms of the children's distress. They attributed this to the fact that the procedure was in full view of the children, and the types of distractions the parents used were not compelling enough to attract their children's

attention away from the procedure. In their concluding remarks they stated: "These results do not preclude the possibility that other forms of distraction, which may be more engaging than nonprocedural talk could successfully relieve stress" (p. 575).

They then mentioned distractors used in other studies: party blowers and video games which had successfully reduced children's pain during venipunctures and the adverse side effects of chemotherapy respectively. What they did not do was compare the attributes of the distraction to try to determine why the parents' attempts to distract their children were not effective. For instance they did not describe the drawings on the wall, which is not unusual- none of the other studies where pictures were used as distractors did either but one would hope that at some point the attributes of pictures could be quantified in terms of their attention holding properties within a developmental framework.

Another study, Fowler-Kerry and Ramsay-Lander (1990) demonstrates the need to use distractors that are developmentally appropriate. In this study, two cognitive strategies: music distraction and suggestion were used in conjunction to reduce the amount of distress children felt during injections. It was discovered that the intervention benefited the older children³ more than it benefited the younger children. The music distraction consisted of "novel music and lyrics," which the children listened to with headphones, (Fowler-Kerry & Ramsay-Lander, 1990, p. 251) apparently did not capture the attention of the younger children as much as it did the older. Nevertheless, by noting that the music and lyrics were chosen because of their novelty the authors took one small step towards specifying dimensions of music that have attention holding power.

As part of a multi-intervention coping strategy to help children cope with bone marrow aspirations, Kuttner, Bowman, and Teasdale (1988) chose interesting objects

"such as hand puppets, squeaky toys, and pop-up books to shift visual and auditory attention in a meaningful manner" (p. 376). Not only were objects chosen which would demand the attention of two of the patients' senses: sight and hearing, physical activities such as bubble blowing, squeezing their mother's hands or breathing with the therapist were part of the intervention. According to the authors "an intense level of interaction was maintained between the child and therapist" (Ibid., p. 376.). This multi-intervention "behavioral distraction" strategy was compared with a "hypnotic 'imaginative involvement' intervention and standard medical practice in order to determine which reduced the patients' pain, anxiety and distress over two intervention sessions. Their results were very intriguing because they demonstrated age related differences. During the first session, the hypnotic treatment was more effective for the younger children who were 3 to 6 years of age, while both treatments were effective for the older children, who were 7 to 10 years of age. Both interventions were effective for both age groups during the second session. This indicated to the authors that there was a learning component with the distraction intervention that had to be considered with the younger children. They also discovered that, over both treatment sessions, the younger children's distress was best mitigated by the hypnotic treatment. (Hypnotic methods will be discussed below.) These results are particularly important because they demonstrate that there is a difference between the way a distraction intervention works with children from different age groups and because they were able to show that the efficacy of different types of interventions may be age dependent.

Developmentally appropriate distractors were addressed by McGrath (1990) within her belief that: "The essential feature for producing pain relief by distraction is the child's ability to attend fully to and concentrate on something... the choice of distraction is critical to the success of this cognitive intervention" (p. 160). She recommended that, if there are

choices available, the specific activities or objects that are used to distract children should be selected based upon what would be most appealing to the children, using their normal interests as a guide. These choices are, to a certain degree, determined by the age of the children. According to McGrath (1990) "Infants and young children require concrete external events or objects to absorb their attention..." while "older children can be distracted by both physical and mental activities" (pp. 160-161). These general statements were attached to specific recommendations about the attributes of the distractors, which, although they were not stated in precisely quantifiable terms, at least identified some characteristics that demanded attention. McGrath (1990) recommended that "interesting toys with complex visual, auditory, or tactile dimensions" (p. 160) be used to distract infants and young children. However, she did not operationalize those dimensions, so even though it makes sense that "the more interesting the object, the more likely it is that children will be attentive to it," (McGrath, 1990, p. 160) without more exact specifications it is difficult to compare toys in a rigorous and scientific manner.

The need to develop age appropriate (and perhaps gender specific) standards to judge the effectiveness of distractors becomes quite clear when another type of distraction, video games, are examined. Video games can be considered very complex toys, with very sophisticated as well as complex visual, auditory and even tactile properties, but they are very different from the toys that I can imagine, which is all that I can do, that McGrath (1990) would recommend giving to infants and young children. They are, however, very effective distractors, at least for older boys.⁴ In studies by McGrath (1990) and Kolko and

⁴In McGrath's (1990) description of the study it is unclear what the patient demographics were of those who were part of the intervention. She does state that the program was "quite successful for 10-12-year old boys" (p. 161). Later she noted that because of "the diversity of games and educational programs for children of all ages, an extensive repertoire of innovative and interesting distractions if available for children" (p. 161). In Kolko & Rickard-Figueroa's (1985) study, 3 boys; 11, 16, and 17 years of age, were the only participants.

Rickard-Figueroa (1985) video games were used to distract patients while they were receiving chemotherapy infusions.

The video games that McGrath gave the patients "required their complete attention during the 3-4 hours in which the intravenous drug was administered" (McGrath, 1990, 161). Both studies found that compared to a baseline condition video games were effective in reducing the severity of the chemotherapy side effects as well as the anticipatory anxiety the boys experienced. These results are especially encouraging because for teenagers the major factor disrupting their adjustment to their disease is the distress related to the chemotherapy treatment. Another benefit, besides the reduction of distress that Kolko & Rickard-Figueroa (1985) hoped that using video games would produce, was the improvement of the patients sense of personal mastery. It is critical to have a very clear understanding about the characteristics of video games that foster such powerful levels of involvement and concentration, so that other interventions could be developed or used that incorporate the same or similar attentional requirement. It has been postulated that the effectiveness of video games as a distraction technique can be attributed to their ability to consume most of the patient's active attention by engaging their different senses in a constantly changing and challenging activity that increases with difficulty the longer the games are played (Redd, et al., 1987). Kolko and Rickard-Figueroa (1985) suggested that the reason video games are so effective is that they provide constantly changing stimuli from different sensory modalities" (p. 227).

Specifying more exactly the properties of video games that make them such effective distractors is an important issue because, although, many children enjoy using video games and find them very engaging, many children do not. So even though there

have been positive results with video games "video game playing is certainly not the only or necessarily the best method of distraction for all patients... the critical factor is the patient's attentional involvement " (Redd, 1994, p. 114). The level of concentration that patients' were able to attain rather than the games themselves were what reduced their side effects and anxiety (McGrath, 1990).

Based upon the literature at this point it is not possible to quantify with any degree of specificity the attention holding powers of distraction techniques or objects in the environment. This does not mean that researchers and clinicians can blindly choose an intervention strategy. They have to be aware that the choices they make when they choose elements in the environment to act as distractors can significantly affect the well-being of their patients, as well as the results of their studies.

2.3.5.2. Hypnosis

Hypnosis has been another non-pharmacological intervention that has been widely used to control anxiety and pain in the pediatric population, (Anderson et al., 1993; McGrath, 1990; Zeltzer, 1990), including pediatric hematology/oncology patients (Jay et. al, 1986, Kellerman, et al., 1983; Kuttner, et al., 1988; Zeltzer, 1983) Precisely how hypnosis is effective in moderating pain perception is unknown, but it has been suggested that it "may have its predominant effect by activating control processes that modulate the input as it is transmitted through the brain" (Melzack & Wall, 1991, p. 261). An alternate, and more recent, hypothesis based on the gate control theory places the effect at the spinal cord level:

The brain in its altered state of consciousness is believed to exert a downward influence on the central nervous system, modulating the "gates" at the dorsal horn of the spine and altering pain perception at the CNS level. (Kuttner, 1993, p. 230)

People vary in their capacity for hypnosis. In general, children are "highly hypnotizable" (Hilgard, 1986, p. 216), with susceptibility rising rapidly after the age of four or five, reaching the peak of hypnotizability between the ages of eight to twelve, and then decreasing slowly as they grow older (McGrath, 1990; Kuttner, 1993). Preschool children do not experience a true state of hypnosis, often needing external stimuli to maintain their imaginative involvement, even though they can become deeply absorbed by their fantasies, indicating that a better term would be "proto-hypnosis" (Kuttner, 1993, p. 231).

The most distinctive and powerful characteristic of hypnosis is that it is "essentially an altered state of consciousness... within a relaxed physical state" (Kuttner, 1993, p. 229). Unlike distraction, where the intention is for the patients to focus their attention on external objects and maintain a strong contact with reality, hypnosis focuses attention inward through the use of imagination and fantasy (Kuttner, 1993). The altered state of consciousness is achieved by first inducing a hypnotic trance through the use of techniques such as eye fixation, hand levitation, visual imagery, slow rhythmic breathing, and progressive muscle relaxation (Kellerman, et al., 1983; Kuttner, 1993). Once the patients are in a trance, a variety of post-hypnotic suggestions can be made that reduce the level of pain perception by creating a "distancing or disassociation from the physical and psychological trauma (Kuttner, 1993, p. 232). There can be suggestions for "increased well-being, reduced discomfort, and greater mastery during the procedure (Kellerman, et al., 1983, p. 87); for "reframing (putting the pain experience in a different perspective), and altering the sensory experience" (Anderson, et al., 1993, p. 440); for "relaxation, reduced anxiety, increased control, and pain reduction... (McGrath, 1990, p. 165), and for "direct hypnoanalgesia such as the 'magic glove' or the 'pain switch' " (Kuttner, 1993, p. 233).

Only one of the authors that I reviewed mentioned any aspect of the setting in which the hypnotic interventions took place. Kuttner (1993) noted that, with younger children, aids such as music, bubbles and puppets could be used to help maintain their trance. Since hypnosis is so inward focusing, it is not surprising that the environment has not merited the attention it has received from people who study and apply distraction interventions. When reading the literature on hypnosis it almost seems as if the context does not effect the intervention. Once the trance is induced and an altered state of consciousness is reached this is probably true, but I know of one case where a patient's concentration was disturbed by screams from an adjacent room while he was in the induction phase. Would loud voices outside the room have had the same effect? Does it matter what is in the cone of vision during eye fixation? And how important is the sociophysical environment before the induction phase begins? Zeltzer, et al. (1983) mentioned the problem of those patients who are "hypnosis rejectors" and offered the opinion that they might do so because they are highly anxious. They then suggested that those patients might be hypnotizable if non-hypnotic techniques were used to reduce their anxiety. Could not the physical environment play a part in reducing their anxiety by a supportive context for a "therapeutic milieu" (McGrath & Unruh, 1993)? Might not a well-considered physical environment also aid in inducing a hypnotic trance?

2.3.5.3. Imagery & Relaxation techniques

Imagery and relaxation techniques, such as progressive muscle relaxation and deep breathing, as noted above, can be used to help patients alter their state of consciousness prior to receiving hypnotic suggestions. These techniques can also be used alone, or as part of a cognitive-behavioral package (Blount, et al., 1994; Jay, et al., 1987; Jay, et al., 1995; McGrath 1990; McGrath & Unruh, 1993; Varni, 1990).

Imagery, when used in the context of trying minimize the amount of pain patients feel during an invasive procedure, involves a deliberate use of an absorbing fantasy that is incompatible with the noxious stimuli. What makes this type of fantasy or daydream so powerful is that involves more than just a visual image. There is an immersion in the tastes, sounds, and feelings of the experience to such a degree that the patients' feel as if they are experiencing them at that moment (McGrath, 1990). Patients can imagine their favorite or special place (Kellerman et al., 1983; Kuttner, 1993), that they are "floating on a soft, fluffy cloud" (Anderson, et al., 1993, p. 444), or that they have their super hero's characteristics (McGrath, 1990). The type of image or fantasy is not important as long as the patients are able to "select an appropriately vivid image consistent with the objectives of relaxation and pain relief" (McGrath, 1990, p. 162).

The most common type of relaxation techniques are progressive muscle relaxation and deep breathing exercises (McGrath, 1990). During progressive muscle relaxation "muscle groups are contracted and relaxed in a specific sequence" (Anderson, et al., 1993, p. 444). Deep breathing exercises require that the patients learn to "breathe calmly and deeply to relax their bodies ... the slower and deeper their breathing, the more their bodies seem to relax naturally" (McGrath, 1990, pp. 149-51). Younger children can be given party blowers or bubbles to assist them in their deep breathing.

Again, as with the hypnosis literature and studies, little or no mention was made of the context where these types of interventions took place. And, again, this seems to be an oversight that needs further study. For instance, during breathing exercises, or progressive muscle relaxation does it matter how comfortable the furniture is, or how harsh or soothing the quality of light is?

2.4. The Institutional Environment

In order to appreciate the types of stress that patients are subjected to, it is important to understand a "typical" hospital setting. The institutional environment of the hospital is a complex web of sociophysical factors that trap patients in a condition of patienthood where their psychological and physical well-being may be adversely affected. Seemingly cruel strangers can frighten young children and even adolescents with their unfamiliar machines and instruments and compromise their abilities to master fears of the medical procedures and hospitalization (Weir, 1983). Hospital rules, regulations, and procedures conspire to strip patients of their individuality and create the role of patient for them. Individuals entering the hospital become patients with a lack of personal control. They are given limited freedom of choice, access to information is controlled, and their behavioral independence is often curtailed. (Winkel & Holahan, 1986). In the hospital milieu, where there is a very traditional and formal organization with an emphasis on status differences and a strict hierarchy, a person is expected to assume the role of a "good" patient and rely on the expertise of the medical professionals. By doing so, patients may neglect to take responsibility for their own health and recovery (Shumaker & Reizenstein, 1982). The dehumanizing aspect of the hospital is often exacerbated by the institutional quality of the physical environment.

For most people in our society, institutional environments are inescapable and shape our lives from life until death. Institutions can be total or partial. Total institutions, such as residential psychiatric hospitals or jails, control all aspects of the residents' or inmates' lives for long periods of time. Partial institutions, such as schools, have many of the same characteristics as total institutions, but they do not control all aspects of the students' lives because, unless they are boarding schools, the students are able to leave every day. Total or partial, institutions share characteristics; the nature of the physical space, activity patterns, and the picture over time, which conspire to create a humane rather

than a human environment (Goffman, 1961; Rivlin, 1986). The typical, homogeneous, sterile institutional environment is also the result of "the mass purchasing of items, the emphasis on easy-to-clean materials," (Rivlin, 1986, p. 7) and particularly in hospitals, the emphasis on maintaining a disease free environment. The "institutional quality" of institutional space has not gone unnoticed, but even though staff and clients may complain, there is what Rivlin called the "unchanging qualities of institutional spaces" (Rivlin, 1986, p. 9). Patients' environmental needs can also be short-changed because patients are low on the user group hierarchy in the hospital. They may be subjected to unnecessarily stressful environmental conditions because they are often not part of the decision making process during design. Space in hospitals is valuable as well as scarce, so that when heads of departments wage battles over space, patient spaces such as waiting areas or lounges may be annexed by the medical professionals (Shumaker & Reizenstein, 1982).

Hospitals can also be threatening, especially for children. Cooke (1967) talked about how the absolute strangeness of the environment could be terrifying, comparing it to a chamber of horrors. Nierenberg and Janovic (1978) described the scale of hospitals as being awesome, as well as being strange, noisy, mysterious places where most of the machines and equipment are larger than children and where even beds are high, hard and cage like. Although major efforts have been made to make the hospital experience easier on children since Cooke (1967) and Nierenberg and Janovic (1978) wrote about the hospital experience, the physical environment of hospitals can still be psychologically "hard," inducing in children a "sense of helplessness, and feelings of anxiety and depression" (Ulrich, Simons, Losito, Fiorito, Miles, & Zelson, 1991, p. 11). Apparently the "overall rational plan" identified by Goffman (1961) is more demanding than the need to create human environments, which means that in addition to having to cope with many strangers

and institutional policies, patients, especially children also have to cope with a new and often threatening environment.

Because patients enter hospitals with their coping abilities diminished "*any* [authors' italics] stressors they encounter that go beyond their illness can threaten them by diverting their physiological and psychological mechanisms ..." (Shumaker & Reizenstein, 1982, p. 189). Winkel and Holahan (1986) also argued that the hospital milieu could be stressful for patients, stating that there is an "interaction between the strains associated with a person's condition and the ambient stressors that may be created as a result of the design and operation of the treatment environment" (p. 19). Patients' well-being and the level of stress they experience can be influenced by aspects of the sociophysical environment such as: the spatial layout of the hospital, lack of personal control over the environment, environmental stressors associated with comfort and level of stimulation, and the symbolic meaning of the hospital environment. In a poorly designed hospital, where these aspects of the sociophysical environment are not considered, their combined negative impact can create tremendous stress for the patients and their families.

Hospitals are not only intimidating because of their size, people can be confused by the layout of the spaces while trying to find their way around in them, which can cause unwarranted anxiety (Carpman, Grant, & Simmons, 1986). The layout of large hospitals that have grown over time can contribute to patients' and their family members' stress because wayfinding can be very difficult. The relationship of spaces may not be self-evident and design features such as signage and graphics, color coding, lines of the floor or walls and redundant cueing may be missing or confusing. Adding to the difficulty of finding a particular room is the fact that most patients' rooms look the same. In addition wayfinding, is influenced by 1; the characteristics of the patients, whose ability to process environmental cues may be impaired because of the stress they are under or their age; 2. the

social milieu of the hospital where the hospital personnel may not have time to give adequate directions (Shumaker & Reizenstein, 1982). On a smaller scale the layout of the space can also affect the amounts and types of social contact that are possible, with one study demonstrating that seating arrangements can affect the amount of social interaction and conversation that occurred (Holahan, 1972).

The layout of the space also can have a direct and often negative impact on patients sense of control of their space which and affect their sense of sense of privacy and territoriality. (See next section for a longer discussion about privacy.) Patients' need to control privacy situations for conversations, for time to be alone, and for freedom from surveillance are so critical that Shumaker and Reizenstein (1982) stated that:

patient control of privacy should be a design principle... privacy provides patients with coping strategies (i.e., access to social support and perceptions of control) that can reduce their stress and assist in their recovery, and its absence can increase the stress experienced from other sources and make the individual feel dependent and helpless. (pp. 209-210)

Patients also need control over their personal territory because the social and physical milieu of the hospital conspire to depersonalize the individual. When patients are allowed to establish their own territory in the hospital by personalization, their sense of security and self-identity are increased, reducing the stress of an unfamiliar and unfriendly environment and opening up the possibility for positive coping strategies (Shumaker & Reizenstein, 1982).

Winkel and Holahan (1986) posited that another area of impact, environmental stressors, may create physical and/or psychological strain because:

the source of these psychologically based concerns stems from an interaction between the strains associated with the person's condition and the ambient stressors that may be created as a result of the design and operation of the treatment environment. (p. 19)

They identified stressors which are either the result of information overload or restricted environmental stimulation. Hospitals are often crowded and noisy with hard surfaces that reflect noise and glare. On the other hand, they can be deadly dull, painted with "institutional" colors and outfitted with a plethora of manufactured items designed for economy rather than for aesthetic appreciation. The environment can also send signals that something painful is about to happen. One patient who had leukemia had to have a bone marrow aspiration. He stated that "when I went into that white room with walls of needles and syringes, I didn't know what to do, whether to run and hide or to go ahead with it" (Kelley, 1983, p. 21). Other environmental factors such as temperature and humidity, lighting, manipulation of switches, buttons, furnishings, or equipment, body positioning, and odors can affect patients' physical and psychological comfort.

The unfamiliar noises in the hospital caused by medical professionals, medical equipment, other patients may sound like a cacophony to patients who may be highly sensitive to sound due to the nature of their illness, pain and the fact that they may have no other positive distractions. And, as demonstrated a quote from a San Francisco newspaper, in some instances a mysterious voice over an intercom may be very frightening to a young child,:

The nurse at the desk tried several times to communicate with four-year-old Johnny via the intercom over his bed. At last she said in some exasperation: "Come on, Johnny, answer me - I know you're there." After a slight pause, a very frightened little voice asked: "W-w-what do you want, wall?" (Caen, 1970, cited in Lindheim, Glaser, & Coffin, 1972, p. 31)

Patients who are already not feeling well will be further stressed if the temperature of the room where they are staying or being treated is not comfortable to them. Rooms may be too hot or too cold depending on the orientation of the building, or the hospital administration may maintain the temperature of the building which is not comfortable to the patient (Shumaker & Reizenstein, 1982).

Poor lighting conditions may be the result of fixtures which are glaring or not bright enough. Light levels that are appropriate for one user group such as nurses and doctors when they are performing their duties may be too bright for another, the patients. Glare may be produced by fluorescent lights shining off of highly polished floors. Windows which allow a view of the outside may also be blinding especially in corridors (Shumaker & Reizenstein, 1982).

When patients are not able to manipulate switches, buttons, furnishings, or equipment their image of themselves as passive and dependent is reinforced whether they put up with the existing condition or whether they act assertively and have either a nurse or an aide help them. Closely associated with patients' ability to manipulate their environment is their ability to use the furnishings. For instance, they should be able to get out of a chair which provides them with proper back support (Shumaker & Reizenstein, 1982).

The symbolic meaning of the hospital environment can have an impact on the amount of stress patients' experience. The design of the hospital can affect the image patients have of themselves. It can tell patients that their needs are "natural, anticipated, and important or that these needs are deviant and unimportant" (Shumaker & Reizenstein, 1982, p. 212). If the factors in the sociophysical environment which can cause stress discussed above are minimized, the symbolic message that patients receive is that they have entered a caring milieu where the stress of hospitalization will be minimized.

2.5. Privacy

With regard to this study, the issue of privacy deserves special attention because it is a complex phenomenon that can and should have a major impact on the design of a clinic. Unlike the inpatient areas of a hospital where privacy needs can be met with single

bed rooms, the issue becomes much more subtle when privacy issues have to be addressed in a clinic setting where rooms for privacy may not be an option.

Privacy has been defined by authors several different ways. Westin (1967) defined privacy as the "claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others" (p. 7). Privacy, as defined by Altman (1975), is an interpersonal boundary regulation process by which a person or group regulates interaction with others, or more succinctly, as selective control of access to the self. Wolfe (1978) rather than defining privacy felt that "the problem of privacy could be viewed along a series of dimensions that might aid the development of theory, research, and application" (p. 177).

According to Westin (1967) there are four basic states of privacy: solitude, intimacy, anonymity, and reserve that people use to achieve "individual goals of self-realization" (p. 39). People achieve a state of solitude when they are separated from a group or not being observed. They may be subjected to stimuli which disturb their presence of mind however, such as noise or odors. Intimacy fulfills a basic human need for close contact with other individuals. In a state of intimacy, individuals form a small group, separated from others, in order to form close relationships. Anonymity occurs in a public space where an individual feels free from identification and surveillance. People achieve a state of reserve by erecting a psychological barriers around themselves, which have to be respected by others, when they want to limit communication about themselves. Westin (1967) argued that these four states served four functions: personal autonomy, emotional release, self-evaluation, and limited and protected communication. Personal autonomy is closely linked to a person's sense of individuality and "core self." A person's autonomy can be severely damaged by others who penetrate the inner zone of the core self either through malice or "because they do not recognize the importance of ultimate privacy

or think that the casual and uninvited help they may be rendering compensates for the violation" (Westin, 1967, p. 33). People need time to be alone with their thoughts and feelings to grapple with and explore aspects of their selves that they are not sure about. They need privacy to adjust the "mask" that they present to the world as they perform their roles.

Maintaining that mask is very demanding and people need time for "emotional release"; a time when they can be "offstage," step out of their roles and be themselves, either alone or with friends or family. They need time when they can vent their anger at the system, deviate slightly from social norms, perform activities of daily living which normally occur behind closed doors, and recover from the shock of losing a friend or loved one. In addition "privacy also performs a protective function at moments of less intense stress, during the periods of anxiety and uncertainty which are a part of daily life" (Ibid., p. 36).

Finally, privacy is necessary for limited and protected communication. Limited communication requires a psychological distance where some boundaries are established and respected in interpersonal relationships both public and private. Protected communication on the other hand involves confidences and trust. The boundaries are lowered and secrets or confidential information are revealed. This can occur on a very personal level such as between family members or between friends or on a professional level between the patients and their families and the medical staff.

Altman (1975) posited that the function of privacy could be examined on two levels: (1.) management of interpersonal relations and social interaction and (2.) the regulation of privacy as being of utmost importance to effective psychological functioning. Altman's dialectic model of privacy regulation is basic to his definition of privacy and as such has a direct relationship to how well a person functions psychologically. In the dialectic model,

privacy is considered a dynamic process in which people selectively control their interaction with other people. Sometimes they seek out interaction with others, and sometime they keep to themselves. In Altman's model there is a "boundary control" process utilizing four privacy-regulation mechanisms: verbal behavior, environmental behavior, nonverbal behavior, and cultural practices which operate in many different combinations to regulate one's "openness" or "closeness" to others to achieve an optimal level of privacy.

The "desire for a given form or quantity of privacy" (Altman, 1975, cited in Wolfe, 1978, p. 179) is not context free and "concepts and patterns of privacy and privacy invasion are strongly tied to or defined by the experiences of given situations" (Wolfe, 1978, p. 179). What does the given situation of pediatric oncology patients mean in terms of privacy? Bearison (1991) stated that:

Children become close friends with other children in the hospital who have cancer, and they share their most intimate thoughts and feelings. In many cases it is easier for children who have cancer to be intimate with a peer who has cancer than with anyone else. (p. 133)

What are the environmental conditions that would facilitate this kind of intimacy? Family relationships are often strengthened when they have to cope with the stress of a child who has cancer (Bearison, 1991). Are the privacy conditions that would facilitate this type of bonding the same or different than the privacy conditions that pediatric oncology patients need for their friendships to grow? Issues surrounding privacy are critical because they have such an impact on children in hospitals.

2.6. Children's Health Care Facility Design Literature

Two books stand out in the children's health care design literature: Changing Hospital Environments for Children by Lindheim, Glaser, and Coffin (1972), and Child Health Care Facilities by Olds and Daniel (1987). In Changing Hospital Environments for Children, Lindheim et al. (1972) were primarily concerned with the design of spaces within

a nursing unit. They based the majority of their design guidelines on the specific developmental needs of infants, toddlers and preschoolers, school-age children and adolescents with additional chapters devoted to family participation and the needs of the staff. In the four chapters devoted to the different developmental stages, Lindheim et al. (1972) first discussed the developmental needs of a particular age range, and then gave specific instructions which directed the design guidelines. Frequently the instructions were followed by specific types of rooms with their own design guidelines. For instance, in the chapter on grade school children, the instruction: "Provide continuity in acquiring and exercising cognitive and motor skills," (p. 60) was followed by descriptions of, and design guidelines for a schoolroom, music practice room, and a play and athletic area.

The chapter on teenagers was particularly effective, especially the authors, consideration of teenagers' privacy needs, recommending not only a teen dayroom but also a quiet room where they could be alone to deal with the stress that they were under or talk to someone. In addition to the dayroom and quiet room, a teen sanctuary was recommended so that teens would have a place that was under their control.

While Lindheim, et al. (1972) discussed many of the problems associated with hospitalization, such as confinement to bed, the lack of privacy, anxieties due to body image problems, separation from friends and familiar environments, the stress and anxiety caused by pain and discomfort was not addressed to any significant degree. In a reference to the hospital schoolroom, they stated that it could be "a refuge from the medical environment and all it means in terms of treatment and pain" (Lindheim, et al. 1972, p. 61). Unfortunately they never discussed how the environment could either help alleviate or aggravate the effects and perceptions of those treatments and pain. In one of the few places that they mentioned comfort, one of the design guidelines for toddlers and preschoolers recommended that raised platforms be built that the children could sit on comfortably while

eating or playing which would also allow nurses to help them without straining their backs while bending over (Lindheim, et al. 1972). This type of guideline is critical because consideration for patients' comfort while they are in a hospital should be a paramount concern. Unfortunately, guidelines proposing ways to minimize the children's discomfort were not included. Many of the guidelines would have been equally suitable for a camp or school. What makes the experience of hospitalization so different from either camp or school are the pain and discomfort associated either with a medical condition or invasive medical procedures. I did not get a feeling for what hospitalization was like for the patients because their voices were not included, except in an appendix where excerpts from essays about misery were introduced almost as an afterthought, rather than being included within the body of the text.

Fifteen years after Changing Hospital Environments for Children was published, the ACCH (Association for the Care of Children's Health) published Child Health Care Facilities with design guidelines by Anita Olds and literature outline by Patricia Daniel (Olds & Daniel, 1987). A major emphasis of the book was on how the physical environment could affect the psychological well-being of all the users: staff, children and their families. Specifically addressed in the first section were the special psychological and developmental needs that have to be considered when designing a health care facility for children. The psychological considerations that Olds discussed were: the impact of beauty, the need for movement, the need to feel comfortable, the need to feel competent, and the need to feel in control (Olds & Daniel, 1987, pp. 1-5). The sections such as external design, public spaces, patient living spaces and medical spaces are thoughtfully grounded in the psychological considerations mentioned above. The major questions that I have after reading Old's guidelines have to do with issues of pain, and discomfort.

Olds (Olds & Daniel, 1987) discussed the need for children to feel comfortable without addressing the pain and discomfort that were the result of illness or medical procedures. She instead was concerned with comfort or discomfort that was the result of sensory stimulation from the environment. She recommended taking cues from the family homes, introducing nature and avoiding institutional elements such as tile floors and fluorescent lights (p. 3). By not talking about pain she missed an important part of the hospital experience. I do not mean to imply that a child's stay in the hospital is all about pain and discomfort; while working with the pediatric patients in the playroom at the Bronx Municipal Hospital I was amazed at their resilience and seeming lack of pain and discomfort. My previous perceptions about a hospital experience were biased to the negative. I thought that children would be in constant pain and discomfort. I have since seen that this is not true but this might also be because I saw the children when they were able to come to the playroom. I did not see them when their condition was such that they could not or did not want to leave their beds. Nevertheless pain and discomfort, two of the distinguishing characteristics of a hospital experience that need to be addressed in any discussion about changing hospital environments, were not addressed by Lindheim et al. (1972) and Olds (Olds & Daniel, 1987).

The design guidelines and literature review in Child Health Care Facilities are quite impressive, but I think that they are missing a most important authority, children. The guidelines are based on theories from developmental and child psychology but from what I can tell none of the sources that they referred to worked with children to find out what they thought about hospitals. In fact Olds (Olds & Daniel, 1987) stated that: "While it is difficult to perceive the environment through a child's eyes, adult perceptions, magnified several fold, may begin to approximate a child's experience." (p. 1) This may or may not be possible, but if it leads to statements such as, "An overriding principle that planners of

health care facilities must bear in mind is the powerfully regenerative force of beauty" (Olds & Daniel, 1987, p. 1). Designers using this book may create woefully inadequate but beautiful designs. A better way of trying to understand children's experience is to ask them.

This approach was taken by several authors whose articles were printed Child Health Design, a semiannual bulletin which was meant to help designers construct supportive health care environments for children. These articles demonstrated how important it is to talk to children about their environmental likes, dislikes, and needs. Dicke (1991), who was interested in creating a more "child friendly" ICU stated that:

the thoughts and the suggestions have provided us with a different view of the hospital- a view from the bed. We need to recognize the importance of this view and to take advantage of their thoughts when we design space for children. (p. 11)

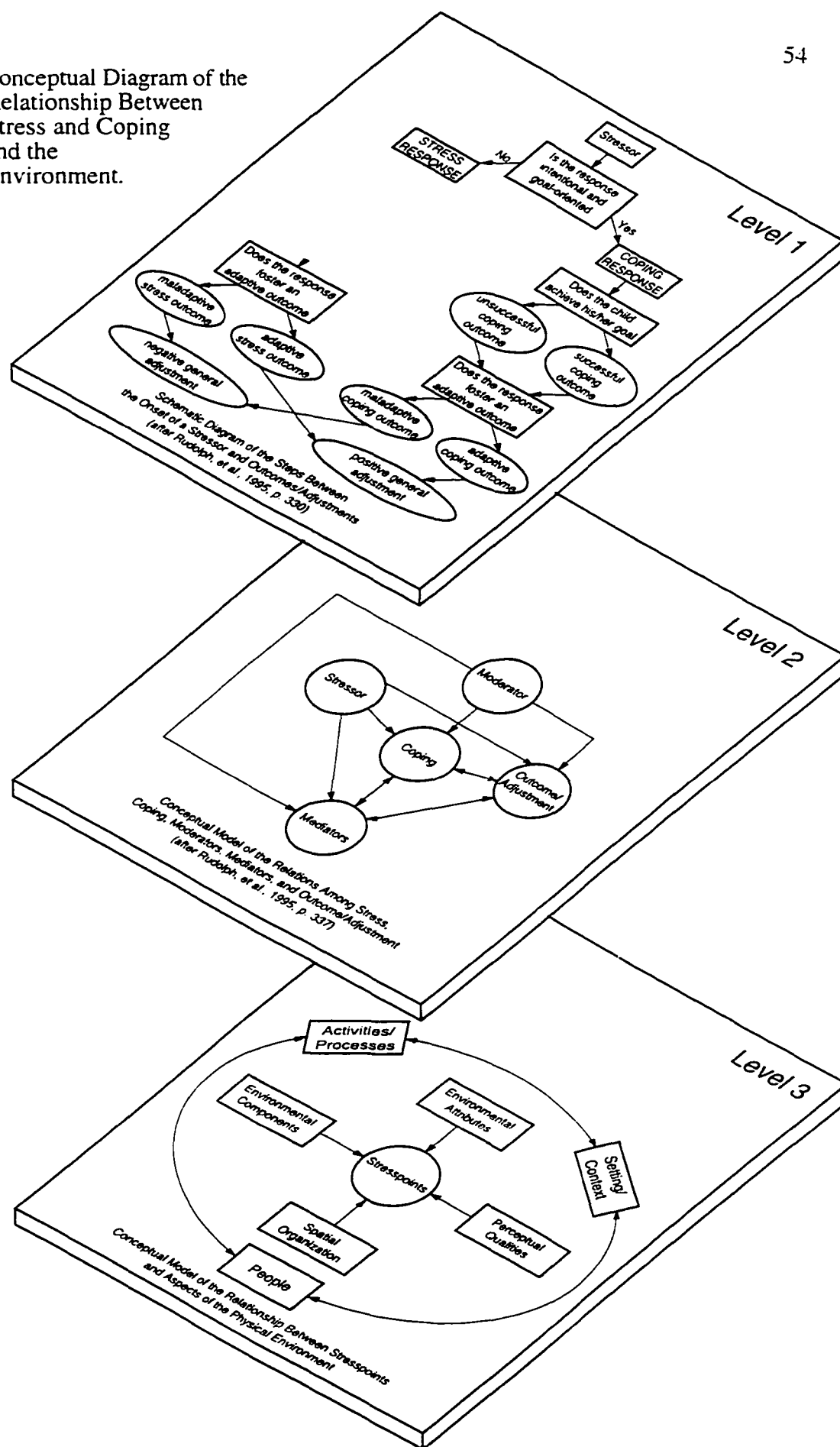
Unfortunately, most of the articles were quite short which did not allow the authors to deal with issues with much depth forcing them to make statements on either end of a generality scale. On the very general end of the scale were statements such as, "A hospital for children should be full of toys, not shots!" (Francis, 1990, p. 6). On the more specific end of the scale were the individually requested items such as pool tables, Nintendo games or a Jacuzzi. What was missing were complete analyses of why certain items or spaces were requested. However, there were many excellent ideas embedded in the articles. Francis (1990) found out that the most threatening rooms were treatment rooms and surgery. The children's suggestions such as "Cover everything up so you don't have to look at all the scary things" (p. 7) are grounded in the idea of trying to create less threatening environments.

2.7. Conceptual Framework

The purpose of the conceptual framework or model presented below is to underline the transactional nature of a stressful event, and to place the physical environment within the analysis of that event. The goal of the framework is twofold. The first and most immediate goal is to offer an argument for the structure of the dissertation; the second goal is to present a model that can be used by both medical professionals and designers to create environments that acknowledge and mitigate the effect of stressors that pediatric patients are subjected to when they are in a medical setting. The framework combines the work of several authors: Rudolph, et al. (1995), Altman and Rogoff (1987), and Shumaker and Reizenstein (1982), and is presented verbally and diagrammatically. In the diagram (see Figure 1 below), their work is arranged hierarchically, as if on a series of levels which are reached sequentially, in order to emphasize that a stressor and the resultant stress response or coping response have to be examined within a context that includes not only the individual but also the social and physical environment.

The first level is a schematic diagram (Rudolph, et al., 1995, p. 330) presenting the steps between the onset of a stressor and the eventual outcome and adjustment. The authors make a distinction between a coping response which is "... an intentional physical or mental action... directed toward external circumstances or an internal state," and a stress response which is a "spontaneous emotional or behavioral reaction to stress, rather than a deliberate attempt to cope (Rudolph, et al., 1995, p. 329). The left side of the diagram represents the pathway between the stressor and the outcome unmediated by an intentional and goal directed coping response. On the right side, the diagram depicts the stressor being modified by a deliberate and purposeful coping response. This level presents a generalized overview of the relationship between stressors and outcomes, making clear the difference

Figure 1: Conceptual Diagram of the Relationship Between Stress and Coping and the Environment.



between coping responses and stress responses. Once this relationship is understood, it is possible to descend to the next level.

The diagram on the second level⁵ dispenses with stress responses and concentrates on diagramming the relationship between the stressor and the intervening variables that affect the coping response. These variables are grouped in two categories: moderators, and mediators. The authors defined moderators as "preexisting variables that influence coping and outcome but that they are not themselves likely to be influenced by the nature of the stressor or the coping responses (Rudolph et al., 1995, p. 336). There are two types of moderators: person-specific and situation-specific. Person-specific moderators that might affect the coping influence include characteristics of the patients, such as their developmental level, gender, prior experience, and temperament. Situation-specific moderators include characteristics of the stressor such as its controllability, type, and stage, as well as what the authors call characteristics of the environment. One of the characteristics of the environment mentioned by the authors is parental influence, which has received considerable attention. The other was simply called "other environmental influences" which have "received little attention as targets of assessment or intervention in psychological research" (Rudolph et al., 1995, p. 345).

Mediators are influenced by moderators but are distinguished from them because "they are activated during the coping episode..." and "explain the relations among different components of a coping episode- stressors, coping responses, and outcome/ adjustment" (Rudolph et al., 1995, pp. 345-346). There are two methods by which mediators influence how patient adjust to a stressor: cognitive appraisal and deployment of attention. Accepting

⁵ Please note: This diagram is a simplification and modification of one produced by Rudolph et al., 1995, p. 337. The changes that I made were for graphical purposes only and did not change the meaning of or the relationships in the authors' diagram.

the work of Lazarus and Folkman (1984), Folkman and Lazarus (1988), and Lazarus (1984), Rudolph et al. (1995) make a distinction between cognitive appraisals that are primary and those that are secondary. During the primary appraisals phase, patients ascribe meaning to the stressor and try to understand its implications. They try to determine "what is at stake at any given encounter" (Rudolph et al., 1995, pp. 346). During the secondary appraisal phase, patients evaluate what their options and coping resources are in order to judge "the extent to which one can influence the outcome of a stressful event" (Rudolph et al., 1995, pp. 348).

The second type of mediator, deployment of attention, can be conceptualized as a continuum between strategies that train the patients' attention on the stressor and those that divert their attention away. Research has demonstrated the efficacy of both approaches. which led the authors to suggest that:

coping responses that enhance attention may be more adaptive in the preparatory phase or in situations where the stressor is controllable (e.g., seeking information about the nature of upcoming medical procedures), whereas coping responses that reduce attention may be more adaptive in the encounter phase or in situations where the stressor is less controllable (e.g., receiving an injection or undergoing a BMA. (Rudolph, et al., 1995, p. 350)

While the first level was necessary to understand the various steps between the stressor and the outcomes/adjustments, it afforded little insight into some of the issues that needed to be addressed to create a therapeutic environment. Issues or variables that need to be addressed appear on the second level. In order to create environments that satisfy the needs of patients and help them cope with the stressors associated with a medical setting, the aspects of the environment as well as the characteristics of the patients and the characteristic of the stressor have to be considered. It is especially important for designers to think about how elements in the environment can be used to distract the patients. As

Rudolph et al. (1995), and I, noted in the literature review above, this has not been done in a consistent or rigorous manner.

This issue is addressed by the third level. Rather than providing explanatory power, however, the purpose of the diagram on this level is heuristic, since so little research has been conducted that attempted to assess the interventional properties or power of the physical environment with regard to helping patients cope with stressors. The diagram suggests that within a transactional worldview, aspects of the physical environment should be examined in order to determine if or how they exacerbate or mitigate the effects of physical or psychological stressors that patients may experience.

The center of the diagram, the environmental constituents and the stresspoints, are circumscribed by a graphic representation of the transactional worldview (Altman & Rogoff, 1987) to indicate that any analysis of either a coping episode or a stress response has to be considered as a holistic unit. These events are comprised of the participants, the setting or context, and the activities or processes which are mutually defined in terms of one another. The transactional worldview emphasizes the importance of understanding the changing "configuration of persons, psychological processes, and contexts" (Altman & Rogoff, 1987, p. 25) over time. This perspective seems particularly apropos within a hospital, because the patients experience a number of different emotions as they move from setting to setting, see a number of different people, and are involved in a number of different kinds of activities. Their experiences are constantly changing and an analysis of their experiences has to recognize that each event is "composed of inseparably existing actors engaged in dynamic psychological processes (actions and intrapsychic processes) in social and physical contexts" (Altman & Rogoff, 1987, p. 25).

This model is also in accord with Rudolph et al's. (1995) viewpoint based upon the work of Folkman (1984), and Folkman and Lazarus (1988). They stated that:

... a true transactional model must also capture the interaction between person- and situation-specific variables in determining the nature and success of coping. Coping must be viewed as a relational process in which the person and the environment participate in a dynamic, mutually influential relationship (Rudolph et al., 1995, p. 345).

The environment in their model, however, is primarily the social environment, especially the interactions between the mother and the child during the coping process. To be truly transactional, the unit of analysis has to include the various aspects of the physical environment: spatial organization, environmental components, environmental attributes, and perceptual qualities (Shumaker & Reizenstein, 1982) at a particular stresspoint or stage of the stressor.

The physical environment is organized spatially by large scale elements or characteristics that impact the overall environment. These might include the size, shape, scale, boundaries, and orientation of space; the relation to other spaces; and barriers in the space such as walls, columns, etc. Environmental components are smaller scale elements that occupy space, such as furniture, furniture arrangements, furnishings, etc. Environmental attributes give the space its character and style or mode. These include the amount of natural light, the type of artificial lighting, the temperature, color, art, materials, acoustics, etc. And finally, the perceptual qualities of the space are characteristics that encode and transmit messages to the user by the use of signs, symbols, visual or tactile cues, the visual dynamics of spatial form, etc (Shumaker & Reizenstein, 1982).

Most researchers in medical settings, who study how children cope with the various stressors they are subjected to, ignore the powerful effect the physical environment can have during coping episodes. Architects and designers, on the other hand, often do not have a sophisticated or differentiated understanding of those stressors and coping mechanisms and concentrate their design efforts on aspects of the context that they do understand, such as functional relationships. Beyond the structure the framework provides

for the dissertation, therefore, it is hoped that the model presented will provide designers and medical professionals with a tool they can use to create therapeutic environments. In this regard it follows the argument made by Shumaker and Reizenstein (1982) that "good hospital design can go beyond merely limiting patient stress. Good design can facilitate patient coping strategies by providing optimal settings for these strategies to occur" (p. 189).

3. METHODOLOGY

3.1. Site

The site of the research was the Pediatric Hematology/Oncology Outpatient Clinic of The Mount Sinai Medical Center. (See Figure 2. In the rest of this dissertation I will refer to it as the Clinic.) The Clinic was located on the northwest corner of the fourth floor of the 31 story Annenberg Building, one of the buildings in The Mount Sinai complex. The Clinic occupied 2250 square feet of the 29,284 square foot floor. What follows is a detailed description of the Clinic environment with some of my own subjective responses to the qualities of the setting.

3.1.1. Circulation

It is not easy to find the Clinic. The Mount Sinai Medical Center, like many large teaching hospitals, has grown in stages over the years. It is therefore housed in several separate but connected buildings making it impossible for patients and their families to even reach the building in which the Clinic was located without first walking through another building. Neither the building that patients and their families typically enter, the Guggenheim Pavilion, nor the Annenberg building are "child friendly."

On the fourth floor there was a main circulation corridor which ran continuously around the perimeter of the building with rooms on either side. The Clinic was laid out along this double loaded, six foot wide, corridor on the north side of the building. Within the Clinic, this circulation corridor took on the nature of a 59 foot long hall and will be referred to as the Hall (see Figure 3). The primary entrance to the Clinic was at the east end of this Hall while the Playroom was at the west end. Between the two were four examination rooms, the Social Workers' room, two screening rooms, the Staff room, the

Figure 2. Floor Plan of the Mt. Sinai Medical Center Pediatric Hematology/Oncology
Outpatient Clinic at 1/12" = 1'-0"

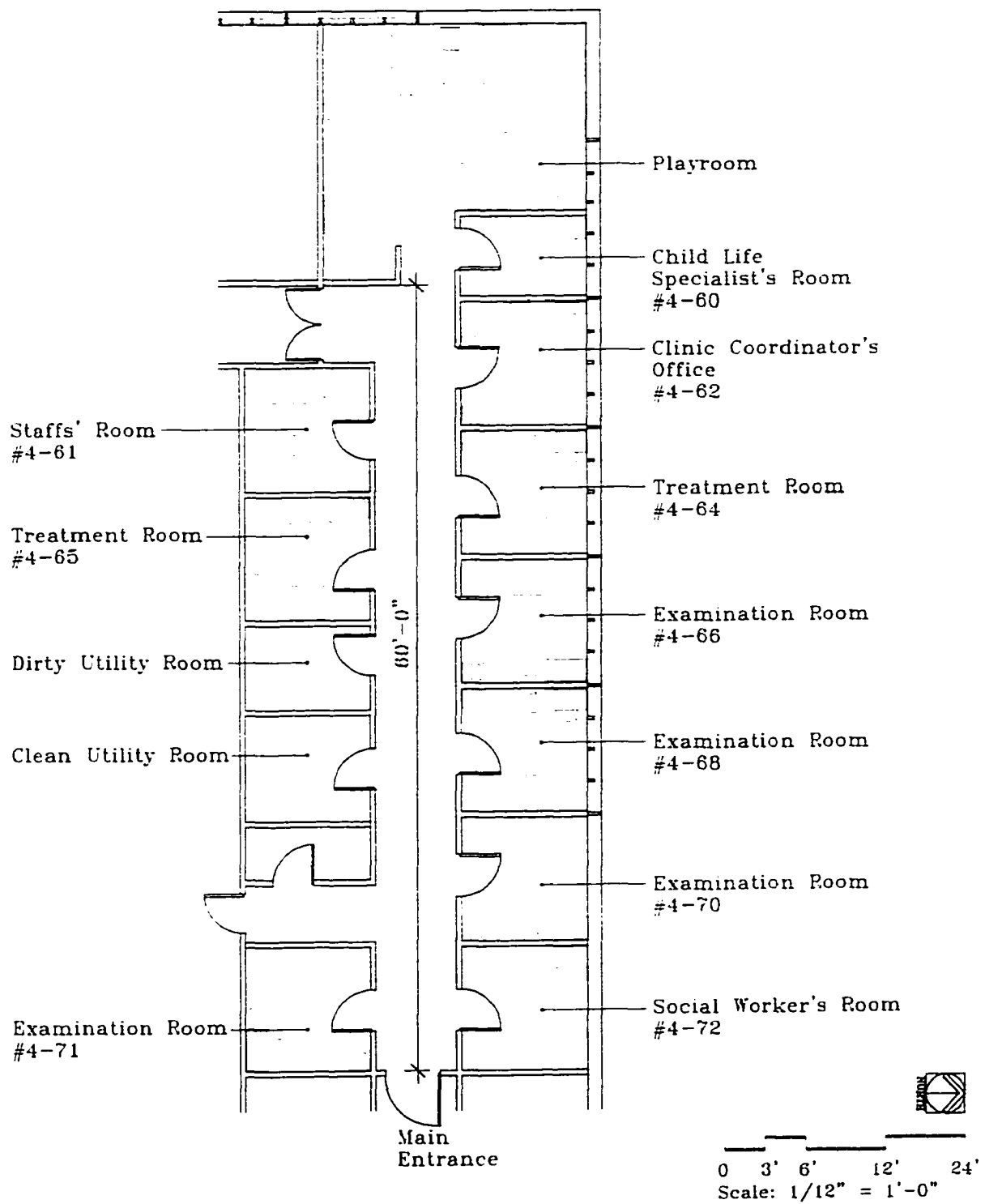


Figure 3. Photograph of the Hall looking toward the main entry door.



Clinical Coordinator's office, the clean utility room, and the dirty utility room. The Hall made a right angle turn at the Playroom and continued south to other areas on the floor.

The primary entrance to the clinic was through a large door, which was painted blue, as were all the doors in the clinic. Immediately on the left and right were doors to an examination room (#4-71) and the Social Workers' room (#4-72) respectively. A short hall leading to fire stairs separated the examination room from the other rooms on the south side of the corridor. On the north side of the corridor there was a continuous row of offices terminated by the Child Life Specialist's room which was an addition protruding into the Playroom.

Two large X-ray viewing boxes with fold down white plastic laminate shelves below, beige sheet metal chart holders outside the screening and examination rooms and trash receptacle, as well as a fire extinguisher added to the institutional quality of the Hall. Two posters were added to the Hall, one between rooms #4-70 and #4-72, the other between rooms #4-64 and #4-72. The colors in these posters were rather subdued and did little to make the Hall more visually appealing.

3.1.2. General Description of the Clinic

The screening rooms, examination rooms, Social Worker's room, Clinic Coordinator's office, and Staff Room, were approximately the same size: slightly larger than 9'-0" x 9'-0". The Child Life Specialist's room was half the size of the other rooms. It was only four feet six inches wide. The Playroom would have been approximately 20'-0" x 20'-0" except that the Child Life Specialist's room occupied the south east corner. All the ceiling heights were eight feet.

There were windows in all of the rooms in the Clinic which were on the perimeter of the building except for one examination room (see Figure 4) and the Social Workers'.

Figure 4: Photograph of the north wall of room #4-70.

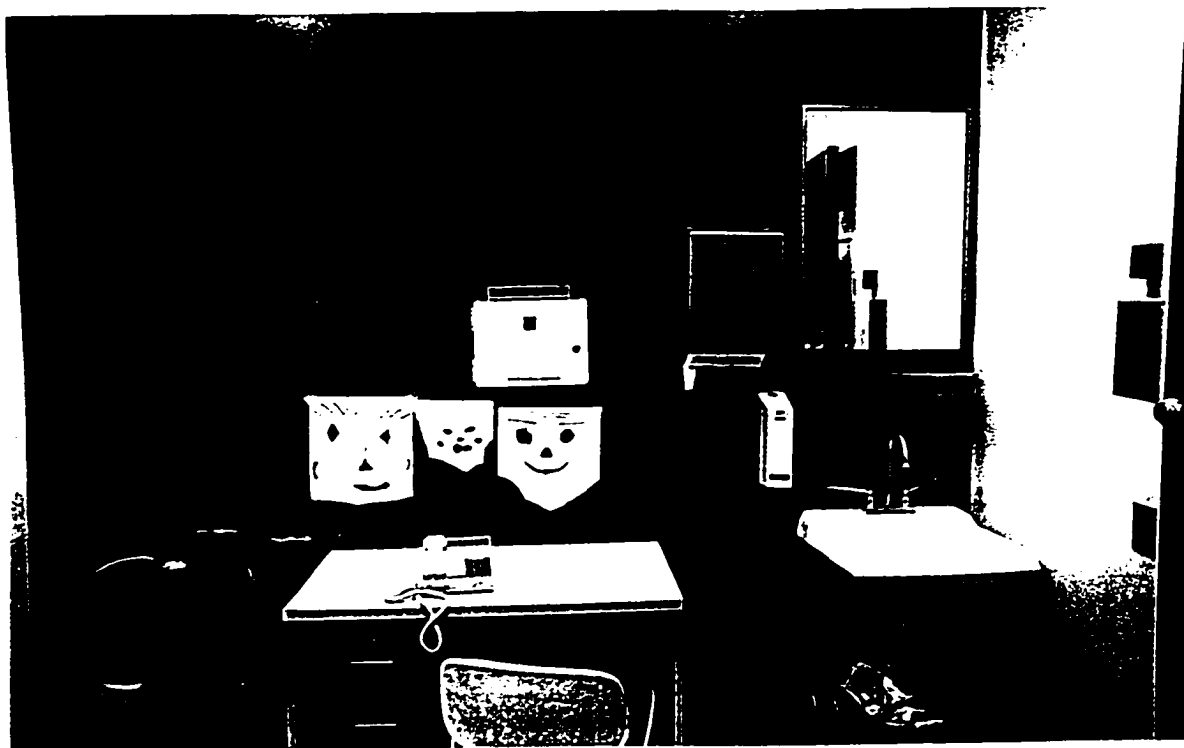
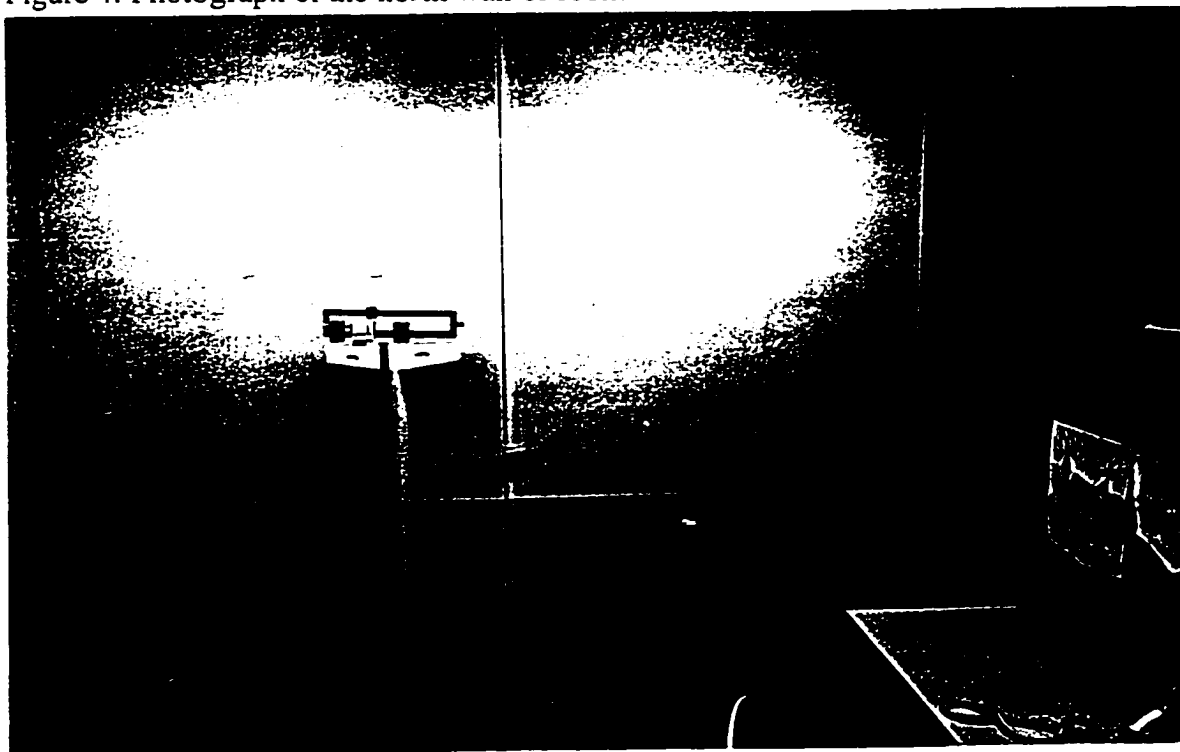


Figure 5: Photograph of the east wall of room #4-70.

room. Because these rooms were on the north side of the building, they did not receive any sunlight but they did get natural light and there was a view to the outside when the shades were not drawn of the Guggenheim Pavilion (another building in the complex) Figure 4: Photograph of the north wall of room #4-70 which was approximately 75' north. The Playroom had windows on both the west and north side so it received sunlight as well as natural light and there was a partial view of Central Park.

As with the rest of the hospital little had been done to the Clinic, except the Playroom, to make it more "child friendly." The walls throughout the clinic were painted off white, except the east wall of room #4-70 which was painted the same color as the doors- a dark blue (see Figure 5), the flooring was beige vinyl tile, and the ceilings were inexpensive 2' x 4' acoustical tiles. Color was added by painting the doors a dark blue, and by the use of room identifying plaques that were blue with white lettering. All lighting fixtures in the Clinic were fluorescent. In the Playroom and the offices the fixtures were 1' x 4' and recessed into the ceiling. In the Hall there was a continuous length of white acrylic fixtures mounted just below the ceiling on the north wall.

3.1.3. Screening Rooms and Examination Rooms

The screening and examination rooms were very much alike with little in them that was not related to the task of seeing patients (see Figures 6,7, 8,9, 10). Each had an examination table which were placed on either the east or west walls of the room. Most of the exam tables were made with stainless steel legs, shelves, and drawers, surmounted by a brown vinyl covered mattress. An extension could be pulled out from the foot of the table to support the legs of the taller patients. The extension was also made of stainless steel with a brown vinyl covered pad on the top. A roll of white paper was hidden under the head of the table and lengths were pulled out as needed to cover the exam table. The exam tables in one of the screening rooms was different, having a white enamel finish on the

Figure 6: Floor plan of a typical examination room at 1/4" = 1'-0".

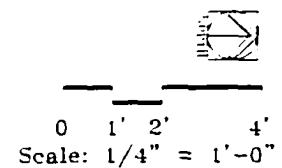
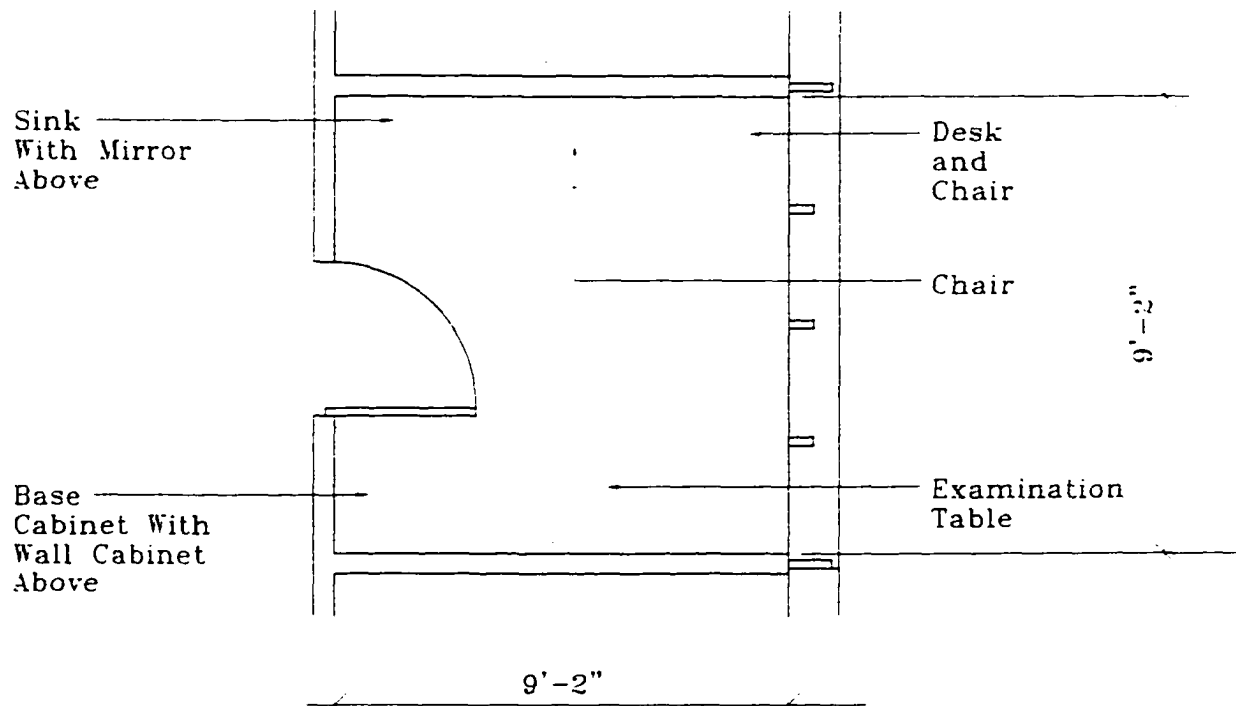


Figure 7. Photograph of the north wall of room #4-68

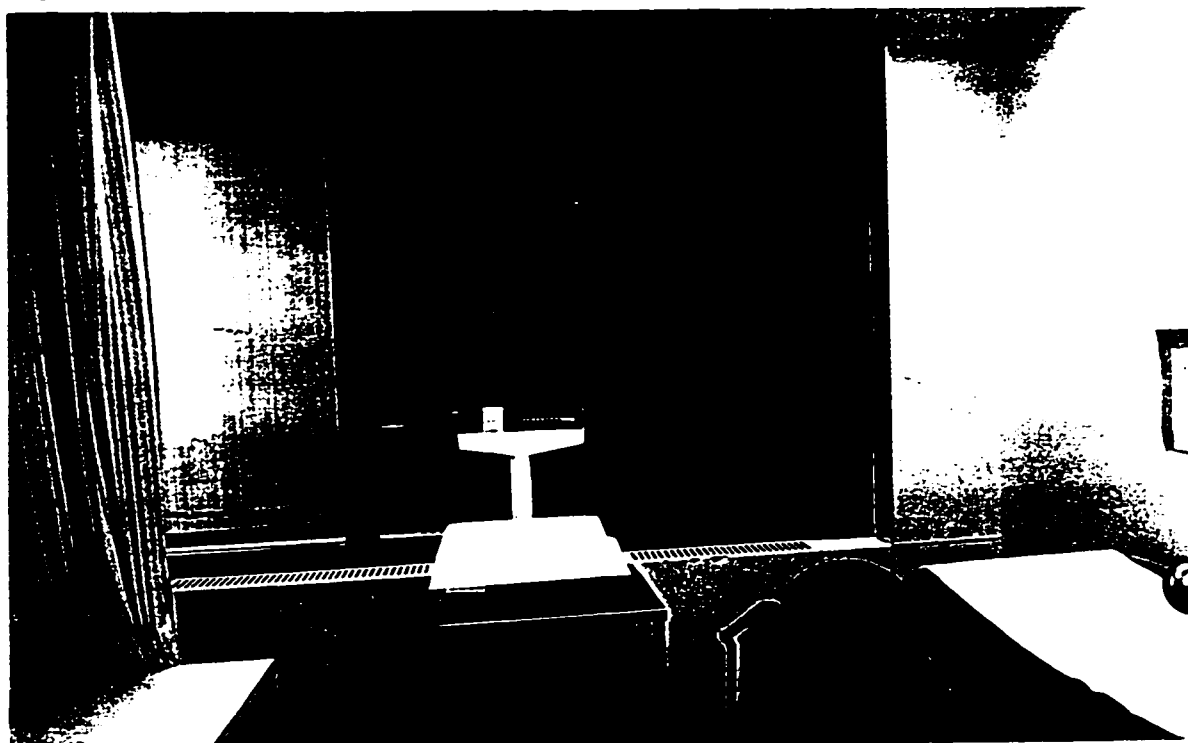


Figure 8. Photograph of the west wall of room #4-68

Figure 9. Photograph of the east wall of room #4-68

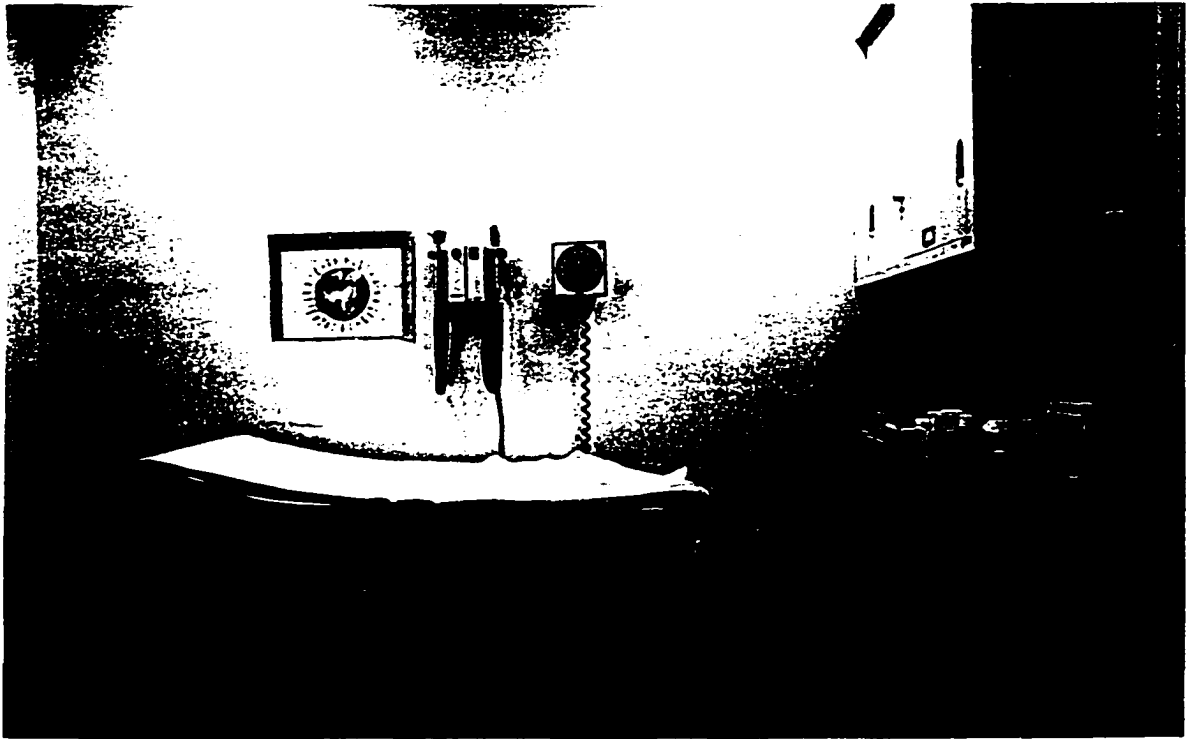


Figure 10. Photograph of the south wall of room #4-68

structure and a black vinyl coated top. An otoscope and an ophthalmoscope were mounted above the examination tables.

All of the screening and examination rooms had white porcelain sinks which were on the wall opposite the examination tables. They were equipped with standard institutional hardware: lever arm handles and an inverted "J" faucet. Above the sinks were a stainless steel shelf and a mirror framed in stainless steel. The paper towel holder which was adjacent to the mirror was also stainless steel. Next to the sinks were beige plastic soap dispensers.

The screening room and examination rooms that had windows also had cloth screens which could be drawn for visual privacy while still allowing some visual access to the outside.

Each screening and examination room had a small, two drawer desk with chrome plated tubular legs supporting a beige plastic laminate top and carrying metal infill panels. The drawers and the infill panels were painted black. The desks were located on the same wall as the sink. The chairs in the rooms were mismatched. Orange was the predominate color but styles and materials were different even within the same room.

Intercoms were located immediately adjacent to the doors, and most of the screening and examination rooms had phones mounted on the wall next to the intercom. On the other side of the doors stainless steel shelves were mounted at waist height on which were placed boxes of medical supplies such as swabs, gauze pads, alcohol prep pads, boxes of latex gloves, etc. Mounted above these shelves were white metal cabinets which contained additional supplies behind two sliding doors. In screening room #4-65, the cabinet was in a different location- opposite the door.

Additional equipment included infant and adult scales in most of the rooms, tables or carts for the infant scales, height scales in the screening rooms, trash receptacles which

by the end of the day were often overflowing, and sharps disposal boxes. The sharps disposal boxes in the screening rooms were transparent red plastic while in the examination room they were beige metal.

Besides the items mentioned above there was little on the walls. In the screening rooms there were some sheets of paper with medical information. Only two of the rooms, #4-68 and #4-65, had small posters above the examination tables, and in room #4-70, three pieces of children's artwork were above the desk (see Figure 5).

The nurses took the patients' temperature, weight, and height in the screening rooms. The nurses also drew the patients' blood in those rooms (see Figure 11). For many of the oncology patients, who were still on treatment, this was a relatively painless procedure because the blood could be drawn through their indwelling catheter.¹ This was not the case for the hematology patients who had to have their blood drawn via a venipuncture in one of their arms. The nurses also flushed the catheters with saline solutions and administered chemotherapy through them in what they called a "push" in the screening rooms. A "push" is a relatively quick procedure requiring less than five minutes even when there was more than one type of chemical to "push." A "push" of chemotherapy is essentially no more than an injection of the chemotherapy into the catheter. The "pushes" were also administered in the examination rooms. Very few of the patients had ever received an infusion of chemotherapy in the Clinic. As far as I know no one did

¹ The most common kind of indwelling catheter used in the Clinic was called a Broviac catheter which is:

A hollow silicone (soft, rubber-like material) tube inserted into a large vein in the chest for long-term use to administer drugs or nutrients. The catheter is inserted through a small incision made near the collarbone. A "tunnel" is made under the skin to another site where the catheter exits. The catheter is then pulled through the tunnel and into the vein leading to the heart.... it may be left in the body for months. (Altman and Sarg, 1992, p. 123)

Figure 11. Photograph of the desk in room #4-65 where patients had their blood drawn.



while I was doing my research. I raise this issue because an infusion of chemotherapy can take four to five hours and therefore the design of the space where this occurs by necessity has to be much different than a space where a "push" of chemotherapy is given.

When they saw patients, the first thing the doctors did, after exchanging social amenities, was take their history. They then physically examined them. The older children and teenagers were examined while they laid on the examination table, while some of the younger patients were examined while they laid in a parent's arms. Following the examination the doctors developed an assessment which initiated a plan that was discussed with the parents and/or the patients if they were old enough.

The doctors also had to perform diagnostic procedures: lumbar punctures and bone marrow aspirations on the oncology patients who were on treatment. Because the clinic did not have a procedure room, the procedures were performed in the examination rooms. Several of the doctors with whom I spoke said that the examination rooms were far from an ideal setting to perform these invasive procedures because the room where the procedure was going to be performed had to be set up each time. A cart with the necessary medical supplies was prepared in the clean utility room and brought into the room. If a patient needed to be restrained during the procedure, the examination table had to be moved away from the wall so that he or she could be accessed from both sides.

3.1.4. Clinic Coordinator's Office

The Clinic Coordinator's Office presented an appearance much different from the screening and examination rooms, even though it had some of the same elements such as the sink, mirror, paper towel holder, soap dispenser, stainless steel shelves, and metal cabinet (see Figures 12 and 13). There was also a desk in the room but it was larger than the others and the top was wood grain plastic laminate. The primary difference was that the

Figure 12. West wall of the Clinic Coordinator's Office.



Figure 13. East wall of the Clinic Coordinator's Office

office contained administrative supplies and equipment rather than the medical supplies and equipment found in the screening and examination rooms.

On top of the desk there were several items the Clinic Coordinator used regularly: a black plastic index card box, a large green tape dispenser, a Medicaid card imprinter, and a telephone. Vials of patients' blood that had to be processed were also kept on the desk. Mounted on the wall next to the desk was a large white bulletin board covered with papers, a smaller cork board, and a system of vertical black file holders. The other major items the office contained were a stainless steel chart rack and black cabinet that stood on the floor with a microwave on top of it, and a small refrigerator under the stainless steel shelf which was below the cabinet.

The Clinic Coordinator's Office was the hub of the Clinic, with patients and staff going in and out of the room constantly. The room was not designed, nor large enough, for all the activities it had to accommodate and frequently became overcrowded. When patients arrived in the morning this is where they checked in. When they left this is where they came to set-up the next appointment, and some parents and patients "hung out" in the office to talk with the Clinic Coordinator. The Clinic Coordinator also had to handle the blood work and paperwork related to the patients. During the outpatient clinic patient charts were kept in this office so it was not unusual to find doctors and nurses in the office picking up, dropping off, or looking at the charts. Volunteers came into the office to get food: cookies or crackers, and beverages: juice, milk, and coffee which were also kept in this office. The microwave was also in this room, so when one of the patients wanted to water heated for hot chocolate or soup, a volunteer would use the office for that purpose.

3.1.5. Child Life Specialist's Room

As noted above, the Child Life Specialist's room was very small (see Figure 14). It contained a small desk similar to those in the screening and examination rooms, a chair which was next to the desk, a stool for the person using the desk, a set of drawers for paper, and some plastic bins for toys in the corner under the window. The windowsill was filled with books and office supplies. On the wall there were several posters, a cork board above the desk, and a coat rack behind the door.

Several different activities took place in this room. The Child Life Specialist or one of the volunteers would conduct play therapy sessions in the room. These sessions were either individual or group. The Child Life Specialist would also speak with the volunteers in this room if the conversations needed to be private.

3.1.6. Staff Room

The Staff room contained two tables, one which held the computers and printer and one which was a work surface. Mounted on the walls were shelves for books, trays for paperwork, and two cork boards. The room also had a sink, shelf, mirror, paper towel holder and soap dispenser similar to the screening and examination rooms. For seating there were several large, cushioned, brown vinyl covered chairs on casters.

The Staff room was, in fact, a multi-purpose room with a number of seemingly incompatible activities occurred there. Mount Sinai is a teaching hospital and some of the teaching that occurred in the Clinic took place in the Staff room. This meant that frequently one of the attending physicians would have an individual or small group (2-5) teaching session with medical students, residents, and/or fellows while the other attending physicians or fellows tried to accomplish their other tasks. The primary task the physicians had to accomplish was to develop treatment plans for the patients. Many of these treatment

Figure 14. Photograph of the north wall of the Child Life Specialist's room.



plans were routine but often they were not straightforward and the physicians had to work through a differential diagnosis to try to determine how best to treat the patients. This required a tremendous amount of concentration. Some of the physicians were able to block out the noise and activity around them but others needed a quieter less distracting environment and had to leave the room.

3.1.7. Playroom

After walking the length of the Hall in the Clinic the patients and their family members were able to reach the Playroom (see Figures 15, 16 17, 18 and 19). Unlike the other rooms in the Clinic, the Playroom did not have a door. Instead there was a large opening on the east side of the room where the Hall and the Playroom were contiguous. A low, approximately 4'-6" high, "L" shaped wall filled in part of the opening. The long leg of the "L" separated the Playroom from the Hall and the bottom and short leg of the "L" created a small entry way between it and the south wall of the Child Life Specialist's room. Several plants were placed on the top of the wall which was covered with wood.

The Playroom was dominated by a large table composed of two tables placed next to each other, forming a work surface which was six feet square. This was the main activity table and between eight and ten chairs were placed around it. The table top was covered with beige plastic laminate which was broken off at some of the corners. The edges and corners of the table top were square presenting sharp points at the corners which were hazardous. The legs of the table and horizontal structural supports were steel.

Surrounding the table on three sides and placed against the walls were cabinets that held supplies, materials or toys that the children used or played with while they were waiting. The cabinets on the east and west walls were identical. They were 4' x 0" long, 2' x 6" high, and 2' x 2" deep, constructed of naturally finished birch plywood with masonite backs and hinged on one end so that they could swing open. The cabinet on the

Figure 15: Floor plan of the Playroom at $1/4" = 1'-0"$.

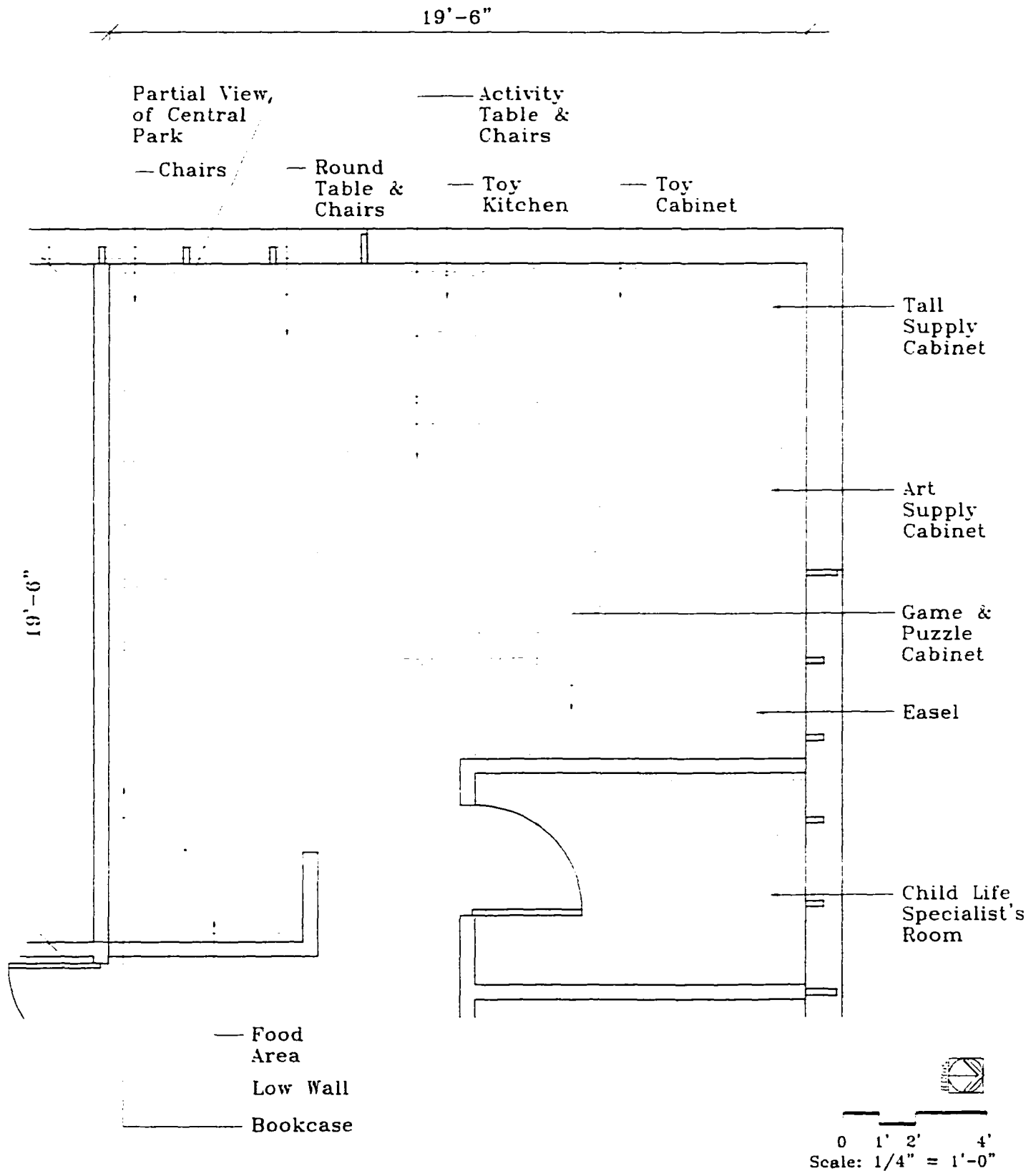


Figure 16. Photograph of the west wall of the Playroom.

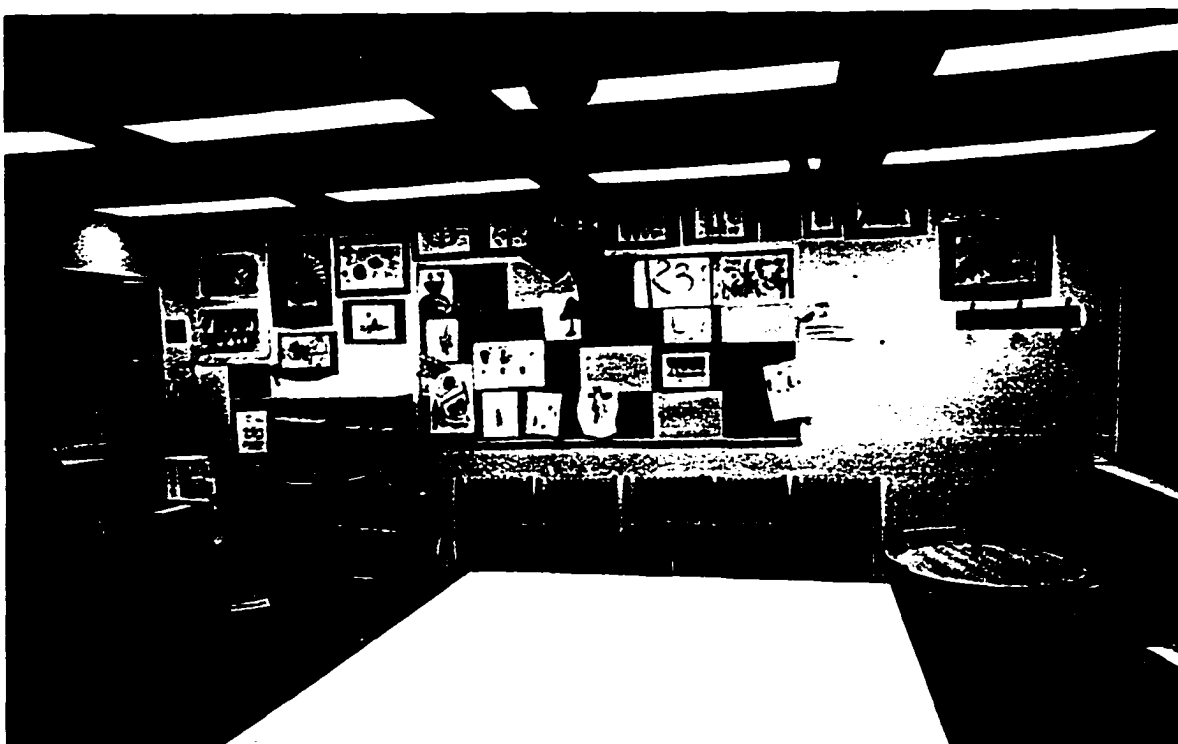


Figure 17. Photograph of the south wall of the Playroom.

Figure 18. Photograph of the north wall of the Playroom.



Figure 19. Photograph of the east wall of the Playroom.

west contained the toys for the young preschooler and toddlers. The one on the east wall contained jigsaw puzzles, board games, etc. for the older children. They were well-constructed, simple but handsome pieces of furniture that can be found in many preschool classrooms.

The two cabinets on the north wall were different. One was located in the north east corner of the room and contained toys and materials that were not needed regularly. It was 4' x 0" wide, 6' x 0" tall, and 2' x 0" deep, covered with wood grain plastic laminate with brown trim and had doors that swung outward. The other cabinet, which was adjacent to it, held the art supplies and was accessed frequently. It was composed of three sections constructed of naturally finished birch plywood with masonite backs. Two of the sections were hinged to the other and swung out to access the supplies.

There were several other large items in the Playroom. An easel had been set up next to the art supply cabinet in the northeast corner of the room in front of the smaller of the two windows. On the west wall, in front of the large window, there was a child sized, round wooden table with four child sized wooden chairs. Between this and the toy cabinet, there was a small plastic play kitchen. In addition, on the south wall in front of the food area, there was a wooden shelving unit for children's books and an assortment of magazines.

Also along the south wall was a row of 6 or 7 chairs that were used mainly, but not exclusively, by the parents. These chairs were constructed of woven wire web covered with orange colored vinyl on a tubular steel frame. When I began the research, these types of chairs were also around the large table, but were later replaced with blue plastic chairs. The woven wire web chairs were old and the web joints were beginning to break. When a person sat on one those breaks very often the chair "bit" or pinched them.

A major difference between the appearance of the Playroom and the rest of the Clinic was that, in the Playroom, the walls were filled with artwork. Most of the artwork were individual pieces done by the patients but there was a "community" mural on the north wall above the art supply cabinet. This mural was not permanent but rather painted on brown wrapping paper and redone several times a year by the volunteers, children, and parents or caregivers. In addition, artwork was hung from the ceiling.

The Playroom was where most of the patients and parents spent time while they were waiting to be seen by a doctor or nurse. The Playroom was the setting for many different kinds of activities. The patients drew, painted, did arts and crafts, played board and card games, read, did homework, ate, engaged in fantasy play, and talked to one another or with their parents or the volunteers. Other patients simply stared out the window or watched the other activities while they waited.

A minority of the parents sat at the table and either engaged in arts and crafts projects on their own or worked with their child. Others parents spent the time talking with other parents or their children. For many of the adults, however, the Playroom was simply a place where they sat on uncomfortable chairs and watched their children while they waited.

3.1.8. Population

The people who used the Clinic had various roles. There were patients, physicians, nurses, a Child Life Specialist, a Clinic Coordinator, and volunteers. The patients were usually accompanied by a parent or caregiver, although several of the older teenage and young adult patients came by themselves. In most cases, the accompanying adult was the mother of the child. Occasionally friends of the patients would come with them.

The children and adolescents involved in the research were pediatric oncology and hematology patients who were being treated at the Pediatric Hematology/Oncology

outpatient clinic at Mount Sinai Medical Center in Manhattan. Patients' visits to the clinic was scheduled so that the pediatric hematology patients (In this discussion I will be referring to the patients who had sickle cell disease because they comprised the majority of the hematology patients.) came to the Clinic on Tuesdays, while the oncology patients came to the Clinic on Mondays and Wednesdays. The number of patients seen during a clinic day varied greatly. On an unusually busy clinic day, the medical staff might see 20-25 patients. On an unusually slow day, which was more apt to happen when the hematology patients were scheduled to come to the Clinic, there might be as few as 10 or 12 patients. On average between 15 and 20 patients came to this clinic.

For the children and teenagers with cancer, this meant that most were initially hospitalized as inpatients, followed by an extended period of time, up to three years, when they had to return to the hospital as outpatients. Some relapsed and required additional inpatient hospitalization followed by more time as outpatients. There were also basic similarities between the courses of treatment that they received.

Most pediatric oncology patients now receive chemotherapy as the major treatment modality. For the most part, the patients at Mt. Sinai received their chemotherapy as inpatients. They also had to go through the same painful procedures, such as bone marrow aspirations, spinal taps, finger sticks and needle insertions for blood samples (although many had their blood drawn through their indwelling catheters). A small part of this population also had to go through imaging studies and surgical procedures and radiotherapy to treat solid tumors. An even smaller percentage of the children had to have bone marrow transplants.

Most of the hematology patients who came to the clinic had sickle cell anemia, although patients with other hematological diseases such as aplastic anemia, thalassemia, and other red cell disorders were seen there. These patients came to the Clinic for regularly

scheduled checkups every 3-6 months. Some of these patients had been coming to the Clinic since they were newborns so the Clinic environment was literally one that they grew up with.

The hematology patients were not subjected to lumbar punctures and spinal taps but, unlike many of the oncology patients, they did not have indwelling catheters so when it was necessary to draw their blood, it had to be drawn via venipuncture from one of their arms.

It was very surprising to me that even though the patients who came to the clinic had very serious illnesses, in general, they did not appear to be, in a lay person's terms, very "sick." The hematology patients in particular seemingly had few complaints. This is not to say that sickle cell anemia, which most of the patients had, is not a devastating disease. It is, especially when the patients experienced a painful crisis, but when the sickle cell patients did have severe painful crisis they were hospitalized.

Oncology patients suffer from the side effects of chemotherapy such as nausea, vomiting, feeling tired, and the most obvious sign of chemotherapy- hair loss, but it was remarkable to me that, for many of the patients, hair loss was the most obvious sign that they were ill. Most of the time, most of the oncology patients behaved in the Playroom like their non-ill counterparts. On those occasions when they were not feeling well, some of them laid down on an examination table in an empty examination room, while others would simply stay in the Playroom. Based upon my review of the literature, I had expected to see patients vomiting frequently and this did not happen.² While I was doing my research, I cannot recall one case where a patient vomited in the Playroom. One teenage boy, who feared lumbar punctures and spinal taps tremendously, developed an extreme case of

² New anti-emetic drugs have reduced the incidence of vomiting tremendously.

anticipatory anxiety, and began to carry a bowl with him in case he vomited unexpectedly, but he was always able to make it to the rest room before he vomited.

There were some other behavioral and psychological differences between the oncology and hematology patients due to the nature of their respective illnesses. While cancer and sickle cell anemia are both chronic illnesses, their onset and duration are completely different. Children are born with sickle cell and there is no cure for the disease. As a consequence, they have to live with it their entire lives. Cancer, on the other hand, is curable but its onset is unexpected and suddenly disrupts the patients' lives.

Seeing the patients were six attending physicians, those who were on the staff at the hospital; three or four fellows; physicians who were in their fourth, fifth or sixth year of postgraduate studies working in the subspecialty area of pediatric hematology/oncology; and two nurse clinicians, nurses who have advanced training and have been certified in a special area of interest.

Working with the patients in the Playroom were the Child Life Specialist who was also on the staff of the hospital and the volunteers. Usually there were at least two volunteers in the Playroom and sometimes there were as many as four. The volunteers typically were interns from an art therapy program who came to the Clinic for a semester or two. On Tuesday, one of the volunteers was a graphic artist who spent the morning drawing cartoons for the children. He had been coming to the Clinic for a number of years and many of the children who came to clinic on Tuesdays had known him since they were babies and had become quite attached to him. And finally, every Wednesday, two or three clowns from the Big Apple Circus came to the Clinic for approximately half an hour.

3.2. Managing the Research Role

3.2.1. Role

While I was doing the research I had several roles: volunteer, volunteer/researcher, and volunteer/participant observer. For the first three months, my role was virtually indistinguishable from that of the other volunteers while we were in the Playroom. We set up the food area and put art supplies on the table before clinic. When the children were there, we opened up the toy cabinets when they wanted toys or games to play with and took out more art supplies when needed. Our most important function was to provide companionship for the patients who needed it. We played games with them, primarily card games and board games, and talked with them. I rarely spoke to them about their illness but rather about their lives outside of the clinic. I got to know several of the patients quite well during this time.

Before I started interviewing the patients there were several differences between my role and the role of the other volunteers. One difference was that I did no therapy with the patients. The other volunteers were in art therapy programs at universities and colleges in the area and were therefore required to have a therapeutic relationship with a patient or patients. Another difference was that when I introduced myself to the patients, I told them about my research, and asked them if they would be interested in being interviewed at a later date. I also gave them a Children's Environments Research Group business card with my name on the front and the anticipated title of the dissertation on the back.³

³ I introduced myself this way primarily to the patients whom I saw week after week: oncology patients who were on treatment and one or two hematology patients who were seen once or twice a month. Since most of the hematology patients visited the Clinic only once every three months to six months, the issue of what my role was did not seem as critical and, therefore, I did not introduce myself in this manner until I started interviewing.

I wanted to make it clear that even though I was acting like a volunteer, I had another role that was significantly different. I wanted to get to know the patients and establish a relationship with them while at the same time preparing them for the idea that, at some point I was going to ask them to leave the Playroom and talk to me in different space. I felt that if I did not introduce myself in this manner it might confuse and possibly disturb the patients when I switched roles and become a volunteer/researcher.

Beginning in April 1994, I began to interview the patients. I tried to maintain a balance between my role as a volunteer/researcher who took the children to a special place and asked them questions and my role as a volunteer who spent time with them in the Playroom. On the days when I interviewed more than one patient, my role as a researcher was much more apparent but this only happened a few times. I still spent a considerable amount of my time in the Playroom on most days.

3.2.2. Reciprocity

It is of course impossible to reciprocate fully for the time, energy, and help that the patients and staff gave me. I was able to offer some help in return, however, because of the methods I used while conducting the research. I spent a considerable amount of time in the Playroom simply being with the patients, talking to them, playing games with them, reading to them, etc. This benefited the patients but it also benefited the Child Life Specialist, especially on those occasions when she had to leave the Clinic and I was the only volunteer.

I did not give the patients whom I interviewed a small gift or reward at the end of the interview but I did send the patients who designed their "ideal" Playroom on the computer copies of the floor plans and perspectives.

In addition I wrote a document called *Purposes, Goals, and Critical Performance Criteria for The Mount Sinai Medical Center Pediatric Hematology/Oncology Clinic*. If the

Clinic moves to a new space, the designers can use this document, as well as this dissertation, to design a new clinic that acknowledges and addresses the patients', their family members', and the staff's wants, needs, and concerns.

3.2.3. Ethics

I had to be very clear when I explained the research project to the patients that, even though I would be asking them about what they liked and disliked about the existing environment, as well as what their "ideal" clinic would be like, that did not mean that any changes would be made based on their concerns.

Another ethical issue has to do with anonymity and confidentiality. In the August 22, 1993 issue of the New York Times magazine, there was an article on breast cancer. One of the women quoted made some critical remarks about one of the medical professionals who was treating her. Even though this medical professional was not named, she felt that she had to make a positive statement about the clinic because she was afraid that she would not be treated as well if the staff became upset with her statements. Since this also might have been a concern of the parents or patients at Mt. Sinai, I told them that I was not associated with the hospital and that everything I was told would remain anonymous unless the patient gave me information that made me believe that he or she was in danger.

Power is an issue in any interviewing situation involving children, and to a lesser degree, adolescents. I made it clear to the patients that they had ultimate control of the interview because they could simply say that they did not want to answer a particular question or any more questions and that they were free to terminate the interview at any time. The patients seemed to have no problem with telling me that they did not want to answer a question or questions and several patients did end their interviews when they had enough.

3.3. Research Methods

3.3.1. Participant Observation

Participant observation is the observational portion of ethnographic fieldwork. The observer becomes part of a group participating in many of the activities while systematically and unobtrusively collecting data. They immerse themselves in the world of their informants trying to see it through their eyes. This method is primarily used by anthropologists and sociologists (see Hart, 1979; Katz, 1986; and Spradley, 1980 for it's use in environmental social sciences).

Participant observation was the first method that I used to familiarize myself with the patients and their environment. I began the research project as a participant observer in January 1994, and spent three months (see role in Research Role Management Section 3.2.1 above) in the Playroom getting to know the children and teenagers as well as their needs and problems before I began interviewing them. I maintained my participant observer status throughout the duration of the research to maintain contact with the patients and staff.

For three days a week (Monday, Tuesday, and Wednesday) I would arrive at the clinic between 9:00 and 9:30 in the morning and stay until after sitting in on the clinic conference⁴ which would often last until two or three o'clock in the afternoon on Monday and Wednesdays and one o'clock on Tuesdays.

As a participant observer, I had to use my role as a volunteer as an opportunity to make observations. Note taking in the Playroom was not allowed because it was supposed to be a place where the patients could feel safe physically and emotionally. I therefore had to leave the Playroom to record my observations. When I had the opportunity, I would

⁴ During Clinic Conference which occurred after the patients were seen, the staff discussed medical and psycho-social issues concerning the patients.

retrieve my laptop computer from the Child Life Specialist's room, find an empty examination room or sit just outside the clinic doors in chairs that were in the hall, and type my observations about what had been happening in the Playroom that morning or since the previous observation.

The number of observations I was able to record during clinic varied. On most days I was able to complete one or two. If I did not take any notes during clinic I would try to remember what happened, and record my recollections after clinic conference.

3.3.2. Interviewing

As a participant observer I was able to observe the activities that occurred in the Playroom but I could only make educated guesses about what the patients thought and felt about the space. And since I was only able to catch glimpses of the activities that transpired in the screening and examination rooms my understanding of those spaces was very limited. In order to discover what the people using the spaces in the Clinic thought and felt about them, it was necessary to interview them. Most of the interviews were with the patients because understanding their thoughts, perceptions, and feeling about the Clinic was the focus of the research. I was also able interview the Child Life Specialist, three volunteers, three nurses, and six physicians for supplementary insights. In addition a parent and a caregiver expressed interest in talking with me. They spoke to me briefly about their and their child's experience in the Clinic.

3.3.2.1. Interviews With the Patients

After spending three months as a participant observer I began to interview the patients about what they thought and felt about the treatment environment. Piloting the interviews was not possible as all of the available children were potentially my subjects. Therefore, I talked to children from each age range before repeating the cycle: an adolescent followed by a schoolage child, followed by a preschool child. Cycling through

the patients this way insured that any changes to the interview were equally distributed among these different age groups.

The interviews were circumscribed by several factors. The most critical limitation was imposed by the hospital staff. I was only able to talk to the patients about what they thought and felt about the environment. I was not allowed to ask them what they thought and felt about their illness or ask them for description of procedures that they underwent. This limitation was imposed for good reason. I am not a clinical psychologist. If a patient had become upset by a question that I asked him or her, I would not have been able to handle the situation.

My access to the patients was controlled by the medical staff. Initially, the medical staff chose the patients for me but within several weeks I began to ask them about patients whom I wanted to interview. Once I was given permission to interview a patient, I approached him/her in the Playroom, explained my research project, and asked both the patient and the parent or caregiver, if the patient was less than eighteen years old, if he or she would like to talk to me. If they agreed to talk to me, I gave the parents the consent form to read and sign. Some read it before the interview, others read it during the interview and gave it to me either during or after the interview. Very few patients declined to be interviewed; less than five, out of approximately 50 that I approached, did not want to participate in the study. In one or two instances it appeared as if the patients were reluctant to be interviewed but the parents wanted them to. In those cases I waited until we were away from the parent and told the patients that they did not have to talk to me unless they wanted to. In all cases they decided to be interviewed.

Once it was established that an interview was going to take place, several steps had to be taken before the interview could begin. First, we had to find a space for the interview and then I had to set up the space for the interview. My access to space where I could

interview the patients was limited to two rooms: #4-71, an examination room and room #4-72, the Social Workers' room. All of the interviews, except one, were tape recorded with the patients' consent. In the case of the one patient who did not want to have the interview tape recorded, I took written notes.

Most of the interviews lasted between 30-45 minutes. Several lasted more than an hour and one only lasted a few minutes because the patient was called to see a doctor shortly after the interview began. I interviewed 46 patients, most of whom I was able only to interview once. Twelve other patients were interviewed twice, three were interviewed three times, and one patient was interviewed four times (see Appendix A). I also interviewed, at their request, one parent and one caregiver. Very few of the interviews had to be terminated because the nurses or physicians needed to see the patient. What happened more frequently was that the patient either had to leave to go to another area in the hospital or the parents wanted to leave.

The interviews were focused because we could only discuss what the patients thought and felt about the spaces in the clinic (see Appendix B). While the interviews were focused, the types of questions and probes that I used were as open-ended as possible. Questions and probes during the beginning of the interview were the most open-ended in order to discover what was most significant about the environment to each individual. Progressively less open-ended questions were then used over the course of the interview in order to examine certain areas more closely. Questions which almost demanded a yes or no answer such as: "Is the room ever too hot or too cold?", or "Are the lights ever too bright or to dim?" were used to open up areas of discussion that had not been covered previously.

The interviews consisted of two different but related types of questions: those that were designed to gather evaluations and descriptions about the environment and those that were designed to find out what the patients' conceptions of an "ideal" treatment

environment would be like. For clarity of review, I will discuss the interviewing methods that I used under two broad categories: Evaluative/Descriptive, or Design oriented. This division is to a certain extent arbitrary because, in reality, there was some overlap in both the questions and the materials used to elicit responses. For instance, during the Evaluative/Descriptive portion of the interview the questions I asked were predominantly about what they thought and felt about the existing clinic space. But a few of the questions were design oriented. In contrast, during the Design oriented portion almost all of the session was design oriented. Occasionally, however, something they said about their designs would initiate a question or two about the existing spaces.

3.3.2.1.1. Interview Materials

For the evaluative/descriptive questions during the interview, I used two tools to help elicit responses from the patients: a highly detailed model (see figure 20) and color photographs of the rooms in the Clinic. With the younger children I also provided small dolls that they could use in the model (see Figure 21). Setting up the room for the interview involved placing the model in a convenient location, usually on the desk, and positioning the tape recorders and microphones. I used two tape recorders with different length tapes, so that the tapes did not end at the same time. This made it possible to have a continuous recording of the conversations.

During the design portion of the interview the primary tool used with the older children and teenagers was a computer aided drafting (CAD) program that I had installed in a laptop computer. Preschool age children were given small dolls, furniture and walls to create their "ideal" Playroom. In addition, I asked some of the patients to choose from a large selection of pictures of cartoon characters, sports figures, entertainment figures, animal pictures, and nature pictures which in the model were the size of posters, and to place them on the walls of the model (see Figure 21).

Figure 20. Photograph of the model used during the interviews.

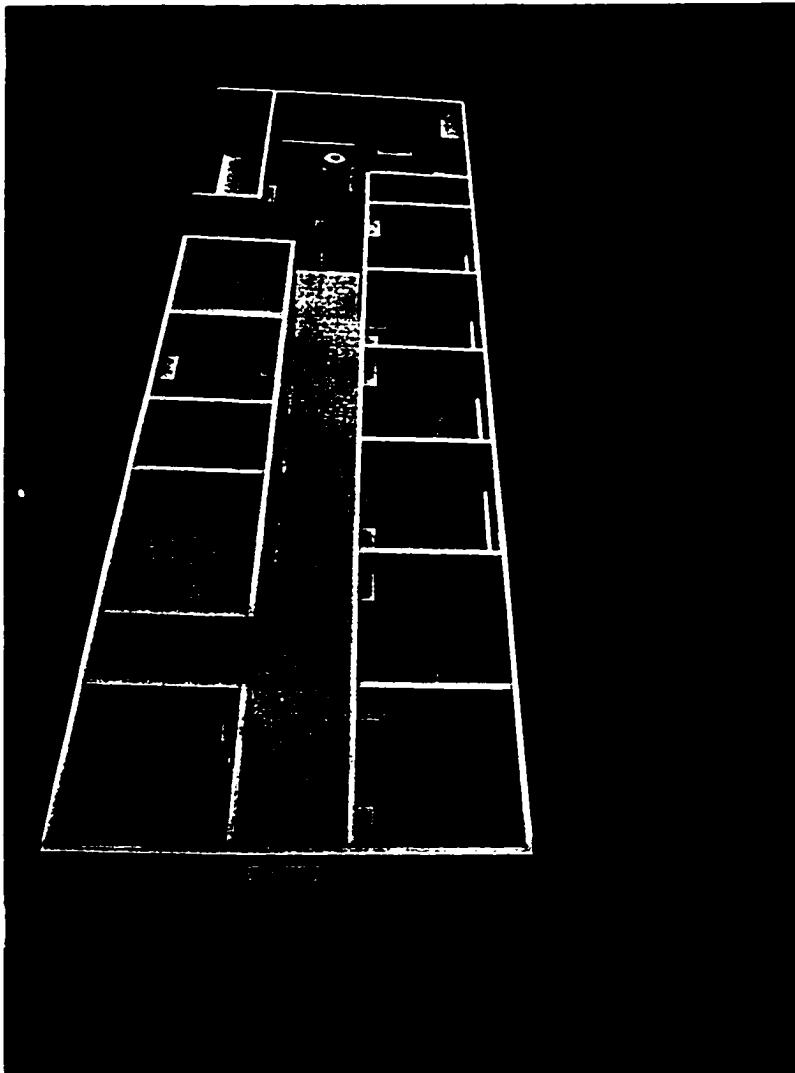


Figure 21. Photograph of the model with dolls, furniture, and pictures used by a patient to create an "ideal" playroom.



3.3.2.1.2. Evaluative/Descriptive

Four techniques were used to elicit the patients' evaluative/descriptive responses about the Clinic environment: interviewing in situ, interviewing while using the model to simulate an in situ condition, interviewing while using photographs of the Clinic, and interviewing while the interviewee was manipulating/playing with small figures and a model of the Clinic.

Questions during this phase of the interview were primarily about the existing clinic spaces although I did ask what their "ideal" playroom or examination room would be like.

In order to help make the patients comfortable with me and to initiate conversation in a non-threatening manner, I "walked" the patient through the model of the clinic. I then asked the patients which room or space they wanted to talk about first. Most of the patients decided to talk about the Playroom first.

3.3.2.1.2.1. In Situ

Interviewing in situ is a form of active interview combining interviewing, observation, and listening while the interviewee leads the researcher through an environment familiar to the interviewee. This method can be used to uncover rich, deep, and salient descriptions about what interviewees like and dislike about the environment. It is a comfortable method whereby issues are raised quite naturally by the interviewee in the process of re-experiencing them. This method allows the children to demonstrate their knowledge rather than being forced into a situation where they have to answer questions. Katz (1986) used child-led walks to learn about the Howa children's knowledge of the environment around their village, particularly how the local plants were used by the villagers. Hart (1979) used what he called place expeditions to learn about children's place feelings and was able to place their favorite places into four major categories: "land-use,"

"commercial," "social," and "aesthetic" (p. 160). He was also able to find out about places of attachment, seclusion and quiet, dangerous and scary places.

The primary purpose for this method in my research design was to determine what the patients' thoughts, feelings, and perceptions about their treatment environment were. In addition, I asked them design-oriented questions: "If you could change it (a particular aspect of the environment) how would you change it?" or "What would your "ideal" playroom, examination room, or screening room be like?" When I asked them these types of questions, I emphasized the fact that there was little or no chance that the existing clinic would be changed but rather their ideas might help architects design clinics in other hospitals.

Even though the interviews took place in the Clinic it was not possible to have the children lead me through the clinic and talk about what they saw. My ability to interview in situ was limited to the room where the interview took place which was usually an examination room. When we are talking about the examination rooms, the examination room where we were was used to generate the discussion. For instance, I could point at different elements in the room, such as the lights, exam table, floor, etc. and ask what they thought about them.

3.3.2.1.2.2. Model

Since we could not walk through the clinic during the interview as a substitute for walking through the actual spaces, a model of the Clinic was used to simulate an in situ situation to help elicit responses. When the discussion was about a room where we were not located, I positioned the model so that the patients had easy access to it so they could refer to it as needed. This seemed to be a very adequate substitute for the real space especially when the patients were discussing the size of the space or activities or behaviors in the space.

3.3.2.1.2.3. Color Photographs

When it appeared as if the patients had nothing more to say about the model, I often showed them photographs of the actual space and asked them if there was anything more that they could tell me about the space. The photographs were quite effective in eliciting patient responses about the two dimensional aspects of the space such as the lighting fixtures, colors, pictures, etc.

3.3.2.1.2.4. Manipulation of Objects in Space

Models of the environment plus other objects such as toys or dolls have been used to stimulate children's thoughts and feelings about a particular space by having them simulate a walk through the space. Katz (1986) gave the children of Howa materials and asked them to "make Howa". She then gave them toys and asked them to show her "life in Howa." Through this environmental modeling exercise, she was able to elicit from the children their knowledge of the "local environment and the human use and manipulation of its features" (pp. 146-149). Rivlin et al. (1974) gave children in a second grade class and a mixed second, third, and fourth grade class unfinished scale models of their classrooms and furniture that were to scale. They were then asked to "set up their real class" (p. 151). By looking at the completed models of the real room and talking to the children, the researchers were able to develop a better understanding about the children's environmental knowledge and attitudes.

Hart (1979) was able to elicit children's place knowledge beyond their homes with the use of a landscape modeling technique. He asked the children to locate on a large, (8' x 8') sheet of paper, all of the places that they knew in their town using model landscape elements such as buildings, toys, trees, cars, trucks and animals. He also provided the children with clay and crayons so they could either make or draw elements of their choice.

I attempted to use the model with small figures that were approximately the correct scale to elicit responses from the preschool age and young schoolage children while I interviewed them. I had little or no success with this method. The children saw the model and the figures as toys and it was almost impossible to ask them a question or questions from the interview schedule once they began playing.

3.3.2.2. Interviewing While Discussing Design Solutions

Participatory design oriented approaches have one thing in common; they try to elicit ideas from the participants about how they would like environment to be. These methods attempt to elicit from children what they would like the environment to be rather than determine what they either know or feel about existing environments. The patients designed their "ideal" space, in most cases a Playroom, using either a computer aided design program, or by building a scale model of the space.

3.3.2.2.1. Interviewing with two dimensional representation of "ideal" environments

Shepley and Gregor (1990) had children at the Camarillo State Hospital (a psychiatric hospital in California) draw floor plans or pictures of ideal housing units showing amenities that they wanted. Many of the patients' ideas such as carpeting, outdoor space, and a kitchen were used in the final design. The amenities that Shepley and Gregor were able to include in the design were not remarkable. In contrast, the "ideal" homes that the five children in a study by Barbey (1974) drew were quite remarkable. The designs that the children Barbey worked with added dimensions to the idea of home that I had never read or thought about.

When there was time, I asked the patients if they wanted to design an "ideal" environment in the Clinic. Almost all decided to design a playroom. Unlike Barbey (1974) and Shepley and Gregor (1990), the tool I provided them to "draw" their designs with was

a computer aided drafting program called MacInteriors that I had installed on my laptop computer. MacInteriors was a relatively inexpensive, easy to use, program that allowed the patients to design a plan in two dimensions and then view the results in perspective as well as elevation. Children as young as seven years old were able to use this program with minimal assistance. The perspectives were distorted but this did not seem to bother the patients.

To begin the session, I would ask the patients what they wanted to do in their "ideal" or, in the case of the younger children, "best" Playroom. I would take notes of what they said and then I would ask them if they thought their Playroom should be bigger or smaller than the existing Playroom. Most of the patients thought it should be bigger. Quite a few said a lot bigger while none said it should be smaller. We would then draw in the walls according to the dimensions they wanted. I usually had to help them do this. Once the walls were in place, I went back to the list of activities and asked them what kind of furniture they needed for those activities.

The program contained a library of furniture symbols that they could choose from and place into the plan. After they had located a piece of furniture in the plan I asked them if they wanted to see what the room looked like in perspective. Almost all of them did. Once we looked at the room in perspective we went back to the plan and added more furniture. By the time a few pieces of furniture had been added to the plan, many of the patients were able to proceed by themselves. They continued to add furniture until they had all they felt they needed. While they were adding furniture, I would occasionally ask them why they thought the activity they were providing the furniture for was important in the Playroom. I was not able to question them as much as I would have liked about their designs while they were working on the computer because that interrupted the flow of their work.

When they completed the design, the session ended and I asked them if they wanted copies of their designs. Almost all of them said yes. I also asked them if they wanted me to send them extra copies so that they could color them in and send them to me. I told them I would make color copies and send the originals back to them. Most of the patients agreed with this but only one sent drawings back that were colored.

3.3.2.2.2. Interviewing with three dimensional representations of "ideal" environments

Environmental psychologists have asked children to build models to demonstrate their knowledge of the environment and how it was used (Hart, 1974; Katz, 1986; Rivlin et al., 1974). Rivlin et al. (1974) also asked children to design ideal environments. They gave children in a second grade class and a mixed second, third, and fourth grade class, unfinished scaled models of their classrooms and furniture that were to scale. They were then asked to "set up the room as they would like it" (p. 151). Interpreting what the children created with the "ideal room" model was difficult. The researchers attributed this to the fact that the children seemed to misinterpret the nature of the task (Rivlin, et al., 1974). They discovered that the way that children that arranged the models could not be considered a blueprint or exact representation of the room. This appears to be analogous with the expressionistic qualities of children's drawings.

In another, study fifty patients at The Children's Mercy Hospital, Kansas City, Missouri were interviewed about what they would like to see in the new inpatient and outpatient areas. They were then asked to make small sculptures out of DUPLOS, Legos, clay or gingerbread, with accompanying text, that "conveyed their ideas about qualities and features important in design" (Wilson, 1992, p. 6). A number of key themes emerged that the architects then used to design the new facilities. The final comment that Wilson (1992) made was that "The children have raised many issues that no adults had thought of" (p. 8).

The primary tool I used when I asked the patients' to design an ideal space in the clinic was the computer aided drafting program. I did not think this technique would work with most of the preschool children so I asked them if they wanted to design an "ideal" Playroom models of furniture, dolls, a playhouse, and moveable walls. I made the furniture and the playhouse out of Legos. These were very close to the scale of the model and the children were able to use them quite easily. I provided the children with two moveable walls so they could define the play space and add color to space by applying colored paper which I had precut to size. Only one of the patients, who was five years old, chose to add color, and this was after his older brother, was seven or eight, asked him about his color preference.

Rob (the older brother): Chris would you like a hot color in the Playroom or just a regular color.?"

Chris: "Hot."

Rob: "Hot pink, or hot orange or hot green?"

Chris: "Hot green"

I gathered very little useful information from this method. The children enjoyed playing with the furniture and the figurines and, especially the playhouse, but their play very quickly became unrelated to the question of their "ideal" Playroom. For instance, one of the boys acted out a very complicated burglary using a ladder to break into the playhouse.

In order to discover what kinds of pictures or photographs the patients preferred to see on the walls of the clinic, I cut out images from various advertisements and glued them to small pieces of cardboard that in relation to the scale of the model were poster sized. The images included pictures of cartoon characters, sports heroes, animals, flowers,

entertainers and other images that I thought would appeal to the patients. I created approximately 100 "posters" for the patients to choose from. When we were talking about artwork for the walls, I would show them the "posters" and would ask them if they would like to put the ones they liked on the walls of the model. I provided a sticky material that is used to hang pictures that could be applied to the back of the "posters" and then stuck to the wall where they wanted the "poster" to go. This method was quite successful in eliciting responses from the patients and they seemed to enjoy the process of picking out the pictures and placing them on the walls. One girl in particular put up numerous "posters" throughout the model.

3.3.2.3. Interviews With the Staff

The interviews with the staff were similar to the interviews with the patients except that I did not use the model while talking with them. (See Appendix D) The primary purpose of the staff interviews was to find out what effect the physical environment of the Clinic had on the performance of their duties. The interviews with the volunteers and Child Life Specialist were in the Playroom, while the interviews with the nurses and physicians were in their offices in another building.

3.4. Analysis

The primary purpose of this study was to gain a better understanding of the children's and adolescents' experience when they visited the Clinic in order to provide information that designers could and should use when they design pediatric hematology/oncology clinics. There was no attempt to test hypotheses. It is important to keep this in mind while reading this discussion of the analysis of the data because the method by which the data was analyzed were guided by my interpretation and conception of the purpose of the study. Therefore the analysis of the data that were collected from the interviews and observations was not "grounded" in what is generally called "grounded

theory" (Glaser and Strauss, 1967). Rather the data were content analyzed, selected, and inserted within the framework of "stresspoints" to be discussed below. The analysis of the data can be described in phases; (1) before I developed the concept of stresspoints; and (2) after I developed the concept of stresspoints.

In the first phase, I transcribed approximately one half the interviews verbatim and then coded them. Coding the interviews proceeded quite smoothly and relatively quickly because I was able to use the interview schedule as a coding guide. In order to save time, I did not transcribe the final half of the interviews verbatim. Instead, I transcribed only the interviewees' responses which corresponded to the coding guide or which had some relevance to the study. Also during the first phase, I began to code my observations using a worksheet based upon Spradley's (1979, 1980) method of ethnographic analysis.

While I was doing the coding during the first phase, some concepts emerged from the data that seemed to promise some explanatory power: control, choice, interpersonal relationships, distraction, boredom, time, activities, bad times, and safety. But none of these concepts were inclusive enough to subsume the others nor powerful enough on which to structure or ground the dissertation. Nor did there seem to be enough connections between the concepts to build a cohesive and useful study. The solution to this quandary presented itself when I developed the concept of stresspoints, and the structure of the dissertation more or less fell into place.

As I began to apply this concept to the dissertation data, together with the addition of the counterpoints to stresspoints: coping mechanisms and strategies, patterns in the data began to emerge. Using the concept of stresspoints and coping mechanisms and strategies allowed me to organize what were previously unrelated concepts on a framework that strongly supported the original purpose of the study.

Following and reinterpreting Kellman's (1987) recommendation that it was necessary to think about the "psychological journey of childhood" (p. 3) in order to understand the effect hospitalization had on children, I determined to follow and mark the stresspoints children faced, beginning with their first visit to the clinic until they either went off treatment or were told there was nothing more that could be done for them.

Stresspoints were differentiated from one another by changes in time, location, the people involved (usually medical staff), activities (usually procedures), and the psychological and/or physical well-being of the patient. Particular attention was paid to elements of the physical environment that were stress inducing because this is an area that has been neglected in most of the literature written about stress and coping in a medical setting.

The data gathered from the staff was analyzed in a slightly different fashion. Instead of focusing on stresspoints, the interviews were content analyzed for functional issues that could be proposed as critical performance criteria which were assembled into a document called: *Purposes, Goals, and Critical Performance Criteria for The Mount Sinai Medical Center Pediatric Hematology/Oncology Clinic*, and given to head of the division.

Table 1. List of patients mentioned in the dissertation.

ONCOLOGY PATIENTS

Name	Age	Gender
Amanda	19	F
Beverly	21	F
Bob	9	M
Brian	14	M
Carl	20	M
Fred	9+-	M
Danielle	10	F
Eric	16+-	M
Dennis	5	M
Erin	9+-	F
Edward	9	M
Francis	13	F
Jasmine	17	F
Jennifer	7	F
Karl	12	M
Ken	13	M
Kevin	5	M
Lauren	17	F
Leon	5	M
Oscar	14+-	M
Norman	17+-	M
Michelle	20	F
Monica	7	F
Ned	22	M
Samuel	14	M
Tyler	9+-	M
Susan	20	F
Tammy	5	F
Tiffany	12	F
Xavier	17	M
Zachary	10	M

HEMATOLOGY PATIENTS

Name	Age	Gender
Amanda	5	F
April	13	F
Barbara	9	F
Beth	10	F
Bonnie	19	F
Evan	6	M
Gary	5+-	M
Harry	11	M
James	17	M
June	12	F
Liam	9	M
Mathew	14	M
Melvin	11	M
Nancy	13	F
Oliver	7	M
Rachel	5	F
Ronald	19	M
Samantha	11	F
Terry	20	M
Wayne	13	M
Wilma	9	F

All of the names are aliases. Most of the patients listed are those that I interviewed (please see Appendix B for the Interview Matrix). The patients that I did not interview have a "+-" after their age to indicate that the age listed is a guess on my part.

4. ENTERING THE CLINIC

Most of the patients that I interviewed did not remember entering the Clinic for the first time so the findings below are based on the statements of just five patients and parents. It is not surprising that so few patients could remember this experience because, for most of them, that experience was several years in the past. Many of the sickle cell patients had been coming to the Clinic since they were newborns. They literally grew up knowing the Clinic and the people who worked there.¹ The impact of entering the Clinic was also lessened for many of the other patients with blood disorders because they had spent a considerable amount of time in hospitals. Many of the oncology patients had also been coming to the Clinic for treatment for several years. Nevertheless, several valuable observations were made by the patients and parents, giving some idea of how scary, and perhaps surreal, that experience can be.

Kevin told me that when kids first come to the Clinic they are scared of the hospital. This was the case for Karl, who said he was scared "'cause I didn't know what I was getting into." His aunt attributed some of his fear to the institutional quality of the hospital.

The layout of the Clinic could add to those fears. Jasmine observed that "... you have to walk past all these examining rooms with all these kids in it in order to get to a nice place. I don't think that's so great." Describing the first time she entered the clinic, she also compared the experience to the surreal aspects of a hall in a movie.

... it was the typical scenario that you see in all the movies... in some of the scenes they watch you walk in and everything looks sort of distorted and you see this long hallway and you hear your footsteps (she then knocked on the table twice to indicate the sound of footsteps). It's kind of funny. It was like being in a movie... I think that what was weird about it was that every, like every, room came onto the hallway.

¹ Many of the children were especially happy to see Joe, a graphic artist, who had been a volunteer at the Clinic for a number of years; he drew wonderful cartoons of and for them. Their faces would light up when they saw him.

In the above statements Jasmine poignantly captures the institutional quality of the Hall, while accurately describing the entry sequence into the Clinic. When using the primary entrance to the Clinic, which first time visitors normally would because it was the closest to the elevators, patients had to walk past all of the Examination and Screening rooms before reaching the Playroom.

The entry sequence also ensured that the patients were forced to cope with the most hectic area of the Clinic before they reached the safety of the Playroom. This arrangement disturbed Ken who said that when he first saw the Clinic he thought it was a "piece of garbage... 'Cause it was so, everybody rushing here, rushing there.' " During the second interview I asked him how it made him feel to see people rushing around. His response was "That I'm in big trouble... I'm in big trouble... I was never in a hospital."

In the statement above, Ken identified some of the reasons why entering the Clinic was so traumatic for him and others in his situation. He had never been in a hospital before. Apparently, most of his anxiety was caused by his fear of what was going to happen to him. But some of his fear stemmed from the unfamiliarity of the Clinic's physical setting which was unlike any he had ever been in since he had never before been a patient in a hospital.

Beth, one of the hematology patients, unlike Ken, had spent a great deal of time in hospitals, so her perception of entering the Clinic was very positive. When I interviewed her, she had been to the Clinic only once or twice before, so, unlike most of the patients, she remembered what it was like on her first visit to the Clinic. She compared the Clinic favorably with another hospital where she had been treated stating that when she first came to the Clinic "I was like, oh, this is cool, 'cause my hospital was pretty dull ... But I come here and I don't know what's new so... it's surprising... but I like it because it is different."

Beth was a "hospital veteran," someone who was very familiar with the socio/physical aspects of medical environments. She did not think the Clinic was "scary"; she preferred the Hall in the Clinic, not because it was less institutional than the other hospital where she had been treated, apparently it was not, but because it was different. Many of the Oncology patients did not have her experience with other hospital environments. The hospital experience for many of them was a new and unfamiliar one. For many of them, their first visit to the Clinic was after the cancer had been induced into remission, and they were still learning to cope with a new illness and its treatment.

4.2. Coping: Environmental Supports

It was suggested that if the design of the Hall was more "children oriented," the patients' level of anxiety would be reduced. It was also suggested that if the Playroom was closer to the entrance to the Clinic, patients would not have to pass the Screening and examination rooms when they entered the Clinic.

Referring to Boston's Children's Hospital, Karl's mother, suggested that a hospital with an entry sequence with child appropriate artwork can reduce a patient's anxiety. She thought the lobby was very nice because "it was set up for children" with cartoons on the windows and statues of animals inside the lobby. She thought it was "children oriented²... You know, it didn't look like a plain hospital, that you walk in. So that's something nice you know. Cause it takes tension, it takes the tension off..." Based upon her experience at Boston Children's Hospital she had some suggestions about how to make the Hall in the Clinic more appealing to the patients.

It would be nice to put cartoons on the wall That's nice, because when the children are walking down, you know, they see things that they are very familiar with... like the mural size... some that children would recognize,

² See 6.4. for a discussion about "children oriented images.

that's why I said it must be children oriented. Things that they are familiar with.

She thought images of Mickey Mouse or other Disney characters would be appropriate because they appeal to teenagers and even adults as well as children.

Beth had similar, but grander ideas about how to make the Hall more familiar to the patients. Even though the Hall did not seem to bother her, she had many ideas about how "The hall could be like a different dimension or something..." a "kids' world." She talked about these ideas with regard to how they would help the patients make the transition between the Playroom and the screening and examination rooms (See 6.2.1.2 and Appendix C). But, like Karl's mother, the environment that she imagined would also provide the patients with familiar images when they first came to the Clinic.

As noted above, the location of the Playroom in relation to the entrance was problematic. According to Jasmine, "they should put the Playroom up front. That way you wouldn't have to walk past all the screaming children the first time here."

4.3. Summary of Findings

- Entering the Clinic could be anxiety provoking for the patients because some of them did not know what to expect as the hospital experience was new to them. There was little in the entrance experience to reduce this anxiety by suggesting that this Clinic would be any different from the remainder of the hospital, or any other hospital. Little had been done to make it less institutional.
- The layout of the Clinic was also problematic because the patients had to walk past the Examination and screening rooms before they could go into the Playroom. This meant that there was the possibility that they would be exposed to other patients' cries of pain, and a high level of activity. Suggested solutions included adding elements to the Hall that would make it more visually appealing to the patients, and locating the Playroom

closer to the entrance so that patients would not have to pass children screaming in pain when they entered the Clinic.

5. WAITING IN THE PLAYROOM

When patients came to the Clinic they often had to wait several hours. Sometimes they waited for a relatively brief period of time, but rarely less than an hour, and frequently for several hours. They waited to be seen by a nurse who took their temperature, height, weight, and blood. They waited for the doctor so they could be examined. They waited for the results of their blood tests to return. And they waited for their medicine.

One of the patients said, "Every visit is different... Every visit for every person is different," but there are certain stressors that can be identified and discussed in order to gain a deeper understanding of what the waiting experience was like for the patients. They reported that they had to cope with stressors associated with their illness and treatment while waiting: adjusting to their newly diagnosed illness and the newness of the Clinic setting, anxiety about seeing the nurse or doctor, and anxiety about procedures in other areas of the hospital. Some patients also reported that while waiting, they felt the adverse effects of their illness or treatment. The patients not only had these illness and treatment related stressors to contend with, they also reported that the length of the wait and the associated boredom and lack of control were stressful.

The environment was also a source of stress for the patients. According to many of the patients, the major problem with the Playroom was that it was too small, which created numerous problems such as: lack of seating and table space, lack of a separate area for teenagers, unsafe conditions, and noise. In addition the patients noted the furniture was uncomfortable.

Even though the Playroom environment could be stressful, it served an extraordinarily useful function in the Clinic; many of the patients reported that certain aspects of the Playroom helped them cope with the stress of waiting. The most important finding regarding this was how important being able to engage in an activity was to the

patients. There were also certain aspects of the physical environment, such as the windows and the pictures the patients made that were on the wall that some patients reported they used as part of their coping strategies.

The patients also had many ideas about how to design an ideal clinic. Especially important to the teenagers would be to have an area where they could gather and "hang out" with an adequate level of acoustical privacy. Patients also noted that they would like to be able to engage in gross motor activities and/or games that were physically competitive.

In the following report of findings, stressors will be addressed first, followed by findings regarding coping strategies and environmental supports.

5.1. Stressors

The stressors the patients had to cope with while they were waiting in the Playroom will be discussed in the following order: adjusting to their illness and the new environment of the Clinic, anticipatory anxiety, the length of time they had to wait, complaint related stressors, stress caused by the relatively small size of the Playroom, patients' cries of pain, disturbing sights, uncomfortable furniture, and the lighting fixtures

5.1.1. Adjusting to the Illness and the Clinic

The amount of time it took the patients to feel comfortable in the Clinic varied greatly. One patient reported that she felt comfortable in the Clinic immediately because it was an improvement over another hospital environment where she had been treated. For some of the patients, primarily the oncology patients in the early stages of their treatment, the stress caused by waiting was exacerbated because they were still adjusting to their newly diagnosed illness. Patients reported feelings of fear, anger, frustration, discomfort, shock due to unmet expectations about the environment, and the need to keep to themselves, or be alone with a family member while in the Clinic during this period of adjustment.

Jasmine had an impression when she first started visiting the Clinic, which was a reaction to an idealized image she had seen on television:

When I first started coming here it was like a shock, cause I always figured that places like these, like, you always see commercials on TV like for St. Jude's, or something like that, and everything is very elaborate because they get a lot of funding, and I just pictured that they would try to make it as accommodating as possible for young children... Not that it is horrendous, but that it wasn't as accommodating as it could have been.

Susan had a similar impression of the effort the staff put into making the patients feel comfortable. But, unlike Jasmine, her discomfort had less to do with the environment than the emotions she was feeling about her illness. She said, "I didn't know anybody, I was very scared, very depressed, very angry. You got to remember these kids are also angry. They're very angry. They're angry at the doctors. They're angry at their parents for making them come here..." Eventually she got used to coming to the Clinic "started playing with the little kids, trying to make them feel better because I kind of knew how it felt."

Xavier had a corresponding feeling of discomfort when he first started to come to the Clinic because, "Just the fact that I knew that I had a disease. I was just, just frustrated so I just blocked everything out. I didn't want to talk to nobody. I stayed quiet. So I kept to myself." His feelings, too, were mitigated by time because, "... if you've been going here for awhile you just get used to it; it feels normal. "But he "outgrew" the Playroom, and by the time I did this research, he spent most of his time sitting outside the entry doors to the Clinic, bent over with his forearms on his thighs, sleeping or listening to his Walkman.

A younger boy, Bob, who was quite outgoing and spent most of his time at the center table by the time I was doing my research, spent some time getting used to coming to the Clinic. He said that in the beginning he "just felt like not being around people... not being with other kids but with my mom."

For some of the patients, primarily the oncology patients in the early stages of their treatment, the disruption to their lives was compounded because they had to return to the Clinic frequently, as often as once a week. These return visits could be, according to Susan, "a pain in the ass"

One of the patients who was comfortable in the Clinic almost immediately was Beth. As reported in the previous chapter she was comfortable with the physical environment of the Clinic upon entering it. In addition, she enjoyed the time she spent in the Playroom because there were a number of activities such as making necklaces that she enjoyed.

While Beth was a "hospital veteran," it should be remembered that at the same time other patients were coming to terms with their illness and a new environment, so they also had to cope with feelings of anticipatory anxiety associated with their treatment. These feelings of anticipatory anxiety will be discussed in the following section.

5.1.2. Anticipatory Anxiety

While the literature would suggest that anticipatory anxiety should have been a major problem for the patients while they were waiting in the Playroom, this was not reported by most of the patients with whom I spoke.¹ However, I did observe patients as they worried about upcoming procedures. Parents mentioned that their children worried and several of the patients said that patients did worry about procedures in the Clinic and in other areas of the hospital. These procedures included venipunctures, examinations, bone marrow aspirations and lumbar punctures, and chemotherapy, which were performed in the Clinic, chemotherapy that was given on an inpatient basis, and imaging procedures such as CAT scans done in other areas of the hospital.

¹ Considering the research that has shown how painful the types of invasive procedures that were performed in the Clinic can be, it is surprising that more of the patients did not report feelings of anxiety about these procedures. The reasons why the findings in this area were so sparse will be covered in the discussion of findings.

Beverly, who was almost amused by the suggestion that she would worry about seeing a doctor said, "No, I think that I am too old to worry about seeing the doctor." Ken denied that he worried: "Doctors I don't care... the doctors are scared of me... I'm never nervous." But, Ken's bravado was contradicted by what his father told me. He said that a week before Ken had to come and have a spinal tap he started getting nervous.

Zachary and Susan acknowledged the nervousness patients felt in the Playroom. While we were discussing the crowding in the room, Zachary suggested there should be more chairs because, "They might be nervous and they might want to sit down and just like relax." "They" also included himself because he admitted that he got nervous while waiting. Susan was much more definite. For her, there was no question that the children worried and therefore the Playroom was a very important place "because that's where these kids sit and wait to go see the big bad doctors..."

Even though many of the patients said that they did not like having their blood drawn, surprisingly, none of them reported any anticipatory anxiety associated with venipunctures.² However, in one instance that I observed, one young boy, about five or six years old, came back into the Playroom crying. The nurse had tried to draw his blood and was not able to do so which meant that she was going to have to try again. The boy was understandably upset about this prospect but fortunately there were things for him to play with. After a short time, he began playing with his father and he obviously stopped thinking about what was going to happen to him and was thus relieved of the anticipatory anxiety which he felt when he came in.

I also do not have much data about whether or not the patients worried about the examinations, although according to Susan "Nobody likes to get examined, especially little kids who don't know what's going on. They don't understand."

² Almost all of the venipunctures in the Clinic were to draw blood. Only one patient whom I interviewed mentioned that he had his chemotherapy administered through a venipuncture in his arm.

While examinations are relatively non-invasive procedures, bone marrow aspirations and lumbar punctures are very invasive procedures that many patients find quite painful. One of the nurses had a special term, "screamers," for those children who screamed during the procedures. The procedure was so upsetting for one preschool girl that in her struggle she bent the needle, which was slightly larger in diameter than a pencil lead. These needles are much larger gauge than either the needle used for drawing blood or shots. This young girl's reaction was not typical but the procedure is uncomfortable, if not painful, and for some patients, an upcoming bone marrow aspiration and spinal tap can create a great deal of anticipatory anxiety. Norman, a 16 year old boy, was one of those patients. His anxiety seemed to get worse because after I had been at the clinic for several months he began to carry a bowl with him in case he had to vomit.

Just asking Karl about the procedures was enough for him to become so upset that he said he wanted to go back to the Playroom. I asked his mother about his reaction to my questions and she said, "He don't really like to dwell on it... Because remember too, it also represents pain. Harsh pain So they would like to block, especially things, you have to deal with it." The harsh pain was such that most patients would rather not think about it but several parents mentioned to me that their children worried about the bone marrow aspiration or lumbar puncture a week or more before they were going to get them. Not all patients, however, find bone marrow aspirations and lumbar punctures anxiety provoking. Tiffany, for example, said, "No, I didn't care really. She (her best friend who stayed with her during the procedures) did but she could feel everything that happens. It doesn't bother me at all."

Most of the patients who were given chemotherapy in the clinic did not worry about it. They were on a maintenance dose which was given to them through their catheters; a "push," which was very quick, taking not much longer than an injection. But most, if not

all, at one point in their treatment received chemotherapy as an inpatient. A number of patients would come into the clinic on the day they were to be admitted as inpatients for their chemotherapy. Recent advances in anti-emetic drugs have reduced the amount of nausea and vomiting caused by chemotherapy considerably but the chemicals used for chemotherapy are poisons which wreak havoc on the body. Therefore, chemotherapy is still something the patients worry about. Ned talked about the pain of chemotherapy and what it was like to wait in Clinic on the days he was to receive chemotherapy.

... as for the pain, they suffer a lot as far as treatment, chemotherapy... once you go to the hospital and something painful is going to happen to you, or you are going to vomit that's all you think about... Waiting in the Clinic you think about a lot, especially if you are not doing anything, you think a lot about the last chemo, or how it went well, or how it didn't go well... chemo is nothing positive to look forward to...

Chemotherapy, besides destroying the cancer cells, can also reduce the number of blood cells being produced to a low enough level so that the administration of the chemotherapy has to be postponed. Having a low blood count in medical terms is not positive, but Norman, on several occasions, was quite happy that his counts were low, which meant that he did not have to get his chemotherapy.

The patients who came to the Clinic for treatment were often sent to other areas of hospital for various types of imaging; such as X-ray, CAT scans, nuclear imaging, as well as radiation treatment. One of the patients, Beverly, was getting what she called a "bone scan" on the day I interviewed her. She said, "Yeah, sure I am worried about that. Like today I had to see my X-rays. 'Cause now I am coming back for X-rays." On another occasion, she was waiting to have one of the doctors look at her X-rays. There was a spot on it that the X-ray technician could not identify. She looked terrified. She was standing in the hall on her crutches, and she looked not only terrified but very uncomfortable.

5.1.3. Length of Wait

Some patients reported that the length time they had to wait in the Playroom and the resulting boredom, pressure, and stress and feeling that they were wasting their time was disturbing. Others, said they were not bothered because they found things to do.

One of the patients who did not like waiting was Ken because his mind wandered into areas that were troublesome. In the following passage he describes how long waits can take their toll:

It's like, it's like you go in there and you sit down and your mind starts to wander... 'Cause you can only do so much when you are sitting down. After you start thinking about the good things, then you start to say "Hey, I have no more good things so I have to think about something else." So you start getting tired more, and anxiety, stress. It all works together in you. And then you get impatient... You just want to get it over with.

For others, it was just that they felt they be could have been doing more productive things with that time and that was in itself a cause of pressure and stress.

Of all the people I interviewed, Carl was the most adamant about how unpleasant waiting was for him. His words capture some of what he expressed, but only part of it; the way he said those words made me almost feel how oppressive and disturbing waiting was for him. He said "... just coming to the Clinic, the whole thing about it, I hated it. I hated coming to the Clinic. So I would sit there for hours. Going nuts. I hated it. Especially doing it once a week."

The stress of waiting was mitigated for different patients according to the strategies they developed. Brian, for example, had made friends in the Hospital whom he could visit, so for him waiting did not mean sitting in the Playroom. And Tiffany did not mind the wait because she was able to talk to and play cards with her best friend.

During the mornings there was a lot of activity in the Playroom that could relieve some of the boredom for even someone who hated waiting as much as Carl did. But by the end of the clinic day there was very little activity. This period was the time when even very active participants in the group, such as Karl and Bob, began to experience the pressures of

waiting. Bob said, "There are times when I just sit there. It comes around the end, when I am about to go... I just walk around." During that time Karl said that he would like to have "videos, maybe a TV they could watch... 'Cause sometimes the medicine takes a while to get up... Some of the kids just mostly go home and you'll be the one like sitting in there, by yourself.... sometimes if the medicine takes all day to get there."

One of the other problems associated with waiting in the Clinic for such a long time was hunger. Food, usually juice, but sometimes cookies or crackers, was put on top of a low storage unit near the entrance. One of the patients, Jasmine, who had been off treatment for several years, mentioned that when she was coming to the Clinic for treatment there was much more food put out. Jennifer thought they should put a cafeteria in one of the empty rooms because "everyone gets hungry" if they are not able to leave the Clinic immediately after they see the doctor.

5.1.4. Complaint Related Stressors

In addition to the stress associated with adjusting to their illness, the Clinic, the anticipatory anxiety they felt while waiting, and the length of wait in the Playroom, the patients reported that they were also were subject to complaint-related stress: sometimes they did not feel well when they came to Clinic. According to one patient, the discomfort that they were feeling was exacerbated by the fact that the Clinic was not set up to enable them to make themselves feel comfortable. On one occasion, I observed that a patient, who was feeling physically ill, also suffered psychologically because she feared that she had relapsed.

Ned explained what he wanted to do when he was not feeling well: "It's just that sometimes if you feel tired or sleepy or you feel sick from the medication. You feel like just being in a corner and sleeping... Just try, you know, just try to keep awake or at least, just go into a corner." Jasmine also wanted to be alone when she "... would come in and

would not be feeling very well. You don't want to be annoyed with anybody else. And your parents also get on your nerves and you want to get away from them, but you can't." She thought this was a problem for many other patients: "And there's not a separate room for kids who want to go lie down. There are the four separate rooms, but a lot of time they're occupied." Another problem according to Jasmine was that even if the patients were able to find an empty room the examination tables were not as comfortable "as it might be if there was like a cot to lie down on." Susan also expressed the need to be alone: "When you are feeling like that, where else do you want to be? I want to be home. I want to go asleep. I want to be in my room."

Approximately one month after I interviewed her, Susan came back to the Clinic with a virus which caused an auto-immune disease and she was having fevers at night. Below are the field notes I took after observing her in one of the examination rooms.

Susan was in really bad shape. She never came into the Playroom. She stayed in room 4-71. I walked by and talked to her and she was a completely different person. She seemed shrunken, her head seemed smaller. Her body seemed smaller. Her face looked thinner. It seemed like all the energy had drained from her. I didn't know what to say to her, so after a few minutes I told her I had to get back to the Playroom. Later I walked by to see if she wanted anything. She seemed to be sleeping huddled inside a purple shawl. She looked like either a child or a very old person. She seemed to have shrunk into the wheelchair. I didn't say anything to her. I walked back to the Playroom and asked her mother if I could get Susan anything, and she told me Susan just wanted to be back home in her bed- that was exactly what she had told me. Her mother also looked like she was distraught, as if she was about to cry any second. I think that they were afraid that Susan was having a relapse. One of the nurses told them that was not the case, but you could almost feel the fear from both Susan and her mom that she had relapsed.

The difference between Susan, the shrunken person in the wheelchair, and Susan the dynamic, energetic person I had previously interviewed was exceptionally striking, as was the difference between where she had to wait: sitting in a wheelchair, in a windowless room with harsh fluorescent lighting, and where she wanted to be: at home in her bed. It is apparent that people need a place to be comfortable when they are not feeling well.

5.1.5. Size of the Playroom

Most of the patients interviewed thought the Playroom was too small in relation to the number of people who used it on days when the census was high. On the days when the oncology patients normally came to Clinic, Monday and Wednesday, the Playroom often felt overcrowded. The patients reported that the overcrowded conditions created several problems: there were not enough chairs for everyone, table space was inadequate, there was not a separate space for the teenagers, the physical safety of the patients, especially the younger patients, was compromised, and the noise level became quite high

5.1.5.1. Lack of Seating/Tables

On the days the Clinic was crowded, the patients reported, and I observed that some of the people did not have a chair to sit on; some people had to stand in the hall, others had to sit on the storage cabinets or stand in the corners, and there was not enough table space. The patients noted that this made it difficult for them to engage in the activities that they wanted to. It also affected the parents which sometimes, in turn, could influence the patients, as with Jasmine who said, "my mother is a little crazy, and when she couldn't have a place to sit, she would start crying or something. It bothered me, just because it bothered her."

She also noted that the Playroom was not big enough to provide adequate space for the wide range of activities that occurred there during Clinic saying, "... for the kids who are into playing games and even doing puzzles, you only have one table. It's kind of hard to do a puzzle if there is someone drawing right next to you, you know."

Not only was it difficult for the patients to engage in activities, according to Ned because there was not "... a lot of space. It's just packed, you know... and there's a lot of confusion," some patients did not participate in the activities at the table because they were either shy or not assertive. He said some patients were not "outspoken, they don't say,

'Hey I want to play too,' or 'I have next.' They don't want to do that." And other patients did not participate because "people are doing different things, and you may want to share it but you don't want to, 'cause you are feeling shy, shy away."

The lack of table space and seats also made it difficult to accommodate the territorial needs of the patients. A primary tenet of the Child Life program was that the children should feel safe and secure in the Playroom. This issue of safety extended to their work and seemed to have a place-based component for some children. When the patients returned from seeing the nurse or doctor they never knew if they were going to be able to get "their" seat. This was an issue for Jennifer who said, "You try to get through something and meanwhile you're trying to get a seat, and someone gets your seat." This loss of a seat was important to someone like Jennifer, who spent her time in the Clinic working on art projects, or for others who worked on jigsaw puzzles. The volunteers tried to save the patient's seat and work, but sometimes that was not possible.

5.1.5.2. Crowding/Safety

While losing one's "territory" disrupted the patient's feeling of psychological safety and security, several patients noted that the patients' physical safety, especially the younger children's, was also compromised when the Playroom became very crowded. One young girl, Jennifer said, "It bothers me because there are so many people... Well, you do get knocked around." When I spoke to her, Jennifer was a very frail seven-year-old, who spent quite a bit of time in the hospital because of complications from her illness.

Two young men also mentioned this problem, which was disturbing to one of them, Carl, who said:

There isn't much room. I guess there could be more room for kids to play 'cause they would be on the floor and everybody would be walking through or walking on top of them, and people would come in with IV's and stuff, in wheelchairs. I just felt bad for the kids. --- stepping over them and stuff.

The other young man, Mathew, recounted that on one occasion, he was walking and talking to a friend and they accidentally knocked a younger child down. Perhaps, because he came on Tuesdays when the Playroom was usually not crowded, Mathew attributed this incident to characteristics of teenagers rather than to the size of the room, but it is apparent that if younger children can be knocked over in a room that is not crowded that danger is increased in a crowded room. He also observed that "they get hurt, like, on the chairs sometimes they get hit. My cousin came, right, so we were talking, so we didn't see it, and we put the chair real back so the kid behind us, he went "POW." As disturbing as incidents such as these were for teenagers, it was probably more disturbing for the younger children who were being bumped or tripped, especially those who were weakened by their illness and/or treatment.

5.1.5.3. Crowding/Noise

The negative effects of crowding have been well documented. Surprisingly only one patient mentioned crowding as a stressor. Although only one patient mentioned crowding as a stressor, the byproduct of a crowd, noise, was mentioned by several people, both as a positive and a negative factor.

Carl was so disturbed by the crowding conditions that when he was able to, he went into a different room. When he "... got too close to people. I don't know, I didn't like it. Because it was too crowded... there's not enough room for everybody."

On crowded days there would often be ten children in the Playroom with an equal number of adults. The noise level could be quite high. This was disturbing to some of the patients, but not to others. One patient, in fact, thought it was a "fun kind of noise."

This was not Michelle's opinion. According to her, the first impression of the Playroom was that it was "extremely crowded. Very uncomfortable because it was very noisy. Kids were arguing about toys. The noise level is loud enough in there... and then

when you add that argument to it, it gets pretty noisy." She explained that for someone "who is not feeling so well or who'd just like to be quiet, it would be very disturbing for them."

The noise in the Playroom was disturbing enough for two patients, Zachary and Susan, that they either left the Playroom or wanted to do so. The noise disturbed Zachary after some medical procedures:

Well, when I was on chemotherapy (in the Clinic) like if, after I would get it, I would always throw up because it made me nauseous... After getting a needle, I don't know why but if sometimes I went back into the room for a little while, if it was really noisy, I would tell my mom that I wanted to go.

For Susan the noise created by "a lot of little kids screaming" was a problem when she was experiencing the side effects of her treatment:

When my blood count was bad it makes you physically feel bad. It makes you tired, it makes you weak. When you are tired you are not up to hearing people screaming in your ear. That's when it's annoying... And I think that was probably the times where I didn't mind being asked to wait in one of these rooms. You know, anything just to get away from the screaming.

She also made the observation that when it became noisy other people, including the parents would start to leave the Playroom.

Depending upon her mood, the noise bothered Jasmine. "Some days it's worse than others. It depends on what kind of mood you're in first of all. I don't blame anybody for it; they're kids but that's why we need another place like a soundproof room." (She laughed when she said this.)

Beverly and Ned were bothered by the noise when they were not feeling well, although not enough to leave the Playroom. Even though the noise bothered Ned when he had "a headache or something," he would still want to stay in the Playroom rather than leave and go to a quiet room because "it's energetic, it's fun... 'Cause a quiet room means that, ah, you're sick..." (See 5.2.2.1 for a longer discussion of this perception).

For Michelle, the noise was not only disturbing for someone who was not feeling well, but it also created communication problems "because by being in a noisy area sometime it is very difficult to communicate with each other. With the nurses and doctors coming back and forth calling each other's names, you get disturbed by talking with other people."

5.1.5.4. Lack of a Separate Area for Teenagers

When a person walked into the Clinic on a busy day, the first thing he or she would have noticed was the beehive of activity at the large table. With further observation, they would have noticed that most of the patients at the table were preteens or younger. One might then have noticed that most of the teenagers were either sitting on a chair against the wall, reading, talking with their parents, watching the activity at the table, looking out the window. Others might be leaning against the short wall that separated the Playroom from the Hall, or sitting in the Hall, exhibiting, in general, a lack of energy and activity. One might even have noticed Xavier sitting on the chairs outside the Clinic. The teenagers did not have a separate area or table designated for them, and consequently they did not become as involved in the activity at the center table as much as the younger patients, and generally they did not engage in as many activities as the younger patients.

Ned (16 years old) spoke at length about the lack of things for teenagers to do, and why they did not join the activity at the center table. He also had some important insights about the consequences of not having a separate area for teenagers. One consequence of this was that the teenagers did not have the opportunity to interact with each other and develop friendships which could help them cope with their illnesses. Another consequence was that the teenage patients who did not participate in the activities in the Playroom had little to do except think a lot- often about things that made them uncomfortable.

Ned thought patients should feel "happy" and "energetic" when they are in the Playroom, and that "there is something for them to do, and they don't have to do it, but they have options. Yeah, that's the main thing. Options." The younger patients had many options but, unfortunately, there were not that many options for the teenagers. As Ned explained, the options for teenagers were limited because many of the activities and games at the table were oriented toward the younger children and therefore, "a lot of people around my age (16) didn't feel comfortable from what I saw." He also noted that because there were more younger patients than teenagers, the teenagers did not want to intrude on younger children: "You know, you ain't going to disturb them or say 'Hey, I want to do this, can I have a crayon please.' You know, you want, hey just let them have fun." Consequently he, and many of the teenagers, did not join the activities at the table. He explained that "I wasn't motivated to do so and mostly the little children would participate and people about my age, when I was about 16, we wasn't too much involved or influenced to participate in the games and so forth." Ned went on to say that because he was not involved in activities "I was more aware of when should I see a doctor. I just sat there and looked at magazines." This was not true for all patients, (Lauren felt very comfortable playing cards at the table) nor for all patients at all times. Even teenagers who rarely used the table when it was being used by many younger children used it when it was relatively empty.

I was curious why the teenagers did not gravitate towards one another. Ned explained that it was difficult to get to know other patients in the Playroom because they did not have activities to bring them together:

A lot of ego. I mean I'm one myself. You feel "Ah, I don't want to bother him, he don't want to bother me." Or sometimes there's not any interest, there's nothing to do unless there's a topic. For instance, someone might bring up cars or a car magazine. They might say "Hey, I like this one, what do you like?" There's no interaction cause there's nothing to do. You're just waiting to see a doctor.

This contrasts to the same patient's experience as an inpatient, where there were a number of ways and means for the teenagers to get to know one another and become friends (See 5.2.2.4 for a longer discussion of this issue).

5.1.6. Patients' Cries of Pain

Cries and screams of children from the screening or examination rooms bothered some of the patients but not others with some of the patients noting that they became used to hearing the cries and screams. Zachary's response had a time component embedded in it demonstrating how the initial visits to the Clinic can be the most disturbing because of the newness of the situation:

Well, first time I got chemotherapy I heard a lot of people crying and that made me feel nervous since I didn't know what I was doing there. I just thought I was coming in for a regular checkup of something... but after awhile I got used to it.

Jasmine's explained how she got used to it:

Yeah you could hear them screaming. I really don't care. It doesn't bother me. I feel bad for them, but I'm not worried that the same thing is going to happen to me. You kind of expect it... Well, I think that you get used to that. I guess it's not such a good thing to get used to it but I think you do. Cause you understand why they're screaming. It's not like "Oh my god, what are they doing to that child." You **know what** they're doing to the child.

But she went on to explain that she felt empathy for the children: "It bothered me because I felt bad for the kids." Similarly, the cries and screams of other patients didn't worry Bob and he also felt empathy for the patients. We had both heard a young girl crying earlier and I asked him if that had bothered him and he said, "It makes me feel like sad."

5.1.7. Disturbing Sights

The patients also reported that they were upset with disturbing sights. Zachary said "sometimes seeing kids with IV's got me a little more nervous." Other patients were bothered by the sight of sick children. Ken said it was, "so boring see a lot of sick people." In general, Carl liked the children in the Clinic, but "some them are bald with just a lit bit

of hair and sick. It's kind of depressing." And Michelle said, "It was very upsetting to come here and see very small children being sick and it was just very difficult."

5.1.8. Furniture

Some of the furniture in the Playroom, such as some of the chairs and the table, was neither safe nor comfortable. The chairs that were constructed of vinyl coated woven wire web on a tubular steel frame were uncomfortable and some of them had broken joints which patients reported pinched skin and grabbed clothes. Another problem with the furniture in the Playroom was that it did not accommodate the patients' needs when they were tired or not feeling well. Patients tried to become more comfortable by placing their arms down on the table to rest their heads and by reclining or laying down on the chairs.

The construction of the large center table created a dangerous and, for some patients, uncomfortable environment. Children could injure themselves on the sharp corners of the table top or bump their heads on the steel structural supports. The square edges of the table could cause discomfort and pain, especially in patients who had injuries on their arms.

When I started visiting the Clinic, most of the chairs in the Playroom were constructed of vinyl coated woven wire on a tubular steel frame. This type of construction made them "bouncy" and that appealed to some children who would bounce on them gently, almost in a meditative state. They were also comfortable for a short period of time. But the construction that made them "bouncy" also created some problems. Some patients thought they were uncomfortable and, as Tiffany said, "if you are waiting for awhile you don't want to sit on an uncomfortable chairs." Michelle identified the source of the discomfort as the holes in the mesh: "By the time you get up you have marks all over you and you feel very uncomfortable. You need to move constantly because sometimes it just hurts after you sit for a long time."

To make matters worse, the chairs were no longer new and the web was beginning to break at the joints. This annoyed Tiffany who said, "if you are playing like a game or something- cards. Spit. They catch on your clothing, and it grabs you and pulls you back. It's annoying," It also annoyed Susan but it was because there was pain involved. She said, " Those chairs used to pinch you right in the ... That was a really annoying thing." And Carl thought the "chairs are uncomfortable... extremely uncomfortable.... I wear shorts. My leg got caught in the middle."

Because the patients in the Playroom were often tired and/or not feeling well, it was not unusual to see them put their heads down on the table. I also saw children and teenagers lie down on the chairs with heads on their mothers' laps. For example, one day Danielle sat next to her mother and put her head on her lap and lay down with her leg over the back of a chair. She repositioned herself quite a few times, trying to find a comfortable position, but couldn't seem to find one. I also saw Steve, a teenage boy, with his head on his mother's lap but the Clinic was not full so he could stretch out on the chairs.

The construction of the large center table (actually two tables placed together) created a dangerous and, for some patients, uncomfortable environment. The edges and corners of the table were square, covered with plastic laminate, and sharp, particularly the corners. One day, a teenage girl was holding a preschool girl on her lap while they were playing a game at the table. After they finished the game, the preschool girl began to bounce up and down on the older girl's legs. This went on for a short period of time and then she fell off, hitting her head on the edge of the table. I remember thinking how fortunate that she "only" hit her head on the edge of the table and not her eye on the corner.

The sharp edges could also hurt patients who had hematomas (slightly raised bruises) on their arms because of their disease, or for patients who had other types of insults to their arms because of procedures. On one occasion, I observed a schoolage girl

put her arm down on the edge of the table. She immediately jerked it back and made a cry of pain. She had a hematoma on her forearm and the pressure of the sharp edge of the table was painful.

5.1.9. Lights

The lights in the Playroom were fluorescent, one foot wide by four foot long fixtures with acrylic diffusers. Most of the patients that I talked to either liked them or had never thought about them. The school age children liked them because they were functional, they provided enough light for their activities. However, their brightness bothered two of the older patients, Ned and Michelle, because sometimes when they came to the Clinic they were not feeling well or wanted to rest. Michelle thought the lights should be controllable because bright lights could be disturbing for patients who were not feeling well.

a lot of times you come in here and you don't feel too well and having a bright light on top of your head is not too relaxing, and if someone wants to rest it is very difficult... under the sickness sometimes you don't like too bright lights because you feel, everything is sensitive to you being everywhere, so even the sound, the light, everything for some reason gets very sensitive...

Similarly Ned became more sensitive to the lights and found them disturbing when he was not feeling well. Describing the cumulative effect the lights had he said, "I just felt like sleeping sometimes. At points, 'cause I was tired and, you know, the lights, **then** (his emphasis) that's when the lights start to build up in my brain, you know."

5.2. Coping Strategies and Environmental Supports

As reported above, the Playroom was the source of stressors such as noise and bright lights for some patients who opted to leave the room. However, many of the patients reported that certain aspects of the Playroom helped them cope with the stress of waiting. The most important finding in this regard was how important being able to engage in an activity was to the patients. There were also certain aspects of the physical

environment, such as the windows and the pictures the patients made, that some patients reported were used as part of their coping strategies.

The patients also had many ideas about how to design an ideal clinic. Especially important to the teenagers would be to have an area where they could gather and "hang out" with an adequate level of acoustical privacy. Patients also noted that they would like to be able to engage in gross motor activities and/or games that were physically competitive.

The following report on the means that were available, or should be available in the Playroom, to help the patients cope is divided into three sections: characteristics of an ideal playroom environment, activities, and environmental supports.

5.2.1. Characteristics of an Ideal Playroom Environment

Several themes emerged when the patients and one parent talked about what an ideal Playroom environment should be like. They thought the Playroom environment should be an environment that was fun and exciting; a place where the patients could feel comfortable, both physically and psychologically. The primary reason they gave why it should have those characteristics was so that the patients would not think about their medical procedures.

Susan thought it was important that the Playroom be as "fun, lively, upbeat kind of environment" as possible rather than a soothing environment which adults might think children would like because she felt "soothing can also be recognized as depressing." Susan thought creating an upbeat environment was critical because the patients did not really want to come to the hospital and be stuck with needles. In her ideal environment, rather than being scared the children could say "Well, I can go into the Playroom and I'll have fun." In fact, that is what she had observed in the existing Playroom.

Another reason for having a fun environment is that it can help distract the children while they are waiting. Tiffany thought the patients should be "happy and comfortable" as

well as have fun and have things to do and look at so that it would "take their mind off the fact they're in the hospital" and not be like "they're in a Playroom waiting for their blood pressure or something to be taken, like someone is coming to stick a needle in them."

Zachary and Michelle also thought the patients should be in an environment that distracted them from the fact that they were in a hospital and specified what the environment should be like. Zachary thought the patients should feel "like they were back at their house with their friends," while Michelle thought they should "know that they are with a bunch of friends, playing toys, like going to a day care center or something or a preschool instead of being in a hospital." This was important to Michelle because the length of the wait was a critical factor to consider because "In the four hours you don't want to be thinking that 'I am here for a checkup. I am here waiting for a doctor.' "

Karl's mother had some additional insights about what a Playroom environment should be like that are worth noting. She thought it was essential that the environment be "child oriented, not adult oriented" because the children are subjected to medical treatments that are "not easy for adults, let alone a child" and therefore, they need "something that they can be very familiar with so that they aren't constantly worried about what they'll have to do or take or whatever procedure that they have to go through." She also raised the issue of choice. Children need to be able to choose the activity that they want to engage in while they are in a hospital because there is so little about their multiple and difficult treatment procedures, over which they have control:

if all the things are brought into the Playroom that they have a choice. Like every week they can also change, but even though they may not change every week, may not be able to set it up like, but if they have a room they can go in and watch videos. The area they can draw or they can play games, they can do this, they can do that. That's very important because they have a choice. And it's very important for children to know that they have a choice, you know, and in different things even though they are going through the medical treatment which they don't have control over but they have a choice in reference to what they can play with, what they can be around...

Even in a well-designed playroom, however, it would be difficult to distract the patients completely, especially the teenagers, as demonstrated by remarks made by Carl:

I think that no matter where I was it just wouldn't be pleasant... 'Cause when I used to come in I used to wait to go into the hospital for two nights so I just wasn't in the mood anyway. So I don't think no matter where I was, I mean, unless it was beautiful surroundings.... I probably still wouldn't be in a good mood because I knew I would be going into the hospital.

In this section I have presented the findings regarding the general characteristics of an ideal playroom, the foremost of which appeared to be that it should be an environment that distracts patients while they are waiting. In the sections to follow, findings will be presented which cover more specific activities and environmental supports the patients reported were present in the existing Playroom or they would like to have in an ideal playroom.

5.2.2. Activities in the Playroom

The level of activity in the Playroom varied tremendously. On some days, all the chairs were occupied and people were waiting in the hall or sitting on the cabinets. On the crowded days, a lot of the volunteers' time was spent simply supplying the patients with arts and craft materials, toys, games, puzzles, or whatever else that they needed or wanted. On other days, when the Clinic was slow, there might be fewer than ten people, including volunteers, in the Playroom at one time. On those days it was possible for the volunteers to spend time with one patient at a time.

Most of the patients whom I interviewed noted how important the Playroom was because the activities helped reduce the stress of waiting. Susan thought the Playroom was a "great idea," because the patients were able to become involved in many activities, making what otherwise would have been a "scary" and "unbearable" experience somewhat fun. She compared it to other waiting areas that were not set up as playrooms.

You know if we didn't have all those games and the drawing, all the people out there who were trying to get them to do things. I mean, what would they be doing. Like the regular waiting rooms, sitting there, you know, depressing. And then you hear the doctor go "Come." (in a deep tomb like voice) You know, it would be like "I don't want to go." (in a scared, timid voice) So, I mean, it helps, it really does help.

Some people, however, did not engage in any activities Ned made a clear distinction between the patients who played in the Playroom, and those who did not get involved in the activities. As an example, he referred to one of the teenage patients who was "just waiting there without any interest or any activities... and just can't wait to get it over with." He contrasted this patient with younger patients who "want to stay here and have fun, and they are having fun."

In the following sections, I will present the different kinds of activities the patients said were available in the Playroom, as well as some that the patients wished were available, to help them cope while they were waiting. These include play, with its subsection physical activities; activities for teenagers, with a special emphasis on counseling sessions; privacy, television, and special events.

5.2.2.1. Play

The patients reported that play served several functions for them: it helped relieve boredom, it helped relieve anxiety about medical procedures, it helped friendships to develop, and it helped to mitigate the effects of illness or treatment related medicine

Play helped Edward and Zachary from becoming bored. Edward thought it was a good idea to have art and toys in the Playroom because "It's like fun, and fun to play with, like if there weren't anything so we would get bored or something like that. You would be tired of sitting." And Zachary was satisfied with the amount of things that he was able to do in the Playroom because "there is a lot of stuff that you can do, so it like never bores you, you have other kids to play with. You have games, you have drawing."

Play not only relieved boredom, it also helped keep the patients from worrying about their medical procedures while they were waiting. Ned made a distinction between himself and his peers, and younger kids, observing that the younger patients "react better to chemo though... Because they play here... all they do is play around... they don't want to be here... but when the kids come they have a moment in time when they forget about being here..." He explained that the patients should have fun because "it keeps their mind off treatment and to prevent anxiety... you go there, you're scared and everything, you just want to keep your mind off things."

The Playroom had this effect on Norman, who often experienced an enormous amount of anticipatory anxiety. On several occasions, he would be so anxious about the bone marrow aspiration and lumbar puncture he was going to have those days that he vomited in the restrooms, but during the time when we played cards he did not seem so nervous. Activities in the Playroom had a similar effect on Zachary and Karl. Although Zachary did experience some anxiety about the procedures, the Playroom helped because "it sort of like calms you down a little if you are really nervous about getting a shot or something... I really don't think about it while I am waiting cause I am usually doing something."

Karl kept his mind off of getting bone marrow or spinal taps by doing different things each week, such as draw or play games. In addition Karl occasionally brought in toys from home, as did some of the other patients. On the day that I interviewed Susan, Karl had brought in a tape recorder that would distort people's voices. It looked like some kind of weapon. Susan recognized how important that was too him, saying "See Karl with his gadgets and things. See that helps. He wasn't thinking about what he had to do here. He was going around annoying everybody else. Going 'Here talk.' It took his mind off it. It was something to do."

Based upon my observations, the Playroom had the same anti-anxiety effect on the preschool age children. Quite frequently, they would come into the Clinic and smile when they saw a friend and play happily until they had to go see a doctor or nurse, at which point some became more upset than others. In one instance, Tammy, who was happily playing until she saw the doctor come in for her, hid under the table and cried on the way to the examination room. In her case, she did not seem to be experiencing any anticipatory anxiety until it was triggered by the sight of the her doctor. Apparently, her level of engagement in the Playroom precluded any nervousness about seeing the doctor.

In addition to providing a place where the children had a moment in time when they could forget about where they were, Ned reported that the Playroom was "a home away from home, so to speak, for that moment," a place where they could "meet new kids so they could have some form of friendships, like they could relate to each other's problems." These friendships are important, according to Ned, because friends "have that little bond, hospital bond... they could relate to each others problems," and it makes the transition from home to hospital easier:

because once you are at home and you are having a good time, you don't want to think about the hospital. But once you have to go... you're not happy. Nothing helps, you know. Only your parents but sometimes they're not there for you because they have to go to work. You make friends in the Clinic and you play around, you play games; it keeps you going.

In addition to its other functions, play also helped some of the patients when they were not feeling well. Sometimes when Karl came to the Clinic his stomach hurt. At those times, he reported it made him feel better to be in the Playroom and he preferred to be in the Playroom rather than in a room by himself where he could lie down. This was confirmed by his mother who said "he would rather be in the play area, nothing to take him out of the play area, you know to make him feel so bad that he would have to leave." Ned felt the same way, noting that "if you feel sick you tend to be just quiet, you know in that little

area," (referring to the chairs against the wall) but if "you see a lot of people doing something and you feel like starting. You might say, 'Hey, why don't I join in?' Especially the counselors assist and you could join in. Or if you just don't want to be bothered you could sit there."

Ned not only preferred to stay in the Playroom because he felt the activity around him would affect him positively, he also thought a room that was designated for, or used by people when they were sick would make them feel even worse.

A quiet room is no good for the Clinic unless there's a big space and there's chairs around so if you feel nauseous or sick like anxiety problems and you just want to sit there. But in the same room there could be children playing games cause you never know. Once you are in the same room you might say "Hey, let me get my mind off the surgery or something; let me just go play with them." Rather than, stay in that room, you become fixed, how do you say. It maintains. I'll put it more simple. It even makes you feel worse. Because, they're saying that, "Hey, you feel bad so stay in this bad place, area. So here, this is for you, it suits you." You know, which is bad. They're supporting, you know, your misery.

Based on what I observed, the liveliness in the Playroom was not as engaging to other teenagers as it was to him because they regularly used the examination rooms when they had complaints. Karl was the only patient who told me that he would rather stay in the Playroom and play, but it may be that many of the school age patients, in particular, also felt the same way because very few of them went into an examination room when they were not feeling well.

The Playroom worked very well for many of the patients, particularly the school age patients because there was a wide range of activities they could choose from to keep themselves occupied and absorbed. But there was little opportunity for action activities, the subject of the next set of findings.

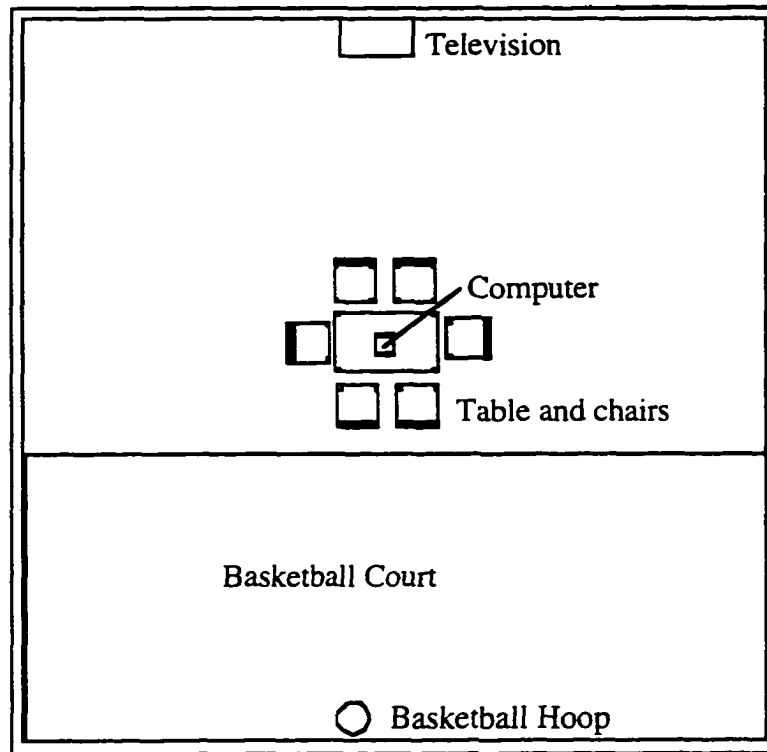
5.2.2.2. Action Activities

Most of the activities in the Playroom did not involve either gross motor activity or competitive physical games. Exceptions to this general observation were the games of Spit and War: card games that required very quick reflexes in order to slap a pile of cards; hand held video games the patients, usually school age boys, brought with them; and running and crawling that the preschool children engaged in. One of the patients, Ned, thought that activities that included some physical activity or competitive challenge could help relieve some of the tension the patients felt. The patients had some ideas about the kinds of games they would like to play in a clinic. These included Freeze Tag, basketball, pinball, ping pong, hockey, and video arcade games. Bob even included an area to play basketball in his design of his playroom (see Figure 22).

Ned said he would like games such as pinball, ping pong and hockey in a room that was separate from the Playroom. His answer is quite revealing because he confirms Csikszentmihalyi's (1990) analysis of physical, competitive activities. He said, "Oh, that's like the challenge, the competition. Like playing the pinball machine. It takes you to another world, you know. You're not in tuned with the hospital. You're intuned with the game. And you sort of get competitive..."

Ned had mentioned several times in the interview that play helped younger children while they were in the Clinic and that teenagers did not have that kind of diversion. I asked Ned if he thought that if there more things for teenagers to do in the Clinic, such as pinball or hockey or something, they would forget about being in the Clinic for a moment like younger kids. He thought it would help but "they wouldn't forget as much as younger kids. But it would give them something to do and they would have at least some interest of looking forward to be there. Especially on time."

Figure 22. Floor plan of Bob's "ideal" playroom.



Room Size: 30'-0" x 30'-0"
Scale: 1/8" = 1'-0"

One type of competitive game the patients did engage in were hand held video games. Several of the boys: Karl, Tyler, and Ken, brought them into Clinic and could become completely absorbed and focused while they were playing them. Karl had been to a hospital in Boston where "They had video games. There's an arcade thing. You press the button. You don't have to put quarters in. You just press the button and they let you play." He agreed with his mother that it helped relieve the tension a lot.

The preschool patients also engaged in some vigorous activity. They would frequently run in the halls or chase each other in the room and occasionally they would crawl under the table, or into the stove in the toy kitchen. Michelle thought that "young

children should have their own room. Taking out some of the chairs and tables would give them more space to run around because I feel little kids would love to have more space."

5.2.2.3. Activities for Teenagers

The teenagers could have had almost as many activity options as the younger patients but they (not all, but many) chose not to do so, apparently because they did not want to take away opportunities from the younger patients. They recognized that, on crowded days, the space was too small for everyone to engage in separate activities so they did not take a seat at the table in order that the younger children would be able to play. Rather than doing something at the table by themselves, several patients reported that they watched the younger children play or played with them.

One of the options the teenagers had was simply watching or being around the younger patients; an option that was incorporated in Ned's design for an ideal Playroom:

You could have chairs on one side for people who just want to sit. Or if their parents want to sit to. It's a place where you could drink coffee or tea or juice, donuts. And the other side for activities like drawing. You know like a special- It could be in the same area but a wider space. A place where you sit down, and just across the room you see people playing games...

This design would have appealed to Susan and Xavier since they wanted to be able to watch children play. Susan happened to like watching children which she didn't think was the norm, and she "got happy just watching the little kids. But that doesn't always work with the other teenagers. That's just how I am. I've always been that way."

Xavier also wanted to be able to watch children play but his reason was more pragmatic. He said that he would rather wait in a room where kids are playing, "Cause I get tired when there's no kind of noise. I got to hear something. Some action. So I can stay up, 'cause I be falling asleep," which is what he did on most days, sitting on a chair in the hall outside the Clinic waiting for his medicine because the Playroom was usually too crowded for him to feel comfortable.

In addition to watching the children, Susan also liked to play with them but "again for me. I'm a hard target because I would have fun just playing with the little kids. 'Cause you have to understand, this is what I want to do." She was not the only teenager who enjoyed playing with children. Jasmine said that she liked to "play with younger kids a lot," but she went on to say, "I think that it would be nice if there was a bigger Playroom so that the actual bigger kids could get down and interact with the younger ones."

Susan made an important observation about the difference between teenagers and the younger children. She made the observation that teenagers needed their own space because:

The thing is that teenagers don't really play. You know. What do teenagers do? They hang out, you know. And a lot of kids you'll see, they come in with gadgets and toys and their Gameboys and stuff like that.... There are not a lot of toys that you can give a teenager.

The teenagers did not have a place to "hang out" in the Playroom, a place where they could have had a certain degree of privacy. As will be seen below, privacy was an important issue for several teenagers.

5.2.2.4. Privacy

The ability to achieve the desired level of privacy was important for some of the patients. Some of the patients were satisfied with the level of privacy, while the lack of privacy was disturbing to others. The teenagers said they needed a space of their own, where they could just "hang out," or have counseling sessions. This was important to them because they would then have a better opportunity to get to know another and create informal support networks.

The examination rooms were used most often for solitude when the patients were not feeling well. Ken and Lauren told me that they had lain down in the exam rooms when they were not feeling well and, occasionally, I would see patients lying on an examination

table. Following are the notes I wrote about one young woman whom I saw lying on the exam table in the screening room.

Amanda came in at 12:10. She looks in pretty bad shape. Her face looks very puffy. There was a call from the admitting room. They said she told them that she was vomiting blood. She has CML. She had oral surgery-dental extraction on Monday- 4 wisdom teeth removed. She is going to the ER.

Amanda is lying on the exam table in a fetal position. Her brother is sitting in the orange chair next to the desk, bent over with his head resting on his arms which are across his knees.

When patients wanted privacy to think, their options were limited. One of the ways that patients were able to gain some privacy was to find a place in the corner of the room as Ned did.

Other times like when I sit in the corner or something like that you know. I like just to think about what I am going to do or I'm going to do this after I'm finished, you know... You don't want to get caught up with the atmosphere of the hospital. It's all over you, **it's all over**, you know, it's all over so you just want to be by yourself or, or think about what you want to do next, the next move.

To a certain degree, Ned was able to establish a place in the Playroom when he needed privacy, Michelle, however, was not able to do that because of all the activity in the Playroom and she would have preferred a quieter environment.

Being in the same room, it was very hard because some kids would like to play around, but unfortunately for me, I just kept on thinking about my illness. I wanted to be alone and to be more in a private room. There was another a girl who was with me who felt the same thing... we both felt that there should be a quieter place for people who need to be more by themselves.

Michelle was one of the patients who was bothered by the noise in the Playroom as well as the sight of very sick children. She wanted a private room where teenagers could get together and support each other but not necessarily a place of solitude because:

... sometimes being alone is not really the best thing especially during the time when you are sick, cause you feel really depressed. But having a room where you can let people, different teenagers of the same age come in and maybe get to know each other and share each other's experiences and hardships of going through the illness.

Michelle wanted a private room where she and other teenagers could have what Westin (1967) would call "limited and protected communication," and perhaps "emotional release." The space she thought the Clinic should have could also have been used to hold counseling sessions which would have been appreciated by some of the patients.

Counseling sessions, where the patients could talk in a group, would be Ned's first priority in an ideal clinic because "I think that it really would help, you know. It really would... it makes you grow as a person. " (He said this with a great deal of insistence.) He thought counseling sessions would be especially beneficial for new patients because it would help them make friends with patients their own age in a new environment. There was a need to make new friends because "As a teenager you know you feel your friends, your friends from your neighborhood or from your school are not there, so you have to try to adjust to a new environment. So it's up to you to make new friends." Mark said that it was rare for patients to bring their friends because:

One- people are afraid of hospitals. Two- They don't want to see a friend in that state. Three- Friends don't really know how to cope because of this life-threatening disease. Four- It's early, there's school. Five- They don't want to be bothered with the whole idea of hospitals and everything. Six- The patients themselves don't want to be bothered. They don't want to see their friends while they're the ones that are sick and everything. Seven- They don't think it's cool.³

He thought it was important for patients to be friends with other patients because they could support one another in ways that people without a similar experience could not:

They could exchange numbers and talk about their problems and interests, sports. I mean that's what I did. ... it's more bonding, it's more

³ In the second interview I asked Mark why it wasn't cool to visit a friend in the hospital and he said:

From a teenagers standpoint you feel that umm, it's not appropriate to bring your friends because they cannot understand where you are coming from. And a hospital is not cool. It's an eerie feeling for young people. They don't feel as quote, unquote 'cool' because there's nothing happening in the hospital. It's basically a place for sick people and they're not sick themselves, why should they be there and they feel nauseous about the idea of going to a hospital? And even though it's their friend they don't know how to cope with their friend who's sick.

friendship, it's more exploring, exploration... you're learning how to be together with the same problems, and it creates more bonding... Sometimes children, I know for a fact, that children have problems, they don't know how to reach out or to explain... sometimes psychologically years later you could still have, you know, like, you could still be, your self-esteem could be lower. You know, you lost a limb or you know you had a disease and everything and many a times your friends that you grew up with, they have a problem coming to see you in the hospital, and you just want to meet new people that have the same problem.

He later explained that he thought it would be important to have a separate room "next door" where teenagers could either get together to talk informally, or more formally in a counseling session, in order not to disturb the other patients:

And you can't just meet in that little area 'cause there's more, there's a lot of people who have to come in there.... Because you can not just like talk about your problems out of the blue, and "Hey we're playing here you know. I don't want to hear this," 'cause then you're going to bring back my problems and then I'm going to "Ahh come on, I don't want to hear this." This guy or girl is going to bring up sob stories.

The lack of a private space where teenagers could talk and participate in counseling sessions were in contrast to his experience as an inpatient, where there were a number of ways and means for the teenagers to get to know one another, become friends, and create their "own support system."

But I guarantee you when they go to the hospital as an inpatient there's activity groups. When they could go to a room and then they could all hang out as teenagers. Cause they're different in methods of activities for kids... so they could join together and exchange numbers. And doctors do that a lot, they say "Hey, there's a patient. There's a patient who's just undergoing chemotherapy, his first time. Would you talk to him?" When they first admit. It's easy to make a friend as an inpatient. As a patient in the hospital, rather than the Clinic. You might have a roommate, like two beds in one room, so you could talk to each other. And there's TV there also. Sometimes some children unfortunately don't have TV so they go to the other room and make friends there. Or radio.

Ned was one of the last teenagers I spoke to, so I was not able to ask all the teenagers if they thought counseling sessions, or even a room to be with other teenagers was a good idea. However, I was able to talk to some teenagers about these issues. When I asked Carl what he thought about that counseling sessions, he said, "I guess that would

be a good idea. Not for me, personally, but for other people." Michelle on the other hand said:

Well, yes, I feel if they had a specific room where they had sessions or even a room where there is no session or if anybody would be interested in going there, just being with the other age groups, or whatever, it would be very helpful because this way either they can talk about it by the group encouraging them to, or they can talk on their own being more private and sharing their feelings in it.

Zachary's needs were similar but rather than talking with a group of his peers, he was at the age when his mother or his father were his confidants. Zachary was quite satisfied with the Playroom but he mentioned that he wished that there was one more table. "So you could like do stuff, like say if you wanted to be alone with your mom. Or if your dad, whoever is there, you could just like sit at that table, without having other kids around." He thought it would be even better if that table was in a separate room, "So if you wanted to like talk about like, like, like say. Well, I have a tumor in my, so if I thought, if I wanted to talk to my mom about it I could just go into that room and just talk with her."

Even if it was not possible to provide a separate room, a bigger Playroom would have allowed for a greater degree and more kinds of privacy than was apparently possible in the existing Playroom.

5.2.2.5. Television

The Playroom did not have a television. Some of the patients missed this feature which is present in many hospital waiting rooms because they felt it would help fight boredom and make the time go faster or distract them from their worries. Others did not like to miss their favorite programs.

Zachary said he would like to have a television, "So you wouldn't have to draw or read. You could watch TV or watch a video... If I'm just bored I watch TV at home. So that's what I would do here. If they had one."

Bob also said that he would like to have a TV to fight boredom. Bob put a television in the playroom that he designed with "nice big couch type, leather, leather chairs" around the table and the patients could lean back," [He gave a short laugh -he was savoring this image.] so they could be comfortable while they watched TV. He said he would like to have a television in the playroom when he "waiting for the counts... So you can watch TV and not be bored, well kinda sometimes you get bored of playing games. I need TV. [Laughing as he says this.] Well, I don't need TV, I like it." Later in the interview, however, he gave another reason for wanting a television. He said patients needed to be distracted from "bad thoughts," by which he meant the hospital and "getting needles." He went on to explain why he put the television in the playroom he designed:

Well, I want them to distract them so they are not thinking about it and so that whole, one little thing, a stick won't be in their mind so they won't make it one big thing but one small thing. It only happens **right then**. It's not going to, you shouldn't have it, be worrying about it when you don't have to be. So I want this to distract them.

I then questioned him about the power of television as a distractor and he said it would work better than drawing and art. In the quotation above, Bob was talking about "them" but he was also talking about himself. In the first interview when we were talking about the younger children crying he said, "So I think maybe it would be better like maybe even before, like before they're having something that they might be worried about they could, like to have a TV or something to calm them down because sometimes that calms me down."

Michelle thought it would be a very good idea to have a television in a waiting area because television had a broad appeal: "Televisions would be very helpful because that is one of the most popular things that everybody would love to do. The major advantage of having a TV in a room where people are waiting, according to Michelle, was that watching

television is very distracting, which means that time goes faster and people don't worry as much. She thought films were especially powerful distractors:

It keeps time going and distracts their minds, especially if they are watching something that is interesting to them. It really kills time. By the time, you know, when the doctors will be calling you. It also keeps their mind off their own problems, thinking what would happen, you would concentrate on what you are seeing. Actually television would be much preferred to radio. It is a bigger distraction and especially films, the latest movies. Because that has a specific theme, specific things. But television itself sometimes just has commercials and everything...

For patients such as Carl, who had a very hard time with the wait in the Clinic, television would be one way to make waiting less stressful. In Carl's ideal clinic, there would have been a dark room with a Lazy Boy: "A nice comfortable place to sit and watch television," because "time goes fast, watching TV," and it "makes you feel a little better." He said having a television probably would have made his stay easier but "it still wouldn't have made me want to come to Clinic."

Ned also thought it would be good to have a television because it would help take the patients to a "different world." But he had some reservations because the effect is only temporary, and the patients wouldn't be as involved with what he called "counselors."

For some reason if you watch something, like a good movie or a good cartoon. Afterwards you have that little emotional letdown because you are not part of it no more. It's over. So during that time it's good, but once the program is finished it's back to reality and makes you feel let down because the counselors can't- You won't be focused as much with the counselors because they're there to provide activities and too help you out but, you know, but you're not too interested in that.

5.2.3. Environmental Features

Activities in the Playroom were the most powerful strategy or mechanism that the patients had to cope with the stresses associated with waiting in the Playroom. In addition to- and sometimes as part of- the activities, there are aspects of the physical environment which can also help patients cope. The patients reported that environmental features such

as the color of the room, lighting, carpet, pictures, windows, food, and even a fish tank could or did help the children and teenagers cope with the stress of waiting.

5.2.3.1. Color

The walls in the Playroom were white. Some of the patients preferred this color. Others, however, objected strongly because they thought the color of the walls was too depressing, dull and institutional. And some of the other patients, while not objecting strongly to the color of the existing walls, would have preferred it if they were more colorful. Several of these patients were able to give more than one reason for making the Playroom more colorful. They thought that if the Playroom was more colorful it would be less boring, less institutional, more cheerful and energizing, and would show that someone cared about the patients. However, as one patient noted, the color scheme for a playroom has to be chosen very carefully in order not to disturb patients who are not feeling well.

Several of the patients and one of the mothers thought colors could have a positive effect on the patients' emotions. It is interesting to note, however, that the colors they thought would have that effect were often very different and even contradictory.

Bob, who thought colors should "pop you right up there," chose "white, white red or something... "green" because those colors "would make it look better... it would make it look more colorful, cheerful." Ned also chose white, as well as "bright rainbow colors." and for a similar reason: to energize the patients. He felt that if a person was in a "dull room, and it's dark and gloomy, you tend to feel, from what I see, you tend to feel sleepy and tired." He thought it was important to have nice colors in the Playroom for the "Brightness, it gives the energy.... To feel lively... the bright room has a vibe to it, it make you feel energetic... bright colors is interesting, it makes it vibrant, it's not dull colors, it creates happiness." He thought it was important to create this kind of mood in the

Playroom, so that the patients would be active participants and not have an "emotional letdown."

Other patients had similar thoughts as Bob and Ned about the kind of mood colors should create, but for them, white was a hospital color with negative connotations. It was for Karl's mother, so it is interesting to note the similarities between the feelings she and Ned attributed to color, even though their definitions of what is a bright color are so different. She said:

And you know what I believe, too, the colors have a lot to do with sometime the way you feel, like if you walk into a dark room, right? Dark colors, it gives you a gloomy feeling. If you walk into someplace bright and it has a lot to do with, you know, the way you feel, especially for the children, especially what they are going through.

She thought it would be better to chose "pretty" colors that were more homelike and 'Cause you know the hospital is white."

Ken also did not like white and thought, "It gots to be like a nice color... It got to be like nice, a glow into your eyes, so you should come in and not be sick." [He groaned making a sound that a sick person would make.] He did not think that it should look like a hospital, "Cause--- they go crazy when they see that."

Tiffany and Carl thought that bright colors could make the patients happier. Tiffany thought the color of the Playroom "should be brighter. They should have different colors, more like for kids... It would make kids happier at least... interesting to look at... cause if you look around it's just the same old color. Carl, who thought the plain white was depressing "like a mental asylum," thought colors that were "bright and cheery" should be chosen because "I guess most of the kids in there are pretty much down, you know, so they could be in a nicer happier surrounding. Make them feel more comfortable."

Two of the other patients thought the color of the room could impart a positive message. Beverly thought the most important thing she would tell architects who were

designing a Playroom, besides ensuring that it was a safe place to be, was that "the room should be big and colorful for the children." She believed patients would like a colorful room because "that makes them forget where they are and it makes them feel like they are in a special place." Similarly Karl thought that nice colors could indicate "that they care in there... about the color and stuff to make it nice."

There are bright colors, and then there are "hot" (One of the patients used this term.) neon colors, such as hot pink, hot orange or hot green which several of the younger children liked. When I asked some of the other children and teenagers what they thought of those colors, they generally thought they were too "bright." Zachary said, "That would be like, that would be like having a neon light, like staring right up at you." Although he would not want the entire room to be a hot/neon color, he said he would not mind if those colors were used as accents. When I showed those colors to Ned and asked him what he would think if he walked into a room painted with those colors he laughed, and said, "Well, honestly that's interesting. My eyes, it just, my eyes just..." I completed his sentence for him by asking a rhetorical question, "Pretty bright, isn't it?" to which he agreed.

Jasmine had picked a light blue for the Playroom. When I showed her the neon colors and asked her what she would think if they had some of those colors in the room, she explained that bright neon colors could be very disturbing for some patients when they were taking certain medications.

If you had neon all over the place then kids would come in... I remember I walked into the bathroom at the Kaplan center and it was that green, (like a neon green) and it was so disturbing I had to leave, my eyes were completely out of whack. I didn't like it all. It was really strange.... You can't stay in there that long. I think that it would hurt a lot of people's eyes.

The pictures that the patients drew, painted or colored which were on the walls of the Playroom added a lot of color to the environment. Some patients did not think the room

needed any more color because of the pictures. For some, the walls were literally background to all the artwork that was on them. When I asked one of these patients, Amanda, if she would change the color of the walls if she could, she said, "Nah because that makes it look like too over designed or something... The artwork is enough already." The other functions that the pictures had as coping mechanism will be discussed below.

5.2.3.2. Pictures that the Patients Drew and Posters

The patients reported that the pictures that they drew served several different functions: some of the patients took a great deal of pride in having their work displayed, patients looked at them when they were bored, patients looked at them for sources of ideas for their own drawings, looking at the pictures helped ease the pain of painful procedures, and looking at pictures helped mitigate anticipatory anxiety. In addition, the pictures served as a memorial for patients who had left the Clinic and they helped the Child Life Specialist gain an understanding of how the patients who drew were coping or adjusting to their illness and treatment.

The pictures had the most positive effects on the patients who spent time in the Clinic drawing. But even for someone like Ned who said "It had no effect 'cause I wasn't part of, I wasn't part of the group that was created those," the pictures provided some visual interest:

... sometimes I would sit back and just daydream a little and I would stare at the wall. Everywhere you go you see the posters, you know the pictures; so I say, hey you know I look at it. I see a couple of "good-bye pictures" like those "nice-being- here" pictures and I would see all the artwork from the kids, you know. It was interesting; it was creative.

Even though the pictures did have the salience for Ned that they did for the patients who drew them, he recognized how important the pictures were for them because they were a means of self display as they were for Terry. Terry was an accomplished artist and he described the pride that patients felt when they saw their own work up on the wall.

... every kid feels proud when they come back to Clinic and they see artwork "Oh, I did that." Yeah, then when they grow up and the stuff is still hanging you know, "I did that, 3 years ago, you know." How much better did it get, you know. That's how I feel like that, like when I see all my old artwork... it's something like "I did that, damn."

Zachary also spent time looking for pictures that he had drawn and he also thought it was fun to look at the other drawings. He liked looking at them to "See what looks good and look around for some of my drawings... I think it's fun looking at them if it's like a comic. Sometimes, like, I read them." In addition, he used the pictures to help ease the pain of painful procedures: "After I had a shot I would feel sick so I would just like look around the rooms and see the pictures. I would look at all of them and it would just like clear my mind. I wouldn't feel sick."

Many of the patients would draw without an outside stimulus; others, particularly school age boys, could be observed copying characters from action comic books; while others would look at the drawings on the wall for inspiration using them to stimulate their imagination. This use of the pictures on the wall was noted by Susan as well as Barbara who said: "In the Clinic they have pictures up on the wall that people drew, and I'm looking at them to see what do I think I should do. Sometimes I don't have ideas and I like to look at other people's drawings."

The Child Life Specialist also looked at the drawings but often she looked at them in order to gain an understanding of how the patients were coping or adjusting to their illness and treatment. She kept the patients' drawings in individual files and was able to see the patients' progress over time. The psychological implications of the drawings as well as the ability of the pictures to make the room more interesting was recognized by one of the patients, Wilma. She felt that if there were no pictures up on the wall, it would be:

really, really boring. You would look around and there no pictures nowhere, anywhere. Only things that you would see was the wall, or maybe see is the wall or some pictures taken with a camera. You wouldn't

see what they think, what they're thinking... If I'm scared in there. They're smiling. (Small laugh) Instead of what they think.

The drawings also served as memorials to those who had been in Clinic either as patients or volunteers. All of the volunteers made a farewell card the day they left the Clinic. This action served as closure and the product served as a marker of our presence that was left up for months after we left. Some of the drawings also served as memorials for patients who had died. Victoria died shortly after I started my research at the Clinic and a drawing that she had done was still up on the wall when I left. The Child Life Specialist deliberately left her drawing up the wall as a memorial.

Pictures that patients do can act as memorials when they are gone but Ned felt there could be a way for pictures or posters of patients who had fully recovered to be displayed to act as optimistic portraits of reassurance and encouragement for patients while they were being treated: "You could have like a few pictures of kids that used to be here. That say 'Hey, I made it, so can you.' 'Stay strong'... 'This is Mike, I used to have cancer'..." He hoped that when they looked at those posters they would think positively about their chance for survival, that they would think they were "the next quote unquote generation of kids, they're going to say 'Hey I'm going to be on that wall.' "

All of the artwork that was in the Playroom was done by the patients or in a few cases by family members. In addition to asking the patients what they thought about the pictures on the wall I also asked them if they would like to have posters on the wall. The response was mixed. Only one patient, Ken, who did not like drawing, thought there should be no children's artwork and only what he called "nice" paintings or posters. "Yeah really nice funny ones like they have in the hospital, every room they have some funny ones" to "keep them (the patients) happy."

The problem with posters, as Jasmine discusses below, is that it would be difficult to find posters that would be suitable for all ages. Jasmine thought there should be as

many children's drawings on the wall as possible and when I asked her if there should be other kinds of artwork like posters or paintings, she said, "That's OK, I just don't think that it should take up too much space because the kids are here to do their own artwork." I asked her what kinds of posters she would like to see up on the walls and she said:

I think that it would be hard to get posters that would be fun for everybody. A lot of people like sports and I don't... Yeah, it is so hard. Like none of these would be real good for everybody. Like I would want some hunk on my wall, and I'm sure a lot of kids would like the *Wrestle Mania*. I just don't think that it would work out.

She thought a mixture of images appropriate for different age levels "would be okay, but then there would have to be so much of a mixture for everybody then there would no room left over on the walls for anything."

It is clear that Jasmine placed a lot of value on displaying the patient's artwork. She also pointed out the difficulty in picking art that would appeal to the various age ranges.

5.2.3.3. Carpet

The carpet in the Playroom was, as Jasmine said, "Old and stepped on by many a children's feet" and it was often dirty as several patients pointed out. Nevertheless, most of the patients preferred having carpet to tile. The primary reason they gave for choosing carpet over tile was safety. Several of the patients mentioned that they thought there should be carpet because children run and fall and, as Brian said, "some of them are just getting off treatment and they bruise easily."

The carpet also looked less institutional than tile and to Ned that was important because it was a "very sensitive area." He thought "rugs are better because the atmosphere feels like your home. Or, or this is a space that's clean and healthy environment... You go over there that's like carpeting. It's like luxury for the patients."

5.2.3.4. Windows

The Playroom had two windows, a large one, approximately five foot square, on the west wall with a view of part of the hospital and part of Central Park and a smaller one approximately two and a half feet wide by five feet tall, on the north wall, with a view of the south wing of the Guggenheim Pavilion 75 feet away. Many of the patients thought the windows were important because they let in sunlight but the lack of view bothered some of them. However, the views from the window were disturbing for one patient because they made him aware that he was not where he wanted to be.

Tiffany didn't like the fact that when she looked out the window she saw another building rather than a view of the park because she felt nice views could help relieve her boredom: "When your get bored. It's just like something nice; it gives the place a nice look. So if you glance over at the window to see what's happening out there, you don't see a brick wall. You just see a park."

When Susan first started coming to Clinic, she was angry rather than bored and did not want to have anything to do with anybody else, so she looked out the window. But she was also not happy with the view because "It's a brick wall. It's not so helpful... when you don't want to be where you are, you look someplace else."

She also felt windows were important because they allowed in sunshine which could have a positive effect on a person's mood. As an example, she talked about what people look for in a home environment.

When it's bright and sunny out, you know, it lends itself to the room. It made the room. I mean in any house, you see people go there and "Oh, I'm looking for windows with lots of natural light because I just want the room to be filled with it." They want that because they want it to be a bright, you know, happy kind of plan. They want it to be pleasant and sunny and cheerful and yippee and hello...

She then went on to explain why windows and the light they let in were so important in a playroom. She felt they helped keep the spirits up of "little kids who just are scared and don't want to be in there... It's so basic and so complex."

The issues are complex, even those having to do with something as seemingly "transparent" as windows. Ned, like Tiffany and Susan, was not completely happy with the windows but for different reasons. The first statement he made about windows was fairly straightforward because it dealt with the properties of the view. He liked the windows "up to a point" but "You cannot see the public outside, they're so far up and the angle, you know, you can't really see. All you can see is the rain or sun. And you feel a little closed in." But the next statements he made were much more revealing because they exposed the emotional state of someone with cancer and why a view out a window may not appeal to all patients.

But, it goes both ways. You could see as it closed in; you don't want to see the outside world for that moment. If you do see the outside world like people walking by and having fun, kids going to school. It starts to play with their minds, say "Hey, I should be out there." And you start to feel sad.

Apparently the advantage to a room without windows is that it is a self-contained environment where they patients can feel free of the outside world. He thought that if he had to wait in a room without windows:

It wouldn't affect me; it would be OK. 'Cause the more windows, the more you see, and the more you see the more you wish you was there. (Spoken very softly) I mean the Clinic should be like another world. So you go in, and then it's like your playtime, or some time you spent. Just to keep your mind off of things for awhile. For that moment.

Ned was one of the few people who said that they would not mind if there were no windows in the Playroom and he was the only one who gave such a subtle reason why the view from a window might be unimportant, if not in some ways disturbing.

5.2.3.5. Furniture

The patients had ideas about how to improve the furniture in the Playroom. Several of the patients who designed rooms included couches or arm chairs in their designs and one

patient included a rocking chair in her design. Another patient believed furniture in the Playroom should be fun. He also thought of ways to improve the existing furniture.

Samuel thought the furniture should be more appealing to the patients: "You know what I want to make, fun. Make it look fun. Don't make it look dull." He thought that if the chairs should be made with "like chairs with characters in it. Goofy ones, cartoony ones. So kids look at it, you know and when they get to the table they would want to go 'Yeah, let's go sit.' "

One of the major furniture stores sells a leather chair that looks like a giant baseball glove, the kind Babe Ruth or Ty Cobb played with. Another idea Samuel had for a chair is remarkably similar to that: "Or make like a hand chair. A chair that's a hand (holding his hand up as if he was cupping something in the palm of his hand). That would be cool for kids. For kids, you know, they come in, they will like it, enjoy it, you know."

Samuel also had ideas about how to improve the design of the table because he thought that as it was it was uncomfortable and unsafe.

I would make a table for kids too, on the side, like that, I would put like a little, like a cushion [He was talking about putting a cushion on the edge of the table so the kids don't get hurt if they bump into it.] I've always thought that when I was small, I always thought of that: they should always have a cushion on the side. You know, like the ones that they got for a bartender'... They should have the same things for kids. You know, it's stupidity cause they mostly concentrate on that more than kids.

Samuel thought the legs should also have cushions to prevent the younger children from injuring themselves.

5.2.3.6. Food Area

The volunteers put juice out every Clinic day and occasionally some cookies or crackers or fruit. According to the patients, food was important because it could act as a treat and could help distract the patients for a period of time. Having food in the Clinic was

so important to Lauren and Jennifer that they said there should be a kitchen attached to the Playroom.

Jasmine recognized that it was good to have healthy food available such as fruit but, in addition, she thought there should have been food that acted like a treat in the Playroom because the patients were someplace where they did not want to be. According to Susan food served a slightly different purpose: rather than being a reward it took the patients mind off of their situation temporarily.

I mean just going to that, that counter and looking at the food is enough to take their minds off it for a second... Food always takes your mind off of things. Are you kidding. Slap a chocolate donut in a kid's mouth, and they don't care what they are doing. You know, shove a powdered donut in their mouth, give them a crayon and some paper. They're happy.

There's a microwave in office manager's office. We used to make popcorn. Pop it into the microwave popcorn in there all the time. And we would pass it out in the little cups and everything. We were like "OK, take another bag." [This was said in a very macho type of voice]... Put another bag in... But it helped. It helped. It helped pass four minutes. [Short laugh] I mean, still if it helps pass four minutes listening to the popcorn pop. It's so stupid, but it did. And then we got to eat it. [Laughing] I mean, what could be better? It was enough, though.

Another type of distraction that the patients mentioned were fish tank, the subject of the last section of findings in this chapter

5.2.3.7. Fish Tank

Two patients thought the Playroom should have a fish tank because they felt watching fish would help relieve stress. Ned mentioned that he had seen a fish tank in the Obstetrics Clinic and said, "Fish, fish relieve stress. You see the fish moving, and you are so into it and then you feel relaxed. It's good for the adults as well."

Amanda's reasoning was similar. She thought there should be a goldfish tank because, "That calms you down. They make you not nervous." But the goldfish tank she had in mind was quite amazing.

They should make that room the tank is only rectangular, they should have tubes going around the room... and then the goldfish swim in the tank and when they want to leave they go swim that tube, and they come back to the tank... I saw that from a movie... the tank was like that big, and there was a place for goldfish... They have those tubes, right, around the whole room and then the goldfish swim and then one go through and one follow the other and come back.

5.3. Summary of Findings

The Playroom environment served an extraordinarily useful function in the Clinic; for most of the patients, for most of the time, it served to mitigate some of the stress of waiting. When patients came to the Clinic that often had to wait several hours. The length of the wait and the associated boredom and lack of control were stressful. The patients not only had this stress to contend with, but they also had to cope with other psychological stressors, the adverse effects of their illness or treatment, as well as some environmental stressors. In this summary, findings about the stressors will be addressed first, followed by findings about how the Playroom environment did or could help to reduce some of the stress of waiting.

Stressors

- For some of the patients, primarily the oncology patients in the early stages of their treatment, the stress caused by waiting was exacerbated because they were still adjusting to their newly diagnosed illness. Patients reported feelings of fear, anger, frustration, discomfort, and the need to keep to themselves or be alone with a family member while in the Clinic during this period of adjustment. In addition, the aggravation caused by waiting was compounded because they had to return to the Clinic frequently, as often as once a week.
- Waiting in the Playroom was stressful because the patients worried about seeing the doctors and nurses, as well as procedures in other areas of the hospital. They worried about venipunctures, examinations, and bone marrow aspirations and lumbar punctures.

None of the patients mentioned worrying about the chemotherapy they received in the clinic but they did worry about the chemotherapy they were going to receive as inpatients after they left the Clinic.

- Sometimes when the patients came to Clinic they were not feeling well due to their illness or side effects of their treatment. The complaints that a patient was feeling not only affected them physically but also psychologically because they might fear that they had relapsed.

The discomfort that they were feeling was exacerbated by the fact that the Clinic was not set up to enable them to make themselves comfortable.

- Most of the patients thought the Playroom was too small. On days when the patient census was high, the Playroom became crowded. This created several problems: there were not enough chairs for everyone, table space was inadequate, the physical safety of the patients, especially the younger patients was compromised, the noise level became quite high, and it was difficult to avoid seeing disturbing sights.

- The teenagers did not have a separate area or table designated for them. They also did not become as involved in the activity at the center table as much as the younger patients. Consequently they did not engage in as many activities as the younger patients. One consequence of this was that they did not have the opportunity to interact with each other and develop friendships which could help them cope with their illnesses. Another consequence was that the teenage patients who did not participate in the activities in the Playroom had little to do except think a lot- often about things that made them uncomfortable.

- The cries and screams of children in the screening and examination rooms could be heard in the Playroom. This was disturbing to some patients.

- Some of the chairs constructed of vinyl coated woven wire web on a tubular steel frame were uncomfortable and some of them had broken joints which pinched skin and grabbed clothes.
- The furniture in the Playroom did not accommodate the patients' needs when they were tired or not feeling well. Patients tried to become more comfortable by placing their arms down on the table to rest their heads and by reclining or laying down on the chairs.
- The construction of the large center table created a dangerous and, for some patients, uncomfortable environment. Children could injure themselves on the sharp corners of the table top or bump their heads on the steel structural supports. The square edges of the table could cause discomfort and pain, especially in patients who had injuries on their arms.

Coping Strategies and Environmental Supports

- The Playroom provided activities for patients of all ages but it met the needs of the pre-teen population, in general, most successfully.
- The activities in the Playroom served several functions for the patients: they helped relieve boredom, they helped prevent or relieve anticipatory anxiety, they helped friendships to develop, and they helped to mitigate the effects of illness or the side effects of treatment related medicine.
- Most of the activities in the Playroom did not involve either gross motor activity or physically competitive games. The patients had some ideas about the kinds of games they would like to play in a clinic. These included Freeze Tag, basketball, pinball, ping pong, hockey, and video arcade games. They thought activities that included some physical activity or competitive challenge could help relieve some of the tension patients felt.

- Some of the teenagers watched or played with the younger patients. Several patients thought that the teenagers would benefit from group counseling sessions held during Clinic in a private room.
- The ability to achieve the desired level of privacy was important to some of the patients. States of privacy such as solitude and reserve could be achieved but it was difficult to find the privacy for confidential conversations and emotional release.
- The Playroom did not have a television. Some of the patients would have preferred having a television because they thought it would help fight boredom, make the time go faster, or distract them from their worries.
- The walls in the Playroom were white. Many of the patients preferred this color. Many others would have preferred it if they were more colorful. They thought that if the Playroom was more colorful it would be less boring, less institutional, more cheerful and energizing, and would show that someone cared about the patients. However, the color scheme for a playroom has to be chosen very carefully in order not to disturb patients who are not feeling well.
- There were many pictures that the patients had done on the walls of the Playroom. These pictures served several purposes: they provided some visual interest, they were means of self display, they acted as a means of distraction, patients looked at them for ideas for their own drawings, and they served as memorials to those who had been in the clinic, either as patients or volunteers.
- There were two windows in the Playroom which allowed in sunlight and natural light which help make the room pleasant and cheerful. One had a view of Central Park and the street and one had a view of a building less than a hundred feet away. The patients preferred the window with a view of the park and the street because it gave them something to look at when they were bored or not feeling well. However, the views from the window

were disturbing for one patient because they made him aware that he was not where he wanted to be.

- One patient suggested that the furniture in the Playroom could be more visually appealing.
- Several of the patients placed comfortable furniture, such as couches, arm chairs, and rocking chairs in their designs.
- Patients thought food was important because it could act as a reward, and it could also take their minds off of their situation temporarily.
- The Playroom did not have a fish tank, but it was suggested by two patients that fish tanks could relieve stress.

6. THE TRANSITION BETWEEN THE PLAYROOM AND THE SCREENING OR EXAMINATION ROOMS

When patients were called to see a nurse or a doctor, it meant that they had to leave a safe environment, the Playroom, to go to an environment which could mean pain and distress. Because the flow of patients in the Clinic could not be planned with any degree of exactitude, patients could be called at any time. When they were called, they not only had to cope with an abrupt change in mood, they also had to cope with an abrupt change in the environment, both physical and social. This change could be disturbing and, as Susan noted, "It needs to be an easier transition, you know. It shouldn't be such a cold smack in the face to go from one to the other."

In this chapter, I will describe the series of events that were initiated when a doctor or nurse entered the Playroom to find the patient they needed to see and terminated when they entered a screening or examination room. Because these events are very closely interconnected but, at the same time, distinct, they will be treated in three sections: Being Called to See the Doctor or Nurse, Walking Down the Hall, and Entering the Room. In each of these sections, findings regarding the stressors the patients experienced, as well as the coping strategies and or mechanisms they used or would have like to have been able to use will be reported.

6.1. Being Called to See the Doctor or Nurse

Being called to see a doctor or nurse meant different things to different patients at different times. It could mean that a long wait was ended, bringing relief from boredom, or it could mean that an invasive medical procedure was imminent. Occasionally some of the younger patients became upset when they were called by a doctor or nurse and they used different strategies and behaviors to avoid going with them. Being called to see a doctor or

nurse apparently could be upsetting for the older patients as well, although the ways in which they expressed their unease were much more subtle than the younger patients.

The arrival of the doctor or nurse meant different things to different patients at different times¹ because, as Susan explained, "Every visit is different. Every visit for every kid is different. He'll come here one week and have a good time. Next week you're not getting them out from underneath that table."

An older patient, for example, who had been waiting for a long time might be glad to see the nurse or doctor one day because it meant he or she could leave shortly, but on another visit the same patient might dread being called because it meant that he or she was about to have a bone marrow aspiration or lumbar puncture. The sight of a nurse or doctor was even more threatening for younger patients because they did not have the cognitive capacity to truly understand why the medical procedures were necessary. They understood, feared and reacted to the pain and discomfort the medical staff represented to them and the means they used to express those emotions took many forms.

In addition to feeling anxiety at the sight of a doctor or nurse, younger patients, who were having fun in the Playroom might also become upset because their play was interrupted. Susan recounted an experience she had with a "little kid, an adorable little girl. We were having some fun. We were playing with some stupid board game that she was having a good time with. The doctor came in. Under the table."

When younger patients reacted very negatively when they were called it was very distressing for all involved. The depth of that distress that Susan felt is evident in her statement:

¹In the following discussion I will focus on the anxiety that some patients experience when they are called to see a doctor or nurse. The examples that I cite are extremes and are not supposed to be representative of the behavior of all the patients, even the younger ones, all the time. However, in these extreme examples lie the shards of anxiety that I suspect many of the patients experienced many times.

it feels like a knife in my gut... I mean, my heart breaks every time I hear one of these little kids get literally pulled out from underneath this table (referring to the large table in the Playroom) to go into one of the exam rooms. And then, some of these kids literally get dragged into these rooms.

Not all of the younger patients reacted this strongly to being called to see a doctor or nurse but it was not unusual to observe the younger patients crying and/or telling their mother or father that they did not want to go.

6.1.1. Coping: Strategies and Environmental Supports

Besides the more usual methods of crying and protesting, the younger children infrequently used very active coping strategies to delay leaving the Playroom when they did not want to be seen by the doctor or nurse. The teenagers used more subtle means to delay leaving the Playroom.

In the following statement, Susan graphically describes what happened when the little girl, mentioned above, went under the table: "We could not get her out... It wasn't going to happen. I mean we were pulling. Little kids develop like superhuman strength when it comes to stuff like this. I mean, you're not moving them."

Hiding under the table, resisting efforts to bring them out, with all their might, was the most obvious place for children to seek haven but, according to Susan, it was not the only place of refuge. She had seen a little girl crawl into the art supply storage unit and another patient lock himself in the Child Life Specialist's Office.

Incidents such as these, while disturbing, were relatively rare. Most of the children left the Playroom peacefully most of the time. This does not mean that they did not feel a certain degree of anticipatory anxiety and develop the means to cope with it in some other fashion.

One of the younger patients, Kevin, was probably using fantasy play to cope with his anticipatory anxiety one on one occasion that I observed. One day Kevin and Gary and

Tammy were playing "werewolf." At one point Kevin and Tammy were under the table. She was biting her mother's leg and he was biting mine. When he came out from under the table, he made frightening faces and clawed me several times. When his doctor came out, Kevin went over to him and clawed him and said he was going to cut out his heart. The doctor took it humorously but, quite possibly, he was expressing his anger and hurt in the only way that he knew how.

The older patients had more subtle and far less disruptive ways of coping with their anxiety, including verbal resistance and/or humor. Lauren, for example continued playing cards when she was called, and said "Lauren who?" There was no question who they wanted because there was only one patient named Lauren in the Playroom. On another occasion, Danielle was told that her counts were satisfactory which meant she could get the bone marrow aspiration and lumbar puncture that were scheduled. Even though this was good news because the counts indicated that there were no complications, she reacted negatively to the news because that meant that she had to have the procedures. When Danielle left the table for the procedures she was treating it humorously, whining in a half joking manner. She did not cry or scream as a younger child might have; she was even smiling, but it was a nervous smile, and it was obvious that she was not looking forward to what was going to happen to her.

6.2. Proceeding Down the Hall

After leaving the Playroom the patients had to proceed down to the Hall to a screening or an examination room. If they were going to see a nurse, this trip was relatively short, less than 20 feet. But if they had to see a doctor in room #4-71, that trek could be almost 60 feet in a space, as the patients noted, that did little or nothing to relieve any anxiety they were experiencing. Two patients' perception about the Hall will be reported first and then in the Coping section, findings will be reported that illustrate how

one young patients used behavioral techniques to cope with his anxiety. Other patients had suggestions about how to improve the Hall that would not only make it look better but also enable the patients to use the physical environment to help them cope with their fears.

There were several pictures on the wall that the patients had drawn outside the Child Life Specialist's room and there were two framed posters on the walls between the examination rooms (see figure 23). The artwork did little to offset the institutional quality of the Hall, which as Susan describes vividly, was quite powerful.

... you're seven years old. You're coming out of here, playing with your crayons or whatever, whoever that you are talking to, and they tell you to go into this room. How long are you going to walk? Down that hallway, that when you're this big (holding her hand up at about waist height) Huge. It's cold. It's white. There's big people walking past you all over the place. You know. It's got to be scary. (She said this in a whisper.) It's got to be like death row to them. You know what I mean. This represents (She made a horrible face and strange noise)... This is just uniform and... Yeah, very rhythmic and steady and... (She hit the desktop with her hand in a steady rhythm) And it's like the Chinese water torture after awhile. Not that these kids are thinking that way, but it's in there.

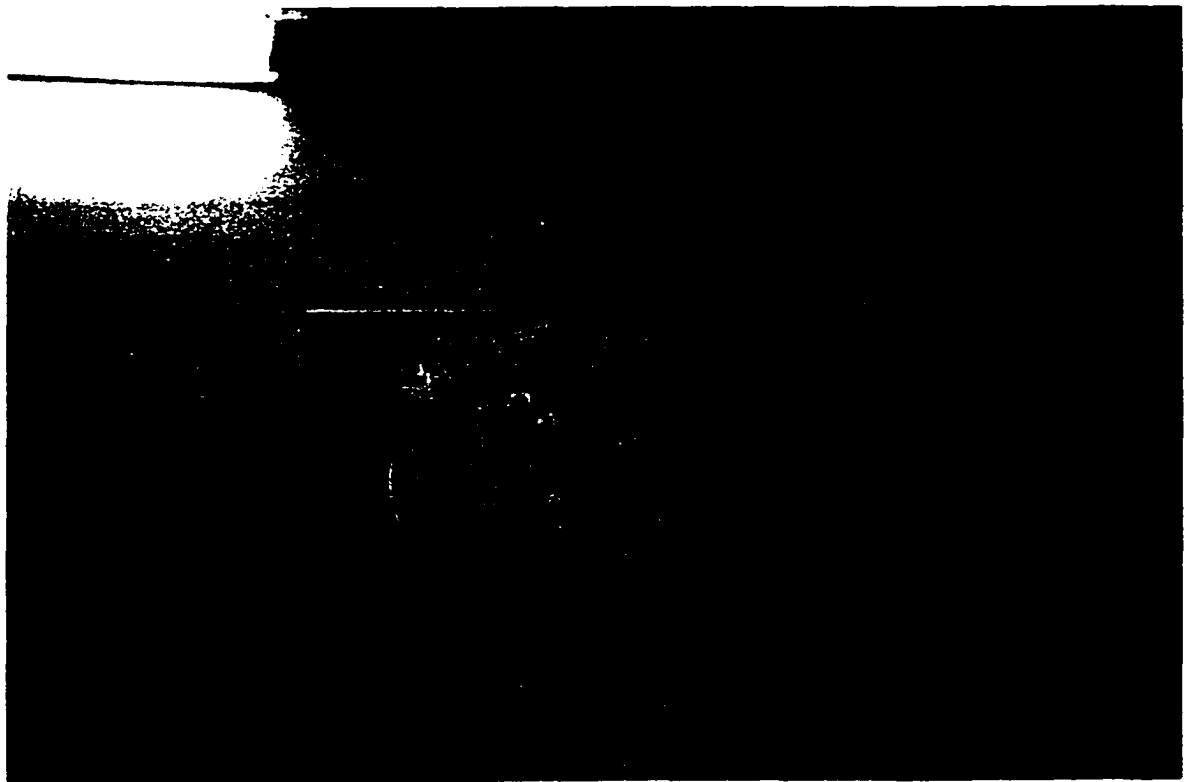
Another problem with the Hall, according to one patient, were the X-ray examining boxes located between the Clinic Coordinator's Office and room #4-64 and between room # 4-70 and room #4-72. She wanted to know if they needed to be there because "I don't think that's a good thing. I mean it is just weird to be walking by and see the doctor examining somebody's chest. "Weird," in this response may not mean frightening but still the X-ray examining boxes were problematic in a Hall where patients may already be upset.

The primary problem with the Hall was not that it added to the patients' anxiety but rather that it did little to help relieve the anxiety that they were feeling.

6.2.1. Coping: Strategies and Environmental Supports

Even though the Hall did not offer much support, some of the younger patients used behavioral means to cope as they proceeded to a screening or examination room. Some of the older patients had ideas about how to improve the Hall to make it less

Figure 23. Photograph of a Poster Placed on the Wall in the Hall.



institutional and which might make the transition between the Playroom and the screening and examination rooms easier for the patients.

6.2.1.1. Activities

For many patients, the Playroom was a place of safety, a place where they did not have to think about the pain and discomfort that often accompanied a visit to the Clinic. The Playroom in essence was a "kids world." Once they left the Playroom they entered the medical staff's "world." Some of the patients coped with this abrupt transition by asserting their independence. On several occasions I observed children, who had to be carried from the Playroom, demand to be put down as soon as they were brought into the Hall.

The need for control or autonomy was also important to Kevin. On the day noted above when he threatened to cut out his doctor's heart, I observed him have a temper tantrum when the Child Life Specialist tried to help him push his IV down the hall to the room where he was going to see his doctor. She insisted that it was necessary for safety reasons and he got angrier and angrier. He finally pushed and may even have hit her, saying that his mother let him do it by himself. Apparently, Kevin coped with his fear and anxiety by making an issue about who was to push the IV pole. By doing so, he used an element in the environment to maintain some control in a situation that was essentially beyond his control. On another occasion I saw him hit his mother and poke her with a pencil while they were going to an examination room, behaviors that he normally did not exhibit.

6.2.1.2. Environmental Supports

Some patients had ideas about how to improve the Hall that would make it less institutional and which might make the transition easier for patients of all ages. These changes included adding more patients' artwork, changing the color of the walls and ceiling, changing the tile pattern on the floor, and adding cartoon characters to greet the

patients at the doors to the screening and examination rooms. Jasmine liked the posters and the patients' artwork that were in the Hall, but she thought too much of the wall space in the Hall was blank and that there should be more patients' artwork on the walls.

James thought that certain elements in the Hall, such as lights, walls and floors, should be changed because the Hall was "so hospital looking":

Like make the walls probably like a light purple shade like this. And the lights you know could be changed... They should have it more for dim... I could see maybe in the rooms they need lights to see, but out in the hallway, you know what I'm saying? With some mirrors on the ceiling. The tiles could be changed up into maybe like... salmon color, sort of peachy pink or something? It doesn't have to be plain floors, maybe some designs on the tiles.

Susan took the idea of changing the tiles one step further and, by doing so, added the possibility of an interactive component to walking down the Hall. She suggested painting the tiles "yellow and make it the Yellow Brick Road. Make it different colors leading into the different rooms. I don't know. Anything." The "anything" Susan suggested was given greater substance by Beth who explained that:

The hall could be like a different dimension of something like... You know of the cartoon's world and make it, each one of the cartoons on the side... and the colors, the color of the floor very colorful. Different colors, and you could make a lot of, you know, making it look like a different galaxy of kid's world. Like if it was Mac World, like let's say...²

After talking about Mac World, she returned to an idea that she had talked about previously. She had discussed in great length how cartoon characters, such as the Jetsons and Flintstones, could be painted on the walls, ceiling and even the floors of the

² She went on to explain what Mac World was.

Yeah, in MacDonald's World. They say that it could happen that a kids' world, your world that you would like, you know... that school would be fun and you know in the water fountains filled with shakes, MacDonald's shakes... and Michael Jordan would be the coach for gym and all that stuff. First they say that school could be squashed by a giant dinosaur, like there is a big school you know they put like a raptors foot on it and then they squash it but then they pump it, they pump, it pops up again and it says maybe a different school. It could be a very fun school, like Michael Jordan as the coach, and a bunch of celebrities as the, as teachers, so it would be like that you know each one, you know.

examination rooms. (See 6.3.1.1.) Using that concept she came up with the idea of having cartoon characters greet the patients at the doors to the room.

Judy (from the Jetsons) is like here and is waving into this room, you know... From here (indicating a place outside an exam room) you could paint that part, something that matched with Judy's dress... And if Flintstones was here (indicating another room), put Fred there or Wilma and paint it like orange, or so it matched with something... So it would be very colorful...

These patients' visions of what the Hall could look like are on the opposite end of the "child friendliness" spectrum from what it was like. Their visions raises the question: Just what should a clinic look like? This issue will be addressed in section 6.4. of this chapter.

6.3. Entering the Screening or Examination Rooms

When the patients first entered either a screening or examination rooms they moved from one environment, the Hall, an institutional environment with some medical elements which one of the patients characterized as "Death Row" into an uncompromisingly medical environment or what another called "Doom Rooms." The patients talked about how disturbing it could be to enter the screening and examination rooms and some of them had some extraordinary ideas about how to make the experience of entering the rooms less threatening.

Entering an examination or screening room could be a stressful experience for patients of all ages because of the fear they had about the imminent procedures and the threatening quality of the rooms themselves. The fear of procedures was mentioned by James. "You know how little kids when, they go into the exam they know what is coming so they're going to cry." Or as Ned said, "to be honest with you, when you come in here from a kid's point of view you feel 'Oh god this is like the death room,' you're getting needles."

Susan described how threatening the room could be from a child's point of view and how inappropriate that image was considering that it was a pediatric clinic.

Look at it. It just looks scary. You know, how high are you, and you are looking up at this room that's just so, not that they're thinking in this way. But it's so sterile... You know, it's sort of. You feel like this weight come down over you like "Oh, god"... It is a hospital and it has to be sterile but... this is a children's Clinic.

James, Susan and Ned emphasized the fear the younger children may have felt when they entered a screening or examination room implying that only younger children felt afraid when they enter the screening and examination rooms. This does not mean that the older children or even young adults did not also feel a certain degree of psychological discomfort when they entered an screening or examination room to be seen by a doctor or nurse, as evidenced by Michelle's statement: "Basically once you step in that room it's more like a sad moment... and you just want to be out of there as soon as possible.

Michelle felt that "seeing a different environment... wouldn't distract her mind," though, and thought that the most helpful thing would be the waiting area because that is where she had the longest wait but many of the other patients thought there were things that could be done to make the screening and examination rooms less threatening.

6.3.1. Coping: Environmental Supports

To a certain degree, the first few moments when the patients entered the screening and examination rooms set the stage for what was to follow, especially for the younger children. James thought it would counteract their feeling of dread: "If they changed it around maybe a room or two for little kids so they could make them feel more comfortable... make it more colorful, things like that so they won't cry maybe as much." This would make for an easier transition because, as Susan noted earlier, "It shouldn't be such a cold smack in the face to go from one to the other." To make the transition easier and minimize the "cold smack in the face," several of the patients suggested changing the

rooms by adding artwork, changing the colors or the walls, and even changing the appearance of the examination table.

6.3.1.1. Artwork

Many of the patients thought artwork should be added to the walls in the screening and examination rooms to help them and/or other, usually younger patients, cope while they were waiting (See 7.2.2.1.). In addition, some patients thought that artwork with or without positive messages could be added to the walls to make the rooms less threatening upon entering. Beth thought cartoon characters on the walls would make the rooms fun to enter, explaining that "you could put some other characters like the Flintstones or Jetsons... Or even you could, walls, you could paint it like, like you know the car the Jetsons have... And make like a big size Judy and Jane, all the family." She went on to describe how the space theme could be carried throughout the room so the patients would not be scared. "And you could paint the whole room blue and put like dots like stars and planets so, and you look at the floor... and you could paint it like like moon craters...." Not only could the room be painted but she suggested that a cardboard spaceship could be put in front of the examination table. She felt these changes would make the rooms "fun to enter in" because "Each child likes space stuff and all that."

She also made a distinction between those rooms for the babies and those for the older children:

... the exam rooms would be like each time a kid enters it, it is like a whole new world painted with characters and, and a sports men... you could have like for babies... make it like babyish so it wouldn't be so scary in it.... like you could paint Big Bird and Cookie Monster... (for the babies) And you could also... paint Perzoobiles...³ a good place, like if the kids like candy, make like a little Candy Land. Make when you enter there could be like big

³ Amy explained that they were characters on "this show called Zoobily Zoo and TLC. It's in the learning channel on cable, channel 32. And they're like animals but people are dressed in them and they sing and all that stuff."

candy canes, peppermint up there and make it like candy so if they like candy or anything.

Beth thought if each room had a different image, patients could choose the one they liked, emphasizing once again the importance of choice in a medical setting. The images that Beth discussed were intended to make the rooms less threatening by making them "kid friendly."

6.3.1.2. Color of the Walls, Flooring and Furniture

The color of the screening and examination rooms was also discussed by many of the patients. As with the artwork, most talked about color in terms of how it affected patients while they were waiting. However, the patients suggested that changing the colors of the walls, flooring and furniture could make the rooms less threatening upon entering.

Susan pointed out the impact color had on patients when they entered one of the rooms and wanted to know "Why do these rooms have to be off-white. Why can't they be like lighter colors? Pretty colors, something. You know what I mean, it is all in the aesthetics." She compared the Playroom, with its bright colors, to the screening and examination rooms and discussed how different colors in those rooms would make a difference to the patients.

It's more soothing than coming into this... You come into this room and even physically your eyes don't adjust to this white... So maybe it would just be an easier transition from a room with all these bright colors and everything... I think it is a big transition from going from here to here.... Maybe if it was, you know, not so cold looking. You know, a different atmosphere. Like I said, just like lighter colors. Like a blue, light blue, light pink, light green.

Beth suggested that painting the floor with different colors or cartoon characters would help relieve the patients' anxiety. Segueing from her first idea; which was to make

the flooring, an unpatterned beige vinyl tile, more appealing to children by making the floor tiles interactive,⁴ she imagined:

... drawing video game characters on the floor. You could make the floor different colors like, or we could make diagonally, this part from here. (From the corner) To here, over here, to this corner. Sort of different colors, like a design, you make it; or we could make all this floor like, like this color. (Choosing a color from the color palette I provided during the interview) and then like make shapes or, or figures like, shapes, like different colors. And you could also make, you know like little doctors or if the kids like Super Nintendo, Mario floor or Princess Toadstool, or like make it all Mario like, or for Super Mario you paint all this floor white and then diagonally there's a head of Mario, Yoshi, Baldur, and all the enemies so it would be like a Nintendo floor...

Beth also thought the examination tables should be more colorful: "Yeah, neon colors are good (she chose a neon orange). And then you make circles out of neon pink and triangles out of green... And rectangles out of neon yellow," because she felt patients wouldn't be as nervous when they came into the room and they saw an examination table that didn't look so threatening:

So you wouldn't have to like, you look at it and it looks normal to you, like a real bed or something. So you pretty much don't get that scared when there is a lot of colors on like a real bed... it's colorful and good... it looks like kinda like a Playroom, but only you got to sit on the bed. Like if I was a baby's point of view, they look at, they know they are going to get pinched, but if they look at neon colors and all that stuff. And all colors and shapes. It looks interesting and they wouldn't come in so nervous. That's what my sister sometimes gets, real nervous.

6.4. Appropriateness of the Decor

Patients ranging in age from infancy to young adulthood came to the Clinic. An issue that arose during the interviews concerned how to make the decor age appropriate. (None of the patients mentioned the issue of gender.) Several of the older patients noted that they would not feel comfortable in a clinic that looked like it was decorated only with

⁴ She said: "The floor we could make it different colors like when you hit the pinball, you go, the pinball goes in the hole? The, the, there's like a screen that lights up different colors... like a computer or something."

younger children in mind. One option to address this issue, suggested by the patients, would be to have a mixture of age appropriate images. They thought this could be achieved several ways: individual pieces of artwork could be chosen with each piece appealing to a different age range, images that appealed to the different ages could be combined in individual pieces of artwork, and artwork could be chosen that appealed to patients of all ages. Another option would be to designate screening and examination rooms for a particular age range and supply age appropriate images. However, one of the patients raised another issue: would some patients be disturbed by a clinic that did not look like a medical setting?

When I asked the older patients what they would think if they entered a screening or examination room with posters of characters that young children would like, their responses were negative. June said, "I would think that it was a childish room, 'cause I am not into all that stuff anymore." Zachary, who had actually had that experience, claimed he would:

start laughing... Well, I do physical therapy now and the first time I went there, they had Oscar the Grouch up and all the Sesame Street stuff, and I'm like "are you sure this is the right place, this whole place is for kids, like small kids."

But, he became used to it and felt "now it is not so babyish." Beth thought the problem of what kinds of images should go on the walls could be solved by using a variety of images to appeal to different ages: "You make all the things that kids like and babies too so they'd be all mixed... So, it would have a lot of kid's styles on it. It wouldn't just be a baby style or kid style. It would be mixed."

This approach would have worked for June and Zachary. During the interview, June had told me that she was interested in music so I asked her what she would think if there were entertainer type pictures as well as cartoon pictures. She said "I would probably

just look at the entertainer pictures and forget all about the cartoons." Similarly, I knew that Zachary liked sports so I asked him if it would have made a difference if there had been some posters of sports figures as well as Sesame Street characters at his physical therapist's office. His answer was: "Yeah, having sports posters up would have been better, then I wouldn't have had to say, 'Are you sure this is the right place?' "

Another option would be to have images that appealed to all ages such as Disney characters. This alternative was raised during my interview with Terry. I had asked him what his opinion would be of screening or examination rooms that had kids' posters such as Barney on the walls. He said "I wouldn't like that. I don't like Barney," but that "any Disney characters... I love that." Karl's mother also thought Disney characters would appeal to a wide age range of patients.

Another option suggested, that might be possible in a much larger clinic, would be to designate the screening and examination rooms by age. One of the patients thought there should be separate rooms for children ten years and younger where there were pictures of "like tiger and lions... and put things 'cause sometimes they get scared... so they can like play in there."

Michelle also thought there should be a room for teenagers and room for "smaller children." But when I asked her what would be the difference between those types of rooms she offered not a design solution, but a process:

One would maybe, design it according to the survey of the older age group and one would do it according to maybe asking simple questions from children and see what would they like. If they were to have the surface of the table, what colors would they prefer? What pictures? Would they like pictures or just one plain color?

The issue of age-appropriate decor has to be placed within the context of what is an appropriate image for a medical setting such as the Clinic. Many of the patients I talked to wanted to change the way the screening and examination rooms looked; others thought they

were fine the way they were. But I suspect they would not be upset if changes were made to make them less institutional. Jasmine, on the other hand, said that she would not want them to radically change the examination rooms "so that it wouldn't look like a doctor's office ... if it was radically different that would be strange," and "that would make me even more uncomfortable. I want it to look like a doctor's office so I know where I am... I want to know what the situation is." She did not think many people would agree with her because "I think that people would like it to be nice and comforting and the doctors come in with jeans and a T-shirt. You know, 'We're just here to talk,' and be really relaxed." She felt more comfortable with the familiarity of a stereotypical doctor's office because that is what she had become accustomed to over the years she had been seeing doctors and "you want to be someplace that is familiar because you'll be more relaxed."

Jennifer was the only patient that I interviewed who felt this strongly about maintaining the institutional qualities of a "typical" doctor's office. Other patients did not mind the way the existing Clinic looked, but most patients' thought the Clinic could be much more attractively decorated and appealing to children.

6.5. Summary of Findings

Being Called to See a Doctor or Nurse

- Being called to see a doctor or nurse meant different things to different patients at different times. It could mean that a long wait was ended, bringing relief from boredom, or it could mean that an invasive medical procedure was imminent.
- Some of the younger children resisted leaving the Playroom quite violently, while the resistance of the teenagers was more subtle.

Proceeding Down the Hall

- After leaving the Playroom the patients had to proceed down the Hall to either a screening room or an examination room. This trip could be relatively short, less than 20 feet, or it

could be as much as 60 feet. If the patients were anxious about seeing a doctor or nurse, the physical environment of the Hall did little or nothing to relieve that anxiety.

- Some of the younger patients coped with their anxiety and fear by asserting their independence and trying to regain some control of the situation.
- Some of the patients had ideas about how to improve the Hall to make it less institutional, and which might make the transition between the Playroom and the screening and examination rooms easier for the patients. These changes included adding more patients' artwork, changing the color of the walls and ceiling, changing the tile pattern on the floor, and adding cartoon characters to greet the patients at the doors to the screening and examination rooms.

Entering the Screening or Examination Rooms

- When the patients entered a screening or an examination room they left an institutional environment with some medical elements and entered an uncompromisingly medical environment. Entering these rooms could be quite disturbing for the patients.
- In order to make the entry into the medical environment less threatening, patients thought the walls could be painted more attractive colors, artwork could be added to the walls to make, the examination table could be colorful, and the floor tiles could be colorfully patterned or painted with cartoon characters or characters from video games.

Appropriateness of the Decor

- Patients ranging in age from infancy to young adulthood came to the Clinic. Artwork for one age may not be appropriate for another. One option to address this issue would be to have a mixture of age appropriate images. This could be achieved several ways: individual pieces of artwork could be chosen with each piece appealing to a different age range, images that appealed to the different ages could be combined in individual pieces of artwork, and artwork could be chosen that appealed to patients of all ages.

- Some of the suggestions made by the patients to change the appearance of the Hall and screening and examination rooms would radically change the appearance of these spaces, disguising them by creating in effect a "kids' world." These radical changes could be disturbing to some patients who are accustomed to and would prefer the familiarity of the appearance of "typical" doctors' offices or other medical settings.

7. WAITING TO SEE A NURSE OR DOCTOR IN A SCREENING OR EXAMINATION ROOM

Patients waited in the screening or examination rooms for numerous reasons. They waited for invasive procedures such as venipunctures, bone marrow aspirations, or lumbar punctures, or relatively non-invasive or non-threatening procedures such as being weighed, having their blood pressure taken, or being examined. Most patients probably waited less than five minutes but patients reported that they could feel bored or tired during that time. They also reported that they worried about what was going to happen to them, with one patient reporting that the wait was like a "moment of doom." Aspects of the environment also created stress. According to some of the patients, the institutional quality of the rooms, needles and other medical supplies or equipment that were out in the open, cries from other rooms and uncomfortable chairs had a negative impact on them while they were waiting. Findings concerning psychological stressors will be reported first.

For some of the patients, waiting could be a very anxiety provoking experience. Dominique said she felt "sad" when she was in the examination room "Because I don't want the doctor to give me a needle." Ned explained that waiting in an examination room was like a "moment that you don't want to wait for, but you have to wait for... if you feel real sick, then it's like the moment of doom. It's not a very positive, it's not happy, it's not happy, it's not happy times."

Kevin, a preschooler, who was still in treatment, felt much the same way as Ned, who was a teenager when he was being treated. After Kevin told me that kids felt bad when they were in a screening or examination room, I asked him if anything could be done so the patients did not feel bad. He replied "... not really... If a kid was just with a doctor, nothing would make them happy" because he's scared the doctor will do something to him.

Apparently having a parent with him would make a difference to Kevin because as he explained:

If a kid was just with a doctor in a room and their daddy wasn't with them... then that kid would be scared... 'Cause he isn't with his daddy, and he's just with a doctor, and he's scared the doctor will do something to him.

In an ideal situation, parents help their children cope with the medical procedures. But sometimes it is very hard for parents to remain with their children because they do not like to see their children suffer, a situation that I observed. As I passed an examination room one day I noticed that Fred was in the room by himself. I asked him how he was doing and at first he said "OK," and then he said "not really" because he was getting a spinal tap. The nurse came in at that point to stay with him but she did not remain with him the entire time he was in the room. His mother was sitting in the Playroom while he was alone. The nurse came out and told her that Fred was going to get the spinal tap and asked her if she wanted to go in now. She did not. One of the volunteers said that his mother had changed over the summer. The Child Life Specialist later told me that Fred's mother just did not like to be in the room when he had a spinal tap. Fred screamed a lot when he had a spinal tap and, apparently, it was too disturbing for his mother to be with him when he was in such agony.

Fred was one of the patients who did not want to be interviewed so his comment about his nervousness is the only indication I have about how he felt while he was waiting in the examination room.

In addition to the psychological stress caused by worrying about procedures that some patients reported, one patient felt waiting in an examination room was "just so tiring," and another felt bored while waiting because "there's nothing to do in there." As will be seen in the next section, apparently the rooms themselves did little or nothing to ease the patients' feelings of anxiety or boredom.

7.1. Environmental Stressors

According to some of the patients, the physical environments of the screening or examination rooms created additional stress. The most common complaints about the rooms were that they were plain and dull, and medical paraphernalia, especially the needles were out in the open. There were also serious complaints about the chairs.

7.1.1. Institutional Quality of the Rooms

While only three patients and a caregiver specifically stated that the rooms were "dull" or "plain" quite a few others thought the rooms should be painted brighter colors and pictures added. (See 7.2.1.1. and 7.2.1.2) Only one of the patients, Edward, did not share the opinion that the room was dull. He thought one of the screening rooms was a "neat" room that "looks real nice."

None of the other patients thought the screening or examination rooms were "neat" or looked "real nice." Michelle thought waiting in one of the rooms was "very dull, everything in there is so hospital in that specific room." For two of the other patients and one caregiver, the consequence of waiting in a dull room was distress and anxiety. The negative impact waiting in a "plain" room could have on a child was expressed by Karl's mother.

Especially for a child, you know. It's kind of plain. Because when you go in with the room looking like this, it's automatically on whatever you gonna, you know, whatever you are going through... You know, it's like your mind must be on it because there is nothing else in here.

Ned recognized that the rooms had to be functional for the doctors and nurses, while at the same time indicating that a functional room did nothing to help the patients cope while they were waiting.

... irritating sometimes, this room... but, as far as luxury, it's hard. I mean, I can't see any luxury here... 'Cause the doctor's concentrating, or the nurse's concentrating on taking your blood pressure, IV, and

everything. But this, this is dull, this is very, this is where all the stuff that you didn't want to think about happens here.

Bonnie made the same connection Karl's mother and Ned made between the lack of visual interest in the screening and examination rooms and feelings of anxiety. In her opinion, the rooms looked "so dull, just like "I am in the Hospital, my god I'm so scared." There's nothing, I mean I'm 19, but sometimes I say "They should have some pictures up on the wall,"

The virtual lack of non-medical elements that the patients could look at could be considered a "sin of omission." For some of the other patients, the needles or medical equipment, which were in the open, could be considered a "sin of commission." In a room with little to look at, those elements that are there, gain primacy and have a special impact. And as will be seen in the following section, those elements, if they are used during medical procedures, can be anxiety provoking for some patients.

7.1.2. Needles/Medical Supplies/Medical Equipment

The needles, medical supplies, and medical equipment were out in the open, and some of those items, especially the needles, served to create a great deal of anxiety in some patients. Other patients reported that they preferred having the needles and medical supplies where they could see them.

Zachary and Beth were two of the patients who found the needles especially disturbing. Zachary did not like waiting because "They would have the needles and the medicine. So that's the part I probably hated the most." It did not scare Beth to watch her blood being drawn but she "hated" to look at the needles while she was waiting. Ken also watched his blood being drawn, stating that "I am a very strong boy. I don't cry... Always look. I want to look," but he objected to having the needles out in the open "Cause the little

boy, kids there, boy that's cruel ... 'cause little kids don't like to see needles, they get scared. So keep them over there and take one out. Get scared."

In contrast, several of the patients preferred having the "hospital stuff" where they could see it. Beverly said she looked in the medical supply boxes to see what was in them. Tiffany preferred to have the supplies readily available to the medical staff so that they could perform the procedures quicker and so that she could see what they were doing.

I think that it kind of makes you feel more comfortable because if you're like waiting for something, like a blood test or something, and if the stuff was out of the room, it is going to take them longer to get it set up and just bring it in where you can see what they are doing.

At this point her friend said that the doctor she went to had it in drawers and it was "kind of neater." Tiffany did not agree with her and said, "I think it is better out, 'cause you can see what they are doing or what they are getting."

Brian also raised the issue that some of the younger patients might also be frightened by the equipment on the walls, the ophthalmoscope and otoscope. He believed the patients should feel comfortable and safe when they are in the rooms, but he thought "like sometimes the little kids might be scared of all the stuff hanging on the walls."

7.1.3. Cries From Another Room

Another problem with the screening and examination rooms was that they were not adequately acoustically isolated from one another. On one occasion, this lack of sound abating material proved quite disturbing for one of the patients. Norman was in one of the examination rooms preparing himself for an invasive procedure, either a bone marrow aspiration or a lumbar puncture, both of which he dreaded. (One of the physicians noted during a clinic conference that Norman had more anxiety about these procedures than any patient she had seen. His level of anxiety was so high that he often vomited and he often carried either a plastic or stainless steel bowl with him in the Clinic so he would have

something to vomit into.) While he was trying to relax and do his breathing exercises, Fred, who was in an adjacent examination room, started to scream during a procedure. This was normal for Fred; he was what the nurses called a "screamer." Unfortunately his screams, which were his coping mechanism, upset Norman, breaking his concentration, and thereby interfering with his coping strategy.

7.1.4. Chairs

The findings in the previous sections were focused on elements or characteristics of the rooms that created psychological stress while the patients were waiting. Another element, the chairs, caused at least two of the patients physical discomfort. Most of the chairs the patients sat in while they were waiting were armless and made of molded fiberglass. The advantage of these chairs from the Hospital's point of view was that they were durable and easy to clean. The disadvantage from one patients' point of view was that they were too hard. These chairs also created a potentially dangerous environment, as one patient reported sliding off of one. According to Bonnie, these chairs were uncomfortable when she was experiencing pain from the sickling of red blood cells in her joints.

... sometimes may be kind of hard, you know, cause when you are in so much pain and then you have like a hard chair... you get kind of cranky when they want you to sit down, you can't really sit down... It's pain you know. The chairs are so hard I don't want to sit on it.

Ken also had a serious complaint about the chairs; they were slippery. When I asked him what he thought about the chairs he said, "Yeah, that stupid chair." He had slid off the chair once. I was not there when this happened but I can imagine why it did. Ken, like several of the patients who came to the Clinic, had problems with his hip joints, a side effect of the chemotherapy, and he had trouble sitting down. He could not lower himself easily into a chair without the aid of his hands. The chairs in the screening and examination

rooms did not have arms, and I suspect that he fell off the chair because he semi-dropped himself into the seat and slid off the slippery fiberglass surface.

7.2. Coping: Activities and Environmental Supports

As the patients reported above, the screening and examination rooms were not designed to help them cope while waiting for the nurses or doctors. However, the patients had many ideas about how to improve those rooms. Their suggestion can be divided roughly into two categories: providing materials for activities, and visual improvements.

The patients thought that if items such as toys, books and puzzles were in the screening and examination rooms, waiting would be less arduous. Edward said that there should be "like a couple of real interesting like toys, tiny toys, a little like those (a little troll on the window sill)... so that the people could play in the room sometimes." Bonnie thought they should have magazines or "comedy books" in the rooms for kids "So while they were waiting they wouldn't get so agitated, start crying and stuff you know." Wilma also thought there should be things for the younger patients to do, so they wouldn't touch or disturb items in the rooms, as well things for the older patients, such as dot-to-dot books in each room or "those books that you flip? And it's like a little story... I like that. I have a Snow White book, you turn it up side down and around and flip it, you can see Snow White cleaning the house."

Lauren was one of the patients who thought it was boring to wait in the examination rooms. To relieve her boredom she would have liked it if there were jigsaw puzzles and televisions in each room, as well as a phone.

In addition to making suggestions about adding objects to the screening and examination rooms that could be used, the patients had ideas, which will be covered in the next section, about how to improve the visual quality of the rooms and the furniture.

7.2.1. Environmental Supports

Many of the patients had suggestions about how to make the screening and examination rooms look less institutional, thereby improving the quality of their waiting time. Some thought the color of the walls should be changed. Others thought pictures or posters could be put on the walls. Windows were important to others. They also had suggestions about how to "camouflage" the medical paraphernalia. It was even suggested that fish tanks be added to the rooms. The need for improvements, as expressed in the statements below, is quite clear. Karl's mother believed that if improvements were made to the rooms, the patients would have something to distract them while they were waiting.

The room could be much better. And even if they did the walls, it would camouflage the stuff in the room, it would camouflage what's in here... Just an environment that a child would enjoy. That's the whole thing, that a child would enjoy... it's really like the walls and the pictures that means a lot. Even if everything else in the room stays the same... I think that would liven it up a lot and it would help them look, you know, pay attention to the things that's going on.

Ned also thought "it would make sense" to improve the examination rooms so that they had "something, some design." He thought that would help the patients because "sometimes with the doctor, 'I'll be back,' he says, 'See you,' you know. You look around here. You do look around, period. But you want to look around at something nice, interesting."

Michelle wanted to change the screening and examination rooms to add some "life" and beauty to them. She suggested

Maybe adding some sort of color to it instead of just brown and beige, all neutral colors. Flowers, like fresh flowers would be beautiful, or one big painting that would kind of add some life to the room. Especially like a vase of flowers and a painting that would probably change the whole view of everything.

Michelle's vision is compelling; a beautiful environment is important but, as the patients discuss below, elements such as pictures or posters in screening and examination rooms can and should serve other functions.

7.2.1.1. Pictures/Posters

As Michelle and Karl's mother noted above, pictures could add color, visual interest, and beauty to the screening and examination rooms. Other patients thought pictures could provide a feeling of safety and positive messages, and/or serve as a source of distraction. (In this section, I do not make a distinction between pictures and posters and will use the term "pictures," unless a specific reference is made to what was said.)

Ted, Beverly, and Beth thought pictures could help the patients feel safe. Beverly thought "paintings or something like that" should be put up on the walls in the rooms without windows because they felt like boxes. She felt the rooms without windows were psychologically "cold" and that patients would feel safe if there were paintings to make the rooms "more warm." Ted suggested that pictures of patients who had been to the Clinic and doctors should be put on the walls because "It shows the patient that's in the room that other patients that came in before you, felt comfortable in the room. They have nothing to worry about."

Beth, who was much younger than Ted and Beverly, thought posters with a different kind of imagery, more cartoon-like, could serve a similar function. One of the images she described was of a "doctor giving a lollipop to a kid or something. So not make them scared. Like a cartoon doctor..." Later in the interview, while we were talking about how to distract the patients while they were getting stuck with a needle, she developed a more complex image which combined sports figures, such as Shaquille O'Neall or Michael Jordan with a doctor. (See 8.2.2.2.2.) Images such as these would also probably help some patients while they were waiting, not just when they were just about to be stuck.

Ned wanted the patients to feel "supportive" when they were in the screening and examination rooms. He thought that adding reassuring messages like "Hang in there" or "Don't be afraid taking needles" or "little slogans saying 'We'll be right here'" to posters with cartoon characters would help them feel that way. As an example he suggested a poster with a Ninja Turtle saying "Take the needle" in order to provide "Motivation... like to show that being here is OK."

Pictures could also give the patients something to look at and occupy their time while the doctors or nurses were not in the room. As noted above, Ted thought pictures would help the patients feel safe. He also thought pictures would make him feel more comfortable while he was in a screening or examination room because they would give him "something to look at," so he would not have to "stare at the walls, stare at the equipment." Similarly, Beverly thought there should be something on the walls because "sometimes when I am waiting for the doctor I could look at something and think about that."

Tiffany thought "they should have like pictures and stuff so it's more like a pediatricians office" (comparing it to her doctor's office). Later she brought up the issue of text which she thought was important because it would make the waiting go faster. She thought there should be "...for little kids, maybe something amusing to look at. Like a big poster that says something that you can read... 'cause I usually just go around reading everything around the room."

Wilma thought having something on the walls that she could read would serve a double function. It would give her something to look at while they drew her blood and "like if the doctor goes to look at one of your records and I'm sitting there messing on the table, looking at the stuff... you could just look at, read it."

In several instances the patients talked about the Clinic as a place where they could learn. Edward thought pictures on the wall in the screening and examination rooms could

serve that purpose as well as serve as a source of distraction when he was left alone in the room. "It's sort of like interesting to watch... find out different things about it... so like, it could like, when the nurse's are gone, like when they get, start to get something you could think about the picture."

An additional layer of meaning could be added if the pictures were humorous. Oliver thought it would be a good idea to have "funny" pictures and animal pictures on the walls of the examination rooms "because when you look at pictures you could laugh and have fun... Because when you are in a doctor's office there's nothing to do in there." In the passage below Beth describes the type of picture that might appeal to children's sense of humor.

You could make instead of realistic, you could mix childish, babyish, and kinda funny, like a penguin in a tuxedo, a panda bear wearing a tie, like a blue bow or something. Or maybe a grizzly bear with an arrow and bow, like Geronimo. And it has a big wig on it like that, and it has a big band of feathers on it. And with flowers or trees. The trees could have nests in them and you could make a cartoon hummingbird and put 'Why does the hummingbird hum? Because he doesn't know the words.' Like make it joyful and, and funny, and make it like a **kids' world** like... [She said this with emphasis and feeling.]

However, one of the parents thought that the positive effect pictures could have is probably compromised if the patient is very fearful and/or young. Mrs. Smith, Amanda's mother, thought pictures or poster would not help patients the age of her daughter who was five years old because

when they go into the room they don't think about no posters. Only one thing comes to their mind and that's a needle. That's the only thing that comes to their mind. They don't think about posters, they don't think about anything on the walls.

While pictures on the walls might not help all of the patients, it is clear from the patients' thoughts above that artwork can not only add beauty to screening and examination rooms, artwork can also engage patients in a number of different ways. Pictures can

provide positive or motivational, as well as humorous messages, and/or act as a source of distraction. They can also add color to a room, the subject of the next section.

7.2.1.2. Color

Many, but not all, of the patients thought the walls of the screening and examination rooms, which were white, should be painted another color or colors. It was suggested that bright colors would improve the patients' mood. In addition, several patients thought the furniture in the rooms should be more colorful. One of those patients thought a colorful pattern on the desk top would give the patients something to look at instead of the needles. They had ideas not only about changing the color of the walls but also the furniture and medical supply boxes.

The majority of the patients I talked to about the color of the walls of the screening and examination rooms, which were white, would have preferred that they be painted another color or colors. (See also 6.3.1.2.) They said white was "too plain," "not advanced," "everything's white." In addition, Bonnie had a practical and a psychological reason why white was not a good color for the walls. Practically, she thought the rooms should be a "little brighter," because "The white, white it accumulate so much dirt." And she thought that another advantage of a brighter color is that "when you are in the hospital dull colors just make you feel so down. You know, you see bright colors, like you know, 'That's nice.' It brightens you up a little bit."

However, not all the patients thought the color of the walls should be changed. Brian, who did not have many complaints about the Clinic also did not have any complaints about the color of the offices. "It's the same color as outside it. It's not gloomy or anything. It's fine" Wilma not only liked the color of the rooms, she would not want the color to change because "It's natural. It's a good color though. Instead of having purple and green and all those colors like some people. Those colors make me sick." Jasmine was

comfortable with the color of the walls even though she thought the room was "pretty tacky." The walls did not bother her because "These are so, this symbolizes doctor's office, like these tables with the paper over them. And so I don't mind that. That's what it is supposed to be."

While Jasmine appreciated the tackiness of the examination rooms because that look was characteristic of a medical environment that she was familiar with, several patients thought the furniture as well as the walls should be more colorful to help patients cope both while waiting and during the procedures.

The furniture in the room did nothing to "brighten up" the patients. The examination tables in the screening and examination rooms were very institutional looking pieces of furniture with stainless steel legs and drawers and a brown vinyl covered top. Zachary thought they should be "like red or something." Beth thought "maybe different colors on the desk would be good... Maybe blue or red or yellow... different colors" would also help patients while they were waiting. I asked her if she wanted to lay thin colored strips of paper out on the desk and show me what colors she wanted. She chose some, laid them out on the table, and arranged them alphabetically by the first letter of the color of each strip; blue, green orange, pink, red, and yellow. She chose the brighter colors and said that she would have used neon colors if I had them. The reason why she would like the table like that was because "it is a little more colorful and it is kind of fun to look at. Instead of looking at needles." (She made a noise indicating that she did not like the sight of needles)

7.2.1.3. Disguising the Medical Supplies

Several of the patients and one of the mothers thought that disguising the medical supplies would relieve some of the anxiety patients felt while they were waiting.

Beth had ideas about how to make the band aids and medical supply boxes, and wrappers for the needles less threatening

You could make like the band aids for kids, like, we could make it like, neon colors or glow in the dark... and make the boxes a little bit colorful, cause they look at kinda, they know they are going get pinched or something... Make it, pictures on it, like a design with different pictures on it. Stuck to it. It is like a disguise for the boxes so... and make the wrappers of those needles... look fun and all that stuff, and exciting and good colors so it wouldn't be that nervous exactly.

Karl's mother thought disguising the medical supplies was a good idea because "If they were colorful... It would take away that, yeah, that gloomy look." Tiffany thought that disguising the medical supplies might work for the younger children but she did not think it would work for teenagers or herself. In fact, when she was bored, she read the labels on the boxes. However, Amanda, who was a teenager, was particularly disturbed by the sight of needles and thought they should be well disguised. She thought it would be better if it was possible to do the venipunctures "... maybe without showing that much needles. They should make the needles look, look cute like have animals on them.... try to make, not make it that scary 'cause every time you look at the needle.... I don't want to look at the needle."

7.2.1.4. Windows

One of the screening rooms and two of the examination rooms had windows, the other screening room and two of the examination rooms did not. The view from the rooms that did have windows was of the Guggenheim Pavilion which was approximately 75 feet to the north. In general the patients preferred the rooms with windows because they allowed in natural light and they provided a view outside that could help improve their mood, help fight boredom, and serve as a source of distraction when needed.

Lauren and Oliver were quite dissatisfied with the rooms without windows. Lauren thought they should "pound a hole in the wall" of the examination room where we were

talking because it did not have a window. Oliver said it was "like it is not fair, because this room doesn't have windows and the other rooms have windows." He felt all the screening and examination rooms should have windows, "because when you are in the rooms and you are bored you can look out of the windows. You can see all the big buildings."

Other patients preferred rooms with windows because they liked to be able to watch activity of one sort or another. Edward liked the windows "a real lot" because they were "tall" and they were "nice to see from and sometimes when in the rooms where there are no pictures you could, you could see some stuff, some interesting stuff outside." Wilma wanted windows in the screening and examination because she felt "cooped up" in rooms without windows and she liked to see what was going on outside.

The issue of outlook was also important to Bonnie because being able to see outside made her feel better psychologically.

I like the windows 'cause you can see. It don't make you feel like you just in a hospital, nowhere to go, can't see no one. Windows are very, it brightens me up. You know, knowing that I can see outside, I'm comfortable with that.

Zachary preferred the rooms with windows because the view provided a source of distraction during the procedures and when the doctors left the room.

I like them with having the windows because if you are like having a checkup then you can, or if a doctor had to go get something you don't just sit there and look around, you can look outside and see what people are doing... I would rather see like the people and stores and stuff, like they have that gift shop. Just see what is happening.

Having something to look at when the doctors left the examination room was also important to Michelle because "You would look out and maybe imagine to yourself, have different thoughts and not instead of just looking at the chair or something and looking at your time, "When are they going to come back?"

Jasmine preferred the rooms with windows, even though she noted that "There is not much out there. There is a building (the Guggenheim Pavilion) across the courtyard"

(she meant the atrium the building where the Clinic was located, the Annenberg Building, and the Guggenheim Pavilion). She thought, "... it would be nicer if we weren't in the research building... if we were in the building on 5th avenue... we could have a view to the park." Nevertheless, she preferred the rooms with windows because "Sunlight is better than artificial light... Even on a rainy day there is something about whatever light is streaming through that looks better... It's just brighter, it's not as gloomy. I think it has to do with the natural light."

This was not Ken's impression. He preferred the rooms without windows, because "When it rains I don't want to be in a window room. Look, when it rains we call a moody day." Privacy was also an issue. He felt, "It's nice in the Playroom and not in the nurse's room... people could look in from the other building." Two of the other patients had no preference. Brian said it did not bother him that some of the rooms had windows and some did not so it did not make any difference to him which one he was in. James would not choose a window room over a windowless room "because that window, all you see the building, ain't no pretty sights to really see, so I don't really pay attention to the window. It doesn't matter."

As noted above windows serve several different purposes in an examination or screening room, including a source of distraction. One of the patients thought fish tanks could serve the same purpose. His thoughts about this will be reported in the next section.

7.2.1.5. Fish Tanks

Ned thought it would be a good idea to have fish tanks in the screening and examination rooms especially the rooms without windows because he thought it would help distract the patients and reduce their anxiety both before and during a blood drawing procedure. He made the observation: "You know, little kids... just little things amaze

them. They see fish, you know they're going to "wow these fish." He felt it was important to try to capture their attention so strongly in order to:

try to further their minds from needles. Cause they don't hurt... it doesn't really hurt them. I think they're scared of you know, cause just looking at it, it looks scary, you know. I don't think little kids should have to look at, you know, their needles or blood or what not, things like that. It's just that, for that short period of time when you are focused on the fish and you leave the room and the fish stay there, then the doctor. It would help.

Ned, as did many of the other patients quoted in this chapter, felt it was important that the patients have some source of distraction while they were waiting. He, and the others, recognized that waiting for a procedure, could be quite disturbing and anxiety provoking, especially for the younger patients.

7.3. Summary of Findings

- Patients waited in the screening and examination rooms for numerous reasons. They waited for invasive procedures such as venipunctures, bone marrow aspirations and lumbar punctures, or relatively non-invasive procedures such as being weighed, having their blood pressure taken, or being examined. The bareness of the screening and examination rooms did not help the patients cope, but they had suggestions about how to improve the environment to help them cope.

Stressors

- In most cases, the patients waited less than five minutes. However, even waiting for this relatively short period of time could be an anxiety arousing experience because the patients because the patients worried about what was going to happen to them
- The rooms were described as dull and plain. As a result the patients had little opportunity find some sort of distraction in the rooms that could keep their minds off of what was going to happen to them.
- The needles, medical supplies, and medical equipment were out in the open, and some of those items, especially the needles, served to create a great deal of anxiety in some

patients, although other patients reported that they preferred having the needles and medical supplies where they could see them. Because the screening rooms and the examination rooms were not acoustically isolated from one another there was an opportunity for a patient waiting in one room to be disturbed by the cries and screams of patients in other rooms.

- Most of the chairs the patients sat in while they were not comfortable. A more serious complaint about the chairs was that patients with disabilities, due to their illness or treatment, could have difficulty sitting in and rising from them. These chairs created a potentially dangerous environment as one patient reported sliding off of one on one occasion.

Coping Strategies and Mechanisms

- It was suggested that keeping needles in a closet until they were needed or making them and the other medical supplies more visually appealing would reduce the patients' anxiety, especially the younger patients' while they were waiting. Other patients reported that they preferred having the needles and medical supplies where they could see them.
- The patients had suggestions about how to improve the screening and examination rooms. These included providing toys, books and puzzles; putting posters or pictures on the walls that would add color, visual interest, beauty, and positive messages; painting the walls colors other than white; making the furniture more colorful; installing televisions or fish tanks; and hiding or disguising the medical supplies.
- Only one of the screening rooms and three of the examination rooms had windows. In general the patients preferred the rooms with windows because they allowed in natural light and they provided a view outside that could help improve their mood, help fight boredom, and serve as a source of distraction when needed.

8. PROCEDURES

When the patients were called from the Playroom by either a nurse or a doctor, it usually meant they were going to be subjected to a medical procedure: initial screening, venipunctures or chemotherapy by the nurses, or examinations, bone marrow aspirations and spinal taps by the physicians.

Screening procedures performed by the nurses included weighing the patients, taking their temperature and blood pressure. These procedures are relatively non-invasive, but one patient reported that a stethoscope or blood pressure cuff can be frightening to young children.

The patients, primarily the hematology patients, had to have venipunctures mainly for blood drawing. Many of the oncology patients had indwelling catheter's which were used to draw blood (as well as to administer chemotherapy), and were, therefore, not subjected to venipunctures. Some of the patients' reported that they were disturbed by the venipunctures, but others reported that the venipunctures didn't bother them. Most of the patients did not have major complaints about the screening rooms with regard to how they accommodated their needs during venipunctures. Some of the other patients, however, did have problems with the furniture.

The patients said they coped with the venipunctures by either watching, not watching, or by observing certain stages of the procedure. Environmental conditions that the patients thought could positively affect their ability to cope with the venipunctures can be divided into two categories: those conditions that affect their physical comfort during the procedure, and those that help distract them from the pain and anxiety associated with the procedure

During a routine examination, the physicians listened to the patient's hearts and lungs, and looked at his or her eyes, ear, nose, and throat. The examination was done with

the patient either sitting or lying on the examination table or, in the case of the younger children, in the arms of one of his or her parents. The patients reported feeling bored, fearful of having their privacy violated, frightened by the stethoscope, and vulnerable during the examinations. Most of the patients did not have major complaints about the examination rooms with regard to how they accommodated their needs during examinations. Some of the other patients, however, did have problems with the examination tables, and several others reported that the fluorescent lights above the table were too bright, and one patient thought the floors were too cold. While lying on the examination table, two patients said they looked at the acoustical ceiling tiles and searched for patterns in the "dots." Other patients thought the ceiling should be more attractive.

The lumbar punctures and bone marrow aspirations were performed in the examination rooms. The procedures have been described in the literature as the most invasive and feared procedures that pediatric oncology patients have to face. The data I have concerning these procedures are very limited, so the findings reported in this chapter have to be considered as very preliminary. The few patients that I was able to talk to about the subject, indicated that they thought nothing could be done to improve the examination rooms to help them cope with the procedures. One patient was taught self-hypnotic techniques and apparently these helped him cope with the procedures.

The oncology patients who received chemotherapy in the Clinic had the drugs administered either via drip infusions, which could take several hours, or by a "push," which took less than five minutes. In the Clinic most of the chemotherapy was given via a "push." As with the lumbar punctures and bone marrow aspirations, the data I have concerning these procedures are very limited, so the findings have to be considered as very preliminary. Apparently a "push" of chemotherapy is not very disturbing, while an

infusion can be. Consequently, the environment where patients received their "push" of chemotherapy did not seem as important as the environment for infusions.

I have relatively rich quotations from the patients about the stress of venipunctures and their coping strategies, but the data from the interviews are very weak with regard to the basic screening procedures that happened in the screening rooms. This weakness was caused by poor research design, rather than my reluctance to talk to the patients about these procedures. Simply put, I concentrated my questions on venipunctures, rather than the screening procedures, ignoring them because I thought venipunctures were the more important, in the sense that they were more invasive, than the screening procedures. Although I regret this oversight, I do not think it is critical because any measures taken that would make the screening rooms better places for venipunctures, such as placing more pictures on the walls, would probably also help the patients cope with the other procedures. Concerning the examination, I have quite a few quotations about how they coped during the examination, but relatively few about why the examinations were stressful. The data concerning BMA's and LP's is relatively weak because, as I will discuss in Chapter 11: Methodological Critique, most of the patients did not volunteer information about these procedures, and I did not feel comfortable asking probing questions.

Findings regarding the procedures will be reported in the following order: screening and venipunctures, examinations, lumbar punctures and bone marrow aspirations, and finally chemotherapy.

8.1. Screening and Venipunctures

The basic screening performed by the nurses, in which they took the patient's temperature, height, weight, and blood pressure was relatively non-invasive, but one patient explained that it could be frightening to young children. Beth explained that, "Sometimes they [young patients] get scared because they are going to take their blood pressure and they wrap their thing, but they think that they are going to take blood out."

The patients had to have venipunctures primarily for blood drawing. One of the oncology patients received his chemotherapy through a venipuncture, but this was very unusual because many of the oncology patients had indwelling catheter's that were used to draw blood and administer the chemotherapy. The children and teenagers reported that their reactions to venipunctures covered the range between kicking and screaming to blasé acceptance or even intellectual curiosity.

In very graphic terms Ned explained how disturbing venipunctures could be for some patients and how a room where the venipunctures were performed could acquire an ominous aura.

Because sometimes when you take the needle and stuff you feel like the doctor is your enemy... 'Cause here it's like, you feel this is the end of the road, this is the doom room, you know... everything lies all the negative things... All the positive things you had over there, the reality hits you here.

The reality for many of the patients, especially the younger ones was that they feared the needle. According to Jennifer, "If anyone gets a needle, everyone goes to the ceiling. Eek! It hurts." Fortunately Jennifer did not have to worry about getting venipunctures because she had an indwelling catheter. The younger patients weren't the only ones who dreaded venipunctures. According to Bonnie, the procedure was over fast, nevertheless, it was disturbing. She said, "You just look at the ceiling (she had her blood drawn while she was lying on the exam table) like 'Oh god, please hurry up. ' "

The type of needle used could also made a difference. When I interviewed Amanda, she said she was trying not to move her arm very much, because it still hurt from having her blood drawn earlier.

It hurt me. Today they put a bigger needle, and they said it was normal. But usually my veins are hard to find; that's why they give me the butterfly needle. But today they didn't give me the butterfly needle, they gave me this silver needle that was really big and she said it was normal. And now it still hurts... The other needles it hurts but it is just like a pinch. But that one lasted longer.

Other patients denied that the needle hurt, but when they said this their voices changed, and I suspect that they were in denial. Susan was just the opposite, she made it very clear that getting stuck was very disturbing to her, especially during the initial stages of her treatment.

When I first started getting my blood drawn nobody wanted to come near me. I have a serious problem with needles. I kicked and I hit. (Laughing) My calm relaxed attitude about getting my blood drawn was a long time coming. I mean when I was a little kid I once kicked my doctor and he wasn't exactly happy about where I kicked him. I mean, you know, I had a serious problem about it. So right now it's a lot easier. I just go. "Do it, do it, do it." And like I brace myself with a pinch and then it's over and whatever. Now it's fine. I go in and it's over.

Venipunctures became less distressing for her over time, but it doesn't sound as though it was as easy for her, as it was for other "hospital veterans," who had become inured to the pain associated with a venipuncture. One of those patients, Brian, explained that "When I first started my treatment in '89, I'd never been stuck before for like that much. And I wasn't used to it. But now I'm used to it... It doesn't bother me. Doesn't hurt at all." Jasmine was another "veteran," who had so many venipunctures that they didn't bother her anymore. She, in fact, thought they were "kind of neat."

Although Jasmine was the only one to describe the blood drawing in this way, several of the other patients did say they watched their blood being drawn. (See 8.1.2.1) Beth was one of those patients. She watched, but she was apparently more disturbed by the sight of the needle before they inserted it, than the venipuncture itself.

... the only problem is when they see a needle... that is when I get the feeling... I feel kind of nervous. And when they pop out the needle, like this, and then put it in your vein. It doesn't hurt or anything it just feels... an eerie thing. It's not that I like watching it, but except that they have been doing this like all my life or something, so I get really used to it.

What is most revealing in Beth's statement is her nervousness at seeing the needle, even though she said she had become used to being stuck. It is evident from what some of

the other patients said, however, that venipunctures were painful procedures, and for the patients with blood disorders they were the most painful procedures in the Clinic.

In general, the patients did not have major complaints about the screening room. When I asked them how it worked as a place to have their blood drawn, many said it was okay. But further probing uncovered that the chair and the desk caused additional stress during the procedures. In addition one of the patients complained that the room was sterile, lacking artwork or other objects that the patients could focus on during the venipunctures.

When I asked Susan what she thought of the room as a place to have her blood drawn, her reply captured the essence of the room: "White, sterile. And what did I do. I put my arm out and turned the other way. I told you I can't look. So I didn't look. So what was I looking at. A wall" [hitting it as she spoke]. Susan was the most vocal in her negative assessment of the lack of amenities in the rooms. Many others said the rooms were okay, but when I asked them if they would like to see posters or art on the walls, many of them said yes. They accepted the rooms as they were, but this does not mean that they felt comfortable in them. In addition to the lack of psychological comfort due to sterility of the room during venipunctures several patients felt physical discomfort because they had problems with the desk and the chair.

The problems attributed to the desk were due to its lack of cleanliness and its surface qualities. Ken and Wilma did not think it was kept clean enough. Ken said "I hate the table that's always there. The soap, the yellow, the brown soap, like brown soap. It's not nice. They never wipe off the table." The soap that he was referring to was the anti-bacterial soap, Betadyne, the nurses used to clean the skin in the area of the venipuncture. Wilma had a different but related concern. She suggested that the desktop be cleaned off after each patient:

so none of the germs get on people's finger or when they take the needle.
After you finish, clean real good I mean... usually I don't like to look,

cause your finger and then your hands are on the table, and the table is dirty. So I usually ask the lady can she put those pad things, the blue padded things under my arm. That way there are no germs if somebody got cut... Like if somebody is writing and they get ink on the desk and they can't get it off, and then somebody has their blood taken on that table.

While Ken and Wilma were bothered by the desk's sanitary condition, others were concerned about its comfort. June thought it was cold and hard, as did Michelle, who also thought the relationship between the chair and desk made her put her arm in an uncomfortable position. Zachary also had trouble positioning his arm comfortably when he received his chemotherapy, but it was because there were a lot medical supplies on the desktop, "so I had to like (he stretched his arm straight out) so I wouldn't knock it over. It was sort of uncomfortable.... because if I just put it like (he demonstrated again what he meant, this time with a grimace on his face) I would have knocked over something." The nurses needed to have their supplies close at hand, but because a shelf was not located above the desk, the supplies had to be on the desk. The desktops in the screening rooms were quite small, and for this reason Zachary had to worry about knocking something over. (See photographs below.) Another problem with the desk, according to one patient, were the edges, which caused him some discomfort when he put his arm down for a venipuncture.

8.1.2. Venipunctures: Coping Strategies and Environmental Supports

The following findings about how the patients coped or would like to have coped with their venipunctures will be discussed under two broad sections: watching or not watching the venipuncture (some patients reported they watched or didn't watch depending on the phase of the procedure), and environmental conditions. Because the screening rooms did not offer much to the patients to help them cope during the venipunctures, the environmental conditions section will, by necessity, concentrate on the changes to the

rooms the patients offered, which included suggestions about how to improve the furniture in the rooms, and ways to provide sources of distraction.

8.1.2.1. Watching or Not Watching the Veipuncture

The patients gave various reasons why they watched the venipuncture. They said they watched the venipunctures as a matter of pride, in order to reduce the amount of pain they experienced, in order to observe the person performing the venipuncture, and to be able to watch their blood being drawn.

For Ken it was a matter of pride. He said, "I am a very strong boy. I don't cry... Always look... want to look." As noted in the previous section, Jasmine thought having her blood drawn was "neat," and she watched "because I like to see when it goes in. I don't mind." For Terry, it was a matter of preparing himself. Terry said he had to look at the needles "so I know when to be ready for it... Yeah. They say like, 'Look away don't look at it,' and I'm 'Nah.' That would hurt more if I didn't look at it." June also had to watch in order to prepare herself. She said, "I have to watch. I have to look... When I was younger I didn't, I used to turn around, but now I have to look at it. So I know what to expect, and when to expect it." What is very interesting in the above statement is how June's coping strategies changed over time. When she was younger she turned away, whereas when I interviewed her she "had" to watch.

Patients who did not want to watch the procedures avoided doing so by either closing their eyes or turning their heads away. Zachary did both because he had a very strong aversion to seeing what was happening. He said, "I usually just closed my eyes and looked away... even if I went like that (turning his head away), I could still see and I don't really like watching." Susan also did not watch. She turned her head, stared at the wall, and talked to the nurse, a different coping strategy than the one she used when she was younger. When she was younger she also turned her head away, but it was to look into

her mother's eyes as she squeezed her hand. She recounted: "All I needed to do is look into her eyes, right. I mean, I would be crying, you know, but it would help."

Some patients reported that they watched or did not watch the procedure depending upon different circumstances or phase of the procedure. Bonnie's coping strategies changed depended on the circumstances. It was not the needle that she watched, it was the person inserting the needle that was her concern: "It depends on the nurse. If I know, because I have been here for so many years, I know the nurses that can get it. If there is someone that I really don't know, I like to watch them."

Michelle turned her head away, but only for one part of the procedure, the insertion of the needle. She then turned her head back "because I am so afraid of losing the blood."

8.1.2.2. Environmental Supports

The environmental conditions the patients mentioned that could positively affect their ability to cope with the venipunctures can be roughly divided into two categories: those that affect their physical comfort during the procedure, and those that help to distract them from the pain and the anxiety associated with the procedure.

In terms of comfort, the furniture in the room, specifically the desk where they laid their arm and the chair upon which they sat during the blood drawing procedure, were the critical items for several of the patients. The elements that helped, or that the patients thought would have helped, to distract them from the pain of the procedures included: artwork, the color of the room, television, fish tanks and windows.

In the following sections, I will first discuss how the furniture could be made more comfortable and then discuss how elements of the screening rooms could act as sources of distraction.

8.2.2.2.1. Furniture

For the patients who talked about the furniture, comfort was the major issues. Michelle thought the relationship between the chair and the desk could be improved by placing "it in a position where people could really extend their arms, not just like against the wall. Maybe a little away from the wall with the chair laying back a little bit more." Zachary also had an idea about how to improve the rooms so that the patients could extend their arms comfortably. He advised taking the "stuff that was on the desk and put it on a shelf over there," so that "then it would be more comfortable...."

Several of the patients had thoughts about how to improve the surface of the desk. Michelle and June thought it would be helpful to have a "little padding, especially something soft, like a small mattress or something. Because that's when your are in pain you would like to rest your hand comfortably, your arms comfortably." To keep his arm off the sharp edge of the desk, Terry suggested attaching "something like a little handcuff that you would like lay down like that" to hold his arm above the desk because the edge caused him some discomfort.

In addition, several of the patients mentioned adding colors to the desktops in order to help distract patients during the venipunctures. Another source of distraction mentioned by the patients were pictures, the subject of the next section.

8.2.2.2.2. Sources of Distraction: Pictures, Objects in the Room and the View From a Window

Several patients thought pictures on the wall would help act as a source of distraction during the venipunctures. They thought the pictures should appeal to patients of all ages, be visually rich or complex in order to hold the patients' attention, and the images in the pictures should be large enough to be seen from a distance. The efficacy patients assigned to the pictures varied, some thought the pictures might help, while others,

definitely thought they would help. Other patients thought objects in the screening rooms, such as toys could also serve as a source of distraction, while others thought the view outside the rooms could serve the same purpose.

Ned thought having some form of distraction was important because "They would look around. Instead of focusing in on the needle and the doctor, you know. Eventually they would, but then they would look around."

In the following statement, Bonnie notes that it is especially important for the younger patients have something to look at to take their mind off the needle, but as noted earlier the experience was also quite disturbing for her.

You know, but pictures would be better. It would get your mind off it, on the wall, like on the side of the wall, to get your mind off the person doing your IV or drawing any type of blood... especially little kids, they want to know what is going on. They should have something that would make them want to look at the wall more, take their mind off of the needle. It would be much better.

Susan thought pictures or posters would not have made a difference for her, because she was older and she could "get through it," but she also felt it would be a great benefit for the younger patients, "if they could turn around see Barney with the **stupid** [her emphasis] smile on his face staring at them. Might make them feel better... A little kid will be like pointing, whatever, and it could be over by the time they even realize it."

Beth also thought this kind of distraction was important and gave an example from a television program she had seen, where a child apparently didn't feel a shot because he was paying attention to something else: "They pinched the kid with a needle right here (in the crook of the elbow) with a shot. And he likes looking at something and they take it and he didn't even cry or anything, but after he cried..."

She even had ideas for the images on the posters, taking into consideration the kinds of images that would appeal to different age groups.

kids have different likes you know... You might have to mix sports, smiley faces and not violence or anything. Just mix it all up like, like, Shaquille O'Neal, or Patrick Ewing or Michael Jordan going to the doctors or something, comic strip or something. With a basketball under his arm, like this, then he gives his arm to the doctor. That would be a good idea... that would make them feel good or something... So it's mixed with sports and happiness. And it is also cartoon... so it wouldn't be that realistic.

Beth was a "veteran," who had gotten used to having her blood drawn, so even though she thought it was important to have something for other patients to look at, she did not feel the need, herself, to be distracted. In addition she recognized another issue that other patients addressed: the content of the image.

The patients thought that there are some images that may be appropriate for one age group and not for another. For instance, Susan thought younger children would like to see a picture of Barney on the wall, and Barney did work for June when she was younger. "I used to have pictures of cartoon characters and child role models, you know like Barney, Barbie. Those are the ones that when I was younger, I used those used to help me." But when she was choosing the pictures that she would like to see on the walls now that she was older they were, "Mostly music and acting, I like all kinds of things but mostly music and acting."

Jasmine raised another issue that is critical to the success of an image in a medical setting; how powerfully the image can distract patients. She claimed it was a "definite, definite necessity to have something to look at," but made a distinction between "Things that will really distract" and "the kinds that you just look at and know what it is and then look away." She suggested using images "Like those games that are on puzzles, or like puzzles that are on posters. Like, can you find somebody's layout? Or "Where's Waldo" posters, or things like that."

A final factor raised by one of the patients was the image size. Wilma had just had her blood drawn in a room with some pictures that she "would change, make a little bigger 'cause people have eye problems can't see it across the room..."

In addition to pictures or posters, several of the patients thought three dimensional objects could be used to distract the children. Ned thought it would be a good idea "to be able to bring in animals, stuffed animals or toys or anything to be distracting," while the needle is being inserted because those kind of objects "Take your mind off, your mind is going to be here, focused here, but you know."

One of the patients thought toys could also help to occupy the younger patients just before they are going to get stuck. James suggested they should:

maybe have a couple of toys here there, you know, to suit the child's age or whatever, bears or whatever. Like some private doctors got rooms like that you know. Make it feel maybe things were happening, like Big Bird or something for the kids, Sesame Street... It would take their mind off the needle... Now if the kids are occupied, probably looking around pointing... Probably won't be paying it too much mind as much as they would, cause you look around, and you're like probably paying no mind.

Toys have an advantage over pictures and posters in that they are "hands on;" children can play with them as well as look at them. This feature of toys was brought up by Beth who said, "We could make something to distract them from the needle or something. Like a toy or something, but that doesn't keep them from moving their arm, like he could play with a little toy like this..."

Windows, or more accurately what was outside the windows, provided some relief or distraction for some of the patients. As noted earlier, there were two screening rooms in the Clinic, one had a window, one did not. Bonnie preferred the screening room with the window, "'Cause you could look out the window while they are drawing your blood. They don't have any pictures." She compared the screening room with the rooms where she had stayed as an inpatient saying, "Most of the time the bed is right next to the

window, so you can just like turn your head around. That would be nice, that would be good."

Wilma explained that the view from a window could help distract patients during a venipuncture and blood drawing by engaging them in an active viewing process where their eyes move and focus on different parts of the view: "You're getting your bloods, then you're looking out the window, real far down, then you're looking down there, and then just look straight, and then you look all the way very high, and then you turn and then you get shot."

8.2. Examinations

During a routine examination, the physician listens to the patient's heart and lungs, and looks at his or her eyes, ear, nose, and throat. The examination is done with the patient either sitting or lying on the examination table or, in the case of the younger children, in the arms of one of their parents. Being examined did not seem to bother as many of the patients as a venipuncture, but they did report feeling bored, fearful of having their privacy violated, and vulnerable during examinations. Environmental stressors mentioned by the patients were the examination tables and the fluorescent lights. And one patient mentioned how even a seemingly benign procedure such as a routine examination can be terrifying for a child. Unlike venipunctures, only one patient, Beth, mentioned any pain related to the examination: "They say to relax and you're like real stiff then. So, you kinda get like a scary feeling when, like when you look at the ceiling you know you are going to get something pinched, pinched or something."

Several of the patients did, however, mention psychological discomfort associated with the examination. One of the patients, Oliver, said the examinations were "no fun... cause you just stand there and look at the lights and it is boring." Some of the younger children might also experience fear caused by the instruments the doctors used during the examination. Based on her own experience Beth described how the stethoscope could be

frightening to young children: "They are going to think that it sucks its blood out... 'Cause when I was small I looked at it, and... I thought that it was going to suck my blood out... So, I was really scared."

Some of the older patients also felt psychological discomfort during the exam. For Jasmine the issue was vulnerability, noting that "You're lying on your back, and you're in a vulnerable position. Others were uncomfortable because their privacy could be violated. In some of the rooms the examination table could be seen from the corridor when the door was open. This bothered Tiffany who said:

I think they should have a sign on the outside saying "occupied or unoccupied" because people are always walking in, and it is kind of annoying sometimes. It's not as private because you know that someone could walk in at any minute.

Lauren had the same problem and thought there should be a sign saying, "Knock before entering." Since the doors were not equipped with signs, she locked the door so people had to knock before entering. Before they entered she went behind the door, unlocked it, and then relocked it before getting back on the exam table.

Generally the patients had few complaints about the examination rooms as places to be examined. However, in addition to the psychological stress and physical discomfort associated with the examination, some of the patients reported that certain aspects of the environment: the exam table, the lights, and the temperature, were stressful.

All of the exam tables were the same size. Some of the older patients did not think that they were long enough. Another complaint about the table was that the paper covering it was uncomfortable. Jasmine said, "Well they are obviously not big enough and they have to pull out this thing. I don't like that. I wish they would just get bigger ones." The extension that was pulled out was also an issue for Bonnie because "sometimes, but your legs go down, instead of being straight, they go down." This was problematic for Bonnie because of the pains in her knee joints associated with her disease, sickle cell anemia. She

thought the bed should be a "little bit longer" for the taller patients because "it is very uncomfortable. Like if you have really bad pains in your leg... It makes it worse. Like your kneecap part, its like hanging off and it hurts right there."

The paper that was pulled over the examination table to cover it bothered Wilma who said, "It's a little cold. Like the paper looks cold... It's noisy... when you get on it's noisy." One of the parents had the same opinion about the paper. During a conversation with Kevin's mother about the examination room, she mentioned that the examination tables were covered with "hard, shiny, cold with horrible crinkly paper. The texture is horrible and the sound... the feel of it... It's awful... It's a big roll and you can just whip it out..."

When the patients were lying on the examination table, the fluorescent lights were directly above them. Many of the patients said the lights were fine, and they would not change them. Other patients thought they were bright, but they were not bothered by the lights enough to want to change them, especially because they felt the doctors needed them to see what they were doing. A few of the patients, however, found them very disturbing.

Tiffany thought they were bright "Only if you stared at them for awhile." Another patient thought the lights were too bright to stare at for any length of time. He said, "Like nobody wants to really look up at the light in the ceiling because after awhile that could just hurt your eyes a little bit." He said he had to close his eyes sometimes because the lights were too bright. Bonnie also thought they were too bright and noted that in other areas of the hospital the lights had dimmer's so that the light level could be adjusted to a comfortable level.

The two patients who were most bothered by the lights were Ken and Zachary. Ken said, "When you look up it, it's like, like flashes in your eyes." When I asked him if he would change the lights if he could he said, "Other lights. I don't like fluorescent.

Fluorescence I don't like. Never. I never did." The fluorescent lights had the same effect on Zachary who said, "just looking at it hurts my eyes.

Temperature is a critical concern for patients with sickle cell disease because a crisis can be precipitated if they become chilled. One of the sickle cell patients, Bonnie, made a comment about the flooring that gave some insight into the fears that some of the sickle cell patients might have. She said:

I think they should have a rug, or something on the floor... The main thing when you get sickle cell is that you are not supposed to get a fever. A fever starts with your feet and your head. You know, the floor be cold, they could get a fever and they couldn't get out of the hospital.

Fevers do not start in the head or the feet, but her misconception about the cause of an illness does not minimize the fact that the floors were cold and she felt uncomfortable.

An examination is a relatively benign procedure compared to a painful procedure such as blood drawing. As noted above, this does not mean that an examination is without stress, either from the procedure or from environmental conditions. In the following sections the coping strategies that patients used, as well as their suggestions to improve the environment, will be discussed.

8.2.2. Examinations: Coping Strategies and Environmental Supports

When patients were being examined, they spent much of the time lying on their backs looking at the ceiling. The ceiling was composed of a grid of acoustical ceiling tiles and lights. Two of the patients reported that they used the dots in the ceiling tiles to help them pass the time while they were examined. Other patients had ideas about how to make the ceiling more interesting. And, as noted above, several of the patients thought the table should be longer. It was also suggested that the covering on the table be more comfortable.

June and Terry looked at the ceiling tiles to help them cope during the examination. June said, "I mostly look at the dots, drawing pictures." Terry thought the ceiling was fine and would not want to change it because he also played "connect the dots." Some of

the other patients, however, had ideas about how to make the ceiling more interesting. Oliver wanted to paint it red so it would not be so boring, but he "would leave the dots." Beth also thought the ceiling, which she thought was boring, could be made more interesting. She suggested that, "the lights could be another color, interesting color, like green or blue or something." And, in order to create a more relaxing environment, she thought the ceiling could be painted "like half, like a rainbow or something, like different colors from here to here. (Indicating on the ceiling where she would like the rainbow.) And then you know if it was like an imaginary sky, you would paint it light blue." Amanda suggested hanging puppets on the wall or ceiling that could "fly around" because "When they examine you, they usually look up on the ceiling. And sometimes they look up and there is nothing to see so they daydream and stuff..."

In addition to making changes to the ceiling it was suggested that the material used to cover the tables be changed. Kevin's mother felt that "if it was a nicer thing that you could lie on, it also might be more inviting..." Wilma thought the paper that covered the examination table should be made "a little non-noisy, like a little sheet."

8.3. Lumbar Punctures and Bone Marrow Aspirations

The lumbar punctures and bone marrow aspirations were performed in the examination rooms. The procedures have been described in the literature as the most invasive and feared procedures that pediatric oncology patients have to face. The data I have concerning these procedures are very limited so the findings described below have to be considered as very preliminary. One of the patients, Tiffany said that the LP's and BMA's didn't bother her. Other patients, however found the procedures quite disturbing. The two patients that I was able to talk to about the examination rooms as places for the procedures had no complaints and didn't think that there was anything that could be done to the rooms to help them cope with the procedures. One patient was taught self-hypnotic techniques and these seemed to help him.

As noted earlier Norman experienced a tremendous amount of anticipatory anxiety before the procedures. They bothered Lauren so much that she did not want to be reminded about them. When I asked her if she wanted to talk about getting LP's or BMA's she said, "Why did you pick this day to talk about this?" I had not known, but she was scheduled for one of those procedures that day. I immediately switched subjects, but her response gives an idea of how much she dreaded the procedures. Ken said he did not mind talking about spinal taps and bone marrow, but his responses to my questions were quite brief. His father told me at an earlier date that Ken worried about the procedures weeks in advance.

The patients that I was able to talk to had few complaints about the examination rooms as a place to have a LP or BMA. Tiffany did not think "that anything is like really wrong with the rooms." In response to my question about how the rooms were to get spinal taps, Ken said, "No room is tempting" without elaborating what he meant. He thought the bed should be softer, but according to one doctor the beds have to be fairly hard so that they offer some resistance when the doctors are pushing the needle through the bone into the bone marrow. This gives an idea of how much pressure is required to penetrate the bone.

8.3.1. Lumbar Punctures and Bone Marrow Aspirations: Coping Strategies and Environmental Supports

As far as I know, only one of the patients, Norman, was taught a particular strategy to cope with the procedures. The Child Life Specialist taught him self-hypnotic techniques. I did not talk to Norman about this coping mechanism but one of the nurses reported during clinic conference that it worked for him.

As noted above, Tiffany thought the rooms worked fine for the LP's and BMA's, and she did not think providing the patients a more attractive or visually richer room would make a difference in terms of how they coped with the LP's and BMA's.

I don't really look around. I just sit there. When they're giving me a bone marrow I'm not like "Wow this room needs like a paint job or something." I don't like go around judging the rooms before I get a bone marrow. Maybe like if you wanted to have like colored wall paper or something which could get like people's mind off it, but I don't think it would work on most people. It wouldn't work on me. You're thinking about what the nurses are going to do to them... then about like "ooh, pretty colors..."

I did not ask Tiffany what she did to help her cope with the bone marrow, but when I asked her if she thought watching a video or television would help she said:

I don't think so because like first of all there are nurses all around here, and also like I don't think that would work because most likely something like would kick the TV; something would like hit the TV, and it wouldn't get my mind off of anything.

What is most interesting about this statement, besides the fact that she thinks the TV's would be in the way, is that she did not think they would help her cope with the procedure anyway. Ken had a similar reaction when I asked him if he would want to watch videos during a spinal tap. He said, "I don't want to watch videos... 'Cause I am too nervous."

Although there has been much written about how to help pediatric patients cope during the time when the LP's and BMA's are actually occurring, I have not been able to find any studies that have examined how patients cope after the procedures. Based on one observation that I made, I think that this may be an oversight.

One day I walked past one of the examination rooms and saw Norman lying on the exam table. He had just had a spinal tap. He was on his side with his back to the door, and hooked up to an IV. The lights in the room were off. Seeing him lying on the exam table recuperating from a very invasive procedure made me wonder what it was like for him to lie in that room on a table designed for examining children much smaller than himself.

8.4. Chemotherapy

Not all of the patients who came to the Clinic received chemotherapy. Oncology patients who were off treatment did not, and neither did any of the hematology patients. And of the oncology patients who were treated with chemotherapy very few of them received it in the Clinic by infusion, a procedure which could take several hours. As with the lumbar punctures and bone marrow aspirations, the data I have concerning these procedures are very limited, so the findings described below have to be considered as very preliminary. The chemotherapy most of the patients in the Clinic received was by what the nurses called a "push." The chemicals were, with a few exceptions, injected into the patients indwelling catheter in less than five minutes. From what I saw during one patient's push of chemotherapy, and from what I was told by another, my understanding is that a "push" of chemotherapy was not a very stressful procedure. This is not the case for an infusion of chemotherapy. One of the most powerful and devastating side effects of chemotherapy, nausea and vomiting, has been greatly reduced by the use of anti-emetic drugs; nevertheless, infusion chemotherapy for most patients is an unpleasant if not a very disturbing experience. This was the case for one of the patients who was given her chemotherapy via infusion in the Clinic. She reported that she did get sick during the infusion. Consequently, she was affected more by the environment than the patient who I observed receiving a "push" or the other patient who reported that the way in the room looked where she received the "push" of chemotherapy "did not matter."

During one of the sessions with Kevin, the nurse came in to give him his chemotherapy. After all I had read about the pain and discomfort associated with chemotherapy, I was amazed at how matter-of-factly the procedure was performed. With no hesitation, and while barely paying attention, Kevin pulled up his shirt. In less than two minutes the nurse had "pushed" the chemotherapy. Kevin continued playing with the

computer while she did it. It did not appear that there were many immediate side effects to the chemotherapy by "push," but Ken, who got pushes, just wanted to go to what he called "home sweet home" after his chemo.

According to Lauren, who also received "pushes," it was boring "when you get your chemo just sitting here in the chair doing nothing." The experience was much different for Jasmine, one of the few patients who received an infusion of chemotherapy over several hours in the Clinic. She said:

First I would get my bloods taken and there would be if my counts were OK, and that would take forever. And then they would get whatever treatments, hook me up... I would be here for hours. I was the last to leave because most kids would either be sent home or up on the floor. Whereas I was supposed to be here waiting for it to be over and then I would go home. Yeah, so that was kind of weird... It always took forever.

She experienced side effects while she was in the Clinic and that made a difference on the way the environment effected her. She recalled that:

... when I would get sick I wouldn't like the place, I would just start whining that "I want to go home, I want to go home, I want to go home." But that's just because you want to be in your bed and fall asleep. So that's what I always do after I got out of here. I would go home and fall asleep.

Jasmine thought it was a problem that the Clinic did not have a room for patients getting infusion chemotherapy. She was able to leave the room where she was hooked up to the chemotherapy because she had a broviac (an indwelling catheter) so she did not have to have the chemotherapy go directly into a vein in her arm which would have required her to stay in either a screening room or examination room. Instead she was able to go wherever she wanted, including the Playroom, but this was not an ideal situation either.

Sometimes I felt really uncomfortable... because a lot of times other kids in there don't have that... There are so many things going on in the Playroom: there's drawing, playing, running. It just gets to be too much. And also it's not very safe. Kids trip over the IV poles or it just gets ridiculous.

The problem with IV poles has been noted earlier, but beyond that Jasmine's level of discomfort in the Playroom had to do with the level of activity there. As she said "It gets

to be too much," presumably when she starting feeling sick. The temperature, as well as activity level, also affected her more when she was feeling the side effects of the chemotherapy. She thought they needed more blankets in the Clinic because "Depending on how I was feeling that day. Like if it was, if I was in the middle of a cycle, then I would probably be feeling very sick and I would probably be cold.:

Time also became more significant when she was hooked up to the chemotherapy. She wanted to know if the clock in the hall was working because:

... it wasn't working for awhile and that was really annoying. That really annoys me because you have no idea what time it is. And you want to know, especially when you are on chemo. They'll go "This will take an hour, this will take 20 minutes" or whatever. You want to know what time it is.

8.4.1. Chemotherapy: Coping Strategies and Environmental Supports

Based on one observation and very little interview data coping with a "push" of chemotherapy apparently was not very difficult, nor did the environmental conditions seem important. When I asked Tiffany what she thought of the examination rooms as places for chemotherapy she said, "I don't really look at the rooms. I don't really care what they look like. It doesn't matter." However, coping with an infusion of chemotherapy, was difficult, and according to one patient the environmental conditions, such as privacy and comfort, were important. As Jasmine explained:

sometimes you don't want to be around other people when you have an IV sticking out of your arm. It would be nice if there was a place to go especially during that time... anyplace that was comfortable; that wasn't so, you know, had so many things going on in it at once.

We did not talk about what she meant as comfortable, but I assume she would have wanted a comfortable bed in a warm room because as noted before when she felt ill she sometimes felt cold, and also just wanted to be at home in her own bed.

Apparently the environmental conditions necessary to help patients cope with an infusion of chemotherapy, which may take several hours and induce uncomfortable side

effects, are by necessity very different than the environmental conditions necessary to help patients cope with a "push" of chemotherapy, or for that matter, other procedures.

8.5. Summary of Findings

In the following summary of findings, the various procedures that the patients were subjected to and their coping strategies and suggestions for improvements to the physical environment will be discussed in the following order: screening and venipunctures, examinations, lumbar punctures and bone marrow aspirations, and chemotherapy.

Screening and Venipunctures

- The basic screening, performed by the nurses in the screening rooms, in which they took the patient's temperature, height, weight, and blood pressure was relatively non-invasive.
- The patients, primarily the hematology patients, had to have venipunctures mainly for blood drawing. (cf: Many of the oncology patients had indwelling catheter's which were used to draw blood and administer chemotherapy.) The patients' reactions to their venipunctures covered the range between blase acceptance or even intellectual curiosity to kicking and screaming.
- Many of the patients did not have major complaints about the screening rooms with regard to how they accommodated their needs during venipunctures. Some of the other patients, however, did have problems with the furniture: the coldness and hardness and sharp edges of the desktop, and the uncomfortable chairs that also were not adjustable.
- Patients coped with the venipunctures by using a number of strategies. Some watched the procedures as a matter of pride; in order to reduce the amount of pain they experienced; in order to observe the person performing the venipuncture; and to watch their blood being drawn. Others avoided watching the venipuncture by turning their heads away from the procedure or by closing their eyes. Still others watched or didn't watch the procedure depending on who was doing it or the phase of the procedure.

- Environmental conditions that the patients thought could positively affect them cope with the venipunctures can be divided into two categories: furnishings that affected their physical comfort during the procedure, and conditions that helped distract them from the pain and anxiety associated with the procedure such as pictures on the wall, age appropriate toys and a view from a window.

Examinations

- During a routine examination, the physicians listened to the patient's hearts and lungs, and looked at his or her eyes, ear, nose, and throat. The examination was done with the patient either sitting or lying on the examination table or, in the case of the younger children, in the arms of one of his or her parents. The patients reported feeling bored, fearful of having their privacy violated, frightened by the stethoscope, and vulnerable during examinations.
- Several of the older patients reported that the examination tables were not long enough them and some thought that the paper that covered the top of the examination bed was cold, noisy, and harsh. They thought longer or adjustable examination tables would allow the taller patients to be more comfortable during the examinations.
- When the patients were lying on the examination table the fluorescent lighting fixtures were directly above them. The glare from these fixtures disturbed some patients.
- For coping during the examinations, while lying on the examination table, some patients looked at the acoustical ceiling tiles and searched for patterns in the "dots." Patients suggested that the ceiling be painted a different color or colors so it would not be so boring or that puppets be hung from the ceiling

Lumbar Punctures and Bone Marrow Aspirations

- The lumbar punctures and bone marrow aspirations were performed in the examination rooms. The procedures have been described in the literature as the most invasive and

feared procedures that pediatric oncology patients have to face and not surprisingly the patients in this research did not discuss their experiences with these procedures except to comment on the hardness of the examination table, the need for the room to be warm, and to express the opinion that nothing about or in the room, including attractive wall colors, televisions or videos could help patients cope with the procedures.

Chemotherapy

- The oncology patients who received chemotherapy in the Clinic had the drugs administered either via drip infusions, which could take several hours, or by a "push," which took less than five minutes. In the Clinic most of the chemotherapy was given via a "push," and this did not seem to trouble them a great deal.
- Only two patients interviewed were given chemotherapy via a drip infusion in the Clinic. One of the patients, a teenage girl, said that she became sick during the infusion and found the crowding in the Playroom stressful. She was also disturbed by the lack of a clock, which made it impossible for her to know how much longer the infusions would last. The other patient said he would have liked to have something to do during the infusions such as reading, coloring or writing.

9. COMMUNICATING IMPORTANT INFORMATION to the PATIENTS AND THEIR FAMILIES

Every time patients and their families visited the Clinic, information concerning their health and well-being was discussed with the medical staff. Most of these transactions were, within the context of the medical setting, fairly routine; some were not. Those non-routine transactions are the subject of this chapter. Most of what I will report will be the transactions accompanying what Buckman (1992) called "bad news": the initial diagnosis of an oncological or hematological disease, difficult treatment related issues, the discovery of a relapse, and being told nothing more can be done. Additionally, in one section, I will discuss the off-treatment talk and the anxiety associated with this good news. The majority of this chapter focuses on transactions between the medical staff and the patients and their families; one section is concerned with the type of transactions that occur when one patient, a "veteran" shares his or her knowledge about the treatment process with a new patient.

The discussion should be considered very preliminary for many are based on my observations of a single incident, and I was only able to talk to one patient and one physician. The patient, a "hospital veteran," discussed what it was like to counsel another patient in one of the examination rooms, and the physician discussed how an examination room functioned during a talk with a patient and her family about a very critical treatment issue. I have included this chapter in the dissertation, because, while the findings in this chapter are very preliminary, I believe that the environment can have a major impact on the actors involved during the communication of important information in a medical setting.

9.1. Being Told You or Your Child Has Cancer or Sickle Cell Disease

Patients and their families were normally told the news about a cancer or sickle cell anemia diagnosis in a conference room in the Pediatric Hematology/Oncology office suite rather than in the Clinic. Rarely were the patients and their families told about a cancer or

sickle cell diagnosis in the Clinic, but that did happen on one occasion while I was doing my research. I observed the father of the patient sitting in an examination room afterwards and thought how inappropriate that setting was for someone who had to cope with such devastating news. This was simply an observation however because I did not talk to this parent or any other about this issue. Below are my observations from that morning.

As I was leaving I heard the father of a boy who was, I think, just being admitted, say something to the effect that he had some decisions to make. He was sitting in a chair in the middle of room 4-66 or 4-68 facing toward the door. His son was in a wheelchair halfway or more through the door. He was saying this to his son. Earlier he or they had a conference with one of the doctors. He was bent over at the waist with his forearms resting on his thighs and his hands were clasped. He did not look pathetic or particularly sorrowful. He just looked like he had an enormous psychic weight pressing down on him. It seemed like he was trying to keep a strong front for his son.

At some point they started playing chess on a portable board. When I walked by the room for the last time there was nobody in it, the chess board was set up, and it looked like they had stopped in mid game. There was a ball of tinfoil on the desk. It all looked so desolate and pathetic while at the same time bathetic; the sterile windowless exam room with the dark blue wall, and the fluorescent lights. When they were in there, the door was open most of the time. I don't remember it being closed. It felt like they were on display or at least they had to look up every time someone passed, and that happened very frequently. I had to restrain myself from looking in the room after I had passed it for the 3rd or 4th time. At the end of Clinic one of the nurses was talking with the boy's mom. Another nurse joined the conversation for a brief time. They seemed to be trying to reassure her about something.

Although, this observation was uninformed by any interaction with the family, the examination room seemed inappropriate and unsupportive for the father who had to come to terms with the fact that his son had cancer.

9.2. Talking to the Patients and/or Their Parents About Treatment Related Issues

Most of the meetings the physicians had with the patients and their families were relatively routine, and according to one physician the examination rooms worked fine as consultation rooms for those discussions. But, occasionally more serious treatment related

issues had to be discussed and the examination rooms became crowded when extra chairs that had to be brought in for the family and medical staff.

Long consultations can result when decisions have to be made concerning the course of treatment that are out of the ordinary. For instance, many of the hematology patients had to have operations to remove their spleens which were damaged by their illness. A major decision that some oncology patients and their families had to face was whether or not to have a bone marrow transplant. This is a difficult decision to make because of the hazards associated with the bone marrow transplant that have to be carefully weighed against the benefits.

On one occasion, this decision was especially problematic because the family was from a culture which valued males more than it did females. The patient was a young woman who needed a bone marrow transplant. One of the potential donors was her brother. In clinic conference the staff discussed how the family, the father in particular, was very resistant to idea of having the boys bone marrow harvested if he was a match. Their resistance was such that they did not even want to have the boy's blood drawn to determine whether or not he was a match. The entire family, minus the brother, came in one day to discuss this with one of the physicians in one of the examination rooms. The subject matter that they were talking about was quite disturbing and controversial, and they had to do it in a physical setting that seemed woefully inappropriate (see Figure 24). Extra chairs had to be brought in, and this made the examination room seem very crowded, and the physician still had to perch on the desk. I spoke to this physician about how the room functioned. He first described how crowded the room was noting that "I was sitting on the desk and everyone else was sitting on chairs around, and the chairs were very much cluttered underneath the wall cabinet. It wasn't ideal, that's for sure." Not only was the room crowded but over time "You get distracted by the chair sticking you in the back." He

Figure 24. Photograph of an examination room with extra chairs brought in for a consultation with a family.



thought a comfortable setting similar to a private doctor's office would be preferable "where you could bring a family that is much softer, with comfortable chairs... where your are comfortable, where you can listen." Comfort was an important issue to him because "There are no distractions... I would rather be in a more comfortable chair, be able to look directly at everybody instead of having to look, twist this way, twist that way." He thought it was important for the families to be comfortable, stating that "It is unfair for them to have hear this kind of important information that has tremendous implications, and to hear it under anything but optimal conditions is unfair."

This physician seemed to be able to cope with an imperfect setting, but as he said "it's just nicer to be able to sit like a human being and just be able to concentrate on what someone is saying instead of rather than get distracted by other things."

9.3. Being Told You or Your Child Has Relapsed

While it is very rare that patients and their families were told about the initial cancer diagnosis in the Clinic, this is not the case when they were told about a relapse. Typically the staff has time to prepare for what was called a First Day Talk with the family at the time of the diagnosis, and as noted above, this Talk was given in the Conference Room.¹ The situation was much different when patients were told they have relapsed, because the physicians discovered that a patient has relapsed while the patient was in the Clinic.² I was in the Clinic one day when one of the patients was told he relapsed. Both he and his mother were very upset by this. He stayed in an examination room while his mother had to go to the Admitting section. The examination room seemed to me to be less than an ideal

¹The Conference Room was in the same area as the Pediatric Hematology/Oncology Division's offices, which were in another building.

² When patients who need blood work come in, their blood is drawn and it is sent to a lab. When the results come back to the Clinic, the physicians are able to determine the patient's status, such as whether or not they may receive chemotherapy that day. The results will also tell the physicians whether or not a patient has relapsed.

place for a patient to have to cope with the news of a relapse, but again, I did not talk to the patient about how he felt about the room. The passage below, which is from my notes, serves to describe in an abbreviated fashion how a typical day in the Clinic for a patient could in an instant be shattered.

Oscar came in late. He looked happy, energetic, not tired, up. He and one of the volunteers played Spit and maybe another card game. He also drew pictures, copying them from comic books. He told me that he collected comic books at one time, that the one where Superman died when new was \$5 and is now worth \$70, the same for the one when he came back to life.

While waiting for his results, he got up from the table and stood near the door to the Child Life Specialist's room. I asked him if he wanted to use the computer, he said that he would be leaving soon. He waited a little bit longer. He was standing on the hall side of the low wall. I think that I was cleaning the top of the food area. He told me that he was going to be 14 next week and that his father was taking him out. I asked him where, and he said for lobster and clams. I was about to tell him that was my birthday dinner when I was his age, when the doctor came and told him they would see him. A little while later his mother came into the Playroom and she was crying. She told me that Oscar had relapsed. She had to go to the Admitting section. Meanwhile, Oscar had to wait in the exam room by himself. After a while I asked one of the nurses if he needed any paper or comic books, and she said he was sort of hysterical, and they wouldn't help. Later she came into the Playroom and told me that it would be a good idea. Later he came out of the room and talked to the clinic coordinator and the nurse in the clinic coordinator's office. He seemed back to normal. He didn't have the energy that he had when he came in, but he was smiling his shy beautiful smile. When his mother came back she was also under control.

Oscar was "hysterical." It would be strange if he wasn't. For one thing, he would have to go through another round of intensive chemotherapy and his skin had "peeled" off the last time. After the shock of the bad news wore off Oscar's mother had to proceed in a rational manner and begin the process of having Oscar admitted to the Hospital.

Again, there are issues regarding the designed environment as a setting which affords opportunities for providing an appropriate social setting, a comfortable space for the desired level of privacy and reflection and, finally, for some spiritual sanctuary.

9.4. Being Told There Is Nothing More that Can Be Done

A relapse does not necessarily mean that the patient is going to die, but approximately thirty percent of the patients with cancer who are treated at the Clinic will die from the disease. At some point the physicians have to tell some of the patients and their families that nothing more can be done for them. I observed one nineteen year old woman who sat next to the door to the Child Life Specialist's Office after she was told there was nothing more that could be done for her in terms of curing her illness. I do not know if she left the examination room when she wanted to, or if the room was needed so that the physicians could see other patients, but when she came out of the examination room she sat in the chair next to the Child Life Specialist's room and glared at people as they walked by. It was obvious that she was very upset and very angry. I don't know why she chose to sit where she did, but her options seemed limited: either stay in the examination room (if it was not needed), or come back to the Playroom area. Neither seemed like ideal choices.

In a second case, I was present at a Clinic conference when the parents of a patient were told that there was no cure for his illness. The patient, a preschool boy, had a jaw mass that had not responded well to treatment except radiation therapy. There was also a paraspinal mass that needed radiation therapy. He was very weak and was brought into the Clinic in a stroller. At a meeting with the physicians, the mother cried and wanted to know about a bone marrow transplant and the father wanted to know about options. The physicians had to tell them that there was no cure, although there were some investigational drugs. The physicians thought the only option was to wait and do the best that they could. It was obvious during the Clinic conference that the physicians were very upset because there was nothing that could be done for this patient. In a situation where a patient or the parents of a patient are told that nothing more can be done, it may be that the physical environment would not make any difference, but for the period immediately afterward there

surely should be some options close by for the child and family to be alone in a comfortable environment. Unfortunately this is an issue that apparently has not been investigated.

9.6. Patient to Patient Counseling

Although a self-help group for patients had not been formalized when I was doing my research,³ the staff occasionally had more experienced patients talk to the newer patients. I saw this happen in the Playroom several times. The discussions were fairly short, and they usually dealt with medical issues. This was not the only kind of patient-to-patient talks that were initiated by the staff. One of the patients that I interviewed, Susan, was asked to talk to other patients several times about psycho/social issues, because the staff knew that she was interested in helping the other patients. These talks required more privacy and time and took place in examination room #4-71. She said that room was a very inappropriate setting for those kinds of talks because it was too small and depressing and the chairs were not comfortable. She thought more comfortable chairs (especially bag chairs) were important because they would allow the patients to be physically comfortable, which would make it more likely that they would be more comfortable psychologically.

When the staff asked Susan to talk to the patients, sometimes they would ask her questions, but at other times she would have to initiate the conversation because the patients were "scared" and didn't know what to say. She thought that, ideally, the room would have been bigger because it was "Kind of close. It's a small room." She said she liked to talk with her arms, and that when she did that "you're up against the walls." In addition she felt a small room actually had an influence on the tone of voices they used, stating that "when you are in close quarters you tend to talk quieter. You get low and everything."

³Since then I have seen fliers for a patient self-help group posted on the walls of the clinic.

She felt that usually when she was talking about illness and treatment related issues to the newer patients, she didn't want that to happen because:

You don't want to get depressing. You don't want to tell them "Oh it's going to be so hard. You are going to go such a terror." [said in a syrupy sweet voice] They don't want to know that. They already know that. They want to know how I got through it. They want to know what to expect and how to get through it. That's what I am asked most of the time. "How did you get through it? What do I do? What's going to happen?"

When she was talking to the new patients about cancer and how she was able to "get through it" she thought it was very important that environment should not have a negative effect on their emotions, in fact, it should evoke a more positive attitude:

You got to get these kids' spirits up. They are so down from everything that is going on. Anything else, anything more depressing I don't even want to think about what it could do to them. You know what I mean. Everything else that they are going through is so upsetting and so depressing and so scary as it is. Why would you want to put them in a room or an environment, like you want to call it, that's detrimental. It doesn't make sense. You look at them and you go, "Why would you want to do something like that? Why would you want to do that?"

Since the space where she had talked to the other patients was not an appropriate setting for that kind of communication, I asked her what she would do, if she were to take a room the size of the room we were in and turn it into a room that would be a better environment in which talk to patients. Her advice was to make the room more comfortable, especially by providing more comfortable chairs. She asserted this was important because without physical comfort, it was difficult to achieve psychological comfort.

A more comfortable chair than this. [Referring to the fiberglass chair]... there are a lot of hard surfaces in here. You know. Ideally. Ideally. You really want to hear ideally. I would throw some bean bag chairs in here. Without going, in my head, ideal. You plop down and relax and really get into a good talk. You can't do that when you are sitting in a hard chair, straight back. How comfortable are you? Physically, how are you going to get comfortable mentally? To be mentally comfortable you have to be physically comfortable.

No doubt Susan's personality and enthusiasm would be able to help patients in any setting but she was clearly articulating that someone in her position should not have to

work so hard to make a patient feel comfortable. An appropriately designed room can help create the atmosphere for a relaxed but informative discussion where issues of utmost importance are discussed.

9.7. Summary of Findings

- There are certain times in a person's tenure as a patient (or a family member of that patient) when the hospital staff's skills as communicators are tested to the utmost. When patients or the patient's family members are told that they have cancer or sickle cell disease, or that they have relapsed, or that they are going to die, that is "bad news," not simply an exchange of information. Even "off treatment" talks can be anxiety provoking. And, occasionally, more experienced patients are asked to talk to the newer patients. Therapeutic communication is necessary within a supportive physical environment, a supportive environment that the Clinic did not provide.
- Rarely were the patients and their families told about a cancer or sickle cell diagnosis in the Clinic, but that did happen on one occasion while I was doing my research, and the examination rooms appeared to be an inappropriate setting was for someone who had to cope with such devastating news.
- Most of the meetings the physicians had with the patients and their families were relatively routine, and according to one physician, the examination rooms worked fine as consultation rooms. Occasionally more serious matters had to be discussed, such as whether or not a family member could provide bone marrow for a bone marrow transplantation. At those times, extra chairs, that were not comfortable for long periods of time, had to be brought in, and the examination room could become quite crowded.
- While it was unusual for patients and their families to be told about an initial cancer diagnosis in the Clinic, this was not the case when the patient relapsed. A relapse was an unexpected event, and the physicians found out that a patient relapsed when the test

results were returned to the Clinic. The examination rooms seemed to be less than an ideal place for patients and their families to have to cope with the news of a relapse.

- Approximately thirty percent of the patients with cancer who are treated at the Clinic will have to be told that there is nothing more that can be done for them. Some of them will be told that while they are at the Clinic and their options, in terms of a supportive environment, seemed very limited: they could either stay in the examination room (if it was not needed), or come back to the Playroom area. Neither seemed like ideal choices.
- Occasionally more experienced patients were asked to talk to the newer patients about psycho/social issues. The examination rooms were not supportive setting for those kinds of talks because they were too small and depressing and the chairs were not comfortable. One patient thought more comfortable chairs were important because they would allow the patients to be physically comfortable, which would make it more likely that they would be more comfortable psychologically.

10. DISCUSSION of FINDINGS

This discussion of findings is organized into five sections. The first section begins by examining the major role activities in the Playroom assumed in alleviating some of the stress of waiting for most of the patients. However, while the Playroom environment served the needs of most of the patients, teenagers have special needs, and the Playroom did not accommodate their needs as well as it did for the younger patients. This issue is discussed in the second part of the first section. The second section focuses on one of the major stresses patients had to cope with, anticipatory anxiety and how the environment did or could mitigate or exacerbate the stress patients experience. This is followed by a section that discusses issues that arose during the study about medical procedures that were performed in the Clinic. The impact the environment did or could have on helping the patients cope with those procedures is briefly mentioned in this section, with a fuller analysis completed in the fifth section. The fourth section deals with the need to create environments that support therapeutic communication. While the environment figures in the discussion throughout this chapter, the fifth and final section examines the role certain aspects of the physical environment: furniture, artwork, color, windows and the perceptual quality of the space can play in the creation of a therapeutic environment.

The implications for design that are suggested by the research have to be placed within what Clare Cooper Marcus (Chapin & Cooper-Marcus, 1993) called the "brew" (p. 115) which makes up the design process. The intent of this chapter is not to provide comprehensive design guidelines for the design of a pediatric hematology/oncology clinic. Nor is the intent to replace existing guidelines for children's healthcare facilities (Lindheim, Glaser & Coffin, 1972; Olds & Daniel, 1987). While it is hoped that some of the findings will be generalizable to other settings, the greater value of the study might be to alert design professionals to look for stresspoints during a participatory design process (Alexander,

1979; Architecture•Research•Construction, Inc., 1985; Carpman, 1990; and Hart, 1987), since the users have first-hand knowledge of the stressors they experience.

10.1. The Importance of a Play Space

Even though the Playroom could be stressful, it served an extraordinarily useful function in the Clinic; for many of the patients, for much of the time, it served to mitigate some of the stress of waiting. For most of the patients, especially the schoolage ones, the Playroom acted as a wonderfully rich and complex coping mechanism, with the activities keeping them occupied while they were waiting. Unlike Evan Handler who wrote, "If anything could compete with the horror of life on the floor at Sloan-Kettering, it was the outpatient Clinic," where the patients waited "in the giant waiting room while the PA system droned incessantly with mispronounced name after mispronounced name" (Handler, 1996, p. 97). In contrast, the patients at the Clinic could engage in a number of activities. On several occasions I observed children who did not want to leave the Playroom to go home because it was no longer a waiting experience for them, but a play experience.

The most powerful element in the existing Playroom environment's ability to act as an "upbeat" coping mechanism was play of one form or another. The importance of play in a medical setting has been well documented and discussed by Bolig (1990), Butler (1983), Committee on Hospital Care (1985), Delpo (1988), and Lemkau (1967). There is some disagreement, however, on how play is structured. Butler (1983) stressed the importance of play therapy with a therapist. Play therapy did occur in the Clinic, but it usually happened in the Child Life Specialist's Room, as a structured activity between the patient or patients and the Child Life Specialist or intern. Bolig (1990) thought that play does not have to be structured to have a therapeutic benefit. And, apparently this was the case in the Playroom. The play that I observed and the play that the patients talked about was not

therapeutic play in the traditional sense, although it apparently had therapeutic effects, keeping anticipatory anxiety at bay.

The Playroom provided activities for patients of all ages, but whether intentionally or unintentionally, it met the needs of the schoolage population, in general, most successfully. This is an age at which children are rapidly developing their skills, and they could use most of the materials, games and supplies that were in the Playroom in pursuit of those skills. The activities that seemed to provide the patients with the strongest coping mechanisms were those that were most absorbing for a particular person or group of people at a particular time, whether it was doing an art project, playing card or board games, or reading. They were activities that engaged the patients and helped make the wait for some enjoyable, for many, more bearable. They were what Csikszentmihalyi (1991)¹ called "flow experiences." Flow activities are enjoyable, and they merge action and awareness so that the person's attention is absorbed completely by the activity at hand. Time can pass quickly and "while it lasts, one is able to forget all the unpleasant aspects of life" (Csikszentmihalyi (1991, p. 58), such as invasive procedures, chemotherapy, etc.² It was not possible for me to formally study the relationship between a patient's level of activity and his or her psychological state, but based on my informal observations, the anger, frustration, and anxiety that the patients felt seemed to decrease in proportion to the extent that they became involved in the activities in the Playroom. This point can not be stressed

¹ It is interesting to note that as part of an obsessive-compulsive disorder therapy study conducted at the Neuropsychiatric Institute of the University of California at Los Angeles the patients were instructed to engage in "15 minutes of an activity they could be absorbed in and found enjoyable or productive," which, according to a Dr. Schwartz who led the study, "shifts their attention away from the compulsion." (Reported in the February 15, 1996 New York Times by Stephen Labaton.) I do not know if anticipatory anxiety and obsessive-compulsive are in anyway related, but the importance of absorbing or "flow" activities to mitigate the effects of each is intriguing.

² An extraordinary example of this can be found in the dance world where "They call it *killing* the choreography. Dance until you achieve transcendence... Dance until you reach an endorphin high, where there is no pain anymore from inflamed iliopsoases (hip muscles) or patella tendons (knees), or hairline fractures of the calcaneus (heelbone). (Smith, 1996. p.C11)

enough: patients need activities that demand all of their attention so that they can "for a moment in time" enter a different world and forget where they are and what is going to happen to them.

One of the activities that Csikszentmihalyi (1990) discussed were competitive physical activities that engage a person's mind and body. Activities that require some physical activity can be very absorbing for relatively long periods of time. These types of activities were, except for the card games Spit and War (See Chapter 5, Section 5.2.2.2.), not the type of activities that usually occurred in the Clinic. Occasionally the younger children would run in the Hall or in the Playroom, but we would have to stop them for safety reasons. Perhaps an ideal clinic would include a small arcade/recreation room with video games, ping pong, air hockey, and other such games for those patients who require physical activity to enter a "flow state," where for a moment in time they can forget both where they are and their anxieties.

Preschool age children could also benefit from a space that acknowledged their need for physical activity, which would not be satisfied with a small arcade/recreation room. This may not be easy to achieve. The recently built Hasbro Children's Hospital in Providence, Rhode Island had a playhouse in the center of the Outpatient Waiting Area that had two levels. The two levels generated a lot of activity and noise and finally injuries, so the second level was taken out, and the playhouse is now used for quiet activities such as reading (Yeaple, Iltus, De Vos, & Sabo, 1994). It may not be possible to accommodate the younger children's need for gross motor activity in other than a fully equipped play area that is separate from the other waiting and play spaces. In an ideal clinic, the preschool children would have one room of their own that would be outfitted with indoor play equipment, where they could be physically active.

The activities in the Playroom not only helped to mitigate the patients' anticipatory anxiety and boredom, they also apparently helped those patients who participated adjust to the Clinic experience. There was a major feeling of accomplishment among the staff when we saw patients who had formerly been withdrawn engage in activities, especially when those activities involved other people.

10.1.1. Special Needs of Teenagers

The Playroom was less successful for the teenagers than it was for the schoolage patients. Given the limited amount of space available, and the relatively small number of teenagers who came to the Clinic, it would have been inappropriate not to have the Playroom set up to fulfill the younger patient's needs. But a major problem with the relatively small size of the Playroom was that the teenagers did not have a space of their own. Because formal observations were not done in the Playroom it is difficult, if not impossible, for me to say for certain what percentage of time the teenagers were not involved in absorbing activities compared to the younger children. But, based on my unstructured observations, and on what the teenagers themselves told me, there were fewer activities for them when compared to what was available to the younger children.

The lack of clear activity space for the teenagers had two major ramifications. One: many of the teenagers did not do much when they were in Clinic except as one of the patients said "think a lot." He thought about chemotherapy; others probably also thought about equally disturbing subjects. Activities would have given them a respite from those thoughts. Two: it was not easy for the teenagers to get to know one another because they did not have activities to "break the ice." The teenage years are a time when social interaction with one's peers is a primary concern and activity. The Playroom did not accommodate this need very well because the teenagers did not have a place that was theirs within it, a place where social relationships could be developed, either just through

conversation, or through conversation mediated and abetted by mutually engaging activities. Some friendships did develop over time, but in general, I was struck by how little interaction there was between the teenagers. The Playroom did not provide the space for the teenagers to develop a support system, which is very unfortunate because to successfully cope with their illness they need the support of their peers.

Before starting the field research, I read They Never Want to Tell You: Children Talk About Cancer (Bearison, 1991). Several of the patients quoted in the book mentioned that they became friends with other patients while they were inpatient. I had expected that to happen in the Clinic also. And for the preschool age patients it did. Tammy's face would light up when she saw Kevin, and they would play together, as did Gary and Kevin. Some of the schoolage children also became very close. Danielle and Erin met while they were both inpatient. Danielle was the "veteran" and she took Erin under her wing. That relationship continued in the Playroom. Other preteen children got to know each other around the table, and they became quite friendly. For the most part this bonding did not happen with the teenagers. An exception was two teenage boys' friendship, which had developed over the years they had been coming to Clinic.

Having been convinced by Bearison's (1991) argument that "children need to be able to talk about their cancer experiences, as a way of helping them adjust to the continuing struggles and uncertainties of having cancer" (p. 171), I found the lack of friendship formation between the teenagers sad and disturbing. The need for friendship is equally as imperative for the patients who have Sickle Cell disease because for many of them the debilitating effects of the disease increase as they grow older.

It is unfortunate that the teenagers, who as a group, have more trouble adjusting to the psycho/social issues associated with their illness (Whaley & Wong, 1985) did not have a space where they could meet each other around mutually enjoyable activities or interests,

become friends, and provide support for one another. Perhaps if they had an area or bookcase, where there were magazines for them, the wait in the Playroom would have been slightly less tedious, and the teenage patients would have been able to get to know one another more easily.

10.2. Anticipatory Anxiety

The anticipatory anxiety that pediatric hematology/oncology patient experience is not only psychologically stressful, it can cause nausea and vomiting, and increase the level of perceived pain during invasive procedures such as venipunctures, bone marrow aspirations and lumbar punctures (Jay et al., 1986; Kolko & Rickard-Figueroa, 1985). Children and teenagers with cancer are particularly vulnerable to what McGrath (1990) called an anxiety-pain-anxiety, or a pain-emotional distress-pain cycle that can increase in amplitude because during the course of their treatment, they will be subject to many and repeated invasive procedures. In other words, the more fear and anxiety a patient feels about a procedure, the more pain and distress they will feel during the procedure. This more intense pain perception will then create more anxiety about the next procedure, which leads to a higher level of pain, and so on.

But, anticipatory anxiety is not a well-defined phenomena. For instance, while pain has been dimensionalized, anticipatory anxiety has not, as far as I know. The field of research surrounding pain is enormous; there are pain institutes, a textbook has been written about pain (Wall & Melzack, 1994), and according to McGrath (1994):

During the past decade, unprecedented scientific and Clinical attention has focused on the special pain problems of infants, children, and adolescents, so that there have been enormous advances in our understanding of children's pain perception and in our ability to alleviate their pain. (p. 1403)

Unlike the control of pain associated with painful procedures, however, the anticipatory anxiety that can precede those painful procedures while the patients are waiting has not been addressed by many researchers. In the literature, anticipatory anxiety is very

closely linked in time to the coping procedures and strategies immediately prior to the medical event. Some researchers in the field of pediatric hematology/oncology researchers have worked to alleviate the anticipatory anxiety associated with chemotherapy, (Kolko & Rickard-Figueroa, 1985) and bone marrow aspirations and lumbar punctures (Blount, et al., 1994; Jay, et al., 1985; Jay, et al., 1986; Jay, et al., 1987; Jay & Elliot, 1990; Kellerman, et al., 1983; Kuttner, et al., 1988), but only one of these studies specifically addressed the anticipatory anxiety that patients experienced while they were waiting in the procedure room (Blount, et al., 1994). Some of the techniques that have been developed to alleviate pain, such as relaxation and hypnosis, would also alleviate some of the children's anticipatory anxiety. But, not all patients are taught these techniques, and the nature of a wait in a screening or examination room, the length of which can not be anticipated, works against time dependent techniques.

Unfortunately, the powerful effect the sociophysical environment of the clinic, a playroom in particular, could have on reducing the amount of anticipatory anxiety patients experience before invasive procedures has not been addressed in a thoughtful and comprehensive manner. Apparently this is because, while anticipatory anxiety has been acknowledged as a factor that can increase patients' perception of pain, it has not been examined as a phenomenon in and of itself. This seems like a critical oversight because anticipatory anxiety is not contingent upon an imminent medical event, it can be felt hours if not weeks in advance. Rather than conceptualizing anticipatory anxiety as being contingent upon, and closely associated with an unpleasant medical procedure, if the phenomenon was studied longitudinally, over time and space, the psychological upset caused by the anticipatory anxiety and hence the physical pain or discomfort associated with the procedure might be decreased. It is beyond the scope of this discussion to make recommendations about how to decrease the patients' anticipatory anxiety when they are

outside the clinic setting, but based on my observations and information gathered during the interviews with the patients, I can discuss the powerful effect, both negative and positive, the social and physical environment can have on the level of anticipatory anxiety patients experience.

The powerful effect that the Playroom could have on reducing the amount of anticipatory anxiety patients experience was discussed by several patients, and I was able to observe the power the Playroom setting had on reducing the effects of anticipatory anxiety on several occasions, when I saw an immediate change in the patients attitude when they were called to see the doctor or nurse. Immediately before they were called, they were deeply involved in an activity, and apparently not thinking about what was going to happen to them. On several occasions I saw young children who were happily playing either start crying or vigorously resist leaving the Playroom when they were called. The older children's' resistance and dismay was more subtle, but their change in attitude and emotional state could also be observed. One moment they were concentrating on what the activity they were engaged in, and the next they were dreading what was going to happen to them.

For many of the patients, the Playroom was the antidote to anticipatory anxiety. They were safe from the reality of the medical world. That safety was immediately threatened when they were called to see a nurse or doctor.³ Some of the younger children resisted leaving the Playroom quite violently, while the resistance of the teenagers was more subtle. The journey down "death row" to the "doom rooms" was described as being like "Chinese water torture." Of course, these characterizations are extreme, but they serve

³ For sake of argument, I am painting a pretty picture of the playroom and a grim picture of what being called by a nurse or doctor meant to the patients. For some of the patients, primarily some of the teenagers who were there for just a checkup, the opposite was true. Being called to see a doctor or nurse meant they were soon to leave the Clinic where they had been waiting in boredom and frustration. Nevertheless, I am using the former scenario because I feel it represents a consequential portion of the patients' experience that has to be given primacy in playroom/waiting area designs.

the purpose of pointing out how traumatic the hospital experience can be for children and teenagers, as well as adults. "Death row" and "Chinese water torture" are therefore less descriptions of the physical properties of the Hall than they are metaphors for what patients may have felt as they walked down the hall to the screening and examination rooms. Russell and Snodgrass (1987) have suggested that "the best prediction of a person's mood in a particular place may be prior mood" (p. 258). Accordingly, the patients carried the emotional response they felt when they were called from the Playroom, as they walked down the Hall. If they were feeling anxious, the Hall did little to relieve that anxiety because the physical environment of the Hall, with the exception of the artwork, none of which was at the eye level of a young child, was not designed to alleviate the patients' fears and anxiety.

As it was, the Hall was not an environment that helped the patients cope with any anticipatory anxiety they may have been feeling as they traveled through it on their way to see a doctor or nurse. It simply provided a circulation path between two points. This need not have been the extent of its function, as I will illustrate below; it could be a place that makes the transition between the safe environment of the playroom and the potentially painful environment of the screening and examination rooms much easier for the patients.

It is quite possible that nothing that could be reasonably done to the hall or corridor between a playroom or waiting area and screening and examination rooms would make a difference on those occasions when the patients' fears were at their highest, such as when they were about to have a bone marrow aspiration or spinal tap. At other times, however, the suggestions the patients made could make a difference.

Without going to an extreme, the environment could be made more "child friendly" and welcoming. Among other things, more colorful posters with cartoon characters that would appeal to all ages could be added to the walls; the walls could be painted a less

institutional color; colorful floor tiles that suggested a leitmotiv could replace some of the existing beige tiles; a different type of lighting fixture could be installed. These changes would be especially effective if they incorporated elements that would engage the patients, especially the younger ones, as they traveled down the hall, because they could retain some control of the situation.

This means that the medical staff has to realize that the time it takes a young child to proceed from the playroom to an examination room may be considerably longer than for the older patients because they might use behavioral delaying tactics. This is because they may have trouble coping with an abrupt transition between a place where they feel safe, i.e., the playroom, and a place that they dread, i.e., an examination room or screening room.

Perhaps if a hall was not thought of simply as a link between two spaces, but rather as a setting where children could assert their independence by delaying the unavoidable the hall would not seem like "death row." One can imagine parents turning the walk to an examination or screening room into a game, asking their children if they could walk on the yellow, red, green, or blue tiles, etc., without stepping off them. Or asking them to see if they could step from a yellow tile to a red blue, or green tile, and back again. The trip would take longer but perhaps the children's minds would be on the journey and not the destination.

The journey to a screening or examination room is only a prelude to entering them, which can heighten some of patients' anxiety if those rooms are institutional and "scary." The moment when patients enter a screening or examination room is a critical one because that is when their worst fears can be confirmed or exacerbated; they can receive as one patient called it a "cold smack in the face, or their fears can be, if not alleviated, somewhat mitigated. When the patients first entered either a screening room or examination room in the Clinic, they moved from one environment, the Hall, which, as noted above, one of the

patients characterized as "Death Row," into what another called "Doom Rooms." A less severe characterization would be to say that they left an institutional environment with some medical elements and entered an uncompromisingly medical environment. The "cold smack in the face" was the result of the physical environment's ability to affect our emotions. We may or may not be aware of what in the environment is influencing us (Russell & Snodgrass, 1987), but we can make a judgment about that environment. Words such as "scary," "cold," and "sterile" were "affective appraisals" (Russell & Snodgrass, 1987) of the screening and examination rooms, probably made after the fact that represented immediate and unconscious impressions.

While the Playroom helped to reduce the amount of anticipatory anxiety the patients experienced while they were waiting, the screening and examination rooms did not have that effect. Waiting in a screening or examination room is not an emotionally neutral experience. The procedures that patients worried about when they were waiting in a playroom or waiting area are now imminent. One of the patients likened the wait in an examination or screening room to a "moment of doom." Patients in the Blount, et al. study (1994) waited between ten minutes and an hour and a half. As far as I know, none of the patients at the Clinic had to wait in a screening or examination room this long. Most patients probably waited less than five minutes, but a five minute wait in a screening or examination room can seem like a very long time, especially if those rooms are not designed with the patients physical and psychological comfort in mind, and the screening and examination rooms in the Clinic were not; the chairs were not very comfortable, children's screams from other rooms could be heard, and there was little in the rooms to distract patients while they were waiting. In two of the rooms some attempt was made to make them less institutional by putting up pictures, but the results did little to allay the institutional quality of the rooms, or provide a significant source of distraction for the

patients while they were waiting. (See section 10.5.3.2 for thoughts about how artwork could help reduce the amount of anticipatory anxiety patients feel while waiting in a screening or examination room.) The other rooms were almost barren of anything except the medical furnishings and materials which the doctors and nurses needed. The barrenness of the rooms did not help the patients cope with the psychological stresses they were feeling. In addition, needles and other medical supplies were out in the open, and some of those items, especially the needles, served to create a great deal of anxiety in some patients.

There is no question that the medical mission is paramount, and a screening or examination room has to serve that need first and foremost. But there is much that can be done to make them if not less frightening, at least more attractive to patients. Patients can enter and wait in a screening or examination room that is cold, and institutional, immediately letting them know that their worst fears will be realized; or they could be welcomed by a cardboard cartoon character into a room with attractive, warm colors and motivational artwork on the walls, a place where they immediately know that people care about them and their needs. The anxiety reducing effect images such as these have for children was apparent in a scene reported by Anderson (1985). She described how one young girl hurried to have her blood drawn, apparently without fear or anxiety, to an examining room which was her favorite "because it had pictures of Little Bo-Peep, and Humpty Dumpty and Jack Be Nimble and Mary Had a Little Lamb" (p. 406).

The positive picture of the ideal screening or examination room I just painted may be too positive, and the negative picture I painted of the existing screening and examination rooms may be too negative. Perhaps there are more people than I imagined who prefer, as did one of the older patients, the familiarity of a "typical" doctor's office. But I doubt it. And perhaps the institutional quality of the rooms over time loses its negative affect and

simply is not noticed, which I suspect is the case. And perhaps the positive affect generated by an ideal screening or examination room would wear away over time. Why, then, should any changes be made? The answer is twofold. The first lies in the area of the unconscious affective quality of the environment. If one agrees that the negative affect of a screening or examination room is minimized over time, and the positive affect of the ideal room would also be minimized over time, then it would appear that there would be no advantage to making the rooms more inviting. That would be the case if the affective effect of the environment in both cases was neutral. This zero balance may be the case with the screening and examination rooms as they were. Over time the physical environment may have no more effect than the physical environment in any other setting that is used frequently. But I think, and I have no way to prove this, that the effect an ideal screening or examination room would have would never be completely neutral. There would always be a certain feeling of warmth, a certain lift when entering. (This, of course, would not be true when the patients were terrified.) It is also possible to build in changes, over time, to deal with the accommodation effects of any one design on long-term patients.

The second answer depends on the trite, but inescapable fact that screening and examination rooms are not simply entered: they are used. They are used while the patients are waiting to see a doctor or nurse, and they are used while they are being examined, or undergoing procedures. The elements that have been discussed that would presumably make entering into the rooms more inviting, would be the same elements that help the patients cope with the rest of the time they spent in them. If an argument needs to be made to make the rooms more "patient friendly," this is the more powerful one because it would be possible to show that the distractional properties of the physical environment help patients cope while they are in a screening or examination room. As it was, the power of the most effective coping mechanism most of the patients had, their parents, was

diminished because there was little in the screening and examination rooms, the patients and their parents could engage in together. The rooms were sterile, lacking artwork or other objects that the parents could have children focus on during venipunctures. And as Blount et al. (1994) have demonstrated, parents, with training, can help their children prepare for imminent/impending procedures

A question I have, and it is a question that is not addressed in the literature, is how exactly does anticipatory anxiety have an effect on patients' perception of pain? While McGrath (1990) suggested that an anxiety-pain-anxiety, or a pain-emotional distress-pain cycle can increase in amplitude, she does not discuss the precise mechanisms by which this happens. Does anticipatory anxiety have an excitatory influence on the pain gate? And if it does, does a greater degree or level of anticipatory anxiety open the gate wider, resulting in greater perception of pain? Above, I suggested that the social and physical environment of a playroom can reduce the amount of anticipatory anxiety that patients experience while they are waiting. Does this make any difference in terms of the amount of pain they experience during an invasive procedure?

Given the hypothetical scenario where two patients are waiting in a playroom for a bone marrow aspiration and a lumbar puncture how does anticipatory anxiety affect pain perception. Assuming that both patients at the start of the wait have exactly the same level of anticipatory anxiety and during previous BMA's and LP's experienced the same level of pain. One patient (patient A) becomes intensely engaged in activities during the waiting period and completely forgets about the impending procedures, while the other (patient B) sits and does nothing except worry about them. They are called from the playroom at the same time. At the moment before they are called, patient A is experiencing no anticipatory anxiety, while patient B is experiencing a tremendous amount. As they walk to the room where they are going to have the procedures, however, patient A begins to experience

anxiety. My question is: By the time the procedures are performed, given that every thing else is equal will there be any difference in the level or intensity or type of anticipatory anxiety the patients experience? When patient A was called, did the anxiety quickly return to its prior level and then increase. Did patient B's increase when he or she was called? Is there an upper limit to the intensity of anxiety a person can feel? And if there is a difference (assuming that patient A is experiencing less) will their perception of pain be any different? Does eliminating or reducing the anxiety patients feel during an anxiety-pain-anxiety cycle have any effect on the amplitude of pain they experience? Even if it does not, simply reducing the amount of anticipatory anxiety patients feel while waiting is surely an important enough goal to pursue.

10.3. Coping With Medical Procedures

Patients had to cope with several different types of medical procedures when they visited the Clinic: venipunctures, examinations, BMA's, LP's, and chemotherapy. Although the focus of the research was not on how patients coped with these procedures, some interesting findings did result, particularly with regard to environmental conditions, and these will be discussed below.

10.3.1. Venipuncture

An issue about venipunctures raised by this research has to do with coping strategies and their efficacy. One of the patients said "different people have different views." This response seems like a fairly straightforward and accurate assessment of people and their coping strategies, not only because patients' coping strategies differ, but also because the procedure is different for different people. There are individual differences in the ease of locating useable veins- a major factor in the level of pain patients experience during a venipuncture. Therefore, it is unfortunate, as noted in the literature review, that some researchers have not acknowledged that people are different, and they have different coping strategies, as evidenced by the very small sample of patients that I

interviewed. The patients had two primary options available to them to help them cope with the venipunctures. In general, they could either watch the procedure, or they could avoid looking at it by either looking away or closing their eyes. The fact that most of the patients used either one or the other of those tactics would seem to confirm what some researchers have postulated about coping strategies during a medical procedure: some people are information seekers and some are information avoiders (Peterson, 1989). Some people need to watch what is happening, and some have to look away or be distracted. However, the phenomenon is more complicated than the literature would suggest. Not only do different people have different coping strategies, individuals may have different coping strategies for each part of the procedure. One of the patients I interviewed, a "hospital veteran," sometimes watched the procedure, and looked away on other occasions, illustrating the distinction that Kuttner et al. (1988) made between what they called the "preparation phase" and the "medical phase."⁴ But even the stages proposed by Kuttner et al. may not be differentiated enough; another patient that I interviewed said that she did not watch when the needle was inserted, but did watch when the blood was drawn. And individual's coping strategies may change over time, either for developmental reasons, or in relation to situational variables such as the size of the needle, or because of the assessment of the nurse's skill. For example, one of the patients, a "veteran" knew who the more skillful blood drawers were, and she was vigilant when they were not the ones taking her blood.⁵

In terms of the design of a space where a venipuncture is going to be performed, a patient can either watch or avoid watching all or part of the procedure. A critical issue,

⁴ Even this differentiation may not be fine enough. One of the patients could not watch the needle inserted but had to watch her blood being drawn. (See 8.2.2.1.2)

⁵ Handler (1996, p.p. 93-95) makes a distinction between talented and untalented phlebotomists. He called phlebotomists who can slip a needle into a vein painlessly "magicians." His description of his experience with an untalented phlebotomist, whom he calls the "worst of all," is harrowing. With this distinction in mind, it is not surprising that the coping strategies used by the patient mentioned above varied depending upon the person who was taking her blood.

therefore, is what the patients, who need to look away, see when they look away. There should be things in the room, such as posters, three dimensional or two dimensional artwork, or even fish tanks that they can focus on during the procedure. Having things that can be studied, rather than merely looked at, is especially important in the rooms without windows. In addition, the room should be laid out so that they do not have to see the needles if they don't want to do so.

10.3.2. Examinations

While much has been written about the strategies and mechanisms patients use to cope with painful medical procedures (see Literature Review), I have not been able to find any studies that examined how patients coped with the stresses associated with an examination. Perhaps this is because an examination is a relatively benign procedure compared to a painful procedure such as blood drawing or bone marrow aspirations and lumbar punctures. This does not mean that an examination is without stress, either from the procedure or from environmental conditions.

Typically, an examination is not a painful procedure. However, this painlessness does not mean that it is without discomfort, either physical or psychological. One young woman mentioned that she felt "vulnerable" during the examination, and a school age girl said that when she was younger, she feared the stethoscope because she thought it would suck out her blood. I did not talk to the younger children about what they thought about their examinations, so I do not know whether this kind of "irrational" fear is widespread among young children. But it seems that this is an area that needs more study. Authors such as Bibace and Walsh (1980), and Mickalide (1986) have discussed children's understanding of illness, but I do not know of any studies that have tried to examine children's understanding of and reaction to the medical equipment they are confronted with during an examination.

An examination typically lasts longer than other procedures such as a blood drawing, shot, spinal tap or bone marrow aspiration. During the procedure the patients noted that they looked at the ceiling and connected or found patterns in the dots in the acoustical tiles. While this activity might help some patients, other patients might prefer to look at something on the ceiling that can be engaging for a relatively long period of time, such as a picture that is a puzzle rather than just a striking visual image. One of the patients suggested a three dimensional object on the ceiling that flew around, a mobile perhaps that the patients could move by blowing at it. Another thought every exam room should have a television. Perhaps in a ideal situation there would be a television or monitor mounted above the examination table with a constantly changing image, either natural or abstract.

10.3.3. Lumbar Punctures and Bone Marrow Aspirations

For many oncology patients, bone marrow aspirations and lumbar punctures (Also called spinal taps.) are the most disturbing procedures they receive during their treatment. (See literature review) Both procedures are multiphasic. The steps for a LP's and BMA's are as follows (Bearison & Pacifici, 1989):

Lumbar Puncture

- Patient waits in the room
- Patient undresses
- Patient is positioned
- Disinfect area
- Lydocain administered
- Needle⁶ inserted (may have to be repeated)
- Two tubes of spinal fluid collected
- Chemotherapy administered
- Withdraw needle
- Patient dresses
- Patient rests

Bone Marrow Aspiration

- Patient waits in the room
- Patient undresses
- Patient is positioned

⁶ The needle that is inserted is approximately the diameter of a pencil lead.

- Disinfect area
- Lydocain administered
- Bone marrow needle inserted
- Marrow withdrawn
- Needle withdrawn
- Patient dresses
- Patient rests

As can be imagined, these procedures can cause quite a bit of distress. Ideally, I would have collected as much data about what the patients thought and felt about the rooms as places to get LP's and BMA's as the other rooms in the Clinic. Unfortunately that was not the case. Unlike the Playroom, where I was able to gather an enormous amount of data while I was acting as a participant observer, I did not observe any LP's or BMA's. In addition, the strategy I followed during the interview to protect the patients from questions that might disturb them worked against my asking many of them what they thought about the rooms as places to get LP's or BMA's (See Chapter 11 for a further discussion of this issue.). Because of the lack of information from the patients, it would be unwise for me to make any generalizations based on the few people I talked to about their thoughts about the rooms where the LP's and BMA's were executed. I can, however, offer some thoughts based upon my readings, the interview data, and a fleeting observation of one of the patients while he was recovering from a BMA and LP. The first observation has to do with the multiphasic nature of the procedures and the relative effectiveness of the environment, or elements in the environment as coping mechanisms. Roughly, there is a waiting phase, preparation for the procedure phase, procedure phase, and recovery phase.

During the waiting phase, an environmental condition that seems paramount is acoustical isolation. This is critical because the patients are nervous; they are waiting for a very invasive procedure, and hearing other children scream or cry can only add to their nervousness. Some of the patients may also be using various cognitive and behavioral

methods to help them cope with the upcoming procedure; outside noises, particularly screams or cries, could disturb them and disrupt their coping activities.

Static visual distraction (pictures, posters, toys, sculptures) may help patients during the waiting phase, and perhaps the preparation phase, but visual distraction by itself is probably not an effective mechanism to help most patients cope during the invasive phase of the LP's and BMA's because of the invasiveness and duration of the procedures. I say "by itself" because perhaps images on the wall could help patients with their positive imagery.

The problem with visual images, is that they only engage one of the senses, vision, or with TV or video: vision and hearing. This is probably not enough to help most patients cope with LP's and BMA's. What is needed is an activity that can help them achieve the flow state (Csikszentmihalyi, 1990) discussed earlier. Kolko and Rickard-Figueroa (1985) found that video games were successful in distracting patients while they were receiving chemotherapy infusions. There are now virtual reality video games played with headsets on the market. Perhaps the focus and isolation provided by the virtual reality headsets, combined with the concentration needed to play the games may be enough to help the patients get through the LP's and BMA's with a minimum of stress.

Once the procedures are completed, some patients may need time to recover. I did not talk to any patients about this but I passed an examination room where a patient was on the examination table, on his side, facing the wall, after the procedures. This very brief observation made me think of some questions. Was he facing the wall because of the location of the IV or was it because he was withdrawing within himself? Would listening to soft music or watching a video have helped him recover? Assuming that his eyes were open, would something as simple as a picture that he could have stared at have helped him? I do not have the answers to these questions, not only because I was not able to talk to the

patient about these issues, but also because I have not been able to find any research in this area. This is unfortunate because the recovery period after an invasive procedure is a time when environmental stressors would be most oppressive because a person's physical and psychological competence are at their lowest.

When patients are recovering from a BMA and LP, a procedure room has to serve an entirely different function. The functional requirements have to change drastically. An environment has to be created which is soothing, comforting, perhaps womblike, an environment that accommodates the needs of a patient who is curled up in a fetal position, not for a LP, but to recover from that LP or BMA.

The existing examination rooms did not serve any of the phases well. They were not acoustically isolated, so patients waiting for their LP's or BMA's could hear other patients' cries. They were not procedure rooms, so they had to be set up each time a procedure was performed. And finally they were not recovery rooms, so they did not suit the patients' needs at that point.

10.3.4. Chemotherapy

Having read about the serious side effects associated with chemotherapy (Maul-Mellot, 1987; Granowetter, 1994; Noyes, 1986; Dahlquist, 1991), before doing the research at the Clinic, I was surprised at how apparently benign the "push" of chemotherapy was that most of the patients were administered in the Clinic. It was, apparently, a relatively short, pain and discomfort free procedure for most of the patients. The chemotherapy that the patients dreaded was administered when they were inpatients. In other hospitals, the patients, who are in remission, receive much of their infusion chemotherapy on an outpatient basis.

Maul-Mellot (1987) reported that some attempts had been made to control or manipulate the environment to control the patients nausea and vomiting. Some of these

attempts included insuring that there were no disagreeable sight or smells and providing age-appropriate distractions such as games which can be played alone or with other children. Some children enjoy watching TV or listening to portable stereos. For many children the sight of the chemotherapy infusion bag sometimes induces nausea and vomiting. A simple method to alleviate this problem is to put a cover over the bag. They also said that some studies (which they didn't cite) advocated multi-patient rooms which afforded patient interaction but other studies (which they also didn't cite) reported that some patients found multi-patient rooms too stressful. Other researchers, Kolko & Rickard-Figueroa (1985), found that playing video games during the chemotherapy infusion helped relieve the side effects of infusion chemotherapy.

The environmental conditions necessary to help patients cope with an infusion of chemotherapy, which may take several hours and induce uncomfortable side effects, are by necessity very different than the environmental conditions necessary to help patients cope with a "push" of chemotherapy, or for that matter, other procedures. I have little to add to literature because I spoke to only two patients who received infusions of chemotherapy.

One apparently did not suffer any side effects, while the other did. When that patient, a young woman, felt the side effects of the chemotherapy, she said that she just wanted to retreat home to the shelter of her bed. Perhaps this would have been the case even if the Clinic had been designed to accommodate the needs of patients who were receiving chemotherapy infusions, but it was not. One thing, in fact, that she noted bothered her about the Clinic was that the clock in the Hall did not work, which made it difficult to keep track of the time. A clock that does not work is such an obvious stress, once the need has been pointed out, I wonder what other "obvious" environmental stressors patients receiving a chemotherapy infusion experience.

Unfortunately I was not able to address this issue to a satisfactory degree with the patients I interviewed. I say unfortunately because chemotherapy can be a devastating experience for some patients, and it is incumbent upon researchers and others who are concerned with their well-being to do as much as possible to ensure that they are as comfortable as possible, in an environment that provides them with as many coping mechanisms as possible to help them deal with the side effects of their treatment.

10.4. Communication Between the Patients and/or Their Family Members and the Staff

There are certain times in a person's tenure as a patient (or a family member of that patient) when the clinic staff's skills as communicators are tested to the utmost. The "formal tasks required for the exchange of information between doctor and patient" (Cassell, 1985, p. 4) are not enough. Therapeutic communication is necessary (Davis, 1994). When patients are told that they have cancer or sickle cell disease, or that they have relapsed, or that they are going to die, that is "bad news," not simply an exchange of information. There are three separate but related issues that have to be considered: the opportunities for establishing different social interactions, the ambiance of setting, and privacy.

(i) Opportunities for Social Interaction

The most important issue that has to be considered is how well does the setting support social interaction and communication between the doctor and the patient and/or the family. Albert and Wittenberg (1986) stated that "One of the most important therapeutic or harmful elements existing in clinical medicine is the personal relationship between physician and patient" (p. 85). They went on to say that "kindness" was an important quality for a physician to have because "Kindness in such a setting (a medical setting where the patients might be fearful, anxious or weakened by their illness) establishes a strong positive physician-patient relationship, often referred to as the therapeutic partnership" (p.

87). What they do not do is discuss the mechanics of how to establish that therapeutic partnership. However, "kindness" may not be enough. According to Davis (1994), there are certain components that "characterize therapeutic or healing communication" (p. 87). The practitioner has to speak with self-awareness to translate ideas from an "inner conviction to an outer clarity"; has to be "fully present" - totally focused on the patient and his or her ideas; listen with the "whole self," with the "third ear"; and develop trust by resisting the urge to try to influence the patient (Davis, 1994, p. 87). These are admirable characteristics and even goals, but the author did not discuss how the setting could affect the therapeutic communication or relationship.

The importance of touch was emphasized by Buckman (1992) who wrote, "You should try to touch a patient at least once during an interview" (p. 47). But he went one step farther by describing how and where physicians should place themselves in relation to the patient. The most important "ground rule," according to Buckman, when breaking bad news was for physicians to sit down unless it was impossible not to because this let patients know that the physicians had time to spend with them. Another ground rule was to "get any physical objects out of your way" (p. 46), such as bedside tables, trays, etc. if the bad news was to be given in a hospital room. If the news was to be given in the office, the ground rule was that the physician should sit at a comfortable distance from the patient, which according to him varied from twenty to thirty-six inches in American cultures "for conversations about personal matters," with the physician's eyes at the same level as the patient's (p. 46). Buckman felt it was important to "get the setting right" (p. 68) because:

... it saves many minutes of dissatisfaction (on both sides) later... this is the point that starts the interview off on a stable course and sends an immediate signal to the patient that you are in the role of a supporter. Doing all this will also make you feel more relaxed, because you are following a pattern that is familiar to you and because you have control of the messages you are sending to the patient. (p. 48)

As an environmental psychologist, I was fascinated by Buckman's ground rules because he was the only author that I could find, who put the communication between patient-physician within a context. The other authors ignored the context within which the communication which they had so extensively analyzed was situated. Unfortunately Buckman's description of the physical environment was quite superficial. For instance, he did not specify the kind of furniture that was required to facilitate the kind of therapeutic communication that he felt was critical to the patient's as well as the physician's well-being. This is an important oversight because "The professional's level of comfort in doing her or his job is an essential part of the equipment and expertise required for the task" (Buckman, 1992, p. 8). Buckman was talking about psychological comfort, but it is more difficult to achieve that when the furniture is not physically comfortable.

While I think that Buckman's ground rules are very good, another ground rule has to be added. A critical consideration revolves around the issue of choice. When my mother was told that she had to have a lump in her breast biopsied, she was grateful that the doctor came from behind his desk and sat close to her because she felt he was more supportive that way. Another woman might have felt more comfortable if he had stayed behind his desk, maintaining a distance and the traditional doctor to patient relationship. The setting has to have an arrangement of furniture that allows the doctor and patient to choose the type of social interaction that they think is appropriate for their needs.

(ii) The perceptual quality of the setting

While Buckman's ground rules are very helpful, he did not indicate what the perceptual quality or ambiance of the office should be. The ambiance of the space may not be as critical as the type of furniture that is in the room, but the image or the ambiance of the room could affect how close (in the psychological sense) the physician could get to the patient, which is a very crucial element in supporting the patient. As Russell and

Snodgrass (1987) have posited, a key aspect of a person's relationship to the physical environment is emotional. To a certain degree communication between the patient and the physician begins when the patient enters the physician's office and is affected by the perceptual quality of the space. This can happen whether or not the person makes what Russell and Snodgrass (1987) call an "affective appraisal" of the physical environment. Color, materials, texture, patterns, and lighting all create an ambiance that immediately let the patients know whether they and their concerns and comfort are important. At this point, I do not know what the appropriate ambiance is of an environment where people are going to be told they have or their child has a life threatening illness. Is the correct choice a warm and comforting environment, or a high tech, ready to wage war against the "lethal, insidious enemy" (Sontag, 1990, p. 87), with all the means available to modern western science, environment? Is there "a" correct choice, or should decisions about the ambiance of a particular setting be left up to the staff members who are going to be using that setting, based upon the image they want to project?

(iii) Privacy of the Setting

Beyond the privacy needed for therapeutic conversations, patients and their families often need privacy in a pediatric hematology/oncology clinic for what Westin (1967) called "self-evaluation" because often there is "bad news." In other words, they may need time, to think about what they have been told. The news that you or a family member has cancer can be quite devastating. In Illness as a Metaphor, Sontag (1989) wrote:

... the healthiest way of being ill- is one most purified of, most resistant to, metaphoric thinking. Yet is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped. (p.p. 3-4)

Her intention when she published those words was to "liberate" people from the metaphors associated with illness in general, and cancer in particular. She chose cancer because she thought it had usurped TB's role as the "illness experienced as a ruthless,

secret invasion" (p. 5). She said cancer has been considered a "predator" (p. 7), "abominable, repugnant to the senses" (p. 9), a "scourge... the barbarian within" (p. 61). The most powerful and the most demoralizing metaphor she mentioned, however, was that "cancer equals death" (Sontag, 1989, p. 7). Cancer no longer equals death; approximately seventy percent of the pediatric patients who are diagnosed with the most common type of childhood cancer, acute lymphoblastic leukemia (ALL) will be cured, and overall, 60% of the children who developed cancer in 1990 can expect to survive (Fernbach & Vietti, 1991). But we have not been liberated from the metaphors associated with cancer, which is why "most people with cancer will indeed be demoralized by learning what disease they have" (Sontag, 1989, p. 7).

Sickle cell disease and other hematological diseases do not carry the metaphoric weight that cancer does, but it is entirely possible that those being told that they or their child has sickle cell also might have had a family member who had died because of the disease, which is genetic.

It goes without saying that people are given the news that they have or their child has a life threatening illness in a particular environment. And that is the problem: little if anything has been written about those environments. As far as I know, they have not been studied by environmental psychologists. Considering that news of this nature is one of the momentous events in a person's life, this is an enormous oversight on our part. What are the issues involved? Does the physical environment make a difference? Could the environment have made a difference for the family, discussed in a previous chapter, who came to the Clinic and were told their son had cancer? Although, my opinion is uninformed by any interaction with the family, the examination room seemed inappropriate and unsupportive for the father who had to come to terms with the fact that his son had cancer. Mr. X could create a private space for himself by closing the door, but if he did

that he was "trapped" with his thoughts in an examination room with little or no outlook. If the shades on the window were drawn, the view to the outside was blocked, and if they were open, the view was of a building approximately seventy-five feet away. How much this matters when people are thinking about their child's life or death is not possible to specify from this research. I wonder if the decisions the father had to make would have been easier made in a different environment, a less clinical environment.

After the initial diagnosis, most of the meetings the staff had with the patients and their families were relatively routine, and according to one physician, the examination rooms worked fine as consultation rooms for those consultations. Occasionally more serious treatment related issues had to be discussed. For those discussions the rooms were quite inadequate. They were too small, and thus became crowded when the full complement of staff and family came together. And, as noted earlier, the furniture was not very uncomfortable, especially after sitting upon them for any length of time. It does seem like an unfair burden to place on both the staff and the families when matters of such import have to be discussed, especially because those discussions can be quite lengthy. This is another kind of situation where a well-designed comfortable environment could provide the flexibility to establish an appropriate seating arrangement and the opportunity for privacy to allow for discussions to proceed as smoothly as possible.

The staff's communication skills were tested to the utmost when they had to tell a patient and/or their family that there had been a relapse because it is equally, if not more, disturbing than being told that you or your child has cancer (Bain, 1995, p. 143). Bain recounts the experience of one patient's parents who "could no longer hold back the tears" when their daughter relapsed because they knew that her chance of a cure was reduced. But "even more distressing, their hopes had been dashed, just as those hopes were

beginning to take hold" (Bain, 1995, pp. 144-145). The reaction that Tina's family had was much more severe.

My mother came in with my sister and brother, Beth, and Chris and I told them, "I relapsed. I've got another tumor." Chris couldn't deal with it. He left the hospital and started slamming his car around. He doesn't handle things like that well. My mother just collapsed, and my sister ran out of the room crying. (Berger, 1992, p. 45)

With remission there is hope; cancer no longer is a metaphor for death, but with a relapse that metaphor crashes back into place with an even greater power. Patients know that cancer can be cured, but through experience they know how difficult the treatment protocol can be. They have also learned that a relapse brings them much closer to death.

As noted in the previous chapter, I was in the Clinic one day when one of the patients, a teenage boy, was told he relapsed. What must it have been like for him to sit in the examination room alone after he found out that he had relapsed? Did he go through the five stages of "anticipatory loss and grief" posited by Kubler-Ross (1964): denial, anger, bargaining, depression and acceptance? While it is not possible to know what he was experiencing, it may be possible to gain some insight by referring to another patient's experience, the overwhelming weight of which is apparent in young woman's recollections about her reaction to the news that she had relapsed.

I'd have dreams about relapsing but I'd wake up and know that they were just dreams and they'd never come true. I started picking up where I left off. Then when I did relapse I figured, "Oh God, this is it. This is the end." The first thing I thought was, "Mom, I don't want to do this anymore. I'm not doing it anymore. I just went through a year of this." ... All I remember is the feeling that I must have done something wrong when I was in remission: I didn't take a pill, I didn't go to church, I was failing at school. I should have known... If I relapsed again, I would just... because of the fact that I know that I wouldn't get into remission again, I don't really know what I'd do. (Berger, 1992, pp. 44-54)

Was an examination room an appropriate setting for the teenage boy, mentioned above, to have to cope with the information that he had relapsed? They offered privacy and little else. At the least he should have had a comfortable place to sit and a visual prospect

other than a building less than seventy-five away. Did he want some distraction, or did he want to be in a space where was little to distract him from his thoughts and emotions? Is there one kind of room that every patient would want? What if he had been sitting in a room painted with cartoon characters such as the Jetson's (See 6.3.1.1); would that have mocked him?

The appropriate physical setting will vary according to the social circumstance. A relapse is an event involving communication and transactions between several different types of actors with different needs. At its simplest there is only a physician and the patient. Tina, the young woman quoted above, was alone, in the sense that no family members were with her in the hospital, when the doctor told her she had relapsed. At that point, being in a private room with comfortable seating and perhaps a window may be the most important requirements. When family members are present, the physical setting has to be more accommodating because the dynamics of the families' interactions have to be supported. Her mother collapsed. What did she collapse onto? If the mother of the teenage boy mentioned above had collapsed, there would have been little to support her: a fiberglass chair, an examination table. In those situations a couch would not be a luxury, but a necessity. A couch would also be essential if the family members wanted to comfort one another while discussing matters of life and death.

Most if not all hospitals have a chapel that serves the entire hospital, but patients in the situations like the ones described above should not have to leave a clinic, get on an elevator, and then find their way to a chapel. It would be much more humane to have a room that could serve as a spiritual sanctuary associated with a clinic so that the patients and their family members could easily find refuge in a sanctuary where they could talk to their God.

Again, there are issues regarding the designed environment as a setting which affords opportunities for providing an appropriate social setting, a comfortable space for the desired level of privacy and reflection and, finally, for some spiritual sanctuary.

It should be noted that the patient's and their families' needs are primary, but their needs cannot be entirely separated from the needs of the physicians. The news of a relapse is a blow to the patients and their families, but it is also a blow to the physicians.

Physicians must somehow maintain their professional standing and demeanor, if not their omnipotence in the face of this hope-crushing news. Over the months or years, the patients and their families have come to trust them, to rely on them, so that at the moment when they are imparting news that will shatter that hope, trust, and reliance they have to somehow remain a fount of not only concern but also hope. The physical environment should then not only be appropriate for the patient, but also support the staff as they try to maintain the relationship they have built with the patients and their families.

A relapse does not necessarily mean that the patient is going to die, but approximately thirty percent of the patients with cancer who were treated at the Clinic will die from the disease. At some point the physicians have to tell some of the patients and/or their families that nothing more can be done for them. As noted in a previous chapter, I was in the Clinic on the day that one of those patients, a teenage girl was told that curative treatment was no longer possible. After being given the news, she came out of the examination room and sat in a chair outside the Child Life Specialist's Room. I wondered at the time why she chose to sit there. Did she leave the examination room because she wanted to, or because it was needed to see other patients? Was it therapeutic for her to sit where everyone could see how angry she was? If there had been a Chapel in the Clinic would she have used it? She did not have any family members with her. If there had been, would she have preferred to stay with them someplace where they had their privacy? How

do people cope with the news that they are going to die? Does the physical environment make a difference to them at that time? Regrettably there has been little research on this subject. Nevertheless there are again clearly implications for the design of the setting that is at least differentiated enough to allow a person to find a suitable space for their state of mind.

And for the doctors, whose goal and lifework it is to keep their patients alive, having to tell patients and their families that there is nothing more they can do for them must be the most difficult task they have to perform. Again, I did not talk to any of the physicians about this, but, as is evident in the excerpt from Berger (1992) below, that communication can be devastating for the physician as well as the patients and family members. The patient's mother said:

A few weeks after the transplant, we felt so positive. We were looking forward to a normal life and I took him to the Clinic to have his catheter removed because he wasn't supposed to need any more chemo. I was waiting for the blood work to come back and I saw the nurse come in with a little piece of paper. I looked at her face, and my heart just fell. I pulled the paper out of her hand, saw the counts, and went running into Dr. Pitel's office; He had not seen it yet, and I said, "Look," and he was in shock. He said, "Oh, Jesus... I cannot take care of him anymore. I cannot do anything. Call hospice... you need help that I'm not able to give you." That was the only time I'd ever seen him cry. (pp. 122-123)

The physician obviously was caught by surprise, and lost his professional composure. This is not a typical scenario. Usually the physicians have the results before the patient or the family, but at some point they have to tell the patients and their families. What are the implications for the environment at that time? How can the setting help the physicians maintain their composure? Do they? Is therapeutic communication warranted or desired? Is the use of touch appropriate at this time? Is there a psychological distancing that is necessary that should be facilitated by physical distancing and boundaries such as a desk? Again, I have more questions than answers, but it would seem that providing physicians options is critical. The setting should be structured so that physicians who want

to create a distance can, and those who want to provide some psychological and perhaps physical comfort, can.

After the oncology patients have completed their course of treatment they are given what was called at the Clinic an "off treatment talk." In comparison to being told that you or your child has cancer, or that there has been a relapse, or that nothing more can be done, being told that the treatment has been completed at that time seemingly would be very good news, and it is. But there is also a great deal of anxiety associated with going off treatment. On the one hand going off treatment is a great relief, on the other it is "surprisingly one of the most stressful times for a family..." (Bain, 1995, p. 144). Bain then quoted a Dr. Kazak who said:

It's much more traumatic than people realize. People have mixed feelings. It's not that they want to keep coming to the hospital, or God knows, that they want to keep having chemo. But their lives have become deeply connected to their team. (p. 144)

He also quoted a Dr. Womer who said, "People tend to be more together on treatment than off because they feel as though they're doing something and the security blanket is there" (Bain, p. 144). One of the parents cited by Chesler and Chesney (1995) expressed similar thoughts.

When my son was on treatment, I knew something was being done. When he went off treatment, I wondered what would happen next. The unpredictability of his response, and the uncertainty about the future, and how we should live our life, is difficult. (p. 37)

The physician's task at the off treatment talk is therefore to help the parents and patients come to terms with their fears and uncertainties about the future. The security blanket provided by chemotherapy has to be replaced with the knowledge that they will not be abandoned. Yet they cannot be given false hopes; patients are not considered "cured" until they are off treatment five years. But at the same time they have to realize that they have passed a major milestone along the path to being cured.

This kind of situation seems to call for an environment, which offers opportunities for a comfortable exchange between doctors, patients and family in private, followed by a time for reflection by the family in the same space.

10.5. The Physical Setting

Embedded in previous sections were brief references to aspects of the physical environment. The intent of this section is to discuss more fully those aspects of the physical environment: furniture, artwork, color, windows, lighting and perceptual quality that play major roles in creating physical and psychological comfort in a clinic.

10.5.1. Furniture

In a medical setting the furniture should be comfortable, especially in a clinic where the patients, who may not be feeling well, may have to wait for several hours. Much of the furniture in the Clinic did not meet these basic criteria.

The edges of the table in the Playroom were square rather than rounded, which made it painful for patients with sensitive tissue on their arms if they placed them on the edge with too much pressure. Some of the chairs were cracked at the seams of their woven wire webs, and they frequently pinched people's legs or posteriors. Besides the pain caused by the web on chairs that were broken, several patients noted that the wire web itself caused discomfort over time. Comfortable chairs should be an imperative. Some large, comfortable chairs should also be provided to accommodate the parents' or guardians' need to comfort or to hold their children when they are feeling sick. Young children (and less frequently, teenagers) often need comforting and this is very difficult to do unless the seating is large enough for a parent and a child. Rocking chairs, which one of the patients included in her design, have, for example, served this purpose in many home settings. Such chairs could be used both by parents comforting their children or by

individuals. I observed some of the patients bouncing gently on the wire web chairs; a rocking chair would probably have served the same purpose.

Furniture used in screening and examination rooms also has to very carefully considered. Most importantly, the furniture, especially the chairs, should not be responsible for creating unsafe conditions. The issue of unsafe seating arises because some of the patients have physical disabilities due their treatment or illness. Patients with bone tumors involving the lower extremities often required surgical procedures to remove part of the leg. Some of the patients have full amputation of a lower extremity, others have a limb salvaging procedure. Others need to use crutches if they were not confined to a wheelchair. These patients have various degrees of difficulty in maneuvering in a Clinic setting. To assist patients with disabilities, therefore, chairs should also have arms. It is much easier to get in and out of a chair with arms, even for people who have full mobility, for people who do not chairs without arms create a significant and unnecessary challenge.

Also, the seats on the chairs should not be slippery. One of the patients who had a problem with his hip said that he slipped as he was sitting down and slid off the chair and landed on the floor. On a chair that was covered with a cloth with a rough weave, he would have simply dropped several inches when he slipped. Once seated, a patient who slid off a chair at the wrong time could pull out a chemotherapy IV lead or rip out a needle during blood drawing. If this happened during blood drawing, it would be very painful. If it happened during a chemotherapy infusion, it could be both painful and dangerous, resulting in serious burns from the chemotherapy.

Comfort is also an issue. Several of the patients thought the chairs in the screening and examination rooms were not comfortable enough. It would be easy to dismiss their complaints about the chairs. One could say that the patients only sit on them for a few minutes. But time is relative. If one is in pain, or has complaints, sitting on an

uncomfortable or unpadded chair can become a source of unnecessary stress to which patients should not be subjected.

During a venipuncture patients should be able to rest their arms on a comfortable surface in a comfortable position while they are sitting on a comfortable and easily adjustable height chair. Adjustable height chairs would make the blood drawing procedure more comfortable because the patients could adjust the seat height so they could rest their arms comfortably on the top of desk or table with edges that are bullnosed (rounded) so that no additional discomfort is caused during blood drawings. Several of the patients also suggested that the surface where they laid their arms during blood drawing be padded.

The psychological comfort of the patients also has to be considered. Some patients are disturbed by the sight of blood drawing paraphernalia. Cupboards directly above the desk or table where the supplies would be easily accessible, but hidden until needed, would reduce some patients' anticipatory anxiety.

A source of discomfort mentioned by several of the taller patients were the examination tables. The examination table should also be comfortable for patients of all ages. In a setting where teenagers, who have attained "adult" size, are being seen, the examination tables should be long enough to accommodate them, either by providing longer tables or tables with properly designed leg extensions. Extensions should be designed so that they are flush with the rest of the table. This flush design is especially critical for patients who might be suffering from a disease, such as sickle cell, that attacks the joints. Patients who are in pain or discomfort caused by diseases should not be subjected to more pain or discomfort because the furniture does not accommodate them properly.

10.5.2. Artwork

Artwork in medical settings can serve many functions. When patients create artwork it can increase their "sense of well-being and self-empowerment" and "give them some sense of control of their lives" (Martin, no date, pp. 13-14). And when patients' artwork is attractively displayed the aesthetics of the environment is improved and the patients' self-esteem and their families' pride are enhanced (Wallace & Cama, 1983).

Artwork was an important theme in the patients' feelings about the environment of the clinic.⁷ In the Playroom the pictures that the patients drew served several different functions: some of the patients took a great deal of pride in having their work displayed, patients looked at them when they were bored, patients looked at them for sources of ideas for their own drawings, looking at the pictures helped ease the pain of painful procedures, and looking at pictures helped mitigate anticipatory anxiety. In addition, the pictures served as a memorial for patients who had died, and they helped the Child Life Specialist gain an understanding of how the patients who drew were coping or adjusting to their illness and treatment.

Artwork in screening and examination rooms can also serve a number of functions. It can, of course, make the environment visually more attractive and appealing, and reduce the institutional quality of the setting. However, when they are chosen or created with their full power in mind they are much more than "pretty" pictures. Pictures can be a very powerful tool to help patients cope while they are waiting in a screening or an examination room by providing a source of distraction, especially if the images are visually complex. They can carry additional messages of inspiration, hope, learning, and even humor, especially if text is included.

⁷ Artwork in this discussion refers to two dimensional images such as paintings and drawing that the patients or non-patient artists created, posters, photographs, etc.

That there were so few pictures in the screening and examination rooms added to the psychological burden that the patients had to carry while they were in the Clinic. It is unfortunate that the patients, many of whom came to the Clinic repeatedly for several years, had to stare at blank walls or medical equipment while they were waiting in the screening and examination rooms because, as one of the patients stated, "There is nothing to take your mind off it. You're just looking around at plain walls and there is nothing to look at except a nurse coming at you with a giant needle."

In terms of the saliency of the images, the question, for the person or people choosing the artwork is as follows: Is it possible to choose images that work for very young children as well as for young adults? The answer I think depends upon how the question is addressed. If there are enough examination rooms so that there could be separate rooms for the different ages then the images in each room or rooms could reflect the interests of a particular age range. In a space that is used by different ages, posters could be used to identify different areas: friendly TV characters might be places in the toddler area, favorite cartoon characters could go on the walls of the preteen area, and posters of male and female performers or sports figures could go in the teenage area. Unless the clinic is very large this approach may not be practical. A more practical solution is available. If the question is addressed in terms of both/and rather than either/or, salient images for the different ages groups could be created. An example of this are the commercials and movie where Michael Jordan and Bugs Bunny have been teamed together. The advantage of this kind of merging of salient images is that cartoon characters appeal to many age ranges, and by including figures from the sports or entertainment world, the chances of capturing the attention and interest of another large segment of the population is insured. Another benefit of this strategy is derived from their almost universal popularity. American cartoon figures and sports figures appeal to audiences across cultures.

Older children, because of their greater emotional and intellectual development, could be positively affected by pictures which included affirmative messages. Combining the patients' ideas, posters could be created with patients, cartoon characters, sports figures, and medical personnel with inspirational or positive slogans.

Another consideration when choosing or designing artwork for screening and examination rooms is their visual richness. By this I mean their ability to engage the patients' attention for several minutes at a time. This issue, which was raised by one of the patients, who made a distinction between art that "you just look at" and art that "really distracts," is a critical one. The images should be designed to engage the patients' attention by inviting study. This could be done several ways. The patient quoted above suggested putting up a "Where's Waldo"⁸ poster because that would engage the patients for several minutes. The artwork could also have a great deal of text that the patients could read.

The location of the artwork is also a factor. To have an effect on patients when they enter a screening or examination room, artwork has to be within their field of vision when they enter the room. Artwork should also be placed so that when patients who do not like to watch their blood being drawn turn their heads away, they have something to look at. This is an important point for the layout of the room. For patients who have a very strong aversion to watching any part of the blood drawing procedure, pictures or other distractions in the room would not be effective unless they were placed in such a way that they could be looked at without seeing the procedure, even with their peripheral vision.

The issue of choosing or creating artwork for a room where venipunctures or other medical procedures take place is obviously not a simple one. The images not only have to be aesthetically pleasing and appeal to patients of various ages, they also have to be

⁸ "Where's Waldo" is a cartoon series in which the Waldo is hidden amongst hundreds of other figures. The challenge is to find Waldo.

complex or rich enough to hold their attention, and also large enough so they can be seen from some distance.

Although artwork can be a powerful distractor, it can not help all patients. Many, if not most, young children have a deep and abiding fear of a needle. It is a fear that makes some children cry when they see their doctor or even a person in a white lab coat. For these children, pictures on the wall would probably not take their minds off the fear of getting a needle, unless the images were designed specifically to help parents or caregivers engage the children's attention while they were waiting. For this age group toys, which can engage younger children's attention more powerfully than images, would probably be more effective. It is also possible to have toys that move⁹, controlled by either the nurse or one of the patient's parents, and activated at the most advantageous time for maximum distraction potential.

10.5.3. Color

There are powerful reasons for making clinics more colorful, but possibly the most compelling reason, even though only two patients mentioned it explicitly, is that a colorful clinic shows that someone cared enough about the patients to make it colorful.

However, the color scheme for a clinic has to be chosen very carefully in order not to disturb patients who are not feeling well. One of the older patients identified a problem that has to be given a great deal of consideration; what is the effect of a very bright color, applied en masse on patients who are not feeling well? It is one thing to hope that colors will energize the sleepy or tired; it is another thing altogether to use bright colors so indiscriminately that they are psychologically and even physically disturbing. In a clinic setting where patients may have complaints caused by their illness or treatment, colors have

⁹A train was mounted on a clear Plexiglas base hung from the ceiling in the Ultrasound Room at the Hasbro Children's Hospital. This apparently was quite successful at distracting the younger patients during the procedure.

to be chosen and applied very judiciously so as not to disturb patients when they were not feeling well. This does not mean that bright or unusual colors cannot be used; what it does mean, however, is that those bright or unusual colors cannot be the dominant colors in space- they should be used as accent colors.

10.5.4. Windows

Past research has proven windows to be very important for patient recovery in hospitals (Wilson, 1972; Ulrich, 1984). And, while the needs of patients who are spending days in a hospital are different than the needs of patients who are visiting a clinic, it is critical to understand why windows are important because it often is not possible in an institutional setting for all rooms to have a window. What might be possible, however, is to create within those rooms some of the qualities that windows provide.

The lack of natural light was the major undesirable characteristic in some of the examination rooms and one of the screening rooms. It is difficult, if not impossible, to recreate the quality of natural light with lighting fixtures, but it is possible to provide fixtures that "brighten up" examination and screening rooms so that they are not "gloomy." Colors can also be chosen that counterbalance the coldness of the ubiquitous fluorescent fixtures that are found in hospitals and other institutional settings. Choosing colors that counterbalance the cold light cast by fluorescent lighting fixtures is especially critical in rooms without natural light.

The lack of windows can also aggravate children's stress level because they can not ignore the elements in the environment that are negative distractions, which they cannot hope to control or change. The combination of negative stimuli combined with the lack of any positive distractions may increase patients stress because they "may focus to a greater degree on their own worries or stressful thoughts" (Ulrich et al., 1991, p. 14).

A critical component of a view from a window, is the constantly changing visual experience. There is not "a" view from a window, but rather an active viewing process where our eyes focus on many different parts of the view. Even when the only view is a building, there is change caused by the changing quality of the light on the building's elevation. Ideally, the view would be more active because, people like to see what is "happening." It is tempting to say "even if it is only" people in a gift shop, pedestrians, or even just traffic. But these are not the leftovers of a visual banquet, secondary choices. Many people would choose these scenes over a landscape without activities. And as one of the patients said, "In New York city nature is traffic." This varied visual experience is a critical point to consider in screening rooms and examination rooms without windows, because it suggests that there should be different objects, whether they be two dimensional or three dimensional, for the patients to study. In an ideal situation, there might even be a fish tank or a VCR in the rooms to give the patients a constantly changing image to watch.

Most of the patients preferred rooms with windows. Several said it didn't matter, but one patient said he would prefer it if windows were not in the Playroom. He gave a subtle and very revealing reason why the view from a window might be unimportant, if not in some ways disturbing. He felt seeing "normal" activity outside made the wait more onerous because it accentuated the fact that patients were forced to be in a medical setting. This is not to say windows are not important in a playroom, they are. But the issue of options raised by this patient's statement has to be considered. A waiting area or playroom should be designed so that if patients want to escape from their problems for a while by looking out the window that should be possible. It should also be possible for patients to create a private world within the playroom if that is what they need.

10.5.5. Lighting

One of the more surprising findings was the generally high level of satisfaction with lighting system in the Clinic, which was fluorescent. This was surprising because the negative effects of institutional lighting has been discussed by several authors: Carpman and Grant (1993), Olds and Daniel (1987), and Shumaker and Reizenstein (1982).

Most of the patients I talked to thought the lighting system in the Playroom worked fine because it provided the correct amount of light for the activities at the table. But, several of the patients complained that the lights were too bright when they were not feeling well. In a larger playroom, perhaps the lighting system could be designed so the entire room was not illuminated to the same level. Or lights could be placed on dimmers so that when patients were not feeling well, they could dim the lights in their area, or choose an area where the lights did not need to be very bright.

I was also surprised that more of the patients did not complain about the lights in the examination rooms because the fixtures were directly above their heads when they were lying down on the examination table. Apparently most of the patients did not mind staring into the fixtures. This does not mean that the lighting should not be improved because some patients did find it quite disturbing.

It should be possible to design a lighting system that provides the physicians enough light for their examination, without having that light shine directly into the patients' eyes. What should not be above the examination table, especially not over the patients head, are lighting fixtures, unless the diffuser is designed in such a way that the bulbs do not glare in the patients' eyes. Lighting placement and design are not simply a matter of providing the code required level of foot candles in a space, the physical comfort of the users also has to be considered.

10.5.6. Perceptual Quality

The perceptual quality of an environment includes the message transmitted to the users. It is our impression of the environment, whether good or bad or neutral. In an ideal situation it could be described as the art of architecture or design. Unfortunately, most medical settings, including the Clinic, can be described as institutional, whereas most of the patients would have preferred that it be child friendly.

We may enter buildings that we have never been in before, but rarely do we enter an environment that is totally unfamiliar. Supermarkets, schools, banks, offices, grocery stores, even dentists' or pediatricians' offices have a familiarity of types. But the Clinic was located in a large hospital and was unlike any other setting that many of the patients, primarily the pediatric oncology patients, might have encountered. Entering an environment, especially for the first time, can be quite anxiety provoking. When the environment that a person is entering for the first time is a medical environment, the fear of the unknown physical environment is augmented by the fear of medical procedures and treatment. Whatever state of confusion and anxiety the patients were in when they arrived at the Clinic was not relieved upon passing through the doors into it. It is probably not possible to alleviate all the fears pediatric patients have when they enter an unfamiliar hospital environment. However, it is possible to create a physical environment that does not add to their apprehension.

When thinking about the decor or the image of a clinic, two of the issues that have to be considered are: (1) patients ranging in age from infancy to young adulthood will be coming to the clinic, and colors and images that are appropriate for one age may not be appropriate for another, and (2) more generally should there be a limit on how far away from the "traditional" look of a clinic a "kid friendly" clinic should be? It would not be necessary and perhaps not advisable to create, as one of the patients suggested, a "different

dimension," a "kid's world." But this vision of what the Clinic could be and what it was are on the opposite ends of the "child friendliness" spectrum. This vision raises the question: Just what should a clinic look like? Would it be appropriate or desirable to create a "kid's world" outside the playroom in a clinic? If not, where along the spectrum between sterility and the world imagined by a very imaginative child does one draw the line? This is an issue not only because the medical staff's sensibilities have to be considered but also other patients, especially the older ones, may not appreciate coming to a clinic that looked like a "kids world." What may work for one age range may not work for others, especially if they were composed of cartoon or video game characters, sports heroes, etc. Older patient may be offended if they felt they were in a clinic designed for "babies," i.e., younger children. I do not think this type of discrimination works in the other direction. I have no way to prove this, but I doubt that young children would be offended by a clinic with images more appropriate for an older population especially if they know or could relate to the images that are provided. One of the patients talked about creating a "kids world." If only "kids" were using a clinic then the designers task would be much simpler but this is not the case. The challenge is to create an environment in a clinic which could appeal to pediatric patients of all ages.

11 METHODOLOGICAL CRITIQUE

In this chapter I will critique the methods that I used, examining the strengths and weaknesses, problems and successes of the various methods. I will discuss my role as a participant observer, and the constraints limiting my role as an observer because I was an active participant in the Playroom. I will then explain why the richness of the interview data was not consistent, not only between patients, but also between the medical side of the Clinic and the Playroom. Next to be discussed is the difficulty I had eliciting profound or deep statements about the Clinic environment. Finally, I will comment on the efficacy of two of the major tools used during the interviews, the model and the computer aided design program.

11.1 Difficulties of Participant Observer Role in a Hospital Setting

As a participant observer in the clinic, I had two primary roles: volunteer and observer. As a Ph.D. candidate doing research for a dissertation, my role as a researcher should have taken priority over my role as a volunteer. This was not the case. Once I was in the clinic setting and my role as a volunteer had been established, it was often very difficult, if not impossible, to observe or record observations in a systematic manner. Sometimes I would be the only volunteer in the Playroom. When this happened because it was imperative that the Playroom run smoothly, all my time and energy had to be devoted to running the Playroom. Fortunately, this only happened a few times. Often I would simply become engrossed in an activity with a child or teenager that demanded all of my attention and would not observe what was happening in the rest of the Playroom for a length of time.

Another problem was that even when I had the opportunity to observe the activity in the Playroom, it was sometimes difficult to leave the Playroom to record the observations. I also found it difficult to follow a child for an entire morning because once they left the

Playroom I would become absorbed in other activities and fail to notice when they came back.

Not being able to record my observations in the Playroom may have impacted the quantity of observations but not the quality of these observations. For, even though I was not able to capture the detailed ebb and flow of the activity in the Playroom as comprehensively, or as rigorously as I would have liked, the very nature of the note taking method acted as a screening process. On most days, there was an enormous amount of activity occurring in the Playroom and because I was not able to make systematic observations of these activities, I had to rely on my memory when I recorded my observations, and my memory, by necessity, was often selective. Since I could not remember everything that I had observed, the most salient or unusual behaviors, activities, or events were the ones that appeared when I stared into the dark and often frustratingly blank hole called my memory. The anomalies or unusual occurrences I remembered were often instances when the patients were reacting to stresses of one kind or another and thus became stresspoints in the analysis. Without these observations (and information about the patients that was discussed during the clinic conferences that helped to explain the cause of the stress that they were experiencing) the dissertation would have been much less comprehensive because the patients did not talk about all the stresspoints that they encountered.

Given the flaws in the methodology would I have done it differently? Ethically and practically I do not think that would have been possible. Spradley (1980) describes five types of participation that are possible when one is doing ethnographic research: non participation, passive, moderate, active, and complete, with degrees of involvement ranging from none to high. As a volunteer, which was the only role available that made it possible for me to do the research, complete participation with a high level of involvement

was the only option. My role as a volunteer had to come before my role as an observer because to do otherwise would have been unfair and perhaps psychologically upsetting to the patients.

Both the quantity and quality of the information that I obtained from the patients varied considerably. On opposite ends of the scale, I was able to gather a great deal of data about the Playroom but very little about how the examination rooms worked for bone marrow aspirations and lumbar punctures. Ideally, I would have asked every patient every question on the interview schedule. This did not happen for a number of reasons. The primary reason was that the interview schedule contained so many items that many of the interviews were terminated before they could be covered, either because the patient had to leave the Clinic or because they decided they wanted to return to the Playroom. In some cases, I was able to interview the patient at a later date, but in many cases that was not possible, either because I could not arrange another meeting or, in several cases because they did not want to be interviewed again.

11.2 Interviewing on Sensitive Topics and Causing Distress

The interview schedule was designed so that the topics that had the greatest possibility of making the patients uncomfortable, such as how the rooms worked for bone marrow aspirations and lumbar punctures, followed questions about the Playroom. The interview was terminated or revised as soon as a patient was disturbed by a question. Fortunately, this only happened a few times. In one instance, I asked a seven year old girl to put herself in the place of a doll that was lying on the examination table and tell me what she thought about the ceiling. This made her very uncomfortable. She thought it was because she was thinking about the spinal tap that she was going to get the next week. In this case because she seemed quite distressed, I stopped the interview.

I have very little data from the interviews about how the examination rooms worked for lumbar punctures and bone marrow aspirations because those were very invasive and

painful and/or uncomfortable procedures that many of the patients I interviewed were still getting. I did not feel comfortable talking to these patients in depth about them because I did not have the skills nor training to handle any psychological distress that my questioning might have caused. For instance, during another interview, I asked a young woman if she wanted to talk about how the rooms worked for spinal taps. She asked me why I had to pick that day to ask her about that. She said this with a very wry, ironic, and slightly humorous tone of voice so even though it was obvious that she was not comfortable talking about that subject it did not seem necessary to end the interview. Instead we moved on to less threatening topics. Another patient would probably have become quite disturbed if we had talked about his BMA's and LP's. I had developed a good rapport with him; we talked quite a bit and played cards frequently. When I first asked him if I could interview him at some point, he said okay. That interview never took place because he always seemed to have what I thought of as an "excuse." I finally realized that those "excuses" were simply his way of protecting himself. It is fortunate that I never did interview him because the extraordinarily high level of anticipatory anxiety he felt would only have been exacerbated. I am afraid that any questions about the procedures would have only served to cause him unwarranted psychological and consequently physical distress in the form of vomiting. This inability to interview a patient who suffered a considerable amount of anxiety and pain because of the LP's and BMA's poses quite a dilemma/conundrum. For someone like this patient, the environment where he has to prepare, receive and recover from LP's and BMA's may have an impact that other patients who are less traumatized by the procedures may not feel. Because I was not able to interview him, I have no idea about what impact the environment actually might have had on him.

11.3 The Quantity and Quality of the Interviewees' Responses

In the Introduction and preface of his book, Bearison (1991) mentioned that the patients "welcomed the chance to talk about their experience" (p. xii). In general, I cannot

say that this was my experience, especially if I asked to interview a patient for the second time. Some of the patients agreed to a second interview but, in general, their enthusiasm had noticeably decreased from the first interview, and it was apparent that some of them seemed to want to end the interview as quickly as possible. I suspect that the subject matter we were discussing, the Clinic environment, was not as salient or as important to them as the subject matter Bearison discussed with his interviewees, namely their experience with cancer.

The quality of the responses was very much dependent upon how involved or interested the patients were in the interview. It was impossible to probe as thoroughly with some of the patients as it was with others. Each interview had a life of its own. Some, I just wanted to finish as quickly as possible because I realized that the patient was just not very interested in talking to me. Sometimes it seemed as if my questions, particularly the probes, became irksome, tedious, onerous, irritating, or burdensome to some of the patients. In those cases the probes were minimized. With other patients, the opposite was true. They liked being interviewed or talking to me, and I felt free to ask them probing questions. Surprisingly, some of the more complex, informative, and rich sessions were with patients whom I had not met before I interviewed them. These patients simply had a lot to say and they were quite willing to talk at great length with me. Apparently some of the patients did not mind being asked to think more deeply about their answers while others did.¹

Although, I was able to gather a great deal of information from the patients about what they thought and felt about certain aspects of the Clinic environment, I found that it was difficult to get to the essential or deeper meaning of the spaces in the Clinic.

¹ Obvious as this may seem, I have not seen this issue discussed in any of the literature that I have read. I mention it simply as a forewarning to other novice researchers who may not have experienced the frustration of trying to interview someone who answers in monosyllables.

Occasionally, there were glimpses of revelations but they happened almost by accident, a word or a question sparked something within someone and they mentioned something quite rich, personal, and deep. For instance, one of the patients described a hall in a movie to illustrate the surrealistic character of the Hall in the Clinic. Another patient described the Hall as "death row," while another called the examination rooms "doom rooms."

Descriptions such as these are critical because in a word or two they capture the experiential qualities of the space very vividly. Insights such as these can then be used by designers to inform their designs.

But, in general, trying to elicit from the patients profound statements about the clinic environment was very hard. Simply finding a way to phrase the question was difficult. I asked one patient how they would describe the room to a friend and he started to describe the physical attributes of the room. I also asked some of the patients: "How does the room make you feel?" or "When you come into the Playroom what do you feel about it?" The patients had a hard time answering these questions. So, eventually, I began to ask a more designed oriented question: "How would you want the kids to feel when they came into _____?" When I phrased the question in this manner most of the patients were able to give an answer such as "safe, happy, comfortable, etc."

Perhaps if I could have spent many sessions with a patient I might have been able to find the key that opened the door to what the space meant to them but working against that is the fact that some people do not like to be interviewed at length or asked probing questions. It is also quite possible that for some of the patients, the Clinic space simply had no deeper meaning or salient attributes² because while the hospital was a place, for them, a set of unwanted procedures was their focus.

² During the course of the research, I went to a H.I.P clinic, for personal reasons, to see a physician. After I visited the clinic I thought about how I would describe it, what my "deep" response to the space was, how did it made me feel? I found that I had no profound thoughts about the space. It was your typical corporate physician's office. A small room with nothing to distinguish it from many other small rooms.

The quantity and quality of the responses were, to a certain degree, age dependent but to a much lesser degree than I would have expected. In general, the more complete and insightful responses were given by the older teenagers and young adults, but some of the older schoolage patients were able to provide me with more information than some of the teenagers. The clearest difference in the quality of the interviews could be seen with the preschoolers and very young schoolage or kindergarten age children. It was very difficult to engage children of this age range in the interview for more than a few minutes, even though I used the model and dolls to facilitate the interview process. (See below for description of and problems with this method.)

11.4 The Failure to Hear the Concerns and Ideas of the Parents

It is unfortunate that I did not talk to more parents about what they thought about the design of the Clinic, especially the parents of the younger children. For instance, during a conversation about the examination room, it was obvious that Kevin's mother had a very good understanding of what was "kid friendly" and what was not. She also offered some information about how she provided emotional and, literally, physical support for her son. She said, "I would be leaning back and Kevin would be much more comfortable on my lap. Now, of course, hopefully closeness to a parent is always preferable emotionally..." How well the physical environment supports the parents in providing emotional succor to their children needs careful consideration. Unfortunately, I did not even ask her if the chairs in the examination rooms were comfortable when she was holding Kevin, and this is an important consideration when choosing furniture for a pediatric clinic. I suspect that other parents could have given data that was just as rich that would have rounded out the research.

It did not have a character other than institutional. But how did it make me feel? What were my feelings in the room? Did the room elicit a reaction from me? I concluded I would have had a very difficult time answering those questions simply because the space was so anonymous and institutional.

11.5 The Use of Models in Interviews

I did not have the success with the model that I was hoping to have. I had expected to use the model and toy figures with the younger children to elicit replies that I could not have gotten otherwise. This did not happen. The children seemed to view the model as a wonderful toy, which is to be expected, and they played with it and the toy figures and did not want to be bothered with my questions about it. If one could spend a long time observing such play, there would be insights to gain from it regarding the hospital environment. And, perhaps if they had been able to first play with it, at length, they would have been willing and able to refer to it and describe their Clinic experiences.

In terms of therapeutic purposes using a detailed scale model with figurines can evoke some tremendously evocative responses. One of the patients I interviewed, a five year old girl with sickle cell disease, immediately started playing with the model and the dolls and very quickly her play evolved into medical play with the doctor (herself) giving the dolls shots or drawing blood. While doing so, she played both the doctor and the patient and it was amazing to see how faithfully she recreated what I assume were the social interactions surrounding those procedures. Later she moved into a much more powerful and provocative play that dealt with the issue of operations: taking the role of the doctor, "Now, hm, first scissors" (she pretended to cut the doll open) - and proceeded to operate on her heart. Rachel was the only child who played with the model in this manner, but I suspect that in the hands of trained therapist, a realistic model of the medical setting where the patient is being treated, could be used very effectively to elicit a therapeutic conversation.

11.6 Computer-Aided Design with Children

I have very mixed feelings about the computer aided design program that I asked the patients to use to design their "ideal" playroom. It was a powerful tool for some and a limit on the imagination of others. On the one hand, I was quite disappointed that so many

of the designs were so similar to the existing Playroom. On the other hand, while the program was not liberating, it was powerful, enabling some of the patients, perhaps most, to create something that they would not have been able to if I had asked them to design a room using a paper and pencil.

I should not have been surprised or disappointed that most of the plans lacked "creativity," because the creativity of even the most accomplished designers would have had been stifled or tested by the program. The program enables users to do one task very easily- lay out furniture in a rectilinear space. Spatial manipulation, while possible with a great deal of time and ingenuity was not an option for the patients. One of the patients wanted to put a sloped roof on his Playroom, but when neither he nor I were able to do it, he became very frustrated and never wanted to use the program again.

The constraints the program put on some of the patients' imagination can be most clearly understood by comparing two patients' verbal descriptions of what spaces in their ideal clinics or hospital would be like with the Playroom they designed on the computer. When I conceived the research design, I was hoping that the patients would develop designs that were as remarkable as the one Andy and Beth talked about. Andy thought the hospital should be:

Big, really big and it would have glass everywhere, the whole place would be glass and then you'd have a dome. It would just be big rich great house... I would have a big house, a big building with windows all over, like covering all the outside. And I'd have a hospital inside. Plus a clinic.

In contrast, his Playroom design was very straightforward and functional, without the spatial richness evident in the images he created in the quote above. It included an area for a very physical activity, basketball, and an area where he could watch television while using a computer (see Figure 25)

Patient: Bob
Age: 9
Gender: Male
Room Size: 30'-0" x 30'-0"
Scale: 1/8" = 1'-0"

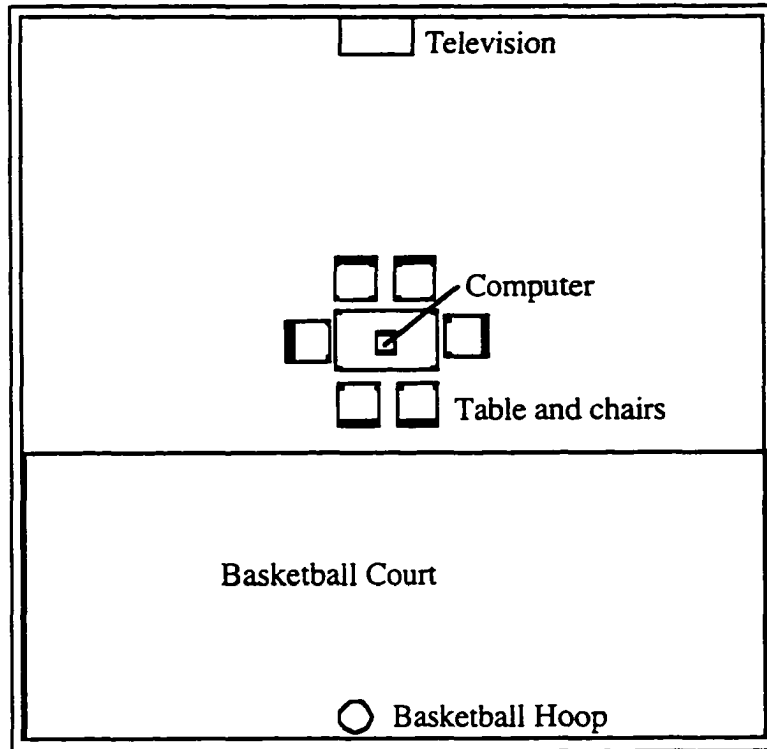


Figure 25. Plan of Bob's "Ideal" Playroom.

The contrast between what Beth imagined: "Like make it joyful and, and funny, and make it like a **kids' world** (her emphasis)" (See Appendix C for a portion of the interview where she describes, in detail, what a "kids' world could be like.), and the playroom she designed (see Figure 26), which was also very functional, was even more striking than in Andy's case.

Patient: Beth
Age: 9
Gender: Female
Room Size: 30'-0" x 30'-0"
Scale: 1/8" = 1'-0"

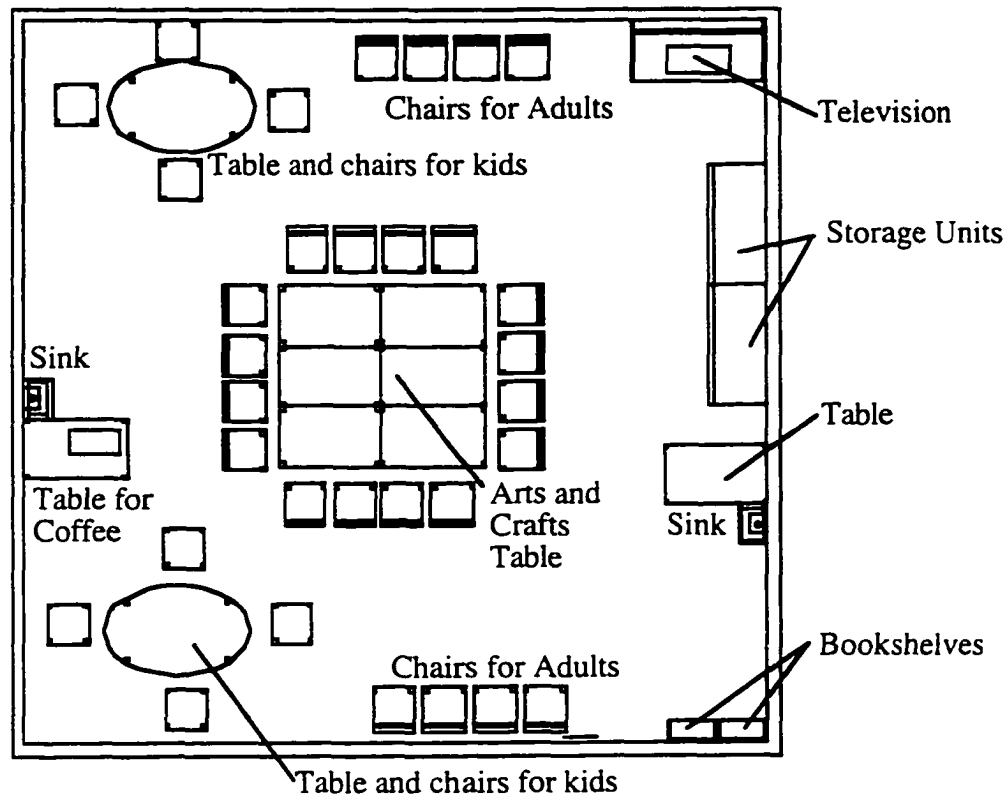


Figure 26. Plan of Beth's "Ideal" Playroom.

But Andy's and Beth's imaginative efforts were exceptional. Only one other patient imagined an alternative to the existing Clinic that was truly extraordinary. For the majority of patients that I worked with, therefore, the computer was not a handicap limiting their design possibilities, but rather a very effective, within its limitations, and engaging tool that magnified their design potential.

I was disappointed with the results of the "ideal" playroom design exercise using the model, models of furniture, doll, a playhouse, and moveable walls, especially since a

similar methodology worked for very successfully for Wilson (1992) . One explanation for the lack of success I had was that designing may have been a cognitive task that some of the children were too young to engage in, at least for any length of time. Wilson (1992) did not specify the ages of the children that she worked with but most of the children that she quoted were older than eight years of age. Children of this age are much better equipped cognitively to understand and complete a task which asks them to design something than the much younger children with whom I was working.

11.7 The "Poster" Method

In order to elicit patients' preferences for the types of artwork that they would like it have on the walls of the Clinic, I made small "posters" at the scale of the model. Even though the "poster" method was successful, after using this method with several patients, I discontinued its use. In terms of the amount of time I had with the patients, the method was quite time consuming, and the information it was generating, the patients' artwork preferences, did not seem to justify the amount of time being spent. However, this method could be used quite successfully as part of a more focused study of the kind of artwork that should be placed on hospital walls.

11.8 Conclusion

While there were problems with the methods that I used, as I suspect is the case in all research, overall I am quite satisfied with the amount of information I was able to elicit from the patients. What is surprising to me, and also very gratifying, is that even though the focus of the questions were on aspects of the environment a great deal of information arose that illuminated the psychological and treatment-related stresses, as well as the environmental stresses, that the patients experienced.

12. CONCLUSION and SUGGESTIONS FOR FURTHER RESEARCH

The goal of this dissertation was to provide architects and designers with information that they can use to design a specific type of medical setting: pediatric hematology/oncology clinics. It was also hoped that some of the findings would be found useful in the design of other types of health care facilities for children and health care facilities in general. More generally, the study serves to demonstrate the benefits of a multi-disciplinary approach to the generation of design concepts (see 2.7, especially Figure 1). It is remarkable that between the fields of medicine, psychology, and architecture and design, there seems to be so little understanding of what the other fields can offer. This is most evident by the almost universal lack of acknowledgment given to the physical environment in studies written by authors in the medical and psychological disciplines. It is almost as if their studies take place in time but not in space. It is also very evident when reading about medical facilities in the architectural press. Popular publications such as *Architecture*, *Architectural Record*, and *Progressive Architecture* (before it ceased publication) seem to exist in a world that is almost exclusively self-referential and aesthetically oriented. And even more surprisingly, authors with different orientations, (see 2.3.5) who address the issue of helping pediatric patients cope with pain do not seem to read each others' literature. One group focuses on the physiological basis of pain, and the other views pain as a stressful event. And neither group acknowledges the powerful effect the social and physical environment can have on how children and teenagers cope with painful medical procedures.

There are several issues that deserve further consideration and research. One of those issues is anticipatory anxiety. This research has demonstrated that the environmental setting is one factor influencing anticipatory anxiety, but exactly how does anticipatory anxiety affect patients' perception of pain? While McGrath (1990) suggests that an anxiety-

pain-anxiety, or a pain-emotional distress-pain cycle can increase in amplitude, she does not discuss the precise mechanisms by which this happens. Does anticipatory anxiety have an excitatory influence on the pain gate? And if it does, does a greater degree or level of anticipatory anxiety open the gate wider, resulting in greater perception of pain? I have suggested that the social and physical environment of a playroom can reduce the amount of anticipatory anxiety that patients experience while they are waiting. Does this make any difference in terms of the amount of pain they experience during an invasive procedure? I wonder if eliminating or reducing the anxiety patients feel during an anxiety-pain-anxiety cycle has any effect on the amplitude of pain they experience. This is probably of most relevance to a clinician helping children cope with invasive procedures; as an architect I feel that simply reducing the amount of anticipatory anxiety patients experience is an important enough goal to pursue.

A related issue is how engaging in activities can contribute to patients' well-being while they are in a clinic. Considering the problems with the Playroom, particularly its small size, it is remarkable how "normal" it appeared, and how well it functioned for many if not most of the patients. It was not possible for me to do a detailed study of the relationship between a patient's level of activity and his or her psychological state, but based on my informal observations the anger, frustration, boredom, and anxiety that the patients felt seemed to decrease in proportion to the extent that they became involved in activities in the Playroom. The activities that seemed to provide the patients with the strongest coping mechanisms were those that were most absorbing for a particular person or group of people at a particular time, whether it was doing an art project, playing card or board games, or reading. They were activities that engaged the patients and helped make the wait for some enjoyable, for many, more bearable. They provided "flow experiences" (Csikszentmihalyi, 1991), absorbing patients' attention so completely that boredom was

not an issue and seemingly helping them to forget imminent and unpleasant medical procedures, enabling them "for a moment in time" to enter a different world and forget where they were. Developmental research needs to be done to identify the characteristics of different types of flow activities. From such research, we should be better able to design and furnish settings to support the very different physical, cognitive, and psychosocial developmental needs of the various age groups.

While there were many positive aspects of the Playroom, the most significant lesson to be learned from the negative aspects of the Playroom is how important it is to create a setting that is comfortable and safe. Size is the most critical issue, but the furniture, lighting system, flooring, color of the room and even its sound isolating properties have to respond to the needs of a special population, some of whom have significant and critical physical complaints that have to be accommodated for a significant length of time on numerous occasions.

The distractional characteristics of the physical environment also need to be very carefully examined. While many authors have discussed how important distraction can be in helping patients cope with painful medical procedures, none of them made a serious attempt to identify the qualities which make objects in the environment distracting. This is not only a serious oversight methodologically, but more importantly the patients involved in their studies suffered pain needlessly.

The special needs of teenagers has to be addressed. Research needs to be done to determine how the physical environment can be arranged to facilitate social interaction between teenagers so that they can get to know one another. It was clear from my research that proximity was not enough. Teenagers need their own space, provided with materials that are age appropriate so that they can engage in activities that will lead to social interaction and hopefully friendship.

There are certain times during a person's tenure as a patient (or a family member of that patient) when the skills of the clinic staff's as communicators are tested to the utmost. Therapeutic communication is necessary. This therapeutic communication has to take place in a physical environment. Unfortunately almost all of the literature on this kind of communication ignores the setting in which that communication took place. This is a tremendous oversight, and the physical setting in which therapeutic conversation takes place needs to be examined much more closely.

Thom Mayne, a partner in the architectural firm, Morphosis, said of a cancer clinic he designed: "If frightening things go on here, then the architecture should reflect it." (Viladas, 1988, p. 70) At the time I read this statement, I thought it was appallingly ignorant and insensitive, but my reaction was based on an emotional response to the way the building looked rather than an informed and reasoned critique/opinion. My critique of that statement now is that the architect had a woefully undifferentiated understanding of the cancer experience and how the social and physical environment can ameliorate the physical and psychological stress of that experience. But, architects are not the only ones who have an undifferentiated understanding of the hospitalization experience. In general the literature treats hospitalization as a uniformly unpleasant experience. This is not the case, and that is why differentiating the experience by identifying stresspoints is a critical step in helping people cope with hospitalization and illness.

I believe that "In architecture... The End is to build well. Well-building hath three Conditions, Commodity, Firmness, and Delight" (Sir Henry Wotton, *The Elements of Architecture*, 1624, cited in Gloag, 1958, p. 250). Thom Mayne, the architect quoted above, is primarily concerned with the condition Wotton called Delight, and which I interpret as aesthetics, as are many, if not most architects and architectural publications¹,

¹ This issue was raised in a letter to the editors of *Architectural Record* (February, 1997) by Ulrich Franzen, FAIA, who wrote:

The problem with this approach is that while architects such as Mayne, have a very sophisticated aesthetic sense, they have a very unsophisticated sense of, and interest in, the other condition, Commodity, how well the physical environment accommodates human needs. At this point I think it is critical that architects who are designing healthcare facilities become familiar with the transactional world view, and familiar with the literature from the fields of psychology and medicine. Just as importantly the hospital staff has to be aware of the powerful effect the environment can have on how well or how poorly patients cope with the psychological and even physiological journey during hospitalization. And all of the actors involved in creating life affirming environments for patients have to be acutely aware of those stresspoints in time and space when and where patients and their families have to cope with an extraordinary and sometimes an overwhelming amount of stress.

In conclusion, major improvements have been made in pediatric health care environments but still there is much to be discovered and understood before environments are constructed that can accommodate pediatric patients' needs. There has been a voice of authority missing in many of the discussions about pediatric health care environments, the voices of the children and adolescents who will be using them. This study was designed to redress that oversight, and during the research I discovered that one of the most gratifying aspects of working with pediatric patients is that some of them have imaginations that are unfettered by the restraints that most adults work within, and they show a willingness to forgo practicality which can be quite liberating. The beauty of working with patients such as these is that they do not seem to be burdened with the constrictions that most adults have on their imaginations. Their imagination is not confined by what is "appropriate" or

You devoted some thirteen pages to this project (a housing project) with some conceptual site and massing studies and numerous trendy photographs of building facades. There was not a single floor plan of the apartments or the buildings, nor was there a discussion of apartment living arrangements unique to the Japanese culture.
Are the people who live in this complex totally irrelevant? (p.16)

"realistic;" they are able to let their imagination take them where it will. These patients are a resource which designers and architects should acknowledge, cultivate, nurture, and encourage because within a child's or teenager's fantasy often lie ideas which have real potential and power, even after being battered by the realities of the world that professionals labor in.

APPENDIX A

INTERVIEW MATRIX

Name	Age	Gender	Illness	Number of Interviews	Design with CAD or Model
Tammy	5	F	O	2	Model
Amanda	5	F	H	1	Model
Rachel	5	F	H	2	Model
Leon	5	M	O	1	
Dennis	5	M	O	1	Model
Kevin	5	M	O	4	CAD
Evan	6	M	H	2	Model
Jennifer	7	F	O	1	CAD
Maggie	7	F	O	1	-
Barbara	9	F	H	2	CAD
Wilma	9	F	H	1	-
Danielle	10	F	O	1	Model
Beth	10	F	H	1	CAD
Samantha	11	F	H	2	CAD
June	12	F	H	1	CAD
Tiffany	12	F	O	1	CAD
Oliver	7	M	H	2	-
Bob	9	M	O	2	CAD
Edward	9	M	O	2	-
Liam	9	M	H	1	CAD
Zachary	10	M	O	2	CAD
Melvin	11	M	H	1	CAD
Harry	11	M	H	1	CAD
Karl	12	M	O	1	
Francis	13	F	O	1	-
Nancy	13	F	H	2	-
April	13	F	H	1	CAD(only)
Jasmine	17	F	O	1	CAD
Lauren	17	F	O	4	CAD
Amanda	19	F	O	1	-
Bonnie	19	F	H	1	-
Michelle	20	F	O	1	-
Susan	20	F	O	1	-
Beverly	21	F	O	1	-
Ken	13	M	O	3	CAD
Wayne	13	M	H	1	CAD(only)
Brian	14	M	O	1	-
Samuel	14	M	O	1	-
Mathew	14	M	H	1	CAD
Xavier	17	M	O	4	CAD
James	17	M	H	1	CAD
Ronald	19	M	H	1	-
Carl	20	M	O	1	-
Terry	20	M	H	2	CAD
Ned	22	M	O	2	-

APPENDIX B

INTERVIEW SCHEDULE

INTERVIEWEE: AGE: GENDER:

TYPE OF ILLNESS:

COMING TO THE CLINIC SINCE:

DATE:

INTERVIEW

PERCEPTIONS ABOUT THE ROOM

1. HOW DOES IT WORK
2. SIZE
3. COLOR
4. PICTURES
5. LIGHTS
6. RUG
7. FURNITURE
8. WINDOWS
9. HOW SHOULD THE ROOM MAKE THE PATIENT FEEL
10. OPINION OF THE EXISTING PLAYROOM
11. CHANGES OVER TIME

PRIVACY

12. WANT TO BE ALONE

ACTIVITIES

13. SOME THE THINGS THAT YOU DO
14. ANYTHING ELSE THAT YOU WOULD WANT TO BE ABLE TO DO
15. TELEVISION AND VIDEO
16. MIXTURE OF DIFFERENT AGE PATIENTS AT BIG TABLE
17. WAITING

VULNERABLE TIMES

18. DO NOT FEEL GOOD
19. WORRIED OR ANXIOUS
20. NOISE

OTHER

IDEAL PLAYROOM

SCREENING ROOMS

PERCEPTIONS ABOUT THE ROOM

21. HOW DOES IT WORK AS A SCREENING ROOM
22. SIZE
23. COLOR
24. OBJECTS IN THE ROOM
25. PICTURES
26. LIGHTS
27. RUG
28. WINDOWS
29. HOW SHOULD THE ROOM MAKE THE PATIENT FEEL
30. OPINION OF THE EXISTING SCREENING ROOM

31. CHANGES OVER TIME**PRIVACY****32. VISUAL PRIVACY****ACTIVITIES****33. DURING BLOOD DRAWING****34. ANYTHING ELSE THAT YOU WOULD WANT TO BE ABLE TO DO****35. TELEVISION AND VIDEO****36. PICTURES ON THE WALL****37. WAITING****AUTONOMY AND CONTROL****DISCOMFORT****38. TEMPERATURE****39. EXAM TABLE****40. LIGHTS****VULNERABLE TIMES****41. NOISE****IDEAL SCREENING ROOM****EXAMINATION ROOMS****PERCEPTIONS ABOUT THE ROOM****42. HOW DOES IT WORK****43. SIZE****44. COLOR****45. OBJECTS IN THE ROOM****46. PICTURES****47. LIGHTS****48. RUG****49. WINDOWS****50. HOW SHOULD THE ROOM MAKE THE PATIENT FEEL****51. OPINION OF THE EXISTING EXAMINATION ROOM****52. CHANGES OVER TIME****PRIVACY****53. VISUAL PRIVACY****ACTIVITIES****54. DURING EXAMINATION****55. DURING SPINAL TAP****56. DURING BONE MARROW****57. DURING CHEMOTHERAPY****58. ANYTHING ELSE THAT YOU WOULD WANT TO BE ABLE TO DO****59. TELEVISION AND VIDEO****60. WAITING****AUTONOMY AND CONTROL****DISCOMFORT****61. TEMPERATURE**

- 62. LIGHTS WHILE LYING ON THE EXAM TABLE
- 63. EXAM TABLE

PAIN

- 64. HOW DOES IT WORK AS A SPINAL TAP ROOM
- 65. HOW DOES IT WORK AS A BONE MARROW ROOM
- 66. HOW DOES IT WORK AS A CHEMOTHERAPY ROOM

IDEAL EXAMINATION ROOM**IDEAL SPINAL TAP ROOM****IDEAL BONE MARROW ROOM****IDEAL CHEMOTHERAPY ROOM****HALL****PERCEPTIONS ABOUT THE HALL**

APPENDIX C

PORTION OF A PATIENT'S INTERVIEW

Bill: What could you do to that ceiling to make you feel more relaxed?

Beth: Umm.

Bill: You mentioned colors and changing the color of the light, is there anything else that you can think of? Because you have a lot of great ideas.

Beth: Umm, I could, if I would do that I would like to umm, umm, a whole, like half, like a rainbow or something, like different colors from here to here. [indicating on the ceiling where she would like the rainbow] and then you know if it was like an imaginary sky you would paint it light blue.

Bill: OK.

Beth: Oh and also we could put umm, you know those posters in each of the rooms that would make them feel good or something like I said Shaquille O'Neal going to the doctor or Patrick Ewing or Michael Jordan.

Bill: OK. That's a terrific idea.

Beth: And umm, so it's mixed with sports and happiness.

Bill: Sports and happiness.

Beth: And it is also cartoon...

Bill: OK.

Beth: ...so it wouldn't be that realistic.

Bill: OK. What about the floor?

Beth: The floor. The floor we could make it different colors like when you hit the pinball, you go, the pinball goes in the hole?

Bill: Yeah.

Beth: The, the, there's like a screen that lights up different colors...

Bill: Yeah.

Beth: ... like a computer or something. You could make the floor different colors like, or we could make diagonally, this, uhh, this part from here.

Bill: Yeah, from the corner.

Beth: To here, over here, to this corner.

Bill: Yeah.

Beth: Sort of different colors, like a design, you make it, or we could make all this floor like uhh, like this color.

Bill: Ok, that's #10.

Beth: #10 and umm then like make shapes or uhh, or figures like, uhh, shapes umm, like umm different colors.

Bill: Ok.

Beth: And you could also make umm, you know like little doctors or if the kids like Super Nintendo, Mario floor or Princess Toadstool, or like make it all Mario like, or for Super Mario you paint all this floor white and then diagonally there's a head of Mario, Yoshi, Baldur, and all the enemies so it would be like a Nintendo floor...

Bill: Nintendo floor. Ok.

Beth: ... and uh, for poster you could put Mario or Yoshi, or both of them.

Bill: Yeah, that would be some room wouldn't it?

Beth: Yeah.

Bill: ---- pretty good. Ok.

Beth: Cause that's pretty good.

Bill: Yeah, that would be a pretty nice environment

Beth: And if the, if umm if you couldn't make Mario or anything you could put some other characters like the Flintstones or Jetsons.

Bill: Ok.

Beth: Or even you could umm, walls, you could paint it like umm, like you know the uhh the car the Jetsons' have.

Bill: Yeah.

Beth: And make like a big size Judy and Jane, all the family.

Bill: Ok

Beth: And you could paint the whole room blue and put like dots like stars and planets so, and um you look at the floor ... and you could paint it like --- like moon craters.

Bill: Ok. Wow.

Beth: So and so they wouldn't get scared like a ---, cardboard, you could put like on it, not on it, like this but umm over here in front of the...

Bill: In front of the table?

Beth: Yeah, like if it was a spaceship or something?

Bill: Ok.

Beth: You know it would be a fun room to enter in.

Bill: Ok.

Beth: Each child likes space stuff and all that.

Bill: Yeah.

Beth: So it would be pretty good to have a different cartoon...

Bill: Yeah.

Beth: a room with cartoons, and umm colors, and neon colors, and you could make instead of realistic you could mix childish, babyish, and umm, and umm kinda funny, like umm a penguin in a tuxedo, a panda bear wearing a tie, you know like a blue bow or something.

Bill: Ok. [laughing]

Beth: Or maybe a grizzly bear with an arrow and bow like this, [she acted like she was holding a bow and arrow] like Geronimo.

Bill: Ok.

Beth: And it has a big wig on it like that and it has a big band of feathers on it. And with flowers or trees. The trees could have nests in them and you could make a cartoon hummingbird and put "Why doesn't the hummingbird uh, uh, why does the hummingbird hum? Because he doesn't know the words." Like make it joyful and, and funny, and make it like a **kids' world** like... [she said this with emphasis and feeling]

Bill: A kids' world.

Beth: You make all the things that kids like and babies too so they'd be all mixed and um it would be a good playroom.

Bill: Ok.

Beth: So, it would have a lot of kid's styles on it. It wouldn't just be a baby style or kid style. It would be mixed.

Bill: It would be mixed.

Beth: And mixed with the real life nature.

Bill: Ok.

Beth: So it would be a fun place to go.

Bill: It sounds like it would be a very fun place to go.

Beth: Yeah.

Bill: And this is like the exam rooms too or just the playroom?

Beth: Umm, oh the exam rooms would be like each time a kid enters it, it is like a whole new world painted with characters and, and a sports men and umm. For like, you could have like for babies that umm you know put checkups in each side like --- room, you know, cause, and make it like babyish so it wouldn't be so scary in it. It would be like colors, like you could paint Big Bird and Cookie Monster...

Bill: This is for the babies?

Beth: Yeah. And you could also umm, you could also umm, paint Perzoobiles you know there is this show called Zoobily Zoo and TLC. It's in the learning channel on cable, channel 32. And um there like animals but people are dressed in them and they sing and all that stuff. They have a good place like if, if um, if the kids like candy, make like a little Candy Land.

Bill: Ok.

Beth: Make um, when you enter there could be like big candy canes, peppermint up there and make it like candy so if they like candy or anything.

Bill: Ok.

Beth: You each show them a room, which one they like.

Bill: Which one they like. Ok. They get to choose.

Beth: And they could choose, and you could also put um outside like which one was the Jetsons, the Flintstones, the Simpsons, which one was it. And put like a character on it.

Bill: Ok. Outside the room?

Beth: Yeah and put like this [making a welcoming gesture with her hand] so it would come in.

Bill: So they sort of welcome you in?

Beth: Yeah, and it was, if it was Judy outside like this [making a welcoming gesture]

Bill: Ok, with her hand out.

Beth: Yeah. It would be fun, you know.

Bill: Ok, so I was going to ask you what you'd like to do with the hall or what you thought about the hall...

Beth: The hall could be like a different dimension of something like..

Bill: A different dimension.

Beth: You know of the cartoon's world and make it ah, each one of the cartoons on the side...

Bill: Yeah.

Beth: ... and the colors, the color of the floor very colorful. Different colors and you could make a lot of umm, you know, making it look like a different galaxy of kid's world. Like if it was Mick World, like let's say...

Bill: MickWorld?

Beth: Yeah, in MacDonald's World. They say that it could happen that a kids' world, your world that you would like, you know...

Bill: Ok.

Beth: ... that school would be fun and you know in the water fountains filled with shakes, MacDonald's shakes.

Bill: Ok.

Beth: And um all those umm, and Michael Jordan would be the coach for gym and all that stuff. First they say that school could be squashed by a giant dinosaur, like there is a big school you know they put like a raptors foot on it and then they squash it but then they pump it, they pump, it pops up again and it says maybe a different school. It could be a very fun school, like Michael Jordan as the coach, um and a bunch of celebrities as the um, as teachers, so it would be like that you know each one, you know. Judy is like here and is waving into this room, you know.

Bill: Ok.

Beth: From here [indicating a place outside an exam room] you could paint that part um, um something that matched with Judy's dress.

Bill: Ok.

Beth: And if Flintstones was here [indicating another room] Put Fred there or Wilma and Paint it like orange or so it matched with something.

Bill: I see, OK.

Beth: So it would be very colorful and when you came to over here it's like playland or something. So...

Bill: When you come into the playroom.

Beth: Yeah. You'd have a lot of stuff to play with and good things and it would be fun like a different kind of world. Instead of the outside that you know you look at it and everything is kinda like adult like...

Bill: Yeah.

Beth: ... and you look at it and it, it all matches.

Bill: Yeah.

Beth: Like blue and, and um it then, and then it's purple or black, like, that if it matches...

Bill: Yeah.

Beth: ...I asked my Mom and she said that blue matches with black. So it is kind of, everything matches in the adult world, not everything but um in the, over here it would be different. Every door is painted some color.

Bill: Ok. So it wouldn't match? It'd be...

Beth: Yeah it would be

Bill: Ok.

Beth: It would be good. This over here all colorful and all that stuff. Over here you again??? and there is a lot of color and excitement and posters and a lot of more space in the room. That would be good.

Bill: That sounds like a terrific place. Wow. [we both laugh]

Beth: So that's about it.

Bill: That's about it huh?

Beth: Yeah.

APPENDIX D

INTERVIEW WITH THE STAFF

1. What do you think about the exam room?
 - How well does it work for an exam?
 - How well does it work for medical procedures?
 - Bone marrows
 - Spinal Taps
 - How well does it work for conferences with the parents?
 - Telling them that their child has cancer.
 - Telling them that their child has relapsed.
 - Telling them that their child is going to die.
 - What do you think about the color or the room.
 - Are there any colors the room should not be painted?
 - What would you think if the room was turned into a "kid's world?"
 - What do you think about the tiles on the floor?
 - What if there was carpet instead?
 - What do you think about the lights?
 - Have the kids ever complained about the lights?
 - What do you think about the windows?
 - If you have a choice do you choose a room with a window or without a window? Why?
 - How should patients feel when they walk into the room?
 - How should doctors feel when they are in the room?
 - If you could change the exam room in any way to make it "perfect" how would you change it.
3. Do you ever need a place for to get away from the clinic?
2. What do you think about the staff room?
 - What kinds of activities occur in there?
 - How well does it work for those activities?
 - What do you think about the lights, color, floor covering?
 - How should you feel when you are in the room?
 - Do you feel like that in the room as it is now? Why? Why not?
4. Overall how well does the clinic work for you?
 - What do you think about the layout of the spaces: the relationship of the staff office to the exam rooms, the

relationship of the staff office to the playroom, the relationship of the exam rooms to the playroom.

5. What do you think about Clinic Coordinator's Office?
How well does it work for you?
6. What do you think about the hall?
Do you ever do any work in it?

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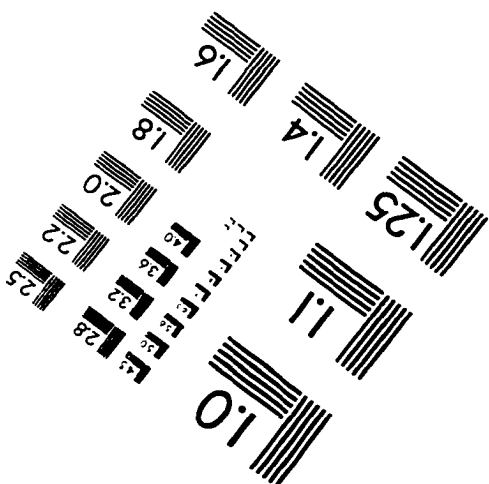
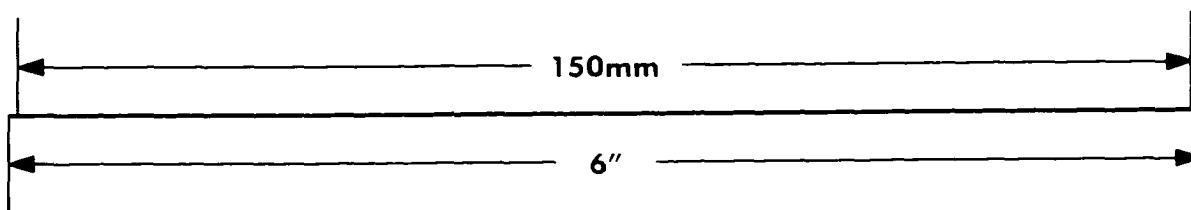
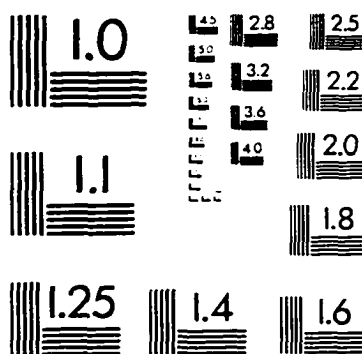
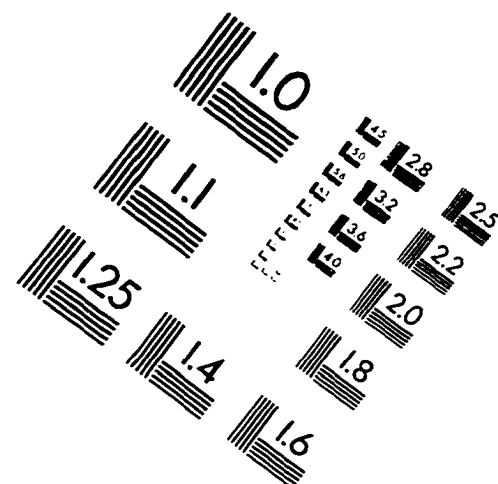
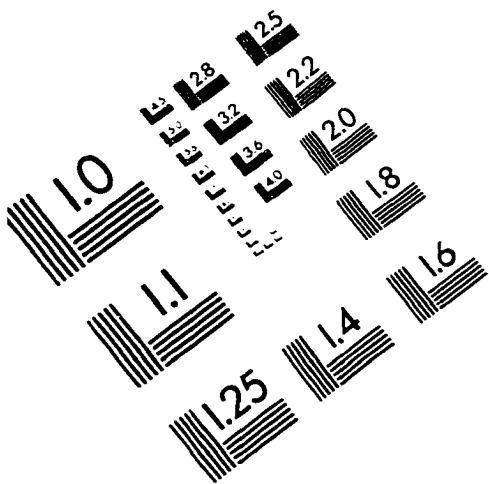
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IMAGE EVALUATION TEST TARGET (QA-3)



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