

Definitions

The word "hospice" comes from the Latin word *hospes*, meaning to host a guest or stranger. Another source mentions that The word "hospice" stems from the Latin word "*hospitium*" meaning questhouse which was originally used to describe a place of shelter for weary and sick travelers returning from religious pilgrimages, as was the *khanqah* in Islam which meant a rest room.

The name hospice was first applied to the care of dying patients by Mme Jeanne Garnier who founded the Dames de Calaire in Lyon, France, in 1842.

In 1967, Dame Cicely Saunders started St Christopher's Hospice after being inspired by a patient, David Tasma, whom she met in 1948 when he was hospitalized with an inoperable cancer and she, a former nurse, was working as a medical social worker. The two had discussed how she might one day open a place that was better suited to pain control and preparing for death than a busy hospital ward. When he died, he bequeathed £500 and told Saunders, "I will be a window in your home." Since then her ideals have spread around the world, which gave her the reputation of being the founder of the modern hospice movement.

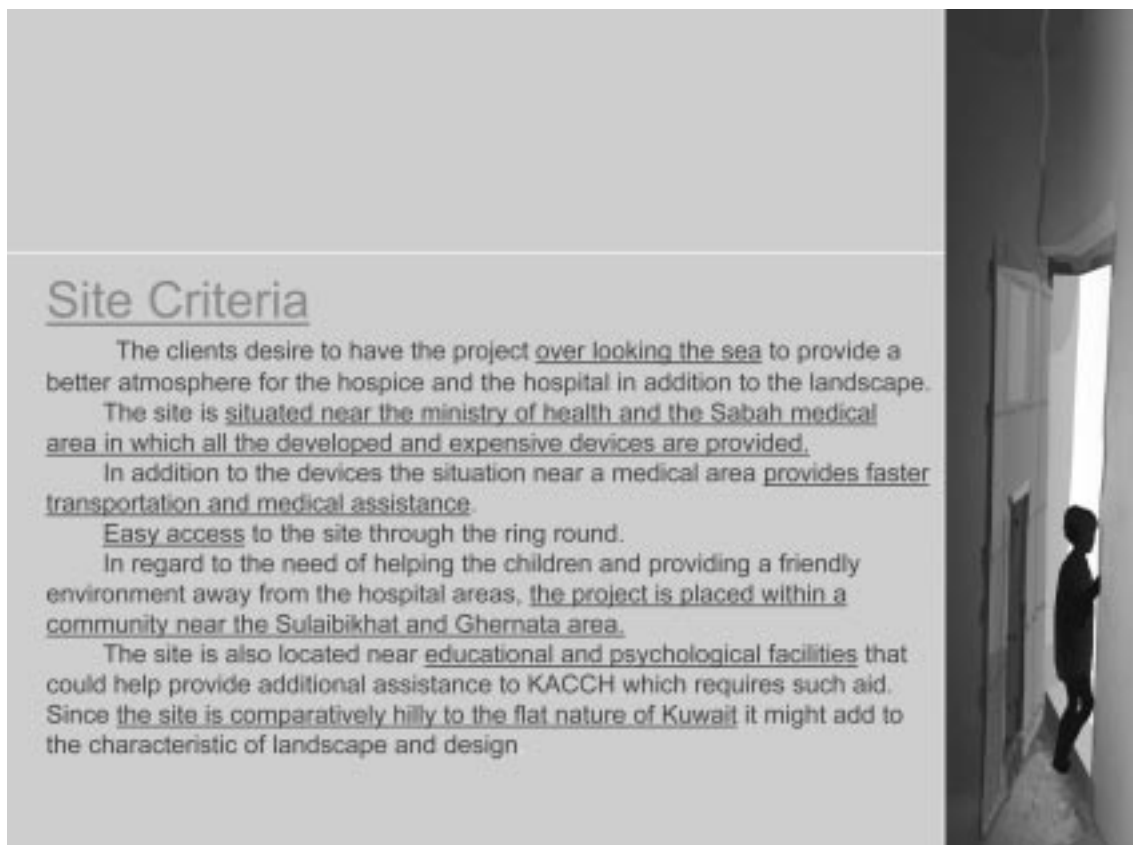
On the other hand in Islam, research seems to indicate that hospices did not exist during Islamic times as an independent building type. most were either incorporated into larger structures as wings or parts of mosques, madrasas, khans or caravanserais, palaces and mausoleum complexes.

Some accounts associate the name of the early Umayyad caliph al-Walid I, who ruled from 705 to 715 (86-96 H), with the founding of a hospice, possibly a leprosarium, in Damascus. Other versions, however, suggest that he only arranged for guides to be supplied to the blind, servants to the crippled and monetary assistance to lepers.

and due to its complex nature the hospice care is related to different definitions:

- **palliative care:** the active, total care of patients as opposed to curative care
- **bereavement:** The state of being bereaved; deprivation; esp., the loss of a relative by death.
- **death and children** in this projects case.

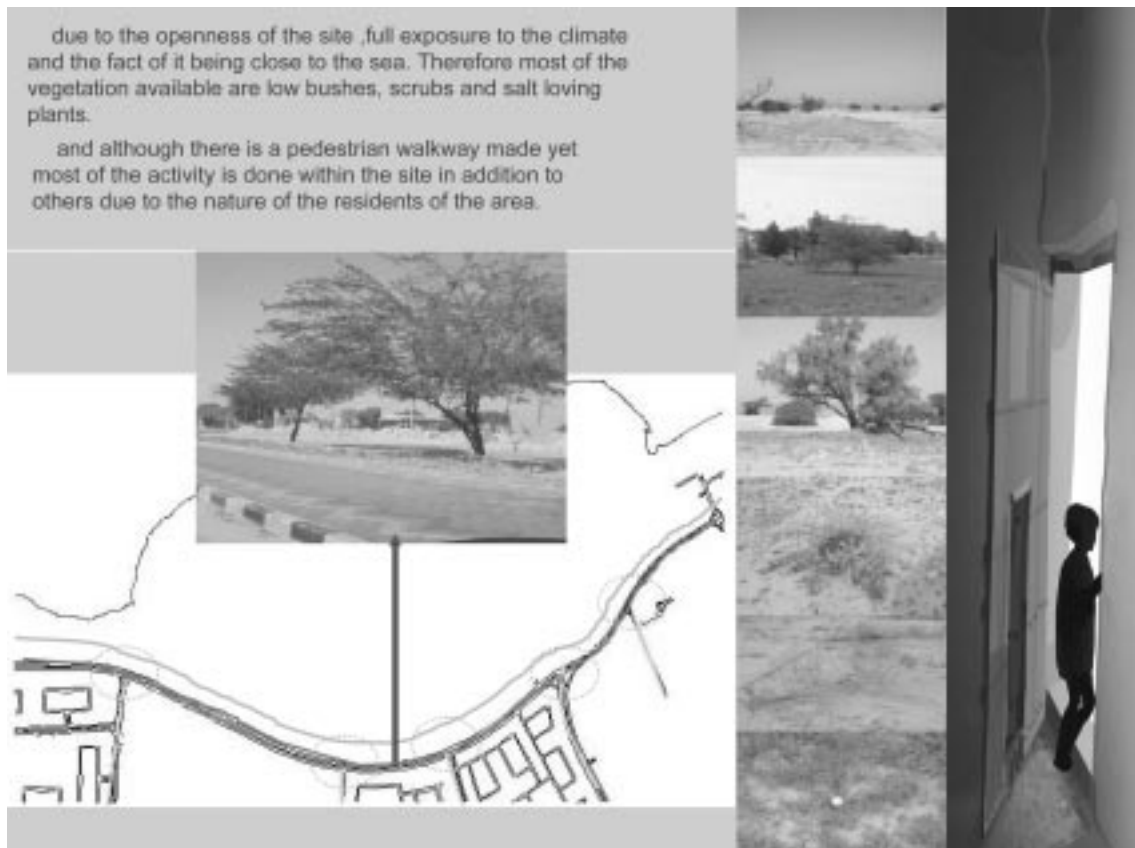


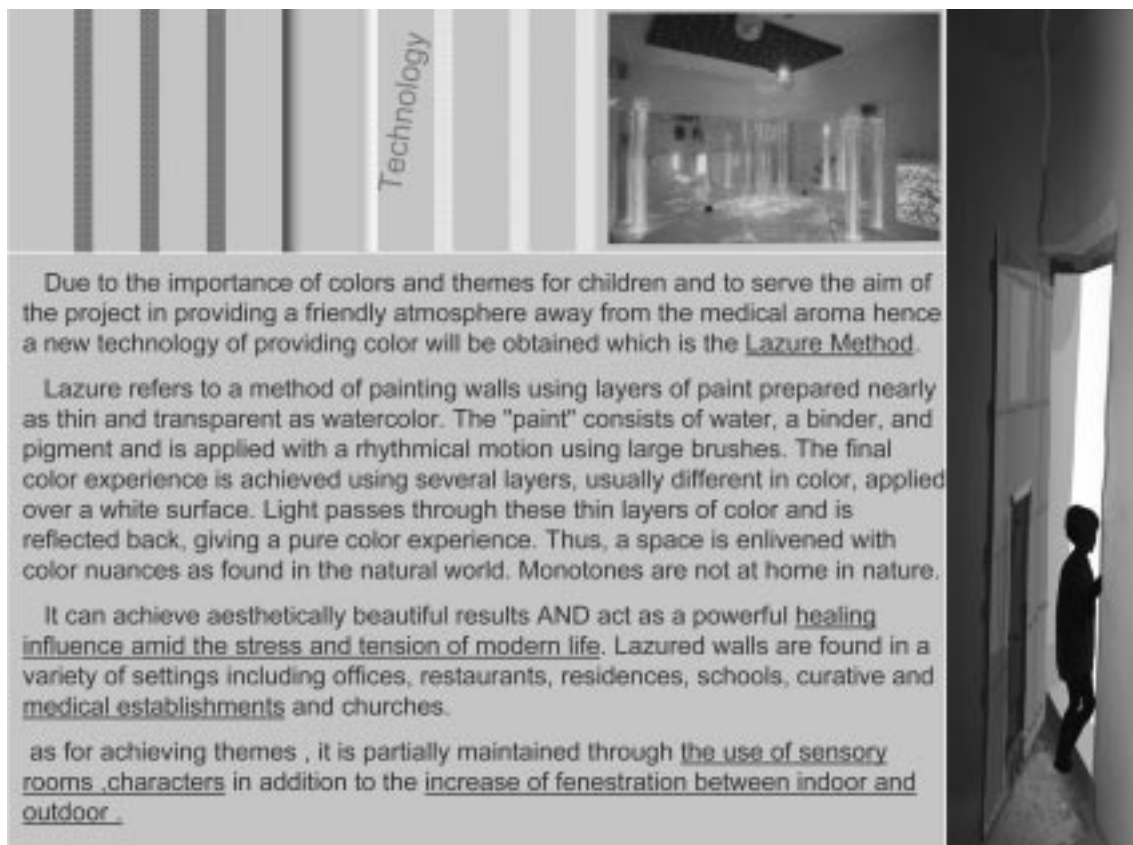
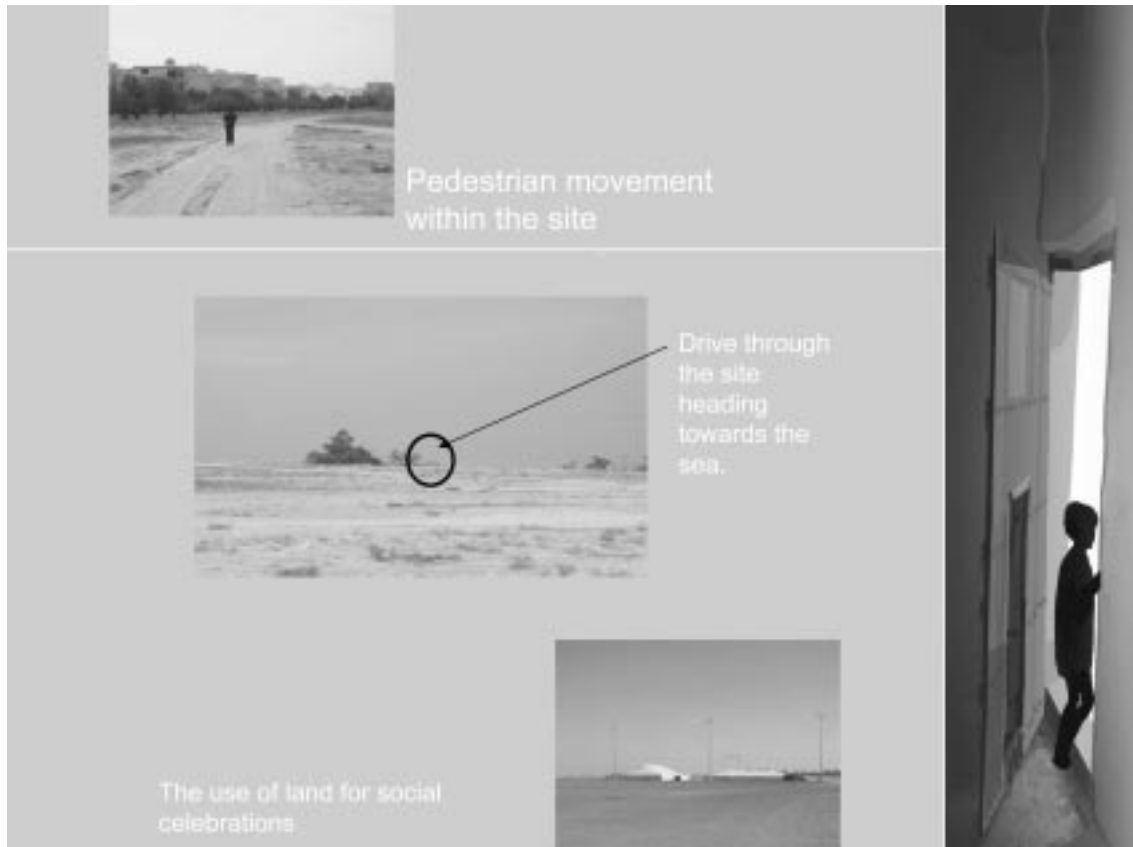




due to the openness of the site ,full exposure to the climate and the fact of it being close to the sea. Therefore most of the vegetation available are low bushes, scrubs and salt loving plants.

and although there is a pedestrian walkway made yet most of the activity is done within the site in addition to others due to the nature of the residents of the area.









a new approach in hospice design is exemplified in the Macmillan Green concept which is :

"Based on a central activity area, acting as a meeting place during daily routine, where communal activities are developed and social contacts generated.

The Green forms the hub for each development and it is an integral part of the unit giving access to all facilities within the centre. Hence, offering an in-built flexibility which allows a project to be tailored to a particular site.

It is provided in this area a reception area and a wide range of social and recreational activities. In which possible screens, plants and mobile storage units enable staff to arrange spaces controlling privacy and access."

Brochure published by Cancer Relief, Macmillan Fund obtained from Mrs. Rana Hammad at Al-Malath hospice in Jordan who used the same concept in their design)



The Design

concept

design

In the name of Allah, Most Gracious, Most Merciful.

2."He who created death 5556 and life, that He may try which of you is best in deed: 5557 And He is the Exalted 5558 In might, Oft-forgiving:-"

sura LXVII.  
Mulk, or Dominion

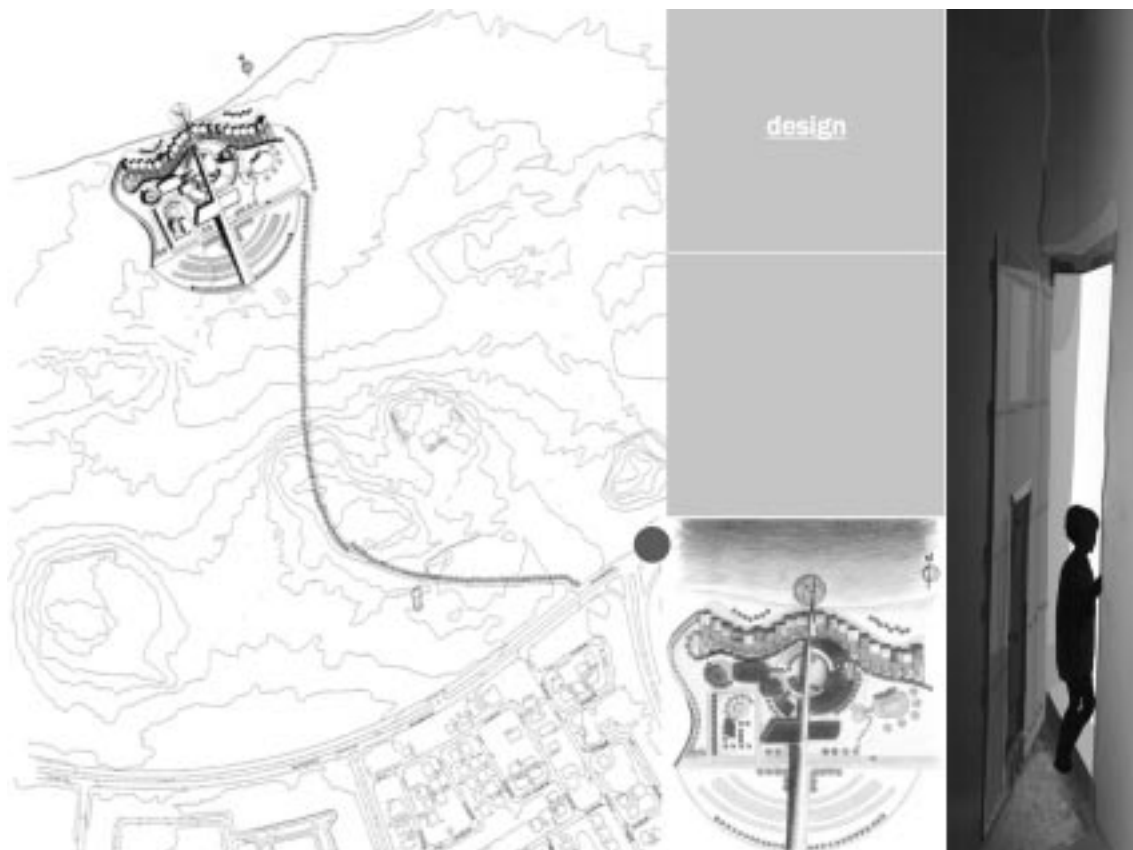
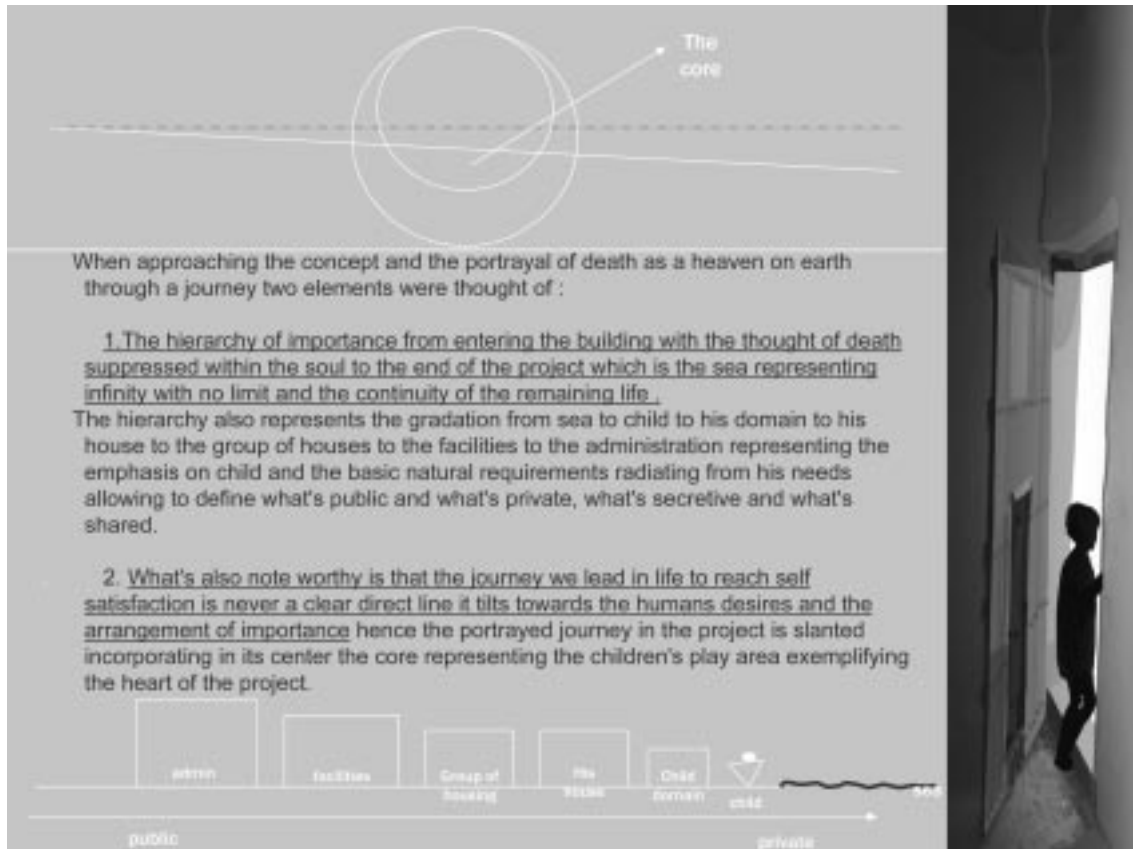
Death therefore is here put before life and it is created being not merely a negative state, better described as the state before life began, which may be non existence or existence in some other form. It is also the state in which life as we know it ceases, but existence does not cease ( a state of partition) after our visible death and before judgment; after that will be a new life which we conceive of under the term eternity.

From this I wanted to create with a building a structure that is to be erected for many years to come that ironically represents death, death of children that themselves exemplify the future. creating a loop of contradictions between the new and the old, the future and the present, the hope and despair.

all these dilemmas experienced via a journey that is never straight but is tilting towards the path we choose.

Bayt Abdullah is this hierarchical journey its the start of realization of what we were, are and can be through the eyes of the future the eyes of children, (dying children).

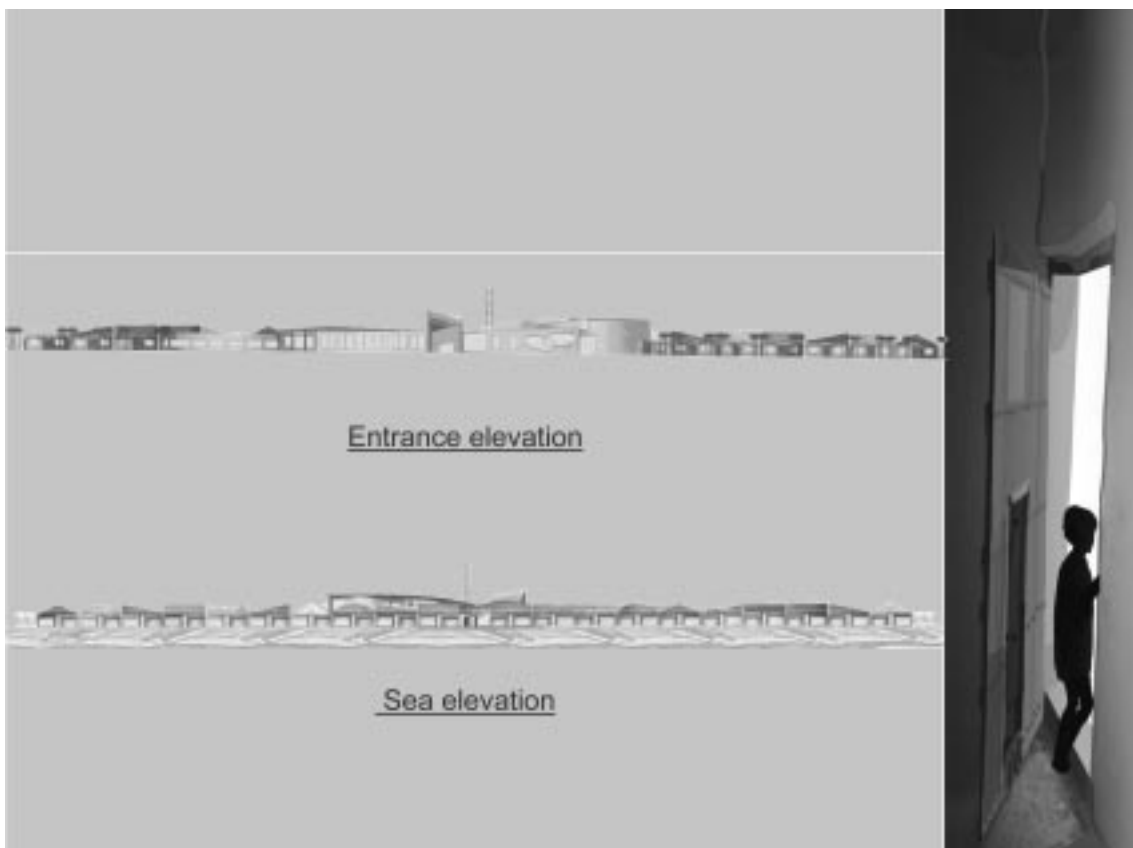
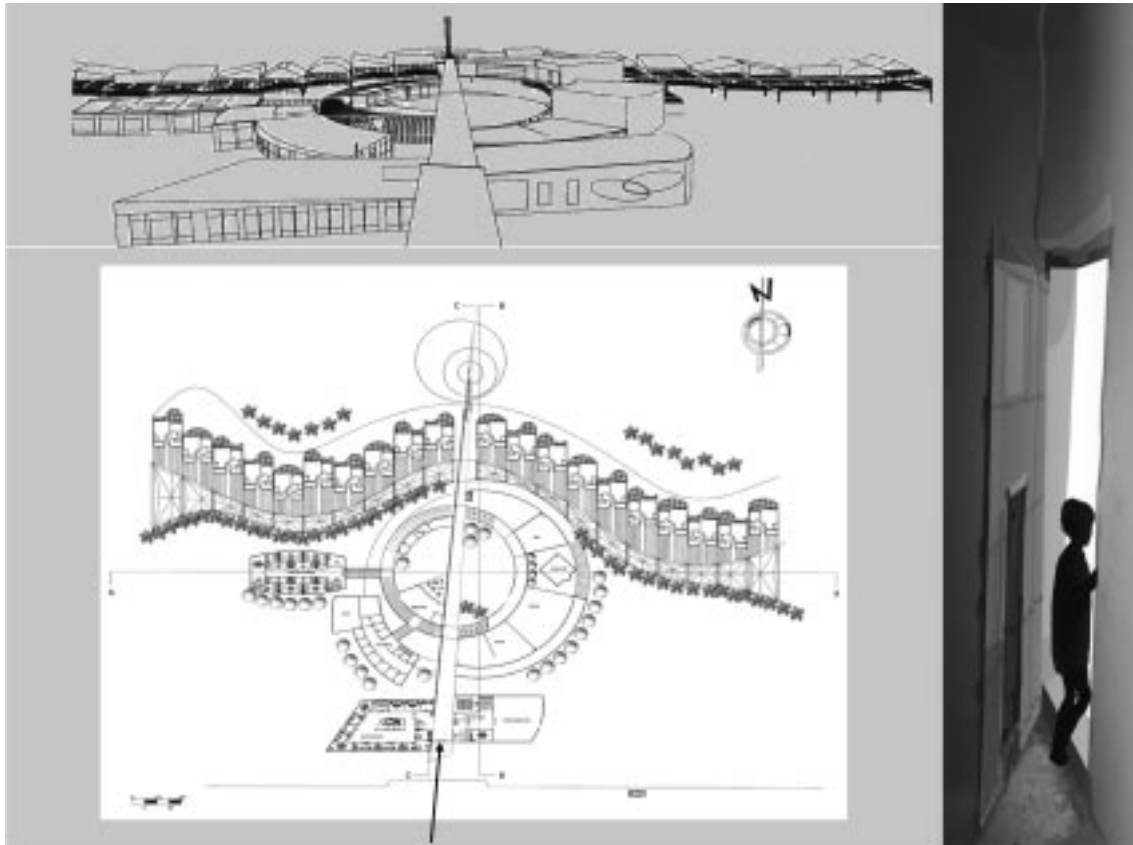




A proposal for a children's Hospice

E10

WORKSHOP X

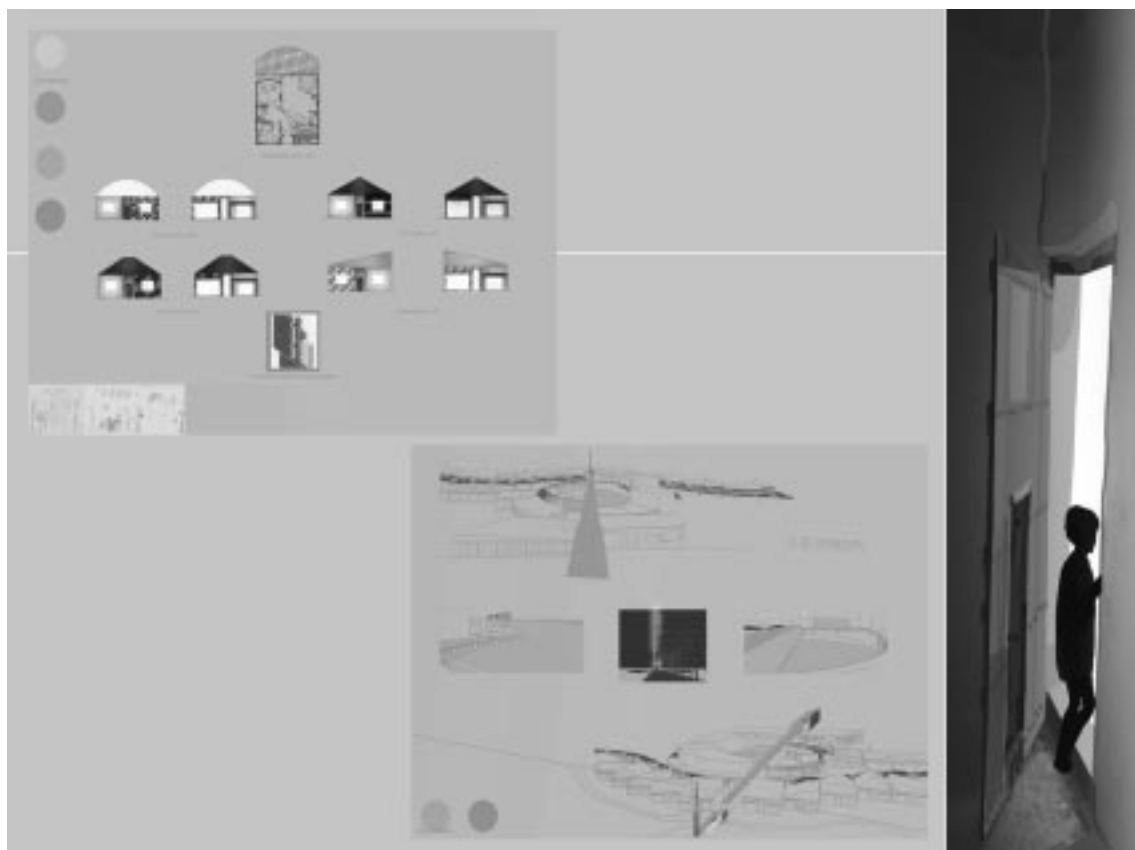
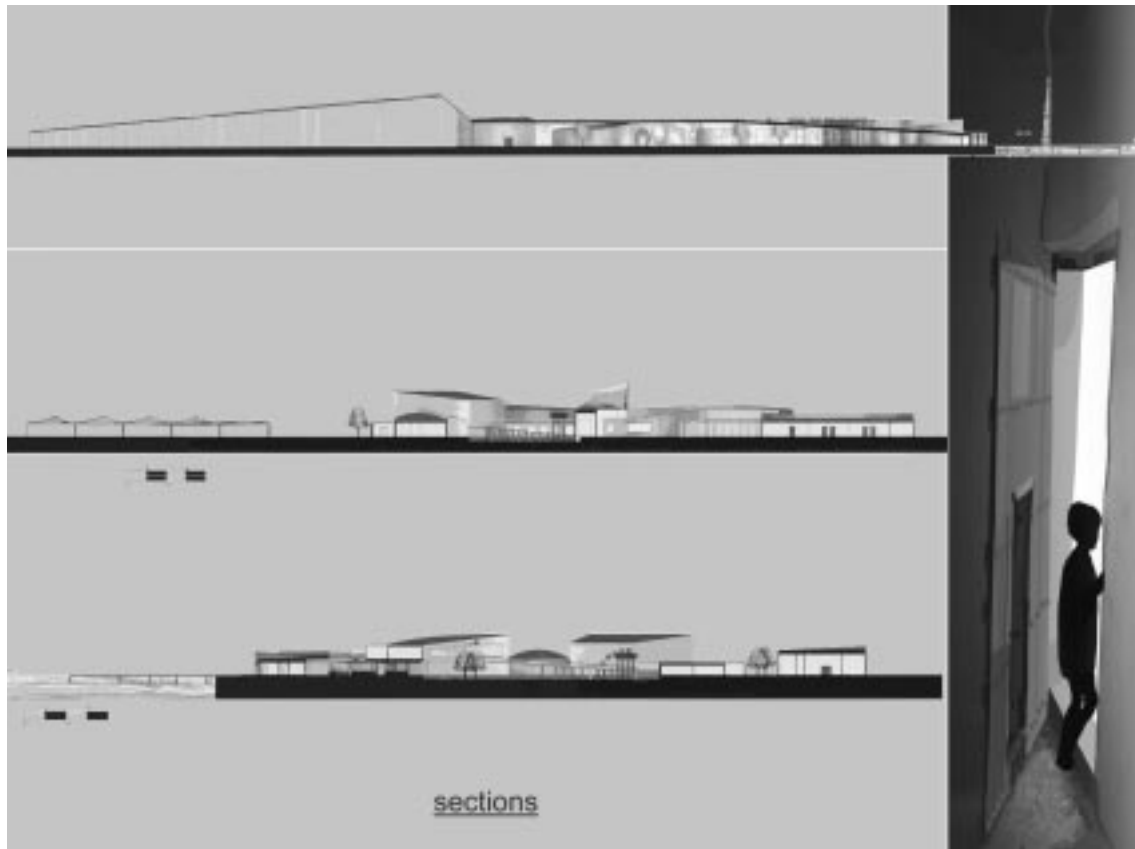


Entrance elevation

Sea elevation



A proposal for a children's Hospice



E10

WORKSHOP X

## conclusion

As a conclusion this project deals with different components each has its own individual character and objectives yet together they provide a complex that serves the child, which in return represents the future of society, hence allowing the integration of architecture in serving the community through a new approach in Kuwait. Based primarily on charity, secondary on children and finally representing environmental psychology .

More specifically the hospice is a concept of providing a home away from home to an ill child and a tired parent (mentally and physically) therefore its the ability to house the psychological needs within an atmosphere that is a mixture of contradictions that raise beauty from ugliness, light from darkness, hope from disappear, LIFE from death.

Love is a star in a mother's eye  
Happiness is when love around you shines  
Joy is the sliver of light at night  
Hope is when others for you, they try.

## Creating Healthy Places for Sick Children: Models for Child Friendly Hospitals

*Edna Mitchell, Linda M. Perez, Nancy Sonleitner, Marie-Anne Glavan*

E10

WORKSHOP X

### I. Introduction to Child Life In Hospitals: The Profession and Practices of the Child Life Specialist.

*Nada was a 12 year old girl, hospitalized for many months with severe injuries after being hit by a school bus. Many broken bones and internal injuries required multiple surgeries and, as she began to recover, daily physical therapy. She was from a rural community and was unable to return home during this period of hospitalization. Her sister stayed with her as much as possible, her father and other family members visited when they could. Nada became increasingly depressed as the weeks wore on, she took no pleasure in what the Child Life Specialist tried to provide for her enjoyment. She just wanted to get out of the hospital and go home. Finally, she reached such a low period that she would not talk with people. On a daring inspiration the Child Life Specialist proposed that she be taken by ambulance and wheelchair to a local shopping mall. The father resisted believing people would look at her, but he finally agreed to let them do it once with her sister and the CLS going along. The change in her affect was almost immediate, she became interested in the trip and once at the Mall her smiles, laughter, and conversation began to emerge. A second trip was planned for the following week, and again each weeks for the subsequent term of her hospitalization. Nada began to plan the trips with her sister – how much money they would spend, where they would shop, where they would have a snack. On one trip Nada's father went along, and nearly wept when he saw his daughter regaining her former happy, spontaneous, confident self. Eventually she was able to return to her home and school, but the family believed the individual program and attention given by the Child Life Specialist was as important to Nada's recovery of life and happiness as was the superior medical treatment she received. This is but one illustration, and perhaps not as uncommon as it may seem, of the ways in which Child Life programs in hospitals promote recovery of the whole child, supplementing medical treatment. This story needs to be seen in a context of the culture of the Arabian Gulf, Abu Dhabi Emirate, where families have a very short history of experience with western medicine and lengthy hospitalization. The content to follow offers historical and current information about how Child Life helps create hospital environments that are "child friendly" and yet responsive to and appropriate for different cultures around the world.*

#### **What is a Child Life in Hospitals Program, and What is a Child Life Specialist?**

This paper will provide a picture of a relatively new profession and the components of a child friendly hospital environment supported by a Child Life Program staffed with trained Child Life Specialists. It will also address emerging efforts to create culturally appropriate Child Life programs in other parts of the world, focusing particularly on the United Arab Emirates in the Arabian Gulf. Briefly, the Child Life Specialist (CLS) is an individual who is a non-medical advocate and developmental specialist working with chronically ill and hospitalized children and their families. Usually this person works in the hospital and is a valued part of the treatment team, but is not responsible for

medication, medical procedures or medical treatment, although he/she can be an important support to the child in retaining dignity and control during those medical events or invasive procedures. The CLS does not usually wear a clinical uniform as a doctor or nurse, but rather dresses in normal clothing to communicate a non-threatening, nurturing presence to the child. The profession has expanded beyond the hospital as increasing numbers of CLS professionals are now working in out-patient clinics, rehabilitation centers, hospices, and non-hospital healthcare centers providing help to children and families facing stressful situations where CLS skills are appropriate.

In the United States, alone, over three million children are hospitalized each year. The hospitalization may be scheduled or it may come suddenly, but in almost all cases it represents a life disruption, a crisis, and emotional stress for the child and the family. Child Life programs in hospitals help reduce the vulnerability of the child and of the family, and provide services that facilitate the delivery of good medical care and the speedier recovery of the patient. While play is central to the work of a CLS, the specialist is neither a volunteer “play lady” nor a certified Play Therapist. The former usually has no professional foundation in working with the wide range of challenges facing chronically ill children. The certified play therapist uses specific techniques and environments to address, through play, the psychological problems in a child’s life, but does not provide the wider range of therapeutic play services for children and families that focus on developmental needs as well as crisis responses. Neither is Child Life in hospitals merely a program of entertainment featuring puppet shows and clowns, although occasional visits from these entertainers may be appreciated by the Child Life staff and the children who are able to enjoy it them.

For a clearer understanding of the role of the CLS, the Child Life Council provides the following definition of Child Life services, and a rationale for those services: (\*in this statement *child* refers to infants, children, and youth. See the Child Life Council listed in websites.)

*“Child life services in healthcare settings strive to promote optimum development of children and their families, to maintain normal living patterns and to minimize psychological trauma. As integral members of the healthcare team in both the ambulatory care and inpatient settings, child life staff provide children opportunities for gaining a sense of mastery, for play, for learning, for self-expression, for family involvement and for peer interaction.”*

### Rationale

- *A child’s healthcare encounter can at times be a positive growth experience when truly comprehensive care is given. Such comprehensive care by definition includes child life services staffed by appropriately educated and trained personnel.*
- *Interruption of normal life experiences can jeopardize growth and development.*
- *Physical limitations of illness and healthcare encounters have the potential to invite dependency and can erode self-esteem.*
- *Anxiety and stress related to illness, separation, hospitalization, and medical encounters interfere with a child’s optimal response to medical treatment and care.” (ChildLife Council, rev. December 2001)*

The CLS focuses on the emotional and developmental needs of children and families, seeking to reduce the stress often associated with healthcare experiences. The CLS is trained in child development and psychology, in multi-cultural issues and communication, and has practical experience working with children and families both in and out of healthcare settings. This provides a background for the CLS to use developmentally appropriate play techniques, communication skills, and medical knowledge to enable children cope with medical crises as well as to support the continuation of their normal development as children.

One nurse reported that “as nurses or physicians, we don’t have the in-depth time to spend helping a

child to relax and understand what's going to happen.” While a physician may explain a procedure once, children often need to hear an explanation several times in order to absorb it.

Recent literature and research have documented the many ways in which children and families are traumatized through hospitalization of a child. The seriousness of the child's illness or the length of the stay in the hospital are not necessarily consistent with the degree of anxiety and the harmful emotional effects experienced by the child and the family. The sights, sounds, smells, equipment, staff uniforms and behavior characteristic of the modern hospital are all unfamiliar and threatening to most people, but these are especially overwhelming for young children regardless of how serious the illness or how invasive the treatment.

In the hospital playroom the child is given an opportunity to play with familiar toys and materials in a setting designed to be comfortable and cheerful. There may be several playrooms in order to accommodate different ages of children. For non-ambulatory children, play activities are brought to the patient's room or other activities are provided that address the psycho-social needs of the young patient. The CLS trains volunteers and monitors the program in the playroom and in the patients' rooms.

While play is essential for the well-being of every child, the CLS is trained to use play techniques for specific purposes to reduce the child's anxiety surrounding the medical procedures and treatment to be used. This type of play is referred to as “medical preparation play” and is used for rehearsing and familiarizing the child with what lies ahead. Medical play is also used by the CLS in assessing the child's understandings, anxieties, and concerns that are often revealed through play but not expressed in conversation. Observations of the child by the CLS provide invaluable insights for the medical team with regard to ways in which to better address the child's recovery.

**Working with families.** The CLS is not a staff social worker, but often finds it necessary to work as a liaison for the medical team with the family. In cases where a child has a terminal illness, and family attention is focused on the sick child, the emotional needs of siblings may be overlooked. The CLS is attentive to the dynamics of the family and may be able to facilitate these relationships through observation, discussion with family members, support groups for siblings and other techniques.

The CLS often needs to work with hospital administrators to promote policies which encourage unrestricted parental visiting, rooming-in and parental presence. This is important in every culture, but the policies enforced by many hospitals often appear uncooperative for families particularly those of non-western cultures. Modifying those policies is most often in the best interest of the child as patient and the family as primary support group. The CLS may be the one member of the staff who can involve the family and the patient in the child life plan and who can provide developmentally appropriate explanations to the family and the child about the sequence, nature and reasons for procedures and routines.

**Emerging areas of specialization.** As Child Life has become a recognized field over the past decades, the need for certain areas of specialization have become more evident. For example, the field of infancy, neonatal care, and infant mental health is emerging as an important area of training in Child Life. The new program in infant mental health offering training for persons working with newborns and infants, and centered at Mills College, will apply research from Harvard Children's Hospital in the field of infant mental health beginning in the neonatal unit. Also, pediatric care does not stop with the school aged child but covers youth through the adolescent years. Adolescent patients require a different kind of emotional/cognitive/social and recreational support when chronically or terminally ill and when hospitalized than do younger children. This awareness has led to a much broader definition of preparation and professional skills than when the field focused on the pre-school and pre-adolescent child. Emotional needs are different; cognitive skills, understandings,



imagination are qualitatively different for adolescents as compared either to the young child or the adult patient. Physical needs are different as well with the arrival of puberty, hormonal changes, and new emotional/sexual needs. These are not patient conditions usually addressed by either physicians or nurses except in an expedient, cursory way. The CLS brings the expertise and responsibility for finding appropriate avenues to help the adolescent cope with the physically debilitating experience of the hospital and the psychologically depressing experience of physical debilitation.

The Child Life Specialist, then, is expected through training, education, and clinical experience to bring to the hospital the ability to assess the psychosocial needs of children and families and to provide appropriate therapeutic relationships and activities to meet a host of individual needs. It is the responsibility of the CLS to create a child friendly environment in the hospital – to provide a protected and healthy space in the hospital in support of sick children.

## II. Background and History of the Field.

**The Early Years.** In the early decades of the 20<sup>th</sup> century as urban hospitals began to serve an increasing population of pediatric patients, the trauma for children who were ill and hospitalized touched the hearts of families, medical practitioners, and others involved in child health. The environments in those early hospitals were clearly not designed for the young child. The child who entered the hospital for short or long term treatment found no response to normal developmental needs and little understanding of how to help a child cope with the strange and frightening world of the hospital. Some hospitals did establish informal play programs, usually staffed by volunteers. The first Child Life program in the United States was established in 1922 at C.S. Mott Hospital in Ann Arbor Michigan as a child play program. Columbia Presbyterian in New York City in 1929, and Montreal Children's Hospital in Quebec in 1936 had made efforts to create play opportunities for child patients. By 1949 there were nine informally staffed play programs now known to exist in hospitals in North America. Many hospitals implemented programs designed to amuse and occupy children through the involvement of the unpaid volunteer Play Lady. However, with increased surgeries and specialized treatment of illness, accompanied by shortage of nurses whose time was already stretched by increasing demands, the emotional and developmental needs of young patients could not be systematically addressed. The child was often lost within an impersonal system of medical care.

**Research Provides a Foundation.** Research completed during the first half of the twentieth century attributed the alarming incidence of infant deaths in hospitals and foundling homes to the inability of babies to tolerate the sensory deprivation imposed by their surroundings and the absence of sufficient human contact. These infant studies were cautionary models for the exploration of capacities in toddlers and older children to interpret and withstand painful and frightening hospital experiences when the familiar comforts of family and home were absent.

Many children faced long hospitalizations for chronic illness. Early observations indicated distress, loneliness and the lack of stimulation within the pediatric population. This provided an opportunity for change. Play/recreation therapists and teachers were hired to organize activities, provide schooling and psychosocial support for listless and bored children. Their work often involved teaching hospital staff about the non-medical and emotional needs of children as well as orienting and supervising volunteers. However, at this time, most play programs were not taken seriously.

Early Child Life workers had much to teach the hospital about the developmental needs of children. They also had much to learn about the culture of hospital life and the interventions that caused children distress, fear and pain.

**Founding a Profession.** Emma Plank, who fled Austria for England and the United States during

World War II, was a student of Anna Freud in psychoanalysis and also became interested in Maria Montessori's work with children. In the 1940's, Ms. Plank completed a Master's Degree in Child Development at Mills College in Oakland, California and went on to Case Western Reserve in Cleveland, Ohio where she began an experimental program in child-care for hospitalized children. In 1955, Ms. Plank was supported by Dr. Fred Robbins (Nobel Laureate) who encouraged her to create a program at Cleveland Metropolitan General Hospital to address the social, emotional and educational needs of hospitalized children. This began as a two-year demonstration project and then became integrated into the hospital's budget. Emma Plank's vision and philosophy was that the hospitalized child has unique needs that require an advocate who is well trained in child development, psychology, and education. She recognized the importance of play for the young child, yet she saw play as going far beyond the well meaning diversions of "play ladies." She believed that the child's play provides keys to facilitating medical therapies as well as a mechanism for supporting on-going healthy development of the child emotionally, socially, and cognitively. She envisioned a team of child-care workers who would bring to the hospital pediatric setting their special knowledge, skills, and experience with children as well as having sufficient understanding of medical treatment and the hospital structure so they could work with the medical team toward the best treatment of and hospital experience for children. In 1962, she published the first book on theory and practice for this new profession, *Working with Children in Hospitals* (Plank, 1962). Nuschi, as she was known to her friends at Mills, was appointed to a faculty position in pediatrics in the School of Medicine at Case Western Reserve University. Her concept of child-care in hospitals as a skilled profession was shared by others, and in 1965 she met with a group of like-minded colleagues to discuss creating a professional organization. The Association for the Well-Being of Hospitalized Children and Their Families was founded in 1966, and was renamed the Association for the Care of Children in Hospitals (ACCH) in 1967. In 1982 the Child Life Council (CLC) was established leading within the next decade to professional certification, standards of practice, and educational program requirements. (website: Child Life Council <http://www.childlife.org/The Evolution of the Profession of Child Life in North America>.)

During the decades of the 1970s and 1980s the ACCH grew in membership and professional status. The United States and Canada shared a common organization until 1987 when Canada formed its own Canadian Association of Child Life Directors, but worked across international borders to build awareness of the profession. University programs were created to educate and prepare Child Life workers through coursework and *practica*. By 1998, professional standards and professional certification were formalized by the Child Life Council, the governing board of the Association. During these decades the ACCH developed international linkages and communication with professionals in other countries who shared common theories and practice. Research on hospital pediatric programs began to accumulate providing empirical evidence of success for programs. Previously programs relied on anecdotal evidence for their validation (see website: Child Life Council <http://www.childlife.org/ Child Life Annotated Bibliography, from the Child Life Council>).

**Physicians Support Child Life.** In November, 2000, the American Academy of Pediatrics produced a position paper and statement in support of Child Life programs. The abstract of this statement reads as follows:

"Child life programs have become the standard in large pediatric settings to address the psychosocial concerns that accompany hospitalization and other health care experiences. child life programs facilitate coping and the adjustment of children and families in 3 primary service areas: 1) providing play experiences; 2) presenting developmentally appropriate information about events and procedures; and 3) establishing therapeutic relationships with children and parents to support family involvement

in each child's care. Although other members of the health care team share these responsibilities for the psychosocial concerns of the child and family, for the child life specialist, this is the primary role. The child life specialist focuses on the strengths and sense of well-being of children while promoting their optimal development and minimizing the adverse effects of children's experiences in a hospital setting (*Pediatrics, Volume 10, Number 5, November 2000, pp.1150-1159*).

This document further states that child life program procedures are mandated in some states, citing especially to Florida where a draft regulation mandated that child life programs include preparation services for children and families, training of volunteers, and provision of age-appropriate play and activities. The ratio of child life specialists to child-patient populations was recommended to be 1 to 15 or 20, depending upon patient age, mobility, type and acuity of illness and the nature of the population on the unit.

**International Development.** Today there are programs in more than 380 hospitals in the U.S. and Canada, with most being in children's hospitals and university-affiliated academic medical centers. The recent push toward cost-cutting and consolidation has forced some hospitals to cut back on their child life programs, but this trend appears to be reversing. Hospitals are beginning to recognize that these programs are both cost effective and essential.

The Child Life Council (CLC) is the major international professional organization serving child life specialists, educators, and students. While the Child Life Council holds examinations for professional certification and for renewal of certification, at this time the Council does not certify academic programs but is moving toward a process of academic endorsement. More than 30 institutions in the United States have identified themselves as having academic programs with a degree-level curriculum in Child Life.

### III. Theoretical Foundations of Practice.

**Play is fundamental.** Before the creation of a professional organization, many hospitals used the services of volunteer play ladies or had recreational therapists who may have had a background in physical education and sports as the "play" providers in the hospital. This did not address the developmental, psychological, social and emotional dimensions of the child in the hospital – those disciplines that ground the profession in theory.

Play theory is fundamental to the Child Life field and has an interdisciplinary base drawn from psychology, sociology, anthropology, economics, biology, and education, Rosemary Bolig (Bolig, 1986) wrote:

*"Play reveals how well or poorly children are coping with stresses. Simultaneously, play can influence the balance between affect and cognition as well as between children and their environments. Play is a process by which children can control contingencies and affect outcomes. It is unstructured play that particularly permits children to control events, ideas, and relationships. This article provides a locus of control rationale for unstructured play in hospital settings and presents implications for adults' roles in young children's play that enhance internal perception of control."*

When all else is out of control in the child's life, play may provide the one way in which the child can gain a sense of control or take power back into his life. Psychoanalytic theory shows that children not only regain power in their play, but through play and fantasy they can express impulses that would not be acceptable in real life. Data also indicate that major illnesses, hospitalization, war, and trauma have lasting and profound effects on children leading to feelings of helplessness and hopelessness. Play can provide a way to counter these effects before they become permanently embedded in the child's view of self.

***Play is therapeutic.*** While playing just for fun without a psychoanalytic theory attached is part of the goal of the Child Life Specialist, all play has meaning and outcomes. The CLS should be a good play companion providing fun as a respite and relief, building a relationship with the child that will build a foundation of trust when needed when the less playful experiences occur. But observation and reflection are useful even in playtime and can provide clues to the child's thoughts, emotions, perceptions, and personality. This information is useful at many points in working for the child's health and creating a child friendly environment in the hospital. The non-purposeful play can also provide a bridge for the CLS to the play that is useful in preparing the child for surgery of painful procedures. It has been demonstrated through many research studies that using play as preparation for procedures reduces the time necessary for anesthetizing a child, improves recovery rate after surgery, and clearly lowers the child's anxiety and post-surgical traumatic memory.

#### IV. Child Friendly Hospitals – Child Life in Practice.

***Welcoming the patient.*** The child friendly hospital has established routines for introducing and preparing a child for the hospital in advance of hospitalization through a visit or other orientation when such advance notice is possible. Child friendly booklets or materials that tell the child what to expect, how to prepare for a stay in the hospital, and what he may bring from home, are widely used. Even little gift packets that the child can keep by the bed may provide some reassurance and comfort. But, the most essential comfort for the child is the presence of the family, and most often the dependence on the mother. . Importantly, children need to understand that they can go home from the hospital—the hospital is not forever.

Often the socio-economic and cultural background of the child is far different from the hospital culture. Food customs, sleeping arrangements, play-life, life's main comforters, will vary from family to family and may be dramatically in contrast to what is practiced in the hospital. The child will frequently withdraw in shyness, sadness and even deep depression. Helping children through this depression is a major challenge for the CLS, requiring getting to know the individual child and family in a trusting empathic relationship.

***Environments for children.*** The child friendly hospital has one or several areas set aside and well equipped for variety in play adaptable to different ages. Whenever possible an outdoor play space should be designed where children be taken for fresh air and sunshine, or just to be in nature. The healing qualities of nature have been recognized for centuries. Play parks and gardens should be incorporated into hospital designs... not just the potted palm in the waiting room (Institute for Family Centered Care, 2002).

Lounges for teens, and access to the internet are commensurate with creating developmentally appropriate environments that recognize the world of adolescence, and their changing needs, as being different from that of younger children although they still may be located in a pediatric wing

A child friendly hospital environment also uses child creativity in its surroundings. Colors, textures, images that appeal to the child's imagination and are appropriate for the developmental levels of the children are signs that hospital administrators understand and enjoy children. If that is not the case, then the argument can be made that environments that make children happier in the face of unfamiliar and unfamily-like institutional rooms are good economics because what makes the child happier and more cooperative will cost the hospital less in personnel time, procedure delays, and length of stay.

***Activities.*** The child friendly hospital has the flexibility to allow child-friendly activities that include noise, laughter, creativity and messiness. Even children who are not allowed out of bed may be able



to play with paint, water, and mess-making materials. The author visited a hospital in Sweden many years ago in which the CLS had covered a boy's bed with a plastic sheet and had set up tubs of water around him for floating boats and having water play. Now that Child Life is an established field, that type of flexibility and adaptation for the joy of a hospitalized child should no longer be unique.

Painting, drawing, crafts, and other creative art activities help children to cope with their hospitalization and illness in many ways. The work itself may reflect inner feelings of anger, fear, and sadness, but the child's conversation while doing the art project provides rich language and insights for adults to better understand the inner preoccupations of the child.

Of course, the use of the plugged-in-drug, television and video games, must also be part of the child-friendly hospital but should be used in age-appropriate ways and limited in length of time spent in front of the screen. The adults in the playroom, or in the child's room, are often tempted to just watch the video rather than to engage in conversation and social interaction with the child. This kind of passive involvement by the patient contributes to the deepening of depression when the family is gone.

Sometimes a child cannot play either because of physical limitations, psychic trauma, language difficulties or other problems. This is another reason the CLS as one who understands the importance of play in a child's life is so important in the hospital. The CLS will find a technique that will help the child play even if it is vicariously through the words and actions of the CLS. Through careful observation it will be possible to engage the child, to detect his communication through eyes or other forms of expression, and to play out for him the theme that is important at this point in his development (Petrillo & Sanger, 1972).

**Supporting child-to-child interaction.** If it is important for children to communicate, they need to be able to communicate with one another verbally and non-verbally. They must be afforded opportunity to interact. Hospital friendly environments will avoid physical arrangements that prohibit child-to-child interaction. Making children's spaces a duplicate of adult spaces is insensitive. Bed arrangements, spacing, the use of single and multi-bed rooms and the use of partitions can all play a important role in promoting child interaction. The hospital staff also needs to understand this need and the therapeutic outcomes for children. Children need not be placed in rooms according to age alone. The interaction among hospitalized children of varying ages can be beneficial (Klinzing & Klinzing, 1977, p.87), except in the case of adolescents previously discussed

**Food and snacks.** It is important for the CLS to be in close communication with the hospital dietitian or nutritionist to monitor the food that is made available to individual children. If there is a specific food problem related to disease or allergies, the nutritionist will surely have been made aware; but often home food preferences and culturally related food habits are not processed into the child's food plan. Parents must be consulted and cooperation with the home will be the work of the CLS. In some cultures the family is accustomed to preparing food in the hospital room. Party times in the Child Life Program are exciting for children, but require careful pre-planning and attention to snack ingredients. Some hospital visitors bring sweets for children, creating havoc with the nutrition plan. The Child Life Specialist at Shaikh Khalifa Hospital in Abu Dhabi goes from room to room collecting the sweets brought daily to children by their visitors, and taking them to a safe place to be eaten by others.

**Supporting Learning.** One of the most difficult aspects of hospitalization and chronic illness for the school age child is being out of school. This includes, of course, the predictable loss of learning time and the fear of falling behind or being out of step with one's class. It also includes the disruption of friendships and social interaction that may not be recoverable. Both the break in schooling and the isolation from one's peers and from an active social group can be sources of despair for a school-age child, and even more so for the adolescent.. The CLS is not the hospital teacher, but will know



enough about the education process to be a partner with the child, family and school. The CLS may be the bridge between the hospital and the school when a chronically ill child returns to school or is absent intermittently. Information about the illness, how to prepare a classroom for the return of the ill child, and helping the teacher set realistic expectations for academic and social performance can come from the CLS with permission from parents and the medical team.

## V. International Needs and Responses.

Most nations have both governmental and non-governmental organizations committed to the health and welfare of children, and many of these organizations do offer services to families and children in hospitals. Programs that provide care to hospitalized and ill children are known by different names throughout the world. However, not only the terminology varies, but the functions and practices also may be differently conceived. In some of these programs, the staff are still viewed a “play ladies” and have little professional status on the team. Even when programs are organized with paid staff, the educational requirements and hospital structures vary widely across settings. A shared vision, created by international dialogue and exchange, can improve program quality worldwide.

The Child Life Council has initiated an international network to bring Child Life Specialists and professionals in related fields into communication with each other. In Scandinavia, Great Britain, and Europe programs under different names have shared a similar philosophy and practice.

The Hospital Organization of Pedagogues in Europe (**HOPE**) is one organization that addresses the school continuity for children as well as some aspects of psycho-social and medical needs. **HOPE** recently held an international conference in Belgrade (October 2003) to bring together professionals, especially those referred to as hospital pedagogues (teachers) to exchange knowledge about needs and practices. The topics included working with children who are chronically ill, children who have life threatening conditions, handicapped children, children with psychic and psychiatric problems, and children who are victims of violence, war or refugee living conditions. These are important topics on which to share information internationally.

The European Association for Children in Hospital (**EACH**) also is a professional organization working toward goals comparable to those of the CLC. Member groups may be found in Austria, Belgium, Finland, France, Germany, Iceland, Ireland, the Netherlands, Norway, Sweden, Japan and in Italy (**ABIO**). The Association for Children in Hospital (**ABIO** – Associazine Per il Bambino in Ospedale) is an active Italian group.

**EACH** is an umbrella organization founded in 1993 with 18 associations from sixteen European countries and Japan who have made a commitment to the 1988 Leiden Charter spelling out the rights of children in health care services.

In Kuwait, KACCH-Kuwait Action for Children in Hospital, founded by Margaret Al-Sayer, has instituted Child Life programs in several hospitals, chiefly Al Shabah Children’s Hospital, and has initiated an academic curriculum in Child Life at Kuwait University. In the United Arab Emirates, the College of Family Sciences of Zayed University has also introduced in fall 2003 its first courses in the hospitalized child, collaborating with Anne-Marie Glavin, the Child Life Specialist at Shaikh Khalifa Medical Center in Abu Dhabi. In Jeddah, Maha Al-Juffali—Founding Executive Director of the HELP Center for Children—planned and hosted in November 2003 the first training program on Child Life Therapy. Participating were nurses from all the private hospitals in Jeddah, volunteer artists, as well as university students specializing in Special Education.

Associations of play therapists exist internationally, and although play is central to the work of the CLS, the Child Life Program includes much broader dimensions of work with children, families, and

the medical team than is done in play therapy, and focuses on the chronically ill, the hospitalized, as well as the traumatized child.

**E10**

**WORKSHOP X**

## **VII. Cultural Relevance for Child Life.**

In every country, in every culture, within all religious and ethnic groups, each day some children are sick and dying. In recent years the mortality rates for children have been reduced dramatically in many nations, most notably in Arab countries ((UNDP, 2002. pp 38-41). The availability of high quality modern health care has increased use of the hospital as a resource for preserving the lives of young children. In nations where technology is advanced, children are treated by highly trained physicians and are often admitted to the hospital. In some cultures the hospital is the first place one takes a sick child if home remedies are not effective. High rates of accidents and injuries, as well as the consequences of war, have also made the hospital a part of daily life for many children and families. Cultural factors, practices, beliefs, communication gaps and accessibility to medical care have an impact on the effectiveness of the medical treatment. Even before admission to a hospital, the cultural component may affect the child's health care. Language barriers, issues of traditional vs. modern medicine, religious customs, gender issues, cost concerns and a host of other areas of misunderstanding keep modern hospitals from being completely successful in health delivery when hospital culture and client culture are at variance. Beliefs about the causes of illness, the meaning of death and forms of grieving may be expressed in ways discrepant to the medical staff's experience. A child friendly hospital and a family-sensitive environment must be prepared well in advance for those differences or major misjudgments and alienation can occur. (Nishimoto, 1996.)

And yet, all families want healthy children. All families rejoice in a happy, healthy, playful child. All families grieve at the death of a child. Most cultures and all major religions place protection and preservation of family and children at the top of their cherished values. Differences in cultures must be understood and respected. Child Life Programs in hospitals can be culturally consistent, culturally relevant, and culturally acceptable if planned within the cultural system rather than being imposed from without using practices familiar to foreign systems but inappropriate for the culture at hand.

## **VI. Child Life in the United Arab Emirates – A Pearl in the Making**

Imagine the opportunity to extend a profession in a new land, in a different culture, and to develop a program from scratch at a brand new hospital! This was a dream that most of professionals have wished for and few have been fortunate enough to experience.

This component will briefly journey through the cultural perspectives and challenges of program development and implementation of a Child Life program in a new facility in the Middle East and the ensuing partnership that developed between Child Life and Zayed University.

In 2000, Shaikh Khalifa Medical Center, administered by Inter-Health Canada, opened its doors as a Canadian run tertiary care hospital, in a Middle Eastern setting. The goal of the hospital was to provide world class care exclusively to nationals (citizens) of the United Arab Emirates. Staff predominately came from Canada but also included the USA, Australia, and South Africa – a truly multi-cultural milieu.

The first Pediatric Nursing Manager was well acquainted with the profession of Child Life and strongly felt that the service was needed at Shaikh Khalifa Medical Center. She felt that the service was essential and would work well within this culture which is very child and family focused. A