

WORKSHOPS about HOSPITALIZATION and ILLNESS

Outline:

The psychological effects of hospitalization and illness on children and suggestions for preventing or alleviating each one:

1. Separation anxiety and the stages of separation
2. fear of pain
3. fear of mutilation due to illness or medical procedures, issues of self-image
4. fear of unknown – medical equipment, staff, routines etc.
5. loss of privacy (issues of personal space and confidentiality)
6. loss of autonomy and passivity
7. loss of abilities
8. unfairness of being different
9. guilt - belief of hospital as punishment, unburdening oneself of guilt = blame
10. regression: coping by returning to earlier stages of development
11. loss of parts or all of identity (illness and self-concept)
12. being labelled (self-fulfilling prophecy and stigma)
13. fear of death

The psychological effects of children's hospitalizations and chronic illnesses or disabilities on their families

1. shock at diagnosis
2. frantic, persistent search for the cure or second opinion
3. loss of dreams and expectations
4. financial pressures
5. time constraints
6. jealousy between siblings
7. the family "on stage" in public
8. shame and stigma associated with certain illnesses and disabilities
9. no or not enough information, confusion
10. overwhelmed with too much information and advice
11. object of pity
12. constant state of anxiety
13. unrealistic expectations placed on family by others
14. powerlessness and locus of control
15. changing family dynamics / interactions

Psychological interventions for helping children to cope with acute pain

1. the problem of identifying and quantifying pain in children
2. techniques for describing and measuring pain
3. people have different coping styles: attention and distraction
4. observable behaviours and categorizing coping styles
5. effective strategies for facilitating preferred coping style
6. practicing coping to deal with painful medical procedures

Facilitating healthy development and adjustment to illness and the hospital through therapeutic play and arts

1. Basic definitions and examples of developmental and therapeutic play

The way in which various activities are helpful and which materials are useful for:

2. physical development (fine and gross motor)
3. cognitive development (thinking, memory, language)
4. sensory/perceptual stimulation (visual, tactile, auditory)

5. self-esteem enhancement
6. encouragement of autonomy / decision – making and taking responsibility
7. channelling and release of negative emotions through constructive activities
8. modification of problem behaviors
9. socialization, developing friendships and support systems
10. moral development
11. facilitation of rapport between therapist and child
12. alternative forms of communicating needs, feelings and ideas
13. humor helps lessen perception of pain and reduces negative thoughts and emotions
14. distraction seems to make time pass more quickly
15. fun way to teach about the hospital and illness

Prevention of emotional trauma and facilitation of physical recovery through health education and psychological preparation for medical procedures

1. what information to provide: content
2. how to provide: methods
3. when and where to provide: context
4. how to adapt to best meet the needs of patients: audience
5. why we use it, how it helps: justification

Assessment of patient & family needs to determine priority & amount of psychosocial support

1. Definition of triage and the need for psychosocial assessments
2. Risk factors to consider: child, family and health variables
3. Guidelines for determining levels of intervention
4. Case studies as concrete examples of different levels of intervention

Guidelines for supportive communication between staff, patients and their families (basic counseling techniques)

1. nonverbal communication
2. active listening
3. use of questions and clarification
4. reflections and affirmations
5. avoiding pitfalls: interpretations and judgmental attitudes
6. dispensing advice and empowerment issues
7. appropriate self-disclosures
8. safe contexts for counseling and ethical concerns
9. the therapeutic use of silences

Strategies for supporting families

1. initiate contact and build a relationship
2. orient families to the hospital
3. facilitate increased collaboration between families and healthcare professionals
4. use families as resources, learn from and empower them
5. share useful info with them about their child: development, emotional status, etc.
6. support the natural role of the family
7. help parents feel useful
8. facilitate interaction and communication among family members
9. do activities related to home and family themes with children
10. plan and host special events for the whole family as well as those designed for siblings, parents, and patients only
11. organize and implement support groups for patients, parents and siblings
12. offer marital and family counseling to prevent family disintegration
13. coordinate educational presentations
14. create a family resource center / lounge in the hospital
15. teach and remind families of their rights and responsibilities while in the hospital

16. allow families opportunities to express their opinions and contribute their ideas to the hospital administration
17. be an advocate for families – speak to law makers and community leaders about the special needs / problems of families with chronically ill / disabled children
18. provide families with pastoral care and spiritual guidance from chaplains
19. connect families with charitable and governmental resources
20. offer a special, private place for doctors to confer with families

Psychological Effects of the Physical Environment of the Hospital

1. Color
2. Space
3. Sound
4. Ventilation
5. Temperature
6. Light
7. Access to Nature
8. Decorative Wall Hangings
9. Furniture / fixture size
10. Safety
11. Orderly, non-cluttered spaces
12. Design to facilitate orientation
13. Layout of furniture to increase intimacy

Recognizing and Preventing Burn-Out

1. Justification for rest
2. Symptom identification
3. Strategies for prevention
4. An area of ministry

Questions for Disability / Care Giver Experience

PSYCHOLOGICAL EFFECTS OF HOSPITALIZATION AND ILLNESS ON THE PATIENT

We must not only study the effects of hospitalization and illness on children as an academic subject, but experience such effects to truly grasp their consequences on children's emotional health. The first thing we must do is to once again put ourselves into the 'shoes' of children – to see their point of view.

****Audience is asked to stand and look around the room, “This is how you see the room now... as an adult.” “Now squat down and look around the room, try to remember the last time you saw objects from this perspective... when you were a child.” “Think how you felt then, how you saw the world and adults.”***

*Person is asked to leave room without any explanation, then invited back in after a few minutes.

1. SEPARATION ANXIETY

- A. greatest fear of many children, especially those under 8 years of age, universal across all cultures
- B. perfectly normal – abnormal NOT to miss parents and NOT want to be with them! *May* be sign of abuse or neglect at home or severely dysfunctional family
- C. Child thinks “Why me?” “What have I done to deserve this, I must be bad!” Results in feeling that they are being punished, that abandonment is their fault which complicates the healing process
- D. 3 Phases – **Protest** (cry, kick, scream, try to run away, resist staff, not easily consoled, etc.) starts immediately when parent leaves or child notices they left – lasts for minutes to several days, protest ends when parents return.

Despair – (child gives up when protests prove unsuccessful – passive, quiet, cooperative with staff, doesn’t take pleasure in usual fun activities – starts within a few hours after parents leave – lasts for days to months, child is happy to see parents when they come back, when parents leave again child re-enters protest phase.

***Hospital staff misunderstand this phase – they think the child is now used to the hospital and content, they see the parents return and resulting re-entry of protest phase as a set back, and as upsetting the quiet, peaceful routine, when in fact it is healthy and normal!**

Detachment – (child becomes emotionally separated from parents, may start attaching to medical staff, child resumes activities in which he is interested, lack of interest in parents when they return – does not seek their comfort or to return home with them, phase can begin weeks or months after parental leave – can be permanent.

- E. SOLUTION – Have parents stay with children in the hospital for as much time as possible – best if one parent (usually mother) can stay overnight with the child. At least they

should be allowed to visit their child for several hours a day, it helps if they can play with their child in the playroom and do normal life activities together – eat, bathe, dress, do school work, etc.

NOTE – Honesty is *extremely* important, parents and all others who must leave the child in the hospital should be told to always tell the child the truth – if they need to go, do not tell the child they are just going away for a moment, tell him that you are going for now, but that you will be back – tell him the time (if a small child use concrete examples (when the sun comes up again, after your favorite TV show comes on, before you eat lunch), and tell him where you will be and what you will be doing (I will be at home taking care of your brother and sister, I will be at work, I will be shopping with grandma at the market)

NEVER wait to the child is sleeping or distracted to sneak away – it makes things easier on the person who is leaving, but not the child or the medical staff who tries to console the child!

* Person is reassured that I am a doctor with lots of training and to be calm, then all of the sudden I pull out a knife.

2. PAIN

- A. Pain is our body's way of protecting ourselves against damaging things (like leaning on a hot stove) or warning sign which tells us to treat an internal illness (like a worsening headaches) – however children do not understand this – they only know, “Pain is BAD!”
- B. This makes hospital treatment very difficult because they think, “How can something that is supposed to help me, hurt so much?!”
- C. Pain is also seen as a punishment – after all, most children experience physical discipline which results in pain so they wonder, “How can that pain from punishment be any different than this one?!” This is complicated by the awful fact that many adults, even some hospital staff, use threats of painful medical treatments as punishments!!! We should

NEVER say, “If you are not well behaved the doctor will give you an injection!”

- D. SOLUTION – Avoid as many painful, invasive medical tests and treatments wherever possible, (why cut open skin when we can look inside with an ultrasound), use anaesthetics whenever possible, explain to children why they must get the procedure - give honest, realistic info about how much the procedure will hurt and for how long it will last, never equate painful medical treatments with punishment.

* Person will be asked if I can cut off all their hair, I will show them my scissors in a non-threatening, not sudden manner.

3. MUTILATION

- A. Children fear damage to body (disfigurement) by actions of others such as cutting open the stomach, removing a leg, by things such as a fire or an explosion, by illness such swollen face and body due to kidney failure or by medical treatment such as losing hair due to chemotherapy
- B. Mutilation is not pain nor vice versa, they’re two separate things and thus two separate fears Example – pinching someone very hard is painful but not mutilating, being exposed to too many ultraviolet rays may not hurt at the time but can later cause skin cancer
- C. Physical appearance is very important to us all because our society values it so highly – even young children learn what a normal, healthy body should look like and thus develop a self-image based on that expectation, older children are especially concerned about appearance due to social relationships with peers
- D. SOLUTION – avoiding all invasive medical procedures and surgeries as possible or minimizing surgical entry through modern techniques, helping to cover scars with make-up, using wigs to cover hair loss, helping children to develop a healthy self-image based on realistic expectations (not based

on models) and to learn to appreciate themselves for things beyond their appearance – like artistic, academic, and athletic talents, good deeds they do for others, etc.)

*Person is asked to place their hand in a bag which contains an unknown item (cooked, but cold oatmeal or similar item)

4. FEAR OF THE UNKNOWN

- A. It is natural for all people, including children, to have increased anxiety when they are exposed to other people, places, things, or events which are unknown to them – the hospital has ALL these elements!
- B. Medical equipment – “What is that used for?” “Will it be used on me?” “Does it hurt?” Staff – “Who are you?” “What are you going to do to me?” “Can I trust him?”
Routines – “Where I am going now?” “What is going to happen to me at night?” “When can my parents visit me?”
- C. Children create their own explanations for why things occur, to link cause and effect, these fantasies are often worse than the reality! (for example I once knew a boy who thought the tumor in his stomach was an alien growing inside of him! He overheard that there was something living and getting bigger inside of him that was slowly eating away at his insides.) We all tend to think the worse when presented with threatening but ambiguous info. (for e.g. “Someone just called from your family and said come quick to the hospital, your sister has been in an accident!”)
- D. SOLUTION – We need to explain to children what is or will happen to them, we need to introduce ourselves and explain what we do in the hospital, we need to educate them about their illnesses, the medical equipment etc.

***MOST IMPORTANT** we need to be honest – never hide the facts – if we say we do not want to tell the children the truth or give them all the facts to protect them from the bad news – we deceive ourselves for we are doing it to protect *ourselves*! (from having to

give the bad news and see the reaction of the child and be called upon to give the necessary support to comfort them after the news)

*A person is inspected very carefully by two other volunteers from the audience – while using a flashlight and a tape measure they lift up his arms, circle around him, stare at him, etc.

5. LOSS OF PRIVACY

- A. In the hospital children are forced to give up a lot of privacy – doctors make them get undressed and look at all their body parts – this is especially hard because they do not know the doctor and they have been taught by their parents from a young age to be modest, i.e. do not go around naked or get undressed in front of strangers, even children from age 3 can feel ashamed to get undressed in such a circumstance, obviously it is even harder for older children and teens. Also may be especially hard if medical staff is of a different gender than the patient.
- B. Children may experience feelings of humiliation or embarrassment, anger, fear, and low-self esteem
- C. Also children do not have any private space, they usually share a room with other patients whom they do not know and when their family or friends visit they have no private place to talk, children may even hear the staff talking about them to other staff and feel their privacy has been invaded (even though it may have been necessary to share the info.)
- D. SOLUTION – Children should be asked to undress with as few observers as possible and then they should be explained why they must undress, they can undress in private and then wait for doctor to come in and examine them, they should be prepared for the experience, especially if sensitive body parts will be examined. A parent or other trusted, supportive family member, friend, or staff person should accompany them during the procedure if they wish. Patients should never be talked about in front of them or within hearing range. Never should info about patients be shared

with people who do not need to know about them for medical or administrative reasons. Special, private areas should be designated in the hospital for counseling and sharing sensitive info with patients and families.

*Person is commanded to move around the room and perform various tasks such as sitting, reaching, bending down, turning around, walking back and forth, sticking out the tongue etc.

6. LOSS OF AUTONOMY

- A. The hospital is a place with many routines, which are necessary to maintain order and to make things run more smoothly. Also the child as a patient must often follow many special treatment regimes including having a special diet, being restricted to the bed, going to physical therapy, getting medical tests, etc. Therefore, the child loses much of his usual autonomy.
- B. The result can create a patient who is passive and becomes apathetic – one who does not actively fight to get better or participate in his treatment, OR conversely, one who rebels and actually may sabotage his treatment as a way to recapture his autonomy. Neither scenario is a good one. Further it creates too much dependence and does not help the child to learn to take responsibility for his body / health.
- C. SOLUTION – give the child choices in the areas where he can have freedom such as in his leisure activities – this is why the playroom is a place where children can chose what they would like to do. Even when a child must get a medical procedure he could still be offered a choice – for example, “In which arm do you want an injection?” or “Do you want to take milk, water, juice or tea with your pills?” In this way the child learns how to make wise decisions and feels like he has some control over his body. Even listening to the child’s complaints and validating his feelings when no choices are available lets him know that you do care

about his opinions and that he at least has control over the ability to voice his needs and make his feelings known.

*Person is asked to pick up some coins on a smooth table while wearing thick gloves (they can not slide them off the table into their other hand).

7. LOSS OF PHYSICAL ABILITY

- A. Due to illness, injury, medical treatment or activity restriction to prevent worsening of the illness or injury the patient can experience temporary or even permanent loss of certain physical abilities. This can create many negative emotions – frustration, “No matter how hard I try I can not do it!” anger, “Why me?!” fear, “How will I be able to play football?!” humiliation, “What will the others think if they know my mom has to dress me now?!” sadness, “I will never be able to have children.”
- B. The child may give up and become helpless, doing less than he CAN actually do for himself and wanting to be babied. Parents who feel sad due to the condition may facilitate this behavior by doing too much for him.
- C. The child could become bitter and withdrawn – jealous of others whom he sees as having the abilities he lacks or perhaps aggressive due to the frustrations of not being able to achieve even small goals.
- D. SOLUTION – Do not overly restrict the child, for example even with an I.V. the child could walk around and even sit and play quiet games if he careful not to bump is hand. Adapt physical activities so that he can participate – use special equipment such as Velcro to increase grip on eating utensils, change the environment – removing barriers, such as installing ramps, change the rules of games as necessary to accommodate – perhaps permitting more time to accomplish goals. Also by letting children with other physical limitations (who have already begun to overcome or adapt to / cope with their limitations) interact with the

patient he will be encouraged by their actions to try and overcome the disability through creative means. They serve as positive models. Let the children experience success in small things and then build toward harder goals.

*Most people in the audience are given candies, but some are deliberately not given any. They are told that they can not have any.

8. BEING DIFFERENT / UNFAIRNESS

- A. Being a diabetic, for example, is tough because the child is told he can not have what others can. Even though he feels and looks just like everyone else and indeed in most respects he is like many other children – he IS different. Children do not like to be singled out, especially when it is for something negative. They feel inferior and it does not seem fair. After all from a young age we teach children to share – to give everyone an equal portion, not to leave anyone out.
- B. To be left out is to feel rejected, and thus to feel not worthy enough to receive – to feel inferior. This obviously hurts self-esteem and can make a child sad and even depressed. The child may become passive-aggressive – not participating in his care – not taking responsibility for monitoring his blood sugar level for e.g.
- C. Also this difference can make children very angry and often they wish to rebel against this control. Not just because they want the candy, for example, but also because they want to be like their peers – to be similar makes their acceptance more likely by their peers.
- D. SOLUTION – Whenever possible find similar substitutes to the thing which they can not have, for example, sugar free candy for diabetics. Encourage the free expression of emotions in appropriate ways – talking, artistic activities, positive attention seeking behaviors such as helping the parent around the house, rather than negative behaviors such

as eating sugar on purpose to play the sick role. Improve self-esteem through activities in which the patient can accomplish concrete goals, for e.g. sports, school, arts, etc.

*People in the audience pass around a rock, each person holding it for a while to feel its heaviness.

9. GUILT

- A. There are many reasons children (and their families) can feel guilty. These feelings can be based upon justified or unjustified guilt. The former is based on actual wrongful activities which the child did knowingly, the latter is based on the child's misunderstanding of cause and effect or misinterpretation of facts or feelings. If the child has a true reason to feel guilty we need to help him seek forgiveness from the person he has wronged and make amends. Quite often though, the child has no legitimate reason to feel guilty.
- B. Young children, may believe they caused harm to themselves or others through their bad thoughts. This incorrect thinking is due to their level of cognitive development – cause and effect is based on magical thinking rather than logic. They may also believe that their misbehavior caused their illness or was the reason for their hospitalization and the separation from their parents. Thus they may feel very guilty about their past thoughts or behaviors. Even older children and teens try to find a link between cause and effect when there is no clear reason for a bad thing to occur such as an illness. They may blame their poor behavior as a reason for punishment from God. Or they may simply feel guilty about getting better while others remain ill (survivor's guilt), "Why should I have fewer problems, I am just as bad as the rest?" AND sometimes guilt is a mask for feelings which are less tolerable, for example, anger toward God or parents or the hospital or even fear that we do NOT in fact have as much control over

our lives as we would like to think. Feeling guilty means that we feel that we could've controlled the situation, when in fact many times we can't. Feeling guilty for some people is better than feeling powerless.

- C. It is necessary to help children relieve their guilt in a constructive way because otherwise they may get tired of carrying the burden and give (pass the guilt, i.e. blame) or even throw it at someone else – OUCH! This can have obvious harmful effects on the quality of social relationships between and among family members and medical staff.
- D. Or children may continue to carry the guilt, but become debilitated – less able to do their activities in life because their hand is occupied (in other words - their mind). This can physically and mentally wear them out, preventing or slowing physical recovery or making them susceptible to future illnesses. Carrying the guilt also makes them less able to cope with current or future stressors.
- E. SOLUTION – For unjustified guilt we need to teach children the logical connections between cause and effect. For example, if we drink spoiled milk chances are very high that we will get sick. However we also need to show them that there are also many times when bad things happen for which we can not find nor place any blame. Children have to be allowed to explore and share all their feelings, even those that may seem taboo, like anger at God or fear of the lack of control over random bad events. Clear communication needs to occur between and among family members and staff with limits set for expression of negative feelings through harmful behaviours.

* A student and I each hold an end of an elastic band while the student moves away from me. As the band stretches the tension increases, how can a “child” reduce this? He or she moves backwards = regression. How can he move forward? Through emotional support and programs which stimulate development.

This is shown by giving more elastic band which reduces tension so student/child can move forward.

10. REGRESSION

- A. Increased stress creates undue pressure for the child to cope in an environment and in situations in which he has no prior experience. This uncertainty creates confusion and thus child doesn't know what methods to use to successfully cope.
- B. To feel more comfortable and sure of himself the child uses coping mechanisms usually employed by younger children because these usually worked in the past and they elicit more support from adults.
- C. Regressive behaviors include returning to thumb-sucking, clinging more than usual, enuresis, temper tantrums, wanting to use a bottle again, loss of ability to walk or talk, problems with school work, etc. according to age. Even adolescents may become more dependent and demanding for parental attention. Such behaviors are almost always temporary, when the child returns home he once again regains the skills he lost.
- D. SOLUTION - Provide the child with enough emotional support and attention while teaching him more effective, age appropriate coping strategies. Also offer activities which stimulate diverse areas development through play, expressive arts and academic instruction. Helping parents realize this is only temporary helps relieve some of their stress which thereby alleviates the stress they put on their child "to act his age."

* Person is given a variety of pictures – each representing a different aspect of their life – work, school, church, recreation, friends, family, illness, etc. Then I begin to take more and more away leaving fewer and fewer choices.

11. LOSS OF PARTS OR ALL OF IDENTITY

- A. An illness can interfere with the development of a child's self-concept. Repeated hospitalizations mean time away from school and friends which are important in helping to

form a child's identity. Peer relationships help children define who they are in relation to others. School helps them realize what their talents are and their possible future vocation.

- B. The illness may limit children from engaging in activities which they enjoy (such as sports, camping, traveling, etc.). Hobbies are an important way for children to explore who they are. Life without recreation can quickly become tedious and meaningless. We should not live to receive medical treatments (just survive), but receive treatments in order to live (enjoy life)!
- C. If there is chronic pain or some sort of discomfort (for e.g. difficulty breathing) this can also interfere in children's perception of themselves. It constantly interrupts their thoughts and prevents them from thinking about something besides their illness. The illness can become so dominant in their lives that it becomes "who they are."
- D. Literally, as the illness takes over a larger and larger percentage of their waking lives, it is harder for children to imagine themselves as something other than patients because they are doing fewer activities which not related to the illness.
- E. SOLUTION - Provide as many opportunities as possible for children (both in and out of the hospital) to engage in activities which are a normal part of their life – school, recreation, socializing, etc. Find ways to lessen unpleasant symptoms and make treatments more efficient (less time consuming). Discuss with children about their identities, let them find ways to express who they are, to show their uniqueness. Help them to realize that they are more than just their illness. Assist them in finding and developing hobbies they enjoy.

* Person is given a sign to wear which reads, "stupid"

12. **BEING LABELLED** – (Self fulfilling prophecies and stigma)

A. Labels create self-fulfilling prophecies. Children begin to act

the way they think others want them to, according to their labels. “Well adults or experts must know what they are talking about, so I should assume the role they have given me.” Thus, they appear just as their labels describe. For e.g. a “weakling” who is supposedly unable to do any sports because of asthma, when actually most children with asthma can do many sports with some adaptations and basic precautions.

- B. Labels can also affect how others treat children which also leads to self-fulfilling prophecies. {Give e.g. of teachers who were told that certain students were smarter, even though they weren't, the students began to perform better based on the labels they were given because the teachers treated them differently, gave more attention and praise, etc. }
- C. Most labels create unnecessary stigma. It is better to be referred to as one who has a particular illness or disability rather than called by that illness. Thus we never say, “the kidney disease boy” but rather the boy who has a kidney disease. This negatively affects identity, which we discussed above and puts people into unrealistic, overly general categories. Such labels devalue the individual's worth. “You are a retard” rather than, “You are a person who has difficulty learning some things.”
- A. SOLUTION – Always refer to children by their names, and use the phrase, “A boy or girl who has _____” which emphasizes the personhood of the child not the illness. Teach and encourage others, especially peers, not to use labels.

*Person is blindfolded and then ignored while I continue to speak to others in the audience, then the person is led out of the room and left, the door shut. After a few minutes the blindfold is removed and the person brought back into the room.

13. FEAR OF DEATH

- A. We can not pretend that children do not think about or perhaps even worry about death. They are exposed to it on so many TV programs, even cartoons. Many see romance and TV drama shows which feature patients dying in hospitals. Therefore quite a few children can associate going to the hospital with dying or at least the possibility of dying – this results in a great fear of hospitalization.
- B. Even if the child is in the hospital for something minor, we can not assume that he realizes that this is minor and has no or little risk of death. For example, as adults we know that an appendectomy is a routine operation, but for children the perceived threat of death is real – being cut open, under anaesthesia, etc. – to them there is no such thing as minor surgery.
- C. Children may even be exposed directly to dying patients or even witnessed a patient die. Or they may overhear staff or family members talk about death / dying. Yet again we keep children from being informed and hope they do not hear, see or realize what is going on. Unfortunately, we only deceive ourselves and leave children to cope with this very scary situation alone.
- D. SOLUTION – we need to sit down and honestly talk with children about death and dying. They need reassuring that most children and adults who go to hospitals do not die. They need to know the truth about their illness, which means for most that they are NOT dying, for those with very serious illness the children can be told that they are indeed very ill and that everything is being done to keep them alive. Talk with them about your religious beliefs – share your faith or invite a religious professional (chaplain) to visit. Open the possibility for discussion, especially when they have seen some disturbing things occur in the hospital (like a

patient dying). Children have been known to protect their parents from the reality they already know.

PSYCHOLOGICAL EFFECTS OF ILLNESS AND HOSPITALIZATION ON THE FAMILY

*Person is handed a baby doll wrapped in a blanket. Tell them to closely look at the doll's face – study its details. After a short while unwrap blanket and reveal that it is missing a leg.

1. SHOCK AT DIAGNOSIS –

- A. When parents are confronted with unexpected illnesses or disabilities in their children, a universal reaction is to be shocked or stunned. They simply do not want to believe the reality. They hope it is all a bad dream or that there has been some mistake in the diagnosis.
- B. Before any coping with the loss can begin parents have to realize that the illness is indeed a reality.
- C. Parents often experience physical symptoms – headaches, stomach upset, muscle tremors, etc. and may have dulled emotions – feeling numb inside. Or their emotions may be extremely erratic – angry one moment, sad the next, for e.g. Any little stressor can trigger a powerful emotional reaction.
- D. SOLUTION – If at all possible we should prepare parents for the diagnosis, explaining in slow, clear, honest language what they can expect to see or experience when their child is born or when they see their child for the first time after a serious accident. This will help cushion the emotional impact. They may still experience shock, but most likely not as traumatic.

*Have person try to complete a puzzle which is impossible since it is missing the necessary pieces (has correct number but some pieces are from another puzzle)

2. FRANTIC, PERSISTENT SEARCH FOR THE CURE OR SECOND OPINION

- A. Parents when confronted with a serious diagnosis or prognosis quite often will attempt to find a solution to fix the problem even though told by doctors no solution is available. They hold out hope that the doctor is wrong – they believe that either he doesn't know about new treatment possibilities or he is not trying hard enough to cure the child. They can become very combative against the very people who are trying to help their child – even accusing the medical staff of incompetence or corruption. These harsh words are said out of sheer desperation.
- B. Thus parents will seek many other medical / expert opinions until they hear what they want to hear – a treatment is available or the prognosis is not so bad. Unfortunately, often parents turn to less reputable or scientifically proven treatments such as those offered by new age practitioners or herbalists / naturalists who lack rigorous training. These treatments can wind up hurting the child even more and many con artist trick parents out of their money. Even repeated diagnostic exams by reputable doctors can cause the children to experience more unnecessary discomfort or pain.
- C. Parents search for a cure because they feel it is their role to protect and aid their children. If they don't they have failed their children. Since they see their children suffering and possibly already feel responsible for the child's condition parents have a strong motivation to find a way to cure their illnesses. Otherwise, parents feel they have let their children down two times, first because the children got sick and second because they did nothing to stop the illness.
- D. SOLUTION – We can certainly allow and even encourage parents to seek at least one other medical opinion – after all the doctor could be wrong. However, most hospitals have a system whereby several doctors review cases, especially when serious, so there probably already are opinions by more than one doctor when the diagnosis is given to the

parents (and this fact should be made known to the parents). It should be explained to parents that repeated diagnostic exams and less reputable treatments can actually harm their child. Parents need a place to vent their frustrations and negative emotions, rather than trying to deal with them by “fixing the problem.” Also, parents should be warned against seeking help from so called experts who just want their money. Other parents who already experienced such things can be very useful in convincing those new to “the game.”

* Two people make paper airplanes – tell them to make them well as the one that goes the farthest will win a prize. When complete take one and damage it (rip it). Then have race.

3. LOSS OF DREAMS AND EXPECTATIONS

A. When children have serious illnesses or disabilities it shatters the hopes and dreams parents had for those children. Even before they are born parents are already envisioning what they will look like and what they will grow up to be – a great doctor or lawyer or perhaps singer or football star. They begin to plan how they will assure their children a good future – enrolling them in the best schools, having them practice the violin 4 hours a day beginning at age 5, etc. It is perfectly normal for parents to want the best for their children and to make a better future for them.

B. Thus when their children have illnesses which dramatically affect their lives and reduce their chances of achieving these dreams parents feel a great loss – not only what they do not have now, but what will not ever be. This is complicated, made worse, when parents live their lives through their children or when they want their children to achieve the dreams they never could because they were too poor as children or did not have the talent. When this occurs the frustration and loss is even greater.

- C. Thus it is normal for parents to experience grief during this period – to have many different kinds of feelings such as sadness, anger, fear, etc. These feelings may come and go, may be re-experienced, and several may be felt at once.
- D. SOLUTION – Parents should be helped to realize that their child can still achieve many things, perhaps not what they wanted, but still something which is of value. Also, they have to be helped to understand that all children, even healthy ones, have the basic right to determine and work toward their own unique aspirations. Alternatives such as focusing on more realistic goals should be emphasized so that children do not experience failure. Even activities which the parents want their children to engage in such as sports can still be an option with appropriate adaptations. And perhaps their children will grow up to win medals in a sport, not in the regular Olympics but the special or para-olympics! Parents should release children from their frustrated dreams – and either let them go or start to work on them for themselves! Offer and encourage parents to attend grief workshops and help them to realize that it is normal to have the feelings they do – they aren't going crazy! Also help them understand it takes time to work through the loss and that they may go through phases of feeling more acute grief when faced with difficult situations or when reminded what their children can not do – like attend regular school or find a job.

*Person is given pretend money (like from Monopoly game) and told that they earned this from his job. Then I ask / take it to pay medical and household bills. Then have him ask from relatives, take more money to pay more bills. Third have him ask from charity – which asks a lot of questions. Take more for bills. Fourth have him ask from government which gives but is very cold. Again take money for bills.

4. FINANCIAL PRESSURES

- A. Parents with disabled children are continually faced with

more financial pressures than normal families. There are medical bills for doctors, physical therapists, medicines, diagnostic exams, etc. as well as for special tutors, adaptive equipment like wheel chairs and special beds or for materials like Braille books. Also parents are often required to travel more (to and from hospitals or treatment centers for e.g.) which means more money spent for gas or train tickets and possibly hotels and restaurants if they are from another city and do not have someone with whom they can stay.

- B. Meanwhile parents may earn less money because they work fewer hours or have no job because they need to visit or care for their ill family member. Or the ill family member used to work and contribute to the family's funds.
- C. Not being able to provide for the financial needs of their family can be very frustrating and even humiliating for parents. The resulting anger and low self-esteem can not only harm the mental health of the parents, but also their physical health. This in turn can make them become even less productive on the job and create tensions amongst family members and between the family and medical staff. For e.g. parents may be forced to decide to either visit their children, but have less money to pay medical bills or to work to pay the bills, but have less time to spend with their children. Medical staff who carelessly comment that parents don't visit long or often enough may further harm the parents already fragile emotional state.
- D. It can be humiliating for parents to have to ask for money from friends and relatives and even more so from charities and the government. It is even harder when institutions treat parents in such a poor way – cold and uncaring or even with suspicion (do they really have an ill child or is it just a scam?)
- E. SOLUTION – More consistent and secure funding needs to exist for families facing these difficult financial situations. This funding could either come from governments or from a combination of public and charitable contributions. Churches

could and should step in to offer a hand in these situations. Aid need not only be money but assistance with in-kind gifts like food and clothing or offer services like transport and accommodation so parents can use their money for medical treatment. When offered money parents need to be always treated with respect. Through careful socio-economic investigations public officials can find out if parents indeed need the money, but they can do it through more tactful and discrete means which do not treat the parents as criminals. When possible parents should be given opportunities to work for funds or to pay back loans – this way they will feel empowered not humiliated. Another important solution is to help the parents budget their money – either assist them directly with the budget or teach them budgeting skills.

*Person is asked to do several tasks within a time limit, for e.g. 2 minutes: fill cup of water and give to “patient,” run to another area of the room and build tower of blocks (represents work), run to yet another area of the room and fold clothing (represents home tasks) and finally another area to answer questions from a friend (represent social). First have the person do just the work, home, and social tasks then have them do all four but keep the time limit the same.

5. TIME CONSTRAINTS

- A. Having a disabled family member creates more stress in the lives of the family because often there is more to accomplish than in a family without a disabled member. For e.g. they have to take the child to physical therapy and then go to a certain store way across town to pick up some special food for her diet. Meanwhile they still have all the usual tasks to accomplish – cooking, cleaning, washing clothes, working, etc. Also the disabled family may not be able to help or help very little with these tasks – for e.g. they might be able to safely set the table, but not be able to cook, even though they are an adult.
- B. This constant heightened level of stress is not good for the

mental and physical health of the parents either. They are quicker to lose their tempers and thus more likely to argue, creating family conflict. As they become increasingly tired they are more vulnerable to infections since their immune system is weakened. Long term stress greatly increases the likelihood of such illnesses as heart disease, stroke and cancer. These two factors put the family at increased risk for disintegration whether through divorce over family conflicts, multiple members with serious illnesses or even death.

- C. There may be resentment by some family members for the added burden of more tasks while the ill member does no or few tasks.
- D. The pressure of trying to get everything accomplished actually reduces the ability of the family member to do everything well. Something has to give – either tasks are left undone or all are Done, but in a poorer quality. This is bad if it means work quality is sacrificed as the boss might become upset with the family member and fire him. Nor is it good if social relationships are sacrificed – less time spent with friends (or even worse with fellow family members like the spouse) means less social support – which is so necessary for mental health and family well-being!
- E. SOLUTION – Family friends and church volunteers could offer to help the family with certain tasks like picking up the medicine from the pharmacy, cleaning the house or watching the younger children. The family could be assisted to better manage their time through a careful analysis of their typical daily or weekly schedules. Home visits by professionals also relieve the family from the responsibility of transporting the disabled member – which is not only time consuming, but can be extremely difficult if relying on public transport. Family members need ways to reduce their stress – both exercise and relaxation are necessary to do this. Recreation times should be included in the family schedule and attention should be paid that the recreation includes healthy outlets like swimming and

walking in the park, not just sitting smoking a cigarette. Social times should also be deliberately built into the family schedule, make specific times to see friends and even reserve times to spend together as a couple. Friends can help by offering to come to the family rather than the family to them.

*Two people play the role of siblings, one well, one ill. Several people come by and offer attention and gifts to the ill one while paying little attention and offering no gifts to the well sibling. Gifts can be a stuffed toy, car, book. Visitors represent dad, grandma, and a friend.

6. JEALOUSY BETWEEN SIBLINGS

- A. As we have seen already parents have both a limited budget and limited time. They are continually forced to make hard choices about how they will spend their money and time. It is only natural that they will want to help the hurting or vulnerable family member first, longer and more often than the healthy members. This is acceptable for older members who understand and can appreciate the temporary reallocation of resources. However younger children who do not understand can easily become jealous of those who receive more attention or toys. Especially if as a younger member they are used to receiving more attention since they need more help or are cuter, etc.
- B. If the ill or disabled member needs more help or receives more attention for a longer period of time even older members of the family can become resentful and jealous. They may interpret the parents' actions as proof that they love the ill member more or that they just don't care about anyone else. Even when the parents are home spending time with the healthy siblings, for e.g. they may be so tired that it is not quality time.
- C. SOLUTION – Parents need to spend at least some time with the other members of the family and show some type of appreciation – even if not material at least praise and physical

affection. It should be carefully explained and as necessary repeated to younger children that they are loved and cared about, but that mom and dad are busy taking care of their ill sister. Other relatives and friends can step in to offer help not only with basic care but also taking the healthy members out to share some fun times together. As relatives can afford they could offer perhaps at least a small token of their love in the form of a simple toy or candy to younger siblings. Allowing the healthy siblings to see and spend time with their ill brother in the hospital helps them appreciate the need for mom and dad to spend more time with them and in this way the whole family can share time together! Special support groups and organized activities like camps and parties can be offered just for siblings so that they have a place to receive help and share their concerns and feelings related to the illness. In these contexts they can receive mutual support from others who understand what they are going through.

*Person puts on silly hat and she is asked to walk with two other volunteers outside. Ask the volunteers how they'd feel if out in public with a person wearing such a hat.

7. FAMILY ON STAGE IN PUBLIC

- A. When families with disabled members are out in public – at a store or restaurant, on the bus or walking in the park for e.g., they often perceive that others are staring at them. These people may whisper or even point at the disabled member. This can make some or all of the members (including the one with disabilities) feel self-conscious. It is an invasion of privacy and personal space and can lower self-esteem of the members.
- B. The healthy members may resent the disabled one for causing the unwanted public attention. They may not want him to accompany the family in public or may not want to seem a part of the family, for e.g., they may walk ahead of the family in the market or act like they do not know the disabled

member.

- C. The members may become hostile toward the public or may try to hide the fact that someone has a disability. The family may withdraw in part or whole from public life – spending most of their time in their home or with close friends and relatives only. Or they may leave the disabled member home, isolating him.
- D. SOLUTION – Public awareness needs to be raised about disabilities and about people who have disabilities. Actually by openly talking about this theme reduces fear and curiosity, two leading causes for unwanted attention. Also by increasing contact with disabled people the public becomes more comfortable with those who have disabilities and the novelty wears off. It is especially helpful if we begin to expose young children to those with disabilities since they are at an age of innocent curiosity and more adaptable to new situations. Families with disabled members can learn social skills to break the ice / tension while in public. This can include ways to introduce themselves to others using an approach which is informative yet warm and one which can even include using humor to lessen the uncomfortable atmosphere.

*Person asked to pick one of two papers to use for making a greeting card. One is clean the other is dirty and / or torn. When they chose the “good” one the person is asked why.

8. SHAME AND STIGMA ASSOCIATED WITH CERTAIN ILLNESSES OR DISABILITIES

A. People who have illnesses or disabilities are automatically perceived as less or as something wrong with them. Even the word invalid means NOT valid, or NOT of value! True there could be something wrong with the body or mind, but it does NOT make the person of any less value. That which is broken can still be useful!

B. Shame and stigma are especially associated with illnesses or disabilities which are perceived as preventable (such as someone with brain damage due to excessive drug use) or those associated with taboo activities, for e.g. AIDS (because it is associated with promiscuous sex / homosexuality). Also illnesses which are contagious are also stigmatizing (for e.g. Leprosy or Hepatitis) because people fear catching the same illness.

C. Stigma is often associated with some physical defect, but unusual or disruptive behaviors also can be stigmatic. For e.g. someone with Tourette's Syndrome who shouts out curse words (also seen as preventable and taboo) and autistic behaviors like hand flapping and rocking. Mental illness often fits into this category since people who are mentally ill may look "normal" but act strange – for e.g. a schizophrenic who is talking to himself.

D. People (whether disabled themselves or their families) who continually experience shame will suffer a great loss of self-esteem. When those with disabilities are rejected by others because they don't want to be associated with someone who has a stigma or because they are not good enough to be on the sports team or not pretty enough to get a date for the dance they can become very depressed. Some even take their lives because of it.

E. SOLUTION – Again education, public awareness and contact with people who have disabilities are key to reducing stigma. When people truly understand the causes and consequences of a disability and get to know the people behind the disability fear and suspicion are reduced. Fear is the greatest cause of stigma. Also when people see what those with disabilities CAN do they won't emphasize or care about what they can NOT do.

*Person is first shown a deck of cards and asked if they know what they are and what they are used for. Then ask them to join you in a game of "I doubt it." When they look confused or say they don't know how to play it - tell them, but I thought you said you knew what these were and how to use them. Focus on lack of info as

cause of inability to play. It is the same with our bodies or illness we may know some facts about them, but still be very confused about how they work or how cause is related to effect.

9. NO OR NOT ENOUGH INFORMATION, CONFUSION

A. When a person becomes ill or disabled most often the family is confronted with medical terminology they can not understand. Also they are asked to run through a bureaucratic maze through which they have no idea how to navigate. Further they may be asked or told to participate in the ill family member's treatment – such as monitoring the blood sugar and giving insulin injections. The family members lack knowledge about and skills for dealing with these illnesses. Often they simply have not had (or have had very little) previous experience with such matters.

B. The inability to understand what is going on, what to expect or what they could or should do in these situations creates a great deal of confusion and frustration. Even though family members can be quite intelligent, their lack of experience and specific knowledge can make them feel stupid or incompetent. This also has a negative effect on self-esteem. The frustration and low self-esteem they feel make interactions with medical staff more difficult. Family members may become aggressive and confrontational or afraid and withdraw. Often they can become suspicious of what they don't understand – especially when they over hear medical staff speaking in jargon.

C. SOLUTION - Family members need information about the illness – its probable causes, usual symptoms, effective treatments, etc. The information should be honest and understandable (this means in their native language and on a level most lay persons would comprehend). Info should be made available in brochures so families can re-read it as many times as necessary. Professionals should allow them to ask questions. Skills needed for dealing with the ill family member such how to safely transfer them from the bed to the wheel chair should be demonstrated and practiced under the supervision of qualified staff.

*Person is asked to draw a house on a piece of paper, or better yet on a chalkboard. As they draw continually stop them and tell them to draw the house in a specific way, for e.g., “No, not like that, bigger, OK, stop, now draw some windows. They’re too close together, spread them out more... etc.”

10. OVERWHELMED WITH TOO MUCH INFO & ADVICE

A. As discussed previously families need information when dealing with a disability. However, they do not need to be inundated with too much info. A couple brochures are helpful, but giving them 50 is overkill! Too much info can be just as confusing as not enough. Remember that these families often do not have a lot of time. Most do not need or want a lot of detailed medical info written for the medical professional audience – it is too complex to understand. Quantity is important, but so is quality.

B. Too much advice – even from well meaning relatives and friends can also be more of a bother than a blessing! Perhaps some helpful words from someone who has went through is or currently facing a similar situation can prove helpful. But constantly offering unsolicited advice is usually upsetting to the family – it comes across as you think they are too stupid to know what to do or not doing a good enough job. Often these well meaning people want to help and feel frustrated because they can not cure the problem or remove the suffering so they try to do what they can – give info and advice.

C. SOLUTION – Provide carefully selected, good quality info. Use surveys of family members to determine what types of info they found useful and understandable. Provide more in depth or more complex info when it is asked for. If someone has good advice for a family – it is always better to offer it in the form of a suggestion. Let the family know you are available to offer your advice – the door is open. They will listen to advice they solicit more than unsolicited advice. Also it helps to explain to families why well meaning people may inundate them with advice so they can at least understand why it is happening.

*Two people are quietly coached to act as givers of pity to a third person. The two volunteers pass by and show their pity through sighs, non-verbal language, comments like, “poor boy” or “oh what a pity” and pats on the head.

11. OBJECT OF PITY

A. People do have compassion for the disabled as they should, but often they express it in less helpful or encouraging ways. Pity is not compassion since it is usually based on little or no true understanding of the person who is disabled or of their plight. Further, it does not involve any sacrifice on the part of the person giving it. Compassion on the other hand demands action. Anyone can shake their head and say, “What a shame!” but it takes more investment of time and energy to get to know the person and actually help them achieve something. If someone sincerely cares for a person who is physically disabled, for e.g., or wants to alleviate their marginalization, they should do more than sigh, they should build a ramp!

B. Pity does not soothe the person with disabilities – its belittles them. The person giving the pity has the power while the one receiving it is dependent. The very expression of pity shows that the person giving it thinks the disabled is less of a person than they are (people do not show pity to those they perceive as equals) and is not capable of rising out of their circumstances.

C. The result of pity is feelings of shame, low self-esteem, passivity, and / or resentment. These discouraging feelings ironically make it harder for the disabled person to feel worthy enough to participate in society and live up to their potential. Thus, the person with disabilities may give up and remain the object of pity.

D. SOLUTION – When people are moved by the difficulties those with disabilities face they should first get to know those with disabilities better. Then ask them if they could be of help and if so, in what way. We all should join together to work WITH those who have disabilities to improve things in society.

*Person is asked to walk while carrying a cup of water balanced on her head (without using their hands to hold it in place).

12. CONSTANT STATE OF ANXIETY

A. Families who have a member with a serious illness are often worried about the current and future well-being of the ill member. They are also are worried that they might not do the treatments in the correct manner, that they might forget an appointment, or that they may give them the wrong thing to eat. Further they worry about meeting financial obligations and completing all that needs to be done each day.

B. Often family members can not show their doubts or fears because they believe they need to be (or at least appear) strong and emotionally stable for the rest of the family, but especially for the ill member. Thus, these members face their anxieties alone without support.

C. Prolonged anxiety physically drains the energy from the body. The tired person has less resources to cope with new situations and thus feels even more worried – which creates a negative downward cycle. Constant anxiety threatens the health of the person by lowering the immune system, raising blood pressure, increasing the amount of stomach acids (which can cause gastrointestinal inflammation) etc.

D. SOLUTION – The family members who are caring for a seriously ill member need respite (time to relax) from their obligations and help with daily tasks. They need to be reassured that they need not be perfect and that it is normal to have doubts about being qualified enough to handle such a situation. Providing info as noted previously and showing them how to do treatments can greatly reduce fear. Family members need a place where they can openly show their fears and receive assistance – such as in a parent support group. However, family members should know that it is OK to talk about feelings in the family also – even worries, since we all have them. It is also OK to talk about worries in front of the ill member – they are scared too, so if the topic is out in the open, there can be mutual support! As long as the person

experiencing fear doesn't become hysterical, revealing that they are afraid doesn't create more fear. Actually hiding it and each suffering in their fear in private is worse.

*Tell person to go to window and look at the current weather conditions. Ask them to change the weather. If it is sunny, ask them to make it rain, tell them that the farmers are depending on them because they need the water. If it is raining, tell them to make it sunny since rain makes travelling more dangerous so the truckers are depending on them.

13. UNREALISTIC EXPECTATIONS PLACED ON THE FAMILY BY OTHERS

A. Family members with ill or disabled members may simply be asked to do too much or expected to do things that are beyond their control or capabilities. Well meaning social workers or even Grandmas may wonder why the house is kind of dirty, why they don't visit more often or why the parents don't enroll the child in special Olympics.

B. Such family members are often expected to do all that needs to be done and still maintain a cheerful disposition, never losing their temper, never getting down-hearted, why? Even those with relatively easy lives go through various moods! In fact so did Jesus – he wept, he got mad at the money changers in the temple.

C. Some people may tell the family that their problems can all be conquered by simply having faith and praying. Or that if they try hard enough, they can pull themselves up by their boot straps. They perceive the families' problems as caused by laziness or lack of belief in God. Even worse some see the disabled person as a special cross to bear from God – in a way their suffering is a special blessing for which they should be grateful. Therefore, the family should be happy to have someone who is disabled!

D. SOLUTION – Disability awareness helps people realize just how hard it is to get things done while disabled. Again by being involved in the actual lives of the family, people who place unrealistic expectations could quickly see the error in their

judgment. Those in the Christian community need to examine more closely their simplistic beliefs about instant healing and immediate prayer response as a solution for all problems. God doesn't usually work that way. They also need to realize that most families don't find martyr status that enjoyable or such a blessing!

*Person is asked to pretend they are the mom of a 5 yr. old boy and then listen to a tape of a child crying and begging his mom to stop the doctor from "hurting" him / giving him a lumbar puncture. She is asked how it makes her feel that she can not stop the pain or make it all better. *OR have thing made of clay and squish it.*

14. POWERLESSNESS AND LOCUS OF CONTROL

A. Parents above all feel they should protect their children, especially from pain and suffering. When they can not prevent it or when they must allow it because it is part of the treatment parents usually feel helpless and powerless. This can create feelings of rage or despair. Parents may lash out at medical staff or give up and not be an advocate for their child. Neither extreme is helpful.

B. When parents feel they have no control over the situation, for e.g. the health care of their children, they perceive the control of their fate (and their child) as determined by external factors (we call this **external locus of control**). However, when they feel they can be an active participant and make a difference they are likely to have an **internal locus of control**. That is they feel the control over the situation primarily rests within them. We used to think that an internal locus of control is better since people take more responsibility for their health and indeed it usually is, but we all have to realize that we can not control everything.

C. If locus of control is too strongly external the person is passive with regards to their health and blames their illnesses on things beyond their control like destiny, superstitious events, the weather, even the acts of the doctors. However if it is too strongly internal than the person will see the state of his health as completely in his control and thus if he is ill, he is to blame so he feels guilty. The key is to realize where and when we can and

should take responsibility for our health – in other words have control over the situation, and when and where control is not possible.

D. SOLUTION – Wherever and whenever possible family members should be given the ability and opportunity to assume control over the health and well-being of their ill family member. If a child was crying for e.g., the parent could be taught how to help the child cope and then given permission to be with the child to comfort him during the medical procedure. In situations where control is not possible, for e.g., a family can not stop the dystrophy of the child's muscles medical and psychological staff should find other means for them to feel like they have some control. Perhaps they could chose which doctor they prefer or which day they want their next appointment. Again, parents need places to vent their anger and frustration over the lack of control they have over certain aspects of their child's health.

*4 People stand in a circle throwing and catching two balls amongst themselves. Then they pair off and each pair only throws one ball back and forth.

15. CHANGING FAMILY DYNAMICS / INTERACTIONS

A. When all members are healthy there are more opportunities for the family to interact as a whole. However when one member becomes ill and another becomes the primary care-giver the remaining two members may be separated (geographically – they are in a rehabilitation center in another city or due to time constraints – mom is caring for the child at the hospital while dad is caring for the younger sibling at home). If this continues over an extended period of time, subgroups may form.

B. The dyadic relationships within the subgroups can become stronger than the relationships between the subgroups. Miscommunication increases which leads to increased conflicts between the subgroups. Alienation can occur which then causes the members of the subgroups to turn towards each other for even

more support – accentuating the divide between the subgroups. If no intervention occurs, then separation and divorce are likely.

C. SOLUTION – Quality time which includes interactions between all members of the family needs to continually occur. Careful attention needs to be paid to prevent miscommunication which is more likely when family members are frequently absent from one another. Family counselling is a good way to prevent misunderstanding developing into hurt which lead to alienation.

PSYCHOLOGICAL INTERVENTIONS FOR COPING WITH ACUTE PAIN

1. Difficult to identify in young children or children who can not express themselves verbally due to motor and / or cognitive impairment.
2. Need to teach children how to describe pain (is it a constant pain or a throbbing pain, sharp or dull, does it move around, etc.) this comes from experience with a variety of painful stimuli/situations then the children can compare.
3. Recent clinical research has revealed that helping children illustrate their pain through drawings is a good way for them to communicate with their doctors. The symbols they use help doctors interpret what kind of pain they have and thus diagnose their illness. (e.g. pictures of pounding hammers and sparkling halo-like auras above the eyes represent migraine headaches while non-specific pain such as a rope being tightened around the head represent tension headaches. – refer to article).
4. Doctors need to quantify the pain, “How much does it hurt?” Best if they compare with other pains the child has had - Does it hurt more than... a regular tummy ache, getting an injection, or a bee sting?” etc.

5. Use of visual scales help children to quantify pain – such as pictures of faces starting from the left side with a very happy face moving to the right with increasingly sad/upset faces. The last face on the right shows a child crying as if in extreme pain. After the medical staff orients the child to the scale and asks questions to make sure he understands, the child is asked which picture best shows how he feels. Older children can use number scales, usually shown in ladder or step format, 1 = lowest pain, 10 = highest.
6. We all have natural coping styles to cope with pain – each style predisposes us to employ certain types of strategies to achieve our goal of successful coping.
7. With a substantial review of experimental studies psychologists have defined two basic strategies people use to cope
 1. **Information seeking or attention oriented**
 2. **Distraction**
8. Attention means the child wants to attend to the painful stimuli, he wants to see the medical procedure and wants know the information connected with the treatment. He looks at the procedure and studies what is going on. He wants to know the various steps involved in the procedure and how and why the doctor does them.

Coping Strategies: often the child **reinterprets the stimuli** as not so painful – for example, “Well this is just like a pinch, no big deal!” Or **compares the stimuli to past experiences in which he coped successfully** for example a bee sting, “This is not so bad I got stung before and nothing bad happened, the pain stopped quickly. The child also often **uses positive self-statements** like, “I can overcome this, I am strong!” Or “Ok, I am doing well, just a little bit more and it will all be over, hang in there!” The child may also accompany the attention with **breathing and relaxation techniques** such as breathing deeply and relaxing his muscles

9. Distraction means the child does NOT want to see the procedure and wants to think as little about it as possible! Therefore he does not want too much information, not too many details –

especially about things he will not sense (see, hear, smell, feel, etc.) Thus he will NOT want to know about how the doctor prepares the syringe, but he will want to know when the injection will begin.

Coping Strategies: **COGNITIVE** - **thinking about unrelated topics** such as what he will do when he gets home or wondering what his friends are doing right now, the child might also **imagine a special place where he feels secure and happy**, he also will **use positive memories** such as being at a party or on vacation, the child may also engage in **mental exercises** such as counting tiles in ceiling, remembering all the European capitals, etc. He may also **sing to himself or out-loud**

PHYSICAL – the child may engage in **body in rhythmic movements** or **tense and relax certain muscles**, he also may **breathe in a special way** **SOCIAL** – the child may **talk** with family or staff about unrelated topics, or **seek comfort and affection** from them by **hugging, patting, stroking**

10. It stands to reason that if children's natural coping styles are allowed or better yet actually supported they will cope better with painful medical procedures. If the medical staff does not allow children to cope in the way they prefer then they will not cope as well.
11. **Unfortunately** often medical staff do not understand or accept the idea that children have a preferred coping style and thus make no interventions to facilitate it or even worse they use strategies which are counter productive. **For example**, a doctor may give too much information to a child who prefers to distract himself from the procedure or he may even force the child to see the procedure in an effort to show him that, "It is not so bad!" **Conversely** a nurse may not allow a child who wants to see a procedure the opportunity to see it, thinking that it will scare him if he does see it.

The experiment

To prove that this hypothesis is true we set about to record how children coped with an uncomfortable stimuli – cold water. After children kept their hands in the water as long as they could we asked them what they did to cope and then based on that info we classified them into 2 groups – attention and distraction. We then divided those 2 groups into 6. A third of the attenders and distracters received coping skills training which facilitated their natural coping style and another third of each group received training which was opposite to their preferred style. The final third from each group received no training, they were the control.

Two measures were used to study subjects' coping with pain – **objective - time**, the longer their hand was in the water we reasoned the better they coped, the other measure was **subjective** – subjects were asked to **rate the pain on a scale from 1 to 10** – (one meaning low or little pain, 10 meaning extreme pain). Better coping would mean the subjects would interpret the water as having a lower number even though the temperature would remain the same.

As hypothesized, children coped better when their coping style was facilitated whether attenders or distracters. They each kept their hands in longer and each reported lower numbers on the pain rating scale. Those who received interventions contrary to their preferred coping style coped worse – hands less time in water, higher pain ratings. The control group showed NO significant change.

The **conclusion** is that medical staff need to find out from children what their preferred style is – through behavioral observations during previous medical situations and interviews of patients and families. Then, at the minimum, allowing the child to use his preferred coping style (or even better training him how to use techniques which facilitate his style) will help him cope more successfully with the painful procedure.

We know that practice makes perfect as the saying goes, and so we apply that in sports, in school and the arts, but why not in psychological interventions. If one wants to cope better, one needs to practice it. AND just as it is too late to wait until the day of the game, concert or exam to practice, so also it is too late to ask the child or oneself to cope when faced with a stressful situation. One needs to prepare BEFORE the event.

Let's say you determine the child naturally prefers to distract. Sit down with him and think together what he would like to do during a procedure to cope with it. You can suggest some activities and try a few out. After a while you will both discover which few work best. (It is always better to have a couple up your sleeve to be better prepared – just as a coach has a few plays in his mind for each situation and a student comes up with a few mnemonic techniques to remember exam data.) **Then practice those techniques – DO them, don't just talk about them, rehearse them!!!**

GUIDED MENTAL IMAGERY

The key to success is getting the child involved in his mental image – to have him concentrate so much on it that he forgets what is going on around him or at least the stimuli is perceived as less intrusive. You can help the child concentrate by asking him a series of questions about the scene – ask for details – use ALL the senses – “What can you see, hear, smell?” Even better ask specific questions like – “What time of day is it? What is the weather like – can you feel any wind?” “Can you hear any birds or other animals?” “Are there people – if so, what are they doing?” “What do you imagine yourself doing?” “Is there anyone special/loved one with you?” “What kind of plants, trees, flowers are there - how do they smell?”

The child is NOT to answer you – this disrupts the process, rather, he is to think about the answers and integrate them into his mental image.

For younger children or those in crisis who can not readily think of an image and have difficulty concentrating on it, you can provide a mental picture for them – “Imagine you are walking on a beautiful mountain path, there are many pretty flowers of all colors and they smell so sweet, the wind blows gently on your face and you can hear it rustle the tree leaves.” “It is a cool day the sun is out and you can see many small white fluffy clouds slowly moving in the sky.” “One even looks like an elephant!” “Then you notice a big beautiful butterfly – with red and purple wings.” “It flutters around and lands on a flower right next to you.” AND SO ON...

PLAY AND ART ACTIVITIES

“Developmental Play” – Play is used to teach new skills or improve upon existing ones in physical (fine and gross motor, sensory / perceptual), cognitive (language, reasoning, memory) and social-emotional areas. Educational and training objectives are met using play as a way to make learning fun. Play can be used to prepare children for school or to supplement learning while in school. It is less important to ask the child how he feels about using certain toys, than to see if the child can use the toys “correctly” or achieve a certain specified goal, such as completing a puzzle. Often developmental play is also used as a diagnostic tool to determine what, if any, developmental delays a child may have. Then, based on this information, a special program can be designed to focus on these deficits.

If the child was playing with Lego blocks the Child Life person would be interested in how the child holds the blocks and if he can put them together. Also they would observe if he can conceptualize and build a vehicle or house. He might show the child how to put

together the pieces so they are more stable and assist the child in following an instruction manual to complete a project.

If the child was drawing, the Child Life person might show the child how to draw incorporating the rules of perspective or guide him to improve his shading techniques.

“Play Therapy” – The therapist uses various play materials as a means of facilitating the child’s expression of his thoughts and emotions. The main objective of play therapy is to help the child deal with past, present or future (expected) crises or stressors. Through specific play therapy techniques the therapist assists the child in learning to cope with and overcome negative thoughts and emotions and use positive or constructive thoughts and emotions as resources to feel more confident – to work through various issues related to the crises. **Crisis can be personal** ones, such as disfigurement due to a severe burn **or situational** ones, such as witnessing violence at school.

If the child was playing with Legos, the Child Life person would be more interested in the themes of what the child wants to build, asking him if he builds things with his family, observing if the child reacts with frustration or discouragement when the pieces do not fit together, for example. He would use the time to build a trusting relationship and have a natural conversation which would allow the child to express himself openly.

Likewise if the child were drawing the Child Life person would not comment on the technical quality of the drawing, but rather ask the child to tell him or her about the contents of it. The drawing would be used to facilitate a discussion about the theme depicted in it. The child’s thoughts and feelings would be explored and validated. Misconceptions would be gently corrected.

It becomes evident that many toys can fulfill more than one of the following goals, they are useful for achieving multiple objectives

simultaneously! That is the beauty of using toys – they are fun and can help the child with several problems at once!

- 1. Physical development** – fine and gross motor skills, muscle strength, joint flexibility, eye and hand coordination
Examples of activities include – bowling, throwing rings onto rods, playing indoor tennis, drawing, threading beads, playing with putty, using a hand held labyrinth, using stencils

- 2. Cognitive Development** – expressive and receptive language, convergent (analytic) and divergent (creative) thinking, visual and auditory memory Examples – pairing cards by object association or opposites, playing the memory game and other table games, putting picture cards into proper sequence, “categories” and “alliteration” circle games

- 3. Sensory/Perceptual Development**– visual, auditory, tactile, olfactory Examples – looking through colored lenses and kaleidoscopes, listening to audio tapes and guessing animal sounds, matching shakers by their sounds, playing tactile dominos, guessing objects by their shape while blind-folded, smelling scented magic markers, making textured rubbings

- 4. Self esteem enhancement** – any activity which is NOT too challenging for children so that they don't experience repeated failure at each attempt, NOR is too easy otherwise the reward of achievement will not impress them. Children should be introduced to the activity and shown how to do it, but NOT helped so much that they feel like they did not do it on their own. **Activities which have a natural conclusion i.e. result in a product** such as paintings, clay sculptures and jigsaw or word puzzles are useful because children can see concrete results of their efforts and they can even give what they made to their parents. Thus, they feel like they can contribute something rather than just be a recipient! **Games**

which allow the player to achieve a goal through skill and strategy (not luck) – for example battleship, operation, math or trivia quizzes etc. are also good esteem enhancers. These are **process** oriented activities. Thus, the process can be just as rewarding as the product.

5. Encourage autonomy / decision making – children are presented with a choice of activities in the playroom and they have the freedom to choose what they like. They also have to make decisions about how they will use their time – will they play one long game or rather another shorter game which allows them time to play the synthesizer? Even in structured activities such as painting, children can choose the colors and themes of their work – thus there are choices regarding use of materials too. Children even have the choice NOT to participate if they want, they can sit back and observe – perhaps until they feel comfortable to join in. **We encourage participation, but, never force it!!!** *Even making bad choices are instructive – such as cheating (with its harmful social results of ostracism) and not paying enough attention during a strategy game which may allow the opponent to win.*

6. Channel and release negative emotions through constructive activities - children need to express their anger, sadness, fear, and guilt. If they try to keep it in, it will only come out through other means such as physical symptoms, destructive behaviors, social conflict, mental illness, etc. Activities which are open ended, that is without too many rules and specific objectives are best – thus art activities like using clay and paints and drama activities such as using puppets and clothes, hats, etc. for dressing up are good, while Monopoly and jigsaw puzzles are less effective. They are closed ended (they have specific objectives which do not allow for free expression). Symbolic toys are also great for this purpose – such as Playmobil sets, dolls and action figures

with their accessories, dinosaurs, animals, cars and trucks, etc. Playing with sand and water are also excellent for releasing pent up emotions (the child can simulate earthquakes, floods, build and destroy, save victims, etc.)

NOTE: You must be careful with children who have IV access in their hands and keep the playroom neat for infection prevention.

7. Modify problem behaviors – Since the playroom and its activities are naturally rewarding hospital staff can use access to this room as a reward for good or appropriate behavior.

Even while in the room the Child Life person can implement behavior change through using **time out** from activities or as a final consequence, **removal from the playroom.** Children are so eager to have a chance to play that they will almost always modify their behaviours to comply with the rules!

When children see that you *not only warn, but carry out the consequences you promise* for inappropriate behavior, they change their behaviors! For example, once there was this 11 year old boy who constantly used foul language and teased younger children. – I warned him, but there were no changes in his behavior so I sent him back to his room. The next day he was incredulous that I would invite him back, but I did and his behaviours dramatically improved! Children need guidance and limits! *These limits are determined by what makes a safe and comfortable environment for all the people in the playroom.*

8. Socializing, developing friendships and support systems – often when children come to the hospital they are in a place where they do not know anyone. They are isolated! The playroom is a place where children can gather and make friends in a natural and relaxed atmosphere. It can happen that a girl has no one of her age to play with on her floor for example and so she looks forward to the playroom where she

can hang out with her peers (same age and perhaps gender). Friendships develop over chats while playing games and making crafts. **Bonds are formed within teams when there are friendly competitions** such as over a game of Pictionary or Make-a-List, as well as during **cooperative activities** such as making a large mural or building a huge tower of blocks together. Children learn they are not alone in their struggle to overcome illness and feelings of anger for being stuck in the hospital. One child, who is perhaps a veteran of the hospital or a particular illness, may provide useful suggestions for coping with medical procedures. While family support is crucial, we should not underestimate the value of peer support. Especially for school age children and adolescents, peers are a valuable resource for emotional and social well-being. Supervised by the Child Life staff interaction with peers can facilitate and encourage appropriate development toward adult independence.

9. Moral Development – Children learn to play fair by following rules, sharing, taking turns, being honest, and even learning when it is acceptable to adapt the rules - making exceptions or being flexible (for example, while playing against a younger or inexperienced opponent). Whatever the game, they learn the process of give and take that is necessary to live in harmony and yet achieve goals. **Playing games or sports which have specific rules and guidelines are especially helpful** – such as Monopoly, UNO and other table or card games. Children quickly learn the consequences of cheating – rejection by peers. Often through positive peer pressure alone (without guidance from the Child Life staff) children learn it is in their best interest to follow game rules and social norms.

10. Facilitate Rapport between Child and Therapist – Children are almost always afraid of being approached by an

adult and asked many questions. Unlike adults who seek out therapy and know and understand its benefits, children are usually unwilling participants (sent by parents, school, medical staff, etc.) and **often do not even know how to define their problem or that they have a problem!** Thus the therapist has the task of making children feel at ease and welcoming them into as natural an environment as possible. For children building friendships and thus trust, is accomplished through play more than just conversation. A place in which play occurs is a natural environment for children. The game a therapist chooses to play with a child can be beside the point as far as therapy is concerned. Remember I said closed ended games can inhibit emotional expression, but a therapist may need to use such games, at least initially to establish rapport and build the relationship because the game may be a favorite, well-known one of the child. Thus he is more likely to be at ease in the situation. The fact that you are willing to play his favorite game shows you care about his opinions. **Case example: an 8 year old boy and I played Connect 4. Suddenly, he confided** to me that he was afraid because his mother's boyfriend forced them to leave his house and they had nowhere else to go. Thus, I now knew what triggered his asthmatic attack. Until then nobody else could determine what caused the attack (doctors, social worker, etc.) – there were no organic causes apparent. The social worker was especially grateful and was able to make the necessary interventions to help the family find a temporary place to live.

- 11. Alternative forms for communicating needs, feelings and ideas** - Each child is unique, some prefer to express themselves verbally, others visually, still others express themselves through their actions or through music. We must use whatever activity will facilitate optimal expression so that therapy can proceed. Children **may have a sensory, motor**

or cognitive impairment which impedes communication in one or more areas **or even their age** may limit their communication abilities. (They may not have the vocabulary necessary to express themselves or they may lack the motor skills required to draw a recognizable picture). Thus the Child Life person must use a variety of activities to try and find out which is most conducive to expression. Drama – puppets, pantomime, skits, etc., Arts – drawing, painting, clay, Writing, Talking, Dancing, Music – Singing, playing instruments, etc... all can facilitate communication.

Sometimes children are non-communicative because of severe trauma (i.e. they may be elective mutes) so using another media may open up channels of communication while slowly building trust. Children may be too afraid to discuss a topic as it pertains directly to them, but they feel more at ease presenting the topic in the guise of a story as told by the puppets, for e.g. Also due to cultural backgrounds, teens, for e.g., may not want to openly talk about a taboo subject in front of their peers such as sex, but they may want to write their feelings about it in private through poetry or journal entries which they could share with the Child Life staff later.

12. Humor reduces perception of pain and negative emotions

It has long been known that humor helps the healing process. Norman Cousins book, *Laughter is the Best Medicine* gave account to his ability to overcome a serious illness through using humor. Laughing releases hormones called endorphins which act as natural pain killers and make us feel good.

Watching funny films, telling and listening to jokes, seeing the antics of a clown and even playing with toys which elicit laughs are useful. Bubbles seem to elicit many, many laughs – even older kids get into the activity! Games or activities which are silly such as having a race – who can fan the feather down the hall the quickest or playing “Can you make me laugh?” are great! Even tickling can be used as long as it

is not forced on the child and is stopped before the child feels uncomfortable. Studies have shown that people require less pain medication, are mobile sooner, and go home from the hospital in fewer days when humor, and for that matter playing, is incorporated into their time at the hospital. People need a rest from focusing their thoughts on a negative event. We need time to process the event (to do the “work of therapy”), but then we need time off from this draining mental and emotional process. These fun times recharge our batteries and make us willing to once again focus on what negative obstacle must be overcome or accepted.

- 13. Distraction seems to make time go quicker!** – We all have experienced the phenomena that time seems to pass by more quickly when we are having fun. This results in children who are not as bored - which translates into less hassles for nurses, less calls for help due to being sad or uncomfortable. ALSO less vandalism in patient rooms due to boredom. Thus a play program means less work for medical staff and a nicer hospital in which you do not need to spend as much money constantly making repairs.
- 14. Facilitates education about illnesses and the hospital** – In a fun and understandable way children learn about why they are in the hospital and what they can do to help themselves get better!!! (we will talk about this later and give examples).

HEALTH EDUCATION AND PSYCHOLOGICAL PREPARATION / FOLLOW UP FOR MEDICAL PROCEDURES/ SURGERY

Health Education – teaches children to live a healthy lifestyle including teaching them about proper nutrition and hygiene, the need for adequate exercise and rest and the way to prevent

accidents (which is the leading cause of death in preschool and school age children in most developed countries!)

GOAL of Health Education – prevent future illnesses and accidents AND if possible, prevent or reduce the need for repeated hospitalizations & treatments. The first is primary prevention, the second, secondary prevention. **Prevent the occurrence of new illnesses or injuries**, for example, a child who is in hospital for a respiratory infection can be taught how to prevent usual household accidents. **Prevent the reoccurrence of illnesses or crises**, for example, a diabetic is taught about nutrition, how to monitor blood sugar levels and how to give himself insulin properly so that he does not have as many diabetic crises. Thus, he doesn't need to be hospitalized as often. Less hospitalization = less possibility for emotional trauma and developmental delays AND reduced cost for the government and ultimately you, the tax payer.

Psychological Preparation for Medical Procedures – Provides children with accurate information about the procedure so they will know what to expect, thus they can mentally prepare themselves for it. There will not be any unpleasant surprises or shocks!

The GOAL of Psychological Preparation for medical procedures – is to prevent emotional trauma and decrease stress which will assist the child physically recover more quickly.

GUIDELINES for Health Ed / Med. Prep.

1. **Give priority to children and families who are assessed as being at high risk for vulnerability to stress.** Those at high levels need help first, more often and for longer periods.
2. **Assess each child's present knowledge, understanding and appraisal of the situation** before deciding what information to

give. Thus, you will know at what cognitive level he is functioning and can adapt your presentation accordingly. Further, you will know what misconceptions to correct and what areas he already knows well so you do NOT need to repeat them.

3. **Prepare yourself for preparing children by familiarizing yourself with exactly how a procedure is done at your hospital.** Watch several being done for different age children (each place has its own policies and routines) find out what materials they use, what the room looks like, what each staff person does during the procedure, etc.
4. **Select materials and style of presentation to match child's cognitive level, experience and interest** (for example, for younger child use more concrete objects in preparation and more action, less talk. Children with more experience may just need a "refresher" while those with little or no experience may need more info and support. More extroverted children may prefer drama, while introverts may prefer drawing.
5. **Use clear language** - For example, avoid words which have double meanings like "boca" which can mean bottle or syringe / injection. It is better to teach and use *shtrcaljka / ushtreati*. Avoid using initials or explain them. Avoid jargon and idioms unless culturally appropriate and well-understood / well-used by children. Check to see if they know what the words mean or to see if the children's understanding of the meaning of the word is the same as yours!
6. **Use minimally threatening words** – Rather than say, "*This is going to burn.*" Say, "*Many children tell me that this procedure makes their arm feel very warm.*" This gives some information about how the procedure may feel without putting pressure on the child to experience the procedure as how other

children reported feeling. **NOTE:** Use ‘many children say,’ ‘NOT ALL children say...’ You can even tell the child that you will ask him how it was for him after the procedure.

Instead of saying, “*This medicine will taste bad.*” Say, “*This medicine may taste different than anything you have had before.*”

Rather than, “*The doctor is going to cut you open,*” say, “*The doctor will make a small opening about the size of your little finger OR smaller than a dime.*” Using concrete examples for size is better than measurements, ‘like about 4 cms.’ Also using smaller than is less threatening than bigger than or as big as.

Instead of, “*After your operation your throat will be painful,*” say, “*Children often say that after their operation their throat feels scratchy or dry.*”

Rather than, “*You will have to say goodbye to your parents,*” say, “*That is the time when you can say, ‘**See you later,**’ to your parents.*”

7. **Use developmentally appropriate vocabulary** – Use words the child can understand. Define medical terms. For example, anesthesia is a medicine which the doctor gives you so that you can go into a very deep sleep during your operation and feel NO pain. When the operation is done the doctor stops giving you that medicine so you will wake up and you will NOT remember it. Ultrasound is a machine which helps the doctor see inside of you. It only takes pictures. It does not hurt. Have you ever gotten an X-ray? It is like that except that the doctor needs to put some gel on the part of the body where the machine will look. This gel may feel cool on your body. The doctor will then place a part of the machine on your body where the gel is and he will roll it around. This part may even tickle a bit.
8. **Words can cause self-fulfilling prophecies** – Rather than saying, “*Lots of children feel sick to their stomachs and throw up when they wake up from surgery,*” say, “*As your stomach*

wakes up too it will need time before you can drink and eat again, some children say their stomach feels unsettled when they wake up others say their stomachs feel fine.”

9. **Don't put words into kids' mouths!** – Instead of saying, “*You are angry / sad / scared now.*” or “*That was hard for you.*”
ASK “*How was that for you?*” “*Was it the way you thought it would be?*” “*How do you feel now?*”

10. **Provide accurate info about what children will actually experience during procedures – avoid irrelevant details.** For example, we do not need to tell children all that goes on during the surgery since during this part they will be asleep and not experience or remember anything. Just give details up to point when children fall asleep due to anesthesia induction and then what they will experience when they wake up in the recovery room. If a child asks for details about the surgery itself (rare, but possible with teens) you can have him talk to his doctor.

11. **Describe the procedure in terms of what the child will sense – ALL five senses as applicable.** What he will see, hear, smell, taste and feel. For example, “*You will see bright lights and hear a machine beeping when you are in the recovery room.*” “*You may smell alcohol as they clean your arm before starting the IV.*” “*When you taste the medicine it may remind you of cherry juice.*” “*The operating room will probably feel cool to you,*” etc.

12. **Give an accurate account of the sequence of events,** for e.g
 - A. First the nurse will clean the area of your arm where the injection will be by using alcohol and a cotton ball.
 - B. Then she will prepare the syringe filling it up with medicine from a little bottle.
 - C. The nurse will make sure the syringe has no bubbles in it by squirting a bit out.

D. She may gently pat or press on your arm to locate a good vein.

E. She will let you know when she is going to give you the injection.

F. She'll place the needle in quickly and then she will hold it there very still while slowly pushing the medicine into your vein.

G. When she's done, she'll tell you and then she'll pull the needle out quickly.

H. She will put the cotton ball where the injection and hold it there for a few seconds.

13. **Let the child know about how long the procedure will last.** For example, starting the I.V. usually takes less than 15 minutes, or for smaller children who do not have a full understanding of time use familiar comparisons, you could say, starting the I.V. will take NO more time than it takes you watch a Tom and Jerry cartoon. Notice language is also softened, but still accurate.
14. **Demonstrate all the steps** involved in the procedure using actual medical equipment when possible.
15. **Encourage, but do not force, the child to handle and explore the actual equipment** that he or she will see during the procedure.
16. **Describe, draw or demonstrate with dolls behaviors that are expected of the child** during each step of the procedure (such as laying in a certain position, breathing slowly or holding his breath & keeping still). To make sure the child understands what's expected of him and to practice the behaviors, have him demonstrate them himself or show them using the doll.

17. **Discuss the different options of how the child might effectively cope** during the procedure. These options should be based on what is allowed and feasible, for e.g. the child may want to watch TV during the procedure, but there is no TV in the treatment room or he may be laying in a position where viewing it would be impossible. Think of several options so that the child has several ideas up his sleeve during the procedure.
18. **Provide the opportunity for the child to rehearse** these coping behaviors. For e.g. if the child wants to hum songs to himself then have him think of which songs he wants to hum and practice humming them. If he wants to make up stories using pictures from the paintings on the treatment room walls then have him look at the pictures and tell a story. During the practice you and he may agree that a strategy is not as effective as was thought and thus make plans to try another approach.
19. **Discuss with parents ways they can support their child before, during and after procedures.** If a parent is calm and able to offer emotional support for their child they can be very helpful, but if they are out of control they can make the situation worse – so it is better to prepare them too! Some parents may NOT want to be with their child because it upsets them too much. If this occurs do not attempt to explain why the parents don't come into the room, rather focus on reassuring the child that his parents are waiting for him just outside the room. If parents are not allowed to be with their child during the procedure, this should be explained to the child.
20. **Encourage children and their families to ask questions** to clarify what they have seen and heard or to ask for additional information. For e.g., “Is there anything that I have said to you or showed you that is not clear?” “Is there something else that you'd like to know, anything that you may be curious about?”

21. **Allow children and parents the opportunity to express their feelings** about the procedure. For e.g., “Now, that you have learned about this procedure, how do you feel about it?”
OR “Do you have any feelings you’d like to share with me about your child getting surgery?”

22. **Assess the child’s understanding and assimilation of the info** (by asking him questions or observing his play / demonstration of the procedure). Correct misconceptions or misunderstandings.

23. **Explore parents’ understanding of their child’s concerns and fears and assess family responses to the preparation.**
Ask parents how they think their child is feeling and if they think he truly understands what is going to happen. Parents know their children the best, therefore, they can provide an accurate assessment of their child’s emotional state. Observe the parents reactions to the information you provide about the procedure. Are they confused, argumentative, shocked, or bored, for e.g.? Perhaps you might need special time with the parents to go over the details again or to talk about other issues that are affecting their ability to understand or apply what has been taught.

24. **Do NOT force info on children** if they clearly indicate that they do not want to hear or experience it, for e.g., if children cover their ears, walk away, purposefully change the conversation, push the doll and medical equipment away, etc. Perhaps now is not a good time, wait and try later or try another approach (they may prefer to read about the procedure than to talk about it). If you continue to talk about it when they are not ready, they will most likely not remember any useful info. and are even less likely to learn how to cope effectively during the procedure – you are wasting time for you and the child. Worse

though is that such an experience in itself could be traumatic, thus completely contradicting the purpose of preparation!

25. **Build upon children's successful coping skills and experiences.** Remind children what they have already accomplished or overcome while in the hospital. Help them to remember what they have learned and what coping skills they have used successfully in the past to cope with similar procedures.
26. **During the procedure reinforce positive behaviors by giving the child a lot of praise, remind him of the coping skills you practiced** and begin to implement them by starting your special routine.

Useful Materials

1. Photo albums with sequences of photos detailing the procedure
2. Books for children about the procedure with plenty of illustrations
3. Actual medical equipment (these can be organized into kits which contain all the equipment necessary to complete common procedures such as starting an IV, putting on a cast, taking a blood sample, etc.)
4. Play medical equipment which children play with safely unattended (no needles etc.)
5. Dolls and puppets (animal and people)
6. Child-sized medical staff uniforms (surgical masks and caps, shirts, gloves, etc.)
7. Art materials – paper, paints, magic markers, etc.
8. Books for parents – about the procedure, illness or hospitalization and also ones which explain how they can cope and support their child's coping

Health Care Play

Expressive Activities can include:

1. Target shooting with syringes
2. Rip up paper and make balls, then throw them at targets
3. Cooking activities
4. Painting with syringes
5. Messy activities like finger painting and making “slime”
6. Body tracings
7. Graffiti posters, with themes such as, “The hardest thing about being in the hospital is...” “When I go home the first thing I will do is...” “If I were a doctor, I would...” “Some GOOD things about being in the hospital are...” “If I were director of the hospital I would...” “I wish...”
8. Drawings or stories about hospital, illness, or emotions
9. Progressive drawings or stories – child life person starts a story about a child or children coping with a difficult situation and children finish it
10. Hospital scrap books – composed of child’s drawings and those from friends, letters from home, photos of family and friends, photos of child in hospital, autograph pages for friends/staff signatures
11. Hospital Journal – older children / teens can write their reflections each day of what happened to them and others around them, what they saw, heard, smelled, felt, thought, and what emotions they experienced, etc. in the hospital

Familiarization Activities:

1. Collages and pictures - created from medically related materials (bandages, tape, wooden tongue depressors, piece of plastic tubing, cotton balls, etc.)
2. Painting with cotton swabs or disposable sponges
3. Mobiles from health care materials
4. Water play – with syringes, vials, plastic tubes, medicine cups, I.V. bags etc.
5. Exploration and manipulation of real medical equipment
6. Making finger casts from plaster of paris and water

7. Decorating disposable surgical masks and casts

Playing for children

Sometimes children are too weak/sick to play, but they can still appreciate play by watching you play for them. They can tell you what toys you should play with/use. For example, a child may watch a child life specialist create an art project and he may direct her how to do it, which colors to use, what to draw, how big, where to draw it on the paper etc. Or the child might get enjoyment watching the child life person play practical jokes on other staff such as squirting them with a special ring. Or the child life person could move game pieces around as they played a table game or work on a puzzle together with the child watching or even suggesting where pieces should go.

PLANNING PATIENT CARE –DETERMINING LEVELS OF INTERVENTION

TRIAGE – we need to determine the priority of our care (who gets helped in what order) **and the amount of care each child/family should receive** because our time is limited and we want to help the patients who need it most!

We need to assess stress vulnerability by systematically looking at the factors which harm children's abilities to cope.

1. **Health Care Variables** – Diagnosis, prognosis, anticipated treatment and procedures required, physical response to illness / injury / treatment, previous health care experiences, number, values and personalities of healthcare professionals involved in patient care
2. **Child Variables** – Chronological and developmental age in all areas of development, responses to previous separations from home and family, emotional responses to current and previous

health care experiences, ability to communicate, ability to function independently / self-care, understanding of health care variables, fears, coping styles and resources, cultural values and beliefs (including religious) other life stressors

3. **Family variables** – availability to child during hospital stay (how often and how long can family members visit), support systems and resources for the family, other family needs and commitments, cultural beliefs and values, anxiety level and emotional status, other life stressors, responses to current and previous healthcare experiences, understanding of child's health care situation, awareness of child's needs and concerns, ability and opportunities to communicate with health care staff

Based on this data children are assigned to levels 1 to 5.

Level 1 – stable medical condition with favorable prognosis, well functioning family support network, child plays and interacts comfortably with staff, and shows minimal signs of emotional distress.

Case example – 10 year old boy admitted with upper respiratory infection. Supportive parents and siblings who visited every day and also relatives visited often. She had made many friends on the ward, was actively participating in play room games. Not many invasive medical procedures were necessary and her understanding of the hospital and illness was excellent.

Level 3 – tend to be patients with chronic diagnoses, they and families familiar with hospital staff and procedures, medically stable and receiving adequate emotional support from financially secure families. Although children at this level tend to cope well with current admission, the chronic nature of the illness means numerous future hospitalizations, daily care and treatments which put additional stress on children/families.

Case study – 6 year old with diabetes whose family had trouble managing his illness was in and out of the hospital 3 times in one year. Although the family showed him love and concern, the parents had trouble accepting his diagnosis and had trouble making

all the necessary adaptations in their family routine to accommodate this new situation.

Level 5 – imminent or recent experience of intensive care, trauma - emergency room care, recent diagnosis of a serious / possibly fatal illness or end stage of a terminal illness. Also challenging family situations, low support from parents, financially insecure etc. Thus children's emotional needs were not being met and they showed obvious signs of being emotionally overwhelmed by their health care experience.

Case Study – 13 year old girl and her 15 year old brother were brought into the hospital, the brother was sicker and died shortly after, the sister was found to have the same diagnosis, but luckily her illness was not as advanced so the doctors were able to reverse the process. However she had to be told that her brother died and that since she had the same illness naturally she was worried about her prognosis. Her parents had been divorced for several years and her mother had not seen her in over 2 years. Her father was often absent due to work and so in the past the siblings had to fend for themselves.

GUIDELINES FOR SUPPORTIVE COMMUNICATION WITH PATIENTS AND FAMILIES

1. Be on their eye level, sit or squat if necessary. Eye contact is very important for communication. **Moderate contact is best – constant staring is threatening while constantly avoiding eye contact makes the person feel unwanted** or unimportant because it seems like you're not paying attention to them. Poor eye contact may be due to shyness, but it can appear as though the communicator is guilty or is deceitful.
2. LEARN the children's names. It helps to make them feel like they count and that you appreciate and care for them. Also it helps to counteract the depersonalization of the hospital

environment in which patients are referred to by numbers, diseases, etc.

3. Show concern for children by using appropriate touch. (Safe areas on the body) Note how children react non-verbally, they may not want or be ready to receive this physical contact. If not sure then ask, for e.g., “Would you like a hug?”
4. Be sensitive to needs for personal space. Each person is unique, but everyone needs at least some personal space. This also **varies according to the relationships of the people involved** (loved ones can be closer to the child than classmates and classmates can be closer than strangers, for e.g.). As a medical staff person assume you are a stranger until you develop a relationship. Then it will be easier to get closer to the child to do procedures or help with personal needs. **Personal space also varies according to culture** – US people for e.g. are used to a lot of space between people, but Japanese can tolerate much more crowded conditions.
5. Actively listen, This means **more than just hearing!** Pay close attention to what the children say and what they do not say – i.e. **concentrate enough on what is said to understand both the explicit AND implicit language** “reading between the lines.” When the children are finished speaking you should be able to summarize what they said.
6. Play close attention to visual cues. This means **being aware of the non-verbal behaviors** (body language, facial expressions, etc.) the children show as well as how they interact with objects and people in their environment (for e.g. fidgeting in their chair while speaking, kicking the table legs, and/or staring out the window).
7. Use open ended questions, they elicit more information and

thus stimulate communication, for e.g. *“How does that make you feel?”* or *“What types of activities do you enjoy doing with your family?”* versus **closed-ended questions, which elicit little info.** leaving the responder with the option of answering yes or no or giving one word answers, for e.g., *“Do you feel sad?”* *“Does your family like to play games together?”* *“Who gave you that?”* *“What color is this?”* **Asking a series of many closed-ended questions can feel like an interrogation, which is intimidating** to the child. This will actually stifle communication and thus hinders trust and relationship building.

8. Never assume anything, when in doubt ask for clarification, for e.g., *“What do you mean when you say you were upset from all the crying?”* *“Can you tell me what was happening?”* OR check to make sure your understanding of what was said is accurate, for e.g., *“If I understand you correctly...”* An example...

Child “...and then I had to go to the WC”

Staff: “So you felt like you had to use the WC or the nurse told you that you had to use it?”

Child “The nurse told me I had to go.”

9. Be careful when using questions to avoid using ones which already define or require a certain answer. For example, *“You don’t think getting injections hurts that bad, do you?”* This question surely wants the patient to answer with a, *“No.”* This **puts pressure on the patient to comply with the staff person’s opinion even though it was framed in a question.** Thus it impedes communication and devalues the child’s own opinion. Other similar questions such as: *“Don’t you think you ought to go to bed now?”* hide commands. If you need to request a child to do something, then it is better to simply tell the child. **Do not ask a question if there is no choice.** Asking such a question misleads the child and if he answers no, then you will be forced to tell him to go to bed anyway. However, it will be harder to command him

after such a question because he will have felt deceived. “*I thought I had a choice, but you didn’t care about what I wanted.*” If it is indeed open to the child to decide then the question should be framed another way, for e.g., “*Would you like to go to bed now?*”

10. Do not act in a judgmental manner (this means both what you say and your non-verbal cues)

AVOID! C. “*I wish I could kick my doctor!*”

S. “*Oh no, you should not think that way!*”

Judging puts the child on the defensive and will lower his ability to place his trust in you; he will not open up so easily again. OR the child will feel guilty for thinking that way and he will then have to deal with 2 layers of emotions, anger and guilt for being angry!

11. Instead of the above use REFLECTIONS (**these mirror what the child says without sounding like a parrot or tape recorder**). A good reflection not only says what the child says but also clarifies...

C “*I wish I could kick my doctor!*”

S “*Right now you are feeling like you want to kick your doctor.*” Another example:

C “*I am so stupid, I can’t do anything right!*”

S “*You think you are not too good at doing things well.*”

NOTE that you do not reject what the child feels/thinks, but nor do you approve of a harmful action or say that he IS in fact stupid. You are **affirming** HOW HE FEELS OR THINKS, not whether it is true or right.

Follow this up with some questions which ask the child what has been happening to make him feel this way. For e.g. “*Would you care to share with me what has been going on that has made you*

feel angry?” OR a mild request: “Tell me, if you’d like to, the things that have been bothering you.”

12. Using reflections also serve to show that you were paying attention to the child and that you value his opinion. This is also a way to VALIDATE or affirm what the child feels. Other ways to validate are to use the following ...

“It is OK to feel sad when you have to say good-bye.”

“Yes, it must be hard to see someone you love suffering.”

13. When confronted with disturbing information try not to act shocked nor in an attempt to mask your shock, try not to appear indifferent, instead express concern and interest. This is mostly done through your non-verbal cues, for e.g., eye contact, leaning toward the child, arms are NOT crossed etc. Also by what you say, for e.g.,

S “I am interested in listening to what you have to say, please share more if you wish...”

If you’d like to hear what the child has to say, but it is not the appropriate time or place then simply convey this to the child.

S “What you have to share sounds very important and I’d really like to listen to it, but right now, I am sorry but I don’t have time.” “Can I come and see you later?” “I’d like to listen carefully, to take our time and not be rushed.”

14. AVOID using interpretations. (For e.g. *“You did that because you were thinking...” “I know why you felt that way, you were...”*)

You can NOT know what the child truly felt or feels, thought or thinks etc. until you ask. **You are the student, the child the teacher with regards to his life.** Seek to understand from their information. The child will feel empowered to know that you are dependent on him for something (info). Handing out interpretations creates dependency and runs the risk of being incorrect.

15. AVOID dispensing advice, since you also run the risk of being incorrect and creating dependency. The role of a good “counselor” is one who helps people to discover for themselves the true nature of their problems and how they can work on resolving such problems themselves. People will follow their own ideas, which they realize are helpful, more readily than someone else’s ideas. Thus, **counseling helps people to gain insights into their behaviors and then guides and encourages them to act on those insights.**
16. Model positive coping and good communication skills, “do as I do” is better than “do as I say” You want the children to listen when you talk, but do you listen when they talk?
You want the children to express their anger without shouting meanly at someone, do you shout this way at others when angry?
17. Provide a safe, quiet space for sharing information, try to prevent interruptions, do not permit others to tease children when they reveal things about themselves, do not allow arguing or fighting, etc. Use **democratic process to make decisions rather than autocracy, but also be aware of the need for the minority to share some power / express their opinions** in the group. If possible try to build group consensus on an issue or activity choice. Help every group member to realize we are all unique and entitled to our thoughts and feelings.
18. To help establish a safe space you need to build trust in your relationships with the children. A very important factor to do this is to maintain confidentiality. Do not share with others any information you have learned about the child UNLESS:
a. they reveal that they have or threaten to hurt themselves
b. they reveal that they have or threaten to hurt others
NOTE: confidentiality includes not only NOT talking with

others about the child, but also NOT writing letters and articles about them unless you have their parents' and (if old enough to understand the request) the child's permission.

19. Ask the parents' and children's permission to take photos or make videos and to allow observers. Remember the children are not zoo animals on display, always ask for their consent. The children **have a right to privacy**, which has been greatly reduced while in the hospital. We do not want to do anything, which will further intrude into their privacy. Most will want the attention, but others will not. By respecting their right to chose, we are empowering them, rather than controlling or exploiting them.

20. Use appropriate SELF-DISCLOSURE. When we share something about ourselves it *shows that we trust the children* enough to take risks and reveal our thoughts, experiences and feelings with them. This aids in building the relationship. It also can show them that we have had similar experiences so we can at least *somewhat empathize* with them. This also *models what we expect from them*. However we must be *careful not to overwhelm the children with our own stories*, the focus should not be on ourselves. Never should we use our own experiences in an attempt to make light of what the children have endured or are enduring, even if our motives are to make them feel that what they have endured is not so bad that they can't cope with it. (For e.g. "Oh, you think that is bad, well I once had to ... and I could cope with it, so you can cope with your situation too!")

21. You should realize that you will become attached to the children and that you may be especially attached to particular ones. It is likely then that you will experience a loss yourself when the time comes to say, "Goodbye." Knowing this you can prepare for such a loss. It will be hard to leave the children, but

do NOT make promises to them which you can not keep, for example, “I will come and visit you at your home.” It is *best to keep well defined professional boundaries*, offer appropriate support and follow up. For example, “I look forward to seeing you again when you come for your check up – come up to the play room and visit me if you have time.”

22. Remember that “Silence is golden!” People need time to ponder what you have just said and then carefully think of their answers. The discussion can provoke many upsetting feelings and people often need temporal space to work through these. Also when a lot of new information has been presented, people may need time to literally gather and make sense of their thoughts relating to the info. We often jump in before or just after someone has finished speaking. And while they are speaking we are already formulating a response. Take time, allow for silences. It can seem awkward especially when we’re used to fast paced conversations, but remember this is not just another conversation, but supportive communication. Some counselors have even waited as long as half an hour – this is unusual – often the client will jump in to fill the silence. Look at the nonverbal behavior if the client is having a particularly hard time speaking, comment on this – “It seems to me that you want to say something, but just can not find the right words to express your thoughts or emotions.”

Practice – In pairs (counselor / client) in front of the whole class or in small groups with one person as counsellor, another as client, and the rest as observers who evaluate and give feedback.

1. **Counselor / Client:** Give an receive non-verbal behaviours. Pay attention to facial expressions, body language, eye-contact, giving appropriate touch, etc. When complete try to interpret what the other person was “saying.”

2. **Counselor:** Ask open-ended questions Use questions to clarify what the person has said. **Client:** talk about how you feel with regard to your experiences at school.
3. **Counselor / Client:** Ask and rephrase questions that hide commands. These can be on any topic.
4. **Counselor:** Use reflections and validations **Client:** Talk about an experience you had when you were very sick, injured or when someone close to you was in this condition.
5. **Counselor:** AVOID dispensing advice **Client:** Share something that is frustrating you right now in your life – it could be a relationship, work, health, finances, etc.
6. **Counselor:** Use appropriate self-disclosures and remember to allow for silences. **Client:** Explore something that worries you about your future – again it could be your health, work, family relationships, etc.
7. **Counselor:** Use all of the techniques of supportive communication. **Client:** Share a situation when you felt powerless, rejected or discriminated.

ALSO a good technique to make students aware of poor counselling skills is to highlight such mistakes in small skits with the professor as the poor counselor and the student / volunteer as the unfortunate client.

STRATEGIES FOR SUPPORTING FAMILIES

Families are a natural source of support and guidance for children – we should do everything we can to facilitate their role, NOT compete with them or take over for them. Thus, health care should be centered on the family – it's *the most important* social context for the nurture and protection of children. By supporting families we are ultimately supporting patients. Families have been providing for their children long before they arrived in the hospital

and will continue to do so long after they leave. We are only here to help them during this difficult period in their children's lives.

1. **Initiate a supportive relationship** by introducing yourself, what you do, how your program helps children and by explaining that you are here to help support the patient & family. Also give specifics about how they can contact you and where and when you offer services (for e.g. the playroom). You do not need to spend a lot of time with families to make them feel at ease. For many families a quick greeting each morning, short conversations during the day and saying goodbye when they or you leave is all that is necessary. Others may want or need more of your time; they'll give you the cues.
2. **Provide information to orient the family to the hospital:** such as locations of facilities, the daily schedule, important policies and safety precautions.
3. **Facilitate increased collaboration between families and healthcare professionals.** You can initiate this process by introducing them to other hospital staff and explaining to them what each staff person does. Encourage parents to talk to their doctors and ask questions. Perhaps you may have to accompany them to offer moral support. Meanwhile remind doctors of parents' needs, assist them in providing for those needs and help them realize how they can benefit by learning from and *working with not just for* families. For e.g., during their pediatric rotation medical students could actually visit a family with a disabled child and see how they cope. Create an atmosphere of openness and mutual respect not suspicion.
4. **Listen to the family, learn about them...** get info about the child – what he likes and dislikes, his typical behavior at home, past experiences with illness or hospitals. Get info about the family – what is the parents' schedule like, how often will they

be able to visit, are there any special needs or concerns the family has, how are the brothers and sisters coping? (as applicable) Get info about parents' perceptions, concerns regarding their child's hospitalization. Allowing the family to teach us about their child empowers them.

5. **Share useful info with the family** – about their child's development and his or her reactions to illness and hospitalization. Let them know how they can help their child, for e.g., how they can prepare their child for future medical procedures. Providing them with info about typical child development and normal reactions to hospitalization according to age, may also be helpful since they can compare their child with his peers and as is quite often the case realize that their child is coping well and is reacting in a normal way to the hospital. This will reassure the family that nothing is wrong and relieve some of their fears.
6. **Support the natural role of the family** by allowing parents to do what they normally do for their child (for e.g. help with bathing, if younger or help with homework, if older). Allowing siblings to come and play with their ill brother or sister also helps them to fulfill their natural roles. Try to preserve as much of the family's daily routine and rituals as possible (for e.g. letting the mom stay until bedtime each night so she can read her child a story as is their custom).
7. **Help the parents to feel useful** – this includes not only letting them carry out as much of their usual responsibilities (such as what was just mentioned) but also teaching them how to care for their ill child (for e.g. changing bandages, preparing special diets, doing rehabilitation exercises, etc.) Thus they will be more prepared to deal with their child at home so the transition will be easier. It also will reduce the frustration and sense of powerlessness many parents experience.

8. **Facilitate interaction among family members** by helping the child and family to organize a way for them to communicate, for example via phone and letters, receiving and sending photos, tape recordings of their voices and drawings. Calling the family to update them with regards to their child's emotional status, if they can not visit so often, is especially helpful.

9. **Do activities with children which address themes or concerns related to their home and family.** Talk, play with toys and games, read stories and do drama activities or art projects which support positive thoughts and feelings about their family. This also provides a forum for children to express concerns about the family, which then can be addressed as needed, for e.g., a child who is mad that his brother never comes to see him in the hospital. Perhaps his brother is not allowed and this needs to be explained or perhaps the brother doesn't want to come because he is scared. Then work could be done with the brother to prepare and encourage him to visit.

10. **Plan and host special events for the whole family as well as those designed for siblings, parents, and patients only**, so that each member of the family feels cared for. Such events could include reunion picnics, Christmas parties, day trips to the amusement park or zoo, and camps. Also these events allow families facing similar issues (for e.g. illnesses or loss) to fellowship in a fun, relaxing and natural way. It is especially rewarding for medical staff to see their patients happier and healthier than they are in the hospital and to see them in a non-medical setting which gives the staff a more holistic picture of the child, as a person, not only a patient.

11. **Organize and implement support groups for parents, patients and siblings.** These groups can offer an outlet for

difficult emotions and provide a place where others can truly empathize with them. Family members can learn positive coping strategies which reduce stress related illnesses and interpersonal conflict. Further, once they have been in the group for a while, they will be able to help new arrivals. This can empower them and improve their self-esteem.

12. Offer marital and family counseling to prevent family disintegration. Divorce rates are very high amongst families who have a chronically ill child. This is due to the unique, chronic, high level stresses the family must endure. Without intervention most normal people can not cope and interpersonal relationships suffer.

13. Coordinate educational presentations. Plan and lead presentations or find those who are able and willing to do so. Workshops, seminars and lectures on topics related to the cause or treatment of illnesses, psychological issues related illness or hospitalization, and financial / social benefits for patients and families can be especially useful for the successful coping of families during this difficult time. With increased knowledge comes a sense of mastery or control over these trying issues.

14. Create a family resource center / lounge in the hospital. This place would serve as a library where families could find information about illnesses, medical treatments, health and social welfare policies, child development, etc. Books, magazines, brochures, videos, and a computer with an internet connection would be very helpful. This is also the place where medical staff could lead seminars for patients and their families. It is important that this place be separate from the medical library so as not to disrupt the study of medical staff. As a lounge it could also offer a place of peace and comfort for families to retreat to for a moment of relaxation. Parents often need a quiet place to take a short rest while their child

naps or is undergoing surgery, for e.g. Such a place not only provides physical, but psychological respite. Perhaps free coffee or light snacks could also be offered by volunteers.

- 15. Teach and remind families of their rights and responsibilities while in the hospital.** Show parents how to tactfully assert themselves to get what they need while also helping them to live up to their responsibilities – such as making sure their child follows his treatment regimen and providing accurate medical history and socio-economic info.
- 16. Allow families opportunities to express their opinions and contribute their ideas to the hospital administration.** Listen to their suggestions for improving hospital policies, routines and the physical environment. Create family and patient (teen) councils where members can study or reflect on issues and make careful recommendations based on actual experiences in the hospital. Who better knows the needs of hospitalized patients and the problems families face than those families and patients who are often in the hospital due to chronic illness.
- 17. Be an advocate for families** – speak to law makers and community leaders about the special needs and problems of families with chronically ill / disabled children. Organize parents to create petitions, walks, media interviews, etc. to change or eliminate harmful laws and create beneficial new ones. Work to improve funding for psychosocial and special educational programs.
- 18. Provide pastoral care and spiritual guidance from chaplains** (priests, pastors, rabbis) for patients and their families. The chaplains should not only conduct services in the hospital's chapel, but also visit with children and parents at their bedsides. It is crucial not to overlook this key element in the holistic healing of patients. We now know that spiritual care speeds

recovery and decreases the need for pain medication and psychological intervention for emotional disturbance. Chaplains also can connect patients to religious resources in the community, including the families' own churches as necessary.

19. Connect families with charitable and governmental resources. Refer families to programs from various agencies and institutions which could provide them with the social, educational, political and economic benefits they need. Such services could help them adjust to the illness, prevent the patient from dropping out of school, relieve financial burdens or simply provide them with a forum to air their grievances. Serve as a link between the family in the hospital and the community. Usually such work is undertaken by a social worker, but unfortunately almost no hospitals have a social worker on staff so this responsibility falls to whomever can provide psychosocial support services.

20. Offer a special, private place for doctors to confer with families. This place is especially necessary when doctors have to give bad news. It is absolutely crucial for families to have a space where they can hear and discuss this info. and be able to show their emotions in private. This place should be comfortable, not clinical (so a doctor's office is usually not appropriate), but it doesn't have to be large. It could also be used for individual or family counseling by a social worker, chaplain or psychologist.

PSYCHOLOGICAL EFFECTS OF THE PHYSICAL ENVIRONMENT OF THE HOSPITAL

1. **Color** – light blue has a calming effect for e.g., bright orange the reverse

2. **Space** – must be adequate for each individual (remember personal space) and areas for group activities like playrooms and auditorium for entertainment / education
3. **Sound** – must use materials to eliminate echo like curtains, carpets and foam ceiling tiles, sound proof certain rooms for private discussions and to prevent distractions
4. **Ventilation** – fresh air is important for health
5. **Temperature** – best if climate controlled – if too cold or hot it increases stress and this can threaten health of patients and cause staff to be irritable and / or tired
6. **Light** – best if natural, worst is fluorescent, incandescent OK, level should be well enough to see, but not too bright – causes eye squinting and headaches
7. **Access to nature** – windows which look out onto trees, gardens and lawns (as opposed to a wall of another building, for e.g.) found to improve health: reduce recovery time from surgery, lessen need for pain medication, reduce calls for nurses, improve mood
8. **Decorative wall hangings** – can improve health too depending on content – 6 patient groups used (2 controls saw either white screen or just wall, 2 groups saw nature scenes – 1 of open area with some trees and a small river the other a shady forest, the other two groups viewed abstract art – one with rectangular forms the other with curvy forms. The group who saw the trees with water recovered significantly quicker and needed significantly less strong pain medication after major heart surgery than the controls, the shady forest group had mildly better results as compared to the controls – patients said it was a bit too dark and spatially restrictive. The patients who viewed the abstract art did worse than the controls, and the ones who had the rectangular art were doing so poorly that they often complained and asked that the picture be taken down, in fact due to ethical reasons all the pictures were removed! Psychologists hypothesize that art which contains ambiguous content – that is art which is open

to widely different interpretations as is abstract art – is inappropriate for healthcare institutions because patients can project their moods onto it. So if they're feeling anxious or angry they will see it in the painting and feel worse.

9. **Furniture and fixtures of appropriate sizes** for all – children as well as shorter people (e.g. those with dwarfism)
10. **SAFETY** – especially if children – need to be careful of sharp edges on furniture, but for all ages – need hand railings for support, textured surfaces to prevent slipping, etc.
11. **Orderly, non-cluttered spaces** are more conducive to relaxation and easier to clean, e.g. playroom should be well organized – if too many toys laying around children can become more hyperactive, confused – harder to focus on one activity and less likely to appreciate the toys so they may break them or throw them around further mixing the pieces of games, for e.g., also it is hard to locate a certain toy when it is needed
12. **Careful design can improve orientation**, reduce confusion – getting lost, using color schemes to indicate paths to follow or sections of large hospitals for e.g., also symbols can be used for those who can not read
13. **Layout of furniture can be used to facilitate intimacy / socialization**, a well thought out layout can make a large impersonal space seem more cozy, less intimidating or boring

RECOGNIZING AND PREVENTING BURN-OUT

1. Even Jesus got tired and needed to rest, if he did, then certainly we do!
2. **Symptoms:**
 - A. If you can not concentrate on your work or truly listen to the people you are visiting
 - B. Also if you become resentful of people demanding your time, short tempered, in general have unusual, rapid mood swings

- C. Changes in eating or sleeping, having bad dreams
- D. Become obsessed with patients' lives ignoring your own life or of your friends and family
- E. Develop physical symptoms with no biological cause – headaches, gastro-intestinal upset, chronic fatigue / joint aches, chest pains, etc.

3. **Prevention:**

- A. Take time to relax, get enough sleep – most people need about 8 hours a night
- B. Pursue enjoyable recreation, including having hobbies (art, sports, etc.)
- C. Keep up social contacts outside of work, spend time with your family (while with these avoid talking a lot about work)
- D. Have adequate time for spiritual renewal – not only attending church but going on group and individual retreats
- E. Seek clinical supervision, accountability from more experienced and qualified professionals (psychologists, pastors who regularly visit hospitals, etc.) You can review your work and get fresh insights on how to cope or deal with particularly difficult situations or patients, they also can help you avoid potentially dangerous ethical situations
- F. Go to a counselor to work on personal issues that are interfering with your work or are surfacing / intensifying due to patients which remind you of painful past experiences for e.g.
- G. Maintain good health by eating properly and exercising (this includes cardio-vascular workout as well as flexibility)
- H. Attend workshops and conferences about your work to learn new techniques which can improve your performance, thus reducing frustration / self-doubt

- I. Network with other professionals to reduce feelings of isolation, they can certainly empathize with you so you can support each other
 - J. Change jobs – try something new for a while
4. We can help recognize burn out in others (medical, psychosocial and religious staff) and help them to prevent it – this can be a valuable ministry on its own. Churches can minister to the staff by offering individual or group counselling or at least provide a space for the staff to meet. It is important that the space is not in the hospital, but rather in a relaxing, non-clinical atmosphere.

QUESTIONS ABOUT DISABILITY AND THE CARE GIVER ROLE

1. How did you feel while disabled – angry, scared, bored, confused?
2. What was the most challenging aspect about being disabled?
3. What did you discover about yourself?
4. How do you think you coped? If well, why, if not, why not? What did you do to cope?
5. Was the experience as you thought it would be?
6. What tasks were the most difficult to complete, why?
7. What did you miss the most?
8. Was there something positive you gained from being disabled?
9. How did your care giver treat you – did s/he rush you, baby you, ignore you, etc?
10. Was the care giving experience like you expected it to be – easier or harder?
11. How did it feel to be a care giver? What was the most challenging aspect?

12. Did you experience any joys or rewards during care giving?
13. Was the person for whom you cared cooperative, appreciative, too dependent, hostile?
14. Would you change anything from this exercise, why?