What Children Need

- A warm, loving environment
- To be treated as a growing child with special needs and interests
- To make choices whenever possible
- The comfort of their family
- A normal schedule with time for play and school work
- To learn about their illness in terms they'll understand

Priorities....

A hundred years from now...

It will not matter what my bank account was,

The sort of house I lived in, or the kind of car I drove...

What will matter is that the world may be a better place because

I was important in the life of a child.

E10

WORKSHOP X

A Guide for the Caregiver of the Hospitalized Child

Explanations of age related issues, stressors and behaviors.

Caregiver interventions to help children and families cope with hospitalization and medical procedures.

Prepared by the child life department at
Children's hospital orange county
Orange, California, USA
January 2004

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NEONATES - 0 to 30 days

Developmental Issues
- Startle reflex when moved quickly or hears loud noises
- Sucking reflex – sucks on anything placed in mouth
- Rooting reflex – opens mouth and turns head toward side where cheek is stroked
- Grasps anything placed in hand, then just lets go
- Focuses on objects 8-12 inches away
- Hearing is fully mature
- Moves head side to side while lying on stomach
- Begin gurgle, coo, and grunt

Hospital Stressors
- Startles to loud noises and sudden movement
- Blinks in response to bright light
- Impaired basic needs

Coping Behaviors
- Crying
- Sucking
- Quiets to soft music, singing, or talking
- Soothes when swaddled in blanket or being rocked

Interventions
- Encourage parent presence and participation in care
- Show parent how to touch or hold infant if connected to unfamiliar medical equipment
- Avoid quick movements
- Decrease noise levels and bright lights
- Avoid hunger and maintain warm room temperature
- Talk in soft, soothing voice 8-12 inches away from face

Pain Management/Comforting Techniques
- Light up toys
- Soft music
- Encouraging statements
- Comfort Positioning
- Singing

INFANTS - Birth to 12 months

Developmental Issues
- Learns through senses
- Development of trust
- Attachment to primary caretaker
- Minimal language
- Meet basic physical needs

Hospital Stressors
- Separation from parents
- Impaired basic needs
- Stranger anxiety

Coping Behaviors
- Crying, fussing
- Hand-mouth activity

Interventions
- Encourage parent presence and participation in care
- Show parent how s/he can still touch or hold infant if connected to unfamiliar medical equipment
- Involve parents in "positioning for comfort" techniques during procedures (act as comforter, not restrainer)
- Decrease number of caregivers
- Avoid hunger
- Talk before touching
- Maintain adequate room temperature

Pain Management/Comforting Techniques
- Light up toys
- Soft music
- Encouraging statements
- Comfort Positioning

Singing

TODDLERS – 1 to 3 years

Developmental Issues
- Seeks independence
- Developing language skills
- Learns new skills such as walking and toilet training
- Mobility is means to learning
- Threatened by changes in routine
- Short attention span

Hospital Stressors
- Separation from parent and fear of abandonment
- Stranger anxiety
- Unfamiliar environment
- Loss of autonomy and mobility
- Change in routine
- Back-laying position frightens toddlers
- Respond fearfully to sudden movements or loud noises

Coping Behaviors
- Regression of recently learned developmental skills
- Clinging behavior
- Temper tantrums

Interventions
- Encourage parent presence and participation
- Allow for motor activity
- Maintain daily schedule
- Offer choices when possible
- Expect treatment to be resisted
- Provide simple explanations

Pain Management/Comforting Techniques
- Light up toys, Music, Videos
- Encouraging statements
- Bubbles, Favorite object
- Singing, Comfort Positioning

Creating a Setting for Child Friendly Procedures

PRESCHOOLERS - 3 to 5 years

Developmental Issues
- Egocentric
- Increased, yet limited language skills
- Fantasy and magical thinking
- Fear of the dark
- Limited concept of time
- View hospitalization and illness as a punishment
- Learn best by doing
- Does not understand death as final

Hospital Stressors
- Separation from parent
- Heightened fears (pain, strangers, medical equipment)
- Feels loss of protection and a sense of abandonment
- Misconceptions develop from lack of understanding
- Unable to distinguish between fantasy and reality
- Loss of competence & initiative in developmental tasks

Coping Behaviors
- Regression
- Temper tantrums
- Aggression and anger
- Guilt
- Fantasy

Interventions
- Encourage parent presence and participation in care
- Offer choices when possible
- Reinforce that hospitalization, treatments, and procedures are not punishment
- Allow expression of feelings through play and verbalization
- Encourage child participation in care
- Allow for manipulation of equipment and explain in concrete terms (touch, smell, taste, sound, and sight)
- Be realistic and truthful
- Avoid words that provoke fantasies (cut, bleed)
- Correct misconceptions

PRESCHOOLERS - 3 to 5 years Continued

Pain Management/Comforting Techniques
- Humor/Jokes
- Soft music
- Encouraging statements
- Bubbles
- Favorite object
- Singing
- Videos

Comfort Positioning

SCHOOL AGE – 6 to 12 years

Developmental Issues
- Heavily involved with peers
- Develops concrete thinking
- Active learners, invent and design things
- Increased participation in self-care
- Well-developed language skills and concept of time
- Concerns about body image

Hospital Stressors
- Loss of bodily control
- Enforced dependence
- Loss of competence
- Fears body mutilation and deformities
- Fears loss of bodily functions and/or body parts
- Fears pain
- Fears death
- Fears anesthesia

SCHOOL AGE – 6 to 12 years Continued

Coping Behaviors
- Guilt (better able to test reality of situation, although fantasies have not entirely disappeared)
- Acting out
- Regression
- Depression
- Withdrawal
- Cognitive mastery

Interventions
- Offer choices when possible
- Teach coping strategies that encourage mastery
- Help child recognize aspects of their effective coping
- Encourage child participation in care
- Give child tasks to help
- Give specific information about body part affected
- Identify and correct misconceptions
- Respect child's modesty

Provide age-appropriate activities that foster sense of accomplishment

Pain Management/Comforting Techniques
- Humor/Jokes
- Music
- Encouraging statements
- Deep breathing
- Favorite object
- Singing
- Videos

Comfort Positioning

ADOLESCENT – 13 to 18 years

Developmental Issues
- Socialization is important
- Rapidly changing body image
- Body image relates to self-esteem
- Need for privacy
- Increasing independence and responsibility
- Struggle to develop self-identity
- Use of deductive reasoning and abstract thought

Hospital Stressors
- Lack of trust
- Loss of independence and control
- Threat of change in body image
- Restriction of physical activities
- Loss of peer acceptance and/or fear of rejection
- Threat to bodily competence
- Threat to future competence
- Fear of death

Coping Behaviors
- Defense mechanisms
- Intellectualization
- Conformity
- Uncooperative behavior

Interventions
- Respect and maintain privacy
- Involve adolescent in care and decisions
- Allow peers to visit
- Communicate honestly
- Discuss potential psychological and physical changes
- Address long-term issues in follow-up

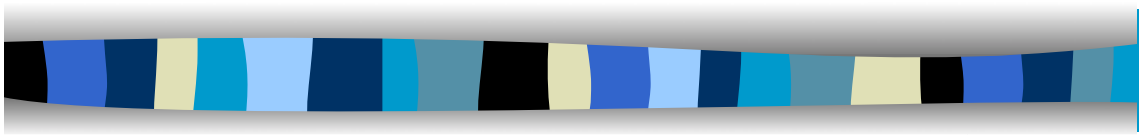
Provide opportunity for follow-up discussion and guidance as needed

ADOLESCENT – 13 to 18 years Continued

Coping Pain Management/Comforting Techniques

- Humor/Jokes
- Music
- Encouraging statements
- Deep breathing
- Videos/DVDs
- Guided Imagery

Please Call Me
or Send an E-mail With Questions.



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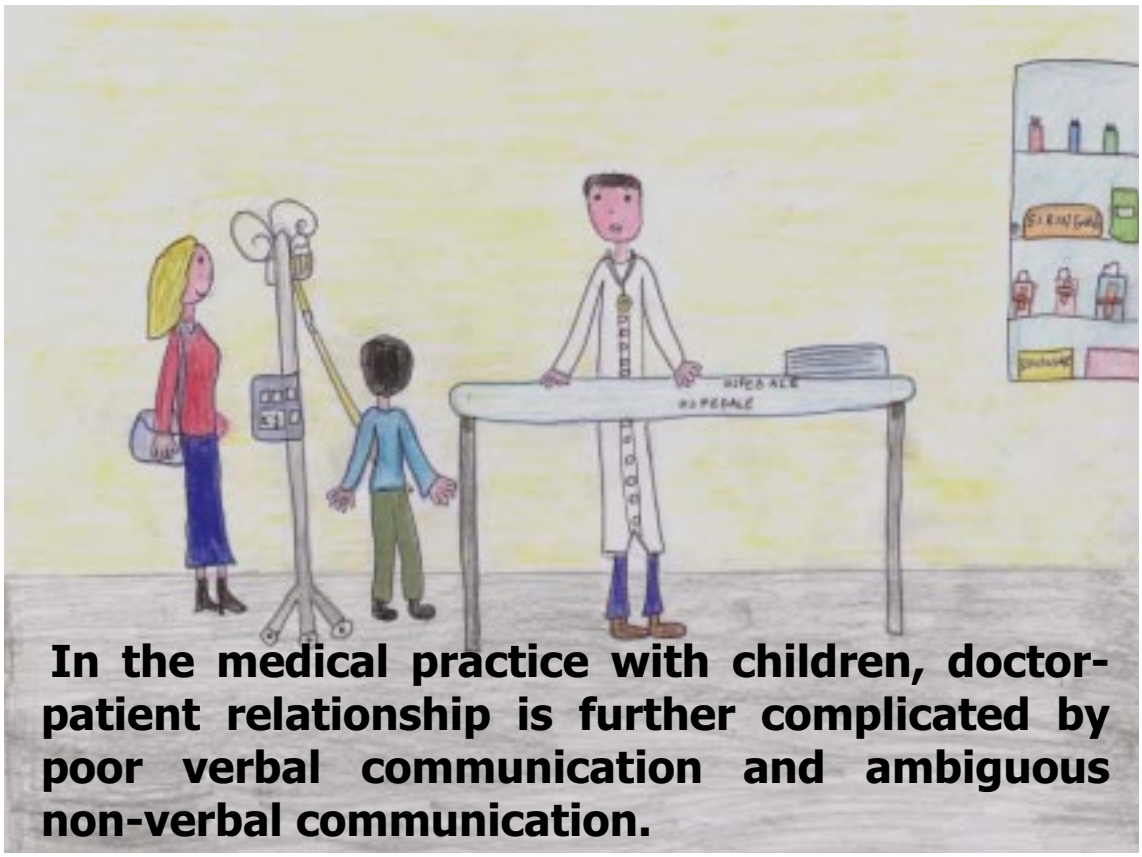
Drawings, the universal language of children. The experience within a Pediatric Hematology and Oncology Unit.

Luisa M. Massimo and Daniela Zarri

Good communication is essential to establish any type of alliance, including therapeutic alliance, which is an agreement between patient and carers whose objectives include not only recovery but also reciprocal satisfaction in therapy and cure processes.



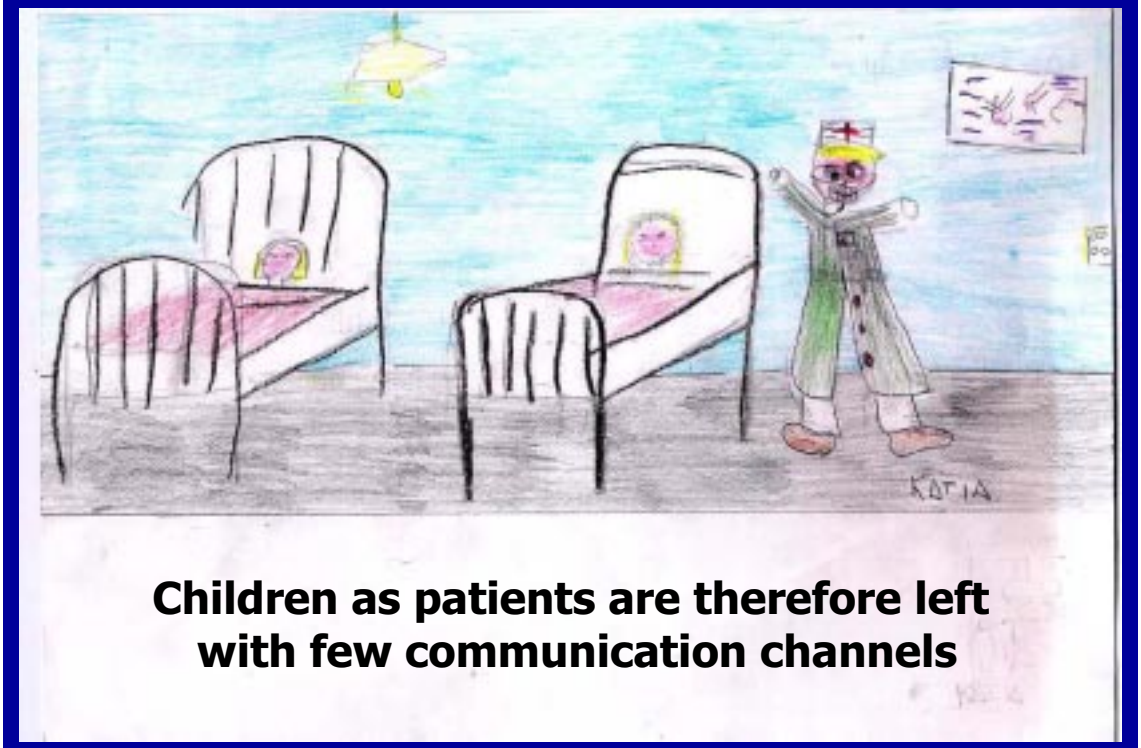
Actually, children rely on this latter more than adults, due to the immaturity of their vocabulary and thought processes, and to the nature of their needs, which can be more easily expressed and then satisfied by gestures, behaviour, voice tone, attitudes rather than by words.

Disease and hospitalization plunge the child into a condition of confusion due to the novelty of the experience and to the multiple and ambiguous signals perceived as related to the new situation.

In addition, the child is afraid of the pain caused by the disease and feels disappointed since his parents are not able to relieve it nor to defend them, and often loose authoritativeness as compared to carers

Besides impaired communication when received, we have ineffective communication when produced.

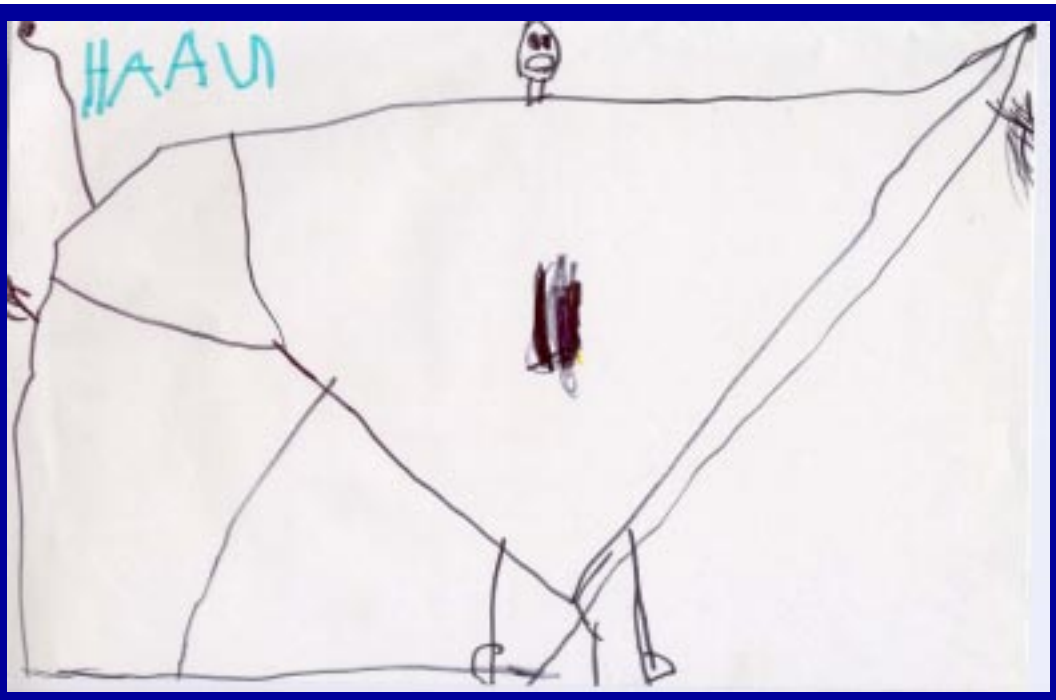
Crying, which in "normal" situations stops pain or anxiety, is ignored when performing a procedure, and the defensive gesture is restrained by the adult who blocks the child's arm or hand, thus hindering the disappearance of pain and not understanding that to the child, who cannot understand therapeutic effectiveness, pain is a danger and can destroy him. The importance of the placebo/nocebo effect is ignored .



Then we have art, ie drawing or shaping, collage and manufacturing of objects and toys, which are favourite activities even for carers (provided no dirt is produced) since children stay quiet and still. Fortunately, a pencil or a pen or a marking pen and a sheet of paper are sufficient to tell things and to tell things about oneself, and, if there are eyes and ears able to receive the message besides collecting data, isolation and fear break up.

However, it is not easy to break down the barrier of prejudice of carers who often think these products are simply scribbles or insignificant things.....

....“since all children scribble the same things”.....

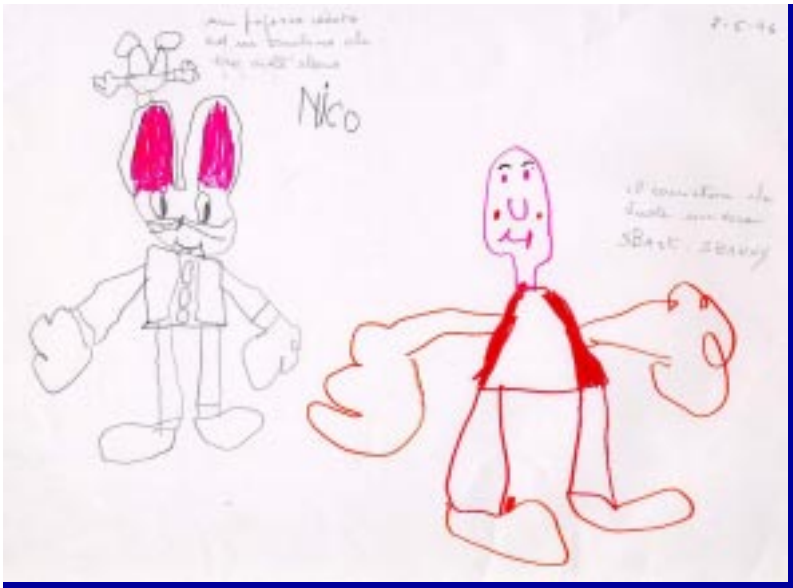


.....or "psychologists alone want to see meaningful things at all costs"

But, since drawing is a valid test used for a long time even in law courts, there are specific protocols for collection and interpretation.
In our case, since drawing has a diagnostic and therapeutic value, we follow the protocol as well as modalities of collection and return of the message which are functional to message communication and feedback. It is staff work involving the psychologist, nursery school teachers and educators, and also doctors and nurses (even though occasionally and spontaneously).

Since our activity was not aimed at making a diagnosis followed by a structured psychotherapy, we chose large and often "public" setting as play rooms in which team activities can be carried out. In our opinion, this choice was advantageous rather than disadvantageous, since the children enjoyed the play rather than test approach, and therefore enjoyed a greater freedom in their expression.

The collection strategy adopted was to establish some rules that could be easily followed by everyone who found himself with a drawing child. In order to establish the rules we have mentioned above, we discussed our project with the teachers to identify more or less appropriate moments for collection and to choose the correct approach not to inhibit or vitiate communication. Subsequently, we evaluated whether it was appropriate to press children for the delivery of drawings and when and whether this urge could elicit refusal or tensions.



Often children start to draw conventional situations, apparently impersonal, to test the open attitude of the adult towards them, especially when their thoughts are improper.

The cartoon character or the classic small house are structured defences against an intrusion into their intimacy or are drawn when they fear an unpleasant reaction.

We decided that each drawing had to be accompanied by an interview with modalities similar to those of CAT collection.
The application of this method yielded very good results since the attention received rewarded the children and made them more willing to cooperate.

We decided on an interview aimed at both communicating our interest to the child and avoiding wild and twisting interpretations of his message.

With this approach, we collected from Italian children many data on which we based our evaluation of drawings of foreign children who, at least initially, we could not interview. We observed that there are different types of messages, communicated using different individual modalities.

The first category includes drawings relating to a far-reaching biography, covering a long time span and a wide range of situations. In that case, the dynamics of the child's relationships with parents, friends, animals, and objects of daily life is evaluated.

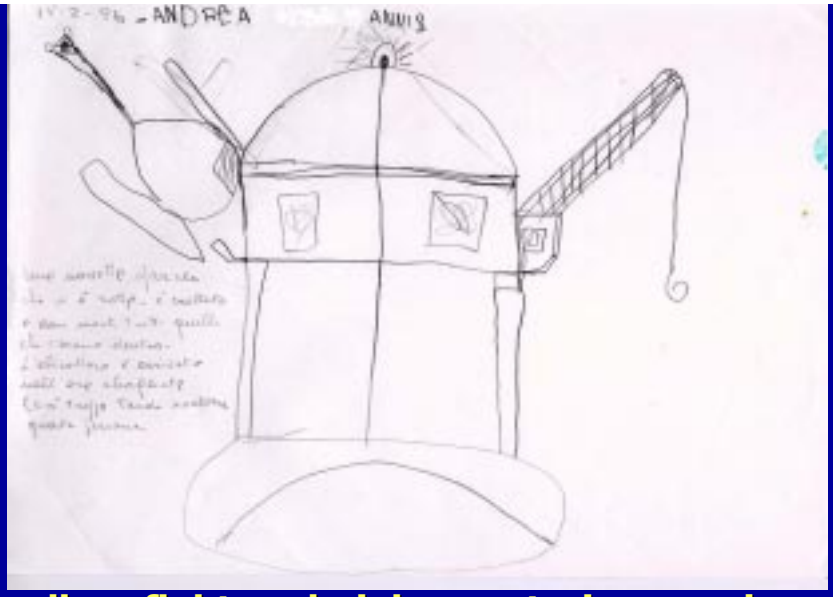
In these drawings, children represent almost exclusively situations not influenced by the disease...

....and they often represent themselves as physically normal, without mutilations or alopecia due to chemotherapy. They have a similar attitude when they tell about present events, ie events characterized by the presence of disease.

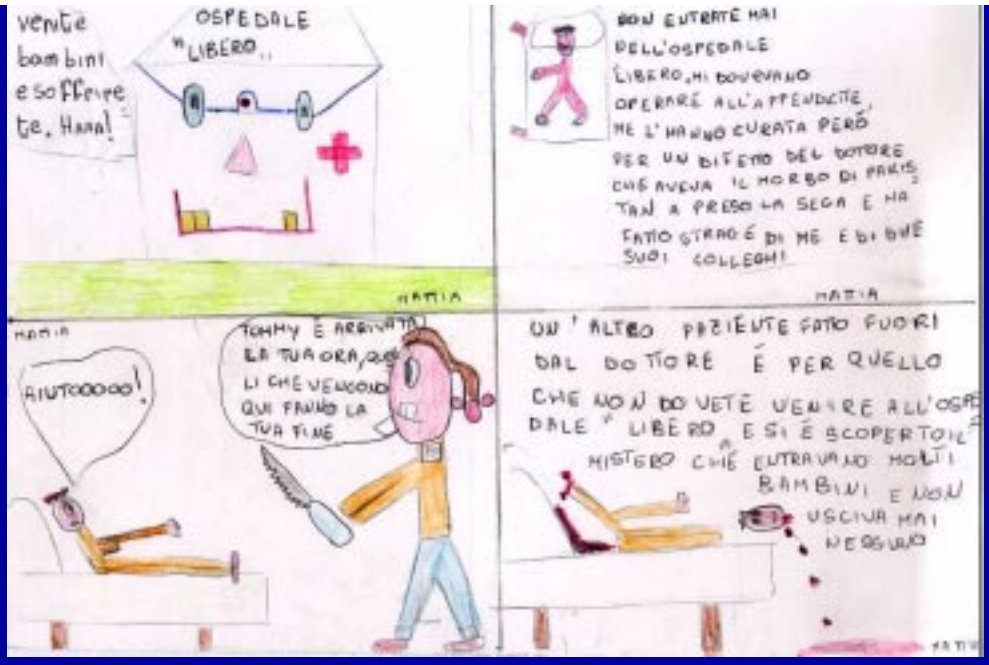
The second category includes drawings showing more clearly the child's perception of the disease and of himself as a patient. In these drawings, patients are either absent protagonists in often painful settings.....

....or stories or they are present and the representation of their physical aspect is often more realistic.

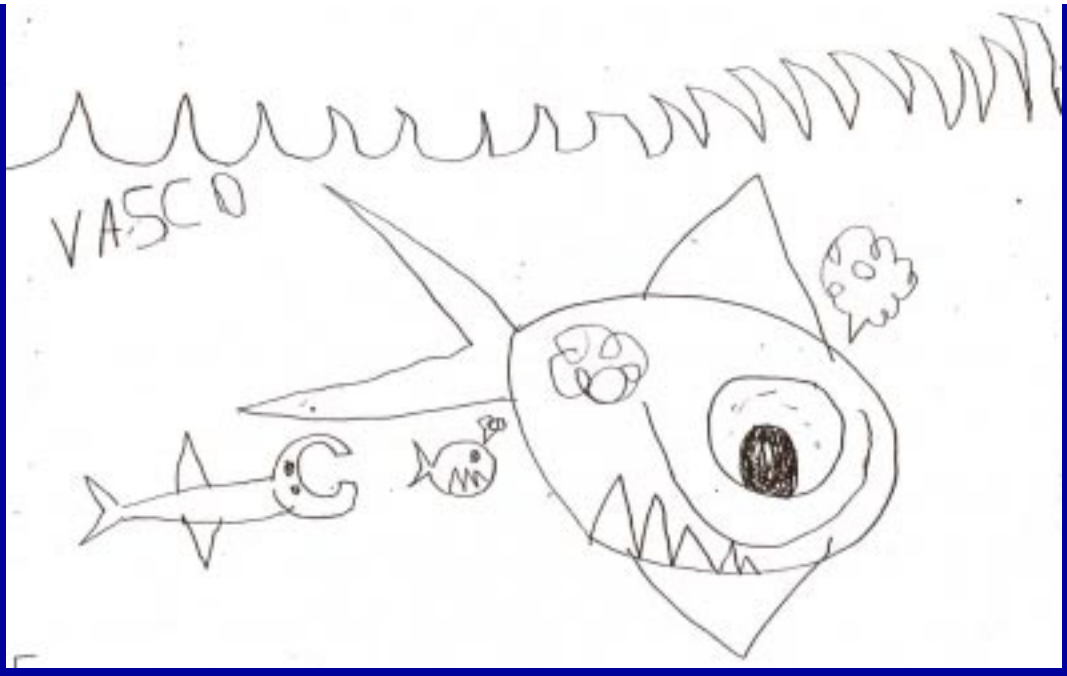
In drawings, predators are frequent characters...



....as well as fight and violence stories, as observed in drawings of healthy children feeling a threat to their safety. In childhood, any type of danger is seen as something bringing about physical destruction and a disease, irrespective of its severity, is as frightening as other events.



Drawings also show the child's fear of loneliness, which is closely related to fear of physical destruction, as the child is always aware of his vulnerability and dependence on adults.

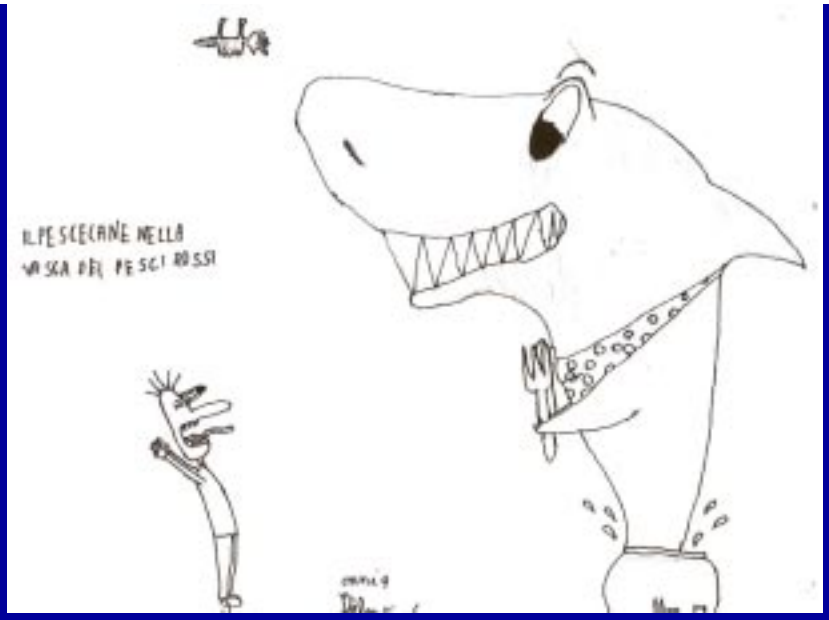


Hunters, witches, monsters, sharks, and wolves recall the frightening characters of fairy tales, and their secret identity is that of a disease...

...and also of carers and parents as seen on their dark side,

...exactly as Cinderella's and Snow White's stepmothers are the bad side (real or perceived) of the mother who is afraid of being supplanted by her daughter and becomes her antagonist. In fairy tales, the figure of the stepmother and of the ogre are needed since, through a splitting defensive mechanism, children can lay the blame on the bad side of the parent who hurt them, sparing the good side that cares for them. This mechanism is adopted not to have a loyalty or ambiguity conflict, as it is not possible to love and hate the same person at the same time, especially when one's well-being and physical and psychological survival depend on that person.

If in fairy tales the characters towards whom it is not possible to be ambiguous are parents alone, ill children's drawings represent even carers, fortunately belonging to the second category of drawings,



thanks to the child's ability to isolate and confine painful situations to which they cannot find an answer to a sort of parallel, stand-by space.

Maybe children want to spare, by not "polluting" it, the healthy portion of their lives and, in this respect, they are more aware than adults that the disease, though present, does not affect all aspects of present and future daily life.

This hypothesis is confirmed by the drawings of patients´ siblings, who are not directly involved and, even though the disease affects psychologically the whole family, are able to represent the disease itself from a more objective standpoint.