ART THERAPY AS SUPPORT FOR CHILDREN WITH LEUKEMIA DURING PAINFUL PROCEDURES

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ABSTRACT

BACKGROUND. Children with leukemia undergo painful procedures such as lumbar puncture and bone marrow aspiration. To overcome pain, certain units offer total anesthesia; others offer generic support; others offer no preparation at all. Since September 1997 we provided leukemic children with Art Therapy (AT), a non-verbal and creative modality that develops coping skills. Our goal is to prevent anxiety and fear during painful intervention as well as prolonged emotional distress.

PROCEDURE. We treated 32 children aged 2-14 years. The modes of AT before, during and after the punctures were as follows: clinical dialogue to calm children and help them cope with painful procedures; visual imagination to activate alternative thought processes and decrease the attention towards overwhelming reality and raise the peripheral sensitivity-gate; medical play to clarify illness, eliminate doubts, and offer control over threatening reality; structured drawing to contain anxiety by offering a structured, predictable reality (the drawing) that was controllable by children; free drawing to allow children to externalize confusion and fears, and dramatization to help children accept and reconcile themselves to body changes.

RESULTS. Children hospitalized before September 1997 exhibited resistance and anxiety during and after painful procedures. By contrast, children provided with AT from the first hospitalization exhibited collaborative behavior. They or their parents asked for AT when the intervention had to be repeated. Parents declared themselves better able to manage the painful procedures when AT was offered.

CONCLUSION. AT was shown to be a useful intervention that can prevent permanent trauma and support children and parents during intrusive interventions.
INTRODUCTION

Children with leukemia or solid tumors experience inevitable changes in their physical and psychological development since their continued traumatic experiences during frequent and prolonged hospitalizations often result in a crisis status (1-3). Most of these young patients, that is to say about 70%, overcome their illness and can be considered cured after a reasonable period of time. Therefore, more than ever before, we now want to ensure that children are adequately cared for not only physically but also mentally so that they can look forward to positive orientation for future development (4).

Children pass through basic developmental stages that lead to psychophysical consolidation and a better-defined personality structure, as well as to a strong capacity for “adaptation” (5-7). During this delicate phase, sudden changes pose a great risk to a child’s balanced growth (8-10) and children with tumors have to face such risks. They are taken away unexpectedly from home, family, school, and friends, from comforting continuity and play, and become helpless observers of the drastic physical changes to which they are subject. In order to explain such changes, the hospitalized child might consider them a punishment and develops an exaggerated sense of the “guilt” that every child faces and overcomes during normal development (11). If a child remains unable to organize the experience of illness and release his or her feelings into the external world, the illness can become a source of internal silent turmoil (12).

Most of these young patients need to undergo diagnostic and therapeutic interventions that are particularly intrusive, such as lumbar puncture (LP) and bone marrow aspiration (BMA). The delicate issue of protecting the child during these stressful interventions has been faced in different ways in various hematology-oncology departments. Some offer total anesthesia, with its associated risks and expenses in terms of time and money (13-15); others offer generic support; and still others offer no preparation at all.
Art therapy (AT) is a psychotherapeutic approach that utilizes creativity and symbolization to facilitate adaptability and release the inner unbearable feelings in a gentle way, preventing the accumulation of the inevitable states of anxiety during hospitalization (16-19). Based on an analogical communication, it facilitates empathy, understanding, reassurance and psycho-emotional processing in a non-traumatic mode. It has shown to be very appropriate for the hospital setting (20-21). In fact, being broad based and offering many modalities, AT is extremely flexible and adaptable to children’s different personalities and, therefore, capable of stimulating their different coping skills. AT modalities can be combined to reach the therapeutic goal. Specific AT modalities intensify the activity of the brain’s right side (22-24), stimulating imagination and creative-symbolization, facilitating children’s capacity to concentrate on pleasurable thoughts. This stimulation enables the young patient to relax, to reduce the level of anxiety, which can cause corporeal hypersensitivity (25). AT is efficient in compensating the lack of control experienced by the child during hospitalization, by stimulating decision-making among materials and techniques while increasing their quality of life. Through creativity, the child engages a space of intimacy, he is in charge of playing alternative “roles” rather than just being the patient. This ability protects his future psycho-emotional health and allows development of an inner identity to continue (26).

Illness and hospitalization define a moment of crisis for parents as well as their children. Their sense of desperation can reach tremendous height because they feel helpless, useless and, often, guilty. Hospitalization tests the intensity of intimacy between the child and the caregiver. The parent’s emotional state, in terms of strength or weakness, has a great influence on the child’s attitude towards hospitalization and treatment (27,28). Through creativity, parents can engage in a lively dynamic interaction, as compared to inaction and tormenting passivity, overcoming a sense of anxiety and anger at having no control or power over the child’s wellbeing.

Prior to September 1997 in the Department of Pediatric Hematology and Oncology of the University of Catania, the support offered to a child during intrusive interventions was exclusively physical, with local anesthesia being given ninety minutes before the intervention. The patient and
the family received very general and limited information about the procedure and were left waiting anxiously. One parent was allowed to accompany the child to the treatment room, reporting in verbal interviews that it was extremely difficult to support the child since the parent was also so confused and upset.

In September 1997, we started a pilot study of AT as a method for helping children with leukemia. Our goal was to support patients during LP or BMA, adopting the most appropriate modality to prepare each child before an intervention, to comfort them during the intervention and help them regain control, a sense of calm and self-assurance after the intervention (29). With this support we hoped: 1) to prevent increased fear and anxiety when the intrusive intervention had to be repeated and to help the child to become more cooperative and to have a better quality of life during hospitalization; 2) to help children and parents during the process of adaptation to the traumatic event and to exploit their own coping capacities; and 3) to prevent a lack of continuity in the ongoing development of each child’s personality structure.
PATIENTS AND METHODS

From September 1997 to September 1998, in the Department of Pediatric Hematology and Oncology of the University of Catania, we treated 32 leukemic children who were candidates for LP or BMA with creative art psychotherapeutic modalities that were offered by a psychologist art therapist. Eleven members of the experimental group (EG) were 2-5 years old, 14 were 6-10 years old and 7 patients were 11-14 years old (Table I). We scheduled and fully respected daily psychotherapeutic encounters that involved parents as well. Our study also included a group of 17 patients whose first hospitalization has been prior to September 1997 and who received no art psychotherapeutic support. This control group (CG) was composed of 3 patients of 2-5 years old, 8 of 6-10 years old and 6 of 11-14 years old.

The AT procedure adopted in our pilot study, was characterized by the following phases:

1) Clinical Dialogue. We utilized it to begin the psycho-emotional supportive procedure. It was the basic tool adopted each time LP or BMA was scheduled. During each one-hour session, through specific questions as inputs (Table II), the psychologist could disclose the patient’s behavioral stile related to the “here and now”, unusual, traumatic environment. This was necessary to understand whether the objectives of calming and developing coping skills for painful procedures, had to be reached by focusing or freeing imagination. A methodological split was adopted to make the clinical dialogue age-appropriate. For children aged 2–5 years, the psychologist systematically introduced a “third object”, an attractive toy such as a puppet, to promote in the child, through a direct association with the toy, a perception of the art therapist as a playful, “safe” person. After the specific questions, the puppet was used as the input to make up a fantasy-projective story.

2) Visual Imagination. It was the following technique, specifically finalized in supporting the child while facing the painful intervention. Visual imagination activated an alternative thinking process involving the right side of the brain, namely, a global, creative, imaginative process that raises the peripheral sensitivity gate (30). It can be differently developed considering the peculiarities of the child’s behavioral stile. A first theoretical and methodological split differentiates the structured-
focusing process from that of free-fantasying. The latter one is ultimately differentiated in fantasy and reality-based imaginative processes (Fig.1). For example, to children in need of control to better deal with the procedure it was proposed to decide about the time-set through a countdown; to children who could better tolerate the intervention through distraction it was stimulated the imaginative process by recalling pleasant events from real life, concentrating on the story before, during and after the puncture; children who needed to totally abandon reality, could invent their own story and let it evolve following the flow of fantasy.

3) Medical Play. It was offered to each child to allow age-appropriate explanations about the procedure. Child’s need to refuse any explanation perceived as overwhelming, was totally respected. It necessitates of a cloth doll and a variety of medical instruments. Medical play, with acting of the procedure on the doll, is of fundamental therapeutic value because it allows a child to a change of roles, from persecuted to persecutor, from passivity to activity (31,32). At the same time, the child regains a sense of control over reality. Prolonged awaiting from the application of local anesthesia to the practice of the intrusive intervention, was filled with certain AT modalities. The choice was based on children’s emotional needs evaluated through the clinical dialogue.

4) Structured Drawing. It was utilized with children who exhibited a great need for control: a sheet of paper with an outlined drawing was given to the patient to fill in with colors. Structured drawing provides an organized external reality, the drawing, with no unpredictable elements. It activates a state of total control since the child makes choices with regard to colors, materials and timing, all of which are very helpful in reducing present anxiety and tension.

5) Redundant Reading. It was specific for preschoolers: reading of a story over and over again stimulated a sense of control comparable to the one of the structured drawing. The infant develops a full knowledge about every detail of the story. This knowledge provides a sense of assurance and security because there are no unpredictabilities.
6) Free Drawing. It was the best solution for children who needed to liberate their inner imagination. It helped the child to externalize and get rid of internal confusion by “throwing” it on a sheet of white paper.

7) Dramatization. We utilized it for children who needed to “act out” their anxiety, to release and lower it through movement. As required by each different child, just words were used or whole scenes were made up with dolls and other toys. The presence of these elements created emotional protection for the young patients, who were able to release and process their emotional distress in a gentle and non-traumatic manner.

In this study, we decided not to use psychometric tests to evaluate patient’s behavioral style, since the pre-defined, pre-structured test within the hospital’s environment, could stimulate and/or accentuate the child’s present defenses (33). Therefore, the efficiency of the AT approach was evaluated by observing patient’s behaviors before, during and after LP or BMA. We selected 15 positive behaviors as indicators that children had developed or not a better compliance to the painful procedures (Table III). Children who adopted 8 or more positive behaviors were considered as “good responders” while “poor responders” were patients who adopted less than 8 behaviors from the list.
To illustrate the application of AT, we have chosen to present the following three cases. The names we used to represent each child, have no correlation with the real ones.

**Case 1.** Maria was a 7-year-old girl with amazing black eyes and long dark hair. It was her first day in the hospital. In the clinical dialogue, she was uncomfortable with verbal communication. Maria had a still, gentle smile frozen on her lips trying to “contain” the fears about illness to protect her mother from further pain, behavior that is typical of this developmental age since children can develop a deep sense of guilt (34,35) about a family’s distress. Watercolors became her media to express and release the contained anxiety in a non-verbal, non-traumatic way. Creativity energized her right side of the brain, the imaginative/playful thinking processes, putting Maria in a much more pleasurable, active condition facilitating relaxation. As she was painting, the child talked about her town and the pleasure of going to the swimming pool. Summertime became the theme for the reality-based visual imagination. The art therapist invited Maria to concentrate on trying to see and feel the details of the swimming pool, of her bathing suit, to sense the warmth of the water on her face and body. The anxiety visible on the child’s face when she reached the treatment room quickly vanished when her mother actively participated by recalling memories of the previous summer. Visual imagination helped the mother behave in a useful way instead of feeling impotent at such a difficult moment. The art therapist became a behavioral example and helped the mother get through the traumatic event, without anxiety, guilt and tension that would be inevitably transmitted to the child. At the end of the procedure, Maria confirmed verbally that she felt no pain. AT techniques were capable of engaging her own coping system and utilizing it to better protect her from a traumatic experience.

**Case 2.** Rebecca’s little, melancholy face was quite shocking, being far too sad for an 8-year-old girl. She had a reputation of being a difficult patient having adopted many “negative behaviors”. Entering her room, there was an illusionary calmness that concealed an unconscious choice of being passive and submitting to events. During the first clinical dialogue, Rebecca was
uncomfortable and resisted verbal communication, while her mother continued repeating that she was lazy and useless. The child showed to be passive to any of the proposed creative activities. The proposal to draw seemed to be attractive but scary at the same time. Staring the white sheet, she was unable to dare to trace a sign on the paper. Rebecca needed to engage in a reassuring, controllable activity that might awaken her faith in herself and gradually generalize this faith to include the therapeutic process. The mother also needed to integrate this reality because she seemed to have initiated a process of resignation and of emotional distancing from a daughter whom she saw as already condemned. The structured drawing was the most adequate modality to use to engage Rebecca’s active self. She had just started coloring when suddenly the timer on the intravenous pole started beeping. Rebecca froze, she stopped breathing and her eyes opened wide: the beeping was the threatening sound of danger. The child followed every single movement of the nurse. Her eyes became shiny, her breathing was now rapid and the desire to give up and weep was evident. When the nurse left the room, the tension was finally dissipated and she started to cry. Fantasmagorical, life-threatening images (36) had sneaked into her young mind. Rebecca needed true clarifications which were given in the following sessions through the medical play. The negative behaviors expressed her anger at having no control over her existence. The clinical dialogue indicated that she needed a focusing visual imagination since the application of a freeing visual imagination would open a door to all her suppressed fears. Control and empowerment were necessary. With the doctor’s cooperation, some control was possible since Rebecca was allowed to count up to 100 seconds during the LP to decide the duration of her procedure. The child’s mother seemed able to develop a belief that her daughter had the right to speak out about her needs and to have her needs satisfied. When the procedure began, the child started counting clearly and loudly. With the exception of a few facial expressions of pain, the procedure went very smoothly. Furthermore, a sense of satisfaction, engendered by the empowerment, stimulated a sense of complicity with the medical staff and allowed her to cope better with the LP.
Case 3. Fatima was a 2-year-old girl of enchanting beauty, with soft, red curls, big green eyes and freckles that moved each time she smiled. Because of her young age, during the first clinical dialogue, the art therapist used a puppet named Gnomy. The young child seemed to be delightfully surprised by Gnomy’s sudden ability to speak. A few minutes later a doctor entered the room to apply the local anesthesia for Fatima’s next BMA. Her smiling face immediately became very serious, she resisted being touched by the doctor and started to cry. So Gnomy started the fantasy-based storytelling (through the art therapist’s voice) and asked Fatima to be a mountain to climb. Meanwhile the doctor applied the local anesthesia. Gnomy’s storytelling soon involved butterflies and bees that landed on the mountain and that sometimes, unwittingly, might pinch the mountain. The child continued to be totally involved in the story and followed Gnomy to the treatment room as part of the game. She kept her attention focused on the story during the entire BMA procedure with a few exceptions, at which times her mother’s intervention was very helpful. Constantly looking at the art therapist, the mother would put her mouth very close to the daughter’s ear and whisper lovely details about the story. Eye contact with the art therapist showed that her mother needed to be reassured that she was doing the right thing. It is important for a parent to feel helpful at such a traumatic time and to overcome any possible sense of guilt. Once Fatima had returned to her room, she went back to her play activity and soon her good mood returned. As her therapy cycle was continuing, dramatization became the most appropriate modality for allowing continued therapeutic release of her inner feelings. When the little girl received a haircut so that she would no longer have to see her hair’s constant falling, her mother reported that the child expressed no emotional reaction. It continued to be so until the play with a doll gave her a chance to express the intensity of the effect of such an event. Dramatization utilizes characters providing the necessary emotional distance such that a person’s feelings belong to the characters. After a long time spent caressing the doll’s hair, she laid the doll down with her face towards the bed saying that the doll was sick. Fatima was recreating, in front of our eyes, the drama of her experience, she was starting to free herself from its weight by releasing her inner trauma into the external world. The
intensity of the experience soon became overwhelming and Fatima suddenly stopped speaking and started searching for her mother’s eye. She kept eye contact with her mother for a few seconds as if she wanted to ask for something that the limited capacity of her little vocabulary was unable to express. She then stretched her little, fragile arms towards her mother and started touching her hair. She was “telling” us that she needed time to process the whole experience. What she needed at that moment was to escape from threatening feelings and to be held in the comforting embrace provided by the warmth of her mother’s touch.
RESULTS

To evaluate the therapeutic effects of the AT approach during LP or BMA, we compared the behavioral styles of the children who participated in the pilot study, as the experimental group (EG), with children in a control group (CG) (Table IV). We sum the positive behaviors adopted by each child within the EG and the CG when the painful procedures had to be applied. The results expressed a relevant difference between the two groups. The number of positive behaviors adopted by the EG was higher when compared to the ones adopted by the CG. More specifically, we have ascertain that from the CG, children from the youngest age range, 2-5 years, showed no good responders; the following age range, 6-10 years, showed 2 good responders among 8; the oldest age range, 11-14 years, showed 1 good responder among 6. From the EG, children in the youngest age range showed 7 good responders among 11; the intermediate age range showed 10 good responders among 14; the oldest age range showed 6 good responders among 7. To better illustrate the results of our pilot study, we chose to point out those behaviors recurring with higher frequency. We observed that from the CG, most of the children aged from 2-5 years and 6-10 years, feared the application of local anesthesia moving energetically to avoid it and started a constant cry prolonged during and after the painful procedure, providing evidence of the persistence of inner fears, anger and anxiety. After LP or BMA, most were unable to get involved in play activities. Some of them rejected their mother’s arms as a possible way to release the anger accumulated in the prior experience. Through a continued observation we noticed a correlation between the mother’s holding still their child during the procedure, and the child’s following response of rejection of that parental figure. Most of the oldest children (11-14 years) reacted to local anesthesia application by adopting altered emotional states, from passivity and withdrawal to yelling and throwing objects in the room. They reported verbally that, during their first experience, the lack of knowledge was the major cause of intolerance and fear since they continued to develop threatening fantasies about the “mysterious” subsequent intervention. For those who needed to repeat the experience, an increase in
anger was linked to the sense of loss of control that the LP or BMA provoked, mostly because no emotional support had ever been given.

Children supported with AT since their first LP and BMA had the capacity to develop positive behaviors while facing the painful procedures. In fact, as children became engaged in a trusting relationship with the art therapist during the clinical dialogue and the creative activities, they showed to release the basic level of anxiety and manifested no increase of negative behaviors at the subsequent application of local anesthesia. When the punctures had to be repeated, most of these older kids asked for the art therapist’s support, affirming that they would be better able to tolerate the unpleasant experience. In the case of very young patients (2-5 years), parents asked for the support, telling us how useful such support had been for them as well. Considering the three different age groups in the EG, patients supported with AT techniques exhibited the following behaviors. 1) Before the intervention, most of the patients aged 11-14 years old showed cooperation and passive compliance; during the intervention, most of them chose to use the countdown. After the intervention, they were able to engage creative activities as well as social relations. The open dialogue that the art therapist stimulated between the two parties helped patients become aware that doctors were willing to respect their needs as far as possible. 2) Before the procedure, most children aged 6-10 years old, showed an active compliance; difficulties were mainly expressed on their way to the treatment room as we described in Maria’s case. Anyway, it was easy for her, as well as for other children, to calm down as the mother actively participated to the story-telling or, as they started the countdown that continued to the end of the medical procedure. During the procedure, the countdown was mostly utilized and was most helpful to this age range as for children aged 11-14 years. The usefulness of the countdown in these two age ranges, is to be related to the sense of control that provides, which is so important at these developmental stages and that hospitalization takes away. This is clearly expressed in Rebecca’s case. In fact, as the art therapist addressed the child’s need of control towards the countdown, Rebecca became able to better tolerate the traumatic experience by engaging such an appropriate coping method. After the procedure, many children
from this 6-10 age range, were able to engage the creative activity prior to the intervention. 3) Before the procedures, most patients belonging to the youngest age group (2-5 years), showed to be annoyed by the application of local anesthesia. However, they would easily collaborate and stop crying as AT modalities were adopted. During the whole intervention, they became totally involved in the story-telling. After the painful procedure, they were easy to console by continuing the story-telling. We can find in Fatima’s case a synthesis of the behavioral peculiarities from this age range.
CONCLUSIONS

We interpreted the results of our pilot study as a clear evidence of children’s difficulties to engage coping skills spontaneously in a state of anxiety and, of their profound need for support in such difficult and traumatic moments. This confirms the importance of providing children with an adequate preparation before facing medical procedures and specifically painful ones (33).

Our study suggests that children treated with the AT technique experience clear benefits from its application facilitating their adaptability and enhancing their capacity to cope with stressful events. Creativity and psychoemotional support seemed to provide appropriate protection for children and their parents before, during and after the puncture. We observed that clarification of the intervention and control, helped each child contain and alleviate the basic level of anxiety, thereby increasing the quality of life. The emotional support and the creative activity enhanced children’s and parents’ capacity to adapt to and accept hospitalization by improving their basic coping skills. The AT modality offers an important avenue for alleviating the consequences of life-threatening, long-term therapy, making the whole experience less traumatic.

AT support was very helpful for parents as well as children. In our study we confirmed that, prior to any psychotherapeutic support, parents easily enter a state of shock when facing a hematology-oncology unit because, as they report, they have read or heard discouraging stories of related illnesses; they develop a sense of guilt because they lack appropriate information about the etiology of the disease; they have an instinctive tendency to want to do something for their child’s wellbeing; and their frustrations cause anger that is often expressed as inappropriate behavior (37-39). We observed three major inappropriate behaviors. Parents can become overprotective, suffocating any initiative from the child; too compliant, destroying the child’s motivation to plan and develop alternative ways to reach their goals or make plans about the future since everything is controlled in the immediate present; or distant and affectionless, defending against the possibility of absorbing the reality of the illness and its severity. For parents, this last is a form of protection but, for the child, it is a message of non-acceptance, of rejection. In these cases, the art therapist led the
parent towards a state of greater self-awareness and became a behavioral example by showing possible ways for the parent to interact with the child in a supportive manner. Considering the supportive quality of AT, we decided to utilize it in all cases and to improve it as much as possible. Aiming at better-quality support during LP or BMA, we need to inform people who are directly related to the child about the procedures. In fact, when parents and the medical and nursing staff are adequately prepared with regard to AT, the child experiences the painful procedure as a less traumatic event. Data reported in this pilot study, indicating how children benefit from the application of AT support, could be invalidated by a study with higher numerous groups so that meaningful statistical results can be achieved. In this pilot study, we also observed that a child’s adaptability is directly related to the parent’s emotional state. For this reason, it is our intention to start a parallel study that is focused on emotional support to the caregiver as a way of improving the quality of life for both leukemic children and their caregivers.
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